

## **The drive for openness in donor conception: Disclosure and the trouble with real life**

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### **Abstract**

Openness and children's 'right to know' about their genetic background have become key issues in debates about donor conception and a significant shift towards transparency has taken place in policy frameworks. But whereas openness is now supported in policy, the issue might be less of a 'done deal' for parents themselves; evidence suggest that many still hesitate to disclose. This has caused concern among policy makers and campaigners, putting parents under increasing pressure to tell. In this context it is important to seek to better understand parents' experiences, and why it is that some might feel uncertain about openness. I explore the issue by drawing on original empirical data from a study exploring donor conception and family life, and I show that there are significant insights to be gained from looking at the impact of openness in families. I explore four particular sets of dilemmas introduced by openness, namely decision-making and family boundaries; telling children; telling the wider family and navigating competing moral doctrines. I pursue the argument that an important factor to consider in understanding disclosure and its difficulties is the importance and complexity of family relationships and the impact they have on parents' decision making process. This leads me to argue for a change in direction in debates on openness and for the need of an increased appreciation of the vitality of relationships. I also suggest that openness needs to be brought into conversation and balanced against other factors which greatly influence children's and adult's personal lives.

## Introduction

Openness and transparency in families have become key issues in debates about donor conception. In the past parents of children conceived using donated eggs, sperm or embryo were encouraged to keep the donation a secret, but over the last decade or so there has been a significant shift towards disclosure, re-shaping policy in the area. An important marker of this shift is the removal of donor anonymity on the 1<sup>st</sup> of April 2005 following from the implementation of the UK Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004. Children conceived in clinics after this date are able to access identifying details about their donor when reaching maturity. The shift has been further consolidated through the Human Fertilisation and Embryology Authority's *Code of Practice*, which now states that parents should be encouraged to be open with their children about their genetic background (Human Fertilisation and Embryology Authority 2012). The UK policy is thus now similar to that of other countries which support openness, such as Sweden, Norway, Austria and New Zealand (Blyth and Frith 2009).

However, whilst the policy framework supports openness, there is evidence to suggest that openness might still not be a 'done deal' among parents of donor conceived children. In the UK, for example, MacCallum (2009) found that 43 percent of mothers and 56 percent of fathers of embryo conceived children were intending to keep the facts around the embryo donation a secret; Murray and Golombok (2003) made comparable findings in the context of egg donation. Similar findings have been made in Sweden, where donor identity release has existed from 1985. In a study from 1998 Gottlieb et al (2000) and Lindblad et al (2000) found that just over half (52 percent) of parents had informed, or where intending to tell their children about their conception. The figures were slightly higher in a follow up study from 2004 (Lalos et al 2007).<sup>i</sup> Although small, these studies indicate that a significant proportion of parents do not make, or intend to make, their children aware of being donor conceived, which means in turn that they later on are not able to benefit from information being made available about their donor through the new policy.

This perceived reluctance has caused concern among policy makers. In the British context, in August 2007, the Joint Committee of the House of Lords and House of Commons, undertaking pre-legislative scrutiny of the (then named) Human Tissue and Embryos (Draft) Bill proposed that, “the fact of donor conception should be registered on a person’s birth certificate” (House of Lords and House of Commons, 2007a: Recommendation 28, para 276 in Blyth et al 2009), which would make it harder for parents to remain silent about donor conception. Exploring this idea more in-depth Blyth et al. (2009) make the case for revising birth certificates in order to address how to ‘promote disclosure without compromising privacy concerns’ (Blyth et al. 2009:207). A similar anxiety is also evident in the Swedish context where the government launched an investigation into the perceived lack of information given to donor conceived children by their parents (Statens Offentliga Utredningar 2007).

The policy focus on openness, at least in the UK, is situated in a broader social context in which the role of openness/secretcy in family life has become the subject of heated discussions where secretcy has become associated with preventing children from ‘knowing who they are’ and from ‘having an identity’ (see e.g. Turkmendag 2012: 62, 64). In 2013, the Nuffield Council on Bioethics launched their report *Donor conception: ethical aspects of information disclosure*, which highlighted the importance of relationships in the context of donor conception and spoke of ‘interests’ rather than children’s ‘rights’ to know (Nuffield Council on Bioethics 2013); a message that was perceived as deeply problematic in some camps (see e.g. Blyth 2013). There is a powerful moral sentiment building around the need for donor conceived children to know their genetic origin, underpinned by the idea that they might otherwise suffer harm (Blyth and Frith 2009, Daniels and Taylor 1993, Eekelaar 2006, Guichon et al. 2012, Hargreaves and Daniels 2007).

Among policy makers and campaigners, in the UK and elsewhere, there is thus an anxiety growing about children being ‘kept in the dark’ about their origins, unable to exercise their ‘right to know’. This adds up to a situation in which parents are now under considerable pressure to share information with their children, which, as I shall go on to demonstrate, means sharing information

more broadly as well. Parents who choose not to disclose may be seen as problematic or out of step with modern and ethical thinking. In this context, it is very important to seek to better understand the context in which parents operate and *why* it is that they may hesitate to share information. One way to explore this question would of course be to interview those parents who are more secretive, but I want to propose that some answers might be found by looking at the experiences of parents who *seek to be open*. I draw on evidence from a recent sociological study into the impact of donor conception on family relationships conducted at the University of Manchester, which involved both lesbian and heterosexual parents, as well as grandparents, of donor conceived children, and in which the majority of the parents believed in openness. As I shall go on to show, these parents however soon found that translating the *idea* of openness into *practice* was not as straightforward as they might have thought. Rather, we discovered, openness could lead to a series of dilemmas in personal life. In this article I explore four areas which raised difficult quandaries: decisions about disclosure and the issue of family boundaries; sharing information with the child; sharing information with the wider family; and moral dimensions embedded in the idea of disclosure and so how to share information in the 'right way'. However, first it might be helpful to locate the issue of genetic relationships in broader social and cultural context, and also provide details of the study.

### **Genetic relationships and family relationships in broader context**

The gene and the perceived implication of genetic connections for the formation of personal identity are central to the contemporary emphasis on disclosure. This is part of a broader cultural and social 'turn' in which genetic thinking is gaining currency more widely (Nelkin and Lindee 2004, Rose and Rose 2012), and in which genetics have become a major way of understanding human life (Finkler 2000, Lippman 1991). Human behaviour and characteristics are increasingly perceived to be 'explained' by a person's 'genetic make up' (Finkler 2000:2). This way of thinking is giving way to a deterministic view of human life, where 'who we are' and 'what we become' is perceived as explained by our genes. The idea that our genes are of vital importance for who we are are now embedded in cultural notions about what shapes human identity; this is where we find the notion

that a person 'needs to know' his or her genetic background in order to know 'who they are' (Lawler 2008) which has become central to debates in the field of both adoption and donor conception (e.g. Carsten 2004, Freeman et al 2009).

Genetic thinking has also greatly impacted on cultural perceptions of meaningful family relationship; Millbank (2008) indicate that a pervasive shift has taken place in policy and family law towards prioritising biological links. The development of DNA testing is of importance here because the ease with which such tests can be conducted has radically altered the management of disputes in families because DNA tests are perceived to offer the irrefutable truth about the 'real' family relationships (Turney 2006). This is significant because DNA testing technology operates in a framework in which the revelation of genetic truths are perceived to benefit any child whose genetic parentage might be in question, and children are also perceived to have the 'right' to know about his or her genetic parentage (Smart 2010: 398). Revealing the genetic truth in families and ensuring that social family relationships map onto genetic ones is perceived as necessarily a positive thing for family relationships. Similar developments have taken place in the context of lesbian motherhood legal disputes and Millbank (2008) shows that biological parentage is deemed to trump the social relationship between a non-biological mother and a child, despite the non-birth mother's involvement in planning and caring for a child previously. Thus, biological or genetic parenthood has become a guiding principle for assessing worthwhile family relationships in courts.

However, real life experiences of family life calls into question the overriding assumption that genetic relationships trump social ones. Smart (2010) discusses the issue with reference to the British court case *Re H*; a complex case that needs to be unpacked briefly for clarity. An eleven year old boy lived with his (presumed) paternal grandmother, a brother and a cousin. Along came a stranger, who presented himself as the boy's (true) genetic father. The man applied to the court for residence and contact orders and he wanted to perform a DNA test to prove his paternity with the intent of removing the boy from his de facto family and raise him as his son. The boy expressed with

utmost clarity that he did not want any testing to take place; the truth might jeopardise the relationships he had with his grandmother, brother and cousin. Smart argues that:

The tendency for public policy, with its enthusiasm for DNA testing, to assume that (genetic) truth is better than (relational) fiction means that the addition of more genetic kin through these means is inevitably seen as producing a positive outcome for children (and possibly for adults). Yet children live in relationships that are delicately interconnected and adding more relatives may disrupt or even break some of these links. (Smart 2010: 409)

This example indicates that any genetic discoveries need to be balanced against the social aspects embedded in 'being' and 'doing' family life (see also Turney 2006). If we prioritise genetic relations over social ones, we also risk squeezing the practice of relating out of the picture. This is not to say that genetic connections are of no consequence to family life, but rather that they need to be balanced alongside other meaningful dimensions that impact on how family relationships are conducted (e.g. Mason 2008). The concept 'relationality' (Finch and Mason 1993, 2001) is useful here because it offers a view on family relationships that highlights the we need to take into account the subtle, intricate and interlinked worlds in which families operate and analyse the reasoning, actions and experiences of the actors of these worlds (see also Smart 2007). It allows us to see that family relationships are imbued with subtle layers of meaning which take shape over time, through the ongoing (explicit and implicit) negotiations of family members.

## The study

I situate disclosure in real life by drawing on the study 'Relative strangers: Negotiating non-genetic kinship in the context of assisted conception' conducted with Carol Smart (PI) and funded by the UK Economic and Social Research Council 2010-2013 (RES 062 23 2810) which considered donor conception and non-genetic kinship within the context of wider family relationships. It was based on interviews with 22 heterosexual parents and 22 lesbian parents of donor conceived children, and additionally 30 interviews with grandparents. In total we collected data from interviews with 74 families, with a total of 119 individuals taking part in couple or individual interviews. We conducted 34 couple interviews and ten individual interviews with parents (total number of parents 78) and 11 couple interviews and 19 individual interviews with grandparents (total number 41). In order not to

risk inadvertently conveying sensitive information to family members, we interviewed parents and grandparents from different families. All names, places and identifying details were anonymised.

Recruitment and fieldwork took place in England and Wales in 2011. We recruited parents who conceived using donor conception around or after 1995 when the shift towards openness started to gain momentum in the UK, but we also included some outliers for comparison. Most of our recruits came through the Donor Conception Network and local Lesbian Mums groups. The grandparents, who were a particularly hard-to-reach sample, were recruited through parents of donor conceived children (who were not themselves taking part) and through our own networks.

Among the 74 families represented, 54 had children through sperm donation, 16 egg donation, 3 embryo donation and 1 through both sperm and embryo donation (a lesbian couple who had one child through sperm donation and who were expecting a sibling through embryo donation). The total number of donor conceived children counted 111 (including five pregnancies at the time of data collection due in 2011). The majority of the children had been conceived using licensed UK clinics (69 percent), but couples had also used clinics abroad, self-arranged sperm donation and accessed Internet company providers of donor sperm available for a while during the 2000s<sup>ii</sup>. The median age of the donor conceived children at the time of the interview was 3 years old, the median age of the parents was 41 and of the grandparents 68.

The interviewees lived in both rural and urban locations in England and Wales, with particular concentration in Greater London and Manchester. Ninety of the 119 participants were women. Ninety nine (83 percent) identified as White British and 13 identified as White European, American or Australian; four as mixed British and three as Asian. Over half of our interviewees (53 percent) identified as atheist or agnostic; 40 percent were of Christian faiths and five percent were Jewish while no one of Muslim faith came forward to be interviewed. 78 percent of the parent generation had gone on to higher education which compared with the general population of women giving birth in Britain (Dex and Joshi 2004), gives a broad indication that the parent group that we interviewed were disproportionately middle class. The demographic constitution of the sample is likely to have

shaped the data in significant ways, not least because religion and ethnicity are important factors shaping perceptions of infertility and donation (e.g. Culley et al 2013). For more details on this and the study, please see Nordqvist and Smart 2014a)

### Decisions about openness and family boundaries

Decisions about openness could be complicated, and the first area that I address is the issue of who makes decisions about openness and how that is shaped by the perceived boundaries of the family. In and of itself, gamete donation creates links between the parents, the child, and the donor, in other words a family constellation that goes beyond cultural understandings of what a family looks like. When couples access donor sperm or eggs from unknown donors, or donors with identity release (usually through reproductive health clinics), the link to the donor is severed in order to ensure that the parents are able to raise the child 'as their own' without any interference from the donor. This means that the unusual network of relations that donor conception gives rise to is to a significant degree circumvented; and on the surface, the family can 'pass' as a conventional one. This is the kind of family by donation that figures predominantly in the debates about disclosure, a debate which focuses on *parents* as those making decisions about disclosure. Although I do not wish to deny the important place of parents in this process, our study suggests that families of donor conceived children are a heterogeneous group and may diverge from this image considerably. We found that this could have important consequences for how decisions are made about disclosure.

It is of particular important to consider how *known* donor relationships alter the framework within which families operate. One illustrative example of a family from the study with a known donor was that of Melissa and David who needed donor eggs. They found the waiting lists for donor eggs in the UK too long (the current waiting time is on average 2.5 years (National Gamete Donation Trust 2014)), and so when female friends of theirs offered to help, the couple decided to accept an offer from 'Jane'. Melissa explains why they choose to go with Jane, rather than someone else:

Well we'd decided that we'd rather go with Jane, because of all sorts of politics like, other people had offered but [...] their husbands would [not] really be on board, or the family dynamics, my niece was too young really. [Jane] offered and we felt comfortable that her



husband's on board and she'd discussed it with all her family before as well, so kind of felt comfortable that everyone knew and everyone was on board with it. (Melissa)

Another example in our study was Bridget and Lori, who wanted children but as a lesbian couple needed to access donated sperm. The cost of clinical donor insemination was simply unaffordable to them as they were both on a low income.

We always knew that we wanted kids, like I always said I wanted kids but realistically how would it ever happen [...] And two of our friends called us over, a married couple and just asked us if you know if we want to use their sperm kind of thing. [...] [Our donor] and his wife have got two kids of their own and [...] we talk about [the donation] openly, because we don't want it to be a secret. (Bridget)

These short quotes signal that a very different set of parameters come into play for families formed through known donor arrangements because at the very heart of these arrangements is the *ongoing relationship* between the parents and the donor. The donor also brings with him or her family connections of their own (a husband or wife, children, sometimes also parents), and these connections are equally important to consider. Melissa's account indicates that the donor's connections are so important that a connection deemed not to be favourable, such as a husband who is not supportive, can tip the balance towards rejecting a given donor. The accounts suggest that donation in families such as these is not only considered to be the private concern of the intended parents, the donor and the donor conceived child, but it is a concern for several whole family networks.

This means that known donation arrangements alter family relationships in important ways because it is not necessarily easy to define the boundaries of the family of the donor conceived. Donation broadens the circle of the family and as well as being a child of the family of the intended parents, the donor conceived child could also, in some way, be perceived to be linked to the family of the donor. This means that decisions about how to manage knowledge about a-link-by-donation between families joined through known donation, are the outcome of delicate *negotiations* not just between the parents, but between a whole network of people. Decisions need to be made about the extent to which the connection is made known, and it was felt to be of paramount importance that

people agree. Melissa and David felt that it was important that everyone in the donor's family knew about the connection, and also felt comfortable about it. Equally, Lori and Bridget, the donor and his wife spoke openly about the donation, and they also told (all) the children. There were cases in the study where the donor refused openness in which case the parents felt they had little choice but to not name the donor because of how that would alter relationships. Moreover, there were cases where the parents felt that the donor wanted 'too much' openness and 'too much' connection (this is explored in more detail in Nordqvist and Smart 2014a).

The example of known donation and how it shapes relationships is important for debates about disclosure because it highlights that decisions about openness can be taken in a context of very complex family relationships where the boundaries of 'the family' is not clear. It highlights the need to understand that openness/secretcy can be the outcome of delicate and sensitive processes where many people's feelings are taken into account, not just the parents'. In contrast to popular assumption they can concern a whole network of relations and span several families.

### Sharing information with children

Translating the idea of openness into practice was also complicated because it meant working out how to talk to the children about donor conception. Telling stories is a central part of family life (Smart 2007) and in order to translate the idea of openness into practice, donor conception has to be made into a story that parents tell their children as they grow up. But donor conception requires that parents tell a story that goes beyond the stories usually told to children about their birth. This means that parents are having to invent strategies about how to do manage the process (see also Blake et al 2010). Delhia explains her thinking about how to manage this dilemma:

You know how you get baby books that say this is the date you were born and this is when you lost your first tooth and all this sort of thing? And I've got a scrapbook and I wanted to almost do the same but do it from even prior to that. So, for instance, we've got scans of her when she was an egg. [...] It's because, those baby books that are tracking, you know, from birth – and generally it starts from birth – and actually, her story starts way before birth. And that's the bit that I think she needs to be aware of [that] the birth stage was way down the journey. (Delhia, with James)

As with Dehlia, some of the parents created their own books when an appropriate format could not be purchased. Others turned to the Donor Conception Network<sup>iii</sup> (the DCN) and used their children's books entitled 'My Story', the aim of which are to convey the story about donor conception in a child friendly way.

The parents also had to take decisions about when to tell the child. The now received wisdom is to start telling the child from a very young age. This means speaking to children of two, three and four years old about 'the facts of life': sperm, eggs, men, women, sex, genetics, the role of the donor, and what it meant to be lesbian or heterosexual. Trying to follow this advice, the parents in our study told their very young children (sometimes as young as six months). But this meant that the adults found themselves negotiating unusual situations because their children would think to use words and ask questions that were unusual for their age. Brian and Fiona recalls:

*Brian:* [Our daughter] knows [about] the donor eggs.

*Fiona:* She asks friends of ours when they've been getting pregnant, the women, so where did you get your eggs from then? And how about the daddy? Was that okay? Which does disconcert people.

We discovered that parents who tell their children about being donor conceived need to then live with and navigate their children's unusual knowledge about conception as part of their everyday lives. This could mean, as with Brian and Fiona, that parents could be 'exposed' by their child, who could indiscriminately and inadvertently convey intimate, and often painful, information about the family publically.

We also discovered that although the parents did tell their children from a young age, this did not mean that the children understood the implications of what they had been told, at least not in the way that the parents expected.

They've got the information, but they don't relate it to real life. (Matthew with Zoe, children aged ten, eight and six)

I don't think he's put two and two together. (Christine with Jared, children aged six and three)

They're [our son and the donor's children] all little and you know, it just seems natural to them, [but] they haven't actually put anything together. (Lori, son four years old)

Many also found that the children showed very little interest in the story. Vanessa talks about how her ten year old twins engage with the facts of their conception:

I mean they're not that interested in [the story] in fairness, I mean I think people imagine children conceived that way it [is] going to be this great [thing] in their life and it's really not. They're more interested in you know are we going to get another hamster now that [ours has] died. (Laughter) (Vanessa, single)

The parents soon realised that telling the children was not a one-off occasion. Instead, it emerged as a process that parents needed to revisit again and again. This meant that the parents became 'gatekeepers' of the information, and they carried with them a sense of having a continuous responsibility for the children 'understanding' the implications of the story, despite already having imparted the information. Cathryn had two girls conceived using eggs donated from two different women, one anonymous and one identifiable. Cathryn felt that although she had told the girls, she remained responsible for talking about the donation and potential problems caused by having different donors:

Cathryn: I feel quite anxious about [the donors] sometimes. I think what I'm finding out is that as long as I'm the one who's holding it all still, I feel really anxious. And then when I start to have the conversations with the girls it gets easier. (Children six and three years old)

These insights complicate the abstract idea of disclosure as information sharing and points to the importance of relationships, care, children's development and the passing of time. What is particularly striking about the data about telling children is that information sharing cannot be understood as a one-off event but as a process that the parents needed to attend to gradually and over time in order for their children to know about their donor background, and to understand its implications.

### **Telling the wider family**

Families of donor conceived children quickly realised that with having disclosed information to the child, they also needed to tell significant others; the family of origin was a particularly important audience. The study data indicated, however, that doing so was not always straightforward. The

cases of Monica and Trevor, and Sheryl (both below), usefully illustrate the complexities that could be involved in telling the wider family.

Monica and Trevor's account of telling their own parents and extended families echoes the experiences of many:

Monica: With my family I found it very easy to tell them and well certainly my mum, you know is someone that I do talk to about it and I'm close with and you know my dad I'm close with but he's not someone who will talk about those kind of things but he'd do it kind of vicariously through my mum anyway.

Trevor: He hovers around.

Monica: He would hover around (laughter) and let her do the talking. [...] And then I would say about Trevor's family it was difficult to tell them. It was difficult [because] once they knew and then they ignored it. [...] And it was never spoken about again by anyone.

Monica's experience of telling her parents reflects a common pattern. She remembers telling her parents as an easy process, but that her father did not seem able to engage in the conversation. We cannot of course know how her father felt about the situation, but it appears from Monica's account that while he is generally supportive, he is not the sort of man who engages *actively* in the intimate and emotional aspects of relating to his daughter; it appears that falls to his wife to manage. This appears unsurprising to Monica who seems unperturbed by her father's distance and passivity and we can assume that this relationality has been established over many years (Finch and Mason 2001). Her account reflects the more general findings we made that grandmothers took the active role in supporting their daughters, or daughters-in-law, through the process of fertility treatment (Nordqvist and Smart 2014b), whilst grandfathers were expected to remain more inactive; the notion of 'hovering' usefully depicting the passive but supportive stance of many grandfathers.

Trevor's experience was also common in the general sample, and one that was often experienced as far more difficult. Both Trevor's parents had greeted his disclosure with silence and we must assume that this family would normally manage potentially intimate and sensitive topics through non-discussion; a way of relating that came into play as Trevor told his family about his

infertility. Finch and Mason (1993) notes how silence can be a prominent strategy that families use to manage potentially controversial topics (see also Nordqvist and Smart 2014c).

The outcome of these initial moments of disclosure to the wider family is very important because they set the scene for subsequent conversations. Whereas it was a topic that Monica was able to discuss with her mother from time to time, Trevor's family remained completely silent on the issue years later. Consequently Trevor, who had struggled greatly with the realisation of being infertile and the subsequent use of a donor, felt that he could not breach the topic with his family. But he could also not 'undo' the telling in the first place because once said the information cannot be taken back again (Strathern 1999), and so lived with a continuous sense of upset about the situation that had developed in his family. Moreover, the couple felt uneasy thinking about how Trevor's family might respond to their daughter talking about the issue in years to come.

It was typical that couples found the process of disclosure complex in these ways. This was not because most parents were outright unsupportive or judgemental about the situation, although that could happen (see below). Instead the complexity was linked to that disclosure meant taking well established ways of relating in families into new territories, and family members were not always willing to follow.

When considering disclosure to wider family networks, it is important to understand how little control parents have over how the process unfolds, and also how vulnerable they can feel at the thought of relatives' disapproving of their method of conception. Many parents found themselves in a situation where they were quite content to tell the child, and yet they found disclosure a very fraught process because of how grandparents or wider family would react. Whereas some grandparents were supportive, others responded with silence or denial. In some families, they even 'blocked' any subsequent sharing of information with the wider family. An example of this emerged in our interview with Sheryl, who had a child through donor insemination with her former partner Penny. When Sheryl 'came out' as gay, her parents distanced themselves from her for many years and they became quite estranged. As she became a mother, her parents got back in touch but still

disapproved of her being gay; according to Sheryl they found the idea of having a child in the context of a lesbian relationship unpalatable. When Sheryl had her baby, the grandparents managed the situation by telling the wider family that the child was the outcome of a heterosexual alliance (which they were able to do because Sheryl and her partner lived far away), thus constructing a lie that rendered Sheryl's sexuality, Penny, as well as the donor conception invisible. Sheryl described her parents as 'very traditional' and perhaps we can assume that the idea of a daughter of theirs being gay and having a child through donation would be an unacceptable blemish on the whole family, and could not be incorporated in the family story and so needed to be kept secret (Smart 2011).

To suppose that a parent in Sheryl's situation could simply disregard her parents' desire for secrecy when taking decisions about openness is to underestimate the power and complexity of family relationships (Smart 2007). In circumstances such as Sheryl's, it is difficult to envisage how openness can be realized without significant damage being caused to those vital relationships. Despite her parents' disapproval, they were meaningful people in Sheryl's personal life, and her daughter's. On becoming a mother herself, she was keen to create connections for herself and her daughter with the wider family. She was also on a low income and single, and her mother offered indispensable help with child care. A tacit agreement not to discuss the donor conception appeared to her the only option to enable family relationships to continue despite the underlying conflict, and to support herself and her daughter. This example illustrates how openness can cut at the heart of family life and that sometime, openness can threaten vital relationships with family.

Sheryl's experience also highlights that disclosure can have significant consequences because it interlinks with economic and social vulnerability. Sheryl's account show how life circumstances such as relationship breakdown, single parenthood, lesbianism in the context of homophobia, poverty and being dependent on the good will of family members for support, can add up to a situation in which a person is vulnerable and *needs* their family for survival (see also Valentine et al 2003). Such a person cannot easily afford to put vital relationships at risk if that means potentially losing vital support.

These findings indicate that wider family have a significant role to play in donor conception and that relationships with grandparents and other family members shape decisions about disclosure in fundamental ways. It also shows that disclosure is a process embedded in relationships formed over time that are delicate and that do not easy change.

### ***Sharing information in the 'right' way***

Negotiating openness could also be complicated as an idea because of underlying doctrines about how information *should* be shared. One particularly powerful idea that parents navigated was that children need to be told about being donor conceived because it is *information about them*, and so the idea of disclosure is framed as a matter of personal identity. The parents were encouraged by clinical staff to think of the information about donor conception as something that 'belonged' to the child, and this was taken to mean that the child should be in charge of the process of sharing. Carrie spoke of her experience of being confronted with this belief. She and her partner Paul underwent a series of difficult and time consuming medical investigations before it became clear that they needed to use sperm donation in. This was a horribly difficult time for them, and Carrie sought the support of her friends in the process, telling them about the situation that she and her husband found themselves in. When Carrie fell pregnant the fertility counsellor at the reproductive health centre told her that she should not have told her friends:

I felt terrible because [the counsellor] said 'Well you don't realise kind of what you've let out of the bag [by telling people]' [...]

Carrie went on to explain:

At this point [when we went through treatment, children] seemed like a sort of minor miracle if they were going to happen at all to us. You don't tend to think that far ahead that it's about their origin, it's then their information to share. But you've already shared it. But then you know [the children] didn't even exist at that point. So it takes a stretch to think about being confidential about your child's information, the child you haven't even got yet.

Parents were charged with the moral responsibility of 'doing the right thing' by their child, constructed as allowing him or her to decide about whether to be open and with whom. However, they soon found that this idea that sounded easy enough in the abstract did not necessarily fit with



their life experience. Carrie's account points to a fundamental understanding of parents who undergo the treatment of donor conception, which is that they do not know if they will ever be able to conceive a child and that they are trying against the odds. Statistically speaking, success rates are still relatively low and the national average for women under the age of 35 (who has the highest predicted chance of success) is 32.6 % likelihood of a live birth following IVF treatment (Human Fertilisation and Embryology Authority 2014a). This means that through the cycles of treatment the parents are having to manage the hopes that it will be successful, whilst also being realistic about their (slim) chances of success (Franklin 1997). Fertility treatment is known to be extremely stressful, partly because it means being on an emotional rollercoaster of hope and despair (Ibid.). Understandably, Carrie felt the need to talk to her friends. However, the clinic counsellor is charging Carrie, and parents like her, with the moral responsibility of keeping that very difficult process private and secret *in case* it results in a child, the idea being that it then becomes the information of that child.

The problem of which Carrie speaks is the discord between the idea that information belongs to the child, and the real life experience of how relational lives work. Her account indicates that donor conception in fact touched the lives of a number of people in her family – herself, her partner *and* her children and that these different people had different needs in relation to that information and at different times. Parents and their children, and wider kin, live interconnected lives, and boundaries could not easily be drawn between events in the parent's lives and matters that concern the child. It would be more accurate to view information about donor conception as something that morphs into different shapes over time, so that it is *simultaneously* a difficult process that the parents went through *and* meaningful for the child. Thus, the contemporary notion of what it means to 'do the right thing' does not fit easily with how families operate.

Another example of how parents tried to get a handle on this irresolvable moral dilemma transpired in our interview with Jonathan and Abigail, who had a son through known egg donation:

On one hand [...] my vision about [the egg donation] is that it's nothing to hide. And it's something to be celebrated and embraced and isn't it a wonderful thing? And so it's really important that [our son] understands that from us. On the other hand the tension is then between [that and] him to be in control of that information as well. (Jonathan)

Jonathan's quote suggests that he and his wife found it hard to know what 'doing the right thing' meant and that there were in fact competing moral parameters that came into play when decisions were made about openness. They were extremely pleased and proud about the way that they had been able to have a child against all odds, and they wanted to communicate this sense of amazement to their son. However, celebrating the egg donation openly was in tension with the idea that he should be in control over sharing the information.

Adding to their sense of bewilderment, was the fact that at three years old, their son could not be in control of the information and so Jonathan and Abigail had to make decisions about who to tell. Jonathan went on to say:

While he's a child he can't be in control of who knows and who doesn't. [We then have to make the decision for him] so you end up with these sort of like record knowledge. But who falls within which circle [of who should know]? And I find that, out of all of it I find that bit ... confusing.

Jonathan refers to information about donor conception as 'record knowledge', by which we must assume that he means a kind of knowledge that is shared with much thought and consideration only to 'the closest circle'.

Jonathan's feeling of being confused is significant because it is suggestive of the difficulty of bringing together the abstract moral idea that information about the donor conceived child 'belongs' to the child, with the idea that a child should be told from a very young age when he or she is too young to make an informed decision about who to tell. These two doctrines cannot possibly be fulfilled both at once; a child cannot both know from a young age about his or her donor origins and yet make informed decisions about if they want to be open and with whom. And yet the parents tried to bring the two together and understandably struggled to make sense of the right course of action. The parents also of course knew the crucial impact of kinship information of this kind: that it does in fact affect a whole network of relationships and that information about biogenetic

connections is in itself constitutive in its consequences and will always alter relationships (Strathern 1999). Once the information is shared, it cannot be taken back.

The accounts also signal that the moral discourse have a significant impact on parents' lives. Carrie said she felt 'awful' about having done the 'wrong thing' and it is evident from Jonathan's account that he and Abigail have thought hard about how to do the 'right thing'. We may understand the potency of these decisions through a notion of being 'good' parents, and so what is at stake by doing the right thing by their child, is the moral identities of parents (Finch and Mason 1993).

In debates on disclosure this adds important insights that parents work quite hard to 'do the right thing' and be open 'in the right way' but that what this means as far from clear. Contemporary moralities introduce competing parameters in the lives of parents, who find that they do not easily translate into practice and that knowing how to navigate between competing doctrines is not straightforward.

## Discussion

The sociological findings introduced in this article highlight the importance of everyday family life experiences in shaping decisions about openness and secrecy. This is the world in which parents operate, and this is the context in which openness with children about their genetic origins is processed and turned into practice. I have demonstrated that seeking to practice openness raises a series of dilemmas for parents of donor conceived children, and I have explored four of the areas in which problems can arise: decision making in the context of porous family boundaries; telling children; telling the wider family and also navigating making decisions in the context of contradictory moral doctrines.

What unfolds through these different angles is the central role of relationships and *relating* for decisions about transparency. Information sharing needs to be understood as both *relational* and as a *process* that unfolds along the lines of already established ways of relating and in accordance with existing family biographies. There is an important difference between information being transmitted

and communication being established; it is more relevant to talk about openness as a process of establishing open lines of communication, rather than an event, and that these lines are shaped by existing family relationships. A focus on relationships also brings into view that donor conception is not only the concern of the donor conceived, but also, their parents and wider families; the idea that the information about donor conception belongs to the child exclusively fails to take into account the relational nature of family life. Parents and donor conceived children are *embedded* in family networks, networks of family of origin or networks of the donor, and these networks are vital in personal life. These networks are also 'sticky' in the sense that they are not easy to shed (Smart 2007), and so if a set of grandparents are unsupportive this is significant because they are still vital in parents and children's lives. Family relationships are imbued with a sense of being in the world, security and history and are hugely significant in personal life. It is important to realise that family relationships are all interconnected and they are also delicate and need to be managed with care. Parents and children are embedded in interconnected networks with one another as well as with wider family, and their experience and choices around openness will, crucially, be shaped by them.

This also means that whereas it is important to consider the child's 'need to know' about being donor conceived and her or him being able to make decisions about disclosure, such needs to be balanced against other needs of that child as well the needs of other members of the family. It is possible to imagine a situation where a child have a need for privacy which is opposed to a mother or father's need for openness about their own history of having endured fertility treatment. Or, as discussed above, it may be that the need to be open needs to be balanced against the need to preserve existing relationships with wider family. Rather than understanding family members as making decisions as autonomous individual, it is more useful to think of these experiences and decisions are structured by people being *connected* in family relationships because their lives are interlinked; even co-constituted.

These findings lead me to argue for a change in direction in the debate on openness and suggest that it is vital to the policy debate to appreciate the importance of relationships in shaping the

decision making process. It is not my argument that openness should be abandoned and secrecy should be reinstated in the world of donor conception, but rather that the desire for openness amongst policy makers and the importance attached to openness need to be brought into conversation and balanced against other factors which greatly influence children's and adult's personal lives. A more nuanced understanding of openness is needed, which acknowledges, for example, the important relationships with wider family, especially grandparents, socio-economic status and material restraints, that family relationships are complex and can be at once supportive and less than perfect, and also that parents make decisions in a context which is not of their own choosing and may be less than ideal. My data lead me to suggest that in driving the agenda of openness, it is crucially important to be mindful of the complex nature of family relationships. It is my argument, then, that it is timely to bring into the debate on openness and the 'child's need to know' the important role of relationships in shaping personal life and parents decision making processes about disclosure. I argue that it is of vital importance to seek to better understand and take account of how openness impacts family relationships and everyday life when developing policy and engaging with parents relative 'unwillingness' to be open with their children.

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<sup>i</sup> In a more recent study conducted 2005-2008 Isaksson et al (2011) found what seems to be more positive attitudes to disclosure, with 90% of the sample stating that parents should be open with their offspring. However, this data were gathered with couples at the time of treatment rather than with parents of donor conceived offspring; we don't know the extent to which these couples went on to become parents, or indeed, if they chose to actually disclose information to their children.

<sup>ii</sup> Since 2007 Internet sperm providers can no longer operate in the UK without a license from the Human Fertilisation and Embryology Authority (Human Fertilisation and Embryology Authority 2014b).

<sup>iii</sup>The UK Donor Conception Network (DCN) was initiated by parents of donor conceived children in the 1990s and campaigns for increased openness.