The role of privacy in families created through assisted reproductive technology: Examining existing literature using Communication Privacy Management theory.

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Rauscher, E. A., & <u>Fine, M. A.</u> (2012). The role of privacy in families created through assisted reproductive technology: Examining existing literature using Communication Privacy Management theory. *Journal of Family Theory and Review*, *4*(*3*), 220-232. <u>DOI:</u> 10.1111/j.1756-2589.2012.00132.x

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Abstract:

The number of families created through the use of assisted reproductive technology (ART) has grown throughout the past decade. Families created through ART face many unique communication challenges both within the immediate family and with others outside the family, such as issues with privacy and disclosure. Whether parents choose to disclose genetic information to the child, to other immediate family members, or to others outside the family are issues that parents who use ART commonly face. This article applies communication privacy management theory to analyze the existing literature on families created through assisted reproductive technology. In doing so, the article highlights the communication and privacy issues these families face.

Keywords: assisted reproductive technology | communication privacy management theory | family communication | family studies | psychology

Article:

According to a report released by the U.S. Centers for Disease Control and Prevention (CDC, 2005), 52,041 infants were born as a result of assisted reproductive technology (ART) in 2005 in the United States. This number is up from approximately 35,000 in 2000 (CDC, 2002). According to a separate report released by the CDC (1998), as many as 7.7 million women and their partners could be infertile by the year 2025. Medical technology advances have responded to the increase in infertility by giving couples several options. One of these options is using a surrogate. Surrogacy has become an increasingly used option for infertile couples. Two types of surrogacy exist, genetic and gestational. In genetic surrogacy, the commissioning father and surrogate mother are the genetic parents. In gestational surrogacy, one or both of the

commissioning parents are the genetic parents of the child (Golombok, MacCallum, Murray, Lycett, & Jadva, 2006). Although surrogacy is an increasingly popular method of conceiving a child, it is also likely the most controversial ART procedure (Golombok, MacCallum, Murray et al., 2006).

Another option for couples is in vitro fertilization (IVF), which uses genetic material from both biological parents, genetic material from the mother and donor sperm, genetic material from the father and a donor egg, or genetic material from a donor egg and sperm. Using a donor involves conception using donated eggs, sperm, or embryos and has been available to infertile men and women since the 1980s (Trounson, Leeton, Besanka, Wood, & Conti, 1983). A complication to conception through donation, specifically, is donor anonymity. When choosing to use donor eggs, sperm, or embryos, both the donor and the recipient must decide on the level of anonymity to be maintained throughout the donation process and for the rest of their lives.

Although couples always have the option of seeking out a known donor, such as a friend or family member, more often they go with an anonymous donor from a donation center or clinic. Laws and regulations across the globe differ in regard to the anonymity of egg and sperm donors. According to an extensive report released by the American Society of Reproductive Medicine in April 2007, the United States currently operates under "guidelines" that leave the option open for donors to allow contact from offspring, but they do not require nonanonymous donation practices. Other countries such as Sweden, the United Kingdom, Austria, New Zealand, and Australia (state of Victoria) have passed legislation allowing children to contact donors when they reach the age of 18 or when they reach "maturity" (Clarke-Stewart & Dunn, 2006; Gottlieb, Lalos, & Lindblad, 2000; Hargreaves & Daniels, 2007; Sydsjo, Lampic, Sunnerud, & Smoog Svanberg, 2007). However, although these laws might be in place in several countries around the world, according to research regarding children conceived through ART, most children are not receiving information on their genetic origins.

A significant body of research has been conducted in the past decade investigating how, when, or even if children conceived through ART are or should be told about the origins of their conception (Golombok, Lycett et al., 2004; Gottlieb et al., 2000; Scheib, Riordan, & Rubin, 2005; Turner & Coyle, 2000). One research study found that approximately 50% of donor insemination (DI) and egg-donating parents indicated that they intended to tell offspring of their conception story, but most studies found a far lower percentage of parental intention to disclose the child's genetic origins to the child (Golombok, Lycett et al., 2004). In one study, 82% of DI parents decided never to tell the child, compared to 38% of egg donation parents (Golombok, Murray, Brinsden, & Abdalla, 1999). In another study, 43% of parents in families created through DI had decided never to tell their child about his or her conception (Lycett, Daniels, Curson, & Golombok, 2005). In yet another study, only 35% of parents using egg donation planned to ever tell their child about his or her conception, compared to 11% of DI parents (Murray, MacCallum, & Golombok, 2006). In a study investigating embryo donation, only 9%

of parents had already told the child about the method of conception, and only 24% had intentions of telling (MacCallum, Golombok, & Brinsden, 2007).

A recurring theme in the literature investigating disclosure about a child's genetic origin is the importance of privacy in the disclosure process, which can be further understood through the application of communication privacy management (CPM). CPM theory provides an informative lens for examining the existing literature on communication in families created through ART (Petronio, 2002). Examining this literature using the tenets of CPM will show the underlying and overt issues of privacy families face when communicating about a child's genetic origins. How, when, and why individuals and families construct rules about privacy, coordinate boundaries around private information, and deal with the fallout of inappropriate disclosures are all important to understanding how decisions of revealing and concealing are made in regard to information about a child's genetic origin.

The goal of this article is to use several tenets of CPM to examine the existing literature on families created through ART procedures such as egg and sperm donation. By doing so, this theoretically guided literature review aims to accomplish several goals. First, it will suggest a theoretical backbone to a body of literature that is, for the most part, without theoretical guidance. Second, it will attempt to explain an important issue families created through ART face, making disclosure decisions, by showing the privacy rules enacted by these families and how these families use these rules to manage privacy boundaries. Finally, this article will also highlight areas of necessary future research to understand how disclosure decisions and privacy boundaries impact families created through ART.

Communication Privacy Management in Assisted Reproductive Technology

Communication privacy management is an ideal theory for investigating family communication about ART, because one of the core tenets of CPM, and of communicating and relating in families, is the dialectical tension surrounding decisions to reveal and conceal (Petronio, 2010). Existing research that uses CPM has shed light on some interesting privacy issues within families, such as how divorced and stepfamilies manage private information (Afifi, 2003; Afifi, McManus, Hutchinson, & Baker, 2007), privacy management in health-care situations (Petronio, 2006; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004), privacy in in-law relationships (Serewicz, & Canary, 2008), and privacy in family planning (Daniels, Gillett, & Grace, 2009; Durham, 2008). The fruitful body of research connecting families and privacy, coupled with the ability of the theory to tap into the dialectical tension of revealing and concealing, make CPM an ideal theory to use as a lens to examine the existing body of research investigating communication in families that choose ART. To get a better understanding of how CPM fits into the existing literature on communication about a child's genetic origins, one must better understand the tenets of CPM theory. First, CPM is a communication theory that uses boundaries as a metaphor to show how individuals manage private information (Petronio, 2002). Broadly, CPM proposes three management processes that encompass the main tenets of the theory: (1) privacy rule foundations, (2) boundary coordination operations, and (3) boundary turbulence (Petronio, 2002). These processes show how people construct rules to manage the revealing and concealing of their private information (Petronio, 2002). Additionally, these processes show how people use these rules to make disclosures about private information to others, thereby linking with that person through the private information disclosure. Finally, these processes also encompass the consequences of private information disclosures if the rules of revealing and concealing are not followed. In this article, each of these three processes is discussed in terms of how they apply to the existing literature investigating communication in families created through ART.

Privacy Rule Foundations

One of the most important principles of CPM theory is that the revealing and concealing of private information depends on rules. Rule development focuses on how people come to know or construct both their individual and their collective privacy boundaries (Petronio, 2002). Privacy rules are developed to help individuals determine when, how, with whom, how much, and in what way to disclose private information to others (Petronio, 2010). Although children may sometimes learn these rules from their parents or other caregivers, often circumstances arise that require individuals to develop new rules or renegotiate previously established rules. CPM proposes a number of underlying criteria that people use to establish privacy rules, not all of which are discussed in this review. The criteria of motivations and risk-benefit ratio are briefly discussed in the context of constructing privacy rules regarding communication about a child's genetic origins in the following sections. The role of these rules in the boundary coordination and boundary turbulence processes is also discussed throughout the remainder of this article.

Motivational criteria. Individuals might be driven by personal motivational factors when making rules about privacy boundaries. When individuals (or families) make rules about revealing and concealing, they might consider specific needs surrounding private disclosures (Petronio, 2002). In the existing literature regarding families created through ART, parents have discussed several motivational criteria for constructing privacy rules related to disclosure decisions. These motivational criteria include wanting to tell the child themselves before someone else does, giving the child the knowledge he or she deserves, wanting the child to have access to medical technology advances related to genetic diseases, and an overall desire to protect the family (Golombok, Lycett et al., 2004; Lycett et al., 2005; MacCallum et al., 2007).

Although most of the research investigating families created through ART shows that parents commonly choose not to tell children about their ART status, they do tell others about children's ART status. According to a study conducted by Golombok, Lycett, et al. (2004), approximately 80% of parents in the study had told at least one other person about their donor conception. Thus, the first motivation is that extending privacy boundaries to individuals outside the immediate

family may motivate parents to make disclosures to children based on a desire for the children to hear the disclosure from the parent rather than from someone else.

A second motivation for disclosure that parents cited in the existing literature on children conceived using ART was the child's right to know his or her genetic origins. According to MacCallum et al. (2007), in their study investigating reasons for disclosing information about ART conception, 57% of parents said they would tell their child about his or her conception because they felt the child has a right to know. Part of the reason parents feel their children have a right to knowledge of their genetic origins is the parents' desire for children to have access to expanding medical technology related to genetics. According to Lycett et al. (2005), parents often said they told or were going to tell their children of the children's genetic origins so that the children could have access to knowledge about genetic health. As the research shows, parents often create privacy rules based on their motivation for children to have access to knowledge of their genetic origins and advances to medical technology related to genetic health.

A third motivation related to disclosure decisions discussed by parents in the literature investigating families created through ART is an overall desire to protect the family. Many parents discussed choosing not to disclose genetic origin information to children on the basis of a desire to protect both themselves and the children (MacCallum et al., 2007). The need to protect the parents, children, and family as a whole can be considered a motivational criterion but also a risk related to disclosure decisions.

Risk-benefit ratio. A second criterion used to make decisions about disclosure of private information is risk-benefit ratio. When people use a risk-benefit ratio criterion to make decisions about disclosure, they contemplate the benefits of disclosure, such as self-expression, self-clarification, social validation, relationship development, and social control (Petronio, 2002). However, when people use risk-benefit ratio criteria, they also contemplate the risks of making private disclosures, such as relationship deterioration, social stigma, loss of face, and emotional hurt (Petronio, 2002). Inevitably, when individuals use risk-benefit ratio criteria to make decisions about private disclosures, they must weigh the risks against the benefits to make a final decision about how to extend privacy boundaries around certain pieces of private information.

The risk-benefit ratio criterion is of primary importance in the literature regarding families created through ART. In this literature, the benefits of disclosure are discussed far less often by parents and with less consideration than risks. In ART families, the primary benefits that promote disclosure to children are a desire for openness in the family and a desire to avoid secrecy (Lindblad, Gottlieb, & Lalos, 2000; Lycett et al., 2005). The benefits of openness in families created through ART may be forecasted by the findings advocating openness in adoptive families, a family type that confronts many of the same privacy issues as families created through ART (Berge, Mendenhall, Wrobel, Grotevant, & McRoy, 2006; Groth, Bonnardel, Devis, Martin, & Vousden, 1987; Jones & Hackett, 2007; Logan, 1999). According to Lycett et al. (2005), 13% of families surveyed had already told the child of his or her genetic

origins, and another 26% intended to tell the child in the future. Those families who had already told or intended to tell in the future said that one of the primary benefits of disclosure was to create and maintain an environment of openness and honesty in the family. Lindblad et al. (2000) produced similar results in their study investigating parents' disclosure decisions. In their study, more than 50% of parents had already told their children or intended to tell their children of their donor origins because of a desire to maintain openness and honesty in the family.

Although the benefits involved in disclosure decisions are important to parents, parents discuss risks in greater detail, and those risks have a significant impact on parents' disclosure decisions. The risks cited by parents in this body of literature do not all focus on protection of the child but instead focus on protection of the child, parents, and family as a whole. Risks of disclosure discussed in this section include distance from the nongenetic parent; the child's possible adjustment problems; and the ability of the child to access any information about the donor, such as the possibility of meeting the donor or knowing any detailed information about the donor.

Child distancing from nongenetic parent. One risk associated with disclosure of genetic origin to a child conceived through egg, sperm, or embryo donation is the parents' fear that the child would distance him- or herself from the nongenetic parent. When parents report this risk as a significant reason for choosing not to disclose a child's ART status to the child, the parents are choosing to enact privacy rules to protect themselves rather than the child. According to Golombok, Murray, Brinsden et al. (1999), parents of children conceived through egg or sperm donation often report that their reason for not disclosing the child's genetic origin was to protect the nongenetic parent. In other words, a wish to protect the mother was given as a reason by 23% of egg donation parents and a wish to protect the father was given by 69% of DI parents (Golombok, Murray, Brinsden et al. 1999). Similarly, parents in New Zealand who have chosen not to tell their children about their genetic origins cited rejection by children as a primary reason for not disclosing (Hargreaves & Daniels, 2007).

Existing research shows that relationships between a child conceived through donation and the nongenetic parent are typically quite similar to relationships between a naturally conceived child and his or her genetic parents (Owen & Golombok, 2009). According to Golombok, MacCallum, Goodman, and Rutter (2002), no significant differences were found between DI, natural conception, and adoptive fathers on father–child expressive warmth and/or closeness, instrumental warmth, expression of affection, and overall paternal involvement. These results suggest that genetic relatedness is unrelated to the quality of relationships between fathers and their children—fathers can have positive (or negative) quality relationships with their children in both types of families. Similarly, in a study investigating parent–child interaction among surrogacy mothers, egg donation mothers, and natural conception mothers, no differences on parent–infant interaction, sensitive responding, or feelings about the parental role were found among family types (Golombok, Murray, Jadva, MacCallum, & Lycett, 2004). Similar results were found in another study showing higher levels of mother–child interaction in egg donation and surrogacy families than in DI families (Golombok, Murray, Jadva, Lycett et al., 2006).

Finally, in a study investigating embryo donation, results showed no differences in expressed warmth, father–child interaction, or mother–child interaction among IVF parents, natural conception parents, and embryo donation parents (MacCallum et al., 2007).

Although the current literature seems to suggest that nongenetic parents and offspring can have positive relationships, one issue with this research must be pointed out before drawing conclusions. Most of these studies that found no significant differences in parent-child relationships among egg donation, sperm donation, surrogacy, natural conception families, and so on have been conducted in families in which the child is young and has no knowledge of his or her genetic origins. That the children have no knowledge of their genetic origins and still have a strong relationship with the nongenetic parent leaves room for the parents to consider whether to tell children about their genetic origins on the basis of the perceived risk of the children rejecting the nongenetic parent. Inevitably, if parents decide not to extend privacy boundaries on the basis of this risk criterion, they are doing so to protect themselves from the consequences of the disclosure rather than to protect the child.

Child adjustment problems. A second commonly cited risk of disclosure from parents of children conceived through ART is how being a child of donation would affect adjustment and development. Parents in several studies said they were leaning toward not disclosing the child's genetic origin to the child because they were afraid of adjustment problems and psychological harm to the child and the child's identity (Gottlieb et al., 2000; Kirkman, 2003; Lindblad et al., 2000; Lycett et al., 2005). However, similar to the previously discussed risk of distance between the nongenetic parent and child, the existing literature does not support the idea that poor child adjustment is a significant risk.

In one study based on a sample of children conceived naturally or through donor insemination, or who were adopted, only 8 children of the 86 interviewed in the sample had emotional or behavioral problems, and 6 of those 8 were naturally conceived (Golombok, MacCallum, Goodman et al., 2002). Murray et al. (2006) also found no differences in child behavioral problems among egg donation, DI, and IVF families on school adjustment or peer relationships. Golombok, Murray, Jadva, Lycett et al. (2006) also found no differences among egg donation, surrogacy, and natural conception families on children's psychological adjustment. MacCallum et al. (2007) found more conduct problems for embryo donation children than adoptive children but no differences among embryo, adoption, and IVF children on hyperactivity, emotional symptoms, or peer problems.

Because previous research has shown that donor offspring have similar rates of adjustment problems as children who were adopted or naturally conceived (Landau, Weissenberg, & Madgar, 2008), it seems that parents should not make disclosure decisions on the basis of fear that the children will develop adjustment problems as a result. As was the case with the risk of distance between nongenetic parents and children, the research cited in this section also comes from studies in which most children did not know their genetic origin. As a result of the trend of

parents choosing not to tell children about their genetic origins, research does not yet exist showing how disclosure and knowledge of genetic origins could affect child adjustment. However, although no research currently exists showing a link between disclosure of genetic origin and adjustment problems, many parents are still basing their disclosure decisions on the assumption that having knowledge of their true genetic origins will cause donor offspring to experience significant problems with emotional, psychological, and behavioral adjustment.

Donor influence. A third risk of disclosure commonly cited by parents of donor offspring is the role of the donor in the child's life. Parents reported choosing not to disclose a child's genetic origin because of a lack of genetic information about the donor, fear of future contact and interference from the donor, and arguments about the donor (Greenfeld & Caruso Klock, 2004; Kirkman, 2003; Lindblad et al., 2000; Lycett et al., 2005). Research investigating the role of the donor, even if he or she is an ambiguous figure, in the lives of donor offspring can be fraught with uncertainty. Research shows that the donor role can be fraught with uncertainty, even if the donor is an ambiguous figure in the lives of donor offspring. However, some existing research also shows that the role of the donor can be extremely benign.

Existing research regarding the role of the donor in the lives of donor families shows a variety of disclosure issues. Several studies have investigated how families, usually parents, talk about the donor. These studies show that it is common not to discuss the donor at all because the parents do not consider the donor an important part of the family. In fact, in one study 60% of DI parents and 61% of egg donation parents reported never talking about the donor (Golombok, MacCallum, Goodman et al., 2002). Greenfeld and Caruso Klock (2004), in their study investigating the differences between families with known and unknown donors, showed that even when donors were known to the families, parents typically wanted information such as family history, photographs, and medical history rather than familial involvement from the donor. In the few existing studies that have included donor offspring who are actually aware that they are donor offspring, research shows that these children do not ruminate about the role of the donor in their lives or actively seek out information or further knowledge about their donor. In a study conducted by Vanfraussen, Ponjaert-Kristoffersen, and Brewaeys (2001), 54% of donor offspring (age 7–17) did not even want information about their donors. According to Scheib et al. (2005), in their study investigating 12- to 17-year-olds with open-identity sperm donors, youths reported that learning and knowing about their donor had a neutral to positive effect on their relationship with their mother, did not affect their life, and did not make them feel different. Further, although some parents may fear that their child will turn to his or her donor for a parentlike relationship, in Scheib et al.'s (2005) study, only 2 of 29 children surveyed envisioned a parentlike relationship with their donors. As was the case with the risk of the child distancing him- or herself from the nongenetic parent, disclosure decisions based on the risk of a child's potential relationship with a donor seem to be enacted more to protect parents than children.

Although the role of the donor was reported as a common risk for parents' disclosure decisions, little research actually investigated the role of the donor because so few of the parents in these studies were open with their children about their donor status. To the extent that donors in ART are similar to birth parents in the adoptive literature, we can conclude that the donor's role may be less threatening to the family than many parents believe. In fact, according to Berge et al. (2006), a relationship between an adoptive child and his or her birth mother can lead adoptive parents to feel less threatened about the interference of the birth parents. A comparison to the adoption literature is informative, but adoptive families and ART families face different issues. To understand the risks and benefits involved in disclosing a child's genetic origins, more studies must be conducted using samples of adult donor offspring who are aware of their donor status. These future studies must investigate any problems actually experienced in families in which the donor is known to the child and is part of the family dynamics, not just examine speculation about hypothetical fears of the donor's presence.

Overall, the risk-benefit ratio criterion plays a significant role in disclosure decisions in families created through ART. Although the existing research cites benefits to disclosure such as openness and lack of secrecy, the more predominant focus is on the perceived risks of disclosure. The primary risks of disclosure cited by parents, such as distance between the child and nongenetic parent, child adjustment, and donor influence, have all been well studied by scholars. However, results of these studies show that nongenetic parents' relationships with their children do not suffer, donor offspring do not have adjustment problems, and knowledge of the donor does not have a negative impact on donor offspring. These results are informative, but in light of how many parents choose not to disclose their child's donor status to the child, the practical utility of these results is questionable.

These privacy rules enacted by parents of children conceived through ART are commonly considered when parents make decisions about when, how, and to whom to make disclosures about the child's ART status. In the following section of this article, the second process of CPM, boundary coordination, is discussed. In this section, the enactment of privacy rules to determine ownership and extend privacy boundaries is explained in reference to the existing literature of families created through ART.

Boundary Coordination

The second process involved in the management of private information, according to CPM theory, is boundary coordination. One of the most important elements to consider when coordinating boundaries is that an individual usually simultaneously balances both personal and collective boundaries (Petronio, 2002). People not only have to construct boundaries and privacy rules regarding their own private information, but they also have to do the same for any private information they have acquired about others. Balancing the private information about oneself and others can often be a complicated undertaking that requires a great deal of boundary management and rule construction. Dealing with the private information of oneself and others

also requires that individuals consider such issues as how, why, or when they will make disclosures to others; how much control they want to exert over their private information; and how much of their private information they are willing to share (Petronio, 2002). Each of these elements is discussed in the following section in looking at how families created through ART coordinate privacy boundaries around information about children's genetic origins. Specifically, the CPM tenets of boundary ownership and boundary linkage are discussed.

(Co-)ownership and control. An important assumption of CPM theory is that individuals believe that their private information belongs to them, thus granting them ownership over their private information (Petronio, 2010). In turn, people believe, because they own their private information, that they have the right to control it and choose who will and will not become co-owners of the private information, as well as how tight the boundaries will be around the private information (Petronio, 2010). The need for ownership and control of private information often makes the transition from personal boundaries to collective boundaries difficult (Petronio, 2010). The dilemma of ownership and control becomes especially pronounced in situations in which ownership of private information is not clear, such as the case of a child's genetic origins. Additionally, the multiple levels of co-ownership that can develop in families add a further level of complication in identifying ownership rules and control issues. This section discusses who does and does not have ownership of this information and how ownership and control of information about children's genetic origins affect decisions to grant co-ownership rights to other family members and individuals outside the family.

The primary issue of control and ownership in families created through ART is the issue of who has knowledge of the conception. The previously discussed disclosure rates show that most parents of children conceived through egg and sperm donation have no intentions of telling their children about their genetic origins. Although recent legislation in countries across the world has attempted to move toward more openness between parents and children, past suggestions from clinicians advocated secrecy in these families, which might still dictate how parents control information about a child's genetic origins (Mahlstedt & Greenfeld, 1989). Such a lack of disclosure begs the question of who actually should own information about a child's genetic origins? Recent debates in the literature on families conceived through ART have still not reached consensus on the issue of who should own and control information about a child's genetic origins, nor is it likely that they will anytime soon.

However, existing research has reached several conclusions about how parents actually go about disclosing that information, which can be explained using CPM theory. Examining how families created through ART manage the ownership of private information on different levels may help us better understand the decisions that parents make regarding disclosure to children, other family members, and outsiders. CPM notes that issues of control and co-ownership develop at several levels in families. Families control private information through the management of both internal and external privacy boundaries (Petronio, 2002). Internal privacy boundaries involve

members of the immediate family, whereas external privacy boundaries involve individuals outside the immediate family (Petronio, 2002). Some parents believe that children should be given the information because it is their right to know or because children should have access to medical history if they want or need it (Greenfeld & Caruso Klock, 2004; Lindblad et al., 2000; Lycett et al., 2005). Parents who choose to be open with their child by co-owning the child's genetic origins with him or her foster a permeable internal privacy boundary. Other parents, however, report feeling that this information should be controlled by the parents and not co-owned with the children because the information is "irrelevant," because the information could harm relationships between the child and the parents, or because having access to this information could psychologically harm the child (Lindblad et al., 2000; Lycett et al., 2005; MacCallum et al., 2007). According to CPM theory, parents who choose not to disclose a child's donor status to the child foster a more impermeable internal privacy boundary, thereby constructing a high level of control over the information.

The owners of the knowledge of the child's donor status must also make control and coownership decisions regarding external privacy boundaries. Whether the owners are just the parents or the parents and the children, owners must make co-ownership decisions about individuals outside the internal privacy boundary. Potential co-owners include other family members such as aunts and uncles, grandparents, and cousins, as well as non–family members such as friends, teachers, and medical professionals (Golombok, Lycett et al., 2004; Kirkman, 2003; Lycett et al., 2005; Scheib et al., 2005). To effectively manage privacy boundaries, owners of private information, such as a child's donor status, must be able to coordinate both internal and external privacy boundaries. Balancing privacy boundaries at multiple levels, as in the case of private information management in families, can often become difficult. In the case of families created through ART, deciding where the boundaries are drawn and with whom to co-own the information are of the utmost importance. Once a decision to co-own private information has been made, owners create boundary linkages with potential co-owners. The following section discusses the issue of boundary linkages in families created through ART.

Boundary linkages. When an individual has made the decision to disclose his or her private information to another individual, and thereby co-own that information with another individual, he or she is contemplating a boundary linkage (Petronio, 2002). An individual must make many considerations before linking with another person through his or her private information, because essentially, by making a linkage, the individual transitions from managing a personal boundary to managing a collective boundary (Petronio, 2002). An individual must consider whether the other person is trustworthy enough to manage the private information the way he or she wants the information to be managed, when the disclosure should be timed, whether the person is the right confidant, and whether the topic of the disclosure is appropriate for the confidant (Petronio, 2002). There is no shortage of considerations that must be taken into account before an individual makes a boundary linkage with another regarding private information. In families created through ART, making boundary linkages and regulating privacy boundaries is very

difficult because of the extremely sensitive nature of the private information. The existing literature investigating families created using ART has highlighted three common linkages made by owners including linkages with children, outside family members, and donors.

Children conceived using donors. Parents of children conceived using donors have stated that they consider a variety of factors when deciding whether to link privacy boundaries concerning a child's genetic origin with the child. When making these decisions, parents enact various privacy rules, which help owners of private information determine when boundary linkages should be made (or not made). Enactment of these privacy rules serves a variety of functions for families created through ART. When trying to conceal information about a child's genetic origin, enacting privacy rules may lead to parents' choice not to link boundaries with the child, family, or friends for several reasons, including protecting the child, the parents, and the family (Golombok, Lycett et al., 2004; Hargreaves & Daniels, 2007). Alternatively, a family's privacy rules may lead parents to be more open to disclosing to children because they feel that the child has a right to know, to avoid disclosure by someone else, to be honest, to avoid keeping secrets and telling lies, or because they feel that they have no compelling reason to withhold the information (Golombok, Lycett et al., 2004; Hargreaves & Daniels, 2007).

Although most parents surveyed in the existing literature chose not to tell the child about the child's donor status, several had already told or were planning on telling. A commonly used privacy rule that parents used to determine an appropriate time to make boundary linkages with children about donor status was the child's age or level of maturity. According to a study that surveyed nurses working in infertility clinics, experienced infertility nurses believed that parents should let children know about their genetic origins as soon as possible, or at least when the child starts asking questions about where babies come from (Sydsjo et al., 2007). These nurses claimed that the average suggested age for parents to tell children is around 7 years old (Sydsjo et al., 2007). Regardless of advice from health professionals, those parents who choose to tell their children about the child's genetic origin do so at a variety of ages. Some parents chose to tell children when they asked pertinent questions, rather than trying to estimate an appropriate age (Lindblad et al., 2000). Other parents surveyed in the existing literature said they plan on telling children at a specific age, ranging from birth all the way to age 18. Overall, although the actual age parents choose to disclose fluctuates, the common advice from infertility specialists given to parents of donor offspring is to tell children as early as possible because they are more likely to react positively during childhood than they would if the disclosure were made during adulthood (Scheib et al., 2005; Sydsjo et al., 2007). On the basis of this suggestion, similarities can be drawn with the adoption literature. Similar to the state of secrecy about donor status now, adoption was once shrouded with secrecy (Berge et al., 2006). However, in the past two decades there has been a shift toward open adoptions and openness in adoptive families early in the child's life because of the benefits of such openness in the family (Berge et al., 2006). If families

brought together through ART are on a similar trajectory as adoptive families, eventually parents will realize the potential benefits of openness about the child's genetic origins.

Another commonly discussed topic in the existing literature is how parents actually make a link with children about their genetic origins, if and when they decide to do so. Parents in two studies suggested that they use books to make the disclosure to their children (Hargreaves & Daniels, 2007; Kirkman, 2003). According to parents in Kirkman's (2003) study, books allow parents to make disclosures at their own pace and allow children to take an active part in building their donor narrative and personal identity by reading along and asking questions. Parents in another study said they used analogies such as comparing their use of donor gametes to donating blood (Lycett et al., 2005). A common mistake that parents seem to make is to assume that the disclosure of a child's donor status to the child is a onetime event. Instead, making this link with a child and managing the privacy boundary around this private information is likely a lifetime effort for families conceived through ART, especially families conceived using donor gametes.

Outside family. Making links and managing privacy boundaries with individuals outside the immediate family (e.g., grandparents of the child, friends, medical professionals) also appears in the existing literature and is an important line of inquiry in understanding how families created through ART coordinate privacy boundaries. The statistics cited earlier in this article show that most parents choose not to tell their children of their donor status; however, the existing literature shows that most parents do tell others about their decision to pursue ART. Several studies have shown disclosure rates of 59% to 88% of the child's donor status to individuals outside the immediate family unit (Golombok, Lycett et al., 2004; Gottlieb et al., 2000; Greenfeld & Caruso Klock, 2004; Lycett et al., 2005). Parents reported telling close family (e.g., the child's grandparents, aunts, uncles), friends, health professionals, teachers, work managers, and babysitters about their donor conception (Kirkman, 2003; Lycett et al., 2005). Even youths who knew about their donor conception reported telling family members and friends closest to them (Scheib et al., 2005). When asked about why parents chose to disclose this private information to confidants outside the immediate family, many said they did so because they needed the support (Greenfeld & Caruso Klock, 2004).

However, although many couples chose to tell confidants outside the immediate family, boundary linkages for some parents were still very controlled. In one study, 64% of couples who had told an outside confidant said that, if given the chance to do the process over again, they would not tell others about their decision to use donor gametes (Greenfeld & Caruso Klock, 2004). In another study, many couples chose not even to tell grandparents of the conceived child. According to Golombok, Murray, et al. (2006), only half of DI parents were open about the donor conception to maternal grandparents and less than one third told paternal grandparents. These results indicate that, although some couples are likely to link boundaries with confidants outside the immediate family, others still choose to tightly coordinate privacy boundaries and make few, if any, boundary linkages regarding information about their donor conception.

Donors. Another important boundary coordination issue involves boundary coordination with the donors. Some parents automatically link boundaries with donors by choosing nonanonymous or known donors. Increasingly, couples choose known or nonanonymous donors who are open to being contacted when the child reaches maturity so that they know the child will have the option of knowing his or her genetic origins (Kirkman, 2003). However, some couples (and children) prefer not linking boundaries and keeping the donor anonymous. According to a study conducted by Craft (2005), 53.5% of donor recipients would not have participated had the donor not been anonymous, whereas 96.5% would receive anonymously donated eggs again. According to Vanfraussen et al. (2001), 54% of donor offspring prefer keeping their donors anonymous, compared to 46% who wanted to know more about their donor.

Expectations of boundary linkages between donor families and donors have been extensively discussed by parents and children. When parents and children hope for boundary linkages with their anonymous or nonanonymous donors, they typically hope for more minor information than is commonly assumed. Children hope for a picture of the donor, information about the donor's current circumstances (e.g., what the donor is doing, whether the donor is married and has children of his or her own), the donor's feelings about being contacted, information about the donor's health and family history, and information about relatives (Scheib et al., 2005). Most children did not imagine developing a parent-child relationship with their donor but rather imagined being friends, something like having an uncle, or even just being able to identify the donor as his or her genetic parent (Scheib et al., 2005).

Although children might not want to link boundaries with the donor in a parent-child relationship, studies show that they do often want to contact the donor. According to Scheib et al. (2005), 82.8% of youths thought they would like to make contact with their donors. In a study investigating nonanonymous donors, 89% of mothers, 38% of fathers, and 78% of children had seen the donor at least once every 3 months in the previous year (Golombok, Murray, Jadva, Lycett et al., 2006). Overall, although many children with nonanonymous donors choose to make the boundary linkage with their donor, just as many choose not to do so. At this point, empirical research has yet to show either advantages or detriments of making this link with donors.

Boundary coordination and making boundary linkages in families created through ART is very complicated and involves a great deal of thought and consideration. Parents must decide whether to make links with the child, outside family members, friends, and even how to deal with linkages with the donor. When making these decisions, parents must take into account how likely the confidant is to tell other, inappropriate confidants their private information. Often rules of boundary linkages between individuals are not made clear and can lead to significant problems between the individuals involved in the boundary linkage. The following section discusses what can happen when boundary coordination is unsuccessful.

Boundary Turbulence

A final concept of CPM theory to be discussed in this article is boundary turbulence. According to Petronio (2002), when people are unable to collectively coordinate the permeability, ownership, and linkages of their privacy boundaries, boundary turbulence can occur. Boundary turbulence occurs, for example, when a confidant commits an unintentional rule violation, meaning that he or she discloses private information without permission but without harmful intent. Boundary turbulence can also occur when privacy rules and boundaries are unclear, when two people have dissimilar boundary orientations, or when a confidant intentionally discloses another's private information (Petronio, 2002). According to existing literature, families created through ART are centrally focused on secrecy and privacy. Because of this emphasis on secrecy, these families must also deal with possibilities of boundary turbulence among parents, children, friends, family, and donors.

Although little existing research specifically addresses boundary turbulence in families, much of the research addresses parents' motivations to reveal or conceal information about their child's genetic origins because of a fear of the potential for boundary turbulence. Boundary turbulence is a significant fear for families created through ART, especially for parents. Regulating boundaries about a secret as life altering as a child's genetic origin is a situation fraught with chances for boundary turbulence. In one study, parents' fear of their children finding out their genetic origin was so great that they refused to even conduct telephone interviews with the researchers (Golombok, Murray, Brinsden et al., 1999). Parents in these families, and sometimes even children, fear the kind of consequences that may occur if an inappropriate confidant becomes a co-owner of their private information or if a co-owner other than themselves discloses the private information to others. In the existing research, parents describe their fear of boundary turbulence based on issues of rule violations, dissimilar boundary orientations with others, and problems with ownership rights.

According to existing research, parents of children conceived using ART often make disclosure decisions on the basis of the fear of children finding out about their conception from someone other than the parents (Greenfeld & Caruso Klock, 2004; Kirkman, 2003; Lycett et al., 2005; MacCallum et al., 2007). According to CPM, disclosures such as these could be classified as either accidental or intentional rule violations, depending on the intentions of the person making the disclosure. As discussed earlier, between 59% and 88% of parents have disclosed the child's donor status to individuals outside the immediate family unit (Golombok, Lycett et al., 2004; Gottlieb et al., 2000; Greenfeld & Caruso Klock, 2004; Lycett et al., 2005), which means that these parents are vulnerable to the possibility that these individuals will tell the child without the parents' consent. Whether one of these co-owners tells the child by accident or intentionally because he or she feels like the child should know, this individual creates boundary turbulence by committing rule violations.

Families created through ART may also experience multiple problems with dissimilar privacy orientations, which can lead to boundary turbulence. In other words, different individuals involved in the disclosure decisions regarding a child's genetic origins may perceive different privacy rules regarding making disclosures. Parents, children, other family members, friends, and even donors may have perceptions about how permeable the privacy boundaries should be, which may differ from the perceptions of others involved in the decision. An example of inconsistent boundaries occurs when parents, children, and nonanonymous donors try to negotiate privacy rules permitting children access to information about their donor or even access to the donor themselves. According to one study, boundary turbulence may occur in families because children want more information about their donor, whereas parents prefer that the donor remain anonymous (Vanfraussen et al., 2001). These families experience boundary turbulence because of an inability to create similar privacy boundaries. Children wish to have more permeable boundaries, whereas their parents wish for more impermeable boundaries. Similarly, when donors are nonanonymous, unless strict rules are set up in terms of the role the donor will play in the child's life, parents can experience boundary turbulence as a result of intrusion or an overbearing presence by the donor (Riggs, 2008). Another example of dissimilar boundary orientations occurs when children are co-owners of information regarding their genetic origins and begin granting co-ownership rights with others. Although children might see boundaries around this information as permeable, other family members might see them as impermeable, which might lead other family members to be uncomfortable being the recipients of these disclosures.

According to Scheib et al. (2005), donor offspring from single-parent households experienced more positive reactions to disclosures and discussions about their donor status with both family members and those outside the family than did children from lesbian or heterosexual households. In addition, although youths from heterosexual-headed households did not report experiencing negative reactions, they reported significantly less positive reactions to their conception origin both from their immediate family and from others outside the household (Scheib et al., 2005). Youths from heterosexual-headed households also expected both their birth mother and their paternal coparent (nongenetic father or stepfather) to be less positive than did youths from other households regarding contact from donors (Scheib et al., 2005). This study shows the possibility that children can experience boundary turbulence when they attempt to create their own boundary linkages as a result of dissimilar boundary orientations. Although they want to disclose information about their genetic origins to friends and family members, those confidants (as well as the children's parents) may feel uncomfortable with more permeable privacy boundaries.

Families created through ART may also experience problems with boundary turbulence as a result of unclear ownership rights. The issue of exactly who owns the information about a child's donor status can often conflict with the moral issue of who should own information about a child's donor status, which in turn can lead to problems regarding who has a right to disclose the information. In the existing research, parents often feared that by not disclosing a child's genetic

origin, they were depriving the child of vital information such as access to information about the child's donor and advances in medical technology that might help the child make better medical decisions (Golombok, MacCallum, Goodman et al., 2002). If the child later finds out the truth, he or she might feel betrayed by the parents, or feel that he or she had the right to own this information, which in turn can create boundary turbulence. Parents' fear of this type of boundary turbulence is not without merit. According to Turner and Coyle (2000), adult children who were told about their donor status as adults felt a significant decrease in relational satisfaction with their parents because they felt they were lied to their entire lives. Adult children who find out their donor status later in life may feel a great deal of anger toward their parents as well for not telling them earlier about their donor status (Kirkman, 2003). Not finding out about their donor status until later in life often caused these adults to have problems with their identity, which they attributed to their mistrust of their parents (Turner & Coyle, 2000).

Overall, boundary turbulence, or more accurately, the anticipation of boundary turbulence, plays a very important role in the disclosure decisions in families created through ART. Disclosure decisions in families created through ART might lead to boundary turbulence through rule violations, dissimilar boundary orientations, and problems identifying who owns private information. Because of the highly secretive nature of using methods of ART such as surrogacy and donor gametes, boundary turbulence is an area of research that should be expanded in the future to investigate the possible consequences of inappropriate or untimely disclosures in families created through ART rather than just focusing on speculation about potential problems with boundary turbulence.

Implications for Future Research

A great deal of research investigating families created through ART, particularly through the use of donor gametes, exists despite the fact that most ART procedures are relatively new. Although no research has explicitly addressed issues of privacy or boundary management, the importance of secrecy and privacy is a strong underlying theme throughout much of the existing research. In this theoretically driven literature review, those themes were brought to the forefront by examining the existing literature on families conceived through ART using CPM theory, which focuses on privacy and how privacy boundaries are formed and maintained. By reviewing the existing literature through a privacy lens, we have shown some of the important issues of privacy and boundary management faced by families created through ART, such as deciding who controls and owns knowledge of genetic origins, which risks and benefits are considered before disclosing, how boundary linkages are made or avoided, and issues of boundary turbulence in these families. However, although the existing literature has investigated many elements of families created through ART, some significant gaps in the research still exist.

First, many studies suggest that children conceived through ART are no different, developmentally, than naturally conceived children. This may be true, but the fact that close to 80% of participants in most studies had not yet told the children of their donor status makes these claims questionable at best. It makes intuitive sense that children with no knowledge of their donor status would not experience developmental differences from naturally conceived children. However, without investigations of the development of children who have knowledge of their donor status, it is problematic to make claims about how being a product of ART affects a child's development.

Second, although several studies examined adolescent children and adult children, most participants were parents of children age 3 and younger. When trying to understand how disclosure and knowledge of donor status affect children, researching parents of children age 3 and younger will not provide much insight given the children's relative lack of cognitive ability to understand their donor status and its implications. The relative lack of studies on adolescents and adult children conceived through ART, specifically through donation, might be attributed to the fact that the procedures are relatively new; however, as children born from these procedures reach adulthood, more of them need to be studied to get a better understanding of how their donor status has affected their lives. Of course, the fact that it seems that most parents are not telling their children about their genetic origins makes studying these children even more difficult.

Third, although privacy and secrecy are important underlying issues in the existing literature, they are currently not explicitly examined in the process of how families manage disclosure and discussions about the use of donor gametes. The existing literature focuses strongly on child development and marital stability in families created through ART while barely grazing privacy concerns. Several researchers have discussed the importance of privacy and secrecy in making decisions to disclose the child's donor status to the child, but no study has empirically investigated discussions about and disclosures of private information related to the method of conception used by the family. If researchers are to claim that privacy in families created through ART is important and relevant, they need to empirically investigate how privacy affects these families.

Each of the three aforementioned gaps in the existing research on families created through ART comes with a call for further research. Although it is important to this area of research to investigate a broader age range of children conceived through ART and to study children who are aware of their donor status, perhaps the biggest area of concern for future research lies in empirically investigating the role of privacy and privacy boundaries in families created through ART. Within a CPM framework, scholars need to focus on explicitly studying how privacy boundaries affect families created through ART. Studies investigating how parents create privacy boundaries, whom they let in and whom they keep out, when and why they choose to make disclosures, how they cope with boundary turbulence when and if it occurs, which criteria they use to make decisions regarding disclosures, and how they coordinate privacy boundaries are all

viable areas of further inquiry that could shed light on how parents deal with privacy in families created through ART. Scholars should also investigate how children, donors, immediate family members, and friends navigate privacy concerns in these families, as these are all important considerations when constructing and maintaining privacy boundaries.

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