

# Donor-conceived children looking for their sperm donor: what do they want to know?

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## Abstract

**Objective:** This paper aims to gain in-depth understanding of why some donor-conceived offspring want to know the identity of their sperm donor.

**Methods:** Step-by-step inductive thematic analysis was performed on first-hand quotes from donor-conceived offspring selected from a wide range of sources (including empirical studies and donor conception networks, registries and support groups).

**Results:** We found that at least 7 different objectives can underlie the wish to know one's donor: to avoid medical risks and consanguineous relationships; to connect with one's roots; to complete one's life (hi-)story; to understand where one's traits come from; to discover or assess one's defining characteristics and capabilities; to rectify a wrong-doing, and to map out one's ancestral history.

**Conclusion:** The analysis shows that there is great variance among identity-seekers in the weight they attribute to wanting to know their donor. It is also clear that they have very different assumptions about the role and importance of genetics in terms of establishing 'who they are' or 'can become', including deterministic misconceptions. Rather than treat all donor-conceived offspring's needs as of equal concern, this analysis should help distinguish between and assess the relevance of the various motivations.

**Key words:** donor conception, open-identity donation, donor searching, donor-conceived offspring, identity.

## Introduction

A number of jurisdictions across the world now require that donor-conceived (DC) offspring be allowed access to their sperm donor's identity upon reaching maturity. The arguments against donor anonymity are strongly inspired by prior developments in the context of adoption, where entitlement to know one's birth parents was advocated with reference to a child's right to identity, family and private life and to the harm caused by genealogical bewilderment. In carrying over these arguments to the context of donor conception, a central claim is that being denied access to donor-identifying information goes against the rights and needs of DC offspring to establish their own identity (Frith, 2001). The genealogical bewilderment as described in the context of adoption – a term that refers to a state of confusion and the undermining of one's self con-

cept due to lack of knowledge of at least one genetic parent (Sants, 1964) – is considered to apply just as well to offspring of anonymous sperm donors (Dennison, 2008).

This notion of the DC offspring's identity rights and needs is however highly ambiguous. For one, the analogy between adoption and donor conception is contested (Horowitz et al., 2010). Two, it remains highly questionable whether reference to the child's 'right to identity' – as defended in Article 8 of the United Nations Convention on the Rights of the Child – is applicable to this context (Blyth, 1998; Fortin, 2009). Three, and perhaps more importantly, a theoretical foundation of what is meant by 'identity' and the identity needs of DC offspring is nearly always lacking. In academic discussions on donor anonymity, little or no effort is made to explain what the identity problems of DC offspring encompass and whether the genealogical bewilderment of

adoptees is in fact readily transmissible to their situation. Most often, identity issues are invoked in general, abstract words and the comparison with adoption is assumed to be convincing enough (Chestney, 2001; Daniels, 2007; Cahn, 2011). Importantly, also, the connection between DC offspring's identity needs and the role of identifying donor information is rarely made explicit.

Given this, it seems helpful to consult the personal experiences of DC offspring themselves in order to have a better understanding of the interests at stake. However, the collection of reliable and generalizable data has proven to be very challenging. This is due to the fact that many DC offspring cannot be consulted as they have not been told about their conception status. Moreover, the research participants are typically recruited from support networks, which in itself carries a risk of selection bias (Ravitsky and Scheib, 2010). There is nonetheless empirical evidence that at least *some* DC offspring would like to obtain identifying information about their donor (Hewitt, 2002; Scheib et al., 2005; McWhinnie, 2006; Jadva et al., 2010; Mahlstedt et al., 2010; Vanfraussen et al., 2001, 2003). Only a few studies have also investigated the *reasons* for wanting to obtain the donor's identity. The main motivation of donor-identity seekers appears to be curiosity (Beeson et al., 2011; Jadva et al., 2010; Rodino et al., 2011; Scheib et al., 2005; Vanfraussen et al., 2003). In a survey of 165 DC offspring conducted by Jadva et al. (2010), it was particularly curiosity about the characteristics of the donor that was most commonly mentioned, followed by 'wanting to meet the donor' and 'medical reasons'. In the open-ended questions, there was an emphasis on the importance of knowing one's genetic or ancestral history and on frustrations due to lack of such information. In a study of adolescent offspring with open-identity donors, Scheib et al. (2005) found that the participants commonly wanted more information about 'what the donor is like'. In the largest questionnaire with DC offspring to date (n = 741), Beeson et al. (2011) found that, of those who responded to the question (n = 518), 82% desired to someday be in contact with their donor, mainly out of curiosity about the donor's looks. The authors conclude, as do Jadva et al. (2010) and Vanfraussen et al. (2003), that a major reason for wanting to know more about their donor is to find out more about themselves. In a survey of Australian recipients, donors and DC offspring, Rodino et al. (2011) found that the DC offspring regarded all types of biographical information (ranging from name to photo, feelings regarding donor-donor offspring contact, and descriptions of interests, physical features, health, education and other background

information) as very important. Their reasons for having chosen certain items as most important included: "the importance of family ties, a sense of incomplete self-identity, the importance of genetic connectedness and a need to satisfy curiosity and a sense of uncertainty/fear of serendipitous encounters with donor-conceived siblings" (Rodino et al., 2011). To some offspring, however, their donor conception status is not important (Vanfraussen et al., 2003) and is said to have no effect on their identity (Scheib et al., 2005; Snowden et al., 1983).

This study is an attempt to complement the empirical research conducted already. In particular, the aim is to gain a better, in-depth understanding of why some DC offspring want to know the identity of their sperm donor and what exactly they hope to gain from this.

## Methods

This study is a qualitative analysis of the reasons given by DC offspring for wanting to know their sperm donor's identity. First-hand quotes from DC offspring were selected from a broad range of sources (academic and popular, published and unpublished), using Google searches. The inclusion criteria for our material were: (i) English, written sources; (ii) which dealt with DC offspring's personal views on and experiences of donor anonymity. Due to the amount of material available, we excluded individual blogs, interviews and focused on (iii) sources which present points of view of multiple DC offspring.

In order to obtain a rich data set, two different searches were conducted. A first search involved listing the online platforms where DC offspring generally seek information and communicate or discuss their views about their donor conception: donor conception networks, registries, support groups and forums. Only forums that were publicly accessible (which required no login) were selected. We chose to do this for ethical reasons: with public internet forums, there is less risk of invading the contributors' privacy as they have chosen to make their posts publicly accessible. Through this search, we identified 9 online sources which contained quotes that fulfilled our criteria: UK DonorLink; Donor Sibling Registry; Donor Conception Support Group; Canadian Donor Conception Coalition; Tangled Webs UK: Support for donor-conceived people; The Victorian Assisted Reproductive Treatment Authority; The Anonymous Us Project; Donor conceived perspectives: voices from the offspring; and Chatterbox.

A second search involved (empirical) studies and reports that present multiple DC offspring's personal

experiences of searching for their donor, using search terms “research” OR “report” “perspective” OR “experience”, “donor offspring”, “search” and “donor”. While such studies have preselected personal accounts in function of their own research questions, they remain a rich source of material. Through this search, 21 studies were identified which fulfilled our criteria (Beeson et al., 2011; Blyth et al., 1998; Clemens and Cushing, 2010; Cushing, 2010; Donor Conception Support Group, 1997; Franz and Allen, 2001; Hertz et al., 2013; Hewitt, 2002; Jadva et al., 2009; 2010; Lorbach, 2003; Marquardt et al., 2010; McWhinnie, 2006; Morrissette, 2006; Nuffield Council on Bioethics, 2013; Kirkman, 2003, 2004; Spencer, 2007; Turner and Coyle, 2000; Victoria Parliament Reform Committee, 2010; Wheatley, 2010).

Within the data corpus, a particular data set was analysed where the respondents referred to the search for their donor or their wish to know (more about) him. Step-by-step inductive thematic analysis was performed, resulting in themes that are grounded in the data. All phases of the analysis were followed by discussions with the co-authors.

## Results

Throughout the thematic analysis, 7 different reasons for seeking one’s sperm donor were identified.

### *To avoid medical risks and consanguineous relationships*

In a most straightforward sense, DC offspring search for their donor to know more about his (family) medical history and to better assess their own (and their children’s) predisposition to inheritable medical conditions:

“I had cataracts removed when I was 48, and then it hit me that this came from the donor, because it was an inherited condition and none of my maternal family have had cataracts. What else is hidden there?” (quote in Spencer, 2007, p. 42).

“As I went through the pregnancy, I wondered, and of course, worried, what would I unknowingly pass on to my child because of my lack of information.” (quote in Canadian Donor Conception Coalition, ‘Shelley Deacon’).

Another common concern is that, not knowing who their donor is, puts them at risk of consanguineous relationships with other offspring of the same donor.

### *To complete one’s life (hi-)story*

A second reason to seek the donor’s identity involves the wish to further develop a ‘life narrative’ about

oneself. This relates to the view that we are ‘story-telling individuals’, that we make sense of our lives through a continuing story that establishes our connection with the past, present and future.

An obvious part of one’s life story relates to the very beginning of that life, the narrative behind one’s existence and the different paths that led to it (including what the parents were like when they were younger, how they met each other, why they decided to have a baby, etc.). This ‘prologue’ of one’s life, so to speak, is comparable to the type of information that adoptees are said to be particularly interested in: the life story of the birth parents and the story behind the adoption (Blyth et al., 2001). Donor-identity seekers share a similar interest in knowing more about the donor, his background and motives:

“For anyone who still doesn’t understand why we DI adults feel such a strong need to find our donors, I heard a quote the other day which was in reference to adoptees but is just as applicable to us. “We know our families love us and wanted us enough to go to “extraordinary measures” to have us, “but who wants to start a book on chapter 2?” I want Chapter 1, the Introduction and the Prologue as well!” (quote in Donor Sibling Registry, 2008, p. 13).

They find the story about ‘a friendly man who gave semen in a vial’ unsatisfying and feel the need to embed their autobiography in narratives and remembrances about their genetic forebear. For some, these stories need a more historical perspective and should include knowledge about his ancestry and social and cultural background:

“If I had the opportunity to ask my donor anything, it would honestly be to tell me more about his history and family. Where does he come from? Where do his parents and grandparents come from? (...)” (quote in Donor Sibling Registry, 2008, p. 10).

For many DC offspring, a rich family narrative is important, not only for them but for their children and future generations as well.

“Why does genealogy, mothers, fathers, grandparents, sisters, brothers, aunts, uncles, cousins of the shared dna kind matter? Because they ground, bind and root us to people and history. Their stories matter. We build our stories from theirs and pass them on to our own children. I do not need to have blood ties to my husband’s father’s family genealogical history to call them family. But I am a part of my children’s genealogical history and so too is my parent’s donor, including the rich history of all the many people whose life both his and ours travelled through.” (quote in The Anonymous US Project, submitted 09 March 2013).

### *To 'connect' with one's natural roots*

Some donor-identity seekers are not only interested in the story behind their donor, they also seek a deeper connection with him. DC offspring often refer to the meaning they attach to the fact that they share a genetic or blood tie. This is often viewed as more than merely biological relatedness, it conveys a meaningful bond of some sort. It 'matters'.

One interpretation of why this genetic tie matter is the fact that the donor lies at the origin of their very existence. Some DC offspring therefore feel a need to trace their donor so to thank him for having made their conception possible:

"When someone gives you a gift, you don't hunt them down to get another one. You hunt them down to thank them for such a wonderful present, for the lovely intention, for giving." (quote in Jadva et al., 2010, p. 529)

For other DC offspring, getting to know one's donor means finding one's biological roots, which they regard as their (more) natural place in the world. The donor is therefore sometimes sought in the hope of creating a sense of true belonging:

"(...) if I was able to find out what family I did belong to as far as my blood was concerned, that would be important. I would be curious to know where I fit in, in a sense." (quote in Spencer, 2007, p. 39)

The meaning attributed to this 'natural' connectedness with the donor may also imply that they explicitly position the donor within their 'family', as part of their kinship network ('kinning'):

"The greatest gift I've been given from my donor conception experience is how precious family is. My parent's donor is my father. He matters. There really is no such thing as a donor in relation to his offspring." (quote in The Anonymous Us Project, submitted 09 March 2013).

This sense of family belonging is often fed by the perceived importance of physical resemblance between family members:

"It is important to feel you fit somewhere, with people like you. (...) It is important to feel you are connected to your family by physical features, not just upbringing." (quote in Tangled Webs UK).

Some donor-identity seekers who relate to their donor as a 'father' wish to meet him and form a father-child relationship with him:

"I do want to find my father one day. (...) It's very hard to think that I have never been nor will ever be in the father's day section in the card isle. It's even harder to think that I will never have a father to

walk me down the aisle when I get married." (quote in The Anonymous Us Project, submitted 08 March 2013).

One DC offspring describes donor conception as a cure for "baby cravings" and feels that he is left without a cure for his "father cravings" (quote in The Anonymous Us Project, submitted 11 October 2010).

In lack of information about this 'father', many DC offspring describe how they fantasize about him and their first encounters with him:

"I day dreamed that my donor father was a doctor in Emergency Ward Ten, an early medical soap. As I matured, slowly and not without ructions, into adolescence and early adulthood I imagined an avuncular, solid GP living in a four square 1920's house with appropriate foliage around the door. I would knock on his door - it would be a shiny brass knocker and the paint work would be green. The door would open and his round, placid face would break into a delighted smile..... (quote in UK DonorLink, 'Shirley's Story').

Some are not only looking for a father figure, they want to connect with his relatives – their 'extended family' – as well:

"It makes me feel physically sick to think that I have a Father/Grandparents/Half Siblings out there that I can never meet!" (quote in Jadva et al., 2009, p. 1914).

### *To understand where one's traits come from*

Another need felt by some donor-identity seekers is to explore and assess their likeness with their donor. In a general sense, many DC offspring seem to be curious about physical, temperamental and behavioural similarities with the donor. They don't necessarily expect to bond with their donor, they just wonder which traits they have in common with him:

"I'm not after money, and I'm too old to want a "daddy." I just want to see if we look alike. What does he do? What are his hobbies? Do we both REALLY LIKE art? I am the only one in my family who is left-handed. Is he?" (quote in The Anonymous Us Project, submitted 20 December 2012).

These people tend to stress the genetic contribution to their physical and mental make-up. They hope that knowing their donor will help pinpoint the biological origin of various traits, to determine "what of me is me, my mother, and the father I never knew." (quote in Donor Sibling Registry, 2008, p. 18).

Such curiosity is not necessarily a source of frustration. As one person declares:



“Of course there is curiosity about what I don’t know, but it doesn’t ever negatively affect me.” (quote in Donor Sibling Registry, 2008, p. 10).

It does however often stem from the experience of incongruities of their physical and personality features within their families:

“Because my interests, appearance, life views, and personality are quite different from my parents, I frequently become curious about which traits I inherited from my biological father.” (quote in Donor Sibling Registry, 2008, p. 5).

The idea here is that they have some traits or personality characteristics which set them slightly apart from their family/social father. Finding out about their donor conception ‘makes sense’ of these differences: they could have been inherited from the donor. For some DC offspring, ideas about inheritance are far-reaching. For one respondent in Spencer’s (2007) study, for instance, the distinctions between her and her family seemed perfectly logical once she found out more about her donor, including his ethnic/cultural heritage:

“I always had a sense that I was slightly different. Now I realized that I am actually half Jewish, and half from Russia. That totally makes sense to me. It totally explains a lot of things to me.” (quote in Spencer, 2007, p. 33-4).

#### *To discover or assess one’s defining characteristics and capabilities*

While some donor-identity seekers want to identify the origin of certain (assumed genetically inherited) traits to better understand *why* they are a certain way, others feel they need a genetic reference point to find out *who* they are or who they can become. The hope is that insight in the (genetic) similarities and differences with the donor will help discover or affirm defining aspect of oneself. Information about the donor is thought to help uncover hidden parts of oneself or to better assess one’s assumed talents, traits and capabilities. Without such a reference point, some donor-identity seekers claim to experience difficulties in validating their interests and capacities:

“An adopted person once described the sensation of what is now termed ‘genealogical bewilderment’ as having to drive through life without a road map. (...) Simply having information about the sort of people they are, and what things they are capable of doing, creates a baseline that you don’t realize is comforting unless you have to live without it.” (quote in Donor Sibling Registry, 2008, p. 18).

By comparing how the shared characteristics developed throughout the genetic forebears’ lives, it is

also hoped that this will provide some insight into how one’s future may unfold and can be put to best use: a ‘road map’ for life, so to speak.

“I know I should have faith in myself, that no matter who my father is, I am a wonderful person, but part of me still wants to know where I am from, to figure out where I can go in my life.” (quote in The Anonymous Us Project, submitted 26 February 2012).

Some take this view a step further and feel that they are essentially the sum of their parents’ genes. For them, the lack of information about one genetic parent implies that they are completely left in the dark about *half* of their identity:

“I attempt to overcompensate for the loss of half of my identity by holding on to the hope of one day finding out who my father was or is ...” (quote in Donor Conception Support Group, 1997, p. 30).

For those who believe that the genetic contribution is substantial in defining who they are, discovering that one is donor conceived can be either liberating or upsetting, depending (amongst other things) on one’s relationship with the social father and image of the donor:

“My initial reaction was to laugh. I thought it was hysterical. The man I thought was my dad was such a creep that it was nice to know I wasn’t genetically related to him. I guess it changed my view of my identity. It changed it in a positive way. Instead of being the child of this terrible man [her social father], I was probably the daughter of a doctor [the donor].” (quote in Turner and Coyle, 2000, p. 2045).

#### *To rectify a wrong-doing*

Many donor-identity seekers are driven by a sense of entitlement to information about their donor. They feel that they are owed such information, as a matter of principle:

“In my view, all of the information about my mother’s donor ought to belong to me, not the clinic. Neither should my access to this information be determined by the directives of the ‘member organizations’, that is the sperm banks.” (quote in Donor Sibling Registry, 2008, p. 3).

These DC offspring feel that information about their donor rightfully belongs to them because it directly and essentially concerns them, it is their ‘business’. They also point out that naturally conceived offspring normally do have access to information about their genetic parents. The unequal treatment between them and DC offspring is regarded as discriminating and unjust:

“The vast majority of people know who their fathers and mothers are. We’re saying we’re entitled to that too. Nobody had the right to give away parts of our heritage.” (quote in Franz & Allen, 2001, p. 15).

Information about one’s genetic forebears is regarded as a universal birthright – something that should not even be up for discussion – and donor anonymity is experienced as a deliberate denial of this right.

Some regard donor conception as a selfish means for parents to fulfil their parental needs, which disregards the interests of the offspring. The decision to use a donor did not involve them, although it affects them most of all. As such, they want their voice on this matter to be heard:

“However, anonymity does NOT benefit the offspring. This type of conversation is one that concerns me because the ones in these situations who have no voice are still not being considered. There’s more to the choice than donors and mothers. Where’s the offspring’s choice?” (quote in Donor Sibling Registry, 2008, p. 13).

Searching for the donor’s identity can thus be regarded as an empowering experience, a way to control at least one aspect of the unilateral decision to use a donor. While access to donor-identifying information may not be ‘enough’, for some DC offspring it seems to serve as rectification in the form of respect for their wishes and access to information that was ‘stolen’ from them.

“These small bits of information that many of us “older” offspring have are surely not enough to replace what has been eliminated from our past. (...) We are human beings, not products of a financial transaction without thoughts and feelings, and we deserve to be respected as much as every other person in the world.” (quote in Donor Conceived Perspectives, ‘Lindsay’s Story’).

### *To map out one’s ancestral history*

A common and basic motivation for donor-identity seekers is the wish to learn more about their genealogy. Even aside of the stories and remembrances about their ancestors, they simply want to know who their donor is in order to trace out their ancestral history and cultural inheritance. Drawing out one’s family tree is considered to be a natural, normal interest, common to everyone:

“CL: Why do we think it’s important to know our genetic history? JR: It’s normal in society. Look at the royal family in England. Worldwide, people have always had knowledge of where they come from, knowledge of their ancestors. It seems to be

an innate part of our sense of humanity. (...)” (quote in Lorbach, 2003, p. 179) .

The fact that naturally conceived individuals are generally granted such genealogical information again raises the concern for some DC offspring that an injustice is done to them.

### **Discussion**

The purpose of this thematic analysis was to get a better understanding of the different reasons that may underlie the wish to know one’s sperm donor. It has brought various reasons to the fore: to avoid medical risks and consanguineous relationships; to connect with one’s roots; to complete one’s life (hi-)story; to understand where one’s traits come from; to discover or assess one’s defining characteristics and capabilities; to rectify a wrong-doing, and to map out one’s ancestral history. It must be noted that these reasons cannot always be neatly set apart; for some donor-identity seekers multiple or all of them may underlie their wish to know the donor.

A clear limitation of this study is that it cannot claim to provide an exhaustive account of identity seekers’ personal motivations. However, the main intention was to provide a richer and more concrete presentation of the experiences and needs of DC offspring than the vague claims about identity needs and rights as rehearsed in the literature and public debate. Moreover, a complete analysis of the DC offspring’s perspective on this matter is inherently problematic, because there is little information about those who are *not* interested in knowing their donor.

It is however clear from the analysis that there is great variance among identity-seekers in the weight they attribute to wanting to know their donor. For some, having no access to the donor’s identity is extremely frustrating; for others, it is not that important. Part of the explanation may have to do with particular challenges facing those who found out about their conception circumstances unexpectedly or at a late age. Several studies have demonstrated that age and circumstances of disclosure are critical factors in DC offspring’s feelings about their conception (Jadva et al., 2009; Lalos et al., 2007; Scheib et al., 2005). Another part of the explanation for differences in terms of the perceived importance may well have to do with the different benefits one hopes to obtain from knowing one’s donor. To some, the role of donor-identifying information is meant to carry the full weight of discovering who one really ‘is’ or ‘can become’; whereas for others such information will advance a richer life narrative or simply fulfill one’s curiosity.

This does not imply that those who experience intense frustration from not knowing their donor should not be taken seriously. It does nonetheless imply that knowing one's donor is not in itself a necessary condition for healthy mental development and general wellbeing. This is consistent with research showing that DC offspring do not fare worse than naturally conceived offspring in terms of general emotional, social and behavioural development (Golombok et al., 1996; 1999), even in families where the children are most likely aware of the donor conception status (Brewaeyns et al., 1997).

It is also clear from the analysis that DC offspring have very different assumptions about the role and importance of genetics in terms of establishing 'who they are' or 'can become'. Some of the motivations to know one's donor contain strong deterministic misconceptions and suggest a need for more information. Proposals to banish donor anonymity do not usually make these nuances and offer a one-size-fits-all solution. This allows rather unbalanced views and risks advancing uncritical attitudes towards the importance of genetic ties. Rather than treat all identity-seeker's needs as of equal concern, this analysis should help distinguish between and assess the relevance of the various motivations.

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