

Secrets and disclosure in donor conception. *Sociology of Health and Illness.*

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ABSTRACT

This paper considers the disclosure, sharing and exchange of information on being donor conceived within families, drawing on data from a study undertaken with donor-conceived adults registered with UK Donor Link (a voluntary DNA-linking register). It considers the narratives of how respondents found out they were donor-conceived and what events triggered disclosure of this information. It goes on to examine the role secrecy played in their family life and uses the concept of ‘display’ to explore how it affected their relationships with their immediate and extended family. Secrets are notoriously ‘leaky’ and we found complex patterns of knowing and uncertainty about whom in the family knew that the person was donor-conceived. We argue that what is kept secret and from whom provides insights into the multifaceted web of social relationships that can be created by donor-conception, and how knowledge can be managed and controlled in attempts to display and maintain family narratives of biogenetic connection.

KEY WORDS

Disclosure, family practices, gamete/sperm donor conception, display, reproductive secrets, secrets, UK Donor Link.

INTRODUCTION

The importance that secrets and secrecy play in social life is well recognised. Simmel (1906) for example, considered the social functions of secrets and how secrecy can illuminate aspects of society and human behaviour, while Bok observed, ‘Secrecy tests human relationships as little else does.’ (1989:44) In the area of personal life, interest in secrets and their relationship to constructions of the family and sense of self is growing. Smart has written extensively on this, and argues that secrets carry importance, ‘not because they reveal a simple “truth” about family life, but because these secrets are a route into understanding the complex relationship between power, the personal, the cultural and the social.’ (2011:539) Specifically, secrets can be explored by seeing them as a core activity in both bonding members together and in excluding – or othering – other members (Smart, 2011). Secrecy is not in itself problematic, it is what is kept secret and from whom that demarcates how secrecy is viewed. Thus, unpacking the purpose and role of secret keeping can provide useful insights into family relationships.

Morgan’s (1996) work on family practices in which families are seen to be constituted by what they do, their customs and practices, rather than by the structural elements of

relationships, marriage and household formation provides a starting point for thinking about the role of secrets in families. Arising out of this work, Finch (2007) develops the concept of family ‘display’, arguing that, ‘*families need to be “displayed” as well as done.*’ (2007:66 - emphasis in original) If family activities are fundamentally social then ‘the meaning of one’s actions has to be conveyed to, and understood by, relevant others if those actions are to be effective as constituting “family” practices.’ (2007:66) Finch argues that when activities are firmly embedded within the family through ‘taken-for-granted’ aspects of practices, there is no need for display. If activities are ‘not fully embedded’ in a particular set of relationships as a ‘family’ practice, then display is needed. Display adds something that has not, hitherto, been explicitly recognised, ‘it is fundamental to successfully constituting “my family relationships” as a meaningful feature of my social world.’ (2007:79) Family relationships can be constituted through narrative display and ‘[secrets] are amongst the kinds of stories that people tell of families as part of the constitution of “the family” and its past.’ (Smart, 2011:540) Finch develops display as a theoretical concept and encourages others to use it in empirical work. In this paper we take up this challenge and show how keeping secrets about donor conception plays an important role in how these families are ‘displayed’.

As secrets and the narratives on which they are based become part of what the family *is*, the family displayed, they also play an important role in individual identity construction. ‘The self is forged on the basis of truths which, while claiming to speak *about* the self, work to *produce* specific forms of self. In this way, *who we are*, is an effect of what (or who) we *know* ourselves to be. And in this being and knowing, power is at work.’ (Lawler, 2000:19 emphasis in the original) Identity is developed in part by the stories that one hears about one’s biography, who one takes to be kin, how this kinship is formed and, at a fundamental level, who one believes to be one’s parents. There is a growing body of work on the autoethnography of family secrets and the effect that secrets have on a sense of both identity and the meaning that one gives to family life (Goodall, 2005; Hudson, 2015; Poulos, 2008). Goodall recounts his discovery that his father was a spy rather than ‘just’ a government employee as he had always believed. He develops a concept of narrative inheritance to explain the impact of this secret, ‘What we inherit narratively from our forebears provides us with a framework for understanding our identity through theirs....Identities are indeed the stuff such stories...are made out of.’ (2005:497 & 504) When these narratives are built on secrets that are later ‘uncovered’, they can have a huge impact on the existing sense of self and force people to re-evaluate their identities. Goodall experienced his family secret as ‘toxic’, drawing on Imber-Black’s work. ‘Toxic secrets poison our relationships with each other. . . . Key family stories remain untold and unavailable. These are secrets that take a powerful toll on relationships, disorient our identity, and disable our lives.’ (Imber-Black, 1998:15)

Since its beginnings, donor conception has been characterised by discourses of partial knowledge and selective telling and has often been kept secret by, or within, families. Using data from a study undertaken with donor-conceived adults registered with UK DonorLink (UKDL), this paper explores the operation of secrecy in relation to donor conception and the role secrets play in the construction and maintenance of donor-conceived families. UKDL was founded in 2004 to enable gamete donors and donor-conceived individuals to register and submit a DNA sample to try and identify a *potential* link to another registrant (see Crawshaw et al, 2015 for an overview of types of searching services). UKDL was funded by the UK government until the transfer of its functions to the Donor Conceived Register in 2013 (Crawshaw, et al., 2013). Secrets can become part of donor-conceived family narratives, the stories people tell (or don’t tell) to make sense of, or manage, their experiences

(Coffey & Atkinson, 1996). In this paper we develop the idea of family narratives as ways of displaying family and explore the role that secrets play in these displays of family life.

This paper makes the following contributions: first, it explores the longer term consequences of forming a family by donor conception as perceived by donor-conceived adults. As Hertz et al (2016) state, most sociological work in this area is ‘on the narrow attitudes of recipients rather than on broader issues of connectedness.’ (p 4) and our study aims to contribute to the limited literature in this area. Second, although the role of secrets in personal life has been extensively discussed at a theoretical level, there has been little empirical work, and we aim to remedy this by using secrets as a lens to understand how donor-conceived families construct themselves, what this says about the social meaning of donor conception and how families seek to place themselves within ‘mainstream’ discourses of family formation. As Nordqvist and Smart (2014) note, how secrecy plays out in the future life of families is generally unknown and our study begins to shed some light on this. Finally, a number of studies have been conducted with donor-conceived individuals making links with donor-conceived relations (see Freeman *et al.*, 2014), but none to our knowledge have examined the experiences of those who have used a DNA-based register.

SECRETS IN DONOR CONCEPTION

What ‘needs’ to be kept secret changes over time and the transition from the promotion of secrecy to encouragement of openness in donor conception illustrates the temporal dimension of secrecy (Blyth & Frith, 2015). Historically, donor insemination was shrouded in secrecy (a practice extended to oocyte and embryo donation once these became available from the 1980s) and there was an underlying assumption that some ‘holding back’ – partial telling or no telling – was justified (Clark, 2012). UK gamete donors were anonymous to recipients of their donation and to any offspring produced. Accepted practice was to not only safeguard the donor’s identity but also – at least until the late 1980s – for recipients to keep secret the fact of donor conception from both the child and members of their social circle (RCOG, 1987). These practices were a response to the stigma of infertility (in particular male infertility), the uncertain social acceptability of donor conception, and fears for the integrity of family relationships (Novaes, 1998). ‘Problems’ with legal paternity contributed to the desire to maintain secrecy and donor anonymity protected the donor from parental responsibility, affording parental rights to the husband of the recipient and protecting the child from the stigma of illegitimacy (Dewar, 1989). Secrecy and anonymity also served to protect the medical profession from potentially critical external scrutiny of donor insemination, a medical intervention that, at the time, had dubious social acceptability (Imber-Black, 1998; Haines, 1993). Secrecy in donor-conceived family life was, arguably, a pragmatic response to the legal and social context in which donor conception operated.

The legal context of donor conception in the UK changed following publication of the Warnock Report in 1984 on the regulation of reproductive technologies. The Report endorsed gamete donation as a legitimate method of family building and subsequently the 1987 Family Law Reform Act provided for the husband of a recipient of donated sperm to be entered on the birth certificate as the child’s father. The Human Fertilisation and Embryology Act 1990 largely adopted Warnock’s recommendations. It enacted the principle of donor anonymity and made provisions for some unspecified non-identifying information about the donor to be released to donor-conceived people reaching the age of 18. The passage of the Act, however, did not put this issue to rest and donor anonymity continued to be questioned (Frith, 2015). In 2005 UK law changed again, requiring all new gamete donors to agree to the disclosure of

their identity to any individual conceived as a result of their donation, if they so requested, on reaching the age of 18. The UK became one of a small number of jurisdictions formally to proscribe donor anonymity (Blyth & Frith, 2015). The legal and social context of donor conception, with greater acceptance of a wider variety of family forms (Golombok, 2015), is now very different from the early 1980s and this contextual shift changes the role secrets ‘need’ to play.

TELLING IN DONOR CONCEPTION

Early research into parents’ disclosure behaviour indicated that very few challenged the prevailing orthodoxy of secrecy (Blyth et al 2012). Over time both professional views and parental practice have changed: in 2008 an amendment to the Human Fertilisation and Embryology Act 1990 provided legislative endorsement for *early* parental disclosure (Section 13(6C)). In other countries this trend is also evident, for example, both the American Society for Reproductive Medicine (ASRM, 2014) and the Australian National Health and Medical Research Council (2007) openly recommend parental disclosure.

Some studies have reported increased parental disclosure of donor conception over time (see Blyth et al., 2012; Söderström-Anttila et al., 2010). There are also different disclosure patterns according to type of donation and family structures. The highest levels have been recorded for oocyte donation and among families headed by lesbian couples and single-parents (Nelson et al, 2013; Scheib et al., 2003). Despite such shifts, some parents do not disclose at all or may engage in partial disclosure, even if they know the identity of the donor (Readings et al., 2011; Yee et al., 2011). In the case of anonymous donors, as Konrad notes, even if parents tell the child they were donor-conceived, ‘The secret “lives on” because it can never be fully spent – it cannot be “exposed” as a final truth. [And this opens up the possibility of] ‘unknown relations.’ (2005:169)

A growing body of research has examined the effects of disclosure of donor conception on relationships within families, and it is generally considered that relationships are not necessarily harmed by disclosure (Freeman, 2015) as was previously thought. A key area of debate has been the timing of disclosure. ‘Early disclosure tends to be associated with more positive outcomes: if children are to be informed of their donor conception, the most favourable situation is to be told from an early age so they are never shocked by discovering this knowledge.’ (Freeman, 2015: 54) A commonly reported response among those told young is curiosity (Jadva et al., 2009) with early disclosure being associated with ‘neutral’ to ‘positive’ impact on parent-child relationships (Blake et al., 2010. MacDougall et al., 2007).

THE STUDY

The wider study on which this paper draws investigated the experiences and views of donor-conceived adults and gamete donors who were searching for their donor, donor-conceived siblings or donor offspring through the UKDL. This paper focuses on the data concerning the role that secrets about donor conception played in the lives of the donor-conceived adult respondents. Findings from the study concerning identity and kinship issues have been reported previously (see the authors in press).

Methods

All registrants of the UKDL (n=244) were approached to participate in the study. Of the 172 donor-conceived adults registered with UKDL, 65 people completed the questionnaires giving a response rate of 37.8%, 50 (77%) were women, 14 (22%) men and one did not give their gender, reflecting the gender mix of UKDL registrants (full demographic information is reported in the authors, 2014). The self-administered questionnaire included quantitative structured questions and invited qualitative unstructured open-ended responses. It was hosted online using Bristol Online Survey software and hard copies were sent to those who requested it (four respondents completed a hard copy). The survey was open from mid-October 2012 to mid-January 2013.

Ethical approval was obtained from xxx Universities. All survey respondents were conceived before August 1991 following anonymous sperm donation. This is a very particular group of donor conceived adults: those who knew how they were conceived; had chosen to search for relatives; and done this through a DNA linking service. Therefore, the results must be read in this context, recognising the specificities of this group.

The data reported here includes responses to specific survey questions as well as themes that emerged from the data. Here we present data from a series of 10 questions that addressed how and when respondents learned they were donor conceived and how it affected their relationships with their family. After each question an open question invited respondents to elaborate. For example: Q. How old were you when you became aware of being donor conceived?years; Q. How did you learn of your donor conceived status? The majority of respondents completed these free-text responses. Further, following each section of the survey, space was provided for comments and/or elaboration on any issues raised by the questions and to clarify responses; enabling inclusion of areas that were 'outside' the specific questions asked by the survey. The responses varied in length from a short sentence to long paragraphs, with about half of respondents completing these sections. The quotes in this paper are taken from the survey responses with the spelling corrected but language and grammar left in their original form. The respondent's number and gender (F = female, M = male) are reported after the quote, i.e. R1F.

A thematic analysis was undertaken, with the transcripts coded for concepts and the relationship between concepts explored using the constant comparative method (Silverman, 2006). The transcripts were coded using Atlas.ti software and the emergent themes discussed by the team to reach agreement and explore different interpretations and linkages. We grounded our analysis in a social interactionist theoretical framework, to develop the concept of 'display' as a particular form of social interaction. This draws on Finch's belief that: 'The processes involved in displaying family relationships... appear to be rooted in direct social interaction between the participants, through which the nature of relationships is established, and reinforced by a sense that relevant others are supporting the social meanings thereby established.' (Finch, 2007: 75) To understand the role that secrecy about donor conception played in our respondents' lives and how certain social interactions constituted aspects of displaying a particular form of family, we approached the data as a form of 'narrative as chronicle.' This focusses on the biographical stories that people tell about their lives (Coffey & Atkinson, 1996). Through asking respondents to tell us when and how they learned they were donor conceived, a chronicle is produced of how the past is related to the present and how this makes sense of their lives. 'This chronicling of a life, or part of a life, often starts from the point of "how it all happened" or "how I came to where I am today"'

(Coffey & Atkinson, 1996: 68) We focused on the content rather than the form of the narrative and analysed both the ‘surface’ content (what happened, which events are retold, how people reacted) and the ‘underlying’ content (what particular events might mean to respondents) (Earthy & Cronin, 2008) in order to understand how our respondents constructed their stories of being donor conceived and gave meaning to this knowledge. The data were seen as socially produced stories, not representations of the truth but as a way to ‘sing up many truths/narratives’ (Byrne-Armstrong 2001:112). As part of our analysis we were attentive to the location of these narrative ‘chronicles’ (Coffey & Atkinson, 1996), situating them in the social context of donor conception and how that influenced what could be told and to whom.

We use the term ‘biogenetic’, following Strathern (2005), to mean the genetic/biological relation and ‘father’ to mean the non-donor father, recognising that terminology in this area is never unproblematic and comes loaded with certain meanings (Freeman et al., 2014).

RESULTS

Finding out

Respondents were asked when they became aware that they were donor-conceived and how this knowledge was disclosed to them. The majority of respondents had been told between the ages of 11 and 30 with nearly half being told after they were 21 (see Table 1).

Table 1: Ages at which donor conceived adults were told of their donor conception

Age	Number (%)
0-10 years	10 (15%)
11-20 years	24 (37%)
21-30 years	22 (34%)
31+ years	9 (14%)

There was an ‘always known’ narrative; in which respondents described this knowledge as part of their identity, not a revelation: ‘Always known but only through conversations with mother’ (R37F who was told when she was five years old). Another reported that it ‘was never hidden by parents’ (R14F, told when she was three years old). Conversely, others had only been told or found out when they were well into adulthood.

The majority of respondents reported being told by their mother (MacDougall et al., 2007; Nelson et al., 2013). The mechanisms of being told or finding out followed certain patterns; there was an ‘accidental or by chance (finding out) narrative’ in which unplanned and unanticipated events prompted disclosure. Most of those in this group were told when they were aged over 11 years. One, who found out when he was a teenager, said, ‘Overheard my mother telling someone, then started asking awkward questions.’ (R91M), and one in her 40s, ‘Put together a few clues and made sudden realisation.’ (R47F) One respondent found out, ‘By accident, my mum wasn’t intending to ever tell me but she said something that made me question things.’ (R21F) Another found out in her 20s during a ‘family row.’ (R59F)

A theme in the ‘accidental/by chance narrative’ was that medically related issues could also prompt disclosure.

‘I had a routine test for blood group when I was pregnant that showed I have blood group AB. As my dad has blood group O I knew he couldn't be my biological father. A few weeks later I spoke to my mother about and she told me I was donor-conceived.’ (R20F)

‘I have suffered with headaches and migraine since I was 14. My GP wanted to run some blood tests on me to find out if I could have diabetes. My father has a family history of diabetes so I was going to tell the GP of this fact. Because of this my parents had to let me know that my father and I were not genetically related.’ (R39F)

Despite parents’ initial intention not to tell their child how they were conceived events, which were often outside their control, resulted in disclosure and this type of situation is rarely discussed in debates about disclosure. Not intending to tell, ‘raises an immediate...risk of “accidental” disclosure which may have profoundly detrimental effects.’ (Freeman, 2015:56). People often tell others they are having infertility treatment and the existence of documents and medical histories conspire to make this knowledge ‘leaky’, the boundaries between what is known and unknown porous (Blyth, 2012). As Edwards (2000) noted in reference to secrets about parentage in adoption, ‘knowledge will out.’

Stories of deception

A frequent theme in the data was that respondents felt resentful about being deceived, in some cases for many years.

‘I felt as if everybody had lied to me.’ (R74M; 27 when he found out)
‘Shock, absolute disbelief, felt I’d been betrayed and lied to all my life.’ (R30F; 38 when she found out)

The respondents were frequently more concerned about prior parental deception than by their parents’ use of donor conception. For some respondents this created relationship problems with their parents (especially mothers) and wider family, trust issues and deep feelings of anger and resentment. This mirrors previous research findings where donor-conceived people who had been told later in life or had discovered by accident or chance, reported the information coming as an unwelcome shock and that the inherent secrecy and deception had an adverse impact on family relationships (Beeson, et al., 2011; Blyth, 2012,; Jadvá et al, 2009; Turner & Coyle, 2000).

Some of our respondents who had found out before adulthood also indicated that deception had resulted in uncertainty over their identity. A respondent who had been told by a family friend at her mother’s behest at age 12 said:

‘felt as though my sense of identity had been fractured. Felt lost and adrift and angry that I had been deceived.’ (R1F)

Another commented:

‘It took me a long time to readdress my identity and realise that it was something that I could talk about, rather than a shameful secret.’ (R29F, who found out at 13)

‘Trust issues for being told at a late age, identity crisis.’ (R51F; who found out when aged 13)

Secrets can be seen as a form of disruption of Goodall's 'narrative inheritance' which, for these respondents – even though still at an age where their sense of narrative inheritance was arguably still being developed – was seen to be based on deception and made them question their previous sense of identity. Imber-Black makes a distinction between living inside a secret (knowing but not being allowed to tell) and living outside a secret (not knowing but 'sensing a secret but lacking confirmation).' (1998:16) Living 'inside' the secret can amplify our doubts about other people's responses to us.' (Imber-Black,1998:16) This was illustrated by respondent R65M (who found out when he was 19) who said, 'It was a 'black secret' and I felt anyone who knew would reject me.' And respondent R65F, 'I was frightened of admitting I was donor conceived to anyone. My parents had agreed never to tell me or anyone.' (R65M, 19 when he found out)

Having information withheld about one's parentage raises the potential for the keeper of the secret to be seen as untrustworthy. These accounts suggest that assumed within the 'doing of family' is honesty about certain key elements that make up family life. As Miształ recognises:

'The significance of trust in family life is normally considered in connection with parent-children relations and in connection with the relationship between partners. The first type of relations are seen as the source of basic trust and, consequently, ontological security, while the second is seen as the most important basis of intimacy, which ensures emotional and moral development.' (Misztal, 1996:160)

What lies inside this implicit 'duty of candour' depends on the socio-cultural context of the family and hence what needs to be displayed. The importance given to biogenetic relatedness, despite changes in family construction, is the backdrop against which these 'secrets' are created. Hence, in our data, what was 'displayed' was a biologically related family, the 'physically-present' family, with the donor removed from any family display by keeping their role in the formation of the family secret. What is kept secret is secret for a reason. Secrets are not simply missing 'factual accounts' about the family. They are stories created that distort the 'facts' in order to provide an account, a display of family that reflects what is perceived to be important in this family (and social) environment. The conceptions of the family that arose out of the functionalist accounts, such as Talcott Parsons', still serve as a powerful rhetorical device when it comes to discussing families created from donated gametes and there are assumptions of biogenetic relationships between family members. Families created from gamete donation can be seen as subverting the nuclear family on many different levels. The biological relationship between at least one parent and the child is absent, an imbalance between parents regarding their genetic relationships to their child is introduced, as is a third party or parties into the reproductive relationship. Donor conception can create unbounded and possibly harmful kinship relations (such as with the donor) and introduces a notion of fluidity into the family. Thus, the third party, the sperm donor, is often kept secret to display a 'biogenetic narrative' of the family.

Relationships with mothers

Respondents' relationships with their mothers could be affected negatively by disclosure of this 'secret' with respondents viewing them as having a special obligation to be truthful in their narratives about family relationships.

'Confused, angry, curious and a loss of trust in my mother.' (R67F, 29 when she found out)

‘It didn't affect other family members relationships (although everyone knew but me which was hard) but affected relationship initially with my mum as I felt lied to.’ (R21F, 26 when she found out)

‘At first I was devastated, but then began to realise why I had a difficult relationship with my mother.’ (R61F, 42 when she found out)

‘I think the real change was with my mum who initially flat-out refused to talk to me about anything to do with it [registering for UKDL]. When I went to a UKDL meeting, she got very upset and angry and said that it was nothing to do with me and that it had happened to her, so didn't understand why I needed to go. Things are a little better now but it's not something she feels entirely comfortable talking about, which is difficult for me.’ (R28F, 18 when she found out)

Adverse relationships with mothers – primarily for withholding information, or lying, about donor conception – are more often reported than adverse relationships with fathers (Blyth, 2012a, b; Jadvá et al., 2009; Turner & Coyle, 2000). One way of reading this greater responsibility placed on mothers for maintaining and overseeing family relationships, why mothers are afforded more social and moral responsibility – and blame (Thurer, 1995) – for maintaining the secret, could be the powerful operation of the ideology of the ‘good’ mother and the distinctive duties of the mother as the ‘prime parent’ that permeates our constructions of this role (Bassin et al., 1994). Mothers were encouraged to abide by the dominant discourse of donor conception prevalent at the time, namely secrecy. However there is a conflicting priority – that openness and honesty are seen as characterising ‘good’ mothering relationships. Thus, the ideal of the ‘good’ mother, one who does not keep secrets, is challenged by professional advice and general admonitions to keep the secret of donor conception.

The importance of prioritising the child is a key part of this ‘good’ mother ideology. Hays identifies this as the increasing prevalence of the concept of intensive mothering, ‘The ideology of intensive mothering is a general model that advises mothers to expend a tremendous amount of time, energy and money in raising their children.’ (Hays, 1996:x). Hudson’s (2015) autoethnography on motherhood and secrets (why her mother abandoned her as a baby) builds on Hays’ work on intensive mothering. ‘Mothers face conflicting priorities for performing “mothering” in accordance with society’s standards for “socially appropriate child rearing”’ (Hudson, 2015:124). The ‘good’ mother is caught in ‘opposing logics’ (Hays, 1996:9) not only between adhering to professional advice and socially appropriate child rearing practices but also between what might be expected of her as a wife as well as a mother. This is illustrated by R42F (who found out when she was 22):

‘Finding out has been good for me, I only wished I had known sooner. When I probed my mum as to why she didn't tell me as a child, she has always been hazy. She claims that if I had known as a child, I may have been mean to my father about it and not respected him. The most painful thing is this... to think that she wanted to protect him more than me. Had I been in her position I would have put my child first.’

R42F saw herself (the child) as her mother’s primary responsibility, and in this regard her mother has failed as a ‘good’ mother. Here the role of keeping the secret is seen as a protective one, protecting the father by concealing this knowledge (and thereby being a ‘good’ wife) is achieved at the child’s expense, whose interests are relegated. Here the

mother has not put her child first and this breach in what are perceived as fundamental mothering obligations is ‘the most painful thing.’

Patterns of knowing

Secrets are notoriously ‘leaky’ and respondents reported complex stories of who in the family knew that they were donor-conceived. As Nordqvist & Smart note, ‘guarding and controlling the kinship information that lies at the heart of donor conception [is] a particularly difficult task’ (2014:85). A frequent observation was, ‘Most of my family don't know I am donor conceived.’ (R4F, 19 when she found out) This, for some, created awkwardness between family members and a barrier to being close. This was alluded to most often in the context of their father’s family.

‘Family members on my father’s side do not know I am donor conceived. Mother said Father didn't want them to know.’ (R3F, 18 when she found out)

‘Nobody in my family knew I was donor-conceived. Those of my dad's family who I am close to still don't know I'm donor-conceived and this makes me feel highly uncomfortable - I think they should know the truth (then they can care about me for me and not just the person they think I am).’ (R20F, 25 when she found out)

The social relations created by donor conception were maintained in these families by keeping the matter secret. As Konrad observes, secrecy plays a key role (in anonymous egg donation) in managing ‘nameless relations’. ‘Knowing what not to know and living one’s life in relation to ‘active not knowing’ are ethico-cultural animations that give fundamental shape and meaning to sociality.’ (2005:161) While keeping it ‘secret’ was the dominant discourse into which the respondents were born, not telling anyone about using donor conception was difficult for some parents. For these parents, there was partial and selective disclosure, telling friends and certain extended family members. This can be seen as a kind of ‘partial’ display, and it created tensions because different forms of family narratives were enacted in different contexts - some family members might know, others did not and these conflicting narratives had to be carefully negotiated, particularly by the donor conceived person.

‘When I asked who else knew, my mother couldn't provide me with a clear answer. She wasn't sure if people had told other people. She also does not like to talk about it.’ (R42F, 22 when she found out)

‘As only my mother spoke to me I was unaware who knew I was DC until I was 23 years old, I even had to ask if my own brother knew.... No one in my family is willing to speak about it ever as it's such an awkward thing.’ (R37F, 5 when she found out)

For respondent R39F, the complex patterns of who knew created further duplicity, by other family members’ attempts to ‘display’ the appearance of a biogenetically related family. ‘After the initially finding out I was told that two of my aunties had known. One of my aunties still to this day makes comments that infer that my father and I are genetically related even though she does not know that I know. I do not know whether she has forgotten or whether it is just a slip of the tongue but I find it quite patronising and as though she is still ‘in on’ the secret.’ (R39F, 17 when she found out)

Alongside this dissonance in information flow and the issues it raised for relationships with both parents, particularly mothers, and extended family, there was also an extension of the role of gatekeeper to the donor-conceived person. This meant that some were required to 'keep' the secret ('living inside the secret' in Imber-Black's sense) and participate in the rituals to keep the knowledge from others and display the biogenetically related family, regardless of their desire to do so and/or the impact on them.

'My mother has tried to make me promise to not to tell anyone, as she is so ashamed. She tells me it makes no difference as my sister and I were wanted. The whole story has come out of the blue and feels unreal. I feel I am a fake and I have to keep it secret (I have in fact told a few people).' (R79F, 30 when she found out)

In donor-conception these narratives of secrecy display the family as biogenetically connected and 'conceal' the other relations from view (Konrad, 2005). As Finch notes: 'The process of seeking legitimacy necessarily entails displaying one's chosen family relationships to relevant others and having them accepted.' (2007: 71) For these families, particularly the parents, there was a need to gain legitimacy by displaying a certain type of family and secrecy maintained this display. Here a particular type of family is displayed, the biologically related family, and the secrecy enabled those elements of family formation that did not fit with this to be concealed. Hence, secrecy is not necessarily the opposite of display, but in this case it allows the display to be perpetuated.

The consequences of secrets over donor-conception can affect not only the donor-conceived person and their extended family but future generations too.

'I feel sorry for my children because they are deprived of a grandparent. I'm also reluctant to discuss my genetic background with them and that perpetuates the secrecy of my origins.' (R40F).

'I am a mum to two girls and do worry about how to tell them when they are older. I cannot tell them at a young age as my father is not aware that I know.' (R89F)

DISCUSSION

Our data illustrate how, according to the experiences of the donor-conceived respondents, individual families have responded to wider social forces that have situated donor conception and how they have constructed family narratives to make sense of their experience of forming families with donor sperm. Our study has limitations. It is not representative of all donor-conceived people: it is drawn from those who know they are donor-conceived; have chosen to search for those to whom they are genetically related through donor conception; and chose to search through a DNA linking register. None of our respondents identified themselves as the offspring of lesbian parents and given that it is more difficult for lesbian parents to display their family as a biogenetic family, such an omission should be borne in mind. Further, the respondents were largely women. This reflects the gender profile of UKDL registrants and, further, gendered participation rates in research involving donor-conceived people more generally (Blyth et al., 2012). Our data were also collected via a self-completed survey and therefore we were not able to probe and explore the interpretations of the questions and the meanings of respondents' responses. However, this format did allow us to reach more participants than would have been possible with face to face interviews. In-depth qualitative interviews with this group would be a useful next step to further explore these issues, as

would be studies that examined the perspectives of a range of family members, their points of convergence and divergence. Such studies could explore the concept of family display in more detail and how display is enacted in different family contexts, i.e. within the nuclear family, extended family and the wider social interactions of family members.

Secrets can be used as a lens to understand what elements of donor conception have important social and cultural significance, and how ‘what is needed to be kept secret’ changes over time as the meanings attributed to donor conception and reproductive technologies change. ‘The existence and the function of secrets changes along with the character of social relations’ (Marx & Muschert, 2008:4). Drawing on Simmel’s work, the dynamics of this flow of information, what is disclosed to whom and how this information flow is organised and delineated, is determined by the social context. This can give us insights into how donor conception was conducted and perceived in respondents’ families. When there was greater stigma and legal uncertainty attached to the use of donor conception, secrecy was viewed as an appropriate, and indeed encouraged, response.

‘Through the study of secrecy, we encounter what human beings above all want to protect: the sacred, the intimate, the fragile, the dangerous and the forbidden.’ (Bok, 1989:281) By foregrounding secrecy we can uncover the web of social relationships and cultural expectations that motivates secrecy over certain elements of life: it tells us how donor conception was seen by certain families; the mechanisms they used to incorporate it into their family stories; and highlights areas of dissonance between donor conceived and ‘traditional’ families and why these might need to be managed. It also tells us about the expectations children had of their parents, including veracity, and the feelings produced when this was found to be lacking. Secrecy is a useful analytic tool that can bring together different but related key elements in family life: the importance of trust, family display, and how certain information is key to the narrative construction of self. By seeing where secrecy goes beyond a personal decision to keep something private and becomes contested, we can uncover interwoven elements of family life and relationships.

We employed Finch’s concept of ‘display’ to explore how the families of our respondents used secrecy about donor conception to display their family. As Finch notes, how display is accomplished in different families and circumstances is an area that needs more empirical research, ‘What forms of direct social interaction are used to convey the meaning that this is a ‘family-like’ relationship?’ (2007: 75) Our project contributes to exploring the concept of display empirically. In a specific time and location, it was important for some families to ‘display’ biogenetic relationships – this is what constituted a ‘family’ for them and aspects that did not fit with this conception of the family were hidden and secrets played a role in enabling this to remain hidden. Generally, in our data it was the biologically related nuclear family that was displayed, but this had implications for the extended family and how relationships and perceptions of the wider family were seen.

There is a widely held presumption that secrets are bad, harmful or to be avoided in intimate life and there has been a growing literature on trust in modern society. ‘At both an individual and societal level, trust is important for health and wellbeing and is “fundamental to effective interpersonal relationships and community living”’ (Ward & Mayer, 2009: 341). However, as Bok (1998) recognises, having secrets is not necessarily a bad thing, privacy is appropriate and necessary in certain circumstances. The challenge that secrecy poses is when is it appropriate? Strathern draws attention to the importance of the knowledge that one is donor-conceived, it has the potential to reconfigure kinship relations and she questions ‘the value

given to openness.’ (1999:80) Bok argues secrecy is inappropriate when, ‘the freedom of choice that secrecy gives one person [i.e. the parents desire to construct and display their idealised ‘biogenetic’ family], limits or destroys that of others [i.e. the child’s desire to find out about their biological parentage].’ (1998:26) Our study shows that this kind of secret was often experienced as harmful and led to respondents questioning the trustworthiness of parents and extended family. In other words, the secret was toxic in Imber-Black’s (1998) sense, a secret that poisons relationships. Disclosure following secrecy had an effect on some respondents’ sense of identity and their sense of narrative inheritance was disrupted. Mothers were given disproportionate responsibility for the secret keeping – perhaps reflecting gendered social norms – for having failed in their mothering role by apparently prioritising their husband’s wishes or needs over their duty as a ‘good’ mother. However, it must also be recognised that not all respondents had experienced secrecy over their conception; some had ‘always known’ and this was part of their narrative inheritance.

Konrad (2005) argues that the use of anonymous donors is a double concealment, what is concealed is concealment itself. The anonymity of the donor is one part of this concealment and parental non-disclosure is a further level of concealment. While anonymity was meant to preclude social relations and break any connection, Konrad argues it is in itself a form of ‘sociality’ in that these ‘nameless relations’ exist and create new forms of relatedness: there is a social component of anonymity. The practice of ‘active non-knowing’ by recipients of gametes is an activity that nevertheless creates something to know. With our cultural assumptions of veracity in intimate relations (Miształ, 1996) and the enduring importance, for some, of biogenetic parentage for forming kinship relations, not knowing this kind of information can create a profound disruption in their narrative inheritance when revealed. In this study, some of the respondents who had been told before they were 18, usually around early teens, found this information hard to fit in with their developing sense of identity. This raises the question of the optimum age to tell about donor conception and what constitutes ‘early’ telling, as for some respondents, finding out in mid-childhood or their early teens still created issues of trust and uncertainty over their sense of identity.

CONCLUSION

How secrets about donor conception are formed, who is told and the patterns of knowing in families give us insight into the social practice of donor conception and donor-conceived families and how knowledge is managed and controlled to, in many cases, display family narratives of biogenetic connection. Our study shows that what needs to be displayed as family has a temporal dimension that will change depending on the social context and cultural meanings given to biogenetic relationships. It is, arguably, the socio-cultural context that grounds these secrets, gives them meaning and resonance and determines how significant such deception is perceived to be.

With a changing social context in which the absence of biogenetic relatedness within families carries less social disapproval (Golombok, 2015) and improved legal security, there may, in the future, be less secrecy surrounding the use of gamete donors. However, there is some evidence that parents of surrogate-born offspring conceived with the use of an egg donor were very likely to disclose surrogacy but much less likely to disclose the involvement of a donor (van den Akker, 2000). Reproductive technologies are increasingly becoming global practices with recipients and donors traversing national boundaries and discourses of disclosure, attitudes to donor conception and availability of information differ internationally. How these different terrains are navigated are areas for future investigation: how recipients

manage receiving treatment in different regulatory settings (for example, parents from the UK seeking treatment in countries where donor anonymity remains in place); and how different social contexts affect the framing of disclosure and advice prospective parents receive.

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REFERENCES

- Adams, D. (2013) Conceptualising a child-centric paradigm, *Bioethical Inquiry* doi: 10.1007/s11673-013-9454-7
- ASRM (2014) Interests, obligations and rights in gamete donation. *Fertility and Sterility* 102: 675-681.
- Australian National Health and Medical Research Council, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (2007).
- Bassin, D., Honey, M. and Kaplan, M. M. (1994) (Eds.) *Representations of Motherhood*. New Haven: Yale University Press.
- Beeson, D., Jennings, P. and Kramer, W. (2011) Offspring searching for their sperm donors: How family type shapes the process. *Human Reproduction* 26:2415–2424.
- Blake, L. Casey, P., Readings, J., Jadva, V. and Golombok, S. (2010). ‘Daddy ran out of tadpoles’: How parents tell their children that they are donor conceived, and what their 7-year-olds understand. *Human Reproduction* 25: 2527–2534.
- Blyth, E. & Frith, L. (2015) Access to genetic and biographical history in donor conception: an analysis of recent trends and future possibilities. In Horsey, K (ed) *Human Fertilisation and Embryology: Regulation Revisited*. Routledge, pp136-152.
- Blyth, E. Crawshaw, M. Jones, C & Frith, L (2012) Donor conceived peoples’ views and experiences of their genetic origins: a critical review of the literature, *Journal of Law & Medicine*, 19 (4) 769-789.
- Blyth, E (2012) ‘Genes r us? Making sense of genetic and non-genetic relationships following anonymous donor insemination’ *Reproductive BioMedicine Online* , 24 (7), pp. 719-726.
- Bok, S. (1989) *Secrets: On the Ethics of Concealment and Revelation*, Vintage Books.
- Byrne-Armstrong H 2001 ‘Whose show is it? The contradictions of collaboration’ in H Byrne-Armstrong, J Higgs and D Horsfall (eds) *Critical Moments in Qualitative Research* Butterworth Heinemann, Oxford: 106-14
- Crawshaw, M., Gunter, C., Tidy, C. and Atherton, F. (2013) Working with previously anonymous gamete donors and donor-conceived adults: recent practice experiences of running the DNA-based voluntary information exchange and contact register, UK DonorLink. *Human Fertility* 16: 26-30.
- Crawshaw, M. Daniels, K. Adams, D. Bourne, K. van Hooff, J. Kramer, W. Pasch, L. Thorn, P.(2015) Emerging models for facilitating contact between people genetically related through donor conception: a preliminary analysis and discussion *Reproductive Biomedicine & Society Online* 1 (2015) pp. 71-80 DOI information: 10.1016/j.rbms.2015.10.001
- Clark, B. (2012) A balancing act? The rights of donor-conceived children to know their biological origins. *Georgia Journal of International and Comparative Law*, 40(3): 619-661.
- Coffey, A. (1996), *Making sense of qualitative data* SAGE, Thousand Oaks.

- Dewar, J. (1989) Fathers in law? The case of AID. In Morgan, D and Lee, R. (eds.) *Birthrights* London: Routledge. pp. 115-131.
- Earthy, S. & Cronin, A. (2008) Narrative Analysis, in Gilbert, N (ed) *Researching Social Life*, 3rd Edition, London: Sage.
- Edwards, J. (2000) *Born and Bred: Idioms of Kinship and New Reproductive Technologies in England*. Oxford: Oxford University Press.
- Finch, J. (2007) Displaying families. *Sociology* 41(1): 65–81.
- Freeman, T. (2015) Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence. *Monash Bioethics Review* 33(1): 45-63.
- Freeman, T. et al. (2014) Making connections: contact between sperm donor relations. In Freeman, et al. (eds) *Relatedness in Assisted Reproduction*. Cambridge: Cambridge University Press.
- Frith, L. (2015) The Limits of Evidence: Evidence based policy and the removal of gamete donor anonymity in the UK. *Monash Bioethics Review*. 33 (1) 29-44.
- Golombok, S. (2015) *Modern Families: Parents and Children in New Family Forms*. Cambridge: Cambridge University Press.
- Goodall, H. (2005). Narrative inheritance: A nuclear family with toxic secrets. *Qualitative Inquiry* 11: 492–513.
- Hertz, R. Nelson, M. Kramer, W. (2016) Donor sibling networks as a vehicle for expanding kinship. *Journal of Family Issues* DOI: 10.1177/0192513X16631018
- Haimes, E. (1993) Do clinicians benefit from gamete donor anonymity? *Human Reproduction* 8: 1518-1520.
- Hays, S. (1996). *The cultural contradictions of motherhood*. New Haven, CT: Yale University Press.
- Hudson, N. (2015) When family narratives conflict: An autoethnography of my mother's secrets. *Journal of Family Communication* 15(2): 113-129.
- Imber-Black, E. (1998). *The secret lives of families: Truth-telling, privacy, and reconciliation in a tell-all society*. New York, Bantam Books.
- Jadva, V., Freeman, T., Kramer, W. and Golombok, S. (2009) The experiences of adolescents and adults conceived by sperm donation: Comparisons by age of disclosure and family type. *Human Reproduction* 24: 1909-1919.
- Johnston, D. D. and Swanson, D. H. (2006) Constructing the “good mother”: The experience of mothering ideologies by work status. *Sex Roles* 54: 509–519.
- Konrad, M. (2005) *Nameless Relations*, Oxford: Berghahn Books.
- Lawler, S. (2000) *Mothering the Self*. Routledge.
- Mac Dougall, K., Becker, G., Scheib, J. E. and Nachtigall, R. D. (2007) Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes. *Fertility and Sterility* 87: 524 –533.
- Marx, G. and Muschert, G (2008) Simmel on secrecy. A legacy and inheritance for the sociology of information. In C. Papiloud and C. Rol (eds). *The Possibility of Sociology: 100 Years of Georg Simmel's Investigations into the Forms of Social Organization*, Wiesbaden, Germany.
- Misztal, B. (1996) *Trust in Modern Societies*. Wiley.
- Morgan, D (1996) *Family Connections*. Cambridge: Polity Press.
- National Health and Medical Research Council (2007) *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* Canberra ACT: National Health and Medical Research Council.
- Nelson, M. K., Hertz, R. and Kramer, W. (2013) Making sense of donors and donor siblings: a comparison of the perceptions of donor-conceived offspring in lesbian-parent and heterosexual-parent families. *Contemporary Perspectives in Family Research* 7: 1-42.

- Nordqvist, P. and Smart, C. (2014) *Relative Strangers*. Palgrave MacMillan.
- Novaes, S. (1998) The medical management of donor insemination. In Daniels, K. and Haimes, E. (eds.) *Donor Insemination: International Social Science Perspectives*. Cambridge: Cambridge University Press
- O'Donovan, K. (1989) What shall we tell the children? Reflections on children's perspectives and the reproductive revolution. In Morgan, D. and Lee, R. (eds), *Birthrights*. Routledge: London, pp.96-114.
- Poulos, C. (2008). Narrative conscience and the autoethnographic adventure: Probing memories, secrets, shadows, and possibilities. *Qualitative Inquiry* 14: 46–66.
- Readings, J. et al (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy. *Reproductive Biomedicine Online* 22(5):485-495.
- Royal College of Obstetricians and Gynaecologists (1987) *Donor Insemination*. London: RCOG.
- Scheib, J., Riordan, M., Rubin, R. (2005) Adolescents with open identity sperm donors: reports from 12-17 year olds. *Human Reproduction* 20:239-252.
- Simmel, G. (1906): The sociology of secrecy and of secret societies. *American Journal of Sociology* 11(4): 441-498.
- Smart, C. (2011) Family secrets and memories. *Sociology* 45(4): 539-553.
- Smart, C. (2009) Family secrets: Law and understandings of openness in everyday relationships. *Journal of Social Policy* 38(4): 551–567.
- Smart, C. (2007) *Personal Life: New Directions in Sociological Thinking*. Cambridge: Polity Press.
- Söderström-Anttila, V., Salevaara, M. and Suikkari, A.M. (2010) Increasing openness in oocyte donation families regarding disclosure over 15 years. *Human Reproduction* 25: 2535-2542.
- Strathern, M. (2005) *Kinship, Law and the Unexpected. Relatives Are Always a Surprise*. Cambridge: Cambridge University Press.
- Strathern, M. (1999) *Property, Substance and Effect: Anthropological Essays on Persons and Things*. London: The Athlone Press.
- Thurer, S. (1995) *The Myths of Motherhood: How Culture Reinvents the Good Mother*. New York: Penguin.
- Turner, A. and Coyle A. (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Human Reproduction* 15: 2041–2051.
- van den Akker, O (2000) The importance of a genetic link in mothers commissioning a surrogate baby. *Human Reproduction*. 15,8, 1849-1855.
- Ward, P. and Mayer, S. (2009) Trust, social quality and wellbeing: A sociological exegesis. *Development & Society* 38(2):339-363.
- Warnock, M. (1985) *A Question of Life: The Warnock Report on Human Fertilisation & Embryology*. Oxford: Basil Blackwell.
- Yee, S., Blyth, E. and Tsang, A. K. T. (2011) Views of donors and recipients regarding disclosure to children following altruistic known oocyte donation. *Reproductive Biomedicine Online* 23(7): 851-859.

