

A qualitative follow-up study of women's experiences with oocyte donation

A.L.Kalfoglou^{1,3} and J.Gittelsohn²

¹Bioethics Institute, Department of Health Policy and Management, Johns Hopkins School of Hygiene and Public Health, and

²Division of Human Nutrition, Department of International Health, Johns Hopkins School of Hygiene and Public Health, Baltimore, MD, USA

³To whom correspondence should be addressed at: Bioethics Institute, Johns Hopkins School of Hygiene and Public Health, 624 N. Broadway, Suite 511, Baltimore, MD 21205, USA

Oocyte donation is growing at an exponential rate. Currently, thousands of women donate each year. The health services that donors receive deserve evaluation. Thirty-three former donors were recruited from IVF clinics, a matching agency, the Internet, advertisements, and word of mouth. In-depth interviews were conducted to learn what motivated the donation, to determine how satisfied donors were with the experience and what issues played a role in donor satisfaction, and to identify recommendations to improve the process. None of the participants regretted their decision to donate, but they were not always completely satisfied with the donation experience. The physical process, compensation, quality of medical care, and level of involvement in the process were the primary factors that affected satisfaction. Matching agencies and IVF clinics may improve donor satisfaction by: minimizing trips to the clinic; using protocols that limit the number of intramuscular injections; reducing the risk of hyperstimulation syndrome; providing follow-up care; reimbursing for expenses such as lost work, travel, and child care; separating direct reimbursements from 'income' to decrease the amount of taxes donors must pay on compensation; treating donors with respect and appreciation; and informing them about the outcome. Improved donor satisfaction is likely to improve donor recruitment and retention.

Key words: evaluation/oocyte donation/qualitative research/satisfaction

Introduction

The ability to create a human embryo with the use of donated oocytes and carry it to term is a relatively new assisted reproductive technology; however, since its introduction in 1984 (Lutjen *et al.*, 1984), the use of donor oocytes has increased exponentially. In 1996, 222 of the 300 in-vitro fertilization (IVF) clinics in the USA and Canada offered oocyte donation as a therapeutic treatment for infertility (Centers for Disease Control and Prevention, 1998). In that same year, 5162 IVF cycles using donor oocytes resulted in

just over 1700 live births (Centers for Disease Control and Prevention, 1998).

As a relatively new and growing practice, it is important to learn how oocyte donors experience and evaluate the health services they receive. While many studies have looked at donor demographics, motivation and medical outcome, two American (Schover *et al.*, 1991; Rosenberg and Epstein, 1995) and three European studies (Fielding *et al.*, 1998; Soderstrom-Anttila, 1995; Ahuja *et al.*, 1998) report on donor follow-up. All five follow-up studies drew their research participants from a single IVF facility, and the research was conducted by investigators affiliated with that facility.

In a predominantly quantitative follow-up study (Schover *et al.*, 1991), it was found that 91% of former anonymous donors were moderately to extremely satisfied with the donation experience. The physical process was well tolerated by a majority of the participants, with one-quarter to one-third reporting it was mildly negative. Two donors reported adverse psychological symptoms, but these symptoms were resolved with medical or psychological treatment. Two women became pregnant following the donation, one of these being unexpected. Many women longed to know the outcome of the donation and to have more interaction with the recipient couple, but these thoughts were not obsessive.

A second follow-up survey was conducted in the USA (Rosenberg and Epstein, 1995) in which both qualitative and quantitative data on anonymous donors' emotional and medical responses to donation were collected. The qualitative component was especially valuable because it gave women the opportunity to express themselves in their own words without being limited by the researchers' predefined categories. In this study, donors reported significant discomfort, particularly relating to bloating before and after the retrieval. The actual retrieval and the hormonal injections were well tolerated except for some anxiety related to self-injecting. Few donors reported serious adverse emotional responses, and most felt very positive about their contribution. Many were curious about the outcome of the donation.

In a later study (Fielding *et al.*, 1998) it was found that most anonymous donors felt the donation was successful, and 60% of former donors were prepared to donate again. Those who reported they would not donate again gave various reasons including advancing age, side effects of treatment, practical difficulties and poor medical care. In this study, when oocyte donors were compared with semen donors, it was found that oocyte donors wanted to be more involved in the process by knowing something about the recipient couple and by being informed if a pregnancy resulted (Fielding *et al.*, 1998). This desire to know the outcome has led some to recommend that

oocyte donors be provided more information about the outcome (Soderstrom-Anttila, 1995), but others (Schover *et al.*, 1991) have argued that informing the donor may only lead to greater psychological harm or greater risk of family conflict or courtroom tragedies.

In a follow-up survey of 30 unpaid donors (Soderstrom-Anttila, 1995) it was found that most donors were satisfied with the process. Some 96% reported that their own feelings were sufficiently taken into consideration during treatment, and 78% reported that they would donate again. Side effects were slight and tolerable. While 42% reported they did not want any information on the recipient couple or resulting offspring, 67% would have liked to know whether a child had resulted from the donation. Approximately two-thirds of the respondents thought the child should be told about its origins, and one-third thought the child should be given non-identifying information about the donor.

In 1998, a follow-up survey was conducted of former IVF patients who had donated oocytes to other patients, receiving a discount on treatment in return (Ahuja *et al.*, 1998). These authors found that donors were typically motivated by empathy for other infertile couples as well as the treatment discount. Even patients who did not become pregnant still supported the idea of egg sharing, although four (of 79 unsuccessful patients) felt they had received inadequate counselling to prepare them for the possibility of failure. Patients rejected the idea that children created from their oocytes were their children.

Finally, a brief report was made on the understanding of donors' experiences, based on the authors' many years of counselling donors (Cooper and Glazer, 1998). These authors state that the medical process is typically not difficult; that some—but not all—donors express interest in knowing some information about the recipient couple; and that it is common for donors to feel somewhat let down after the donation is complete.

Data on how donors experience the donation process are essential to inform policy makers, as they formulate policy recommendations that will ultimately affect this group of women. Data are also helpful to guide IVF clinics as they seek to improve the services they provide to oocyte donors. Donor satisfaction is likely to influence participants' willingness to repeat the experience. It will also influence potential donors' willingness to participate and society's acceptance of oocyte donation as a permissible assisted reproductive technology.

Materials and methods

Thirty-three former oocyte donors were recruited for study in four ways. Eighteen participants were recruited through three IVF clinics and one matching agency in the Baltimore, Washington DC, and Philadelphia areas of the USA. Twelve former donors were recruited from an Internet web site devoted to oocyte donation. Three women were recruited through a local newspaper advertisement or via word of mouth. To minimize recall bias, only women who had donated within the past 3 years were included.

Informed consent was obtained prior to the interview. Participants were not compensated for participating. Maintaining the privacy of the participants was of the utmost concern. All data tapes, transcripts

and files were labelled with a code rather than the women's names. All transcripts were edited to remove identifying information. Pseudonyms were used for all reporting of the research findings. At the conclusion of the study, audiotapes and all links between the data and participants' identifying information were destroyed.

Qualitative research methods are especially useful for capturing information on women's experiences. In-depth interviews were chosen to give participants the opportunity to speak about their experience in their own words and to keep the research process flexible so that new areas of research could be added as they emerged from the interviews.

Demographic data were collected and recorded on a prepared form. In-depth interviews were conducted following an interview guide (see Appendix). Questions were open-ended and were often followed by probes to elicit more information. The interview times ranged from 1 to 3 h. New interview questions were added to the interview guide as new themes emerged during the interview process. Interviews were conducted either in person (21%) or over the telephone (79%). Interviews were tape-recorded with the participants' permission. Audiotapes were transcribed. Field notes were taken throughout the interview and data analysis process.

Transcripts were read repeatedly and notes taken on emerging themes. A list of codes was developed that represented these themes. Codes were also developed for demographic data. Data were entered into the qualitative data analysis program NUD*IST 4.0 to facilitate coding and data analysis (Qualitative Solutions and Research Pty Ltd, 1997). Throughout the data analysis process, codes and themes were continually reviewed and revised. At various points during the data collection and analysis process, other researchers trained in qualitative methods reviewed the interview guide, data transcripts, coding scheme and findings to minimize investigator bias.

A number of steps were taken to ensure the trustworthiness of the findings. First, three researchers trained in qualitative research methods conducted an independent review of a sample of the transcripts. Second, one of the participants reviewed a sample of the transcripts and provided feedback on the interviews and the conclusions drawn by the investigators. Third, the findings from this research were compared with similar findings in the literature. Fourth, peer review of the preliminary findings was solicited through formal work-in-progress sessions, graduate seminars, and a qualitative research methods working group.

Results

Demographic data

Former donors ranged in age from 21 to 36 years at the time of donation. Twenty-nine self-identified as Caucasian, two as Jewish, one as Hispanic, and one as African American. Half were married at the time of the donation, and two-thirds had children. Thirty-one self-identified as heterosexual, and two as lesbian. Four had a history of personal infertility. Five former donors had also been surrogate mothers.

Donor characteristics

Based on the participants' recall, the 33 former donors completed 66 stimulated cycles with four additional cycles cancelled due to poor response. The average number of donations for women recruited through the matching agency and through IVF clinics was 1.6 (range 1–3) and 1.8 (range 1–5) respectively. Women recruited from the Internet website donated an average of 2.5 times (range 1–7).

Twenty-two women (66.7%) donated anonymously and were given little to no information about the recipients. Three (9%) had a prior friendship with the recipient. Four (12%) met their recipient over the Internet for the express purpose of oocyte donation. One (3%) donated through an IVF clinic and was able to meet all three of her recipient couples. Three (9%) donors completed multiple donations, including anonymous donations and donations where they either knew or met the recipients.

Motivation to donate

Approximately half of the participants stated that they were motivated primarily by the financial compensation. Most of these women donated only once and did not see the donation as a major life event. A few of these women had donated multiple times and agreed with 'Danielle' (Note: participants were given pseudonyms) who said, 'I consider what I am doing a business. I'm providing a service'. 'Audrey' said that participating in third-party reproduction has changed her standard of living. 'My first [surrogate pregnancy] got me off of welfare and got me through nursing school. My second one paid off all my loans and credit cards that I had accumulated. My egg donation went to pay rent for six months, and my next surrogacy money completed my Bachelor's degree'.

One participant donated specifically to finance her own treatment. In some cases she donated all her eggs for financial compensation, and other times, she 'shared' half of her eggs in exchange for free medical care. After seven stimulated cycles, she has been pregnant once, but she has not yet had a successful delivery.

Some of the women who were initially attracted by the financial compensation ended up feeling more altruistic about their donation as the process progressed. 'Janet' reported, '... [the money provided] the motivation to call, and then once I got more involved in it, then it was—I don't need the money. This isn't for the money'. It is unclear whether the development of altruistic feelings is a result of the donor adopting the motivation that IVF clinics and recipients find more palatable, or whether there is some internal shift that happens within these women as a result of the donation experience. Of the women who thought they were simply in it for the money, some were actually surprised at how personally satisfying the experience was. 'Sally' remarked, '... after having been an egg donor, I just feel so good about myself'.

Other women stated that their primary motive was to help an infertile couple. Half of the women knew someone struggling with infertility, and four had experienced infertility themselves. Others pointed to their own love of motherhood and how devastated they would be if they had been unable to have children. For some women, this desire to help was satisfied with one or two donations; however, there was a subset of women for whom participating in third-party reproduction was a major part of their lives. Such women are probably over-represented in this sample because they are more likely to participate in the Internet-based directory from which we recruited. These women report that participating in third-party reproduction makes them feel special. As one donor reported, 'I am just a housewife and mom, so it is kind of like my own

little glory thing'. This particular group of women is more likely to pursue careers in a health care-related field or get more involved in third-party reproduction by working for or starting their own matching agency. At least two of these women created Web pages, complete with photographs of the children they helped create—not only as a tribute to these children but also as marketing materials for future customers.

Three women stated that they were motivated to donate to compensate for a previous abortion. Another woman disclosed that she had been raped as a teenager and had a subsequent abortion, but she said that this experience was unrelated to the oocyte donation. In all four cases, the women concealed this information during their psychological interviews out of fear that they would be judged and excluded from participation.

Four participants were motivated to donate because a friend either asked them to, or they offered when they became aware of their friend's infertility. Three out of four of these women were not interested in helping anonymous infertile couples. They only got involved to help their friend.

A small number of women had fairly unconventional motivations for donating. Three specifically stated that they did not intend to have children, and that oocyte donation provided them with an opportunity to pass on their genes without any responsibility for the resulting child. Another woman had an academic interest in new reproductive technologies and said she donated 'to have the experience'. Two women said they were oocyte donors because it was something they were good at that built their self-esteem and got them attention from others. Others mentioned that they donated because it fed into a sense of genetic pride. They fit the profile of the perfect donor and liked the feeling of being desired. Finally, one woman stated that she participated specifically because she felt an obligation to help 'build the Jewish people'.

The physical process: ovarian stimulation, monitoring, retrieval and accompanying side effects

Hormonal injections were well tolerated. The vast majority of participants were surprised at how easy it was to give themselves subcutaneous injections; however, a number reported some anxiety before administering the first injection. The intramuscular injections were more difficult and painful, and participants often found someone else to help administer these. Participants found it helpful when they were given extensive instruction on self-injection, were asked to give themselves the first injection at the clinic in the presence of a nurse, and were given written or video-taped instructions to take home. Participants reported minor side effects from the hormonal injections such as hot flashes, bloating, moodiness, pain at injection site, headaches, queasiness, increased appetite, weight gain and tiredness. A few participants experienced major mood swings and bloating that caused significant discomfort. Some participants reported being inadequately prepared for these side effects. 'Barbara' reports, 'Those last two days my clothes didn't fit, and I was just huge ... and I didn't, obviously, anticipate that at all'. Other side effects included one case of intrauterine polyps resolved with a dilatation and curettage, one case of ovarian cysts that resolved without treatment, two cases of anaemia due to frequent blood withdrawal, and a

urinary tract infection caused by a latex allergy. One woman passed out and experienced convulsions four days before her scheduled retrieval. She was hospitalized and diagnosed with low potassium and magnesium concentrations. The cycle was cancelled, but she never learned whether this event was related to the hormones she was injecting. She continues to experience hot flashes, even though her physicians told her that her hormone levels were normal.

Many participants complained about the frequency of clinic visits for the initial screening and subsequent monitoring. Some had to drive an hour or more each way for each visit, and one woman drove for over 8 h. A number of participants commented that it would have been more convenient if blood tests and monitoring could have been arranged closer to their homes. The one woman who was able to arrange this was upset when she learned that the recipients were being double-billed for these visits. Some participants also commented that the clinic scheduling made the process more difficult. For instance, screening visits for psychological counselling and the medical examination were scheduled on separate days, necessitating multiple trips. At other times, women complained that they had to come in for a visit when the interaction could have been handled over the telephone.

The majority of the participants reported that the retrieval was 'easy', 'quick' and 'painless'. All 26 participants who received general anaesthesia experienced no discomfort during the retrieval process other than six participants who reported discomfort from the i.v. infusion. Five of the seven women who received only a light sedative reported significant pain and discomfort during the retrieval. One woman received an epidural; although the procedure was painless, she had residual pain from the spinal injection site for 7 weeks following the retrieval. One participant was informed that she had stopped breathing briefly during the retrieval process, reportedly due to congestion.

Many women felt little to no discomfort following the retrieval. Some were even able to resume their normal activities almost immediately. Others needed a few days to feel fully recovered, and two reported having a painful period following the retrieval. However, nine women (27%) reported a week or more of discomfort so significant that it kept them in bed, prevented them from working, or interfered with their ability to care for their children. These women were much more likely to have produced a large quantity of oocytes (between 20–60), suggesting that they were experiencing hyperstimulation syndrome. The woman who produced 60 oocytes was so bloated she stopped eating for 12 days, could not walk, and was out of work for 3 weeks. Another woman was hospitalized with internal bleeding which resolved after a few days. Yet another woman became pregnant unintentionally immediately following the donation and had an abortion.

Most participants reported little to no concern about their long-term well-being; however, two women mentioned that they have experienced minor gynaecological abnormalities and will always wonder whether these were related to the donation. Four women reported concern about their future fertility. Five mentioned concerns about the possibility of an increased risk for ovarian or breast cancer. 'Cassie' was concerned about

both: 'I still have that kind of worry in the back of my mind that it might affect my future fertility chances, or breast cancer, or whatever'. Another woman said she was concerned that some day a child will appear on her doorstep. All of these women describe these concerns as passing thoughts, and not something they dwell on regularly.

Compensation

Participants were asked how much they were compensated and whether they thought the compensation was adequate. One participant donated to a friend without compensation, but the others were paid. Compensation averaged from US\$2000 to \$3000 (range US\$500–4000). One participant was in the process of negotiating a US\$10 000 donation at the time of the interview. Over half of the participants thought the compensation was adequate or more than enough, but one-third thought they were undercompensated based on what they experienced, primarily because the compensation did not include expenses. Many women lost hundreds of dollars due to lost work, travel expenses and additional childcare. 'Leslie' reported, 'I live about 150 miles outside [the city], so I had to drive in. It cost me about \$500 in gas, and I was compensated \$2500, so \$500 went to gas and \$2000 to my family'. Most of these women did not feel comfortable discussing the compensation with the matching agency or IVF clinic because they did not want to appear to be greedy. Many women stressed that the financial compensation was completely secondary to the psychological gains they received from knowing that they were helping someone. Others felt judged by the clinic staff and the media because they were accepting compensation.

Participants were asked to assess the purpose of the compensation. Most said it was for their time, inconvenience, travel, effort, expenses such as lost work, and pain and risk related to the donation. Others mentioned that it provided an incentive for women to show interest in donating and thereby increased the genetic selection available to recipients. Three participants thought the compensation was to buy eggs, even though they were told by the clinic that the compensation was for their time. Five participants said that the promise of the compensation at the end of the donation provided an incentive to stay compliant with the protocol. One woman said the compensation was to pacify her husband and keep him from complaining when she was gone because of the appointments. Finally, two women received cheques in the post after they complained about the poor quality of medical care. Both believed that this money was a pay-off to keep them from complaining. 'Katie' complained, '... they think money fixes everything'. 'Christine' used the compensation to pay for follow-up care that the IVF clinic refused to provide.

The Internal Revenue Service (IRS) states that compensation received in exchange for oocyte donation must be declared as income (The NABER Report, 1996). Participants were asked whether they thought that they would have to pay taxes on the compensation. Approximately half did pay taxes, but they were not always informed about this ahead of time. A number of women were shocked when a W-2 (tax) form arrived in the post, or their accountant informed them about this rule. Many of these women were frustrated not only because they thought

the tax was unfair, but also because they did not know ahead of time, so they could set money aside. Women who did not pay taxes were under the impression that either it was not enough money to declare; it was reimbursement for pain and suffering and was therefore not taxable; or that it was a gift and was therefore exempt.

Quality of medical care

Over half of the participants reported that they were satisfied with the medical care they received, and many thought they were treated even better than a typical patient. For instance, 'Molly', 'Natalie' and 'Nancy' reported that the clinic staff were extremely flexible with scheduling to accommodate them as much as possible. 'Audrey' felt especially well cared for because the nursing staff called her every couple of days following the retrieval to see how she was doing. Similarly, 'Tara' felt that the health care providers were looking out for her best interest because they were willing to cancel her cycle at the first sign that her health was in danger. Donors also liked the positive feedback they received from clinic staff. 'Janet' had the following to say about her physician, '... he was very eager to answer any questions, very supportive, and was constantly saying you're doing a really good thing here'.

A number of specific issues created discontent. First, while many women reported that their medical care was adequate, they often described it as cold and impersonal. Women disliked being asked to use a pseudonym, and they especially disliked being called by a number. Two women were annoyed because they were isolated in a private room to keep them separated from the general patient population. A number of women commented that they felt distrusted by the staff when they were instructed not to discuss the fact that they were a donor with other patients or ask the staff questions about the recipients or the outcome of the donation. Others, like 'Chris' and 'Melanie', described feeling like a commodity. They used metaphors such as farm animals, produce, meat, and prostitution to describe how the experience made them feel. 'Chris' thought that 'I just got the feeling you were second class ... I wondered did they treat everybody that way, or is it 'cause I was a donor? ... I'm just the produce stand ... like a cow at the market or something'. Likewise, 'Melanie' remarked that 'I definitely wasn't in charge there. It was a little like what I would think prostitution would be like ... you've rented your body out ... You would be prepped, and there would be none of the small talk that usually goes on to put the patient at ease. And it's kind of like 'spread your legs, there we go' ... It was like you were some prized heifer or something'.

Second, at least seven donors felt that promises clinic staff made when they were trying to recruit the women were not kept once the women were engaged in the process. Four women requested or were promised a specific kind of anaesthesia before committing, but they had to argue with the anaesthesiologist on the day of the retrieval. 'Barbara' requested that she be treated only by a female physician. She was reassured that this would not be a problem, but she learned the day before the retrieval that a male physician was scheduled to do the procedure. She felt intimidated and harassed by him when he learned she was uncomfortable with men. 'Christine' was

promised free follow-up care if she experienced any side effects because she was uninsured at the time of the donation. When she returned to the clinic a week following the retrieval because she was still in pain, she was told they were no longer responsible for her care. Finally, 'Daphne', who was infertile herself, negotiated to share half of her eggs for free infertility treatment. Following the retrieval, she learned that the physician had fertilized all of her eggs with spermatozoa from the recipient couple that had paid for the procedure, instead of splitting them as agreed. 'Daphne' decided not to pursue the case legally because she did not have this agreement in writing.

A third area of concern for donors was that many felt that their best interest was not a primary concern of the medical staff. At least three women mentioned that they thought they were kept on the hormones longer than necessary just to produce more eggs. 'Melanie' said, '[I wanted to know] how many of these little eggs do they need? Because they were pumping me full of the stronger and stronger drugs and when I first went, I said 'well what's a good take?' ... They [said] 'well, 10 or 12 is a usual one.' And I had something like 25 in one [ovary] and almost 20 in the other, and I was swollen pretty big ... and they were *still* putting me on the stronger drugs'. All three women said they did not feel comfortable discussing this with their health care providers because they did not want to appear whiny. This sentiment was also reflected when women discussed their follow-up care. Participants who received a follow-up examination felt cared for and reassured that their bodies had returned to normal. Those that did not have a follow-up examination described feeling abandoned and concerned about their long-term well-being. Other participants described being treated with disrespect by the clinic staff, and attributed this to the fact that they were not the paying customers.

A fourth issue that affected the participants' satisfaction with the medical care was the amount of information they received before donating. The vast majority of women felt well informed and thought they had ample opportunity to have all their questions answered, but there were a few exceptions. Two women reported that they repeatedly asked for information on the risks of donation. In 'Christine's' case, she was told there were no risks. She recounts that, '... [the counselling] did not outline any of the risks involved, any of the time involved, any of the discomfort involved. It really focused on the joy of giving—the gift of giving. It focused on the recipient and the family's joy. It didn't mention the donor much at all'.

'Anita' lived on the East Coast, but was donating to friends on the West Coast. She was working with an IVF clinic at long distance. She requested information, and was promised that it would be sent, but it never arrived. She recalls, '... [the] informed consent forms for the drugs said something like, 'I agree that I have been informed of side effects and known studies indicating what the risks may be in taking these drugs.' I was *never* informed of anything. All I was given was those forms What I really wanted were the studies...and they never had any of that. They said, '... well you can look it up on the Internet.' In other words, it's not my job'.

Others commented that the IVF clinic or recipient couple provided their drugs, and the drugs either lacked a package

insert or the insert was in a foreign language. One woman even mentioned that her drugs were from Mexico and stamped with a warning that use of the drugs in the USA was illegal. Additionally, a number of participants were concerned about the lack of information available on the long-term risks. While most of the women attributed this to the fact that oocyte donation is a new technology, others felt there was a lack of information because IVF clinics are profit-orientated and there is no financial incentive to conduct follow-up research.

Finally, some participants mentioned that they were disappointed with the amount of time they had with a physician. All of the donors from one clinic mentioned that they had almost no interaction with a physician. All of the testing, counselling and monitoring was carried out by nurses or technicians. At other times, there was no continuity of care. 'Georgia' saw at least three physicians during the stimulation process and said that the physician doing her retrieval '... didn't come in before the procedure or anything which I thought was rude'.

Level of involvement

The majority of the donors in this study also wanted to know the outcome of the donation. With one exception, they wanted to know that the donation had been successful and that their efforts had been worthwhile. Many reported feeling left out once the retrieval was completed. A few reported fantasizing about or praying for the recipient woman around the time she had the embryos implanted, received the results of her pregnancy test, and would potentially be giving birth. None reported obsessive thoughts about the child.

Seventeen participants learned the outcome of the donation. Those that learned there had been a pregnancy felt very good about the outcome. Of the four participants who donated to women with whom they had a prior relationship, only one resulted in a pregnancy. Friends whose donations failed to result in pregnancy reported being unprepared for their profound disappointment with the outcome. Of the seven donors who met or had some communication with the recipients before donating, six knew it had resulted in an ongoing pregnancy and the seventh was waiting to learn the outcome. A few of these donors had ongoing communication with the recipient family and some had received photographs of the resulting children. All of these donors reported they were comfortable letting the recipients define the boundaries of the relationship and did not have any yearnings to establish a parent-child relationship with the child(ren). These donors found the donation experience extremely rewarding.

Discussion

None of the participants reported that they regretted the oocyte donation; however, this did not mean that they were all completely satisfied with the experience. There were a number of areas that affected donors' overall satisfaction with the donation experience, including the physical process of ovarian stimulation, retrieval, and accompanying side effects, the compensation, the quality of medical care, and level of involvement in the process.

There are a number of ways that IVF clinics can make the medical process easier for donors. The most burdensome aspect of donating for many women was the time and inconvenience. Steps should be taken to minimize the number of trips to the clinic. For instance, during the screening process, various appointments could be combined. IVF clinics might also consider helping donors schedule blood withdrawals or other simple tests at a health care facility closer to their home.

Next, extra assistance that the IVF clinic provided to help the donor feel more comfortable self-injecting was appreciated by the donors. Participants especially appreciated practising injections in the IVF clinic with the assistance of a skilled health care provider and having a video-tape of the injection process to take home. Since the donors found intramuscular injections were more difficult to administer alone, clinics should consider using protocols that limit the number of intramuscular injections. They may also offer to make staff available to help the woman if she does not have someone to help her.

Steps can be taken to make the donor feel as though she was adequately compensated. As the IRS requires that donor compensation be reported as income, IVF clinics and matching agencies should inform participants before the donation. Potential donors should be informed whether or not this money will be withheld. To the extent possible, IVF clinics and matching agencies should be willing to reimburse directly for expenses related to the donation such as travel, lost wages and childcare so the donor does not have to pay taxes on these monies.

Participants said that the financial compensation was not the only benefit of participating in oocyte donation. Many stated that the 'good feeling' they got from knowing they were helping someone was more important to them than the financial compensation. IVF clinics can facilitate this benefit by showing their own appreciation for the donor's contribution, or by passing along thoughts of appreciation from the recipient couple.

One of the classic ethical principles that guides medicine is 'respect for persons.' Often this is interpreted as respecting the autonomy of an individual by ensuring there is no coercion and there is adequate informed consent; however, respect for persons also includes respect and the expression of shared goals. IVF clinics can improve the quality of medical care they provide donors by respecting donors in the following ways. First and foremost is to let the donor know that her contribution is appreciated. Participants who thought they were treated with respect and appreciation typically reported a positive donation experience. Even women who experienced significant side effects felt good about their medical care if the side effects were taken seriously and treated promptly. Participants who thought they were treated with indifference were more likely to report feeling disappointed with the care. Participants who felt they were treated poorly said they felt used. Donors felt good when they were treated like collaborators rather than employees or adversaries. They want the health care providers to understand that, in most cases, their goals are one and the same.

Psychological care can be improved by giving donors the freedom to disclose sexual trauma and previous abortions in

a safe environment. Psychologists have recognized that donors often exhibit a history of sexual trauma and abortion and may be attempting to 'make up' for a loss through oocyte donation (Cooper and Glazer, 1998). This research not only supports this claim, but also demonstrates that potential donors are intentionally concealing this information during the psychological screening and counselling session out of fear that they will be judged and rejected. Other studies have found that both semen and oocyte donors have a response bias on psychological tests because of their understanding that the tests are being used to screen them (Schover *et al.*, 1992). Psychologists may want to discuss exclusion criteria with potential donors before the session so that they feel more comfortable discussing this motivation. Alternatively, the National Advisory Board on Ethics in Reproduction (Cohen, 1996) recommends that counselling be provided separately from psychological screening. During the counselling session, potential donors should be assured that any information revealed that does not have a direct bearing on the donation will be kept confidential and will not be used to exclude the donor from participation.

IVF clinics need to take steps to build trust between the health care provider and the donor. Trust is built by being forthright about the risks related to donating. Participants tend to be resourceful and will seek out this information. They are wary that this information may be presented in a biased fashion in order to convince them to donate. When the risk of hyperstimulation syndrome is discussed, health care providers need to prepare donors not only for the rare possibility of hospitalization but also for the possibility of a more common milder reaction that may result in a week or more recovery time. Every attempt must be made to minimize the likelihood that the donor will be hyperstimulated and to treat the symptoms if they occur. Donors should be given a clear indication ahead of time of approximately how many oocytes are expected to be harvested. If the donor is being stimulated beyond the norm, the health care provider should explain why. Trust is also built when the health care provider spends time with the donor. This gives the donor the opportunity to ask questions, which in turn makes her feel cared for and maximizes the goals of the informed consent process.

In addition, health care providers who ask women to donate their oocytes in order that they may treat infertile women have an obligation to provide follow-up care and to conduct follow-up research so donors can be better informed about the long-term medical and psychological risks related to donation. Both of these steps will make donors feel as though their well-being is just as important as that of the infertile patients.

Prior follow-up studies have found that oocyte donors want to be more involved than semen donors (Schover *et al.*, 1992; Fielding *et al.*, 1998) and are interested in knowing the outcome of the donation (Schover *et al.*, 1991; Rosenberg and Epstein, 1995; Fielding *et al.*, 1998). We believe that more research needs to be done to determine the long-term effects of informing the donor about the outcome before a recommendation can be made. Based on this research, donors are happy to know that the outcome is successful, and knowing the outcome does not appear to increase the donor's thoughts

about the resulting child; instead, it appears to increase the 'good feeling' donors have about alleviating the suffering of others. Counselling needs to be provided before the donation to prepare the donor for the possibility that the donation may not be successful. This appears to be especially important for known donors. This preparation should include information on current success rates using donor oocytes, clarification that the donors are not responsible for failures, and reassurance that a failure is not a reflection of the donor's fertility. Donors should also be told that, regardless of the outcome, their contribution was still valuable.

Many donors mentioned that they wanted to know the outcome so they could better prepare for the future possibility of meeting the child(ren). These concerns are legitimate. Other countries give children born through third-party reproduction the right to know their genetic parents, and there have been recent changes in attitudes about adoptive children's right to know their genetic parents in two states in the USA (Heinz, 1998). Donors also wanted to know the gender and birth date of any resulting offspring in order to prevent their own children from inadvertently marrying or reproducing with a genetic half-sibling. Consanguineous relationships may be statistically unlikely, but the fear is great. Providing such information may reduce this fear.

Additional research is needed to learn more about the effect of having women travel to complete a donation. Internet-based matches and the use of relatives and friends as donors are increasing long-distance arrangements. Among these participants, at least four women travelled out of state for their retrieval, and two additional women were planning long-distance donations. Travel had a negative impact in at least two cases. 'Anita' felt that the IVF clinic did a terrible job communicating with her. In another, 'Diane' became very ill at the airport as she was leaving and did not have anyone with her to help her. Additional follow-up should investigate whether there is an impact on the quality of care for donors who travel. Health care providers participating in long-distance arrangements also need to consider who is ultimately responsible for the woman's care if there are complications—the health care provider monitoring the cycle or the health care provider doing the retrieval.

Some have suggested that a high level of donor satisfaction can be assumed because many donors are willing to repeat the process (Cooper and Glazer, 1998), but this should not substitute for sound follow-up research. Identifying and implementing ways to improve donor satisfaction may lead not only to better recruitment and retention of donors, but also to better medical care and a more positive experience for donors.

Acknowledgements

The authors would like to thank the IVF clinics and matching agency that assisted in recruiting and the women who were willing to share their experiences. We are particularly indebted to Anne Pollock, a research participant and qualitative researcher, who provided feedback on other donors' interviews, our analysis, and this manuscript. We would also like to thank Gail Geller, Adrienne Asch, Nancy Reame, Ruth Faden, Edward Wallach, Barry Zirkon and Heather Rutz for their generous assistance on this project. This study was supported

in part by the Department of Health Policy and Management, Johns Hopkins School of Hygiene and Public Health.

References

- Ahuja, K.K., Simons, E.G., Mostyn, B.J. *et al.* (1998) An assessment of the motives and morals of egg share donors: policy of 'payment' to egg donors requires a fair review. *Hum. Reprod.*, **13**, 2671–2678.
- Centers for Disease Control and Prevention (CDC) (1998) *1996 Assisted Reproductive Technology Success Rates National Summary and Fertility Clinic Reports*. Available online at: <http://www.cdc.gov/nccdrph/drh/art.htm>
- Cohen, C. (ed.) (1996) *New Ways of Making Babies: The Case of Egg Donation*. Indiana University Press, Indianapolis, IN, pp. 274–275.
- Cooper, S.L. and Glazer, E.S. (1998) *Choosing Assisted Reproduction: Social, Emotional & Ethical Considerations*. Perspectives Press, Indianapolis, IN, pp. 195–243.
- Fielding, D., Handley, S., Duqueno, L. *et al.* (1998) Motivation, attitudes and experience of donation: a follow-up of women donating eggs in assisted conception treatment. *J. Community Appl. Soc. Psychol.*, **8**, 273–287.
- Heinz, S. (1998) Adoptee requests, privacy clash: Oregon and Tennessee laws give access to birth records, but confidentiality previously was assured. *The Oregonian*, December 27, 1998.
- Lutjen, P., Trouson, A., Leeton, J. *et al.* (1984) Establishment and maintenance of pregnancy using IVF and embryo donation in a patient with primary ovarian failure. *Nature*, **307**, 174–175.
- The NABER Report (1996) IRS Views Compensation for Oocyte Donation as Income. **2**, 6.
- Qualitative Solutions and Research Pty Ltd (1997) QSR NUD*IST. Thousand Oaks: Sage Publications Software.
- Rosenberg, H. and Epstein, Y. (1995) Follow-up study of anonymous ovum donors. *Hum. Reprod.*, **10**, 2741–2747.
- Schover, L.R., Collins, R.L., Quigley, M.M. *et al.* (1991) Psychological follow-up of women evaluated as oocyte donors. *Hum. Reprod.*, **6**, 1487–1491.
- Schover, L.R., Rothmann, S.A. and Collins, R.L. (1992) The personality and motivation of semen donors: a comparison with oocyte donors. *Hum. Reprod.*, **7**, 575–579.
- Soderstrom-Anttila, V. (1995) Follow-up study of Finnish volunteer oocyte donors concerning their attitude to oocyte donation. *Hum. Reprod.*, **10**, 3073–3076.

Received on July 16, 1999; accepted on January 17, 2000

Appendix. Interview guide

1. Tell me how you first learned about oocyte donation.
Probe: Why did it interest you?
2. What made you think that you would make a good donor?
3. How did you learn about this programme?
4. What happened after you contacted the centre?
5. What information do you remember getting?
6. At what point did you make the final decision that you would go ahead with the donation process?
Probe: Did anything else influence your decision to proceed? (knowing another egg donor or an infertile person.)
7. Did you fill out a personal profile?
Probe: What kind of information?
Probe: Were you comfortable with all the questions?
Probe: How do you think this profile was used?
8. Did you know anything about the recipients?
9. How did you feel about that?
Probe: Can you think of any characteristics that might have made you uncomfortable about the recipient couple?
Probe: Do you know if the recipients went through any screening?
10. Tell me about the medical screening process.
Probe: What did you get tested for?
Probe: Did you receive any pre or post human immunodeficiency virus (HIV) test counselling?
Probe: How did you get the results of your tests?
11. Tell me about any meetings you had with a psychologist or counsellor.
Probe: What was the purpose of the visit?
12. Tell me about the legal process.
Probe: Did you have a legal contract?
13. What would have happened if you had decided to stop the process

- after the drugs but before the retrieval?
14. Who would pay in the event there were medical complications?
15. What information did you have about what became of your eggs?
16. What kind of counselling did you receive about sexual activity and risk of pregnancy during this process?
17. What do you remember learning about the medical risks?
18. Were you given any information about the psychological risks?
19. What kind of consent forms did you sign?
20. Did you have the opportunity to have all your questions answered?
21. What information was especially important to you?
22. Tell me about the relationship you had with the clinic staff.
23. This is an unusual relationship with a health care provider because you are getting paid and it's not for your medical benefit. How did this affect the relationship you had with the health care providers?
24. Did you feel like the clinic staff was acting in your best interest?
25. What happened next?
26. Tell me about getting the injections.
Probe: What was it like giving yourself injections?
Probe: How did your body react to the drugs?
27. Tell me about the retrieval.
28. What kind of follow-up care did you receive?
29. How much information did you receive about the outcome?
30. Do you think about what might have happened?
31. What were your arrangements for future contact?
32. What was the purpose of the money you received?
33. Was it an adequate amount for what you experienced?
Probe: Was the money taxed as income?
Probe: Did you know it was going to be taxed at the time you agreed to participate?
34. Tell me why you would or would not do this again.
35. What would you tell a friend who was considering being an oocyte donor?
36. Who have you discussed your donation with?
Probe: mother, spouse/significant other, family, extended family, friends?
Probe: did you tell your obstetrician/gynaecologist?
37. As you know, oocyte donation is relatively new, and different clinics have different policies. What policies are good and which should be changed?
38. At this time, is there anything you didn't feel comfortable sharing with the clinic staff that you want to share with me?
39. [Tell story about motivation related to past abortion.] Was this at all a part of your experience?
40. Is there anything else you would like to discuss that you think is especially important about oocyte donation and your experience?
41. Do you know anyone else who has been an oocyte donor?
42. Are there any questions you would like to ask me?