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Pepperdine University  
Graduate School of Education and Psychology

EGG RECIPIENT PARENTS' EVALUATIONS OF PARENT-TO-OFFSPRING  
DISCLOSURE SCRIPTS

A clinical dissertation submitted in partial satisfaction  
of the requirements for the degree of  
Doctor of Psychology

by

Danielle Penny Vorzimer

June, 2010

Barbara L. Ingram, Ph.D. – Dissertation Chairperson

This clinical dissertation, written by

Danielle Penny Vorzimer

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

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## DEDICATION

I want to thank my husband, Andy, for his eternal optimism, patience, encouragement, and love. I am profoundly grateful for my parents, Marlene and Ted Penny, for their inspiration and constant support, without which I would be lost. I am also extremely appreciative of my step-children—Haley, Matthew, and Corey—who ground me and motivate me to be the best I can be. I am dedicating this dissertation to my grandfather, Robert M. Penny, whose hard work made it possible for me to have the unique, humbling, and extraordinary experience of earning a doctorate in clinical psychology.

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## HONORS AND AWARDS

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## LANGUAGES

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## PROFESSIONAL EXPERIENCE

Pre-doctoral Intern  
The Maple Counseling Center  
Beverly Hills, CA  
September 2009-present

- Provide psychodynamic psychotherapy in non-profit setting to children between the ages of 6 and 10 years old struggling with emotional challenges such as Generalized Anxiety Disorder, Specific Anxieties, Major Depressive Disorder, Posttraumatic Stress Disorder, problems with primary support groups, economic problems, and occupational problems
- Provide 1-2 times per week psychodynamic psychotherapy to adults between the ages of 25 and 65 suffering from disorders including Major Depressive Disorder, Generalized Anxiety Disorder, Posttraumatic Stress Disorder, Personality Disorders, problems with primary support groups, financial struggles, social skill deficits, grief and loss, and sexual orientation conflicts
- Co-facilitate Mindful Parenting group with parents and their toddlers, encouraging mindful and empathic perspectives, slowing down, narrating for their children, and examining triggers and reactions to difficult parenting situations
- Utilize family therapy sessions with clients' caregivers to address problems at home, concerns about the child/adolescent transition, goals for treatment, and appropriate interventions to employ outside of the therapeutic setting

- Participate in Infant Observation seminar: attend weekly in-home visits to observe an infant's biopsychosocial development and attachment; and provide written synopsis of observation for weekly supervision
- Attend weekly didactic seminars addressing: financial issues in therapy; play therapy; art therapy; working with Persian-American clients; psychodynamic approach to child, individual, and couples treatment; working with gay/lesbian/bisexual/transgendered clients; crisis response; theories of attachment; psychopharmacology; and working clinically with families

#### Pre-Intern Therapist

The Help Group, Coldwater Canyon Prep

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August 2008-June 2009

- Provided psychotherapy in non-public school milieu to children and adolescents between the ages of 13 and 18 years old with learning disabilities accompanied by behavioral and emotional challenges, including Major Depressive Disorder, Bipolar Disorder, ADHD, Generalized Anxiety Disorder, Posttraumatic Stress Disorder, Obsessive-Compulsive Disorder, Oppositional Defiant Disorder, Trichotillomania, social skill deficits, concentration difficulties, task avoidance, low frustration tolerance, deficits in empathy and perspective, poor anger control, and impulsivity
- Co-facilitated group therapy to encourage development in the areas of peer-to-peer communication, conflict resolution, emotional processing, and anger management
- Utilized family therapy sessions with clients' caregivers to address problems at home, concerns about the child/adolescent transition, goals for treatment, and appropriate interventions to employ outside of the school setting
- Collaborated with teachers, teachers' assistants, school staff, psychiatrists, case managers, LCSWs, medical doctors, behaviorists, interns, occupational therapists, and speech therapists in order to ensure a systematic, consistent, multi-disciplinary approach to treatment
- Submitted Initial Assessments, Client Care Coordination Plans, and other Department of Mental Health intake and progress paperwork to ensure accurate goal setting, suitable interventions, and program appropriateness
- Received Professional Training in "Pro-Act" (a risk management, safety enhancement tool seeking to establish a zero-restraint environment)
- Attended weekly didactic seminars addressing: ethical and legal issues with children; bi-polar disorder; working with children with autism-spectrum disorders; play therapy; art therapy; psychodrama; psychodynamic approach to teamwork

### Pre-Intern Therapist

San Fernando Valley Community Mental Health Center's Homebound Program  
Van Nuys, CA.

August 2007-June 2008

- Provided in-home and clinic-based psychotherapy to older adults (60+ years) and physically ill and disabled adults between the ages of 43 and 88 years old, presenting with a wide variety of disorders including Generalized Anxiety Disorder, Panic Disorder with and without Agoraphobia, Posttraumatic Stress Disorder, Bipolar Disorder, Major Depression, Adjustment Disorder, Relational Problems, Bereavement, and Age-Related Cognitive Decline
- Collaborated with psychiatrists and other mental health professionals in client medication monitoring and psychiatric evaluations
- Evaluated and updated Client Coordination Plans to include current client goals, progress, and medication charts
- Coached client care providers, adult children, and other client family members on working with the disabled and elderly adults in home environments
- Submitted Adult Initial Assessments, intake interviews, and other Department of Mental Health intake paperwork to ensure accurate goal setting and program appropriateness

### Pre-Intern Therapist

The Child Development Institute  
Woodland Hills, CA.

August 2006 – July 2007

- Provided therapy to clients 18 months to 4 years old in school, clinic and/or home setting using floortime and behavioral approaches with children diagnosed with disorders on the autism spectrum, developmental disorders NOS, and mental retardation, as well as children presenting with ADHD-like symptomatology, partial deafness, verbal delays, and learning disabilities to improve communication skills, attention span, social appropriateness, positive familial dynamics, and functional play
- Facilitated social skill groups in clinic to foster growth in the areas of peer-to-peer interest, communication, and play
- Coached parents on discipline techniques, communication, and boundary setting to foster child's independence in social, academic, and home environments
- Collaborated with teachers, interventionists, occupational therapists, speech therapists, case managers, medical doctors, and interns in order to ensure a systematic, consistent, multi-disciplinary approach to treatment
- Submitted daily, monthly, and yearly reports in order to document clients' goals and progress
- Executed intake interviews with parents in order to ensure accurate goal setting
- Assisted use of Bailey and Millen Assessment tools to provide recommendation for client hours to Regional Centers

Case Manager  
Egg Donation, Inc.  
Encino, CA

August 2004 – January 2007

- Coordinated and managed cases for the country's first and largest egg donation program in order to facilitate pregnancy for infertile individuals
- Served as the principal liaison between the psychological, medical, and legal professionals to assure that all applicable government and inter-disciplinary protocols and guidelines were satisfied
- Corresponded daily with recipient couples, egg donors, nurse coordinators, attorneys, insurance agencies, and travel agencies to ensure multi-disciplinary support for each case
- Worked closely with mental health professionals on recipient couple and egg donor screenings, assessments, and issuance of clearance documents to meet ASRM guidelines
- Counseled couples and donors informally during their involvement in the egg donation process in order to facilitate smooth, efficient, and positive experiences for all parties

#### PROFESSIONAL ORGANIZATIONS

American Psychological Association  
Los Angeles County Psychological Association  
The American Society of Reproductive Medicine, Mental Health Professionals Group  
The National Society of Collegiate Scholars  
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Proficient in MS Word, MS Powerpoint, MS Outlook, MS Excel, Word Perfect, Quickbooks, Adobe Acrobat, Adobe Photoshop, Virtual Private Networks, and most Internet applications



## ABSTRACT

This study focuses on *parent-to-offspring* (PTO) disclosure, the dialogue from parent to child about the child's genetic makeup, with the intention of contributing to the creation of resources for egg recipient parents struggling with PTO disclosure decisions. A comprehensive literature review synthesized the literature on the disclosure decision, identifying key controversial issues. The principal investigator then created nine disclosure scripts based on the qualitative research of Mac Dougall, Becker, Scheib, and Nachtigall (2007) as well as a book written by a psychologist working in the field of third party reproduction. Egg recipient parents were invited to evaluate the scripts and provide additional information about the PTO decision process through an online survey. Fifty-two completed surveys were analyzed, a 4% response rate. Participants were predominantly mothers, married or partnered, American, Caucasian, heterosexual, highly-educated, and with children under five years old. Findings provide evidence for the need of script resources and the benefit of professional consultation to reach a disclosure decision. Further analyses were conducted after classifying participants into three categories: Disclosers (59.1%), Non-disclosers (18.4%), and Undecided (22.5%). The Disclosers rated two scripts significantly higher than the others, suggesting the usefulness of "Helper" and "Come and Talk" approaches with very young children. The discussion addresses limitations of the study, recommendations for professionals, and directions for future research. The review of the literature and this study's findings demonstrate the need for increased efforts towards identifying and disseminating helpful PTO resources to gamete recipient parents.

## Chapter 1. Introduction

Gamete donation, a method of conception that has been available since 1883, has given life to hundreds of thousands of children worldwide, and made parenthood an option for individuals with non-viable sperm or eggs. Whereas the medical technology of reproductive cell donation is well-established, the psychological impact of this method of reproduction on the offspring continues to present challenges to parents, researchers, physicians, and mental health professionals. This dissertation addresses one such challenge: the profound decision parents face of whether and how to inform their donation conceived offspring (DCO) of their genetic heritage.

*Parent-to-offspring* (PTO) disclosure, the focus of this dissertation, refers to the dialogue from parent to offspring about the child's genetic origins. Although the ongoing debate of whether or not to disclose to DCO is widely documented in both the professional literature and in the popular media, it remains without resolution. Recipient parents continue to struggle with the profound and complex decisions regarding if, how, and when to tell. Researchers are just beginning to understand the multifaceted aspects of the disclosure issue. For instance, several investigators have organized and documented gamete recipient parents' attitudes and reasons for and against PTO disclosure and non-disclosure (Australia's Infertility Treatment Authority, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hershberger, Klock, & Barnes, 2007; Leiblum & Aviv, 1997; Nachtigall, Becker, Quiroga, & Tschann, 1998; Shehab et al., 2008). Reports have also been collected from DCO discussing their opinions about the appropriate timing of disclosure and both favorable and unfavorable disclosure methods (Kirkman, 2004; Scheib, Riordan, & Rubin, 2004; Turner & Coyle, 2000). These studies have provided

invaluable information about DCO and their families; however, more longitudinal research is needed to fully understand the complexities involved.

Despite the growing number of studies addressing aspects of PTO disclosure, there continue to be large gaps in our understanding of the decision process and outcome. The majority of offspring research involves a population of adults born from sperm donation, as that procedure has been practiced for over 100 years. There are far fewer studies collected about egg donation conceived offspring (EDCO), and it is not clear whether results from sperm donation studies can be generalized to EDCO. More relevant to this study is that there is no research addressing parents' need for resources to help them make effective and appropriate PTO disclosure decisions.

The many unexplored factors relevant to PTO disclosure decisions are relevant to both reproductive medicine and clinical psychology. The need for more helpful resources for recipient parents is addressed comprehensively in this review. Recipient parents' requests for disclosure-related assistance have been repeatedly documented in the literature, warranting the investigation of potentially useful clinical interventions for working with this population (ASRM Ethics Committee, 2004; Australia's Infertility Authority, 2007; Cook, Golombok, Bish, & Murray, 1995; De Jonge & Barratt, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hershberger et al., 2007; Leiblum & Aviv, 1997; Mac Dougall et al., 2007; Mahlestedt & Greenfeld, 1989; Murray & Golombok, 2003; Rumball & Adair, 1999). Despite parents' requests for assistance, no empirically-validated disclosure-related interventions have been established for this population.

## **Purpose and Importance of the Study**

The topic of the current study was largely influenced by the principal investigator's (PI) experience working with infertile women, couples, and egg donors. In the role of case manager at the egg donation agency from which participants for this study were recruited, the PI worked intimately with recipient parents and began to feel emotionally invested in the outcomes of cycles and the offspring conceived. The PI first learned about the issues of disclosure while attending an American Society for Reproduction conference in Montreal, Canada in October 2005. PTO disclosure was addressed during conference seminars, which inspired the proposal of this study's topic and dissertation. Thus, both personal experiences of connecting with infertile individuals and being exposed to disclosure theory and research impassioned the PI to pursue work in this field. As a result of this project, the PI expects to acquire tools to utilize in the future as a mental health professional when working with children and families who were created via gamete donation.

Research indicates that parents want resources to facilitate PTO, and one such resource might be samples of scripts that other recipient parents have endorsed as effective. The purpose of this research was to conduct a descriptive study assessing egg recipient parents' desire to read PTO disclosure scripts, and to obtain their appraisals of several scripts. It is the responsibility of mental health practitioners working in the field of third party reproduction to provide objective information about disclosure as well as to provide effective assistance to families struggling with issues relating to conception. The results of the present study have the potential to assist parents in these goals, as they

provide one step towards the development of a resource that will facilitate parents' disclosure to their children, should they choose to do so.

Recipient couples and DCO experience psychological challenges that are distinct from other populations, such as access to an accurate medical history. The challenge of discussing genetic origins that are different from one's parents can make it difficult to navigate situations often taken for granted by naturally-conceived families. Although PTO disclosure has not been proven to be necessary to a child's healthy development, research studies suggest that disclosure has either neutral or positive effects.

Specific scripts may benefit those parents for whom not knowing what to say is the main obstacle to disclosure. Several reports indicate that the experience of not knowing how to disclose may prevent recipient parents from considering the option of telling their children the truth about their true genetic makeup (Australia's Infertility Treatment Authority, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Leiblum & Aviv, 1997). Recipient parents in these studies report that the act of maintaining the secret of gamete donation can be anxiety provoking and distressing, reactions that could perhaps be avoided if parents had access to more helpful resources.

Many recipient couples who participate in research ask their investigators what other recipient parents have decided regarding if, how, and when to disclose to their children (Australia's Infertility Treatment Authority, 2007; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hershberger et al., 2007; Mac Dougall et al., 2007). No research has explored recipient parents' evaluations of scripts used by other recipient parents who have disclosed to their children. However, one study has provided professionals with an initial understanding regarding the patterns of disclosure among

this population (Mac Dougall et al., 2007). Using qualitative methods and coding procedures, Mac Dougall and researchers documented a number of disclosure script themes used by recipient parents to disclose to their children. Describing recipient parents' responses to script themes used by other recipient parents will facilitate the development of effective resources for the disclosure decision process. Therefore, the purpose of the current study was to evaluate the benefit of reading scripts reflecting Mac Dougall et al.'s (2007) research data, with the hope that the scripts will help recipient parents make appropriate disclosure decisions.

### **Definitions of Key Terms**

**Third party reproduction.** Human conception via donated gametes, embryos, gestational carrier, or surrogate (Burns & Covington, 2000).

**In-vitro fertilization (IVF).** A procedure in which sperm and an unfertilized egg are placed together in an artificial environment (e.g., test tube) to achieve fertilization, and the resulting embryo is placed into the woman's uterus (Williams & Wilkins, 1995).

**Gestational carrier.** (i.e., surrogate) Woman who carries a pregnancy for another person/couple (when the offspring is not genetically related to the surrogate; Burns & Covington, 2000).

**Gamete.** Germ cell, such as ovum or sperm (Williams & Wilkins, 1995).

**Recipient parent.** An adult man or woman who obtains donated gametes in the hopes of becoming a parent (Sauer, 1998).

**Egg donation (ED).** The process by which one woman's eggs are given to recipient parent(s). Alternative names for egg donation include oocyte or ovum donation (Sauer, 1998).

**Donor Insemination (DI).** Introduction of a man's donated sperm into a uterus (Sauer, 1998).

**Egg donation conceived offspring (EDCO).** Children born by means of donated eggs

**Sperm donation conceived offspring (SDCO).** Children born by means of donated sperm

**Donation conceived offspring (DCO).** Children born by means of fertilizing either donated eggs or donated sperm

**Donor anonymity.** Term used when little or no identifying information about the gamete donor is provided to the gamete recipient parents (Burns & Covington, 2000).

**Parent-to-offspring (PTO) disclosure.** Term used by the PI referring to the means by which recipient parents tell their gamete donation offspring that they were conceived by means of obtaining donated gametes.

## **Summary**

The major objective of this research was to conduct a descriptive study addressing egg recipient parents' desire to read PTO disclosure scripts and their appraisal of a variety of scripts. To assist in determining the content of the current study's disclosure scripts, an extensive literature review was conducted. The scripts were created by the PI using contributions of data generated by Mac Dougall et al.'s (2007) research and suggestions from a book written by a psychologist working in the field of third party reproduction (Friedman, 2007). A questionnaire to gather recipient parents' opinions of the scripts was created and administered on an online survey site. The questionnaire also gathered data measuring general disclosure-related issues such as participants' receipt of

professional advice on disclosure, participants' category of disclosure status (disclosers, non-disclosers, or undecided), perceived difficulty or ease with which they have made disclosure decisions, and interest in receiving assistance or accessing relevant resources. In the following chapters, the recipient parents' responses will be documented, the author will present recommendations for future research, and implications for clinical practice with gamete-recipient parents will be discussed.



## **Chapter 2. Review of the Literature**

The following literature review will provide a historical background of gamete donation, present a brief overview of gamete donation laws, address the controversies surrounding egg donation, describe research data on the psychological well-being of children born via gamete donation, identify issues related to donor anonymity, and illustrate how the literature presents arguments for and against PTO disclosure. In addition, it will provide evidence for recipient parents' need for PTO disclosure resources.

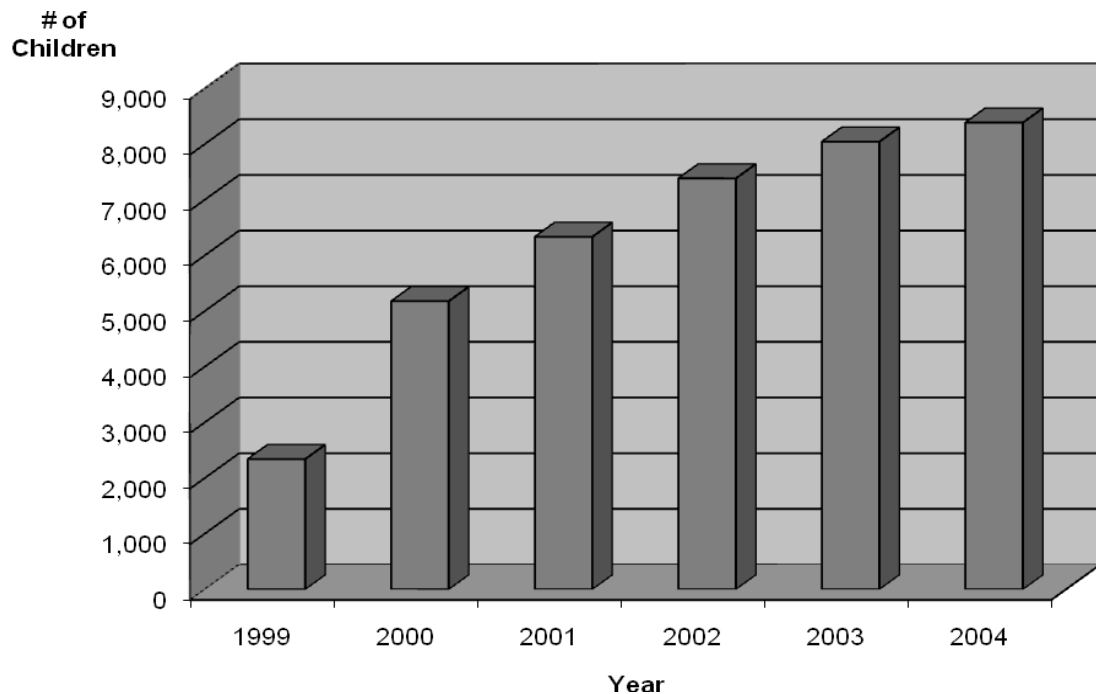
### **Search Process**

The journal articles, book chapters, reference books, and other resources utilized for this literature review were accessed via several methods. Web-based searches were primarily initiated via library databases including PubMed, PsycINFO, and PsycARTICLES, and references were organized utilizing RefWorks. The search terms utilized included, "egg donation," "oocyte donation," "gamete donation," "embryo donation," "infertility," "third party reproduction," "egg donation, offspring," "egg donation, disclosure," "gamete donation, disclosure," "family secrets," "adoption, disclosure," "egg donation, telling children," and "gamete donation, telling children." Resources relating to gamete donation were also acquired by accessing library catalogues, bookstores, and engaging in personal correspondence with experts in the field of third party reproduction.

### **Background Information**

Across the globe, donated gametes have allowed the expansion of families for over 100 years. In the U.S., data collected from the Department of Health and Human

Services' Centers for Disease Control (CDC), found that between the years of 1999 and 2003, approximately 29,275 children were born as a result of donated eggs (see Figure 1), less than half the number of children born from the use of donated sperm (Wright, Chang, Jeng, & Macaluso, 2006; Wright, Schieve, Reynolds, & Jeng, 2003; Wright, Schieve, Reynolds, & Jeng, 2005; Wright, Schieve, Reynolds, Jeng, & Kissin, 2004).



*Figure 1.* Number of children born from egg donation in the U.S. per year

In 2004, the most recent year for which data have been published, 8,386 children were born from egg donor conceptions, with the number continuing to steadily rise (Wright, Chang, Jeng, Chen & Macaluso, 2007). In the United Kingdom, more than 37,000 babies have been born from donated gametes and embryos (Human Fertilisation and Embryology Authority, 2007), with recent figures predicting that between 1998 and

2010, some 45,000 children will have been born in the UK by donor-assisted conception (Blyth, Cranshaw, & Speirs, 1998). Each year in Australia, more than six hundred children are created through the use of donated sperm, eggs, or embryos, the relatively smaller figure attributable to Australia's strict laws and regulations surrounding third party reproduction (Waters, Dean, & Sullivan, 2006). Unfortunately, data have not been published revealing the number of DCO born in non-English speaking countries; however, as more countries begin to require national registries, it can be expected that, in the near future, those data will become available.

The first documented case of artificial insemination using donor semen took place in America in 1883 (Snowden, Mitchell, & Snowden, 1983). One century later, the first report of a successful donor-assisted conception using donated eggs was published in Melbourne, Australia (Trounson, Leeton, Besanko, Wood, & Conti, 1983). The egg donation process is now fairly uniform, and is described in detail by Burns and Covington (2000). The first steps typically include a medical screening and a psychological evaluation of the donor. These steps are taken to assess the donor's physical and mental appropriateness, as well as to ensure her informed consent and willingness to proceed. The medical procedures begin with the donor receiving an injection of a hormone used to synchronize her menstrual cycle with the egg recipient mother's or surrogate's menstrual cycle. The donor then begins daily injections of hormones to stimulate her ovaries. When the ovarian follicles are adequately mature, the donor receives an injection of a hormone used to trigger ovulation; and soon after this injection, the donor undergoes the egg retrieval procedure. The medical procedure requires a twilight sedation and is typically an outpatient procedure. The average egg

donation cycle lasts approximately three weeks from the first hormone injection until the egg retrieval procedure. Soon after the egg retrieval aspiration, the retrieved eggs are generally fertilized in vitro with the sperm from a donor or the recipient father, and the embryos are typically either cryopreserved (frozen) or transferred into the recipient parent or gestational carrier.

**Gamete donation laws.** The practice of gamete donation is widespread and has been recognized for decades; however, much debate continues to exist around the world regarding its use. In fact, egg and sperm donation are forbidden in several countries for religious and/or cultural reasons (Jones & Cohen, 2007). Donor eggs are not allowed by law in Germany, Italy, Norway, Switzerland, Tunisia, Turkey, China, Croatia, Egypt, Japan, Morocco, or the Philippines. Egg donations can, however, take place in 21 other countries, including Argentina, Australia, Brazil, Chile, France, Greece, Hong Kong, India, Israel, Mexico, the Netherlands, Singapore, Spain, South Africa, Thailand, the United Kingdom, and the United States (Jones & Cohen, 2007). Donor sperm are not allowed by law to be used for IVF in Austria, Germany, Italy, Tunisia, Turkey, Egypt, Japan, Morocco, or the Philippines. However, it is legal to donate sperm in 23 countries, including France, Norway, Sweden, Argentina, Australia, Brazil, Chile, China, India, Lithuania, Mexico, Singapore, South Africa, Thailand, and the United States (Jones & Cohen, 2007). Individuals living in countries that outlaw gamete donation frequently travel to other countries to pursue treatment.

**Psychological implications of gamete donation.** Longitudinal research has examined gamete recipient families, and findings suggest that DCO are generally well-adjusted and psychologically stable (Golombok, et al., 2004; Mac Dougall, et al., 2007;

Murray, MacCallum, & Golombok, 2006; Scheib et al., 2004). One study compared egg donation families, sperm donation families, adoptive families, and families created via IVF, in order to investigate parents' emotional well-being, quality of parenting, and children's socioemotional development (Golombok, Murray, Brinsden, & Abdalla, 1999). To address their research questions, the authors used questionnaires assessing marital quality and parenting stress, standardized interviews, and the observations of children. They found that families with DCO reflected greater psychological well-being among mothers and fathers when compared to families with a genetic link between both parents and child. The authors provide a theoretical explanation for this finding, suggesting that infertile couples who choose to raise DCO may be even more committed to parenthood and may find parenting more satisfying than those parents who conceived via traditional methods (Golombok et al., 1999).

Later research by Golombok and associates (2004) also found more positive parent-child relationships among gamete donation families when compared to naturally conceived families. These authors found greater emotional involvement between parents and children, and concluded that "infants conceived by egg or sperm donation did not appear to be at risk for parenting difficulties" (Golombok et al., 2004, p. 443). Such evidence suggests that many DCO-parent relationships may have healthier attachments than those traditionally conceived. With no evidence to date that the act of conceiving via gamete donation is damaging to the child-parent relationships, recipient parents and mental health practitioners working with the infertile population can be assured that gamete donation in-and-of itself does not predict offspring-parental conflict.

**Donor anonymity.** Historically, medical practitioners and governmental agencies have endorsed the utmost anonymity in gamete donations, implying that no information about the donor was to be given to the recipient parents. Anonymity was highly recommended or even required. In the first published case of embryo-donated conception, “The [Australian] ethics committee...allowed oocyte donation provided that the donor and recipient remained anonymous” (Trounson, et al., 1983, pp. 837-838). While anonymity was presumably easier for medical practitioners to navigate than non-anonymity, total anonymity is arguably dangerous in light of the many medical and psychological disorders now understood to be genetically-based.

Governmental agencies began scrutinizing anonymity regulations in the late 1980s, bringing the benefits of secrecy into question. A handful of countries have since taken steps towards mandating non-anonymity by writing legislation requiring all gamete donors to provide personal information to national registries, with the intent of making it possible for donor-conceived adults to learn about their donors. Sweden was the first country, in 1985, to make legislative provisions for the person conceived by gamete donation to have access to donor information (Gunning, 1998). Austria, Switzerland, Australia, the United Kingdom and the Netherlands have similar legislation in place (Loughnane & Kirkman, 2006; Mac Dougall, et al., 2007). An alternative has been established in the United States, where a double-track system allows for the donors to choose between anonymity and identification, as well as allowing the recipients the choice between an anonymous and an identifiable donor (Rumball & Adair, 1999).

While many government agencies, professionals, and national organizations still require or advise non-anonymity, it has been suggested that gamete donors and recipients

may prefer some anonymity. In a study of 504 former egg donors and 363 recipients in the UK, 36.4% of the donors reported that they would not have participated had donor anonymity been waived, and 69.1% reported they would donate anonymously again. Of the recipients questioned, 53.5% would not have proceeded had donor anonymity been waived, and 96.5% would receive anonymously donated eggs again (Craft, et al., 2005). These data suggest that requiring known (non-anonymous) donations would reduce the number of adults willing to donate eggs or sperm, thereby decreasing the number of donors available to recipient parents.

Donor anonymity is a complicated issue, especially as it relates to PTO disclosure. Although the two issues are distinct, some recipient parents have argued that they do not want to disclose to their children if they cannot provide substantial information about the donor to the child. This argument is one of several that are discussed in more detail below.

**Parent-to-offspring disclosure.** There exists tremendous variability in reports of disclosure patterns across the globe, with a trend appearing to grow in the direction of disclosure (see Table 1). Reviewing the available studies chronologically, it appears that from 1995 to 2007 there was an attitude change in favor of disclosure. While more research is needed to confirm the reliability of the trend, researchers are beginning to explore and understand mechanisms influencing recipient parents' disclosure decisions, such as how and when disclosure takes place.

Table 1  
*Reported Percentages of PTO Disclosure Found in Previous Research*

<b>Publication</b> (Chronological Order)	<b>Participants</b>	<b>Methods</b>	<b>% of Disclosers</b>	<b>% of Non-Disclosers</b>	<b>% of Undecided</b>
Cook et al., 1995	45 DI Parents	Quantitative; Semistructured interviews	4%	80%	16%
Nachtigall et al., 1998	156 DI Parents	Qualitative; Self-administered questionnaires	30%	54%	16%
Rumball and Adair, 1999	181 DI Parents	Quantitative; Self-administered questionnaires	77%	17%	6%
Broderick and Walker, 2001	265 DI and 19 ED Parents	Quantitative; Self-administered questionnaires	31%	62%	7%
Hahn and Craft-Rosenberg, 2002	58 ED Parents	Qualitative and Quantitative; Semistructured interviews	57%	19%	24%
Becker et al., 2005	62 DI and 79 ED Couples	Qualitative; Semistructured interviews	80%	12%	8%
Mac Dougall et al., 2007	48 DI Couples	Qualitative; Semistructured interviews	77%	16%	7%
Mac Dougall et al., 2007	64 ED Couples	Qualitative; Semistructured interviews	81%	10%	9%

**The disclosure debate.** Historically, issues surrounding gamete donation were largely addressed by physicians and nurses. In an early medical article on the scientific aspects of sperm donation, Behrman (1959) wrote that couples “should be advised for their own protection that discussion of the [donor insemination] should preferably be limited to their physician and themselves, or at most to include their religious counselors” (p. 250). It was only in the early 1990s that mental health professionals began actively exploring the many complex challenges that exist in the third party reproductive field,



including PTO disclosure. Some indications suggest that medical practitioners continue to advise non-disclosure (Shehab, et al., 2008); however, this advice is becoming much rarer. Whereas non-disclosure was explicitly advised by physicians during early years of gamete donation, evidence suggests that secrecy has become less popular. Although disclosure trends have shifted, the disclosure decision continues to be controversial, an issue that is debated by mental health professionals, physicians, parents, and even major organizations involved in the field of third party reproduction.

No current legislation has been established mandating PTO; however, several organizations have published recommendations to be utilized by professionals working in the field of third party reproduction. The American Society for Reproductive Medicine (ASRM) published an Ethics Committee Report that supports disclosure from parents to offspring about the use of donor gametes in their conception, and, if available, non-identifying characteristics of the donor which “may serve the best interests of offspring” (2004, p. 527). This report further presents considerations for disclosure, citing the potential legal right for all human beings to know their biological origin, the violation of a child’s autonomy in the case of non-disclosure, the potential effect of secrecy on a child’s self-esteem and/or strain on the family relationships, and the indication from research that disclosure of conception may have a positive effect on the parent/child relationship. The committee also cites growing acceptance of disclosure among medical professionals as they have begun to work more closely with mental health practitioners.

A more ambiguous contribution to the disclosure debate can be found in the United Nations Convention on the Rights of the Child (1989) which proposes that “we must undertake to respect the right of the child to preserve his or her identity, including

nationality, name and family relations as recognized by law without unlawful interference” (Part 1, Article 8). Many have argued that the meaning of the UN statement includes providing children with information about their genetic origins; however, this claim is speculative (Rumball & Adair, 1999). It is crucial for psychologists, researchers, and medical professionals to consider the empirical research surrounding the disclosure decision in order to more comprehensively understand the factors relevant to recipient parents’ decision about whether or not to tell.

Many articles present arguments for and against disclosure to DCO (Australia’s Infertility Treatment Authority, 2007; Daniels & Taylor, 1993; Ethics Committee of the American Society for Reproductive Medicine, 2004; Kirkman, 2003; Lycett, Daniels, Curson & Golombok, 2004; McWhinnie, 2001; Midford, 1996; Murray et al., 2006; Murray & Golombok, 2003; Nachtigall et al., 1998; Rumball & Adair, 1999; Shenfield & Steele, 1997; Snowden et al., 1983; Sokoloff, 1987; Walker & Broderick, 1999). However, much of the literature on donor offspring tends to be strongly argued opinion from medical and mental health professionals, rather than empirically based research. Opinions for and against disclosure are typically rooted in philosophical, psychological, and medical concerns. There are, however, a handful of empirical studies that address the impact of disclosure on DCO. Appendix A provides an itemization of the most important research studies addressing the implications of disclosure on DCO.

Unfortunately, relatively small sample sizes and lack of longitudinal data may prevent empirically-validated studies from accurately representing the disclosure decision’s effects on the children and families of gamete donation. Several factors make it difficult to collect data from DCO, such as HIPAA confidentiality laws. Additionally,

many recipient parents and DCO may avoid participating in studies relating to gamete donation for fear that their community will have access to their private information.

Another problem may be that not enough DCO know their true genetic origins, making it difficult to locate DCO who are in the know and willing to participate in related research. Luckily, with current trends shifting towards disclosure, we may see more research on this topic become available in the future.

### **Disclosure Debate Issues**

The most frequently cited disclosure debate issues include: (a) risk of psychological damage to the child; (b) recipient parents' shame surrounding infertility; (c) risk that the child will reject the parents; (d) risk of negative consequences from unintended disclosure; (e) offspring's moral right to know their genetic makeup; (f) honesty as an ethical principle/negative effects of secrecy; (g) lack of information about the donor; and (h) the relevance of adoption research. Although some of these categories overlap with one another, together they represent a comprehensive perspective on the disclosure debate.

**Risk of psychological damage to the child.** Theorists have suggested that protecting the couple and child from existing negative societal attitudes about gamete donation is a valid rationale for non-disclosure (Nachtigall, Tschann, Quiroga, Pitcher, & Becker, 1997). The relevance of societal stigma is also documented in Shehab and colleagues' (2008) qualitative research on 141 married couples with DCO. The authors reported that many of the participants indicated that their residency in a "progressive" area of the country (Northern California) made their decision to disclose easier because they believed their DCO would be well accepted by others (Shehab, 2008). These

researchers suggest that “the prevalence and acceptance of the use of assisted reproductive technologies, existing models for alternative family structures (e.g., adopted, single parent, gay/lesbian, multiracial, multicultural), and a politically liberal environment” (Shehab et al., 2008, p. 181) contributed to a decreased perception of societal stigma relating to the use of donor gametes. In terms of increasing community awareness of gamete donation, disclosing parents in the same study reported that “being open with information was best for society in general” (Shehab et al., 2008, p. 183). This perspective argues that secrecy contributes to social stigma, as non-disclosure prevents DCO from normalizing the experience within the greater community.

One small qualitative research study assessing the psychological effects of PTO disclosure on 29 SDCO adolescents found that most of the participants were somewhat to very comfortable about their parents’ use of donor sperm to conceive. When asked why they felt this way, 44% reported that having been the result of donated sperm “did not affect their life,” and one participant stated, “It’s all I know” (Scheib et al., 2004, p. 243). In the same study, 40% of the youth reported feeling very loved, wanted by their family, and unique in a positive way; and 8% reported being very comfortable with their origins because “it was much more preferable than being conceived in other ways (e.g. casual sex)” (p. 243). Only 8% of the sample reported feeling neutral or uncomfortable about their conception. Unfortunately, the research findings do not include mention of the timing or methods of disclosure, which are important considerations when determining the effects of PTO on children. Additionally, the small sample size of the study and the lack of EDCO participants make it difficult to generalize the findings to other populations.

Lycett and colleagues (2004) conducted qualitative research using standardized interviews and questionnaires to examine the effects of PTO disclosure on 46 families with SDCO aged four to eight years. The authors found that mothers from disclosing families reported significantly fewer and less severe arguments with their children, considered their children to show a lower level of conduct problems, and found their children to be less of a strain than mothers from non-disclosing families. Additionally, the disclosing parents viewed themselves as more competent at parenting than did the non-disclosing parents. Unfortunately, the researchers again did not assess the timing or methods of disclosure, nor did they include EDCO participants. The data collected do, however, provide preliminary evidence that disclosure may be psychologically beneficial not only for the offspring, but for recipient parents, as well.

**Recipient parents' shame surrounding infertility.** The psychological impact of infertility is undoubtedly profound. Indeed, one quantitative study documented that infertile women report equivalent levels of anxiety and depression as women suffering from heart disease, cancer, and HIV+ status (Domar, Zuttermeister, & Friedman, 1993). In a qualitative study of 185 infertile couples, Abbey, Andrews and Halman (1991) found that infertile women perceived their infertility as more stressful and felt more responsible for it than did infertile men. In a different qualitative study of 22 infertile couples, the majority of women reported that their infertility caused a catastrophic failure that prevented them from leading normal lives; while their husbands tended to see infertility as a distressing event, but not tragic (Greil, Leitko, & Porter, 1988). Given the gender differences observed in such studies, using donated eggs may be arguably more distressing to the family unit than utilizing donated sperm. In general, it has been

hypothesized that unresolved issues surrounding fertility problems may make disclosure decisions difficult to process cognitively and emotionally (McWhinnie, 2001; Salter-Ling, Hunter, & Glover, 2001). The indignity, shame, and trauma of infertility may prevent recipient parents from actively addressing issues relating to the use of donor gametes, such as PTO disclosure.

An example of recipient parents' desire to avoid confronting issues associated with the donation is found in Shehab et al.'s qualitative research on 254 recipient parents (62 couples who utilized donated sperm; 79 couples who received donated eggs). Using in-depth ethnographic interviews, these researchers found that several of the non-disclosing parents used expressions such as "we just don't think about [the donation]," "we don't mention it," and "we've decided to deal with it by not dealing with it" (2008, p. 184). These forms of passive responses to PTO disclosure decisions may indicate a need for mental health practitioners to address how the psychological implications of infertility might affect important decisions relating to gamete donation and offspring.

**Risk that the child will reject the parents.** Australia's Infertility Treatment Authority suggests that it is possible but rare for DCO to reject their parents in response to PTO disclosure (ITA, 2007). These authors posit that rejection is often a result of pre-existing conflict between offspring and parents, as well as a variety of extraneous variables including the age and gender of the offspring. Similarly, Midford (1996), a psychologist with clinical experience working with adopted children and DCO argues that, "The fear that the child will reject the parents [after disclosure has taken place] is overwhelmingly groundless...If rejection happens there are other factors in the relationship which have caused it" (p. 2). While these resources provide interesting

arguments, the hypotheses are largely theoretical and do not appear to be based upon empirical findings.

Demonstrating empirical evidence of offspring's response to PTO disclosure, Scheib and colleagues' (2004) qualitative and quantitative research on 29 SDCO adolescents between the ages of 12 and 17 years old describe overall positive effects of disclosure. Responding via mail-back questionnaires, all but one of the participants reported that knowing their donor origins "had a neutral to positive impact on their relationship with their birth mother" (p. 239). Furthermore, most of the participants (75.9%) reported being "somewhat to very comfortable with their conception origins" (p. 239). When asked to rate the level of comfort they felt about their parents having used a donor, most of the participants reported being somewhat to very comfortable, with all but two responding at least neutrally. Unfortunately, this research measured a small sample population, does not provide information regarding participants' cultural identities, and it lacks specific information about the timing and methods of disclosure, making it difficult to generalize findings. While these preliminary data are promising, future research measuring outcome of PTO disclosure is warranted.

**Risk of negative consequences from unintended disclosure.** It has been proposed that the relationship between the non-genetic parent and the child, as well as the child's psychological stability, are at risk if information about the donor conception is unexpectedly revealed in an otherwise non-disclosing family (Walker & Broderick, 1999). Disclosing parents from a recent qualitative study ( $n=108$ ) reported that "nondisclosure was not a secret that could be kept" (Shehab et al., 2008, p. 183). Reported in ethnographic interviews, the parents "considered a pragmatic assessment of

the likelihood that the information could be kept hidden” (p. 183). The participants cited three reasons for this argument: (a) responses from people noticing that the child looked markedly different from the parents; (b) accidental “slips” by individuals who had been told of the child’s genetic origins; and (c) the child’s unavoidable discovery of their genetic heritage through future technology or “an experiment in high school biology class” (p. 183). Turner and Coyle (2000) conducted qualitative research on 16 SDCO between the ages of 26 and 55 years, and found that sudden, unintentional or unplanned disclosure during adolescent years and beyond may result in difficulty for offspring to assimilate the new information, which may threaten their existing identities.

The theory that unintended disclosure may be harmful to DCO has been empirically supported in two published studies. Kirkman (2003) completed qualitative research measuring a small sample of 12 DCO who learned of their genetic origins post-childhood. Although the author does not address the timing or means by which disclosure took place (e.g., from a parent, other family member, outsider, etc.), the research documents that several of the DCO participants reported understanding that their parents had “wanted a baby so badly” that they had deprived them of knowing of their genetic heritage; however, the participants also reported that “this was seen, nevertheless, as a severe deprivation, including ignorance of medical history and a fractured sense of identity” (Kirkman, 2003, p. 15). McWhinnie’s (2001) discussion of studies documenting interviews with DCO reported that many DCO “wished they had been told much earlier” (p. 812). Despite the small sample sizes of these studies, consistency of the findings suggests that it may be better for DCO to learn of their genetic makeup early on from the parents, rather than in a context outside of the family unit.



**Offspring's moral right to know their genetic makeup.** Several authors have argued that DCO have a right to know their genetic composition, especially in light of medical predispositions, future sexual partner choices, and general self-concept knowledge (Blyth, 2002; Hershberger et al., 2007; Kirkman, 2004; Shehab et al., 2008; Snowden et al., 1983; ITA, 2007; Turner & Coyle, 2000). In Loughnane and Kirkman's (2006) review of gamete donation literature, the authors suggest that the child's right to know represents "a basic human right to have information about one's family, the need for knowledge that could be medically relevant (such as the presence of inherited disorders), and the desirability of avoiding marriage (and the conception of children) with a close blood relative" (p. 8). It is also argued that, in the case of a medical emergency, an individual ought to have as much information about his/her genetic composition as possible. This "right to know" perspective has been acknowledged in several publications, including Rumball and Adair's (1999) description of the U.S. Nations Convention on the Rights of the Child (1989), which states that we must "undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference" (p. 1392). From another perspective, an early book describing the results of a qualitative study on 66 SDCO adults provides a more philosophical approach to the "right to know" debate:

The right of a small baby to such a complex and abstract matter as an accurate knowledge of his own origins can, parents feel, be safely and honourably ignored. But there is evidence from the interviews with older couples, that as the child grows older his or her rights begin to exert a greater claim for consideration and begin to compete with the right of the husband to secrecy (Snowden et al., 1983, p. 120).

Current research also suggests that the “right to know” argument is a factor considered by recipient parents making disclosure decisions. Using qualitative, phenomenological methods to investigate the controversy surrounding disclosure, Hershberger and colleagues (2007) interviewed egg recipient mothers between 9-23 weeks of pregnancy. The researchers found that the participants’ disclosure decisions were influenced by various factors emerging from the women’s beliefs and values, as well as from their social and cultural environments (Hershberger et al., 2007). The “values and beliefs” cited by the recipient mothers included the child’s “right to know” and the parents’ “duty to protect” (p. 288). Notably, the researchers concluded that the disclosing recipient mothers of the study typically cited the child’s right to know and perceived social and cultural factors as conducive to PTO disclosure.

The offspring’s right to know his or her genetic makeup is confounded further by those who argue that pregnancy provides a biological connection between offspring and mother. For SDCO, the offspring’s biology is necessarily distinct from their recipient father’s; however, evidence exists that, for EDCO some recipient mothers consider themselves to be biologically related to their children “through the pregnancy and exchange of ‘blood’ and other nutrients delivered by mother to fetus,” thereby maintaining a biological connection between mother and offspring (Shehab et al., 2008). In cases such as these, recipient parents may feel that the use of donor gametes is biologically irrelevant. Further research is necessary to determine DCO’s response to this argument.

**Honesty as an ethical principle/ the negative effects of secrecy.** In a qualitative study of 156 recipients of donated sperm, Nachtigall et al. (1998) found that recipient

parent disclosers cited honesty as an ethical principle, as well as the concept that deception would undermine family trust and that inadvertent or inevitable disclosure could cause the child to feel betrayed. In a theory-based argument, Sokoloff (1987) asserts that a significant effect of secrecy in families who choose not to disclose to anyone inside or outside of the immediate family is that the couples effectively cut themselves off from the benefits of support from extended family, friends, and support groups. This argument is also made by Daniels and Taylor (1993), who assert that openness can be directly beneficial to the couple themselves, resulting in moral support, relief from the discomforts of evasiveness, and greater likelihood of seeking counseling services for assistance in coping with these complex experiences. These authors also suggest that family relationships are frequently damaged by deception, and that deception frequently leads to stress and anxiety. Furthermore, Murray et al. (2006) draw from family therapy theorists to assert that “secrets in families threaten the harmony of family relationships, distancing those family members who know the secret from those who do not” (p. 610). In another theory-based argument, a pamphlet on Australia’s Infertility Treatment Authority’s website (<http://www.ita.org.au>) asserts that, “The stress of keeping secrets can cause arguments, conflict and stress...Being secretive may indicate to others, especially to the child, that you are ashamed” (ITA, 2006). Notably, one donor-conceived adult who was told about the donation as a young adult, stated, “We aren’t weird or bad. Why keep it a secret?” (Infertility Treatment Authority, 2007a, p. 31). The argument has also been made that parents ought to model honesty and acceptance for their children, as reported by several disclosing parents in a research cohort of 254 recipient parents (Shehab et al., 2008).

Further support for the harmfulness of secrecy is provided by Turner and Coyle (2000), who utilized qualitative research to study the experiences of 16 SDCO between the ages of 26 and 55 years, from the U.K., U.S.A., Canada and Australia. While the researchers found “little commonality among participants about the time, place and style of disclosure,” they did find that most of the study participants reported feeling “shocked” at discovering their status as sperm donation conceived offspring (p. 2044). Comments from the participants included, “I felt my entire life was based on a lie and I was furious with my mother for dying with this secret”; “I was shocked and unforgiving. I now have a total distrust for my mother [following disclosure], and have realized that it is very hard for me to totally trust someone else”; and “I felt a considerable amount of regret about how utterly senseless it had been for my parents to keep this information [being a donor offspring] from me for so long” (p. 2045). Another participant stated, “Part of me was shaken and profoundly shocked. Part of me was utterly calm, as things suddenly fell into place, and I was faced with an immediate reappraisal of my own identity...On the one hand, it was immensely liberating, and on the other, it meant the loss of the ‘bottom’ of my world and all the familiar parameters” (p. 2044). Although the authors do not provide information regarding the details of participants’ disclosure experiences, the participants’ comments suggest that they were told about their genetic origins later in life (i.e., as adolescents or adults). It is again unfortunate that more information about the timing of disclosure is not provided by the research authors; however, it can be inferred that such “shock” would be experienced by an individual who had lived a good deal of time thinking otherwise about his or her genetic origins.

The benefit of early disclosure is supported by data collected by Scheib, Riordan, and Rubin (2004) who used mail-back questionnaires to investigate the disclosure experiences of 29 adolescent SDCO between the ages of 12 and 17 years. Most of the participants (75.9%) reported always knowing the origins of their genetic makeup, and most reported feeling somewhat to very comfortable about their parents having used a sperm donor to have them. Many of the participants (44%) reported that having been conceived with the help of a donor did not affect their life, with one participant commenting, “It’s all I know” (p. 243). The researchers postulate that “more positive outcomes will be observed among individuals who learn of their origins as children, allowing time to incorporate DI [donor insemination] as part of their life and not feel that their origins were something to hide and be ashamed of” (p. 240). While offering this compelling argument, the authors also note a confounding variable: Perhaps those parents who choose to disclose to their children at a very early age are more likely to provide a particularly positive, open-minded, and honest family environment.

Countering arguments that secrecy is harmful, Shenfield and Steele (1997) refer to evidence from the limited available research on offspring’s psychological stability to argue that, “The assumption that all secrets are harmful...is one that psychoanalysis might want to challenge, especially in the field of sexuality and procreation” (p. 394). Supporting this perspective, a quantitative study of 17 families found that “despite egg donation parents’ decision to opt for nondisclosure, early adolescent EDCO seem to be functioning well, suggesting that the secrecy surrounding the circumstances of their conception...was not exerting strong negative effects on the children’s psychological well-being or on family relationships in general” (Murray, MacCallum, & Golombok,

2006, p. 6117). Those authors make the assertion that for the time being, there is not enough evidence that the secret of gamete donation is harmful to the child, and “therefore we have no duty to convince prospective parents to choose openness, but should listen to their concerns” (Shenfield & Steele, 1997, p. 394). The importance of considering unique qualities of a given family when making decisions about disclosure is supported by family therapy literature addressing secrets within families. For instance, “Under certain circumstances, it may be wise to be discreet, but if the information is causing the secret-bearer great mental and emotional distress, the child will experience the distress without any way of decoding it” (Imber-Black, 1993, p. 73)

**Lack of information about the donor.** Unsurprisingly, DCO may desire information about their donors as a result of PTO disclosure; however, information is unavailable in cases of anonymous donors. Several studies have found that some recipient parents avoid PTO disclosure because of their inability to provide information or answers to their children about their anonymous donors (Blyth, 2002; Cook et al., 1995; Daniels & Taylor, 1993; Ethics Committee of the ASRM, 2004; Hahn & Craft-Rosenberg, 2002; McWhinnie, 2001; Murray & Golombok, 2003). Notably, however, one qualitative study measuring survey responses of 157 American recipient mothers showed that no differences were found in parents’ plans to inform the offspring based upon whether or not they knew the identity of their donors (Greenfeld & Klock, 2004). Alternatively, in cases of donor non-anonymity, recipient parents may feel conflicted about providing their children with ample information about the donor if they fear the child will search for his or her egg or sperm donor. More research is needed to fully

determine the extent to which donor anonymity influences recipient parents' decisions about PTO disclosure.

**Application of adoption research.** It may seem reasonable to review adoption literature in consideration of offspring disclosure; however, the differences between adoption and gamete donation are considerable. Specifically, (a) the child was not given away after its birth; (b) the recipient mother may have carried the pregnancy or, in the case of a surrogate, the recipient parents are involved in the pregnancy from conception to birth; (c) the recipient parents often handpick the genetic makeup of the child; (d) one parent is often genetically related the child; and (e) gamete donation typically provides the opportunity for genetically-related siblings to be born. Also, adoption is more well-known and perhaps more socially acceptable (e.g., to religious groups, in government legislation, etc). Given these differences, comparisons between adoption and gamete donation have become increasingly challenged by researchers in the field of third party reproduction (Broderick & Walker, 2001; Cook et al., 1995; Shenfield & Steele, 1997; Sokoloff, 1987; Walker & Broderick, 1999). Not only do many researchers and theorists view the differences between gamete donation and adoption to be too great to warrant comparison, but Broderick and Walker's (2001) study of the attitudes of 77 donors and 327 recipients found that neither gamete donors nor the recipient parents perceived donation and adoption as similar. Similarly, Nachtigall et al. (1998), in a qualitative analysis of 182 recipient parents, reported that overall, the parents did not identify with the adoption experience.

Nonetheless, the similarity between gamete donation and adoption is easily identifiable. Certainly, child rearing by at least one non-genetic parent is applicable to

both experiences. And while many individuals directly impacted by gamete donation perceive it to be dissimilar to adoption, a handful of professionals use their experiences with adoption and family therapy to make arguments for disclosure. For example, the UK government referenced adoption research when citing that children born from egg donation have “the same right to know their biological parent as adopted children on reaching the age of 18” (Craft et al., 2005, p. 325). Moreover, Shehab and colleagues’ (2008) qualitative research on 141 couples with DCO found that some parents’ disclosure decisions were informed by their awareness of adoption literature and the related concept of family secrets. Given these results, concepts relevant to both experiences do deserve attention.

### **Mac Dougall’s (2007) Research on Disclosure Scripts**

The most legitimate source of understanding the PTO disclosure process would be the parents, themselves; however, only one study to date has explored recipient parents’ disclosure patterns. Researchers in Northern California (Mac Dougall, Becker, Scheib, & Nachtigall, 2007) interviewed 141 couples who had utilized donor eggs or sperm. The results of the study focus solely on the responses of disclosing couples regarding their PTO disclosure decisions and strategies (112 families; 48 who had received donor sperm, 64 who had received donor eggs). The couples were recruited from medical infertility practices and one sperm bank located in Northern California. After administering in-depth ethnographic interviews, Mac Dougall, et al. (2007) conducted a thematic analysis of the interview transcripts. Husbands and wives were interviewed together and separately in order to provide descriptions of how parents envision, plan, and enact PTO disclosure. The research was the first of its kind and has provided a number of



contributions to understanding disclosure: (a) identification of timelines used by disclosing parents; (b) identification of narratives/scripts used by disclosing parents; and (c) recipient parents' attitudes and responses to disclosing.

Mac Dougall et al. (2007) identified two basic timelines parents used for telling their children of their conception by use of donor gametes. The authors refer to these timelines as *seed-planting* and *right-time* approaches. Recipient parents in Mac Dougall et al.'s (2007) research who utilized the *seed-planting* timeline began speaking to their children about their genetic origins when the child was between the ages of 3-4 years, around the time that the child began asking basic origin questions such as "Where do babies come from?" or "Did I grow in your tummy?" These parents voiced the opinion that, "because the child would have 'always known' the information about their conception from his or her earliest recollection, there would be no time where it would be necessary to 'sit down and have this [disclosure] discussion'" (Mac Dougall, et al., 2007, p. 526). These parents reportedly sought opportunities to discuss the use of donor gametes with their children so that, through repetition and positive reinforcement, the information would become routine and be "part of the fabric of their lives" (Mac Dougall et al., 2007, pp. 526-527).

The study's parents who used the *right-time* strategy chose to disclose at "an optimal time" or "window of opportunity" in the child's development during which he or she was thought to be best able to receive and understand the disclosure information (Mac Dougall et al., 2007, p. 527). These parents thought of the initial disclosure as one singular event. Although these parents typically projected the *right-time* to be approximately between the child's ages of 10-12 years (when most children receive

sexual education in schools), the researchers found that the parents who had already used the *right-time* strategy for disclosure actually began between the ages of 6-7 years (Mac Dougall et al., 2007).

In addition to documenting variation in disclosure timelines, Mac Dougall et al. (2007) also documented five scripts/themes that the parents used to disclose to their DCO: (a) *the helper*, (b) *spare parts*, (c) *families are different*, (d) *labor of love*, and (e) *nuts and bolts* (p. 528).

**The helper.** In the *helper* story, parents conveyed the idea that they needed assistance to have a baby and that someone (e.g., “helper,” “doctor,” “donor”) provided the needed assistance (Mac Dougall et al., 2007, p. 528). In cases in which the helper was the donor, he or she was presented positively as a “special” or “nice” person, and the donor was often described as having provided a “gift” to the parents (p. 528). Typically parents said “a doctor helped us to have you;” and some parents combined elements of both helper stories, for example, “a nice person gave us sperm (or eggs) and a doctor helped us to have you” (p. 528)

**Spare parts.** The *spare parts* theme documented by Mac Dougall et al. (2007) describes the concept that the non-gamete-contributing parent had a “missing” or “broken” part that needed replacing in order to have a baby (p. 528). Sometimes recipient parents highlighted that their bodies “worked differently” than other people’s (p. 528). Parents told their children that the “spare parts” were provided by doctors or by other people. One couple told their SDCO that, “daddy’s sperm was broken, so we got sperm from a doctor,” while another couple said, “we got medicine from a doctor” (p. 528).

**Families are different.** *Families are different* was a story in which the donor conception was identified within the context of “a multiplicity of family-building techniques” (Mac Dougall et al., 2007, p. 528). Parents who utilized this narrative typically conveyed to children that there are several different ways to create a family and that their particular choice was to use a donor. “In comparison with families created with donor gametes, other family descriptions included those with adopted children, step-children, single parents, gay or lesbian parents, and biracial families” (p. 528). Some of parents who utilized this technique also reported using children’s books to convey this message as a launching point for disclosure.

**Labor of love.** Mac Dougall et al. (2007) reported that parents who had not yet disclosed often described intending to use the *labor of love* theme to convey to their children how much they were wanted (p. 528). In these stories, their decision to choose donor conception was explained by “being motivated by a great love and desire to have their children” (p. 528). This script often took two subtly different forms. In the first version, parents expressed the idea that they wanted their children “so badly” and that they “love them so much” that they did what they needed to do to have them (p. 528). In the second version, parents described wanting their children so badly that they “worked so hard” and “went to great lengths to have them” (p. 528).

**Nuts and bolts.** Some of the parents in Mac Dougall et al.’s (2007) research who had not yet disclosed imagined describing the technical details or *nuts and bolts* of the donor conception to their children (p. 528). This approach was based on the assumption that the child would have a certain knowledge and maturity level enabling an understanding of reproductive parts and concepts. For example, some parents predicted

saying “we used a donor’s sperm” or “a donor egg” “which was placed inside mommy and then you grew” (p. 528).

Mac Dougall et al. (2007) also document recipient parents’ attitudes and responses to PTO disclosure. They found that, “although parents reported a variety of feelings after disclosing that ranged from neutral to a profound sense of relief, no parent expressed regret or reported a negative outcome after having initiated disclosure” (p. 529). These authors reported that, in most cases, parents reported that their children had no visible reaction to the disclosure, itself, or that they “took the information in stride” (p. 529). The parents who had reported feeling uncertainty before disclosing, often expressed relief, such as “that was pretty easy” and “the only one with difficulty with it was us, stumbling around” (Mac Dougall, et al., 2007, p. 529). Similarly, Lindblad et al. (2000), in their study of sperm recipient parents using qualitative methods, found that parents reported that their children responded neutrally or positively to PTO disclosure, and no parents reported regretting the decision to share the information with their children. Such data may prove to be encouraging for recipient parents struggling with the issue of whether or not to disclose to their offspring of their genetic conception.

### **Cultural Considerations in the Disclosure Decision**

There is a significant lack of cultural considerations in the literature published on PTO disclosure and third party reproduction. No government statistical data exist quantifying racial, ethnic, socioeconomic status, or religious affiliation among the gamete recipient parents in the United States. Only one research group, Hershberger et al. (2007), found that cultural factors were relevant in their qualitative, naturalistic, phenomenological analysis of recipient parents’ disclosure decisions. This team identified

factors influencing the disclosure decisions of eight donor oocyte recipient women between 9-23 weeks of gestation. All eight participants were Caucasian, married, and “well-educated” (p. 290). The authors discuss the cultures of the participant families as being relevant to their disclosure patterns by referencing one recipient mother’s report that, “there is a strong social preference for maintaining the existing culture and ethnicity of family members” (Hershberger, et al., 2007, p. 293). This participant reported feeling significant concern about disclosing her child’s genetic background to her extended family, fearing their disapproval.

The issue of “resemblance talk” raised by this participant is one that has been addressed in previous research on disclosure to extended family about the use of donor gametes (Becker, Butler, & Nachtigall, 2005; Shehab et al., 2008). Similarly, Shehab and colleagues (2008) found that some of the 141 couples interviewed for the study reported “feeling apprehensive about their family’s response to disclosure because of their family’s religious convictions or cultural beliefs” (p. 182). Their study sample included individuals of Catholic and Jewish traditions, as well as parents of Latino and Asian ancestry, with many of the parents reporting concern about how their children’s grandparents would perceive and treat their DCO. The authors note that parents who had not told family members about their use of donor gametes experienced the disclosure decision as more complex and associated with considerable anxiety as compared to parents who shared their experiences with extended family members.

Another important cultural issue is the relevance of recipient parents’ socioeconomic status. According to Andrew Vorzimer, an experienced attorney with expertise in third party reproduction, the expense of hiring a surrogate and receiving

donated gametes is significant. Combining the medical, psychological, legal, and agency fees, the cost for working with an egg donor for one to two cycles typically falls between \$30,000 and \$45,000 (personal communication, 2010). The costs of the medical, psychological, legal, and agency fees for working with a surrogate for one to two cycles typically add up to \$75,000 - \$125,000 (Vorzimer, personal communication, 2010). The IVF procedure alone is also fairly costly, at an average of \$15,000 per cycle. Very few insurance companies will reimburse infertility treatment, though insurance coverage varies from state to state, where some legislation mandates that insurance companies cover infertility procedures (e.g., Illinois & Massachusetts; Vorzimer, personal communication, 2010). Given these figures, the use of third party reproduction is generally limited to the affluent individuals and couples who can afford it, making it difficult to determine the extent to which cultural variables may play a role in PTO disclosure.

### **Resources for Helping Recipients with PTO Disclosure Decisions**

The American Society for Reproductive Medicine (ASRM) suggests that prospective recipients and donors receive counseling with a qualified mental health professional about the psychological implications of disclosure for the recipients, donors, and children (ASRM Ethics Committee, 2004). Other professionals suggest that third party reproductive clinics offer assistance regarding disclosure, including a “balanced education about privacy, rights of the child to know their origins, and how the parents can work toward formulating their informed decision” (De Jonge & Barratt, 2006, p. 501). Unfortunately, gamete recipient parents may face a number of contradictions from resources helping with disclosure decisions.

Research indicates that many recipient parents prefer alternative forms of support, despite ASRM's suggestion that they speak with a mental health professional about disclosure-related issues. For example, of 254 recipient parents interviewed in Shehab and colleagues' (2008) research on disclosure patterns, peer support was the most highly valued disclosure decision resource. The authors note that peer support, often in the form of professionally-led groups, reduced feelings of stigmatization and isolation by normalizing the recipient parent experience. The findings also emphasized that peer support provided "information acquisition...from other parents in the same unique life situation" (Shehab et al., 2008, p. 187). These findings are consistent with those of similar studies in which recipient parents tend to voice a desire for peer support, rather than potentially biased suggestions from a mental health professional (Greenfeld & Klock, 2004; Hershberger, 2007). A website created by Australia's Infertility Treatment Authority provides helpful resources to families created by gamete donation (<http://www.ita.org.au>). The website contains podcasts and transcripts of actual families discussing their disclosure experiences, as well as pamphlets, guides, brochures, book references, and support group networking. The support group networking provides relevant information for Australian and United Kingdom residents; however, much of the website's information is pertinent to families worldwide.

Other important resources are the handful of published children's books intended to address issues of PTO disclosure (Bourne, 2002; Celcer, 2007; Gordon, 1992; Jover, 2005; Nadel, 2007; Nathalie, 2002; Stamm, 2003). The majority of books are intended for young children. For instance, Bourne's (2002), *Sometimes it Takes Three to Make a Baby*, is an illustrated guide for young children, explaining in simple language the

process of egg donation. Bourne's (2002) publication includes a workbook for the child to complete, including their own personal photos, mementos and drawings, and advice for parents on how to talk to young children about their special conception. Stamm's (2003), *Phoebe's Family: A Story about Egg Donation*, follows an eight year old little girl whose mother explains her anonymous egg donation to her. Both Bourne and Stamm's books are intended for slightly older children who may be learning to read and write.

An example of a book in which the story's main character is slightly older (between 6-9 years old) is Celcer's (2007), *Hope & Will Have a Baby: The Gift of Egg Donation*, in which the reader follows a little boy who discovers his parents' quest to have children, and the success they ultimately achieve in creating a family. A comparable book, written by Nathalie (2002), titled *A Part was Given and an Angel was Born*, describes a husband and wife who wanted a baby. The author describes that "a part in mommy just didn't work as it should," to introduce the concept of egg donation to a young child.

Practical for a wide range of children (between 4-12 years old), Gordon's (1992) *Mommy, Did I Grow in Your Tummy? Where Some Babies Come From* provides sensitively written and colorfully illustrated explanations of IVF, egg donation, sperm donation, surrogacy, and adoption. It is a book meant to be read aloud to children, and for that reason it provides a building block for parents to discuss issues relating to egg donation and other ways for babies to come into the world. This book is especially relevant to families who have adopted children or who utilized surrogacy services.



Examples of children's books intended for younger audiences include Jover's (2005), *A Tiny Itsy Bitsy Gift of Life*, *An Egg Donor Story*, in which a happy couple of rabbits long for a baby bunny and a lady rabbit brings the couple an egg. Nadel's (2007) story, *Mommy, Was Your Tummy Big?*, describes elephant characters who use donor eggs to conceive. Both stories show the animal mothers' pregnancies and the births of the baby animals. Both are colorful, use simple wording, and are intended to be read to very young children.

### **Recipient Parents' Need for Resources**

Researchers have consistently documented that gamete-recipient parents want more resources and guidance to assist them with PTO disclosure (ASRM Ethics Committee, 2004; Australia's Infertility Authority, 2007; Cook et al., 1995; De Jonge & Barratt, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hershberger et al., 2007; Leiblum & Aviv, 1997; Mac Dougall et al., 2007; Mahlestedt & Greenfeld, 1989; Murray & Golombok, 2003; Rumball & Adair, 1999). Mac Dougall et al. (2007) document that parents express "frustration with the perceived lack of comfortable language and 'scripts' available to discuss donor conception with their children, especially as they struggle to find unambiguous terminology with which to refer to the donor" (p. 530). Those researchers also report that many couples would "like someone to tell [them] what to say" and many said that they "would like to talk to others that have actually gone through this experience to find out what worked" (p. 528). A similar struggle was described in Kirkman's (2003) qualitative research on 32 Australian recipient parents: "Some of the parents wished that they had repeated access to experienced counselors or to information about others who had dealt successfully with

when, what, and how to tell” (p. 2239). This question of whether recipient parents would rather receive PTO disclosure advice from professionals or from other recipient parents is one that deserves attention and is often addressed in research.

Several published reports on disclosure suggest that while parents are indeed searching for assistance on the disclosure decision, they are generally unsatisfied with the present counseling and available resources. For example, Hershberger and colleagues used qualitative means to interview seven pregnant egg recipient mothers in America, and found that, while these recipients reported that the general counseling session they received at their medical doctor’s office was beneficial, several of the women openly questioned the disclosure recommendations made by mental health professionals (2007). As one undecided woman stated, “I don’t know if psychologists are always right” (Hershberger et al., 2007, p. 295). This response was similarly observed in Greenfeld and Klock’s (2004) qualitative research on 157 mothers of gamete-donor children, the majority of whom reported that when a recommendation about disclosure or privacy was made by any member of the medical or counseling treatment team, it did not influence their disclosure decision. Furthermore, most of the 141 couples interviewed in Shehab and colleague’s (2008) qualitative research reported that above individual counseling and support groups, they “valued peer support most highly, and many would have liked to talk with others about their experience with gamete donation and disclosure” (p. 182).

Several researchers have documented that recipient parent participants inquire about what other study participant parents have done regarding how and when to disclose to their gamete-donated offspring (Australia’s Infertility Treatment Authority, 2007; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hershberger et al., 2007; Mac

Dougall et al., 2007). Hahn and Craft-Rosenberg's (2002) interviews with 31 egg donor parents found that parents in this sample were clear about their educational needs. "They wanted to know how and when to tell" (p. 292), and one parent commented, "I think one thing that would help me would be if there were experiences of other people that they could share anonymously..." (p. 289). Unfortunately, few peer support groups focusing on PTO disclosure currently exist, suggesting a need for disclosure resources that can be easily and readily accessed.

One rationale recipient parents have provided regarding non-disclosure is their uncertainty about how and when to disclose appropriately to their children (Australia's Infertility Treatment Authority, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Leiblum & Aviv, 1997). Several researchers have advised counselors that providing couples with written materials regarding the pros and cons of PTO disclosure, as well as real life stories and scripts for telling, may be helpful for parents to refer to over time as their decisions evolve (Australia's Infertility Treatment Authority, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002; Hersherberger et al., 2007). This suggestion is supported by Cook et al.'s (1995) qualitative research of 45 UK donor insemination families, in which recipient parents report lacking the "scripts available to adoptive parents when telling children" (p. 557).

The available research on this population demonstrates a significant lack of valued support for recipient parents regarding disclosure. While mental health professionals are often unambiguous in writing about their philosophical stance on this issue, research suggests that their theories may not be valuable or practical to the individuals struggling with disclosure decisions. While researchers have just begun

documenting recipient parents' stories and scripts for PTO disclosure (Mac Dougall, 2007; Rumball & Adair, 1999), no research to date has evaluated how these findings might be received by recipient parents in search of resources to help them with the disclosure decision.

### **The Use of Disclosure Scripts**

Another source of disclosure assistance for recipient parents can be found in a book written by Friedman (2007), a psychologist who has worked exclusively with clients struggling with infertility and reproductive losses for over 25 years. Her book, *Building Your Family Through Egg Donation*, provides four, age-dependent scripts to which parents may refer for guidance in the PTO disclosure dialogue: (a) Child from 4-6 years of age; (b) Child from 6-8 years of age; (c) Child from 8-11 years of age; (d) Child from 12-13 (or older) years of age. Summaries of the scripts are provided below.

1. *Child from 4-6 years of age.* Friedman (2007) suggests that recipient parents need only describe the use of donated gametes in very general terms this early in a child's life, i.e., "There were some good people who helped us so that we could have you" (p. 49). Friedman also recommends that parents may begin using terms such as "doctors" and "nurses" in explanation of the people who helped the parents give birth to the child.
2. *Child from 6-8 years of age.* It is suggested that during this stage in a DCO's life, the recipient parents begin using the term, "special gift," to indicate the donation from donor to parent (p. 50). Friedman also suggests that parents refer to the mother's womb as her "baby sac," where the child can "grow healthy" (p. 50).

3. *Child from 8-11 years of age.* Parents are advised to begin utilizing more specific dialogue, i.e., referring to the donor as, “a kind lady who donated a small piece of her body, called a cell” (p. 51). It is suggested that parents analogize the donation of gametes to the donation of other bodily organs, such as blood or kidneys.
4. *Child from 12-13 (or older) years of age.* At this stage in a child’s life, Friedman (2007) suggests that parents utilize specific and scientific language to describe the use of donor gametes such as, gene cell, DNA, egg or sperm cells, ovum, oocyte, eggs, embryo, etc. If parents have information about the donor in the case of non-anonymity, it is further recommended that recipient parents offer to present this material to the child.

From a child development perspective, these scripts appear to be suitable for their recommended age groups; however, the author provides no rationale for the development of the scripts, and there is no evidence to suggest that the scripts resonate with the recipient parent population.

No researcher has explored recipient parents’ evaluations of scripts for PTO disclosure. Describing recipient parents’ response to scripts inspired by other recipient parents is the first step towards understanding how to improve resources for the disclosure decision process. The skepticism with which recipient couples respond to disclosure advice from mental health and medical professionals suggests that these individuals may need support from those who have first-hand experience making disclosure decisions.

## Summary

The literature review in this chapter has provided a basis for understanding gamete donation, with special attention to egg donation and its various components. The history of egg donation and current legislation that affects gamete donation on a worldwide level have been addressed, as has the research that has been published examining various aspects of PTO disclosure. According to the available research, disclosure has neutral to positive effects on offspring, and there is no evidence that knowledge of being the offspring of egg donation has negative consequences on the DCO or their families. Nevertheless, professionals continue to disagree about the consequences of PTO disclosure. In the absence of studies that gather longitudinal data measuring large sample populations of GDCO, psychologists and other professionals working in the field of third party reproduction have provided a robust body of literature rooted in philosophy and theory addressing several arguments for and against disclosure. Research indicates that many recipient parents also struggle to determine whether or not to tell their children of their genetic origins.

Researchers also repeatedly describe that many recipient parents would like resources to facilitate their disclosure decision process. Mac Dougall et al.'s (2007) research is the first of its kind to study recipient parents' decisions regarding how and when to disclose. Given recipient parents' requests for information from other recipient parents regarding their disclosure methods, the aim of the current study is to present egg recipients with scripts inspired by Mac Dougall et al.'s (2007) research to determine their potential benefit in helping parents make disclosure decisions.

### **Chapter 3. Methods**

This chapter will delineate the methodology and procedures of this study:

(a) research approach and design; (b) participants; (c) instrumentation/measures; (d) consent procedures and recruitment; and (e) data processing and analysis.

#### **Research Approach and Design**

The major objective of this research was to conduct a descriptive study addressing recipient parents' appraisals of PTO disclosure scripts.

In order to determine the helpfulness of disclosure scripts for egg recipient parents, the PI created an online survey and recruited egg recipient parents to complete the questionnaire. The survey measured the demographics of the sample population and the status of their disclosure decisions. The author also designed scripts inspired by Mac Dougall et al.'s (2007) research data and Friedman's (2007) suggestions for PTO disclosure. The scripts were presented to the recipient parents who were then asked to rate each script's level of helpfulness on a Likert-scale. They were also asked to rate how likely they would be to use the script, or, for parents who had already disclosed, how similar the script was to their own method of disclosure. The data were analyzed and described in order to address this study's research questions.

**Question 1.** What level of difficulty do recipient parents rate making disclosure decisions?

**Question 2.** Do recipient parents find it valuable to read PTO disclosure scripts?

**Question 3.** What is the level of perceived helpfulness of reading each of the several PTO disclosure scripts?

**Question 4.** What is the level of perceived helpfulness of reading disclosure scripts in relation to participants' PTO disclosure status?

**Question 5.** Are there differences in perceived helpfulness of the scripts based upon demographic variables (e.g., age of offspring, age of parent, ethnicity, and religious affiliation)?

### **Participants**

Approximately 1,000 egg recipient parents from Egg Donation Inc., an egg donor agency located in Southern California, were recruited by email to participate in this study. Egg Donation Inc. was established in 1989 and is one of the oldest egg donation companies in the world ([www.eggdonor.com](http://www.eggdonor.com), retrieved on January 30, 2009). The PI had access to the agency as she was previously employed there as a case manager. Egg recipient parents from this agency were from over 35 different countries, and were identified via a list of recipient parents from the agency's database. The recruited individuals were selected if they registered with the agency between the years 2004-2005. The year was chosen for convenience because it was recent enough so email addresses would be current and the DCO, while young, would be old enough for parents to be addressing the PTO disclosure decision. All of the recruited individuals had registered with the agency using its online website, suggesting that, theoretically, each individual had access to a computer and internet. The recipients in the database were aware that they might be contacted in the future, based upon information they received when they registered with Egg Donation, Inc (see Appendix C). Participants for this study met inclusion criteria if they had any EDCO under the age of 14, if their email addresses were still current, if they had internet access, and if they were not currently pregnant.



## **Instrumentation/Measures**

**Scripts.** The scripts used in current study were inspired by Mac Dougall et al.'s (2007) qualitative research documenting recipient parents' methods of PTO disclosure. In documenting their research, Mac Dougall, et al. (2007) essentially provided a peer-generated collection of skeletal scripts for how and when to disclose to a child about his or her genetic origins. The PI spoke with Dr. Robert Nachtigall to address the data he had collected with Kristin Mac Dougall, Dr. Gay Becker, and Dr. Joanna Scheib (personal communication, 2007). The PI expressed her opinion that, in consideration of recipient parents' request for peer-informed resources, it would be appropriate to allow recipient parents the opportunity to review the research and report whether or not they found it to be helpful or useful to them. Furthermore, the author explained that should the response from the current study's participants be positive, mental health professionals and physicians would be better prepared for working clinically with this frequently in-need population. Dr. Robert Nachtigall expressed agreement and provided verbal consent to this author for application of the research data for further study.

The PI combined her ideas with the disclosure approaches reported by Mac Dougall et al. (2007) and the approaches suggested by Friedman (2007). The author received feedback on early drafts of the scripts (e.g., from professors, psychologists with expertise in third party reproduction, colleagues, etc.) and incorporated the changes into the final scripts. The scripts are lettered A through I and are also labeled with titles, several of which resemble Mac Dougall et al.'s research article (2007). Each script contains three sentences:

### The Helper

We wanted you very much to be our baby. We needed some help to have you and some good people gave us the help we needed. A nice woman gave us an important gift and a doctor helped us so that you could grow healthy and be a part of this family.

### Spare Parts

We love you so much and wanted you so badly that we worked hard to have you. We had a missing part (or broken part) that needed to be replaced (or fixed) in order to bring you into the world. Our bodies work a little differently than other people's, so doctors and other nice people gave us spare parts (or healthy parts) so that you could be born.

### Families are Different

There are so many different types of families! Some families have step moms or dads, some families have children who are adopted, some families have parents and children who are different races, other families have one parent, or two mommies or two daddies. There are all different kinds of ways to make a family, and our family is special too.

### Organ Donor

Did you know that people who want to help other people sometimes donate some of their blood to help other people stay healthy? Some people even donate organs to people who need them, like kidneys, because most people have two normal kidneys but one is enough. Well sort of like that, when we were trying to have you, we needed someone to donate a small piece of her body to us, called a cell or egg.

### Labor of Love

Our family is special in all different ways. [Can insert examples such as activities/foods your family enjoys, religious or other cultural traditions – i.e., anything that makes your family unique.] Also, we wanted you so badly that we worked extra hard so that you could come into the world. In order for that to happen, we put a donor egg inside mommy and then you grew. (Or, in the cases of a gestational carrier, “We asked someone to carry a donor egg for us so that you could grow and be a part of our family.”)

### Nuts & Bolts

When we were trying to have you, we asked a nice lady to donate a gene cell to us so that we could have the DNA we needed to make you. You'll probably learn more about DNA and genes in school, but for now it's important to know that DNA holds the plan for the way people look, and carries other information like a tiny computer. The woman who donated the DNA doesn't know us, but she knew we wanted you very badly, and she knew that mom's egg cells didn't have exactly the right ingredients.

### Great Young Lady

When we were trying to have you, we needed a young lady to donate some of her eggs to us in order for you to be born. [If applicable, "We can show you what subjects she liked in school, what her favorite things to do were, what kind of sports she played," etc.] She must have been a great person because of how great you are! The most important quality we know about her is that she wanted to help make people happy."

### Privilege to Love

The nice young lady who donated eggs to us had a big heart and she wanted us to have the privilege of loving a child as wonderful as you. We are so proud of you and always want what is best for you. We will always be there for you and will always love you."

### Come & Talk:

Whenever you want to talk more about the egg donation or anything about your conception story, we'll be ready to talk with you. You may have some questions or thoughts or feelings that you might want to share. We hope that you'll always come to us when you're wondering or having strong feelings about our family story.

**Confidentiality and Zoomerang.** A survey was created by this researcher for the purposes of this study to examine recipient parents' experiences with PTO disclosures. The survey was available to the study's participants over a 60-day period via the website, [www.zoomerang.com](http://www.zoomerang.com). There were several reasons for utilizing services provided by the online company, Zoomerang. First, the company's surveys are user-friendly and simple to navigate. Additionally, Zoomerang employs multiple layers of security such as a third-

party firm who conducts daily audits of their security to make sure that collected data remain private and secure. Zoomerang also utilizes the latest in firewall and intrusion prevention technology (www.zoomerang.com, 2009). Lastly, the website has a privacy policy that complies with the United States/European Union Data Protection Safe Harbor Arrangement regarding data protection and confidentiality. When data were transferred from Zoomerang to computer files for analysis and storage (i.e., Microsoft Excel, Microsoft Word, SPSS), all data collected were password protected and only the researcher and her dissertation chairperson know the password and have access to password protected files.

**Online questionnaires.** The online survey created by this investigator consisted of three parts: (a) participant demographics; (b) assessment of aspects of participants' disclosure decisions; and (c) responses to the disclosure scripts. Online Questionnaire A included questions about demographics and participants' disclosure decisions (see Appendix G). Participants were then presented with the PTO scripts and questions regarding their perceptions of the scripts (i.e., helpfulness, similarity to their style, likelihood of being used; see Appendices H and I). Online Questionnaire B included questions about reading the scripts, requested participants' suggestions, and provided closing statements (see Appendix J).

Research Question 1 (*What level of difficulty do recipient parents rate making disclosure decisions?*) was assessed with Online Questionnaire A (see Appendix G), which prompted participants to report the status of their disclosure decision (e.g., whether they had decided not to disclose, had already begun disclosing, etc.). Participants were also asked if they have, at any time, received professional advice on the PTO offspring

disclosure decision; and if so, from whom. Participants were then asked to rate the level of difficulty with which they perceive making disclosure decisions. This question was based on a Likert-scale from 1 “Very easy” to 5 “Very difficult.”

Research Question 2 (*Do recipient parents find it valuable to read PTO disclosure scripts?*) was assessed by reviewing participants’ responses to the prompt, *How desirable would it be for you to read disclosure scripts that other recipient parents have used to tell their children about their genetic origins* (using a Likert-scale from 1 “Very desirable” to 5 “Not at all desirable”). Notably, this question was presented prior to participants’ review of the disclosure scripts. A second relevant question is asked after the scripts have been presented: *How helpful, in general, do you rate reading the above parent-developed disclosure scripts* (using a Likert-scale from 1 “Very helpful” to 5 “Not at all helpful”). Responses to both questions were assessed for the purposes of evaluating Research Question 2.

Research Questions 3 and 4 (*What is the level of perceived helpfulness of reading each of the several PTO disclosure scripts? & What is the level of perceived helpfulness of reading disclosure scripts in relation to participants’ PTO disclosure status?*) were assessed via presentation of the scripts and subsequent inquiry. Participants were automatically directed to Form A or Form B (see Appendices H and I) depending upon whether they had previously endorsed: (a) that they had not disclosed to their children; or (b) that they had already disclosed to their children. Participants were asked to read the scripts and respond to two questions per script. Using Likert-scale categories, all participants were asked to rate how helpful they thought each approach might be for parents who are making disclosure decisions (i.e., very helpful, somewhat helpful,

neutral, not very helpful, not at all helpful). Parents who had not disclosed were asked to rate on a Likert-scale how likely they would be to use each script to disclose to their children (i.e., very likely, somewhat likely, neutral, not very likely, not at all likely). Participants who had already begun disclosing or who had completely disclosed were asked how similar each script was to the approach they used or are using to disclose to their children (i.e., very similar, somewhat similar, neutral, not very similar, not at all similar).

Research Question 5 (*Are there differences in perceived helpfulness of the scripts based upon demographic variables (e.g., age of offspring, age of parent, ethnicity, and religious affiliation)?*) was addressed using Online Questionnaire A and responses to the presentation of scripts. Online Questionnaire A assessed recipient parent's age, gender, relationship status, ethnicity, and religious affiliation, as well as the number and age(s) of their EDCO (see Appendix G). Questions following the presentation of scripts assessed participants' responses to the scripts (see Appendices H and I).

Additionally, research participants were prompted to report whether they would be interested in accessing resources intended to assist in the disclosure decision process. Participants were also asked whether they believe PTO disclosure resources should be provided to all recipient couples, and whether they believe disclosure scripts would be helpful (i.e., absolutely, maybe, undecided, probably not, absolutely not). Participants had the opportunity to provide their thoughts about resources that they might find useful. Participants were then presented with the study's concluding comments (see Appendix J).

The concluding screen expressed the researcher's appreciation for participants' efforts, offered the opportunity to rate the difficulty of completing the survey based on a

Likert-scale (i.e., very easy, easy, neutral, difficult, very difficult) and provided the researcher's information, as well as contact information for the dissertation chairperson and Pepperdine University's Institutional Review Board. The participants were encouraged to contact the author or the dissertation chairperson with any questions, concerns, or suggestions.

### **Consent Procedures and Recruitment**

Online Informed Consent (see Appendix F) summarized information about the study and reviewed participants' rights. Participants were asked to provide electronic informed consent by clicking on an "I Accept" button or a "No Thank You" button, after reviewing information about the study.

After permission was granted from Pepperdine University's Institutional Review Board, recruitment of recipient parents began. An initial email was sent from the owner and CEO of Egg Donation Inc. to approximately 1,000 recipients (see Appendix D). The email provided a general welcome message, as well as a brief introduction to the research. The email also reassured recipients that their information was being kept strictly confidential. Recipients of the email were given the opportunity to respond if they were interested in receiving further information about the study. To those recipients who responded positively to the initial email, a follow-up email was sent requesting that they complete an anonymous questionnaire addressing PTO disclosure (see Appendix E). The email message included a subject heading titled, "Research Study." The email message provided information about the identity of the researcher, the participation requirements, and a request that interested volunteers click on the link directing them to the Zoomerang website to answer brief questions related to their parenting experiences. The email

message also stated that email recipients could direct any questions to the researcher via email. The email explicitly stated that the information gathered was utilized only for the purposes of this study and was kept strictly confidential. In both the recruitment email and online informed consent, participants were asked not to participate if they were pregnant or if their spouse/partner was pregnant.

### **Data Processing and Analysis**

The five research questions were evaluated using descriptive analyses to evaluate the collected data. Charts, pie graphs, frequencies, means, cross tabulations, ANOVAs, correlations, t-tests, and Repeated Measures MANOVAs were conducted and presented for research questions 1, 2, 3, 4, and 5.

In order to address Research Question 1 (*Level of difficulty making disclosure decisions*) the investigator reviewed results from Questionnaire A: question #17, to which participants were asked to rate their responses on a Likert-scale (very easy, easy, no opinion, difficult, very difficult). Descriptive statistics were used to determine the mean, median, mode, and standard deviation of the responses. To assess a relationship between parents' ratings of disclosure decision difficulty and receipt of professional disclosure advice, cross tabulations were performed. Further exploration examined comparisons between participants' reported levels of difficulty making disclosure decisions and their plans to disclose.

Research Question 2 (*Level of value attributed to reading PTO disclosure scripts*) was assessed by reviewing participants' responses to two questions: (a) *How desirable would it be for you to read disclosure scripts that other recipient parents have used to tell their children about their genetic origins?*; and (b) *How helpful, in general, do you rate*



*reading the above parent-developed disclosure scripts?* Responses to both questions were described to report the percentages of participants endorsing each level of desirability and helpfulness.

To address Research Question 3 (*Level of perceived helpfulness of reading each of the several scripts*) the investigator grouped participants by their disclosure status (Disclosers, Non-disclosers, and Undecided) and described their ratings of each script (see Tables 13-21). Repeated Measures MANOVA were then conducted to determine whether statistical significance existed between each scripts' ratings of helpfulness (see Table 23). Participants' Likert-scale ratings of the question presented after each script, *How helpful do you think this approach might be for parents who are making disclosure decisions*, were compared and recorded to determine which scripts were found to be most and least helpful.

In order to address Research Question 4 (*Level of perceived helpfulness of reading scripts in relation to disclosure decisions*) cross tabulations were used, grouping participants by their disclosure status, and describing their ratings of each script (see Tables 13-21). ANOVA and t-test analyses were also used to determine differences between groups' ratings of each script (Disclosers, Non-disclosers, Undecided). The ANOVA analysis compared the helpfulness ratings of each script (*how helpful might this approach be for parents making disclosure decisions*) among the three categories of participants (Disclosers, Non-disclosers, Undecided). A t-test analysis compared participants' ratings of likelihood that they would use each script (*how likely would you be to use this approach*) to their disclosure-status group membership. In order to examine more condensed data, responses to Questionnaire B question #1 (*Helpfulness, in general*,

*of reading the disclosure scripts*) were grouped according to participants' disclosure plans.

Research Question 5 (*Level of perceived helpfulness of reading scripts in relation to demographic characteristics such as ethnicity, age, and religious affiliation*) was addressed by examining the data using cross tabulations comparing participants' religious affiliations, ages, children's ages, and ethnicities in relation to their ratings of the helpfulness of the scripts. A correlation analysis was performed to identify whether significant relationships existed between participants' ages, children's ages, and ethnicities as compared to their perceptions of the scripts' helpfulness. An ANOVA analysis was used to identify whether a statistically significant relationship existed between participants' religious affiliations and their perceptions of the scripts' helpfulness.

### **Summary**

In order to determine egg recipient parents' evaluations of various PTO disclosure scripts, the PI of this dissertation conducted a descriptive study measuring participants' ratings of the helpfulness of reading disclosure scripts. Nine scripts were created by the PI, inspired by Mac Dougall et al.'s research (2007) and Friedman's disclosure suggestions for recipient parents (2007). The scripts were presented to egg recipient parents, along with a questionnaire assessing a variety of relevant information.

Five research questions were posed, exploring: (a) the level of difficulty recipient parents rate making disclosure decisions; (b) the level of value recipient parents attribute to reading disclosure scripts; (c) the scripts' perceived helpfulness to recipient parents; (d) the level of the scripts' helpfulness compared to parents' disclosure status; and (e) the

differences in scripts' perceived helpfulness compared to parents' demographic variables. The method of data collection was internet-based, using an online questionnaire that asked primarily Likert-scale type questions. The data was analyzed using descriptive analyses such as charts, pie graphs, frequencies, means, cross tabulations, correlations, ANOVAs, t-tests, and Repeated Measures MANOVAs.

## Chapter 4. Results

Data will be presented that describe the characteristics of the study participants. Analyses for each of the research questions will then be explained, and participants' suggestions for resource development will be presented. Results will be summarized and presented utilizing pie graphs, tables, figures, and cross tabulations.

### Participant Characteristics

The link to the questionnaire was accessed electronically by a total of 61 individuals over a 60-day period of time. Of the 61 individuals who accessed the questionnaire a total of 52 individuals consented to participate and completed at least one survey question. Given the number of recruited participants, the response rate for the current study was approximately 4%. Table 2 summarizes the demographic characteristics of the study population.

Table 2  
*Participant Characteristics*

Participants	Percentage
Recipient Mother	90% (n=46)*
Recipient Father	8% (n=4)
Recipient parents together	2% (n=1)
Marital Statuses	Percentage
Married/Partnered	86% (n=44)*
Single	8% (n=4)
Divorced/Separated	6% (n=3)
Sexual Orientations	Percentage
Heterosexual	92% (n=47)*
Gay Male	8% (n=4)

(table continues)

Ethnicities	Percentage
White/Caucasian	96% (n=49)*
Asian/Pacific Islander or Asian-American	2% (n=1)
Latino/Hispanic	2% (n=1)
Nationalities	Percentage
American	78% (n=40)*
Australian	10% (n=5)
British	6% (n=3)
Canadian	2% (n=1)
Israeli	2% (n=1)
South Korean	2% (n=1)
Religions	Percentage
Christian	33% (n=17)*
Catholic	25% (n=13)
Non-Religious	22% (n=11)
Jewish	16% (n=8)
Agnostic	2% (n=1)
Atheist	4% (n=2)
Muslim	2% (n=1)
Buddhist	2% (n=1)
Highest Level of Education Completed	Percentage
Graduate/professional school	53% (n=27)*
Some graduate/professional school	16% (n=8)
College	25% (n=13)
Some college	6% (n=3)

(table continues)

Participants' ages	Percentage
33 – 40	12% ( <i>n</i> =6)
41 – 45	33% ( <i>n</i> =16)
46 – 50	35% ( <i>n</i> =17)*
51 – 56	20% ( <i>n</i> =10)
Participants' children's ages	Percentage
6 months – 2 years	46% ( <i>n</i> =34)
3 – 5 years	47% ( <i>n</i> =35)*
6 – 8 years	7% ( <i>n</i> =5)

\* Indicates highest values

The participants were predominantly American (78%; *n*=40), Caucasian (96%; *n*=49), female (90%; *n*=46), heterosexual (92%; *n*=47), and married (86%; *n*=44). No participants endorsed lesbian or bisexual orientations. There was also a noticeable lack of participants representing Black/African American/of African descent, Native American, or Bi-racial/Multi-racial ethnic and cultural backgrounds. One respondent provided an open-ended response regarding her ethnicity: “My husband is Arab-Israeli.”

The educational level of participants was exceptionally high, with the majority of parents having earned advanced degrees. Over half (*n*=27; 53%) of the recipient parents reported that their highest level of education completed was graduate/professional school. The age range of participants was 33-56 years old. The mean age of participants was 46.25 years old, the median age was 46 years, and the mode was 45 years of age. Only 12% (*n*=6) of participants were under the age of 40. The range of religious affiliations survey participants endorsed is slightly atypical of common population samples. As expected, the largest religious subscale included the “Christian” and “Catholic” religions (33%; *n*=17; and 25%; *n*=13, respectively). However, the second largest subscale that

was endorsed included “Non-religious” (22%;  $n=11$ ); “Atheist” (4%;  $n=2$ ); and “Agnostic” (2%;  $n=1$ ) affiliations. Furthermore, the “Jewish” participants represented a much larger population than typically found worldwide (16%;  $n=8$ ). Four individuals provided open-ended responses describing their religious affiliation: (a) “Unitarian Universalist;” (b) “Catholic upbringing;” (c) “Armenian Orthodox;” and (d) “My husband is Muslim.”

Participants were asked to report the number of children they have who were conceived via egg donation. The highest reported number of EDCO was reported to be four, with a mean amount of 1.5 children. The reported age range of EDCOs was from six months of age to eight years of age, with a mean age of 2.9 years. Given that 93% of participants had children under the age of six years, it could have been expected that the percentage of Disclosers would be lower than if the average age of the EDCO was older.

The majority of participants in this study were female, affluent, highly educated, primarily Caucasian and heterosexual. Due to the recruitment of participants from Egg Donation Inc.’s database between 2004 and 2005, it was to be expected that the majority of participants would have children under the age of five years. This increased the likelihood that participants had begun considering disclosure issues, though it limited the probability that participants had already completely disclosed to their children. Also, the response rate of 4% was quite low and could relate to a number of factors including the sensitive topic of the survey, the email recruitment method, and the likelihood that participants did not have spare time to complete the survey.

## Disclosure Decision Results

Over half of the study sample ( $n=29$ ; 56%) endorsed a disclosing status, while a smaller percentage ( $n=11$ ; 22%) reported an undecided disclosure stance, and the smallest percentage ( $n=9$ ; 17%) endorsed a non-disclosure status. Given recent trends towards disclosure, these results were generally expected. Table 1 (see page 15) showed that the percentage of disclosers in studies after the year 2000 increased substantially compared to earlier studies. The data collected in the current study is fairly consistent with previous findings, with a slight decrease in this study sample's reported plans to disclosure. Figure 2 presents participants' reported statuses of disclosure, grouped by the original disclosure status categories.

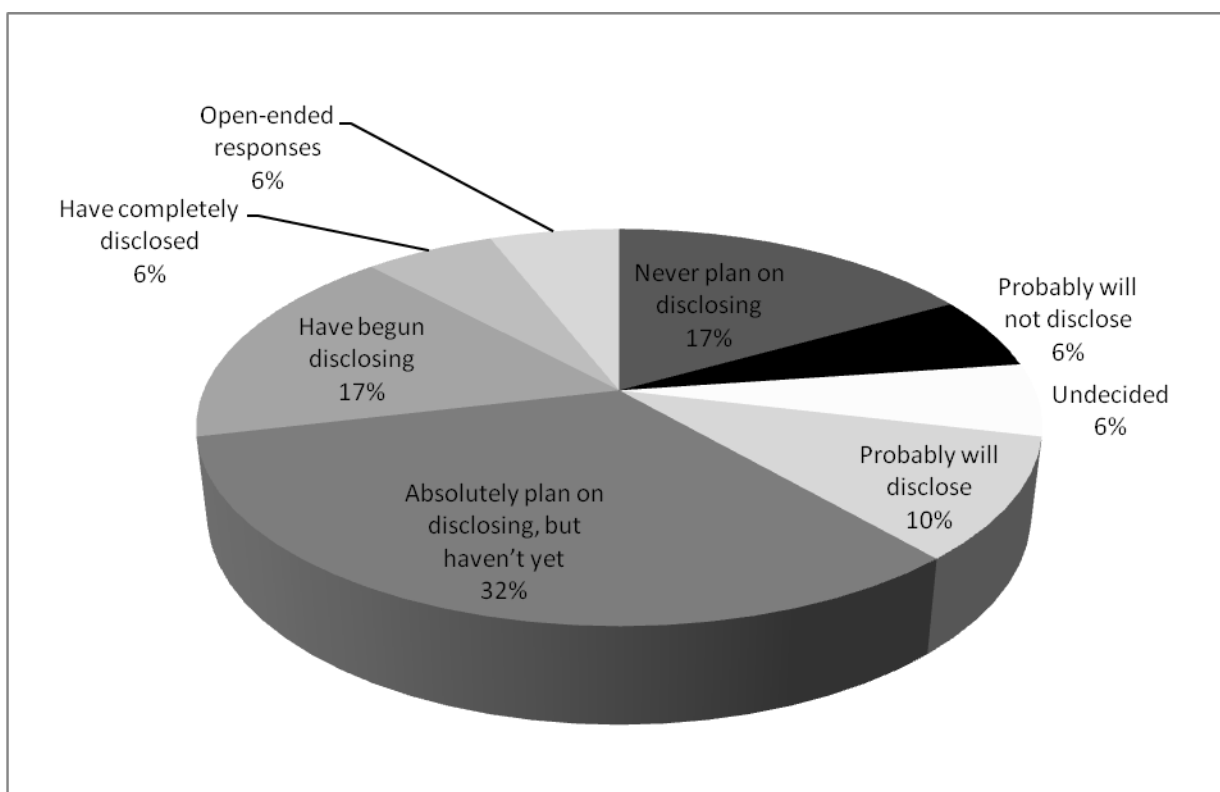


Figure 2. Attitudes of PTO disclosure found in the current research



The largest category of participants, those who absolutely plan on disclosing but have not yet begun ( $n=17$ ; 33%), compared to the small group of participants who have completely disclosed ( $n=3$ ; 6%) and those who have begun disclosing ( $n=3$ ; 6%) is expected given that 93% of participants' children were under the age of 6 years.

The following statements were provided by those participants who endorsed the "Other" category: (a) "Will disclose when age appropriate;" (b) "All family and some friends know, child too young;" (c) "Have completely disclosed to my eldest when he was about 5 and to my niece and nephew, then 4, 5. Will around the age of 4 to the twins themselves." The first and third responses explicitly state that the participants plan on disclosing. The second response is more ambiguous but also implies a stance towards disclosure (i.e., that the child will be told when s/he reaches a certain age). If all three open-ended responses were coded such that they fall into the category of "Absolutely plan on disclosing, but haven't yet," that group would represent 38% ( $n=20$ ) of the population sample. All other categories would represent the same percentages. Given that the three participants chose not to endorse a Likert-scale response, it is reasonable to propose that none of the Likert-scale responses wholly resonated with them. Therefore, the open-ended responses are not included in this report's analyses.

In order to better compare the data, the participants have been placed into three categories: (a) Disclosers; (b) Undecided; and (c) Non-disclosers, the descriptions of which are described in Table 3. Participants' disclosure statuses are described in Table 3.

Table 3  
*Combined Disclosure Decision Results*

Groupings	Reported Disclosure Plan	Percentage
Disclosers	Absolutely plan/ Have begun or completely disclosed	59.1% ( <i>n</i> =29)*
Undecided	Undecided/ Probably will not/ Probably will disclose	22.5% ( <i>n</i> =11)
Non-disclosers	Never plan on disclosing	18.4% ( <i>n</i> =9)

\* Indicates highest value

Among participants with multiple children, 99% (*n*=27) reported utilizing the same disclosure decision for both/all their children, while one participant reported being unsure whether s/he will use the same disclosure decision and another provided an open ended response to this question: “Have already disclosed, when pregnant with twins. It comes up now and then.” The response is unclear regarding whether the participant is using the same disclosure decision.

Table 4 displays the relationships between parents’ disclosure plans and the ages of their children. In order to display the only difference found, the participants have been grouped according to their originally endorsed disclosure status rather than the three groups created by the PI (i.e., Disclosers, Non-disclosers, and Undecided).

Table 4  
*Mean Age of DCO Compared to Parents’ Disclosure Decisions*

Rating	Mean ages of children
Never plan on disclosing	2.9 years old
Probably will not disclose	2.9 years old
Undecided	2.9 years old
Probably will disclose	2.9 years old
Absolutely plan on disclosing	2.9 years old
Have begun disclosing	2.9 years old
Have completely disclosed	6.0 years old

These findings were expected, given that participants who have completely disclosed to their children would be more likely to have older children compared to those parents who had not yet disclosed to their younger children.

The relationships between participants' religious affiliations and their disclosure decisions are displayed in Table 5.

Table 5  
*Religious Affiliations Compared to Disclosure Decisions*

Religious Affiliation	Disclosers	Non-disclosers	Undecided
Christian	69% (n=11)	19% (n=3)	12% (n=2)
Catholic	80% (n=33)	13% (n=5)	7% (n=3)
Muslim	100% (n=1)	0% (n=0)	0% (n=0)
Buddhist	100% (n=1)	0% (n=0)	0% (n=0)
Jewish	71% (n=5)	0% (n=0)	29% (n=2)
Non-religious	45% (n=5)	18% (n=2)	37% (n=4)
Atheist	100% (n=1)	0% (n=0)	0% (n=0)
Agnostic	75% (n=3)	25% (n=1)	0% (n=0)

Figures total 100% in each row

In response to being asked if participants had ever received professional advice on the disclosure decision issue, 49% (n=25) reported that they had received such advice, and 51% (n=26) reported that they had not received said advice. Of participants who had received disclosure advice, 8% (n=2) reported receiving the advice from their physician, 4% (n=1) reported receiving advice from a nurse; 65% (n=17) reported receiving the advice from a mental health professional; and 23% (n=6) provided open ended responses. The open ended responses included: (a) "Websites related to the issue;" (b) "One appt w/ counselor before DE cycle began;" (c) "Surrogacy agency;" (d) "Physician, mental health professional, books." Notably, one response stated: (e) "Wanted to answer "no" to

question 13 [*Have you received professional advice on the disclosure decision issue*].

Can't change it!" Unfortunately, the Zoomerang survey website did not allow the participant to undo the response provided on a previous screen. Had the individual changed her response, the following data would have been calculated: 47% of participants ( $n=24$ ) having received disclosure advice; and 53% ( $n=27$ ) having never received said advice. These data indicate that approximately half of the study's recipient parents received PTO disclosure advice from professionals in the field or from other resources such as websites or surrogacy agencies.

Table 6 displays the relationships between participants' disclosure plans and having received disclosure advice.

Table 6  
*Disclosure Advice Compared to Disclosure Plans*

Rating	Disclosers	Non-disclosers	Undecided
Received advice	59% ( $n=17$ )	56% ( $n=5$ )	20% ( $n=2$ )
Did not receive advice	41% ( $n=12$ )	44% ( $n=4$ )	80% ( $n=8$ )

Figures total 100% in each column

The majority of parents who have made their disclosure decision received advice (59% of Disclosers; 56% of Non-disclosers). Within the Undecided group of participants, only 20% had received professional advice on disclosure issues, suggesting that professional consultation may facilitate the disclosure decisions process.

**Research Question 1: What level of difficulty do recipient parents rate making disclosure decisions?** When asked, "How easy or difficult do you rate making parent-to-offspring disclosure decisions," using a Likert scale from (1) Very easy to (5) Very difficult, the mean response was 2.96, the median was 3.00 ("No opinion"), the

mode response was 4 (“Difficult”), and the standard deviation was 1.356. Table 7 presents the participants’ ratings.

Table 7  
*Ratings of Ease/Difficulty of Disclosure Decisions*

Rating	Percentage
Very easy	18% (n=9)
Easy	27% (n=14)
No opinion	8% (n=4)
Difficult	35% (n=18)*
Very difficult	12% (n=6)

\* Indicates highest value

Forty-five percent (n=23) of this study’s participants reported that PTO disclosure decisions are very easy or easy to make, while 47% (n=24) reported that they are difficult or very difficult to make. Only 8% (n=4) reported no opinion.

Table 8 presents the relationships between participants’ disclosure plans and the levels of difficulty with which they report making disclosure decisions.

Table 8  
*Disclosure Plans Compared to Ease/Difficulty of Decisions*

Rating	Disclosers	Non-disclosers	Undecided
Very easy	21% (n=6)	23% (n=2)	10% (n=1)
Easy	41% (n=12)	0% (n=0)	0% (n=0)
No opinion	7% (n=2)	11% (n=1)	0% (n=0)
Difficult	28% (n=8)	33% (n=3)	70% (n=7)
Very difficult	3% (n=1)	33% (n=3)	20% (n=2)

Figures total 100% in each column

As expected, the majority of the Undecided participants (90%) reported that making disclosure decisions is difficult or very difficult. Almost two-thirds of the

Disclosers (62%) reported that disclosure decisions are very easy or easy to make, while two-thirds of the Non-disclosers (66%) endorsed that disclosure decisions are difficult or very difficult to make.

Table 9 presents the relationships between participants' receiving professional advice on disclosure issues and the levels of difficulty with which they report making disclosure decision.

Table 9  
*Ease/Difficulty of Decisions and Receiving Professional Advice*

Rating	Received advice	Did not receive advice
Very easy	56% (n=5)	44% (n=4)
Easy	50% (n=7)	50% (n=7)
No opinion	50% (n=2)	50% (n=2)
Difficult	50% (n=9)	50% (n=9)
Very difficult	33% (n=2)	67% (n=4)

Figures total 100% in each row

Most of the groups included equal percentages of parents who received advice and did not receive advice. The group that theoretically needed advice the most—those who reported that the decisions are “very difficult” to make—were the individuals who sought advice less often than all other groups.

### **Data from Participants Reading Disclosure Scripts**

The following data were collected from participants who were directed to either Presentation of Scripts—Form A (i.e., participants who indicated that they (a) never plan on disclosing; (b) probably will not disclose; (c) are undecided; (d) probably will disclose; or (e) absolutely plan on disclosing, but haven't yet; or if they did not respond to the question); or Presentation of Scripts—Form B (i.e., participants who indicated that

they had already begun disclosing, or who had completely disclosed; see Appendices H and I.)

### Research Question 2: Do recipient parents find it valuable to read PTO

**disclosure scripts?** Table 10 describes the data collected when participants were asked to rate how desirable it would be for them to read disclosure scripts that other recipient parents have used to tell their children about their genetic origins.

Table 10  
*Desirability of Reading Scripts*

Rating	Percentage
Very desirable	31% (n=15)
Desirable	38% (n=18)*
Unsure	21% (n=10)
Not desirable	4% (n=2)
Not at all desirable	6% (n=3)

\* Indicates highest value

Table 11 presents the relationships between participants' disclosure plans and the levels of desirability they have towards reading disclosure scripts.

Table 11  
*Disclosure Plans and Desirability of Reading Scripts*

Rating	Disclosers	Non-disclosers	Undecided
Very desirable	41.4% (n=12)	11.1% (n=1)	30% (n=3)
Desirable	41.4% (n=12)	33.3% (n=3)	30% (n=3)
Unsure	14% (n=4)	22.3% (n=2)	30% (n=3)
Not desirable	3.2% (n=1)	0% (n=0)	10% (n=1)
Not at all desirable	0% (n=0)	33.3% (n=3)	0% (n=0)

Figures total 100% in each column

These results suggest that once parents are firm in their decision not to disclose, they may prefer not to expose themselves to material that might challenge their decision.

After the presentation of the scripts, participants were asked the question, “*How helpful, in general, do you rate reading the disclosure scripts.*” The following responses were collected: 25% ( $n=13$ ) reported that it was “Very helpful”; 49% ( $n=25$ ) reported that it was “Helpful”; 20% ( $n=10$ ) endorsed that they were “Undecided”; 2% ( $n=1$ ) reported that it was “Not very helpful”; and 4% ( $n=2$ ) reported that it was “Not at all helpful” to read the scripts. Cross tabulation measures presented in Table 12 provide data displaying the relationships between participants’ disclosure decisions and perceived helpfulness of reading the disclosure scripts.

Table 12  
*Disclosure Decisions and Perceived Helpfulness of Reading Scripts*

Rating	Disclosers	Non-disclosers	Undecided
Very helpful	38% ( $n=11$ )	11.1% ( $n=1$ )	10% ( $n=1$ )
Helpful	52% ( $n=15$ )	33.3% ( $n=3$ )	60% ( $n=6$ )
Undecided	10% ( $n=3$ )	33.3% ( $n=3$ )	30% ( $n=3$ )
Not very helpful	0% ( $n=0$ )	0% ( $n=0$ )	0% ( $n=0$ )
Not at all helpful	0% ( $n=0$ )	22.3% ( $n=2$ )	0% ( $n=0$ )

Figures total 100% in each column

**Research Question 3: What is the level of perceived helpfulness of reading each of the several PTO disclosure scripts?** Tables 13-21 below present participants’ responses to each script. The data in each row titled “Helpful” represent the percentages of the Disclosers, Non-disclosing, and Undecided participants who rated that the various scripts might be “very helpful” or “somewhat helpful” to parents making disclosure decisions. The data in each row titled “Not helpful” represent the percentages of participants who rated that the various scripts might be “not very helpful” or “not at all helpful” to parents making disclosure decisions. The data in each row titled “Likely/Similar” represent the percentages of Disclosers, Non-disclosers, and Undecided



participants who rated that the approach is “very similar” or “somewhat similar” to the approach they used for disclosing to their own children or that they would be “very likely” or “somewhat likely” to use the approach. The data in each row titled “Not likely/Similar” represent the percentages of participants who rated that the approach is “not very similar” or “not at all similar” to the approach they used for disclosing to their own children or that they would be “not likely” or “not at all likely” to use the approach.

Table 13  
*Responses to The Helper Script*

	Disclosers	Undecided	Non-disclosers
Helpful	90% ( <i>n</i> =26)	60% ( <i>n</i> =6)	67% ( <i>n</i> =6)
Neutral	7% ( <i>n</i> =2)	30% ( <i>n</i> =3)	0% ( <i>n</i> =0)
Not helpful	3% ( <i>n</i> =1)	10% ( <i>n</i> =1)	33% ( <i>n</i> =3)
Figures total 100% in each column			
Likely/Similar	76% ( <i>n</i> =22)	40% ( <i>n</i> =4)	0% ( <i>n</i> =0)
Neutral	14% ( <i>n</i> =4)	20% ( <i>n</i> =2)	33% ( <i>n</i> =3)
Not likely/Similar	10% ( <i>n</i> =3)	40% ( <i>n</i> =4)	67% ( <i>n</i> =6)

Figures total 100% in each column

Of the Disclosing participants, 90% endorsed that The Helper script would be generally helpful to parents making disclosure decisions; however, only 76% of Disclosers reported that they would likely use the approach, or that it is similar to the approach they have used. The wording of The Helper script is arguably most appropriate to young children. Given that 93% of participant’s children were under the age of 6, it would be expected that this script would be a good match for Disclosing participants. Of the Undecided participants, 60% endorsed that The Helper script would be generally helpful to parents making disclosure decisions while only 40% reported that they would likely use the approach.

Table 14  
*Responses to Spare Parts Script*

	Disclosers	Undecided	Non-disclosers
Helpful	52% (n=15)	50% (n=5)	67% (n=6)
Neutral	17% (n=5)	20% (n=2)	11% (n=1)
Not helpful	31% (n=9)	30% (n=3)	22% (n=2)
Figures total 100% in each column			
Likely/Similar	41% (n=12)	20% (n=2)	22% (n=2)
Neutral	21% (n=6)	20% (n=2)	0% (n=0)
Not likely/Similar	38% (n=11)	60% (n=6)	78% (n=7)
Figures total 100% in each column			

Of the Disclosing participants, 52% reported that the Spare Parts script would be helpful to parents making disclosure decisions. However, only 41% of Disclosers endorsed that they would be likely to use the approach in disclosing to their children, or that the approach is similar to one they have used.

Table 15  
*Responses to Families are Different Script*

	Disclosers	Undecided	Non-disclosers
Helpful	58% (n=17)	70% (n=7)	38% (n=3)
Neutral	21% (n=6)	10% (n=1)	12% (n=1)
Not helpful	21% (n=6)	20% (n=2)	50% (n=4)
Figures total 100% in each column			
Likely/Similar	48% (n=14)	50% (n=5)	13% (n=1)
Neutral	11% (n=3)	20% (n=2)	13% (n=1)
Not likely/Similar	41% (n=12)	30% (n=3)	74% (n=6)
Figures total 100% in each column			

Of the Disclosing participants, 59% endorsed that the Families are Different script would be generally helpful to parents making disclosure decisions; however, only 48%

participants reported that they would likely use the approach, or that it is similar to the approach they have used.

Table 16  
*Responses to Organ Donor Script*

	Disclosers	Undecided	Non-disclosers
Helpful	76% (n=22)	80% (n=8)	78% (n=7)
Neutral	14% (n=4)	20% (n=2)	11% (n=1)
Not helpful	10% (n=3)	0% (n=0)	11% (n=1)
Figures total 100% in each column			
Likely/Similar	61% (n=17)	55% (n=5)	33% (n=3)
Neutral	18% (n=5)	22% (n=2)	0% (n=0)
Not likely/Similar	21% (n=6)	22% (n=2)	67% (n=6)
Figures total 100% in each column			

Of the Disclosing participants, 76% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions; however, only 61% participants reported that they would likely use the approach, or that it is similar to the approach they have used.

Table 17  
*Responses to Labor of Love Script*

	Disclosers	Undecided	Non-disclosers
Helpful	78% (n=21)	40% (n=4)	44% (n=4)
Neutral	7% (n=2)	40% (n=4)	12% (n=1)
Not helpful	15% (n=4)	20% (n=2)	44% (n=4)
Figures total 100% in each column			
Likely/Similar	41% (n=11)	30% (n=3)	22% (n=2)
Neutral	15% (n=4)	30% (n=3)	0% (n=0)
Not likely/Similar	44% (n=12)	40% (n=4)	78% (n=7)
Figures total 100% in each column			

Of the Disclosing participants, 78% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions; however, only 41% participants reported that they would likely use the approach.

Table 18  
*Responses to Nuts & Bolts Script*

	Disclosers	Undecided	Non-disclosers
Helpful	32% (n=9)	30% (n=3)	33% (n=3)
Neutral	25% (n=7)	20% (n=2)	0% (n=0)
Not helpful	43% (n=12)	50% (n=5)	67% (n=6)
Figures total 100% in each column			
Likely/Similar	18% (n=5)	0% (n=0)	0% (n=0)
Neutral	14% (n=4)	20% (n=2)	0% (n=0)
Not likely/Similar	68% (n=19)	80% (n=8)	100% (n=9)
Figures total 100% in each column			

Of the Disclosing participants, 32% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions; however, only 18% participants reported that they would likely use the approach, or that it is similar to the approach they have used.

Table 19  
*Responses to Great Young Lady Script*

	Disclosers	Undecided	Non-disclosers
Helpful	68% (n=19)	70% (n=7)	44% (n=4)
Neutral	18% (n=5)	10% (n=1)	23% (n=2)
Not helpful	14% (n=4)	20% (n=2)	33% (n=3)
Figures total 100% in each column			
Likely/Similar	43% (n=12)	40% (n=4)	11% (n=1)
Neutral	11% (n=3)	20% (n=2)	0% (n=0)
Not likely/Similar	46% (n=13)	40% (n=4)	89% (n=8)
Figures total 100% in each column			

Of the Disclosing participants, 68% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions; however, only 43% participants reported that they would likely use the approach.

Table 20  
*Responses to Privilege to Love Script*

	Disclosers	Undecided	Non-disclosers
Helpful	82% (n=23)	70% (n=7)	44% (n=4)
Neutral	14% (n=4)	10% (n=1)	33% (n=3)
Not helpful	4% (n=1)	20% (n=2)	23% (n=2)
Figures total 100% in each column			
Likely/Similar	52% (n=15)	40% (n=4)	11% (n=1)
Neutral	20% (n=6)	30% (n=3)	11% (n=1)
Not likely/Similar	28% (n=8)	30% (n=3)	78% (n=7)
Figures total 100% in each column			

Of the Disclosing participants, 82% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions; however, only 52% participants reported that they would likely use the approach.

Table 21  
*Responses to Come & Talk Script*

	Disclosers	Undecided	Non-disclosers
Helpful	90% (n=26)	50% (n=5)	56% (n=5)
Neutral	10% (n=3)	20% (n=2)	22% (n=2)
Not helpful	0% (n=0)	30% (n=3)	22% (n=2)
Figures total 100% in each column			
Likely/Similar	83% (n=24)	50% (n=5)	22% (n=2)
Neutral	10% (n=3)	20% (n=2)	11% (n=1)
Not likely/Similar	7% (n=2)	30% (n=3)	67% (n=6)
Figures total 100% in each column			

Of the Disclosing participants, 90% endorsed that the Organ Donor script would be generally helpful to parents making disclosure decisions, and 83% reported that they would likely use the approach, or that it is similar to the approach they have used.

Table 22 provides a summary of participants' positive ratings of helpfulness, similarity to own experience, and likelihood of using the scripts. The data in each column titled "Helpfulness" represent the percentages of the Disclosers, Non-disclosers, and Undecided participants who rated that the various scripts might be "very helpful" or "somewhat helpful" to parents making disclosure decisions. The data in the column titled "Sim/Lik" represent the percentages of Disclosers who rated that the approach is "very similar" or "somewhat similar" to the approach they used for disclosing to their own children or that they would be "very likely" or "somewhat likely" to use the approach.

Table 22  
*Positive responses to each script*

Scripts	Disclosers		Non-disclosers		Undecided	
	Helpfulness	Sim/Lik	Helpfulness	Likelihood	Helpfulness	Likelihood
The Helper	90%	76%	67%	0%	60%	40%
Spare Parts	52%	41%	67%	22%	50%	20%
Families are Different	59%	48%	33%	11%	70%	50%
Organ Donor	76%	59%	78%	33%	80%	50%
Labor of Love	72%	38%	44%	22%	40%	30%
Nuts & Bolts	31%	17%	33%	0%	30%	0%
Great Young Lady	66%	41%	44%	11%	70%	40%
Privilege to Love	79%	52%	44%	11%	70%	40%
Come & Talk	90%	83%	56%	22%	50%	50%

Helpfulness = very helpful or somewhat helpful

Sim/Lik = very similar / somewhat similar or very likely / somewhat likely

**Research Question 4: What is the level of perceived helpfulness of reading disclosure scripts in relation to participants' PTO disclosure status?** To determine whether each script's helpfulness rating differed significantly, a Repeated Measures MANOVA was conducted. Participants were placed into three groups (Disclosers, Non-disclosers, and Undecided), and their responses to the question, "*How helpful do you think this approach might be for parents who are making disclosure decisions,*" were compared to determine whether statistically significant differences were found between each script. The repeated measure MANOVA statistics with post hoc results are described in Table 23. Of the Disclosers ( $n=29$ ), several differences were found among the scripts. Of the Undecided group ( $n=11$ ), no differences were found among the scripts. The Non-disclosers group ( $n=9$ ) was too small to produce follow up univariate statistics.

Table 23

*Repeated Measures Multivariate Analysis of Variance of Scripts' Helpfulness*

Source	$\Lambda$	$F$	$df$	$p$	Significant post hoc test
Disclosers*	.422	3.25	8	.017	A, I > C, D, E, G, H > B, F
Non-disclosers	--	--	--	--	
Undecided	.136	1.58	8	.444	

*Note.* Multivariate statistics cannot be calculated for Non-disclosers due to insufficient degree of freedom.

\*  $p < .05$

Of the Disclosers, results indicated that there were significant differences between the helpfulness ratings of the nine scripts (A-I) by participants in this study, Wilks' Lambda  $\Lambda = .42$ ,  $F(8,19) = 3.25$ ,  $p = .017$ ,  $\eta^2 = .578$  (this is effect size). Interpretations of these data are described in Table 24.

Table 24  
*Disclosers' ratings of scripts' helpfulness*

Most Helpful	Moderately Helpful	Least Helpful
A: The Helper	C: Families are Different	B: Spare Parts
I: Come & Talk	D: Organ Donor	F: Nuts & Bolts
	E: Labor of Love	
	G: Great Young Lady	
	H: Privilege to Love	

To examine whether there were any statistically significant differences between participants' disclosure decisions and their perceived helpfulness of reading the scripts, a One-way ANOVA was performed. Participants were placed into three groups (Disclosers, Non-disclosers, and Undecided), and their responses to the question, "*How helpful do you think this approach might be for parents who are making disclosure decisions,*" was the criterion variable. The results of the One-way ANOVA indicated that at least one pair of means significantly differ,  $F(2, 45) = 5.20, p = .009$ . However, the Dunnett T3 post hoc test, while assuming that the variances of the three subgroups do significantly differ (Levene's homogeneity test:  $F(2, 45) = 4.54, p = .016$ ), did not revealed any statistically significant differences between any groups. It should be noted that results from the Scheffe post hoc test (when equal variances among groups can be assumed) indicate that there may be significant differences between Disclosers' and Non-disclosers' responses to the scripts. This discrepancy may be due to the very small sample sizes and unequal group sizes in this study.

To identify whether significant differences exist between Non-disclosers and Undecided participants regarding the likelihood that they would utilize the scripts, an independent-samples t-test was performed. Results of the t-test indicate that there is a



significant difference between the likelihood of using the scripts based upon participants' disclosure decisions,  $t(9.184) = -3.36, p = .008$ , when equal variances not assumed (Levene's  $F = 8.01, p = .012$ ). As hypothesized, Undecided participants reported higher likelihood of utilizing the scripts than did Non-disclosers.

**Research Question 5: Are there differences in perceived helpfulness of the scripts based upon demographic variables (e.g., age of offspring, age of parent, ethnicity, and religious affiliation?)** To compare participants' demographic variables (e.g., EDCO age, participant age, ethnicity, and level of education) to their ratings of how helpful in general they found reading the scripts, Table 25 presents a cross tabulation. The data in each row titled "Helpful" represent the percentages of the Disclosers, Non-disclosers, and Undecided participants who rated that the various scripts might be "very helpful" or "somewhat helpful" to parents making disclosure decisions. The data in each row titled "Not helpful" represent the percentages of participants who rated that the various scripts might be "not very helpful" or "not at all helpful" to recipient parents.

Table 25  
*Demographic Variables and Ratings of Scripts' Helpfulness*

EDCO Age	Helpful	Undecided	Not helpful
6 mos - 2 yrs	68% ( $n=13$ )	32% ( $n=6$ )	0% ( $n=0$ )
3 yrs - 5 yrs	80% ( $n=25$ )	10% ( $n=3$ )	10% ( $n=3$ )
6 yrs - 8 yrs	100% ( $n=2$ )	0% ( $n=0$ )	0% ( $n=0$ )
Figures total 100% in each row			
Participant Age	Helpful	Undecided	Not helpful
33 - 40	70% ( $n=7$ )	10% ( $n=1$ )	20% ( $n=2$ )
41 - 45	81% ( $n=13$ )	19% ( $n=3$ )	0% ( $n=0$ )
46 - 50	69% ( $n=11$ )	31% ( $n=5$ )	0% ( $n=0$ )
51 - 56	80% ( $n=8$ )	10% ( $n=1$ )	10% ( $n=1$ )
Figures total 100% in each row			

Level of Education	Helpful	Undecided	Not helpful
Graduate/Professional School	70% ( $n=19$ )	23% ( $n=6$ )	7% ( $n=2$ )
Some graduate/professional School	75% ( $n=6$ )	25% ( $n=2$ )	0% ( $n=0$ )
College	77% ( $n=10$ )	15% ( $n=2$ )	8% ( $n=1$ )
Some college	100% ( $n=3$ )	0% ( $n=0$ )	0% ( $n=0$ )
Figures total 100% in each row			

In order to determine whether statistically significant relationships exist between participants' ages, their children's ages, and their perceptions of the scripts' helpfulness, correlation analyses were performed. Results from the Pearson Correlation analysis showed no significant relationships between participants' ages, children's ages, and participants' perceptions of the scripts' helpfulness.

A One-way ANOVA was performed to identify whether statistically significant differences exist between participants' religious affiliations (Christian, Catholic, Non-Religious, Jewish) and their perceptions of the scripts' helpfulness. Results indicated that there were no statistically significant differences in participants' perceptions of the scripts' helpfulness based on their religious affiliations,  $F(3, 40) = 3.44, p = .794$ . Unfortunately, the homogeneity of the participants' ethnicities was also too great to produce statistically significant data using ANOVA or other analyses.

In response to the question: *Do you think some type of disclosure decision assistance should be provided to all recipient couples*, the following data were collected: 53% ( $n=27$ ) reported that it "Absolutely" should be provided; 25% ( $n=13$ ) endorsed that it "Maybe" should be provided; 16% ( $n=8$ ) reported being "Undecided;" 2% ( $n=1$ ) endorsed that it should "Probably not" be provided; and 4% ( $n=2$ ) reported that it should "Absolutely not" be provided.

The question, “*Do you think examples of disclosure scripts should be provided to all recipient couples,*” yielded the following results: 49% ( $n=25$ ) reported that scripts should “Absolutely” be provided; 37% ( $n=19$ ) endorsed that scripts “Maybe” should be provided; 8% ( $n=4$ ) reported that they were “Undecided;” 2% ( $n=1$ ) endorsed that scripts should “Probably not” be provided; and 4% ( $n=2$ ) reported that scripts should “Absolutely not” be provided to couples.

### **Desire for Resources**

Lastly, 61% ( $n=31$ ) of participants reported that they would be interested in accessing resources intended to assist in the disclosure-decision process, while 39% ( $n=20$ ) reported that they would not be interested. When participants were asked to provide their thoughts about resources that might be helpful to them (i.e., *Please provide any suggestions for improving the scripts. You might have ideas about how a specific script could be improved, or you might have an idea for a different script*), 32 individuals provided open ended responses. The responses are documented in Table 26.

Table 26  
*Open-Ended Responses*

Comment #	Response
1	Went through IVF doc’s counselor for resources, also on eBay. Really like the children’s books that you read to preschoolers.
2	Psychological studies on children who found out that they were egg donor conceived highlighting their concerns and fears.
3	Age group resources would be terrific. Our twin daughters are almost 4 and are very aware of the surrogate who helped us to have them; however explaining egg donation to very young children is a bit harder. A lot of the resource material / books we have come across are more suitable for older

*(table continues)*

Comment #	Response
3 (cont'd)	children (e.g. 10 onwards). The amount of information provided to a child will change as the child gets older, hence it would so helpful to have information/suggested guidelines that are tailored to age groups (e.g. 2-5 / 5 - 8 years etc.). The professional advice we have received is that "less is enough" until the girls turn about 10, hence we have kept things very simple to date, and now we will begin to talk about our egg donor we plan to follow the same path. Also, suggested answers to the most likely asked questions would be great. Thank you.
4	I'd like to see more books written for young children that show families made in different ways, and tell the ED story too.
5	I think it is a very private matter, and I found websites and information online that guided me in my future responses and resources. I plan to take a very natural approach to disclosing and leave it up to our daughter to decide if she would like to meet her biological mother. I think it should be less clinical and more embracing of the gift that she the biological mother gave. I want our child to feel very comfortable about it. The less clinical the better especially at a younger age.
6	Not sure
7	Leaflet/Video-could be via internet
8	Now that I have made by decision regarding disclosure and come up with my "game plan," I don't need it, but for someone just starting this process I think it's very helpful and gives some good ideas abt. addressing the topic.
9	On line web site, etc
10	I think these scripts are very helpful; I would love a copy of them!
11	Would be great to have examples for gay and lesbian parents, as our stories are likely going to be different
12	Outcome discussions with other parents who have been through it with older children. First, personal conversation, responsive to the parent's

*(table continues)*

Comment #	Response
12 (cont'd)	particular issues, with professional who has seen many ways to do it.
13	Would appreciate copies of the scripts used in the survey. Even the ones I did not 'warm' to on this occasion.
14	Studies that show the children's reaction to varieties of approaches and which are most beneficial to the children.
15	It would be nice to see scripts that are categorized by the child's ages. These scripts seem to be targeting very young children, however I don't intend to disclose until my father has passed away (83 yrs now, but very healthy). My children may be adolescents or young adults by the time I am able to disclose.
16	Books, online resources, blogs, list serve, easy access to therapist/specialist in the field
17	I like the scripts, perhaps there are children's books available. It would be nice to hear actual examples/stories from others and to find out how the children handled it.
18	My child is young. I am currently using XY and M books. I do not like them and have a long way to go. Additional assistance in the area of dealing with reactions to my child's finally comprehending the concept would be helpful. These scripts are also helpful. Role play scripts would help to prepare me.
19	Scripts, as you have presented. But also, what if you decide not to disclose and at a later date, your children become aware of the donation (one parent is genetic in our case). We really don't want to go down this road at all unless absolutely necessary, and as loving as we are, we feel that if they do find out when they are older, they will understand our non-disclosure. Give us your thoughts on that!
20	Simple details on how assisted reproductive techniques work, so that young person can understand

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*(table continues)*

Comment #	Response
21	Our IVF psychologist Kate Bourne wrote a book "Sometimes it takes 3 to make a baby" so talking about it to our children very early (age about 4 onwards) was very helpful for them to accept it as a "normal" way to have a family. The book is a story from a child's perspective with the ability for them to draw pictures and become involved in the experience. Invaluable resource
22	About telling the kids and the world around us. We didn't want anyone to know but we are going to tell
23	Professional and parent ideas
24	Scripts, books, stories about what has worked well and not worked well for other families, and opinions of children, teenagers, young adults who were conceived through donation- what did they find helpful and not helpful
25	A few simple examples like this seems to serve the purpose of communicating, but what would be most helpful would be more assistance on determining appropriate timing of disclosure (developmental age-appropriate suggestions)
26	I have a bit of fear when it comes to my son's thinking when he becomes a teenager. I have two teenage daughters that seem to question everything and I'm a bit nervous that he may rebel at that age.
27	It seems that the disclosure issue sways toward disclosure - but nondisclosure is also an option. The pros and cons of both options need to be considered, not just what disclosure script should take place. I thought I had to disclose for the health of my children until a psychologist made me understand that nondisclosure is a viable and good option as well. I would like more studies on nondisclosure.
28	Disclosure decision is a result of how the couple deals with their loss of having their "own" baby and their understanding of communication and openness. Secrets are probably one of the most toxic issues for family

*(table continues)*

Comment #	Response
28 (cont'd)	cohesion (in my opinion). We bring up the subject of my sister's egg donation to me, as part of sex education. And of course it is something that is not a one-time thing. My eldest is seven, and my nephew and niece (6, 4) come back on it now and then with questions on how and why my sister donated the eggs to me. Our version is direct and names things by their names, no vagueness. Like: "my eggs were up. So my sister gave me some so me and daddy could have more kids. A doctor took the eggs from my sister's womb. Gave them to me and helped us fertilize the egg (egg meets up with dad's sperm)". Then we put it in mommy's womb and then the twins grew there". The kids had many questions, like whether they could have grew in my sister's womb. What if she wants them back (she can have them - joke). And I am sure that with our kids' development, the questions will develop too.
29	I would like to read about actual experiences of other parents.
30	Different script / ideas will be helpful...also at what age would it best be shared with the child
31	Storybooks would be nice appropriate to different age groups. We are just making our daughter's story part of her life; nothing extraordinary.
32	Referral to mental health professional during the donation process

## Summary

The majority of participants in this study were female, affluent, highly educated, primarily Caucasian and heterosexual. Due to the recruitment of participants from Egg Donation Inc.'s database between 2004 and 2005, it was to be expected that the majority of participants would have children under the age of five years. This increased the likelihood that participants had begun considering disclosure issues, though it limited the probability that participants had already completed disclosure to their children. Also, the

response rate of 4% was quite low, and could relate to a number of factors including the sensitive topic of the survey, the email recruitment method, and the likelihood that participants, as parents of young children, did not have spare time to complete the survey.

Disclosure decision results indicate that over half of the study sample ( $n=29$ ; 59.1%) endorsed a disclosing status, while a smaller percentage ( $n=11$ ; 22.5%) reported an undecided disclosure stance, and the smallest percentage ( $n=9$ ; 18.4%) endorsed a non-disclosure status. These data are fairly consistent with previous findings, with a slight decrease in this study sample's reported plans to disclosure. In response to being asked if participants had ever received professional advice on the disclosure decision issue, 49% ( $n=25$ ) reported that they had received such advice, and 51% ( $n=26$ ) reported that they had not received said advice.

Approximately half ( $n=23$ ; 55%) of this study's participants reported that PTO disclosure decisions are very easy or easy to make, while 47% ( $n=24$ ) reported that they are difficult or very difficult to make. As expected, the majority of the Undecided participants (90%) reported that disclosure decisions are difficult or very difficult to make. In response to the question, "*How helpful, in general, do you rate reading the disclosure scripts,*" 25% of participants ( $n=13$ ) reported that it was "Very helpful"; 49% ( $n=25$ ) reported that it was "Helpful"; 20% ( $n=10$ ) endorsed that they were "Undecided"; 2% ( $n=1$ ) reported that it was "Not very helpful"; and 4% ( $n=2$ ) reported that it was "Not at all helpful" to read the scripts. A little less than two-thirds of the participants (62%;  $n=32$ ) provided open-ended responses when asked to provide suggestions for improving the scripts.



## Chapter 5. Discussion

Parent-to-offspring disclosure has been contemplated, disputed, and studied for several years, with the first research measuring recipient parents' disclosure decisions published in the mid '90s (Cook et al., 1995). Since that time, a dramatic shift has occurred in gamete recipient parents' decisions regarding whether or not to disclose the donation to their EDCO (see Table 1, page 15). The current research was aimed at contributing to knowledge about disclosure patterns while also addressing recipient parents' need for helpful resources. This study was created in response to the frequency with which gamete recipient parents have requested information about other parents' disclosure decisions. The intention of the research was to provide preliminary data on the usefulness of providing scripts to help recipient parents make the difficult decisions of whether and how to talk to their children about their genetic origins.

### Discussion of Results

Following are discussions regarding the main findings from this survey study, organized by the research questions that guided the investigation.

**Difficulty of making disclosure decisions.** In regards to the difficulty or ease with which participants have found making disclosure decisions, the data collected were surprising. The results describe that 45% of the participants find making PTO disclosure decisions relatively "easy," while 47% reported that disclosure decisions are "difficult" to make (see Table 7). These data appear slightly inconsistent with reports that recipient parents often request help in making disclosure decisions (ASRM Ethics Committee, 2004; Australia's Infertility Authority, 2007; Cook, Golombok, Bish, & Murray, 1995; De Jonge & Barratt, 2006; Greenfeld & Klock, 2004; Hahn & Craft-Rosenberg, 2002;

Hershberger et al., 2007; Leiblum & Aviv, 1997; Mac Dougall et al., 2007; Mahlestedt & Greenfeld, 1989; Murray & Golombok, 2003; Rumball & Adair, 1999). Although 45% of the present study's participants rated making disclosure decisions as "easy" or "very easy," a larger percentage (69%) of this study's population reported that reading disclosure scripts would be "very desirable" or "desirable." This study's data is consistent with previous research findings that recipient couples value disclosure resources inspired by real recipient parents.

To explore the relationship between participants' reported ease of making disclosure decisions and participants' disclosure statuses, a cross tabulation was performed (see Table 8). Results indicate that 62% of the Disclosers report making the decisions "very easy" or "easy"; and 31% of the Disclosers find making the decisions "very difficult" or "difficult." Notably, only 22% of the Non-disclosers find making the decisions "very easy" or "easy"; while 66% of the Non-disclosers find making the decisions "very difficult" or "difficult." As could be expected, the majority of the Undecided participants (90%) reported that disclosure decisions are "very difficult" or "difficult" to make. These robust findings support the conclusion that further empirical and clinical attention needs to be paid to helping recipient parents make disclosure decisions.

In regard to recipient parents' plans to disclose or not disclose to their offspring, participants' reports were generally consistent with recent literature (see Table 1), with slightly lower reports of disclosure found in the current study (see Table 3). Important differences exist between the present study and those studies summarized in Table 1. For instance, many of the studies listed in Table 1 included larger population samples.

Another important difference is that several of the more recent studies listed in Table 1 utilized in-person or over-the-phone semi-structured interviews as the primary means of data collection, while the present study utilized a more confidential means of collecting information. It may be that the current study's participants provided more honest answers, knowing that the information they provided was coded anonymously (participants did not provide their names when completing the online survey). As such, it may be that recipient parents felt more comfortable endorsing attitudes of non-disclosure or uncertainty as compared to the non-anonymous data collected in previous studies. Regardless of the minor discrepancies, the findings from the present study are generally consistent with the growing number of research data documenting recipient parents' increasing trend towards pro-disclosure.

When the study's participants were asked if they had received disclosure-related advice or assistance, approximately half of the Disclosers and half of the Non-disclosers reported receiving PTO disclosure advice from professionals in the field of third party reproduction. The majority of the Undecided group of participants (80%) report having not received professional advice on disclosure issues. This finding implies that recipient parents who receive support from professionals working in the field of third party reproduction may be more likely to make disclosure decisions compared to those parents who do not receive support and remain undecided on disclosure issues. This interpretation supports the perception that mental health professionals working in the field of third party reproduction ought to initiate discussion about disclosure and/or provide disclosure-related support to parents who have conceived successfully using donor eggs.

In order to determine a relationship between participants' reported ease/difficulty of making disclosure decisions and participants' receipt of disclosure advice from mental health professionals, physicians, nurses, or other resources, a cross tabulation was performed (see Table 9). These analyses suggest that there is little difference between participants ease of making disclosure decisions regardless of whether or not they received disclosure advice. These data suggest that professionals ought to identify and utilize more helpful resources for assisting recipient parents make these difficult decisions.

**Perceived value of reading PTO disclosure scripts.** Prior to the presentation of the scripts, participants were asked to rate how desirable it would be for them to read disclosure scripts that other recipient parents have used to disclose. In response, 38% ( $n=18$ ) reported that it would be desirable, 31% ( $n=15$ ) reported that it would be very desirable, 21% ( $n=10$ ) were unsure, 6% ( $n=3$ ) reported that it would be not at all desirable, and 4% ( $n=2$ ) indicated that it would not be desirable. After the scripts had been reviewed, participants were asked, *“How helpful, in general, do you rate reading the above parent-developed disclosure scripts,”* and the following responses were collected: 49% ( $n=25$ ) indicated that it was helpful, 25% ( $n=13$ ) reported that it was very helpful, 20% ( $n=10$ ) were undecided, 4% ( $n=2$ ) reported that it was not at all helpful, and 2% ( $n=1$ ) indicated that it was not helpful. When comparing the figures, it appears that participants were slightly more likely to rate the scripts as being helpful than they were to report desirability of reading scripts prior to the presentation of the scripts, themselves.

**Perceived helpfulness of reading the specific parent-to-offspring disclosure scripts.** In regard to the scripts themselves, differences were observed between responses

from Disclosers, Non-disclosers, and Undecided parents (see pages 49-50 for descriptions of each script.) Among parents who had already disclosed, there were several statistically significant differences between scripts' ratings: These parents found The Helper and Come & Talk scripts most helpful, and the Spare Parts and Nuts & Bolts scripts least helpful. No statistically significant differences were found when comparing Undecided participants' responses to each of the scripts. The Non-disclosing group was too small ( $n=9$ ) to produce statistically significant data. However, in general it appears that Non-disclosers found The Helper, Organ Donor, Great Young Lady, and Come & Talk scripts most helpful, and the Spare Parts and Nuts & Bolts scripts least helpful. Notably, several Non-disclosers responded positively when asked the likelihood of their using a particular script. These responses may be a reflection of ambivalence in Non-disclosers' decision, or they may be indicative of a desire to help the principal investigator or other parents.

A number of inferences may be drawn from responses to the scripts. One of the most favored scripts, The Helper, was inspired by the "*The helper*" theme (Mac Dougall et al., 2007, p. 528) and Friedman's (2007) suggestions for parents of children between the ages of 4-6 years (p. 49). Given that 47% of the participants' children were between the ages of 3-5 years, the data results support Friedman's age suggestion. The Come & Talk script was the other most favored script; and it included general language encouraging question-asking and openness within the child-parent relationship. Notably, the Come & Talk script was the only script that included the term "egg donation," and its simplicity would make it easy to pair with any other script. The Come & Talk Script would also be an appropriate script to use as a follow-up to an earlier PTO disclosure conversation. The Spare Parts script was considered one of the least helpful scripts,

inspired by Mac Dougall et al.'s (2007) "*Spare parts*" theme (p. 528). Notably, this script describes that a part of the recipient mother was "missing" or "broken" and needed "fixing." The terminology presented in this script may have been emotionally distressing for many of the participants of the study. Given the literature's description of infertility's impact on women in particular, (p. 20) it may be that a script such as this triggered negative or unwanted feelings in the recipient mother.

Another relevant factor for understanding participants' script preferences is that the average age of participants' offspring was 2.9 years old. Future research is needed to measure the relationship between offspring age and perceived helpfulness of various disclosure-related resources. For instance, the Nuts & Bolts script provides detailed and technical descriptions of gametes, genes and DNA, inspired by Friedman's (2007) suggestions for parents of 12-13 year olds. It may be that parents of 3 year olds are less likely to perceive such verbiage as helpful, similar to their approach, or likely to be used any time soon. It is certainly possible that participants were determining the helpfulness of the scripts based upon the appropriateness of the script for their children's current developmental age.

Another important finding from participants' responses to each script is that recipient parents consistently provided higher ratings in response to the first prompts (i.e., *How helpful do you think this approach might be for parents who are making disclosure decisions?*) as compared with their responses to the second prompts (i.e., *How similar is this to the approach you are using?* or *How likely would you be to use this approach?*). Apart from The Helper script, participants responded more positively when asked about scripts' helpfulness for other parents than they did when they were asked about their own

use of the scripts. The Helper script produced the only exceptional data, with Disclosers reporting that the script was very similar to the approach they were using, while reporting less positive opinions about the script's helpfulness to parents making disclosure decisions. The discrepancies between responses to the first and second prompts are difficult to interpret. It may be that Non-disclosers and Undecided participants reported being less likely to use the approach because they are uncertain as to whether they will be disclosing at all to their children. Disclosers may have simply been utilizing other scripts, stories, or narratives to disclose to their children. Future research may help to clarify reasons why recipient parents might perceive a script to be more helpful to another parent than to themselves. For further information on this issue, it is helpful to consider the open-ended responses parents provided when asked to provide any suggestions for improving the scripts (see Table 26).

The general themes addressed in participants' open-ended responses included interests in: (a) disclosure outcome studies, real-life experiences, professional opinions, and other psychologically-based resources; (b) children's books; (c) child development and various age-appropriate disclosure resources; and (d) the scripts provided in this study. Very few suggestions were made regarding modifications of the current scripts. However, the information gathered provides preliminary insight into clinical applications and suggested directions for future research.

**Perceived helpfulness of reading disclosure scripts in relation to participants' disclosure decisions.** It appears that individuals who had begun disclosing or who had completely disclosed found the scripts in general to be more helpful than those participants who had not begun disclosing (see Table 22). The Disclosers reported that

the scripts were more helpful on average than the Non-disclosers or Undecided participants, with 90% of the Disclosers reporting that reading the scripts was very helpful or helpful. The remaining 10% of the Disclosers reported being undecided on the helpfulness of reading the scripts. The Non-disclosers were the only study participants who reported less than neutral opinions of the scripts, with 22.2% endorsing that the scripts were not at all helpful to read. Notably, however, 44.4% of the Non-disclosers reported that the scripts were very helpful or helpful to read. Given that these individuals had previously reported that they absolutely planned on non-disclosure, a 44% positive response to reading the scripts is unexpectedly high. The Undecided group reported neutral to positive opinions of the scripts, with 70% endorsing that the scripts were very helpful or helpful to read, and 30% reporting that they were undecided about the helpfulness of reading the scripts.

**Differences in perceived helpfulness of the scripts based upon demographic variables (e.g., age of offspring, age of parent, ethnicity, and religious affiliation).** To explore relationships between participants' demographics and their perceptions of reading the disclosure scripts, several cross tabulation measures were performed. The age of participants' children, for instance, has proven to be an important variable to this study's data outcomes. Table 4 addresses the relationship between age of EDCO and their parents' disclosure plans. The data indicate that the age of children whose parents reported having completely disclosed was, on average, higher than the ages of the other participants' children (6 years old versus 2.9 years old, respectively). These data are expected, given that parents were more likely to have "completely" disclosed to older



children than were parents with younger children who may be in the beginning stages of disclosure or who remain undecided on disclosure issues.

A cross tabulation was also performed to determine the relationship between EDCO's ages and their parents' opinions of the helpfulness of reading the disclosure scripts (see Table 25). The data indicate that the majority (68%) of the parents with the - youngest children, between the ages of 6 mos-2 years, found the scripts to be generally helpful, while the remaining percent were undecided about the helpfulness of the scripts. None of the parents with children between the ages of 6 mos-2 years found the scripts to be unhelpful. The majority (80%) of parents of EDCO between the ages of 3-5 years also found the scripts to be generally helpful, with the remaining percentages reporting being undecided (10%) or perceiving the scripts to be unhelpful (10%). Both of the parents of EDCO between the ages of 6-8 years ( $n=2$ ) reported that reading the scripts was helpful.

The ages of the parents were also included as variables in measuring differences in opinions of reading the disclosure scripts (see Table 25). The majority of all participants found that reading the scripts was either very helpful or helpful (75%;  $n=39$ ). The age groups of participants were relatively homogeneous, in that the majority of each group reported that reading the scripts was helpful. The age group of participants who most often reported that reading the scripts was unhelpful was the youngest category of participants, between the ages of 33-40 years. Of those participants, 20% reported that reading the scripts was unhelpful. The participants who were most often undecided about the scripts' helpfulness were between the ages of 46-50 years. Of those participants, 31% reported being undecided about the scripts' helpfulness.

Identifying differences between participants' perceptions of the scripts and their religious affiliations is difficult given the homogeneity of the sample; however, a few interpretations can be made. For instance, the majority of Christian or Catholic participants ( $n=30$ ) reported finding the scripts helpful or very helpful to read (70%;  $n=21$ ); while 27% ( $n=8$ ) reported being undecided and 3% ( $n=1$ ) endorsed that reading the scripts was not at all helpful. The second largest religious category of participants, the non-religious participants ( $n=11$ ), generally found the scripts to be either very helpful or helpful (73%;  $n=8$ ). Two of the non-religious parents (18%) were undecided about the helpfulness of the scripts; and one of the non-religious parents (13%) reported that reading the scripts was not at all helpful. Of Jewish participants ( $n=8$ ), no participants reported that reading the scripts was very helpful, though 63% ( $n=5$ ) indicated that reading the scripts was helpful. Two of the Jewish participants (25%) reported being undecided about the helpfulness of reading the scripts; and one of the Jewish participants (13%) reported that reading the scripts was not very helpful.

The homogeneity of the sample also impacted findings measuring the relationships between participants' ethnicities and their opinions of reading the scripts, with White/Caucasian participants representing the vast majority of the sample (96%;  $n=49$ ; see Table 2). The majority of Caucasian participants found the scripts to be either very helpful or helpful to read (73%;  $n=36$ ); with only 6% ( $n=3$ ) indicated that reading the scripts was either not very helpful or not at all helpful. The only Asian/Pacific Islander or Asian-American participant reported that reading the scripts was helpful; and the only Latino/Hispanic respondent indicated that reading the scripts was very helpful. Further research is needed to determine the extent to which a recipient parent's ethnicity

impacts their perceptions of reading PTO disclosure scripts in order to identify the appropriateness of using the scripts as a resource for non-Caucasian parents.

### **Clinical Implications of Findings**

The existing trend in PTO disclosure, as reflected in the literature review and findings of this study, is increasingly pro-disclosure. Current opinion papers from professionals in the field typically encourage disclosure and recipient parents are more often opting to disclose than previously reported. Approximately 72% of this study's population reported that they probably will disclose, absolutely will disclose, have begun disclosing, or have completely disclosed to their children. This expected finding is consistent with the relevant research in this area. A surprising inconsistency between the literature and this study was found when approximately half of the research participants rated making disclosure decisions as "very easy" or "easy." It may be that a response bias exists—i.e., parents who find PTO decisions easy may have been more likely to participate in a study addressing disclosure. Nevertheless, with 47% of this study's population endorsing that PTO disclosure decisions are "difficult" or "very difficult" to make, there is clearly a need for mental health professionals to investigate the most effective and valuable tools for assisting recipient parents.

Approximately half of the entire study sample reported receiving professional advice on the disclosure decision issue. Half of the participants who did not receive professional advice rated disclosure decisions as difficult or very difficult to make, a relatively close comparison to the 44% of participants who did receive professional advice and still rated disclosure decisions as difficult or very difficult to make. These data suggest that the professional advice received did not necessarily increase parents' ease of

making disclosure decisions. However, it is important to note that 80% of the Undecided participants reported having never received disclosure advice. Therefore, while receiving advice on the disclosure decision does not necessarily decrease the difficulty of making these decisions, it may be that receiving advice helps parents move towards making a decision. Given the number of recipient parents in this study who accessed advice from mental health professionals on the disclosure issue (65%), it appears safe to conclude that mental health professionals practicing in the field of third party reproduction ought to have access to effective PTO disclosure resources so that they may be able to provide valid information to recipient parents requesting support.

In regard to the helpfulness of various PTO disclosure resources, the current study has provided preliminary data. The cross tabulations performed present information about the characteristics of recipient parents who may be most likely to benefit from reading disclosure scripts. Given the small study sample and homogeneity of the population, future research is certainly needed to determine the reliability and validity of these early findings. However, the findings suggest that individuals who are pro-disclosure generally respond more positively to reading disclosure scripts, while individuals who are against disclosure or undecided may perceive disclosure scripts as less helpful. If these findings are replicated, it will be important for clinicians to be aware that disclosure decision-making may depend on the status of the recipient parents' decisions. Until more data has been collected, the best approach may be for clinicians to advise recipient parents to suspend a firm disclosure decision before they have reviewed resources, research, or other relevant material that may inform their decisions. Further research and attention to these issues may provide mental health professionals with the knowledge to determine

the most effective approach to working with recipient parents who are struggling with these concerns.

Another relevant factor to understanding participants' script preferences is that the average age of participants' offspring was 2.9 years old. Future research is needed to determine the correlation between offspring age and perceived helpfulness of various disclosure-related resources. For instance, Scripts F: Nuts & Bolts provides detailed and technical descriptions of gametes, genes and DNA, inspired by Friedman's (2007) suggestions for parents of 12-13 year olds. It may be that parents of 3 year olds are less likely to perceive such verbiage as helpful, similar to their approach, or likely to be used any time soon. It is important that future research address ways in which offspring age plays a role in the validity or helpfulness of disclosure resources so that clinicians are better able to provide effective tools for assisting recipient parents.

This suggestion is supported by the open-ended comments that participants made about suggested improvements to the scripts (comments: 3, 15, 25, 30, and 31). These statements indicate that participants are interested in gaining assistance in determining the best timing at which to disclose. The comments suggest that storybooks or scripts ought to have age indicators. A few participants suggest that information regarding developmentally appropriate resources would be helpful. Comment 25 indicates that it would be more helpful for parents to have an idea about the appropriate timing of disclosure than to have ideas about how to communicate the disclosure. These comments suggest that recipient parents might find research in the area of disclosure timing helpful, such as the data gathered by Mac Dougall et al. (2007). The relevance of children's ages is clear, and is notable in Friedman's (2007) resource with script ideas organized

according to DCO age (pp. 43-44). Future resources ought to provide suggestions for the timing with which to use various disclosure methods.

The open-ended responses provided by this study's participants are also useful in considering: (a) other improvements to make to the scripts; (b) additional tools for professionals to utilize in working with GDCO families; and (c) future directions for research. The most often mentioned theme involves an interest in outcome studies, real-life experiences, professional opinions, and other psychologically-based resources (comments: 2, 12, 14, 16, 17, 23, 24, 27, 29 and 32). These comments tend to indicate that participants are interested in empirical research documenting responses from children and parents to various disclosure techniques; or they reflect a desire for assistance from mental health professionals with experience working with PTO disclosure. These comments are consistent with the available literature on PTO disclosure, documenting that recipient parents most want to know what other parents have done and what the responses from the children were using clinical, empirically-validated, or scientifically generated resources.

Another oft mentioned interest is in children's books (comments: 1, 3, 4, 17, 21, and 31). These comments generally suggest that parents either have utilized children's books or would like more suggestions for appropriate children's books to which they can refer when disclosing to their EDCO. Unfortunately, there exist only a handful of children's books addressing egg donation (Bourne, 2002; Celcer, 2007; Gordon, 1992; Martinez, 2005; Nadel, 2007; Nathalie, 2002). More DCO children's books targeting various age groups are arguably needed.

Another subject matter cited several times in the open-ended responses is the helpfulness of the scripts provided in this study's questionnaire, developed by the primary investigator and inspired by Mac Dougall et al.'s (2007) research and Judith Friedman's (2007) book for recipient parents. Several participants indicated that they found the scripts helpful or that they would like copies of the scripts to use as a resource (comments: 10, 13, 17, 18, and 19). Statements regarding the scripts or suggestions for improvements of the scripts are strong indicators for further research and resource development. For instance, comments 3 and 5 suggest a "less is more" attitude towards disclosure, suggesting that some recipient parents want less clinical and simpler terms of disclosing. Lastly, several comments indicated an interest in online resources (comments: 5, 7, 9, and 16). This information is undoubtedly important to the development and dissemination of future studies and clinical resources.

The themes identified provide valuable information relevant to mental health professionals assisting recipient parents with PTO disclosure decisions. For instance, this dissertation's findings suggest that psychotherapists or professionals working in the field of third party reproduction ought to have access to children's books that are appropriate to a wide range of age groups. Professionals may want to have hardcopies of children's books on-hand, and they may want to compile a list of references for recipient parents. The data also suggest that recipient parents may want data from outcome studies measuring children's responses to PTO disclosure. This particular suggestion indicates that: (a) more outcome studies are needed, measuring children's responses to various disclosure techniques; and (b) the findings of such research ought to be made accessible and understandable to the parents of GDCO. For instance, a resource mirroring the

literature review table presented in this dissertation may be considered valuable to recipient parents (see Appendix A). Furthermore, several of this dissertation's research population indicated interest in the scripts provided by this researcher. It may be that a resource of scripts ought to be generated and provided to professionals working in the field of third party reproduction. More research and further development of the scripts are indicated.

Although this dissertation addresses parent-to-offspring disclosure, it is also important for clinicians to be aware that several sources encourage clinicians to maintain a non-committal stance regarding disclosure (Imber-Black, 1993; Murray et al., 2006; Shenfield & Steele, 1997). Blyth (2002) argues that a significant relationship exists between the medical field's longstanding desire to maintain anonymity and recipient parents' disclosure patterns. Clinicians may want to keep in mind that the secrecy with which medical practitioners have traditionally treated gamete donation may contribute to a continued attitude of secrecy in recipient parents. Also, given that some DCO will want access to information about their donor, clinicians might want to encourage recipient parents' to identify and explore their feelings about their child's potential desire to learn more about his or her donor before making a disclosure decision. In light of these suggestions, it is important for clinicians working with recipient parent populations to maintain a balanced perspective when addressing PTO disclosure, thereby making it easier for parents to discuss and explore their PTO disclosure decisions freely.

For recipient parents struggling with the decision of whether or not to disclose, clinicians may want to draw from the research suggesting that many young children respond neutrally or positively to PTO disclosure, and rarely do parents report regretting



the decision to share the information with their children (Mac Dougall, et al., 2007; Lindblad et al., 2000). It is also important to note that 44.4% of the Non-disclosers in the current research reported that reading the scripts was very helpful or helpful. Given that these individuals reported that they absolutely do not plan on disclosing to their children, a 44% positive response to reading the scripts suggests that clinicians may want to present even their non-disclosing clients with disclosure resources. In general, it is important that clinicians working with these populations gently explore these issues before assuming recipient parents' needs.

In sum, it may be that the most helpful resources for clinicians to utilize when working with disclosing parents are: children's books, empirically substantiated materials such as outcome studies on disclosure, professional opinions rooted in knowledge on child development, knowledge of real-life experiences of other families, and scripts like the ones found in this study. It is important to recognize the worth that recipient parents place on other recipient parents' disclosure decisions and patterns, suggesting the need for more support groups facilitated by mental health professionals (see page 38). Results of the current study also suggest that it is important for mental health professionals to become comfortable discussing and exploring non-disclosure and its potential implications for the family.

### **Methodological Assumptions and Limitations**

The current study was limited by threats to internal validity as a result of data collection procedures, participant characteristics, and the characteristics of the utilized instruments. Utilizing a website questionnaire may have increased the probability of error in volunteer responses; however, research indicates that internet methods of collecting

research data are typically consistent with findings from traditional methods (Gosling, Vazire, Srivastava, & John, 2004). Participants included a voluntary, nonrandom, convenience sample from a non-randomly identified egg donation agency. Only those recipient parents who volunteered to participate in this study were included in the sample, indicating that participants may have been psychologically curious and/or interested in learning more about PTO disclosure decisions. Additionally, recipient parents from Egg Donation, Inc. may have felt obligated to participate in the research if they had had a positive experience with the agency or if they have personal relationships with the CEO or employees. Conversely, recipient parents may have avoided participation if they did not have a pleasant experience with Egg Donation, Inc. or if they were uninterested in addressing PTO disclosure.

Another important variable to consider is the disclosure stance of participants. Both the recruitment email and informed consent provided explicit information about the PTO disclosure-related content of the study. It may be that recipient parents who experienced strong feelings against PTO disclosure avoided accessing the survey or chose not to participate after reading the informed consent. Conversely, recipient parents who felt confident or positive about their disclosure decisions may have been more likely to engage in the research project after learning of its focus. Consequently, this sample may have included more pro-disclosure recipient parents than typically represented in the population as a whole. This study sample may also have included more recipient parents who were interested in PTO disclosure issues than the average population of egg recipient parents. This theory was addressed by Lycette and colleagues (2004) who suggested that research participation may be interpreted as a threat to maintaining

disclosure secrecy, thereby discouraging non-disclosing recipient parents from engaging in disclosure-related research. This implication should be taken into account when considering the current research findings.

The low response rate of 4% may be explained in a number of ways. As stated above, non-disclosing parents may have wanted to avoid participation if they interpreted it as a threat to maintaining secrecy (e.g., if their children have access to their computers or email). In order to decrease participant concern regarding confidentiality, privacy was reassured in both the introductory email and at the start of the survey; however, some parents may have had a strong aversive reaction to being contacted by Egg Donation, Inc. several years after their work with the agency for fear that their information was being disseminated. Furthermore, parents of young children simply may not have had spare time to complete the survey. Lastly, given the occasional unpredictability of online surveys, it may be that some parents had technical difficulties accessing the Zoomerang survey. Though no parents contacted the PI regarding website problems, technical difficulties may have discouraged an already ambivalent parent from engaging in the research.

The sample was drawn from a single egg donation agency located in Southern California. Although recipient couples from over 35 countries have worked with Egg Donation, Inc., the sample reflects only a small proportion of egg recipient parents. Egg Donation, Inc. does not require that recipient parents undergo psychological counseling at any time before, during, or after the egg donation procedure. The sample population from this agency may be very different than recipient parents who utilize the services of other egg donation agencies. For instance, there may be factors relating to the experience of

registering with this specific company that played a role in recipient parents' perceptions (e.g., access to qualified mental health professionals, referrals to knowledgeable medical staff, etc). Furthermore, there is a strong likelihood that the individuals who chose to participate are generally helpful individuals. While the number of Non-disclosers was quite small ( $n=9$ ), those individuals may be considered especially helpful in that they volunteered to participate in a study focusing on disclosure. Their participation may be a reflection of their disclosure decision ambivalence or a reflection of participants' tendency to want to be helpful.

Also, relative to the number of recipient parents who have EDCO all over the world, the study sample of 52 was quite small. Few findings were statistically significant; however, implications for future research can be made. For instance, pregnant individuals (or partners of pregnant individuals) were instructed to not participate in the current study. Future research may be aimed at the differences between pregnant populations' perceptions of PTO disclosure as compared to their non-pregnant counterparts. Another important factor is that 47% of participants had children between the ages of 3—5 years, and no participants reported having children over the age of 8 years. It is therefore unclear whether the data gathered in this study may be relevant to recipient parents with much older EDCO.

Another limitation regarding the population sample is that all of the individuals necessarily had access to a computer and internet availability, given that they completed an online questionnaire. This factor is especially relevant in consideration of the participants' suggestions that disclosure resources be accessible via the internet. Future research and resource development may need to include in-person, postal service, or

telephone correspondence to access those parents who do not have access to digital resources or Internet research participation.

A number of additional aspects of the sample warrant comment. For instance, the sample was overwhelmingly female and Caucasian, with over half of the population reporting completion of graduate or professional school. This restricted variability with respect to ethnicity and educational status may not be representative of the general population of egg recipient parents. In regards to the homogeneity of participants' gender, the number of male participants was too small to determine differences between mothers' and fathers' perspectives on PTO disclosure. Additionally, it is notable that one participant reported having no EDCO. However, the individual did agree to the informed consent stating that the survey is intended for parents of EDCO. It may be that the participant is working with a pregnant surrogate. In such a case, the participant may consider her or himself to be a parent of a yet-to-be-born EDCO.

The survey was developed by the author for the purpose of shedding light on egg recipient parents' evaluation of the helpfulness of reading parent-to-offspring disclosure scripts. Although the survey was reviewed by three psychologists, one of whom has expertise in the field of third party reproduction, it was not piloted prior to its use and no information on its psychometric properties is available. Therefore, the reliability and validity of the survey measures are unknown. Furthermore, the scripts were presented to participants in a non-randomized order, which may have contributed to response biases.

Another potential limitation of the study involves its content validity. The scripts were generated by the PI in conjunction with research findings from Mac Dougall et al. (2007) and suggestions written by a psychologist practicing in this field (Friedman,

2007). The scripts were constructed using qualitative research (e.g., findings from Mac Dougall et al.'s study measuring recipient parents' disclosure narratives); however, they were not written by egg recipient parents. Therefore, questions based on the scripts may not have adequately or ideally tapped domains of interest (e.g., perceived disclosure-related topics of relevance, use of specific parenting language, etc).

Problems inherent to self-report data may have also compromised the current study findings. Answers may not accurately reflect the participants' actual beliefs or behaviors in parenting their children, making disclosure decisions, or disclosing to their children. Responses may be subject to social desirability response biases (e.g., participants being disinclined to acknowledge plans to avoid PTO disclosure or may not be open to learning new tools or scripts for disclosure). These possibilities may have resulted in inflated or deflated estimates of participants' interest in, use of, and receptivity to the scripts presented by the PI.

### **Future Directions**

There are a number of implications for future research that have emerged as a result of this study. Given the aforementioned limitations of the current research, future studies with improved methodology may help to further advance our understanding of recipient parents' disclosure patterns and may help to develop more effective tools for assisting this population. For example, research replicating the current study might survey a broader range of parents with EDCO, access random samples drawn from other professional organizations, address additional questions about the relevance of children's ages, utilize longitudinal research methods to evaluate the impact of disclosure over an EDCO's lifespan, and incorporate non-internet-based recruitment methods and data

gathering techniques so as to access a more diverse population. It is also imperative that future research emphasize the role that race, ethnicity, socioeconomic status, religion, age, and gender play in PTO disclosure issues so that clinicians and physicians are better able to practice culturally competent interventions when addressing the disclosure decision with recipient parents.

With a larger sample size and more diverse participants, it would also be possible to identify whether statistically significant differences exist regarding the perceived helpfulness of reading the scripts in relation to various participant characteristics that were not sufficiently represented in this study (e.g., pregnant populations, diverse ethnicities, diverse sexual orientations, etc). Furthermore, qualitative research is indicated as it would provide more detailed information regarding the helpfulness/un-helpfulness of various aspects of the scripts or other disclosure resources. It is also suggested that future studies measuring disclosure script ratings utilize randomization techniques when presenting the scripts.

It would also be interesting to explore individuals' decisions to participate in studies relating to disclosure. A last open-ended question could have been added to this study – *Why did you choose to participate in this research?* Responses could help future researchers develop more appealing recruitment methods to increase the likelihood of successfully engaging this often difficult-to-access population. For instance, future recruitment methods could include alluring incentives emphasizing the role that participation might play in helping other parents make disclosure decisions. Furthermore, future researchers may find it useful to utilize a tiered questionnaire format, breaking

questions into smaller groups so that participants can choose whether to discontinue participation or move onto the next set of questions.

As mentioned previously, the recipient parents of this study requested data on outcome studies measuring children's responses to various forms of disclosure methods. Future studies should utilize quantitative and qualitative methods to document children's reactions to various PTO disclosure methods and the outcome data ought to be made understandable and accessible to recipient parents. Furthermore, future research identifying the process by which such information ought to be disseminated to the appropriate individuals (e.g., mental health professionals, physicians, nurses, religious counselors, schools, recipient parents, etc.) is warranted.

With the increasing growth in the number of children conceived via methods of gamete donation comes the need for more empirical-based clinical treatments and resources for working effectively with these families. The absence of an evidence-base for psychotherapeutic interventions may prevent families from receiving the support and assistance they deserve. Parent-to-offspring disclosure scripts appear to be promising because they can incorporate professional opinions rooted in knowledge of child development with real-life scenarios that other recipient parents have successfully utilized. Scripts can also be condensed in a pamphlet or other booklet that can be distributed by physicians, nurses, agencies, religious counselors, or mental health professionals. Increasing the opportunity for recipient parents to access resources that facilitate PTO disclosure may increase the likelihood that families will be better able to determine the best choices for them and for their children. Access to resources may also decrease parental anxiety or distress, increase effective communication between family



members, and facilitate problem-solving behaviors for parents who feel conflicted about disclosure-related issues.

### **Summary**

The major objective of this research was to conduct a descriptive study addressing egg recipient parents' desire and appraisal of the helpfulness of reading parent-to-offspring disclosure scripts. To assist in determining the content of the disclosure scripts, an extensive literature review was conducted. The scripts were then created by the PI, inspired by data gathered by Mac Dougall et al. (2007) and suggestions from a book written by a psychologist working in the field of third party reproduction (Friedman, 2007). A questionnaire was created to gather recipient parents' opinions of the scripts. Recipient parents who had not disclosed were asked how helpful they found each script to be, and how likely they would be to utilize the script in disclosing to their child/ren. Recipient parents who had begun or completed disclosed were also asked how helpful they found each script to be; and they were asked how similar each script was to their approach in disclosing to their child/ren.

Most of the research participants reported mild to moderately favorable attitudes about the scripts, and several indicated that they would consider incorporating aspects of the scripts into their own disclosure decisions. The Helper and Come & Talk scripts were most favored among participants, while the Spare Parts and Nuts & Bolts scripts were least favored. Data were also collected measuring general disclosure-related issues such as participants' receipt of professional advice, perceptions of the difficulty/ ease of making disclosure decisions, and interest in receiving assistance or accessing disclosure resources. The data were analyzed in order to identify trends that may be useful to mental

health practitioners and other professionals working in the field of third party reproduction.

A total of 52 individuals completed the online questionnaire. The recipient parents' responses were documented and described so that recommendations for future research directions could be made and implications for clinical practice with gamete-recipient parents could be identified. Specifically, findings from this study combined with material gathered in the literature review suggest that the most useful tools for clinicians to utilize when working with families of DCO include: children's books, empirically substantiated materials such as outcome studies on disclosure, professional opinions rooted in knowledge on child development, knowledge of real-life experiences of other families, and scripts like the ones found in this study. Although much work needs to be done before PTO disclosure scripts are acceptable for distribution or resource development, it is hoped that the current study represents a contribution to the evolution of a promising resource for families adapting to the unique experience of life created via egg donation.

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## APPENDIX A

### Research on Impacts of Disclosure

<b>Author, Year</b>	<b>Type of Study</b>	<b>Sample</b>	<b>Design/Method</b>	<b>Key Variables</b>	<b>Measures/Data Collection/Analysis</b>	<b>Main Findings</b>
Kirkman (2003)	Qualitative	12 DCO from Australia, Canada, US, England, and Argentina	Email interviews, audio-taped interviews, written interviews, and telephone interview.	Dependent variable was parental narratives relating to disclosure; Independent variables included age of offspring and type of donation (i.e., egg, sperm, embryo)	All began with the general question, "Please tell me your story of using [donation/being born as a result of] donor sperm, eggs, or embryos: what it means to you." Interviewing, editing, further communication with participants, multiple readings of the approved narratives, and immersion in the literature.	Without exception, participants who were adult offspring of donor-assisted conception argued the necessity of developing an identity that accurately reflected their conception, and a chance to negotiate its meaning with their parents.
Lycett, Daniels, Curson, Chir, &	Qualitative/ Quantitative	46 families with SDCO aged 4-8 years; from United Kingdom	Parents were interviewed & children were administered	Dependent variables: measures of marital relationship, parent-	Standardized interviews & questionnaires (Strengths and Difficulties	Mothers from disclosing families reported significantly less

Golombok (2004)			psychological tests	child relationships, and child adjustment. Independent variable: decision regarding disclosure information to their child (i.e., disclosers vs. non-disclosers)	Questionnaire; the Berkeley Puppet Interview; and the Weschler Pre-school and Primary Scale of Intelligence)	frequent and less severe arguments with their children. Disclosing parents viewed themselves as more competent at parenting than the non-disclosing parents. Non-disclosing mothers were reported to engage in more frequent and more severe arguments with their children than disclosing mothers.
Murray, MacCallum, Golombok (2006)	Quantitative	17 egg donation families, 35 sperm donation families, and 34 IVF families with a 12-year-old child; from the United Kingdom.	Standardized interviews and questionnaires	Dependent variables were quality of parenting and psychological adjustment ratings. Independent variables were type of family (i.e., DI vs IVF) and disclosure decisions	Golombok Rust Inventory of Marital State; the State-Trait Anxiety Inventory; and the Beck Depression Inventory; the Child and Adolescent Functioning and Environment Schedule; and the Strengths and Difficulties Questionnaire.	EDCO were more likely to accept and successfully assimilate info about their donor origins if parents began disclosure discussions with them at a young age.

Scheib, Riordan, Rubin (2004)	Qualitative	29 adolescent SPDO; Their average age at interview was 14.7; No information is provided about countries-of-origin	Self-administered mail back questionnaires	Dependent variables: experiences of adolescent SDCO Independent variables: sexual orientations and relationships status (i.e., single, lesbian, heterosexual)	Questions included a 5-point Likert scale, adjective endorsements, and open-ended questions. A chi-square was used and likelihood ratio analyses, <i>t</i> -tests, and ANOVAs.	Testimonials from SDCO youths and adults who learned of their origins before adulthood indicated that they felt little resentment toward their family. Youths reported that learning and knowing had a neutral to somewhat positive effect on the relationship with their birth mother.
Turner & Coyle (000)	Qualitative	16 DCO aged 26-55 years; recruited from the UK, USA, Canada, and Australia	Self-administered mailed questionnaires and e-mail questionnaires.	Exploring DCO “identity experiences”	The data were qualitatively analyzed using interpretative phenomenological analysis.	Participants believed that withholding of information about the manner of their conception had been damaging. The “right to know their genetic origins” was a common theme for the DCO.



## APPENDIX B

### Research on Disclosure Attitudes

<b>Author, Year</b>	<b>Type of Study</b>	<b>Sample</b>	<b>Design/Method</b>	<b>Key Variables</b>	<b>Measures/Data Collection/Analysis</b>	<b>Main Findings</b>
Becker, Butler, Nachtigall (2005)	Qualitative	148 couples (79 w/ EDCO; 7 used a combo of donor eggs and sperm).	Couple interviews were followed by individual interviews approximately 3 months later. Interviews were semi-structured with many open-ended questions that focused on how the couple decided on whether or not to tell the child about the use of a donor.	Dependent variable: Perceptions of resemblance talk. Independent variables: use of egg or sperm donation, and attitudes about disclosure.	Topics of interviews included philosophy of the family, family relationships, feelings about having used a donor, and approaches taken to telling children and others. Interviews were coded manually and then coded using QSR Nud*ist. Codes were analyzed and cross-checked.	27% were disclosers, 53% future disclosers, 12% non-disclosers, and 8% were undecided.
Broderick & Walker (2001)	Quantitative	77 donors and 327 recipients in Western Australia	Mail-back questionnaires	Dependent variables: disclosure attitude. Independent variables: gender & participation (donor, recipient).	Questionnaires about treatments and outcomes of gamete donation, and attitudes towards disclosure. Means and standard deviations were calculated.	31% intended to disclose; 62% intended not to disclose; 7% unsure

Cook, Golombok, Bish, Murray (1995)	Qualitative	45 SD families; 55 adopted families; and 41 IVF families. The children in all 3 groups were between 4 and 8 years old.	Standardized semi structured interviews with mothers in their homes. Fathers were not interviewed, b/c of difficulties in the recruitment and interviewing of fathers.	Dependent variables: measures of parents' emotional functioning, parental stress, and children's problems. Independent variables: family types	Interviews were audiotaped, transcribed, and coded.	80% of mothers were non-disclosers; 16% were undecided; and 4% planned to tell. One reason parents chose not to tell is because they were concerned that their child would be distressed by the absence of information about the donor. Parents expressed concerns about the timing and method of disclosure, including not knowing at what age it becomes appropriate to tell the child. Parents also worried about what to tell their children.
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Hahn & Craft-Rosenberg (2002)	Qualitative and Quantitative	31 couples with EDCO aged 6 weeks or older.	Exploratory, comparative, and descriptive. Audiotaped telephone interviews, measures of social support and family environment, and a demographic survey were completed via mail delivery.	Dependent variables: variables that influenced the disclosure decisions. The independent variables were the family's disclosure decisions.	The Disclosure Decision Interview Guide was developed by the investigator and used in the research. Content analysis of interview transcripts and comparison of recurring themes among groups.	Disclosing parents (N=33); Non-disclosing (N=11); Undecided (N=14). Undecided parents reported concerns about how and when to tell and the child's possible reaction. Parents in all groups expressed concern about their disclosure decisions. One parent said "I think one thing that would help me would be if there were experiences of other people that they could share anonymously..."
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Becker, Butler, Nachtigall (2005)	Qualitative	148 couples (79 of which used donor eggs; 7 used a combo of donor eggs and sperm).	Couple interviews were followed by individual interviews 3 months later. Interviews were semi-structured with many open-ended questions that focused on how the couple decided on whether or not to tell the child about the use of a donor.	Dependent variable: perceptions of resemblance talk. Independent variables: use of egg or sperm donation, and type of disclosure decision (i.e., disclosers, non-disclosers, undecided, future disclosers).	Topics of interviews included philosophy of the family, family relationships, feelings about having used a donor, and approaches taken to telling children and others. Interviews were coded manually and then coded using QSR Nud*ist. Codes were analyzed and cross-checked.	27% were disclosers, 53% future disclosers, 12% non-disclosers, and 8% were undecided.
Mac Dougall, Becker, Scheib, Nachtigall (2007)	Qualitative	112 families (48 used donor sperm; 64 used donor eggs)	In-depth ethnographic interviews. Husbands and wives were interviewed together and separately.	N/A	Thematic analysis of interview transcripts.	Of the EDCO families, 23% had already disclosed, 58% planned to disclose, 10% did not plan to disclose, and 9% were undecided.

## APPENDIX C

## Email Sent to Recipients Who Register with Egg Donation, Inc.

Welcome to Egg Donation, Inc. We have received your request for a user account and it will be processed within the next few hours. We will email you as soon as your account has been activated. In the interim, if you have any questions, please do not hesitate to contact either [name of case manager] or [name of manager]. You may also view some of our most recently added donors "<http://www.eggdonor.com/?page=donordb>"; however you will not have access to full profiles until your account has been validated. For more information on our program and the process of egg donation, please view "<http://eggdonor.com/?section=recipient&page=rfaq>"> Frequently Asked Questions</a> page.

If you have already found a potential donor on our site or have questions about one of our donors, you do not need to wait for your account to be activated, you can call us at 818.385.0950 or email us at [support@eggdonor.com](mailto:support@eggdonor.com). Also, please do not hesitate to contact us to speak to one of our matching counselors to assist you in finding the best available donor. Any information you provide to us will be kept confidential and not provided to any outside entity or individual.

In an effort to provide more personalized and comprehensive services, we now offer video conferencing. If you would like to have a video conference with one of our Program Coordinators, please let us know so that we can schedule the video chat. We are also offering video conferencing with prospective egg donors -- if you are interested.

We will periodically keep you updated via email about new features in our program, any developments in the field of egg donation and **notify you of any research projects which might be of interest to you.** [Bold added by PI.] Should you not desire to receive these updates or be contacted regarding research opportunities, please let us know. Please also be advised that it is our policy to never release any information about you or your interest in our program to anyone.

Here is your login information:

Your Username is : #USERNAME#

Your Password is : #PASSWORD#

If you would like immediate assistance, please call us at 818.385.0950.

Thank you again for your interest in our program!

## APPENDIX D

## Initial Recruitment Email Message

Hello,

We hope this email finds you well and want to thank you again for having previously registered as a user to gain access to our database. We realize it may have been a while since you have heard from us, but we wanted to contact you to inquire as to whether you would be interested in participating in a brief, anonymous research study that we are sponsoring.

Please understand that while we believe the research is important, your privacy is our paramount concern. It has been and always will be our policy to never release any information about you or your interest in our program to anyone. With respect to the current research project, one of our employees, under the auspices of Pepperdine University, is studying an area where very little literature exists and the results of the study could prove to be very beneficial.

The survey is completely voluntary, with all information being coded anonymously. We reiterate: all of your information has been and will remain strictly confidential. The researcher is an employee of EDI and this email is being sent to you solely as a registrant within our database – it has not nor ever will be shared with anyone outside of our program.

If you are interested in obtaining more information on this worthwhile study, please reply to this email and we will forward to you more details about the researcher and the survey. Again, under no circumstances will we release any information about you or your previous interest in our program. If you are not interested, there is no need to reply as you will not be contacted again.

Thank you for taking the time to read this email. If you have any questions, please do not hesitate to contact us.

Sincerely,

Andrew Vorzimer, CEO  
EDI

## APPENDIX E

## Follow-up Recruitment Email Message

In response to your expressed interest in this research, I am including the following message from the principal investigator. Please feel free to contact the principal investigator, Danielle Penny, at [Daniellepenny@gmail.com](mailto:Daniellepenny@gmail.com) with questions about the research study, or contact me at [Andy@eggdonor.com](mailto:Andy@eggdonor.com) if you need assurance that we are protecting your confidentiality.

Sincerely,

Andrew Vorzimer, CEO  
EDI

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Hello,

I am a graduate student working on my Doctorate in Clinical Psychology at Pepperdine University's Graduate School of Education and Psychology in Los Angeles, CA. I also am a part-time employee of Egg Donation, Inc. Some of you may recognize my name from previous egg donation cycles, though I am not actively involved in any existing cycles. Only individuals who did not opt-out to be recruited for research purposes are being contacted for this study.

I am currently in the process of collecting data for my dissertation project. My research is aimed at understanding egg recipient parents' needs. Specifically, I am interested in "parent-to-offspring disclosure," which refers to the dialogue from parent to child about the child's biological origin. Decisions regarding if, how, when, and why to disclose are deeply personal and vary significantly among individuals, families and cultures. My research is intended to explore the decision-making process, but by no means will I attempt to sway your decision in any direction.

The online survey takes no more than 10-25 minutes to complete. If you are the parent of an egg donation-conceived child who is under the age of 14, and would like to participate in this study, please click on the following link and complete the survey. **This study is intended for persons who are not currently pregnant.** If you or your spouse or partner might currently be pregnant, please do not complete the survey.

You may complete the survey alone or with a partner. The survey can be completed on two separate occasions if two parents want to respond separately. Note: all information entered will be coded anonymously and will be kept strictly confidential. Participating in

this research study is completely voluntary. Your decision to participate or not participate has no bearing whatsoever on your relationship with Egg Donation, Inc.

Here is the link to the survey. The first page of the survey gives a detailed description of the study and provides an informed consent form. After reading that page, you will have the option of agreeing to participate, or declining to participate.

<http://www.zoomerang.com/Survey/?p=WEB229QSEQE57Q>

Please feel free to email me at Daniellepenny@gmail.com with any questions you may have. You may also contact my dissertation chairperson, Dr. Barbara Ingram, at Barbara.Ingram@pepperdine.edu, or you can contact Dr. Doug Leigh, Chair of Pepperdine University's Graduate and Professional School's Institutional Review Board by calling (310) 568-5753.

Thank you very much for your time,

Danielle Penny, M.A.  
Clinical Psychology Doctoral Student  
Pepperdine University



## APPENDIX F

### Informed Consent

This survey is designed for parents of children who were conceived via egg donation. The major objective of this research is to conduct a descriptive study addressing parent-to-offspring disclosure decisions. "Parent-to-offspring disclosure" refers to telling children that they were conceived via egg donation. Decisions regarding if, how, when, and why to disclose are deeply personal and vary significantly among individuals, families and cultures. The questions in this survey are intended to explore the decision-making process, but by no means will they attempt to sway your decision in any direction. Please read the following consent form and then decide if you would like to participate.

#### Consent Form

I understand that I am invited to participate in a research project being conducted by Danielle Penny, M.A., as part of her dissertation requirements for a doctoral degree in clinical psychology at Pepperdine University Graduate School of Education and Psychology. I understand that this project is being conducted under the supervision of Barbara Ingram, Ph.D., Professor of Psychology at Pepperdine University Graduate School of Education and Psychology.

I am being asked to participate in this study because I have sought egg donation from Egg Donation Inc. within the last 20 years. I am eligible to participate because I have had at least one child conceived via egg donation, and at least one of the children is **under 14 years old**. To the best of my knowledge, I am **not** (or my spouse or partner is not) pregnant at the present time. (If you are pregnant or may be pregnant, or if your spouse or partner is pregnant, please exit the survey now - thank you for your interest in this study.)

I understand that I am being asked to fill out this online survey, which is estimated to take a total of 10-25 minutes to complete. First, I will be asked for some information that describes who I am, including my gender, age, race/ethnicity, country of origin, religious affiliation, sexual orientation, and relationship status. I will be asked questions regarding my children and parent-to-offspring disclosure. I will also be asked to evaluate scripts of how parents might disclose to their children.

I understand that my involvement in the study and the completion of the survey is strictly voluntary. I also understand that I may refuse to participate or withdraw from the study at any time. My refusal to participate or discontinue participation at any time will involve no penalty or loss of benefits to which I am otherwise entitled. I also have the right to refuse to answer any question I choose not to answer. I understand there is no compensation provided to study participants agreeing to take part in any or all of this survey.

I understand that participation in this study involves no more than minimal risk. Possible

risks include boredom or mild fatigue. Some individuals may feel uncomfortable answering questions about egg donation, parent-to-offspring disclosure, or about being asked to provide basic demographic information. I understand that I have the right to not answer any question that makes me uncomfortable.

While some participants may experience no perceived benefit from completing the survey, other participants may find it helpful to learn more about the research topic. The findings of this study may be used to help create a resource for professionals in the field of clinical psychology who provide therapeutic services to individuals seeking third party reproduction assistance. Some participants may consider it beneficial to contribute to the creation of that resource.

I understand that my personal identity will never be paired with any of the research measures that I complete. At no time will I be asked to put any personally identifying information on any of the research questionnaires. Only the researcher, Danielle Penny, M.A., and her faculty supervisor, Barbara Ingram, Ph.D., will have access to the answers from the surveys, but they will not know the identity of the people who responded. The information that is collected will be kept in a secure manner for five years and destroyed once it is no longer required for research purposes.

The website hosting the survey ([www.zoomerang.com](http://www.zoomerang.com)) has a privacy policy that complies with the United States/European Union Data Protection Safe Harbor Arrangement regarding data protection and confidentiality. The survey website does not collect personally identifiable information about me except when I specifically provide this information. The option within the Zoomerang.com website to track my responses on the basis of my computer's IP addresses has been turned off, thereby preventing the program from recording my IP address. The survey website uses cookies, or small text files, to recognize repeat visitors and to help Zoomerang measure how their website is being used. After completing the survey I can remove the cookies from my computer through Internet Explorer. From the Tools menu dropdown, select Internet Options. On the General Tab, press the Delete Cookies button. In order to decrease the likelihood of this survey being viewed by unintended individuals (e.g., children or other computer users), I can delete the history from my internet browser. From the History menu dropdown, select Show All History. Right click on the "Zoomerang" listing and select the delete option.

I understand that Danielle Penny, M.A. is willing to answer any questions I may have regarding the research study and I can contact her directly by email at [daniellepenny@gmail.com](mailto:daniellepenny@gmail.com). I understand that I may also contact Barbara Ingram by email at [Barbara.Ingram@pepperdine.edu](mailto:Barbara.Ingram@pepperdine.edu), if I have other questions or concerns about this research. If I have any other questions about my rights as a participant in this study, I may also contact Doug Leigh, Ph.D., Chairperson of the Graduate School and Professional Schools Institutional Review Board, Pepperdine University, Graduate School of Education and Psychology, 6100 Center Drive, Los Angeles, CA 90045; (310)

568-2845.

I have read and understand, to my satisfaction, the information in the consent form regarding my participation in this research project. If I had any questions, they have been answered to my satisfaction. In this consent form I hereby consent to participate in the research described above.

## APPENDIX G

## Online Questionnaire A

1. By clicking “I ACCEPT” below and completing the survey, I am indicating that I have read this consent form and agree to the terms of study participation. If I do not wish to participate, I can click, “NO, THANK YOU” to exit.
  - a. I ACCEPT
  - b. NO, THANK YOU
2. Who is completing this survey?
  - a. Recipient mother
  - b. Recipient father
  - c. Recipient parents together
  - d. Other, please specify: \_\_\_\_\_
3. What is your current relationship status?
  - a. Married / Partnered
  - b. Divorced / Separated
  - c. Single
  - d. Widowed
  - e. Other, please specify: \_\_\_\_\_
4. What is your sexual orientation?
  - a. Heterosexual
  - b. Gay Male
  - c. Lesbian
  - d. Bisexual
  - e. Other, please specify: \_\_\_\_\_
5. What is your ethnicity?
  - a. Asian/Pacific Islander or Asian-American
  - b. Black / African American / of African descent
  - c. White (e.g., European, Canadian, Australian ancestry)
  - d. Latino / Hispanic
  - e. Native American
  - f. Arab-American or of Arab descent
  - g. Biracial / Multi-racial
  - h. Other, please specify: \_\_\_\_\_
6. What is your age?: \_\_\_\_\_
7. What is your highest degree of education completed?
  - a. Did not complete high school
  - b. Completed high school
  - c. Some college

- d. Completed college
- e. Some graduate/professional school
- f. Completed graduate/professional school

8. Where do you currently live?

- a. United States of America
- b. Australia
- c. Belgium
- d. Brazil
- e. Canada
- f. Cyprus
- g. Denmark
- h. France
- i. Germany
- j. Great Britain
- k. Hong Kong
- l. India
- m. Indonesia
- n. Israel
- o. Italy
- p. Japan
- q. Mexico
- r. Netherlands
- s. Norway
- t. Portugal
- u. South Korea
- v. Spain
- w. Sweden
- x. Switzerland
- y. Taiwan
- z. Other

9. What is your religious affiliation?

- a. Christian
- b. Catholic
- c. Muslim
- d. Hindu
- e. Buddhist
- f. Jewish
- g. Non-Religious
- h. Atheist
- i. Agnostic
- j. Other: \_\_\_\_\_

10. How many children do you have who were conceived via means of egg donation?:
11. What is/are your child(ren's) age(s) who were conceived via means of egg donation?
- a. Child 1 age: \_\_\_\_\_
  - b. Child 2 age: \_\_\_\_\_
  - c. Child 3 age: \_\_\_\_\_
  - d. Child 4 age: \_\_\_\_\_
  - e. Child 5 age: \_\_\_\_\_
  - f. Child 6 age: \_\_\_\_\_
12. How much contact did/do you have with your egg donor(s)?
- a. In-person meeting
  - b. Over-the-phone meeting
  - c. No contact at all
  - d. Other, please specify (box to receive text)

The following questions will be addressing the decision to tell children that they were conceived via egg donation. We call this the “disclosure decision”. Decisions regarding if, how, when, and why to disclose are deeply personal and vary significantly among individuals, families and cultures. The following questions are intended to explore the decision-making process, but by no means will they attempt to sway your decision in any direction.

13. Have you received professional advice on the disclosure decision issue?
- a. Yes
  - b. No
14. If so, from whom did you receive this professional advice? (Check all that apply)
- a. Physician
  - b. Nurse
  - c. Mental health professional
  - d. Attorney
  - e. Minister/Rabbi/Other religious official
  - f. Other, please specify \_\_\_\_\_
15. Please rate your status of disclosure. \*
- a. Never plan on disclosing**
  - b. Probably will not disclose**
  - c. Undecided**
  - d. Probably will disclose**
  - e. Absolutely plan on disclosing, but haven't yet**

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\* Participants who endorse responses a, b, c, d, or e, will be directed to Form A after completing Questionnaire A. Participants who endorse responses f or g will be directed to Form B after completing Questionnaire B.

- f. Have begun disclosing
- g. Have completely disclosed

16. If you have multiple children, do you plan on utilizing the same disclosure decision for both/all?

- a. Yes
- b. No
- c. Not sure
- d. Not applicable

17. How easy or difficult do you rate making parent-to-offspring disclosure decisions?

- a. Very easy
- b. Easy
- c. Have not thought about it
- d. Difficult
- e. Very difficult

18. How desirable would it be for you to read disclosure scripts that other recipient parents have used to tell their children about their genetic origins?

- a. Very desirable
- b. Desirable
- c. Unsure
- d. Not desirable
- e. Not at all desirable

Please proceed to the following screen.

## APPENDIX H

## Presentation of Scripts - Form A

The following scripts were created by this investigator for the purposes of this research study in order to determine the helpfulness of reading brief disclosure scripts for recipient parents. The scripts are strongly based upon recent research documenting recipient parents' strategies for disclosing to their children, conducted by Drs. Mac Dougall, Becker, Scheib, and Nachtigall, in 2007. The scripts were also influenced by a resource written for recipient parents titled, *Building Your Family Through Egg Donation* (2<sup>nd</sup> Ed.), written by Dr. Judith Friedman in 2007.

In deciding how to disclose their biological origins to children, how helpful are the follow parent-to-offspring disclosure scripts?

Script A: "We wanted you very much to be our baby. We needed some help to have you and some good people gave us the help we needed. A nice woman gave us an important gift and a doctor helped us so that you could grow healthy and be a part of this family."

- a. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- b. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely



Script B: “We love you so much and wanted you so badly that we worked hard to have you. We had a missing part (or broken part) that needed to be replaced (or fixed) in order to bring you into the world. Our bodies work a little differently than other people’s, so doctors and other nice people gave us spare parts (or healthy parts) so that you could be born.”

- c. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- d. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script C: “There are so many different types of families! Some families have step moms or dads, some families have children who are adopted, some families have parents and children who are different races, other families have one parent, or two mommies or two daddies. There are all different kinds of ways to make a family, and our family is special too.”

- e. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral

- iv. Not very helpful
  - v. Not at all helpful
- f. How likely would you be to use this approach?
- i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script D: “Did you know that people who want to help other people sometimes donate some of their blood to help other people stay healthy? Some people even donate organs to people who need them, like kidneys, because most people have two normal kidneys but one is enough. Well sort of like that, when we were trying to have you, we needed someone to donate a small piece of her body to us, called a cell or egg.”

- g. How helpful do you think this approach might be for parents who are making disclosure decisions?
- i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- h. How likely would you be to use this approach?
- i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script E: “Our family is special in all different ways. [Can insert examples such as activities/foods your family enjoys, religious or other cultural traditions – i.e., anything that makes your family unique.] Also, we wanted you so badly that we worked extra hard

so that you could come into the world. In order for that to happen, we put a donor egg inside mommy and then you grew.” (Or, in the cases of a gestational carrier, “We asked someone to carry a donor egg for us so that you could grow and be a part of our family.”)

- i. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- j. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script F: “When we were trying to have you, we asked a nice lady to donate a gene cell to us so that we could have the DNA we needed to make you. You’ll probably learn more about DNA and genes in school, but for now it’s important to know that DNA holds the plan for the way people look, and carries other information like a tiny computer. The woman who donated the DNA doesn’t know us, but she knew we wanted you very badly, and she knew that mom’s egg cells didn’t have exactly the right ingredients.”

- k. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- l. How likely would you be to use this approach?

- i. Very likely
- ii. Somewhat likely
- iii. Neutral
- iv. Not very likely
- v. Not at all likely

Script G: “When we were trying to have you, we needed a young lady to donate some of her eggs to us in order for you to be born. [If applicable, “We can show you what subjects she liked in school, what her favorite things to do were, what kind of sports she played,” etc.] She must have been a great person because of how great you are! The most important quality we know about her is that she wanted to help make people happy.”

- m. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- n. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script H: “The nice young lady who donated eggs to us had a big heart and she wanted us to have the privilege of loving a child as wonderful as you. We are so proud of you and always want what is best for you. We will always be there for you and will always love you.”

- o. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- p. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

Script I: “Whenever you want to talk more about the egg donation or anything about your conception story, we’ll be ready to talk with you. You may have some questions or thoughts or feelings that you might want to share. We hope that you’ll always come to us when you’re wondering or having strong feelings about our family story.”

- q. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- r. How likely would you be to use this approach?
  - i. Very likely
  - ii. Somewhat likely
  - iii. Neutral
  - iv. Not very likely
  - v. Not at all likely

## APPENDIX I

## Presentation of Scripts - Form B

The following scripts were created by this investigator for the purposes of this research study in order to determine the helpfulness of reading brief disclosure scripts for recipient parents. The scripts are strongly based upon recent research documenting recipient parents' strategies for disclosing to their children, conducted by Drs. Mac Dougall, Becker, Scheib, and Nachtigall, in 2007. The scripts were also influenced by a resource written for recipient parents titled, *Building Your Family Through Egg Donation* (2<sup>nd</sup> Ed.), written by Dr. Judith Friedman in 2007.

In deciding how to disclose their biological origins to children, how helpful are the follow parent-to-offspring disclosure scripts?

Script A: "We wanted you very much to be our baby. We needed some help to have you and some good people gave us the help we needed. A nice woman gave us an important gift and a doctor helped us so that you could grow healthy and be a part of this family."

- s. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- t. How similar is this to the approach you are using to disclose to your children?
  - i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script B: “We love you so much and wanted you so badly that we worked hard to have you. We had a missing part (or broken part) that needed to be replaced (or fixed) in order to bring you into the world. Our bodies work a little differently than other people’s, so doctors and other nice people gave us spare parts (or healthy parts) so that you could be born.”

- u. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- v. How similar is this to the approach you are using to disclose to your children?
  - i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script C: “There are so many different types of families! Some families have step moms or dads, some families have children who are adopted, some families have parents and children who are different races, other families have one parent, or two mommies or two daddies. There are all different kinds of ways to make a family, and our family is special too.”

- w. How helpful do you think this approach might be for parents who are making disclosure decisions?
  - i. Very helpful
  - ii. Somewhat helpful

- iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- x. How similar is this to the approach you are using to disclose to your children?
- i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script D: “Did you know that people who want to help other people sometimes donate some of their blood to help other people stay healthy? Some people even donate organs to people who need them, like kidneys, because most people have two normal kidneys but one is enough. Well sort of like that, when we were trying to have you, we needed someone to donate a small piece of her body to us, called a cell or egg.”

- y. How helpful do you think this approach might be for parents who are making disclosure decisions?
- i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- z. How similar is this to the approach you are using to disclose to your children?
- i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script E: “Our family is special in all different ways. [Can insert examples such as activities/foods your family enjoys, religious or other cultural traditions – i.e., anything



that makes your family unique.] Also, we wanted you so badly that we worked extra hard so that you could come into the world. In order for that to happen, we put a donor egg inside mommy and then you grew.” (Or, in the cases of a gestational carrier, “We asked someone to carry a donor egg for us so that you could grow and be a part of our family.”)

aa. How helpful do you think this approach might be for parents who are making disclosure decisions?

- i. Very helpful
- ii. Somewhat helpful
- iii. Neutral
- iv. Not very helpful
- v. Not at all helpful

bb. How similar is this to the approach you are using to disclose to your children?

- i. Very similar
- ii. Somewhat similar
- iii. Neutral
- iv. Not very similar
- v. Not at all similar

Script F: “When we were trying to have you, we asked a nice lady to donate a gene cell to us so that we could have the DNA we needed to make you. You’ll probably learn more about DNA and genes in school, but for now it’s important to know that DNA holds the plan for the way people look, and carries other information like a tiny computer. The woman who donated the DNA doesn’t know us, but she knew we wanted you very badly, and she knew that mom’s egg cells didn’t have exactly the right ingredients.”

cc. How helpful do you think this approach might be for parents who are making disclosure decisions?

- i. Very helpful
- ii. Somewhat helpful
- iii. Neutral
- iv. Not very helpful
- v. Not at all helpful

- dd. How similar is this to the approach you are using to disclose to your children?
- i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script G: “When we were trying to have you, we needed a young lady to donate some of her eggs to us in order for you to be born. [If applicable, “We can show you what subjects she liked in school, what her favorite things to do were, what kind of sports she played,” etc.] She must have been a great person because of how great you are! The most important quality we know about her is that she wanted to help make people happy.”

- ee. How helpful do you think this approach might be for parents who are making disclosure decisions?
- i. Very helpful
  - ii. Somewhat helpful
  - iii. Neutral
  - iv. Not very helpful
  - v. Not at all helpful
- ff. How similar is this to the approach you are using to disclose to your children?
- i. Very similar
  - ii. Somewhat similar
  - iii. Neutral
  - iv. Not very similar
  - v. Not at all similar

Script H: “The nice young lady who donated eggs to us had a big heart and she wanted us to have the privilege of loving a child as wonderful as you. We are so proud of you and always want what is best for you. We will always be there for you and will always love you.”

gg. How helpful do you think this approach might be for parents who are making disclosure decisions?

- i. Very helpful
- ii. Somewhat helpful
- iii. Neutral
- iv. Not very helpful
- v. Not at all helpful

hh. How similar is this to the approach you are using to disclose to your children?

- i. Very similar
- ii. Somewhat similar
- iii. Neutral
- iv. Not very similar
- v. Not at all similar

Script I: “Whenever you want to talk more about the egg donation or anything about your conception story, we’ll be ready to talk with you. You may have some questions or thoughts or feelings that you might want to share. We hope that you’ll always come to us when you’re wondering or having strong feelings about our family story.”

ii. How helpful do you think this approach might be for parents who are making disclosure decisions?

- i. Very helpful
- ii. Somewhat helpful
- iii. Neutral
- iv. Not very helpful
- v. Not at all helpful

jj. How similar is this to the approach you are using to disclose to your children?

- i. Very similar
- ii. Somewhat similar
- iii. Neutral
- iv. Not very similar
- v. Not at all similar

## APPENDIX J

## Online Questionnaire B

1. How helpful, in general, do you rate reading the above parent-developed disclosure scripts?
  - a. Very helpful
  - b. Helpful
  - c. Undecided
  - d. Not very helpful
  - e. Not at all helpful
2. Do you think some type of disclosure decision assistance should be provided to all recipient couples?
  - a. Absolutely
  - b. Maybe
  - c. Undecided
  - d. Probably not
  - e. Absolutely not
3. Do you think examples of disclosure scripts should be provided to all recipient couples?
  - a. Absolutely
  - b. Maybe
  - c. Undecided
  - d. Probably not
  - e. Absolutely not
4. Would you be interested in accessing resources intended to assist in the disclosure-decision process?
  - a. Yes
  - b. No
5. If yes, please provide your thoughts about resources that might be useful to you.: -  
\_\_\_\_\_
6. Please rate your experience in completing this survey.
  - a. Very easy
  - b. Easy
  - c. Neutral
  - d. Difficult
  - e. Very difficult
7. Please provide any suggestions for improving the scripts. You might have ideas about how a specific script could be improved, or you might have an idea for a different script.: \_\_\_\_\_

Thank you very much for your participation. Should you have any questions or concerns about this research, parent-to-offspring disclosure, or anything related to your experience with this survey, please contact the researcher at [daniellepenny@gmail.com](mailto:daniellepenny@gmail.com).

Researcher: Danielle Penny Vorzimer

Supervising psychologist: Barbara Ingram, Ph.D.

This study was approved by Pepperdine University's Institutional Review Board.