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Donor information considered important to donors, recipients and offspring: an Australian perspective


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Abstract Donor conception research supports open-identity donor programmes and disclosure to donor-conceived offspring. This study examines Australian donors', recipients' and donor-conceived offspring's views on the importance of different types of biographical information about the donor. Participants (125 recipients, 39 donors (known, identity-release and anonymous), 23 donor-conceived offspring) completed an online or paper self-administered anonymous questionnaire. Individuals rated the importance of 15 types of biographical information and subsequently chose the three they deemed most important. All groups included donor's health history and name as key variables to be available to donor-conceived offspring. Recipients viewed the donor's decision to donate as important, donors thought their feelings about being contacted were important and donor-conceived offspring expressed an interest in the donor's own family. Sperm donors were less inclined to view the provision of information as important compared with offspring. For recipients, the importance of information became apparent once they had disclosed to their children. This is the first study to gauge Australian stakeholders' attitudes to release of information in the donor conception process. The findings support the move to open-identity donation systems and emphasize the importance of considering the varying perspectives of all stakeholders by policy developers. 

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KEYWORDS: donors, donor-conceived offspring, gamete and embryo donation, recipients, release of information

Introduction

Donor conceptions form a major component of assisted conception births around the world. In Australian and New Zealand fertility centres, approximately 10% of all treatment cycles involve the use of donated gametes or embryos

(Wang et al., 2009) and this figure does not include sperm donation carried out in hospitals or private clinics. Figures for the UK are similar with 10% of all babies born after IVF or donor insemination treatments being the result of donated spermatozoa, oocytes or embryos (HFEA, 2009). In the USA, donated oocytes or embryos are used in ~12%

of treatment cycles (Centers for Disease Control and Prevention, 2008), but there are no official records for sperm donation. Unofficial estimates suggest that between 30,000 and 60,000 children are born of sperm donation in the USA each year (Evan B Donaldson Adoption Institute, 2009).

In the past, the processes surrounding donor conception were secretive and few donor-conceived children were told of the manner of their conception. The donor was anonymous and only limited, non-identifying information (e.g. hair and eye colour, education and interests) was made available to recipients. More recently, however, social attitudes to donor conception have changed with a move from non-disclosure and secrecy towards openness. This is reflected in changing clinic and legislative practices of donor conception around the world. Legislation for open-identity donor systems allowing children born of gamete or embryo donation access to select identifying information about their donor on reaching maturity have been introduced in Sweden, The Netherlands, UK, New Zealand and the Australian states of Victoria and Western Australia (Daniels et al., 2005; Godman et al., 2006; Gong et al., 2009; Gottlieb et al., 2000; Janssens et al., 2006).

While a policy of open-identity donation may foster an environment in which more parents feel able to tell their children about the nature of their conception (Godman et al., 2006; Lalos et al., 2007), it does not provide a guarantee that parents will actually do so (Daniels et al., 2009; Gottlieb et al., 2000; Lalos et al. 2007; MacCallum and Golombok, 2007). Parental intention to disclose is influenced by many factors including parental views on the child's moral right to know about donor conception (Frith, 2001), parental relationship status (e.g. single, lesbian, heterosexual) (Godman et al., 2006; Scheib et al., 2003; Wendland et al., 1996), cultural and religious issues towards infertility (Gong et al., 2009), the extent of agreement between mothers and fathers or biological mothers and social mothers towards disclosure (Brewaeys et al., 1997; Daniels et al., 1995; Shehab et al., 2008) and the attitudes and guidance of advising healthcare professionals (Skoog Svanberg et al., 2008). Scheib et al. (2003) contend that the ability to access substantial biographical information about the donor facilitates parental disclosure because parents feel better equipped to answer questions about the donor should they arise. A number of recent studies support this view with higher levels of accessible donor information being associated with higher rates of disclosure (Klock and Greenfeld, 2004; MacCallum, 2009).

It is evident from the literature that the extent of biographical information available to recipients and donor-conceived offspring varies within and between countries and is determined by the regulatory frameworks governing assisted reproduction treatment in that country (Gong et al., 2009; Schneller, 2005), which has potential to influence outcomes on disclosure. In Australia, there has been no research which critically evaluates, nor any national guidelines which stipulate the information that should be stored, updated and released. Registries that exist are based on assumptions rather than empirical evidence as to what information would be in the child's best interest. In Western Australia, information stored in clinic records includes the donor's physical characteristics (hair and eye colour, complexion, build, height), marital status, occupa-

tion, religion, family background, education, limited information on their interests and personality and a summarized health history. Since December 2004, state legislation has required the storage of donor's name, date of birth and postcode of residence and this information can be accessed by offspring upon reaching the age of 16 years. Donor information is recorded at the time of donation and is not routinely updated. Whether recipients perceive such information to be adequate for their or their offspring's needs has not been explored in an Australian context. Neither has the importance of the extent and availability of biographical information in the decision to disclose.

Donors may also have a perspective on what information they feel a donor-conceived offspring should have access to. While this issue has been assessed indirectly in studies of donor views on conditions of donations (Cook and Golombok 1995; Daniels et al., 1997, 2005), these studies were primarily conducted at a time when anonymity of donation was standard practice and contact by offspring was highly unlikely. The subsequent changing philosophy of donor conception from anonymous to open-identity systems now makes it imperative for the opinions of donors to be gauged and for donors to consider the possible short-term and long-term social and health implications of their donation through the lens of the donor-conceived offspring.

Few studies have examined the offspring's views, mainly because until recently most donor-conceived individuals have not known of their donor conception status. Therefore the type and extent of biographical information about the donor that the offspring would want remains largely unknown, although a number of studies have found that offspring exhibit curiosity about information on their donors as it has relevance for their view of self (Hewitt, 2002; McWhinnie, 2006; Scheib et al., 2005; Turner and Coyle, 2000).

This study aimed to gauge the views of Australian donors, recipients and donor-conceived offspring as to the importance of different types of information available for release and to compare opinions between donor parties. The study included individuals from known, identity-release and anonymous donor programmes reflecting the variation in donor programmes across Australian states. The study has direct relevance to Australian policy and to other countries around the world that embrace an open-identity donor conception system.

Materials and methods

Participants

Approval for this study was granted by King Edward Memorial Hospital Institutional Ethics Committee.

The study sought participation from gamete and embryo donors, gamete and embryo recipients and donor-conceived individuals by advertising nationwide on various Australian donor conception support website forums, emails to members of the Australian and New Zealand Infertility Counsellors' Association, the Reproductive Technology Council of Western Australia and Infertility Treatment Authority websites and to existing clinic patients of Concept Fertility Centre. Participation of donor-conceived offspring was restricted to individuals aged 12 years or older.

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