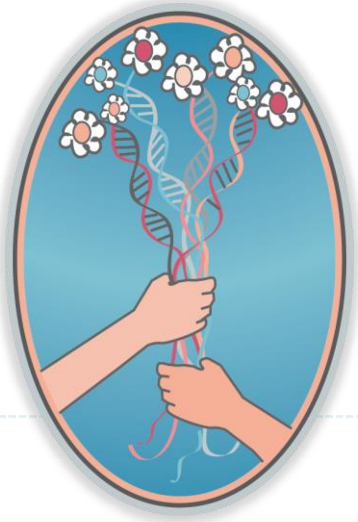

The Donor-Conceived Adult

Implications Within Family, Medical, and Mental Healthcare Systems

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DONOR SIBLING REGISTRY

Original paper by Hilary Bertish, PhD, and Wendy Kramer

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

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 presentation 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 such as 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.

Outdated Advice: Secrecy

Previous recommendations for adoption and donor conception:

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 or donor conception.

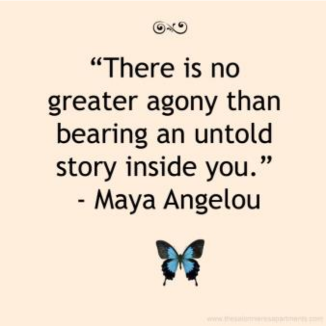
More current research:

Preverbal disclosure is recommended.

Late discovery (teen or adult) adoptees and donor-conceived people report feelings of betrayal, loss of trust, confusion, and difficulty forgiving in relation to the late discovery experience.

Clinicians should therefore be prepared to work with these themes and associated distress in treatment.

Such work also delves into the systemic nature of family secrets, and how clarifying these dynamics within a particular family can assist in the therapeutic process.



"There is no greater agony than bearing an untold story inside you."
- Maya Angelou

Early Disclosure

Given the history of secrecy and stigma surrounding infertility and donor conception, it is hardly surprising that there is limited 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 histories across healthcare settings.

While it's generally recommended to inform children of their DC status when they are preverbal, so that it becomes a natural part of their personal stories, these recommendations are not uniformly implemented. Many parents are still held back by the shame of infertility, embarrassment, and the fear of telling. Consequently, many older DC people are finding out as adults, either from their parents, other family members, found documents, or now more commonly, via DNA testing.

Donor information is still typically kept anonymous in the clinics, medical information is not shared amongst families, thus perpetuating gaps and misinformation distributed on individual, family, and healthcare system levels.

Understanding the needs and issues of donor-conceived (DC) adults across healthcare systems is critical

- For many decades, donor conception was kept secret from the offspring because infertility was associated with secrecy/shame.
- Parents were advised not to tell anyone. This built upon the fear that the child and others would view the non-bio parent as "less than."
- Around 30 million people now have submitted their DNA to companies such as Ancestry and 23andMe.
- Large numbers of individuals are discovering for the first time as adults that they were donor-conceived.
- DC adults are increasingly likely to present to 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.

Current Research

Current research shows that donor-conceived people fare much better when told early on, even before they can remember, whereas late disclosure can be quite difficult for many to process.

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 toward these efforts, including the secrecy that followed for decades.

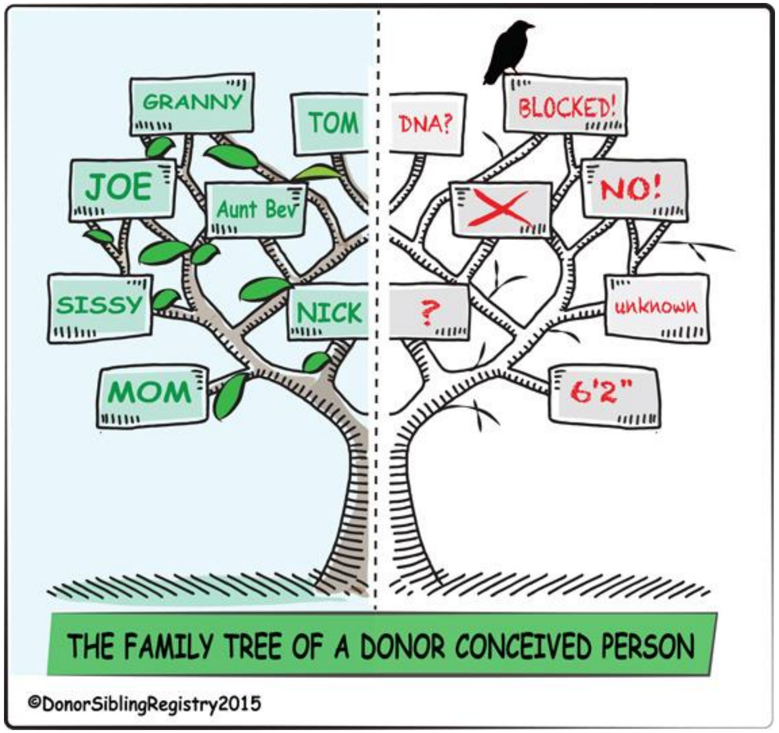
Some feel that they were very wanted children, and understand that the prolonged secrecy their parents lived with was an attempt to protect them from trauma.

Many struggle with anger and confusion and feel a sense of betrayal that they were lied to about something so core to their identity.

Psychological effects of anonymity on offspring

The psychological effects of donor anonymity on donor-conceived people include the following:

- Wondering where they got some of their physical characteristics
- Wondering where they got their talents and personality traits
- Curiosity about genetic family history and ancestry
- A longing to know and/or connect with their unknown genetic parent and other close relatives
- Donor-conceived people desire to know more about themselves, find connections, and fill in the missing pieces.



Implications for Mental Healthcare

- ALL psychologists 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.

- Mental healthcare systems have responded well to address the needs of infertile, single, and same-sex parent(s).

- As such, there are numerous instances of DC individuals who have already received poor guidance from uninformed clinicians.

Implications for Psychotherapy

Common Themes for Donor-Conceived Adults:

1) Being lied to by the people they trust the most
2) Having their worlds and identities "turned upside down"
3) Experiencing a lack of parental support and/or a feeling of betrayal from parents when wanting to learn more about their biological identities
4) Having curiosity about and establishing relationships with biological parents (donors) and half-siblings
5) Having curiosity about medical history
6) Feeling frustrated with the lack of available information
7) Having feelings such as anger, confusion, relief, curiosity, and sadness
8) Being overwhelmed by finding 20, 50, or more than 100 half-siblings
9) And ultimately … needing to find a deeper understanding of forgiveness

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Current Advice

Current research shows that late discovery (i.e., adult) donor-conceived people report feelings of betrayal, loss of trust, and difficulty forgiving in relation to the late discovery experience.

Clinicians should therefore be prepared to work with these themes and associated distress in treatment. Forgiveness and empathy are key components in moving forward.

Address the systemic nature of family secrets and how clarifying these dynamics within a particular family can assist in the therapeutic process.

Implications for Healthcare

NEW PATIENT FORM

ABC Pediatrics

Name

Address

Phone

Insurance

Donor Conceived?

☑ yes ☐ no

Welcome!

Medical issues can be a big problem in donor-conceived populations:
most donor offspring know little to nothing about their family medical histories.

- **Minimal regulation or oversight** regarding comprehensive genetic and medical testing for donors***, no tracking or limiting** the number of offspring, and no universal standards for updating/sharing medical information amongst donor families.

- More than three-quarters of 2,013 surveyed offspring were searching for their donors to learn more about their medical history.

- **84%** of 164 surveyed sperm donors have **never been contacted** by their clinic(s) for medical updates.

- **23%** of these sperm donors felt that they or close family members **had medical/genetic issues** that would be important to share with families.

- **97%** of 155 surveyed egg donors have **never been contacted** by their clinic(s) for medical updates.

- **31%** of these egg donors felt they or close family members **had medical/genetic issues** that would be important to share with families.

*U.S. and Danish sperm banks ship sperm around the world, so this is a global issue. In the U.S., the FDA only mandates the testing for communicable diseases and a handful of other diseases such as Cystic Fibrosis and Tay Sachs, both of which have been reported by donor families.

8 TIPS FOR DONOR-CONCEIVED ADULTS
Who Just Found Out

1. Talk to your parents.

Take some deep breaths, and try to relax. Many people have walked this path before you, and although the road can get a bit bumpy for a little while, they have all survived. Secrecy implies shame, and you have nothing to be ashamed of, so do not let the "secret" persist. Set aside time as soon as possible to discuss the situation with your parents. Talk with other close family members and friends who can provide good support.

2. Ask questions.

Ask your parents why they used a donor and what the experience was like for them. Ask them why they kept the secret. Most parents don't tell because they're afraid of how the truth will affect the family. Often, the non-biological parent is afraid of being looked at as not the "real" parent. You can assure your non-bio mom or dad that this news changes nothing in your relationship. Your parents will always be your parents. This knowledge doesn't change that fact or diminish your love for the parents who loved and raised you.

3. Explain *very honestly* how this news has affected you.

Tell your parents what you are feeling. You might be experiencing a wide variety of emotions, including anger, sadness, confusion, or even relief. Understand and explain that your feelings are valid and to be expected — and that working through these emotions might take some time. Have patience with yourself. If you're upset, don't feel guilty. This was your information to have, and it was kept from you.

4. Listen.

Your parents may have made the best decisions they could with the information they had at the time. Many parents were advised to lie to everyone, including their children. Find out what they know about the donor or any half-siblings. Gathering information about the other half of your genetic identity and relatives may help you better understand yourself. Many offspring report feeling a sense of relief as they reassemble the puzzle of their physical, emotional, & intellectual selves.

5. Be willing to forgive.

You may never fully understand or agree with your parents' reasons for keeping this information from you. However, staying angry doesn't help you move forward. Empathy and compassion will be extremely helpful in repairing any damaged relationships. Work through your emotions, with the help of a therapist if necessary. Understand that forgiveness is the only path to true healing. It's important for your parents to know that you can forgive them for not telling you the truth, even if this might take some time.

6. Continue the conversation.

This is not a one-time conversation. Let your parents know that you will ask them to continue the conversation as you process this new information, tell family and friends, and incorporate it into your identity. Invite your parents to walk beside you as you explore your genetic roots and figure out what it means to you and your life to be donor-conceived. There is great opportunity for a stronger family bond if you can keep the lines of communication open. Let your parents love and support you.

7. Accept your new reality.

Feel good about the fact that your family will now have a basis in truth. Understand that any curiosities you have about your half-siblings and/or your unknown biological parent, your ancestry, and your medical history are normal and to be expected. It's an innate human desire to want to know where we come from. You can't change the past, but you can control how you move forward. This is your story to own and share as you see fit.

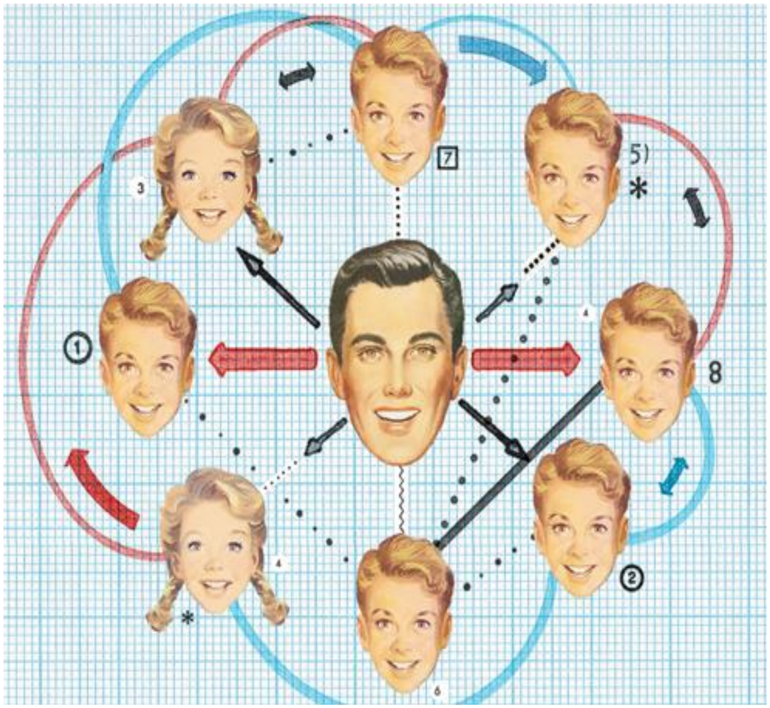
8. If you are curious...

If you do desire to know more about your donor family, give yourself permission to search for the information and the genetic relatives you're curious about. Your curiosity is not a betrayal to your parents, particularly your non-biological parent, in any way. Adding new family members or ancestral information doesn't take away from or diminish the importance of your family of origin. Let your parents know how important it is for you to have their support as you look to discover more about your ancestry, your medical background, and your genetic relatives. Join the Donor Sibling Registry for connection and support.

> ***"You can't really know who you are and where you're going unless you know where you came from."*** **—Bruce Springsteen**

Donor Sibling Registry:
Educating, Connecting, and Supporting Donor Families

DSR: 20 years: 2000-2021

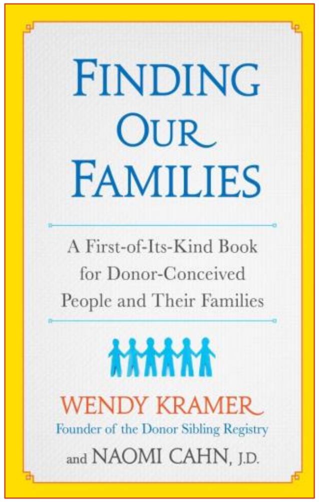


72,000 Donors, Parents, and Offspring in 105 Countries

19,800

people matched with half-siblings and/or biological parents

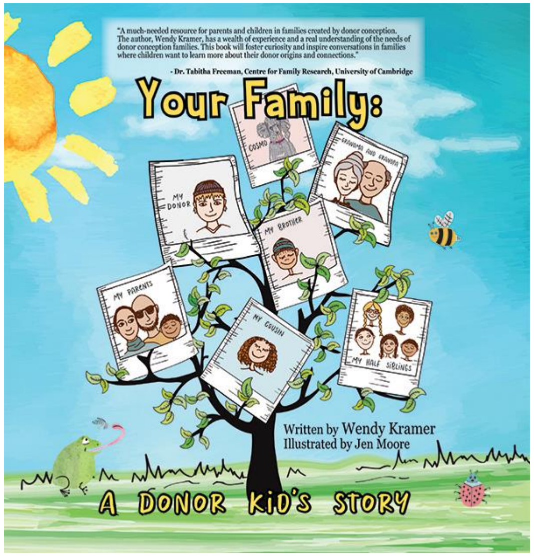
BOOKS



Finding Our Families: A First-Of-Its-Kind Book For Donor-Conceived People and Their Families

“If you are thinking about having a baby through donor conception, this book is for you. If you are a donor conceived person, this book is for you. If you are a parent raising a child who came to you through the help of an egg or sperm donor, this book is for you. If you are a medical or mental health professional, helping people build their families through donor conception, this book is for you…”

— Ellen Sarasohn Glazer LICSW, Co-Author, “Having Your Baby Through Egg Donation”



“A much-needed resource for parents and children in families created by donor conception. The author, Wendy Kramer, has a wealth of experience and a real understanding of the needs of donor conception families. This book will foster curiosity and inspire conversations in families where children want to learn more about their donor origins and connections.”

- Dr. Tabitha Freeman, Centre for Family Research, University of Cambridge

Your Family: A Donor Kid’s Story

"A much-needed resource for parents and children in families created by donor conception. The author, Wendy Kramer, has a wealth of experience and a real understanding of the needs of donor conception families. This book will foster curiosity and inspire conversations in families where children want to learn more about their donor origins and connections.”

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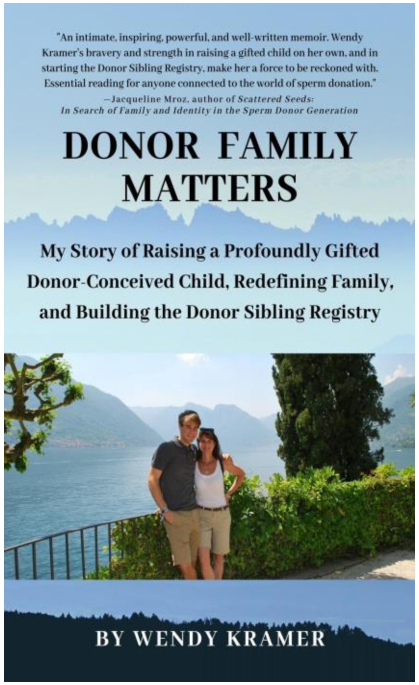

"An intimate, inspiring, powerful, and well-written memoir. Wendy Kramer's bravery and strength in raising a gifted child on her own, and in starting the Donor Sibling Registry, make her a force to be reckoned with. Essential reading for anyone connected to the world of sperm donation."

—Jacqueline Mroz, author of *Scattered Seeds: In Search of Family and Identity in the Sperm Donor Generation*

Donor Family Matters

"Wendy Kramer tells an absolutely riveting story that only she could tell — one that documents a profound shift in the way we negotiate our biology ... and each other. *Donor Family Matters* captures what Kramer calls the 'difficult, messy, joyful, and rewarding endeavor' of raising a family in a way that will break your heart and then put it back together again."

— Misha Angrist, Ph.D., author of *Here is a Human Being: At the Dawn of Personal Genomics*