Alla Tirsina

Orientadora

Doutora Susana Manuela Ribeiro Dias da Silva Instituto de Saúde Pública da Universidade do Porto Departamento de Ciências da Saúde Pública e Forenses e Educação Médica, Faculdade de Medicina da Universidade do Porto

Coorientadora

Doutora Cláudia Susana Soares de Freitas Instituto de Saúde Pública da Universidade do Porto Departamento de Ciências da Saúde Pública e Forenses e Educação Médica, Faculdade de Medicina da Universidade do Porto

Donating gametes to family and friends: the views of donors and recipients

Dissertação de candidatura ao grau de Mestre em Saúde Pública apresentada à Faculdade de Medicina da Universidade do Porto e ao Instituto de Ciências Biomédicas Abel Salazar.

Porto, 2020





Este trabalho foi cofinanciado por Fundos Nacionais através da FCT - Fundação para a Ciência e a Tecnologia, I.P. (Ministério da Ciência, Tecnologia e Ensino Superior), pelos Programas Operacionais Competitividade e Internacionalização (COMPETE 2020) e Capital Humano (POCH), Portugal 2020, e a União Europeia, através do Fundo Europeu de Desenvolvimento Regional e o Fundo Social Europeu, no âmbito dos projetos POCI-01-0145-FEDER-016762 (Ref. FCT PTDC/IVC-ESCT/6294/2014) e UIDB/04750/2020, do contrato Investigador FCT IF/01674/2015 e do contrato DL57/2016/CP1336/CT0001.



ACKNOWLEDGEMENTS

Although the words are unable to express all my appreciation, I am happy to be now wrapping up this journey by writing down my thanks and best wishes for those who took part of it. I have truly enjoyed doing this work with all its ups and downs.

First and before all, a huge thanks for the Professor Susana Silva and for her great coaching. Deeply grateful for all your time and efforts, wisdom, professionalism, and verticality. Honoured to have you as my mentor.

Many thanks to Professor Cláudia de Freitas for her valuable contribution in developing this dissertation.

To Inês Baía and all the others involved in the ENGAgED project that directly and indirectly impacted this work.

To the Institute of Public Health, University of Porto, and all its collaborators for the chance to undertake the Master's degree at one of the most competitive institutions in Portugal and abroad.

To the Research Unit of the Environmental Health Department of the Ricardo Jorge Institute in Porto, where I have awakened the scientist in me. So thankful for your kindness, availability, and fellowship.

To the MEDEA Erasmus Mundus Action 2 project partners for the mobility exchange granted to me. Thank you for the life changing opportunity that brought me to *who* and *where* I am now, not only professionally but also personally, since in Portugal I have met my future husband, a "phenomenon" also called the *Erasmus love*, as I would later find out from one of the project representatives at our award ceremony.

To my alma mater, the State University of Medicine and Pharmacy "Nicolae Testemitanu", Republic of Moldova, that this year accomplished 75 years since it sculptures medical doctors and pharmacists through its excellence and innovation.

To Ion Bahnarel, PhD, MD, for believing in me and supervising my professional growth as a doctor in public health in my home country. Thank you for being a source of professionalism, motivation, and tenacity.

To my beloved parents, to my roots, to whom I bend my knees. Mother, I cherish your dedication and acknowledge your fight. Father, you will be always living in my heart.

To my sisters, I just love you all.

To my best friend Paulo, the father of my son, the husband and accomplice of my crimes. Thank you for commitment and patience along this way. Thanks for making a better Me!

To my son and my inspiration – Vladimir, for his genuine love, who first saw the world during the writing process.

To my foster family, my husband's family. To my mother in law, to whom I owe a lot.

To my dearest friend Fátima Brandão, for simply being always herself!

To everyone not mentioned here but who at some stages of my life contributed to my professional and emotional growth.

And finally, given my medical background and through Hippocratic Oath I have taken – "...burning, illuminating to others...", I dedicate this dissertation to everyone to whom it might privilege.

Vă mulțumesc!

TABLE OF CONTENTS

RESUMO	1
ABSTRACT	3
1. INTRODUCTION	5
1.1. The supply-demand gap in gamete donation	6
1.2. Known gamete donation: an overview	10
1.3. Gamete donation between family and friends: ethical and social challenges	13
2. OBJECTIVES	16
3. METHODS	17
3.1. Study design	17
3.2. Participants	17
3.3. Hospital-based questionnaire	18
3.4. Data analysis	19
3.5. Ethics	20
4. RESULTS	21
4.1. Characteristics of the study participants	21
4.2. Willingness to donate gametes to family and friends	23
4.3. Factors influencing willingness to donate gametes to family	23
4.4. Factors influencing willingness to donate gametes to friends	25
5. DISCUSSION/CONCLUSION	27
REFERENCES	30
ANNEX 1. Informative leaflet	41

LIST OF FIGURES

Figure 1 Fortility	v clinics in Portugal 2020	8	
	y cillics in Follogal, 2020		1

LIST OF TABLES

Table 1. Treatment cycles using donated gametes in European countries with national
registers, 20156
Table 2. Heterologous treatments registered in Portugal, 2007-2015
Table 3. Characterization of the participants, stratified by donors and recipients 22
Table 4. Willingness to donate gametes to family and friends, according to experience with
gamete donation
Table 5. Willingness to donate gametes to family, according to the sociodemographic and
reproductive characteristics of the donors and recipients
Table 6. Willingness to donate gametes to friends, according to the sociodemographic and
reproductive characteristics of the donors and recipients

ABBREVIATIONS

- ACART Advisory Committee on Assisted Reproductive Technology
- ART Assisted Reproductive Technology
- ASRM American Society for Reproductive Medicine
- CBRC Cross Border Reproductive Care
- ED Egg Donation
- ESHRE European Society of Human Reproduction and Embryology
- HFEA Human Fertilisation and Embryology Authority
- IUI Intra-Uterine Insemination
- IUI-D Intra-Uterine Insemination using Donor sperm
- IVF/ICSI In Vitro Fertilisation / Intracytoplasmic Sperm Injection
- MAR Medically Assisted Reproduction
- PCO Portuguese Classification of Occupations
- SART Society for Assisted Reproductive Technology
- SASREG Southern African Society of Reproductive Medicine and Gynaecological Endoscopy
- SNS Serviço Nacional de Saúde [National Health Service]
- UK United Kingdom

RESUMO

A utilização de gâmetas doados na Procriação Medicamente Assistida tem aumentado ao longo das duas últimas décadas. A expansão do leque de beneficiários (por exemplo, casais de mulheres, mulheres solteiras e pessoas transgénero), o aumento da prevalência da infertilidade e o adiamento da maternidade e da paternidade têm convergido num número crescente de candidatos a gâmetas doados. Regista-se, no entanto, um diferencial entre a procura e a oferta de gâmetas doados em diversos países europeus, incluindo Portugal, sobretudo pela dificuldade em recrutar dadores, em particular para os bancos públicos. Este desequilíbrio endurece os longos tempos de espera e os custos dos tratamentos, e contribui para a circulação de gâmetas e a procura transfronteiriça de cuidados reprodutivos.

A lacuna entre a procura e a oferta pode ser colmatada através da doação de gâmetas entre familiares e amigos, mas esta possibilidade raramente é considerada, quer na literatura, quer pelos centros de Procriação Medicamente Assistida. Considerando a escassez de estudos sobre as perspetivas de dadores e beneficiários acerca desta combinação reprodutiva não convencional, é eticamente aceitável que os centros não considerem o uso de gâmetas doados por familiares e amigos para atenuar o desfasamento entre a procura e a oferta de gâmetas doados observado no Banco Público existente em Portugal. Esta dissertação pretende, por isso, gerar conhecimento acerca da utilização de gâmetas doados por familiares e amigos no contexto do Banco Público de Gâmetas, em Portugal. Fá-lo-á através da análise da disponibilidade de dadores e de beneficiários para doar ovócitos e espermatozoides a familiares e amigos, tendo em conta a influência de características sociodemográficas e reprodutivas.

Realizou-se um estudo observacional e transversal. Entre julho de 2017 e junho de 2018, 72 dadores e 179 beneficiários (proporção de participação: 76,3%) responderam a um questionário estruturado autoaplicado no Banco Público de Gâmetas. Recolheram-se dados sociodemográficos e da história reprodutiva. Este trabalho baseia-se nos dados de 70 dadores e de 165 beneficiários que reportaram a disponibilidade para doar gâmetas a familiares e amigos, avaliada através de uma escala de Likert de 5 pontos, desde "não disponível" a "sempre disponível" (intervalo 0-4). As variáveis categóricas são apresentadas como contagens e proporções, e as variáveis contínuas são resumidas como mediana e percentis. As associações foram quantificadas através do teste de Qui-Quadrado ou teste exato de Fisher, quando apropriado. A significância da diferença de idades foi calculada por meio do teste de Kruskal-Wallis.

Aproximadamente 60% dos participantes, quer dadores quer beneficiários, revelaram disponibilidade para doar os seus gâmetas a familiares e amigos, enquanto um quarto dos dadores e 30% dos beneficiários expressaram indisponibilidade.

As dadoras (p = 0,030) manifestaram-se mais propensas a doar gâmetas para a família, por comparação com os dadores. A disponibilidade para doar gâmetas a familiares foi mais frequente em beneficiários que consideraram ter rendimentos suficientes (p = 0,041) e sem um diagnóstico de infertilidade (p = 0,005), assim como nas beneficiárias, nos dadores mais escolarizados, e nos participantes solteiros/divorciados. Os dadores com filhos tenderam a reportar indisponibilidade para doar gâmetas a familiares com mais frequência do que aqueles que não tinham filhos, contrastando com a tendência observada nos beneficiários.

A disponibilidade para doar ovócitos e espermatozoides a amigos foi mais frequente nos beneficiários solteiros/divorciados (p = 0,006), sem diagnóstico de infertilidade (p = 0,020) e sem experiência prévia de tratamentos (p = 0,052). Esta intenção foi expressa principalmente por beneficiários que consideraram ter rendimentos suficientes, bem como por dadores solteiros/divorciados. Os dadores do sexo masculino, com filhos e que consideraram ter rendimentos insuficientes tenderam a reportar indisponibilidade para doar gâmetas a amigos com mais frequência.

Este estudo, pioneiro na análise da disponibilidade de dadores e beneficiários para doar gâmetas a familiares e amigos em Portugal, revelou recetividade a esta combinação reprodutiva não convencional, o que suportará a possibilidade de considerar a sua utilização no contexto do Banco Público de Gâmetas. Os resultados apelam, ainda, a um debate eticamente robusto em torno de diretrizes para a prestação de cuidados psicossociais sensíveis ao género e estatuto marital de dadores e beneficiários, assim como às respetivas experiências prévias na reprodução assistida, diagnóstico de infertilidade, estatuto parental, rendimento e nível de escolaridade.

Avaliar a disponibilidade para beneficiar de gâmetas doados por familiares e amigos e explorar as perspetivas de profissionais de saúde, incluindo todos os atores envolvidos em bancos privados de gâmetas, facilitará a discussão em torno das circunstâncias que deverão moldar a utilização de combinações reprodutivas não convencionais em Portugal. Importa desenvolver estudos que mobilizem métodos mistos e abordagens compreensivas para promover a antecipação e a reflexividade sobre as implicações éticas e sociais da doação de gâmetas para familiares e amigos.

ABSTRACT

Applications of Medically Assisted Reproduction using donated gametes have been spreading for the last two decades. The expansion of the spectrum of recipients (e.g. same sex female couples, single women and transgender), increasing infertility rates, and postponement of maternity and paternity to later stages in life have converged to raise the number of candidates for donated gametes. Many European countries, as it is the case of Portugal, experience a supply-demand gap in donated gametes, which is mainly explained by difficulties in the recruitment of donors, particularly in public banks. This imbalance originates increasingly long waiting lists and costs and contributes to the transnational flow of gametes and to the search for cross border reproductive care.

This supply-demand gap can be addressed through the donation of gametes between family members and friends, but it is rarely considered both by literature and by fertility clinics. Given the scarcity of studies about the perspectives of donors and recipients concerning such unconventional reproductive combination, it is ethically acceptable for programs not to consider the use of gametes donated by family and friends to address the supply-demand gap of donated gametes observed in the Portuguese Public Bank. Thus, this dissertation aims to produce knowledge concerning the use of gametes. It will do so through the analysis of donors' and recipients' willingness to donate eggs and sperm to family and friends, taking into account sociodemographic and reproductive characteristics.

An observational cross-sectional study was carried out. From July 2017 to June 2018, 72 donors and 179 recipients (participation rate: 76.3%) completed a self-report structured questionnaire at the Portuguese Public Bank of Gametes. Data on sociodemographic and reproductive characteristics were collected. The present work relies on data obtained from 70 donors and 165 recipients with values for willingness to donate gametes for family and friends, which was assessed using a 5-point Likert scale, ranging from "very unwilling" to "very willing" (range 0-4). Categorical variables are presented as counts and proportions and continuous variables are summarized as median and percentiles. Associations were quantified through the Chi-square test or Fisher's exact test when appropriate. The significance of the median difference was calculated through the Kruskal–Wallis test.

About 60% of both donors and recipients were very willing or willing to donate their gametes to family and friends, while around one quarter of the donors and 30% of the recipients expressed unwillingness.

Egg donors (p = 0.030) were more likely to be willing to donate gametes for family. A similar position was primarily expressed by recipients who perceived their income as sufficient (p = 0.041) and who were not diagnosed as infertile (p = 0.005), being more common among female recipients, donors with higher levels of education, and single/divorced participants. Donors who had children tended to report unwillingness to donate gametes to family more often than those who had no children, contrasting with the trend observed among recipients.

Willingness to donate eggs and sperm to friends was more frequent among single/divorced recipients (p = 0.006), and those without a diagnosis of infertility (p = 0.020) or who did not experience previous treatments (p = 0.052). This intention was mainly expressed by recipients who perceived their income as sufficient, as well as by single/divorced donors. Male donors and those who had children or perceived their income as insufficient tended to report unwillingness to donate gametes to friends more often.

This first study providing evidence regarding donors' and recipients' willingness to donate gametes to family members and friends in Portugal revealed receptiveness to this unconventional reproductive combination, which may support its use in the context of the Public Bank of Gametes. Findings also call for a discussion about the contours of ethically robust psychosocial care sensitive to donors' and recipients' sex, marital status, history of previous treatments/donations, fertility and parental status, income and level of education.

To assess willingness to receive gametes donated by family and friends and to explore the perspectives of health professionals and all actors involved in the private healthcare system would facilitate the discussion on the circumstances under which unconventional reproductive combinations could be used in Portugal. Further studies guided by a mixed-methods comprehensive approach are needed to understand how to promote anticipation and reflexivity around the ethical and social implications of donating gametes to family and friends.

1. INTRODUCTION

Standard and non-standard applications of Medically Assisted Reproduction (MAR) using donated gametes have been spreading for the last two decades. Heterologous treatments are offered to heterosexual couples based on medical reasons such as infertility or avoidance of genetic transmissible diseases (1-4), as well as to single women, transgender and same sex female couples grounded on their right to reproduce and on the ethical principles of beneficence, non-maleficence and justice (5-8). Access to MAR has also been promoted to face declining fertility rates and ageing and to foster healthy population renewal (9). The expansion of the spectrum of recipients, increasing infertility rates due to environmental issues and radiation therapies (10), and postponement of maternity and paternity to later stages in life (11-15) have converged to raise the number of candidates for donated gametes. Alongside the increasing demand for donated gametes there have been difficulties in the recruitment of both male and female donors, particularly in public banks, as it is the case of Portugal.

We discuss how this supply-demand gap can be addressed in the first section of the introduction, pointing to the lack of empirical studies about a particular strategy - the donation of gametes between family members and friends. Given the scarce assessment of the perspectives of donors and recipients about such unconventional reproductive combination, it is ethically acceptable for programs not to use gametes donated by family and friends to address the supply-demand gap of donated gametes observed in the Portuguese Public Bank.

In the second section, we provide a brief overview about the legal and regulatory framework on known gamete donation, and revise the few data on its frequency, background and practical implications. A synthesis of the limited body of knowledge on the willingness to donate gametes for family and friends is also presented.

In the last section, we analyse the ethical and social issues involved in the use of gametes donated by family and friends, calling for evidence on the perspectives of donors and recipients in the context of the Portuguese Public Bank of Gametes.

1.1. The supply-demand gap in gamete donation

Nowadays, donor-assisted conception is widely recognized as a way of forming a family (3, 8, 16-19). The most recent report published by the European Society for Human Reproduction and Embryology (ESHRE) estimates that a total of 64 477 treatments with egg donation (ED) were carried out in 29 European countries during 2015; 797 of those treatments were done in Portugal (20). The proportion of assisted reproductive technology (ART) treatment cycles that use donated eggs in each country was higher in Greece, Cyprus, Iceland and Portugal (Table 1). In countries such as Slovenia and Austria that practice was scarce. Regarding intrauterine insemination using donor sperm (IUI-D), a total of 49 202 treatments were carried out in Europe, of which 236 were done in Portugal (20). Spain, Denmark, Belgium, UK, Russia and France registered the highest activity on the number of IUI-D treatments, while the lowest values were witnessed in Slovenia, Macedonia, Latvia and Estonia (Table 1). Portugal was positioned in the eight lowest place.

		ART ^a	Intrauterine insemination (IUI)			
Countries	Total	Egg donation	Total	Sperm donation		
	n	n (%)	n	n (%)		
Armenia	-	-	884	313 (35.4)		
Austria	8778	7 (0.07)	-	-		
Belgium	30300	802 (2.6)	21274	8112 (38.1)		
Bulgaria	9849	612 (6.2)	3566	590 (16.5)		
Cyprus	1737	318 (18.3)	-	-		
Denmark	17454	360 (2.0)	20263	9924 (48.9)		
Estonia	2955	180 (6.0)	230	91 (39.5)		
Finland	9343	831 (8.8)	4297	1171 (27.2)		
France	93918	1072 (1.1)	54008	3294 (6.0)		
Greece	27149	5182 (19.0)	4848	287 (5.9)		
Iceland	739	108 (14.6)	302	177 (58.6)		
Italy	73403	1615 (2.2)	23062	513 (2.2)		
Kazakhstan	-	-	935	125 (13.3)		
Latvia	-	-	149	53 (35.5)		
Macedonia	-	-	1215	29 (2.3)		
Norway	-	-	21322	614 (2.8)		
Poland	-	-	10765	1729 (16.0)		
Portugal	8660	797 (9.2)	2424	236 (9.7)		
Romania	-	-	2282	191 (8.3)		
Russia	-	-	14141	4128 (29.1)		
Slovenia	4649	3 (0.06)	247	1 (0.4)		
Spain	-	-	38903	11944 (30.7)		
Sweden	18603	311 (1.6)	760	760 (100)		
Ukraine	-	-	2038	468 (22.9)		
UK	65461	3321 (5.0)	9790	4941 (50.4)		

Table 1. Treatment cycles using donated gametes in European countries with national registers, 2015

^a This includes in vitro fertilization and embryo transfer, intracytoplasmic sperm injection, frozen embryo replacement, preimplantation genetic diagnosis, other gametic or embryonic manipulation techniques.

Source: Adapted from ESHRE (20).

Taken together, ED and IUI-D cycles accounted for 9.3% of the total treatments occurring in Portugal in 2015, a proportion that has been steadily increased since 2013 mainly due to ED (Table 2).

Year	Proportion of cycles using donated gametes	Number of ART treatments using donor eggs	Number or IUI using donor sperm
2007	4.6	101	236
2008	6.0	194	250
2009	6.4	274	235
2010	4.7	282	161
2011	4.9	269	190
2012	6.4	403	239
2013	5.7	360	190
2014	6.8	493	199
2015	9.3	797	236

Table 2. Heterologous treatments registered in Portugal, 2007-2015

Source: ESHRE (20, 26-33).

In Portugal, there are 28 fertility centers, including 10 public and 18 private centres (Figure 1). They are mainly located in the Northern Region (4 public and 6 private) and in Lisbon (3 public and 6 private)¹: 18 offer treatments with donated sperm (two public, 16 private) and 14 perform cycles with donated oocytes (one public and 13 private). The Portuguese Public Bank of Gametes was instituted in Porto in 2011 to recruit and select gamete donors, and to collect and store donated sperm and oocytes (21). Two additional centers for donating gametes were inaugurated in 2017. They are located in Coimbra and in Lisbon (22).

All women aged between 18 and 40 or 42 years (in the case of IVF/ICSI or IUI, respectively) have access to treatments with donated gametes offered by the national public healthcare system, up to 3 IVF/ICSI + 3 IUI, independently of marital status and sexual orientation (23). There is no age limit for prospective fathers (24). Age limits for egg donors are 18-33 years and for sperm donors 18-40 years (25).

¹ Information available at http://www.cnpma.org.pt/cidadaos/Paginas/centros-de-pma.aspx, last access 7 October 2020.



Figure 1. Fertility clinics in Portugal, 2020

In a context where many European countries experience an increasing demand for donated gametes, a supply-demand gap has been observed. This gap is mainly explained by difficulties in the recruitment of both male and female donors, particularly in public banks (1, 4, 5, 12, 16, 34-36), as it is the case of Portugal (37, 38). This imbalance originates increasingly long waiting lists and costs and contributes to the transnational flow of gametes (39) and to the search for cross border reproductive care (CBRC) (16, 19, 40). Furthermore, the shortage of reproductive cells in gamete banks (41, 42) has been associated with legal and policy movements towards non-anonymous gamete donation (1, 43, 44) and removal of payment to gamete donors (11, 42). However, the literature shows that the scarcity of donors persists in countries with anonymous donation (45), and after short-term drops following a shift in the legislation the number of gamete donors rises steadily (16).

Several strategies have been developed to address this supply-demand gap, namely: egg sharing²; increasing payment to gamete donors; implementing campaigns to raise awareness on the importance of donating gametes and to alert for the scarcity of donations; improving access to donation in public banks; lessening the criteria for accepting donated sperm while maintaining its quality and safety; increasing the use of cryopreserved surplus gametes; and using gametes donated by family and friends (3, 16, 36, 38, 46, 47).

Since 2016, the Portuguese Government has been adopting some of the abovementioned strategies for promoting gamete donation, including the opening of two new public centres for donating gametes; the implementation of publicly funded campaigns; the creation of the first webpage on gamete donation hosted by the National Health Service Website; the use of flyers, posters and media; and the updating of the recompense to gamete donors to a maximum of 843€ for oocyte donation and 338€ for sperm donation³ (22, 25, 48-51). However, the use of gametes donated by family and friends has not been adopted by fertility clinics located in Portugal (37).

Given the scarcity of studies about the perspectives of donors and recipients concerning the donation of gametes between family members and friends, it is ethically acceptable for programs not to consider such a strategy to address the supply-demand gap of donated gametes observed in the Portuguese Public Bank. This unconventional reproductive combination (52) is acknowledged for the presence of genetic links and physical resemblance, donors' availability and access to donors' data (2, 16, 53-56), which comes together with debates about the ethical challenges emerging from its implications for family relationships and well-being of those involved in the process (38, 53-55, 57, 58).

² Egg sharing is when a woman who is already having IVF agrees to share a part of her eggs with another women or couple in need, usually in return for some free or discounted treatment.

³ Gamete donors are also exempted from the payment of user charges under the National Health Service.

1.2. Known gamete donation: an overview

Gamete donations between family members and friends are frequently described as known donation⁴ (53, 55, 59, 60) or directed donation (54, 61, 62). When it only concerns donation between family members, the terms intra-family donation (43, 44) or intrafamilial medically assisted reproduction (53) are also used in the literature. Familial gamete donation may occur at intra- or inter-generational levels (44), and involve first (i.e. brother, sister, father, mother), second (i.e. aunt, uncle, niece, nephew) or third (i.e. cousins) degree relations (43, 53). It can be consanguineous (i.e. when donor and recipient share the same genetic background) or not (53).

When third-party reproduction first became possible, the use of a known donor was interdicted in most countries, mainly due to mandatory anonymous donation regimes (13). As the demand for donated gametes increased, the ethical, legal and social issues convoked by collaborative reproduction gained relevance in the academic debate (56). A transition toward identifiable donation started in the 1980s, invoking donor-conceived children right to have access to information related to their genetic origins (19, 38, 43, 58, 63).

Gamete donations between family members and friends are forbidden in countries such as Italy (64), Poland (65), France (2) and Greece (66). Some forms of known donation are commonly accepted in the UK (67), USA (54), Finland (1), Belgium (68, 69), Canada (11, 42, 70), New Zealand (43, 58), South Africa (71), Australia (10), Middle East countries (72), Netherlands (73), Hungary (74), Republic of Moldova (75), Russia (76) and Israel (77), frequently after a request addressed by a formal ethics committee. Several Indian IVF clinics offer interfamilial and other reproductive arrangements, although the Indian Council of Medical Research (ICMR) does not allow known donation (78, 79).

The legal and regulatory framework in Portugal does not explicitly approach the issue of gamete donations between family members and friends (37). Anonymous gamete donation was declared unconstitutional in 2018 (80), and there is now a transitional regime toward openidentity donation in Portugal (81). The new regime guarantees anonymity for all gamete donations registered before May 7, 2018 and used until April 2021, unless donors freely allow the disclosure of their identity.

⁴ Known donation is also used to describe three distinct situations: 1) when donor-conceived individuals are aware of donors' identity, although donors and recipients are completely unrelated; 2) when the offspring is aware of the mode of conception; and, 3) when recipients meet donors during a holiday trip or find them via magazines (2, 63, 73).

De Wert (2011) suggests that gamete donation for family and friends is a rare practice. However, data on its frequency, background and practical implications is lacking in Europe (53), America (54) and worldwide (43, 82). Studies conducted in 1992 and in 1998 by the Society for Assisted Reproductive Technology (SART) depicted the predominance of intragenerational donations among women. Sister-to-sister and friends egg donation were admissible in the vast majority of the programs in North America, while only about half of those programs accepted brothers as sperm donors. Intergenerational donation was approved by almost 40% of the egg donation programs and one quarter of the sperm donation programs (83). Other available data for the nineties showed that 90% of US ART clinics accepted oocytes from family members and 80% from friends, while around 60% accepted requests with family members as sperm donors (52). The use of gametes donated by known donors was also observed in more than one third of the children conceived between 1986 and 1992 by planned lesbian families in the USA (59, 60). The Human Fertilisation and Embryology Authority (HFEA) reported that, in 2010, approximately 40% of the clinics based in the UK registered applications for intra-family donations at least once per month, 50% at least four times per year and 75% at least two times per year, with a dominance of calls for intra-generational donations (i.e. sister-to-sister or brother-to-brother donation) (43, 44).

Lessor (1993) stated that one in four patients requesting egg donation at one university clinic in USA specified a sister, other relative or a close friend to donate oocytes. At the fertility centre of the Erasmus Hospital in Belgium, almost one third of the couples in need of egg donation between 2005 and 2006 intended to go for a known donation, with 86% of the donors belonging to family/friends' networks (2).

A survey on the preferences and experiences regarding online sperm donation found that 29.3% of a sample of 383 registered sperm donors chose known sperm donation, of whom 25.8% were heterosexual and 43.8% gay and bisexual (84). From 1991 to 2003, the University Medical Center located in Utrecht, The Netherlands, recruited 77 non–anonymous egg donors, mostly family members, friends or acquaintances of the recipients (73). A similar trend was observed in three fertility clinics in Finland between 1990 and 2012: 13% of women who donated their eggs were known donors, in particular sisters, other relatives or friends of the recipients, a proportion that increased after the removal of anonymous gamete donation in 2007 (1). In Canada, 3 of 18 intended mothers involved in a qualitative study about the role of normative ideologies of motherhood in the experiences of egg donation had family members or friends as egg donors between October 2013 and March 2015 (11). Sub-Saharan Africans who preferred an anonymous donation, which has been explained by the fact that for some

ethnic minority groups known donation emerges as the only solution in pursuing the ideal family (2).

Empirical studies in the field of gamete donations between family members and friends have focused on egg donation, considering its burden and novelty when compared with sperm donation (13, 42, 56, 68, 69, 85). They have explored the perspectives of donors (1, 2, 11, 42, 56, 61, 69, 85-87) or recipients (11, 14, 44, 73, 88) around the conceptualization of reproductive cells, the motivations and struggles surrounding their experience, and the risks and benefits involved in gamete donations between family members and friends, giving particular attention to the role played by the ideologies of parenthood, geneticization and normality, and to psychosocial counselling. A few researches also addressed the views of the recipients' or donors' partners (13, 41, 67), donor-conceived children (68) and IVF providers (52). The studies assessing the willingness to receive gametes donated by family members and friends are scarce (89) and those analysing the factors influencing the donors' and recipients' willingness to donate eggs and sperm for family and friends are missing, to the best of our knowledge.

Chliaoutakis (2002) investigated the intention of receiving or donating gametes among 365 adults from urban areas of Crete, Greece, and concluded that participants would prefer to receive sperm and oocytes from a stranger than from a relative or a friend, but were more in favour of donating eggs to a family member than to a friend or a stranger. Studies tended to report higher odds for donation to a family member or a close friend (90), but some resistance regarding the use of gametes donated by a family member (89).

Unwillingness to receive gametes donated by a family member or a friend has been justified by concerns regarding child-donor and/or recipient-donor relationship, in particular donor's involvement into child's education, a too close or a too distant relationship, or the probability of worsened recipient-donor relationship (89, 91). Recipients also fear child's physical resemblance with the donor, and to remember the non-genetic tie with the child and the pain associated with the donation process (14, 89). The thought of occurring changes in donor's mind (e.g. asking for legal rights and duties related with parenthood) might filled recipients with dread, although only few cases of such donors' misconduct have been reported so far (92).

Lessor et al. (1990) conducted a pioneering study with 501 adults from Orange County California, USA, that showed positive attitudes toward sister-to-sister egg donation. This option tends to be more accepted than brother-to-brother sperm donation. Familial and/or cultural beliefs point to egg donation as a selfless practice that tightens family relations, while sperm donation is viewed as potentially inducing family conflicts by threatening the masculinity of the recipient (4, 13, 67, 69, 89). In fact, egg donors usually describe their experience as meaningful

(86) and satisfactory (1), and as a gift (13, 56) that helps relatives and friends (1, 42) and improves donors' life through feelings of pride and gratitude (42). Positive experiences of sister-to-sister egg donation have been also described by the recipients (44, 68) and donor-conceived children (68, 87, 94). Nevertheless, sometimes egg donors hide negative feelings to avoid disturbing their recipient sisters (56) and even tightly intimate sisters might find quite problematic to share their fears and expectations (13, 57). Thus, work on continuous optimal communication is requested to maintain the balance and overcome emerging barriers (68).

1.3. Gamete donation between family and friends: ethical and social challenges

The preference for gametes donated by family members and friends has been sustained by the existence of a genetic link and emotional ties between donor and recipient, the opportunity of reducing costs (no payment to gamete donors) and/or the waiting times for treatment, and access to donors' medical, genetic, social, psychological and familial data (2, 13, 14, 16, 42, 53-56, 67, 69, 83). There is also the belief that disclosure might be "smoother" and more welcomed by donor-conceived offspring (44), as well as the idea that "occasional" donors tend to be more psychologically unstable or to have an anamnesis of violence and trauma (69) and that egg donation implies health risks that are only assumed by those closest to the recipients (43, 56, 69).

Egg donors invoke altruism (1, 42, 53, 56, 85-88), genetic bonds with additional progeny (13, 53, 56) and internal and/or external pressure (e.g. a sense of subtle obligation and/or familial and societal expectations) (2, 43, 67, 85) as the main triggers for donation. Altruism is frequently analysed as stemming from a multitude of feelings and reasons (42): the genuine desire to help recipients to construct a family (2, 41, 42, 61, 69, 86-88); readiness to undergo eventual risks to support recipients' right to motherhood (85); to benefit the well–being of the future child (2, 86); enact solidarity to overcome recipients' pain associated with infertility and the inability to conceive (42, 56, 67, 69); and gain self-esteem and respect from others (85).

Although known gamete donation is generally acknowledged as an acceptable form of family building that shall not be regarded as disturbing (11, 53, 54, 68, 87, 95, 96), literature points to ethical and social challenges posed by unconventional interfamilial and other reproductive combinations, in particular:

- The occurrence of collaborations between two genetically closely related individuals each providing gametes (38, 53-55, 58, 68, 72), and possible genetic risks or birth defects for the offspring when there are consanguineous connections (53, 54).
- Feelings of pressure or coercion may undermine donors' autonomy. These feelings increase when the relationship between donor and recipient is closer (37, 38, 41, 43, 53-55, 58, 86), in particular when the donor is financially dependent on the recipient, or when the latter has moral and/or physical authority over the former (42, 43, 53, 54, 69).
- Having a relative or a friend as a gamete donor involves by default a confession on the part
 of the recipient of his/her infertility and/or desire to engage in a heterologous fertility
 treatment, which can compromise recipients' intimacy and enhance judgment, stigma and
 emotional pressure (42). Offspring's physical resemblance with the donor, for example,
 provides comfort but also challenges recipients' self-confidence (14, 68).
- Difficulties in defining the status of the child within the family and family relationships (38, 53-55, 57, 58, 68, 72), and emotional load in the post-donation period (4, 37, 53, 57, 86). Hammond (2018) states that recipients' concept of normality shapes the relationship established with the donor, which can range from "distance and cancelling out" to "acknowledgment and gratitude" to "contact and intimacy". Feelings of uncertainty (42), disappointment and blame (86) might occur in donors, alongside with positive experiences (56), depending mainly on the success of the outcomes (85).
- Stigma, social exclusion and other negative reactions from society (4, 37, 53, 55). However, literature has been showing that the quality of life and the psychological adjustment of the offspring from US lesbian families is independent of the regime of gamete donation (59, 60, 97).

Aiming to avoid the development of genetic diseases, as well as to prevent family conflicts or social disruptions, professional guidelines stipulate the possible and impossible relationships for closely related persons in gamete donation: to donate sperm to brothers, cousins or sons, and eggs to sisters, nieces and daughters is considered acceptable, as well as donating gametes to third–degree relatives; consanguineous unions of first or second degree relatives are forbidden, even marriage among first cousins are legal in some countries; intergenerational gamete donation and collaborations among individuals whose relationship give a social impression of incest⁵ require examination or additional counselling (43, 53, 54, 58). When the prospective donors are against disclosure, and a high risk to inadvertently disclosure exists, gamete donations between family members and friends shall be discouraged (53).

⁵ For example, when a brother donates sperm to a sister who will use donated eggs.

Professional guidelines dedicated to unconventional reproductive combinations focus on *what* to do regarding counselling, informed consent, coercion and undue influence in gamete donations between family members, and less on *how* to ethically solve the challenges faced by providers during routine delivery of healthcare (52, 55), assigning such responsibility to each clinic (54). Furthermore, evidence calls for the need to address specific challenges related to gamete donations by friends (42, 52, 85-87).

Beyond the availability of psychosocial counselling (2, 42, 53-56, 62, 67), the literature adds other recommendations to facilitate the experience of gamete donation between family members and friends, namely: previous arrangements on family relationships and disclosure (2, 73); to assure the support from partners and other family members (67, 85, 86); trusting donor-recipient relationship, which favours donors' positive experiences across the journey, simplifying and assisting on a proper relationship with the child (87). Approaching sensitive issues and debating scenarios previously to donation facilitates emotional preparedness and prevents ungrounded expectations (2, 73). Arrangements can be discussed during individual and/or group counselling, which are encouraged for all the participants in gamete donations between family members and friends (43, 53-55, 58).

2. OBJECTIVES

This dissertation aims to produce knowledge concerning the use of gametes donated by family and friends in the context of the Portuguese Public Bank of Gametes. It will do so through the analysis of donors' and recipients' willingness to donate eggs and sperm to family and friends, taking into account sociodemographic and reproductive characteristics.

3. METHODS

3.1. Study design

This observational cross-sectional study comprises a hospital-based questionnaire that was carried out at the Portuguese Public Bank of Gametes. This center is located at a public hospital in Porto and performs IUI and IVF/ICSI heterologous and homologous treatment cycles.

3.2. Participants

From July 2017 to June 2018, gamete donors and recipients who attended at least one medical appointment at the Portuguese Public Bank of Gametes were invited to participate in the study, independently of the stage of the treatment. At the end of the medical appointment, a health professional delivered an informative leaflet about the study (Annex 1) to gamete donors and recipients. Subsequently, a research team member (consisting of a total of four researchers) invited them to participate in the study and answered to all of their research doubts and questions. Those who agreed to participate were then accompanied to a private room at the healthcare service, where they read and signed the informed consent and completed a self-report structured questionnaire.

Of the 329 people invited, 72 donors and 179 recipients agreed to participate in the questionnaire (participation rate: 76.3%). Those who refused to participate invoked lack of time (n=39), unwillingness to participate (n=20) and psychological unavailability (n=8); 11 did not report the reason for the refusal. The present work includes 70 donors and 165 recipients with values for willingness to donate gametes for family and friends.

3.3. Hospital-based questionnaire

The structured questionnaire was developed by an interdisciplinary research team for the project "Bionetworking and Citizenship on Gamete Donation" (ENGAgED) to assess social, ethical and legal issues involved in gamete donation, based on a literature review and a complete inventory of existing questionnaires on the topic. The final version of this instrument, available at Baía et al. (2019), included 34 major multiple-choice, close- and open-ended questions, divided into four sections: 1. Opinions about access to and governance of gamete donation; 2. Willingness to donate gametes for family, friends and research purposes, as well as willingness to receive donated gametes by family, friends or unknown donors; 3. Willingness to donate embryos for reproductive and research purposes, and opinion about who should be involved in decision-making on the use of embryos created by gamete donation in research; 4. Sociodemographic and reproductive characteristics. Filling in the questionnaire required 15 minutes on average.

The present study relies on data obtained for the topic concerning the willingness to donate gametes to family and friends, according to experience with gamete donation (donors or recipients) and sociodemographic and reproductive characteristics (age, sex, marital status, educational level, country of origin, working status, occupation, perceived income adequacy, subjective social class, parental status, diagnosis of infertility, and previous treatments/donations).

Willingness to donate gametes to family and friends was assessed using a 5-point Likert scale, ranging from "very unwilling" to "very willing" (range 0-4). For the analysis, the answers were recoded into a three-category variable: "yes" (including "very willing" and "willing"), "neither willing nor unwilling", and "no" (including "unwilling" and "very unwilling").

Educational level was assessed through a multiple-choice item with the following answer categories: 1) None, and can't read or write; 2) None, but can read and write; 3) 1st cycle of basic education (4th grade); 4) 2nd cycle of basic education (6th grade); 5) 3rd cycle of basic education (9th grade); 6) Secondary education (12th grade); 7) Bachelor's degree; 8) Licentiate degree; 9) Master's/Integrated Master's; 10) PhD. For analysis, this variable was dichotomized in \leq Secondary education (12th grade) and > Secondary education (12th grade).

Working status was categorized as employed and other (including students, unemployed and retired individuals). The occupation of participants was classified by major professional groups, according to the Portuguese Classification of Occupations (PCO) 2010 (99) and then grouped in three categories: 1) upper white collar, including individuals classified in the upper three major groups of the PCO 2010 – executive civil servants, industrial directors and executives,

professionals and scientists, middle management and technicians; 2) lower white collar, comprising individuals classified in the fourth and fifth major group of the PCO 2010 – administrative and related workers, and service and sales workers; and 3) blue collar, including individuals classified in the sixth to ninth major groups of the PCO 2010 – farmers and skilled agricultural, fisheries workers, skilled workers, craftsmen and similar, machine operators and assembly workers, and unskilled workers. Students were excluded from this classification. Unemployed or retired participants were classified considering their previous main occupation, when mentioned.

Perceived income adequacy was assessed through the question: "Thinking of your household income, would you say that your household is able to make ends meet?". The answers contained four categories: insufficient, caution with expenses, enough to make ends meet and comfortable. For this study, the answers were recoded into a dichotomous variable: insufficient, including respondents who reported subjective economic hardship, i.e. difficulty in making ends meet (insufficient or caution with expenses); and sufficient, gathering respondents who considered their household income enough to make ends meet or comfortable.

Subjective social class was assessed by asking participants to include themselves in one of the following social classes: low, middle-low, middle-high, high or none of above. For this work were considered only the first 4 categories which afterwards were dichotomized as follow: low/middle-low, middle-high/high.

Parental status was dichotomized as children and no children. Participants were considered to have previous treatments or donations if they had at least one previous MAR treatment, regardless of using donated or their own gametes – for recipients, or if they had donated gametes at least once before the current donation – for donors.

3.4. Data analysis

Categorical variables are presented as counts and proportions and the continuous variable "age" is summarized as median and percentiles (P25 and P75). Associations were quantified through the Chi-square or Fisher's exact test in the cases that did not meet the Chi-squared test assumption that less than 20% of cells with expected frequencies have values less than 5. The significance of the median difference was calculated through the Kruskal–Wallis test due to the non-parametric distribution of data in this variable.

Statistical analyses were performed using the IBM Statistical Package for the Social Sciences (SPSS) Statistics for Windows, version 24.0 (Armonk, NY, USA). Statistical significance was set at a value of p < 0.05.

3.5. Ethics

Ethical approval was granted by the Portuguese Data Protection Authority and the Ethics Committee for Health from the Centro Hospitalar Universitário do Porto on 11 January 2017, where data was collected. All procedures were in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments. Written informed consent was obtained from all the participants prior to participation in the study, following the World Medical Association Declaration of Helsinki and the Oviedo Convention, to obtain personal contacts, collect information and publication of data.

4. RESULTS

4.1. Characteristics of the study participants

The characteristics of the study participants, stratified by donors and recipients, are summarized in Table 3. Most participants were female (67.1% of donors; 61.2% of recipients), born in Portugal (80.0% of donors; 93.3% of recipients), perceived their income as sufficient (68.6% of donors; 70.6% of recipients) and their social class as low/middle-low (72.1% of donors; 71.7% of recipients), and had no children (80.0% of donors; 90.2% of recipients) and no previous experience with gamete donation (91.4% of donors; 66.7% of recipients). Almost half of the donors (48.8%) and of the recipients (47.6%) had an upper white-collar occupation.

Donors were younger than recipients (median [P25-P75] = 26.0 [24.0-29.25] vs. 36.0 [34.0-39.0]), more educated (> secondary education) (58.6 % vs. 43.8%) and less frequently employed (56.5% vs. 91.4%). Most donors were single or divorced (81.4%), while over 90% of the recipients were married or lived with a partner.

	Total <i>N</i> = 235	Donors <i>n</i> = 70	Recipients <i>n</i> = 165
Age, Median (P25-P75)	34.0 (28.0-38.0)	26.0 (24.0-29.25)	36.0 (34.0-39.0)
	n (%)	n (%)	n (%)
Sex			
Female	148 (63.0)	47 (67.1)	101 (61.2)
Male	87 (37.0)	23 (32.9)	64 (38.8)
Marital status			
Married/living with partner	163 (69.4)	13 (18.6)	150 (90.9)
Single/divorced	72 (30.6)	57 (81.4)	15 (9.1)
Educational level			
≤ Secondary education (12 th grade)	119 (51.7)	29 (41.4)	90 (56.3)
> Secondary education (12 th grade)	111 (48.3)	41 (58.6)	70 (43.8)
Country of origin			
Portugal	209 (89.3)	56 (80.0)	153 (93.3)
Other ^a	25 (10.7)	14 (20.0)	11 (6.7)
Working status			
Employed	188 (81.0)	39 (56.5)	149 (91.4)
Other ^b	44 (19.0)	30 (43.5)	14 (8.6)
Occupation ^c			
Upper white collar	90 (47.9)	20 (48.8)	70 (47.6)
Lower white collar	68 (36.2)	19 (46.3)	49 (33.3)
Blue collar	30 (16.0)	2 (4.9)	28 (19.0)
Perceived income adequacy			
Insufficient	70 (30.0)	22 (31.4)	48 (29.4)
Sufficient	163 (70.0)	48 (68.6)	115 (70.6)
Subjective social class‡			
Low/Middle-low	135 (71.8)	44 (72.1)	91 (71.7)
Middle-high/High	53 (28.2)	17 (27.9)	36 (28.3)
Parental status			
Children	30 (12.8)	14 (20.0)	16 (9.8)
No children	204 (87.2)	56 (80.0)	148 (90.2)
Diagnosis of infertility			
Yes	78 (33.6)	0 (0)	78 (48.1)
No	154 (66.4)	70 (100)	84 (51.9)
Previous treatments/donations			
Yes	61 (26.0)	6 (8.6)	55 (33.3)
No	174 (74.0)	64 (91.4)	110 (66.7)

Table 3. Characterization of the participants, stratified by donors and recipients

^a Angola, Australia, Brazil, Cape Verde, France, Luxemburg, Russia, USA and Venezuela; ^b Students, unemployed and retired participants; ^c Students were excluded; unemployed or retired participants were classified according to their previous main occupation.

Notes: In each variable, the total may not add 70 donors and 165 recipients due to missing values. The proportions may not add 100 due to rounding.

4.2. Willingness to donate gametes to family and friends

Donors and recipients shared similar positions regarding willingness to donate gametes to family and friends, with about 60% being very willing or willing and around one quarter of the donors and 30% of the recipients very unwilling or unwilling (Table 4). The proportion of those who were neither willing nor willing to donate gametes to family and friends was higher among donors than among recipients.

Table 4.	Willingness	to	donate	gametes	to	family	and	friends,	according	to	experience	with	gamete
donation													

Willingness to donate gametes to:	Total (N=235)	Donors (n=70)	Recipients (n=165)
C C	n (%)	n (%)	n (%)
Family			
Very willing	114 (48.5)	34 (48.6)	80 (48.5)
Willing	29 (12.3)	9 (12.9)	20 (12.1)
Neither willing nor unwilling	25 (10.6)	10 (14.3)	15 (9.1)
Unwilling	12 (5.1)	2 (2.9)	10 (6.1)
Very unwilling	55 (23.4)	15 (21.4)	40 (24.2)
Friends			
Very willing	108 (46.0)	36 (51.4)	72 (43.6)
Willing	32 (13.6)	6 (8.6)	26 (15.8)
Neither willing nor unwilling	27 (11.5)	12 (17.1)	15 (9.1)
Unwilling	15 (6.4)	3 (4.3)	12 (7.3)
Very unwilling	53 (22.6)	13 (18.6)	40 (24.2)

Notes: The proportions may not add 100 due to rounding.

4.3. Factors influencing willingness to donate gametes to family

Donors' and recipients' willingness to donate eggs and sperm to family, taking into account their sociodemographic and reproductive characteristics, is presented in Table 5. Egg donors (p = 0.030) were more likely to be willing to donate gametes for family. A similar position was primarily expressed by recipients who perceived their income as sufficient (p = 0.041) and who were not diagnosed as infertile (p = 0.005).

Although not statistically significant, willingness to donate eggs and sperm to family was more common among female recipients, donors with higher levels of education, and single/divorced participants. Donors who had children tended to report unwillingness to donate gametes to family more often than those who had no children, contrasting with the trend observed among recipients.

Table 5. Willingness to donate gametes to family, according to the sociodemographic and reproductive characteristics of the donors and recipients

	Donors							
	Yes	Neither willing nor unwilling	No	р	Yes	Neither willing nor unwilling	No	р
Age, median (P25-P75)	26.0 (24.0-29.5)	26.0 (22.0-29.0)	27.0 (23.0-30.0)	0.634	36.0 (34.0-39.0)	35.0 (30.0-38.5)	36.0 (34.0-39.0)	0.441
	n (%)	n (%)	n (%)		n (%)	n (%)	n (%)	
Sex								
Female	33 (70.2)	7 (14.9)	7 (14.9)	0.030	67 (66.3)	9 (8.9)	25 (24.8)	0.131
Male	10 (43.5)	3 (13.0)	10 (43.5)		33 (51.6)	6 (9.4)	25 (39.1)	
Educational level								
≤ Secondary education (12 th grade)	16 (55.2)	4 (13.8)	9 (31.0)	0.535	54 (60.0)	7 (7.8)	29 (32.2)	0.554
> Secondary education (12 th grade)	27 (65.9)	6 (14.6)	8 (19.5)		44 (62.9)	8 (11.4)	18 (25.7)	
Marital status								
Married/living with a partner	7 (53.8)	0	6 (46.2)	0.060	87 (58.0)	14 (9.3)	49 (32.7)	0.075
Single/divorced	36 (63.2)	10 (17.5)	11 (19.3)		13 (86.7)	1 (6.7)	1 (6.7)	
Country of origin								
Portugal	34 (60.7)	8 (14.3)	14 (25.0)	1.000	91 (59.5)	15 (9.8)	47 (30.7)	0.716
Other ^a	9 (64.3)	2 (14.3)	3 (21.4)		8 (72.7)	0	3 (27.3)	
Working status								
Employed	24 (61.5)	6 (15.4)	9 (23.1)	0.930	91 (61.1)	12 (8.1)	46 (30.9)	0.229
Other ^b	18 (60.0)	4 (13.3)	8 (26.7)		8 (57.1)	3 (21.4)	3 (21.4)	
Occupation ^c								
Upper white collar	14 (70.0)	2 (10.0)	4 (20.0)	0.481	43 (61.4)	8 (11.4)	19 (27.1)	0.711
Lower white collar	13 (68.4)	4 (21.1)	2 (10.5)		31 (63.3)	3 (6.1)	15 (30.6)	
Blue collar	1 (50.0)	0	1 (50.0)		15 (53.6)	2 (7.1)	11 (39.3)	
Perceived income adequacy								
Insufficient	14 (63.6)	1 (4.5)	7 (31.8)	0.234	22 (45.8)	6 (12.5)	20 (41.7)	0.041
Sufficient	29 (60.4)	9 (18.8)	10 (20.8)		77 (67.0)	8 (7.0)	30 (26.1)	
Subjective social class								
Low/ Middle-low	28 (63.6)	5 (11.4)	11 (25.0)	0.474	56 (61.5)	10 (11.0)	25 (27.5)	0.266
Middle-high/ High	9 (52.9)	4 (23.5)	4 (23.5)		22 (61.1)	1 (2.8)	13 (36.1)	
Parental status								
Children	8 (57.1)	0	6 (42.9)	0.081	12 (75.0)	1 (6.3)	3 (18.8)	0.611
No children	35 (62.5)	10 (17.9)	11 (19.6)		87 (58.8)	14 (9.5)	47 (31.8)	
Diagnosis of infertility								
Yes	0	0	0		37 (47.4)	8 (10.3)	33 (42.3)	0.005
No	43 (61.4)	10 (14.3)	17 (24.3)		60 (71.4)	7 (8.3)	17 (20.2)	
Previous treatments/donations								
Yes	5 (83.3)	0	1 (16.7)	0.584	30 (54.5)	6 (10.9)	19 (34.5)	0.525
No	38 (59.4)	10 (15.6)	16 (25.0)		70 (63.6)	9 (8.2)	31 (28.2)	

^a Angola, Australia, Brazil, Cape Verde, France, Luxemburg, Russia, USA and Venezuela; ^b Students, unemployed and retired participants; ^c Students were excluded; unemployed or retired participants were classified according their previous main occupation.

Notes: In each variable, the total may not add 70 donors and 165 recipients due to missing values. The proportions may not add 100 due to rounding.

4.4. Factors influencing willingness to donate gametes to friends

Willingness to donate eggs and sperm to friends was more frequent among single/divorced recipients (p = 0.006), and those without a diagnosis of infertility (p = 0.020) or who did not experience previous treatments (p = 0.052) (Table 6).

Despite the lack of statistical significance, a similar position was mainly expressed by recipients who perceived their income as sufficient, as well as by single/divorced donors.

Male donors and those who had children or perceived their income as insufficient tended to report unwillingness to donate gametes to friends more often than their donors' counterparts.

Table 6. Willingness to donate gametes to friends, according to the sociodemographic and reproductive characteristics of the donors and recipients

	Donors				Recipients			
	Yes	Neither willing nor unwilling	No	p	Yes	Neither willing nor willing	No	р
Age, median (P25-P75)	26.0 (24.0-29.0)	26.5 (24.0-30.0)	25.5 (23.0-29.5)	0.941	36.0 (34.0-39.0)	35.0 (31.5-39.5)	36.0 (33.0-39.0)	0.898
	n (%)	n (%)	n (%)		n (%)	n (%)	n (%)	
Sex								
Female	28 (59.6)	10 (21.3)	9 (19.1)	0.318	63 (62.4)	9 (8.9)	29 (28.7)	0.592
Male	14 (60.9)	2 (8.7)	7 (30.4)		35 (54.7)	6 (9.4)	23 (35.9)	
Educational level								
≤ Secondary education (12 th grade)	17 (58.6)	4 (13.8)	8 (27.6)	0.662	52 (57.8)	9 (10.0)	29 (32.2)	0.741
> Secondary education (12 th grade)	25 (61.0)	8 (19.5)	8 (19.5)		44 (62.9)	5 (7.1)	21 (30.0)	
Marital status								
Married/living with a partner	6 (46.2)	2 (15.4)	5 (38.5)	0.324	85 (56.7)	13 (8.7)	52 (34.7)	0.006
Single/divorced	36 (63.2)	0	11 (19.3)		13 (86.7)	2 (13.3)	0	
Country of origin								
Portugal	34 (60.7)	9 (16.1)	13 (23.2)	0.915	90 (58.8)	15 (9.8)	48 (31.4)	0.798
Other ^a	8 (57.1)	3 (21.4)	3 (21.4)		7 (63.6)	0	4 (36.4)	
Working status								
Employed	22 (56.4)	9 (23.1)	8 (20.5)	0.353	90 (60.4)	13 (8.7)	46 (30.9)	0.586
Other ^b	19 (63.3)	3 (10.0)	8 (26.7)		7 (50.0)	2 (14.3)	5 (35.7)	
Occupation ^c								
Upper white collar	12 (60.0)	4 (20.0)	4 (20.0)	0.840	41 (58.6)	8 (11.4)	21 (30.0)	0.691
Lower white collar	10 (52.6)	6 (31.6)	3 (15.8)		31 (63.3)	5 (10.2)	13 (26.5)	
Blue collar	2 (100.0)	0	0		16 (57.1)	1 (3.6)	11 (39.3)	
Perceived income adequacy								
Insufficient	14 (63.6)	1 (4.5)	7 (31.8)	0.124	24 (50.0)	6 (12.5)	18 (37.5)	0.303
Sufficient	28 (58.3)	11 (22.9)	9 (18.8)		72 (62.6)	9 (7.8)	34 (29.6)	
Subjective social class								
Low/ Middle-low	28 (63.6)	6 (13.6)	10 (22.7)	0.560	56 (61.5)	8 (8.8)	27 (29.7)	0.796
Middle-high/ High	9 (52.9)	4 (23.5)	4 (23.5)		22 (61.1)	2 (5.6)	12 (33.3)	
Parental status								
Children	8 (57.1)	1 (7.1)	5 (35.7)	0.372	9 (56.3)	2 (12.5)	5 (31.3)	0.885
No children	34 (60.7)	11 (19.6)	11 (19.6)		88 (59.5)	13 (8.8)	47 (31.8)	
Diagnosis of infertility								
Yes	0	0	0		37 (47.4)	9 (11.5)	32 (41.0)	0.020
No	42 (60.0)	12 (17.1)	16 (22.9)		58 (69.0)	6 (7.1)	20 (23.8)	
Previous treatments/donations								
Yes	3 (50.0)	1 (16.7)	2 (33.3)	0.836	26 (47.3)	8 (14.5)	21 (38.2)	0.052
No	39 (60.9)	11 (17.2)	14 (21.9)		72 (65.5)	7 (6.4)	31 (28.2)	

^a Angola, Australia, Brazil, Cape Verde, France, Luxemburg, Russia, USA and Venezuela; ^b Students, unemployed and retired participants; ^c Students were excluded; unemployed or retired participants were classified according their previous main occupation. **Notes**: In each variable, the total may not add 70 donors and 165 recipients due to missing values. The proportions may not add 100 due to rounding.

5. DISCUSSION/CONCLUSION

This is the first study that provides evidence regarding the views of donors and recipients about the donation of gametes between family members and friends in Portugal. There are few studies assessing the factors and reasons associated with willingness to receive gametes donated by family and friends (14, 89, 91), but literature focusing on the topic of this dissertation is missing, i.e. donors' and recipients' willingness to donate gametes to family members and friends, taking into account sociodemographic and reproductive characteristics.

Most of our participants were willing to donate eggs and sperm to family and friends, which may support the use of such unconventional reproductive combination in the context of the Portuguese Public Bank of Gametes. The overall positive attitude towards gamete donation between family members or friends is aligned with findings from other studies: Chliaoutakis (2002) concluded that 48.9% and 50.7% of the adults residents in Crete, Greece, were ready to donate sperm and oocytes, respectively; and Genuis (1993) revealed that most of the habitants of the city of Edmonton, Canada, were willing to donate eggs (66%) or sperm (63%) to a sibling, whereas 49% were willing to donate gametes for a friend.

Our results may indicate participants' acknowledgment of the advantages of gamete donation between family members and friends for overcoming the supply-demand gap of donated eggs and sperm (3, 16), in a context where genetic bonds are highly valued as a key element that founds parenthood and family relationships (14, 42, 54-56, 67, 69, 100-102). Receptivity to donate gametes to family members or friends may also reflect a desire to help others and to enact solidarity and altruism, which has been previously described in the donation of embryos for research (98, 103, 104), as well as in the donation of biological material (50, 105-107) in Portugal. Further, growing evidence supporting "good news" from donor-conceived families (108) and low parenting stress in known donations (41, 57), as well as feelings of "joy and excitement", positive experiences of donation and harmonious or a stable relationship with the donor (44, 67), might buffer critical reflections about ethical and social challenges (68), thus fostering willingness to donate gametes to family and friends.

This study also revealed that there are differing positions concerning willingness to donate gametes to family and friends. There is room to discuss the contours of ethically robust psychosocial care guided by donors' and recipients' preferences and sensitive to their sex, marital status, history of previous treatments/donations, fertility and parental status, income and level of education.

Although public perspectives about gamete donation, in general, are complex (54) and sociocultural bounded (66), egg donation between family members, in particular sister-to-

sister, tends to persist as the most acceptable form of known donation (1, 13, 14, 44, 56, 68, 93). Our findings also show that women are more likely to be willing to donate eggs to family than men, which may be explained by the reproduction of familial and/or cultural gendered beliefs that regard egg donation as a therapeutic and selfless nonsexual practice that tightens family relations, while sperm donation is viewed as sexually meaningful and potentially inducing family conflicts by threatening the masculinity of the recipient (4, 13, 67, 69). Moreover, maternity can be grounded on the embodied process of pregnancy, whereas paternity is usually established through the genetic link, an accommodation mechanism frequently used by recipients to make sense of egg donation (14, 73, 85, 86).

Willingness to donate gametes to family and friends tended to be more common among the single/divorced participants in this study. Decision making may involve a dyad when it occurs in couples (86), and the partners' position could be supportive or contradict participants' opinion, who would assume a prudent approach by reporting unwillingness to donate. Also, to discuss willingness to donate gametes to family and friends might complicate the couple's relationship (54, 68). This study did not assess the quality of couple relationship as a variable that influences willingness to donate gametes to family and friends (66), and future research should explore it.

Recipients who perceived their income as insufficient expressed unwillingness to donate gametes for family and friends more often than those who reported a sufficient household income. This may reveal concerns about eventual impacts of financial hardship in the health and well-being of future children, since recipients would be aware of the economic status of their extended family and friends. A similar position was observed among donors with children, who usually handle gamete donation by being away from the recipients, both emotionally and geographically, and focusing on their own children, as recognized in Laruelle's work (2010).

As observed by Genuis (1993), donors with higher levels of education were more frequently willing to donate gametes for family. Additionally, recipients with no experience of previous treatments cycles with donated gametes tended to report willingness to donate gametes to friends more often, which may be explained by a special sensitivity to the need to address the supply-demand gap due to the long waiting times before first treatment.

Despite the innovativeness and relevance of the present study, some drawbacks should be acknowledged. The willingness to be involved on an unconventional reproductive combination by donating eggs or sperm to family or friends may be overestimated in this study, as the public bank does not consider such possibility. Thus, participants could conceptualize it as a distant and hypothetical event and not a short-term real decision. However, data related with unwillingness to donate gametes by those recipients who, in fact, cannot do it due to a

diagnosis of infertility supports the robustness of our findings. Furthermore, previous literature showed that willingness to donate gametes for family and friends tends to be more frequent than willingness to receive gametes donated by family and friends (66), which can weaken the use of such strategy to address the supply-demand gap observed in the Portuguese Public Bank of Gametes. The same study speculated that due to higher preference to receive gametes from strangers than from relatives/friends, the population trusts more in medicine and cherish discretion, or they are less willing to discuss their fertility issue with their micro-environment.

The sample size is small, and participants are not representative of all donors and recipients in Portugal. Nevertheless, these are the first data on willingness to donate gametes to family and friends, which encourages future larger and qualitative and mixed-methods studies. Data were collected at the Public Bank of Gametes when the anonymous donation regime was in force in Portugal, and future research should include participants from private healthcare systems, where the supply-demand gap is not an issue, to explore the positioning of donors and recipients facing a transitional regime toward open-identity donation. The perspectives of health professionals also need to be assessed, as they do not always see unconventional reproductive combinations as "normal" (52), which might constrain the use of gametes donated by family and friends.

The use of a comprehensive approach will contribute to better understand how to promote anticipation and reflexivity around the ethical and social implications of donating gametes to family and friends, facilitating the discussion on the circumstances under which unconventional reproductive combinations could be used in Portugal.

REFERENCES

- Söderström-Anttila V, Miettinen A, Rotkirch A, Nuojua-Huttunen S, Poranen A-K, Sälevaara M, et al. Short- and long-term health consequences and current satisfaction levels for altruistic anonymous, identity-release and known oocyte donors. Human Reproduction. 2016;31(3):597-606.
- Laruelle C, Place I, Demeestere I, Englert Y, Delbaere A. Anonymity and secrecy options of recipient couples and donors, and ethnic origin influence in three types of oocyte donation. Human Reproduction. 2010;26(2):382-90.
- Sauer MV, Kavic SM. Oocyte and embryo donation 2006: reviewing two decades of innovation and controversy. Reproductive Biomedicine Online. 2006;12(2):153-62.
- 4. Thorn P. The shift from biological to social fatherhood counselling men and their partners considering donor insemination. Human Fertility (Camb). 2013;16(1):40-3.
- 5. Hamilton M. Sperm donation in the United Kingdom in 2010. Human Fertility. 2010;13(4):257-62.
- De Wert G, Dondorp W, Shenfield F, Barri P, Devroey P, Diedrich K, et al. ESHRE Task Force on Ethics and Law 23: medically assisted reproduction in singles, lesbian and gay couples, and transsexual peopledagger. Human Reproduction. 2014;29(9):1859-65.
- Richards M, Pennings G, Appleby JB. Reproductive donation: practice, policy and bioethics: Cambridge University Press; 2012.
- Fauser BC, Boivin J, Barri PN, Tarlatzis BC, Schmidt L, Levy-Toledano R. Beliefs, attitudes and funding of assisted reproductive technology: Public perception of over 6,000 respondents from 6 European countries. PloS One. 2019;14(1).
- 9. Kocourkova J, Burcin B, Kucera T. Demographic relevancy of increased use of assisted reproduction in European countries. Reproductive Health. 2014;11:37.
- Hammarberg K, Johnson L, Petrillo T. Gamete and embryo donation and surrogacy in australia: the social context and regulatory framework. International Journal of Fertility & Sterility. 2011;4(4):176-83.

- Hammond K. The role of normative ideologies of motherhood in intended mothers' experiences of egg donation in Canada. Anthropology & Medicine. 2018;25(3):265-79.
- Pennings G, de Mouzon J, Shenfield F, Ferraretti AP, Mardesic T, Ruiz A, et al. Socio-demographic and fertility-related characteristics and motivations of oocyte donors in eleven European countries. Human Reproduction. 2014;29(5):1076-89.
- Lessor R. All in the family: social processes in ovarian egg donation between sisters. Sociology of Health and Illness. 1993;15(3):393-431.
- Wyverkens E, Van Parys H, Provoost V, Pennings G, De Sutter P, Buysse A. Sister-to-sister oocyte donation: couples' experiences with regard to genetic ties. Journal of Reproductive and Infant Psychology. 2016;34(3):314-23.
- Barsky M, Blesson CS. Should we be worried about advanced paternal age? Fertility and Sterility. 2020;114(2):259-60.
- Bracewell-Milnes T, Saso S, Bora S, Ismail AM, Al-Memar M, Hamed AH, et al. Investigating psychosocial attitudes, motivations and experiences of oocyte donors, recipients and egg sharers: a systematic review. Human Reproduction Update. 2016;22(4):450-65.
- 17. Nahata L, Stanley N, Quinn G. Gamete donation: current practices, public opinion, and unanswered questions. Fertility and Sterility. 2017;107(6):1298-9.
- 18. Allan S, Balaban B, Banker M, Brinsden P, Buster J, Mocanu E, et al. International Federation of Fertility Societies (IFFS) surveillance 2016.
- Courduriès J, Herbrand C. Gender, kinship and assisted reproductive technologies: future directions after 30 years of research. Enfances Familles Générations Revue interdisciplinaire sur la famille contemporaine. 2014(21).
- De Geyter C, Calhaz-Jorge C, Kupka MS, Wyns C, Mocanu E, Motrenko T, et al. ART in Europe, 2015: results generated from European registries by ESHRE. Human reproduction open. 2020;2020(1):hoz038.
- Gabinete do Secretário de Estado Adjunto e da Saúde. Despacho 3219/2011, de 17 de Fevereiro. Autoriza o Centro Hospitalar do Porto, E. P. E., a criar um Banco

Público de Gâmetas, que será financiado pelo Serviço Nacional de Saúde. Diário da República n.º 34/2011, Série II de 2011-02-17; 2011. p. 8375-8376.

- 22. Gabinete do Secretário de Estado Adjunto e da Saúde. Despacho n.º 679/2017. Redefine a estratégia de acesso a técnicas de Procriação Medicamente Assistida (PMA) no Serviço Nacional de Saúde (SNS), definindo como objetivo estratégico, entre outros, o desenvolvimento de uma rede nacional de Centros Públicos PMA afiliados ao Banco Público de Gâmetas. Diário da República n.º 8/2017, Série II de 2017-01-11. p. 1098 - 1099.
- 23. Governo de Portugal. Lei nº 17/2016 de 20 de Junho. Alarga o âmbito dos beneficiários das técnicas de procriação medicamente assistida, procedendo à segunda alteração à Lei n.º 32/2006, de 26 de julho (procriação medicamente assistida). Diário da República, Série I n.º 116; 2016. p. 1903 1904.
- Conselho Nacional de Procriação Medicamente Assistida. Deliberação n.º 05-III/2019 11 de outubro. Reapreciação do limite de idade do elemento masculino dos casais elegíveis para a aplicação das técnicas de PMA.
- 25. Serviço Nacional de Saúde [Internet]. Portugal: Governo da República Portuguesa. Banco público de gâmetas; 2020 [cited 6 May 2020]. Available from: <u>https://www.sns.gov.pt/cidadao/banco-publico-de-gametas-2/</u>
- De Mouzon J, Goossens V, Bhattacharya S, Castilla JA, Ferraretti AP, Korsak V, et al. Assisted reproductive technology in Europe, 2007: results generated from European registers by ESHRE. Human Reproduction. 2012;27(4):954-66.
- Ferraretti AP, Goossens V, de Mouzon J, Bhattacharya S, Castilla JA, Korsak V, et al. Assisted reproductive technology in Europe, 2008: results generated from European registers by ESHRE[†]. Human Reproduction. 2012;27(9):2571-84.
- Ferraretti AP, Goossens V, Kupka M, Bhattacharya S, de Mouzon J, Castilla JA, et al. Assisted reproductive technology in Europe, 2009: results generated from European registers by ESHRE[†]. Human Reproduction. 2013;28(9):2318-31.
- Kupka MS, Ferraretti AP, de Mouzon J, Erb K, D'Hooghe T, Castilla JA, et al. Assisted reproductive technology in Europe, 2010: results generated from European registers by ESHRE[†]. Human Reproduction. 2014;29(10):2099-113.

- Kupka MS, D'Hooghe T, Ferraretti AP, de Mouzon J, Erb K, Castilla JA, et al. Assisted reproductive technology in Europe, 2011: results generated from European registers by ESHRE[†]. Human Reproduction. 2016;31(2):233-48.
- Calhaz-Jorge C, de Geyter C, Kupka MS, de Mouzon J, Erb K, Mocanu E, et al. Assisted reproductive technology in Europe, 2012: results generated from European registers by ESHRE[†]. Human Reproduction. 2016;31(8):1638-52.
- Calhaz-Jorge C, De Geyter C, Kupka MS, de Mouzon J, Erb K, Mocanu E, et al. Assisted reproductive technology in Europe, 2013: results generated from European registers by ESHRE[†]. Human Reproduction. 2017;32(10):1957-73.
- De Geyter C, Calhaz-Jorge C, Kupka MS, Wyns C, Mocanu E, Motrenko T, et al. ART in Europe, 2014: results generated from European registries by ESHRE: The European IVF-monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE). Human Reproduction. 2018;33(9):1586-601.
- Janssens PM, Thorn P, Castilla JA, Frith L, Crawshaw M, Mochtar M, et al. Evolving minimum standards in responsible international sperm donor offspring quota. Reproductive Biomedicine Online. 2015;30(6):568-80.
- Pennings G, Vayena E, Ahuja K. Balancing ethical criteria for the recruitment of gamete donors. In: Richards M. PG, & Appleby J. B., editor. Reproductive donation: Practice, policy, and bioethics. Cambridge: Cambridge University Press; 2012. p. 150-67.
- Le Lannou D. [What strategy to improve the recruitment of gamete donors?].
 Gynécologie, Obstétrique & Fertilité. 2013;41(12):711-4.
- 37. Da Silva SP, De Freitas C, Baía I, Samorinha C, Machado H, Silva S. "Doação de gametas: questões sociais e éticas (não) respondidas em Portugal".
 Cadernos de Saúde Publica. 2019;35(2).
- Silva S, Samorinha C, Baía I, Pinto da Silva S, De Freitas C. Genes, cidadania e participação na doação de gâmetas. In: Machado H, editor. Genética e Cidadania, Porto: Edições Afrontamento; 2017. p. 221-40.
- 39. Hertz R, Nelson MK, Suñol J. Attitudes toward regulations of reproductive care in the European Union: a comparison between travellers for cross-border

reproductive care and citizens of the local country. Facts, Views and Vision in Obstetrics and Gynaecology. 2016;8(3):147.

- 40. Salama M, Isachenko V, Isachenko E, Rahimi G, Mallmann P, Westphal LM, et al. Cross border reproductive care (CBRC): a growing global phenomenon with multidimensional implications (a systematic and critical review). Journal of Assisted Reproduction and Genetics. 2018;35(7):1277-88.
- Khamsi F, Endman MW, Lacanna IC, Wong J. Some psychological aspects of oocyte donation from known donors on altruistic basis. Fertility and Sterility. 1997;68(2):323-7.
- Yee S, Hitkari JA, Greenblatt EM. A follow-up study of women who donated oocytes to known recipient couples for altruistic reasons. Human Reproduction. 2007;22(7):2040-50.
- 43. Vayena E, Golombok S. 10 Challenges in intra-family donation. Reproductive Donation: Practice, Policy and Bioethics. 2012:168.
- Jadva V, Casey P, Readings J, Blake L, Golombok S. A longitudinal study of recipients' views and experiences of intra-family egg donation. Human Reproduction. 2011;26(10):2777-82.
- 45. Blyth E, Frith L. The UK's gamete donorcrisis'-a critical analysis. Critical Social Policy. 2008;28(1):74-95.
- 46. Daniels K. Anonymity and openness and the recruitment of gamete donors. Part2: Oocyte donors. Human Fertility (Camb). 2007;10(4):223-31.
- Daniels KR, Grace VM, Gillett WR. Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception. Human Reproduction. 2011;26(10):2783-90.
- 48. Gabinete do Secretário de Estado Adjunto e da Saúde. Despacho nº 3192/2017 de 17 de abril. Estabelece as condições de que depende a atribuição da devida compensação dos dadores de gâmetas. Revoga o Despacho n.º 5015/2011, publicado a 23 de março. Diário da República, Série II - n.º 75/2017; 2017. p. 7192 - 7193.
- 49. Ministério da Saúde. Decreto-Lei 113/2011 de 29 de Novembro. Regula o acesso às prestações do Serviço Nacional de Saúde por parte dos utentes no que

respeita ao regime das taxas moderadoras e à aplicação de regimes especiais de benefícios. Diário da República n.º 229/2011, Série I de 2011-11-29. p. 5108 – 5110.

- Samorinha C, De Freitas C, Baía I, Machado H, Vale-Fernandes E, Silva S. Payment to gamete donors: equality, gender equity, or solidarity? Journal of Assisted Reproduction and Genetics. 2020;37(1):133-40.
- Moura A, Samorinha C, Silva S. Letter to the Editor: National Awareness Campaigns About Gamete Donation-The Role of Healthcare Providers. Acta Medica Portuguesa. 2018;31(4):229-30.
- 52. Klitzman R. Unconventional combinations of prospective parents: ethical challenges faced by IVF providers. BMC Medical Ethics. 2017;18(1):18.
- De Wert G, Dondorp W, Pennings G, Shenfield F, Devroey P, Tarlatzis B, et al. Intrafamilial medically assisted reproduction[†]. Human Reproduction. 2011;26(3):504-9.
- Ethics Committee of the American Society for Reproductive Medicine. Using family members as gamete donors or gestational carriers. Fertility and Sterility. 2017;107(5):1136-42.
- 55. Mindes EJ, Covington LS. Counseling known participants in third party reproduction. Fertility Counseling: Clinical Guide and Case Studies2015. p. 136.
- Winter A, Daniluk JC. A gift from the heart: The experiences of women whose egg donations helped their sisters become mothers. Journal of Counseling & Development. 2004;82(4):483-95.
- 57. Josephs L, Grill E, Crone K, Applegarth L, Cholst I, Rosenwaks Z. Sister ovum donation: Psychological outcomes. Fertility and Sterility. 2004;82:S102.
- 58. Advisory Committee on Assisted Reproductive Technology (ACART). Guidelines on Donation of Eggs or Sperm between Certain Family Members. 2013.
- Bos HM, Gartrell NK. Adolescents of the US National Longitudinal Lesbian Family Study: the impact of having a known or an unknown donor on the stability of psychological adjustment. Human Reproduction. 2011;26(3):630-7.

- Gartrell NK, Bos H, Goldberg NG, Deck A, van Rijn-van Gelderen L. Satisfaction with known, open-identity, or unknown sperm donors: reports from lesbian mothers of 17-year-old adolescents. Fertility and Sterility. 2015;103(1):242-8.
- Greenfeld DA, Mazure CM, Olive DL, Keefe DL. Similarities and differences between anonymous and directed candidates for oocyte donation. Journal of Assisted Reproduction and Genetics. 1995;12(2):118-22.
- Practice Committee of the American Society for Reproductive Medicine. Recommendations for gamete and embryo donation: a committee opinion. Fertility and Sterility. 2013;99(1):47-62. e1.
- Blyth E, Crawshaw M, Frith L, Jones C. Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence. Journal of Law and Medicine. 2012;19(4):769.
- Malvasi A, Signore F, Napoletano S, Bruti V, Sestili C, Di Luca N. 2014-2017. How medically assisted reproduction changed in Italy. A short comparative synthesis with European countries. La Clinica Terapeutica. 2017;168(4):e248e52.
- 65. ESHRE and Fertility Europe. A policy audit on fertility. Analysis of 9 EU countries 2017.
- Chliaoutakis JE. A relationship between traditionally motivated patterns and gamete donation and surrogacy in urban areas of Greece. Human Reproduction. 2002;17(8):2187-91.
- Martin N, Mahmoodi N, Hudson N, Jones G. Recipient and donor experiences of known egg donation: implications for fertility counselling. Journal of Reproductive and Infant Psychology. 2019:1-13.
- Van Parys H, Provoost V, Zeiler K, De Sutter P, Pennings G, Buysse A. Constructing and enacting kinship in sister-to-sister egg donation families: a multi-family member interview study. Sociology of Health and Illness. 2017;39(6):847-62.
- Baetens P, Devroey P, Camus M, Van Steirteghem A, Ponjaert-Kristoffersen I. Counselling couples and donors for oocyte donation: the decision to use either known or anonymous oocytes. Human Reproduction. 2000;15(2):476-84.

- 70. Havelock J, Liu K, Levitan S, Petropanagos A, Kahn L. Guidelines for Third Party Reproduction. CFAS; 2016.
- Southern African Society of Reproductive Medicine and Gynaecological Endoscopy. SASREG guidelines for Egg Donation agencies. [cited August, 14, 2020]. Available at <u>https://sasreg.co.za/</u>.
- 72. Inhorn MC, Tremayne S. Islam, Assisted Reproduction, and the Bioethical Aftermath. Journal of Religion and Health. 2016;55(2):422-30.
- Van Berkel D, Candido A, Pijffers W. Becoming a mother by non-anonymous egg donation: secrecy and the relationship between egg recipient, egg donor and egg donation child. Journal of Psychosomatic Obstetrics & Gynecology. 2007;28(2):97-104.
- Busardò FP, Gulino M, Napoletano S, Zaami S, Frati P. The evolution of legislation in the field of Medically Assisted Reproduction and embryo stem cell research in European union members. BioMed Research International. 2014;2014:307160.
- PARLAMENTUL Republicii Moldova. LEGE Nr. 138/2012 din 15.06.2012 privind sănătatea reproducerii. Publicat : 28-09-2012 în Monitorul Oficial Nr. 205-207 art. 673., (2012).
- 76. Приказ Министерства здравоохранения РФ от 30 августа 2012 г. № 107н "о порядке использования вспомогательных репродуктивных технологий, противопоказаниях и ограничениях к их применению", (2012).
- 77. Ministry of Health [Internet]. State of Israel. Egg and sperm donation in Israel. Health Ministry of Israel; 2020 [cited 4 May 2020]. Available from: https://www.health.gov.il/English/Topics/fertility/Pages/ovum_donation.aspx [
- Jadva V, Lamba N, Kadam K, Golombok S. Indian egg donors' characteristics, motivations and feelings towards the recipient and resultant child. Reproductive Biomedicine & Society Online. 2015;1(2):98-103.
- Malhotra N, Shah D, Pai R, Pai HD, Bankar M. Assisted reproductive technology in India: A 3 year retrospective data analysis. Journal of Human Reproductive Sciences. 2013;6(4):235-40.

- Tribunal Constitucional. Acórdão do Tribunal Constitucional nº 225/2018 de 7 de maio. Diário da República, Série I - n.º 87; 2018. p. 1885 - 1979.
- 81. Governo de Portugal. Lei nº 48/2019 de 8 de julho. Regime de confidencialidade nas técnicas de procriação medicamente assistida, procedendo à sexta alteração à Lei n.º 32/2006, de 26 de julho (procriação medicamente assistida). Diário da República, Série I - n.º 128; 2019. p. 3415 - 3416.
- Adamson GD, de Mouzon J, Chambers GM, Zegers-Hochschild F, Mansour R, Ishihara O, et al. International Committee for Monitoring Assisted Reproductive Technology: world report on assisted reproductive technology, 2011. Fertility and Sterility. 2018;110(6):1067-80.
- Ethics Committee of the American Society for Reproductive Medicine. Family members as gamete donors and surrogates. Elsevier; 2003. Report No.: 0015-0282 Contract No.: 5.
- 84. Freeman T, Jadva V, Tranfield E, Golombok S. Online sperm donation: a survey of the demographic characteristics, motivations, preferences and experiences of sperm donors on a connection website. Human Reproduction. 2016;31(9):2082-9.
- 85. Acharya S, Bryant L, Twiddy M. Altruism or obligation? The motivations and experience of women who donate oocytes to known recipients in assisted conception treatment: an interpretative phenomenological analysis study. Journal of Psychosomatic Obstetrics & Gynecology. 2017;38(1):4-11.
- Yee S, Blyth E, Tsang AKT. Oocyte donors' experiences of altruistic known donation: a qualitative study. Journal of Reproductive and Infant Psychology. 2011;29(4):404-15.
- Blyth E, Yee S, Tsang AKT. "They were my eggs; they were her babies": known oocyte donors' conceptualizations of their reproductive material. Journal of Obstetrics and Gynaecology Canada. 2011;33(11):1134-40.
- Yee S, Blyth E, Tsang AKT. Views of donors and recipients regarding disclosure to children following altruistic known oocyte donation. Reproductive Biomedicine Online. 2011;23(7):851-9.

- Hudson N, Culley L, Rapport F, Johnson M, Bharadwaj A. "Public" perceptions of gamete donation: a research review. Public Understanding of Science. 2009;18(1):61-77.
- Genuis SJ, Chang W-C, Genuis SK. Public attitudes in Edmonton toward assisted reproductive technology. CMAJ: Canadian Medical Association Journal. 1993;149(2):153.
- 91. Urdapilleta L, Chillik C, Fernandez D. News and Views: Do Fertile and Infertile People Think Differently About Ovum Donation? Journal of Assisted Reproduction and Genetics. 2001;18(1):1.
- 92. Ethics Committee of the American Society for Reproductive Medicine. Electronic address aao, Ethics Committee of the American Society for Reproductive M. Misconduct in third-party assisted reproduction: an Ethics Committee opinion. Fertility and Sterility. 2018;110(6):1012-6.
- 93. Lessor R, Reitz K, Balmaceda J, Asch R. A survey of public attitudes toward oocyte donation between sisters. Human Reproduction. 1990;5(7):889-92.
- 94. Daniels K. The Perspective of Adult Donor Conceived Persons. Assistierte Reproduktion mit Hilfe Dritter: Springer; 2020. p. 443-59.
- 95. Nordqvist P. Un/familiar connections: on the relevance of a sociology of personal life for exploring egg and sperm donation. Sociology of Health and Illness. 2019;41(3):601-15.
- Gürtin ZB, Faircloth C. Conceiving contemporary parenthood: imagining, achieving and accounting for parenthood in new family forms. Anthropology & Medicine. 2018;25(3):243-8.
- Van Gelderen L, Bos HM, Gartrell N, Hermanns J, Perrin EC. Quality of life of adolescents raised from birth by lesbian mothers: The US National Longitudinal Family Study. Journal of Developmental and Behavioral Pediatrics. 2012;33(1):17-23.
- 98. Baía I, de Freitas C, Samorinha C, Provoost V, Silva S. Dual consent? Donors' and recipients' views about involvement in decision-making on the use of embryos created by gamete donation in research. BMC Medical Ethics. 2019;20(1):90.

- 99. Statistics Portugal. Portuguese Classification of Occupations 2010. [Accessed 11 August 2020]. Available at: <u>https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_publicacoes&PUBLICAC</u> <u>OESpub_boui=108021532&PUBLICACOESmodo=2</u>.
- 100. Silva S. "Direito, genética e família: o caso da doação de gâmetas em Portugal". In: Veloso L, Silva S, (orgs.), editors. Representações jurídicas das tecnologias reprodutivas: contributos para uma reflexão. 10. Porto: Universidade do Porto; 2009. p. 83-99.
- 101. Silva S, Machado H. The construction of meaning by experts and would-be parents in assisted reproductive technology. Sociology of Health and Illness. 2011;33(6):853-68.
- 102. Henriques A, Samorinha C, Ramos E, Silva S. Reproductive trajectories and social-biological dimensions in parenthood: Portuguese version of the Meaning of Parenthood scale. Porto Biomedical Journal. 2020;5(4).
- 103. Samorinha C, Pereira M, Machado H, Figueiredo B, Silva S. Factors associated with the donation and non-donation of embryos for research: a systematic review. Human Reproduction Update. 2014;20(5):641-55.
- 104. Samorinha C, Severo M, Alves E, Machado H, Figueiredo B, Silva S. Factors associated with willingness to donate embryos for research among couples undergoing IVF. Reproductive Biomedicine Online. 2016;32(2):247-56.
- Machado H, Silva S. Voluntary participation in forensic DNA databases: altruism, resistance, and stigma. Science, Technology, & Human Values. 2016;41(2):322-43.
- 106. Machado H, Silva S. Public participation in genetic databases: crossing the boundaries between biobanks and forensic DNA databases through the principle of solidarity. Journal of Medical Ethics. 2015;41(10):820-4.
- 107. Silva S, Machado H. Trust, morality and altruism in the donation of biological material: the case of Portugal. New genetics and society. 2009;28(2):103-18.
- 108. Scheib JE, McCormick E. Adults from donor-conceived families: some good news (from a longitudinal study). Fertility and Sterility. 2020; 114(4): 764-5.

ANNEX 1. Informative leaflet

Quem coordena o estudo?

A coordenação é da responsabilidade do Instituto de Saúde Pública da Universidade do Porto (ISPUP), sendo a investigadora principal Susana Silva.

Este estudo é financiado pela **Fundação para a Ciência e a Tecnologia**.

Como será usada a informação?

Os resultados deste estudo serão divulgados de diversas formas (relatórios, artigos científicos e comunicações orais), junto de pessoas que podem tomar decisões em relação aos serviços prestados e às políticas que regulam a doação de gâmetas.

Referimo-nos, por exemplo, a membros do Conselho Nacional de Procriação Medicamente Assistida e da Sociedade Portuguesa de Medicina da Reprodução. A sua participação será muito valiosa!

A aplicação do questionário só acontecerá depois de esclarecidas todas as suas questões e após assinatura do consentimento informado. Ser-lhe-á dado este folheto informativo e uma cópia do consentimento informado.

Para qualquer dúvida, sugestão ou comentário, por favor, entre em contacto connosco:

Investigadoras: Susana Silva | Catarina Samorinha Instituto de Saúde Pública, Universidade do Porto Rua das Taipas, 135 4050-600 Porto, Portugal Tlf.: 222 061 820 | 926 333 369 E-mail: engaged@ispup.up.pt



Este estudo é financiado por Fundos FEDER através do Programa Operacional Competitividade e Internacionalização e por Fundos Nacionais através da FCT - Fundação para a Ciência e a Tecnologia (POCI-01-0145-FEDER-016762), no âmbito do projeto "ENGAGED – Bionetworking e cidadania na doação de gâmetas" (Ref.ª FCT PTDC/IVC-ESCT/6294/2014).



FOLHETO DE INFORMAÇÃO AO PARTICIPANTE

Doação de gâmetas: Envolvimento público e cuidados centrados nas pessoas

Informação sobre o estudo

Bom dia,

Estamos a desenvolver um estudo sobre as opiniões e experiências de dadores, beneficiários e profissionais de saúde envolvidos na doação de gâmetas.

Gostaríamos de contar com a sua colaboração!

Antes de decidir, é importante que saiba mais acerca deste estudo e do que lhe é pedido se aceitar participar.

Por favor leia atentamente este folheto informativo e coloque todas as perguntas que achar necessário.

Obrigado pelo tempo concedido à leitura desta informação!

Porque queremos falar consigo?

A finalidade deste estudo é conhecer as opiniões de dadores e dadoras de gâmetas, beneficiários e profissionais de saúde sobre os cuidados de saúde e as políticas que regulam a doação de gâmetas.

Serão convidados a participar neste estudo mulheres e homens que pretendem doar ovócitos e espermatozoides a um banco de gâmetas, beneficiários e profissionais de saúde.

Quais serão os benefícios da minha participação?

Será participante de um estudo inovador que procura conhecer as opiniões dos/as dadores/as de gâmetas, beneficiários e profissionais de saúde, contribuindo para:

- Promover sistemas de saúde centrados nas pessoas, que tenham em conta as suas necessidades e preferências;

- Conhecer as opiniões de todas as pessoas envolvidas na doação de gâmetas sobre as políticas que regulam esta prática;

 Incentivar o debate público em torno das respostas aos desafios que enfrenta a doação de gâmetas em Portugal.

Em que consiste a sua participação?

Gostaríamos que respondesse a um questionário, com uma duração prevista de 15 minutos.

Durante a aplicação do questionário, pode colocar todas as suas dúvidas e questões aos investigadores. Como participante não terá que falar sobre assuntos que prefira não abordar.

A informação é confidencial?

Sim, nos termos exigidos pela lei. Este estudo foi aprovado pela Comissão Nacional de Proteção de Dados.

A informação será armazenada de forma segura. Sempre que as informações recolhidas forem utilizadas, nunca será usado o seu verdadeiro nome.

Sou obrigado/a a participar?

Não. Caso decida não participar, esta decisão não terá quaisquer desvantagens nem influenciará os cuidados de saúde. Mesmo depois de aceitar, poderá desistir em qualquer altura e sem justificação.