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Review Article

The Donor Conceived Adult: Implications Within Family, Medical and Mental Healthcare Systems

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Abstract

Introduction: The utilization of alternative approaches to creating families, including the use of donors and embryo adoptions, has increased exponentially in recent years. Previously, adoption and donor conception were kept secret from the offspring, but with the recent popularity of commercial DNA testing, large numbers of individuals are discovering for the first time as adults that they were donor-conceived (DC) decades prior. As DC adults are increasingly likely to present to mental health professionals for this or other unrelated issues, an understanding of the DC adult, particularly within the context of the family, the treatment, and across healthcare systems is critical.

Method and Results: This article discusses current knowledge of the experience of DC adults and their functioning within family, therapeutic, and healthcare systems. Although major pathology has not been identified in this group, they demonstrate a unique set of challenges and strengths. More research is critical to characterizing these individuals for the purposes of developing interventions as reproductive medicine continues to expand the use of methods like donor conception.

Discussion: DC adults represent a rapidly growing group of individuals with distinct needs within family systems and healthcare. As mental healthcare systems have become better equipped to meet the needs of prospective parents who are likely to utilize these alternative methods of conception, including individuals with infertility, same-sex couples, and single parents, we must also prepare to support current and future generations of offspring who were conceived using these methods.

Introduction

In this day and age, the use of commercial DNA testing such as Ancestry.com and 23andMe is increasingly widespread, with an estimated 26 million individuals tested by the four leading commercial companies as of early 2019 [1]. In June of 2018, the cover story of the APA Monitor on Psychology was entitled "Genetic Testing and Family Secrets," and described the experience of individuals who inadvertently discover through commercial DNA testing that they were conceived through anonymous sperm donation decades prior [2]. Until now, donor-conceived (DC) individuals represented a marginalized and elusive subgroup, but in today's society where women more often have children later in life, same-sex and single-parent families are more prevalent, and infertility is less stigmatized than in the past, alternative methods to creating families, including the use of donors and embryo adoptions, is increasing exponentially [3].

A Brief History

Most people, including many DC offspring themselves, are surprised to learn that the use of donor sperm dates back centuries, with the first reported human instance occurring in 1884 with a Quaker family presenting with male-factor infertility at Jefferson Medical College in Philadelphia [4]. The wife was anesthetized and unaware that she was inseminated with donor sperm from a medical student; the husband provided consent and the procedure was successful. Similar procedures continued off-the-record in doctors' offices for decades. The Uniform Parentage Act of 1973 stated that with his consent for the procedure, the legal father would be the man who raised the child and not the biological donor. Within the next decade the sperm banking industry flourished. As there were no records kept, there are no clear estimates of how many children were conceived in this way, and parents were uniformly advised not to tell their offspring about their means of conception.

Gaps in Knowledge

Given the history of secrecy and stigma surrounding infertility and donor conception, it is hardly surprising that there is insufficient research on adults who are DC, in large part because most are unaware of their own status. On a systems level, this also extends to DC individuals misreporting medical and family histories across healthcare settings. Today, the field of reproductive medicine generally recommends informing children of their DC status when they are preverbal (i.e., under age 2) so that it becomes a natural part of their personal stories [5]. These recommendations are not uniformly implemented, however, and donor information is still typically kept anonymous in the clinics, thus perpetuating gaps and misinformation distributed on individual, family, and healthcare system levels.

Implications for Mental Healthcare

As psychologists, ALL of us are increasingly likely to encounter DC adults who discover their origins through DNA testing or similar means. This may be their primary reason for treatment, or they may be seeking services for unrelated reasons, and discover this during the course of assessment or treatment. As assisted reproductive technologies continue to advance and become more available, mental healthcare systems have responded well with preparation to address the needs of infertile, single, and same-sex parent(s), but we have much less preparation to manage the needs of the DC offspring, particularly those who learn of their origins as adults. As such, there are numerous instances of DC individuals who have already received poor guidance from uninformed clinicians, which can significantly compound the impact of such a discovery.

Implications for Psychotherapy

More research is needed to characterize DC adults and their experience in order to develop the most effective methods of intervention. Although there are differences between the fields, some information may be generalized from the more established literature on adoption, which itself is believed to have its historical roots during Biblical times in the story of Moses [6]. Systems of adoption have developed considerably from maintaining complete secrecy historically to promoting a child-centered focus in more recent years. The work of Wendy Kramer, founder and director of the Donor Sibling Registry, the largest organization representing DC individuals and their families in the world, has similarly brought substantial attention to issues faced by DC adults and provided most of the available research in this area. In her experience consulting with individuals who learn they are DC as adults she regularly encounters themes including

- 1. being lied to by the people they trust the most,
- 2. a deeper understanding of forgiveness,
- 3. having their worlds and identities "turned upside down,"
- 4. lack of parental support and/or a feeling of betrayal from parents when wanting to learn more about their biological identities,
- 5. curiosity about and relationships with donors and half-siblings,
- 6. curiosity about medical history,
- 7. frustration with lack of available information [7], and
- 8. feelings such as anger, confusion, relief, curiosity, and sadness.

In adoption, previous recommendations stated that it was critical not to tell individuals of their status "until after they had progressed beyond the challenges of childhood, due to the belief that psychological distress was caused by the disclosure of adoption [5]," and some families still align with this perspective. More current research, however, has shown that "late discovery [i.e., adult] adoptees report feelings of betrayal, loss of trust, and difficulty forgiving in relation to the late discovery experience, which has also extended to available work with DC adults [5]." Clinicians should therefore be prepared to work with these themes and associated distress in treatment. Such work also describes the systemic nature of family secrets, and how clarifying these dynamics within a particular family can assist in the therapeutic process. These themes, for instance, may be associated with reduced disclosure across healthcare relationships, and/or maladaptive coping mechanisms within society [5]. If the individual leans of his/ her origins through a DNA website, confronting the family who raised him/her about this discovery can be extremely delicate, contingent on the level of shame and secrecy within the family. Further, if the family system doesn't support the curiosity that the adult DC person may have about his/ her origins, the individual may perceive these feelings as a betrayal to his/ her family, which may extend to reluctance to meet new biological relatives from the donor's side(s), and/or ongoing shame and secrecy about his/her origins [8]. If the individual does choose to form these relationships, it can be overwhelming to navigate the complexities of large and ever-growing sibling cohorts and continually updated medical information, especially if this discovery was unanticipated. These sibling relationships can be very rewarding as the individual redefines him/herself and his/her concept of "family," yet they may also be kept secret contingent on the levels of individual and family shame across the members. Ultimately, our definition of family will need to be expanded to accommodate these new kinds of family systems.

Fortunately, the available research that has focused on the experience of DC offspring has not identified major pathology resulting from their origins, although some of these studies have generally been with younger children [9]. They have also found that openness about the DC method of conception has not caused serious issues in individual or family functioning [9]. In fact, many DC individuals have a great appreciation of not only their very existence and their lives because of the efforts it took for them to be conceived, but also a profound respect for their parents who demonstrated much determination and sacrifice towards these efforts, including the secrecy that followed for decades. They know that they were very wanted children, and many understand that the prolonged secrecy their parents lived with was an attempt to protect them from trauma. Finally, both because of the expectations resulting from their effortful conceptions and from the beliefs about the quality of the genetic material from which they were derived, some DC individuals may demonstrate a profound motivation to achieve, just as their parents overcame the challenges necessary for their conception during the very early stages of third-party reproduction.

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