

ASSISTED REPRODUCTION

Donor Gametes and Embryos: Who Wants to Know What about Whom, and Why?

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Abstract. Many treatments for infertility require the use of donated gametes or embryos. Arguments have been made that all parties involved (donors, recipients, and children) should have open access to information about one another. The present article reports a survey of attitudes of 77 donors and 327 recipients in the state of Western Australia. Donors and recipients endorsed a register of nonidentifying information, but were less keen on a register of identifying information. They believed that medical personnel should have access to such registers, and that donors and recipients (but not children) should have access to nonidentifying, but not identifying, information. Typically, the sort of information respondents wanted to access pertained to health status and physical characteristics. Overwhelmingly, both donors and recipients saw gamete and embryo donation as more like blood donation than like adoption.

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The use of donated gametes and embryos in assisted reproduction is medically accepted, but socially controversial. The present article focuses on just one of the many social issues involved in the use of donated gametes and embryos—whether donors, recipients, and resulting children should have, or want to have, access to information about each other.

Until recently, donors and recipients were advised not to tell anyone of their actions. More recently, though, counsellors, social workers, and psychologists have argued that recipients should tell their children of the circumstances of their conception, and that they should tell family and friends of their use of donated gametes or embryos. Furthermore, it has been argued that donors, recipients, and children should have knowledge of, and access to, one another, and that this ought to be encouraged (Brandon and Warner, 1977; Daniels and Taylor, 1993; Lauritzen, 1993; Triseliotis, 1993; Turner, 1993; Winkler and Midford, 1986).

These arguments come from two main sources. First, parallels are made between the use of donated gametes and embryos and the case of adoption. Arguments in favor of “open-adoption” are extrapolated to the case of assisted reproduction using donated materials (Brandon, 1979; Brandon and Warner, 1997; Daniels et al., 1996a; Daniels and Taylor, 1993; Winkler and Midford, 1986). The degree to which adoption and donation are analogous is not usually questioned, but is indeed highly questionable (Broderick and Walker, 1996a; Cook et al., 1995; Shenfield, 1994; Shenfield and Steele, 1997; Walker and Broderick, 1999).

The second source relies on the small and generally flawed psychosocial research literature on the use of donated gametes and embryos. Our concern here is primarily with this research, rather than that in adoption, since this is the appropriate base for developing counselling practice, advice, and even legislation in this sensitive area. A review of this literature reveals it to be, as a whole, flawed and limited to such an extent that it cannot support any firm conclusions about whether donors and recipients want, or

should have, access to information about each other (Broderick and Walker, 1995). The present study is an attempt to redress many of the common limitations of individual studies in the area, and to furnish reliable evidence about whether donors and recipients want access to information (either identifying or nonidentifying) about each other, whether they view donation as similar to adoption, and what the likely effect would be of legislation enabling access to identifying information.

The research reported in this article was conducted in Western Australia in 1994. Medically assisted reproductive practices in this state are controlled by the Human Reproductive Technology Act (1991). This act requires the Human Reproductive Technology Council (HRTC) to maintain separate registers of identifying (defined as name and postcode) and nonidentifying (all other) information about donors and recipients. Only nonidentifying information is currently accessible, but a recent review of the legislation recommended that access to identifying information be allowed.

Method

The present study involved a mailed survey of all contactable donors and recipients on record at three of the four fertility clinics in Western Australia. Thus, the sample represents both past and current donors and recipients. Questionnaires were mailed from the clinics by registered mail, so that we were not privy to the names and addresses of the clinics' clients, and the questionnaires could only be received by the intended addressees. Completed questionnaires were returned to us, so that clinics were not able to match responses to individual clients. Two questionnaires were mailed to each recipient household, in order that, where applicable, both partners could complete and return their own questionnaires (see Broderick and Walker, 1996b for an analysis of couple agreement and disagreement). The questionnaires were lengthy and asked about many aspects of treatments and outcomes, as well as attitudes and beliefs about many issues. Prior to administration, the questionnaires were rated by 20 undergraduate psychology students for neutrality on a 7-point scale from 1 (completely opposed to increasing access to information) to 7 (completely in favor of increasing access to information). The mean score for the donor questionnaire was 5.00 (SD = 1.00), and for the recipient questionnaire, the mean score was 4.86 (SD = 1.14), indicating that the raters found the tone of the questionnaires to be neutral, or just slightly in favor of increasing access to information.

Participants

Donors. The three clinics had the names of 268 donors (sperm, egg, and embryo) dating from 1980. Of these, 207 were successfully contacted by telephone, 105 were will-

ing to receive a questionnaire, and 77 responded. Thus, the response rate for those who were sent a questionnaire was 73.3%, but for those who were contacted, it was only 37.2%. Donors contacted who declined involvement generally indicated either that they were disinterested in the research issue or that the period since their donation was too long for them to be interested.

Of the 77 replies, 57 were from sperm donors (5% of whom had experienced infertility themselves), 19 were from egg donors (74% of whom had experienced infertility themselves and had undergone some form of fertility treatment), and 1 was from an embryo donor. Because there was only one response from an embryo donor, she is excluded from all further analyses. The mean age of sperm donors was 32 years, and 55 (96.5%) did not know the recipients of their donations. The mean age of the egg donors was 33.1 years, and 14 (73.7%) did not know the recipients.

Recipients. The clinics had 302 recipient couples on record, and each was mailed two questionnaires. Three hundred and twenty-seven completed questionnaires were returned, giving a response rate of 54% if it is assumed that each recipient had a partner (this clearly underestimates the real, but unknowable, response rate). This response rate is considerably higher than in many such studies. It is generally acknowledged that most heterosexual couples do not wish to be reminded of their past infertility treatment using donated material (Leiblum and Aviv, 1997).

The 327 questionnaires are treated here as separate units. Two hundred and sixty-five questionnaires (from 158 females and 107 males) were received from sperm recipients; 19 questionnaires (from 13 females and 6 males) were received from egg recipients; and 11 questionnaires (from 8 females and 3 males) were received from embryo recipients. The mean age of sperm recipients was 36.8 years (ranging from 23 to 56 years), and 10 (3.8%) knew the donor. For egg recipients, the mean age was 33.8 years (ranging from 28 to 50 years), and 7 (37%) knew the donor. For embryo recipients, the mean age was 38.5 years (ranging from 34 to 50 years), and none knew the donor. Overall, the recipients had undergone a mean of 8.4 treatment cycles, ranging from 1-50. While the modal number of cycles undertaken was 2, 79% of the recipients had undergone between 2 and 12 cycles.

Results

We focus on key questions pertaining to three issues:

- respondents' beliefs about, and attitudes to, access to identifying and nonidentifying information about themselves and others;
- the likely effects on their involvement if information could be accessed; and

- respondents' beliefs about the similarities between gamete and embryo donation, adoption, and other forms of donation.

Beliefs about Registers of Information

Respondents were asked if they thought registers of nonidentifying and identifying information should be kept, with responses on a scale from 1 (definitely not) to 7 (definitely yes). They were also asked who should have access to such registers and for what purpose. Respondents were relatively supportive of the maintenance of a register of nonidentifying information, donors more so than recipients (see Figure 1). Most recipients were in favor of such a register (M= 4.91; SD = 2.36), although a substantial proportion was strongly against. As a group, donors were more in favor of maintaining a register of nonidentifying information ((M= 5.62; SD = 2.03) than were recipients ($t = 2.42, p < .05$).

In comparison, there is a clear lack of support for a register of identifying information, particularly from the recipient group (recipients' M = 2.88; SD = 2.41; mode = 1). Donors were again more in favor of a register than recipients (donors' M = 4.05; SD = 2.48; mode = 1; $t = 9.19, p < .001$), and a considerably higher proportion of donors than recipients indicated "definitely yes." For both samples, the distribution was bimodal, with relatively few responses falling between the endpoints of the response scale, indicating that recipients and donors tend to be unequivocally either in favor of, or opposed to, a register. Recipients' and donors' responses to more detailed questions about the registered information (see below) provide the reasons for their varying levels of support for the maintenance of both types of registers.

Access to Registers

The question of who should have access to registers, and for what purpose, illuminated the donors' and recipients'

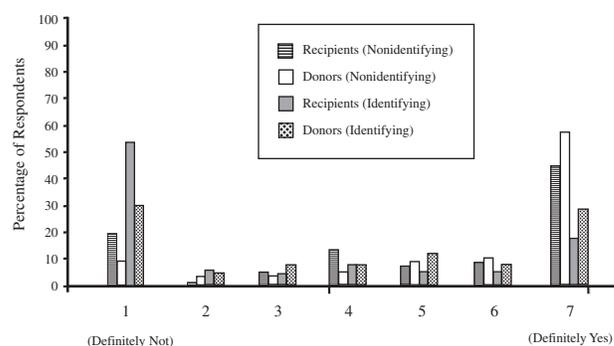


Figure 1. Support for Nonidentifying and Identifying Information among Recipients and Donors

Note. The percentage of recipients and donors responding at each level of a 7-point scale to the questions: (1) Do you think a register should be kept containing *nonidentifying* information about donors, recipients, and children? (2) Do you think a register should be kept containing *identifying* information about donors, recipients, and children? Recipients (*nonidentifying* information): N = 321, M = 4.91, SD = 2.36. Donors (*nonidentifying* information): N = 77, M = 5.62, SD = 2.03. Recipients (*identifying* information): N = 323, M = 2.88, SD = 2.41. Donors (*identifying* information): N = 77, M = 4.05, SD = 2.48.

reasons for supporting the maintenance of information registers. Donors and recipients were presented with a list of several categories of people and asked to indicate (yes/no) if each category should have access to a register of identifying information, and, in a separate question, to a register of nonidentifying information. Table 1 shows the percentages of recipients and donors who indicated each category should have access to each type of register. Respondents were also asked what use should be made of each register, and responses to these questions are presented in Table 2.

Between 56% and 75% of donors and recipients thought that medical personnel or researchers should have access to *nonidentifying* information about donors, recipients, and resulting children only for research purposes or medical follow-up studies. These figures dropped considerably when the same questions were asked about the use of *identifying*

Table 1. Percentages of Recipients and Donors Supporting Access to Registers of Identifying and Nonidentifying Information

	Recipients		Donors	
	Identifying Information	Nonidentifying Information	Identifying Information	Nonidentifying Information
Donors	13	29	48	66
Recipients	28	57	44	79
Children, at any age	7	13	16	30
Children, only over 18	22	27	35	51
Medical personnel	59	70	61	75
Medical researchers	40	56	52	74
Members of donors' families	0	3	4	8
Members of recipients' families	1	6	4	13
Others	7	4	8	1

Table 2. Percentages of Recipients and Donors Supporting Different Uses of Identifying and Nonidentifying Information

	Recipients		Donors	
	Identifying Information	Nonidentifying Information	Identifying Information	Nonidentifying Information
To provide information to participants (donors, recipients, children) if legislation is passed in the future.	24	45	43	75
For research purposes	38	51	60	69
For medical follow-up studies	49	60	73	70
Don't know	11	8	1	6
Other	18	1	13	6

data held in the registers. Between 40% and 61% of donors and recipients thought that medical personnel or researchers should have access to identifying data only for research purposes or medical follow-up studies.

These figures should be contrasted with those for other suggestions the data could be put to. For example, only 13% of recipients and 48% of donors thought that donors should have access to identifying information; 28% of recipients and 44% of donors thought that recipients should have this access; and only 7% of recipients and 16% of donors thought that children of any age, and 22% of recipients and 35% of donors thought that children over 18 years, should be able to access identifying information. The percentages agreeing to access to nonidentifying information are higher, especially for the provision of nonidentifying information to all participants in the program; however, the provision of this information to medical personnel and researchers specifically for research or medical follow-up studies is still strongly favored.

What Do Recipients and Donors Want to Know?

Given the data reported above, it is unsurprising to find that donors want to provide, and recipients want access to, information that facilitates the best outcome for the potential child and the child's family.

Recipients were presented with a long list of attributes (physical and social characteristics as well as name and address) and asked to indicate to what degree they wanted to know each piece of information about their donor, and to what degree they wanted their donor to know each piece of information about themselves. Donors were presented with an identical list and asked to give ratings about the recipients of their donations. Responses were on a scale from 1 (definitely do not want to know) to 7 (definitely want to know). Table 3 presents the mean ratings for both recipients and donors. Recipients overwhelmingly do not want to know the name and address of their donor (i.e., "identifying" information), nor do they want the donor to know their name and address. The small standard deviations indicate little variation in the recipients' responses and a higher degree of

agreement with each other on this issue than on any other. Only 2.8% of recipients (N = 8) indicated *to any degree* that they wanted to know their donor's name, and only 1% (N = 3) indicated to any degree that they wanted to know their donor's address. Still fewer (less than 1%) recipients indicated *to any degree* that they wanted the donor to know their name (N = 3) or address (N = 2). More than 85% said they *definitely* did not want to know the donor's name or address (score = 1), and more than 90% said they *definitely* did not want the donor to have their name or address (score = 1). When recipients who used anonymous donors (N = 277) are analyzed alone, there is even less support for the exchange of identifying information. The mean score for wanting to know the name of the donor falls to 1.17 (from 1.26), and the mean score for wanting to know donor's address falls to 1.06 (from 1.14). The same pattern is revealed for these recipients when they are asked about providing information about themselves. The mean score for wanting to provide the donor with names falls to 1.17 (from 1.19), and with addresses, to 1.14 (from 1.16).

As a group, recipients indicated that they wanted, first, to have information about the donor's health status and medical history, and, second, to have information about their donor which, taken together, could reasonably be used in selecting a donor to maximize the correspondence between donor and recipient so that the potential child would resemble the parents as much as possible. So, recipients most wanted to know about the characteristics of the donor (e.g., height, weight, ethnicity, coloring, and health status) that would most likely be transmitted to, or directly affect, a child born from the donation. In contrast, recipients uniformly did not want donors to know much of anything about them.

Donors were almost as strongly opposed to having access to identifying information about recipients and to recipients having access to that information about them. When looking at *any* sort of response indicating willingness (responses from 5 to 7 on the 7-point scale), 10% of donors wanted to know the recipient's name and 10% wanted the recipient to know their name; 9% wanted to know the recipient's address and 8% wanted the recipient to know their address. However, most donors *definitely did not* (score = 1)

Table 3. Degree to Which Recipients and Donors Want Information About Each Other and Want Information About Themselves Shared, by Category of Information

	Recipients		Donors	
	Want to Know M (SD)	Want Known M (SD)	Want to Know M (SD)	Want Known M (SD)
Medical history	4.68 (2.63)	1.67 (1.57)	2.42 (2.04)	3.94 (2.42)
Health Status	4.54 (2.70)	1.72 (1.62)	3.03 (2.31)	4.30 (2.41)
Race/Ethnicity	4.16 (2.87)	1.63 (1.49)	2.25 (1.86)	3.80 (2.38)
Coloring	4.10 (2.77)	1.62 (1.47)	2.08 (1.72)	3.80 (2.37)
Height	3.75 (2.65)	1.51 (1.31)	1.88 (1.50)	3.70 (2.35)
Weight	3.40 (2.55)	1.47 (1.24)	1.92 (1.61)	3.65 (2.29)
Education	3.34 (3.01)	1.60 (1.49)	2.17 (1.80)	3.41 (2.34)
Personality	3.09 (2.48)	1.56 (1.36)	2.60 (2.15)	3.67 (2.24)
Occupation	2.60 (2.25)	1.51 (1.33)	2.28 (1.92)	2.99 (2.17)
Number of children from same/your donations	2.45 (2.23)	1.68 (1.58)	3.89 (2.47)	3.04 (2.21)
Age	2.43 (2.14)	1.49 (1.27)	2.32 (1.82)	3.32 (2.27)
Hobbies	2.39 (2.16)	1.47 (1.24)	2.06 (1.74)	2.06 (2.12)
Sports	2.39 (2.13)	1.46 (1.25)	2.02 (1.71)	3.06 (2.18)
Reasons for using donor/donating	2.26 (1.98)	-----	3.16 (2.29)	3.21 (2.24)
Frequency of donating	2.04 (1.84)	-----	-----	-----
Number of children conceived naturally	1.91 (1.81)	1.45 (1.28)	2.50 (2.02)	3.01 (2.23)
Religion	1.78 (1.67)	1.46 (1.25)	2.11 (1.64)	3.16 (2.15)
Marital status	1.70 (1.67)	1.66 (1.54)	2.44 (2.03)	2.93 (2.19)
Income	1.34 (1.13)	1.33 (1.07)	2.06 (1.74)	2.31 (1.89)
Name	1.26 (0.96)	1.19 (0.78)	1.99 (1.66)	1.81 (1.54)
Address	1.14 (0.66)	1.16 (0.70)	1.75 (1.46)	1.70 (1.45)
Number of children from other donors	-----	1.41 (1.24)	2.39 (2.02)	-----

Note: Ratings are on a 7-point scale from “Definitely do not want to know/want known” (1) to “Definitely want to know/want known” (7).

want the recipient to know their name (69%) or address (71%) and *definitely did not* want to know the recipient’s name (56%) or address (62%). In general, donors were less inclined to want to know features of the recipients than recipients were about donors, and donors were more in favor of having recipients know information (except name and address) about them than recipients were about donors knowing about them.

Thinking about One Another

Figure 2 displays the distributions of responses of recipients and donors to the question “How often do you think of the donor/recipient?” In both cases, most respondents are at the “never” end of the scale, especially so for recipients. The means of both distributions are also toward the “never” end of the scale: for recipients the mean rating is 1.86 (SD = 1.24; mode = 1), and for donors the mean rating is 2.81 (SD = 1.48; mode = 2).

Telling Others

All respondents were asked whether they had told their child/ren, family, friends, medical personnel, or others about their use of donated gametes or embryos in treatment, or

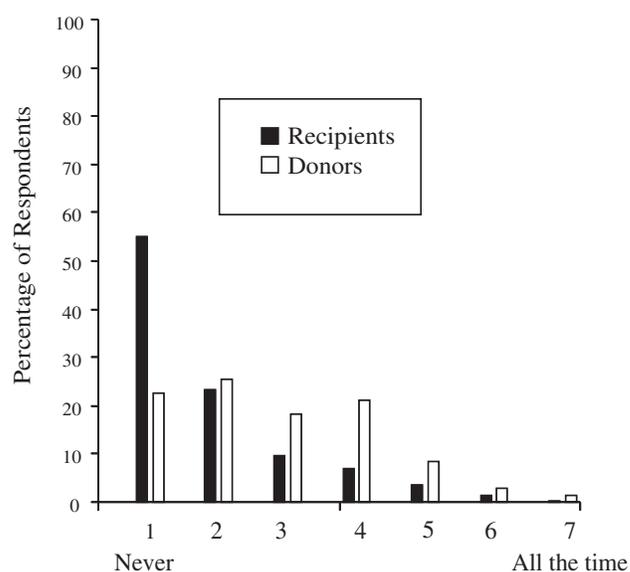


Figure 2. Frequency of Thought about Donor/Recipient

Note. The percentage of recipients responding at each level of a 7-point scale to the question: How often do you think about your donor? (N = 289, M = 1.86, SD = 1.24), and the percentage of donors responding on a 7-point scale to the question: How often do you think about the recipient/s of your donation/s? (N = 71, M = 2.81, SD = 1.48).

Table 4. Disclosed and Intended Disclosure among Donors and Recipient, by Category of Person

	Have Disclosed		Intend to Disclose	
	Recipients (%)	Donors (%)	Recipients M (SD)	Donors M (SD)
Partner	---	67	---	3.50 (2.48)
Child/children	8	5	2.87 (2.46)	3.11 (2.13)
Family	56	48	1.81 (1.72)	2.36 (1.74)
Friends	41	50	1.63 (1.37)	2.28 (1.58)
Medical personnel	64	17	2.71 (2.28)	3.09 (2.02)
Others	9	10	1.49 (1.36)	1.71 (1.17)

Note: Percentages of Recipients and Donors who have told people of their use of, or donation of, sperm, eggs or embryos, and the mean rated likelihood of their telling people of such use or donation on a 7-point scale from “definitely do not intend to tell” (1) to “definitely will tell” (7).

about their donation of gametes or embryos. The percentages of recipients and donors indicating that they had told, or intend to tell if they had not already done so, each of these categories of people are presented in Table 4. Responses to the “intend to tell” question were on a scale from 1 (definitely not) to 7 (definitely will).

A majority of recipients had told a family member and a medical person of their use of donated gametes or embryos, but few (8%, or 11 of the 136 with a child) had told

their child/ren. Of those recipients who had not told people of their use of donated material, the overwhelming tendency was to indicate that they did not intend to tell those people in the future. Focusing especially on telling family and the child, of those recipients who had not already told at least one family member, 76% indicated they definitely would not tell any family member (i.e., scored 1), and only 12% gave any sort of indication that they did intend to tell. Recipients appeared to be less sure about their intentions to tell the child/ren. Of those with children to whom they had not disclosed their method of conception (N = 122), 51% said they definitely intended not to do so, and slightly more than a quarter (26%) said they definitely intended to disclose to their children. The mean score for intention to disclose to children on the scale of 1-7 is 3.18 (SD = 2.58). While 31% gave a response indicating some sort of intention to disclose to their children in the future (i.e., scored 5-7), double that number (62%) gave a response indicating an intention not to disclose to their children (i.e., scored 1-3) in the future. Only 7% (9 recipients) responded at the midpoint, indicating they are unsure about their intentions.

The pattern of responses from those recipients who did not have children as a result of treatment (N = 129) is slightly different from those who did have children. The mean score (on the scale from 1-7) for intention to disclose to children is slightly higher (M = 3.80; SD = 2.63); fewer recipients (41%) stated that they definitely would not disclose to children, and slightly more stated that they definitely would disclose to children (32%). The numbers indicating any sort of intention to disclose to children (scored 5-7) or any sort of intention not to disclose to children (scored 1-3) are very similar to each other (45% vs. 47%), and again very few (8%, or 10 recipients) were unsure about their intentions to disclose.

Most donors had told their partners of their donation, and about half had told family and friends. On the whole, those donors who had not already told people of their donation gave responses indicating they were disinclined to tell those people in the future.

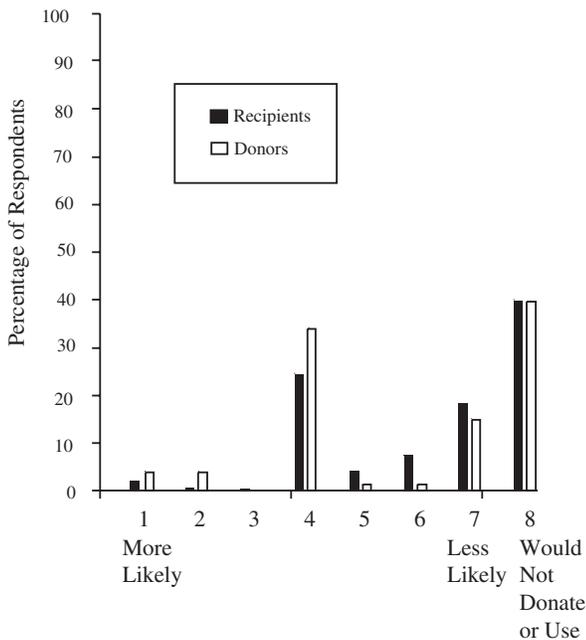


Figure 3. Response of Recipients and Donors to the Establishment of a Register of Identifying Information

Note. The percentage of recipients responding on an 8-point scale to the question: If legislation were introduced tomorrow enabling a register of identifying information (e.g., names) about donors, recipients, and children to be available to donors, recipients, and children, how would this affect the likelihood of you using donated sperm, eggs, or embryos in any future treatment? (recipients) / that you would continue to donate? (donors). Recipients: N = 293, M = 6.18, SD = 2.04. Donors: N = 73, M = 5.88, SD = 2.20

Effects of Access to Identifying Information

Given respondents' (especially recipients') antipathy to the maintenance of a register of identifying information, there is a need to know how donors and recipients would respond if this information were to be made available. Respondents were asked "If legislation were introduced tomorrow enabling a register of identifying information about donors, recipients, and children to be available to donors, recipients, and children, how would this affect the likelihood of you using donated sperm, eggs, or embryos in any future treatment?" (for recipients), or "... the likelihood that you would continue to donate?" (for donors). Responses could range from 1 (would make more likely) to 7 (would make less likely), and also allowed respondents to indicate 8 (would not use gametes/would not donate gametes).

Figure 3 presents the distributions of responses for recipients and donors. The modal response for both groups is 8—39.7% of donors would stop donating, and 39.9% of recipients would not have future treatment using donated gametes if access to a register of identifying information were to become possible. Few respondents (3.1% of recipients and 8.2% of donors) gave *any* kind of response indicating that access to identifying information would make them *more* likely to use or to donate gametes, although there was a significant degree of uncertainty, as 25% of recipients and 34% of donors scored at the midpoint on this question.

Of the anonymous donors, 95% (66 of 69 donors) said that they would not donate at all or would be less likely to donate (i.e., scored 7 or 8) if the legislation changed to allow exchange of identifying information. Similarly, of the recipients who used gametes donated by an anonymous donor, 95% (264 of 278 recipients) said that they would not use donated gametes at all, or would be less likely to use donated gametes (i.e., scored 7 or 8) if the legislation changed.

Similar to Adoption and Other Forms of Donation?

The responses we have reported are substantially different from those reported to similar questions by participants in the adoption process (i.e., adoptive and relinquishing parents). And given the many strongly argued analogies drawn between the two procedures in the clinical literature (e.g., Brandon, 1979; Brandon and Warner, 1977; Daniels and Taylor, 1993; Winkler and Midford, 1986), we were interested in whether donors and recipients viewed the use of donated gametes as similar to, or different from, adoption. Respondents were presented with a series of questions asking them to rate the similarity between sperm donation, egg donation, and embryo donation, on the one hand, and blood donation, kidney donation, bone marrow donation, and adoption, on the other. Ratings were made on a scale from 1 (completely different) to 7 (identical). Table 5 presents the means and standard deviations of responses, separately for recipients and donors. The modal response for all comparisons is 1.

The important comparisons for present purposes are those involving adoption. Recipients consistently rate sperm, egg, and embryo donation to be more like blood, kidney, and bone marrow donation than like adoption, and looking across the rows of comparisons for sperm, egg, and embryo donation, adoption is viewed as the least similar of all the comparisons. The pattern holds true for donors, with the exception that they see embryo donation to be more like adoption than like blood, kidney, or bone marrow donation. Even here, though, the mean response is on the "different" side of the scale midpoint, and the mode is 1.

Discussion*Beliefs about Registers of Information*

The majority of donors and recipients surveyed believe that a central register of identifying information should not be

Table 5. Assessed Similarities between Gamete/Embryo Donation and Other Forms of Donation/Adoption

	Blood donation M (SD)	Kidney donation M (SD)	Marrow donation M (SD)	Adoption M (SD)
Recipients				
Sperm donation	3.36 (2.33)	2.58 (2.13)	2.66 (2.15)	1.73 (1.46)
Egg donation	3.00 (2.26)	2.73 (2.14)	2.77 (2.16)	2.28 (1.81)
Embryo donation	2.60 (2.16)	2.76 (2.21)	2.77 (2.16)	2.28 (1.81)
Donors				
Sperm donation	3.36 (2.17)	2.42 (1.93)	2.45 (1.96)	2.16 (1.75)
Egg donation	3.00 (2.11)	2.69 (1.91)	2.67 (2.01)	2.29 (1.80)
Embryo donation	2.36 (1.99)	2.52 (1.90)	2.53 (1.92)	3.00 (2.17)

Note: Similarity was assessed on a 7-point scale from "completely different" (1) to "identical" (7).

kept, but that a central register of nonidentifying information should be kept. Recipients are more opposed to having identifying information held in central registers than are donors, but their views regarding the storage of nonidentifying information are similar to donors' views. Prior to this study there has been little specific information concerning donors' and recipients' attitudes to the retention of information, and none distinguishing between identifying and nonidentifying information. One of a few previous studies to report on recipients' attitudes to general information storage (Bolton et al., 1991) found that most (British) sperm and oocyte recipients surveyed were in favor of some records being kept about both donors and recipients, although 80% felt that these records should not be held centrally by the government. Several studies of Australian sperm donors report that while most would allow retention of their personal details, they believed that whatever information was provided should be kept only by clinics, rather than in a central register (Daniels, 1991; Kovacs, Clayton, and McGowan, 1983; Nicholas and Tyler, 1983; Rowland, 1983).

A more recent British study, conducted after the introduction of mandatory information registers, found that the majority of 28 sperm donors surveyed thought that information identifying them should be held in a central register, while a quarter of the group stated that this information should not be kept at all (Daniels, Lewis, and Curson, 1997). This generally positive attitude to registers being kept is probably a result of respondents knowing that the legislation is clear that only nonidentifying information could be released, and because potential donors opposed to the information register would not have become donors.

Access to Registers

Tables 1 and 2 indicate that respondents, and recipients in particular, want only restricted information to be available to participants in the process, with more information available to medical personnel or researchers, which then should be used primarily to protect the health of the participants. The main motivation for donors' and recipients' support for any maintenance of information registers is to protect the welfare of the resulting children, and the belief seems to be that this is possible through the use of nonidentifying information. The idea that recipients will agree to almost anything for the benefit and welfare of their children is reiterated in a British study of sperm recipients (Robinson et al., 1991) in which almost 60% reported that they would agree to the release of medical records identifying donors for medical purposes (although 85% of 71 sperm recipients stated that they would not inform their children of their genetic origins).

Donors are clearly and consistently more liberal than recipients in their willingness to allow different categories of people access to both types of registers. However, the

majority of both donors and recipients are opposed to allowing donors, recipients, or children (of any age) access to a register of identifying information, implying that they themselves did not want access to information about the other parties involved in their own treatment or donation. Donors in particular indicate that a nonidentifying register should be used to provide information to participants, a point which is examined in more detail later. Other reports of donors and recipients indicate much the same response. For example, only 9% of 110 recipients and 16% of 37 sperm donors in a New Zealand study thought that children should have access to identifying information (Daniels, 1988), while a majority of 75 Australian sperm donors was opposed to either children (67%) or recipients (84%) having access to information identifying them (Handelsman et al., 1985). Even more British sperm donors (92% of 144) opposed children having access to identifying information about them (Cook and Golombok, 1995).

The pattern of difference found between donors and recipients in the present study is similar to a British study of 35 oocyte donors and 60 recipients (Kirkland et al., 1992). In that study, 63% of donors would still donate if the recipient could know their name, but only 26% of recipients would accept if the donor were given their name; 90% of recipients were strongly opposed to the donor contacting the child, but only 46% of donors strongly objected. The donors surveyed were all female, which may account for the differences between that study's findings and those of the present study.

Recipients and donors most strongly favor medical personnel and medical researchers having access to both forms of registers for the purposes of research and medical follow-up studies. Anecdotal evidence (mostly from handwritten comments in the margins of the questionnaires and phone calls to the researchers) indicates that the respondents are primarily concerned with health issues for resulting children and for themselves; that any medical problems with donors should be able to be traced to children born from donations; and that further assessment of any possible adverse consequences of medical treatment for infertility is desirable. This is made even clearer when recipients were asked what information about donors they wanted access to.

What Do Recipients and Donors Want to Know?

It is no surprise that the information donors and recipients want to exchange pertains directly to the welfare of the child. The pattern of findings in the present study mirrors that of other studies, and also makes sense in the context of family formation using donated gametes (Brewaeys et al., 1997b; Klock, Jacob, and Maier, 1994; Nachtigall, Becker, and Wozny, 1992; Nielsen, Pedersen, and Lauritsen, 1995; Pettee and Weckstein, 1993). Anecdotal evidence suggests that recipients regard the use of do-

nated gametes as simply another step in their quest to have a child. Once the treatment is successful and they have a child, they want to live without the prospect of interference in their family from anyone. It follows that recipients feel that they have more to lose if identifying information is accessible. For that reason, they generally do not want access to identifying information about donors, and they do not want donors to have access to identifying information about them. On the other hand, donors appear to feel that they have less to lose and consequently are slightly less protective of information exchange. Recipients have good reason to want the information they specify (see Table 3). They want their child to be healthy and free from future medical problems (Brewaeyts et al., 1997b; Klock, Jacob, and Maier, 1994; Nachtigall, 1993; Pettee and Weckstein, 1993), to resemble them as much as possible (Brewaeyts et al., 1997b; Klock, Jacob, and Maier, 1994; Nachtigall, 1993; Nielsen, Pedersen, and Lauritsen, 1995), and to have the best possible intellectual potential, as donors' educational level is usually specified as information recipients want to know (Leiblum, Palmer, and Spector, 1995).

Donors clearly perceive the situation the same way. They have good reason to want to provide the information recipients want. They recognize that recipients want information about their health status and medical history so that the child is likely to be healthy, about their physical characteristics so the child has the best chance of resembling the parents, and about their education level so that the child has the best possible intellectual potential. Sperm donors in previous studies have indicated that they are happy to provide any amount of nonidentifying information to recipients (Kovacs, Clayton, and McGowan, 1983; Lui et al., 1995), and they particularly wish to provide relevant information to assist in a physical match and to reduce health risks, as well as to provide information about their own educational level (Daniels, 1987; Daniels, Curson, and Lewis, 1996a; Daniels, Ericsson, and Burn, 1996; Mahlstedt and Probasco, 1991). Typically, though, they do not want to provide identifying information (Handelsman et al., 1985).

Donors have less need of information about the recipients. As a group, donors in this study (see Table 3) and others (Cook and Golombok, 1995; Daniels, 1989; Kovacs, Clayton, and McGowan, 1983; Mahlstedt and Probasco, 1991) are most interested in the success of the program using their gametes, the number of children born as a result of their donations, and the recipients' reasons for using donated gametes. In an Australian study, some sperm donors were also interested in nonidentifying information about children (43%) and recipients (25%) (Handelsman et al., 1985).

Donors and recipients agree on the specific information recipients want, and donors are happy to provide that information. They do not want to know each other's

names; neither do they want to provide their own. They also agree that donors do not want much information about recipients at all. The most likely explanation for this pattern of results is that both groups focus on the welfare of the child. Donors rate their own medical history and current health status as the most important information to provide to recipients, and this is the information recipients want most keenly. Information to maximize the child's likeness to the parents and the child's intellectual potential is agreed by both donors and recipients to be the next most important information to provide.

Thinking about One Another

The data concerning how often participants think about each other are unambiguous: donors and recipients do not often think of each other, indicating that they do not see a role for each other in their lives. While no other studies have asked donors or recipients directly whether they think about each other, 55% of 55 potential sperm donors in a British study agreed that as soon as they had donated, they forgot all about it (Lui et al., 1995). However, when asked about children conceived as a result of their donations, a majority of 43 Swedish sperm donors (Daniels, Ericsson, and Burn, 1996) and 23 Australian sperm donors (Daniels, 1989) stated that they thought about them at least sometimes, although a significant minority said that they never thought of them.

Telling Others

The present findings regarding the people to whom recipients and donors have disclosed or intend to disclose their involvement in a program are consistent with the majority of the literature (e.g., Cook et al., 1995; Daniels, Curson, and Lewis, 1996a; Daniels and Taylor, 1993; Durna et al., 1997; Klock, Jacob, and Maier, 1994; Nachtigall et al., 1998). This is particularly the case for the issue of recipients disclosing to their children, over which there has been considerable heated debate. Moreover, the greater the personal involvement with a program using donated gametes, the less likely the respondent is to be in favor of disclosure to the child (Bolton et al., 1991).

Typically, a majority of sperm donors (48-89%) surveyed in Australia, New Zealand, and the UK report that they have told someone of their donation, usually a partner, family, or friends (Daniels, 1987; Daniels, Curson, and Lewis, 1996a, 1996b; Purdie et al., 1992; Rowland, 1983; Sauer et al., 1989). This finding is consistent, also extending to potential sperm donors in Australia (Handelsman et al., 1985) and oocyte donors in the United Kingdom (Kirkland et al., 1992).

Again consistent with the present study, typically the majority of recipients surveyed have told family, friends, and/or medical personnel about their use of donated gametes

(Cook et al., 1995; Cook et al., 1997; Durna et al., 1997; Kirkland et al., 1992; Klock, Jacob, and Maier, 1994; Leiblum and Aviv, 1997; Purdie et al., 1992; Rowland, 1983). An interesting point, reported in only one study—presumably because of the specific nature of the question—is that more than 80% of couples who did disclose to someone else their use of donated gametes would choose not to do so if they were in the same situation again (Klock and Maier, 1991).

In the light of this last point, it is significant that the recipients surveyed in the present study indicate that they will not disclose their use of donated gametes to people who have not already been informed. And, in fact, two recent studies have reported that 40% of a Danish and Swedish sample of recipient couples (Nielsen, Pedersen, and Lauritsen, 1995) and 50% of a Dutch sample (Brewaeyts et al., 1997b) did not disclose to anyone their use of donated gametes.

Centering on the most heated debate surrounding the use of donated gametes, the present study shows that recipients are somewhat divided over whether they intend to disclose to their children or potential children the nature of their conception using donated gametes. In fact, very few (11 of 130) recipients have disclosed to their children the role of donated gametes in their conception. The majority of recipients have not disclosed, nor do they intend to do this in the future. While it could be argued that this may be due to the young age of the children, only slightly more than a quarter say that they definitely intend to, while more than half state that they definitely will not disclose to their children.

Typically, published studies report that the majority of heterosexual recipient couples have not disclosed to their children that they were conceived using donated gametes, and do not intend to do this in the future (Daniels and Taylor, 1993; Klock, Jacob, and Maier, 1994, 1996). Studies dating from the early 1980s in France (Manuel, Chevret, and Czyba, 1980), Britain (Bolton et al., 1991; Cook et al., 1995), Western Europe (Brewaeyts et al., 1997b; Cook et al., 1997; Golombok et al., 1995, 1996; Nielsen, Pedersen, and Lauritsen, 1995), Australia (Clayton and Kovacs, 1982; Durna et al., 1997; Rowland, 1983), Canada (Berger et al., 1986), and the United States (Amuzu, Laxova, and Shapiro, 1990; Klock and Maier, 1991; Klock, Jacob, and Maier, 1994; Leiblum and Aviv, 1997; Nachtigall et al., 1998; Schover, Collins, and Richards, 1992) find that a consistent majority (56-86%) of recipients have not disclosed and do not intend to disclose to children, while between 8% and 39% in the same studies intend to disclose to their children.

Several distinctions must be drawn between different groups of recipients. First, lesbian couples and single heterosexual women typically opt to disclose to their children (Brewaeyts et al., 1993, 1995, 1997a; Leiblum, Palmer, and Spector, 1995). In fact more than half of lesbian couples would prefer a known sperm donor (Brewaeyts et al., 1993, 1995, 1997a), and would like their child to meet the sperm donor (Leiblum, Palmer, and Spector, 1995). The issue of

an absent father was most relevant in their decisions, and so they felt that not disclosing was not a viable option.

Second, there is a recurring pattern of difference between the attitudes of those recipients who do have children and recipients who do not as yet have children as a result of treatment with donated gametes. Generally, heterosexual couples in donated gamete programs without children are more likely than couples with children to state that they intend disclosing to their children (Cook et al., 1995; Schover, Collins, and Richards, 1992). Moreover, once couples have children, the likelihood of their disclosing to their children the use of donated gametes further diminishes (Cook et al., 1995; Durna et al., 1997; Klock and Maier, 1991). Reports indicate that even those who state that they intend to disclose to their children may not have initiated the discussion by the time the child is seven years old (Cook et al., 1995; Durna et al., 1997). Recipients surveyed in the present study show this familiar pattern. Compared to recipients with children, slightly more childless recipients intend to disclose to potential children (21% vs. 16%), while less state that they definitely will not disclose to their children (41% vs. 64%), suggesting a change of attitude towards disclosure with the birth of children via donated gametes. When recipient couples are reported to change their minds about disclosure following the birth of a child, they invariably opt for less disclosure than they originally planned, especially in regard to disclosing to the child (Cook et al., 1995; Durna et al., 1997; Leiblum and Aviv, 1997; Schover, Collins, and Richards, 1992).

Given the similarity across studies of the attitudes of recipient couples to disclosing to their child/ren, the comments of two groups of authors form an interesting comparison. Leiblum and Aviv (1997) report that the majority of couples in their U.S. sample were not offered psychological counselling, yet had definitely decided not to disclose to their children. Durna et al. (1997) in Australia also report that in the face of extensive pretreatment counselling, particularly about telling children of their origin, the attitudes of parents remain relatively unchanged—they choose not to disclose to their children. Leiblum and Aviv (1997) conclude that mental health professionals should be aware of the divergence between what they believe about the positive benefits of counselling and disclosure, the fact that the majority of infertile couples are not interested in counselling for disclosure and do not believe that disclosure would be helpful to either their children or themselves, and the fact that almost nothing is known about the benefits of disclosure among all parties involved (Broderick and Walker, 1995; Shenfield and Steele, 1997; Walker and Broderick, 1999).

Effects of Access to Identifying Information

The majority of sperm donors questioned in European studies would not donate without a guarantee of anonymity.

Between 52% and 89% of English samples state this (Cook and Golombok, 1995; Daniels, Lewis, and Curson, 1997; Lui et al., 1995; Robinson et al., 1991), as well as 60% of a Danish sample (Pedersen, Nielsen, and Lauritzen, 1994). A smaller but still sizeable proportion of a small sample of Australian sperm donors (27% [Daniels, 1989]), and U.S. sperm donors (29% [Mahlstedt and Probasco, 1991]) would not donate without a guarantee of anonymity. Considerably more indicated that they were quite unsure about any change reducing the degree of anonymity available to them. Clearly, for most donors, remaining anonymous is a primary concern. The reasons the donors gave included that they did not feel the resulting child was theirs; they did not want to have any contact; they were afraid of someone wanting to contact them or wanting help later on; they did not want disruption to their own families; and they had given something away, and now they were through with it.

The main argument for retaining donor anonymity is that loss of donor anonymity would severely reduce the recruitment of new donors. This is indeed what happened in Sweden, where the number of children born from donated gametes fell from 200-230 per year to 30-50 per year following legislation requiring that donors allow children born as a result of their donations access to the donor's name and address (Daniels, Ericsson, and Burn, 1996).

Recipients of donated gametes are just as clear in their stance in favor of anonymity. Almost 40% of the present sample would opt out of treatment using donated gametes if donor anonymity is not retained, and most of the remainder would seriously reassess their options. Other studies report equally strong opinions. In a British sample of 35 oocyte donors and 60 oocyte recipients, 63% of donors would donate if identifying information exchange was required, but only 26% of recipients would accept donation under the same conditions (Kirkland et al., 1992). Nineteen percent of 168 Danish couples who had undergone donor insemination would not have used donated gametes if anonymity could not have been guaranteed. Significantly, the percentage was even higher among recipients who had children using donated sperm: only 39% would have continued using donated sperm without qualms (Nielsen, Pedersen, and Lauritzen, 1995).

Most current and previous donors and recipients would choose not to be involved if legislation allowed identifying information to be accessed. Some researchers have argued that this is not problematic, since a different sort of donor and recipient would be involved (Daniels, 1995; Daniels, Curson, and Lewis, 1996b; Daniels, Lewis, and Curson, 1997; Daniels and Taylor, 1993). The donors would ideally be older married men and women who had completed their own families, and the recipients would be couples who would undertake to provide all information to the child and remain in contact with the donor (Daniels, 1988, 1995; Daniels, Curson, and Lewis, 1996b; Daniels, Lewis, and Curson, 1997; Daniels and Taylor, 1993; McWhinnie, 1993;

Triseliotis, 1993; Turner, 1993; Winkler and Midford, 1986). Even more ideally, according to one Australian counsellor, only known donors actually recruited by the recipients should be used, preferably friends or relatives (Wellsmore, 1999). But recent Swedish data show that changing the legislation does not change people's attitudes (Nielsen, Pedersen, and Lauritzen, 1995). When legislation made it mandatory to agree to identifying information being provided, the number of donors fell dramatically (Cooke, 1993; Daniels, Ericsson, and Burn, 1996), and there were strong indications that infertile Swedish couples were simply crossing the border to neighboring countries to use donated gametes under conditions of anonymity (Daniels, Ericsson, and Burn, 1996). The Swedish situation sends a clear message: parents believe they know more about what is best for their child than government legislators or infertility counsellors, and they believe they have the same rights to make decisions about their families as do families who have not used donated gametes.

The evidence suggests that the effect of allowing access to identifying information would exclude a large number of potential donors and recipients and effectively change the types of both donors and recipients who would be involved in the process.

Similar to Adoption and Other Forms of Donation?

Neither the donors nor the recipients surveyed view donation and adoption as similar. In fact, with the exception of one comparison (donors comparing embryo donation to adoption), donation and adoption were viewed as the least alike of all comparison pairs presented.

No other study has asked respondents to directly compare the procedures of reproduction using donated gametes and adoption, although Daniels et al. (1996a) specifically asked 28 U.K. sperm donors whether they thought the common adoption policy of telling children about their origins has any relevance to children conceived using donated sperm. While about a third of the donors said adoption policies were relevant to donor insemination, more than half viewed adoption policies as irrelevant to donor insemination.

In an earlier study asking 37 New Zealand sperm donors to compare sperm and blood donation, 25 (68%) said the forms of the donation were different, and only a quarter of the sample (24%) said they were the same (Daniels, 1987). But that study did not include the relevant comparisons between donation and adoption; the present study suggests that donors view gamete donation as more similar to blood donation than to adoption.

One British and one American study have indirectly assessed recipient couples' attitudes to the adoption-donation analogy. In a comparative study of British families formed using either donor insemination, IVF, or adoption, Cook et al. (1995) found consistent and significant differences in

terms of disclosing information to the child and others, as well as in the reasons for disclosure or nondisclosure. These authors argue that the experience of adoption is unlikely to be useful for families formed through donated gametes because there are important differences between parental experiences in these two ways of creating a family (Cook et al., 1995). Nachtigall et al. (1998), in a qualitative analysis of comments from a sample of 182 American parents who used donated sperm, found no evidence that these parents identify at all with the adoption experience. In fact, the authors argue that in contrast to the adoption model—which suggests that children lacking knowledge of their genetic heritage may have an incomplete sense of identity—the parents' comments focus on the child's attachment to the parent, which fosters healthy social and emotional development.

Further indirect evidence for recipients viewing the two procedures as dissimilar is found in an examination of the choice of options made by Dutch infertile couples where medical assistance was found to be overwhelmingly favored, while adoption was chosen very infrequently, and chronologically much later than any other option (van Balen, Verdurman, and Ketting, 1997), indicating little perceived similarity between the two options by these couples.

Recently there has been an increasing sense of disquiet concerning the unquestioning acceptance of the analogy between adoption and medically assisted conception using donation (Broderick and Walker, 1996a; Cook et al., 1995; Klock, Jacob, and Maier, 1994; Shenfield, 1994; Shenfield and Steele, 1997; Walker and Broderick, 1999), the consequence of which is counselling for prospective parents to reveal the method of conception to the child. The data presented here show unequivocally that the recipients and donors, whose gametes, children, and families are at issue, do not agree with the analogy either, and furthermore, they view donation as more similar to blood donation than adoption.

Conclusion

Donors and recipients agree that registers of information should be retained, although there is considerably more support for the maintenance of registers of nonidentifying information, and in all cases, recipients are more conservative in their views of all aspects of maintaining and exchanging information than are donors. The respondents agree that recipients should have access to nonidentifying information, but only medical personnel and researchers should have access to identifying information, and then only for medical purposes or long-term follow-up studies, all of which focus on maintaining the health and well-being of the child. The same theme recurs with a striking level of agreement over the issue of what donors and recipients want to know about each other. Although they report that they do not think of each other often, recipients want information about the do-

nor that maximizes the health and welfare of the child, and maximizes the likelihood of a physical match with the parents. However, they do not want to provide much information about themselves. Complementing this view, the donors want to provide the information the recipients find most important, although they do not wish to know much about the recipients themselves. Both donors and recipients are adamant that they do not want to know who the other parties are. They do not want identifying information, nor do they want to be identified. Most donors and recipients state that if the legislation were changed so that identifying information could be accessed, they would either be less likely to be involved or would not be involved at all in programs as donors or recipients of donated gametes.

Both donors and recipients have typically told some family and friends of their involvement in a program, recipients have usually told some medical personnel as well, and neither group report any intention to tell any others they have not already told. Recipients generally have not disclosed to their children the method of their conception, nor do they intend to disclose this to them. This is not surprising, considering that neither donors nor recipients see any similarity between the procedures of adoption and conception using donated gametes, and the impetus for full disclosure comes from those who promote similarity between donation and adoption.

No doubt the reader will be left with three questions:

- What most benefits the children born from donated gametes?
- What do such children want to know about the details of their conception? and
- What do these children want to do with, or about, the information concerning their conception?

There has been a great deal written about the benefits of informing children and the dangers of "keeping secrets," all of which is debatable and none of which is informed by research (Broderick and Walker, 1996b; Cook et al., 1995; Klock, 1993; Klock, Jacob, and Maier, 1994; Shenfield, 1994; Shenfield and Steele, 1997; Walker and Broderick, 1999). Unfortunately, this is likely to remain the case, as any full exploration of the effects on children of privacy, confidentiality, secrecy, or disclosure on a truly comparative basis is not possible as so few parents have disclosed or plan to do so to their children. And importantly, many studies now show that those parents who do disclose or intend to disclose are in fact atypical, and thus cannot adequately inform us of any adverse effects of "secrecy" (Cook et al., 1995).

Recipients of donated gametes and embryos clearly want to make their own decisions for their own families formed with the assistance of donated materials, in the same way that all other parents want to make their own decisions for their own families formed without the assistance of donation. The view that our society should allow them this right

is now gaining momentum (Cook et al., 1995; Klock, Jacob, and Maier, 1994, 1996; Leiblum and Aviv, 1997; Shenfield and Steele, 1997; Walker and Broderick, 1999). From a clinical perspective, Shenfield and Steele (1997) state, "For the time being, there is no evidence that either anonymity or the specific secret of gamete donation is harmful to the child. Therefore we have no duty to convince prospective parents to choose openness, but should listen to their concerns" (p. 394).

Fundamentally, what matters most to the existing or prospective child conceived with donated gametes are the beliefs and concerns of the parents or prospective parents, as they are the ones who will directly influence the well-being and welfare of the child (Shenfield and Steele, 1997). The recipients in our study are clear about their intentions: the majority intend to maintain the privacy of the method of conception used (62% of those who have children and 47% of those who have attempted to conceive using donated gametes).

The data for the present study come from one of the few representative samples of donors and recipients in one location, rather than from a convenience sample from one clinic. The data show strongly that donors and recipients do not agree with the current push for openness and access to identifying information. Although the data were collected in 1994, there is no reason to believe that the results would be much different in data collected today.

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