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The Controversy Regarding Privacy Versus Disclosure Among Patients Using Donor Gametes in Assisted Reproductive Technology

At a recent workshop in Australia, two young women in their 20s became very angry with a doctor, who they felt was not acknowledging theirs and others' needs and rights for information about the semen donors who contributed gametes for their conception. The emotions aroused were intense. The women are part of a growing number of persons, having been told of the nature of their conception, who want to know why they cannot have information about the donor to which they feel they are entitled. Issues surrounding information sharing in gamete donation (GD) and its management is, in my view, the most controversial issue in assisted reproductive technology (ART). The growth in the numbers of offspring knowing of their gamete donation conception means that the controversy is set to escalate. The controversy has been portrayed in this journal as being about "privacy versus disclosure among patients. . . ." Two comments seem appropriate regarding this conceptualization of the issue. The first is that the words privacy and disclosure are presented as opposites, but of course neither is an absolute, there being degrees of privacy and degrees of disclosure. For example, par-

ents do disclose the nature of GD conception to others but expect that privacy will be maintained—it has just been extended to a wider group (1). Joyce (2) has suggested that there are four degrees of openness in donor insemination (DI): (i) DI may be shared with chosen members of the family or close friends, (ii) there may be sharing of the DI conception with the child, (iii) there may be sharing with society in general, and (iv) the identity of the donor may be shared with the child and perhaps the family.

In earlier writings, I also portrayed the issue as opposites, using the terms secrecy and openness (1,3). As a result of the value connotations associated with these words, as well as in recognition of the complexity surrounding the topic, I now discuss the topic in terms of information sharing and information exchange (4,5), thus moving away from the presentation of the issue in either/or terms.

The second point relates to the use of the term "patients." It is to be expected that doctors will see the infertile couple (and increasingly the single woman) sitting in front of them as their patients; after all, the consultation is occurring because of

their inability to conceive. It is also expected that staff seeing a prospective gamete donor will focus on that individual, looking to respond to his or her needs. Controversy arises about what responsibility staff should have in relation to the potential child resulting from GD. It seems inappropriate to think of a potential child as a "patient," yet virtually every government or government-appointed committee set up to review ART has stated that the "welfare of the child" must be taken into account in the provision of services. The second revised edition of the Human Fertilization and Embryology Authority's Code of Practice states that "centers should have clear written procedures to follow for assessing the welfare of the potential child and of any other child who may be affected" (6). Eighteen clauses follow covering how this is to be carried out.

Most health care staff focus on the "here and now" issues, and in the case of infertility and ART it is the individuals or couples who have approached the service who are the first concern. Taking account of, or giving consideration to, a potential child, who later becomes an adult, calls for a significant mind shift. The health professionals who can most readily focus on all of the parties involved—including the child—are those who provide psychosocial services. These may include counselors, social workers, psychiatrists, and psychologists. They are also the ones who are most likely to be involved with families that have used ART and who wish or need to discuss developmental issues at a later stage.

One of the consequences of different health professionals having differing conceptualizations of the issue—couple or individual versus family—is that misunderstanding and conflict are likely to occur. This can be personalized to the individual staff involved, or it can be seen as conflict between disciplines. I think that it is more appropriate to view such differences as being related to who is the focus of attention—almost, who is the patient. The fact that bodies such as the HFEA have required the child's interests to be considered means that the matter cannot be ignored. One of my fears is that one way in which clinics are dealing with this is to leave the matter to the counseling staff. As a result, couples and individuals may end up receiving contradictory messages from, for example, doctors and counselors. The same concern applies to the gamete donors, for whom psychosocial issues relating to the meaning, both now and in

the future, of donating part of themselves have to be considered as part of informed consent. I have argued (7) that payment for gametes, i.e., the presentation of the issue as a commercial transaction, may serve to limit the need for consideration of the psychosocial issues, particularly matters relating to donor responsibility and informed consent.

While the focus to date has been on the providers and beneficiaries of ART services, it is important to take note of McWhinnie's (8) point that society is also involved in this issue: She argues that secrecy in this field serves to undermine the whole basis of our society, in which family and kinship are based on honesty and truth. When health professionals advise couples or individuals to withhold the nature of the child's conception, they are adopting a moral position. The consequences of such advice flow from the couple to their child and family, to their wider networks, and to society as a whole. Lauritzen (9) argues that while DI can be justified morally, that is not to say that it is always justified. His view is that DI undertaken in secret is morally unacceptable.

The debate surrounding information sharing is often presented in terms of rights—the right of the couple to privacy versus the right of the offspring for information. This has often led to a ranking of rights, some arguing that the child's rights are more significant and important than the parents', and vice versa. An alternative way of viewing this issue is to focus on the "needs" of the various parties. The two young women at the workshop in Australia were expressing views associated with their needs as individuals. The growth in the number of DI support groups (United Kingdom, Canada, United States, Australia, and New Zealand) shows that many parents are expressing their needs for contact, support, and information. In many instances these groups have become advocates for greater information sharing. This is based on their experiences of having only limited information that they can share with their offspring and the impact this has or is having on their family functioning.

The history of DI shows that the "culture" that has developed around DI, particularly the emphasis on not sharing information, was established by doctors. There were understandable reasons for this—DI being regarded as akin to adultery, the social attitudes surrounding sexuality, and the legal status of donors and offspring to mention the most

obvious. That culture developed because of the privacy of the doctor/patient relationship. The social dimensions of GD are now being widely recognized and debated. One consequence of this is the move in many countries to introduce legislation covering birth records and access to information, e.g., the keeping of registers. Gamete donation is no longer a closet subject. With the move to social recognition and endorsement, aspects of the existing culture are being challenged and this is particularly so in relation to information sharing. As with all challenges, there will be controversy, conflict, and debate. In a recent editorial in *Fertility and Sterility*, Jones (10) suggests that the time has come "to meet face to face the concept of surveillance—a genteel name for regulation." Sweden and Austria have enacted legislation providing for offspring to have access to information concerning donor identity. The State of Victoria in Australia has introduced similar legislation, but this has not been enacted as yet. Other countries such as Norway and United Kingdom have legislation prohibiting access. Opinion clearly differs a great deal and it is therefore highly appropriate that this journal should raise the issue for debate. I welcome the opportunity to contribute to that debate.

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Parenting and Secrecy Issues Related to Children of Assisted Reproduction

Of the various concerns that have been expressed regarding the potential negative consequences of gamete donation for children's psychological well-being, the effects of keeping information about genetic origins secret from the child has been the subject of greatest debate. As few children are told that a donated sperm or egg had been used in their conception, the large majority grow up not knowing that their father or their mother is genetically unrelated to them. Although clinicians have

traditionally advised parents that there is no need to tell the child (1), it is increasingly argued that parents should be open with their children, either on the grounds that they have a right to know or because it is believed that secrecy will result in psychological problems for the child (2,3).

Findings suggestive of an association between secrecy and negative outcomes for children have come from two major sources: research on adoption and the family therapy literature. It has been