

Sister-to-Sister Oocyte Donation: Couples' Experiences with regard to Genetic Ties.

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ABSTRACT

Objective. This study aimed to gain an in-depth understanding of the experiences of genetic ties in intra-family oocyte donation families.

Background. Previous research has shown that most mothers have a good and stable relationship with their donor. Little is known about the meaning of the difference in genetic ties for parents who conceived through sister-to-sister oocyte donation.

Methods. An Interpretative Phenomenological Analysis was performed and focused on both individual experiences and couple experiences with regard to genetic ties. Ten participants were recruited via an infertility clinic and took part in semi-structured couple interviews.

Results. Our analysis revealed that the donation was seen as a way to equal genetic parenthood. Participants struggled with this prevailing ideal of genetic parenthood and questioned the legitimacy of their motherhood. Several dynamics were identified when couples tried to deal with the imbalance in genetic ties: they acknowledged each other, convinced one another or pushed away the difference in genetic ties. Couples also managed the presence of a genetic tie with the donor by negotiating the closeness in their family relationships.

Conclusion. The lack of a full genetic tie remained a meaningful absence for some mothers and the way couples dealt with this varied. We plead that the option of post-donation care should be offered to support couples with the complexities they try to deal with.

Keywords: Assisted reproduction; Oocyte donation; Intra-family donation; Qualitative research; Family Relationships.

Introduction

Over the past thirty years, the development of IVF techniques have made it possible to build a family through donated oocytes. The rise of assisted reproductive technology reflects the importance that is attached to genetic parenthood (the development of invasive and expensive techniques to ensure a genetic child), while it also facilitates the creation of non-genetically related families (Daniels, 2005). This particular tension is reflected in parents' accounts, who consider genetics as both irrelevant and relevant (Grace & Daniels, 2007; Author, 2014). Studies on the experiences of donor-conceived families are particularly interesting in intra-family donation, because the donor is present in the family. Unlike anonymous donation, in intra-family donation, the recipients and the donor have to negotiate their disclosure

preferences and their relationship with the children, making it much more socially and psychologically complex (Yee, Blyth, & Ka Tat Tsang, 2011). Given the international trend towards non-anonymous donation, it is necessary to conduct empirical research about the experiences of the different parties involved in known donation. Laws regarding gamete donation are changing rapidly and we need to understand the psychosocial and ethical challenges that come along/arise in the case of intra-family donation.

The current study was conducted in Belgium where oocyte donation was legally regulated in 2007 (Belgian Act of 6 July, 2007). Although the law prefers anonymity, known donation is allowed on the condition that both the recipient and the donor give their consent. Known donors are mostly sisters or good friends. Anonymous donors can be voluntary donors who spontaneously present themselves at the clinic, egg sharers or cross donation. The latter system is also known as known-anonymous donation, which means that aspiring parents bring a donor (a relative or friend) whose oocytes are used for other recipients (anonymously) (see also Laruelle, Place, Demeestere, Englert, & Delbaere, 2011). In return, the recipients can use other donors, recruited by other recipients. Findings regarding the decision to use known or anonymous oocyte donors seem inconsistent as Baetens, Devroey, Camus, Van Steirteghem, and Ponjaert-Kristoffersen (2000) found that most couples preferred known donation, while Laruelle et al. (2011) reported that most couples preferred anonymous donation. Despite these differences, both studies pointed out that the main reason for choosing anonymous donation was the desire to establish clear boundaries and roles. Couples that opted for known donation were motivated by the trust they had in their donor and the genetic link with the donor. They valued the fact that they would become genetically related to their children, through the common genetic heritage with their sister (Vayena & Golombok, 2012).

In the literature, there are only two studies focusing specifically on the experiences of sister-to-sister oocyte donation families (Lessor, 1993; Winter & Daniluk, 2004) and one study focusing on intra-familial egg donation both from sisters or sisters-in-law (Jadva, Casey, Readings, Blake, & Golombok, 2011). In all of these studies, the donors and recipients reported a deepened and strengthened sister relationship (Jadva et al., 2011; Lessor, 1993; Winter & Daniluk, 2004). Van Berkel, Candido and Pijffers (2007) also explored the experiences of women who had a child from a known donor (47% of whom were family members). In comparison with IVF mothers, egg donation mothers presented more defensive reactions, denial, anxiety and uncertainty. However, how these particular feelings and reactions are displayed and experienced, remains rather unclear. Furthermore, most studies on oocyte donation tend to focus on the experiences of mothers alone (e.g. Van Berkel et al.,

2007; Jadva et al., 2011), not taking into account the way couples deal with the donation and the possible dynamics that occur. Current study aimed to explore the meaning of the genetic link for couples who conceived through sister-to-sister oocyte donation.

Method

Participants

The current study is part of a larger qualitative research project on participants' thoughts and experiences with building a family through donor conception. For this study, five couples (ten participants) were interviewed. The participants were recruited by the fertility counsellor (of the Department of Reproductive Medicine, Ghent University Hospital) whom they had seen during their treatments. A list of eight eligible couples was set up, based on the inclusion criteria: Dutch-speaking and having at least one donor-conceived child (aged seven – ten years). Two couples refused participation and one couple pulled out after initial consent.

Interview

Semi-structured couple interviews were performed by two psychologists of the research team, between February and May 2014. We conducted conjoint interviews to obtain couples' shared constructions and to observe interactions between the partners. As argued by Bjornholt and Farstad (2014), conjoint interviews provide a 'common reflective space', which enables partners to complement and contradict each other. The data in the current study are derived from the following interview questions: 'You (addressing the father) have a genetic link with your children and you (addressing the mother) do not. How is that for you (as a couple)?' and 'What does the genetic link means to you?'. Interviews took place at the location the participants preferred: the Ghent University Hospital or at home. Participants gave their written informed consent at the time of the interview and were offered the possibility to contact the counsellor in case questions or psychological needs arose during or after the interview. Each interview lasted between 90 and 120 minutes and was audio-taped and transcribed verbatim using pseudonyms to protect the anonymity of the participants. Transcripts were checked for accuracy by a team member and by the interviewer. The study was approved by the Ethics committee of the Ghent University Hospital.

Analysis

This qualitative study used a phenomenological approach in order to obtain rich data on people's lived experiences (Smith, Flowers, & Larkin, 2009). Interpretative

Phenomenological Analysis uses relatively small and homogeneous sample sizes to allow for a close and ideographic analysis of each case before turning to a cross-group analysis (Smith, 2004). The following steps were taken: first, transcripts were read and descriptive and interpretative notes were made. In the next phase, each case was coded and codes were clustered into themes and subthemes. Third, a comparison across cases was performed to identify higher-order themes. Finally, the structure of themes was described in a research report and illustrated using quotes from the interviews. The validity and trustworthiness of the analysis was improved by an intensive auditing process. A team of auditors (second, third and last author), discussed and challenged the structure of the themes and provided alternatives and counterexamples (Hill, Thompson, & Nutt-Williams, 1997). MAXQDA, a software package that aids the storage and analysis of qualitative data, was used to facilitate data management.

Results

Description of the participants

All women had received oocytes donated by their sister. In three cases, women had suffered from cancer (Hodgkin, Leukemia) which had affected their fertility. In these cases, sisters offered to help and proposed to donate their oocytes. Four mothers mentioned that they opted for known donation because they wanted to be partially genetically related to the children. One couple also reported that they sought to prevent long waiting lists. More information about the participants and their children can be found in table 1.

[Table 1 near here]

Equaling genetic parenthood

Although the mothers in this study were not the ‘full genetic’ mothers, they did feel like they were genetically related to their children, due to the genes they shared with their sister. The sister-to-sister donation provided an indirect way to become a genetic mother. The extent to which mothers felt they ‘equaled’ genetic motherhood differed, with some mothers claiming to be 99% genetically linked to the children, whereas others thought they became partially linked to the children. Freya explained that: ‘*For me it feels like they [the children] could just as well have been mine, I mean, it’s my sister, so for sure a lot of the genetics she has, I have as well.*’ Whereas scholars often define the donor as the *genetic* parent and the recipient as the

social parent, Naomie even turned this the other way around. In her experience, she became the genetic mother (for 99%) and Julia (her donor) only has a social bond with the children, in the role of godmother and aunt. Ava - who also tried to equal genetic parenthood through sister-to-sister-donation - was confronted with a different reality once her children were born.

Ava: It's important for me that they belong to the family. That they've got at least the same genes running in my family. Especially in my case, that they're maybe a little piece of me. It's not like I totally don't consider them as our children, I mean, 'my' children in this case. (..) But yes, as I said, looking back at it [the donation], it's not so easy to deal with. (..) Yes, now I finally realize how difficult this situation really can be.

One of the aspects that played an important role here was family resemblances. Ava's neighbor once said to her: *'Gosh, your children, they resemble more your sister, than you isn't it?.'* Ava experienced this as a painful comment, because it reminded her of her failure to become a genetic mother and the clear link that existed between the children and her sister, for the outside world. Initially she valued the sharing of family genes, but once the children were born she also encountered the difficulties that arose due to the clear resemblances between her sister and the children. By contrast, for Naomie, Freya and Caroline, the resemblances with their children were not questioned by others, which felt reassuring. Naomie explained that this created a comfortable situation: *'But yes, I believe, no one will ever notice that those were not my eggs. I mean, these kids do not look like they could not be ours. All of this feels right, the picture's perfect.'* While the presence of mother-child resemblances seemed to increase mothers' confidence, the absence of these resemblances together with the presence of donor-child resemblances challenged mothers' confidence, in particular when others made comments about it.

Questioning the legitimacy of motherhood

Several women questioned their identity as mother and even expressed doubts about their ability to be a mother. Freya, for instance, raised fundamental questions about her right to become a parent.

Freya: And sometimes I really believe Mother Nature wanted to tell me, that I can't. That I cannot do this. That it was, like they really, like it was written in the stars.

Justin: Yes you still think that, you believe that.

Freya: Yes and it's always in the back of my head. And as long as everything goes fine, that's all right, but as soon as something would go wrong...it's quite persistent actually.

Freya questioned whether she had a 'natural mother instinct'. She found herself relying on the experience of her husband, who grew up with a younger sister and was used to take care of his sister. She interpreted her lack of confidence as 'a sign of nature': she was not allowed to have children. Some participants struggled with these uncertainties occasionally, while for other these popped up regularly. In some cases, doubts surfaced due to the interview. Scarlett, for instance, questioned aloud: *'yeah I'm like: "I can't know it now". And I think, and I wonder: "Would this be better if there was a genetic link? Or is this now the feeling of parenthood? Or maybe that doesn't matter?"* Mothers also wondered whether their child would sense that 'a part was missing'.

Ava: Sometimes I think "maybe they feel it somehow?" Sometimes when they're sitting on my lap, I look at them, and I reflect on that: "Yes, actually, they don't look like me". And when playing with that thought I ponder "maybe they feel this, do I give them enough love? Can I give them love, when I'm actually not their biological mom?" Sometimes I wonder if I'm enough 'mother' for them...

Carter: Of course!

Ava: I try to, but...

Dealing with the imbalance in genetic ties

Couple dynamics surfaced when women questioned the legitimacy of their motherhood. Most men acknowledged their wives' uncertainties while at the same time they tried to convince them and to strengthen their position. Carter regularly responded to his wife saying: *'They are your children! I don't consider them as "her child", it is "your child"!*' Justin also tried to change Freya's thoughts by saying; *"You can't think that way", followed by: "but that's easy for me to say."* The latter shows that he acknowledged that it might be more difficult for Freya than for him, because his genetic link automatically made it easier. The imbalance in genetic ties was experienced differently by each partner, influenced by their personal background and history. Mike, for instance, attached great importance to the genetic tie with

his daughter because he was foundling as a child and he had never experienced having a genetic tie with somebody before.

Mike: Taking into account my personal background, for myself it's very important. I don't know if Maya will consider this important or not. But, for me it is important. Because I don't have that. So..

Scarlett: For me it's different. I could just as well adopt a child. Of course it is a special feeling when you have a bond with a child, a genetic bond. It's something extra, but yes, of course I haven't experienced the same as you.

The couples' ways of dealing with those differences varied from attempting to nullify them and construct an equal parent subsystem, to making room for different individual meanings. In the following interaction, Freya acknowledges that the genetic tie mattered for Justin and space was made for experiencing and expressing differences.

Freya: but you really wanted something from yourself, no?

Justin: Yes.

Interviewer: What makes it important that it is "part of you"?

Justin: Yeah, just, ... I don't know.

Freya: Extending your family?

Justin: Maybe yes, but not only that, I don't know. And that I...

Freya: I think for you, that you would feel yourself less a "dad" if it wasn't really yours, no?

Justin: I wouldn't know.

In other couples the men tried to eliminate differences, sometimes compensating the partial lack of a genetic tie, for instance; by stressing the importance of the pregnancy.

Andy: I, if I can speak for myself? I don't think about that difference. Maybe that's easily said for me, because I indeed have a genetic bond, but yeah, I experience no difference.

Naomie: For me, it doesn't make a difference in loving them, or how they are, because I carried them in me. I think it is different for adoption or surrogacy. It must be different. But I never considered them as not my children. They were from the

beginning inside me, except for the first little cell divisions, the only ones that happened externally. But then they were immediately inside me, yes, you carry them, so that makes it...

Andy: ...more yours than mine.

Naomie: Yes, the moment you are pregnant, they are indeed more mine than his.

Negotiating closeness in family relationships

A lot of the narratives about the importance of genetic ties can be traced back to the negotiation of closeness and distance in family relationships. The donor as well as the recipients tried to position themselves in relation to each other, acknowledging the special bond with the donor and the child - while limiting the significance and the prominence of that bond. Adam stated that Riley (the donor) has a special fondness for their daughter, that she looks at her through different eyes, while at the same time he thinks that she tries not to do so and wants to keep a distance. This was reflected in Riley's decision not to become the godmother. According to Adam, Riley had stated: *'I've already a special bond with my niece, so why should I be the godmother?'* Creating this psychological distance was managed both by the donor and the recipients, by emphasizing the donor's role as aunt and the recipient's role as 'full' mother.

However, at some points closeness to the sister or sister-in-law was expressed. Mike and Andy carefully admitted that they sometimes felt closer to their sister-in-law. This was accompanied by hesitations as: *'So yeah, that's maybe a bit difficult to say but'* (Mike) and *'Well, to be honest'* (Andy), showing the emotional tension surrounding their statements and their expectation that this could threaten their wives' position. Aside from the men, women also referred to the special position their sister had. This was particularly mentioned when they imagined what would happen if they would become sick or if they would pass away. Naomie mentioned that *'it would be the most natural place for my children to be taken care of'*. Ava even takes it one step further:

Int: How do you see the role of Primrose towards your children?

Ava: yeah, the role...like I said, so far I see it more as the role of aunt. But if one day, I would become very ill and you know; soon I won't be here anymore. Then I think I would ask her to "please be a mother to my children".

Carter: And me?

Ava: Together with you, yes.

Carter: hm.

Ava: But, just, you know children also need a mother. And yes, she would be perfect for that role.

Ava privileged the genetic tie with her sister and by doing this, she almost ignored her husband's role as father. She also used the term 'mother' instead of 'aunt'. These accounts apparently co-existed with the idea that genetic ties do not matter in their family. All couples stated that the way they related to each other was not prescribed by the genetic discourse. For instance, while genetically their children and those of their sister are half-siblings, in their family reality, they are just cousins. Scarlett explained that she experienced a great bond with her child, making it difficult for her to understand that she lacked a genetic link and was therefore considered not the 'real mum' from a normative genetic script.

Scarlett: It's not that I consider her not mine. No, that's not the case. I carried her in my belly and from the beginning, when she was born, I felt an intense connection to her. That love was so great that I thought "wow" (tears fill her eyes) Look, I'm still emotional yes.

Good family relationships seemed to overrule genetic ties. Naomie and Andy explained that their children '*loved to hang out with the children of aunt Julia*', because they simply liked each other and not because of genetic ties. In this respect, parents tried to deal with questions from others and emphasized the 'realness' of their family and feelings of 'belonging' between the family members.

Discussion

So far, little has been published on the couple dynamics related to the imbalance in genetic ties in known oocyte donation families. In this study, we found some couples trying to erase the differences, or compensating the lack by stressing the importance of the pregnancy. Others acknowledged and accepted the existence of an imbalance. Although the gestational and the indirect genetic connection made most mothers feel that the child belonged to them, for some the lack of a full genetic tie remained a meaningful absence and led them to question the legitimacy of their motherhood. This is in accordance with Van Berkel et al. (2007), who found that a third of the women almost continuously or regularly thought about the issue of missing a genetic link. Researchers have found that the experience of being pregnant and

giving birth to the child was an important factor for egg-donation mothers as it created the belief that the child was genetically theirs, it helped them to view the child as their ‘own’ (Hahn & Rosenberg, 2002; Kirkman, 2008; Murray & Golombok, 2003). At the same time, women using donor eggs express concerns about the ‘realness’ of their motherhood (Hahn & Rosenberg, 2002; Kirkman, 2008). They found it difficult to identify as a social mother within a culture dominated by the importance of genetic ties for the family. While previous studies have investigated attitudes of aspiring parents and found that they wanted to preserve a genetic link with their future child (Baetens et al., 2000; Laruelle et al., 2011), our study within the sister-to-sister donation context revealed that this initial preference may turn out challenging once the children are born and clear resemblances with the donor occur. Recipients and donors seemed to deal with these challenges by managing the closeness in their family relationships (e.g. not wanting to become the godmother of the child). This so-called ‘psychologically distancing’ was also found by Blyth, Yee, & Ka Tat Tsang (2011) who investigated donors’ conceptualizations of their reproductive material.

There are a number of limitations that must be borne in mind. First, as interviewers, we entered the participants’ worlds and tried to capture their ideographic meanings but we inevitably influenced participants’ stories. By asking questions about their experiences with regard to genetic ties, we tend to install the idea that ‘genetics’ are important. Furthermore, the findings of this study should be interpreted within the context of sister-to-sister oocyte donation, which is different from that of other types of known oocyte donation, due to the presence of a partial genetic link between the recipient mother and her offspring. Third, our sample might be biased as the treatment options in Belgium are somehow limited. Due to the scarcity of oocyte donors and long waiting lists, patients might have chosen sister-to-sister donation without fully considering all other options. By the same token, people’s narratives about their motivation to conceive with sister-to-sister donation are post hoc constructions and inevitably influenced by the options that were available and the tendency to present their choices as consistent and logic during the interview. Finally, as this study is intended to further our understanding of people’s lived experiences for a specific sample in a specific context, we opted for a small-scale qualitative study. This implies that the principle of statistical generalizability is not applicable to our findings. Rather, we aim to maximize the theoretical generalizability of the findings, which means that – in order to maximize the external “validity” of the data – we provided contextual information so the reader can assess whether these new insights can be transferred and are meaningful to other contexts (such as the counselling practice).

Current study adds to the existing literature on oocyte donation as it provides insight in the way couples deal with the donation once their family was formed. Some mothers in our sample struggled with the partial lack of a genetic connection and questioned their identity and sense of being the ‘real mother’. In dealing with the lack of shared genetic parenthood, several couple dynamics were identified. Reflecting on the implications for practice, we think that the option of postdonation care should be offered, apart from the psychoeducational preparation that is offered predonation.

Table 1. Participant characteristics

Mother (years of age)	Father (years of age)	Children (range of age: 3-7)
Scarlett (40)	Mike (36)	Maya
Naomie (37)	Andy (41)	Ivo, Harper, Lou
Ava (39)	Carter (41)	Gunnar, Jayden
Freya (37)	Justin (39)	Henry
Caroline (42)	Adam (46)	Audrey

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Conflict of interest

None.

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