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ARTICLE

Review of International Research on Ethical and Psychological Barriers to Reproductive Donation

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ABSTRACT

This review examines the international research literature discussing the barriers for those considering the possibility of becoming donating sperm, eggs, or embryos or becoming surrogate mothers. While there is a significant body of research on donors' motivations, less attention is given to the reasons why potential donors decide not to donate or withdraw from donation procedures. Nevertheless, we have collected about 70 studies, including journal articles, book chapters and reports. Contemporary findings show that as much as there is no single motivation for reproductive donation, there is also no single barrier to it. The studies we considered deal with two salient themes. First, barriers to reproductive donation serve as a space for negotiation of a donor's beliefs, fears and perceived consequences of donation to themselves, the recipients and resulting offspring. Second, these barriers are a complex web of intersecting factors, influenced by secondary factors. This review reveals the limited nature of our current knowledge of barriers to reproductive donation. Indeed, research on this problem needs to catch up with research on motivation because obstacles to reproductive donation are no less important than the stimuli.

KEYWORDS

assisted reproductive technologies (ART); motivation of reproductive donation; motivational barriers; legal regulation of assisted reproduction

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Introduction

In the light of the rising number of infertility cases across the globe, reproductive donation has been the subject of extensive international interest in the past decade. This interest has been propelled by two main developments. First is the availability of technology for different types of donation such as sperm, eggs, and embryo donation, and surrogacy. Second is the growing need for ethical frameworks of legislation and medical practices in assisted reproductive technology (ART). Studies on reproductive donation have predominantly been aimed to identify the ways in which donors are motivated to donate; but less attention has been given to the reasons why potential donors may decide against it. To our knowledge, no systematic review of the literature on this topic has been done yet, especially the studies of the factors that hinder certain types of donation more than others.

This review focuses on the current body of knowledge on ethical and psychological barriers in reproductive donation. It is also aimed to provide insight into the specific differences in the barriers' characteristic of each type of reproductive donation. In our analysis, reproductive donation refers to donation of sperm, eggs, embryos and surrogate motherhood. Barriers are understood here as the factors that impede the initiation or continuation of the process of reproductive donation. These aspects are crucial because even though significant efforts have been made to improve the quality of reproductive donation, there are still potential donors who opt out of donation, which calls for a more in-depth consideration of decisionmaking in reproductive donation. This review can also be beneficial for professional ART organizations, in particular those engaged in recruitment of new donors. The results of this review are meant to provide useful information for medical and legal professionals as well as policy makers on reproductive health.

To this end, we collected materials written in English such as academic articles, book chapters and reports dealing with factors that deter potential donors from participating in reproductive donation. The reference search was conducted in 7 databases (EBSCOHost¹, ScienceDirect², Sage Journals³, PubMed Central⁴,ProQuest Central⁵, Scopus⁶, and JSTOR⁷), using the following terms alone and in combination: "motivation", "reproductive donation", "reproductive donors", "sperm donors", "sperm donation", "egg donors", "egg donors", "oocyte donors", "surrogates", "surrogacy", and "ethical aspects".

¹ https://www.ebsco.com/

² https://www.sciencedirect.com/

³ https://journals.sagepub.com/

⁴ <u>https://www.ncbi.nlm.nih.gov/pmc/advanced/</u>

⁵ https://about.proquest.com/products-services/ProQuest_Central.html

⁶ https://www.scopus.com/home.uri

⁷ https://www.jstor.org/

The search was limited to articles published in scientific journals in English between years 1992 and 2018. To be included in the sample, materials had to include a description of ethical and psychological reasons why donors may be hesitant about participating in reproductive donation. Criteria used for exclusion include: date range, data on reproductive recipients alone, clinical research on gamete donation. However, articles containing information on donors' perception on reproductive donation were not excluded because data on why they did not donate can be considered as barriers to reproductive donation. After the materials were screened and checked for eligibility and all duplicates were removed, about 70 references were identified as fitting the inclusion criteria. These were quite diverse in focus and method, with some works covering reproductive donation in general rather than dealing exclusively with the barriers to reproductive gamete donation. This systematic review has some important limitations. First, it provides a comprehensive overview only of the research on ethical and psychological barriers to reproductive donation published in English; this implies that there may be also non-English publications describing other barriers. Second, we recognize that the references reviewed in this work do not comprise all information about donation barriers, and thus the information used in the discussion may not have been fully comprehensive. These limitations, however, are opportunities for further research.

Sperm Donation

Barriers to sperm donation provoke a lot of discussions as different countries face a number of ethical and psychological challenges in dealing with this sphere, such as donor recruitment, donor compensation, donor anonymity, contact with donorconceived offspring, etc. Psychological matters are usually related to donors' altruistic motives and their concerns about the well-being of the resulting children while ethical issues, to donors' anonymity, compensation, and contact with the resulting offspring (van den Broeck et al., 2013).

Ethical Barriers to Sperm Donation

Since matters of privacy are crucial for sperm donors, anonymity is an important consideration in donating. Some donors are ready to participate in the process only if they remain anonymous because this way they can avoid conflicts or tensions in their own families (Mohr, 2014). This becomes more relevant because of the global changes in regulations of anonymous donorship. For instance, Denmark allows anonymous sperm donation (Mohr & Koch, 2016), but there is an increasing number of countries that mandate the removal of donor anonymity and urge fertility banks to register all potential donors with necessary information (van den Broeck et al., 2013). Donors might consider this as a threat to their privacy since donor-conceived offspring will be able to trace and find their donors as well as half-siblings through these registries. There are also cases with courts mandating sperm banks to turn over a donor's medical records when there is a need to check his or her medical history to resolve some health issues of the offspring (Andrews & Elster,

1998). Therefore, it can be difficult both for donors and sperm banks to have control over anonymity, which can lead to the scarcity of sperm donors (Pennings, 2005). However, it is not much of a hindrance to donors if the release of information only includes non-identifying information, such as physical characteristics and the level of education (Godman et al., 2006). As such, in countries where anonymous donation is prohibited by law, donor anonymity is ensured through the informal settings, in which this procedure is carried out (Bossema et al., 2014).

There are also barriers related to the moral side of reproductive donation itself or to how it is practiced. Some potential donors hesitate to donate because of religious considerations about the unnaturalness of ART, which can be seen as a form of discreet eugenics (van den Broeck et al., 2013). Meanwhile, there is also a moral concern about ART disturbing the traditional bilineal kinship (Mohr, 2018). For instance, potential donors may not be willing to share their sperm with single/lesbian women and lesbian couples because they believe that a child should be raised by parents of both sexes (Ekerhovd & Faurskov, 2008).

Psychological Barriers to Sperm Donation

Donors may experience feelings of anxiety, insecurity and disgust concerning the process of donation. They may feel uneasy about having masturbatory ejaculation of semen in a sperm bank on moral grounds, which constitutes a "possible transgression of these boundaries for sperm donors" (Mohr, 2018, p. 139). Some may see the secretion of bodily fluids in plastic cups as inappropriate because this action is beyond their normative boundary (Mohr, 2016). Muslim men, in particular, experience conflicting attitudes to delivering semen samples in sperm clinics since masturbation promotes "guilty pleasures", especially when pornographic materials are offered in clinics (Inhorn, 2007). Interestingly, donors may also be anxious about the possibility of discovering a fertility problem of their own (Cook & Golombok, 1995).

Sperm donors may also feel anxious lest others should find out about their donorship (Schover et al., 1992; Shepherd et al., 2018). Anonymity may be particularly important when family issues are involved, which can serve as secondary barriers. While in some countries sperm donation between brothers is considered to be an acceptable intra-family situation (American Society for Reproductive Medicine [ASRM], 2017), anonymity is crucial for other forms of donation (brother-sister, father-daughter) because it can be classified as incest. This may prove to be a relevant dealbreaker for married heterosexual men since it can cause frictions in their relationships with their spouses and children (Riggs & Russell, 2011). The donor's partner and family members can react differently to the situation of donation. Therefore, in some cases, donors prefer not to inform their partners about their participation in the donor program while in other cases, donors, on the contrary, seek their partners' explicit approval (Lalos et al., 2003; Thorn et al., 2008). Thus, donors tend to be serious about the consequences of their donation both for themselves (van den Broeck et al., 2013), for their families, and for the future children. Each of these considerations can act as a barrier to donating (Bossema et al., 2012).

Egg Donation

An important theme in research literature on egg donation is donors' motivation to donate only for a specific segment of the population, which restricts the act of donation. In egg donation, barriers are mainly related to the process of donation and concerns about the welfare of the resulting offspring. Yet donors may also have other ethical and psychological reasons to opt out of the donation process.

Ethical Barriers to Egg Donation

There are two main ethical obligations that egg donors feel: towards the recipient women and towards the resulting children. First, while women might feel a moral obligation to share their eggs with infertile women (Blyth et al., 2011), this obligation can be restricted. Some donors would only donate if they are personally acquainted with the prospective recipients (Winter & Daniluk, 2004; Yee et al., 2011), which means that they may have reservations concerning donation to other recipients in need. Moreover, as much as some donors would be delighted to meet the resulting offspring, some might not be at ease about it. Second, donors might also feel morally obliged to ensure that the resulting offspring will be in good hands. Some donors feel that they are responsible to ensure the resulting child's emotional stability by being identified as his or her biological mother (Bracewell-Milnes et al., 2016). Therefore, they express the desire to obtain information about the recipients before donating in order to evaluate the kind of life the resulting offspring will have (Yee et al, 2011).

Interestingly, financial compensation is related to egg donors' perception of fairness (Partrick et al., 2001). Some donors would be unwilling to donate unless monetary compensation was provided (Ibid.), which can be corroborated by the fact that there are fewer egg donors from countries that prohibit commercial egg donation (Gezinski et al., 2016). There are statutory restrictions such as legal measures that limit donation of oocytes due to the risk of possible kinship in the future (ASRM, 2017). For instance, in Canada it is prohibited to share one's eggs and to engage in any commercial transactions of selling or buying oocytes (ASRM, 2017). Aside from ethical issues, religion also plays a part in potential donors' decision not to donate. For example, the dominance of Catholicism in Italy and Costa Rica currently makes their context very restrictive for reproductive donation. Likewise, Muslim countries are very strict in regulating gamete donation (Inhorn & Patrizio, 2012). Another factor that may be off-putting for potential egg donors is the mandatory lower age limit for those who want to be a donor with the goal of "ensuring donor maturity sufficient to understand the conditions of the procedure and make an informed decision" (ASRM, 2017, p. 5).

Psychological Barriers to Egg Donation

Fear and anxiety are crucial barriers to egg donation (Shepherd et al., 2018). Women may feel uncomfortable in the process of egg donation because of such medical procedures as injections and penetrations (Ibid.). Fear of the physical and psychological risks associated with oocyte donation also plays a role in potential donors' decision-making, especially when they are considering the implications of the procedure for their own reproductive health in the future (Kenney & McGowan, 2010; Yee et al., 2011). Furthermore, donors might have the fear of regret. For example, when the previous donation did not result in pregnancy, the donor may experience a feeling of disappointment that may deter her from donating again (Winter & Daniluk, 2004). Donors may also feel uncomfortable with the idea of having "unknown" offspring (Blyth et al., 2011). Some donors would only donate if their anonymity is guaranteed (Gürtin et al., 2012).

Embryo Donation

Unlike gametes, which are the biological sources of human reproduction, an embryo is not a raw resource but rather an outcome from an assisted union between gametes. As such, embryo donation is a multi-party decision, which can be a battle between donors themselves or donors against time. There are two purposes of embryo donation: for reproduction or research. Yet some couples choose to have their embryos destroyed. The general practice in embryo donation involves giving a written consent to freezing the embryos resulting from the IVF treatment. Couples are also expected to communicate their desire to donate or discard their frozen embryos before the expiration of the storage period (Svanberg et al., 2001).

Ethical Barriers to Embryo Donation

Ethical principles, such as perceiving embryo donation as "child relinquishment", play a part in donors' decision-making (de Lacey, 2005, p. 1661). In these cases, couples would choose to discard their embryos rather than donate them for research when the storage time has ended (Svanberg et al., 2001). Some donors view an embryo as a person/child and see the situation as an ethical dilemma. Donors who eventually became parents through successful IVF brood over the idea that their embryos-turn-child would be mistreated and decide that it is better to terminate their embryos than to open the likelihood of these embryos having a life different from what their genetic parents want them to have (de Lacey 2005). In another work of de Lacey (2007, p. 1757), it is shown that provisional donors and discarders differ in terms of their interpretation of embryos, that is, embryo donors relate more to the "metaphor of pregnancy termination" while those who discard embryos emphasize the adoption metaphor.

Couples may choose to discard an embryo even after they have given their initial agreement to donate it, at the final stage of agreement and after passing all the necessary procedures (Bangsbøll et al., 2004; Laruelle & Englert, 1995). Nachtigall et al. (2005) report that as many as 88 percent of the couples who had initially decided to donate their embryos to research reconsidered their decision later. When they decided to donate, they might have "supported ED in principle, but only a small subgroup would actively consider donation" (Newton et al., 2003, p. 27). This finding is consistent with the earlier studies that showed that more than a half of couples change their initial

intention to donate embryos to research (see Brinsden et al., 1995; Cooper, 1996; Hounshell & Chetkowski, 1996; Klock et al., 2001; Saunders et al., 1995).

Psychological Barriers to Embryo Donation

The option to delay the decision to donate serves as a psychological barrier to embryo donation because this option reinforces the "behavior in which individuals seek to avoid the responsibility of making a decision" (Anderson, 2003, p. 139). McMahon et al. (2003) report that 70 percent of participants intended to delay their decision on what to do with their embryos for as long as possible. In some cases, partners failed to reach a joint decision or forgot about the request (Provoost et al., 2001). Decision avoidance results in many embryos remaining in storage unclaimed or "lost to follow-up" (e.g. case in Canada, See Royal Commission on New Reproductive Technologies, 1993 cited in Cattapan & Baylis, 2016).

Decision avoidance (Anderson, 2003) intersects with the dual nature of embryo donors: a sperm donor and an egg donor. Deciding with another person is much more complicated than making an individual decision, and usially state regulations in clinics require the consent of the two donors. For instance, the Iranian Parliament passed a law stating that infertility centers can donate embryos to the infertile only after the permission is obtained from the donor couples (Alizadeh & Samani, 2014). Decision avoidance happens when some donor couples struggle with decision-making and find it difficult to reach a joint decision (Provoost et al., 2011), especially whether to donate or to discard their frozen embryos. Davis (2012, p. 386) observed that the possibility of a dispute within a couple led clinics "to require couples undergoing IVF to sign a cryopreservation consent or agreement to address the disposition of embryos in the case of divorce, death, or abandonment". In the US, for example, in the event of death or divorce, which prevents donor couples from using their embryos for conception, courts can decide which donor's interests must prevail (Sheinbach, 1999). For many couples, however, financial reasons meddle with their decision-making as keeping embryos in storage will inevitably incur more expenses (Davis, 2012). For example, the Advanced Fertility Center of Chicago charges \$800 for embryos to be cryogenically frozen and stored for one year, and a certain amount for each subsequent year⁸.

Surrogate Motherhood

Surrogacy is the most service-oriented type of reproductive donation. Compared to the transactions of sperm, oocyte or egg donors, the duration of the surrogate's involvement in the reproductive process is substantially greater and longer. Barriers to surrogacy are related to donors' trust in the recipients and fear of risks.

Ethical Barriers to Surrogate Motherhood

Most ethical concerns about surrogate motherhood are related to donors' religious views. For instance, in Islam, surrogacy is ethically problematic because a woman

⁸ http://www.advancedfertility.com/ivfprice.htm

becomes "impure" when she receives sperm from a man to whom she is not married (Inhorn, 2006). Muslim women believe that surrogacy can presumably be connected to ethical issues because it meddles with the sacredness of the husband-wife relationship (Lasker, 2015). While the idea of surrogate motherhood is gradually gaining acceptance among the Shiite population in Iran and a part of Iraq, Lebanon, Bahrain, Syria, Saudi Arabia, Afghanistan, Pakistan, and India (Abbasi-Shavazi et al., 2008), many might still not be comfortable with being a surrogate mother. Moreover, for some Christians, surrogacy may confuse the child's identity; obstruct the naturalness of procreation and child rearing (Lones, 2016).

In some cases, surrogates would only enter in a surrogacy arrangement with close relatives. Some may involve sister-sister (Kirkman & Kirkman, 2002) and mother-daughter (Brazier et al., 1997). Some potential surrogates fear that they will eventually develop affection for the gestated offspring (Agnafors, 2014; Larkey, 2003) and this may complicate the separation later on. However, if the surrogate knows the recipients, it will be easier to compartmentalize her feelings because her duty as a surrogate is clear.

Psychological Barriers to Surrogate Motherhood

Potential surrogate mothers have a common fear of having to regret their decision over time (Teman, 2008). Since potential surrogates need to feel sure of the people they are going to deal with, an initial negotiation is set (van den Akker, 2000). Agreements are based on trust arrangements (Edelmann, 2004). An important factor is whether a surrogate mother has already experienced a positive relationship with the trusted couple or not. Depending on this factor, she would want to make subsequent surrogacy arrangements in the future or not (Imrie & Jadva, 2014). However, in cases of mediated surrogacy, "surrogacy agencies choreograph the entire process, from matching of the surrogate and intended parents to administration and enforcement of contractual matters" (Holcomb & Byrn, 2010, p. 651). In this case, potential surrogates agree if they trust the agency involved.

Potential surrogates are also affected by the fear of hostility and humiliation from their families or friends (Jadva et al., 2003; Shenfield et al., 2005). The approval of their spouses may indirectly affect their decision to become a surrogate mother because a surrogate's husband must agree to abstain from sexual intercourse during the given period (Sama, 2012).

Conclusions

It is now evident that in so far as there is no single motivation for reproductive donation, there is also no single barrier to it. As the studies covered by this review have shown, there may be multiple barriers to reproductive donation related to each other. Barriers may overlap and can be influenced by secondary factors, which inform the donor's decision. Thus, a more comprehensive approach is necessary to the study of the psychological and ethical aspects of reproductive donation (Sandberg & Conner, 2008). The decision not to donate may be even more significant for donors

than the decision to do so. More importantly, the decision not to donate does not necessarily mean that potential donors are against reproductive donation as such. Donors' selectivity is based on what they think is best for themselves, the recipients and the resulting offspring. Moreover, as shown in this review, barriers to reproductive donation vary depending on the type of donation (reproductive material). For instance, some donors might be very picky regarding the sexuality of the recipient couple, their socio-economic status or even personality. Of particular interest in this review are instances when donors would rather not donate for the fear that their donation's costs will outweigh the benefits.

Barriers are often indicative of the fact that non-donation is not inaction. First, barriers remind donors of their expectations of themselves and the ways their bodies should be handled. Second, non-personal barriers show that potential donors are not isolated individuals and interact with other stakeholders in the field of reproductive donation. Barriers serve as a space for negotiation of a donor's beliefs, fears and perceived consequences of their donation to themselves, the recipients and resulting offspring.

This review has shown that research on the barriers to reproductive donation needs to catch up with the research on motivation because hindrances to reproductive donation are not less important than what motivates donors to participate in reproductive donation. One aspect to focus on is the population included in research. While reproductive donation is practiced globally, there seems to be an imbalance in terms of what segment participate in research for each type of donation. For instance, there is a lack of comparison between what could be a barrier for sperm donors and what prevents non-donors from donating (Daniels et al., 2005; Frith et al., 2007). While there were reports on non-donors' attitudes towards sperm donation (Cook & Golombok, 1995; Lui & Weaver, 1996), it still remains unclear if these attitudes were actual barriers. Moreover, the research on sperm donation has been conducted predominantly in Western countries, with an emphasis on actual sperm donor population (Del Valle et al., 2008; Ernst et al., 2007), which means that some research findings should be interpreted with caution as there may be biases influencing their generalizability.

As for the practical implications of the contemporary studies described above, they demonstrate the need for clear guidelines for reproductive donors. A more nuanced evaluation of informed consent should be discussed: if informed consent is measured only in terms of signed papers this concept can have hidden exploitative practices. Donation contracts also often lack clarity regarding donors' rights and obligations at different stages of the donation process. The majority of donors face a range of psychological and ethical problems concerning the reaction of their partners/ spouses, their immediate family members and friends to this situation, as well as diverse anxieties about the future of their own families, on the one hand, and the future of their potential offspring, on the other. We hope that the findings discussed in this review will allow researchers, medical practitioners, policy makers and reproductive donors alike to formulate recommendations on how to ensure more ethical practices of reproductive donation.

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