Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals?

Running title: Disclosure of donor conception in the era of non-anonymity

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Abstract

This paper responds to a debate article published in Human Reproduction earlier this year. In that article, the authors suggested that parents should be encouraged to disclose the use of donor gametes to their children given rapid and widespread advances in genetic testing and sequencing. However, there is an urgent need to engage with the assertion that in this context, telling children about their donor conception both safeguards and promotes their interests, particularly if such disclosure is motivated by parents’ anxieties about accidental discovery. Disclosure that is motivated by the notion of non-anonymity may also encourage parents to share misinformation about donors, and encourage their children to have unrealistic expectations. Fertility professionals must remain mindful of these outcomes when discussing disclosure and the future implications of increasing access to genetic information with both prospective and current parents. It is strongly advised that future discussions about the end of donor anonymity are not conflated with the debate on disclosure.

Keywords: gamete donation, donor conception, anonymity, identifiability, disclosure
Introduction

The debate about disclosure of donor conception to children is not new. Yet, in their recent article (Harper et al., 2016), Harper and colleagues argue that the terrain upon which gamete donation is practiced has undergone significant shifts that present numerous novel challenges for those working in the field. Specifically, it is suggested that legal requirements of donor anonymity are of little significance in an age of increasing access to genetic information. While the authors present important evidence of the uses and outcomes of genetic testing and screening amongst some donor-conceived persons, their conclusions regarding parental disclosure are of concern.

The authors firstly suggest that disclosure of donor conception at an early age does not cause distress, yet mitigates the risk of accidental discovery that may result from genetic testing and/or sequencing. It is elsewhere argued that the majority of children, if told this information, would like to trace their donor. These two arguments are used to substantiate the claim that disclosure of donor conception ought to be encouraged. The present article will consider the accuracy of each of these arguments in turn, before outlining three substantial concerns regarding disclosure that is motivated by information about the end of donor anonymity. It will be shown that providing parents with information about the non-existence of donor anonymity within the context of advice about disclosure does not appear to meet the original article’s stated aim of safeguarding and promoting the interests of those who are donor-conceived. Rather, such advice runs the risk of encouraging: (i) anxiety-driven disclosure, (ii) disclosure that is based upon misinformation, and/or (iii) disclosure that fosters unrealistic expectations.

Early disclosure and accidental discovery
The suggestion that age is likely to impact upon the way in which information about donor conception is received is empirically well supported; a number of studies have found a positive association between early disclosure and feelings about donor conception (Jadva et al., 2009; Beeson et al., 2011; Freeman & Golombok, 2012; Hertz et al., 2013). It is also correct that accidental discovery is likely to result in negative feelings about donor conception (Turner & Coyle, 2000; Hewitt, 2002; Jadva et al., 2009; Blyth, 2012), and the argument that not telling is a ‘risky strategy’ for parents of donor-conceived children is one that therefore has traction (Appleby et al., 2012; Ilioi & Golombok, 2015).

However, several factors have been identified as important to parents’ disclosure decisions (Indekeu et al., 2013), and in spite of the general recommendation that parents share information about donor conception with their children (Nuffield Council on Bioethics, 2013), the majority of heterosexual couples who have conceived through anonymous sperm or oocyte donation decide against disclosure, or are uncertain about whether or not to do so (Cook et al., 1995; Brewaeys et al., 1997; Nachtigall et al., 1998; van Berkel et al., 1999; Golombok et al., 2002; Lycett et al., 2004, 2005; Laruelle et al., 2011; Freeman & Golombok, 2012; Salevaara et al., 2013; Blake et al., 2014), or report intentions to tell (Hahn & Craft-Rosenberg, 2002; Murray & Golombok, 2003; Greenfeld & Klock, 2004; Klock & Greenfeld, 2004) which are generally not borne out in practice (Golombok et al., 2002; Readings et al., 2011). In some empirical studies, higher rates of disclosure or intentions to disclose have been found amongst prospective (Greenfeld et al., 1998; Brewaeys et al., 2005; Godman et al., 2006; Crawshaw, 2008; Isakkson et al., 2011) and current (Scheib et al., 2003; Lalos et al., 2007; Isakkson et al., 2012) parents who use identifiable sperm or oocyte donation, yet others have failed to find an association (Baetens et al., 2000; Gottlieb et al., 2000; Greenfeld & Klock, 2004). It is therefore not clear that arguments for disclosure that are based upon either the risk of accidental discovery or the possibility of donor identifiability are sufficient
motivators to parental disclosure. Moreover, even if it is accepted that not telling may pose a risk of harm to donor-conceived persons through accidental discovery, and it is accepted that this risk is exacerbated in the age of genetic testing and/or sequencing, the argument that parents ought to thus be encouraged to tell their children about their donor conception fails to adequately address both the risk of anxiety-based disclosure and the potential for disclosure of misinformation.

Tracing the donor

It is also suggested in the original article (Harper et al., 2016) that if told about their donor conception, the majority of donor-conceived people would like to trace their ‘biological parent’ (elsewhere termed ‘donor parent’). Notwithstanding the fact that the terminology used by donor-conceived people to describe the donor(s) involved in their conception varies widely, and may be unrelated to the nomenclature of parenting (Scheib et al., 2005; Jadva et al., 2009; Hertz et al., 2013; Nelson et al., 2013), it is not clear what is meant by ‘tracing’ the donor. In general, the majority of studies of donor-conceived persons’ attitudes towards, and interest in, the donor have highlighted predominant feelings of curiosity (Vanfraassen et al., 2003; Scheib et al., 2005; Jadva et al., 2009; Rodino et al., 2011; Persaud et al., 2016; Slutsky et al., 2016), but not necessarily a desire for identifying information (Vanfraassen et al., 2001, 2003), nor a majority wish to meet the donor (Mahlstedt et al., 2010) or to establish a familial relationship (Hewitt, 2002; Cushing, 2010; Jadva et al., 2010). Moreover, what is known on this subject may be limited by biased sampling methods (Freeman, 2015), insofar as several studies on this topic have either recruited participants via support group networks (Hewitt, 2002; Cushing, 2010; Mahlstedt et al., 2010) or online forums for those interested in making connections with the donor and/or other children conceived using the same gametes (Jadva et al., 2009, 2010; Beeson et al., 2011; Hertz et al., 2013; Persaud et al., 2016; Slutsky et al.,
This is not to deny that some donor-conceived children, adolescents and adults are acutely interested in identifying the donors involved in their conception, and/or that lack of access to information is for some a highly negative experience (Turner & Coyle, 2000; Hewitt, 2002; Mahlstedt et al., 2010; Klotz, 2016), but to highlight that others are not interested in such information (Nuffield Council on Bioethics, 2013). It is not clear which, if either, is the ‘majority’ view so described by Harper and colleagues, and the argument that most donor-conceived people are interest in ‘tracing’ the donor is therefore not substantiated by empirical evidence. Even if it is accepted that some donor-conceived people are interested in ‘tracing’ their donor, citing this evidence in support of parental disclosure risks the possibility that disclosure will involve parents providing misinformation, and result in unrealistic expectations amongst those who are donor-conceived.

The risk of anxiety-based disclosure

One possible outcome of the argument that donor anonymity (and hence, parental secrecy) can no longer be guaranteed is raised levels of parental anxiety, particularly amongst those who have not yet disclosed. Amongst those who have disclosed, there appears to be some variation in what and how information is shared (Rumball & Adair, 1999; Hargreaves & Daniels, 2007; Mac Dougall et al., 2007; Blake et al., 2010), and the frequency of conversations about donor conception may vary, with some parents only discussing this issue once or twice when their children are very young and seem to understand little (Blake et al., 2010) or may forget what they have been told (Freeman, 2015). Moreover, disclosure is not always associated with positive outcomes with regards parents’ psychological adjustment (Freeman & Golombok, 2012; Blake et al., 2014), and negative associations between avoidance of conversations about donor conception and family functioning have been found (Paul & Berger, 2007). The conclusion to be drawn from such evidence is not that parents
ought not to share such information with their donor-conceived children, but that recommendations to disclose must be sensitive to family context, and may need to be accompanied by appropriate instrumental support (Hargreaves & Daniels, 2007; Crawshaw & Montuschi, 2013). Indeed, given that some non-disclosing parents with now adult donor-conceived offspring regret not having shared this information earlier, and although anxious, would like to do so (Daniels et al., 2011), framing disclosure as a process (rather than a one-time event that must be undertaken in the era of genetic testing and/or sequencing) would minimise the possibility that parents who have not yet shared this information will be anxious to learn that there is now an increased risk that their donor-conceived children (who may now be adults) will find out by accident (and therefore respond negatively). Disclosure that is anxiety-driven is likely to be less than optimal, and may not best safeguard the interests of those who are donor-conceived.

The potential for misinformation

Arguments in support of disclosure in the era of donor non-anonymity may also run the risk of encouraging parents to provide their children with misinformation. Unpublished data recently obtained as part of an ongoing longitudinal study of mothers of children conceived using anonymous and identifiable sperm donors in the UK (Golombok et al., 2016; Zadeh et al., 2016) has highlighted that some mothers who have conceived under the legal requirement of donor anonymity describe the donor to their children as though he will be identifiable in the future, despite no knowledge of the donor having re-registered as identifiable under UK law (HFEA, 2015). Others’ approaches to disclosure appear to be based on the hypothetical possibility of retrospective legislation, which has to date only been enacted in Victoria, Australia (Allan & Adams, 2016). Such evidence attests to the potential risks that may arise from advising parents to tell their children about their donor conception on the basis of the
non-anonymity argument, and the as yet unknown, but potentially negative, consequences of doing so, for both what parents tell, and what children may anticipate as a result. It is essential that those working with prospective or current parents of donor-conceived children provide accurate information about donors, and their legal commitment, if any, to future identification. Disclosure that is based upon misinformation about the donor’s current legal status may not best safeguard the interests of those who are donor-conceived.

The possibility of unrealistic expectations

Parents who are advised to disclose information about donor conception with ideas about the non-existence of donor anonymity may further run the risk of fostering children’s unrealistic expectations. At present, genetic testing and/or sequencing is neither universally readily available nor advanced to the stage at which all donor-conceived people could in theory use such services, should they wish to do so. Moreover, very little is known about what happens when donors are identified, not least because in several countries, the legislation that has mandated identifiable donation is relatively new. Moreover, attempts to access information about the donor (including those that have employed the direct-to-consumer genetic testing described by Harper and colleagues) are not always successful (Klotz, 2016). In addition, successful attempts to ‘trace’ the donor, although often positive, are not always so (Cushing, 2010; Jadva et al., 2010). It has been suggested that a lack of communication about expectations and boundaries and a mismatch in desire for contact may be detrimental to all involved (Freeman et al., 2014); again, the processes of seeking contact may benefit from the provision of external support (Crawshaw et al., 2015). Disclosure that leads to unrealistic expectations, both about the possibility of donor identification and the level and type of interaction that may result if donors are successfully identified, may not best safeguard the interests of those who are donor-conceived.
Conclusion

This article began by illustrating that while some of the claims made by Harper and colleagues have significant empirical support, others are less well evidenced. The efficacy, and ethics, of relating arguments about the end of donor anonymity to advice about disclosure were subsequently and substantively called into question. The present paper has shown that reflections on the future of genetic testing and/or screening must be distinguished from the longstanding debate about disclosure of donor conception to children. Contrary to Harper and colleagues’ claims, it has been argued that the advice that parents ought to disclose in an age of increasing access to genetic information may result in: (i) anxiety-driven disclosure, (ii) disclosure that is based upon misinformation, and/or (iii) disclosure that fosters unrealistic expectations. Overall, these outcomes cannot be said to best safeguard and promote the interests of those who are donor-conceived. It is firmly recommended that fertility professionals remain mindful of these issues when discussing disclosure and the future implications of increasing access to genetic information with both prospective and current parents. Further opinions on this topic, particularly those that draw upon evidence other than that primarily relating to the use of sperm and oocyte donation by heterosexual couples in licensed fertility centres, are strongly welcomed.

Acknowledgements

I am grateful to Susan Imrie, Dr Vasanti Jadva, Jacqueline Zadeh, and the anonymous reviewers for their helpful comments on a previous version of this paper. I gratefully acknowledge the generous support of The Brocher Foundation, Geneva (www.brocher.ch), and Corpus Christi College, Cambridge.
Authors' Roles

Funding

No funding was obtained for this work.

Conflicts of Interest

The author has no conflicts of interest to declare.

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