Colouring the different phases in gamete and embryo donation

P.M.W. Janssens¹

Department of Clinical Chemistry and Haematology/Semen Bank, Hospital Rijnstate, Alysia Zorggroep, PO Box 9555, 6800TA Arnhem, The Netherlands

¹E-mail: pjanssens@alysis.nl

Gamete and embryo donation, although technically fairly straightforward, are psychologically, emotionally and socially complex, having significant impact on parents and donor offspring. The activity follows a pathway that can be distinguished in multiple phases, each characterized by specific choices and dilemmas for which no standard solutions are available (Figure 1). The expectations, beliefs and considerations of parents and offspring, in combination with past and present experience, are crucial for the choices made in each phase. Choices that, often, cannot be reversed once they are made. This underlines the importance of providing good information for participants and all others involved: professionals, policy makers and governments. For the latter, having balanced information is of additional importance as they make the regulations that determine the freedom of choice.

Gamete and embryo donation are relatively new, having been used on a wide scale for just ~30 and 15 years, respectively. Only now are significant numbers of children from the first gamete and embryo donation period approaching adolescence or adulthood. Moreover, the significant use of donors whose identity can be revealed to donor children stems only from the last decade. So there is still much to be learned about the later phases of gamete and embryo donation, and even more concerning the use of open-identity donors. Accordingly, the development of donor parents and offspring through different stages is followed in the scientific literature. Research groups based around Golombok (UK) and the Scheib (CA, USA), as well as others, have presented useful information in this context. In the present issue of HR, another relevant piece of knowledge is added, concerning the contacts of donor parents plus their children with donor (half)siblings and, to a lesser extent, donors (Freeman et al., 2009). In addition, a second study by MacCallum (2009) is presented, which compares embryo donation parents with adoption parents. This highlights the importance of the gestational link in conceiving children. The findings presented, as usual, will probably affect our views on gamete and embryo donation issues and may be also influence our views on adoption and surrogacy.

In an extensive study, Freeman et al. (2009) describe the motives, impact and experiences of parents searching for and contacting donor siblings and the donors of their donor children. The research data were gathered by means of questionnaires filled in by 791 parents registered in the Donor Sibling Registry set up in the USA. This registry, with more than 22,000 registrants at the end of 2008, is presently by far the largest of various worldwide family and donor-matching services on the internet (www.donorsiblingregistry.com/; some other registries: www.ukdonorlink.org.uk, www.groups.yahoo.com/group/BCdonorconception, www.voluntaryregister.health.wa.gov.au/, www.cibg.nl/burgers/donorgegevenskunstmatigebevrucht ing/ and www.donorkind.nl/), all with the aim of facilitating contact of donor conceived children and their parents with each other, and/or with donors. The study of Freeman et al. neatly complements that of a smaller Californian study (14 respondents with only one heterosexual couple) published a little earlier (Scheib and Ruby, 2008). What are the results? Almost all responding parents declare that they and their donor children were very positive about the contacts they made with the families of children from the same donor. The experience of meeting with these families and their donor children was felt to be so positive that in many cases the other families were referred to as friends, and donor siblings were referred to as being members of one big family (all together suitably described as 'extended families'). The experience with contacts appeared not to differ between single mothers, lesbian or heterosexual couples. Also the contacts with donors were definitely rated as positive (Freeman et al., 2009). These latter contacts occurred much less frequently (21) than donor sibling contacts (291) and were not investigated by Scheib and Ruby (2008). Overall, these findings suggest that knowledge of donor sibling families is a good thing, and that disclosure of the donor identity makes sense, and need not be a problem. They also suggest that for many parents and children, having only information about donors is not satisfactory—real encounters are the ultimate desire. Unexpectedly these findings might also lead us to question the importance of a common family history for the creation of a ‘family feeling’. After all, none of the donor families calling their donor sibling relatives shared anything but genes. Nonetheless, many said they felt intuitively bonded.

The findings presented by MacCallum (2009) show that a common family life is crucial for a feeling of being ‘one of us’. The ultimate factor for parents and children in this respect proves to be the gestational link and the rearing of the child by the parents from the outset. MacCallum, by means of standardized semi-structured interviews, compared the attitudes of parents having children by means of embryo donation with those having children via adoption. The original aspect of MacCallum’s approach is that two groups of parents were compared, both...
being similar in having no genetic link with their children, but differing with respect to the pregnancy, the birth and the initial rearing of the children. As such, the one group can be considered the ‘control group’ for the other. For embryo donation parents, the donors play almost no role in their family life. Parents almost forget they had ever used a donor in conceiving the child. For many disclosure of the means of conception to their children is not a consideration (let alone an option). This strongly contrasts with the case of adoption parents. For these, keeping secret the origin of their children is not a possibility as, usually, people in the immediate environment will know about the adoption. MacCallum’s findings demonstrate that it is the original perspective that one has in combination with the state of mind, which determines how the relationship to the child is experienced. Why should this not be so for gamete donation and the contacts among the aforementioned donor relatives? More concrete, MacCallum’s findings extrapolated to the findings in Freeman’s and Scheib and Ruby’s studies (2008) suggest that it is not so much the sharing of genes which provokes the feelings of unity among donor sibling families, but the initial expectations of the participants.

Very aptly in their lengthy paper on the contacts among donor parents, children and donors, Freeman et al. (2009) give ample space to the expectations parents and their children had (as communicated to the parents by the children) when searching for donor siblings and donors. These expectations, indeed, were optimistic from the outset. Respondents aimed openly for the formation of relationships by registering in a registry or answering a questionnaire. This is apparent from the main motives given for searching for donor siblings, described in phrases such as ‘giving the child a better understanding of who he/she is, a sense of identity’, ‘create a family, give my child siblings’ (Freeman et al., 2009; Scheib and Ruby, 2008). Similar motives, excluding the creation of family, apparently are given for the search for donors, although Freeman’s paper gives little detail on this aspect (Freeman et al., 2009). Viewed in this way, the outcome of both studies may be considered a kind of self-fulfilling prophecy. Appropriately, Freeman et al. themselves pay explicit attention to the various reservations that might be expressed regarding their results: the selection bias because of the use of a registry that is approached primarily by those interested in contacts, the understandable, albeit relatively low response rate to the invitation to participate in the study (19%), the bias in the gender and family type of respondents (98% of the respondents being female), the over-representation of lone mothers and under-representation of heterosexual couples (compared with the society) and finally, the fact that the questionnaires were answered by parents, not by children (resulting in indirect information, i.e. the parent’s estimates of the children’s expectations and experience). Similar limitations are also present in the study by Scheib and Ruby (2008). In fact, they are difficult to circumvent, given the difficulty of investigating the practise of gamete donation, especially with heterosexual couples. Although it is true that in both studies heterosexual couples participated, one cannot but wonder about the opinion of those couples, especially the heterosexual ones, who never registered in a registry or answered a questionnaire.

Heterosexual couples who use gamete or embryo donation are the most difficult to investigate. They are the only parents who can effectively keep the atypical conception secret. Under normal conditions, it may even be considered unethical to approach them for study, as this unwillingly might break the code of secrecy. With respect to possible contacts with donors or donor siblings, by heterosexual couples, there is always the risk that one of the parents will feel superfluous: contacts with a ‘third party’ may cast doubt on their role as (birth)parent. The reluctance to having contacts with donors or donor siblings is manifested clearly in the statistics that show that many couples have doubts about or are unwilling to reveal the donor conception to their child. Data in the literature on real or intended disclosure among heterosexual couples for gamete donation vary between 0% and 83%, figures for semen donation generally being somewhat higher than for oocyte donation. MacCallum’s data on embryo donation (33–39% intending to tell or already having told, 43% definitely not telling) are compatible with these figures, but, in addition definitely show that in embryo donation, significant numbers of parents do not feel like disclosing the secret (MacCallum and Golombok, 2007; MacCallum, 2009). Illustrative of the ambiguity of the disclosure issue is that in some countries the use open-identity donors is imposed (Sweden, Austria, Switzerland, Australian State of Victoria, the Netherlands, New Zealand and the UK), whereas in others

Figure 1 Stages for parents and children in gamete and embryo donation.

The lightening of the grey bar symbolizes the diminishing role and responsibility of the parents, and the concomitant increasing role and responsibility of the donor child.
donor anonymity is legally guaranteed (e.g. France, Belgium and Denmark). Worldwide, looking at various nations, and also at a large country like the USA (where no regulations with regard to the disclosure of donor identity are in force as yet), the use of open-identity donors seems to be increasing (Daniels, 2007; Scheib and Cushing, 2007; Thorn et al., 2008). The effects of this change require clarification, management and coaching. In contrast to heterosexual couples, for lone mothers and lesbian couples the formation of donor sibling families and contact with donors seems to be promising, if not for the parent at least for the child, as suggest the data of Freeman et al. (2009). A word of caution here, however, might be prudent. Good contacts could lead in time to unwelcome interference with the personal or the family life of parents, offspring or donors. In the worst case, this might end with the Court, deciding on unwanted claims from either of the parties, as cases in the USA, Sweden and the Netherlands have shown (ABC News online, 2005; Daniels et al., 2005; Sifris, 2005; News.com.au, 2007; Nederlands Juridisch Dagblad, 2007; Maxwell, 2008). Examples like these, although exceptional, must be borne in mind by all those making contact with donor sibling family and, above all, with donors.

References


Submitted on October 29, 2008; accepted on November 6, 2008