An Auto-Ethnodramatic Study of the Lived Experiences of Becoming a Mother Via Anonymous Egg Donation

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Abstract

This auto-ethnodramatic study investigated the experiences of becoming a mother via anonymous egg donation. Few studies have explored the experience of women who become pregnant with donor eggs; women who both embody and disrupt the dominant narrative of motherhood by not being genetically related to the children they nurture. The study presents vignettes informed by performance practices and auto-ethnography that interrogate my struggles as the recipient of donor eggs, including: travelling for fertility treatment in the United States where egg donors are paid, in comparison to Canada where remuneration beyond basic expenses is a criminal offense; relinquishing my privacy regarding my infertility and use of donor eggs; worrying about the physical/mental health of young egg donors; navigating the rights of donor-conceived children to know their genetic progenitors versus the donor's right to anonymity; and facing the difficult decision regarding what to do with leftover embryos. I drew upon my experience interpreting and performing scripted dialogue as a professional actor, reflexive journaling, personal artifacts and memories, online discussion forums, and the extant literature. Live performance and discussion of personal stories create educational spaces for medical and nursing students and their professors, parents in donor conception support groups, and the general public, troubling social stigmas surrounding women's reproductive bodies, infertility, and assisted reproduction. Respectful, empathetic dialogue can encourage participants to push against the rigid structures of the heteronormative family and discover their own stories of self, family, and belonging. These stories can be used to advocate for more dignified and compassionate practices within the fertility industry for donors, parents, and most especially the children we are so eager to love.

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CHAPTER ONE: INTRODUCTION

“The longing to tell one’s story and the process of telling is symbolically a gesture of longing to recover the past in such a way that one experiences both a sense of reunion and a sense of release” (hooks, 1995, p. 5).

Statement of Purpose

In this auto-ethnodramatic study, I used methodologies of auto-ethnography, performance ethnography, and arts-informed research (Adams et al., 2015; Denzin, 2003; Knowles & Cole, 2008) to identify the experiences of becoming a mother via anonymous egg donation. I gathered data using reflexive journaling, personal artifacts, memories, and cultural sources such as online discussion forums, magazines, plays, films, and scholarly literature. Drawing upon my 30 years of experience interpreting and performing scripted dialogue as a professional actor, and working with the data I collected, I then wrote and performed a series of auto-ethnodramatic (Saldaña, 2011) vignettes to critically interogate and embody my emotional and ethical struggles as the recipient of donor eggs. These struggles include travelling to the United States for fertility treatment where egg donors are paid, contrasted against the Canadian medical system where remunerating donors above basic expenses is a criminal offense; relinquishing my privacy regarding my infertility and use of donor eggs; worry about the physical and mental health of young egg donors; navigating the rights of donor-conceived children to know their genetic progenitors versus the donor’s right to anonymity, and the difficult decision regarding what to do with leftover embryos. Educational implications include the use of auto-ethnodrama in medical and nursing education; knowledge prospective parents and donors might access prior to engaging in fertility treatments with donor eggs, as well as my own lived experience of going through this fertility treatment; the impact on the body medically; as well as ethical and affective impacts and considerations.

Rationale

Despite in vitro fertilization (IVF) with donor eggs being one of the fastest-growing infertility treatments (Orenstein, 2018) in Canada, there remains little information and public discussion about donor-egg conception. “As with any new reproductive technology, it has provoked a torrent of social, legal, and ethical questions about the entitlement to reproduce, what constitutes parenthood, children’s rights to know their origins, and the very nature of family” (Orenstein, 2018, p. 248). The educational value of public discussion of such an intimate and traditionally private topic intrigued me and I wondered how I could contribute to such a conversation. Kirkman (2008) interviewed women who became mothers using donated eggs and found that women experience varying degrees of tension by both embodying (gestating, birthing, and breastfeeding) and disrupting the dominant narrative of motherhood by not being genetically related to the children they nurture (p. 247). As a mother of donor-conceived children, I have lived with and embodied this tension and I wanted to grapple with what might lay beneath it. Bagheri-Lankaran et al. (2016) state that “studies exploring the experience of women who become pregnant with donor eggs have been rare” (p. 63). When I take on an acting role, I embody and perform other people’s words and experiences; I put their intimate, private moments on the stage/screen and in the process, work to create meaning for myself and the spectators. I wanted to turn that process towards my own stories, eliminating the safety net of personal distance from the character (it’s not *me*; I’m just the actor). The goal was to deepen and share my understanding of motherhood via egg donation. I offer auto-ethnodramatic narratives as scripts and performances that are inspired by Denzin's (2003) performance auto-ethnography and Saldaña's (2011) auto-ethnodrama. My scripts and performances take the form of theatrical monologues and dialogues.

In fertility clinics and doctors' offices the focus is on reasoned, quantitative data to help clients make informed decisions. I propose that additional modes for understanding fertility issues through the emotional interplay between performer and audience may result in more embodied understanding and knowledge creation. As Lakoff and Johnson (1999) state, "The mind is not only corporeal but also passionate, desiring, and social. … A major function of the embodied mind is empathic" (p. 565).

This study offers possibilities for multi-modal educational resources for medical students and professors, families considering this fertility treatment option, young adults considering donating their eggs or sperm, and organizations offering peer support groups for persons engaging with the donor conception industry given that the emotional and ethical issues that arise need to be more visible.

Statement of Subjectivity

This thesis is an exploration of my lived, embodied, subjective experiences and so I inevitably bring personal biases to the work. I have the family I yearned for through egg donation so I can hardly argue against it. I hope to contribute conversation about how we can do egg donation better but even that is a subjective yearning. I struggle with my own moral and feminist compass around egg donation, so when I argue for more ethical treatment of donors and donor-conceived children, I am in some way soothing my own anxiety about whether I have caused unintended harm to my donor or to my children.

Other recipient parents, donors, and donor-conceived people may feel wildly different than I do based on their own unique lived experiences, morals, values, faiths, and cultures and their stories are equally valuable and necessary in ongoing conversations.

Statement of Privilege

I am a cisgender, White, middle-class woman and that has afforded me certain privileges. I have not had to defend my partnership or parenting abilities the same way LGBTQ2+ couples or single parents do. Egg banks and fertility clinics usually have a large pool of White and Asian donors to choose from, but Black and Latina donors are often underrepresented (Daniels & Heidt-Forsythe, 2012, p. 729). Having a large pool of donors to choose from allowed me to choose a donor who had similar ancestry to mine and her reasons for donating also appealed to me on a personal level. Such luxury of choice is lacking for women of colour. Angela Hatem (2020), in an article for *Insider*, tells the story of an African American woman who wanted to find an African American egg donor; when she narrowed her search by race, she found only two potential donors compared to the 50 White women found in a similar search (para. 16). Although I couldn’t use my own eggs, I did have the privilege of being able to carry my babies, and pregnancy within a heterosexual partnership gave me the option of not disclosing the use of a donor, while same-sex couples and single parents have to decide how they might approach this issue. As a middle-class person, I had savings in the bank and access to credit. Fertility treatment is expensive in both Canada and the U.S. and the ever-increasing costs make it inaccessible to people in lower socio-economic groups, often disproportionately comprised of minority groups and communities of colour. This can play out in different ways; people may choose to travel beyond North America for treatment and make unwanted compromises, such as whether the donor is anonymous or open to contact, what information they can receive about the donor, and any knowledge of how/if she received counselling or was at risk of coercion. They may risk the wait for donated embryos or feel forced to accept life without children because any kind of fertility treatment is financially out of reach.

By naming and discussing privilege, especially with people who share the same kind of privilege, I hope to approach what Nixon (2019) calls critical allyship, learning from and working in solidarity with historically marginalized groups to actively resist systems of inequity (p. 8).

Definition of Terms

The following terms are used throughout the document and have the meanings set forth below.

Third-Party Reproduction

According to the American Society for Reproductive Medicine (ASRM, n.d.-b), third-party reproduction "refers to the use of eggs, sperm, or embryos that have been donated by a third person (donor) to enable an infertile individual or couple (intended recipient) to become parents" (para. 1).

In Vitro Fertilization (IVF)

Huang and Rosenwaks (2012) state that IVF is the most common procedure of assisted reproduction technology (ART) and involves

> controlled ovarian hyperstimulation … to stimulate ovarian follicle development, followed by transvaginal oocyte retrieval, fertilization of the oocytes with sperm in vitro, culture of the resultant embryos and transfer of the embryo(s) to the

> recipient. An important innovation in ART is the fertilization of eggs via intracytoplasmic sperm injection (ICSI). (p. 778)

Egg Donation

The ASRM (2016) defines egg donation as one woman giving her eggs to another woman to allow the recipient woman to have a baby. Egg donors must undergo part of the IVF processes described above; she is

> given medications that will cause her to develop multiple eggs over a single cycle. The eggs are then removed from the donor by placing a needle that is attached to an ultrasound probe through the vaginal tissues. The eggs are then gently aspirated (suctioned) from the ovaries. (ASRM, 2016, para. 1)

Known Donor

Discussing the different types of donor arrangements, Rachel Gurevich (2020) defines a known donor as someone you know personally: “They may be a friend, a relative, or an acquaintance. Unlike other donor arrangements, the person isn’t found through an agency or fertility clinic” (para. 12).

Anonymous Donor

Gurevich (2020) describes an anonymous donor as a donor whose identifying details are not revealed as there is not to be any contact between the donor and the recipient. Anonymity was once considered the ideal arrangement but can no longer be guaranteed due to the ease of genetic testing kits. Also, we now know that many donors, recipients, and donor-conceived children are curious about and even long to connect with each other.

In an anonymous donor arrangement, the agency or clinic will offer information on the donor profile that can help the intended parents choose a donor, such as medical and family history, cultural or religious background, profession, and hobbies. It is expected that this information will not be used to locate the specific donor. The donor typically receives no information about the intended parents or the outcome of their donation (Gurevich, 2020).

Open ID Donor

In a study on open-identity within sperm donation, Ravelingien et al. (2015) describe open-identity donation as an arrangement where donor-conceived people can ask for and receive identifying information about their donors once they reach the age of maturity, usually 18 years old. Contact is to be initiated by the donor-conceived child, not the donor or the recipient parent(s) (Ravelingien et al., 2015)

Intended/Recipient Parent

A recipient parent is the person who receives eggs/sperm/embryos and intends to raise the child or children created. Law Insider (n.d.) defines an intended parent as "an individual, married or unmarried, who manifests an intent to be legally bound as a parent of a child conceived by assisted reproduction" (para. 2).

Gamete

"Gametes are an organism's reproductive cells. They are also referred to as sex cells. Female gametes are called ova or egg cells, and male gametes are called sperm. … Each cell carries only one copy of each chromosome" (Nature Education, n.d., para. 1).

Embryo

Encyclopedia Britannica (n.d.) defines an embryo as:

> The early developmental stage of an animal while it is in the egg or within the uterus of the mother. In humans the term is applied to the unborn child until the

> end of the seventh week following conception; from the eighth week the unborn child is called a fetus. (para. 1)

Embryo Donation

The ASRM (n.d.-a) defines embryo donation as a

> procedure that enables embryos either that were created by couples undergoing fertility treatment or that were created from donor sperm and donor eggs specifically for the purpose of donation to be transferred to infertile patients in order to achieve a pregnancy or to a researcher to further the study of reproductive medicine. (para. 1)

Blastocyst

According to the Mayo Clinic (n.d.-a), 5 or 6 days after fertilization, “the fertilized egg is known as a blastocyst—a “rapidly dividing ball of cells” (para. 1). A blastocyst has two groups of cells, the inner group of cells becomes the embryo and the outer group will become the placenta (Mayo Clinic, n.d.-a). When eggs are fertilized outside a woman’s body, as in IVF, blastocyst(s) are removed from the petri dish in the embryology lab and placed in the recipient mother or gestational carrier’s uterus in the hopes it/they will implant and continue to develop via pregnancy.

Intracytoplasmic Sperm Injection (ICSI)

Rachel Gurevich (2019) writes:

> During regular IVF, many sperm are placed together with an egg, in hopes that one of the sperm will enter and fertilize the egg on its own. With ICSI–IVF, the embryologist takes a single sperm and injects it directly into an egg.

> Some fertility clinics recommend ICSI for every IVF cycle. Others reserve the treatment for those with severe male infertility or another medically indicated reason. (paras. 2–3)

Ovarian Hyperstimulation Syndrome (OHSS)

According to the Mayo Clinic (n.d.-b), ovarian hyperstimulation syndrome is:

> An exaggerated response to excess hormones. It usually occurs in women taking injectable hormone medications to stimulate the development of eggs in the ovaries. Ovarian hyperstimulation syndrome (OHSS) causes the ovaries to swell and become painful…
>
> Treatment depends on the severity of the condition. OHSS may improve on its own in mild cases, while severe cases require hospitialization and additional treatment. (paras. 1, 3)

Personal Ground

I always wanted to be a mother. My partner during my most fertile years, however, did not want to be a father. We put off any attempts to get pregnant until he felt ready, building our separate careers in the meantime. I was 36 when we began trying in earnest. We produced 3 years of monthly failures, countless inconclusive tests, and a diagnosis of unexplained infertility. The day I broached the topic of fertility treatment, my partner looked at me with such terror that I dropped the subject immediately. Over the next year, as our marriage disintegrated, he confessed that he had never wanted children. My monthly failures had been a relief for him. When we divorced, I was tired, depressed, and uninterested in pursuing single parenthood.

I met my current partner on a television show where we played a couple in the last throes of their unhappy marriage. While we were melodramatically battling each other onscreen, off screen we were falling deeply in love. He too had always wanted to have children and, like me, had spent the better part of two decades in a relationship with someone who did not.

In 2008, we consulted a Canadian fertility clinic and after extensive testing the doctor confirmed that I did not have the ovarian reserve necessary to conceive. My chances of becoming pregnant with or without IVF were less than 1%. If we wanted to have a family, we had two options; adoption or attempt IVF with donor eggs. The clinic explained to us that while egg donation is legal in Canada, it is illegal to pay donors or a person acting on behalf of a donor. Violations can result in a jail term of up to 10 years and/or a fine of up to $500,000 (Assisted Human Reproduction Act, 2004).

The Canadian clinic told us they could only provide donor egg IVF services if the donor was (ideally) someone we knew who would donate altruistically. We didn't know anyone suitable and even if we had, Canadian law in 2008 was unclear whether the donor had any parental rights or responsibilities. The clinic went on to explain that they had a professional relationship with a fertility clinic in the United States where the laws were significantly different. Egg donors are compensated above and beyond their medical expenses and clinics often encouraged anonymity between donors and recipient families. Donors waived any parental rights to embryos or children created from their donated eggs and anonymity was also thought to protect donors from future financial claims. My first reaction to egg donation was "no thanks"; it all sounded a little too *Handmaid's Tale* for me and I was not eager to inhabit the character of Serena Joy in Atwood's (1985) dystopian novel in my personal life. We decided to explore adoption.

We attended an adoption educational meeting provided by Family Services of

Greater Vancouver (FSGV) and left feeling very overwhelmed by the lengthy process and high price tag of international adoption. FSGV has since closed its adoption agency due to a steep drop in international adoptions citing the high cost (upwards of $80,000), changing regulations in other countries to favour local adoptive families, and concerns about child trafficking (Lindsay, 2018). Adopting a local infant also had a potentially long timeline; the growing acceptance of single parenting meant more birth parents were choosing to raise their children themselves and if not, they would likely have several hopeful adoptive families from which to choose (Adoptive Families Association of BC, 2021). By now I was 43 and uncomfortable accumulating debt, hoping for a child that may never come. We grieved. We bought a dog. Then my 46-year-old girlfriend got pregnant (with her 59-year-old boyfriend) and joyously birthed a healthy baby girl. It became clear that the dog, as lovely as he was, was not enough. “What are you waiting for?” my friend asked as she handed me my new Goddaughter; “go find an egg donor!” We made an appointment with the U.S. fertility clinic to learn more about egg donation. That first meeting completely changed how I felt about egg donation and I left the building with a sense of hope I hadn’t felt in years.

CHAPTER TWO: LITERATURE REVIEW

This literature review focuses on issues/themes that I found “sticky” and unresolved as I reflected on my egg donation experience. Such issues and themes included: paying donors; donor anonymity; whether donor-conceived people have a right to know the identity of their donor or have possible future contact with donors and/or donor siblings; choosing how, when, or if to tell children about their conception; and what to do with surplus embryos.

Legal Aspects of Paying Donors

Canada’s Assisted Human Reproduction Act (AHRA) laws centre on the idea that it is morally repugnant to buy and sell tissues that can create human life—sperm, eggs, embryos—and in the case of gestational carriers, wombs. In the U.S., the egg donation coordinator joked, “this is the United States, we’ll sell you anything” (U.S. Clinic Coordinator, personal communication, November 2008). There is an uncomfortable truth in her jest.

Drummond and Cohen (2014) call for the decriminalization of paying gamete donors in Canada, arguing: “The staggering penal penalty to which parents, physicians, and others are exposed is grossly out of step with current social expectation and moral interest” (p. 208). They suggest repealing the criminal provisions regarding payment of ova providers and thoughtfully regulating third-party reproduction in Canada with non-criminal law instead. Regarding payment, Drummond and Cohen suggest that “the recipients of ova should be positioned to provide fair compensation to ova providers for the services that they render—the rate of such compensation to be driven principally by donors themselves (p. 240).

Baylis and Downie (2014) argue the opposite, saying that financially compensating egg donors should not only remain a criminal act in Canada but that the federal government should enforce the law both domestically and transnationally (p. 180). Drummond and Cohen (2014) respond saying it is the fear of this law, coupled with its "chilling effect on the availability of third-party gametes, that transnational trade in ova exists" (p. 239). I wonder how Baylis and Downie envisage the enforcement of these laws? I imagine a paternalistic special task force, hunting down, imprisoning, and bankrupting potential parents and families—very *Handmaid's Tale* indeed.

Although the AHRA was created with the intention of protecting egg donors from coercion and exploitation, the lack of reasonable payment for donors has effectively coerced some donors into accepting illegal payment in a "grey market" (CBC News, 2014) where the likelihood of being exploited is high. Drummond and Cohen (2014) state that donors and recipients may be too frightened of the potential penalties associated with a breach of the AHRA to be honest with their doctors, legal counsel, and psychologists for fear they have done something illegal. "In the absence of the severe sanctions associated with third-party reproduction in Canada, all parties would have improved access to services, support, and legal remedies" (Drummond & Cohen, 2014, p. 239).

Perhaps Canadian lawmakers are ready to entertain a new discussion. In May 2018, Member of Parliament Anthony Housefather's private members bill C-404 had its first reading in the House of Commons. Bill C-404 would amend the AHRA by decriminalizing payment for gamete donors and clearly defining the reasonable expenses for which donors should receive compensation (An Act to amend the Assisted Human Reproduction Act, 2018). Liberal MP Anita Vendenbeld, at a press conference with

Housefather in March of 2018, said: “I think we need to be clear here that assisted human reproduction is the one area in law where we are still criminalizing women’s bodies and this has to change” (as cited in Aiello, 2018, para. 11).

On April 28, 2019, fertility lawyer Sara Cohen (of Drummond & Cohen) attended my support group for egg donor parents in Toronto for an informal discussion. She told us that without regulated payment for donors, Canada’s donor supply will remain woefully low and intended parents will continue to search for donors in the U.S. and beyond.

Although paying donors may not happen anytime soon, Health Canada has drafted new regulations detailing the exact expenses for which Canadian donors can legally receive compensation. Surrogates and gestational carriers may be reimbursed for lost wages, but egg donors cannot, which troubles me because donors may feel forced to return to work before they are well rested and recovered from any side effects of the hormone regimen and egg-retrieval procedure (Reimbursement Related to Assisted Human Reproduction Regulations, 2019).

Social/Cultural Aspects of Paying Donors

Philosopher Bonnie Steinbock (2004) suggests there is room for compromise between those who prefer an altruistic system of egg donation and those who think egg donors should be paid:

> Rather than paying donors for their eggs, they should be compensated for the burdens of egg retrieval. Making the distinction between paying for burdens and payment for a product has the advantages of limiting payment, not distinguishing

> between donors on the basis of their traits and ensuring that donors are paid regardless of the number or quality of eggs retrieved. (p. 255)

Fair compensation would be preferable to the expectation that women undergo risky medical procedures as a gift to other women, perhaps a subtler kind of coercion, incurring debt for expenses and lost wages in the process. Rethinking egg donation as valuable embodied labour in an industry where all the other actors (doctors, nurses, lawyers, counsellors, embryologists) are being well paid for their work could help shape new approaches to governing egg donation according to Cattapan (2016), who argues that understanding egg donation as work "highlights the potential for egg donors to be autonomous, agentic subjects within exploitative circumstances" (p. 234). This social validation of donors as well as the possibilities it offers for safety and legal protections through more effective regulation "identify how the embodied reproductive labor of egg donation is already embedded in a gendered labor system, and thus requires more than its contemporary and conventional understanding as a mere 'gift' or as a healthcare intervention" (Cattapan, 2016, p. 242).

Rene Almeling (2011) studied the gendered renderings of the U.S. market for eggs and sperm, examining the different experiences of sperm and egg donors. Sperm donors are encouraged to see their participation in the market as a job, one that does not require a social or emotional connection to the recipient. Egg donors, on the other hand, are encouraged to see the donation process as a precious gift, from one woman to another, and the social connection between donor and recipient is nurtured through the entire process, whether the two women ever meet or not. Egg donors are paid to undergo the process of donating, the risk of hormone shots and surgery related to IVF, to help another woman have a baby, rather than the unladylike (and unmotherly) idea of selling their eggs. Sperm donors on the other hand are paid every 2 weeks and sperm quality is paramount. In Almeling's study, the men and women were performing traditional gendered family roles: the men "working" while the women "nurtured." Ironically, many of the sperm donors felt objectified, their bodies commodified, while many egg donors felt valued and proud of giving the precious gift of family. Almeling asks us to look much deeper into the subject of bodily commodification, proposing a "sociological approach to thinking about what happens when people are paid for bodily goods and services" (p. 170). As Almeling puts it,

> First, it is crucial to view commodification of the body as an interactive social process, one that occurs over time between people who occupy particular social locations. This contrasts with the prevailing view of commodification in bioethical writings, which is essentially that of a light switch: once money is exchanged, then there is commodification, and the author does not need to know much more than that to speculate about its objectifying, alienating, and dehumanizing effects. (p. 170)

Feminist economist Julie A. Nelson (2006) sees economic life as one aspect of social life, and argues against the idealistic view that a meaningful social and political life must exist outside of the economy, that market economies are "intrinsically mechanical and demeaning of human subjectivity and personal relationships" (p. 1055). Nelson argues that "The idea that social and cultural life must be protected from money and markets leads, ultimately, to an attitude of victimization" (p. 1071). In Canada, paying egg donors is considered morally reprehensible, implying automatic coercion and commodification. Nelson suggests that

> This attitude does not encourage people to investigate whether specific market

> institutions add to or subtract from human dignity in specific cases because, it asserts, we know a priori that markets always objectify. This attitude does not motivate people to lobby unambivalently for an adequate flow of financial resources to support caring and nurturing work because, it assumes, the entry of money is corrupting. (p. 1071)

In the U.S., where donors are paid, sometimes enormously well, the social element is performed in a different way; caring doctors and fertility counselors help you through the process of paying for someone's eggs. But when the transaction is complete, those social services often evaporate. There is no doubt that many egg donors do feel victimized by their experiences in the egg market, and for this reason social and cultural factors should be deeply studied. Social factors matter, Almeling (2011) insists, such as "the language of the gift which serves to manage the cultural tension of women being paid for eggs that become children and create families" (p. 169) or the place where the money changes hands be it a medical clinic, the black market, or a country with more or less regulation.

Curtis (2010) found that many egg donors are motivated by both altruism and the desire to be paid, and both motivations carry risks, rewards, and protection. For instance, altruism and gift rhetoric encourages donors to care deeply about the family making goals of their recipients, sometimes to the detriment of their own health, in that they may feel that a "good woman" will keep donating until the recipient's family is complete, even though their intention was to only donate once. Being paid may give donors an extra tool to negotiate bodily risk, such as OHSS, by setting limits on how much pain and suffering they will endure and giving them the confidence to openly discuss such pain with their doctors throughout the process of donating. On the other hand, if being paid is constructed as money for time and suffering; donors, especially first-time donors, may feel that suffering is necessary, since they are being paid for it and they may feel coerced to finish the job without complaint (Curtis, 2010, p. 95). Clearly, each circumstance is different and complex and as Almeling (2011) states, “Learning more about how markets work in practice can offer a way out of interminable debates about whether commodification is objectifying or liberating, dehumanizing or empowering, because normative questions such as these cannot be answered a priori” (p. 172).

Nelson (2006) asks:

> Consider this: Which of the following is likely to have more positive results in the complex contemporary economies in which we live, teaching that economic life must be harsh and ugly and that people have no responsibilities to others when acting in their economic roles or teaching that ethical (and even caring) behavior is the responsibility of people and organizations across all spheres of life? To the extent that our academic work has aspects of self-fulfilling prophecy—to the extent that it influences public discourse—the implications of teaching the first theory are chilling. (p. 1071)

Ethics: Donor Anonymity vs. Donor-Conceived Persons’ Right to Know

Countries including Australia, Britain, Sweden, Norway, Italy, and New Zealand have banned anonymous gamete donation due to the belief that the rights of donor-conceived children to access the identity of their donor when they are sufficiently mature overrides the privacy rights of parents and/or donors who wish to keep the donation a secret. Many other countries, such as Spain, the Czech Republic, Greece, India, and Israel offer strictly anonymous donation either by law or by practice. Canada and the U.S. have begun to encourage openness but allow both known and anonymous donation.

Gruben and Cameron (2017) support comprehensive legislation in Canada that would move our third-party reproduction practices towards more openness for three reasons:

> access to ongoing health information for donor-conceived people from gamete donors, the ability of sexually active donor-conceived people to determine if their sexual partner is genetically related to them, and the release of identifying information to donor-conceived people to alleviate the stress, anxiety, and frustration that may be caused by not knowing their genetic origins. (p. 667)

They disagree however, that “anonymous donation is a catalyst for mental health concerns in donor-conceived people” or that donor-conceived people have a right to know their biological progenitor under the Canadian Constitution or international human rights law (pp. 666–667). They argue that it is secrecy; when parents do not tell their children that they are donor-conceived, rather than donor anonymity that causes more direct harm to donor-conceived people and characterizing

> access to the identity of the donor as a “right” fails … to balance other, equally important interests such as protecting the privacy of women who become pregnant following incest, sexual violence or sexual relationships outside of common law or marriage relationships. (p. 667)

Law professor and ethicist Margaret Somerville (2006) argues the opposite—that children’s right to know their biological parents is a fundamental human right, and as humans unlike other animals, we need to know our biological relatives because it is central to how we form our human identity and our sense of belonging within humanity (p. 154). Somerville states that new reproductive technologies, such as egg and sperm donation, unlink child–parent biological bonds (p. 147) and that

> any benefits provided by modes of transmission other than sexual reproduction are far outweighed by the risks and harms—not only to the resulting child, including but not limited to physical risks, but also to our sense of what it means to be human, how we find our own identity and meaning in life, and to the meaning we attach to passing on human life to the next generation in the way it was passed on to us. (p. 140)

Somerville's argument privileges the traditional heteronormative family, implying that children who are brought up by single parents or LGBTQ2+ parents are being physically and psychologically harmed.

Leighton (2013) states that the right-to-know argument, although intended to put the best interests of donor-conceived children ahead of parental or family privacy, can be harmful, in that "the claim that we have a right to know genetic relatedness is linked to the claim that family-making should be done through biogenetic reproduction" (p. 54). Therefore, when heterosexual couples keep their mode of conception secret so that they can pass as "normal" or "natural," they "contribute to the power and intelligibility of the claim that genetics—not love, or trust, or parental care—is what makes a family" (p. 55). Leighton argues that "If we are to promote true pluralism when it comes to family making, we cannot even indirectly support the view that people have a right to know to whom they are related by genetics" (p. 55).

Ravitsky responds to Leighton: "The literature and advocacy in favor of a right to know is *not* based on normative assumptions that favor genetic relatedness as a better basis for family life" (Leighton & Ravitsky, 2014, p. 6). Ravitsky agrees that having some degree of knowledge of our genetic progenitors contributes to our sense of personal identity, but states that this knowledge is not "more or less valuable than other elements that shape our identity (such as family and cultural environments). But it does justify protecting our ability to have access to this type of information" (Leighton & Ravitsky, 2014, p. 6).

Immaculada de Melo-Martin (2016) discusses the difference between Spain, a country that only allows anonymous gamete donation, and the U.K., a country that entirely prohibits it, asking which system best protects the vital interests of donor-conceived individuals. Vital interests that may be damaged by donor anonymity include strong family relationships, health interests, and the formation of a healthy identity. Critics of anonymity say these interests are given less priority than the privacy of donors and intended parents. In terms of family relationships and the damage that keeping secrets can do therein, de Melo-Martin agrees with Gruben and Cameron (2017), stating that it is not donor anonymity by itself that is responsible for the damage to family relationships; many parents choose not to disclose the existence of a donor to their children, even if that donor is willing to be identified. Neither Spain nor the U.K. mandates or prohibits disclosure although both encourage it and if parents and donors in the U.K. prefer anonymity there is nothing stopping them from travelling abroad for treatment. de Melo-Martin (2016) finds it is the desire, particularly among heteronormative families, to pass as normal that is the biggest barrier to disclosure and

> effecting cultural and social changes that contribute to ensuring the equal status of

> all families and moving towards a debunking of the normative force of the biogenetic family might go a long way towards increasing the rate of disclosure following both anonymous and non-anonymous donation. (p. 103)

Lack of disclosure more than anonymity can also create problems for donor-conceived individuals to access important health information. Parents who do not disclose are not likely to share any medical family history or information they have been given about the donor. Both Spain and the U.K. have policies that are consistent with donor-conceived individuals having access to the medical history of the donor, but better methods need to be implemented to ensure that donor-conceived people have access to relevant updated donor medical information. de Melo-Martin (2016) suggests that promoting policies such as donor registries could help to safeguard the health interests of donor-conceived people by safeguarding their ability to obtain genetic information about their donors; information can be shared via registries whether the donor is anonymous or not (p. 105).

In terms of donor-conceived people being able to construct healthy identities, de Melo-Martin (2016) points out that if a personal relationship with one's donor is pivotal to healthy identity then anonymity may be harmful in that it gets in the way of being able to identify and create a relationship with the donor, but if a healthy identity is conceived of as purely genetically produced, then perhaps "disrupting and challenging this ideology … might be a good way to protect the legitimate interests of donor-conceived individuals" (p. 106).

Petra Nordqvist and Carol Smart (2014) studied heterosexual and lesbian couples who built their families through sperm and egg donation. In their book *Relative*

Strangers, they introduce the study participants as unwitting pioneers because they opted for donor conception "at a time when public policy on issues of donor anonymity was changing but had not settled into a generally accepted pattern"; they began the process "just as popular discourses around the importance of genes and genetic connections reached a kind of zenith" (p. 4).

The parents in Nordqvist and Smart's (2014) study were all born between 1956 and 1986. I was born in 1965 and found my experience to overlap that of their participants in many ways. Nordqvist and Smart state Western societies have undergone "a kind of 'geneticisation' of the popular imagination, such that now genes are increasingly believed to be of overwhelming significance in every aspect of life" and "the idea that it is important to know precisely who one's genetic progenitors are has really gripped the popular consciousness" (p. 4).

Campaigns to end donor anonymity focus heavily on the idea that personal identity is derived from one's genetic forbears and transported down the generations, and "it is implicit in the argument that full ontological security cannot be truly accessed unless the bearer of the genes is known in person" (Nordqvist & Smart, 2014, p. 24).

> The idea of being embedded in a *proper* genealogical tree, with an *accurate* family history and a *certainty* about who one's biological relatives are, is both comforting and alluring. By comparison, the opposite condition of being denied knowledge of one's origin can clearly give rise to a strong sense of dislocation and uncertainty. (Nordqvist & Smart, 2014, p. 24)

Nordqvist and Smart (2014) argue, however, that this idea "tends to obliterate all the other factors that might contribute to the ongoing construction of personal identity"

(p. 25). A person’s family life provides many sources of identity construction: social class, ethnicity, religion, cultural values, education, place, birth order, being an only child, a twin, and so on. Once we start to understand identity in these more complex terms, we also begin to understand that identity is relational, “it ebbs and flows and changes (imperceptibly perhaps) in relation to the people one relates to in different contexts over time” (p. 25). Such relationships begin with family members and then widen to the playground, university, work, et cetera. Nordqvist and Smart suggest that it is family practices that create relatedness. In most families, this sense of relatedness and belonging maps onto genetic kinship or it appears to. This has “led to an understanding that biological or genetic links automatically give rise to a sense of bonding and belonging” (p. 27). While family practices and genetic kinship are clearly entangled, it is important to distinguish between them because in the fields of donor conception and adoption,

> there is a tendancy for some of the more populist arguments to sweep aside all the evidence that exists on the importance of family practices in order to focus solely on genetic links, as if all the work that families do to create belonging, connectedness, biography and bonding is superfluous. (Norqvist & Smart, 2014, p. 27)

de Melo-Martin et al. (2018) studied the role of anonymity for oocyte donors and the reasons why it was important to them despite the current trend towards more openness in gamete donation. Egg donors who desired anonymity felt it relieved anxieties about family structures and obligations for both themselves and the recipient and protected them from future financial or emotional claims from the donor-conceived child (pp. 241–242). Donors acknowledged potential harm to donor-conceived children if children desired a relationship with them in the future which they may not reciprocate (p. 243). This is a worry I share. de Melo-Martin et al. suggest that the ease of direct-to-consumer genetic testing kits has made it easy for donor-conceived individuals to find information about their donors, their donors' family, and even the donors themselves online; therefore donors should be clearly informed and counselled regarding this future possibility (p. 246).

Anonymity can no longer be taken for granted, but the reasons that donors and recipients desire anonymity are important for future research into best practices and policies. Stuart-Smith et al. (2012) found that moms who chose anonymous donors over known donors were "motivated by a wish to feel secure in the role of mother as well as to avoid possible intrusions into family relationships" (p. 2067). Many women come to egg donation feeling insecure about who the "real" mother will be. Using another woman's eggs is not an option we consider without first struggling through years of physical, psychological, and financial losses due to illness or infertility.

Madeline Feingold (2002), a clinical psychologist and specialist in reproductive medicine, states: "Couples are so traumatized by the losses associated with their infertility, that they often guard themselves from the prospect of another loss" (p. 5). When we are presented with the high success rates of egg donation, we often tend to put any troubling ethical dilemmas, such as donor anonymity, aside until after that long-sought-for pregnancy is achieved. We are busy grieving the child we thought we would have and struggling to embrace hope for a different child.

It is interesting to note that cis-gender persons arrive at third-party donation feeling like they have culturally and physically failed whereas LGBTQ2+ couples and single parents by choice arrive with a sense of hope and excitement because these reproductive technologies give them opportunities to build the family they want (Nordqvist & Smart, 2014, p. 46). In Nordqvist and Smart's (2014) study, many of the lesbian couples wanted their children to know who their sperm donor was as long as "their family unit was protected against undue interference" (p. 46). Lindsay King-Miller (2018) writes about donor conception and anonymity from the point of view of queer, trans, and gender non-conforming parents and discusses the difficulty of feeling confident that their family unit has that protection:

> While straight couples using donor gametes are generally presumed to be their children's biological ancestors and can chose to elide their use of a donor, queer parents are faced with the necessity of defending our parental roles on a daily basis. While our rights as LGBTQ parents and families are still new and precarious, it feels safer to keep the donor as abstract and distant as possible. (para. 14)

In 2009, when my children were conceived, the law was clear in the U.S.; children born through anonymous donation did not have the right to information or records on the donor that their parents utilized (Egg donor coordinator, personal communication, March 3, 2009). Two years later, in 2011, Washington State become the first American jurisdiction to chip away at donor anonymity with a new law giving donor-conceived people the right to their donor's medical histories and full names when they turn 18.

The ASRM thinks Washington State is intruding on donors' privacy: "We think families and donors ought to be allowed to make decisions in terms of anonymous vs.

non-anonymous donation. We don't think we know the answer to that question, and we certainly don't think states know the answer" (as cited in Rochman, 2011, para. 8). However, this right to identifying information about a donor is not facilitated by fertility clinics unless the donor choses to allow it. At the time of their donation, they can declare themselves open for later contact or closed. If they are closed, the clinic will not give a child any identifying information about them.

Fertility clinics, agencies, and egg/sperm banks in the U.S., according to Johnson (2013), "actively shape expectations and manage relationships between donors, recipients, and donor-conceived children" (p. 70), a process she refers to as organizational boundary work. Clinics must balance the industry tension between the children's need to know their donor, the donor's right to privacy, the donor's need to be morally recognized, and the recipient families' right to privacy and integrity (Johnson, 2013, p. 70). Parents, donors, and donor-conceived children who want to connect often need to go around the clinics and turn to online sibling and/or DNA registries.

Disclosure

Anonymous or not, one of the first ethical questions egg recipient mothers need to think through is whether they will tell their children about the egg donor. Despite their connections, anonymity and disclosure are separate issues; anonymity can be regulated against but "worries about lack of disclosure will require other types of solutions such as counselling or removing barriers that make disclosure difficult for parents of donor-conceived individuals" (de Melo-Martin et al., 2018, p. 236).

The documentary film *Father Mother Donor Child* (Arlamovsky, 2017) points out that excepting adoption, a social parent and genetic parent were traditionally one person and third-party reproduction has created a divide in these two roles, which lack of disclosure can hide. The egg donor coordinator at our U.S. fertility clinic cautioned us that if we were not going to tell our children they were donor conceived, then we would be wise not to tell anyone at all, so that the children would not find out inadvertently from someone other than us. It took me by surprise that in 2009 there were people who thought building their families on this secret foundation was completely reasonable, yet Orenstein (2018) states: “The idea that disclosure could be a viable, even preferable, option is relatively new” (p. 267). In 2018, at a support group for parents via egg donation, I met a young mother who told me she was struggling to decide whether to tell her 2-year-old son he was conceived with a donated egg. Her doctor had encouraged her not to disclose, telling her that the world was not ready, despite her son being conceived 32 years after the world’s first egg-donor baby had been born (Personal communication, 2018).

Greenfeld and Klock (2004) sent questionaires to 524 individuals (262 couples) of which 157 (92 women and 65 men) were returned. The researchers found no difference in plans to inform the child based on the use of a known or an anonymous donor. “Regarding disclosure to the child, the anonymous and known recipients were virtually identical” (p. 1568). In both groups, approximately 10% have told, 49% plan to tell, 31% are not telling, and 10% are not sure (p. 1565) Greenfeld and Klock found that the primary motivator for mothers, whether they were planning to disclose the use of a donor or keep it secret, was concern for their child’s well-being. Women who planned to disclose felt the child would benefit from more information about the donor, and in some cases, access to the donor, and women who planned not to tell felt that knowledge about the donor would unnecessarily complicate their child’s life (p. 1570). Greenfeld and Klock recommend pre-treatment counselling regarding disclosure for intended parents to “clarify their opinions and to come to a consensus about their disclosure plan” (p. 1571).

The parents who were planning on disclosing were "interested in getting help with the issue of disclosure. They also expressed a need for better educational materials" (p. 1570), such as a children's book.

Since then, many have appeared on the market, including Wendy Kramer's (2018) *Your Family: A Donor Kid's Story* published by the Donor Sibling Registry. I found the book *What Makes A Baby* by Silverberg and Smyth (2013) very helpful. The book does not include information about sexual intercourse or any kind of assisted reproduction although it does create space for the reader to add those details if they want. It introduces the three things you need to make a baby—an egg, a sperm, and a uterus—in a way that is inclusive of all genders: "This is an egg. Not all bodies have eggs in them" (Silverberg & Smyth, 2013, pp. 3-4).

Hershberger et al. (2007) state there is a scarcity of research examining disclosure among individuals involved in gamete donation and most of the limited research has focused on recipients of sperm donation: "Less is known about donor oocyte recipient women, even though the added complexity of obtaining an oocyte donor and the women's ability to experience pregnancy may significantly alter disclosure decisions" (p. 288). Hershberger et al. conducted a qualitative, naturalistic study using a phenomenological approach to obtain a richly detailed narrative account of pregnant donor oocyte recipient women's disclosure decisions and the factors that influenced those decisions. Nine eligible participants contacted the principal researcher, however one removed herself from the study because she was not planning to disclose the nature of the conception to her child and viewed participation in the study as a risk for potential accidental disclosure (p. 289).

The two broad themes identified in Hershberger et al.'s (2007) study were the “overwhelming responsibility to the resulting child, and the women’s attempts to gain control over disclosure about conception” (p. 294). Previous studies have found that the age of the parent is not associated with their decision to disclose or not, but interestingly Hershberger et al.’s study describes differences in the woman’s *reasoning*, “such that younger women fear nonacceptance and stigma because of their diagnosis of infertility, and older women fear nonacceptance and stigma because of their mature status during childbearing” (p. 294). Whether they intended to inform their child about the egg donor depended a great deal on the amount of social and cultural support they felt from their friends, family, and greater community. Some felt that disclosing to the child would bring stigma to the child and others felt that *not* disclosing would bring stigma to their child and their family. The women who intended to disclose to their children were unsure again of how and when to do so and asked the investigator for appropriate information on how to disclose, leading the researcher to speculate that it is plausible that “both undecided and disclosing parents may need more information about how and when to tell their child” (p. 294).

Nordqvist and Smart (2014) explore the reasons some parents choose not to tell their offspring about their donor conception as well as some specific challenges that parents who sought openness faced explaining donor conception both to their children and to members of their families. Nordqvist and Smart begin to “map the terrain that parents who sought openness are negotiating in the absence of an established narrative about donation” (p. 8). Parents who chose not to reveal the donor to their children or their families usually did so for three reasons:

1. A commitment to sharing the information first and foremost with their child when

he or she is old enough to understand because it is the child’s story and he or she should have the right to choose whether he or she shares it with others. This means keeping it a secret until the child is deemed ready and this can create tension within the family (p. 86).

2. Parents and grandparents were concerned about privacy and avoiding social stigma. The conception of children was a private matter and not for public consumption. The lesbian couples in the study did not have the option of keeping the use of donor sperm a secret but some of them still wanted to keep some aspects private, “such as how they conceived or who the donor was” (p. 86).
3. “Third, decisions about non-disclosure were shaped by the complexity of living embedded and connected lives” (p. 86). For example, some parents might not want their child to know but they felt it was important to tell the grandparents who would be part of the child’s life, leading to more people making difficult decisions about how to manage information (pp. 85–86).

Patricia Mendell, a New York therapist who specializes in reproductive issues, says “the reasons people don’t want to tell may come in layers” (as cited in Hass, 2015, para. 24). What she usually hears first is the parents don’t want their child hurt socially, suffer an identity crisis, or get disinherited. Beneath these concerns there are often painful, unresolved issues with their own childhood. A deeper reason is the shame of being infertile. There is also an element of simple self-defense; they fear the day their teenager says, “I hate you, you’re not even my real mom.” A more poignant reason, she reports, is that they fall in love with their baby and want the child to be perfect and their relationship with the child to be normal: “So they want to rewrite that part of the story.

They become convinced it's better for the child not to know the truth" (as cited in Hass, 2015, para. 30). The most politically incorrect reason Mendell believes women want to keep egg donation a secret is that they can't bear to confront their age, especially women in cities like New York and LA: "Not admitting to using a donor is a way to keep up the illusion of fecundity, the ultimate proof that you're still in the game" (as cited in Hass, 2015, para. 31).

Almost every time I stand in line at the grocery store and scan the magazine collection, I see headlines announcing a female celebrity's miracle baby, conceived in their late 40s and even in their 50s. The television and film business is especially cruel to women performers and looking young can still mean the difference between working and not working so I understand why celebrities may not want to discuss donor eggs or infertility. Willson and Goldman (2017) analyzed 416 issues of *US Weekly*, *Cosmopolitan*, and *People Magazine* published between January 2010 and January 2014, hypothesizing that "popular media over-represents celebrity pregnancies surrounding age-related fertility decline" (p. e64). Forty-five women subjects were over the age of 40, and only two of those were mentioned as utilizing assisted reproductive technology (ART) with their own eggs. Donor gametes received no mention. The authors concluded that "magazine content reflects a continued stigma surrounding the use of ART and furthers the public's misconceptions about fertility at advanced reproductive ages" (p. e64).

Maggie Kirkman (2003) conducted research using narrative inquiry exploring parents' contributions to the narrative identity of their donor-conceived offspring, and found that

> Parents are the narrators from whose stories their children begin to construct their

> own narrative identities. … In a culture that elevates genes above all else, children whose family stories include an anonymous donor of gametes or embryos may feel ill-equipped to negotiate an acceptable sense of self. (p. 2231)

Parents in Kirkman's study fell along a continuum, "from omitting any mention of third-party involvement to inclusion of the donor in the story told from birth" (p. 2234). Parents who had no intention of incorporating the use of donated gametes often did not want to incorporate that information into their own narratives, or they were prevented from doing so by a partner who feared their non-genetic child would reject them, and/or they believed the child as well as the parents would suffer negative reactions from society (p. 2234).

In Kirkman's (2003) study, participants in the middle of the continuum grappled with the same issues as the parents who were not disclosing but they also felt that the child had a right to know their genetic history. Parents in this group were leaving the discussion dangerously late because they felt reluctant, confused, and uncertain of how to proceed (p. 2234). Some of them were still struggling to incorporate infertility and the need for a third party into their own stories in a way that was tolerable, the fear of stigma and shame about infertility playing a large role in their discomfort.

For participants in Kirkman's (2003) study who fell into the disclosure group, where donor conception will always be a part of their family story, it seems likely that the parents have been able to revise their own narrative identities and "therefore have the words and some degree of confidence to incorporate the donor into the narratives constructed for their children" (p. 2236). Kirkman concludes that disclosure to children should be encouraged before the children become adolescents.

Carole LieberWilkins (2008), a family and marriage therapist and founding member of RESOLVE, The National Infertility Association, lectures widely on a wide variety of infertility subjects including talking to kids about their unique conceptions. LieberWilkins states:

> To tell a child of age nine or ten, essentially pre-adolescence, that they are not related to or connected to their mother or father in the way that their friends or other family members are related to their parents would be a tremendous shock, indeed perhaps perceived as a betrayal. Speaking about third party reproduction casually, and early often normalizes it. It makes the information simply a part of the family story. (What to Say section, para. 2)

Advocates of early disclosure now suggest talking about the donor in babyhood. “The pre-verbal months provide a perfect opportunity for parents to practice talking to children about their conceptions. Children will pick up on the non-verbal—the touch, the affect, the giggle” (LieberWilkins, 2008, When and How to Talk with Kids section, para. 4).

We told our twins about the egg donor when they were 3 years old and asked, “but *how* did you make us”? It was a very straightforward conversation; they seemed to easily understand that Mama didn’t have any eggs and so a donor gave us some of hers, the doctor mixed them with Daddy’s sperm, and then put them in my belly to grow. I don’t remember if they had specific questions, but they were content with the information offered. As soon as the words were out of my mouth, my anxiety of having the conversation dissolved. The first step had been taken and as they’ve grown, I’ve been able to build an ongoing conversation without feeling overly stressed.

It is not my intention to judge other parents’ disclosure decisions; every family is filled with complex relationships that can complicate the issue and, as Kirkman (2003) states, all of us must develop and negotiate our narratives "within a context of social and political discourses that may be antagonistic, is less likely to be encouraging and will, almost inevitably, be shifting" (p. 2240).

Future Contact and Donor Registries

In 2000, Wendy Kramer and her son Ryan created the Donor Sibling Registry (DSR). The DSR operates from Colorado, USA, but is used worldwide by donor-conceived people, parents, and donors who wish to make mutually desired contact. When Ryan Kramer became curious about his anonymous sperm donor, Wendy helped him research public records and complete a DNA test. In a matter of weeks, they had identified the donor and made contact. The donor was thrilled to hear from them, and they have a very positive relationship now. In a recent podcast interview, Ryan said that because he was told at a very young age about being donor conceived (2 years old), he never felt his identity was incomplete, but he was very curious about his donor, and finding him and having his questions answered brought him an enormous sense of contentment. The ongoing personal relationship that developed is "icing on the cake" (Evans, 2019).

Ryan's experience spurred Wendy on to create the DSR so other donor-conceived individuals could contact half-siblings or donors. The DSR is not a DNA registry but Wendy and Ryan encourage parents to test their children's DNA and join DNA registries such as Ancestry or 23andMe to increase the chances of identifying donor siblings and donors. As of January 22, 2021, the DSR has an international membership of 72,000 donors, parents, and offspring, and has facilitated genetic matches and social connections between 22,000 offspring with their half-siblings and/or their donors. “The DSR advocates for the right to honesty and transparency for donor-conceived people, for social acceptance and legal rights, and values the diversity of all families,” believing that “people have the fundamental right to information about their biological origins and identities” (DSR, n.d.-a, History and Mission section, paras. 1-2.

The DSR conducts research on donor families. Blyth et al. (2013) surveyed 108 DSR parents who had used an anonymous egg donor, either by choice or because anonymity was their only option. They found that 54.1% of parents wished they had used an open-identity donor, 87% of respondents were interested in finding and contacting their donor or donor siblings, and 19% of families had already done so (p. 179).

Another large, ongoing study with the DSR surveyed 2,013 donor-conceived children school aged and older. Ongoing issues related to anonymity and the children’s desire to know their donor have been published on the DSR website (DSR, n.d.-b). In terms of donor anonymity, 87% of offspring raised in heteronormative families and 69% of offspring raised in LGBTQ2+ families said their parents used an anonymous donor. Fifty-nine percent (59%) of the LGBTQ2+ offspring and 73% of the heteronormative offspring answered “yes” to the question: Do you wish your parent(s) would have used a willing-to-be-known or known donor? The percentages are significant, but it should also be noted that all the participants in both studies are DSR members, which may have an influence on the data as members of the DSR are primarily folks who desire openness for their children.

I have become a lifetime member of the DSR in the hopes that if our donor desires contact with us one day, she will find us there. Perhaps it will also be important to her emotional or mental health to know how her donation turned out. Egg donor Ruth Ragan spoke to journalist Lisa Belkin (2011) about the lasting psychological effects of her egg donation. She was never told the outcome of her donation and she worries about the happiness, safety, and well-being of any donor-conceived children, worries that intensified after she became a mother herself.

In 1985, during the early days of egg donation, Sweden became the first country to legislate identity-release donation, giving donor-conceived children the right to identifying information about their donor when they are sufficiently mature (Isaksson et al., 2014). Isaksson et al. (2014) studied the issue of future contact from the donors POV and found that most donors, especially donors with children of their own, felt positively about being contacted in the future by grown-up offspring of their donation, although one in four reported a need for counselling concerning how to handle that contact, especially contact between the donor-conceived children and the donor's family and extended family (pp. 4–6). I found Isakkson et al.'s study very encouraging in that the construction of gift-giving from the donor to the recipient included the idea that an older donor with children of her own was donating eggs as "a gift from one "complete" family to another "would be" family" (p. 2). I love this because the donor's "proven" fertility (a term used in the U.S. for repeat donors whose recipients have had successful pregnancies) is more than a selling feature for recipients; it concerns itself with the potential future needs of the donors as well. If the donor's family is already complete, any future worries about infertility as a side effect of donating may be assuaged. Being a little older and a little more mature may help donors be more aware of the need of any offspring to know their genetic origins, and recipients may be very relieved not to worry whether a young woman, with no children of her own, was fully capable of informed consent.

When Canada's Assisted Human Reproduction Act (AHRA, 2004) was first drafted, it included the creation of a national personal health registry, "to identity the health and safety risks of assisted reproduction and to stay on top of ethical and human-rights concerns" (Motluk, 2018, para. 9). After legal challenges from Quebec, Saskatchewan, Alberta, and New Brunswick, claiming that some sections of the AHRA overlapped with provincial jurisdiction, "the Supreme Court of Canada abolished 22 sections of the Assisted Human Reproduction Act in 2010 on the basis that they exceeded the legislative authority of Ottawa" (Couture et al., 2014, p. 372). Included in those 22 sections were articles 17 and 18 which "aimed to establish a national registry to gather and store personal and medical information on donors, users and donor-conceived children" (Couture et al., 2014, p. 372). Whether third-party reproduction in Canada and the U.S. continues to move to a more open system or not, the implementation of provincial/state registries would go a long way to help donors, recipients, and offspring access valuable health information. The donor's health and the health of their extended family is only a snapshot in time, taken at the time of donation. Things change, and updated information can be critical to everyone involved.

Rochman (2011) tells the story of genealogist Rebecca Blackwell who, after determining the identity of her son's sperm donor online, sent him a certified letter to which he did not respond. The donor's sister responded years later, telling Rebecca that her brother, the donor, had suffered a ruptured aortic aneurysm, and any children he'd helped conceive had a 50/50 chance of inheriting the condition. Tests revealed that Rebecca's son did have the condition and it was corrected with surgery. Blackwell posted her son's condition on the DSR so that his five half-siblings on the site would also be aware. In his case, access to that knowledge was lifesaving.

Couture et al. (2014) examine gamete and embryo donor registries (GEDR) through the lens of nonpaternalistic beneficence, highlighting the strengths and pitfalls of such registries: “On the one hand, [a federal GEDR] is ethically justified as a beneficent action towards lessening the harm associated with the transmission of hereditary diseases, the choice of the most appropriate treatments and prevention options” (p. 370). On the other hand, based on Riviera’s concept of nonpaternalistic beneficence, “for an action to be truly beneficent, it has to be based on pertinent and reliable data and to recognize beneficiaries’ free agency” (p. 370). A multi-directional flow of information, so that donors, as well as beneficiaries can benefit from updated health information offers a minimal bioethical justification of GEDR but may not fully respect a donor’s or recipient’s free agency, autonomy, and privacy (pp. 374–375). Couture et al. note that

> Overall, the necessity to respect beneficiaries’ future free agency implies a continuous consent mechanism that would allow for the possibility of withdrawing from the registry. Under these conditions, what appears to be beneficent to the donor can be disadvantageous for their offspring. (p. 375)

Also, even if a good continuous consent system is in place, it may not guard against potential privacy breaches in the form of data over-collection. The original registry established in Canada’s AHRA was supposed to collect “information as diverse as identity, family status and personal characteristics such as height, drug use, sexual behavior, etc.” (Couture et al., 2014, p. 375). Information about drug use or sexual behavior could clearly become a breach of privacy for donors and even be harmful to beneficiaries’ future opportunities. Couture et al. (2014) also discuss the possibility that promoting registries “may work against the movement in favour of disclosure and the removal of donor anonymity” (p. 376). Couture et al. suggest that gamete and embryo donation registries in Canada, whether they be federal, provincial, institutional, or independent, should be developed as political initiatives that promote the rights of donor-conceived people, but also to expand the conception of donation as individual choices to “complex networks of relationships functioning through time engaging all of society” where social justice issues are of great concern (p. 376). Couture et al. point to the Australian state of Victoria as an example of a “state-based system that combines both centralized and decentralized as well as mandatory and voluntary registries” (p. 372). Victoria has also abolished the practice of anonymous donation.

I think Canadian and U.S. registries would be a valuable middle ground for families who desire genetic information and donors who wish to remain anonymous as information can be exchanged with or without personal identities being revealed. Anonymous (or not) contact on the DSR can be negotiated into parent–donor agreements from the beginning, allowing mutually agreed upon contact between parties from pregnancy and birth.

Registries would play another valuable role: due to lack of registries in many countries including Canada and the U.S., there has not been any long-term data collection to study the physical or psychological side effects for egg donors and such research is essential to protect the young women who are recruited for this work. Medical anthropologist Diane Tober at University of California, San Francisco is completing a documentary inspired by this lack of research. She is working with the group We are Egg Donors, a support group for egg donors around the world (Cool, n.d.).

Surplus Embryos

Surplus embryos are frozen at the same time as the first live embryo transfer to a perspective mother's uterus and can be used for subsequent pregnancy attempts. In a large cross-sectional survey of U.S. fertility patients, Lyerly et al. (2010) found that during this time people are focused on having a child and are often not prepared to think about how they feel about unused embryos. Lyerly et al. (2010) also found that when it came time to decide what to do with any surplus embryos, "patients either prefer options not generally available to them, such as research donation, or reject available options, including reproductive donation or thawing and discarding" (p. 506). The study emphasizes the need for intensive restructuring of the informed consent process for IVF patients, including early disclosure about the potential for excess embryos.

In a later study, Lyerly et al. (2011) analyzed the same data further, finding that individuals' decisional conflict increased or decreased depending on whether they attributed higher or lower moral status to embryos and that these attitudes evolve over time as needs around family building and finances change. Participants in this study who experienced the most anguish deciding what to do with frozen embryos were the individuals who assigned "high, but not full, moral status to the embryos. For these individuals, embryos may not demand the same moral stance as a person or child but do require a level of respect well beyond that applied to human tissue generally" (Lyerly et al., 2011, p. 650).

Somerville (2006) describes three different moral views of a human embryo, "representing a continuum from permissiveness to prohibition with respect to what is ethical to do to it" (p. 135). The most permissive view holds that human life does not begin at conception; an embryo is not a form of human life but rather a collection of cells and what can be done to other cells can be done to an embryo. The people who hold this view of an embryo, according to Somerville, do not believe that an embryo is deserving of any special respect. The second view is that an embryo has the *potential* for human life, and thereby deserves some respect, but not as much as people who are already alive in the world, and the third, most restrictive view is that "the human embryo is the *earliest stage of each human life and as such has the same moral status as the rest of us* –we are all ex-embryos" (p. 136). This construction of an embryo demands our full respect because it sees the embryo as becoming, and a human life with potential.

Goedeke et al. (2017) conducted a discourse analysis of the literature related to embryo status/views/perceptions/narratives and disposal options, including embryo donation (p. 1530). Their analysis revealed many varied and complex ways that subjects construct their view of frozen embryos and how such subjective views affect their decisions to donate or dispose of them. Discourses of the embryo include embryos as "surplus" embryos that should not be "abandoned" in storage facilities indefinitely and therefore "wasted," the embryo as a collection of cells, the embryo as human life, the embryo as having interim or limbo status, the embryo as my/our child/family member, the embryo as property, and the embryo as precious (pp. 1531−1535). Goedeke et al. conclude that making such decisions will almost always be distressing and therefore counselling is recommended before, during, and after IVF treatment, as decision making may have long term social and emotional impacts (p.1537).

Elissa Strauss (2017) sums up the dilemma in ELLE:

> There are an estimated one million frozen embryos in the United States right now. If you're somebody who believes life begins at conception, you might see a

> potential tragedy. If you’re somebody who has long been struggling with infertility, you might wish that someone, somewhere, would send one your way. If you’re a clinic or storage facility, you might see a logistical struggle. And if you’re a former patient of IVF to whom one or more of those embryos belong, you might see indecision, an unyielding maybe that you can avoid dealing with for the not insignificant cost of approximately $750 per year. (para. 1)

CHAPTER THREE: METHODOLOGIES

I have drawn upon several methods and theories in the creation of this thesis. I map them below. I have included examples of my writing process in the appendices.

Qualitative Methods: Theoretical Framework

This qualitative study employs arts-informed research (Knowles & Cole, 2008), auto-ethnography (Adams et al., 2015), performance auto-ethnography (Denzin, 2003), and auto-ethnodrama (Saldaña, 2011). I discuss how this study is framed in praxis by these constructs, followed by a discussion of literature on ethnodrama in nursing and medical education, embodiment, embodied knowledge, storytelling, and performance.

Arts-Informed Research

Knowles and Cole (2008) list seven defining elements of arts-informed research. "First and foremost, arts-informed research involves a *commitment to a particular art form* … that is reflected in elements of the creative research process and in the representation of the research "text" (Knowles & Cole, 2008, p. 61). Since I was a child, I have dramatized my problems in my imagination, I run them over and over, trying to understand what happened, exploring different circumstances, different dialogue and endings. Never have I imagined these anxious ruminations as a research method but my work on this thesis has shown me how writing and performing drama (or comedy) can excavate and communicate knowledge, for both the performer and the audience. Data mined from my personal experience, written into scenes that tell stories of my motherhood became my research "texts" that I then interrogated further by embodying/ performing them.

Second, “the *methodological integrity* of the research … is determined in large part by the relationship between the form and substance of the research text and the inquiry process reflected in the text” (Knowles & Cole, 2008, p. 61). How and how well does drama/storytelling as text and performance illuminate and achieve my research purposes? In this project, I asked: What was/is my *experience*? By recreating versions of my experience in script form, and re-embodying the experience in performance, I have gained deeper knowledge of those experiences. Eisner (2008) speaks of “knowing” as a verb, “And knowing may be a much more appropriate descriptor of the process of inquiry made in pursuit of a problem that will not yield to a set of rigified procedures” (p. 4). Acting is like that; characters are always seeking to understand the circumstances they find themselves in, to understand other characters and resolve conflicts. Playwright Anna Chatterton once quoted her teacher Judith Thompson as saying “all plays should start with an impossible question. We write because we have a question that is impossible” (A. Chatterton, personal communication, January 22, 2019). In examining my experience of motherhood through egg donation, it often felt like I am searching for impossible answers, but sharing the story of my search, could open spaces for learning, for me and the audience. Drama and performance offer us an opportunity to show rather than tell, watching fellow humans wrestle with hard questions gives an audience an opportunity to empathize with another person’s experience.

Third, “*the creative inquiry process* of arts-informed research is defined by an openness to the expansive possibilities of the human imagination” (Knowles & Cole, 2008, p. 61). Arts-informed research does not follow rigid guidelines and often relies on commonsense decision making, intuition, and happy accidents of discovery. Arts-informed researchers work moment-by moment rather than follow a pre-programmed research process. My writing process is embodied, improvisational, and reflexive. For instance, in a first draft of a monologue where my character is attempting to write a letter to her anonymous donor, I found myself sitting and rocking on the couch. I thought, why am I rocking? My whole family rocks, what do we use it for? Those questions brought up an image of my brother rocking as he was dying, which led me to wonder what my brother had to do with this? That led me to write about my experience visiting him before he died and the realization that he had quite a few secrets that he was ashamed of. I thought: Oh! this is about shame. We rock because we're anxious but underneath the anxiety is shame. I need to explore my shame as a recipient of donor eggs. That first draft, which included the story of my brother rocking, is not included in this thesis, but it was a happy accident I needed to investigate on the journey to a different monologue.

Fourth, "Extending the idea from qualitative inquiry of 'researcher as instrument,' in arts-informed research the 'instrument' of research is also the researcher-as-artist" (Knowles & Cole, 2008, p. 61). When I mine my personal stories for data, I am the instrument that interprets it, the data is interpreted through my body, the actor's instrument. I am the researcher as I write and the artist as I perform.

Fifth, arts-informed research has strong reflexive elements, but the researcher need not be the subject of study. Although some vignettes have elements of fiction, my personal experience is the subject of study in this project.

Sixth, "Consistant with one of the overarching purposes of arts-informed research, there must be an explicit intention for the research to reach communities and audiences including but beyond the academy" (Knowles & Cole, 2008, p. 61). Filmmaker and philosopher Rick Stevenson has filmed more than 5,500 interviews with kids and teens from 12 countries, helping them to tell their stories and raise their emotional intelligence. “You own nothing more valuable than your own story. By learning to fully understand and apply it we can put our most valuable asset to work improving our lives and the lives of others” (Stevenson, n.d., Speaking section, para. 2). The vignettes in this thesis, written in plain language, have many potential audiences including academic conferences, support groups for parents of donor-conceived children, medical classes for students specializing in infertility treatments, and public storytelling events.

Lastly, audience engagement is central to arts-informed research. “The use of the arts in research … is explicitly tied to moral purposes of social responsibility and epistemological equity. Art can both inform and engage, and the research text is intended to evoke and provoke emotion, thought, and action” (Knowles & Cole, 2008, p. 62). Stories need an audience. Meaning is created in the moment of connection between performer and audience members, a moment of contact that is embodied and evocative.

Auto-Ethnography/Performance Auto-Ethnography

Adams et al. (2015) cite Holman Jones, who writes:

> Working at the intersection of performance and ethnography meant understanding field work as personal and knowledge as an embodied, critical and ethical exploration of culture. Performance was a stage and a means for writing, telling and living the story of my research with others. (p. 5)

Writing and performing stories of my motherhood experiences gives me stories to offer other families as they navigate similar challenges. Auto-ethnography is a method that affords an *insider’s* perspective:

> Researching and writing from the lived, inside moments of experience allows

> autoethnographers to cultivate an “epistemology of insiderness” of being able to describe an experience in a way that “outside” researchers never could. Further, insider knowledge can be used to call attention to the complexities of commonly held, taken-for-granted assumptions about cultural phenomena. (Adams et al., 2015, p. 31)

Before I began my egg donation journey, I certainly had “taken-for-granted assumptions” about using another woman’s eggs to get pregnant. Using auto-ethnography as a method allows me to study my own lived experience and craft an insider story. Applying an arts-informed process to my auto-ethnography creates a space for others to know/make meaning of my experience. “Drama (Art) makes us human, because it provides spaces of universal social connection, critical thinking, empathy, and trial and error” (Dr. Kari-Lynn Winters, personal communication, October 8, 2020).

Adams et al. (2015) speak about auto-ethnography as “equipment for living” and “stories to live with during times of relational distress”; living with story is “one way to understand the connection between story and theory: stories *are* theories that we use to understand experience” (p. 90). This makes me reflect on Hannah Gadsby’s comedy show *Nanette* (Olb & Parry, 2018). Gadsby calls herself “gender not-normal” and reflects on whether she needs to quit comedy because the act of writing and telling jokes about her life experience inevitably becomes a self-deprecating act—an act that devalues her story, because the most traumatic and meaningful parts of her stories need to be left out of the telling to make a punchline work. “Do you understand what self-deprecation means when it comes from somebody who already exists in the margins? It’s not humility. It’s humiliation.” After watching her show, I have *lived with* her story, it has changed how I might tell my own stories, and how I think about the privileges I have as a cisgender, straight White woman as well as the risks I face as a female storyteller; a woman doing motherhood differently than the cultural norm.

Anne Bogart (2014) uses stories as a method of teaching: “By telling my own stories, the ones that have helped to shape my thinking and action, I can offer my students a slice of my original experience” (p. 10). Phillips and Bunda (2018) in turn use the word storying, and define it as “the act of making and remaking meaning through stories” (p. 7). More than the study of lived experience, they see storying as what we do when we propose/conceptualize research, gather data, theorize and analyze the data, and present the research. “Storying is axiological, ontological and epistemological. We argue for story “as theory, as data, as process, as text on the ethical grounds of accessibility and foregrounding the marginalized” (Phillips & Bunda, 2018, p. 7).

Decisions around family-making can trouble personal morals and values, cultural assumptions, or religious beliefs. Building family with donated eggs can force private decisions into the public and political realm. Performing one’s vulnerability, auto-ethnographer’s risk being hurt or attacked, but they do so, according to Adams et al. (2013),

> in order to call attention to the vulnerabilities that other human beings may endure in silence and in shame. … Indeed, the choice to make a self vulnerable … is often made with the hope that audiences will engage with and respond to the work in constructive, meaningful—even vulnerable—ways. (p. 25)

Silence and shame have been a large part of my journey to motherhood. Telling my story is a way of releasing myself, and others, from shame’s grasp. Brené Brown (2010) states: “Shame hates it when we reach out and tell our story. Shame loves secrecy.

When we bury our story, the shame metastasizes" (p. 10). bell hooks (1995) asserts: "The longing to tell one's story and the process of telling is symbolically a gesture of longing to recover the past in such a way that one experiences both a sense of reunion and a sense of release" (p. 5); and Denzin (2013) adds:

> The goal with this work is to create a safe space where writers, teachers and students are willing to take risks, to move back and forth between the personal and the political, the biographical and the historical. In these spaces they perform painful personal experiences. Under this framework, we teach one another. We push against racial, sexual and class boundaries in order to achieve the gift of freedom; the gift of love, self-caring, the gift of empowerment, teaching and learning to transgress. (p. 139)

Auto-ethnodrama

Johnny Saldaña (2011) defines ethnodrama as the combination of *ethnography* and *drama*, a written play script consisting of dramatized, significant selections of narrative collected from various sources such as field notes, historic documents, journals et cetera; simply put, "this is dramatizing the data" (p. 13). When the source material for an ethnodrama is collected from the writer's personal lived experience, an ethnodrama becomes an auto-ethnodrama. "The autobiographical—preferably performed by the writer himself or herself—now becomes *auto*ethnodramatic" (p. 24). Saldaña states that the writer/performer has an ethical responsibility to tell the truth, and, unlike fictional theatre where the audience suspends belief, the audience in auto-ethnodramatic performance assumes it (p. 24). The scripted vignettes included in this thesis have elements of fiction, such as a fictional setting or character, but where all of them line up with “truth” is within the exploration of my subjective emotional experiences as I lived them and as I remember them; they are emotionally truthful.

Ethnodrama in Medical Education

As a fertility patient, I often felt like a set of medical, psychological, or bioethical problems rather than a human being who was struggling emotionally as well as physically. I am interested in how drama and performance can contribute to medical education, increasing empathy and improving dialogue between doctors and their patients.

Ethnodrama draws from Brazilian theatre practitioner Augusto Boal’s Forum Theatre, or Theatre of the Oppressed, a form that uses role play and improvisation with audience members “to aid marginalized and disenfranchised people in transforming and transcending social oppressions” (Rossiter et al., 2008, p. 134). Although North American health care practitioners and patients do not face the same oppression as Boal and his participants, “the tremendous strain from increased levels of bureaucratization and its effects on clinical decision-making comprise a new form of marginalization and moral distress” (Brown & Gillespie, 1997, as cited in Rossiter et al., 2008, p. 134).

There is a great deal of moral and emotional distress affecting women struggling with infertility and women who choose to have children with donated eggs (or sperm, embryos, gestational carriers). Rossiter et al. (2008) found that ethnodrama and other forms of theatre, like verbatim theatre as practiced by actor/playwright/professor Anna Deavere Smith, have an “ability to communicate research findings in an emotive and embodied manner, theatre holds particular potential for health research, which often engages complex questions of the human condition” (p. 130).

Anna Deavere Smith’s play *Let Me Down Easy* began with an invite from the Yale School of Medicine to come as a visiting professor and interview patients, doctors and administrators and later present a performance for the school based on those interviews. After the project for Yale was completed, Smith found the subject matter too fascinating to let go. Eight years and over 300 interviews later, the 21 vignettes in *Let Me Down Easy* address the hot-button issue of health care without overtly dealing with the politics of the current health care debate (Isherwood, 2009). By telling these emotionally charged stories, she hopes to get people talking. In a radio interview for the NPR show *All Things Considered*, Smith said: “It’s not just policy, it’s not just politics. There are lives at stake; our lives, how we're going to live. And also, I think, our dignity as Americans” (Siegel & Norris, 2011).

Shapiro and Hunt (2003) explored the use of theatrical performance within the context of medical education. Two theatrical programs were presented to an audience of medical students, university and community doctors, patients, family members, and caregivers. Both programs were one-person shows, presented by professional actors who also were patients sharing their lived experience living with HIV/AIDS in the first show, and a journey through diagnosis, treatment, and survival of ovarian cancer in the second (pp. 923–924). “Evaluations for both performances indicated increased understanding of the illness experience and greater empathy for patients. Respondents obtained additional insights into patient care issues and developed new ways of thinking about their situations” (p. 922). What I found most exciting about this study was that the live performance of these stories reminded the audience of the humanity of the people who become patients and sharing these theatrical events “provided students with a greater sense of belonging to a community dedicated to healing in its largest sense” (p. 926).

Jeff Nisker (2012) is coordinator of Health Ethics and Humanities, and Professor of Obstetrics-Gynaecology, at the Schulich School of Medicine & Dentistry, Western University. He has written nine plays to encourage compassion in health promotion and care. Nisker states: “Theatre can help humanity re-emerge as the primary imperative of health policy deliberation by encouraging audience members to approximate empathy for persons too often invisible to health policy makers, too often different from ourselves, but not really” (p. 1). When asked to take over the bioethics curriculum, Nisker agreed on the condition that he could “use theatre to engage the students’ hearts as well as their minds” and to “protect their hearts from succumbing to medical education’s over-objectivity” (pp. 4–5).

Ahmed et al. (2015) studied the use of ethnodrama as a tool to fill the knowledge gap about lymphedema among breast cancer survivors (BCS) and health care professionals (HCP). Eighty-four percent of their respondents (BCS, HCP, and greater community members) reported a greater understanding of BCS’s lived experience of lymphedema after cancer treatment and 96.3% of the respondents were motivated to seek out more information after watching the performance of the ethnodrama.

Kontos and Naglie (2006) also contend that dramatic performance provides an “accessible presentation of research to audiences of diverse disciplinary backgrounds, it recovers the experiential immediacy of the body present in the original data-gathering setting, and it can foster critical awareness and engage audiences to envision new possibilities” (p. 301). To produce the ethnodramatic *Expressions of Personhood in Alzheimer’s*, Kontos chose vignettes she had written for her doctoral dissertation describing Alzheimer’s patients; how they embodied personhood despite no longer being able to converse with words. She partnered with Act II, a theatre school and creative drama centre for older adults, part of the Seniors Education Programs in Ryerson University's G. Raymond Chang School of Continuing Education in Toronto, Canada. The director and actors whom she worked with became a vital part of the process of re-embodying the research:

> Bodily participation was not only a mode of intensifying understanding of the nuances of embodiment in the lived experience of the illness, as observed by Kontos, but also of portraying those experiences with the highest possible degree of verisimilitude and mimesis. (Kontos & Naglie, 2006, p. 313)

I have followed a similar process as Kontos, writing vignettes that describe my past embodied experiences, and then re-embodying the experiences in performance.

Embodiment, Stories, and Performance

Auto-ethnography/auto-ethnodrama demands I pay attention to bodies, particularly mine. Thinking and writing about personal experience has led me to define embodiment through phenomenological and theatrical lenses.

Theatre scholar Erika Fischer-Lichte (2008) discusses the doubling of bodies in that human beings are perpetually in a state of both "having a body" and "being a body" (p. 82). She builds on the phenomenology of Merleau-Ponty, who claimed the body is connected to the world by its flesh and any human grasp on the world occurs through the body. "In this sense, the body transcends each of its instrumental and semiotic functions through its fleshiness" (Fischer-Lichte, 2008, p. 83). In defining embodiment, Fischer-Lichte states: "By emphasizing the bodily being-in-the-world of humans, embodiment creates the possibility for the body to function as the object, subject, material, and source of symbolic construction, as well as the product of cultural inscriptions” (p. 89). For Fischer-Lichte, characters do not exist on the page; they exist only in and through a performer’s body, a character is different every time it is embodied by a new actor, despite the text being the same. The body, then, is a site of meaning-making, rather than simply a tool in service of the written text.

I have a body and I am a body. As I worked to become pregnant in 2009, I was the object/subject/material that was acted upon by myself and medical practitioners, a cultural inscription of motherhood in the 21st century. My body was transformed in the process and has continued to transform, always in the process of becoming a different body, a different object/subject/material. Writing stories of my past bodily experience and telling them with my present body allows me to re-embody the past, not to reproduce the same experience (impossible), rather to interrogate it, to make sense of it, and expand on it.

When I step onto a stage, there is a theatrical doubling of my body: I am Allison, the body in performance onstage, and I am also a theatrical double of myself, the character I am playing/embodying which, in the case of these auto-ethnodramas, is also me, Allison, in a different time and place—an Allison that no longer exists except in my performance of her. That other Allison was also performing, although not in the theatrical sense. That Allison was performing gender (woman), and a gendered identity (mother), what Butler (1988) terms performative embodiment, “an identity instituted through a *stylized repetition of acts*” (p. 519). The actions I performed (and continue to perform) in my everyday life, produce(d) myself as female, heterosexual and capable of sexual reproduction. “Gender is an act which has been rehearsed, much as a script survives the particular actors who make use of it, but which requires individual actors in order to be actualized and reproduced as reality once again" (Butler, 1988, p. 526).

My present (theatrical) performance investigates my past performative actions, seeking meaning. There is a danger is exposing my past in this way, unlike fictional roles I have embodied I cannot say "it's only an act, this is not the real me." As Butler (1988) asserts, there are punishments in the real world for performing gender wrong, and some may feel that a real mother is someone whose body can produce children without the help of an egg donor and medical technology, that there is something unnatural about me. However, the dangers I face are minimal compared to the dangers others face as they perform "gender not-normal" every minute of every day, like Hannah Gadsby, who shared the very real danger of being "gender not-normal" in her show *Nanette*.

Tanaka (2013) discusses embodied knowledge, also revisiting Merleau-Ponty: "Embodied knowledge is a type of knowledge in which the body knows how to act"—a type of knowledge where "the lived body is the knowing subject" (p. 48), as opposed to the Cartesian view of knowledge where the mind, separate from the body, is the subject that "knows." Embodied knowledge is "experienced as a prereflective correspondence between body and world, without being mediated by mental representations" (p. 47), and comes about through repeated bodily practice, like when we learn how to ride a bike. We know how to ride a bike because the knowledge has been imprinted in our body and we "lived through it, without being consciously represented" (p. 48). "It is what we do without trying to do or what we know before trying to know" (p. 53). Tanaka suggests that to expand on the embodied view of knowing, "we have to rediscover the prereflectively lived knowledge and give explicit descriptions to it" (pp. 59–60), to reflect on the prereflective, to become aware and mindful of it.

Tanaka (2013) builds on Merleau-Ponty’s notion of intercorporeality, which “focuses on the embodied interaction between two persons: the reciprocal relation between one’s body and that of another, which appears as a perception-action loop between self and others” (p. 62). Contagious yawning is an example of this loop, where perceiving another’s action (yawn) creates the same intention in us.

Fischer-Lichte (2008) also talks about a feedback loop; the actors act, the spectators perceive their actions and respond to them, both the other spectators and the actors perceive those responses and again respond. This ever-changing feedback loop generates and determines performances, keeping them “unpredictable and spontaneous to a certain degree” (p. 38). What is certain, however, is that the bodies of both actors and spectators is a pre-condition for performance.

For Phillips and Bunda (2018), storytelling enables connection with the other, sharing personal stories creates intimacy and draws the listener in, as she identifies her life with that of the storyteller. This relationship with others is at the core of storytelling; there must be tellers and listeners, the involvement of others is necessary for meaning. Stories can translate embodied knowledges from diverse communities who are often silenced. “Through storying we foreground bodies (privileging sensation, emotion and spirit) and relationships—an antithesis to much of the modern academic joint, which is designed and still operates on Cartesian thinking of separating the mind from the mechanical pragmatics of the body” (Phillips & Bunda, 2018, p. 12).

Kathleen Gallagher (2015) states that “embodied experiences, in the hands of careful methodologists, are the very ground from which knowledge can be discovered” (p. xiv). Gallagher has used storytelling to attend to embodied knowledge of histories, contexts, and social relations. I must admit, in my hands, this research has felt more fumbled than careful, but I too have turned to stories and performance to make meaning of my past, to reflect upon the prereflective.

Although they think about it differently, these scholars and scientists agree there is a feedback loop between actors and audiences, storytellers and listeners. For me, this feedback loop creates opportunities for embodied, often intimate connection.

Data Collection

> Beginning any project requires us to do the simple, yet deeply reflexive work of starting where we are. … From there, we begin to situate ourselves in *story*—our own story, the story told in existing writing and research on our topic of experience, and the stories told by others. (Adams et al., 2015, pp. 48–49)

Reflexive Journaling

This allowed me to examine memories, emotions, questions, and struggles from my present point of view, and provided a basis of comparison to and context for journal entries I wrote during the years before, during and after my pregnancy. Other personal data sources included emails sent and received from the U.S. fertility clinic's counsellor, copies of medical test results, drug prescriptions and instructions, a personal archive of photos and videos taken during my pregnancy, and (non-identifying) written information we received from the clinic regarding the egg donor and her extended family.

Cultural Critique

To complement my fieldwork, I explored other women's stories of infertility and donor conception by reading blogs, participating in Facebook groups, and attending in-person support groups. I also read plays, non-fiction books, articles, and essays (Chatterton, 2017; Flacks, 2005; Hass, 2015; Orenstein, 2018).

Research-Creation

After looking for themes in the field notes described above, I began the process of crafting stories based on my personal experiences, dramatizing the data (Saldaña, 2011) into scripted monologues and dialogues. Blaikie (2013), views “the words *create* and *research* as verbs that enact and perform the research question” (p. 59). Writing for performance gave me the opportunity to gather more field notes, to research my experience of sharing deeply personal experiences. “The writing of an ethnographic text is really a continuation of fieldwork rather than a transparent record of past experiences, leading to the production of a historically, politically, and personally situated representation of human life” (Tedlock, as cited in Wall, 2008, p. 6). Adams and Manning (2015) also describe auto-ethnography as “a process that unfolds through the research and writing process” (p. 362). I have chosen to include six vignettes in this thesis, two of which I had the opportunity to publicly perform in a theatrical setting before the COVID-19 pandemic ended live performance opportunities. Three of them were performed for and discussed within my actor/creator writing group and two or three of them will be performed during the defence of this thesis.

Data Analysis

Adams and Manning (2015) discuss how different orientations to auto-ethnography require different criteria for evaluating field data. Creative-artistic auto-ethnographers may focus on storytelling techniques such as narrative voice, composite characters, and dramatic tension to create interesting accounts of personal experience and it may be inappropriate or even silly to use traditional social scientific criteria such as reliability, validity, and generalizability to evaluate creative-artistic auto-ethnographies

(p. 360). However, I speak briefly about these three issues and how they are applied in auto-ethnography below.

Reliability

“For an auto-ethnographer, questions of reliability refer to the narrator’s credibility. Could the narrator have had the experiences described, given available ‘factual evidence’? Does the narrator believe this is what actually happened to her or him?” (Bochner, 2002, as cited in Ellis et al., 2011, p. 4). A few of my stories may be quite surprising to some but they are grounded in my life experience and backed up by relevant literature of other women’s similar experiences. Although some vignettes have been fictionalized to protect the identity of people or institutions, I strove to share the emotional truth of the stories under realistic circumstances. Knowles and Coles (2008) note: “As in most qualitative research, the subjective and reflexive *presence of the researcher* is evident in the research text. … In arts-informed research, however, the researcher’s artistry is also predominant” (p. 61). As an auto-ethnographer I am the instrument that interprets the data, and it will be performed with my body. To assist in addressing the subjectivity and biases I bring to this project, I have included a statement of subjectivity and a statement of privilege in the first chapter of the thesis to reveal my positioning within the study (Farrell et al., 2015, p. 979).

Validity

Much like reliability, validity in auto-ethnography “means that a work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible, a feeling that what has been represented could be true” (Ellis et al., 2011, p. 10). To judge the value of a story, Ellis (2000) suggests asking questions such as “Can the author legitimately make these claims for his story? Did the author learn anything new about himself? ... Will this story help others cope with or better understand their worlds?” (as cited in Wall, 2006, p. 10). These questions guided me in the writing of this thesis.

Generalizability

In auto-ethnography, generalizability is tested by readers as they determine if a story speaks to them about their experience or the experience of someone they know (Ellis et al., 2011, p. 10). Wall (2006) emphasizes that “no individual voice speaks apart from a societal framework of co-constructed meaning. There is a direct and inextricable link between the personal and the cultural” (p. 9). My experiences of motherhood are uniquely mine, yet I believe they will speak to and encourage dialogue with many people who have struggled with infertility and built families with the help of gamete donors.

Limitations

In qualitative research, and particularly in auto-ethnography, the most obvious limitation is the subjectivity the researcher brings to the study as the “main character.” Despite my best efforts to be scientifically rigorous, the reflections in this study will remain personal and biased interpretations of my experience. Still, with the help of my supervisor, the literature, and other colleagues, I hope I have presented a valuable contribution to the culture of infertility and third-party reproduction (Farrell et al., 2015, p. 981).

A second limitation to this study is the geographical location. Egg donation takes place all over the world in many different cultures. This study is limited to my experience in Canada and the U.S.

Ethical Concerns

I wrote explicitly about my own experiences without involving other human subjects; however, writing personal narrative not only implicates myself but can also implicate those close to me, in this case, my partner, my children, and some members of my extended family. Ellis (2007) asks, “What are our ethical responsibilities toward intimate others who are implicated in the stories we write about ourselves?” (p. 5). Ellis writes about relational ethics in auto-ethnography, a kind of ethical practice closely related to ethics of care and feminist ethics (p. 4). In deciding what to tell/not tell, she suggests strategies such as omitting things, using pseudonyms or composite characters, altering the plot or scenes, writing fiction and sometimes writing without publishing (p. 24). I have made use of all these strategies to protect my family from any unintended harm or breach of privacy.

CHAPTER FOUR: FINDINGS

In this chapter I have included six vignettes, each one followed by my thoughts and a discussion of the piece.

Finding 1: "Donuts" Vignette

(Exterior city street. February. Kate, a woman in her mid-40s, speaks to the audience)

KATE

Winter's over. You know how I know? It's snowing cherry blossoms. We have two seasons here, rain and not-rain. They seem to change overnight too. It's not subtle. One day it's unbearably gray and soggy and the next the world is exploding in color. Oh. A blossom just landed on my cheek.

(She takes it off her face, puts it in her pocket)

It's so soft, it's like newborn skin.

Jack and I are looking for a restaurant. We've been inside the clinic for three hours and we need food. And wine. Definitely wine.

You see, we thought we had made peace with being childless. We grieved. We got a dog that doesn't shed. We moved to an island, bought a fixer-upper, planned on travelling, we were *fine*.

And then, my best friend, a fellow actor, got pregnant. At forty-six. With her fifty-nine-year-old boyfriend. By accident. I had been auditioning for that role for a decade and she just stumbled in after a bottle of red and scored it. Nine months later she handed me my newest Godchild and said "What are you waiting for? Go get an egg donor!" Seriously, she pisses me off. She threw away our script, the one where we're too old to be having babies, and now she's just...*improvising*.

I guess it's my fault I don't have any eggs. I waited too long, waited for the wrong man to be ready when he was clearly never going to be ready, I shoulda been braver, shoulda left sooner, shoulda-shoulda-shoulda, I made the bed and now I can't sleep in it. I have become an insomniac.

I sit in the living room most nights and watch the rain, fall asleep around five or six am, after a good cry. Jack came to visit me there the other night.

JACK

(The actor playing Kate also plays Jack)

Watcha thinking about?

KATE

The usual.

JACK

Egg donation?

KATE

Yup, it just seems so...Margaret Atwood.

JACK

Why don’t we go down and meet the people at the clinic, we’ll just listen. Get info, like we did at the adoption seminar, *then* we can decide if we’re done or not.

KATE

Just info?

JACK

Just info.

KATE

The people we met in the clinic just now were so...*kind*. The clinic in Canada told us that our chances of getting pregnant using my own eggs were less than one percent. Here, in the US., where we have more access to treatment with donor eggs, the chances of me getting pregnant are seventy to eighty-five percent.

(Using her hands to weigh the options)

Less than one/Seventy to eighty-five. This is not a subtle change. This is Rain/Not rain.

We find a Greek restaurant, it’s early for dinner but they’re open. There’s a camera crew in the kitchen, the restaurant is showcasing their most popular dish for a local TV show. We ask the server what their dish is. “Donuts” he says. Donuts? Not roast lamb or baklava? Turns out the chef has a soft spot for donuts. He makes them from scratch, serves them in brown paper bags full of cinnamon sugar with side dishes of fresh mascarpone and homemade jam.

We order the donuts.

Normally, I don’t eat donuts. I have an auto-immune disease and I avoid inflammatory foods. And donuts are the most unholy of trinities: Gluten, dairy and sugar. The server brings them to the table. The donuts are fresh out of the fryer and the paper bag is hot. I open it and stick my whole face inside, inhale sugar and cinnamon. "Sin big" I say to Jack. "Sin big" he replies. I spread the donuts with cheese and jam and take a big bite. Oh. My. God.

Jack reaches for my hand across the table, and I start to babble. You know Jack, every time I walk the dog, I watch mothers and their kids. I can't help myself. And there's this one gesture that takes my breath away. It's this small, common, everyday gesture. The mom wants to move along, and she stretches out her hand, wiggles her fingers, the kid catches up, their little hand reaches for hers and off they go. Every time I see this little ritual, I imagine how it must feel, it's not just a thought, I can feel it. It's like a ghost in my hand, and I think that's the grief, right? That's the child I'll never have. But Jack, what if it's not a ghost, what if it's a message? What if it's just Love waiting for me to take the leap? Say yes? I know how to improvise. So what if the baby isn't genetically related to me? It doesn't matter, it's probably a good thing, but I'll get to carry the baby, nurture the baby, that's enough, it's more than enough. I'm sick of playing moms on TV. I want that sticky little hand in mine.

Holy shit these donuts are good.

The server comes back and asks if we would like the check. I look up at him and say No. No, we are not done. We are NOT DONE. We'll have some more donuts.

Discussion

Although not verbatim, this piece unfolds the way I remember it. That Greek restaurant will always be a special place, along with the donuts. I performed a version of this piece early in 2019 at Theatre Aquarius in Hamilton. The evening of readings from works in process was a free public event. I had never spoken about being an egg donation recipient or of having an auto-immune disease (the version I performed that night named my disease – MS) with people I didn't know, and I was nervous. It felt like a coming-out and I had no idea how I would be judged. It was also the first time I performed my own words and my own story, which was equally terrifying.

I felt the audience lean in and listen, I heard them laugh when I hoped they would, the more they responded the more confident I felt and as the performance went on, I felt a lifting of the shame I carried about having MS, being infertile, and using donor eggs. I'm not sure I understood how deep a sense of personal failure I was lugging around until I spoke it out loud. Looking backwards through time, I don't have any memories of sharing how infertility made me feel, I think it was more painful than I was willing to admit, and I didn't want to talk about it for fear people would think I was "feeling sorry for myself." I kept very silent about it. The people who approached me at the end of the evening spoke about how the gesture of a parent reaching out for the child's hand touched them, and the lengths we as humans are willing to go to have children. They found just as much or even more meaning in the gesture—what my body was *doing* rather than the words I spoke.

Revisiting this piece now, I read the gesture of reaching out with my hand, as a metaphor not only for a potential child but also for connection, infertility can be a lonely place. My mother used to say that she didn't feel her life had purpose until she had children. I internalized that message; that a woman finds her deepest life-meaning through the bearing and raising of children, even as I outwardly rebelled against it.

The staff in the U.S. clinic handed me back my dream of motherhood. They gave me back the ability to hope, to feel excited. The clinic gave us a feeling of belonging, of community, a village, and the sense that maybe just maybe, my body was not broken beyond repair. They offered an abundance of empathy, compassion, and humor on that first visit and every following visit. I realize that women in my shoes can be easily manipulated and possibly I was; there is always a power imbalance between doctors and patients. I came to egg donation feeling broken. The high odds of success, coupled with the loud ticking of an invisible clock, tempted me to jump in, putting ethical/moral doubts aside.

Fertility clinics are for-profit businesses and along with their kindness and understanding that day they gave us a long list of fees, including the donor's. It is difficult to untangle their compassion from their business sensibilities. As Nelson (2006) asserts, economic markets, social life, and caring work are bound up together. That day in 2009, I decided to embrace/embody hope one last time rather than remain childless. The decision was embodied; I felt it move inside me, a re-opening, a release. Separating my physical/emotional body from some sort of "reasonable" mind was not possible. My *embodied mind* (Fischer-Lichte, 2008; Lakoff & Johnson, 1999) said yes; to pleasure and possible harm, via donuts and donor eggs, yes to a life of improvisation, what else is motherhood?

Finding 2: "At Sea" Vignette

(A woman in her 40s waits in a doctor's exam room)

KATE

I'm ten weeks pregnant. With twins. It took a team of scientists and an egg donor, but I am pregnant. For the first time, it feels like my body is working. Well, not my eggs, they never worked, but my uterus is a rock star. That's what the nurse at the fertility clinic said.

NURSE

Kate, it's Jennifer, I'm looking at your ultrasound pictures and your uterine lining is perfect. Your body is responding like a rock star!

KATE

They were so awesome. I never felt like a freak for wanting to carry a child even though I was…older.

When it was time to transfer the embryos from their little petri dishes to my uterus, we had to decide how many we would put in; one or two. The doctor told us that statistically the chances of a pregnancy were a bit higher if we put in two BUT we should only put in two if we were willing to raise twins. They had clients in the past who put in two to increase their chances but when they got pregnant with twins, they asked the clinic to remove one. That completely blew my mind. I don’t know how you do that, how do you survive infertility, the years of endless loss, and then demand an abortion? I mean, really, who does that?

We went for it, we put in two, we were forty-four and this was going to be the absolute last try, one baby, two babies, we were in. Ten days later the nurse called.

NURSE

Kate? It’s Jen at the clinic. I’m looking at your blood test results.

KATE

And?

NURSE

You’re pregnant.

KATE

Really?

NURSE

Oh yes, Kate, you’re *really* pregnant, I’d say *doubly* pregnant, but we won’t know for sure until the six-week ultrasound.

KATE

At that ultrasound, we saw two tiny, fluttering hearts. Having two babies in there along with my “advanced maternal age”, makes this pregnancy a high-risk one, so, I’m here to meet the specialist. I’m

feeling good, except for the nausea, which is brutal.
I already threw up in the parking lot.

(There is a delicate knock on the door)

Come in!

(A very young-looking woman enters, carrying a clipboard)

DR. YOUNG

Hello.

KATE

(To the audience)

Oh my God, the doctor is twelve years old.

DR. YOUNG

I’m Dr. Young, Dr. Bishop’s resident.

KATE

Oh good! I mean, sorry, it’s just that you look so...I’m sorry, it’s wonderful to meet you.

DR. YOUNG

(Dr. Young gets this reaction a lot and she doesn’t like it)

She sent me in to talk to you about the risks of twin pregnancy.

KATE

Okay.

DR. YOUNG

(Reading off her clipboard, rather monotone)

The human body was designed to carry one baby at a time. So, one or both babies may have to stay in the NICU for a considerable amount of time.

KATE

The NICU?

DR. YOUNG

The neonatal intensive care unit.

KATE

Right.

DR. YOUNG

But if labor doesn't begin before 38 weeks, we'll induce you for your own safety.

KATE

My safety?

DR. YOUNG

Yes. You will probably experience double the nausea and vomiting of a singleton pregnancy.

KATE

Um hum.

DR. YOUNG

You have a higher-than-normal risk of gestational diabetes. You have a higher-than-normal risk of anemia, during the pregnancy as well as after. You have a higher-than-normal risk of blood pressure problems such as preeclampsia during the pregnancy. This can be fatal to both mother and babies and the babies will have to be delivered early. You also have a high risk of incompetent cervix.

KATE

My *cervix* is incompetent?

DOCTOR YOUNG

It could be.

KATE

Wow.

DOCTOR YOUNG

You have a higher risk of placenta previa which is another cause for early delivery, by C-section. You have a higher-than-normal risk of intrauterine growth restriction. This is when the fetuses don't grow properly inside your uterus. You have a higher risk of being put on bed rest for a large part of the pregnancy. You should have a plan in place for that. You have a high risk of hemorrhaging during delivery, especially if the babies are delivered by C-section, but we'll just remove your uterus if we can't stop the bleeding.

KATE

My uterus is a fucking rock star.

(Dr. Young looks at her blankly)

DOCTOR YOUNG

(Looks back down to her clipboard)

I see you've been treated for depression in the past.

KATE

Yeah. Anxiety really, which gave me insomnia, which was depressing.

DOCTOR YOUNG

In that case, you have a much higher risk of post-partum depression as well as post-partum psychosis. And lastly, a baby born before 28 weeks is a non-viable baby. Do you have any questions?

(Kate tries to answer but vomits instead, grabbing the barbage bin just in time. Dr. Young practically rolls her eyes and makes a quick exit)

Great! She'll be in soon.

(The obstetrician enters without knocking. Dr. Bishop is in her late thirties, impeccably put together, professional and warm)

DR. BISHOP

Hello. I’m Dr. Bishop.

KATE

Oh my God, I’m so sorry.

(Dr. Bishop efficiently moves the garbage bin outside the exam room)

DR. BISHOP

I see Dr. Young filled you in on the risks of twin pregnancy?

KATE

She did, I'm completely overwhelmed.

DR. BISHOP

You know, it's hard to teach that.

KATE

Teach what?

DR. BISHOP

How to talk about risk. She needs more practice.

KATE

You know, uh, the doctor at the clinic didn't tell me all that stuff, he only talked about potential bedrest near the end of the pregnancy, and if the babies came early, they would stay in the nursery for a while. Funny, he called it the *nursery*.

DR. BISHOP

I know, they're good people but, perhaps a touch too eager. So, we need to plan for your care, and we should also discuss genetic testing.

KATE

Genetic testing, okay.

DR. BISHOP

Normally we would start with bloodwork to screen for things like Down Syndrome and Trisomy 18, but the numbers are always off the charts in twin pregnancies, so blood tests won't tell us anything. We can do what's called a Nuchal Translucency ultrasound between 11 and 14 weeks where we measure the fluid space behind the babies' necks and if those numbers are higher than average you might want to consider invasive testing.

KATE

Because…?

DR. BISHOP

Because the ultrasound doesn't give you a definite answer, if you want a definite answer than you need to do genetic testing and those tests also carry risk.

KATE

What are those tests?

DR. BISHOP

A chorionic villi sampling can be done earlier in the pregnancy, but it carries a one in one hundred chance of miscarriage. An amniocentesis carries a smaller risk of miscarrying, one in two hundred, but we can't do that test until somewhere between fifteen and eighteen weeks.

KATE

Wait, hold on, isn't the risk of these things related to the age of the egg? The clinic told us that our risk was - one in five thousand.

DR. BISHOP

That's true. How old is your donor?

KATE

Twenty-four.

DR. BISHOP

Then your risk is low, the same as a twenty-four-year-old.

KATE

(Palpable relief)

Okay. Good.

DR. BISHOP

Did you have ICSI?

KATE

They told us that was standard practice.

DR. BISHOP

(Sighs)

I always suggest that if there's nothing wrong with the sperm that they don't do ICSI.

KATE

Why not?

DR. BISHOP

There are some studies that suggest a higher risk of sex chromosome abnormalities when they do ICSI.

KATE

Sex chromosome abnormalities?

DR. BISHOP

When a child is missing an X or Y chromosome, or they have an extra. It can be quite serious. The risk is one in two hundred, for each of the fetuses.

KATE

Are you saying that because the clinic used ICSI, that we have lost the benefits of the twenty-four-year-old eggs?

DR. BISHOP

There are some studies that imply that.

KATE

They told us it was safe.

DR. BISHOP

It's their job to get you pregnant. It's my job to look after you now.

KATE

I see.

DR. BISHOP

Look, these are only the conditions we can test for. Most things we can't, like autism for instance. Having children is always risky. Life is risky.

KATE

So, the risk of me losing one or both babies after amniocentesis is one in two hundred?

DR. BISHOP

Yes.

KATE

And the risk of one or both babies having a chromosome abnormality is also one in two hundred?

DR. BISHOP

Yes.

KATE

You recommend amnio then?

DR. BISHOP

I can't *recommend* anything. I can only tell you the risks so you can make your own decision. I can tell you that we are very good at amniocentesis here and miscarriages are rare.

KATE

One in every two hundred.

DR. BISHOP

Well yes, but...

KATE

So, one hundred and ninety-nine out of two hundred amnios do not cause a miscarriage.

DR. BISHOP

Sure, you can look at it that way.

KATE

And both my babies have one hundred and ninety-nine chances out of two hundred to be born without any genetic abnormalities.

DR. BISHOP

You need to be aware of the risks.

KATE

We'd have to do two amnios right? Since each baby is in their own sac?

DR. BISHOP

Yes.

KATE

Let's say that we have two amnios and they both go perfectly, no miscarriage, but the tests find that one of the fetuses has a chromosome abnormality, just one, the other one's perfectly normal, and let's say that we decide to...

(Realizes what she's about to say)

Abort that one fetus. Can you abort one fetus without harming the other? Is that even possible? Do you have numbers for that?

DR. BISHOP

I can tell you about that if we get to that point.

KATE

No. Tell me now.

DR. BISHOP

We inject potassium chloride into the heart. And it stops. The fetal tissue is usually reabsorbed into the mother's body.

(Pause)

Are you okay?

KATE

I'm ten weeks pregnant. With twins.

Discussion

This scene is an amalgamation of conversations my partner and I had with our obstetrician, her resident, and a genetic counselor. I did not vomit in the doctor's office, (although I did in the parking lot) but by the end of Dr. Young's speech I was curled up in the fetal position on the exam table and my partner was rendered uncharacteristically speechless. The last section of the scene, where Kate asks how you go about aborting one twin, took place in the office of the genetic counselor, who also looked like a teenager through our eyes. She provided more upsetting details on the various sex chromosome disorders but, like Dr. Bishop, refused to offer advice or counsel, she simply delivered a lot of numbers. We left the appointment angry and upset because she would not acknowledge the seemingly equal (to us) risk of amnio causing miscarriage compared to ICSI causing chromosome abnormalities. She kept telling us how good the hospital was at doing amnios. We felt naive and incompetent. How could we have been so stupid? Why didn't we do more research? Why did we put in two embryos?

My partner found a single inconclusive study about ICSI and sex chromosome abnormalities. Despite the study being inconclusive, the small print suggested informing patients of the potential risks in case *future* studies confirmed them. When I began to think about this thesis, I could not find the same study. I did find others which, as Dr. Bishop implied, pointed to sperm quality rather than the ICSI procedure as the potential culprit (Coates et al., 2015), for example.

We called the fertility clinic who told us the studies our OB was speaking of were flawed, inconclusive, and that in over 2,000 babies conceived by ICSI in their clinic they had not had a single case of *any* kind of chromosomal abnormalities. Premature twin births, yes, NICU, yes, bed rest, yes, but not chromosome abnormalities. Then we spoke to my GP who had delivered hundreds of babies. She told us that the risk we were being informed of was not much higher than the risk in the general population, and she rarely discusses it with her patients. She didn't know why the OB (who she had referred us to) was bringing it up at all.

When we returned to Dr. Bishop's office, we shared what the team at the fertility clinic had told us. Dr. Bishop's reply was that she would like to see that data but because the clinic was a private business, they did not share their data publicly. Further conversation revealed that Dr. Bishop was an American practising in Canada because firstly, she had married a Canadian and secondly, she "believed in socialized medicine." What can't be gleaned from the text of this scene is Dr. Bishop's tone and body language. We both felt as though she was sharing a very strong moral/ethical opinion about assisted reproduction along with this rare medical risk. Some Canadian provinces offer small amounts of financial help, but fertility treatment is generally not covered under our socialized health care system. Canadian clinics work in business partnerships with American clinics and egg/sperm banks and patients in both countries pay for their services out of pocket or through private insurance. I don't know exactly what Dr. Bishop meant to communicate to me that day. It is possible that since I had paid for access to medical treatment, when others could not, I was hearing my own shame in her words. My body and the egg donor's body in the U.S. fertility clinic were constructed as a source of great hope and agency. In Dr. Bishop's office, my body became a physical and bioethical problem that I felt powerless to solve.

In the end, we decided against amniocentesis because the nuchal translucency ultrasound looked very positive, and the babies appeared to be growing normally. Besides extreme nausea and heartburn I had a very healthy pregnancy, and the babies were born big and healthy via a scheduled C-section at 38 weeks, which is considered full term for twins. My uterus was a rock star, and my cervix was competent after all. I had also been very lucky.

Reproductive technology has come a long way since 2009. Now parents have the option of preimplantation genetic screening (PGS) also called chromosomal screening (CS). An embryologist biopsies several cells from the in-vitro blastocysts (embryos that have been developing for a few days in petri dishes) and the cells are then sent for genetic testing. Embryos without the correct number of chromosomes are not transferred to the intended mother or gestational carrier. This reduces miscarriage rates and increases successful implantation with a single embryo, thereby decreasing multiple pregnancies and their inherent risks. If the option of PGS was available in 2009, we probably would have done that too, adding several more thousand dollars to the bill. When we began treatment with donor eggs, we understood that miscarriages were very possible, but having to consider abortion came as a shock.

Looking backwards through time, our level of naiveté is embarrassing. I thought that once pregnant, I would be treated the same as a woman who had conceived the old-fashioned way. Would Dr. Bishop take the same judgmental tone in discussing risk with a woman who was carrying twins conceived in her marriage bed? Would that woman leave her obstetrician’s office feeling ashamed for getting pregnant at all? That maybe she should abort and give up? When I performed an earlier version of this vignette for my writing group there was a lot of laughter and the question: How do you get to be 10 weeks pregnant with twins and not know any of this stuff? I didn't have an answer.

I became a mother that day in her office. I was carrying two potential humans and I had to make hard choices for their future, including a choice that risked losing them altogether. I had a lot of judgment for the couples the fertility clinic told us about, the ones who asked for a reduction to a singleton pregnancy, *those people*. The *others*. Now, as I look at how that story overlaps with ours, I can imagine how they might have felt when faced with the risks of twin pregnancy, the risk to the mother as well as the babies, the increased risks of postpartum depression, the emotional and financial strain on a partnership, and I have empathy for them. I imagine their story was a lot more complex than the single story we were told. Nigerian novelist Chimamanda Ngozi Adichie (2009) warns of the dangers of a single story. She eloquently explains how power makes use of a single story, by creating stereotypes that are an incomplete picture of a person or place. When we hear/tell a single story we risk a critical misunderstanding. “Stories can break the dignity of a people, but stories can also repair that broken dignity” (Adichie, 2009).

When I visit our clinic's website now, I see a very big push for single embryo transfer to avoid twin pregnancies. The technology has become better and the odds of pregnancy with one embryo is equal to that of two, even if the embryo has been frozen. The doctors strongly encourage one healthy pregnancy at a time. The only time they say putting in two embryos may be warranted is when couples, like us, are not going to try for a second pregnancy due to age. Ironically, it was because of our age that we took the risk of having twins, in the hope that if two babies came, they would have each other when we were *really old* or gone.

Many women over the years have told me that their dream is to have twins, to get it all over with in one shot, a two-for-one deal. I am tempted to tell them to adjust their dreams, to have one at a time, that twin pregnancies are dangerous, post-partum is a nightmare and bonding is harder when there's two of them and one of you, they will fight hard for your individual attention and you will never feel like you are enough. If you use donor eggs to have those twins that you are struggling to bond with, you might be left wondering if it's because they are not genetically related to you, rather than the torture of competitive screaming and extreme sleep deprivation. There were many times, especially in the first year, that I secretly, shamefully wished we had only put in one embryo. I don't tell them that, nor do I tell them to adjust their dreams, but I do try to share something of the physical and psychological risks of parenting twins.

As well as sending us to a genetic counselor (I take issue with the term "counselor"), a dietician (how to eat for three), Dr. Bishop also sent me to a psychiatrist who specialized in maternal mental health, due to my history of anxiety and depression. I wanted to decrease my anti-depressant dose during the pregnancy, the psychiatrist was adamantly against it. She also had a research story for me; that the risks of taking anti-depressants while pregnant were negligible compared to the risk of suffering anxiety and depression during pregnancy. She had no tolerance for my side of the story, to how I felt my own body was communicating to me: "Do you want me to sign something Allison? I will. I will sign a piece of paper saying that your babies will be fine if you stay on your meds. But you're asking for big trouble if you go off them" (Personal communication, April 2009) I was terrified of doing something else, like ICSI, that could possibly hurt the babies, I remembered my mother's story of being offered thalidomide but something "didn't feel right," so she went against her doctor's advice. My "back was up"; the psychiatrist and I did not listen well to each other, we were entrenched in our competing single stories. I conducted an experiment with myself (something my GP always encouraged), and decreased my dose, listening intently for any psychological distress and monitoring my ability to sleep on the lower dose. The psychiatrist was angry, refused to see me anymore, and sent a bad report card to my GP. I returned to my regular dose postpartum when my body told me in no uncertain terms it was needed.

It was my GP who commented on how difficult it is to teach new doctors how to discuss risk with patients. I remember her saying there was an art to it. Hartley Jafine teaches theatre arts in the health sciences program at McMaster University in Hamilton, Ontario. He believes that healthcare education needs the arts, specifically theatre. “The pressures on healthcare professionals are immense. There’s this constant need to perform perfection” (Jafine, 2014). Jafine explains that over the course of medical school, doctors’ focus shifts from being empathetic to getting it right. His courses are not required but he argues they should be. Why? Because theatre skills are life skills. Theatre skills promote deep listening and empathy, an ability to be present, to be aware of bodies in space, to listen and receive the message the patient’s body is sending. Doctors are trained to ask, “what’s wrong with this patient” rather than “what is this patient fighting for?” If you know what a person is fighting for, you can “view the world from their box”; they are the lead character in their story, a story that becomes important and complex. Jafine (2014) argues that theatre skills need to be embedded in the curriculum, benefitting the healthcare professionals which in turn benefits the patients.

The University of Toronto offers a course in Narrative-Based Medicine. The course description:

> Narrative-based medicine is premised on the understanding that, knowingly and unknowingly, practitioners and patients together construct narratives over the course of their encounters; that these stories – with their multiple characters, conflicts and desires, subtleties and miscommunications – affect the nature and meaning of health events in all our lives; and that getting better at working with stories of all kinds has a powerful impact on both patient care and physician fulfillment. (University of Toronto CPD, n.d., para. 1)

It is exciting to think that story as theory can be used in the health sciences as well as the social sciences. As medicine becomes more and more patient centered, I hope that the use of auto-ethnodrama, teaching and learning how to tell and receive intimate, personal stories will play an important role. The relationship between patients and doctors, is an intimate one, and that intimacy can produce personal empowerment or leave folks feeling victimized by the professionals who are meant to help them. Everyone will benefit by learning how to tell a good story, to gain an understanding of where we feel shame, put that shame aside, and create a story that seeks dignity instead.

Finding 3: "Resemblance Talk" Vignette

(A woman in her mid-40s, Kate, enters a coffee shop pushing twins in a double stroller, other characters come and go, all played by a second actor)

KATE

(speaking to the audience)

There's this thing, this cultural thing called 'resemblance talk', and I had no idea how pervasive it is until these two came into the world. As soon as people see a new baby, the first thing they do is look at the parents to see who they look like. It's just what we do, I did it all the time, I still do it, but I’m more aware of it now that I'm on the receiving end of the conversations. Like this one, in my neighborhood café.

CAFÉ OWNER

Oh! Here they are! The new babies, let me look, let me look. They're so beautiful! Wow, she looks just like her father.

KATE

Yes, she does.

CAFÉ OWNER

And he looks...

(A confused look at the baby and Kate)

He looks just like his father too!

KATE

I know.

(An awkward pause)

CAFÉ OWNER

Well, they say that babies always look like their Dads in the beginning, right? That way they won’t abandon their children.

KATE

They say that?

(Another awkward pause)

CAFÉ OWNER

Do you want a chocolate croissant?

KATE

Yes please. And a cup of your strongest coffee.

CAFÉ OWNER

Aren't you breastfeeding?

KATE

Yes, but I gotta be awake to do it.

CAFÉ OWNER

Coming right up!

(The café owner exits. Kate sits, takes out one baby and starts breastfeeding, the other baby starts to cry, Kate rocks the stroller with her foot,)

KATE

Then there are the conversations with well-meaning perfect strangers.

(Perfect stranger enters)

PERFECT STRANGER

Oh wow! You certainly have your hands full.

KATE

I do, yeah.

PERFECT STRANGER

Do twins run in your family?

KATE

No.

PERFECT STRANGER

Oh.

(waits for an explanation)

KATE

We had a lot of scientific help getting pregnant, so we knew we might get twins.

PERFECT STRANGER

Oooh, so they're not natural then.

KATE

Well, they're not robots.

PERFECT STRANGER

No, but...

KATE

Or clones.

PERFECT STRANGER

Of course not, well, aren’t you funny! Well, good luck!

(Perfect stranger exits. Kate burps the baby, puts that baby back in the stroller, picks up the other baby and puts her/him on her other boob.)

KATE

With acquaintances, the ones who know we did IVF, but don't know we used donor eggs, the conversation usually goes something like this.

(Acquaintance enters)

ACQUAINTANCE

Hi Kate! Wow. Nature is amazing. Your daughter looks just like Jack and your son looks just like you.

KATE

That's funny, I don't see it. I think Clara looks a lot like Jack's mom and Will looks a lot like Jack's dad.

ACQUAINTANCE

No way, that boy is all you.

KATE

Huh. Weird.

ACQUAINTANCE

Want me to get you a coffee? Decaf, right?

KATE

That'd be great, thanks.

(The acquaintance exits.)

Every time some well-meaning person mentions how much Will looks like me it’s like a little stab right in the heart, a reminder that they’re not genetically related to me. We told our families and our closest friends about the egg donor, but do I have to tell everyone else? If I don't tell, I feel like I'm lying, but is it really any of their business? How much of my intimate life am I required to share?

(Kate finishes feeding the second baby and puts her/him back down in the stroller. A blissful moment of silence and Kate closes her eyes, instantly falls asleep. A woman in her late thirties/early forties enters, carrying a tiny dog, she stops and stares at the double stroller. Kate’s head falls forward, jerking her awake.)

Hi.

DOG LADY

Hi. Your babies are beautiful.

KATE

Thank you. I think so too.

DOG LADY

I, I have this friend, she's been trying to get pregnant for ten years and having twins is her dream. She's been doing IVF for two years already, but she keeps losing the babies. She's going to try it one last time but after that she's out of money.

KATE

Oh, I'm really sorry to hear that. It's so hard, and so damn expensive.

DOG LADY

Did you do IVF? I'm sorry, that's none of my business.

KATE

It's okay. We did, yeah.

DOG LADY

How many tries did it take?

KATE

One.

DOG LADY

One? Oh my God, I don’t know anyone who had it work the first time.

KATE

I know, we got really lucky.

DOG LADY

(Fighting emotions)

Well, congratulations. I'll tell my friend, maybe it'll give her some hope.

(Starts to leave)

KATE

Um, hang on a second, um, it really wasn't that simple, I'm forty-five and I didn't have any good eggs left and we did do IVF and it did work the first time, but we had an egg donor, who was twenty-four. That's why it worked. It was a lot more than just luck.

DOG LADY

Oh. I see.

KATE

I did get lucky with the pregnancy, twin pregnancies are a lot more dangerous than I thought and postpartum - despite how sweet they look now, is a fucking nightmare, excuse my language. I hope your friend can have one baby at a time, if she wants more than one.

DOG LADY

I hope so too. She's always wanted lots of kids.

KATE

(Searches for a scrap of paper and writes down her number)

If your friend wants to talk about it, I'm happy to tell her our story.

DOG LADY

Thanks. I'll tell her.

(She exits the way she came, without ordering a coffee, Kate watches her go, understanding the other woman's pain, looks to the audience and shrugs her shoulders as if to say, "what else can I do?")

Discussion

To whom do I owe an explanation (besides my children)? The ending of this scene has happened many times and in different situations. Despite wanting more privacy, I always tell women who have struggled with infertility. I know how alone they feel, and regardless of their age, I think perpetuating the cultural myth of perfectly functioning female reproductive systems in our 30s and 40s is cruel and selfish. Women have enough selfish labels to field, we're selfish if we focus on a career when we're young and have kids later in life, we're selfish if we keep working after having babies, we're selfish if we choose not to be mothers, we're selfish if we make babies instead of adopting, selfish if we choose anonymous donor eggs, the list goes on; we don't need to keep adding to it.

Sometimes people get uncomfortable or embarrassed when I talk about my egg donation experience (this was the case with some family), they may have assumptions and judgements and like to gossip. Brené Brown (2010) reminds me that not everyone is entitled to my story. However, telling people is good practice, practice of letting go of shame and sadness, letting go of trying to control how people see me.

Talking openly about infertility/assisted reproduction in front of young children can be an opportunity for them to see how proud and happy you feel about how they were made, rather than a silence they may internalize as something negative, an othering of sorts. I wish I had done that more when my kids were younger.

Parents are now being encouraged to begin practicing telling their children about their origins during pregnancy. The longer parents wait to have the conversation the harder it becomes. I am very glad we told our kids before they were three, having to tell them now, when they are struggling through the ravages of puberty would be terrifying, I can understand why parents who wait, often never end up telling at all.

Some of the most off-putting and hurtful comments have come from close family members. Top of the list is this one: “Why would you want to find her? What if she’s a psychopath? I mean, what kind of person *does* something like that?” This was in response to me talking about posting on the Donor Sibling Registry. Another doozie was this one, said to my partner when he was explaining how we got pregnant: “It’s your sperm? Good. Then the babies are *yours*.” Sometimes it is the silence that is awkward or upsetting, I used to bring up the donor in conversation with family members, but I was often met with an uncomfortable silence. I wondered why they seemed so embarrassed when I wasn’t, maybe it was because I was referring to infertility and they didn’t want to talk about that. Different family members would go on and on about how my children resemble my partner, carefully omitting any reference to me or the donor. The thing I find the strangest of all is when friends (and one family member), even when they know about the egg donor, comment on how much my son resembles me. Sometimes I think the donor, or her brother, must have looked a lot like my family, or maybe my very last egg got in the mix somehow. Either way, it pleases me.

Why bring this conversation out in the open? Because it addresses a bigger problem than individual shame/embarrassment/sadness. My family story speaks to other family stories, families that look different than mine. The fact that I can hide the egg donation part of my story to avoid social stigma contributes to the ongoing social judgement and othering of families who are outside the social norm, LGBTQ2+ families, single parent families, anybody who has had to turn to science to build a family. Telling my story, to a wide variety of audiences, gives me the opportunity to oppose limiting and harmful definitions of what a *normal*, *natural* family is.

It's no longer just my story to tell or not, it is a family story, and my children will soon make their own decisions about how to tell it. As a steward of their story, I can frame it positively, and be sensitive to their feelings, separate from my own, in the hope that they will take ownership of their story unburdened by mine. They are growing up in a world very different than the one I grew up in.

Finding 4: "Mother's Day" Vignette

KATE

I never thought this day would be mine; lounging in bed waiting for my kids to bring me breakfast. It's still a kind of miracle delight to me that I'm a mom. I want to roll around in the decadent pleasure of it. I'm going to indulge myself, just for today I'm going to forget that I'm not like other moms, moms who got to pass down their own genetics to their kids.

(Kate's son, Will, nine-year-old science geek enters the bedroom)

WILL

Hi Mom.

KATE

Hi baby.

WILL

So, Mom?

KATE

Yeah?

WILL

I was thinking.

KATE

Oh oh.

WILL

I was thinking, I mean, you're my Mom, but in a way, you're not my Mom.

KATE

Dude, you know it's Mother's Day, right?

WILL.

Yeah, that's why I was thinking about it.

KATE

Oh. Hey, how about you go downstairs and help Daddy and Clara make me breakfast?

WILL

Nah, that's their thing.

KATE

True.

WILL

So...

KATE

So, you want to talk about the egg donor?

WILL

Yeah.

KATE

Okay. Okay, um, yes, I'm your Mom, of course I'm your Mom, I mean, I grew you in my belly.

WILL

But I don't have your genes?

KATE

No, you don't. You have Daddy's genes and the egg donor's genes.

WILL

So, is she my mother too?

KATE

No, she’s your donor. But she did give you half of your DNA and so you could say she’s your *genetic* mother, but she’s not your birth mom, uh, shit, do you know if Dad made coffee yet?

WILL

Wait, did they have S-E-X?

KATE

Who?

WILL

Dad and the egg donor.

KATE

No. Dad gave the doctor some of his sperm and she gave some of her eggs and the doctor put the eggs and the sperm together in the lab. And when the fertilized eggs started to grow the doctor took them and put them into my uterus, and luckily, they kept growing and they grew into you and Clara. That's another kind of mother, a biological mother, who used to be the same person as the genetic mother but I like to think I'm your biological mom because I grew you and birthed you and -

WILL

And I drank your boob milk.

KATE

And you drank my boob milk.

WILL

Mom?

KATE

Uh huh?

WILL

Did you know that human DNA is ninety-five percent the same as our closest biological relative the chimpanzee?

KATE

Really? Who told you that?

WILL

YouTube. And you know what else? All human DNA is ninety-nine percent the same.

KATE

Ninety-nine?

WILL

Ninety-nine. Maybe even more than ninety-nine, maybe ninety-nine and a half.

KATE

That's amazing.

WILL

So why is everyone so different?

KATE

It's a beautiful mystery.

WILL

Mom, come on, it's science.

KATE

Every time a new person is made, their DNA gets arranged in a different way, put into a different order, like a code and every person has their own special code.

WILL

You mean like video game code?

KATE

Yeah. I think.

WILL

With alternate endings.

KATE

Exactly. Which is why you and Clara are so different even though you're twins. Do you want to know another way to be a mom? I think it’s the most important way.

WILL

Okay.

KATE

So, there's something called a social mom, which is a dumb term because it sounds like all that person does is arrange playdates or something but what it means is that she takes care of you every single day and loves you forever.

WILL

We learned about color blindness in school.

KATE

Jumping to color blindness, okay.

WILL

And Mom, it's super rare for a girl to be color-blind, you know why?

KATE

Why?

WILL

Because her Dad has to be color-blind and so does her Mom, or the mom has to carry the color-blind gene.

KATE

You know what Will?

WILL

What?

KATE

I'm color-blind.

WILL

What the beeeep?

KATE

I'm color-blind. Grandpa Art is color-blind, and Grandma Marie carries the gene. And when my optometrist told me that I was color-blind she said if I ever had a son, he would one hundred percent be color-blind.

WILL

So, I'm color-blind?

KATE

Nope.

WILL

What? Oh!

KATE

I'm your mom and I'm color-blind but you and I aren't genetically related so...

WILL

So that's a good reason to have an egg donor!

KATE

Being color-blind isn't really a big deal for me, but making a family was a big deal, that’s why we had an egg donor.

WILL

So, you're my social mom and my biological mom but not my egg mom.

KATE

I'm not your egg mom, but you can just keep calling me mom, okay?

WILL

(shrugs)

Okay. I love you Mom.

KATE

I love you too. Can you go tell Dad I really, really need my coffee now?

WILL

(running off)

Happy Mother's Day Mom! Hey Clara! Moms color-blind!

Discussion

This vignette is an amalgamation of two conversations I had with my son, the first on Mother’s Day in my bedroom, the second during a bedtime cuddle in his room. Kirkman (2008) shares a study participant’s thoughts regarding talking with her children about their conception: “it makes me feel so worthless and inferior again, just when I’m enjoying being a ‘real’ mother…I just hope they won’t think less of me” (p. 244). Do I feel worthless and inferior? No, eleven years of nurturing my kids have largely healed the losses of my infertility. However, these conversations are never as light and easy as the text of this scene implies, my heart races, there is a distant, blunt jab to the gut, and I need to remind myself to breathe and tell the truth, to be present. Kids want to know where they came from, and how they got here. I have come to know that in normalizing egg donation for my kids, I am simultaneously normalizing it for myself. It is through our ever-evolving relationship that this learning happens, through the stories we create together.

I carry the loss of genetic motherhood, but that loss no longer defines my motherhood, it does not overshadow my day-to-day experience of mothering. At the same time, the donor is important and how we talk about her is important. She did not relinquish a child to my care as in adoption, but she did more than provide a few cells, her role is bigger and more complex than that and I'd like to construct a respectful story. I can't predict how my son's feelings about being donor-conceived will evolve as he becomes an adult, but I can attend to the ongoing relational identity (Nordqvist & Smart, 2014, p. 25) we are constructing now. When my son showed up in my room on Mother's Day, with all his beautiful curiosity, he was looking for a story about belonging, *how* do we belong to each other? I take a lot of comfort from Kirkman (2008) when she states: "The child of reproductive technology reflects the world that is real and familiar to him, in which he takes for granted the complex contributions to his conception" (p. 247).

My daughter's first questions/concerns about the egg donor were similar: "is she *also* my mother?" I had the feeling she was looking for reassurance, that our family unit wasn't going to change, that there wasn't an ambiguous "*other* mother" somewhere that might replace me. I look for opportunities to discuss our donor. When my daughter wanted to know why we were all fair-skinned and blonde and she wasn't, I reminded her of the Greek heritage on her father's side of the family, but I also took the opportunity to tell her that our donor was a brunette too. She asked me recently what I was writing about and when I told her I was writing about being a mother with the help of an egg donor, her reply was, "Why are you so obsessed with her?" I don't have an elegant answer for that one but she's right; I am the one who is "obsessed," not them. I asked them recently if they thought about the egg donor and they both replied, "No, I only think about her when you bring her up." It's a difficult balance, I need to bring her up when an opportunity arises because quite frankly, they forget. It's important that they grow up knowing so they don't feel the information was withheld or that I am ashamed of how they were made. On the other hand, it's important that I don't push the information on them so much that the knowledge itself becomes a source of stress or trauma for them: You're donor-conceived and that's okay! Nothing to be ashamed of!

I am a member of three private facebook groups where parents, donors, and donor-conceived adults share and discuss their experiences. The issue of whether donors should be called mothers/fathers is a volatile one. Many recipient moms object to the word "mother" when applied to the donor, others are fine with it providing the word "genetic" precedes it, but no one, including me, wants to be called the "social" mother. I imagine adoptive moms feel the same way. We worked too hard to become parents to accept such a limiting title. Some of us want to take ownership of the word "biological" if we carried the baby, and others insist that biological and genetic mean the same thing so we can't claim that title. There is at once too many words to describe us and not enough. I'm going with "Mom."

Finding 5: “Marina and Me” Vignette

(A woman in her 50s speaks to her therapist/audience)

KATE

Last night I dreamt I was that famous performance artist, Marina Abramović, and I was performing the piece where she sat in a bare room and people waited hours or even days, just to sit across the table from her for a few minutes, no words allowed, just bodies in a room responding to each other, you know? I was sitting there, in a long blue dress, and I could feel people watching me as they waited, I could hear the shuffle of feet as the line snaked around the room. A bell would sound when it was time for a new person to come and sit and in between I would close my eyes, breathe, do whatever I needed to do to let go of the last person and bring myself to the next, empty and curious.

It was almost the end of the day when she sat down, I had already been sitting for close to nine hours and all the little muscles next to my spine were complaining. When I opened my eyes, the first thing I noticed was the necklace. A gold circle with a curved bump, hanging on a delicate chain. Underneath my blue dress, I wore the exact same necklace, except mine was silver and second hand because I couldn't afford the gold. I brought my eyes up to hers and that's when I knew, not just because she was wearing the gift I had given her but because I was looking into my daughter's eyes. I didn't need a DNA test, I knew it was her, our egg donor. She didn't know that I was the woman who received her eggs, or that I have a daughter with her eyes. My heart was pumping so hard I thought she must be able to see it, my ears were ringing, I had to remind myself to breathe before I fainted. I smiled at her. I was so happy to see her. She smiled my daughter's big, beautiful smile back. I had so many questions I wanted to ask. Does she want to know whether we had a child? Does she want to know that child? Does she have children of her own now? Does her family know she donated? Did she have side-effects? Does she regret it? Did she really understand what she was consenting to? I know I didn’t.

I circled my head and rubbed my neck, casually reached for my necklace, and brought it out on top of my dress. She looked at it, and smiled again as if to say, 'that's funny we have the same necklace'. She didn't get it, how could she? Plenty of people have the same necklace, it's Tiffany's for God's sake, it's not unique. What a dumb gift. I wanted to stand up, open my arms, hug her, tell her thank you, thank you for

> making me a mother, thank you for risking your body to fill up mine. I wanted to tell her that I have a daughter who is well loved and doing great and there’s plenty of room in our hearts for more people that care about us, *more family*, a bigger village, you know? But the room was full of press, their cameras poised and ready, and if I broke the rules of the performance, they'd follow her out, wanting to know who she was. The bell began to ring, she pushed her chair back from the table and stood up, and I…I let her go, I let her walk out, back into an ocean of anonymity. How was I going to tell my daughter I had been sitting with her and then just let her go? The damn bell wouldn't stop ringing, it got louder and faster, screeching at me.
>
> That’s when I woke up, standing at the window of my bedroom, looking out.

Discussion

It was very hard to write a story about the anonymity piece of this puzzle. Anonymity is an ongoing struggle; it is far from resolved for me. The attempts that came before this were all born out of real-life events with my genetic brother and sister, and they felt ethically out of bounds. So, I tried to make something up, a truthful fiction, something that would plunk me right in the middle of a child’s (potential) need to find/know their donor and any half-siblings they may have, and the donor’s (potential) wish to remain anonymous, to keep her private life, private. The “real” piece of data in this story is the necklace. The clinic asked us to write the donor a letter and give her a small gift when the donation process was complete. What do you buy a woman who gives you eggs that become your children? The “gift” donors give is priceless and impossible to reciprocate, whether they are paid a fee for the process or not. When I started thinking about this thesis, I found a second-hand matching necklace, wearing it gives me a sense of connection to her.

There was a lot to sift through. When we conceived our kids in early 2009, adult donor conceived folks were finding donors and half-siblings online through direct-to-consumer DNA testing. True anonymity had become a myth, yet the industry was still recruiting donors and intended parents with anonymity written into the contract. Our clinic's donors were all anonymous. The clinic sent us three donor profiles, all amazing women, most had donated before, some had children of their own, but I didn't feel any connection to them. The process still felt disembodied and strange. Then we were sent the profile of a potential new donor, who would be available pending the results of her genetic tests. The egg donor coordinator was very excited about her and when I read her profile (we never saw any photos of donors, it never occurred to me to ask), I was moved to act, again my body said yes, she and her family felt like people we would want to have in our lives. Her ancestors came from the same part of the planet as mine, we were the same height, blood type and had a lot of the same interests. She wanted to donate during her next cycle, and we decided that if she was willing to donate to us, we would go for it. The anonymity issue was troubling me, but we put it aside because she felt like the right donor for us. She was "the one."

During my pregnancy, I asked the egg donor coordinator if she had spoken to our donor, and she replied that she had spoken to her twice since her donation; that she was a one-time donor, she had had a wonderful emotional experience donating but a terrible recovery (Personal communication, September 16, 2009). I panicked. What had happened? I asked but was not told. Left with only my imagination, which tends to go straight to dark places, I worried. Had they overstimulated her? Did she suffer ovarian hyperstimulation syndrome? Was she okay now? She had produced 27 eggs. That sounded like too many. Therapist Jana Rupnow (2021) spoke with Diane Tober on her podcast *Three Makes Baby*. Tober is conducting the first long-term study on egg donors and has found that American donors are producing a lot more eggs than egg donors in other countries. For example, her data shows Australian egg donors produce between 10 to 15 eggs/donation cycle, which is on the high side, while the higher range produced by American egg donors is between 30 and 80 eggs. Twelve years after our treatment cycle, I am still worrying about our donor. Has she experienced any long-term side effects or health issues that *might* be connected to her donating? There are no long-term studies on egg donors. None. Tober's will be the first. We are all, recipient's and donors, left with the ambiguity of not knowing.

Living through the COVID-19 pandemic has given me another reason to wish I could contact her. I can contact any of my extended kin to find out if they are safe, but I can't contact the woman who participated in one of the most intimate experiences of my life, who made my motherhood a possibility. Tober's ongoing interviews (there are over 500 egg donors in her study, with more asking to join) reveal that 90% of donors want to have an open relationship with the recipient family but the clinics tell them it is not possible and will not facilitate any contact. A full 95% of egg donors want registries, not only for potential contact in the future but to track any adverse effects of treatment for study. In 2019, I contacted our egg donor coordinator again by email, asking if she thought our donor might be open to contact. She offered to reach out to our donor on our behalf. She did so twice, over a period of 6 months, but never received a reply. I was devastated. Worse, I began to question the truthfulness of the coordinator, whom I had found so caring and helpful over the years. Other clinics had lied to both donors and recipients regarding contact; maybe she was lying too.

Anonymity protects donors from any legal responsibilities of parenting, and places those responsibilities squarely on the recipient’s shoulders. Anonymity addresses the legal needs of donors, intended parents, and clinics, but leaves the needs of donor conceived children out in the cold. So far, my kids have shown no interest in knowing the donor, but the teen years are coming. It’s possible they may grow to feel they are missing a valuable piece of knowledge about themselves, their identity, an “intentional separation, and loss of nurturing and identity-forming relationships with their biological relatives due to their donor conceptions” (Rose, 2001, p. 1).

To counter the fear that we may have caused harm to our kids, many recipient parents are testing their young children’s DNA, using DNA sites like Ancestry.com to find donor siblings and sometimes the donor themselves, hoping their kids can benefit from these relationships as they grow up. I have watched the heated discussions on the fb groups, felt the anger of donor conceived adults and the intense desire from parents, mostly mothers, to do the right thing by their offspring, to fix their “mistake.” On the other side of the argument, some donor conceived adults say they would be furious if their parents had tested and banked their DNA with a private company without their consent and mothers, of which I am one, who feel that although we did the best we could with the limited knowledge we had at the time of choosing an anonymous donor, making a second decision with a similar lack of information and another healthy dose of shame would be reckless. I do not want to make another “mistake” in an uneasy attempt to fix the first one. When my kids are older, when they can consent for themselves, and if they want to find more information through DNA testing, I will help them. In the meantime, I have found some solace in becoming a member of the Donor Sibling Registry (DSR). The DSR offers a place for parents, donor-conceived people, and donors to connect, with mutual consent, maintaining their anonymity if they desire. If our donor wants to connect, she will find us there. The DSR, based in the U.S., has become well known around the world, facilitating 20,000 connections to its current membership of 75,000 parents, donor-conceived people, and donors.

It's been 2 years since the day I shakily pushed the button on the DSR post. Writing this monologue, I came to the realization that like the character who dreamt she was Marina, I also need to let our donor go, back into the ocean of anonymity. She may be in the 5% of donors who do not want to have openness or, she may be hoping we find her, as many donors feel it is not their place to do the reaching out; they are wary of intruding upon the family life of the recipient parents, but I must live with not knowing how she feels. Choosing an anonymous donor doubles down on the grief of infertility; it's another way to feel like I've failed as a mother, and it can be silencing. I remain stuck in the middle of "what if my kids need to know her?" and "what if she never wants to be known?" Keeping the conversation open with my kids, letting them know that it is okay to be curious, that I am not hurt by their curiosity; rather I share it, and will be by their side, as mom, to help them find more information if they want/need to is the uneasy bargain I have struck with myself for now.

What/who is family? Over the last few years writing and thinking about my donation experience, I have come to define family as: the people who look after us, who listen to us, see us, make sacrifices for us, big or small. These people/animals may live with us or not, be genetically related to us, or not. A family member is active in making loving, compassionate relationships. Family and extended family is built from these relationships, whether there is a genetic tie or not.

If our donor does answer my post someday, or my kids find her someday, if she wants to be known, our relationship doesn't have to be deep, but it does need to be kind, putting the needs of the children we created together at the forefront.

A recipient parent on my fb discussion group was forthcoming about why, in her culture, and in many countries of the world, keeping the use of a donor secret is felt to be in the best interests of the child. Use of donor gametes is considered adulterous, and families can be shunned from their community. Blanket statements about right/wrong are not compassionate or ethical as each family is different and should have room to make their own parental decisions. However, there is room for more education, and depth of informed consent for both donors and recipients. In a world where home DNA testing kits are given as Christmas gifts, and world-wide social media networks, clinics can no longer promise anonymity, even if the country they practice in legislates it.

Circumstances and feelings often change over time. For example, Tober (as cited in Rupnow, 2021), states that when egg donors go on to become mothers they often feel differently about wanting to know and be known by their donor offspring, and on the other side of things, many donor-conceived adults who have always known about their conception report no need or interest in knowing their donor, while others may feel the need to know more about their genetic heritage in later stages of their adult life.

Finding 6: "Confessional" Vignette

(We find Kate standing in a hospital room, looking at her mother who has been placed on life support. We hear the ventilator and a heartbeat monitor, sounds that fade as Kate begins to speak.)

KATE

Hi Mom.

I just met with your doctor. He gave me this document and told me I need to sign it, as your medical power of attorney. When did I become your medical power of attorney? I'm more than a little confused Mom. Aaron's the oldest, the two of you agree on everything. Besides, I thought we weren't speaking. That last fight we had, that was a big one. You shouldn't have said those things in front of Clara, Mom. Against God's will? Unnatural? She's an 11-year-old girl, she has enough on her plate she doesn't need your shame. You know, she's had your picture on her bedside table since she was about three and she says goodnight to you every night? You're her grandmother and she loves you without any conditions. It's that simple for her. It should have been that simple for you too. And you know Aaron's going to fight this, he'll want to keep you on the machines and pray for a miracle and no matter how I reason this out, or how much I agree with the doctors who tell me that you're already gone, I'm still going to feel like, I, ... (killed you), which doesn't feel very natural. Congratulations Mom, you win. You got the last word. Good for you.

Mom, do you remember when I was in university and you called me up out of the blue to tell me that if I ever had an abortion, you'd never speak to me again? That was a weird day. No hello or goodbye, just I'll never speak to you again, and click. And we never talked about it, you never asked, and I never told. That was one of our silent stand offs.

Of course, I never had an abortion, I could never get pregnant, even when I was twenty, and I tried. A lot. Sorry.

I have two papers to sign today, Mom. When we made the babies, the doctors chose the two healthiest looking fertilized eggs, but what I've never told you is that there were more than two, there were fourteen fertilized eggs, so twelve of them are frozen, in storage, in a kind of technological limbo, a bit like this one. But unless they are thawed out and successfully implanted into someone else's uterus, they will never become fetuses, or babies, although they have the potential to become those things, but they don't have bodies, they don't feel pleasure or pain, they don't get sad, they don't have heartbeats. Do you know what I think they are Mom? I think they're cells of frozen hope.

And I want that hope to continue, I want to give them back to science because science can be miraculous, Mom. I'm having trouble signing that paper even though I think it's a good choice, maybe even a beautiful choice, but I keep hearing your voice, on the phone, accusing me of twelve abortions and telling me you'll never speak to me again. And I guess you never will.

Did I ever tell you about the day we took our two sprouts out of their petri dishes and put them inside me? I call them sprouts because the medical term for them, at this point, five days after fertilization, is blastocyst, from the Greek word blastos, meaning sprout, and kystis, meaning capsule. The embryologist scooped them up into a tube, and she put an air bubble in front of them and another air bubble behind them. Then the gynecologist pushed that tube up into my uterus and we all watched on a big ultrasound screen. The blastocysts were too small to see on the screen, but we could see the air bubbles. We watched them float up out of the tube. Of course, they were just bubbles, but on the screen, they looked like, stars moving through space. Even in that sterile room, with my feet in stirrups and all the white coats standing by it was strangely intimate. Natural. They told us that we had arrived at the point where science had to step aside, that they couldn't make the sprouts take root and grow. It was up to the spouts, or a higher power if we believed in one. I told her I was in recovery from religion.

I don't know why I told you all that. I love you Mama. Of course, I'll be here when they turn off the machine and I'll deal with Aaron for you. Mom? Do you think you could give me one of those signs you're so fond of?

(Nothing except the sounds of the ventilator and the heartbeat monitor fading back up. After a moment, Kate climbs up onto the bed beside her mom and the lights fade.)

Discussion

Most of this monologue is fiction, but all of it is true. I was raised in the Anglican Church (what I call “Catholic light”); my mother was not overtly religious and stopped going to church decades before her death. She loved my kids unconditionally and never questioned the morality of how we made them. She did make the abortion phone call although she called my sister, not me. There were dinner conversations about assisted suicide and my parents both considered it amoral and unnatural. They felt it was not up to us to choose when we die or if we end a pregnancy. It was up to God. I am not religious; I have both feet planted firmly in a pro-choice world. And yet, I cannot escape the church's influence on my thinking, despite my constant struggle against its dualities; good/evil, right/wrong, body/soul, heaven/hell, thinking/feeling. It is part of me, an embodied knowing that social scientist Pierre Bourdieu (1990) termed habitus, "as society written into the body" (p. 63). Religious language pops up in my writing quite a bit, like the phrases "Unholy Trinity" and "Sin big" in the first monologue, *Donuts*. Knowing how difficult it was for me to decide what to do with our leftover embryos, I often wondered how much more difficult it would be for women of deeper faith.

When you create children through assisted reproduction, you often end up with embryos you will not use for an attempted pregnancy. Those embryos occupy a liminal space between life and death, they are both alive and not alive and their fate is up to you to decide. After a decade of trying and failing to become pregnant, the concept of leftover embryos was difficult to grasp and there was no in-depth discussion of the possibility of leftovers at the clinic before we began treatment. We thought of our frozen blastocysts (embryos) as precious, potential humans and at the same time we could not bring ourselves to donate them to other infertile couples who would provide an opportunity for them to have a human life. Donating them to other couples would be facilitated through the clinic where they were stored. The donation would be anonymous again. How could we give away our children's genetic siblings to be raised by people we didn't know? How would this impact all the kids in the future? Would any of us ever stop looking for each other? What if the other parents didn't tell them about their origins? Today there are options for open embryo donation, perhaps if we had kept them in storage longer, we would have donated them. Maybe.

We did not want to thaw the embryos out and dispose of them. My parents were children of the great depression and I abhor waste. Donating the embryos to scientific research felt like a reasonable choice, particularly embryonic stem cell research. U.S. President Barack Obama had lifted George W. Bush's limitations regarding the use of human embryos for stem cell research to allow the use of surplus embryos that would not be used in attempts to have a child. The making of stem cell lines held great promise for potential treatment of several debilitating diseases including Parkinson's disease, Alzheimer's disease, diabetes, and multiple sclerosis. Such valuable research felt meaningful and helped us conceive of the embryos' human potential in a different way. Still, I agonized over the decision and after we made it, I continued to agonize over it, my practical logic at war with my spiritual side. Thinking about this decision through the lens of embodiment; in that embryos do not have a soul or consciousness floating around outside of their body has helped combat my dystopian imaginings about the embryos being conscious of their destruction in a research lab.

There are very few people I feel safe talking about it with, telling people we used donor eggs is easy in comparison. Embryo disposition is a new addition to the list of deeply personal, embodied reproductive issues woman don't talk about for fear of social stigma, like miscarriage and abortion. For those of us who feel that an embryo is more than a bunch of cells but less than a human being who has an inherent right to life, our desire to have children has ironically thrust us into the abortion debate. I couldn't help but wonder if disposing of frozen embryos is a new kind of abortion, in that disposing of them terminates their potential to become human beings. I know, I KNOW, I did not have

12 abortions. Unless the embryos are implanted in a woman's uterus their lifespan ends in the petri dish, there is nothing to abort. Still, pro-lifers gather outside fertility clinics, protesting the "murder" of children inside and the Christian Right in the U.S. continues to fight against women's reproductive rights.

The clinic gave us photographs of the two blastocysts we transferred to my uterus. I considered putting them on the fridge, daring myself to hope they would become actual children, well before my mother or grandmother would have considered her period was late, much less pregnant. I waited for the first ultrasound pictures instead.

I dread the day my kids ask me if there were any other embryos and what we did with them. If we connect with our donor in the future, she might have the same question. I have grieved the embryos we donated to research. It is a type of "disenfranchised grief," a term coined by grief researcher Ken Doka (1999), who describes it as "grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned" (p. 37). I brought the subject up in a donor conception support group meeting. My small group discussion included a Jewish woman whose two children were conceived via sperm donors and surrogacy, and her last embryo had been in storage for 18 years. Also in the group was a lesbian couple who had recently become parents via embryo donation, the only path to parenthood that was financially viable for them. I found it hard to look anyone in the eye. I wanted to apologize to the lesbian couple. I felt ashamed. The Jewish woman, who also happened to be a fertility lawyer, gave me the gift of telling me that our donation to research was also "a beautiful choice."

When I performed this monologue, I was met with a lot of empathy from the audience members. One person wanted to share his own experience of allowing a loved one to pass without more medical interventions. Another didn’t want to talk but asked if she could give me a hug. Loss is a human experience most of us share. Sharing stories offers us the opportunity to see loss from different points of view and for me, brought some self-forgiveness and healing as I allowed emotion to move through my body. I think that theatrical spaces, mutually created by performer and audience, have educational power. They are a place to explore “impossible questions” and disrupt ideological, limiting “single stories.”

CHAPTER FIVE: IMPLICATIONS AND CONCLUSION

Reproductive science is evolving at light speed; the treatment I underwent in 2009, where I cycled and synced my body with an egg donor's and then transferred fresh embryos (as opposed to frozen) to my body almost feels quaint. Now we have egg banks, donors donate when they want to, eggs (as well as sperm and embryos) are purchased frozen and sent around the world. The medical technology is astounding but the social/cultural aspects of assisted reproduction are left behind in a lower tech world struggling to catch up. We need de-stigmatized, empathethic discourse to evolve best practices and social support for all parties, especially the children conceived. Theatre, performance, and storytelling can remind us of our humanity in a post-human world.

Public School Education

The current Ontario high school health and physical education curriculum (Ontario Ministry of Education, 2015) does not include infertility or third-party reproduction. While it is given that medical and nursing students study these subjects, it would be very helpful to youth in Canadian high schools and beyond to engage in these topics. Adults as young as 18 can be recruited to donate. Also, discussions of these subjects could help students accept and embrace families that do not fit neatly into heteronormative structures, particularly single parent families and LGBTQ2+ families. All families are entitled to respect, dignity, and social support.

Clinical Education and Peer Support

I am learning how to facilitate peer support groups for parents, donors, and donor-conceived persons with the non-profit organization Donor Conception Canada. Telling our stories and listening to the stories of others offers the opportunity for participants to gain insight into their embodied knowledges while connecting to and learning from each other. I think offering a live performance followed by discussion of some of these pieces could be valuable in such support groups as well as medical educational settings. The issues that they bring forward are important in different ways for different audiences. The more we can openly discuss infertility and donor conception, the better chance we have of implementing more openness in the fertility industry, improving communication between medical practitioners and their patients, and easing the social stigma of infertility and assisted reproduction.

I don't think I would offer these vignettes to fertility clinics as they may read as negative press for the industry. Donors and recipients need education and support before they enter the industry process; once inside, the process of finding a donor, the medical processes for both parties and the loudly ticking clock (for recipients) are overwhelming. It would be a positive change to see clinics help donors and recipients access research, specialized counselling and independent legal advice to help them navigate the emotional, legal, and psychological challenges.

Revisiting the Original Themes

Where am I now? A discussion of the "sticky" issues in the literature review follows.

Paying Donors

I did not write a piece specifically about paying donors. When I began this project, I did not feel that paying our donor was unethical. Our U.S. clinic was committed to following the guidelines of the American Society for Reproductive Medicine (ASRM) which stated that egg donor payments over $5,000 may not be justifiable, and anything over $10,000 was inappropriate. The guidelines were not mandated but were widely followed (Martineau, 2019). Payment is constructed as bodily labour, that involves risk, and donors are paid a fee for undergoing the process. Their income is taxed. Her extended insurance and medications were also paid for by us. However, in the U.S., the free market prevails and in 2011, egg donors sued the ASRM, claiming the compensation guidelines were a form of illegal price-fixing. In 2016, the ASRM settled the case and agreed to eliminate its payment suggestions and agencies and clinics were free to offer donors more money, especially attractive, highly educated donors (Martineau, 2019). It is not uncommon for a tall, thin, attractive Ivy-league student to be offered $50,000 and up to donate. Donors of colour with specific ancestries are also high in demand and low in supply so they can negotiate very high fees as well. I am a middle-ground person, always looking for solutions in the grey areas, away from extremes. I have a lot more questions now. Is paying donors in the U.S a better system than turning them into criminals for accepting a reasonable payment in Canada? It is certainly cause for more study. When Canada enacted the Assisted Human Reproduction Act (AHRA) in 2004, making payment illegal the supply of Canadian egg and sperm donors dwindled, sending many hopeful parents to the U.S. Although some donors do not accept payment (if they donate to a family member or friend), most donors are motivated by payment as well as the desire to help others. Making Canadian donors and parents feel like criminals is not going to stop coercion; I believe it will contribute to it. Without any reasonable payment in Canada, many Canadian donors travel to the U.S. to donate to American clinics and egg banks, often for very high fees and promises of anonymity. I think reimbursement of expenses as well as a legal, reasonable fee for egg donors is warrented in Canada and I agree that donors should be able to negotiate their own terms as they are doing valuable embodied labour. What payment is reasonable and how to make treatment accessible to everyone regardless of economic class are questions that desperately need more study.

Anonymity/Disclosure and Registries

Like adoption, third-party reproduction is (slowly) moving towards more openness, acknowledging the needs of the children conceived to have information about their donor. However, Canada and the U.S. continue to “sell” anonymous donation to parents and donors. Clinics worry that their supply of willing donors will dry up if donors can’t choose to be anonymous (Egg donor coordinator, email communication, April 30, 2018). When England banned anonymous donation their donor supply took a tumble, then gradually came back up to reasonable levels. True anonymity no longer exists, as even without names or pictures folks can easily find individuals’ identities through DNA testing, social media, and online records. Even if a donor is an open ID donor and is willing to be known if the adult donor-conceived person asks, she can change her mind at any time. I think registries can provide families with a middle ground. Some clinics are writing the Donor Sibling Registry in their contracts, so mutually agreed upon contact can take place there. Every family is different; some donor conceived children will feel a need to know their donor, to be able to ask questions and share any genetic medical information, and others may not. Some parents feel that an open relationship with donors and their families is beneficial and enriching for everyone, others disagree. Along with voluntary registries like the Donor Sibling Registry I would love to see regulated provincial registries, where information can be shared, anonymously or not, between donors, children, and parents and individual families can do what they feel is best for their children. Registries would also be an excellent starting point for long term studies, allow the tracking of adverse effects and a place for donor conceived individuals to know how many genetic siblings they have. This is more troublesome with sperm donation as popular sperm donors can “father” many more children than egg donors, but the issue applies to egg donation as well. Donors provide three generations of family medical history at the time of donation and unfortunately there is no way of knowing how truthful they have been. It is not easy to be accepted as a donor; there are a lot of tests to pass. If family history is standing in the way of their acceptance, it could be tempting to omit serious information. If donors were required to share updated medical histories over time, they may be less likely to fudge their family history to be accepted as a donor.

At this point in their life my children do not have any pressing need for an accurate medical history from their donor, but health needs change over the lifespan and updated medical family history from the donor’s side could be important in their future. Although some clinics have sibling registries, most clinics will not facilitate contact between parents and donors. Registries would be a valuable middle ground for all parties to share information while maintaining a high level of privacy.

Surplus Embryos

Our donor was counselled about the possibility of surplus embryos as she gave up any legal rights and responsibilities to the eggs and embryos produced with her eggs. She also gave her consent for any surplus embryos to be donated to research if the recipient parents chose that. I was not counselled before the donation cycle, clinics save that conversation for later, if there are leftover embryos after the recipient’s family is complete. Infertility, miscarriage, and abortion carry a lot of social stigma in Canada and the U.S. That same shame and stigma continued for me when I had to decide what to do with our surplus embryos. When you use assisted reproductive technology to make human embryos you do not have the luxury of letting fate or a higher power decide what happens to these embryos, you must make the decision. Your decision may involve grief, grief that is often unacknowledged by our larger culture, disenfranchised grief, a grief, like abortion grief, we do not have a public ritual for. The decision of what to do with surplus embryos is individual, complex, and messy, like families themselves. Accessing knowledgeable emotional support can help women let go of internalized guilt and shame as they make their decisions. In response to the growth of assisted reproductive technology, specialized counselling practices have also grown. Parents and donors should have subsized access to this level of support.

Twins and Postpartum Depression

I did not go deep into the issue of the psychological effects of parenting twins; that is another study. I agree with Klock (2004) who calls for more studies to “assess the differential impact of twins, as compared to singletons, on maternal adjustment, postpartum depression and marital functioning” (p. 645). Would I have put in two embryos if I had had a better understanding of the psychological risks? I don’t know.

Conclusion

One last story.

Immersion

We throw rings for each other,
Diving deeper each time.
She shapes her fingers into a heart,
And blows love bubbles to me.
Now you do it, she says.

After we surface, she instructs:
Hold your breath!
And we sink again,
Her arms and legs wrapped around me,
Her cheek against mine.

And then it happened.
My Mother, who also loved to swim,
Dove in.
And it was her body I held,
Her body that held mine.

Inside my daughter's fierce embrace
Lives my Mother's last frail one.
That last, I-don't-ever-want-to-let-you-go hug.
Her baby-bird body,
Skin as soft as a cherry blossom.

I wished you lived closer, she whispered.
Me too, I replied.

Although I know nothing of poetry, I offer an attempt because the story seemed to fit that form. The intensity of this moment shook me. I am still feeling it more than 2 years later. I was swimming with my daughter. My mother had recently passed away, suddenly, of a heart attack. I had travelled to see her a few months before, and our last hug had been imprinted on my body. When my daughter and I embraced underwater, my eyes shut tight against the chlorine, her 9-year-old body seemed to transform, and the body I felt was my mother's, her vulnerable, bent spine, the breathtaking softness of her skin, our mutual heartache due to the physical distance between us. It was so startling that I almost inhaled the pool. When we rose to the surface I asked my daughter for another hug, desperate to see if the experience would repeat itself. She opened her arms and down we went. And there was my mom again, alive in that embrace, my physical knowledge of her somehow embodied within my daughter.

I offer this moment because I have realized that although I can’t pass down my family’s specific genetic make-up to my children, I can pass down their stories. Thomas King (2003) said: “The truth about stories is that that’s all we are” (p. 2). I understand this quote now. Genetics matter, especially in the world we are inhabiting now, but, when people search for genetic relatives on DNA sites, isn’t it *stories* they’re searching for? Ancestral stories to live with and learn from? I think of stories now as living entities, and the relationships we build with them teach us where, how, and to whom we belong. Stories, like us, change their shape over time, and offer us paths to emancipation and new worlds, like the story that visited my daughter and I that day in the pool.

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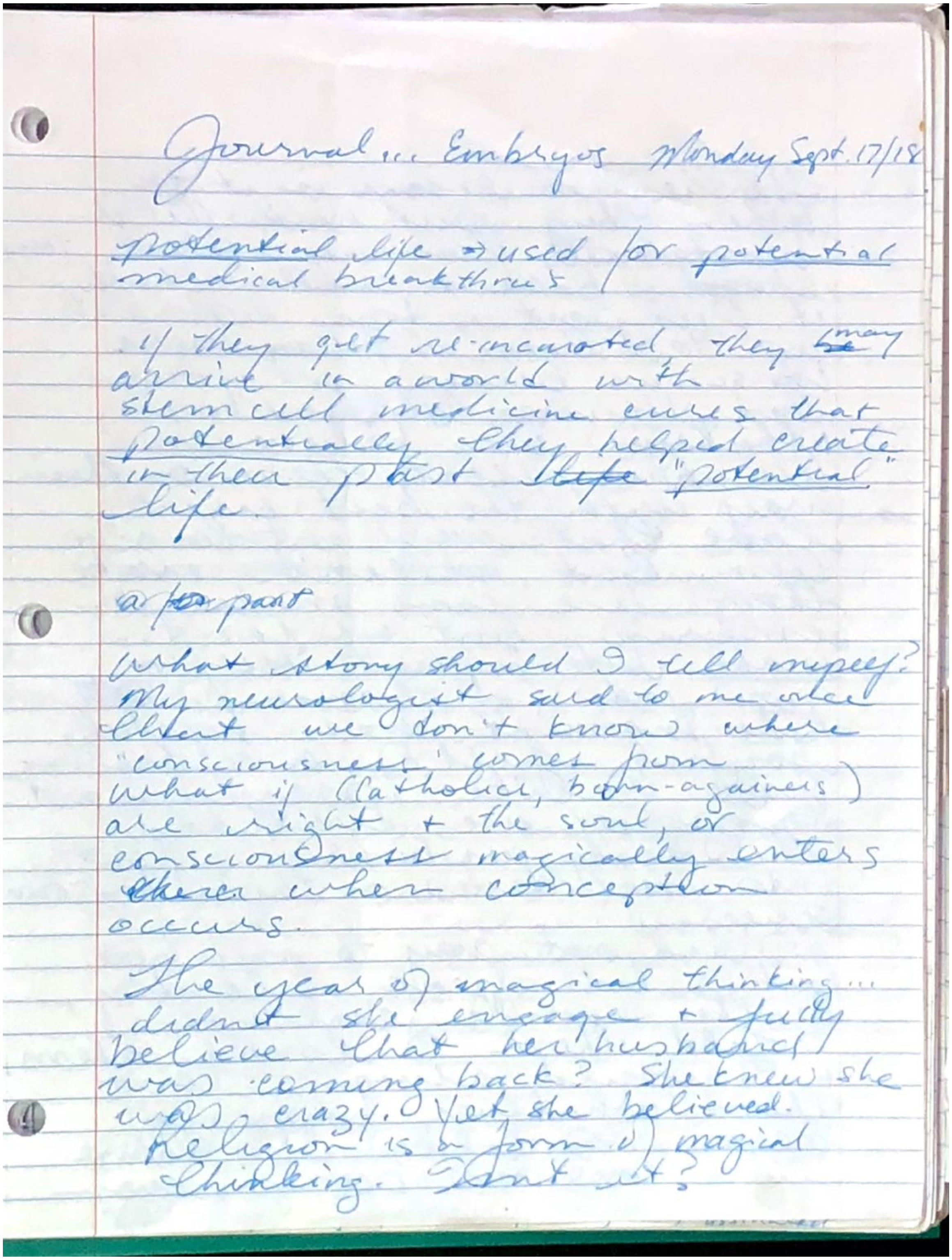
Appendix A

Journal Entries



Journal... Embryos Monday Sept. 17/18

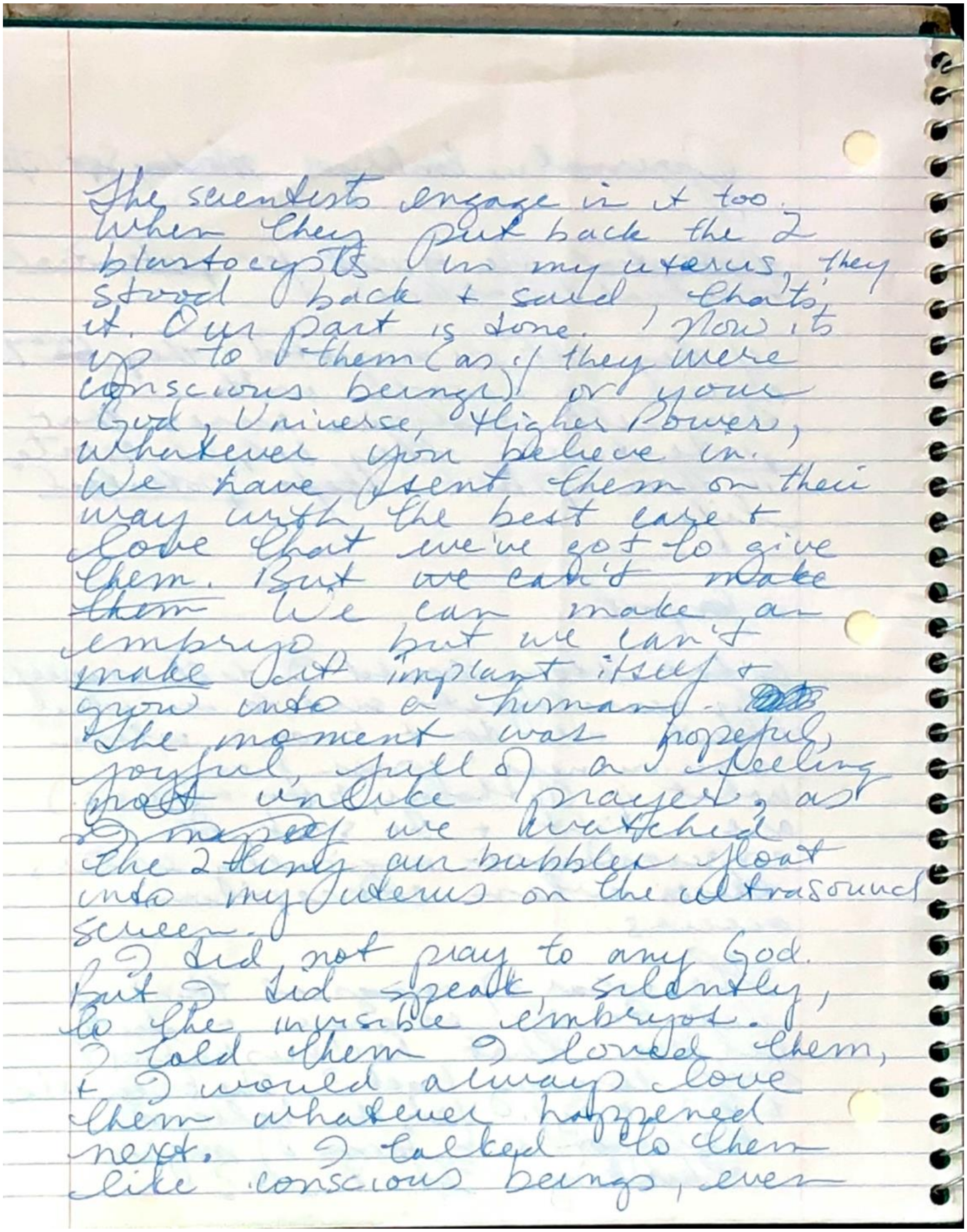
potential life → used for potential
medical breakthru's

If they get re-incarnated they ~~be~~ may
arrive in a world with
stem cell medicine cures that
potentially they helped create
in their past ~~life~~ "potential"
life.

a ~~for~~ part

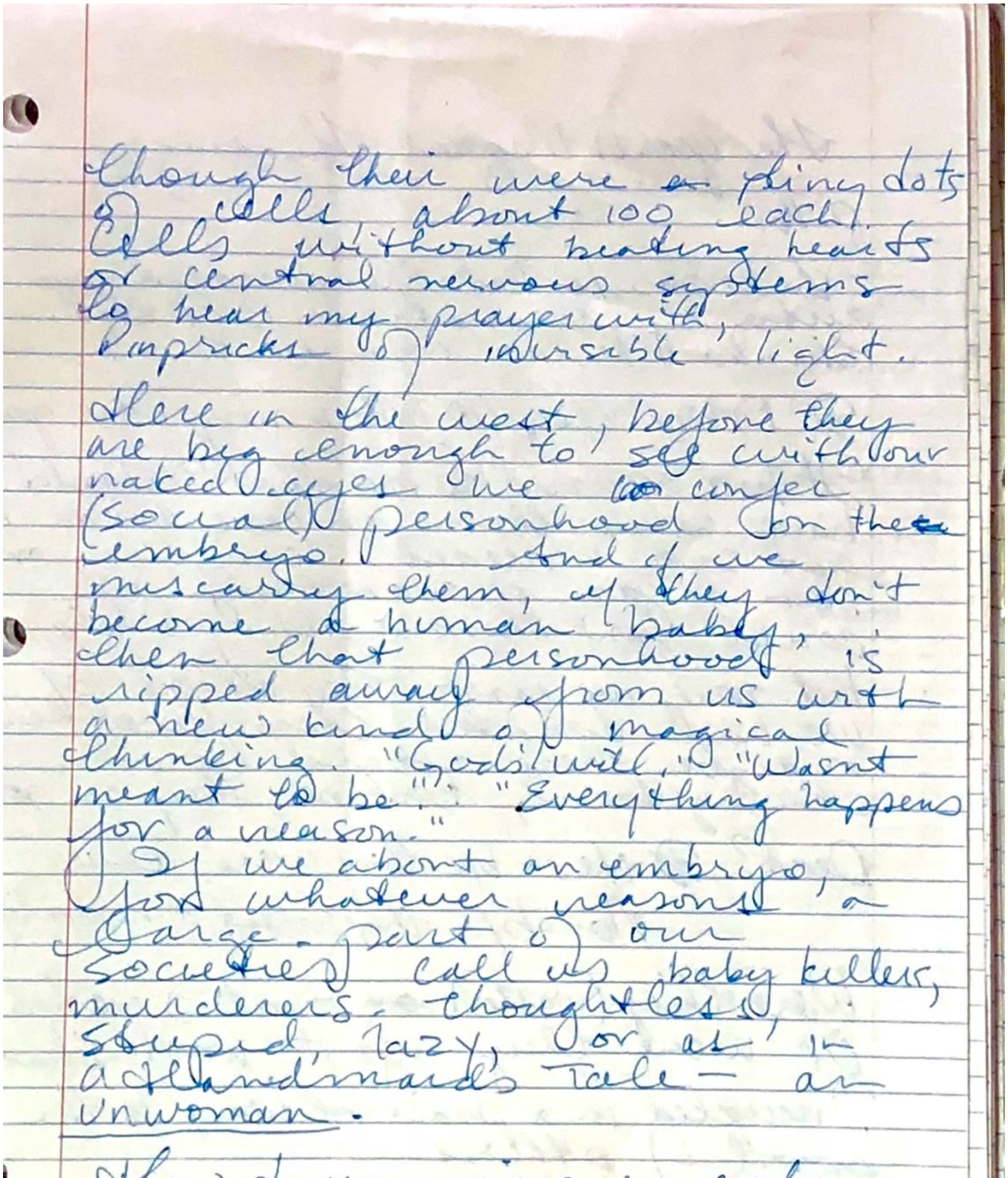
What story should I tell myself?
My neurologist said to me once
that we don't know where
"consciousness" comes from
What if (Catholics, born-againers)
are right + the soul, or
consciousness magically enters
~~there~~ when conception
occurs.

The year of magical thinking...
didn't she engage + fully
believe that her husband
was coming back? She knew she
was crazy. Yet she believed.
Religion is a form of magical
thinking. Isn't it?



The scientists engage in it too. When they put back the 2 blastocysts in my uterus, they stood back & said, 'that's it. Our part is done. Now its up to them (as if they were conscious beings) or your God, Universe, Higher Power, whatever you believe in. We have sent them on their way with the best care & love that we've got to give them. But ~~we can't make them~~ We can make an embryo but we can't make it implant itself & grow into a human.' The moment was hopeful, joyful, full of a feeling not unlike prayer, as ~~I myself~~ we watched the 2 tiny air bubbles float into my uterus on the ultrasound screen.

I did not pray to any God. But I did speak silently, to the invisible embryos. I told them I loved them, & I would always love them whatever happened next. I talked to them like conscious beings, even



Though their were ~~a~~ tiny dots
of cells, about 100 each.
Cells without beating hearts
or central nervous systems
to hear my prayer with,
pinpricks of invisible light.

Here in the west, before they
are big enough to see with our
naked eyes we ~~co~~ confer
(social) personhood on the
embryo. And if we
miscarry them, if they don't
become a human 'baby,'
then that personhood is
ripped away from us with
a new kind of magical
thinking. "God's will," "Wasnt
meant to be". "Everything happens
for a reason."
If we abort an embryo,
for whatever reasons, a
large part of our
societies call us baby killers,
murderers, thoughtless,
stupid, lazy, or as in
a Handmaid's Tale — an
<u>Unwoman</u>.

How do you grieve an embryo
that your own mother would
~~insist~~ ~~on~~ that you ~~ko~~
~~to~~ say (butchered) (slaughtered) ~~destroyed~~? assinated

Appendix B

First Draft Notes for "Confessional"—Becoming Reasonable, Finding Faith

Offstage a woman is singing a lullaby, God Speed, by The Chicks. As she finishes the verse she tiptoes onstage and sits in an easy chair. On the table beside the chair is a small Buddha-like statue and a candle. A basket of knitting is on the floor beside the chair. She takes out a small red knitted hat and tries it on the statue.

Everyone keeps telling me to nap when they nap but my brain never settles down before they're up again so I've stopped trying. Another thing people tell me is that raising children keeps you young. I would like to know who exactly started that rumor? Because that is bullshit. Want to see a picture of them? My twins? *She digs two photos out of her knitting bag and holds them up. Each photo contains a blob of similar looking cell material.*

I found these the other day when I was going through the papers from the clinic. This is Clara and this is Will. Or, maybe this is Clara and this is Will. It's hard to tell them apart at this stage. They're only about a hundred cells each. These pictures were taken five days after the donor's eggs were fertilized with my partner's sperm. They gave me these pictures the day they put the embryos into my uterus. I took them home and put them on the fridge. Weird huh? Ten days later we did a blood test to see if they took. The nurse who called said, "Congratulations Kate, you're pregnant! In fact, you're very pregnant. Doubly pregnant". The high hormone levels in my blood indicated twins, but that wasn't confirmed until six weeks later when an ultrasound picked up two tiny beating hearts. (If I wasn't pregnant would that have been a miscarriage? The hundred microscopic cells? What do I do with the pictures?) There's no service, no ritual for lost potentials.

I tried to get pregnant with my own eggs all through my thirties, but after a decade of monthly failures I had to accept that my eggs had essentially left the building. At least any viable eggs. All that sex and standing on my head and I never missed a period! The doctor told us that the chances of me getting pregnant with or without IVF was less than one percent. With donor eggs, those odds jumped to somewhere between seventy and eighty-five percent and I could carry, nurture them from the very beginning. I was willing to gamble with those odds.

At this stage of their development embryos are called blastocysts. They measure between one and two millimeters wide, about the size of a very fine dot from the tip of a pen. When we put these two up inside my uterus, the embryologist sucked them up into a tube between two air bubbles, one bubble in front of them and another behind them. The doctor pushed the tube up through my cervix and into my uterus. We all watched on an ultrasound screen. The blasts were too small to show up on the screen, but we could see the air bubbles floating out of the tube into my uterus. Once both air bubbles were in, we knew the two blasts were in there too. It was beautiful, two tiny light bubbles, floating in space. In that moment, for the first time in my life, I knew for certain that there was potential life inside me. Even in that sterile space, with my legs in the stirrups, and the white coats standing by, it was magical, a miracle. And then they turned off the screen and wished us luck.

Their job was done, they said. Science could bring us to this point but it could not force the miracle to continue. Now it was up to the embryos to decide if they would implant and grow. It was up to the embryos and a higher power, if we believed in one.

I don't do the higher power thing. The God thing. I'm in recovery; Adult Children of Catholics Anonymous. What I wanted to have faith in was my body, despite years of infertility, I still had hope that it could pull this off. And I wanted to believe in them, the embryos, that one or maybe even both were the children we were meant to have. I was all for hope and faith, just not God. I don't trust that guy, too many strings attached.

I really wanted to stand on my head on last time. I was more than willing to embarrass myself and do it right there in the transfer room. They smiled and reminded me that the embryos were already inside my uterus so standing on my head really wasn't necessary and there was no evidence that women who rested after the embryo transfer became pregnant any more often than women who jumped off the table and rushed back to very stressful jobs. They assured me that I was not going to cough them out, fart them out or poop them out. If you don't become pregnant, they said, it is not your fault. But really, if you are not going to invoke God, who else is there to blame?

Turns out I didn't have eggs but I had a rock-star womb. Those two little sprouts dug right in and nine months later they came back out looking like actual babies and now we are a family of four. We look like all the other white, middle-class families but we are part of a growing minority of folks who can't make a family the traditional way. No bottle of red for us and oops we have a baby, we need scientists and good credit, a lot of good credit. We share this struggle with single parents and LGBTQ parents, we all just want to make families and love them. For us, not only does it take a village to raise a child, it takes a village to make one. Infertility village. You have no idea how big the population of this village is. So many people suffering the same kind of despair, over and over and over again. Villagers are tired. We really need to nap. The people who help you navigate through the village are amazing too; egg and sperm donors, gestational carriers, gynecologists, nurses, counselors, embryologists, fertility lawyers, loads of people to help you make the best use of your most intimate spaces. Business is booming.

When the embryologists give you these first pictures and encourage you to bond with a fertilized egg, they do it because research shows that hope and prayer make a difference. When they say, "it's up to them now," meaning the embryos, or pre-embryos, as some people are calling them now, they endow them a kind of personhood, as if they have consciousness, as if they are in there weighing the pros and cons of sticking around.

Consciousness is a pretty fascinating thing, at least to me. One day last year when we were looking at MRI images of my brain, my neurologist dropped this interesting tidbit; that science still has no idea where consciousness comes from. I see a neurologist because I have MS. I'm lucky, it's very mild, I have what they call "benign" MS, but it is still there, inside me, lurking, kind of like the pope. He lurks in my brain too.

I think of consciousness as a kind of knowing, a kind of awareness, of being here. I imagine this awareness as a presence that gets built over time, a knowledge that comes to us through our central nervous system and that's what the neurologist meant that day, that science can't point to a section of my brain and say that's where consciousness lives, that's the seat of your soul. Oh! Did you hear that? That last part? That was the pope shoving himself into the conversation uninvited. What an asshole. He's in there pointing his finger at me, declaring that we receive a soul when the sperm meets the egg. Kind of like the embryologist did when she said, "it's up to them now." But the embryologist left room for interpretation.

Our egg donor was a rock star too. When she donated, the doctor retrieved twenty-seven eggs. Twenty-one of those eggs were fertilized. Three days later I received an email from the clinic saying that fourteen embryos were still doing well, tucked away in their little petri dishes. I started to imagine these microscopic babies, tucked up nice and snug in their little round cribs. On day five the embryologist chose the two strongest looking ones and we put them inside. I knew they were in there, these cells, pre-embryos, these beings? I imagined them trying to implant. I talked to them. I hoped. Despite myself I prayed.

We put two inside and we froze the other twelve.

Now I need to decide what to do with the other twelve.

We've narrowed it down to two choices.

1. We can donate them anonymously to other infertile couples. Couples who are not in a financial position to make their own. They will "adopt" them and try to make their own families with them.
2. We can donate them to scientific research. Obama lifted the ban on embryonic stem cell research. There is a lot of promise for stem cell treatments for neurological diseases like Alzheimer's and Parkinson's, maybe even MS. Perhaps our embryos could, in some small way, be part of a different kind of hope.

The first option means that they have a chance to become human but someone else will raise them. People who may not want to have a relationship with us, or Clara and Will. They would be raising Clara and Will's full genetic siblings. My partner can't wrap his head around this choice, not necessarily because they were made with his sperm but because he too, sees them as "his kids". If he gives them away to strangers to raise what guarantee is there that they will be kind? Chances are they'll be just as good at parenting as us. Maybe better. They want a family just as much as we did. Will I ever stop wondering about the kids? Where they might be? How they're doing? And what will

Clara and Will think of all this? They have enough to come to terms with already, donor eggs and all.

I have the consent form from the research lab. *(She takes out a piece of paper from her knitting bag and reads:) "*In the process of developing human embryonic stem cell lines, the embryos you donate will no longer be capable of development into human beings. The process of removing selected cells from the embryo to make embryonic cell lines destroys the ability of the embryo to develop further. Some people find this type of research objectionable. If you do not want us to try to make a line from your embryos, you should not donate them to our research." *(She folds the paper up and puts it back in the bag)*

Is it abortion if the embryos have never been implanted in a woman's body? There's no pregnancy to abort. And besides, I am pro-choice. I have always been pro-choice, even before my recovery from religion. I will stand beside any woman, under any circumstances, who has had to make the decision to abort a pregnancy. We must have sovereignty over our own bodies. No exceptions. But these are not part of my body. They are separate.

It feels dangerous to talk about this, doesn't it? There's so much judgement. Haters ready to pounce. We don't seem to be able to think about abortion in shades of grey, just black and white. But other cultures can. For example, in Japan, abortion is accepted as a legal, and regrettable necessity. And at the same time, Japanese culture acknowledges that an embryo is a form of human life.

I get it. This is a problem that comes along with privilege. There are a lot of other families who would like to have this problem. More and more, this is how babies are made, and it doesn't do anyone any good not to bring it out into the open and talk about it. My Grandmother wouldn't have begun to wonder about being pregnant until she had missed two periods. That's eight or nine weeks in from conception. And if she did get her period after that length of time, she would have been "late", not "miscarrying". Two generations later, I have bonded with fertilized eggs even before I am carrying them. Before a drug store test, an ultrasound, long before a kick. And I feel a motherly responsibility to those frozen twelve, an invisible, and unreasonable bond.

How do I say goodbye to them? How do I let them go? Because I need to let them go.

I've had a bit of a relapse. This is Jizo. He's a Buddhist Bodhisattva. He looks enlightened, doesn't he? So serene and childlike. One of his jobs is to watch over miscarried and aborted fetuses until they are ready to be reborn, reincarnated in another time and place. I'm not sure I believe in reincarnation but it's better than believing in eternal damnation. I'll take Buddha over the pope any day. You can have a dialogue with Buddha, the pope, not so much.

I don’t want religion but I do need faith. Faith goes all the way down, all the way down to the deepest, motherly parts. Without faith, having children is meaningless.

In Japan, the word for embryo is Mizuko. It means Water Child. Zen Buddhists have given Jizo here the job of watching over the Mizukos, ferrying them in and out of primordial waters. Mothers can make offerings to him, prayers, money, toys, (*holding up the knitted hat)* winter hats. It’s getting cold out there. He needs a hat.

Part of recovery is acknowledging the harm you have done to others and asking forgiveness. I am not strong enough to let other people adopt these Mizukos, other people who have suffered more losses than I have on this journey. Instead, I am returning them to the primordial waters. I hope they can forgive me.

We hear the children waking up on the baby monitor. One of them says Mama? She places the hat on Jizo. Gives him a kiss. Lights the candle and leaves the stage. The lights fade and all we are left with is the small single flame as we hear her tenderly talking to her children offstage.