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The Controversy Surrounding Privacy or Disclosure Among Donor Gamete Recipients

INTRODUCTION

There is probably no area of greater debate among mental health professionals working with infertile patients than the debate about privacy or disclosure among donor gamete recipients. In the first five or six decades of donor insemination (DI) use, the focus of studies among recipients was satisfaction (1, 2). It was assumed by all concerned that confidentiality would be maintained.

In the past 15 years a debate has arisen about whether to tell or not tell the donor gamete child and whether to tell family and friends. This debate was initiated by mental health professionals working in adoption who applied the "open" adoption model to the donor gamete situation. They observed the sometimes dramatic negative impact of nondisclosure to an adoptee regarding their biologic parents' identity. It was assumed that the same negative psychological impact would occur among donor gamete children even though the two methods of family building are dissimilar. Based on these beliefs, many mental health professionals began counseling donor gamete recipients to tell the child and others. This position was held in the absence of (i) an examination of the differences between adoption and donor gamete use, (ii) an examination of the data regarding donor gamete recipients' attitudes regarding disclosure, (iii) an

appreciation for the need of a neutral position by a mental health professional, and (iv) studies addressing the impact of disclosure or nondisclosure on child development. If we examine these four factors, it becomes clear that a recommendation of disclosure for all gamete recipients is premature.

IS ADOPTION AN APPROPRIATE MODEL?

The first factor to consider is the use of adoption as a model for disclosure in the donor gamete situation. The donor gamete child who is aware of his/her donor origin faces many of the same issues as an adopted child, including (i) being raised by at least one nonbiologically related parent, (ii) having some understanding that he/she is "different" from other children; (iii) at times rejecting his/her nonbiological parent; and (iv) wanting more information about the donor, the "missing parent." Alternatively, the donor gamete child is different from an adopted child in several important ways, including (i) having a genetic connection to one recipient parent, (ii) his/her gestation and delivery occurring in the context of the recipients' relationship, (iii) not being "given up" or "surrendered" by the biological parents, and (iv) being aware of the general lack of societal approval of donor gamete use as a means of family building (3,4). The existence of these differ-

ences needs to be considered prior to making a recommendation regarding disclosure to a donor gamete offspring.

Because of the genetic relationship to one parent and the control over the gestational environment, the recipient couple may feel that the donor gamete child is more "theirs" than an adopted child, therefore they may feel less willing to tell the child of its donor origin. Donor children are often conceived after years of infertility treatment and are highly desired by their parents, therefore the intrapsychic dynamic of having been "given up" that the adopted child may feel is not relevant for the donor gamete child. Additionally, adoption is generally highly approved of in our society, whereas donor gamete use is not. Recipient couples may be acutely aware of the general societal disapproval and therefore may be hesitant to tell the child for fear that the child will be socially ostracized. In addition, nondisclosure allows the couple to maintain privacy about the infertility problem, which may be particularly relevant in cases of male infertility. Finally, the suggestion of openness between the donor and the recipient may give unwanted responsibility to the donor and may undermine the parental role of the nongenetic recipient parent.

A SUMMARY OF THE RESEARCH

A second factor to consider prior to recommending disclosure to gamete donation recipients is the research findings regarding recipients' attitudes and behaviors regarding disclosure. The majority of the studies addressing this issue have been conducted with couples who have used donor sperm to conceive. Both retrospective and prospective studies indicate that the majority of heterosexual couples plan not to tell the child (see Ref. 5 for a summary). Results from longitudinal studies indicate that attitudes toward disclosure change over time. Prior to conceiving, the couple may plan to tell the child, but after treatment begins and the child is born there is a trend toward privacy, with 77–100% of couples choosing not to tell the child (6–8). It is important to note that these percentages apply only to heterosexual couples. Data regarding single women and lesbian couples who have children via DI indicate that virtually 100% of these parents will tell the child that he/she was conceived via DI (9). Based on these findings, a uniform recommendation to tell the child of his/her donor

gamete origin is inappropriate. To recommend something that only a minority of couples feel comfortable with could lead to psychological dissonance for the recipients.

THE ROLE OF THE MENTAL HEALTH PROFESSIONAL

A third factor to consider is the role of the mental health professional in counseling prospective donor gamete parents. There is a tradition in psychology and psychiatry to maintain a neutral stance with patients to facilitate their exploration of the pros and cons of an action, instead of giving direct advice or recommendations. This is based on the belief that each person is different and that what is right for one person is not necessarily right for another. A neutral position by a mental health professional also alleviates the feelings of disapproval or guilt that the patient may have if he/she does something contrary to what the therapist recommends. For these reasons a direct recommendation of disclosure by mental health professionals and others to donor gamete recipients is detrimental. If a direct recommendation for disclosure is made, parents may subsequently feel conflicted over their wish not to tell the child. In these cases not only is the parents' mental conflict uncomfortable, but also it does a disservice to the family by making them hesitant to seek further consultation from a mental health professional for fear of more mandates and suggestions.

A more helpful approach is a psychological consultation in which the pros and cons of both disclosure and privacy are discussed with the prospective recipients. The discussion can consider the recipients' feelings at the present time and speculation into the future about how they may feel after the child is born. Also, the couple can consider if they want to tell others and, if so, how and when. After a thorough discussion of the pros and cons of disclosure and privacy, what they feel comfortable with usually becomes clear to a couple. Then, either way, they can come up with a short-term plan, for example, they may want to tell only the wife's mother initially, then reassess their position when the child is 2 years old. This helps bring closure to the issue and allows for further discussion after the child is born. At that time the parents may have a better understanding of what is right for the child and the family. Whether disclosure or privacy is

chosen, programs should continue to keep detailed records of the donor child's origin.

THE NEED FOR OUTCOME RESEARCH

The last factor to discuss in relationship to the privacy and disclosure issue is the need for longitudinal research on the children of gamete donation. Longitudinal studies are needed to determine how the recipients feel about disclosure before treatment and if these attitudes change over time. Additionally, assessment of the child and family would be useful in determining if there are differences in outcome based on disclosure or privacy. This would provide an empirical foundation for our clinical recommendations about disclosure. Until that time, I believe that it is in the best interest of the families that are created via gamete donation to take a nonbiased approach and not assume that disclosure is best for all donor gamete families.

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