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Part of my story. The meaning and experiences of genes and genetics for sperm donor-conceived offspring

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Introduction

It is well known that, even with the current state-of-the-art of fertility technologies, every human beginning starts out with the genetic material of a sperm and egg cell, which combines into a zygote, and eventually develops into an embryo, a fetus and finally a human being. Most children still carry genetic material from one male contributor and one female contributor, except in the few documented cases where mitochondrial DNA from a second female contributor has been used. However, although this appears to be a biological truth set in stone, biology is never just a *given*; it is also socially constructed (Hauskeller 2004). Indeed, while we are still grasping the meaning and significance of genes and genetics on a biological level, “the term ‘genetics’ appears to be the most elusive and pervasive of all, carrying fluid, multiple, and sometimes conflicting meanings, despite the often essentialist rhetoric” (Freeman et al. 2014a, 16).

This seems even truer for the field of human reproduction, where genes often play a normative role in philosophical discussions, legal discourse, and in popular opinions about parenthood. For example, in our Western culture, we distinguish between biological parents, those who *contribute genes*, and social parents, *those who care* (Cutas and Chan 2012). However, even within the field of assisted reproductive technologies (ART), contrasting messages are expressed regarding the significance of genetics for parenthood. On the one hand, it is argued that having a genetic link is not so important for parenting, as the basis of good parenting is love. On the other hand, it seems that genetic parenthood is the utmost goal as current and future technologies try to mimic genetic parenthood as closely as possible.

In the context of ART, the meaning of genes is mainly considered in the context of what it means for parenthood, namely the presence (or absence) of a genetic link between a parent and his or her child. The meaning of genes is equally relevant in the context of donor offspring. However, as most donor-conceived offspring grew up in a culture of non-disclosure and secrecy, and did not know they were donor-conceived, children's accounts of their experiences of donor conception were noticeably absent in literature until recently (Blyth et al. 2012). Researchers show that some sperm donor-conceived offspring have an interest in their unknown genetic ancestor (the donor). They start a search for their donor or donor half-siblings and they articulate reasons why information about their donor, their genetic heredity, is meaningful to them (Jadva et al. 2010; Beeson, Jennings, and Kramer 2011; Freeman et al. 2014b). This suggests that how they experience the meaning of genes has a larger significance in their lives, and they probably reflect on this meaning **more** than those who are not conceived through donor conception. The most important motivations for why they search for this information appear to be: (1) to avoid medical risks and consanguineous relationships; (2) to satisfy curiosity; (3) to learn more about the self or to complete their identity; (4) to learn more about what kind of person the donor is (biographical information, why he donated, etc.); (5) to form a relationship with the donor and/or his family; and (6) to learn about their ancestry/genealogy (Turner and Coyle, 2000; Vanfrausen, Ponjaert-Kristoffersen, and Brewaeys 2003; Scheib, Riordan, and Rubin 2005; Jadva et al., 2010; Mahlstedt, LaBounty, and Kennedy 2010; Beeson et al. 2011; Rodino, Burton, and Sanders 2011; Ravelingien, Provoost, and Pennings 2014; van den Akker et al. 2015; Scheib, Ruby, and Benward 2017) .

Ravelingien et al. (2014) point out that in these studies the reasons people give for the need for genetic information is often very vague. Moreover, existing studies shed little light on how exactly meaning is given to this information about their genetic origins. Indeed, one of the great unknown issues in reproductive ethics nowadays is the meaning of genes for adults who are donor-conceived. Growing up in a society where genes are omnipresent and pervasive, and discussions of genes and genetic connection are prevalent, donor-conceived offspring for whom (at least) half of their genetic

Met opmerkingen [MOU1]: Than which other group? Those who are not born of donor egg or sperm? What about people of colour who search for their genetic ancestry? What about people with inherited diseases? What's the comparison here?

Met opmerkingen [AI2R1]: @ Kristien: those who are not born of donor egg or sperm ?

Met opmerkingen [K3R1]: Idd, suggestie toegevoegd.

background is unknown, are challenged to give meaning to the concept of genes (Finkler 2000; Nuffield Council on Bioethics 2013; Freeman et al. 2014b). Ideally, an ethical reflection taking into consideration the opinions of all stakeholders should take place before new technology is put into practice. In the case of reproductive technologies, some of the stakeholders (individuals resulting from these technologies) do not yet exist at the moment when a decision is needed on their acceptability. Hence, it is even more necessary that the opinions of these stakeholders should be considered when they are old enough to contribute to the debate. The study we discuss in this paper contributes to the knowledge about the experiences of sperm donor-conceived offspring themselves. We focus on the meaning of genes for donor offspring and try to shed light on the complicated and ambiguous ways genes, identity, information, and kinship are linked.

Materials and methods

Participants and procedure

Individuals who were conceived by anonymous sperm donation and who were over the age of 18 were eligible to participate. Advertisements were placed on websites of two Belgian (Flemish) organizations for donor-conceived offspring, one Belgian (Flemish) organization for donor-conceived families, advertisement boards at the universities the authors are affiliated with (University of Antwerp, KU Leuven), one fertility clinic (University Hospital Leuven), and circulated via social media. Twelve sperm donor-conceived adults participated: eleven were from Belgium (Flanders) and one from the Netherlands. Our participants were conceived at a time when fertility doctors often still advised their patients not to disclose to their child or others that the child had been conceived through donor conception. Indeed, all the participants who grew up in a heterosexual family did not know they were sperm donor-conceived until adolescence or later. As the participant from the Netherlands was also born under a legal system of donor anonymity and an atmosphere of secrecy, she was included in the

study. One participant had recently contacted her donor through a DNA databank. No other participants had contact with their donor or donor half-siblings.

This also means that many donor-conceived adults in Belgium are still unaware of the mode of their conception and are therefore unavailable for study inclusion. Also, many of those who are aware that they are donor-conceived may, given the prevailing secrecy, feel uneasy about discussing their origins. We believe that with our sample of twelve participants, we have reached a sufficient variety of experiences and meanings given to genes. Table 1 shows an overview of the participants. Ethical approval for this study was provided by the Ethics Committee for the Social Sciences and Humanities, University of Antwerp. Information about the study was given orally and in written form, and informed consent forms were signed before participation. The participants received no financial compensation. Data collection took place between September and December 2016. The short time frame of the interviews was due to restrictions of the project's funding.

We used interpretative phenomenological analysis (IPA) (Smith, Flowers, and Larkin 2009) as a method for qualitative interviewing and analysis, as we were interested in the living experience: we wanted to investigate how individuals give personal meaning to and make sense of genes and genetics in the specific context of being donor-conceived. This approach is characterised by an open-ended interview style that grants participants the opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns extensively. As IPA can be applied to focus groups (Smith et al. 2009, p 71), we originally planned to conduct focus groups as we assumed that people with the same or similar experiences were able to connect easily, and consequently would enhance richer sharing of and reflecting on experiences. We chose small focus groups (three people) to give participants enough space to talk about their experiences in sufficient detail. Six people participated and were divided into two focus groups. The second author was the moderator of the focus group, while the first author took on the role of observer. We deliberately did not want to steer the conversation too much but let participants' responses dictate the course of the conversation. An open

interview guide was developed, based on expertise in the field of donor conception of the first author and based on literature. This guide contains a short list of questions/topics to be discussed (experiences of genes in relation to the donor, the genetic parent, the social parent, to siblings, the wider family, their own development, and society). The moderator and observer ensured that all participants were given the opportunity to voice their experiences. It was noticed that all focus group participants were respectful of each other's experiences. The two focus groups each took about two hours.

Six participants were unable to participate on the given dates of the focus groups or preferred to stay anonymous but still wanted to participate. They were interviewed individually. The first author conducted two interviews, the second author four. The interview used the same open interview guide with short questions/ topics as used during the focus groups. The individual interviews took between 45 and 90 minutes. Both interviews and focus groups discussions were transcribed verbatim.

Data analysis

IPA involves a step-by-step analysis of each case before turning to the level of comparison across cases. Each author first read all the transcripts, descriptive, linguistic and conceptual notes were made to obtain familiarity with the case and enhance interpretation of the data (Smith et al. 2009). Experiences of the focus group participants were separated and collected into individual cases. The next step consisted of a first coding of the annotated transcript, with a search for patterns and connections across the data. In several sessions, the authors discussed the different codes, patterns and connections that they had found, eventually reaching agreement. Subsequently, the codes were clustered into themes and subthemes according to similarities and oppositions. We created an overview of themes and subthemes for each case. The last stage was the creation of a group analysis across the cases, containing an overall narrative account. The overview of the themes is given in table 2. Representative quotations were grouped around themes and are presented in this paper. Original quotations were translated from Dutch to English and back-translated by a third person.

Met opmerkingen [MOU4]: Only adds up to five. You indicate six participants wanted to be interviewed individually.

Met opmerkingen [A15R4]: @ Kristien : gij 4 he?

Met opmerkingen [K6R4]: klopt

IPA deploys double hermeneutics: participants making sense of their own experiences, and the researchers interpreting this making sense of it by the participants. Both authors took a reflexive stance and discussed their experience with genes, genetics that might color the analysis, with each other. We used an inductive approach to analyze the data, rather than a general theory on the meaning of genes. Basic assumptions included firstly that genetics was seen as referring to the process of how, in all living things, the characteristics and qualities of parents are passed on to their children by their genes. Secondly, based on layman knowledge of heredity, resemblance is seen as the outward, bodily expression of a genetic relationship; those who resemble each other are perceived as connected by genes through passing on genes (Strathern 1992; Rapp 1995; Becker 2000; Emslie, Hunt, and Watt 2003; Becker, Butler, and Nachtigall 2005).

[Table 1]

Context information

Concerning donor assisted treatment, Belgian law adheres to donor anonymity. Known donation with the agreement of both donor and receptor is not legally forbidden, but rarely employed (Belgian Act of July 6th, 2007, B.S. 17.07.2007). Clinics in Belgium are not allowed to inform patients -and thus indirectly the offspring- of any physical characteristics of the anonymous donor. All information about the donor that has no medical value is refused, because it is thought there is no objective reason for giving it (Pennings 2007). The rationale behind this, a minister of the Belgian government explains, is first that by not passing on such information to the child or the family, they hoped "not to sustain the myth that, for example, the character of the child is determined by the genes of the donor" (Nys and Wuyts 2007, 60 note 150). A second important element expressed was related to the question about *who* is to be considered the parent. In this respect, The Belgian Federal Advisory Committee on Bioethics states that: "in our society, the opinion that the biological parent is the 'real' parent is still too prevalent. This is even more explicit in relation to the role of the man than to the role of the woman." (Belgian Federal Advisory Committee on Bioethics 2004, 41).

Results

In the next section, we describe the experiences and different meanings genes have for the sperm donor-conceived adults we interviewed. The meaning of genes was defined on a socio-cultural level, on an individual level (genes as starting package, as a unique combination and reference point) and on a relational level (genes were person-al; connected and located individuals), each level addressing specific themes. A summary of the themes can be found in Table 2.

[Table 2]

Genes are part of daily life

The importance the participants attributed to knowing their own genetic origin varied, between different participants or, in the same participant, over time or within a specific context, but they all thought that genes had *some* significance. Genes were part of *their daily lives* as well as *their specific context of being donor-conceived*.

The following respondent explains how the meaning of genes gained more importance when her own children were born:

My son's birth was for me the first time I could actually see myself reflected in someone; he looks so much like me. Of course, he has something of his dad too (laughter). That made clear to me what I was missing: I can mirror myself in the future in my children, but I also want to mirror myself backward, in the past. Now I know it is there, because I have clearly seen it [in my son]. The characteristics I have, they have to come from somewhere. (F, 37)

Other situations in which the participants were confronted with the topic of genes included meeting a new partner, and wanting to know whether they were donor-conceived as well, being confronted with

an already existing genetic condition in the family or with a genetic condition they had inherited from the donor, and when seeing strong resemblance between family members. Several participants had received remarks from others that they differed so much from their family, and had been asked questions regarding “where this specific characteristic came from?”:

My brother and sister didn't resemble each other and outsiders often made joking remarks about “the milkman”, that was very much present. (F, 23)

Participants often specified that genes are not something that they, in particular, want to make important, but that it is hard to avoid genes as you are confronted with it in so many ways in daily life.

I don't think I give different importance to the meaning of genes since I learned [that I am sperm donor-conceived], but you are simply confronted with it. People are just not aware of it. I question myself a lot and I never had the feeling that I attach too much importance to genes. Yet I very often hear the remark ‘donor offspring attach too much importance to genes’. (F, 32)

Moreover, participants felt that society sometimes attributed different meaning and value to genes in different contexts or times. Genes were seen as having importance in a medical context (for example in the context of diseases, hereditary conditions), while in other contexts the importance of genes was trivialized. In the context of donor conception, participants experienced that fertility clinics or parents –while valuing the importance of genetic screening of the donor- often minimized the meaning of donated genes: they are just cells. Some felt great unease about certain remarks or jokes people made regarding sperm donation or certain recruitment campaigns for sperm donors. Participants felt that although the parents' perspectives and their sorrows about the loss of a genetic tie with the child were acknowledged, the offspring's perspective was largely neglected. Overall, there was a feeling that society dealt very lightly with what they considered important to them, and they felt blamed for paying too much attention to their genes ('being deterministic'). The denial of the fact that genes may be

important to them by others (such as fertility clinics, policy makers or academics) was experienced as humiliating.

Genes as part of who you are

Genes are your starting package

Participants talked about their genes as *their starting package or building blocks*. Genes are the pure biological material out of which an individual develops. In this respect, they did not agree with the fact that gamete donation was often compared to other types of donation, or could just be ignored:

Contrary to blood or an organ, DNA or sperm or eggs are not a generic product. It is a big difference. Sometimes they say that donating sperm is the same as donating blood. However, that just is not true. It is your starting package for the rest of your life [...] I do not think you can deny that, your genetic package. It defines to a large extent who you are. Okay, you are also formed by other influences, if monozygotic twins grow up in two different families, they would probably grow up to be different people, but there will be resemblances anyway, and not only physical resemblances. There will be differences, but also many resemblances between these two children.

[M, 31]

While they regarded genes as their starting package, they were all struggling in what way *nature and nurture* had each contributed to their lives. Most participants expressed feeling 'different' -physical or character-wise- from their family members. This made them reflect on the origins of the differences.

My brother and I had different donors. We experienced the same education, the same people around us, the same schools, the same...and we are completely different, 180 degrees! So, yeah then you think 'nature'. I have tried to fit in, but I

never succeeded. So, in my case, in my family, nature clearly dominates. I think it could be different for each case, I don't know. (M, 28)

I think, because there is no link between my dad and me, neither physically, nor character-wise, that who you are is determined to a high degree by your genes, your starting package. (M, 31)

Genes constitute the beginning of an individual's life story and were therefore perceived as vital information about themselves. Not knowing part of their genetic origins left several participants with a feeling of emptiness. In this respect, the donors were considered *a source of information* that could fill in the missing details. Participants were curious about possible siblings from the same donor, but they were seen as secondary information sources, less 'pure' than having information directly from the donor. The following respondent describes how he feels that, by not having this information, part of his personality is unknown:

There are a billion people on earth who do not know their parents or their genetic connections. Still, it bothers me a bit. It's like a part of your personality that you do not know. Even if you are an individual, and it is merely a biological connection, it still is a part of you that you are missing. (M, 24)

Genes are a unique combination

The participants further spoke about how *genes* are also part of *what makes you unique*; the combination of a specific egg cell and sperm cell developing into a unique person. The participants described a certain degree of unease about how sperm and eggs were handled as tradeable material and the possibility that there might be many siblings from the same donor. It made them feel like they were part of an industrial mass production process, which jeopardised their feeling of uniqueness.

I would find it really strange if there are another 13 copies [of me], it makes it very industrial, impersonal (M, 28)

Also, differences in handling egg and sperm cells and their effects were discussed:

I don't see it happen, posters saying "come and donate your eggs" ... it's often more romanticized. In contrast to sperm cells, and sperm banks, and the campaigns and marketing around it...that is a different atmosphere compared to egg donation. Due to this marketing I get the feeling as if I am a product. (F, 23)

Knowing which genetic talents, traits, and characteristics they had inherited from their donor would help to complete the picture: by knowing this, they would be able to localize better what they had inherited from their mother and what was unique to them.

I want to be able to define myself, I want to know what I got, and from whom, and what I don't have from these people, what makes me 'me,' but a piece of them makes 'me' too. (F, 37)

We are all pieces of a tree, and some things are visible, and other things are invisible, but you know that these branches exist, even when they are behind a thick mist, they are part of you, and you want to... Poof, chase away the mist. Because I want to define myself: what is mine, what do I have from him and what from my mother. (F, 37)

Genes as a reference point

Genes were experienced as containing information about their potential, and could, therefore, be guiding them in their identity development. Genes functioned as a *point of reference*. This feeling was especially strong for those who experienced differences with their family members and difficulties to identify with them. They "tried to fit in" but felt left behind with many questions and insecurities.

Looking back, they felt that it would have helped if they had been informed earlier about the donor conception, so they would have understood the difference they experienced and felt freer to explore their own potential, apart from the reference point that their parents represented.

My brother and I have different donors. He has always, since he was 10-12, psychologically struggled with his identity. My mother always said he had a psychological problem. So, she went to the doctor and asked if the donor had psychological problems [she told us later]. Now I see my brother never could identify with our father. He had so much problems; he couldn't recognize himself in him. [F, 32]

I think it would have made a difference if they had said "do your own thing, we will see, we will support you, or even we will say that is foolish." But at least there would have been a platform. Now it was just me running behind the facts. (M, 28)

One respondent also stated, about a colleague of hers who was a single parent and who had said that she hoped that having her as a mother would be enough for her daughter, and that she would therefore not have the desire to explore her genetic origin:

I told her 'yes, but, the desire to know where you came from is unrelated to the love she feels for you. That [the genetics] is part of her story' [F, 32]

However, genes as reference point were not seen as absolute. Participants constantly deliberated if aspects of their identity could be attributed to genetic heredity or not. A 23-year-old woman expresses this as follows:

That always made me curious: children who are biologically related to their parents and who also wonder, who have something that they can't attribute to their family. That's possible. That something in their behavior or interests develops that they

can't allocate to family, although they are biologically related...it's this constant deliberation, what is genetics? There are things you think must come from the donor, and things you just leave in the middle. (F, 23)

Genes are relational

Although participants acknowledged that kinship is not necessarily defined by genes, they also experienced how genes do refer to something relational. There was general ambiguity about how the relationships conveyed by genetic connections should be conceived.

Genes are 'person-al'

Genes are not freestanding, but they are *wrapped up in a human being*. Sharing a genetic link with someone (regardless of the value that is placed on that link by any party) who is not part of your family, and who has never been involved in your education, created additional challenges. How to think about this kind of connection was still a great unknown. The following quote, by the person who had met her donor through the Dutch DNA bank, demonstrates this ambiguity:

I do not want to think of him as a father, but it is all so interconnected and linked that you cannot but think about it in terms of fatherhood, it is your only point of reference, you cannot think 'ah yes, a donor'. How to relate to a donor? (F, 32)

Genes are donated to create a human being. The personal motivation of the donor and how genes were donated (given away or carefully thought about), seemed to co-create the meaning of genes. Being treated as a product was experienced as hurtful and dehumanizing.

The whole marketing surrounding it.... People are surprised that this actually leads to human beings. They don't think it through that far. (F, 23)

Genes are not something you just trade between each other, like lending a grass mower to your neighbor because his is broken. No, this is about human lives,

children. I find it very disturbing that people compare it to blood donation. I find that really offensive (F, 32)

Genes connect

Despite the fact that participants considered genes mostly of importance to their own identity, it seemed undeniable that genes are associated with concepts like relatedness and belonging. As genetic ties in our society are closely linked to kinship, they felt they had no alternative template on how to think about the donor. The merger between donor and kin was therefore easily made. For this reason, participants felt that their interest in their genes was often threatening for others.

What they feared, or still fear, is that that bond [between donor offspring and donor] will be at the expense of the bond with my mothers. Apparently, that is what society fears as well. However, that is not what would happen in reality. (M, 24)

The participants often felt that they had to balance their own interests in their genetic origins with the perspectives of others, and often felt a strong desire to be loyal to their parents. Even when the relationship with their social parent was not good, it was clear that the donor could not just replace him. Having an interest in their genetic origins was considered to be independent from the relationship with their parents. They were two different things that could co-exist:

If everything had worked out better, I would have probably had a father-daughter bond with him. However, that does not change the fact that I biologically descend from someone else and that that person is relevant to me. But it doesn't undermine my dad's capacities to educate children or to love or whatever. (F, 32)

The conflation between genes and kinship was also observed on sibling level. When participants talked about sperm donor-conceived offspring from the same donor, they often used the words "half-sister", "half-brother". They were still finding ways on how to think and feel about these connections. With

regard to the brothers and sisters they grew up with, some participants found out later in life that they were not fully genetically related siblings but half-siblings:

The idea that there are people out there to whom I am genetically related in the same way as to my brother and sister, well that's crazy. Theoretically, around twenty-five half-brothers or half-sisters could be walking out there. (F, 23)

I never thought about it until I met other donor-conceived offspring. Most of them were not fully genetically related to their brothers and sisters. They were very occupied with that. When someone new joined the group, they immediately asked: "Are you kin?". That was completely new to me. I think it might have to do with the fact that my sisters are my [full genetic] sisters and that I don't have any real need for that. (F, 32)

Participants talked about how this information regarding their sharing/ not sharing of genes between siblings made them rethink their own views on genetic connections and kin. It did not change their kinship bond, and they often kept seeing each other as full "brother, sister."

I noticed, so I now have three half-sisters with whom I share fifty percent and the other half not, that I feel a little bit more isolated, though. However, the love for my sisters has not changed at all. I feel more on my own. I have a special side [being donor-conceived] to me that I do not share with my other sisters. Although one sister also has that special side, so in that respect, I feel more closely related to her. However, I think these thoughts are normal in the beginning. I do not expect it to change much in our relationship. (M, 34)

While genes were not associated directly with kinship, at the same time several participants considered a genetic link not noncommittal, but also associated with some responsibilities:

It gives me a very unpleasant feeling; it's not like donating blood, I find that very difficult, how can that person just leave his sperm. I exist, I'm in some way your child and you don't care about me (F, 32)

The following participant describes how he thinks that sharing genes also increases affinity between the involved individuals, even if such affinity does not correspond to actually *liking* your kin, and that this affinity also engenders responsibilities:

I don't like my sister so much but the fact that I share a genetic bond with her means, well, I would give my life for her. I don't know why exactly, but that is just how it is. It means something, I don't know, you feel morally obligated to do that, it is an automatism. Seriously, I think it has much more significance than people actually think ...it's not all rational, it's emotions. (M, 24)

Genes locate

When they were children, our participants had expected to resemble their parents - as they were not informed about the donor conception at that time. At least some degree of familiarity, recognition of traits, was expected based on a presumed genetic connection. Instead, participants often had the experience of non-resemblance, being different character-wise and/or physically from their family members. These perceived differences evoked feelings of “not fitting in”, “being an outsider”, and “not feeling at home”. Hence, genes were associated with locality, genes –through resemblance- locate you within (or outside) a network. For example, in the following quotes, participants explain how they connect their lack of similarities with their family members, or their feeling of not fitting in, to sharing fewer genes:

In my family, there is nobody [who is like me]. Also, with regard to interests, they are all good people, ordinary people, but I am always looking for that connection or that percentage that we have in common, I always have the feeling the rest is

completely different from who I am. Maybe it is just a feeling, and perhaps I focus too hard on it because I am so different. Having this click, like that is my type of people and this is where I belong, I haven't experienced that yet [M, 28]

I always wondered, how are they acting so normal to each other, this small talk, how are they doing that? I'm not able to do that. I think because I didn't have that connection with my dad, we didn't share the same interests[...] so I noticed these differences and I focused on it, so you try to be like them. But it didn't work out, I failed. [M, 28]

One participant explained how the contact with her donor helped her answer certain questions she had about herself and to place herself more firmly within her family.

Before, I didn't recognize myself in my mother. Now I see the resemblance more clearly because I can compare to him and think, ah, no, that I do not have from him, that is really from my mother. (F, 32)

She therefore implies that, contrary to the general expectations that knowing your donor's identity and even meeting him is disruptive to family connections, having these questions answered can actually strengthen connections. Another participant, of the same age, who had expressed being angry at her parents for not telling her about her genetic origins, expressed a similar idea:

I think the great fear that families and parents have, that this person will take away their children, is unwarranted. It is actually the opposite. Not knowing, and everything that makes you a bit different, places you on the outside. I am much more on the outside now, whereas if I were able to see [where some of my genes come from], I would see my identity confirmed, and I would understand what I have from my genes and what I have from my social father. I think this can also bring families together. [F, 32]

Discussion

Our study provides an insight into what meanings adult sperm donor-conceived offspring give to genes and their experiences. Sperm donor-conceived offspring in our study reported that genes are part of daily life and pop up in several situations, contexts or times of their life (as news, resemblance remarks, inquiries about family history.) While they did not intend to highlight the role of genes, they felt it was difficult to avoid genes in the current society. Donor-conceiving parents have described a similar feeling, (Becker et al. 2005; Nuffield Council on Bioethics 2013; Nordqvist and Smart 2014, 151; Indekeu 2015).

When talking about genes, the participants relied on metaphors such as 'genes as information sources'. Metaphors help people to shape their understanding of a certain concept, and to grasp how it works. Obviously, the metaphor people used is highly significant. Metaphors are not randomly chosen but already have their origin in dominant social conditions. In a digital computer age, metaphors based on the notions of 'information' or 'codes' are quickly understood and assimilated (Nordqvist and Smart 2014, 149). So, phrasing genes as bits of information should not be seen purely as a personal preference/choice, but also within a wider societal framework on how we talk and think about them. The metaphors also generate questions about the kind of information that is shared in genes and expectations about the value of this information. Our research has shown that how genes are conceived may also differ, depending on whose meaning is given, e.g., the parents to the child or vice versa. Also, Nelkin and Lindee (1995) point to the influential social side of genes and describe the gene as a cultural icon. Their research explains that genes in popular culture draw on scientific ideas, but the concept is not constrained by the technical definition of the gene as a section of DNA that codes for a protein. Moreover, they show how DNA is infiltrated in all parts of daily life such as in soap operas, comic books, advertising, and other expressions of mass culture.

Participants saw the idea of 'genes as information' linked to their sense of self, their identity, in several ways. *Firstly*, genes are literally *the essential biological components* you were made of, which could not just be denied. Simultaneously, genes are the starting point of your own narrative. People have a fundamental need to make sense of their lives in terms of stories (Nuffield Council on Bioethics 2013, 209). Having a narrative available is critical, both in one's daily life and for one's sense of self (Griffin 2015). Information about your genetic ancestry, your origins, and your biological make-up is part of your identity-story. *Secondly*, genes symbolize *uniqueness*. On the one hand, this refers to each person's unique genetic combination. Genes are seen as information that is used to identify individuals in the sense of picking them out reliably and uniquely, such as in genetic fingerprinting and in tests of paternity (Ashcroft 1999). On the other hand, genes create (or diminish) feelings of uniqueness. Sharing genes with too many same-donor siblings could threaten this feeling of uniqueness. This has been expressed by sperm donor-conceived offspring as well as donor-conceiving parents (Nordqvist and Smart 2014, 111). Indeed, as Nordqvist and Smart have argued, too many children born from the same donor does not only have effects on the level of individual specialness, but also on the particularity of intergenerational genetic links (Nordqvist and Smart 2014). *Thirdly*, genes were seen as *a reference-point*, a kind of tool that could help them clarify what they inherited biologically and/or socially and what was their unique. This was also observed by Cushing (2010) and Scheib et al. (2017). This support in obtaining a better view of who they were was considered especially important during adolescence, the time of identity development. Normally, one biological parent and that side of the genetic family are present during the donor-conceived offspring's upbringing and can already provide a useful reference point (Ravelingien et al. 2014). However, participants in this study had often experienced striking non-resemblance to their family members (physical differences and/or differences in personality traits or interest). This enhanced the need for a reference point to frame these differences. Subsequently, if such information is thought to be crucial for discovering one's self and for assessing one's potential, access to donor information at age 18 comes rather late (Turkmendag 2012).

While genes had significance on the individual level, at the same time they were perceived as very relational. Genes were regarded as a biological substance ‘wrapped up in a person’ (See also Hertz, Nelson, and Kramer 2013). This created several challenges: what value to give to this genetic tie with the donor and with offspring from the same donor, and how to manage the presence and absence of a genetic tie within their family and view on kinship (Kirkman, 2004). Biology does not necessarily define ‘kinship’, and conflation between genes and kinship can easily occur. Although our participants themselves did not suggest that they were looking for a replacement father, donor offspring’s interest in their genetic ancestry was often experienced, by family members, as threatening due to this conflation of genes and kinship. Similar to Blyths’ results (2012), our participants were clearly their own agents in determining what it is about their genetic *and* social histories and relationships that matters to them, not only regarding their parents and their donor, but also in relation to their full or half-siblings.

Moreover, as resemblance is often seen as an outward expression of genetic relatedness, the experiences of non-resemblance by several participants raised questions about (not) belonging to their family, as is also seen in other studies (Finkler 2000; Becker et al. 2005; Nordqvist and Smart 2014, 135; Indekeu 2015). Similarly, (grand)parents have reported that situations in which a child expressed something that did not seem to fit in with the rest of the family, e.g. having a specific talent or an interest that seemed foreign reminded them that the child was genetically related to someone else. (Nordqvist and Smart 2014; Indekeu 2015). Recently, van den Akker et al. (2015) provided empirical support for theoretical arguments that a sense of belongingness is critical to identity. While the practice of matching, which involves choosing gametes or embryos in such a way as to minimize physical differences between the donor and the recipients, is legally allowed and applied in the clinics, resemblance cannot be guaranteed. Further research on the meaning of (non)resemblance in relation to connectedness and belonging is needed.

Although genes seem to be intrinsically linked with health, and having access to your genetic background for medical reasons is a frequently mentioned reason for searching for donor information (Rodino et al. 2010; van den Akker et al. 2015), references to medical information contained in genes were surprisingly far less made than we had expected. It often came up only after we explicitly asked about it. This could be a consequence of how the questions were asked, or the fact that for this group of participants other meanings of genes prevailed at this point in their life.

In this study, we have demonstrated that the significance genetic origin has for those who do not have this information is multilayered and cannot be reduced to mere information or biology. How we think about genes is, on the one hand, shaped by the societal, professional and political discourse on the topic. But it is also undeniable that genes are the biological building blocks of a human being and are linked to resemblance and identity. Hence, genes carry a certain significance, but as our participants testify, this is not necessarily related to the quality of family relations, or in a hydraulic relation to the amount of love that is available between family members.

Limitations

We acknowledge that our way of recruiting may have introduced some self-selection bias: it may be that our participants were for some reason more motivated to participate and talk about genes in the context of being donor-conceived, which might have co-created their feelings and meanings. However, we did not aim to collect representative experiences, but to gain a detailed understanding of sperm donor-conceived offspring's experiences and their meaning of genes. Notwithstanding the variety of families (heterosexual, lesbian, single mother, same or different donor for siblings, age at disclosure), we were able to identify some common themes in their accounts.

Due to circumstances, we had to adopt two methodologies of data-collection. In contrast to focus group participants, participants in individual interviews were not triggered by co-participants' experiences to enhance richer sharing of experiences. However, individual interviews give the

opportunity of asking more probing questions to enrich the account. One author conducted two interviews, the other one four. While some difference in interviewing style might have occurred, using the same interview-guide should have accomplished sufficient conformity in interviews.

All of the participants were sperm donor-conceived offspring. While the number of children born through sperm donation continues to outweigh significantly those born through egg donation (Freeman et al., 2014a, p 275), these results cannot without thought be transferred to egg donor conceived offspring. While egg donor-conceived offspring are genetically related to the egg donor, at the same time they are biological related to their social mother and the practice of known donation is more common in egg donation than in sperm donation treatments. Differences that might color egg donor-conceived offspring experiences in a different way than for sperm donor-conceived offspring and should be explored in further research.

All of our participants, except the two growing up in a lesbian or a single mother family, learned about their donor conception during late adolescence or adulthood. It should be noticed that overall, participants in the first instance vividly talked about genes in relation to the non-resemblance and the associated feelings they had experienced before they were informed about their donor conception. Later on, they talked about genes in relation to the disclosure and (non) genetic relations. Hence, this experience of non-resemblance and the late disclosure may have co-created their meaning of genes.

The majority of our participants were women. This might reflect a greater willingness of women to participate in such studies and/or a greater level of interest in their biographical origins, as found in studies on adoptees and sperm donor-conceived offspring (Finkler 2000; Jadva et al. 2010; Blyth et al. 2012). Yet, this might also be context-dependent. Vanfraussen, Ponjaert-Kristoffersen, and Brewaeys (2001, 2002, 2003) found a greater interest among boys within lesbian families than girls in meeting their donor.

Met opmerkingen [MOU7]: This section highlighted should go into the methodology section.

Met opmerkingen [AI8R7]: @ kristien: dit vind ik heel raar. ...dat is toch niet wetenschappelijk structuu. Het is zoiezoa al raar wat de mens nog eens geaa heefteb al een correctie op zijn aanpassing aangebracht maar soit (ij had verbeerd dat het zo kon vertaald worden naar egg donaiion...terwjl wij juist zeidn van iet) wat doen we? Aangeven dat dit niet de gewoonte is??

Met opmerkingen [K9R7]: Ik vind het ook raar, en heb het alleszins zelf nog nooit zo gedaan, maar aangezien we subheadings hebben in de M&M section denk ik dat we wel gewoon een subheading daar kunnen onder zetten 'limitations' en dit eronder plaatsen, het kan wel denk ik.

Regarding the wider relevance of our study, we note that our work was performed in the context of the Belgian legal system of donor anonymity in which no information at all is given about the donor (except those with medical value in case of medical necessity). Blake, Ilioi, and Golombok (2016) suggested that, in terms of families created by donor insemination and egg donation, perhaps those who experience the greatest barriers in finding their donors (i.e. those conceived using anonymous donors in clinics in which there are no medical records) may have a greater preoccupation with their donor origins, compared to those who can access information about the donor with relative ease. Therefore, the meanings of genes and genetics might be different for donor offspring with an identifiable or known donor, and this warrants further study.

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