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ORIGINAL ARTICLE

Telling donor-conceived children about their conception: Evaluation of the use of the Donor Conception Network children's books

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Abstract If parents have used donated gametes, it is a personal choice whether they disclose to their children. For those that do, there is, however, little advice on how to tell their children. The Donor Conception Network (DCN) has made a series of books to help parents disclose. This study evaluated parents' experience of using these books. An online survey with both quantitative and qualitative questions was used. The DCN membership and social media were used to publicize the survey, and 108 responses were analysed. At the time of conception, the parents' family types were mainly mother and father (56.5%) and solo mothers (36.1%). The method of conception was mainly donor spermatozoa (55.6%) followed by donor egg (38.0%), double donation (8.3%) and one case of surrogacy. Most parents had read the book to their children before 2 years of age (76.9%). Before reading the books, some of the parents had some confidence in telling (43.5%) or were very confident in telling (30.6%). After reading the books, 60.2% reported having much more confidence in telling. Most parents felt their children had no understanding (76.8%) or only some understanding (22.3%) of donor conception before reading the books. After reading the books most parents felt their children's understanding had increased (71.3%). Most parents felt that reading the books had given them more confidence in using donor conception language (90.7%). The use of books to tell children about their conception may be a useful resource for parents wishing to be open with their children.

KEYWORDS: disclosure, donor conception, egg, fertility, spermatozoa

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Introduction

With the increasing removal of donor anonymity globally, starting with Sweden in 1984, followed by Austria, Finland, Iceland, the Netherlands, Switzerland, the UK, New Zealand and the Australian states of New South Wales, Victoria and Western Australia (Carr, 2015, Clark, 2012; Frith, 2001), parents are encouraged to be honest with their children regarding their method of conception.

But it is the parents' decision whether they tell their children that they were donor conceived. Schrijvers and colleagues (Schrijvers et al., 2017) found that the donor-conceived children in their study would like to be told about their conception and would have liked their parents to be supported in doing so. Zadeh and co-workers (Zadeh et al., 2018) have shown that when told early, donor-conceived individuals' feelings about their conception are mostly indifferent, positive or ambivalent. In contrast, when told later in adolescence or adulthood, telling is more likely to be associated with feeling upset, shocked, angry or confused (Jadva et al., 2009). Overall, the presiding attitude is shifting towards offering support and education to parents who wish to be open (Pasch, 2018), which may be partly prompted by the possibility of children tracing their lineage through genetic testing (Harper et al., 2016).

Mac Dougall and colleagues (Mac Dougall et al., 2007) found that disclosing parents subscribed mainly to one of two disclosure strategies. The first was the 'seed-planting strategy', in which there was the belief that early childhood telling will ensure that the child was always aware of their donor conception. The second was the 'right-time strategy', with the belief that delaying the telling time will allow the child to be psychologically mature. The study additionally showed that parents who chose early disclosure were more at ease, and those who chose late disclosure were confused as to the right time to do it. The parents were, however, sure to want help in counselling at the time of disclosure and beyond, and children reported that they felt that support would have been helpful to them.

A systematic review by Indekeu and colleagues (Indekeu et al., 2013) highlighted the complexity in decision making around disclosure. They found that the parents' decision on how to tell their children was influenced by a 'myriad of intrapersonal, interpersonal, social and family life cycle features'. A meta-analysis of 19 studies of autologous and donor-assisted reproductive technology examined parents' disclosure of the conception method to their children. With children under the age of 10 years, there were no differences between the two groups comparing 'Told' versus 'Planning to tell/Uncertain/Planning to not tell'.

In addition to the evidence around telling, motivation for telling is often based on a value system that requires no evidence base. This is often expressed as a desire to build the relationship with one's child based on trust and the desire to avoid telling untruths (Burns and Pettle, 2002). For some, this is also motivated by a wish to express pride to one's offspring so that they themselves can also adopt that attitude or the belief that children have a right to that information (Montuschi, 2006).

The Donor Conception Network (DCN) is a UK-based membership organization with a global reach offering contact, community support and information to donor-conception families around the world (Membership of the DCN, 2019). It was established in 1993 by five families who used sperm donation and were intent on being open with their children about their origins. DCN publishes a journal twice a year, runs two family conferences a year, runs workshops for those considering donor conception and for 'telling and talking' in families, sells a range of books and has a website that provides information on the disclosure of donor conception.

The books for parents to use with their children are called *Our Story*. The books have undergone revisions since originally written. The original *Our Story* books used the word 'sperm', but the new version uses the word 'seed'. The books currently have 44 versions for heterosexual couples, same-sex couples and single parents with the use of spermatozoa, egg, double donation (egg and spermatozoa) and embryo donation (Table 1A). There are also versions with references to surrogacy (Table 1B), donor insemination outside a clinic setting and reciprocal egg donation (in same-sex female couples), with twin versions for all of these. *Our Story* was written with two goals: (i) to offer parents a positive and simple tool to talk about donor conception, and (ii) to give children an introduction to the idea of having a person outside the family involved with their conception. The books specifically written for the parents to aid them further are in the *Telling and Talking* series; these are tailormade for different age ranges of 0—7-year-olds, 8—11-year-olds, 12—16-year-olds as well as 17-year-olds and above.

Only one previous study has examined the use of books to help parents tell their children about donor conception. Freeman and colleagues (Freeman et al., 2016) found that 64.7% of solo mothers and 100% of partnered mothers had used story books about sperm donation to tell their child.

Since the publication of *Our Story*, the books have not been scientifically evaluated. The aim of the study was to evaluate the experience of parents who had used the donor conception books to tell their children about their conception in the hope that these books could be used globally to support parent disclosure to their donor-conceived children.

Materials and methods

The study was cross-sectional and data were collected using an online survey created using Qualtrics Survey Software (Qualtrics). After developing the survey, a think-aloud validation was undertaken to ensure that all of the questions were easily understandable (Someren et al., 1994) and the survey was checked by members of the DCN. The DCN membership and social media were used to publicize the survey. All participants had to be aged over 18 years, had to have successfully used donor conception and had to have read the DCN books to their children.

Survey

The introductory part of the survey contained information about the project, the research institutions — the Institute for Women's Health, University College London and the

Table 1 Donor conception network book types currently available.

(A) Donation

Family type/donation	Egg	Sperm	Double	Embryo
Heterosexual	✓	✓	✓	✓
Same-sex female couple	✓	✓	✓	✓
Single woman		✓	✓	✓

(B) Surrogacy

Family type/donation	Surrogacy	Surrogacy and egg donation	Surrogacy and sperm donation	No-clinic insemination and sperm donation
Heterosexual	✓	✓	✓	✓
Same-sex female couple				✓
Same-sex male couple		✓		
Single woman				✓
Single man		✓		

DCN — ethics approval information, data protection measures and contact details of the lead researcher, the project supervisor and the DCN research officer. Ethical approval was obtained from University College London Research Ethics Committee (ID Number: 9831/003). The liaison and advice services were included to make sure that any distress or concerns could be reported and managed.

Demographic data were collected to determine the characteristics of the parents who completed the survey.

Questions were asked of family composition now and at the time of conception, the method of donor conception (donor spermatozoa, egg donation, double donation, surrogacy), which books were read, the age at which the books were first read, how often they were read and by whom. Parents were asked to rate how confident they had felt about telling their children about donor conception before (very confident, some confidence, a little confident, not confident) and after reading the books (much more confidence, some confidence, a little confidence, did not make a difference) and whether reading the books had given them more confidence in using the language around donor conception (definitely yes, probably yes, might or might not, probably not, definitely not). The parents' view of their children's understanding of donor conception before reading the books was evaluated (no understanding, some understanding, a good level of understanding), as was whether their children's understanding of their conception increased after reading the books (definitely yes, probably yes, might or might not, probably not, definitely not). The parents were asked to rate the books from 1 to 100 where 1 was 'poor' and 100 was 'brilliant' and asked to answer in free text what they thought about the use of the words 'seed' and 'sperm'.

Data analysis

The data from the survey were analysed descriptively and inferentially to determine the usefulness of the DCN's *Our Story* books. Parents were asked a number of free-text questions to explore their experiences of using the books. Content analysis was used for the qualitative data results to categorize the comments into positive comments, negative comments and suggestions to improve the books.

Results

As is usual in surveys, not all participants completed the survey. A total of 139 parents started the survey, with 108 fully completing it.

Demographic characteristics of parents

The demographic characteristics of the parents are summarized in Table 2. The age range of the parents was 20–69 years, while their mean age was 46.9. Most participants were white (71.3%, 77/108) and had a graduate or postgraduate degree (86.1%, 93/108), with the vast majority (93.5%, 101/108) not reporting any disability. Parents without any religious background or belief were in the majority, with 48.1% (51/108), followed by Christians (35.2%, 38/108).

The parents' sexuality was mainly heterosexual (84.3%, 91/108), followed by bisexual (9.3%, 10/108), homosexual (5.6%, 6/108) and one 'other' (0.9%). At the time of conception, the parents' family types were mainly mother and father (56.5%, 61/108) and solo mothers (36.1%, 39/108). The method of conception was mainly donor spermatozoa (55.6%, 60/108) followed by donor egg (38.0%, 41/108), double donation (8.3%, 9/108) and one case of surrogacy. At the time of completing the survey, the parents raising the child(ren) were mother and father (52.8%, 57/108), solo/single mothers (40.7%, 44/108; this included 39 solo mothers and five single mothers due to divorce and separation), two mothers (5.6%, 6/108) and two fathers (0.9%, 1/108). No single fathers answered the survey.

Table 2 Demographic characteristics of the respondents.

Variable	Number	Percentage
Age of the parents (years)[a]		
<40	12	11.1
40–49	63	58.3
50–59	27	25.0
60–69	6	5.6
Age range of the children (years)		
0–9	93 70.5	
10–19	28 21.2	
20–29	11 8.3	
Ethnicity background		
White – English/ Welsh/ Scottish/Northern Irish/British	77	71.3
White – Irish	7	6.5
Any other White background	20	18.5
Black/Black British – Caribbean	1	0.9
Mixed ethnic background	2	1.9
Any other ethnic group	1	0.9
Disability status		
Sensory impaired	3	2.8
Specific learning difficulty or disability	2	1.9
Long-term illness or health condition	1	0.9
Autistic spectrum disorder	1	0.9
No disability	101	93.5
Religious background		
No religion or belief	52	48.1
Christian	38	35.2
Jewish	10	9.3
Buddhist	1	0.9
Others	7	6.5
Educational status		
School or college	14	13.0
University undergraduate	28	25.9
University postgraduate	65	60.2
Other	1	0.9

[a]Mean age 46.9 years, range 31–69 years.

Quantitative results

How *Our Story* was used

A summary of how *Our Story* was used is shown in Table 3. Most parents had read the book to their children before they were 2 years of age (76.9%, 83/108); the rest of the children were introduced to the book between the ages of 2 and 4 years. Heterosexual parents were mainly reading the egg donor book (66.7%, 38/57). Homosexual and bisexual parents were mainly reading the sperm donation book (80.0%, 8/10).

In terms of who read the book out, mothers read most often (42.6%, 46/108), followed by fathers and mothers (36.1%, 39/108). Reading the book once a month was the most frequent (29.9%, 32/108). In terms of the period of reading, most parents were still reading the books at the time of the survey (58.3%, 63/108).

Parents and child(ren) confidence before and after reading *Our Story*

Before reading the books, some of the parents had some confidence in telling their child about their conception (43.5%, 47/108) or were very confident in telling (30.6%, 33/108) but 25.9% (28/108) had little or no confidence in telling (Table 4). After reading the books, 60.2% (65/108) reported having much more confidence in telling and 24.1% (26/108) had some more confidence in telling.

Most parents felt their children had no understanding (76.8%, 83/108) or only some understanding (22.3%, 24/108) of donor conception before reading the books. After reading the books most parents felt their children's understanding had increased (71.3%, 77/108). Most parents felt that reading the books had given them more confidence in using donor conception language (90.7%, 98/108).

Overall rating of *Our Story* by parents

The parents were asked to rate the books on a scale of 1–100, with 1 being 'poor' and 100 being 'brilliant'. The majority of parents rated the books as 75–100.

Qualitative results

Parents were given the opportunity of expressing how they felt about the books.

Table 3 How *Our Story* was used.

Variable	Number	Percentage
Age of child when first read to (years)		
<2	83	76.9
2–4	25	23.1
Which *Our Story* was read (heterosexual) (*n* = 57)		
Donor spermatozoa	17	29.8
Donor egg	38	66.7
Double donation	2	3.5
Which *Our Story* was read (homosexual and bisexual) (*n* = 10)		
Donor spermatozoa	8	80.0
Donor egg	1	12.5
Double donation	1	12.5
Which *Our Story* was read (single parent) (*n* = 41)		
Donor spermatozoa	33	80.5
Double donation	8	19.5
Person reading the book		
Mother and father	39	36.1
Mother	46	42.6
Two mothers	5	4.6
Child/children themselves	1	0.9
Anyone else	17	15.7
How often *Our Story* was read		
Once daily	7	6.5
Once a week	26	24.1
Once a month	32	29.6
Once every 2 months	10	9.3
Once a year	3	2.8
Others	30	27.8
Period over which *Our Story* was read		
<1 week	9	8.3
1 month	5	4.6
2–12 months	5	4.6
1–2 years	8	7.4
>2 years	18	16.7
Still reading it	63	58.3

To the question 'Is there anything else you would like to tell us about how your child or children felt about the books?', there were 55 positive answers, three negative answers and 24 suggestions. Positive comments included, 'These books have been amazing for our family. The kids have the vocabulary to discuss and ask questions, they have empathy for the characters and have been able to relate it back to how it was for us to create a family. We love these books.' In addition: 'They enjoyed reading about their story and adding their own drawings.' The negative comments included, 'They preferred their other books. She knew her story and preferred other stories.' And 'Just another story book, I think.'

When asked if there was anything the parents would like to tell us about their experience with using the book(s), there were 56 positive answers, seven negative comments and 13 suggestions. Positive comments included, 'It gave us a consistent way of talking about it' and 'Very happy. The books have really given me confidence and made me psychologically stable.' The negative comments included, 'Neither my child nor I liked the illustrations much.' And 'Sadly it's factually incorrect as it doesn't describe IVF accurately.'

When asked about the use of the word 'seed' instead of 'sperm', many parents (50) wanted to use the proper words, with 34 being OK with 'seed'; 24 made suggestions. Two quotes relating to using the proper words: 'I hate the use of tummy and seeds, makes me think my children are like plants.' And, 'I am disappointed about that change. I feel it is a backwards step and contradicts the general DCN line about being open and honest.'

From those who were happy with using the word 'seed' one comment was, 'We found ''seed" is better. It is a warmer word and something the children can relate easily. Egg and sperm are far too abstract for the early years', and 'I think it's fine — makes it more understandable for younger children.'

Parents were asked if there were any additional books they would like, and 44 gave suggestions including that 'One for older teenagers and young adults would be a welcome addition, but realize there would have to be very different books for those who had been told versus those who had

Table 4 Respondents evaluation of the confidence/understanding before and after using *Our Story*.

Variable	Number	Percentage
Before using the books, how confident did you feel about telling your children about their conception?		
Very confident	33	30.6
Some confidence	47	43.5
Little confidence	16	14.8
No confidence	12	11.1
Did reading the books give you more confidence in telling your children about their conception?		
Much more confidence	65	60.2
Some confidence	26	24.1
A little confidence	9	8.3
Did not make a difference	8	7.4
What was your child(ren)'s level of understanding of their conception prior to reading the books?		
No understanding	83	76.8
Some understanding	24	22.2
Good understanding	1	0.9
Did your child(ren)'s understanding of their conception increase after you read them the book?		
Definitely yes	41	38.0
Probably yes	36	33.3
Might or might not	20	18.5
Probably no	5	4.6
Definitely no	6	5.6
Do you feel that the book(s) gave you more confidence in using donor conception language?		
Definitely yes	65	60.1
Probably yes	33	30.8
Might or might not	6	5.6
Probably no	3	2.8
Definitely no	1	0.9

found out late', and 'It would be good to add a sibling. My children get a little confused as there is only one baby in the book the story refers to. My older [child] thinks it's all about his younger sister now because she is the ''baby".'

Discussion

This study is the first to evaluate the use of donor conception books to help parents tell their children of their conception. It clearly shows that using the DCN books helped parents and children find the words to discuss donor conception. Such books could be used globally to support a culture of openness and offer parents the confidence to share essential information with their offspring.

In this study, most heterosexual couples read the *Our Story* donor egg book and most single parents read the *Our Story* donor spermatozoa book. A study that looked at the transition to parenthood among solo mothers and mother and father parents concluded that family type and caregiver role did not influence the reported parental competence (Rubio et al., 2017).

The consensus with telling children early about donor conception is that they never remember a time when they did not know. This has been reflected in this study as the majority of parents started reading the book before the children were 2 years old. Early age of disclosure is recommended as best practice by the DCN and equally confirmed by others (Blake et al., 2010, 2014; Illios et al., 2017).

One of the main issues for parents in telling their children is finding the confidence and words to discuss this sensitive matter with their children. After reading the *Our Story* books the majority of parents felt more confident and felt that their children were more confident to discuss donor conception. The majority of parents felt that reading the books had given them more confidence in using donor conception language and they rated the books highly.

From the qualitative answers, most of the parents were positive about the books, although some parents expressed a dissatisfaction with the new version's use of the term 'seed'. The DCN decided to change from 'sperm' to 'seed' as many of the parents were reading the book to younger children and they felt that 'seed' was age appropriate. A study has shown that parents find it difficult to find appropriate language in referring to the donor and mentioning spermatozoa (Provoost et al., 2018).

The DCN's work in producing 44 different *Our Story* books has provided a useful resource for parents who wish to be open with their children. Performing this survey has

given useful information for the development of future books, especially the need for books aimed at different ages, especially older children, and families in which there were older siblings. Future research to evaluate new books will be required.

Limitations of the study

With surveys of this type, it is not possible to know how representative the sample is which could bias the results towards a more favourable feedback about the books. There was no comparison conducted between the responses of those with younger children or with older children, or between the different family types, as the numbers were too low. Although reading the book daily was related to a positive assessment of the books, this was not assessed in terms of length of time reading at this frequency.

Conclusions

Because most surveyed parents found that use of the DCN book *Our Story* had given them more confidence in using donor conception language, fertility clinics providing donor conception may find DCN books helpful in encouraging and supporting early disclosure. By informing parents about the availability and potential usefulness of DCN books, including the *Telling and Talking* titles that provide advice to parents, fertility clinics can assist parents in starting a dialogue with their donor-conceived children.

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