THE MOTIVATIONS AND EXPERIENCES OF KNOWN EGG DONORS

by

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The purpose of this exploratory study was to evaluate the experiences of women who had donated their eggs to help a family member, friend, or acquaintance become a parent. An experimenter-generated questionnaire was distributed to all donors who had participated in the egg donation program at Genesis Fertility Centre since the egg donor program’s inception in 1999. Of the 29 women who were able to be contacted, 20 elected to complete and return the questionnaire for a response rate of 69%. The first section of this three-part questionnaire sought to gather general information from the donor about: how the subject of being an egg donor first arose, the nature of the donor’s relationship with/to the recipient, whether a viable pregnancy resulted from the cycle, and whether the donor’s relationship with the recipient(s) has changed since she participated in treatment. The second part dealt with the decision-making process of the donor, and inquired about the importance of the following factors in the donor’s decision to become an egg donor: the relationship of the donor to the recipient, personal factors, family factors, broader social issues, and consequences to the child(ren) produced if treatment was successful. The third section assessed the donor’s experience in the treatment process as well as her overall experience of being an egg donor. Irrespective of the outcome of her donation or the challenges of the treatment process, 90% of the participants reported having no regrets about having donated their eggs to a family member, friend, or acquaintance. Given the chance to reconsider their decision, all but two participants said they would make the same choice again to be a known egg donor.
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CHAPTER ONE

Introduction

It may be fair to surmise that for many couples starting a family is not solely experienced as a natural progression in their relationship but also as a social responsibility. In fact, the expectation and resulting societal pressure that a couple has children cannot be denied in many cultures and societies. However, the ability to conceive is often taken for granted and the high rate of infertility is often not widely recognized. The prevalence of infertility is reported to be as high as 1 in 7 couples (American Society of Reproductive Medicine (ASRM), 2003), with the suggestion by some that we could see a rise in this number as more couples postpone starting a family to later on in life (i.e., mid-to-late thirties or early-forties). Irrespective of the validity of such arguments, a significant number of individuals are affected by infertility, and the psychosocial issues faced by these individuals, and often their family and friends, often are too frequently unacknowledged (Daniluk, 2002; Lieblum, 1998).

Infertility may be attributed to either male, female or a combination of both male- and female-related factors. Common causes of fertility problems in women include problems with ovulation; ovarian failure, whether premature or due to advanced age; tubal damage; poor quality of eggs; or genetic disorders (Klein & Sauer, 2002). Male factor problems in terms of sperm parameters or the complete absence of viable sperm can be caused by congenital or genetic factors, previous injury to the testicles, cancer treatments, environmental factors, or endocrine dysfunction (Corson, 1999).

Current advancements in reproductive technologies have resulted in an increase in available treatment options which, in turn, have significantly improved successful
conception rates (Sauer, 1996). However, in cases where either the man’s sperm or the woman’s eggs are not viable for conception, the available options require the involvement of a third party who donates his/her sperm or eggs, commonly referred to as third-party or collaborative reproduction.

In the case of male infertility, the option of artificially inseminating the woman with sperm donated by a man, other than her partner, has been available for over 100 years. As a result, there is a substantial body of literature examining the psychological and social implications of this form of family building, from the perspective of the donor, the recipients, and more recently, the offspring created through the use of anonymous and known sperm donations (Applegarth and Kingsberg, 1999; Cooper, 1997; Cooper and Glazer, 1996; Klock, 1997; Zolbrod and Covington, 1999). Conversely, in the case of female infertility, it is only relatively recently that the option of utilizing eggs donated by another woman has become possible (Sauer, 1996). With advances and success in the procedure by which egg donation is performed, this is becoming a first line treatment in many centers, for women who suffer from premature ovarian failure and for the increasing number of women in their forties and fifties, who are seeking a pregnancy when their fertility is no longer viable (Braverman, 1993; McShane, 1997; Sauer).

The procedure involved in egg donation is much more complex than that for sperm donation (Klein & Sauer, 2002). It is more time consuming and difficult for the donor and in rare cases, can lead to severe complications. The donor firstly has to be assessed and accepted as a donor based on her medical history, physical health and certain laboratory investigations. Specifically, potential egg donors are screened for any blood-borne infections such as Hepatitis B, Hepatitis C and HIV, sexually transmitted
diseases, and inheritable genetic disorders. Most programs also require that the donor undergo psychological screening, as recommended by the mental health special interest group of the American Society for Reproductive Medicine (ASRM) (Hammer-Burns & Covington, 1999).

Once the woman has successfully completed the medical and psychosocial screening process, the donor begins a course of hormonal medications one of which needs to be administered in the form of a daily injection, and another that frequently requires nasal inhalation. Both procedures can be associated with anxiety and physical discomfort (Sauer, 1996). There are also a number of potential side effects associated with these medications, including headaches, short-term memory loss, mood swings, hot flashes, abdominal swelling, the most severe being ovarian hyperstimulation (Greenfield, 1999). Frequent assessments with blood tests and ultrasound examination are conducted to determine when the donor’s eggs are ready for retrieval. The eggs are then removed percutaneously with a suction needle, guided by ultrasound. This procedure is considered by some donors to be somewhat invasive and physically uncomfortable (Sauer).

The process of egg donation raises a number of different important ethical and psychosocial issues. Firstly, there is the issue of anonymous versus known egg donation. In cases where the egg donor is known to the recipient(s), there is always the concern of coercion as it pertains to the donor. Due to this and other concerns largely related to boundary issues and role confusion, only anonymous donation is allowed in some countries such as France. Currently, in Canada there is new legislation (Assisted Human Reproduction Act) mandating that all egg donations be uncompensated, as in the case of organ and blood donations. According to Orobitg and Salazar (2005) the practice of egg
donation is altogether forbidden in some countries such as Norway, Sweden, Italy, and Germany. This is in contrast to countries such as Spain which at the time of the approval of its first Law of Assisted Reproduction in 1988 possessed one of the most liberal laws in Europe. These differences in legislation between European countries is explained based on the distinction made by these countries as to whether the issue of egg donation is considered to be a private matter, as in the case of Spain, or a public/national concern, as in the case of Norway (Orobitg & Salazar, 2005).

Interestingly, the practice of egg donation began with known donors (Braverman, 1993). As the procedure became more successful and popular, and as recruitment programs offering significant monetary compensation flourished, more young women volunteered to donate their eggs anonymously. The recruitment of, and compensation for young donors with particular characteristics has resulted in this being “big business” in the U.S. (Sauer, 1996). As the anonymous pools grew, the use of anonymous donation became the preferred method for many couples. Consequently, much of the available research has been conducted on the motivations and experiences of anonymous egg donors (Fielding, Handley, Duqueno, Weaver & Lui, 1998; Jordan, Belar & Williams, 2004; Kalfoglou & Gittelsohn, 2000; Schover, Collins, Quigley, Blankstein & Kanoti, 1991). However, issues of supply and demand surfaced, and as countries such as Canada passed legislation banning monetary compensation for genetic donations, alternatives to the anonymous donors were sought, with known, altruistically-based donations becoming the only option for many couples trying to produce a child. To this day, the issue of anonymous versus known egg donation remains controversial, with considerably more
research being necessary to determine the short- and long-term implications of both methods of family building (Applegarth & Kingsberg, 1999).

Aside from donor anonymity, there are other ethical issues related to collaborative reproduction and in particular the invasive and costly process of egg donation, such as the accessibility of these technologies. Clearly, if the recipients have to pay for the medical procedure which in Canada, typically costs between $8,000 and $12,000 per treatment attempt, only economically privileged individuals may be able to afford treatment. Other important ethical issues include the issue of donor compensation and the development of policies regarding disclosure to the off-springs of their origins (Cooper, 1997). Some countries, such as Sweden, England and Australia have legislation in place to ensure that individuals conceived by gamete donation have access to information about the medical and social histories of donors. Other countries such as New Zealand, Finland and the Netherlands are also considering similar legislation (Blyth, 1998).

Equally important are the psychosocial issues associated with egg donation. Unfortunately, due to a number of different reasons, the body of literature in this area is limited especially as it pertains to known donors. For instance, due to the fact that there is a certain social stigma associated with infertility, many participants in third party reproduction are reluctant to reveal themselves in public, making it difficult to study this population of donors and recipients. There is also the issue of privacy invoked by fertility clinics which understandably can make it more difficult to access research participants. Some research has been conducted to understand the motivations and experiences of anonymous egg donors (Bartlett, 1991; Bolton, Golombok, Cook, Bish & Rust, 1991; Fielding, Handley, Duqueno, Weaver & Lui, 1998; Kan, Abdalla, Ogunyemi, Korea &

Contrary to the anonymous donation research, relatively little research has been done for the purpose of understanding the impact of the experience of known egg donation, particularly the experiences of known donors. What little research exists on this topic has focused primarily on the experiences of the donor recipients (Baetens, Devroey, Camus, Van Steirteghem & Ponjaeri-Kristoffersen, 2000; Kazem, Thompson, Hamilton, & Templeton, 1995; Lessor, Reitz, Balmaceda & Asch, 1990; Nachtigall, Pitcher, Tschann, Becker, & Quiroga, 1997; Bertrand-Servais, Letur-Konirsch, Raoul-Duval & Frydman, 1993; Weil et al., 1994). Despite the widespread use of egg donation and concerns raised of possible adverse psychological consequences for some participants, there have been few follow-up studies that systematically assess known donors’ experiences of participation and their post-donation satisfaction (Winter & Daniluk, 2004). More research is needed on donors’ motivations, on their emotional and physical experience of the donation, as well as the short- and long-term effects on known donors when treatment fails, or when it is successful and they live with the knowledge that their biological offspring is another woman’s gestational and social child. Data on the experiences of the egg donors especially as it pertains to known egg donors is limited and needs further study. This becomes especially important in places such as Canada where the new legislation (AHRA) will place limitations on who is allowed to donate eggs. A
number of different important questions still need to be answered not only for policymakers but also for prospective third party reproduction participants. Considering that the option of known egg donation remains controversial in many countries, and in light of the fact that the majority of donations in Canada will by necessity, be made by women known to the recipient, the motivations and experiences of known donors need to be further examined and better understood.

**Purpose of the Study**

The purpose of this exploratory study was to begin to evaluate the experiences of women who have donated their eggs to a family member, friend, or acquaintance. An experimenter-generated questionnaire was distributed to all donors who had participated in the egg donation program at Genesis Fertility Centre since the egg donor program’s inception in 1999.

The questionnaire consisted of three parts. The first part sought to gather general information from the donor about: how the subject of being an egg donor first arose, the nature of the donor’s relationship with/to the recipient, whether a viable pregnancy resulted from the cycle, and whether the donor’s relationship with the recipient(s) has changed since she participated in treatment. The second part of the questionnaire dealt with the decision-making process of the donor, and inquired about the importance of the following factors in the donor’s decision to become an egg donor: the relationship of the donor to the recipient, personal factors, family factors, broader social issues, and consequences to the child(ren) produced if treatment was successful. The third and final part sought to assess for the donor’s experience in the treatment process including the
donor’s preparation and orientation, the treatment, the support the donor felt she received from the clinic staff, and her overall experience of being an egg donor.

It was hoped that participants’ responses to this questionnaire will help us better understand and appreciate the experiences of known egg donors, as they reflected on their motivations to donate their eggs, their expectations, their treatment experiences, and their negotiation of issues around boundaries and disclosure. Information from this study may be particularly useful in identifying the pre- and post-treatment informational and counselling needs of egg donors and their recipients. Furthermore, data from this study may help in the development of policies regarding the process of egg donation. Also, it is hoped that the findings from this preliminary study will provide direction for future research.
CHAPTER TWO
Literature Review

In this chapter the background information and relevant literature on the treatment of infertility, focusing on egg donation, will be presented. The background information includes a description of common types of infertility and the available options for treatment. The procedure for egg donation will be outlined to highlight how the procedure can be both physically difficult and time consuming for the donor. The current available data on the demographics and psychological characteristics of donors and what is known about their motivations for donation will be reviewed. The remainder of the chapter will include a literature review on the attitudes and experiences of egg donors, both anonymous and known, during the procedure and post donation.

Background Information

Infertility may be caused by a number of different factors, such as genetic abnormalities in either or both the male and female or specifically male related or female related factors. Male factor infertility is usually related to either an inadequate sperm count or abnormal sperm morphology or motility. The treatment for male factor infertility, which includes the donation of sperm from a third party, has been available for over 100 years (Sauer, 1996). It is risk free and easy for the donor and it is not time consuming. The donor collects his own sample and deposits it into a waiting container. The semen is first screened for diseases and is then frozen. It is re-screened before being used by a recipient. Sperm donation is widely available in most fertility clinics around the world.
Female factor infertility leading to egg donation may be due to the ovaries failing to produce eggs, either due to diminished ovarian reserve, premature ovarian failure (hypergonadotropic hypogonadism), ovarian failure secondary to advanced age. Other indications leading women to seek egg donation, include cases where a woman is known to be affected by, or be the carrier of, a significant genetic defect or have a family history of a genetically determined condition but the carrier status cannot be determined. Finally, women with poor oocyte, and/or embryo quality or multiple failures during prior attempts to conceive via one of the assisted reproductive technologies may turn to egg donation as their best hope to achieve a viable pregnancy (ASRM, 2002). The treatment for female factor infertility which requires the donation of an egg from a third party has only recently been available and is far more complex and difficult for the donor than sperm donation.

Egg donation was initially undertaken in mammals in 1891 when a donated embryo resulted in a successful pregnancy and birth in a rabbit (Klein & Sauer, 2002). This technique was eventually used in various other species and in the early 1980's the first successful human pregnancies and births from egg and embryo donation were reported. Initially donated embryos using uterine lavage following artificial insemination and in vivo fertilization of a donor were utilized. Although this technique led to several successful pregnancies, lavage was eventually abandoned due to concerns surrounding HIV transmission and retained pregnancies in donors. Shortly thereafter in Australia, the technique of using in vitro fertilization of a donated oocyte and subsequent transfer to a recipient with premature ovarian failure, who was primed with female sex hormones (oral oestradiol and progesterone suppositories) resulted in a successful pregnancy. Thus began
the era of human oocyte and embryo donation (Klein & Sauer, 2002). Since then, there has been significant evolution of the egg donation process with improvement in preparation of the recipient, and less invasive methods for harvesting eggs from the donor. The procedure has also become increasingly more efficient and successful. Life-table analysis of 500 consecutive cycles performed at the University of Southern California demonstrated live births in > 50% of the women using donated eggs by the third consecutive cycle and >90% by the fifth attempt (Sauer, 1996). As a result of improved procedures and success rates, the practice of egg donation has increased dramatically. By the early 1990’s in the USA, an egg donation program was established or in development in 73.2% of the 82 programs reporting data to the American Society of Reproductive Medicine (Braverman, 1993). This number has certainly increased today.

The use of third party donation is clearly now an integral tool in the treatment of infertility. However, there are a number of social, ethical, and legal issues surrounding this method of treatment. These issues pertain to both sperm and egg donation but appear to be especially debated in the case of egg donations (Sauer, 1996). Possible explanations for this difference could be the fact that egg donation began mostly with known egg donors (Braverman, 1993), the fact that unlike sperm donation egg donation is often well compensated financially, or perhaps because the egg donation procedure is more difficult both physically and psychologically, risky, and time consuming for the donor. To fully understand the impact on the egg donor, it is necessary to take a close look at the egg donation procedure.
The Egg Donation Procedure

Screening of Recipients. Thorough screening of prospective recipients is required to ensure the physical and psychosocial well-being of the couple, and the future offspring if treatment is successful. The oocyte recipient undergoes a thorough medical history, physical examination and routine blood tests as well as screening for HIV, syphilis, rubella and hepatitis. In cases where there is a family history of genetic abnormalities, appropriate chromosomal analysis is done. Evaluation of the uterine cavity is mandatory to rule out conditions that may affect implantation and/or pregnancy (Klein & Sauer, 2002). The partner of the oocyte recipient also undergoes serologic tests for syphilis, hepatitis, and HIV, and similar appropriate genetic screening and testing. As well, thorough semen analysis is completed (ASRM, 2002). In addition to medical screening, psychological and social assessment and counselling of recipient couples are recommended. Infertility is known to be associated with significant stress, and the inability to have a genetically related child for a woman requiring egg donation poses further pressure such as issues of self-esteem in being unable to use her own eggs, and concerns surrounding disclosure to offspring and the short- and long-term impact of the donation (successful or not) on the recipient’s relationship with the donor (if using a known donor). It is recommended in the guidelines set for by the mental health special interest group of the American Society of Reproductive medicine that both the oocyte recipient and her partner receive psychological counselling (Hammer-Burns & Covington, 1999).

Screening and Selection of Donors. Donors are given a detailed overview of the egg donation process as well as the possible risks and side effects associated with the
medications utilized in order to ensure that they are making well informed decisions. In fact, one of the main reasons that recruiting donors has been shown to be difficult is the medical procedure that the donors must undergo. In a study designed to assess the recruitment of egg donors, approximately 45% of the 339 potential donors that met the criteria for an interview, removed themselves from candidacy due to reservations about the procedure (Lindheim, Frumovitz, & Sauer, 1998). Donors must be of legal age and preferably be between the ages of 21 and 34. If the prospective donor is over 34 years of age, the age of the anonymous egg donor is usually revealed to the recipient. After making the decision to go ahead with the donation process, the donor undergoes an extensive health history and physical examination by a physician. A detailed personal and sexual history is also conducted when applicable. Routine blood screening as well as screening for HIV, Hepatitis B and C, and sexually transmitted diseases such as syphilis is completed. Appropriate genetic tests such as cystic fibrosis screening are conducted when considered relevant.

Regulating bodies, such as the American Society for Reproductive Medicine (ASRM) also recommends psychological evaluation and counselling for the donor and her partner. Counselling sessions typically involve screening procedures, possibly including psychological interviews, personality assessments, and other psychological testing (Hammer-Burns & Covington, 1999). In the case of known donors, related issues such as the potential impact of the relationship between donor and recipient are explored. Once the donor has successfully completed the screening process, the donor initiates the course of medications for harvesting of the eggs.
The Egg Donation Process. The synchronization of the menstrual cycles in the donor and recipient is necessary for the egg donation procedure to result in a successful pregnancy. The donor, therefore, often begins oral contraceptives prior to synchronizing the start of the cycle with the recipient (Klein & Sauer, 2002). The donor then receives a medication, a gonadotropin releasing hormone agonist such as Synarel (Nafarelin) or Suprefact (Buserelin) to desensitize her pituitary gland. This helps enhance the maturation of multiple follicles to maximize the number of eggs that may be collected. It also controls the timing of ovulation by preventing a premature surge of luteinizing hormone (LH). This medication is taken every day until the day before the egg retrieval procedure. This medication is usually taken nasally twice a day. Following this, the donor is treated with another hormone, Follicle Stimulating Hormone (FSH) which is injected subcutaneously daily for 7-10 days. The injections can be very stressful for the donors and cause both significant physical discomfort (pain and bruising at the injection site), anxiety, and are as well associated with a number of potential side-effects including headaches, hot flashes and mood swings (Cooper and Glazer, 1994). The donor is closely monitored during this time with repeat blood tests, clinic visits and ultrasound scans to assess her ovarian response. FSH can cause several side effects including headache, nausea, loss of appetite, joint aches, bloating, weight gain and irritability (Rosenberg & Epstein, 1995). A more severe and rare side effect is the excessive stimulation of the ovaries (Ovarian Hyperstimulation Syndrome) resulting in enlarged ovaries and abdominal pain. In a small percentage of women ovarian hyperstimulation syndrome occurs, requiring immediate intervention and sometimes even hospitalization (Klein & Sauer, 2002).
The donor continues to have frequent ultrasound scans and blood tests throughout the stimulation process. Once the donor’s eggs are deemed to be ready for retrieval, the donor receives another hormone Human Chorionic Gonadotrophin (HcG) by injection and her eggs are collected (harvested) the following day. The egg retrieval is performed vaginally under ultrasound guidance. A needle is inserted into the ovarian follicles through the posterior vaginal wall and each follicle is aspirated separately. The donor is usually able to go home shortly after the procedure. Although most of the time, the donor is able to resume her normal activities, occasionally the donor can continue to suffer from side effects such as fatigue, nausea, and abdominal cramps requiring bed rest (Rosenberg & Epstein, 1995).

Considering the complexity of the donation process and the fact that it can be quite onerous for the donor, the characteristics of the women who choose to become egg donors and the motivations behind their decisions has warranted investigation. In the next section I will review the literature pertaining to the demographic profile and psychological characteristics as well as the motivations and attitudes of women who elect to donate their eggs.

The Egg Donor

Potential Donors. The last twenty years have witnessed a change in the primary source of donated eggs. Initially excess eggs of women undergoing in vitro fertilization (IVF) made up the chief source of oocyte donations, which actually remains the only legal option in some countries such as Denmark and Israel (Ahuja, Mostyn & Simons, 1997). However, recent trends indicate that most women undergoing IVF choose to fertilize all their harvested eggs and freeze them for their own possible future use (Klein
& Sauer, 2002). Other possible sources of oocyte donors are known egg donors, anonymous egg donors, and fertile women undergoing elective sterilization procedures such as tubal ligation. This last group of donors has received little attention in the literature apparently due to the fact that these potential donors do not comprise a reliable source of donated eggs given that women are often of a more advanced reproductive age when they elect to undergo sterilization (Cooper & Glazer, 1994). Thus far the majority of research has focused on anonymous egg donors, drawing attention to the need for studies on non-anonymous, or known, egg donors.

Non-anonymous of “known” egg donation, the method by which egg donation procedures initially began, usually involves women who are often close friends or family members, including siblings, parents and sometimes even children from previous marriages. Factors that require consideration in the case of non-anonymous egg donors are: the impact of donation on the relationship between the donor and the recipient, issues of disclosure, possible occurrence of grief and/or depression in donors when they are not able to successfully provide a child, as well as the possibility of donors feeling obligated or even coerced to donate their eggs (Klein & Sauer, 2002).

By contrast, anonymous egg donors are unknown to the recipients and are usually recruited through advertisements, and matched according to phenotypic characteristics such as height, complexion, and ethnic/cultural ancestry, as requested by the recipient (Klein & Sauer, 2002). In the case of anonymous egg donors, the question of reimbursement and/or amount of reimbursement received by donors is a matter of great controversy. For these reasons payment of donors is not allowed in some countries such as Canada and the United Kingdom. However, most programs in the US not only
compensate donors, but as well place no restriction on the amount of the payments donors receive for their efforts, resulting in large sums of money ($5000 - $10,000) being offered to donors – the amount varying depending on the locale and clinic or agency (Klein & Sauer).

Regulating bodies, such as the American Fertility Society (AFS) (cited in Pierce, Reitemeier, Jameton, Maclin & De Jong, 1995) have published guidelines pertaining to gamete donation. They recommend the use of anonymous donors to reduce the potential for legal and emotional complications for all parties involved. The AFS has also made the following recommendations: donors be of legal age but not more than 34 years old; donors have a previous history of documented fertility; and that donors be made fully aware of the medical procedures involved and all potential risks, as well as the legal and ethical aspects involved in donation. Guidelines for oocyte donation published by the American Society for Reproductive Medicine also recommend assessment of the donors underlying motivations for donation, current stresses, emotional stability and coping skills (ASRM, 2002).

The British regulating body, the Human Fertilization and Embryology Authority (HFEA) allows donation from anonymous donors (though known donors are accepted under special circumstances) under the age of 35 (Marcus & Brisden, 1999). However, they make explicit that payment for gametes is not to be made, in order to reduce the possibility of coercion and trading in human genetic material. Taking into consideration the fact that both the British and the American regulating bodies recommend the use of anonymous egg donors it seems that exploration of the experience of known egg donors in Canada would be important and pertinent to policy makers in this country.
Donors. After attaining an initial picture of potential egg donors, it follows to investigate who the actual donors are including their demographic and psychological profiles as well as the motivations and attitudes of these women who elect to participate in the egg donation process.

In terms of demographic characteristics, a review of the literature revealed two studies that set out to investigate the demographic profile of egg donors; however, several other studies have included demographic information on egg donors. The first study to be reviewed was conducted by Sauer and Paulson (1992) in the form of interviews designed to gather information on prospective egg donors’ demographic profiles, past and present health status, as well as past reproductive histories. The majority (66%) of the donors participating in the donor program were known donors. Of the 61 prospective donors, the 50 that went on to actually donate their eggs were described as married, middle-class, college-educated mothers, with an average age of 31.7 years.

The study by Kan, Abdalla, Ogunyemi, Korea, and Latarefe (1998) surveyed 145 anonymous egg donors. The questionnaire used by the researchers inquired into the age, marital status, fertility status, ethnic background and occupation of the egg donors. The results of their study showed similar findings as Sauer and Paulson (1992) in terms of a trend towards donors who are married/cohabiting, employed, and mothers, with an average age of 31.2 years. Other studies which include demographic information on egg donors (Power et al., 1990; Kirkland et al., 1992; Fielding et al., 1998; Lindheim et al., 1998; Kalfoglou et al., 2000; Klock et al., 1998; Soderstrom-Antilla, 1995) report that on average, participants in their study ranged in age from 26.4 to 31.2 years, a large majority of donors were married (50% to 88%), had children (68% to 93%), and were employed
(62% to 99%). However, it is important to note that these studies are dated and that more current studies would likely show much younger demographics as many programs in the U.S. seek to recruit young, educated donors through the placement of advertisements in college newspapers, with these younger women frequently being motivated by promises of significant financial compensation for their egg donation (Sauer, 1996).

Despite similarities in findings, caution must be exercised in drawing generalizations from these results. However, generalizations of the results from the first two studies reviewed (Kan et al., 1998; Sauer & Paulson, 1992) might be quite applicable in Canada. Firstly, the study by Kan et al. (1998) was conducted in the United Kingdom where compensation for egg donation is forbidden, as it is in Canada. Secondly, the study by Sauer and Paulson (1992) was chiefly comprised of non-anonymous donors (66%) as is the case in Canada. The authors of this study state that the participants in their study were drawn from an American university egg donor program that “has functioned without the need for solicitation of donors” (p.726), which is, in general, contrary to customary practice in the United States where egg donor programs advertise openly and aggressively for donations which largely seem to be from unmarried, nulliparous women who are still in school (Sauer, 1996). Another reason why the results of these two studies may be applicable to Canada is the fact that donors were not compensated for their donation, which is consistent with current Canadian laws and general practices.

While refraining from making generalizations from the results of the above studies it does, nevertheless, seem possible to draw some conclusions regarding the demographic profile of women who are likely to choose to donate their eggs, without compensation. These women on average seem to be women in their late twenties to early
thirties; married with children of their own; employed; and well educated. Any significant differences among egg donors appear to be as a result of compensation for participation in an egg donor program, as demonstrated by Lindheim et al. (1998). This study reviewed the demographic characteristics of a paid, predominantly anonymous (95%) oocyte donation program in New York at Columbia University. The authors describe donors as being typically students and thus usually single, nulliparous and in their twenties. The researchers in comparing the donors in their registry with donors in the oocyte donation program at the University of Southern California (USC) where donors are commonly non-anonymous, multiparous, married and in their thirties, state that these demographic differences are largely attributable to the practice of direct solicitation in their program. The majority of the women (85%) in their egg donor registry were unmarried and nulliparous. Therefore it appears that whether a donor is anonymous or known may have less bearing on the demographic profile of the donor except when the anonymous donor receives monetary compensation for her donation. In these cases, the motivations for donating, may well be, more financially than altruistically motivated.

Psychological profile. As part of the screening of women as potential anonymous egg donors, a psychological assessment is typically conducted. Such screening is recommended by the Mental Health Specialty Group of the American Society for Reproductive Medicine (Hammer-Burns & Covington, 1999). The recommended guidelines for the screening and counselling of oocyte donors call for a semi-structured comprehensive clinical interview and psychological testing. The clinical interview should be comprised of a psychosocial history for infertility, determination of motivation to
participate (psychological, financial, physical), ability to comprehend and assimilate the information provided, education about treatment for donor and recipient (and respective partners, if applicable), as well as counselling pre-, post, and during treatment on recipient specific issues, information and consents. Psychological testing should include structured personality tests and self-report measures (Hammer-Burns & Covington, 1999).

In the case of known donation it is recommended that a clinical interview be undertaken with the recipient and her husband/partner, with the donor and her husband/partner, and subsequently with the recipients and donor together for discussion, summary, and recommendations. The elements recommended in the known donor interview (and not included in the recommendations for an anonymous donor interview) are as follows: assessment for the presence of coercion (financial or emotional), information from both the donor and recipient regarding their interpersonal relationship, interactions among all three or four parties, dysfunctional family history, plans for future relationships, information regarding intentions of all four parties regarding custody arrangements in the event of the death of the recipients, issues regarding cyropreservation and future disposition of the frozen embryos, prenatal testing and selective reduction, donor’s role and relationship with future child(ren), impact on donor if treatment is unsuccessful, estimation of number of cycles in which donor is willing to participate, and in cases of sister-to-sister donation parents’ role and issues of disclosure or privacy (Hammer-Burns & Covington, 1999). The psychological profile of the egg donor as reported in some of the available literature is reviewed in the next section.

Bartlett (1991) studied the psychological issues associated with non-anonymous egg donation. Sixteen women who had been accepted as donors completed a series of
psychological tests and interviews as part of the donation intake process. These tests included the Perceived Stress Scale, the Hopkins Symptom Checklist 90, as well as a life events checklist. The women on average scored within the “normal” range and did not report any distress during or following their donation. Klock, Braverman, and Rausch (1998) studied anonymous donors who had previously donated their eggs. Twenty-five women were given five tests to complete: the Personality Assessment Inventory, State Trait Anxiety Inventory, Rosenberg Self Esteem Scale, Donor Ambivalence Scale, and the Pennsylvania Reproductive Associates Infertility Scale. The women again generally scored within the normal range. The conclusion of these two studies was that in general, the women selected to donate were psychologically well adjusted.

The importance of a thorough psychological screening of potential egg donors was highlighted in a study by Lindheim et al. (1998). In this study, 166 egg donors completed two sets of interviews for inclusion into an unknown donor registry program. Of the 166 potential donors, 13% were rejected due to psychological factors such as failure to resolve previous sexual abuse, presence of mood and eating disorders, sexual dysfunction and active recreational drug use.

Motivations for donation. According to Cooper and Glazer (1994), the majority of anonymous donors appear to be motivated by empathy. It is not uncommon that a donor will have witnessed the heartache and stress that infertility may have caused to someone she knows. As a result, the desire to help others with a similar problem will be her primary motivating factor. For others, their motivation to donate is to make up for past reproductive losses such as abortions, giving up a child for adoption, or medically indicated hysterectomies. Cooper and Glazer’s findings are contradictory to those
reported by other findings such as those reported by Lindheim et al. (1998) where they state that donors' "initial interest centers on financial remuneration" (p.2023); however, the authors elaborate that "donors also claim that their motives for participation are driven by compassion which enables them to endure better the inconvenience and discomfort of a donor cycle and probably explains why many accept the medical risks" (p.2023).

In the study by Klock et al. (1998), altruism was again reported to be one of the stronger motivators for donation as well as empathy for an infertile friend. Other motivators reported by the 25 women in Klock et al.'s study included increased self-esteem, testing their own infertility, making up for a past reproductive loss, technological interest, and financial compensation.

In Bartlett's (1991) study of 16 non-anonymous donors, 94% of the donors reported that their main motivation to donate was altruism. Other motivating factors for this cohort were: wanting to test their own genetics, alleviation of feelings of infertility, and feeling flattered that they were asked to donate.

Weil, Cornet, Sibony, Mandelbaum, and Salat-Baroux (1994) studied both anonymous and non-anonymous donors. Of the 110 donors interviewed, 48% of the anonymous and 42% of the non-anonymous donors viewed their donation as an act of feminine solidarity: "to help an infertile woman by using their own fertility given by fate or chance" (p.1345).

Contrary to the findings discussed above, in the study by Kalfoglou and Gittelsohn (2000) of both anonymous and non-anonymous donors, the participants did not identify altruism and empathy as being strong motivating factors in their donation
decisions. In this study, financial compensation was identified as the primary motivation for approximately half of the donors (22 anonymous and 7 non-anonymous donors). The other major motivating factor was helping an infertile couple since many of the donors knew someone with fertility problems. Other reported donation motivators for the women in this study included feeling special, interest in the technology, and the desire for genetic continuation without the responsibility for a child.

In a recent study by Orobitg and Salazar (2005) ethnographic interviews were conducted with 25 anonymous donors. These researchers found that donors did not have a single motive that explained their donation. Rather, some women reportedly donated their eggs “to help someone else by giving something that is of no use to them, to compensate for a painful situation in their lives, to avoid the risk of suffering from these same problems at a later stage in their own lives, or because they cannot afford to have any more children themselves” (p.37). Donation was seen by some as an act of rebellion, an assertion of agency, or an act of love towards another woman.

Other motivating factors reported in the literature by egg donors include: curiosity about the procedure (Soderstrom-Anttila, 1995), a desire to test their own fertility (Power et al., 1990), having seen programs on television expressing a need for donors (Fielding et al., 1998), compensation (Rosenberg & Epstein, 1995), compassion for the recipient couple’s struggles in the case of known donation (Winter & Daniluk, 2004), and altruism and empathy for women who are unable to have a child (Ahuja et al., 1997; Baetens, Devroe, Camus, Van Steirteghem & Ponjaert-Kristofferson, 2000).

In summary, in the majority of the studies evaluating the reasons women choose to donate their eggs anonymously or to someone they know, altruism and empathy
emerge as the most common motivators. Known donors who have seen the pain infertility can cause, in particular seem to be motivated by their desire to help a friend or family member. The exception may be in the motivations of young, nulliparous women for whom financial compensation appears to be a significant factor in their decision to become an egg donor.

**Attitudes.** Studies in third party reproduction have sought to investigate the attitudes of donors and recipients involved in this type of assisted reproduction. Issues of ethical and social implication inevitably arise as participants strive to negotiate matters pertaining to disclosure, anonymity, and boundaries. According to the recommendations made by the Mental Health Specialty Group of the American Society for Reproductive Medicine (ASRM) the following donor attitudes warrant exploration prior to the commencement of treatment: decisions regarding disclosure to family members, friends and the child; the nature of future contact between the donor and the child conceived; as well as the relationship between the donor and recipient (Applegarth & Kinsberg, 1999; Hammer-Burns & Covington, 1999). The following four studies address the attitudes of women who chose to donate their eggs.

A quantitative study conducted by Bolton, Golombok, Cook, Bish, and Rust (1991) sought to investigate participants’ attitudes regarding the acceptance of gamete donation, donor anonymity, donor records, and donor contact with the child. The study of 399 participants was comprised of recipients, potential donors, and the general public. It should be noted that 168 of the participants were potential egg donors, which in this case meant that they were IVF patients willing to donate excess eggs. The study endeavoured to compare the attitude of gamete recipients, potential donors, and the general public
toward donor insemination and egg donation. Researchers found that: donors viewed
treatment of infertility more favourably than the general public, but not as favourably as
gamete recipients (as might be predicted); that donors were in favour of donor
anonymity, interestingly more so in the case of sperm donors than egg donors; and that
donors seemed uncertain about whether records containing identifying information about
them should be kept, doubt being especially expressed regarding who should keep such
information.

The researchers found that only 21% of potential egg donors felt that children
conceived of donor gametes should be told of their origins. In terms of donors’ attitudes
towards known donors remaining in contact with the child born from their donation, 80%
of egg donors surveyed were against a donor who is a friend or relative remaining in
contact with the child. The number certainly signifies a real concern and clear
disagreement on the part of the women participating in this study, with the notion of
known donors remaining in contact with children conceived through egg donation.

The findings of the above study must be understood while keeping in mind that
the potential donors were all IVF patients who were themselves seeking treatment for
infertility and were possibly future gamete recipients, depending on the success of their
own treatments. Therefore the attitudes being expressed by these participants more
closely reflect those held by egg donor recipients rather than those of egg donors. Thus it
is important to note that generalizations of the attitudes reflected in this study to donors
who are not infertile women being treated in an attempt to have their own child, would be
inappropriate.
The study conducted by Kirkland et al. (1992) compared the attitudes of donors and recipients toward oocyte donation. The authors found that although these two groups of women broadly shared similar attitudes, they diverged on some issues pertaining to disclosure and anonymity. Sixty questionnaires were sent to recipients, 50 of which were returned, while all 35 questionnaires sent to donors (3 of whom were known donors) were returned. Involvement in the egg donation procedure was not a secretive process for either donors or recipients. Eighty-six percent of donors and 74% of recipients reported telling someone other than their partner about their participation in the donor program. Although both groups of women indicated that they would prefer anonymity, donors' responses indicated that the issue is much less important to them than to recipients. Sixty-three percent of donors indicated that they would donate if their names were revealed while only 23% of recipients said they would accept a donation if it meant their names would be revealed. Furthermore, in response to a hypothetical donation situation where study participants were asked whether they would “donate/accept to/from a known recipient/donor” (p.356), 70% of donors responded that they would, in comparison to only 44% of recipients.

In response to the item on the survey inquiring into participants attitudes in regard to future contact between the donor and the resulting child, 54% of donors stated that they would not object to the child making contact with them when an adult, in contrast to nearly 90% of recipients objecting to the donor contacting the child when the child is an adult. Recipients' feelings regarding the child contacting the donor as an adult in the future were not explored. The authors did not mention any differences between the responses of anonymous donors and (3) known donors, perhaps suggesting that none
were found. Findings from this study highlight the importance of issues of anonymity and
disclosure to the parties involved in egg donation, and the need for clarity surrounding
these issues, if participants are to be ensured a satisfactory experience with the egg
donation process.

The study by Weil et al. (1994) explored the psychological aspects of anonymous
and non-anonymous oocyte donation including assessment of the attitudes of donors and
recipients by means of a questionnaire distributed to 69 non-anonymous donors, and 41
anonymous donors. In regard to the donors’ attitudes towards the oocytes, 75% of donors
reported that they felt that the oocyte represented “nothing if one does not use it” or “an
organ like any other” (p. 1345). Both the known and anonymous donors appeared to view
the donation of their oocytes much like that of donating blood or organs such as the
kidney.

Exploration of participants’ attitudes towards disclosure revealed that 62% of
known donors and 42% of anonymous donors chose to tell their families; 31% of known
donors told their children; and 19% of anonymous and 20% of known donors also told
their friends. Findings from the study demonstrated a very clear boundary definition for
both donors and recipients when it came to the matter of whether to tell the child of his or
her genetic origins, with an overwhelming majority of donors (96-97%) indicating that it
was up to the recipients to make this decision, based on their determination of what was
in their future child’s best interests. Furthermore, specific to known donors, these
researchers found that “the majority of donors considered it natural to continue their
previous relationship with the parents, and therefore to be able to see the child” (p. 1346).
These findings are important as they provide contrary evidence to what has been argued
by some (such as the American Society for Reproductive Medicine - ASRM as a complication inherent in non-anonymous egg donation. The exploration of parental boundary issues and their negotiation by the parties involved is an informative part of the study’s results, and very relevant to my study which also seeks to shed light on this issue, seen as “contentious” by some.

The last study to be reviewed in this section was conducted by Baetens et al. (2000), and reflects the practice of a fertility centre where, in order to avoid long waiting periods, couples in need of donor oocytes search for a donor among family and friends, but still have the choice of either a known donation or an anonymous donation (where there would be an exchange of the donor recruited by the couple with a donor recruited by another couple in order to assure anonymity between donor and recipient). Data was gathered via semi-structured interviews conducted during counselling sessions set up to support recipient couples in making treatment decisions. Issues related to anonymity and disclosure arose during the course of the sessions.

In total 144 subjects participated in the study, of which 103 had elected for known oocyte donation while 41 had opted for anonymous donation. The interviews revealed that 58% of donors felt that there was a clear distinction between the oocyte donated and the child born afterwards. They viewed the woman who carries and gives birth to the child as the mother, and consequently had no desire to take any parental responsibility for the child. However, 39% of donors were not able to make a clear distinction between the oocyte and the child, which caused 6% of donors to opt for anonymous donation as a condition of continuing treatment, while 12.5% of donors stated that they preferred anonymous donation in order to avoid contact with the child. Ambivalence was evident
among 27% of donors when it came to their feeling towards the child born from their donation, with 9% stating that they preferred known donation since they “felt responsible to the child and wished to be sure that the child was well taken care of by the parents” (p.478).

Regarding issues of disclosure, researchers assessing recipients’ attitudes (though there was no mention of donors’ attitudes) found that 32% of recipients were open about their infertility problem, 36% told no one but the donor about the treatment, 16% wished to keep the treatment more or less a secret but told one or two relatives or close friends, while 15% told family and close friends. Concerning the matter of disclosure to the child, while 13% of recipients were unsure about whether they would tell the child, half of the remaining number of participants stated that they would be willing to inform the child while the other half had no intention of doing so.

This study’s findings provide some important information regarding the relationship between recipient couples and donors revealing that intentions to remain in contact depended upon the frequency of contact the recipients and donors had before the donation procedure. In cases where contact before treatment was frequent (65% of cases), all parties involved believed that the same level of contact would continue after treatment. The only qualification provided was that geographical distance was an obstacle in allowing donors who were close relatives or friends to meet as often as they would have chosen to with recipients. The results of this study are quite relevant as the continuation of the same level of contact pre- and post- donation, in the case of known donors, seems to indicate clarity in parental boundaries, one of the factors being addressed in the current study.
In summary, the findings from the above studies seem to suggest that most egg donors feel little need for secrecy, often telling family members and friends about their donations. Only one of the above studies (Weil et al., 1994) assessed the attitude of donors regarding the child’s right to know that he/she was conceived via egg donation, revealing that donors believed that recipients need to decide this matter for themselves. The view expressed by some donors in the study by Kirkland et al. (1992) indicated a preference on the part of donors for not wanting the child to know if he/she had been born of an egg donation procedure, a rather odd finding, leading one to infer that these donors perhaps do not believe in disclosing to the child. The differences found in two of the studies regarding how donors view their eggs and consequently, their role in relation to the resulting child reveal some conflicting findings. While participants in the study by Weil et al. (1994) reported that they felt that donating their eggs was akin to donating blood or an organ such as a kidney, some of the participants in the study conducted by Baetens et al. (2000) indicated that there was no distinction for them between their eggs and the child born from them, suggesting some possible boundary confusion on the part of these respondents. These findings suggest that assessing for these attitudes may be an important part of the pre-donation procedure, and warrant special attention in the post-donation experience of donors, perhaps especially those of known donors.

Findings from the above studies seem to suggest that the level of contact between known donors and the child born from their donation depends on the relationship of the donor with the recipient. In the case of known donors with pre-donation contact with their recipients, it appears that donors may assume they will continue to have a relationship with the recipient and therefore believe that they will see the child in the
future, while not surprisingly there appears to be uncertainty regarding this matter in the case of anonymous donors given that they would not have know the recipient. For known donors however, there is a different significance to the donation of their gametes in the creation of the child given their relationship with the recipient. The issue of how to negotiate their continuing a relationship with the recipients requires clarity as does their role in the life of the child or children born of their donation.

**The Post-Donation Experience**

In this section, some of the current available literature on the overall post-donation experience of egg donors will be reviewed. The body of literature is limited especially as it pertains to non-anonymous donors. As well, the studies have mostly been conducted following the donation and therefore provide information on the short-term outcomes of the women. The long-term outcomes are predicted and hypothesized based on current knowledge of the short-term outcomes. The experiences of donors with the donation process can have a number of consequences. If the overall experience is an adverse one, the donor will likely not want to donate again, and it may have negative consequence on the donor’s relationship with the recipient. Studies in this area are therefore crucial to provide a better understanding of improvements or changes that may need to be made by clinicians and policy makers in the process to ensure more favourable pre- and post-treatment experiences and outcomes for the donors and recipients.

Schover, Collins, Quigley, Blankstein, and Kanoti (1991) evaluated the experience of 45 women participating in an anonymous egg donation program. The women were sent a questionnaire after completing a donation cycle and again 6 months and 12 months after their first donation cycle. The questionnaire asked the donor to rate
her general satisfaction with her experience, to rate the advice she would give to a friend contemplating being a donor, and to state her own willingness to donate for a future cycle. Satisfaction with their experience of the psychologist and the bioethicist with whom they had contact was rated as well. The women ranked the impact of the following factors on their overall experience: helping another woman have a child, donating to make up for personal loss, being paid, being part of a new medical procedure, religious or moral feelings, interactions with clinic staff, husband or partner’s attitude, not knowing the recipient, not knowing whether a pregnancy occurred, and impact on sex life. They were also asked to rank their experience with medical issues such as: having blood tests, taking the hormones, trips to the clinic, the vaginal aspiration, and worry about the medical risks of donation. Women who did go through the initial assessment but did not go through a donation cycle were also sent 6 and 12 month questionnaires that addressed their experience of the donor evaluation process and the outcome. Follow-up data on donor satisfaction was obtained for 23 women. Ninety-one percent were moderately to extremely satisfied with the experience and 74% indicated they would donate for another cycle if given the chance. Only one donor rated herself as moderately dissatisfied at follow-up. Her complaint was that she did not have a chance to go through the vaginal aspiration and complete her cycle because of recipient factors. The medical process of donation was only mildly aversive for most women. Although a few dreaded the shots or blood taking, the most unpleasant experience for most was the vaginal aspiration during egg retrieval. One issue that was identified to be common amongst the donors was the donors’ continual longing to know whether a pregnancy occurred and to have some contact with the recipient couple. This issue would evidently not be present in known
donation as the donor is most likely to have knowledge of the outcome of her donation due to her prior relationship with the recipient.

In the study by Rosenberg and Epstein (1995), the emotional and medical responses of anonymous egg donors to participation in an egg donation procedure was evaluated. Follow-up questionnaires were mailed out to 55 of the 74 women (who could be located) who participated in the program during the study period, 32 of whom responded. Donors reported that the medical procedure caused them significant discomfort. The main side effect reported was bloating during the retrieval process which had resolved by the time of the follow-up. There was also an element of anxiety experienced by the donors associated with the self-administration of the injections. The emotional responses were reported to be mostly positive and the donors reported a willingness to donate again and would recommend egg donation to other women.

In this study the authors explained their attempt to address the issue of donors' longing to known the outcome of their donation in their orientation seminar by making statements that “make it clear that IVF New Jersey has formulated a policy that no information about the outcome of the cycle will be available” (p.2747). The researchers report that “questions about this policy are invariably raised by the women attending the seminar, and several of them choose not to participate knowing that this information will not be available to them” (p.2747). They go on to explain that they inform the potential donors at the seminar that they “can use their imagination to construct the scenario that they find most gratifying for themselves” (p.2747). Despite these researchers efforts, not knowing whether a pregnancy occurred was found to be a negative aspect of participation for some of the donors. It is important to note that despite the program’s efforts to
address this issue prior to donation, it remained a negative aspect of the egg donation experience for these anonymous donors – as commented on above, one not likely to arise for non-anonymous donors.

Soderstrom-Anttila (1995) studied the experiences of unpaid anonymous egg donors. A questionnaire was sent to the first 30 volunteer donors at 12 to 18 months post-donation. Similar to the other above mentioned studies, most of the donors indicated that they were very satisfied with the donation experience. Fifteen percent of the respondents reported subsequent gynaecological problems that were mild and did not appear to be related to the donation. In total, 96% reported that their own feelings were sufficiently taken into consideration during the treatment and 78% said they would donate again. No one reported regretting her donation. Sixty-seven percent reported a desire to know whether a pregnancy had been achieved by the recipient, and 89% reported that they had thought about the possibility of a child from their donation. Again these findings point to possible negative implications that may arise for anonymous donors who are not privy to information regarding the outcome of their donation.

Another study evaluating the post-donation experience of anonymous donors was conducted by Klock et al. (1998). In this study the researchers also looked at the egg donors’ pre-donation and post-donation demographics and any psychological variables that were correlated with post-donation satisfaction. Twenty-five consecutive donors completed satisfaction ratings following completion of the egg donation cycle. Post-donation satisfaction was reported to be high and 80% of the women stated that they would be willing to donate again. Similar to other studies (Schover et al., 1991; Soderstrom-Anttila, 1995) more than half of the donors (68%) wanted to know if a
pregnancy resulted from their donation. Another 28% did not want to know, and 4% did not know if they wanted any feedback regarding a pregnancy. The factors that were found to have a negative correlation with post-donation satisfaction were pre-donation financial motivation and pre-donation ambivalence. These findings highlight the importance of pre-donation counselling in addressing issues of ambivalence for donors, as well as affirming the likelihood of post-donation satisfaction for known donors in the present study for whom financial motivation was not an issue. One factor that had a positive correlation with post-donation satisfaction was pre-donation motivations of “helping another women” (p.235). These results would suggest that the likelihood of post-donation satisfaction would be very high for known donors whose chief motivation, often sole motivation, is to help another woman – a loved one.

Fielding et al. (1998) examined the experience of 39 women of which 7 were known donors donating to sisters and friends. Participants, who had donated between January 1992 and June 1996, were given 2 questionnaires; one assessing the donor’s experience of donation, the other the attitudes and motivations for donation. Comparisons were made to the experiences of 34 anonymous semen donors. Most of the anonymous egg donors felt their donation was a success with 60% reporting a willingness to donate again. Compared to the semen donors, not surprisingly the egg donors tended to be more involved in the process and wanted to know something about the recipients. Similar to the findings of other anonymous egg donation studies, the egg donors wanted to be informed about the outcome of their donation. As noted in the literature reviewed in this chapter, a desire to know the outcome of their donation is a recurring issue in
anonymous egg donation, one which has possible negative consequences for donor’s experience.

Of particular interest in this study is the experience of egg donation for the 7 known donors – one of the first studies to evaluate the post-donation experience of known donors. As might be expected, researchers found evidence that the process had a greater effect on the donors’ relationships with their family members for known donors than for anonymous donors. Three of the seven known donors indicated that donation had influenced their relationships with their partners/families/friends/others. Two of the responses from these donors alluded to a deterioration in their relationship with the recipients following the donation. The authors note that pressure from recipients lead to feelings of obligation in the donor to continue to donate, making this a concern for known donation. However, there is no indication of pre-donation counselling for any of the participants. The authors reported that neither anonymous nor known donors felt a need for counselling; although they mention that pre-donation counselling “may need to be strongly encouraged” (p.286) in these circumstances, or perhaps more aptly, should be a required component of the egg donation process.

Also of interest, and in contrast to previously reviewed literature, is the study’s findings of evidence of greater secrecy in the known donor group. The researchers report that four out of the seven known donors had not told their own children about their donation, and the two donors whose donations resulted in successful live births had told only one member of the family and had no plans to tell their own children. The authors draw attention to the need for further research on the post-donation outcomes of participating in known donation. The aim of the present study was to explore the
experience of women who participated in a non-anonymous egg donation program including longer-term outcomes of their participation.

The study conducted by Kalfoglou et al. (2000) was a qualitative, follow-up study of the experiences of 33 egg donors. Of these women, 22 were anonymous donors, 3 were known donors, and 4 had met the recipients over the internet. Interviews were conducted to determine satisfaction with the process, and the experience of donation itself. Some of the participants had donated multiple times and therefore may have been reporting on donations that may have occurred years ago or on their overall experience of the various donations. In contrast to the other, above-mentioned studies, although none of the donors expressed regret about having donated their eggs, they also did not report complete satisfaction with the process. Based on their findings and with the aim of improving donors' experiences of donation, the authors made the following recommendations: efforts on the part of IVF clinics to make the medical process easier for donors by minimizing the number of trips to the clinic (time spent and the inconvenience of numerous trips were found to be the most burdensome aspect of donating for some donors), a showing of appreciation for the donor's contribution, respect and expression of shared goals, as well as improved medical care (including follow-up care and commitment to conducting follow-up research), and counselling (to be provided separately from psychological screening mostly in regard to allowing the donor the freedom to disclose relevant information without the fear of exclusion from participation). Similar to the other studies, these anonymous donors again stated their desire to have information about the outcome of their donation. These researchers felt that more research needs to be conducted to determine the long-term effects of informing
the donor about the outcome before they could make a recommendation. Studies investigating the long-term effects of participating in egg donation are needed, especially those exploring the experience of known egg donation.

A recent study by Jordan, Belar, and Williams (2004) evaluated the experiences of anonymous donors. A follow-up questionnaire was mailed to 54 identified egg donors asking them about aspects of clinic interactions, medical procedures, and experiences during and after the process as well as their expectations and level of fulfillment. Twenty-four donors out of 54 responded. Overall, 79% were satisfied with their experience, 42% said they would donate again, and 50% stated they would recommend donation to a friend. The medical procedure was generally tolerated well but most of the donors experienced cramping and pain at the injection site. Eighty-three percent of the donors experienced some level of anxiety during the retrieval process. Expectations were fulfilled regarding helping another woman. Most of the donors (87.5%) expressed the desire to know the outcome of their donation — a common issue in the case of anonymous egg donation and yet one which would not be relevant in the case of known donations.

In a qualitative, narrative study conducted by Winter and Daniluk (2004), three known donors whose donations had resulted in the birth of a child for their sisters participated in an in-depth interview to assess their donation motivations and decisions, the challenges of the donation procedure, and their post-donation experiences. Overall, the participants reported positive post-donation experiences. Contrary to Fielding et al.'s (1998) study, these women reported a deepening of their relationship with the recipient. They reported experiencing anxiety awaiting the confirmation of a pregnancy. The
donors found that they were able to maintain clear boundaries between their role of aunt and that of the recipient parents after the child was born.

Apart from the exception of the study by Winter and Daniluk (2004), there is to date an undeniable lack of empirical studies examining the post-donation outcomes for participation in known egg donation; therefore, little is known about the post-donation experiences of this group of egg donors. Efforts by researchers to address the experience of egg donation by known donors have been made in the form of general comments or by reporting their knowledge anecdotally.

Cooper and Glazer (1994) provide an example of such reports in their writing about the clinical experience of the post-donation issues likely to be faced by known egg donors. They mention the possibility of known donors experiencing feelings of letdown after pregnancy occurs, attributing this to the fact that they are no longer an integral part of the reproduction process. According to the authors some of the other issues with which known donors may need to deal are: donor’s concern over passing on “good genes,” determining/clarifying their obligations toward the child and parents, and the necessity of being able to relinquish the importance of the genetic tie as secondary to the importance of gestational/social parenting.

Saunders and Garner (1996) also provide a report on their clinical experiences with known donation. Theirs is based on two case studies of known egg donation, out of the 20 cases performed at their clinic. They describe unresolved and ongoing problems for the donors as a result of their donations. In the first case the known donor perceived a lack of recognition by her recipient sister after a successful pregnancy, and insisted the couple discard embryos formed with her eggs. The second case involved feelings of
anger on the part of the donor’s husband after the recipient allegedly denied that donation occurred. These authors had hoped that known egg donation might be a way to augment anonymous sources. They express caution regarding this option, commenting that if the known donor option is pursued, then one must ensure that adequate counselling and long-term follow-up are provided. The present study aims to provide long-term follow-up of the experiences of known egg donors so that it may inform those involved or planning on being involved in known egg donation procedures.

Some researchers, whose studies have been previously reviewed in this chapter, have also made general comments regarding the possibility that participation in known egg donation may impact the donor-recipient relationship negatively. Baetens et al. (2000) mention the possibility that known donation may cause the recipient to harbour negative feelings of indebtedness to the donor and possibly make it difficult for the recipients to construct their own parental status. In discussing the matter of disclosure, these authors express that openness in known donation situations “might upset ongoing relationships in recipient and donor families” (p.482). Fear of openness in known donation was also reported in the study by Bertrand-Servais, Letur-Konirsch, Raoul-Duval, and Frydman (1991). These authors believe that even if recipients plan on telling their children the means by which they were conceived, they would prefer to have an anonymous donor in order to avoid “the fantasy of child claims by the donor” (p.877), further alleging that “anonymity also protects against the fantasy of the husband’s adultery” (p.877). Concerns regarding “complications” that may arise in known donation by some researchers are clearly evident.
However, these fears are not expressed by all researchers. Sauer and Paulson (1992), in commenting upon their clinical experiences with known donation, state that they have yet to witness any difficulties in the relationships between donors and the children produced by their donation. These authors believe that the donors in their program have achieved “a desirable level of emotional detachment from the resulting offspring” (p.728) as they have not seen any evidence of possessiveness, loss or grief. Naturally, they comment on the necessity of longer-term follow-up in order to determine the nature of these relationships over time. As well, Weil et al. (1994) do not mention any negative outcomes from the non-anonymous (or anonymous) donations in their program, and state that “no significant differences in behaviour were noted in the recipients of the two systems of donation, when interviews and consultations with the patients and follow-ups of the children born from donation were completed” (p.1346) (follow-ups of the children were conducted until the age of 3). In fact these researchers advocate that clinics offer donors and recipients a choice of donation method for it creates a degree of freedom. They state that “professionals must not judge or oppose their patient’s demands but must listen, help them to listen to themselves, and accommodate their wishes as far as possible” (p.1347).

Summary

The studies discussed and reviewed in this chapter highlight a number of important issues. In the case of both anonymous and non-anonymous donation, it appears that donors generally feel satisfied with the donation process and experience a sense of accomplishment (Jordan et al., 2004; Winter & Daniluk, 2004; Klock et al., 1998; Fielding et al., 1998; Soderstrom-Anttila, 1995; Rosenberg & Epstein, 1995; Schover et
al., 1991). The medical adverse effects were reported to be relatively few and when present, mild in nature and short-lived. In the majority of the studies (Rosenberg & Epstein, 1995; Soderstrom-Anttila, 1995; Schover et al., 1991; Klock et al., 1998; Jordan et al., 2004), the donors stated that they would choose to donate again and would recommend egg donation to their friends. The main negative feeling that was identified (Schover et al, 1991; Jordan et al, 2004; Fielding et al, 1998; Klock et al, 1998) was the desire of the anonymous donors to know about the outcome of their donation.

Possible concerns pertaining to the experience of known donors raised by some researchers (Fielding et al., 1998; Saunders & Garner, 1996; Ahuja et al., 1997; Cooper & Glazer, 1994; Baetens et al., 2000; Bertrand-Servais et al., 1991) included the possible deterioration of the relationship of the donor and the recipient, overwhelming feelings of obligation on the part of the donor to donate as a result of pressure from the recipient, as well as negotiating the issue of secrecy between the donor and her own children or partner about the donation process. However, these issues were not found to be of any concern by other researchers (Winter & Daniluk, 2004; Weil et al., 1994; Sauer & Paulson, 1992).

There is a wide range of varying opinions and experiences regarding known egg donation, signalling a need for empirical studies investigating the post-donation experiences of known egg donors. It is clear that a large gap exists in the literature regarding the post-donation implications and outcomes of participating in known egg donation. This information is not merely pertinent to policy makers contemplating implementation of legislation, but also of great importance to future known donation participants as well as professionals, including counsellors, involved in the provision of
third party reproduction. Inherent in non-anonymous egg donation is the potential for more complicated relationships between donors and recipients. Are concerns expressed by some researchers regarding known egg donation real or are they unjustified? Are donors and recipients able to negotiate these ongoing relationships?

The intention of the present study was to explore the ongoing donor-recipient relationship in the hopes of shedding some light on this largely unknown aspect of the egg donation process: the actual post-donation experience and the outcomes related to non-anonymous egg donation. In the current study, a questionnaire was utilized to gather information on the known donor's relationship with/to the recipient, if and how this relationship has altered or been affected; the outcome of the treatment cycle and/or any possible bearings on the donor's subsequent experience; factors important in donor's decisions to participate in egg donation; as well as her experience in treatment. It was hoped that the information gathered for this study will begin the process of addressing some of the gaps in our knowledge of the post-donation experience and outcomes of known egg donation.
CHAPTER THREE

Methodology

Design

This quantitative study was designed to explore the decision-making process of women who have elected to donate their eggs to a family member, friend, or acquaintance, and their subsequent experience of the donation process. As noted in the previous chapters, although there are a few studies evaluating the experience of egg donors, the majority of the research has been conducted with anonymous donors. This exploratory, descriptive study is one of the first on known egg donors. As such, there is no extant literature upon which to base hypotheses. The main purpose of the study was to attain an initial understanding of the important factors pertaining to the experiences of known egg donors in order to help direct future studies.

A quantitative approach was chosen as the appropriate research method when the intent of a study is to utilize a set of instrument based-questions on a group of individuals to generate hypotheses that may apply to the larger population and which can then be further tested by a properly designed experiment (Palys, 1997). Creswell (2003) describes the quantitative approach as “a research method in which the investigator primarily uses post positivist claims for developing knowledge, employs strategies of inquiry such as experiments and surveys, and collects data on predetermined instruments that yield statistical data” (p.7). The post positivist position sometimes called the “scientific method” refers to the thinking after positivism, challenging the traditional notion of the absolute truth of knowledge and recognizing that we cannot be “positive” about our claims of knowledge when studying the behaviour and actions of humans (Phillips &
Barbules, 2000, cited in Creswell, 2003). The post positivist method is based on careful observation and measurement of objective reality; therefore, the development of numeric measures of observations and studying the behaviour of individuals are of utmost importance. In this method, the researcher begins with a theory, collects data that either supports or refutes the theory and then makes necessary revisions before additional tests are conducted. However, prior to formulating a theory an exploratory phase is required to provide information to direct and aid in generating theory. This study therefore endeavoured to provide preliminary data on the decision-making process and experiences of women who have chosen to be egg donors for a family member, friend, or acquaintance. It was hoped that perhaps further similar exploratory studies will contribute to the eventual formulation of a theory regarding the needs, motivations, and experiences of known egg donors.

The method of inquiry that can be utilized to collect quantitative data may be either in the form of a survey or a designed experiment (Creswell, 2003). In this study, a survey design in the form of a self-administered questionnaire was chosen to evaluate the responses of a group of individuals in order to help identify possible themes that may pertain to the larger population. A survey design was appropriate since it includes either cross-sectional or longitudinal studies using questionnaires or structured interviews for data collection with the intent of generalizing from a sample to a population (Babbie, 1990). The present study employed a cross-sectional design. The questionnaire was researcher-generated and was used to collect data to attain an initial understanding in this exploratory study.
Participants

Participants were comprised of a self-selected sample of women who donated their eggs either to a friend, a family member, or an acquaintance. The study sample consisted of women who had participated as oocyte donors at Genesis Fertility Centre since the program's inception in 1999. The participants were accessed by staff at the fertility centre who mailed out questionnaire packages in order to ensure patient anonymity. The packages were assembled by the researcher and included the questionnaire (see Appendix A), a letter of introduction explaining the aim of the study (see Appendix B), as well as an addressed and stamped return envelope. More information regarding the participants and response rates is provided in Chapters Four and Five.

Procedure

Upon receiving approval of the research protocol from the Behavioural Research Ethics Board at UBC, staff from Genesis mailed out a questionnaire package, to women who participated in the egg donation program at Genesis from its inception in 1999. The questionnaire package included the questionnaire, an introductory letter and a stamped and addressed return envelope. The introductory letter explained the purpose of the study, introduced the researchers involved and indicated that the questionnaire would take approximately 10-15 minutes to complete. It explicitly stated that participation is entirely voluntary and that by completing the questionnaire and returning it, she would be consenting to the study. If they decided to participate in the study, questionnaire recipients were instructed not to put their names anywhere on the questionnaire. If they had chosen not to participate, they were requested to simply destroy the questionnaire.
The researchers' contact numbers and the number to the UBC research subject information line were also provided in the letter in the event that the participants may have had any additional questions about the study. The researcher allotted a period of three weeks for the questionnaires to be completed and returned. It was hoped that at least 50% of the women contacted would choose to participate and complete the questionnaire within the specified time frame. Questionnaires received after the specified period but in time for data analysis were be included. Once completed and returned, the questionnaires were stored in a locked filing cabinet.

**Instrumentation**

The instrument that was used to gather data was a researcher-generated questionnaire. The items on the questionnaire were divided into three parts. Part one, entitled *General Information*, was comprised of twelve questions, including three open-ended ones, and sought to gather the following information: how the subject of being an egg donor first arose; the nature of the donor's relationship to/with the recipient; length of time passed since completion of treatment; whether a viable pregnancy resulted from the cycle, and if yes, whether it was a multiple pregnancy and whether the baby (or babies) was born healthy; whether there are frozen embryos still available for use by the recipients; whether the donor still maintains contact with the recipients, and if yes, how often; whether the donor's relationship with the recipients has changed since she participated in treatment, and if yes, to briefly describe how and why; whether she would consider being an egg donor for this couple again or for someone else in the future; in retrospect would she make the same choice to be an egg donor, and if no, why not; whether there was any difference between the *expectation* and the actual experience of
being an egg donor, and if different, in what way; and lastly, overall, how would she rate her experience of being an egg donor (very positive, positive, negative, very negative).

The second part of the questionnaire entitled, Making the Decision, asked participants to rank how important each of the listed factors were to the donor in her decision to become an egg donor on a 5-point Likert scale: not important (1), not very important (2), somewhat important (3), fairly important (4), very important (5). The items in part two of the questionnaire were categorized into five sections focusing on various areas pertaining to the decision making process: a) the relationship of the donor to the recipient, b) the personal factors in the donor’s decision, c) the family factors in the donor’s decision, d) the importance of broader social issues in her decision, and e) the consequences to the child(ren) produced if treatment was successful.

The section pertaining to the donor’s relationship with the recipients asked participants to rank how important the following factors were in their decision to become an egg donor: the closeness of their relationship with the recipients; their expectation that being a donor would strengthen their relationship; their belief that the relationship would not be damaged if the participant refused; their belief that the recipients would be good parents and would be respectful of the participant’s needs, rights, and boundaries; and the participant’s agreement with recipients’ feelings regarding disclosure to the child and privacy issues with others. The section dealing with the importance of certain personal factors in the donor’s decision to become an egg donor included the following: the donor’s expectations that her health would not be affected, her belief in her abilities to set appropriate boundaries, her expectations that she could cope with the treatment (medications, procedures, etc.), her confidence in her ability to deal effectively with the
consequences, her personal beliefs that this was the "right" thing to do, and her expectations that her family members would be accepting of her decision.

The next part asked participants to rank the importance of the following family factors in their decision to become an egg donor: her partner's support for her decision to be an egg donor, her belief that her children would not be affected if she became a donor, her confidence in her family's ability to cope with the treatment process, and her confidence in her family's ability to handle the long term consequences. Under the category of questions referring to the importance of broader social issues in her decision to become an egg donor, the donor was asked to rank the importance of: her belief that egg donation is a socially acceptable reproductive option, her belief that egg donation is a morally appropriate way to create a family, and her belief that egg donation is an ethical form of treatment for infertility. The section pertaining to the consequences to the child(ren) produced if treatment was successful asked participants to rank the importance of the following factors in the decision to become an egg donor: her belief that the child(ren) would be fully accepted by the recipients, her belief that the child(ren) would be fully accepted by the recipients' families, her expectation that the child(ren) would be born healthy, her expectations that she would develop a healthy relationship with the child(ren), her ability to set appropriate boundaries in her relationship with the child(ren), and her expectation that the child(ren)'s psychological health would not be affected.

The donor was then asked to rank the above mentioned sections (i.e., donor's relationship with the recipients, personal consequences, consequences for her family, broader social issues, and consequences for the child(ren) in terms of their overall importance in her decision to become an egg donor using the same five-point Likert
scale. Following this there was a space made available for any additional comments the participant might like to make, as well as a question asking participants which people in her life were most influential in her decision to become an egg donor.

The third part of the questionnaire focused on the donor’s experience in the treatment process. It was divided into four sections: a) the egg donor preparation and orientation, b) the egg donor treatment, c) the support the donor felt she received from the fertility clinic staff and the d) overall experience of being an egg donor. In the section on the egg donor preparation and orientation, the donor was asked to rate how helpful (very helpful, helpful, not very helpful) she found the session with the various program team members such as the counsellor, the nurse, the doctor, and finally the overall preparation. This was followed by an open-ended question asking participants: What other information or services would have been helpful to you prior to beginning treatment? In the section on the egg donor treatment, the donor rated how difficult or easy (very easy, easy, difficult, very difficult) she found the drug monitoring, the pain management, and the egg retrieval. They were also asked to comment on what would have made the treatment process easier for them to cope with. In the third section, the donor was asked how supportive (very supportive, supportive, not very supportive) she found the various staff member of the fertility clinic to be, such as the front desk staff, the counsellor, the nursing staff, and the physicians. The last section asked the donor to indicate her perception regarding the overall experience of being an egg donor (very positive, positive, negative, very negative).
Data Analysis

After receiving the completed questionnaires they were coded for the purposes of data entry. As this study was exploratory and descriptive in nature, it follows that descriptive statistics were utilized in order to provide a summary of the findings of the questionnaire. This was done through the depiction of the distributions of each of the various items investigated in the donor questionnaire. A summary of these findings was represented by means of frequency tables and/or graphs for each of the variables studied. Measures of central tendency and variability found in each distribution were reported wherever they were deemed to be applicable and appropriate.

Limitations

The limitations of our study include the small sample size and the difficulty that presents in making generalizations. However, most other studies in this area have had similar numbers. A sample size of 20 to 30 egg donors, although modest, would be acceptable for such an exploratory study which aimed to attain an initial understanding of known egg donors’ experiences. Selection bias was one of the limitations of this study, where participants’ self-selection may have included either a positive or a negative slant with respect to the participant’s experience of egg donation. Another limitation was the fact that 50% of the participants had completed the egg donation program approximately 52 weeks prior to participating in the study which may introduce some recollection bias. However, this also provided an opportunity to observe the ongoing, post-donation donor-recipient relationship on a longer-term basis.
CHAPTER FOUR

Results

This quantitative exploratory study was conducted in two phases; phase one included women who participated in the egg donation program between 1999 to 2001, phase two included women who had participated between 2003 to 2005. The same investigator-generated questionnaire was used for both periods of the study. During phase one, 22 women were identified and questionnaires sent to them. Out of the 22 questionnaires mailed, 5 were returned unopened due to the addressee having moved without a forwarding address available. From the remaining 17, 11 were completed and returned, 6 were not returned. During phase two of the study, potential participants had to be contacted via the telephone and asked whether they were willing to receive a questionnaire with the understanding that they were under no obligation to complete and return the questionnaire. By indicating their willingness to receive it; verification of current address was also confirmed at this time. Thirty-three women were identified in this phase of the study. We were able to establish telephone contact with 12 of the women, all of whom indicated their willingness to receive a questionnaire. Out of the 12 questionnaires mailed out, 9 were completed and returned, 3 were not returned. A total number of 20 women (phase one and two combined) participated in this study. Fifty percent of donors completed the treatment cycle 52 weeks prior to the completion of the questionnaire. The rest of the participants completed the treatment cycle between 28.5 and 91 weeks. The most recent treatment cycle was completed 2 weeks prior to completion of the questionnaire. The longest completion time was 156 weeks prior to completion of the questionnaire (2.5 years).
The results of the three parts of the questionnaires, General Information, Making the Decision, and Experience in Treatment are presented in the same three part division below.

Part One: General Information

This section of the questionnaire addressed information pertaining to: the donor's relationship with/to the recipients, how the subject of being an egg donor first came up, information regarding the treatment cycle, and the experience of egg donation for the donor.

As illustrated in Figure 1.1 most of the donor's donated to family members (70%), while the remaining 30% were equally distributed between the category of close friend (15%), and acquaintance (15%). Of the donors that donated to family members, 9 out of 14 donated to their sisters, 3 to their sister-in-law (2 donors specified as follows: brother-in-
law’s wife, and husband’s sister), 1 to a cousin, and 1 to her same-sex partner. Among the participants that donated to a close friend, 2 indicated being a close friend of the woman; 1 indicated being a close friend of both the man and the woman. Among the 3 participants who donated to an acquaintance, all indicated that they are acquaintances of the woman.

**Table 1.1: Summary results for Q1 for Part 1**

<table>
<thead>
<tr>
<th>Q. How did the subject of being an egg donor first come up?*</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I raised the issue with the recipient(s)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>The recipients raised the issue with me</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>A family member raised the issue with me</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>A friend of the recipients raised the issue with me</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

*a subject could select multiple answers*

Table 1.1 demonstrates the break down of how participants responded to the question of how the subject of being an egg donor first came up. Forty percent of participants indicated that they raised the issue with the recipient(s). An equal number of women (40%) stated that the recipients raised the issue with them. One participant selected both of the above categories. A family member raised the issue with three of the participants. Two participants selected the “Other” category; one indicating that a physician raised the issue with them as a couple; the other stated that “A casual conversation with the recipients, which evolved into a more serious undertaking after understanding why the recipients could not conceive naturally.”

For the women who completed the program, the treatment cycles were successful (i.e., a viable pregnancy resulted) in 75% of cases (Table 1.2). One of the participants did not answer whether the cycle was successful, but wrote down that the second attempt was underway. Among the 15 donors that indicated that the cycle was successful, in 4 of the cases the pregnancies resulted in multiple pregnancies (i.e., twins). Ten of the 15 donors
reported that the baby (or babies) was born healthy, 3 indicated that they did not know, and 2 indicated that the recipients are still going through their pregnancy. Frozen embryos were still available for use by the recipients in 60% of cases (Table 1.2).

**Table 1.2: Summary results for Q4 and Q5 in Part 1**

<table>
<thead>
<tr>
<th>Q4. Was the cycle successful (did a viable pregnancy result?)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15 (75%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (20%)</td>
</tr>
<tr>
<td>Not answered</td>
<td>1 (5%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q5. Are there frozen embryos still available for use by the recipients?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>1 (5%)</td>
</tr>
</tbody>
</table>

All of the donors still maintained contact with the recipients (Table 1.3) with the following breakdown: 35% “daily”; 35% “weekly”; 1 participant indicated “daily/weekly”; 1 participant selected “bi-monthly”; while the remaining 20% maintained contact on a “monthly” basis. Sixty percent of donors indicated that their relationship with the recipients had not changed since they participated in treatment (Table 1.3).

**Table 1.3: Summary results for Q6 and Q7 in Part 1**

<table>
<thead>
<tr>
<th>Q6. Do you still maintain contact with the recipients?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20 (100%)</td>
</tr>
<tr>
<td>No</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q7. Has your relationship with the recipients changed since you participated in treatment?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>No</td>
<td>12 (60%)</td>
</tr>
</tbody>
</table>

Eight of the donors indicated that their relationships had changed with the recipients since they participated in treatment. Seven of these 8 donors describe their relationships as closer and strengthened:
“We share a wonderful bond, we were close before the treatment but sharing such an experience has strengthened our relationship.”(Donor no. 1)

“Brought us closer.”(Donor no.4)

“Our relationship has strengthened.”(Donor no. 12)

“We seem to be closer, they respect me, because if it wasn’t for me they wouldn’t have a family.”(Donor no. 15)

“There was always a special bond between me and my sister, it is now even more special. My brother-in-law and my new little niece are also extra special members of my family. The experience has enriched our lives.”(Donor no. 16)

“Have become closer.”(Donor no. 18)

One donor appears to have experienced a distancing in her relationship with the recipient after donation commenting: “Lives change when you have children. People go their own ways.”(Donor no. 5)

In response to the question querying the donor’s willingness to consider being an egg donor for this couple again, 60% of donors responded “yes” (Table 1.4). Conversely, when the participants were asked whether they would consider being an egg donor for someone else in the future 55% responded “no”; 35% responded “yes”; and the remainder were undecided. None of the donors that had donated to their sisters responded that they would consider donating to someone else in the future. Of the women who indicated their willingness to consider donating to someone else in the future, 2 had donated to their sister-in-laws, 1 was a cousin of the woman, 3 were acquaintances of the woman, and 1 was a close friend of the woman.
Table 1.4: Summary of results for Q8 to Q12 in Part 1

<table>
<thead>
<tr>
<th>Q8. Would you consider being an egg donor for this couple again?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>No</td>
<td>8 (40%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q9. Would you consider being an egg donor for someone else in the future?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>No</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q10. Looking back over your experience of being an egg donor, if you had the chance to reconsider your decision, would you make the same choice to be a donor?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q11. How different was your experience of being an egg donor, than what you had initially expected when you offered?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Different</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>Somewhat Different</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Very Different</td>
<td>3 (15%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q12. Overall, how would you rate your experience of being an egg donor?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Positive</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Positive</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Negative</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Very Negative</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Positive and Negative</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

When asked if they had the chance to reconsider their decision, whether they would make the same choice to be a donor, 90% of the women responded “yes,” 10% (2) responded “no” (Table 1.4). The reasons stated by the 2 donors that responded that they would not make the same decision to donate were expressed in the following manner: “I experienced a lot of sadness due to the side effects of the chemical dosages. This strained a lot on my relationship.” The other participant’s sentiments were thus expressed: “After trying to be a donor, I found it difficult to get my cycle and body back to normal. Plus as I get older I’m worried about future complications.”
In response to the question regarding how different participants experiences of being an egg donor was than what they had expected, 35% of participants indicated that it was “not different,” 50% said that it was “somewhat different,” and 15% found that it was “very different” (Table 1.4). For the participants that found the experience of being an egg donor “somewhat different,” 2 of the participants found the experience much easier and more positive than they thought it would be. From the 8 other participants that found the experience “somewhat different” than they expected, 2 did not elaborate on their experience, while the rest of the donor’s responses reflected more difficulty or discomfort with the medications and the subsequent side effects than expected. These donors cited reasons such as: “Took longer than expected”; “More physical discomfort than I expected”; “I felt more on edge than I expected to be”; “I didn’t realize how many times during treatment that something could go wrong and we wouldn’t be able to proceed. It was a little stressful for me because I wanted it to work so badly”; and “There were a few more needles and procedures!” One of the donors who found the experience to be “somewhat different” also expressed dissatisfaction with her experience at the clinic: “The recovery from the procedure was more difficult than I had expected. There was no follow up by the medical staff at Genesis – which shocked me.”

Three participants indicated that their experience of being an egg donor was “very different” than what they had initially expected. For one of these women, who had donated to her sister, the subsequent discrepancy between expectation and actual experience was a positive one. She expressed it in the following manner: “Different only in the way I reacted once the children were born. Concerned about the after effects, would I be looking into a mirror (my image in the children). I accepted them as just an
egg donor and not mine.” For the other two donors whose reported their experience of egg donation as being “very different” than what they expected, it seems to have been the severe side effects of taking the medications that affected them quite adversely. One of the donors wrote: “I didn’t think my body would experience such change. Moods, sadness, cramping (extreme). Lethargic and weight gain;” the other one wrote: “I was not fully prepared for the emotional upheaval (mood swings) that I experienced while on the fertility drugs. I also experienced difficulty with my body not responding “normally” to the drugs” referring to her experience of the process of harvesting the eggs taking a lot longer for her.

With regard to how they would rate their overall experience of being an egg donor (Table 1.4) 90% of the donors rated their overall experience as either “very positive” or “positive” (60% “very positive,” 30% “positive”). None of the donors rated their experience of being an egg donor as “negative” or “very negative.” Two of the participants selected both “positive” and “negative” for their response. One of these 2 participants did not write any additional comments but had previously expressed that it had been difficult for her to get her cycle back after being on the fertility medication. The other of these two participants who had experienced adverse reactions to the medication wrote: “negative because it took so long but positive because my sister has a beautiful baby.”

An investigation of associations was made between: success of treatment cycle and change in donor-recipient relationship, future considerations regarding egg donation, and experience of egg donation; discrepancy between donor’s actual and initial expectation of egg donation and future considerations regarding egg donation; and lastly,
donor's overall experience of egg donation and future considerations of egg donation.

Table 1.5 demonstrates associations between the success of their treatment cycle and change in donor-recipient relationship, consideration of donating to this couple again, consideration of donating to someone else in the future, reconsideration of decision to donate, and overall experience of egg donation.

Table 1.5: Association between success of cycle and donor experience

<table>
<thead>
<tr>
<th>Was Cycle Successful?</th>
<th>Yes (n=15)</th>
<th>No (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with recipients has changed</td>
<td>7 (46.7%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Would consider to be an egg donor for the couple again</td>
<td>10 (66.7%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Would consider to be an egg donor for other people in the future</td>
<td>6 (40%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>Would make the same decision of donating egg</td>
<td>14 (93.3%)</td>
<td>3 (75%)</td>
</tr>
<tr>
<td>Positive/Very Positive experience as egg donor</td>
<td>14 (93.3%)*</td>
<td>3 (75%)**</td>
</tr>
</tbody>
</table>

* 1 subject answered “positive because baby is beautiful, but negative because the length of process was too long”
** 1 subject answered “positive and/or negative”

Close to 50% of donors whose donations had resulted in a viable pregnancy (i.e., a successful treatment cycle) indicated that their relationship with the recipients had changed. For all except one participant the change was positive in nature, it strengthened their relationship/brought them closer; however, one donor (donor no.5) seems to have experienced a distancing in her relationship with the recipients remarking: “Lives change when you have children. People go their own ways.” Only one out of four participants whose donation did not result in a successful pregnancy indicated a change in her relationship with the recipients – one that was positive, stating that their relationship had
strengthened. Two-thirds of the donors with successful cycles responded that they would consider donating to this couple again, while only 40% would consider donating to someone else in the future (this is likely to be reflective of the nature of known donation); 25% of donors with unsuccessful cycles responded in the affirmative to both of the aforementioned questions. The majority of participants, regardless of whether the cycle was successful or not, answered that given the chance to reconsider they would make the same decision of being an egg donor; and rated their overall experience of being an egg donor as “positive/very positive.”

Table 1.6 illustrates the difference between donor’s actual experience of egg donation and their initial expectation of egg donation in relation to consideration of donating to this couple again, consideration of donating to someone else in the future, and reconsideration of decision to donate.

<table>
<thead>
<tr>
<th>Difference between actual experience and initial expectation as an egg donor</th>
<th>Not Different (n=7)</th>
<th>Somewhat Different (n=10)</th>
<th>Different (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would consider to be an egg donor for the couple again</td>
<td>5 (71.4%)</td>
<td>6 (60%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Would consider to be an egg donor for other people in the future</td>
<td>4 (57.1%)</td>
<td>3 (30%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Would make the same decision of donating egg</td>
<td>7 (100%)</td>
<td>9 (90%)</td>
<td>2 (66.7%)</td>
</tr>
</tbody>
</table>

This table seems to suggest that if the actual experience of being an egg donor did not differ much from the initial expectation then participants would be more likely to respond affirmatively to the above 3 categories.
Table 1.7 outlines the association between the participant’s overall experience of being an egg donor and consideration of donating to this couple again, consideration of donating to someone else in the future, and reconsideration of decision to donate.

**Table 1.7: Association between overall experience of being an egg donor and future decisions on egg donation**

<table>
<thead>
<tr>
<th>Overall experience of being an egg donor</th>
<th>Overall experience of being an egg donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Positive (n=12)</td>
<td>Positive (n=6)</td>
</tr>
<tr>
<td>Would consider being an egg donor for the couple again</td>
<td>Would make the same decision of donating egg</td>
</tr>
<tr>
<td>10 (83.3%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td>Positive (n=6)</td>
<td>Positive (n=6)</td>
</tr>
<tr>
<td>Would consider being an egg donor for other people in the future</td>
<td>Would make the same decision of donating egg</td>
</tr>
<tr>
<td>2 (33.3%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>Positive/Negative (n=2)</td>
<td>Positive/Negative (n=2)</td>
</tr>
<tr>
<td>Would consider being an egg donor for the couple again</td>
<td>Would make the same decision of donating egg</td>
</tr>
<tr>
<td>0 (0%)</td>
<td>1 (50%)</td>
</tr>
</tbody>
</table>

Eighty-three percent of participants who had a “very positive” overall experience of being an egg donor indicated they would consider being an egg donor for the couple again; half said they would consider being an egg donor for other people in the future; and all of them responded that they would make the same decision to donate given the chance to reconsider their decision. For the six participants who rated their overall experience of egg donation as “positive,” the breakdown of the above categories was approximately 33%, 16%, and 83% respectively. Two donors fell into the “positive/negative” category in overall experience of egg donation: one of them indicating “positive and negative,” the other “positive and/or negative.” Neither of these two donors would consider donating to the couple again nor to someone else in the future although one of them indicated that she would make the same decision to donate given the chance to reconsider.
Part Two: Making the Decision

Part 2 of the questionnaire focused on the importance of various factors involved in the respondents’ decision to become egg donors. These factors are grouped into 5 categories: the donor’s relationship with the recipients, the personal factors in her decision, the family factors in her decision, the importance of broader social issues in her decision, and the consequences to the child(ren) produced if treatment was successful. Donors were also asked to rank the above 5 factors in terms of their overall importance in their decision.

As illustrated in Figure 2.1, the donor’s relationship with the recipient was ranked by donors as being either “very important” or “fairly important.”

Figure 2.1: Distribution of the degree of importance in the egg donation decision with regards to relationship with recipients, personal consequences, consequences for family, broader social issues, and consequences for the child(ren).

As well as the donor’s relationship with the recipient, the other factors that were ranked as important were, in order of importance: consequences to the child(ren) produced if
treatment was successful, consequences for the donor's family (her partner and her children), and personal consequences. Social issues were not ranked as very important in donors' decision making.

**Relationship with the Recipients.** As indicated in Table 2.1, the closeness of the donor's relationship with the recipients was reported as being a "very important" factor in donors' decision making for 75% of donors; it was "fairly important" for 15% of donors, and somewhat important for the remaining 10%.

**Table 2.1: Summary results for "Relationship with the Recipients"**

<table>
<thead>
<tr>
<th>The closeness of your relationship with the recipients</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
<td>15 (75%)</td>
</tr>
<tr>
<td>Your expectations that being a donor would strengthen your relationship</td>
<td>8 (40%)</td>
<td>3 (15%)</td>
<td>4 (20%)</td>
<td>0 (0%)</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>Your belief that the recipients would be good parents</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>19 (95%)</td>
</tr>
<tr>
<td>Your expectations that they would be respectful of your needs and rights</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
<td>4 (20%)</td>
<td>1 (5%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Your belief that your relationship would not be damaged if you refused</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
<td>1 (5%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Your expectations that the recipients would respect your boundaries</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>5 (25%)</td>
<td>2 (10%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Your agreement with their feelings regarding disclosure to the child</td>
<td>1 (5%)</td>
<td>2 (10%)</td>
<td>5 (25%)</td>
<td>2 (10%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Your agreement with their feeling regarding privacy issues with others</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>3 (15%)</td>
<td>2 (10%)</td>
<td>10 (50%)</td>
</tr>
</tbody>
</table>

1=Not Important  2=Not Very Important  3=Somewhat Important  4=Fairly Important  5=Very Important

Note: 1 subject answered "Not Applicable"

2 1 subject answered "Not Applicable," 1 subject did not answer

3 1 subject answered "Not Applicable," 3 subjects did not answer
A donor's expectations that being a donor would strengthen her relationship with the recipients was ranked as "not important"/"not very important" for more than half of the women (40% "not important," 15% "not very important"); 20% of the women indicated it was "somewhat important;" while 25% said it was a "very important" factor in their decision to become an egg donor.

All of the participants that answered the item pertaining to their belief that the recipients would be good parents, expressed this as being a "very important" factor in their decision to donate (1 did not answer). Sixty percent of participants said it was "very important" for them that the recipients be respectful of their needs and rights; 20% said it was "somewhat important." More than half of donors (55%) indicated that their belief that their relationship with the recipient would not be damaged if they refused to donate their eggs, was a "very important" factor for them in making their decision to become an egg donor. Participants' responses to issues pertaining to the donor's expectations that the recipients would be respectful of their boundaries and the donor's agreement regarding disclosure to the child(ren) were quite similar with 55% indicating this factor as being either "very important" or "fairly important," and 25% finding it as being "somewhat important" in their decision-making process. Sixty percent of participants indicated that it was either "very important" or "fairly important" that the recipients agreed with their feelings regarding privacy issues with others.

**Personal Factors in Your Decision.** As illustrated in the summary Table 2.2, all participants responded that it was "very important"/"fairly important" that their health would not be affected by the egg donation process. Eighty percent of donor indicated that their ability to set appropriate boundaries was somewhat (20%), fairly (10%) or very
important (50%) in their decision to donate their eggs. Only 1 participant indicated that this factor was “not very important” in her donation decision. More than half of the participants (60%) reported that their expectations that they could cope with the treatment was a “very important” factor in their decision to donate. Their confidence in their ability to deal effectively with the consequences was reported as being “very important for 50% of these donors, “fairly important” for 20%, and “somewhat important” for another 20% of respondents. For 75% of donors their personal belief that this was the “right” thing to do was reported as being “very important” / “fairly important” in their decision to be an egg donor. Donors were more divided on the importance that the expectation that their family members would be accepting of their decision played in their decision to donate with 40% of donors indicating that it was “not important” / “not very important” and 40% indicating that it was “very important.”

Table 2.2: Personal factors in donors’ decision

<table>
<thead>
<tr>
<th>Factor</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your expectation that your health would not be affected *1</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>9 (45%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Your belief in your abilities to set appropriate boundaries *2</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>4 (20%)</td>
<td>2 (10%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Your expectations that you could cope with the treatment *1</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
<td>2 (10%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Your confidence in your ability to deal effectively with the consequences *2</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>4 (20%)</td>
<td>4 (20%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Your personal beliefs that this was the “right” thing to do *2</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>Your expectation that your family members would be accepting of your decision *2</td>
<td>3 (15%)</td>
<td>5 (25%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>8 (40%)</td>
</tr>
</tbody>
</table>

1=Not Important  2=Not Very Important  3=Somewhat Important  4=Fairly Important  5=Very Important

Note: *1 subject did not answer
*2 1 subject answered “Not Applicable,” 1 subject did not answer
Family Factors in Your Decision. As is evident in Table 2.3, the majority of donors (80%) expressed that it was "very important" to them that their partner supported their decision to be an egg donor. Fifty-five percent of donor's also reported that the belief her children would not be affected if she became a donor was "very important" in her decision to become a donor. It is important to note, however, that not all donors had children at the time of their donation. On the next two items: the donor's confidence in her family's ability to cope with the treatment process and the donor's confidence in her family's ability to handle the long term consequences, participants responses were varied; with the largest percentage (45%) indicating that both factors were "very important" in their decision to be an egg donor.

Table 2.3: Family factors in donors' decision

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your partner's support for your decision to be an egg donor *1</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>16 (80%)</td>
</tr>
<tr>
<td>Your belief that your children would not be affected if you become a donor *2</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>2 (10%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Your confidence in your family's ability to cope with the treatment process *2</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
<td>2 (10%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Your confidence in your family's ability to handle the long term consequences *2</td>
<td>3 (15%)</td>
<td>0 (0%)</td>
<td>3 (15%)</td>
<td>3 (15%)</td>
<td>9 (45%)</td>
</tr>
</tbody>
</table>

1=Not Important  2=Not Very Important  3=Somewhat Important  4=Fairly Important  5=Very Important

Note: *1 1 subject did not answer
*2 1 subject answered “Not Applicable,” 1 subject did not answer

Importance of Broader Social Issues. As indicated in Table 2.4, the three items in this category: the donor's belief that egg donation is a socially acceptable reproductive option; her belief that egg donation is a morally appropriate way to create a family; and her belief that egg donation is an ethical form of treatment for infertility were responded
to similarly by participants. About half (45%, 55%, and 55% for each item respectively) viewed these factors as "very important," and between 15 and 20% as "fairly important" in their decision making. However, between 10 and 25% indicated that they saw these factors as "not important" in their decision to donate their eggs.

**Table 2.4: Importance of broader social issues in donors' decision**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your belief that egg donation is a socially acceptable</td>
<td>5 (25%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>3 (15%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>reproductive option *</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your belief that egg donation is morally appropriate way to</td>
<td>3 (15%)</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>create a family *</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your belief that egg donation is an ethical form of treatment</td>
<td>2 (10%)</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>4 (20%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>for infertility *</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 = Not Important  2 = Not Very Important  3 = Somewhat Important  4 = Fairly Important  5 = Very Important

Note: *1 subject did not answer

**Consequences to the Child(ren) Produced if Treatment was Successful.** Table 2.5 indicates that the items in this category seem to have played a significant role in the participants' decisions to donate. The three items which almost all donors selected as being "very important" were: the donor's belief that the child(ren) would be fully accepted by the recipients (95% "very important"); her belief that the child(ren) would be fully accepted by the recipients' families (90%); and the donor's expectations that the child(ren)'s psychological health would not be affected (90%). Eighty-five percent of participants indicated their expectations that the child(ren) would be born healthy was also "very important" / "fairly important" in their decision. The remaining two items in this category: the donor's expectation that she would develop a healthy relationship with the child(ren); and the donor's ability to set appropriate boundaries in her relationship
with the child(ren) were viewed as "very important" / "fairly important" by 70% of the donors; while 10 to 25% of donors identified these items as "not important" / "not very important" factors in their decision to donate their eggs.

Table 2.5: Consequences to the child(ren) produced and donors’ decision

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your belief that the child(ren) would be fully accepted by the</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>19 (95%)</td>
</tr>
<tr>
<td>recipients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your belief that the child(ren) would be fully accepted by</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>the recipients' families</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your expectation that the child(ren) would be born healthy</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>3 (15%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>Your expectation that you would develop a healthy relationship</td>
<td>3 (15%)</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
<td>2 (10%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>with the child(ren)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your ability to set appropriate boundaries in your relationship</td>
<td>0 (0%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>with the child(ren) *1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your expectation that the child(ren)'s psychological health</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>would not be affected</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 = Not Important  2 = Not Very Important  3 = Somewhat Important  4 = Fairly Important  5 = Very Important

Note: *1 1 subject answered “Not Applicable,” 1 subject did not answer

Donors added the following additional comments to this section of the questionnaire:

“I feel very blessed to have been part of such a wonderful thing. I have two beautiful nephews who are in this world because of this process. My children have "special" cousins. The boys have made a wonderful couple a family.”

“It was important that donating wouldn't adversely affect my health.”
“My decision was based on the fact that my sister has a genetic disease and that I'm not a carrier of this. Also, I knew what wonderful parents they will be and wanted to help them fulfill this desire with the health of the baby in mind.”

“I was not terribly close to the recipients for one, donating seemed to be very easy because I stood to lose nothing, but could help people that really needed help.”

In response to the question, “Which people in your life were most influential in your decision to become an egg donor?” participants’ answers fell into the following categories:

i) recipients:
Donor #7: “The recipients - they needed help; otherwise I probably never would have done it.”
Donor #9: “My sister as we are very close and I would do anything I could to help her and vice versa. It was an easier decision because all my friends and family were very supportive.”
Donor #19: “My sister, the recipient.”

ii) husband/parents/loved ones:
Donor #1: “When I brought up the thought of becoming an egg donor I discussed it with my husband. Because the recipients were so close to us, and family members, we could easily discuss how the decision would impact everyone involved. The 4 of us openly discussed all the factors. I really could not think of anything negative that could possibly come out of this experience!”
Donor #8: “My husband - he was completely supportive of my decision. My parents - if they were uncomfortable with the idea of me donating to my sister then I would have reconsidered my decision.”

Donor #16: “My husband, my mom and two very close friends. My sister and brother-in-law always made it clear to me that there wasn't any pressure to finish the process if it affected me negatively.”

Donor #17: “The acceptance of my spouse was very important to me as well as my desire to help my sister.”

Donor #20: “My husband's acceptance was important but not vital.”

Donor #14: “My children. Just knowing how much I need and love them.”

Donor #18: “Made the decision on my own. However, partner was very supportive.”

iii) no one/oneself:

Donor #3: “No one. Just something I wanted to do.”

Donor #4: “No one in particular; wanted to give help where I could.”

Donor #11: “Myself.”

Donor #6: “No external influence - this was a personal decision carefully considered and undertaken by me because the recipients are two wonderful people that deserve to be parents.”

Donor #15: “No one, the decision was made on my own, with the hopes of my husband's support.”

iv) other:

Donor #5: “Everyone was cautious but supportive.”
Donor #12: “It was a decision between myself and God. My husband, other family members and friends lovingly supported my decision.”

**Part Three: Experience in Treatment**

Part three of the questionnaire deals with the participants experience in treatment, and asks the donor about her perception of the preparation, treatment, and support she received from the staff at the clinic.

**Egg Donor Preparation and Orientation.** In this section of the questionnaire, the donor was asked to select whether she found the session with the counsellor, nurses, and doctor to be “very helpful,” “helpful,” or “not very helpful”; she was also asked to rank her perception of the overall preparation. As illustrated in Table 3.1 about half of the participants found sessions with the counsellor, the nurse, the doctor as well as the preparation overall to be “very helpful” while 35 to 40% found it be very “helpful.” Three participants indicated that the session with the counsellor was “not very helpful,” 2 indicated the same for the session with the nurses, 1 for the session with the doctor, and 2 found the preparation overall to be “not very helpful.”

**Table 3.1: Egg donor preparation and orientation**

<table>
<thead>
<tr>
<th></th>
<th>Very Helpful</th>
<th>Helpful</th>
<th>Not Very Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session with Counsellor</td>
<td>10 (50%)</td>
<td>7 (35%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Session with Nurse</td>
<td>11 (55%)</td>
<td>7 (35%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Session with Doctor</td>
<td>11 (55%)</td>
<td>8 (40%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Overall</td>
<td>10 (50%)</td>
<td>8 (40%)</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

When participants were asked, “What other information or services would have been helpful prior to beginning treatment?,” donors identified the following:
• Donor #4: "More time spent on how to take meds; consultation was done too early; by the time I actually took the meds I had forgotten most of the procedures."

• Donor #6: "Assignment of the process to one nurse only - too many people involved in our case which resulted in mixed communications and very poor follow-up after the extraction procedure. In fact there was zero follow-up after the extraction."

• Donor #8: "My time spent at Genesis felt very rushed and disorganized. The nurse I dealt with at times seemed frazzled and forgetful. Perhaps each nurse should have a smaller case load to ensure more thorough and supportive service."

• Donor #9: "There was a miscommunication about the dose of Syneral and so I ended up taking twice the amount and delaying the process. It would have been helpful to have the medical instructions written out in detail to avoid this."

• Donor #17: "I don't think anyone realized how long the treatment would take and I do not know if being told there was this possibility would have impacted my decision."

• Donor #19: "An information sheet outlining exactly what tests were needed by whom. I was told my husband needed an HIV test which wasn't necessary and some of the tests I was told I needed weren't needed also, I can't recall exactly which ones they were. That was time consuming and expensive because we had to pay for the tests since we live in the U.S."

• Donor #11: "Self education."

• Donor #12: "Naturopathic. I went to a naturopath for natural remedies to help my body process receipt of hormones and flush them quickly out of my system - Aiding my recovery and lessening the chance of long term effects."
Other donors did not identify anything that might have been helpful. Rather, most expressed how pleased they were with the services and information provided to them:

- Donor #1: “The staff at Genesis were great, I was able to contact them by phone whenever I needed. I was given all the information I needed and felt comfortable about the procedure and upcoming treatment.”
- Donor #2: “Nurses at Genesis were very helpful to talk with.”
- Donor #7: “The staff did an amazing job prepping me for everything and were always able to answer any of my questions.”
- Donor #16: “At first, I wanted more information but when we got involved with the clinic, I received all the information I needed. I was amazed at the efficiency and organization of the process. I also felt totally supported by the staff whenever I needed them - they were always there.”

**Egg Donor Treatment.** The three items included in the treatment category were: drug monitoring, pain management and egg retrieval. As is apparent in Table 3.2, sixty percent of participants found the drug monitoring to be “easy,” 30% found it to be “very easy,” while 2 participants found it to be “difficult.” About the same division in numbers among participants was evident for pain management with 65% reporting that it was “easy,” 30% “very easy,” and 1 participant found it “difficult.” Donors’ responses to how they found egg retrieval were as follows; 45% found it “easy,” and 35% found it “very easy,” while 20% found it difficult. None of the participants indicated that they found any of the above three items “very difficult.”
Table 3.2: Egg donor treatment

<table>
<thead>
<tr>
<th></th>
<th>Very Easy</th>
<th>Easy</th>
<th>Difficult</th>
<th>Very Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Drug Monitor</strong></td>
<td>6 (30%)</td>
<td>12 (60%)</td>
<td>2 (10%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Pain Management</strong></td>
<td>6 (30%)</td>
<td>13 (65%)</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Egg Retrieval</strong></td>
<td>7 (35%)</td>
<td>9 (45%)</td>
<td>4 (20%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

In response to the question, “What would have made the treatment process easier for you to cope with?” some participants responses were related to services or information:

Donor #8: “More support from the nursing staff and follow up after the procedure - once I was at home. I think sometimes people who work in a health care field forget how emotional it is for those of us going through the experience and forget that it’s an entirely new experience for us.”

Donor #19: “Being able to call in and talk to only one nurse that was familiar with our care. Having phone calls returned more promptly.”

Donor #20: “A more detailed list of what I’d need to do when. I also found that I didn’t know when I’d have to stop/start things. After each monitoring session, it would have been good to be told what you were looking for and where I was in respect to your findings.”

Flexibility regarding ability to conduct some of the pre-retrieval treatment at a closer, more convenient location was expressed as having been helpful by one out-of-town participant (donor no.16): “I was thankful that some of the beginning treatment could be done in my home city. Traveling to Vancouver added quite a lot of stress to me and my family. I wish we could have done more at home before the retrieval. I realized that this would have been a difficult thing to do.”
One participant (donor no. 15) voiced her desire to have had some form of help in addressing the after effects of the medication: “The only thing that I found most difficult was the after effect; meaning once egg retrieval was done, the mood swings were horrible. I needed some sort of drug to help out with the hormone level afterwards. I found it the most difficult and frustrating time of my life, having 2 children of my own made for an unpleasant living condition, till I sought help from our family doctor and had to be put on medication. It took a long time to work the treatment medication out of my body.”

Some participants expressed that they felt everything went well; they did not have any suggestions regarding what would have made the treatment process easier to cope with:

Donor #1: “I think the treatment process went well considering I had suffered a violent bout of the flu exactly the night prior to retrieval of the eggs. I was up all night vomiting and had to be given gravol and additional medication to manage the pain. I think the procedure went well although I spent most of the time sleeping!”

Donor #9: “Besides the miscommunication, I thought the process was well managed and scheduled. I got used to the injections but for others it might be less daunting to take the drugs orally though I’m not sure this is possible.”

Support Received from Genesis Staff. As indicated in Table 3.3, forty percent of participants indicated that they found the front desk staff to be “very supportive,” while 60% found them to be “supportive.” When it came to evaluation of the counsellor, 60% found her to be “very supportive,” and the remaining 40% selected “supportive.” Seventy percent of donors found the nursing staff to be “very supportive” while 20%
indicated they were "supportive." However, 2 of the participants (10%) felt the nursing staff were "not very supportive." Sixty-five percent of the women found the physicians to be "very supportive," with the remaining 35% reporting that they were "supportive."

Table 3.3: Support felt received by Genesis staff

<table>
<thead>
<tr>
<th></th>
<th>Very Supportive</th>
<th>Supportive</th>
<th>Not Very Supportive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Front Desk Staff</td>
<td>8 (40%)</td>
<td>12 (60%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Counsellor</td>
<td>12 (60%)</td>
<td>8 (40%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Nursing Staff</td>
<td>14 (70%)</td>
<td>4 (20%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Physicians</td>
<td>13 (65%)</td>
<td>7 (35%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

All but 1 of the donors rated their overall experience at the Genesis Fertility Centre to be "very positive" or "positive." When asked whether they would be willing to be contacted in the future to participate in a long-term follow-up study, 80% of donors responded "yes," 1 participant did not answer the question, and 3 participants responded "no."

Table 3.4 provides a more detailed description of the various aspects of the preparation and orientation and possible impact on donors' rating of the overall preparation. Of the 10 participants who found the overall preparation to be "very helpful," 8 reported that all 3 sessions (i.e., with the counsellor, nurse, and doctor) were "helpful"/"very helpful." Two respondents perceived the session with the counselor as being "not very helpful." Of the 8 donors who found the preparation overall to be "helpful," most found the sessions with the doctors, counsellor, and nurse to be "very helpful"/"helpful." Only one donor reported that the session with the doctor was "not very helpful." Another found the session with the nurse "not very helpful," remarking that "calling in to talk to nurses was not very helpful because they weren't familiar
enough with our case. We usually spoke to someone different each time.” Two donors indicated that they found the overall preparation “not very helpful.” One of these donors indicated that she found the other (3) sessions “helpful,” while the other reported finding the session with the nurse as “not very helpful,” as well as that with the counsellor.

Table 3.4: Association of the various aspects of the preparation process on the donors’ perception of overall preparation

<table>
<thead>
<tr>
<th></th>
<th>Overall Preparation</th>
<th>Very Helpful (n=10)</th>
<th>Helpful (n=8)</th>
<th>Not Very Helpful (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counsellor</td>
<td>Very Helpful</td>
<td>7 (70%)</td>
<td>3 (37.5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Helpful</td>
<td>1 (10%)</td>
<td>5 (62.5%)</td>
<td>1 (50%)</td>
</tr>
<tr>
<td></td>
<td>Not Very Helpful</td>
<td>2 (20%)</td>
<td>0 (0%)</td>
<td>1 (50%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>Very Helpful</td>
<td>10 (100%)</td>
<td>1 (12.5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Helpful</td>
<td>0 (0%)</td>
<td>6 (75%)</td>
<td>1 (50%)</td>
</tr>
<tr>
<td></td>
<td>Not Very Helpful</td>
<td>0 (0%)</td>
<td>1 (12.5%)</td>
<td>1 (50%)</td>
</tr>
<tr>
<td>Doctor</td>
<td>Very Helpful</td>
<td>10 (100%)</td>
<td>1 (12.5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Helpful</td>
<td>0 (0%)</td>
<td>6 (75%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td></td>
<td>Not Very Helpful</td>
<td>0 (0%)</td>
<td>1 (12.5%)</td>
<td>0% (0%)</td>
</tr>
</tbody>
</table>

Table 3.5 indicates a breakdown of the preparation and support provided by the staff at Genesis Fertility Centre in relation to how donors rated their overall experience. Of those donors who rated their overall experience as “very positive,” almost all of them found the preparation session with each of the various staff (nurse, doctor, counsellor) to be “very helpful” / “helpful.” Two participants indicated that they found the session with the counsellor “not very helpful.” One found the session with the doctor “not very helpful.” Of the donors who rated their overall experience at the centre as having been
“positive” all found the preparation sessions to be “helpful” / “very helpful;” but one
found the preparation session with the nurse “not very helpful.”

Table 3.5: Relationship of the preparation and support provided by Genesis staff
and donors’ overall centre experience

<table>
<thead>
<tr>
<th></th>
<th>Overall Experience</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Positive</td>
<td>Positive</td>
<td>Negative</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=10)</td>
<td>(n=9)</td>
<td>(n=1)</td>
<td></td>
</tr>
<tr>
<td><strong>Counsellor (Prep)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Helpful</td>
<td>5 (50%)</td>
<td>5 (55.6%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>3 (30%)</td>
<td>4 (44.4%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Helpful</td>
<td>2 (20%)</td>
<td>0 (0%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Nurse (Prep)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Helpful</td>
<td>8 (80%)</td>
<td>3 (33.3%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>2 (20%)</td>
<td>5 (55.6%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Helpful</td>
<td>0 (0%)</td>
<td>1 (11.1%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Doctor (Prep)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Helpful</td>
<td>8 (80%)</td>
<td>3 (33.3%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>1 (10%)</td>
<td>6 (66.7%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Helpful</td>
<td>1 (10%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Front Desk Staff (Support)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Supportive</td>
<td>5 (50%)</td>
<td>3 (33.3%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>5 (50%)</td>
<td>6 (66.7%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Supportive</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Counsellor (Support)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Supportive</td>
<td>6 (60%)</td>
<td>6 (66.7%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>4 (40%)</td>
<td>3 (33.3%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Supportive</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Nursing Staff (Support)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Supportive</td>
<td>10 (100%)</td>
<td>4 (44.4%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>0 (0%)</td>
<td>4 (44.4%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Supportive</td>
<td>0 (0%)</td>
<td>1 (11.2%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Physician (Support)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Supportive</td>
<td>8 (80%)</td>
<td>5 (55.6%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>2 (20%)</td>
<td>4 (44.4%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Not Very Supportive</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Participation in a Long-term Follow-up Study</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8 (80%)</td>
<td>7 (77.8%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1 (10%)</td>
<td>2 (22.2%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Not Answered</td>
<td>1 (10%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
</tr>
</tbody>
</table>
The one donor who rated her overall experience at the centre as “negative,” indicated that she found the preparation session with the nurse and the counsellor “not very helpful,” the preparation session with the doctor she perceived as “helpful.” She reported that the front desk staff, the counsellor, and the physicians were “supportive” while she experienced the nursing staff as “not very supportive” providing the following additional remark by her “negative” rating of the centre: “because the nursing staff was who I dealt with the most.” Interestingly, donors’ ratings of their overall experience at the centre did not seem to have any bearing on their willingness to participate in a long-term follow-up study with all but 3 donors indicated a willingness to be contacted in the future for a follow-up study.
CHAPTER FIVE

Discussion

In the current study, a questionnaire was utilized to gather information on the known donor's relationship with/to the recipient, if and how this relationship has altered or been affected; the outcome of the treatment cycle and/or any possible bearings on the donor's subsequent experience; factors important in donor's decisions to participate in egg donation; as well as her experience in treatment. The findings are discussed below, relative to the available literature on the experiences of anonymous, as well as known egg donors' demographic profiles, donation motivations and decision-making, and post-treatment experiences. Particular attention is paid throughout this discussion, to the implications of these findings based on concerns expressed in the literature about the potentially problematic nature of known versus anonymous egg donation.

Demographic Profile

The response rate in our study was 69% (20/29) which is similar or better than the response rate reported in the literature from similar quantitative studies (Jordan, Belar & Williams, 2004). The main reason some of the donors who participated in the egg donor program during our study period (55 identified women) were not included in the study was due to an inability to contact the donors. Some of the donors had moved since completing the program without leaving a forwarding address.

The majority of the participants donated to a family member (70%). The remainder (30%) was equally broken down to those who donated to a friend (15%) or an acquaintance (15%). This is somewhat different from studies where some of the donations were conducted non-anonymously (Baetens, Devroey, Camus, Van
Steirteghem & Ponjaert-Kristoffersen, 2000), where there was more of an even
distribution between donors who were family members and those who were friends. The
familial nature of many of the donations in the current study should be kept in mind when
considering the motivations, experiences, and perceptions of the outcome of their egg
donation for the women in this study – given that many of these donors were related by
blood or marriage to the recipients and were likely to have a continuing familial/social
relationship with the recipients and any children conceived through their donation.

**Motivations and Factors in their Decision to Be An Egg Donor**

The current study found empathy and altruism as the motivating factors behind
participants’ decisions to donate their eggs. This motivation was so strong that on an
equal number of occasions it was the donor that raised the subject of being an egg donor.
This motivation is evident in additional comments made by donors: “...I stood to lose
nothing, but could help people that really needed help;” “My decision was based on the
fact that my sister has a genetic disease and that I’m not a carrier of this. Also, I knew
what wonderful parents they will be and wanted to help them fulfill this desire with the
health of the baby in mind.”

Empathy and altruism are often cited in the literature as primary motives for egg
donation (Bartlett, 1991; Cooper & Glazer, 1994; Klock, Braverman & Rausch, 1998;
Ahuja, Mostyn & Simons, 1997; Baetens et al., 2000; Sauer & Paulson, 1992; Jordan,
Belar & Williams, 2004). Other motivating factors reported in the literature include:
feminine solidarity (Weil, Cornet, Sibony, Mandelbaum & Salat-Baroux, 1994); curiosity
about the procedure (Soderstrom-Attila, 1995); a desire to test their own fertility (Power,
Baber, Abdalla, Kirkland, Leonard & Studd, 1990); increased self-esteem (Klock et al.,
1998); making up for a past reproductive loss (Jordan et al., 2004; Klock et al., 1998); and technological interest (Soderstrom-Anttila, 1995; Klock et al., 1998). Financial compensation seems to be the chief motivating factor found in some studies where participants were young, nulliparous women recruited through advertisements in college newspapers (Lindheim, Frumovitz & Sauer, 1998; Kalfoglou & Gittelsohn, 2000). Given that the donors in this study were not compensated for their donation, it is not surprising that altruism, rather than economics, was a more important factor in the participant’s decision to become an egg donor.

Donors ranked the five factors in their decision to be an egg donor in the following order of importance: donor’s relationship with the recipient, consequences to the child(ren) produced if treatment was successful, consequences to donor’s family (her partner and her children), personal consequences, and lastly, broader social issues.

As might be expected, the most important item under the category of donor’s relationship with the recipient was the closeness of this relationship, with 90% of participants ranking it as a very important/fairly important factor in their decision to be an egg donor. It is on the basis of this relationship and the importance of this relationship that the women in this study elected to donate their eggs. These relationships appear to be stable and strong as more than half of the donors expressed that the expectation that her donation would strengthen her relationship with the recipient was not important/not very important in their decision to donate. Furthermore, the same number of donors indicated that their belief that their relationship with the recipients would not be damaged if they refused to donate their eggs was a very important factor in their decision.
relationship – these findings suggest the donor-recipient relationship may be especially important in non-anonymous egg donations.

Donors’ belief that the recipients would be good parents was ranked by all donors as very important in their decision to donate their eggs to help the recipients create a child. It is interesting to note that two studies on anonymous donors found concern on the part of donors regarding the parenting style of recipients (Kalfoglou & Gittelsohn, 2000; Jordan et al., 2004). The donors in our study knew the recipients very well and were therefore in a position to judge whether the recipients would be good parents and to use this information in making a decision regarding donation of their eggs. However, this is not so in the case of anonymous egg donation such as in Kalfoglou and Gittelsohn’s study of anonymous donors wherein many donors assumed that recipients were screened by the fertility centre for parenting capability in order to qualify as oocyte recipients.

More than half (55-60%) of the participants in this study indicated the following as very important factors in their decision to be an egg donor: that the recipients be respectful of their needs and rights; that the recipients would be respectful of their boundaries; that they agreed regarding disclosure to the child(ren); and that the recipients agreed with their feelings regarding privacy issues with others. The existing literature reveals that these are issues important to most donors and recipients – in both anonymous and known donation situations (Kirkland, Power, Burton, Baber, Studd & Abdalla, 1992; Weil et al., 1994). None of the participants in this study indicated any infringement on her needs, rights, or boundaries; nor did any report any disagreement regarding disclosure or privacy issues. This might be due to the fact that these issues were discussed and sufficiently addressed between all parties and through donor/recipient counseling prior to
the donation taking place – something that does not appear to be mandated in other studies which included non-anonymous donors (Fielding, Handley, Duqueno, Weaver & Lui, 1998).

The belief that the child(ren) produced would be fully accepted by the recipients, and the recipients’ families was ranked as a very important factor by 90%-95% of donors in their decision to be an egg donor. It is understandable that for most donors it would be extremely important that they have the confidence that the recipients and their families would accept any child produced through egg donation.

Eighty-five to 90% of donors indicated that their expectation that the child(ren) would be born healthy and that the child(ren)s’ psychological health would not be affected was very important in their donation decision. The donor’s expectation that she would develop a healthy relationship with the child(ren), and the donor’s ability to set appropriate boundaries in her relationship with the child(ren) were also viewed as very important/fairly important by 70% of the donors in their decision to donate their eggs. This is again a reflection of the differences between anonymous and known egg donation, given that the physical and psychological health of the child does not seem to be a significant factor in the donation decisions of non-anonymous donors (Kalfoglou & Gittelsohn, 2000; Klock et al., 1998; Rosenberg & Epstein, 1995; Soderstrom-Anttila, 1995).

The majority of donors in the current study (80%) expressed that it was very important to them that their partner supported their decision to be an egg donor. One donor expressed it in the following manner: “The acceptance of my spouse was very important to me as well as my desire to help my sister.” This finding is consistent with,
and appears to support the recommendation of the Mental Health Specialty Group of the American Society for Reproductive Medicine (Hammer-Burns & Covington, 1999) that pre-donation counseling of donors necessarily include the donor’s husband/partner. Fifty-five percent of donors reported that the belief that their children would not be affected if they became a donor, was very important in their decision to become a donor – a finding that again that likely reflects the fact the majority of donors in this study were family members who, along with their children, were likely to have an ongoing and long-term relationship with the recipients and their offspring.

Consistent with the experiences of anonymous donors reported in the literature, the known donors in this study ranked their health not being affected by the egg donation process as a very important factor in their decision making. One donor stated: “It was important that donating wouldn’t adversely affect my health.” Most donors (80%) indicated that their ability to set appropriate boundaries was also important (50% very important, 10% fairly important, 20% somewhat important) in their decision – an issue that would appear to be specific to know donations where the donor is likely to have an ongoing relationship with the recipients and their child(ren), as in the case of familial donations.

More than half of the participants in this study (60%) reported that their expectations that they could cope with the treatment was a very important factor in their decision to donate their eggs, while their confidence in their ability to deal effectively with the consequences was also important (50% very important, 20% fairly important, 20% somewhat important) for them. For 75% of donors their personal belief that this was the “right” thing to do was reported as being very important/fairly important in their
decision to be an egg donor. This is perhaps reflective of this group of women’s sense of confidence of knowing what was right for them; and is further demonstrated in their belief that egg donation is a socially acceptable reproductive option, a morally appropriate way to create a family, and an ethical form of treatment for infertility – which 70% of donors found to be very important/fairly important factors in their decision to donate their eggs.

The Treatment Experience

Participant responses regarding the treatment cycle and how different their experiences of being an egg donor actually was when compared to what they had expected revealed that for most participants the experience was not different, or even more positive than they expected. However, 8 of the participants found treatment to be more difficult and experienced more discomfort with the medications and subsequent side effects than they expected, with 2 of the 8 participants reporting much more adverse medical side effects than they had anticipated. This finding flies in the face of many advertisements for anonymous egg donors – promoting the relative ease of egg donation – and is consistent with Lindheim et al.’s (1998) study in which approximately 45% of the 339 women who met the criteria for egg donation, removed themselves from candidacy due to reservations about the procedure and side effects. The findings in the present study seem to support those in the literature (Kalfoglou & Gittelsohn, 2000; Klock et al., 1998) which point out that side effects are experienced differently by different donors, and that the medical procedure involved in egg donation is strenuous, and requires due thought and consideration.
Interestingly, in rating their overall experience of egg donation, 90% of the donors in this study rated their experience as very positive/positive. This is consistent with findings from other studies which found overall satisfaction with the donation experience to be generally quite high (e.g. Ahuja et al., 1997; Fielding, Handley, Fuqueno, Weaver & Lui, 1998; Jordan et al., 2004, Kalfoglou & Gittelsohn, 2000; Klock et al., 1998; Soderstrom-Antilla, 1995). None of the donors in this study rated their experience as negative/very negative – even the 2 donors who reported experiencing the most problematic reaction to the medications and the treatment procedure. A high rate (83%) of participants who had a very positive overall experience of being an egg donor indicated they would consider being an egg donor for the couple again, also consistent with findings in the literature mentioned in the above studies.

Perhaps the strongest endorsement for known donation comes from the fact that ninety percent of the donors in this study reported that, given the chance to reconsider their decision, they would make the same choice again to be a donor. A closer look at participants’ responses confirmed that regardless of whether the cycle was successful or not, the majority of participants had no regrets about their involvement in the egg donation program. The two participants who said they would not make the same decision to donate again, given the chance to reconsider, had had quite adverse reactions to the medications and treatment process. However, this was not the case for all the participants who had experienced difficulty and discomfort with the medications and treatment procedure. This is evident from a comment made by one of these participants who, despite having had an adverse reaction to the medications, said she would make the same decision to donate: “I would like to state that the overall results are a wonderful joy to see
a couple with children, and to have them experience the joy of having a child(ren) grow in their own body, give birth & raise it was overwhelming...It was worth it!"

With regards to donors’ overall experience with egg donation, because these donors were participating in a non-anonymous egg donation program, unlike anonymous donors, they likely experienced greater satisfaction from knowing the outcome of their donation and whether it resulted in a successful pregnancy. In multiple studies of anonymous donation, the donors indicated not knowing the outcome of their donation as being a particularly negative and difficult aspect of their overall experience (Fielding et al., 1998; Jordan et al., 2004; Kalfoglou & Gittelsohn, 2000; Klock et al., 1998; Rosenberg & Epstein, 1995; Schover et al., 1991; Soderstrom-Anttila, 1995).

In commenting upon the preparation and orientation they received prior to their donation, the majority of donors (85%-90%) stated that they found the sessions with the counsellor, the nurse, and the doctor as well as the overall preparation to be very helpful/helpful. Regulating bodies, such as the American Society for Reproductive Medicine (ASRM) recommend counselling for the donor and her partner. While a few donors suggested that more information and organization might have been helpful in terms of the medical preparation, most expressed how pleased they were with the services and information provided to them. Consistent with the recommendation of Kalfoglou and Gittelsohn (2000) regarding the donors’ need for information and the relationship to informed consent and counselling, the donors in this study valued being fully informed prior to treatment and supported by the staff during treatment.

The egg donor treatment was comprised of three components: drug monitoring, pain management, and egg retrieval. Drug monitoring was found to be easy/very easy by
90% of donors while only 2 donors found it to be difficult. Ninety-five percent of donors also reported the pain management to be easy/very easy while only 1 participant found it difficult. Egg retrieval was found to be easy/very easy by 80% of donors while 20% found it difficult. While none of the participants indicated that they found any of the above three parts of the donation process very difficult, it would appear that the actual egg retrieval process was experienced by more donors as difficult, as compared to the drug monitoring and pain management. This finding is consistent with other studies reported in the literature, in which donors reported the actual egg retrieval as being the most challenging part of the oocyte donation process (e.g. Jordan et al., 2004; Schover et al., 1991).

When asked what would have made the treatment process easier for them to cope with, a few of the participants felt that having ongoing correspondence and support throughout the treatment by one staff member who was familiar with them and their case, would have helped them. While not always easy to ensure, providing continuity of care may well be a factor that clinics need to take into consideration in their egg donation programs.

Post-Treatment Experiences

Sixty percent of donors in this study indicated that they would be willing to consider being an egg donor for this couple again, while only 35% stated that they would be willing to consider being an egg donor for someone else in the future. This finding, points to the importance of the pre-existing relationship between known donors and recipients and to the differences in motivations to donate when compared to anonymous donors – many of whom donate their eggs several times and receive financial
compensation for each donation. When asked whether they would be willing to be contacted in the future to participate in a long-term follow-up study, 80% of donors in this study responded “yes,” an apparent testimony of the continued investment of these donors in their relationship with the recipients and child(ren).

There has been concern expressed by some researchers (Ahuja et al. 1997; Baetens et al., 2000; Bertrand-Servais et al., 1991; Cooper & Glazer, 1994; Fielding et al., 1998; Saunders & Garner, 1996) regarding “complications” that may arise in known donation such as: the possible deterioration of the relationship of the donor and the recipient, overwhelming feelings of obligation on the part of the donor to donate as a result of pressure from the recipient, as well as negotiating the issue of secrecy between the donor and her own children or partner about the donation process. Although all researchers do not share these concerns (Sauer & Paulson, 1992; Weil et al., 1994; Winter & Daniluk, 2004), regulating bodies such as the American Fertility Society (AFS) and, the British equivalent, the Human Fertilization and Embryology Authority (HFEA) recommend the use of anonymous egg donors to reduce the potential for legal and emotional complications for all parties involved. Non-anonymous egg donation intrinsically entails the potential for more complicated relationships between donors and recipients. However, none of the “complications” cautioned against by some researchers were reported by the known donors in our study.

In regard to the participant’s post-donation relationship with/to the recipients and child(ren), it was found that all of the donors still maintained contact with the recipients. Sixty percent indicated that their relationship with the recipients had not changed since they participated in treatment. All but one of the participants who indicated that their
relationship with the recipient had changed, reported that their relationship was closer and stronger now, as a consequence of their participation in the egg donation process — irrespective of whether their donation resulted in the birth of a child. Donors made the following additional comments about their post-donation relationships: “We share a wonderful bond, we were close before the treatment but sharing such an experience has strengthened our relationship;” “There was always a special bond between me and my sister, it is now even more special. My brother-in-law and my new little niece are also extra special members of my family. The experience has enriched our lives;” “I feel very blessed to have been part of such a wonderful thing. I have two beautiful nephews who are in this world because of this process. My children have “special” cousins. The boys have made a wonderful couple a family.”

The importance of pre-donation counselling in facilitating the participants positive experiences cannot be overstated. Every participant in the present study underwent pre-donation counselling, as did their recipients, prior to committing to the egg donation process. The provision of pre-donation counselling is vital to ensuring that prospective known egg donation participants make informed choices that are right for them. The need for pre-donation counselling is not only to ensure that donors are adequately screened, but so that all participants are made aware of the possible complications inherent in third party reproduction (Ahuja et al., 1997; Cooper & Glazer, 1994; Fielding et al., 1998; Saunders & Garner, 1996). Pre-donation counselling provided to the participants in the current study seems to have enabled them to acquire clarity regarding their role as a donor, what their expectations were and whether these were realistic or needed to be reconsidered, as well as learning what was expected of them.
The positive experiences of the donors in this study should support the call for clinics offering third party reproduction treatment procedures to provide pre-donation counselling to all participants as part of their mandate.

In conclusion, according to the findings from our study, concerns expressed regarding known egg donation appear to be unjustified. Contrary to these common expectations, the participants in this study seemed able to negotiate these ongoing relationships successfully – and many felt their relationships with the recipients were enhanced and strengthened as a consequence of their donation.
REFERENCES


APPENDIX A

Donor Questionnaire

Part One: General Information

1) How Did the Subject of Being an Egg Donor First Come Up?
   a. I Raised the Issue with the Recipient(s) _____
   b. The Recipients Raised the Issue with Me _____
   c. A Family Member Raised the Issue with Me _____
   d. A Friend of the Recipient Raised the Issue with Me _____
   e. Other: ____________________________________________

2) What is Your Relationship to/with the Recipients?
   a. Family Member........... (Please Specify..............................)
   b. Close Friend of: the woman ____; the man ____; both ____; the family ____
   c. Acquaintance of: the woman ____; the man ____; both ____; the family ____

3) How Long Ago did you Complete the Treatment Cycle? ___ Weeks ___ Months ___ Years

4) Was the Cycle Successful (Did a Viable Pregnancy Result?) Yes ____ No ____
   d. If Yes Was This a Multiple Pregnancy? Twins ____ Triplets ____
   e. Was the Baby (or Babies) Born Healthy? Yes ____ No ____ Don’t Know ____

5) Are there Frozen Embryos Still Available for Use by the Recipients?
   Yes ____ No ____ Don’t Know ____

6) Do You Still Maintain Contact With the Recipients? Yes ____ No ____
   If Yes, How Often? Daily ____ Weekly ____ Monthly ____ Yearly ____

7) Has Your Relationship With the Recipients Changed Since You Participated in Treatment?
   Yes ____ No ____
   If Yes, Briefly Describe How and Why ____________________________________________
8) Would You Consider Being An Egg Donor For This Couple Again? Yes ___ No ___
9) Would You Consider Being An Egg Donor For Someone Else in the Future? Yes ___ No ___
10) Looking Back Over Your Experience of Being an Egg Donor, if You Had the Chance to
Reconsider Your Decision, Would You Make the Same Choice to Be a Donor? Yes ___ No ___
   If NO, Why Not? ____________________________________________________________

11) How Different Was Your Experience of Being an Egg Donor, than What You Had Initially
   Expected When You Offered? Not Different ____ Somewhat ____ Very ____
   If Different, In What Way? __________________________________________________

12) Overall, How Would You Rate Your Experience of Being an Egg Donor?
   Very Positive ____ Positive ____ Negative ____ Very Negative ____

**Part Two: Making the Decision:**

Please read each of the following questions and indicate on the 5 point scale that appears on the
right of each question, how important each of these factors were to you in your decision to
become an egg donor.

5 means *Very Important*
4 means *Fairly Important*
3 means *Somewhat Important*
2 means *Not Very Important*
1 means *Not Important*

**The Following Questions Refer to Your Relationship with the Recipients**

1) The Closeness of Your Relationship with the Recipients 1 2 3 4 5
2) Your Expectations that Being a Donor Would Strengthen Your Relationship 1 2 3 4 5
3) Your Belief that the Recipients Would be Good Parents 1 2 3 4 5
4) Your Expectations that They would be Respectful of Your Needs and Rights 1 2 3 4 5
5) Your Belief that Your Relationship Would Not be Damaged if You Refused 1 2 3 4 5
6) Your Expectations that the Recipients Would Respect Your Boundaries 1 2 3 4 5
7) Your Agreement with their Feelings Regarding Disclosure to the Child 1 2 3 4 5
8) Your Agreement with their Feelings Regarding Privacy Issues with Others 1 2 3 4 5

The Following Questions Refer to The Personal Factors in Your Decision:

1) Your Expectations that Your Health Would Not be Affected 1 2 3 4 5
2) Your Belief in Your Abilities To Set Appropriate Boundaries 1 2 3 4 5
3) Your Expectations that You Could Cope with the Treatment (Medications, Procedures, etc.) 1 2 3 4 5
4) Your Confidence in Your Ability to Deal Effectively with the Consequences 1 2 3 4 5
5) Your Personal Beliefs that this was the “Right” Thing to Do 1 2 3 4 5
6) Your Expectation that Your Family Members Would be Accepting of Your Decision 1 2 3 4 5

The Following Questions Refer to The Family Factors in Your Decision:

1) Your Partner’s Support for Your Decision to be an Egg Donor 1 2 3 4 5
2) Your Children Would Not Be Affected if You Became a Donor 1 2 3 4 5
3) Your Confidence in Your Family’s Ability to Cope with the Treatment 1 2 3 4 5
4) Your Confidence in Your Family’s Ability to Handle the Long Term Consequences 1 2 3 4 5

The Following Questions Refer to The Importance of Broader Social Issues in Your Decision:

1) Your Belief that Egg Donation is a Socially Acceptable Reproduction Option 1 2 3 4 5
2) Your Belief that Egg Donation is a Morally Acceptable Option 1 2 3 4 5
3) Your Belief that Egg Donation is an Ethical Form of Treatment for Infertility 1 2 3 4 5
The Following Questions Refer to The Consequences to the Child(ren) Produced if Treatment Was Successful:

1) Your Belief that the Child(ren) Would Be Fully Accepted by the Recipients
   1 2 3 4 5

2) Your Belief that the Child(ren) Would Be Fully Accepted by the Recipients’ Families
   1 2 3 4 5

3) Your Expectation that the Child(ren) Would be Born Healthy
   1 2 3 4 5

4) Your Expectations that You Would Develop a Healthy Relationship with the Child(ren)
   1 2 3 4 5

5) Your Ability to Set Appropriate Boundaries in Your Relationship with the Child(ren)
   1 2 3 4 5

6) Your Expectation that the Child(ren)’s Psychological Health Would Not be Affected
   1 2 3 4 5

When You Think Back on Your Decision to Become an Egg Donor, Rank the Following Factors in Terms of Their Overall Importance in Your Decision:

1) Your Relationship With the Recipients
   1 2 3 4 5

2) Personal Consequences
   1 2 3 4 5

3) Consequences for Your Family (Your Partner and Your Children)
   1 2 3 4 5

4) Broader Social Issues
   1 2 3 4 5

5) Consequences for the Child(ren)
   1 2 3 4 5

Additional Comments:

________________________________________________________________________

________________________________________________________________________

Which People in Your Life Were Most Influential in Your Decision to Become an Egg Donor?
Part Three: Your Experience in Treatment:

Please read each of the following questions and indicate on the scale that appears to the right of each question, your perceptions of the preparation, treatment, and support you received from the staff at Genesis.

Please Complete the Following Sentences Related to the Egg Donor Preparation and Orientation:

I found the Session with the Counsellor to be: Very Helpful ___ Helpful ___ Not Helpful ___

I found the Session with the Nurses to be: Very Helpful ___ Helpful ___ Not Helpful ___

I found the Session with the Doctor to be: Very Helpful ___ Helpful ___ Not Helpful ___

I found the Preparation Overall to be: Very Helpful ___ Helpful ___ Not Helpful ___

What other Information or Services Would It Have Been Helpful To You Prior to Beginning Treatment?________________________________________________________

Please Complete the Following Sentences Related to the Egg Donor Treatment:

I found the Drug Monitoring to be: Very Easy ___ Easy ___ Difficult ___ Very Difficult___

I found the Pain Management to be: Very Easy ___ Easy ___ Difficult ___ Very Difficult___

I found the Egg Retrieval to be: Very Easy ___ Easy ___ Difficult ___ Very Difficult___

What Would Have Made the Treatment Process Easier for You to Cope With? ________________

Please Indicate Your Perceptions Regarding the Support You Felt You Received from Genesis Staff:

Overall, I found the Front Desk Staff to be: Very Supportive ___ Supportive ___ Not Supportive ___

Overall, I found the Counsellor to be: Very Supportive ___ Supportive ___ Not Supportive ___

Overall, I found the Nursing Staff to be: Very Supportive ___ Supportive ___ Not Supportive ___

Overall, I found the Physicians to be: Very Supportive ___ Supportive ___ Not Supportive ___
Please Indicate Your Perceptions Regarding Your Overall Experience of Being an Egg Donor:

Overall, How Would You Rate Your Experience at the Genesis Fertility Centre?

Very Positive _____ Positive _____ Negative _____ Very Negative _____

Would You Be Willing to be Contacted in the Future to Participate in a Long-Term Follow-Up Study? Yes _____ No _____
APPENDIX B

Letter of Introduction

This letter is to ask for your participation in a study examining the experiences of egg donation for women who acted as an egg donor for a family member, friend, or acquaintance. The study is being conducted through the University of British Columbia and in conjunction with Genesis Fertility Centre. Alexia Kiaii, a Master's student in Counselling Psychology, will be using the information collected from this study as partial fulfillment of the requirements for her Master of Arts degree at UBC. The study is being supervised by Dr. Judith Daniluk, the counsellor at Genesis Fertility Centre, with whom you may have met prior to your donation. As you may or may not know, Judith is also a Professor in the Department of Educational and Counselling Psychology at the University of British Columbia.

In this study, we are interested in finding out about the factors that you considered to be important in your decision to become an egg donor, and about your experiences of participating in the egg donor program at Genesis. Egg donation is based on relatively new technology, and most programs in the United States use unknown donors who are financially compensated for their efforts. As such, currently we know very little about the decision-making and experiences of women who agree to donate their eggs to a family member, friend, or acquaintance.

We have developed the attached questionnaire, which takes approximately 15 to 20 minutes to complete. The questionnaire has been designed for the purpose of beginning to understand: why you decided to be an egg donor; the weighing you gave to a number of personal, relationship, and social factors in making your decision to become an egg donor; and your experiences of, and reactions to, participating in the egg donor program at Genesis. All women who have been egg donors at Genesis are being asked to complete this questionnaire so that we might use the information to better identify the pre- and post-donation psychosocial needs of egg donors, and to guide the type of support and medical services that we provide to those involved in the egg donor program at Genesis.

It is critical for you to know that your participation is entirely voluntary, and that you are under no obligation whatsoever to complete and return this questionnaire. The study is anonymous and completely confidential. This package was sent out by the Genesis staff, and your name does not appear anywhere on the questionnaire. If you decide to participate in the study, we ask that you NOT put your name anywhere on the questionnaire.

If you decide not to participate in this study, please just destroy the questionnaire. You do not need to provide any explanation for your decision.