ORIGINAL ARTICLE

Anonymity and Secrect in Gamete Donation: Reconciling Family Values and Individual Rights

Tuua Ruutiainen

Supporting Professors: David Smith, Ph.D, Carol Pollard, and others at the Yale Interdisciplinary Center for Bioethics

At present, the large majority of parents in the United States who use gamete do not tell their children that they were conceived through gamete donation. Competing interests and different views of what is in the child's best interest complicate the situation. While parents attempt to protect family cohesiveness, they risk psychologically harming their child, depriving her of important medical information, and infringing on her right to know her genetic origins. In this paper, I explore the arguments for and against disclosing information about the gamete donation to the child. I then conclude that parents have an obligation to tell the child about the gamete donation; however, they do not have an obligation to reveal identifying information about the donor. It may be suitable to institute a law allowing donor gamete children to gain access to non-identifying information about the gamete donor when they turn 18.

HISTORICAL INTRODUCTION

In 1884, physicians at a Philadelphia medical college impregnated an unconscious woman by placing sperm in her reproductive tract. The woman was led to believe that the sperm belonged to her husband when in fact it belonged to the "best-looking" student in the medical school class.[1] This covert procedure was the first example of gamete donation, which later became a known and sought after practice that offered hope to infertile couples while raising a host of new ethical considerations concerning secrecy.

Although couples were soon jointly making the decision to use donor insemination, they were still reluctant to tell others about their children's "unorthodox" method of conception using donor sperm. Motivated by their desire to conform to the traditional family model and to avoid the stigma attached to male infertility, couples raised the gamete donor children as their own, never disclosing to them that they were not genetically related to their social fathers.

With the rise of oocyte donation in the 1980's and the popularization of embryo donation this past decade, third party reproduction became an option for more couples. At the same time, a new emphasis on children's rights and new studies of adopted children led physicians and parents to reconsider their decision to conceal the genetic origins of these children. Many countries enacted new laws allowing adopted children to access information about their birth parents. In 1985, Sweden became the first country to extend similar considerations to donor gamete children by adopting a law granting these children the right to access identifying information about their donors upon turning 18.

Although other countries now have analogous statutes, gamete donation in the United States remains largely secret and anonymous. According to a retrospective study of parents who used donor insemination in the United States, 86.5% had not told their children how they had been conceived and 40% had told no one about their use of donor gametes.[2] The few non-anonymous programs that exist remain unpopular and even those parents that opt to participate may later decide not to tell their children about the donor.Nursing on a global level.

INTERESTS AT STAKE

Fear of Straining Family Relationships

The argument for secrecy and anonymity is well summarized in the words of Ecclesiastes: "he that increaseth knowledge increaseth sorrow." Parents who use donated gametes fear that if they tell their children how they were conceived, their relationships with their children will be jeopardized. A parent who has already been forced to accept that he cannot be genetically related to his child is usually reluctant to see his child's perception of him change. Gamete donor children who are told about their genetic origins may even emotionally reject their non-biological parents.

Nondisclosure also helps protect the family's privacy. The child might tell others outside the family whose negative perceptions of gamete donation could harm the family as a whole. Even other family members may react negatively. Parents often worry that grandparents would turn against the child if they realized that they did not share a biological bond. In a culture where infertility and parenting of non-biological children continue to be stigmatized, secrecy creates a façade that allows the couple to blend in with the traditional family model.

Differentiating between values for public and private spheres

Parents may be justified in withholding information about gamete donors from their children in the interest of family cohesion and privacy because a family does not need complete openness in order to be healthy. Thomas Murray points out that truth and openness are crucial in the public sphere where it helps preserve justice; however, within families, values such as love, loyalty, trust, and care are more crucial than justice.[3] Since the values in the family sphere are different than in the public sphere, an alternative ethical approach is certainly reasonable, one that emphasizes the well being of the family unit rather than solely the rights of the individual. If disclosure leads to conflict within a family, it may be best not to tell a

Author Contact: T.R. University of Pennsylvania, 2010. Address correspondence to T.R. at tuua.ruutiainen@gmail.com

child about her conception through gamete donation.

Risk of psychological harm to the child

Parents are often concerned that their child may face psychological harm if she learns about her donor. If a child discovers that she was conceived through gamete donation, she may feel "obliged" to seek out information about her biological parent. She may feel disappointed if she is unable to uncover the identity of the donor or if the donor does not wish to be contacted. Even if the child successfully contacts the donor, the relationship that she forms with him has the potential to significantly impact her relationship with her immediate family. Her family may feel wary about her relationship with a possible competing parental figure.

Children may also develop expectations about their encounters with their donors, which, if left unfulfilled, could leave them disappointed. In Schieb's 2005 study of 29 adolescents conceived using open-identity sperm donors, the majority wished to contact the donor upon reaching adulthood. Of those, 80% wished to find out more about the donor in order to gain a better understanding of themselves and 7% wished to develop a father-child relationship.[4] Some children, particularly those who hope to develop a strong parent-child relationship, may be frustrated if their donors do not wish to invest in their relationships to the same degree that they had hoped.

A different set of problems arises when the identity of the donor is unknown. Most programs and sperm banks make anonymous information about the donor's characteristics and medical history available; however, parents who want identifying information must choose programs and sperm banks where donors have agreed to be identified immediately or in the future. Therefore, in the case of anonymous donations, knowledge about the origin of the gametes may be considered unnecessarily stressful for the offspring who cannot trace the identity of the donor.

More importantly, data seem to indicate that donor gamete children enjoy reasonably happy lives regardless of whether or not they know about the donor. According to a study by Golombok, 12-year-old donor insemination children were as well adjusted as their peers who were naturally conceived.[5] Even though some of the children in the study experienced discomfort when they later learned that their parents did not disclose their genetic background, they did not necessarily experience any lasting traumatic impact from this discovery.

Transient importance of the donor

Even if they feel grateful towards the donor, parents may see no need to discuss a figure who was only of transient importance in their lives in the context of their fertility treatment.[3] The birth of a donor gamete child in many ways resembles that of any other infant: the couple deliberately chooses to conceive the child and the mother carries the pregnancy. The mother then bonds with the child after birth through breastfeeding and daily maternal interaction. Unlike adopted children who are separated from their biological parents after birth, donor gamete children are never cared for by the gamete donors. The child's social parents exclusively fill the parental role. Consequently, many parents do not perceive the donors as important figures in their children's lives.

Questioning the Value of Genetic Information

Couples may be particularly reluctant to strain family ties and forfeit their reproductive privacy when they perceive biological ties as relatively unimportant. Many believe that American society has come to overemphasize genetic relationships – a trend that has been encouraged by new reproductive technologies and a culture traditionally obsessed with paternity tests as a measure of legitimacy. Katherine O'Donovan, for example, fears that a system of donor identification will further overemphasize the concept of identity sanctioned by social and legal structures, while devaluing committed social parenting.[6] It is crucial therefore to consider whether or not genealogical awareness has intrinsic value or if society is overstressing its importance.

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DONER'S DESIRE TO REMAIN ANONYMOUS

The impact of disclosure on donors must also be considered. Many donors opt to remain anonymous because they do not wish to be contacted by the recipient parents or offspring. Some donors may even be unwilling to donate their gametes if they are required to reveal their identity. According to a 1996 survey of men who donated sperm in the United States, 79.4% wished to donate anonymously, 6.3% were willing to register their identity, and 14.2% found both options acceptable (n=63).[7] Consequently, a policy mandating the disclosure of identifying information could lead to a shortage of gametes.

In Sweden, there was a temporary decrease in the number of donors when the mandated disclosure policy was first instituted in 1985. However, the supply of gametes was soon replenished because older men who already had children of their own began donating in greater numbers.[viii] There is no evidence that these results can be extrapolated to the U.S. where the motives for "donation" may be different. In Sweden, donors receive no compensation for their gametes, whereas in the U.S. there is a rampant unregulated market for gametes in which donors are less likely to be motivated purely by altruism. Nonetheless, the net loss in sperm donors caused by mandated disclosure might be justified if the psychological benefits of disclosure are deemed to outweigh the benefits of anonymous donation.

ARGUMENTS FOR DISCLOSURE

Value of truthfulness

Proponents of disclosure emphasize the importance of truthfulness within families and the right of a child to know her origin. According to Katherine O'Donnovan, lies lead to a loss of control and autonomy by distorting information, perceptions, and choices.[6] Even when parents do not explicitly lie to their children they are committing a deliberate falsehood through omission. Non-disclosure by the parents can be construed as deception because children assume by default that they are being raised by their biological parents.

Philosopher Sissela Bok argues that, save for exceptional circumstances (e.g. lying to a child to convince her to jump out of a burning building) children should not be lied to, even if the intention is to protect the child. She argues that in most cases "benevolent lies" are wrong because they are not entirely motivated by altruism, but rather by self-protection the parents to maintain power and avoid confrontation.[9] Parents do in fact benefit when they lie to their children about their nature of conception. By not discussing gamete donation with the child, a parent maintains power by concealing a potentially competing parental figure. Furthermore, the lie protects the parent from confronting his infertility and the child's possible interest in the donor. Therefore, according to this argument, the lie is more in the interest of the parent than in the interest of the child it is supposed to protect.

Lack of Informed Consent

Lies are also problematic because the children who are being deceived could not have given their consent in advance. Such consent is simply impossible to obtain because it would defeat the purpose of deception. Furthermore, the child's implied consent cannot be assumed unless it can be judged that she would want to be duped or would give her retroactive consent to the deceit when asked. If it could be assumed that any reasonable person would want to be lied to then the lie would be justifiable.[9] This is not the case when lying to children about their origins because many people are naturally interested in their genetic background.

Jeopardizing Family Cohesion

From a consequentialist perspective, children are wronged when their family members hide information about their origin because lies jeopardize the close relationships that nurture moral and emotional development within families. Since family relationships require trust over a long period of time, parents face a highly detrimental loss of credibility if their lie is discovered.[9] Evidence shows that children who discover that they were conceived through gamete donation late in life feel betrayed by their parents. Lies can also have more subtle consequences: avoidance of this topic in conversation can impair communication and have a negative impact on the child who has a natural curiosity about her origins. Finally, parents can feel burdened by their own lies: they may fear discovery or be troubled by the need to tell multiple lies to conceal the truth.[10]

Children's interest in their genetic origins

Children also have an interest in knowing the truth about their origins because the information is of value to them socially and medically. According to Lisa Cahill:

Genetic connections are important as part of our interest in perceiving the connections between our lives and the lives of others, connections which add depth and richness to the continuing story in which we participate, and which can therefore be referred to as narrative connections. Such connections give cohesiveness and quality to our lives and make us feel both situated and recognized as individuals.[11]

Although biological ties should not be idolized to such an extreme that they threaten to supplant social relationships, it should be recognized that such ties can help an individual develop a solid sense of identity.

Information about the donor is also valuable in addressing a child's medical needs. A child who is not told about the donor may be unaware of certain medical conditions for which she is at risk. Although fertility centers may screen gametes for certain diseases, this information is nevertheless inherently incomplete. Genetic markers are not always diagnoses; they may indicate risk categories, which must then be integrated with other information that is known about the individual, such as family history. The ability to test for genetic risk markers changes and advances with time: conditions may appear later in the biological parent's life which are important for the medical safety of a child and for which genetic markers are not yet available. A donor gamete child who is led to believe that both of her parents are genetically related to her may also be kept in undue fear of conditions to which she is not predisposed. For example, a child whose mother develops breast cancer may fear that she is at risk for the disease, not knowing that she was conceived with a donated oocyte.

Furthermore, a child who is unaware of the identity of her genetic parents risks having sexual relations with another member of her family. Consanguineous sexual relations are a genuine hazard since the distribution of gametes with the population is rarely regulated. Officially, the American Society for Reproductive Medicine guidelines limit the number of children to one donor to 25 live births per population area of 850,000. However the guidelines are neither monitored nor enforced, but rather left up to the discretion of the fertility clinics.[12]

Establishing Children's Rights

Some argue that children have both an interest and a right to information about their genetic origin. According to Neil McCormick's definition, rights are "normative orders that can afford to individuals security in the enjoyment of what are normally goods for individuals."[xiii] Information about one's genetic origins fits into the category of normal goods for individuals since other members of society are granted at least some minimum amount of information about their biological parents. In fact, almost all states grant adopted children access to non-identifying information about their birth parents upon turning 18. Therefore, similar consideration should be granted to donor gamete children. If it can be established that children have the right to information about their origins, the government has a positive duty to provide them with this information.

RECONCILING CONFLICTING INTERESTS

Although parents who withhold information about their child's origins believe that they are acting in the best interests of their family and their child, they nevertheless have a duty to disclose the truth. The parents' silence harms the child psychologically, deprives her of important medical information, and infringes upon her right to know her genetic origins. Exceptions should only be made in cases where disclosure threatens to overwhelm the psychological well being of the family.

Moreover, empirical evidence indicates that the fears that parents have concerning family cohesion are unsubstantiated. Studies show that disclosure may have a positive effect on parent-child relationships. A study of 46 families with children between four and eight who were conceived through gamete donation found that parent-child relationships were more positive in families where children were told about their origins than in non-disclosing families.[14] Despite this data, non-disclosing parents continue to believe that disclosure will have a negative impact on their families. Society reinforces their misperceptions by continuing to stigmatize infertility and non-traditional families, thereby motivating parents to act in a way that is ethically questionable.

However, competing interests must be taken into account when attempting to create a public policy that is morally justifiable. Bringing the government into family life can be dangerous. Thomas Murray writes: "Understanding the moral intricacies of family relationships through a concept such as rights is like opening a beautifully carved door with an ax. It is undeniably effective; it is justified only by an emergency such as a fire."[3] Therefore, an effective policy should recognize the importance of the child's right to her origins, while protecting the welfare of the family unit in which both children and adults develop morally and emotionally.

One suitable option might be creating laws that allow donor gamete children to gain access to non-identifying information about their gamete donor upon turning 18. Although the family unit should be entitled to flourish in privacy, by the time the child becomes an adult her individual rights should begin to override any paternalism on the part of the family. Since there are clearly dangers to any mandatory policy, efforts need to be made to educate parents and improve access to counseling before such a policy is instated. If parents are informed about the harms of nondisclosure, they might be more receptive to talking about gamete donation with their children. Also, since children feel more resentment when they find out about the donor as adults, parents should be told about the risks of waiting to tell the truth.

Psychological support to the child and families is crucial because the current cultural climate does not support donor gamete families. In the long-term, society may grow more receptive to families with non-biological children and the need for fertility treatments. However, since these stigmas currently exist, families need strong psychological guidance to help them grapple with the social consequences of gamete donation.

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NEWS BRIEFS

"First Trial of Embryonic Stem Cells in Humans" reports BBC News

Virginia Saurman

About 12,000 people in the US sustain spinal cord injuries each year, usually from car accidents, gun violence, falls, or sport injuries. The biotech company Geron has been granted FDA approval to start clinical trials treating patients with spinal injuries using human embryonic stem cells. The cells, which are "coaxed" into becoming nerve cells, are injected into the spinal cord. The trials are being conducted in an Atlanta hospital on patients who sustained spinal cord injuries about 14 days before the start of the trial to determine whether the treatment is safe, let alone successful. Research has shown that mice with spinal cord injuries regained some movement after being treated with the cells.

According to its president, Dr. Thomas Okarma, Geron has "[been working with] human embryonic stem cells since 1999" and spent approximately $170 million on developing the treatment. The stem cell treatment still has years of trials and approvals ahead of it before it can be put on the market. According to Ben Sykes, executive director of the UK National Stem Cell Network, "This is indeed a significant milestone in our journey towards the promise of stem cell-based medicines."

Meanwhile in the UK, at the University College of London, Professor Chris Mason, an expert in regenerative medicine hopes to begin trials next year with a stem cell treatment for macular degeneration.

Judge Rules Health Law Is Constitutional

Recent health reforms mandate most Americans to obtain health insurance, a commercial good might fall to the Supreme Court hearing. Meanwhile however, a federal judge in Michigan dismissed one of the 15 challenges to the recent health laws, becoming the first judge to state that the law is constitutional. Foregoing insurance would increase the cost of insurance in addition to affecting 'interstate commerce.'

Virginia Saurman is a staff writer for TuftScope.