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“I never felt left out”: perceptions of patients on transitioning to gamete donation treatment

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“I NEVER FELT LEFT OUT”: PERCEPTIONS OF PATIENTS ON TRANSITIONING TO GAMETE DONATION TREATMENT

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Resumo

A infertilidade tem consequências pessoais e sociais no indivíduo e no casal. Especificamente, o tratamento com recurso à doação de gametas provoca dor e sofrimento e pode ter um impacto negativo no bem-estar pessoal e relacional. Apesar de ser, atualmente, uma opção de tratamento comum, pouco se sabe acerca do processo de tomada de decisão na transição dos casais para o mesmo. Este estudo tem como objetivo avaliar as experiências e preferências dos pacientes de doação reprodutiva no processo de tomada de decisão, com o objetivo de informar os esforços futuros de auxílio deste processo. Foi desenvolvida uma abordagem qualitativa através das entrevistas semiestruturadas de 9 pacientes em relações heterossexuais. Com base na *Grounded Theory*, os dados foram analisados com o software NVivo 12. Da análise resultaram duas grandes categorias: facilitadores, dos quais foram encontradas onze categorias; e barreiras, dos quais foram encontradas seis categorias. Em relação aos facilitadores, as categorias foram: tomada de decisão partilhada (SDM), estar informado, ajuda psicológica, rede de apoio, sucesso do tratamento, plano de parentalidade, ter apenas uma opção disponível, "pais são quem cuida", relação médico-paciente, acordo entre o casal e idade materna avançada. Quanto às barreiras, as categorias foram: luto da parentalidade genética, relação médico-paciente, receios pelo futuro da criança, isolamento, custos do tratamento e lista de espera do SNS. Descobrimos que o processo de tomada de decisão para a utilização de gametas doados é extremamente complexo e pode ser auxiliado pela intervenção psicológica e implementação de SDM.

Palavras-Chave: Infertilidade, Tratamento com recurso a Doação de Gâmetas, Processo de Tomada de Decisão

Abstract

Infertility has personal and social consequences on the individual and couple. Specifically, gamete donation treatment causes pain and suffering, and may have a negative impact on personal and relational wellbeing. Though being, nowadays, a common treatment option, little is known about the decision-making process behind couples' transition to it. This study aims to assess reproductive donation patient's experiences and preferences in the decision-making process, with the goal of informing future efforts of aiding this process. A qualitative approach was developed through semi-structured interviews of 9 patients in heterosexual relationships. Based on grounded theory approach, data was analyzed with NVivo 12 software. The analysis resulted in two major categories: facilitators, in which eleven categories were found, and barriers, in which six categories were found. Regarding facilitators, the categories were: shared decision making (SDM), being informed, psychological help, support system, treatment success, desiring to be a parent, having only one available option, "parents are the ones who nurture", doctor-patient relationship, couple's agreement and advanced maternal age. As for barriers, the categories were: grieving genetic parenthood, doctor-patient relationship, fearing for the child's future, feeling isolated, treatment costs and SNS's waiting list. We found that the decision-making process of usage of gamete donation is extremely complex and may be aided by psychological intervention and implementation of SDM.

Key words: Infertility, Gamete Donation Treatment, Decision-Making Process

Résumé

L'infertilité a des conséquences personnelles et sociales sur l'individu et le couple.

Plus précisément, le traitement ayant recours au don de gamètes est source de douleur et de souffrance et peut avoir un impact négatif sur le bien-être personnel et relationnel. Bien qu'il s'agisse aujourd'hui d'une option de traitement courante, on sait peu de choses sur le processus décisionnel des couples qui y ont recours. Cette étude vise à évaluer les expériences et les préférences des patients concernés par le don reproductif dans le processus de leur prise de décision, avec pour objectif d'éclairer les efforts futurs de ceux qui viennent en aide dans ce processus. Une approche qualitative a été développée à partir des entretiens semi-structurés réalisés auprès de neuf patients ayant des relations hétérosexuelles.

Basées sur la *Grounded Theory*, les données ont été analysées à l'aide du logiciel NVivo 12. Deux catégories principales ont résulté de l'analyse : les facilitateurs, parmi lesquels onze catégories ont été répertoriées, et les obstacles, parmi lesquels six catégories ont été répertoriées. Concernant les facilitateurs, les catégories sont les suivantes : prise de décision partagée (SDM), être informé, aide psychologique, réseau de soutien, réussite du traitement, projet parental, n'avoir qu'une seule option disponible, parents sont ceux qui élèvent, relation médecin-patient, accord entre le couple et âge maternel avancé. Quant aux obstacles, les catégories sont les suivantes : deuil de la parentalité génétique, relation médecin-patient, craintes pour l'avenir de l'enfant, isolement, coûts liés au traitement et liste d'attente du SNS. Nous avons constaté que le processus de prise de décision concernant le recours au don de gamètes est extrêmement complexe et qu'il peut être facilité par une intervention psychologique et la mise en œuvre de la SDM.

Mots-clés: Infertilité, Traitement par don de gamètes, Processus de décision.

“I never felt left out”: perceptions of patients on transitioning to gamete donation treatment

Infertility

Most couples desire to be parents and have life plans and dreams that include children (ESA/P, 2003; Boivin et al., 2007). However, not all of them are able to achieve a pregnancy spontaneously and, therefore, will need medical help to solve underlying fertility issues. Infertility is characterized by “the failure to establish a clinical pregnancy after 12 months of regular, unprotected sexual intercourse or due to an impairment of a person's capacity to reproduce either as an individual or with his/her partner” (Zegers-Hochschild et al., 2017, p. 401). According to Mascarenhas et al (2012), an estimated 48.5 million couples worldwide were infertile in 2010, of which 19.2 million were unable to have a first child (primary infertility) and 29.3 million were unable to have an additional child (secondary infertility). In fact, it is estimated that about 10% of couples (Boivin et al, 2007) who try to achieve a pregnancy will fail to do so within 2 years of regular unprotected sexual intercourse. Similarly, the prevalence of infertility in Portugal for women between the ages of 25 and 69 is 9-10% (Silva Carvalho & Santos, 2009). This is, of course, experienced as a stressful and frequently heart-breaking situation (Cousineau & Domar, 2007).

Most men and women describe infertility as a life changing experience that often entails unexpected stressors (Nichols & Pace Nichols, 2000). In fact, approximately 30%

of women and 10% of men undergoing ART fulfil the criteria for a depressive and/or anxiety disorder (Volgsten et al., 2008). For women, unsuccessful treatment, in general, tends to result in an increase of depressive symptoms, which aren’t likely to diminish shortly after treatment (Verhaak et al., 2007). On the other hand, successful treatment tends to alleviate negative emotional responses (Verhaak et al., 2007). Similarly, men’s psychological adaptation to fertility treatments in the year following the initial evaluation tends to be poor (Martins et al., 2016), with increases to infertility related stress and depression. Jordan and Revenson (1999) report that men tend to cope by increasing their involvement in work and other activities and are more optimistic and problem-solving-oriented, but also less apt to use social support.

Infertility can have harmful social consequences on the individual and couple, such as overt ostracism as well as subtle forms of social stigma, leading to isolation and mental distress (Cousineau & Domar, 2007). Although disclosure of fertility status has a big impact in constructing and maintaining relationships (Greene et al., 2006), couples may feel stigmatized and fear disclosing their infertility to their social networks. In fact, Martins et al (2013) reported that approximately 22% of couples had hidden their fertility issue from at least one close relationship, and 35% to at least one distant relationship. Moreso, those experiencing infertility often receive unhelpful social support from well-intended others, which results in additional stress (Mindes et al., 2003; Slade et al., 2007).

Indeed, dealing with infertility can be extremely dishevelling for a couple's sense of order in their world. For many couples, their infertility becomes the focal point of daily conversation and tasks, often overlooking other important aspects of life (Cousineau &

Domar, 2007). Nonetheless, couples undergoing ART report that infertility and subsequent treatment has brought them closer together and strengthened their marriage, affecting their partner relationship for the better (Schmidt et al., 2005; Holter et al., 2006). Braverman (2004) adds that infertility can cause significant disruption in an individual's our couple's sex life. Couples report feeling like their intimate life is being intruded upon by the testing. In fact, women with a diagnosis of infertility are at a higher risk for sexual dysfunction compared with women without infertility (Millheiser et al., 2010) Some men may also experience short term episodes of impotence and sexual performance anxiety after detection of abnormalities in the results of their analysis (Saleh et al., 2003).

Once couples decide to pursue medical treatment, they're forced to make significant changes to their lifestyle. Fertility treatment often supersedes other aspects of life such that important career choices or lifestyle aspirations may be postponed or dismissed (McLaney et al., 1995). Moreover, maintaining a rigorous medication schedule, recovering from procedures, and dealing with mood fluctuations may hinder the ability to concentrate on long term goals (Mahlstedt, 1985). Further, patients report that the shock of treatment failure requires some processing time before they feel able to discuss additional treatment (Peddie et al., 2005). The decision process of whether to undergo more treatment or not is in itself distressing for couples (Peddie et al., 2005) and better decisional support should be provided.

In conclusion, the psychological and social impact of infertility and subsequent treatment must be taken into consideration.

Transition to gamete donation

Since IVF and other notable developments (ICSI, pre-implantation diagnostic testing, and most recently mitochondrial replacement techniques) became an option, considerable resources have been invested to give patients a genetically related child. In fact, assisted reproduction techniques have been criticized for overvaluing genetic relatedness in parent-child relationships (Kirkman-Brown & Martins, 2020).

However, for many couples, assisted reproduction treatment is often unsuccessful, especially when "own genes" techniques are prioritized. In fact, live birth rate per embryo transfer with egg or embryo donation is above 50% and the chance of a live birth is significantly higher in donor IVF cycles than autologous cycles (Yeh et al., 2014). Furthermore, the odds of not having a live birth decrease with the use of own oocytes and female age, as well as with treatment history and each ART cycle (Vaegter et al., 2017). Nonetheless, opting for gamete donation is usually a patient's last resort (Richards et al., 2012), starting after many years of trying to conceive and unsuccessful treatments. Therefore, repeating cycles with couples' own gametes instead of transitioning them to donation may be contributing to unnecessary burden and painful experiences.

Despite great techno-scientific advances, in some cases the use of reproductive donation remains the only way for a couple to achieve a pregnancy (Gürtin & Vayena, 2012). Whilst these techniques are increasingly seen as socially accepted among heterosexual couples in some cultures, in others they remain prohibited, heavily stigmatized, and unacceptable (Gürtin & Vayena, 2012). There are multiple reasons why a couple might opt for donated gametes techniques, such as premature menopause, advanced age, azoospermia, ... Nonetheless, in general, it is a choice that causes pain and suffering, and which may have a negative impact on personal and relational wellbeing (Carrillo & Pareja, 2007). For most couples there's a sense that they failed to achieve their dream, their family planning needs to be restructured and their self-esteem is affected (Carrillo & Pareja, 2007).

Couples considering gamete donation face issues such as their feelings and attitudes towards the donor, the role the donor plays in the couple's relationship, feelings about not being the genetic parent and whether to disclose the nature of conception and genetic origins to the child and other family members and friends (Cramond, 1998). Some patients may also feel like gamete donation techniques contradict their religious beliefs (Pettee & Weckstein, 1993). However, Daniels et al (1996) report that couples' feelings tend to improve overtime, concluding that while couples may experience ambivalent feelings during the initial stages, concerns about the method of treatment subside.

In fact, evidence supports that donor-conceived children and their parents are psychologically well adjusted and do not differ from families with own-gamete conceived children (Golombok et al., 2011; Golombok et al., 2013; Golombok et al., 2017). Further, relationship quality also does not seem to be impaired, with reports of high quality and similar representations between both genetically related parents and non-related (Golombok et al., 2005; Imrie et al., 2018).

It has been argued that the priority given to genetic ties in the science and regulations associated with ART might invalidate forms of parenthood that do not imply shared genetic relatedness (Griffiths, 2016). Social and cultural expectations in favour of genetic motherhood may also put pressure on women to engage in physically, psychologically, and financially risky ART (Petropanagos et al., 2015; Petropanagos, 2017). Similarly, the same social and cultural expectations favour genetic fatherhood, leading to experiences of infertility as a threat to masculinity and sense of self (Hinton & Miller, 2013).

Thus, considering the psychosocial impact of reproductive donation, psychologists may play an important role in helping couples determine whether donated gametes is a valid and tolerable option for them, as well as helping them cope with possible stressors inherent to this treatment (Carrillo & Pareja, 2007).

Shared Decision Making

Shared decision-making (SDM) is a collaborative clinical process in which patients and health care professionals (although friends and family members may be invited to participate as well) make appropriate care decisions together, considering not only the best scientific evidence available (options and their risks and benefits), but also patients' values, preferences, life situation, and desire to know about disease process and prognosis (Barry & Edgman-Levitan, 2012; Søndergaard et al., 2019). In essence, SDM is a process in which decision-making is performed with the patients and not for the patients (Steffensen et al., 2018).

Optimal care of patients with complex illnesses requires clinicians and patients to share several distinct types of information and make difficult decisions. Sometimes, there is one clearly superior choice and patient preferences play little or no role. However, most of the times, namely infertility, more than one reasonable option exists (including doing nothing), and different choices imply different possible therapeutic effects and side effects (Barry & Edgman-Levitan, 2012). In these cases, patient involvement in decision making adds substantial value (Barry & Edgman-Levitan, 2012).

Developed by Irving Janis and Leon Mann, the conflict-theory model of decision-making views the decision maker as both a thinking and sentient being, who must choose from among a set of alternatives, each of which has both positive and negative outcomes (Loneck & Lola, 1988). Moreso, the decision making is described as a process, rather than an event. According to the theory, a stressful event – “any change in the environment that typically induces a high degree of unpleasant emotion (such as, anxiety, guilt, or shame) and affects normal patterns of information proccssing" (Janis & Mann, 1977, p. 50 as cited in Loneck & Lola, 1988) – triggers decisional conflict within an individual - "simultaneous opposing tendencies within as individual to accept and at the same time to reject a givcn course of action" (Janis & Mann, 1982, p. 50 as cited in Loneck & Lola, 1988) – which results in psychological stress and, consequently, leads to entry into the stages of decision making (Janis & Mann, 1977 as cited in Loneck & Lola, 1988). These stages include: appraising the challenge, in which “the individual assesses the stressful event regarding possible consequences if the continues on his present course of action” (Loneck & Lola, 1988, p. 123); surveying the alternatives, in which “the person begins consideration of courses of action available to them" (Loneck & Lola, 1988, p. 123); weighting the alternatives, in which "the individual considers the positive and negative aspects of each alternative and makes a tentative selection based on his assessment" (Loneck & Lola, 1988, p. 123); deliberating about commitment, in which "the person begins to think about starting the new plan of action and telling others about his intentions to do so" (Loneck & Lola, 1988, p. 123); and adhering despite negative feedback, in which "the individual begins the new course of action" (Loneck & Lola, 1988, p. 123).

Thus, Janis and Mann (1977 as cited in Semmel, 1979) claim good decisions are those characterized by "vigilant information processing", which occurs when an individual adheres to a rigorous checklist involving systematic search, appraisal, and contingency planning. Deviating from these criteria leads to defective information processing, exemplified by various forms of "defensive avoidance" (e.g., buck-passing, procrastination, pre- and post-bolstering, over-reaction in the form of hypervigilance). These and other dysfunctional coping mechanisms are likely to result in decision error or post-decision regret.

Therefore, when there is more than one viable option, healthcare professionals can facilitate and promote shared decision-making by encouraging patients to let them know what is important to them, as well as providing decision aids that increase patient awareness and understanding of treatment options and possible outcomes (Barry & Edgman-Levitan, 2012). According to Stacey et al (2017), the use of patient decision aids for a range of preference-sensitive decisions led to increased knowledge and risk perception accuracy, a greater number of decisions congruous with patients' values, reduced level of decisional conflict for patients and fewer cases of passivity or indecisiveness. Not only can SDM increase patient involvement by making the patient comfortable in taking active part in decision making, but it may also help physicians respect the fact that patients value the potential benefits or harms of a certain option differently (Søndergaard et al., 2019). However, SDM should incorporate questions to clarify the amount of information desired and to which degree the patient wishes to participate in the decision-making process (Søndergaard et al., 2019). Taking an active part in decision making should always be an option, but never an obligation.

Elwyn et al (2012) proposed a three-step model for achieving SDM, in which the three key steps are choice talk, option talk and decision talk. Choice talk refers to making sure that patients know that reasonable options exist and consists of stepping back and acknowledging the problem and the fact that a choice needs to be made, offering said choices and justifying them, while emphasising the importance of respecting individual preferences and the role of uncertainty, checking reactions and deferring closure (clinicians should reassure patients that they are willing to support the process, but shouldn't tell them directly what to do) (Elwyn et al., 2012). Option talk refers to providing more detailed information about options and consists of checking patient's knowledge (misinformation, etc), listing options and describing them, being clear about harms and benefits, providing patient decision support and summarizing (Elwyn et al., 2012). Decision talk refers to supporting the process of considering preferences and deciding what is best and consists of focusing on preferences and eliciting them, checking for the need to defer or make a decision and reminding the patient, when feasible, that decisions may be reviewed and reconsidered (Elwyn et al., 2012).

The importance of doctor–patient communication in the process of health care has been established, with studies demonstrating clear links between the quality of communication and patient satisfaction, adherence, and clinical outcomes (Hall et al., 1988; Roter et al., 1988; Stewart, 1995). Regarding infertility treatment, couples appear to cope better and make more informed decisions when they feel they are being treated sensitively and honestly, with mentions of health care provider's ability and willingness to listen, answer questions and checking in after a failed treatment making an enormous difference in couple's ability to reconcile treatment experiences and cope with failure to produce a child (Daniluk, 2001).

Psychological stress might decrease the decision-making capacity (Blennborn et al., 2005). In fact, when it comes to treatment adhesion, a significant portion of couples decide to discontinue fertility treatment before achieving a pregnancy, choosing not to undergo multiple cycles of ART, even when the prognosis is favourable and the financial costs are not a problem (Brandes et al., 2009). Whilst discontinuation rates vary across studies, due to different conceptualizations of treatment discontinuation, an estimated 30% of couples are discontinuers (Brandes et al., 2009; Domar et al., 2010). According to several studies, the most common reason for discontinuation of treatment mentioned by patients is emotional distress, which can be due to various reasons, such as relational problems or feeling too anxious/depressed to continue (Brandes et al., 2009; Domar et al., 2010; Gameiro et al., 2012). Indeed, evidence indicates that when cost is not a noteworthy factor, psychological issues may play a very significant role in contributing to the patient's decision to drop out of infertility treatment (Domar, 2004). Some studies report that patients who have made well informed decisions through shared decision making also adhere better to treatment regimens (Joosten et al., 2008), which would prove extremely beneficial for ART.

Therefore, given the psychological impact of infertility and infertility treatment, its complex decision-making process, and the additional stressors of choosing gamete donation treatment, it's extremely relevant to include psychologists in multidisciplinary teams and encourage all couples who may be confused/indecisive to seek psychological help and counselling, instead of promoting the misconception that it is only available as a last resort for extreme psychological distress.

Thus, implementing shared decision making in decision making processes for infertility treatments may be extremely beneficial for couples and healthcare professionals alike.

The present study

In the past years, the psychosocial impact of infertility and its treatment has been extensively researched and reported. However, literature regarding the decision-making process is still scarce, especially for reproductive donation. Further, though shared decision-making and the use of decision aids have been studied and proven beneficial in other health areas (e.g., Søndergaard et al., 2019; Mcalpine et al., 2018;), little is known about their applicability to infertility treatment.

Considering the complex choices ART patients must make, as well as couple's critics to the treatment process, one could argue that implementing shared decision making would be beneficial and correspond better to patients' expectations and needs. Because SDM reconceptualizes client-clinician communication and redefines the terms by which participants come together to make treatment decisions (Patel et al., 2008; Drake et al., 2010), it's extremely important to listen to patients and health professionals alike, in order to understand their perspective and experiences, and what exactly needs to be altered in the decision-making process.

This study aims to assess reproductive donation patient's experiences and preferences in the decision-making process, with the goal of informing future efforts of aiding this process. Therefore, its focus will be heterosexual couples who've gone through reproductive donation treatment. These couples will be asked to reflect on their past experiences and give their honest opinions about them, namely what they think could have been done better, through a semi-structured interview.

1. Method

1.1 *Participants and Procedures*

The present study's target population were patients in a heterosexual relationship who had gone through gamete donation treatments. Therefore, after obtaining approval from the Ethics Committee of the Faculty of Psychology and Educational Sciences of the University of Port, we contacted several institutions related to infertility and asked them to share our study on their social media pages, in hopes of reaching as many couples as possible. The initial contact was made through a form, in which the participant described their preferred contact method, interview format (virtual or in person) and availability. Afterwards, the participants were contacted either through email or phone to schedule the interview. Informed consent (see attachment B) was then obtained, and any questions or doubts were answered.

The final sample was composed of nine participants (see table 1). Of these, seven women and one man were interviewed alone, and one couple was interviewed together. Interviews were all conducted online and were video recorded. The average duration of these interviews was 1 hour. After being transcribed verbatim, all video records were deleted and any information that could possibly identify the participants was omitted.

Table 1

Patients' sociodemographic and biomedical characteristcs

Participants	Age	Partner's Age	Gender	Education	Partner's Education Level	Beginning of trial for conception	Beginning of treatment	Treatments
P1	46	44	F	Bachelor	12th grade	2014	2015	IUI; IVF
P2	41	46	F	Bachelor	Master	2014	2019	Donation IVF (ooycites)
P3	35	39	M/F	Master	Master	2017	2018	AI; Donation IVF (sperm)
P4	41	41	F	Doctorate	Master	2009	2010	3 IUI; IVF (13/14 cycles); Donation IVF
P5	43	39	F	Doctorate	Bachelor	2019	2020	3 AI; 2 Donation IVF
P6	40	41	F	Master	12th grade	2019	2020	OI; 2 IFV (no transfer); Donation IVF (oocytes)
P7	36	40	F	Master	12th grade	2014	2018	Donation IVF (sperm)

P8	34	38	F	12th grade	12th grade	2017	2019	Ovary Transplant; IFV; Donation IFV (oocyites)
P9	48	45	M	Bachelor	Bachelor	2019	2021	OI; Donation IFV (oocyites)

Note. Interviews made between 12/2021 and 05/2022. IUI – Intrauterine Insemination; IVF – In Vitro Fertilization; AI –Artificial Insemination; OI – Ovulation Induction.

1.2. Measures

The conducted interviews followed a semi-structured style and focused on couples' decision-making process regarding the transition to gamete donation. A script developed by the research team (see Annex A) was used and its aim was to understand facilitators and barriers to decision making, as well as explore couples' perceptions on communication with health professionals and shared decision making.

1.3. Data Analysis

The present study followed Grounded Theory's guidelines for qualitative analysis, which offers systematic yet flexible rules for data collection and analysis, enabling the construction of theories rooted in the data themselves (Charmaz, 2006). In short, data serve as the basis for theory and the analysis of these data generates concepts (Charmaz, 2006).

In qualitative research, coding is the process through which labels that represent segments of data are attached to the latter. As such, coding allows us to filter data, sort and compare them with other segments of data (Charmaz, 2006). Thus, relevant data from each interview was coded through a line-by-line microanalysis, using NVIVO software.

Afterwards, coded data underwent a focused coding process, in which the most significant and/or frequent codes were used to sift through the data. The aim of this phase is to determine the adequacy of those codes and decide which ones make the most analytic sense to categorize data (Charmaz, 2006). Finally, categories were related to subcategories through axial coding, to reassemble the data and give coherence to the emerging analysis. Furthermore, these categories and subcategories were thoroughly compared in an effort to create exclusivity and avoid repetition.

Each theme and subtheme's relative frequency (rf) of references was calculated and is presented in the results section along with the total number of interviews (I) that mentioned each one.

2. Results

Considering the present study's investigation questions, the analysis of the interviews focused on facilitators and barriers to the decision-making process when transitioning to gamete donation treatment. The former – facilitators – culminated in eleven major themes (see figure 1) and the latter – barriers – in six major themes (see figure 2).

2.1. Facilitators

Facilitators were defined as anything that, in the participant's opinion, allowed for a more conscious and tranquil decision-making. A detailed analysis of the eleven themes and respective subthemes is found bellow on table 2.

Figure 1

Facilitators’ themes and subthemes

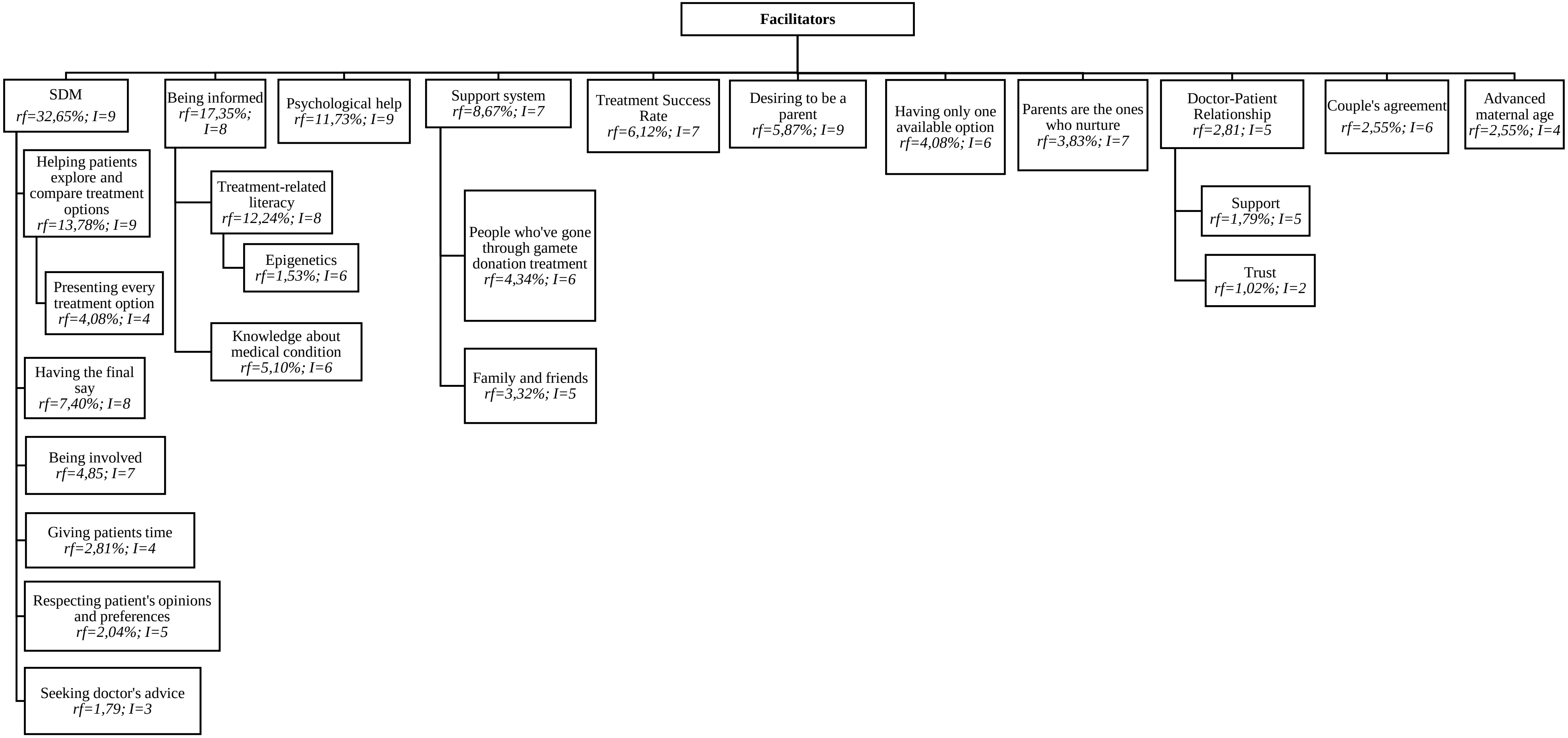

Table 2

Facilitators' themes and subthemes analysis

Themes and subthemes	Definition	Example
SDM **1. Helping patients explore and compare treatment options** **a. Presenting every treatment option** **2. Having the final say** **3. Being involved** **4. Giving patients time** **5. Respecting patient's opinions and preferences** **6. Seeking doctor's advice**	1. The doctor provides information based on the best available scientific evidence and is available to answer any questions. a. The doctor presents every treatment option and provides information on each treatment's odds. 2. Believing patients should have the final say in the decision-making process and the doctor shouldn't impose their opinion on the couple. 3. The patient feels involved in the decision-making process and is comfortable participating in it. 4. The doctor gives patients time to reflect on things and doesn't rush conversations or choices. The couple feels listened to and is able to reflect on the presented options more consciously. 5. The doctor seeks to understand patient's preferences, opinions, and concerns in order to reach a decision that they feel comfortable with. 6. Patients value doctor's expertise and seek their opinion and advice in order to make a more conscious decision.	1. "His responsibility as a doctor to advise, explain and enlighten me is as great as mine in regard to having all this information and having to make a decision." a. "I remember her saying: in this scenario, maybe we have to think about the option of gamete donation. It's a process that women are sometimes reluctant initially but, in my experience, there are no issues later regarding pregnancies, with rare exceptions, and even after, if things go well, so I think we should keep this option in mind." 2. "It's such a personal decision, it's such an intimate decision that it can't be based on science alone. We have to understand the science behind it, and we have to understand the odds, right? But the decision of whether we move on to another 5 cycles of IVF treatment with our own eggs or we move on to egg donation right away has to be ours. As I say, it's intimate and it's personal. The doctor can't decide that, because it's our body, it's going to be our baby." 3. "I was always involved, so… I never felt left out. I always felt I had control, power, call it what you want." 4. "She took the steps, little by little… We always arrived first *(at the next phase);* she wouldn't let us proceed before we were ready. All the information was given very calmly, very carefully and at the right time, so to speak." 5. "There were times when the doctor suggested either medication or treatment, and we also tried to give our opinion. Because it might not be this this month: maybe we don't want it now, we want it later… Or I didn't like this medication, I don't want to take it and I have to find an alternative. In those situations, we always made adustments." 6. "We added this to the doubts we wanted to discuss with our doctor, to see what he would recommend as a professional."
Being informed **1. Treatment-related literacy** **a. Epigenetics** **2. Knowledge about medical condition**	1. Being informed and feeling enlightened in regard to donated gamete treatment a. Information about how the uterine environment affects gene expression 2. Having clear and specific information about one's medical history and nature of the problem allows for a more informed and conscious decision	1. "I had known about it *(donated gamete treatment)* for a while, I had thought about it, I started looking for people who had already done it… a friend, even people online who offered to help, to answer questions." a. "I read a lot about epigenetics. Because the fact that the embryo is inside my body results in genes… they *(genes)* aren't modified or altered, but there is a lot of a genetic part that is transferred, in this case, from whoever's carrying the pregnancy, which is me. And that side of epigenetics, which is like 20% or something… we hold on to that a lot, in the beginning, to make a decision." 2. "And this *(egg quantity and quality declines with age)* was something that I only realized in the end in this last clinic when it was explained to me very clearly. And I think the more information we have, the better we are able to deal with the subject. If we aren't informed, we are deceived and deluded into believing something that will either not happen or that is very unlikely."
Psychological help	Getting psychological help throughout the decision-making process, in order to discuss fears and doubts, prepare for possible negative outcomes and have a support figure	"Psychologists, without a doubt. It *(seeing a psychologist)* should be mandatory in my opinion: to clarify expectations; anticipate scenarios – some that I think should be anticipated; to share this experience, this pain, the weight… I think it's sharing the weight of a secret."

Themes and subthemes	Definition	Example
Support system **1. People who've gone through gamete donation treatment** **2. Family and friends**	1. Having the support of people who've gone through the same treatment and being able to share experiences and ask questions about the process 2. Feeling supported by friends and family and being able to share the experience (doubts, fears, etc) with them	1. "I was able to find people who were going through the same thing, and some friends of friends who talked about it because their friend was also going through the same. And with these people, through the internet, I was able to talk to them and I was able to share doubts and exchange ideas and even talk about things regarding 5-10 years from now, because some of them already have older children. And there were a lot of people online who were willing to talk about it, and that was very important." 2. "I think family would also be an essential element. Because whether we like it or not, family is our foundation; it is the basis of life so I think having the support of family *(would be important)*."
Treatment success rate	Taking donated gamete treatment's success rate into consideration and weighting it alongside couple's resources (emotional, financial, etc)	"And then it was kind of like either we insist on the same thing, and it doesn't work again and *(we go through)* the loss process, the grieving process, right? In the end, it's mourning… *(and)* it doesn't work, or we move forward to another level."
Desiring to be a parent	Having parenthood as a life goal and dream and eagerly wanting to achieve it	"Either I resorted to egg donation, or I would not be a mother. And not being a mother, without even trying, was out of the question."
Having only one available option	Donated gamete treatment as the only available option to achieve parenthood	"Through science, it was the only way for us to be able to have children, since my husband has a disease, which is azoospermia, and so this was the only solution for having our own children, so to speak."
Parents are the ones who nurture	Believing that parenthood is not defined by genetics, but built and maintained through love, care, and affection.	"My goal has always been to have a child in a relationship and in a project for two; to have a family. And the rest is genetics, it's different, because the emotions, the feelings and the family are there."
Doctor-Patient Relationship **1. Support** **2. Trust**	1. The couple feels supported by the medical team throughout the treatment process 2. The couple trusts the medical team	1. "I think it's important to have people like that, like my doctors, who were so, so dear and so close in this process." 2. "And looking for a good clinic, doctor… a medical team, it's not just a doctor, it's a team; a team they trust, with whom they feel good, cared for, accompanied, so that they can, if they decide to opt for donated gametes, enter this process with minimal doubts."
Couple's agreement	Both parties feel comfortable opting for donated gametes and support each other in their decision	"Our decision as a couple was already made and we were going to support each other, regardless of not having external support."
Advanced maternal age	Opting for a younger person's donated gametes results in a healthier and safer pregnancy, as well as allows for one to be achieved more quickly.	"I was 39 years old, and we know that the donor would have to be 35 or younger and, therefore, despite my pregnancy being an advanced age one, I would not have to go through those amniocentesis tests and so on because the embryo wasn't from an older person. It was from a younger person and so that was a point in favour *(of donated gamete treatment)*. We knew that the embryo, from the get-go, would be a healthy embryo and that was a point in favour *(of donated gamete treatment)*."

Note. Interviews' excerpts were translated from Portuguese to English as accurately as possible.

2.2 Barriers

Barriers were defined as anything that, in the participant's opinion, hindered the decision-making process. A detailed analysis of the six themes and respective subthemes is found bellow on table 3.

Figure 2

Barriers' themes and subthemes

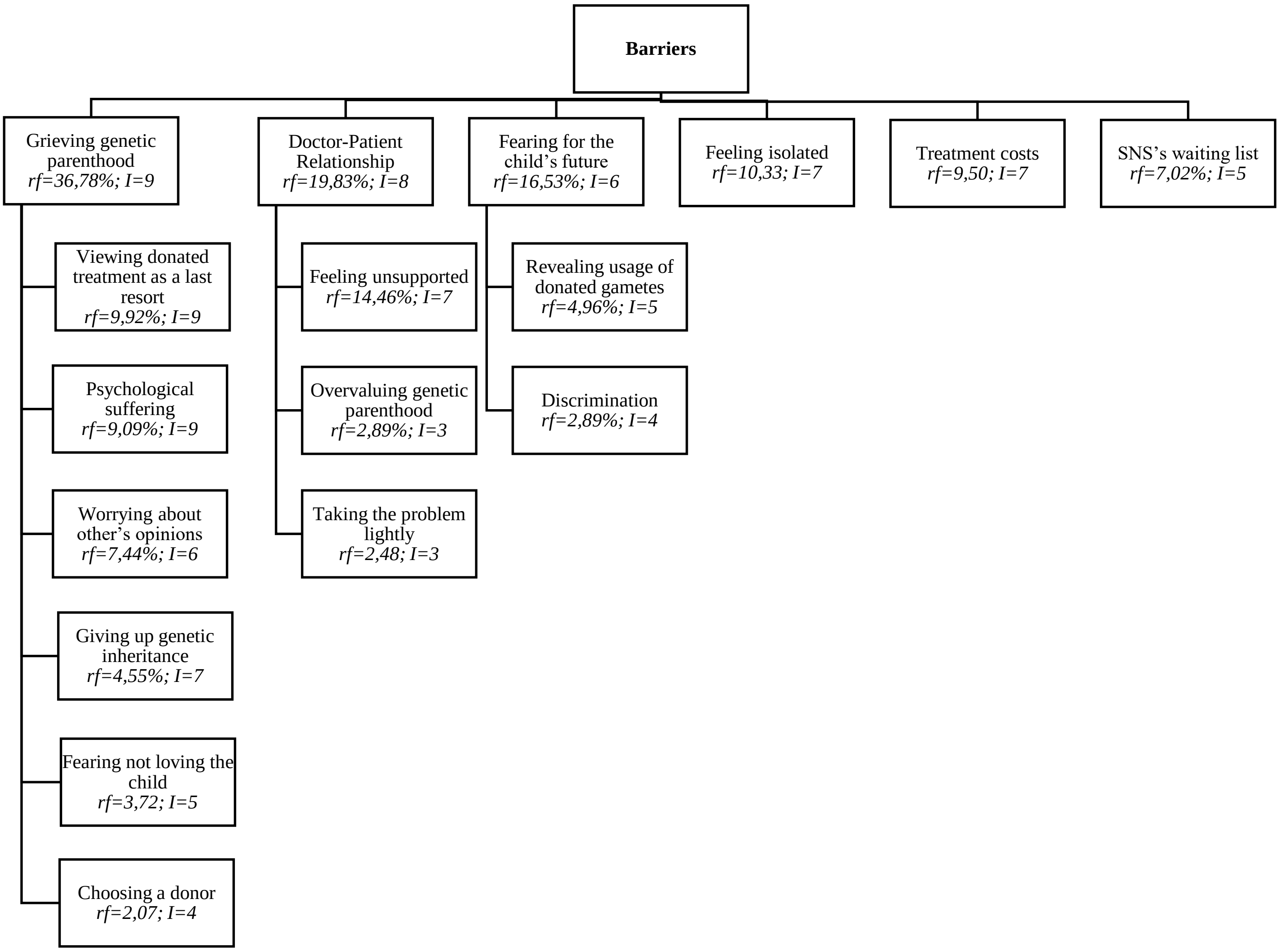

Table 3

Barriers' themes and subthemes analysis

Themes and subthemes	Definition	Example
Grieving genetic parenthood **1. Viewing donated gamete treatment as a last resort** **2. Psychological suffering** **3. Worrying about other's opinions** **4. Giving up genetic inheritance** **5. Fearing not loving the child** **6. Choosing a donor**	1. Wanting to opt for treatment with their own gametes, despite probable success rates, and viewing donated gametes as a last resort 2. Feeling in shock and denial and needing time to accept the fact they can't have genetically related children and reorganize their life plan 3. Fearing other people's judgment and opinions about treatment nature 4. Having to accept the possibility of the child not looking like them, as well as worrying about their "unknown" medical history 5. Fearing and doubting if they'll love the child as their own and feel like a "true parent" 6. Worries and doubts about choosing a donor, mostly regarding how closely they will resemble the parent	1. "I think we should take our chances. I took mine. Mine were probably too low, and maybe I even wasted time and money and *(endured)* the emotional side trying something seemingly very unlikely. But emotionally and psychologically, maybe I needed to have this journey for my grief process, my loss and maybe the possible acceptance of egg donation." 2. "Of course, this whole acceptance and change process is not easy… First, acceptance that we can't have our own *(genetically related children)* and then acceptance that we may have other people's *(children)*, if we want to, if we agree to it, if there's the opportunity." 3. "I know I shouldn't care about other people and what they say, but I do and that's something that… it didn't haunt or terrify me, but I thought about it." 4. "You go from one stage, which is just *(in vitro)* fertilization, to another, in which you have to give up on your genetic material and wanting *(the child)* to look like you and all that." 5. "Maybe in her mind she had some doubts surrounding the topic of love. Because it's something to think about, we're talking about love that we're going to give, right? *(Someone)* we will raise…. It's a life goal, obviously, but based on love, isn't it? It's not a business, it's not something cold (*hearted*). It's something you really need to cherish and want." 6. "I asked a lot of questions about how the donor would be chosen, concerning their features, because in the beginning there are always these kinds of doubts, right? Because no one wants to have a child… The plan is for embryos to be as similar as possible to us."
Doctor-Patient Relationship **1. Feeling unsupported** **2. Overvaluing genetic parenthood** **3. Taking the problem lightly**	1. Doctor isn't available or open to answer questions and/or speaks in an insensitive or unempathetic way. Consequently, the couple doesn't feel at ease and comfortable with them. This is described more prominently in the public healthcare system (SNS) 2. Doctor focuses on treatment options with couple's own gametes. 3. Doctor doesn't take the infertility problem seriously, which in consequence slows down the process.	1. "Because, as I told you, this is a violent process. Psychologically it's very violent and if we aren't comfortable with the people who are taking care of us, we tend to close ourselves off and withdraw into our shells and then it doesn't work out." 2. "I felt like we talk about this *(donated gametes treatment)*, there's places that offer it… now there's even a public medical centre that offers it, but then we contact them and don't get answers, or it takes months; we talk with doctors, and they say, "okay but let's explore other options first." 3. "Those were two years that I wasted, which could have maybe made the whole process a little easier… and that I wasted because of a doctor who didn't have the empathy to understand that not everything can be solved with a vacation, rest and melanin from the sun, so I hated it."
Fearing for the child's future **1. Revealing usage of donated gametes** **2. Discrimination**	1. Concerns about how the child will feel about the fact that they were not conceived normatively, as well as whether this should be revealed 2. Concerns about how the child will be viewed and treated in their daily life	1. "The downside is not knowing exactly how to deal with this situation later in life and thinking about what could happen in terms of psychological consequences for this child when they discover they were conceived in an unconventional way." 2. "Now society also has to play its part, and I think there will be more and more openness to this, so as not to create stigmas for these children, obviously. Because otherwise there won't be any sufficient parental protection, right? If society doesn't accept it."

Themes and subthemes	Definition	Example
Feeling isolated	Feeling isolated throughout the treatment process, due to keeping the nature of the treatment secret and consequent difficulty in sharing fears and doubts with others	"Whoever has done it like us *(donated gamete treatment)* doesn't talk about it, because there are a lot of people who have very particular opinions and so there are things that we keep to ourselves, to protect us from certain comments sometimes."
Treatment costs	High treatment costs and consequent difficulty to afford them	"Thank God, I could afford it. My parents lent me money, it is what it is... Otherwise, I'd have to get a bank loan or sell something, because this is very tough."
SNS's waiting list	Serviço Nacional de Saúde's long waiting list for gamete donation treatment is a drawback for older women and couples wanting to achieve a pregnancy quickly	"It took two or three years before we were told that there was nothing else *(we could do)*, just this option. And then it takes another two or three years waiting on a waiting list in which our turn may never come."

Note. Interviews' excerpts were translated from Portuguese to English as accurately as possible.

3. Discussion

This study aimed to understand patients' perception on the decision-making process in the transition to gamete donation treatment. More precisely, we were seeking to analyse what factors positively (facilitators) and negatively (barriers) influence the aforementioned process. Since our research question hadn't been studied in depth, an exploratory research approach was used. This was the first time a study like this was conducted with a Portuguese infertile population that has gone through gamete donation treatment.

SDM has been proven to lead to well-informed, preference-based patient decisions (Stiggelbout et al., 2015, Stacey et al., 2017), as well as higher perceived quality of care (Kehl et al., 2015) in other health contexts. Moreso, patients have reported preferring SDM when considering invasive medical procedures (Mazur et al., 2005). Whilst literature is scarce when it comes to SDM applied to infertility treatments, especially gamete donation ones, this is congruent with our findings. Participants mentioned key aspects of SDM – being involved and actively seeking doctor's advice; doctor helping them explore and compare treatment options, giving them time to reflect and discuss options, as well as respecting their preferences – as important factors for a smoother and easier decision process. In fact, engaging patients according to their preferred role in treatment decision-making has been found to be beneficial, especially in instances associated with intense emotions and demanding treatment (Deber et al., 2007).

Interestingly, participants also mention the need to have the final say in the decision. On the one hand, this can be explained by the preference of patient-centred care and need for autonomy; on the other, it can be related to the intrinsically intimate and personal goal of infertility treatment, as well as the enormous responsibility it implies: the creation of life. Additionally, when we consider how prominent grief of genetic parenthood was in the present study, it's easy to comprehend why patients feel the need to have the authority to decide what, ultimately, shall happen.

Being informed, not only in regard to treatment itself, but also patient's medical condition was also considered important. This is in accordance with literature, as couples report having full confidence in clinical staff and believing that the doctors know what is best for them in the beginning, but, after a few treatments, wanting more information about their specific condition and less general information about treatment or other alternatives (Olafsdottir et al., 2013; Peddie et al., 2005). Couples who have been through several treatments, as is the case for most of our participants, also express a greater need for information (Olafsdottir et al., 2013). Furthermore, Elwyn et al. (2012) consider that uninformed patients are unable to assess what is important to them and, therefore, establish informed preferences. Likewise, Anguzu et al (2020) found that going into an initial consultation, the vast majority of couples were seeking information and advice about options.

This demand for feeling informed demonstrates the vital role the doctor plays in the decision-making process. In fact, doctor-patient relationship had a significant part in decision making according to our participants. Similarly, other studies suggest that the quality of doctor-physician interaction and communication is a powerful indicator of the quality of medical care and plays a fundamental role in the medical care process (Matusitz & Spear, 2014) When our participants felt informed, they reported being able to make a more conscious decision on their preferred treatment option – which, in this case, mostly means one more likely to the achieve their goal: parenthood. As such, it is unsurprising that patients value treatment success rates and weight it alongside their resources.

Our results, as well as other patient surveys, have shown that patients want better communication with their doctors (Duffy et al., 2004). Efficient communication not only helps patients develop deep understanding of their condition and take part in mutual decision making, which ultimately, contributes to better health outcomes (Beck et al., 2002), but also may help regulate patients' emotions, facilitate comprehension of medical information, and allow for better identification of patients' needs, perceptions, and expectations (Arora, 2003; Brédart et al., 2005; Platt & Keating, 2007). As such, this is clearly an area that requires attention and further investigation, as few studies have focused on doctor-patient relationship and communication in gamete donation treatment settings.

Besides the technical aspects of communication, our participants also valued feeling supported by the medical team. However, a lot of them considered doctors were, in one or more occasions, unempathetic and unavailable. Olafsdottir et al (2013) similarly reported couples would have liked to feel more listened and seen. In fact, lack of empathy, poor listening skills, unkind treatment and negative interactions with staff have been cited as contributing factors to treatment discontinuation (Olivius et al., 2004; Rajkhowa et al., 2006). It is hypothesized that these results are not necessarily a reflection of doctors not valuing a good relationship with their patients, but that there are bigger problems at stake, such as workload, difficult time management as well as lack of interpersonal skills training.

Not only do participants report valuing support from the medical team, but also from friends and family, as well as people who have gone through the same treatment. On the other hand, they report lacking this support system due to secrecy of treatment nature and consequent isolation. This is corroborated by other studies, which prove infertility patients often worry about being perceived negatively, as fertility is often associated with issues around adulthood, health status and gender roles (Swanson & Braverman, 2021). Social coping resources are associated with a decrease in infertility stress (Gibson & Meyers, 2002), however, due to concerns or experiences of not receiving support, people with infertility may withdraw from their social networks (Burns, 2006). This may be even more prominent when patients opt for donated gametes because of society's deeply rooted importance given to genetic parenthood.

Indeed, patients with infertility often report difficulties with social support, as their family and friends are not aware or able to be supportive. One study found that patients who desired more social support also reported lower quality of life (Karabulut et al., 2013). For many with infertility, disenfranchised grief is experienced, that is, an intense grief that others perceive as a minor loss. Doka (2002) describes disenfranchised grief as a relationship that is lost and is not socially recognized. As such, the person grieving is not perceived to have suffered an actual loss and, therefore, their grief isn't viewed as justified (e.g., loss of genetically related child). This type of grief can be particularly intense and painful because it often implies less social support and inability to openly mourn a loss (Doka, 2002).

As for the support of people who have gone through the same treatment, internet has changed couple's experience of infertility, giving people quick access to other's experiences. Malik and Coulson (2008) highlighted the beneficial role of Internet for those going through fertility treatment, or coming to terms with its aftermath, with reports of involvement in online support groups as tool for reducing sense of isolation and burden on relationships, as well as providing information and empowerment. In fact, internet communication is highly valued by couples, especially those who feel isolated in their "real-world" relationships (Hinton et al., 2010).

Although the psychological impact of infertility has been thoroughly explored (Cousineau & Domar, 2007; Swanson & Braverman, 2021), we found gamete donation treatment has its own particular concerns, such as the grief of genetic parenthood, and doubts surrounding the child's future. Some articles suggest that the decision to use donor gametes often begins with an emotional reaction to the loss of a genetic child, a jointly created genetic child or the loss of hope that they will be able to successfully carry a pregnancy and have a genetically related child (Swanson & Braverman, 2021). This apparently inevitable feeling of loss may explain why couples feel the need to try to conceive a genetically related child, even when their chances are low, and resources are scarce. In fact, the grief process may be especially painful for the parent that will not have genetic ties to the child (Golombok et al., 2017). Another common concern is fearing how bonding with the baby will be affected by the loss of genetic ties (Swanson & Braverman, 2021) – something we also found in our study. However, despite this, one study found that even though mothers reported grief about infertility and the use of donor eggs, they also found unique ways to build a connection and bond with their babies (Hammond, 2018).

Another concern we found of couples using donor gametes is if and/or how to reveal to their children the usage of donated gametes. Intended parents often worry that telling their child they are donor conceived will introduce confusion as who the "real" parent is, as well as producing negative feelings about the nature of conception (Swanson & Braverman, 2021).

Considering the psychological impact and suffering associated with gamete donation treatment, it is clear why all participants considered psychological help as essential. In fact, due to the complex emotional and psychosocial aspects to using donor gametes, the American Society for Reproductive Medicine (ASRM) guidelines recommend a psychoeducational consultation for intended parents (Ethics Committee of American Society for Reproductive Medicine, 2013). Carrilo & Pareja (2007) suggest that psychological help for couples going through reproductive donation treatment should: assess the way infertility and its treatment have affected the patients individually and as a couple; help the couple in the decision-making process; discuss issues specific to the treatment and help develop positive ways of coping; and facilitate the expression of emotions. Moreso, common grief processes are associated with better adjustment to unsuccessful fertility treatment, including emotional acceptance of failed fertility treatments, making meaning of their experience, and finding a purpose in their current life (Gameiro & Finnigan, 2017). As such, psychologists may play an important role in guiding gamete donation patients through their grief process. This aspect constitutes possible evidence of the need for a multidisciplinary team, in which mental health professionals are included, with an emphasis in psychoeducation and therapy.

One of the present study's limitations is the possibility of not having reached saturation. Because most participants (eight out of nine) were able to have a child through gamete donation treatment, we must take into consideration that their perceptions may not be the same as those whose treatments were not successful. Similarly, many of our participants were presented with other treatment options besides gamete donation. For patients who are only presented with this option, the decision-making process may be different and other themes may be brought up. Such is the case of single and/or lesbian couples, which our study did not include. Therefore, future research focusing on the aforementioned groups is needed.

Throughout our analysis, participants reported some differences in care in the public healthcare system versus the private one. However, because all of them had the opportunity to get treated at a private clinic, it would be of relevance to explore patients' experience for whom only public healthcare system was available. This would, hopefully, aid in creating a better environment for decision-making despite the clinical context.

Furthermore, the representative status of our sample may arise questions, since it is mostly constituted by women. As such, a more complete analysis of patients' perceptions on the decision-making process would've been achieved if we had a similar number of participants from both sexes. In fact, it might have been interesting to understand how both parties of a couple may experience the same event differently. Zeiler (2009) discusses the problem of shared autonomous decision-making when couples must reach an agreement and argues that individual contributions to a shared final decision may be unequal; this is particularly true regarding fertility treatments, where women often dominate the decision-making (Olafsdottir et al., 2012; Peddie et al., 2004).

Taking into consideration how scarce literature is when it comes to the decision-making process of transitioning to gamete donation, as well as the fact that couples nowadays get pregnant later in life and, therefore, the need to use donated gametes may arise, the need for future research must be taken seriously.

However, the present study still holds its relevance. Scarce literature on the topic is not a reflection of its (ir)relevance, but of its contemporary character. Therefore, any studies focusing on the decision-making process of transitioning to gamete donation are welcome and appreciated. Additionally, not only is this important in a scientific perspective, but also a social one – the more we talk about the subject, the less taboo it will, hopefully, be.

Our findings may also provide fruitful contributions to clinical practice, as we outline what factors are essential to a conscious and easier decision and which ones need improvement. According to patients' reports of their experiences, doctors should pay more attention to communication – e.g., being available to answer questions, providing clear information and being transparent – as well as the relationship they maintain with their patients – e.g., treating them with empathy and providing emotional support when needed. Since SDM was the most frequently mentioned theme, it would be beneficial for medical institutions and doctors to implement it. In fact, having a patient-centered approach and making sure to involve the patient in the decision-making process as much as they want, as well as helping them explore and compare treatment options is recommended. Furthermore, doctors should pay attention to their patients' mental well-being and refer them to a psychologist whenever needed.

Moreso, an increased number of well-designed studies looking into the psychological issues surrounding gamete donation of different patient groups, could allow more directed assessment and counselling of donated gamete recipients. According to some researchers, infertility counseling and support groups seem to be the most efficient psychosocial interventions within the infertility context (Wischmann, 2008). Therefore, designing group therapy intervention for gamete donation patients may be useful in diminishing their reported distress.

Additionally, the great importance given to patient-doctor relationship, information and involvement in decision-making process provides us a glimpse of how these procedures may be designed. Creating clear and evidence-supported guidelines for this decision process can be of help not only to patients, but also medical staff. In fact, Bieber et al (2009) found SDM training programs effective in improving SDM related confidence and knowledge for practicing physicians. As such, designing a similar program for Portuguese health professionals may be beneficial.

References

Anguzu, R., Cusatis, R., Fergestrom, N., Cooper, A., Schoyer, K. D., Davis, J. B., Sandlow, J., & Flynn, K. E. (2020). Decisional conflict among couples seeking specialty treatment for infertility in the USA: a longitudinal exploratory study. *Human reproduction (Oxford, England)*, *35*(3), 573–582. https://doi.org/10.1093/humrep/dez292

Arora N. K. (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Social science & medicine (1982)*, *57*(5), 791–806. https://doi.org/10.1016/s0277-9536(02)00449-5

Barry M. J. & Edgman-Levitan, S. (2012) Shared Decision Making– The Pinnacle of Patient-Centered Care. The New England Journal of Medicine, 366(9), 780-781. https://doi.org/10.1056/NEJMp1109283

Beck, R. S., Daughtridge, R., & Sloane, P. D. (2002). Physician-patient communication in the primary care office: a systematic review. *The Journal of the American Board of Family Practice*, *15*(1), 25–38.

Bieber, C., Nicolai, J., Hartmann, M., Blumenstiel, K., Ringel, N., Schneider, A., Härter, M., Eich, W., & Loh, A. (2009). Training physicians in shared decision-making-who can be reached and what is achieved?. *Patient education and counseling*, *77*(1), 48–54. https://doi.org/10.1016/j.pec.2009.03.019

Blennborn, M., Nilsson, S., Hillervik, C., & Hellberg, D. (2005). The couple's decision-making in IVF: one or two embryos at transfer? Human Reproduction, 20(5), 1292-1297. https://doi.org/10.1093/humrep/deh785

Boivin, J., Bunting, L., Collins, J. & Nygren, K. (2007) International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Human Reproduction, 22(6), 1506-1512. https://doi.org/10.1093/humrep/dem046

Brandes, M., Steen, J. O., Bokdam, S. B, Hamilton, C. J., Bruin, J. P, Nelen, W. L. & Kremer, J. A. (2009) When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. Human Reproduction, 24(12), 3127-3135. https://doi.org/10.1093/humrep/dep340

Braverman, A. (2004). Psychosocial aspects of infertility: Sexual dysfunction. International Congress Series, 1266, 270-276. https://doi.org/10.1016/j.ics.2004.01.085

Brédart, A., Bouleuc, C., & Dolbeault, S. (2005). Doctor-patient communication and satisfaction with care in oncology. *Current opinion in oncology*, *17*(4), 351–354. https://doi.org/10.1097/01.cco.0000167734.26454.30

Buchanan, J., Borland, R., Cosolo, W., Millership, R., Haines, I., Zimet, A., & Zalcberg, J. (1996). Patients' beliefs about cancer management. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, *4*(2), 110–117. https://doi.org/10.1007/BF01845760

Carrillo, M. M. T. & Pareja, P. D. C. (2007). Apoyo Psicológico en Pacientes que Recurren a Tratamiento de Reproducción Asistida com Donácio de Gametos. In Moreno, A., Díaz, D. G., Baccio, G., Molla, V. G., Pareja, P. D. C., Carrilo, M. M. T., Herrera, K. G & Rabanaque, M. G, *Guías de evaluación, consejo, apoyo e intervención psicológica en reproducción asistida*. Revista Iberoamericana de Fertilidad, 73-87.

Charmaz, K. (2006). Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE Publications.

Cousineau, T. M. & Domar, A. D. (2007) Psychological impact of infertility. Best Practice & Research. Clinical Obstetrics & Gynaecology. 21(2), 293-308. https://doi.org/10.1016/j.bpobgyn.2006.12.003

Cramond, J. (1998). Counselling Needs of Patients Receiving Treatment with Gamete Donation. Journal of Community & Applied Social Psychology, 8(4), 313-321. https://doi.org/10.1002/(SICI)1099-1298(199807/08)8:4<313::AID-CASP493>3.0.CO;2-F

Daniels, K. R., Gillett, W. R. & Herbison, G. P. (1996). Successful donor insemination and its impact on recipients. Journal of Psychosomatic Obstetrics and Gynaecology, 17(3), 129-134. https://doi.org/10.3109/01674829609025673

Daniluk, J. C. (2001). "If we had it to do over again...": Couples' reflections on their experiences of infertility treatments. The Family Journal, 9(2), 122-133. https://doi.org/10.1177/1066480701092006

Deber RB, Kraetschmer N, Urowitz S, Sharpe N. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. Health Expect. 2007; 10:248–58.

Department of Economic and Social Affairs/Population Division. (2003). Partnership and reproductive behavior in low-fertility countries (ESA/P/WP. 177), United Nations Secretariat, Revised version for the Web, May.

Doka, K. J. (2002). Disenfranchised grief: new directions, challenges, and strategies for practice. Champaign, Ill: Research Press.

Domar, A. D., Smith, K., Conboy, L., Iannone, M. & Alper, M. (2010). A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment. Fertil Steril, 94(4), 1457–1459. https://doi.org/10.1016/j.fertnstert.2009.06.020

Domar, A.D. (2004) Impact of psychological factors on dropout rates in insured infertility patients. Fertil Steril. 81(2), 271-273. https://doi.org/10.1016/j.fertnstert.2003.08.013

Drake, R. E., Deegan, P. E., & Rapp, C. (2010). The promise of shared decision making in mental health. Psychiatric Rehabilitation Journal, 34(1), 7–13. https://doi.org/10.2975/34.1.2010.7.13

Duffy, F. D., Gordon, G. H., Whelan, G., Cole-Kelly, K., Frankel, R., Buffone, N., Lofton, S., Wallace, M., Goode, L., Langdon, L., & Participants in the American Academy on Physician and Patient's Conference on Education and Evaluation of Competence in Communication and Interpersonal Skills (2004). Assessing competence in communication and interpersonal skills: the Kalamazoo II report. *Academic medicine: journal of the Association of American Medical Colleges*, *79*(6), 495–507. https://doi.org/10.1097/00001888-200406000-00002

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: a model for clinical practice. Journal of general internal medicine, 27(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Ethics Committee of American Society for Reproductive Medicine (2013). Informing offspring of their conception by gamete or embryo donation: a committee opinion. Fertility and sterility, 100(1), 45–49. https://doi.org/10.1016/j.fertnstert.2013. 02.028

Gameiro, S., & Finnigan, A. (2017). Long-term adjustment to unmet parenthood goals following ART: A systematic review and meta-analysis. Human Reproduction Update, 23(3), 322–337. https://doi.org/10.1093/humupd/dmx001

Gameiro, S., Boivin, J., Peronace, L. & Verhaak, C. M. (2012) Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. Human Reproduction Update, 18(6), 652–669. https://doi.org/10.1093/humupd/dms031

Gibson, D. M., & Myers, J. E. (2002). The effect of social coping resources and growth-fostering relationships on infertility stress in women. *Journal of Mental Health Counseling*, *24*(1), 68–80.

Golombok, S., Blake, L., Casey, P., Roman, G., & Jadva, V. (2013). Children born through reproductive donation: a longitudinal study of psychological adjustment. Journal of Child Psychology and Psychiatry, 54(6), 653–660. https://doi.org/10.1111/jcpp.12015

Golombok, S., Ilioi, E., Blake, L., Roman, G., & Jadva, V. (2017). A longitudinal study of families formed through reproductive donation: Parent-adolescent relationships and adolescent adjustment at age 14. Developmental Psychology, 53(10), 1966–1977. https://doi.org/10.1037/dev0000372

Golombok, S., Ilioi, E., Blake, L., Roman, G., & Jadva, V. (2017). A longitudinal study of families formed through reproductive donation: Parent-adolescent relationships and adolescent adjustment at age 14. Developmental Psychology, 53 (10), 1966–1977. https://doi.org/10.1037/dev0000372

Golombok, S., Jadva, V., Lycett, E., Murray, C., & Maccallum, F. (2005). Families created by gamete donation: follow-up at age 2. Human reproduction, 20(1), 286–293. https://doi.org/10.1093/humrep/deh585

Golombok, S., Readings, J., Blake, L., Casey, P., Mellish, L., Marks, A., & Jadva, V. (2011). Children conceived by gamete donation: psychological adjustment and mother-child relationships at age 7. Journal of Family Psychology, *25*(2), 230–239. https://doi.org/10.1037/a0022769

Greene, K., Derlega, V. J. & Mathews, A. (2006) Self-Disclosure in Personal Relationships. In: Vangelisti, A. and Perlman, D. (Eds.), Cambridge Handbook of Personal Relationships, Cambridge University Press, 409-427. http://doi.org/10.1017/CBO9780511606632.023

Griffiths, D. (2016). The (Re) Production of the Genetically Related Body in Law, Technology and Culture: Mitochondria Replacement Therapy. Health Care Analysis, 24(3)**,** 196–209. https://doi.org/10.1007/s10728-016-0329-z

Gürtin, Z., & Vayena, E. (2012). Reproductive donation. In M. Richards, G. Pennings, & J. Appleby (Eds.), Reproductive Donation: Practice, Policy and Bioethics, 70-89. Cambridge University Press. https://doi.org/10.1017/CBO9781139026390.005

Hall, J. A., Roter, D. L., & Katz, N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. Medical Care, *26*(7), 657–675. https://doi.org/10.1097/00005650-198807000-00002

Hammond, K. (2018). The role of normative ideologies of motherhood in intended mothers' experiences of egg donation in Canada. Anthropology & Medicine, 25(3), 265–279. https://doi.org/10.1080/13648470.2018.1507483

Hinton L., Kurinczuk J. J., Ziebland S. (2010). Infertility; isolation and the internet: a qualitative interview study. *Patient Educ. Couns.* 81 436–441. 10.1016/j.pec.2010.09.023

Hinton, L., & Miller, T. (2013). Mapping men's anticipations and experiences in the reproductive realm: (in)fertility journeys. Reproductive Biomedicine Online, 27(3), 244–252. https://doi.org/10.1016/j.rbmo.2013.06.008

Holter, H., Anderheim, L., Bergh, C., & Mo¨ller, A. (2006). First IVF reatment – short-term impact on psychological well-being and the marital relationship. Human Reproduction, 21(12), 3295–3302. https://doi.org/10.1093/humrep/del288

Imrie, S., Jadva, V., Fishel, S. & Golombok, S. (2018). Families created by egg donation: parent–child relationship quality in infancy. Child Development, 90(4), 1333-1349. https://doi.org/10.1111/cdev.13124

Joosten, E. A., DeFuentes-Merillas, L., Weert, S. T., Staak, C. P. & Jong, C. A. (2008) Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychotherapy and Psychosomatics, 77(4), 219-226. https://doi.org/10.1159/000126073

Jordan, C., & Revenson, T. A. (1999). Gender differences in coping with infertility: a meta-analysis. *Journal of behavioral medicine*, *22*(4), 341–358. https://doi.org/10.1023/a:1018774019232

Karabulut, A., Özkan, S., & Oguz, N. (2013). Predictors of fertility quality of life (FertiQoL) in infertile women: Analysis of confounding factors. European Journal of Obstetrics, Gynecology and Reproductive Biology, 170(1), 193–197. https:// doi.org/10.1016/j.ejogrb.2013.06.029

Kehl, K. L., Landrum, M. B., Arora, N. K., Ganz, P. A., van Ryn, M., Mack, J. W., & Keating, N. L. (2015). Association of Actual and Preferred Decision Roles with Patient-Reported Quality of Care: Shared Decision Making in Cancer Care. *JAMA oncology*, *1*(1), 50–58. https://doi.org/10.1001/jamaoncol.2014.112

Kirkman-Brown, J. & Martins, M. (2020). 'Genes versus children': If the goal is parenthood, are we using the optimal approach? Human Reproduction, 35(1), 5-11. https://doi.org/10.1093/humrep/dez256

Loneck, B. M., & Kola, A. L. (1988). Using the Conflict-Theory Model of Decision Making to Predict the Outcome in the Alcoholism Intervention. Alcoholism Treatment Quarterly, 5(3/4), 119-136.

Mahlstedt, P. P. (1985) The psychological component of infertility. Fertility and Sterility, 43(3), 335-346. https://doi.org/10.1016/s0015-0282(16)48428-1

Malik, S. H., & Coulson, N. S. (2008). Computer-mediated infertility support groups: an exploratory study of online experiences. *Patient education and counseling*, *73*(1), 105–113. https://doi.org/10.1016/j.pec.2008.05.024

Martins, M., Basto-Pereira, M., Pedro, J., Peterson, B., Almeida, V., Schmidt, L. & Costa, M. (2016). Male psychological adaptation to unsuccessful medically assisted reproduction treatments: a systematic review. Hum Reprod Update, 22(4), 466-478. https://doi.org/10.1093/humupd/dmw009

Martins, M.V., Peterson, B., Costa, P., Costa, M. E., Lund, R. & Schmidt, L. (2013) Interactive effects of social support and disclosure on fertility-related stress. Journal of Social and Personal Relationships, 30(4), 371-388. https://doi.org/10.1177/0265407512456672

Mascarenhas, M. N., Flaxman, S. R., Boerma, T., Vanderpoel, S. & Stevens, G. (2012) National, Regional, and Global Trends in Infertility Prevalence since 1990: A Systematic Analysis of 277 Health Surveys. PLoS Medicine, 9(12), 1-12. https://doi.org/10.1371/journal.pmed.1001356

Matusitz, J., & Spear, J. (2014). Effective doctor-patient communication: an updated examination. *Social work in public health*, *29*(3), 252–266. https://doi.org/10.1080/19371918.2013.776416

Mazur, D. J., Hickam, D. H., Mazur, M. D., & Mazur, M. D. (2005). The role of doctor's opinion in shared decision making: what does shared decision making really mean when considering invasive medical procedures?. *Health expectations: an international journal of public participation in health care and health policy*, *8*(2), 97–102. https://doi.org/10.1111/j.1369-7625.2005.00315.x

McAlpine, K., Lewis, K. B., Trevena, L. J., & Stacey, D. (2018). What Is the Effectiveness of Patient Decision Aids for Cancer-Related Decisions? A Systematic Review Subanalysis. JCO Clinical Cancer Informatics, 2(2), 1–13. https://doi.org/10.1200/CCI.17.00148

McLaney, M. A., Tennen, H., Affleck, G. & Fitzgerald, T. (1995) Reactions to impaired fertility: the vicissitudes of primary and secondary control appraisals. Womens Health, 1(2), 143-159.

Millheiser, L., Helmer, A., Quintero, R., Milki, A. & Lathi, R. (2010). Is infertility a risk factor for female sexual dysfunction? A case-control study. Fertility and Sterility, 94(6), 2022-2025. https://doi.org/10.1016/j.fertnstert.2010.01.037

Mindes, E. J., Ingram, K. M., Kliewer, W., & James, C. A. (2003). Longitudinal analyses of the relationship between unsupportive social interactions and psychological adjustment among women with fertility problems. Social Science & Medicine, 56(10), 2165–2180. https://doi.org/10.1016/s0277-9536(02)00221-6

Nichols, W. & Pace-Nichols, M. (2000). Childless Married Couples. Handbook of Family Development and Intervention, 171-188.

Olafsdottir, H., Wikland, M., & Möller, A. (2013). Nordic couples' decision-making processes during assisted reproduction treatments. *Sexual & reproductive healthcare: official journal of the Swedish Association of Midwives*, *4*(2), 49–55. https://doi.org/10.1016/j.srhc.2013.04.003

Olivius, C., Friden, B., Borg, G., & Bergh, C. (2004). Why do couples discontinue in vitro fertilization treatment? A cohort study. *Fertility and sterility*, *81*(2), 258–261. https://doi.org/10.1016/j.fertnstert.2003.06.029

Patel, S. R., Bakken, S., & Ruland, C. (2008). Recent advances in shared decision making for mental health. Current Opinion in Psychiatry, 21(6), 606–612. https://doi.org/10.1097/YCO.0b013e32830eb6b4

Peddie, V. L., van Teijlingen, E., & Bhattacharya, S. (2004). Ending in-vitro fertilization: women's perception's of decision making. *Human fertility (Cambridge, England)*, *7*(1), 31–37. https://doi.org/10.1080/1464727042000198069

Peddie, V. L., VanTeijlingen, E. & Bhattacharya, S. (2005) A qualitative study of women's decision-making at the end of IVF treatment. Human Reproduction, 20(7), 1944–1951. https://doi.org/10.1093/humrep/deh857

Petropanagos, A. (2017). Pronatalism, geneticism, and ART. International Journal of Feminist Approaches to Bioethics, 10(1), 119–147. https://doi.org/10.3138/ijfab.10.1.119

Petropanagos, A., Cattapan, A., Baylis, F., & Leader, A. (2015). Social egg freezing: risk, benefits and other considerations. Canadian Medical Association Journal, 187(9), 666–669. https://doi.org/10.1503/cmaj.141605

Pettee, D. & Weckstein, L. N. (1993) A survey of parental attitudes toward oocyte donation. Human Reproduction, 8(11), 1963-1965.

Platt, F. W., & Keating, K. N. (2007). Differences in physician and patient perceptions of uncomplicated UTI symptom severity: understanding the communication gap. *International journal of clinical practice*, *61*(2), 303–308. https://doi.org/10.1111/j.1742-1241.2006.01277.x

Rajkhowa, M., McConnell, A., & Thomas, G. E. (2006). Reasons for discontinuation of IVF treatment: a questionnaire study. *Human reproduction (Oxford, England)*, *21*(2), 358–363. https://doi.org/10.1093/humrep/dei355

Richards, M., Pennings, G., & Appleby, J. (2012). Introduction. In M. Richards, G. Pennings, & J. Appleby (Eds.), *Reproductive Donation: Practice, Policy and Bioethics* (pp. 1-12). Cambridge University Press. https://doi.org/10.1017/CBO9781139026390.001

Roter, D. L., Hall, J. A. & Katz, N. R. (1988). Patient–physician communication: a descriptive summary of the literature. Patient Education and Counselling, 12(2), 99-119. https://doi.org/10.1016/0738-3991(88)90057-2

Saleh, R. A., Ranga, G. M., Raina, R., Nelson, D. R., & Agarwal, A. (2003). Sexual dysfunction in men undergoing infertility evaluation: a cohort observational study. Fertility and sterility, 79(4), 909–912. https://doi.org/10.1016/s0015-0282(02)04921-x

Schmidt, L., Holstein, B. E., Christensen, U., & Boivin, J. (2005). Does infertility cause marital benefit? An epidemiological study of 2250 women and men in fertility treatment. Patient Education and Counselling, 59(3), 244–251. https://doi.org/10.1016/j.pec.2005.07.015

Semmel, A. (1979). The American Political Science Review, 73(1), 213-214. https://doi.org/10.2307/1954755

Silva Carvalho, J. L., & Santos, A. (2009). Estudo AFRODITE: Caracterização da Infertilidade em Portugal (Vol 1 – Estudo na Comunidade).

Slade, P., O'Neill, C., Simpson, A. J., & Lashen, H. (2007). The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. Human reproduction, 22(8), 2309–2317. https://doi.org/10.1093/humrep/dem115

Søndergaard, S. R., Madsen, P. H., Hilberg, O., Jensen, K. M., Olling, K., & Steffensen, K. D. (2019). A prospective cohort study of shared decision making in lung cancer diagnostics: Impact of using a patient decision aid. *Patient education and counseling*, *102*(11), 1961–1968. https://doi.org/10.1016/j.pec.2019.05.018

Stacey D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R. & Trevena, L. (2017) Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews, 4. https://doi.org/10.1002/14651858.CD001431.pub5

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews*, *4*(4), CD001431. https://doi.org/10.1002/14651858.CD001431.pub5

Steffensen, K. D., Vinter, M., Crüger, D., Dankl, K., Coulter, A., Stuart, B., & Berry, L. L. (2018). Lessons in Integrating Shared Decision-Making into Cancer Care. Journal of oncology practice, 14(4), 229–235. https://doi.org/10.1200/JOP.18.00019

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. Canadian Medical Association Journal, 152(9), 1423–1433.

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. (2015). Shared decision making: Concepts, evidence, and practice. *Patient education and counseling*, *98*(10), 1172–1179. https://doi.org/10.1016/j.pec.2015.06.022

Swanson, A., & Braverman, A. M. (2021). Psychological Components of Infertility. *Family Court Review*, *59*(1), 67-82. https://doi.org/10.1111/fcre.12552

Vaegter, K. K., Lakic, T. G., Olovsson, M., Berglund, L., Brodin, T., & Holte, J. (2017). Which factors are most predictive for live birth after in vitro fertilization and intracytoplasmic sperm injection (IVF/ICSI) treatments? Analysis of 100 prospectively recorded variables in 8,400 IVF/ICSI single-embryo transfers. Fertility and sterility, 107(3), 641–648. https://doi.org/10.1016/j.fertnstert.2016.12.005

Verhaak, C. M., Smeenk, J. M., Evers, A. W., van Minnen, A., Kremer, J. A., & Kraaimaat, F. W. (2005). Predicting emotional response to unsuccessful fertility treatment: a prospective study. Journal of behavioral medicine, 28(2), 181–190. https://doi.org/10.1007/s10865-005-3667-0

Volgsten, H., Svanberg, A. S., Ekselius, L., Lundkvist, Ö. & Poromaa, I. S. (2008) Prevalence of psychiatric disorders in infertile women and men undergoing *in vitro* fertilization treatment. Human Reproduction, 23(9), 2056–2063. https://doi.org/10.1093/humrep/den154

Wischmann T. (2008). Implications of psychosocial support in infertility - A critical appraisal. *J. Psychosom. Obstet. Gynecol.* 29 83–90. 10.1080/01674820701817870

Yeh, J. S., Steward, R. G., Dude, A. M., Shah, A. A., Goldfarb, J. M. & Muasher, S. J. (2014). Pregnancy rates in donor oocyte cycles compared to similar autologous in vitro fertilization cycles: an analysis of 26,457 fresh cycles from the Society for Assisted Reproductive Technology. Fertility and Sterility, 102(2), 399–404. https://doi.org/10.1016/j.fertnstert.2014.04.027

Zegers-Hochschild, F., Adamson, G. D., Dyer, S., Racowsky, C., Mouzon, J., Sokol, R., Rienzi, L., Sunde, A., Schmidt, L., Cooke, I. D., Simpson, J. L., & Van der Poel, S. (2017). The International Glossary on Infertility and Fertility Care. Fertility and Sterility, 108(3), 393-406. https://doi.org/10.1016/j.fertnstert.2017.06.005

Zeiler K. (2007). Shared decision-making, gender and new technologies. *Medicine, health care, and philosophy*, *10*(3), 279–287. https://doi.org/10.1007/s11019-006-9034-2

Attachments

A. Semi-structured interview guide

Tal como descrito no consentimento informado enviado, queremos compreender melhor como é realizada a tomada de decisão quando o casal passa por tratamentos de fertilidade com recurso à doação de gâmetas, e esperamos que deste modo possamos ajudar futuramente os clínicos e os pacientes a melhor comunicarem.

Vou fazer em seguida algumas perguntas, lembrando que pode não responder ou terminar a qualquer momento esta entrevista se assim o desejar.

1. Quando se colocou como hipótese recorrer à doação de gâmetas, como é que lhe foram apresentadas as várias opções para concretizar o seu projeto de parentalidade? Estas opções foram apresentadas de uma forma clara? (Pode-me contar um pouco mais?)
2. Pode-me contar, resumidamente, como foi o processo de tomada de decisão, por parte do casal, no sentido de recorrer à doação de gâmetas, na sua perspetiva? O que pesaram em termos de prós e contras?
3. Como carateriza a comunicação com a equipa médica ao longo do processo?
    a. O que correu bem e o que correu mal? (O que poderia ter sido melhor?)
    b. Sentiu que deram resposta às suas questões?
    c. Sentiu que conseguiu transmitir ao seu médico tudo aquilo que queria?

Gostaria de lhe falar sobre o conceito de tomada de decisão partilhada, que se refere ao facto de as decisões ao nível de tratamentos médicos serem deliberadas em conjunto por médico e paciente. Uma característica importante desta abordagem é o questionamento, por parte do médico, acerca daquilo que é mais importante para o paciente – por exemplo, efeitos secundários dos tratamentos, parentalidade genética, etc. No fundo, no âmbito da doação de gâmetas, o médico procura perceber, com o paciente, se o tratamento é uma opção viável para o mesmo, permitindo que o paciente tome uma decisão que vá ao encontro dos seus valores, prioridades e preferências.

4. Em relação ao tratamento com doação, sente que houve uma tomada de decisão partilhada? Quem colocou inicialmente esta hipótese?
    a. Gostaria de ter estado mais ou menos envolvido nesta decisão?

    b. Em perspetiva, qual a percentagem que atribuiria à influência do médico na sua decisão? (de 0 a 100%)
    c. Houve outros profissionais de saúde que influenciaram esta transição? Se sim mencione quais e refira a percentagem de influência? (de 0 a 100%)
    d. Houve familiares ou amigos que influenciaram esta transição? Se sim mencione quais e refira a percentagem de influência? (de 0 a 100%)

5. Olhando para trás, o que acha que deveria ou poderia ter sido diferente e que vos ajudaria a tomar esta decisão de uma forma mais consistente ou tranquila?
6. Neste processo, alguma vez discordou de uma proposta ou plano de tratamento? Se sim, sentiu-se suficientemente confortável para dizer que não concordava?
7. Neste processo, alguma vez sentiu que não conseguia ou podia comunicar o que sentiu sobre algum passo ou procedimento relativo ao tratamento com doação?
8. De que forma é que os diferentes profissionais de saúde podem melhorar a comunicação com os pacientes para ajudar ~~n~~esta tomada de decisão?

(há alguma coisa que ache que se tenha esquecido de dizer até agora e queira mencionar?)

De seguida vou apresentar 2 cenários hipotéticos que gostaria que comentasse se possível.

O primeiro: A Joana tem 39 anos e foi-lhe diagnosticada uma reserva ovárica muito baixa. Vem com o marido à consulta de follow-up após 5 tentativas falhadas de fertilização in vitro. O médico diz-lhes que não há condições médicas para realizar novo tratamento e que, por isso, não “aceita” realizar novo tratamento àquele casal, a não ser que optem pelo tratamento com gâmetas doados.

9. Nesta situação, que pensa acerca de como foi tomada a decisão em relação ao recurso a gâmetas doados? Acredita que foi a melhor abordagem? Se não, porquê?

Vou agora descrever o segundo:

A Clara tem 41 anos, pesa 71 kg e mede 1,68 m. Não tem nenhum diagnóstico específico para além dos parâmetros expetáveis para a sua idade, nem o marido. Fizeram 2 ciclos FIV com insucesso. Neste momento as suas probabilidades de alcançar uma gravidez são as seguintes: conceção espontânea - 8%, FIV com gâmetas próprios - 19%, e FIV com ovócitos doados 54%.

10. Qual seria a melhor opção para este casal?
    10.1. Que fatores deveriam pesar?
11. Qual deveria ser o grau de implicação do médico na tomada de decisão? Idealmente, qual a percentagem que deveria ser atribuída ao médico nesta de tomada de decisão?
12. Há outros profissionais de saúde que deveriam estar implicados na tomada de decisão? Que percentagem lhes deveria ser atribuída?
13. O que poderia mais ajudar a Clara e o marido?
14. Gostaria de acrescentar ou perguntar alguma coisa?

B – Informed Consent Form

A presente investigação visa melhor compreender o percurso realizado por casais heterossexuais que realizaram tratamentos de Reprodução Medicamente Assistida com recurso à doação de gâmetas.

Para isso utilizamos uma metodologia qualitativa, que se operacionaliza na realização de uma entrevista semiestruturada confidencial, cuja gravação áudio será *transcrita verbatim* (palavra a palavra) e os dados pessoais eliminados ou anonimizados. A participação neste estudo poderá desencadear memórias e emoções não desejadas, visto provocar o reviver de um processo complexo e bastante pessoal. No entanto, mesmo que aceite participar, terá todo o direito de recusar-se a responder a qualquer pergunta ao longo da entrevista, sem precisar de se justificar sobre essa decisão. Além disso, poderá desistir de participar na entrevista e no estudo em qualquer fase do processo.

Por outro lado, a partilha da sua história poderá provocar um sentimento de bem-estar e altruísmo por se disponibilizar a ser parte integrante num processo cujo objetivo será melhorar os contextos em que estes tratamentos de reprodução medicamente assistida ocorrem, permitindo facilitar o processo futuro de mulheres que percorram esta caminhada.

Os seus dados pessoais, assim como as respostas ao questionário e/ou a entrevista, não serão divulgados. A privacidade sobre os dados confidenciais envolvidos na investigação será respeitada e o seu tratamento ocorrerá em conjunto com o dos demais participantes. A sua participação não incorrerá em custos financeiros.

Este projeto teve parecer favorável da Comissão de Ética da Faculdade de Psicologia e Ciências da Comunicação da Universidade do Porto.

Caso surja alguma dúvida em relação à sua participação, investigação, ou caso queira conhecer os resultados globais do estudo, poderá contatar as investigadoras responsáveis, através dos seguintes contatos: Ana Rita Nogueira up201608515@edu.fpce.up.pt; Catarina Rodrigues up201709408@edu.fpce.up.pt; Juliana Pedro juliana_bpedro@hotmail.com; Mariana Veloso Martins – mmartins@fpce.up.pt

Fui informado(a) e devidamente esclarecido(a) a respeito do projeto de investigação intitulado "**O caminho até à PMA com doação de gâmetas – obstáculos e aprendizagens**", Assim, DECLARO, que após recebidos todos os esclarecimentos CONSINTO, voluntariamente, em participar nesta investigação.

Porto, ... de .... de 202_.

Nome do/a participante:

____

____

Assinatura do participante