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Abandoning Anonymity

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Abstract

In the arena of bioethics and reproductive science, anonymity among sperm donors has been a hot topic. Currently, donors are granted anonymity in an attempt to protect autonomy and shield privacy. But at what cost? This article examines the other side of the debate: the children that, as a result, have little to no access to literally half of their family. Not only does this have serious mental and emotional implications, it also represents a serious ethical dilemma in terms of the autonomy, health, and well-being of the child.

Keywords: donors, autonomy, offspring, anonymous, privacy, beneficence, children

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When keynote speaker Kathleen LaBounty took the stage at the Infertility Network Symposium, no one expected to be so moved by her words. Her life experience, her perspective, and her journey to find her donor father made for a story that spoke to the reality of anonymous gamete donation:

The men who are targeted are so young...and I think a lot of them are naïve, and they're just trying to help another family. They also need money, usually. So I don't think that they go into it fully understanding that they're creating a person, not just helping a family. [The industry allows him to] walk away with a fatter wallet, and depending on the clinic, some coupons and movie tickets. The sample he gets to immediately forget about goes into a woman who gets her chance at motherhood. And the result might be a child who winds up flipping through old yearbooks looking for eyes of a certain shape or the way a pair of lips curl into a smile (Malisow, 2008).

Kathleen later went on to say, "I look in the mirror, and I don't know whose face is reflected back... This is intentionally creating children that have no access to half of their family."

(Malisow, 2008) Kathleen is just one of a vast population of donor children that share the same sentiments. Many individuals in these situations, no matter their age, often feel an emptiness and a confusion about their heritage, their history, and their identity – a void that can be filled when core donor information is provided and anonymity is abandoned.

Beneficence

The ethical principle of beneficence is applicable and fundamental to all areas of life; it is also particularly important in cases of gamete donation and donor offspring. No universal protocols currently exist in the United States regarding the provision of identifying donor information (Dennison, 2008). This lack of "procedure" often keeps donors' information anonymous, preventing their children from discovering information that could prove vital to their health and well-being:

...the issues that all these families face and which the parents of the older children were beginning to experience or recognize through incidents in their daily lives relate to the consequences of 50% of the genetic and family history of the child being unknown to the parents. This raises issues about the health and development of the

child and presents an immediate problem...[which could result in] life or death situations or serious medical conditions (McWhinnie, 2001).

Genetic information and family medical history is vital to the maintenance of health and well-being via early detection, diagnosis, and treatment; therefore, providers have a duty to apply the principle of beneficence in their decision to provide children with donor information. Think of the child that inherits the gene for Huntington's disease – one known to be fatal for 100% of those that carry it. Anonymity in gamete donation prevents her from accessing this information crucial to her quality and duration of life. She has no idea that she will lose virtually all cognitive ability or suffer from extreme paranoia and psychosis, nor does she understand that she will likely die before she sees age 50. Shouldn't this individual have the chance to plan her future based upon information that should be hers to access in the first place? Shouldn't she have the opportunity to partake in responsible and autonomous family planning based upon her knowledge of family medical history and her likely prognosis? The principle of beneficence tells providers that they have a duty to provide her with such information.

Autonomy and Moral Status

Bioethicists generally agree that moral status is a foundational concept that plays a crucial role in making decisions that affect others. While a variation of ideas exist regarding the exact definition of the term, many ethicists associate moral status with an individual's capability to contribute positively to society, capacity for rational thought and decision-making, ability to feel pain, and demonstration of some level of awareness of self and his surroundings. Based on these defining characteristics, certainly few would argue that donor children lack moral status. Respect for them as autonomous beings of moral stature, then, requires providers to avoid acts that threaten that very idea. Frith (2001) argued that, in order

for individuals to afford moral status to donor offspring, the practice of keeping vital biological information from them must be abandoned.

Common knowledge and rational thought makes obvious that putting one's mental health at risk negatively affects his ability to think logically, make sound decisions, and contribute to society. This attacks the principle of autonomy at its very foundation; without a sound mind, one cannot make logical decisions appropriate to his situation and is certainly not able to voice autonomous concerns or desires. Furthermore, medical science is not unfamiliar with the concept that impaired mental health negatively affects physiological function; in fact, research has shown that mental and physical health are virtually inseparable, and inflicting harm to one results in harm to the other (U.S. Department of Health and Human Services, 1999). At the root, then, failure to provide genetic background and family medical history to donor children represents a blow to the beneficent treatment of a deserving individual and serves as blatant disrespect for moral status and autonomy.

Objection

A great number of objections have been presented in regards to the case for non-anonymous gamete donation. One popular objection is the idea that removing anonymity will likely result in a decrease in the number of donors, threatening the availability of gametes to those that desire them. Though this has remained a major concern, studies have shown that it is relatively unwarranted. In fact, in other countries in which anonymity has been removed, any decline in gamete donors was short-lived and resolved itself within a short amount of time (McWhinnie, 2001). Furthermore, research indicates that the removal of anonymity affects the desire to donate for only a small portion of the donor population: "...sperm donors would be happy to have identifying information about them provided to any possible children conceived as a result of their donation(s)." (Akker, 2006) Another study confirmed that, in regards to loss of anonymity, only "about a third of the respondents were concerned... and

about the same number were either not concerned, or welcomed it. Almost half the donors indicated that they would continue to donate even if anonymity was removed.” (American Society for Reproductive Medicine, 2005) So, while providers must be cognizant of the risk for a reduction in the number of donors, they can also rest assured that most of those fears are unfounded; this realization, in turn, allows them to remain focused on the pressing issue of the moral status and inherent rights of the donor offspring.

Conclusion

These days, the protection of personal information seems increasingly important by the minute. With identity theft on the rise and an ever-increasing incidence of fraud, it is no wonder that most individuals are somewhat sensitive regarding to whom their information is given. When considering cases of gamete donation, however, one must remember that the issues at hand rise above those of social security numbers and checking account access. The decision for or against anonymous donation has the potential to impact a child’s mental and physical health – things that medical professionals have sworn to protect. In order to effectively do so, genetic background and medical history must be available in order to afford these individuals the moral status to which they are entitled. The opportunity must be provided for donor offspring to live as individuals deserving of respect, autonomy, and choice, and removing the possibility to discover their biological roots is certainly not the way to do it.

Please note that the opinions expressed by authors represent those of the authors and do not reflect the opinions of the editorial staff of The Online Journal of Health Ethics, editors, and reviewers.

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