

Understanding parents' intention to disclose the donor conception to their child by application of the theory of planned behaviour

Claudia Lampic^{1,2,*}, Agneta Skoog Svanberg³, Kimmo Sorjonen⁴, and Gunilla Sydsjö⁵

¹Department of Women's and Children's Health, Karolinska Institutet, 171 77 Stockholm, Sweden ²Department of Public Health and Caring Sciences, Uppsala University, 751 22 Uppsala, Sweden ³Department of Women's and Children's Health, Uppsala University, 751 85 Uppsala, Sweden ⁴Department of Clinical Neuroscience, Karolinska Institutet, 171 77 Stockholm, Sweden ⁵Division of Obstetrics and Gynaecology, Department of Clinical and Experimental Medicine, Faculty of Health Sciences, Linköping University, 581 85 Linköping, Sweden

*Correspondence address. Department of Women's and Children's Health, Karolinska Institutet, Tomtebodavägen 18A, 171 77 Stockholm, Sweden. E-mail: claudia.lampic@ki.se

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STUDY QUESTION: Does the theory of planned behaviour (TPB) contribute to understanding parents' intention to share information about genetic origin with their donor-conceived child?

SUMMARY ANSWER: Parents' intention to start disclosure was associated with beliefs that disclosure would have desired consequences and a desire to act in accordance to societal norms.

WHAT IS KNOWN ALREADY: Despite a growing consensus on donor-conceived offspring's right to information about their genetic origin, disclosure to the child remains a challenge for many parents, particularly heterosexual couples. TPB has successfully been applied to many health-related contexts and may contribute to increase understanding of parents' decision-making about disclosing the genetic origin to their children.

STUDY DESIGN, SIZE, DURATION: A cross-sectional survey study of heterosexual couples with children aged 7–8 years following identity-release oocyte donation (OD, n = 83) or sperm donation (SD, n = 113).

PARTICIPANTS/MATERIALS, SETTING, METHODS: The study is part of the prospective longitudinal Swedish Study on Gamete Donation. Couples accepted for oocyte or sperm donation treatment at seven fertility clinics were recruited in 2005–2008 and requested to complete four postal surveys in the following 10 years. The present study sample includes heterosexual couples with donor-conceived children aged 7–8 years. Data were collected with the study-specific TPB Disclosure Questionnaire and analysed with path analysis.

MAIN RESULTS AND THE ROLE OF CHANCE: More than half of parents following OD or SD had already disclosed the donor conception to their child (OD 61%, SD 58%). Among parents who had not yet started the disclosure process, the belief that disclosure would have desired consequences ($P < 0.05$) and a desire to act in accordance to social norms favouring disclosure ($P < 0.01$) were positively associated with their intention to talk with their child about the donor conception during the upcoming year. In contrast, perceived confidence to talk with the child about his/her genetic origin was found to be negatively associated with the intention to start the disclosure process ($P < 0.05$). Type of treatment (OD/SD) and the existence or absence of a genetic link to the child were not directly associated with parents' disclosure intentions.

LIMITATIONS, REASONS FOR CAUTION: The study was performed with heterosexual couples within the context of the Swedish legislation on identity-release donation, which limits the generalizability to other populations. Also, attrition may have introduced selection bias to the study findings. Future studies using the TPB Disclosure Questionnaire (TPB-DQ) with larger samples are needed to validate this measure.

WIDER IMPLICATIONS OF THE FINDINGS: Application of the theory of planned behaviour highlighted the importance of attitudes and social norms for parents' intention to share information about the donor conception with their child. The present results add to the

complexity of disclosure of donor conception, and may contribute to promote open communication and support family life following donor conception.

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Key words: disclosure / donor conception / donor insemination / oocyte donation / theory of planned behaviour

Introduction

Despite the growing consensus on donor-conceived offspring's right to information about their genetic origin (Ethics Committee of the American Society for Reproductive Medicine, 2018), disclosure to the child remains a challenge for many parents, particularly heterosexual couples (Kirkman, 2003; Daniels et al., 2011; Tallandini et al., 2016). A broad spectrum of explorative research on disclosure has been conducted (van den Akker, 2006; Indekeu et al., 2013; Tallandini et al., 2016) and a systematic review identified a complex interplay of factors having an impact on parents' decision-making on disclosure (Indekeu et al., 2013). The need for a theoretical framework to advance knowledge in the field of disclosure of donor conception has been addressed (van den Akker, 2006; Indekeu et al., 2013). Theoretical models of potential relevance include the revelation risk model and the disclosure decision-making model, which have been used to identify factors that influence couples' disclosure of infertility (Steuber and Solomon, 2011), and the theory of planned behaviour (TPB) (Ajzen, 1991). These models all include factors concerning the perceived confidence in communicating private information and the risk of negative consequences. The TPB also includes a factor concerning the social pressure to perform a specific behaviour, which may be of particular relevance for parents' disclosure of donor conception. The TPB aims to explain and improve prediction of human behaviour and has been applied in many different health-related contexts (Ajzen, 2011, 1991). According to the TPB, the intention to perform a specific behaviour is the most proximal predictor of behaviour, and there are three conceptually distinct determinants of intentions: the individual's belief that the behaviour will have desired consequences (Attitudes), perceived social pressure to perform the behaviour (Subjective norms) and the extent to which the individual feels able to perform the behaviour (Perceived behavioural control). The TPB is believed to be relevant for application to the issue of parental disclosure as its components are reflected in previously reported reasons for (non-)disclosure. With regard to attitudes, parents have stated both desirable consequences of disclosure, such as an open and trustful family atmosphere, and undesirable consequences, such as disrupted relationship between the child and the non-genetic parent (Indekeu et al., 2013). Parents' perceptions of social pressure to disclose are reflected in previous research in terms of social contexts that are (non-)accepting of different family forms (Shehab et al., 2008). Regarding perceived behavioural control, previous studies have reported a range of parents' perceptions of control over disclosure and their ability to talk with offspring about the donor conception (Shehab et al., 2008; Isaksson et al., 2012, 2016). Among parents who want to disclose, uncertainty about how to talk with their child has been reported to hinder disclosure (Readings et al., 2011; Applegarth et al., 2016; Hershberger et al., 2019), which suggests a relation between parents' perceived confidence in this regard and their disclosure

behaviour. Other factors with potential influence on disclosure concern gender, infertility status and the importance placed on the biogenetic link between parent and child. A systematic review included previous results concerning type of donation, parent gender and genetic linkage but showed inconclusive results regarding their relation to parents' disclosure behaviour (Indekeu et al., 2013).

Offspring age at disclosure has been reported to vary considerably, from a very early age to adulthood (Blyth et al., 2012). The literature suggests that there is an advantage to disclose when children are young (Ethics Committee of the American Society for Reproductive Medicine, 2018), and findings of more positive family relationships and higher levels of well-being among adolescents who had been told about their genetic origins in preschool age indicate that disclosure to the child before the age of seven is preferable (Ilioi et al., 2017). By age seven children have reached an age mature enough to understand simple principles of conception (Williams and Smith, 2010), although their understanding of donor conception may be limited (Blake et al., 2010).

To conclude, disclosure of the donor conception to offspring remains a challenge for many parents and there is a need for a theoretical-based approach to advance knowledge in this field. Application of the TPB has the potential to increase understanding of the factors that influence parents' decision-making process regarding disclosure, which may contribute to the development of support to parents following donor conception. The aim of the present study was to apply the theory of planned behaviour to identify factors associated with parents' intentions of disclosing information about genetic origin to their 7-year-old child. It was hypothesized that more positive attitudes about disclosure, stronger social pressure favouring disclosure and greater perceived behavioural control are related to stronger intentions to disclose. In addition, we aimed to explore whether type of donation, parent gender and absence/presence of genetic link to the child were associated with disclosure intentions.

Materials and methods

Participants

The present study is part of the multicentre longitudinal Swedish Study on Gamete Donation (SSGD), conducted in the context of the Swedish legislation that gives donor-conceived offspring the right (at mature age) to obtain identifying information about the donor (Stoll, 2008). As part of the medical and psychosocial evaluation of potential recipients of donor gametes, they are encouraged by clinicians and counsellors to start sharing information about the donor conception with the child from an early age (The National Board of Health and Welfare, 2004). Within the SSGD, recipient couples of donor oocytes

or sperm were recruited during a 3-year period (2005–2008) at all seven university hospitals providing gamete donation treatment in Sweden. Eligibility criteria for the SSGD were being able to read Swedish and undergoing at least one round of treatment, and a total of 255 (81%) heterosexual recipients of donor sperm and 309 (72%) recipients of donor oocytes were included. The present study is based on the fourth wave of data collection of the SSGD. Eligible were heterosexual couples who had given birth to a child following treatment with donor oocytes or sperm, and they were approached in the year following their child's seventh birthday. Individual questionnaires were sent by post together with a letter explaining the study aims and voluntary nature of participation, as well as a prepaid envelope. Two reminders were sent to non-responders, and responders received gift vouchers (≈ 10 Euro). Couples who had conceived with gametes from a donor known to the couple were excluded from the present study. Of 147 eligible parents following oocyte donation (OD), 83 individuals completed the survey for the present study (56% response). Similarly, of 174 eligible parents following sperm donation (SD), 113 individuals chose to participate (65% response). Participants' mean age was 45 for males and somewhat lower for females (OD = 43; SD = 41). Full details of participant characteristics are presented in Table 1.

Measurements

The TPB Disclosure Questionnaire (TPB-DQ) was developed by three of the authors (C.L., G.S., A.S.S.) on the basis of the TPB (Ajzen, 1991), specific constructing guidelines for the TPB (Francis *et al.*, 2004), previous research in the field of donor conception, and clinical experience with families following donor conception. The TPB-DQ

comprises 31 items that measure parents' beliefs and intentions regarding talking with their child about his/her genetic origin during the upcoming year (see Fig. 1 for the TPB-DQ in full). The questionnaire includes indirect measurement of Attitudes (behavioural beliefs \times outcome evaluation) and Subjective norms (normative beliefs \times motivation to comply), direct measurement of Perceived behavioural control (control beliefs) and measurement of Behavioural Intention. Participants were requested to report on 7-point Likert scales to what extent they agreed on each statement or to what extent the expected outcome of the behaviour was perceived as desirable. The following parts were included in the TPB-DQ:

Attitudes

Behavioural beliefs (seven items) concern potential consequences of disclosure, including acting in accordance with personal values and specific outcomes (e.g. disruption of parent–child relationship). *Outcome evaluation* (seven items): For each behavioural belief, respondents assess a corresponding subjective judgement in terms of how desirable/undesirable the outcome is. Scores for each belief and corresponding evaluation are multiplied and form an indicator, with higher scores indicating a stronger belief that disclosure will lead to a desirable consequence.

Subjective norms

Normative beliefs (four items) concern perceived opinions about disclosure to offspring in society and the social network. *Motivation to comply* (four items): For each normative belief, respondents assess a corresponding subjective judgement of how important it is for them to act in accordance to these groups/persons. Scores for each belief and corresponding judgement are multiplied and form an indicator, with higher scores indicating a stronger desire to comply with perceived societal opinions of disclosure behaviour.

Perceived behavioural control

Control beliefs (six items) assess perceived behavioural control regarding disclosure to the child. Three items assess this on a general level, i.e. the extent to which the decision to disclose is perceived to be within one's control. Three items assess perceived behavioural control on a specific level, i.e. the extent to which disclosure is perceived as easy/difficult to perform. Higher scores indicate a stronger belief to be able to perform the specific behaviour.

Behavioural intention

Behavioural intention (three items) measures to what extent the respondent plans, wants and intends to talk with the child about his/her genetic origin during the upcoming year. Higher scores indicate a stronger intention to disclose.

In addition, participants were requested to report whether they already had started talking with their child about his/her conception with OD or SD. Five response options were provided, and for the purpose of this study, responses were dichotomized into 'disclosers' (Yes, I have started talking about it) and 'non-disclosers' (No, I intend to do it later on; No, I intend to do it if/when the child raises the question; No, I am uncertain/hesitant; No, I will not tell the child about the donor conception). Finally, socio-demographic data (sex, age, education, occupation and partner/marital status) was collected.

Table 1 Characteristics of participating parents following oocyte or sperm donation.

	Oocyte recipients		Sperm recipients	
	Women n = 43 (%)	Men n = 40 (%)	Women n = 61 (%)	Men n = 52 (%)
Age, mean (SD)	43 (3.5)	45 (4.6)	41 (3.8)	45 (5.2)
Education ^{a,b}				
Elementary	2 (5)	1 (3)	1 (2)	3 (6)
Upper secondary	13 (31)	18 (45)	23 (38)	31 (60)
University	27 (64)	21 (53)	37 (61)	18 (35)
Main occupation				
Full-time work	25 (58)	38 (95)	32 (52)	49 (94)
Part-time work	15 (35)	2 (5)	23 (38)	2 (4)
Unemployed	1 (2)	0 (0)	1 (2)	0 (0)
Studying	1 (2)	0 (0)	3 (5)	0 (0)
Other	1 (2)	0 (0)	2 (3)	1 (2)
Same partner ^c				
Yes	40 (93)	36 (90)	53 (87)	44 (85)
No	3 (7)	4 (10)	8 (13)	8 (15)

^aHighest accomplished level.

^bMissing data for one female oocyte-recipient.

^cLiving with the same partner at time of the study (child age 7) as at donation treatment (i.e. co-parent of the donor-conceived child).

How do you think about talking to your child about his/her genetic origin?

ATTITUDES

Behavioral beliefs (7-point scale from *Strongly disagree* to *Strongly agree*)

1. I am being honest to my child if I talk to him/her about his/her genetic origin.
2. I am respecting my child's rights by talking to him/her about his/her genetic origin.
3. My child will feel out of place if I talk to him/her about his/her genetic origin.
4. My relationship with my child will be disturbed if I talk to him/her about his/her genetic origin.
5. The relationship between my child and the other parent will be disturbed if I talk to him/her about his/her genetic origin.
6. Talking to my child about his/her genetic origin will lead to him/her talking to other people about this.
7. Talking to my child about his/her genetic origin will lead to him/her contacting the donor.

Outcome evaluations (7-point scale from *Extremely undesirable* to *Extremely desirable*)

8. To be honest to my child is
9. To respect the rights of my child is
10. That my child feels out of place is
11. To disturb the relationship between my child and myself is
12. To disturb the relationship between my child and the other parent is
13. That my child talks to other people about his/her genetic origin is
14. That my child contacts his/her donor is

SUBJECTIVE NORMS

Normative beliefs (7-point scale)

15. The message from society/media is that I (*shouldn't – should*) talk to my child about his/her genetic origin.
16. Most of the people that I feel are important to me think that I (*shouldn't – should*) talk to my child about his/her genetic origin.
17. My partner thinks that I (*shouldn't – should*) talk to my child about his/her genetic origin.
18. Other couples with donor-conceived children (*don't talk – talk*) to their children about their genetic origin.

Motivation to comply (7-point scale from *Strongly disagree* to *Strongly agree*)

19. To act according to the messages from society and the media is important to me.
20. To act according to what people that are important to me feel is right is important to me.
21. My partner's opinion of what I should do is important to me.
22. To act in the same manner as other parents with donor-conceived children is important to me.

PERCEIVED BEHAVIOURAL CONTROL (7-point scale from *Strongly disagree* to *Strongly agree*)

23. I am convinced that I would be able to talk to my child about his/her genetic origin if I wanted to.
24. The decision to talk to my child about his/her genetic origin is beyond my control.
25. If I talk to my child about his/her genetic origin or not is not entirely up to me.
26. I can't find the proper moment when to talk to my child about his/her genetic origin.
27. I don't know how to talk to my child about his/her genetic origin.
28. I feel insecure when I am about to talk to my child about his/her genetic origin.

BEHAVIORAL INTENTION (7-point scale from *Strongly disagree* to *Strongly agree*)

29. I plan to talk to my child about his/her genetic origin.
30. I want to talk to my child about his/her genetic origin during the coming twelve months.
31. I intend to talk to my child about his/her genetic origin during the coming twelve months.

Figure 1 Theory of Planned Behaviour Disclosure Questionnaire (TPB-DQ).

Data analysis

Path models with the TPB-factors Attitudes, Subjective norms and Perceived behavioural control as mediators and the TPB-factor Behavioural intention as outcome, were fitted to data using R.3.5.0 statistical software (R Core Team, 2018) and the lavaan package (Rosseel, 2012). A moderator variable (interaction association of type of donation and sex) was used to model the existence/absence of a genetic link of a parent to the child. We separately applied the models

in parents who already had started and in parents who had not started the disclosing process. The statistical approach was performed in two steps: First, a confirmatory factor analysis (CFA) was applied within the total sample (N = 196) to test the internal consistency of, and to detect and eliminate weak indicators within the TPB measurement. Factor loadings are correlations between the observed indicators and the latent factors and according to a rule of thumb, these loadings should be >0.5. However, due to theoretical considerations and a

small number of indicators, in the present study, we decided to retain indicators with loadings >0.3 . Various fit indexes can be used to assess the fit between CFA models and data, including the Comparative Fit Index (CFI), the Tucker-Lewis Index (TLI) and the Root Mean Square Error of Approximation (RMSEA). According to Hu and Bentler (1999), values >0.95 on CFI and TLI and values <0.06 on RMSEA indicate good fit between the model and data, respectively. As a second step in the analysis, the direct, mediated and total associations between type of donation and the moderator variable and intention to disclose were tested. This analytical approach is known as mediated moderation (Hayes, 2009).

Ethical approval

The Regional Ethical Review Board in Linköping, Sweden approved the study (M29/05/1-06; 2013/299-31).

Results

More than half of participants reported that they had started talking with their child about his/her conception with donor gametes, 61% ($n=50/82$) of oocyte recipients and 58% ($n=64/110$) of sperm recipients (missing data for four participants).

Descriptive statistics for the TPB-DQ indicators, separately for the four combinations of type of donation \times sex of respondent, as well as factor loadings revealed in a CFA, are presented in Table II. Due to their very low loadings (<0.2), four indicators (including six items) were deleted from further analyses, two belonged to the concept Attitudes and two belonged to the concept Perceived behavioural control (see Table II and Fig. 1 for the TPB-DQ in full). In the next step, a CFA with four factors was performed and results indicated mediocre model fit, $\chi^2 = 336.7$, $df=98$, CFI = 0.891, TLI = 0.778, RMSEA = 0.112. Due to theoretical considerations and acceptable homogeneity (Cronbach's alpha 0.72, 0.71, 0.79 and 0.75 for Attitudes, Subjective norms, Perceived behavioural control and Behavioural intention, respectively), a decision was made to retain the four factors in the analyses. Thus, the indicators of the factors Attitudes (five indicators), Subjective norms (four indicators), Perceived behavioural control (four indicators) and Behavioural intention (three indicators) were standardized and merged into four composite variables to be included in the path model.

The path model in Fig. 2 was fitted to data separately for those respondents who had started the disclosure process and those who had not. While adjusting for the other predictors, attitudes were positively associated with intention to disclose both for those who had started the disclosure process ($P < 0.01$) and those who had not ($P < 0.05$). This indicates that the more parents believed that disclosing the genetic origin to the child would have desired consequences, the more they intended to talk with their child about the donor conception during the upcoming year. The mean values of the indicators included in this factor, with a max value of 49, indicate overall strong beliefs that disclosure would support certain values (honesty, respect for child's rights) and not have negative consequences (Table II).

Among the group of parents who had already started the disclosure process, neither subjective norms nor perceived behavioural control were associated with their intention to continue the disclosure

process. In contrast, in the group of parents who had not started talking with their child about his/her genetic origin, subjective norms were positively ($P < 0.01$) and perceived behavioural control was negatively associated ($P < 0.05$) with the intention to disclose. This indicates that non-disclosing parents who reported a desire to act in accordance to perceived positive attitudes towards disclosure in society and their social network, to a larger extent intended to start disclosing in the coming year than parents who were less concerned with others' opinions of disclosure. The tested path model also indicates that, the more confident non-disclosing parents felt about their ability to talk with their child about his/her genetic origin, the less they were inclined to start sharing this information during the upcoming year.

Type of donation had no significant crude association with any of the TPB-factors (attitudes, subjective norms and perceived behavioural control) nor with intention to disclose, neither for those who had started the disclosure process nor for those who had not. However, when including sex and type of donation \times sex interaction into the model, a significant interaction association could be observed with subjective norms in both groups (disclosers and non-disclosers) ($P < 0.05$). While women expressed similar social pressure to disclose independently of type of donation, men expressed a higher degree of subjective norms (i.e. a stronger desire to act in accordance to perceived positive attitudes towards disclosure in society and their social network) in the case of sperm compared to oocyte donation (Fig. 3). Although the total association between type of donation \times sex interaction and the intention to disclose was non-significant ($d = -0.089$, $P = 0.810$ and $d = 0.586$, $P = 0.196$ among those who had and had not started the disclosure process, respectively), a significant indirect association via subjective norms, i.e. a case of mediated moderation, was revealed among those who had not started the disclosure process ($d = 0.377$, $P = 0.041$). This means that, among non-disclosing parents, a tendency for a stronger intention to disclose when there is a match between type of donation and sex (i.e. OD for women and SD for men) is to some degree accounted for by a similar difference in subjective norms. This, somewhat paradoxical, finding of a weaker indirect association being significant while a stronger total association is not, is due to a smaller standard error in the former case ($SE = 0.185$ and 0.453 , respectively). Further inspection of the low mean values of three indicators of the subjective norms factor for the whole sample (Table II) showed that these reflect moderately strong beliefs that disclosure is favoured by society and their social network, and relatively low motivation to act in accordance to these groups' opinions (data not shown).

Discussion

The present results revealed that all components of the TPB were significantly associated with parents' intentions to initiate or continue disclosure. For both parents who had started and parents who had not started the disclosure process, greater belief that disclosing the genetic origin to the child would have desired consequences was associated with greater intention to talk with their child about the donor conception during the upcoming year. The importance of beliefs regarding honesty about the child's genetic origin and respect for the child's rights reflect previous findings in the literature (Indekeu et al., 2013; Bracewell-Milnes et al., 2016).

Table II Mean (SD) and factor loadings for the items/indicators of the TPB-DQ separately for the four combinations of type of donation × sex of the respondent.

Scale/item	Oocyte donation		Sperm donation		Loading
	Women	Men	Women	Men	
N	43	40	61	52	
Attitudes ^a					
i1 × i8	45.55 (10.82)	45.54 (8.79)	45.72 (8.64)	44.80 (9.44)	0.515
i2 × i9	45.52 (9.85)	44.31 (8.16)	46.15 (7.02)	44.75 (8.41)	0.384
i3 ^c × i10 ^c	34.59 (13.06)	33.23 (12.08)	29.18 (11.76)	30.22 (13.03)	0.656
i4 ^c × i11 ^c	40.55 (11.27)	42.05 (9.96)	44.02 (9.98)	39.43 (11.63)	0.840
i5 ^c × i12 ^c	44.33 (8.65)	41.42 (10.85)	41.58 (12.00)	43.49 (7.83)	0.838
i6 × i13 ^d	21.62 (9.99)	18.87 (9.95)	20.75 (10.21)	20.08 (10.68)	0.102
i7 × i14 ^d	17.45 (9.31)	16.37 (8.78)	17.97 (9.61)	15.40 (6.96)	0.079
Subjective norms ^a					
i15 × i19	18.95 (12.77)	12.83 (10.60)	19.83 (14.58)	20.75 (11.85)	0.664
i16 × i20	21.21 (13.75)	12.65 (10.03)	19.05 (12.22)	23.45 (11.68)	0.799
i17 × i21	35.92 (12.84)	37.62 (9.88)	33.80 (14.85)	38.53 (10.45)	0.394
i18 × i22	14.28 (11.51)	9.47 (7.46)	9.87 (7.29)	16.77 (10.91)	0.682
Perceived behavioural control ^b					
i23	6.59 (1.12)	6.64 (0.67)	6.68 (0.82)	6.67 (0.74)	0.391
i24 ^{cd}	6.78 (0.69)	6.56 (1.19)	6.76 (0.90)	6.55 (1.27)	0.195
i25 ^d	4.88 (2.23)	4.59 (2.44)	4.22 (2.53)	4.67 (2.30)	-0.004
i26 ^c	5.95 (1.75)	5.39 (2.28)	5.00 (2.25)	5.28 (1.88)	0.686
i27 ^c	6.07 (1.74)	5.69 (1.85)	5.37 (2.18)	5.41 (1.83)	0.812
i28 ^c	5.83 (1.90)	5.32 (1.86)	5.07 (2.21)	5.18 (2.06)	0.914
Behavioral intention ^b					
i29	5.89 (2.18)	4.70 (2.30)	5.76 (2.17)	5.98 (1.80)	0.337
i30	5.08 (2.50)	4.92 (2.33)	5.28 (2.21)	5.24 (2.08)	0.988
i31	5.03 (2.51)	5.08 (2.28)	5.10 (2.21)	5.02 (2.11)	0.901

^aRange 1–49.^brange 1–7.^creversed item and^ddeleted from the path analysis.

TPB-DQ, Theory of Planned Behaviour Disclosure Questionnaire.

Among participants, ~40% reported that they had not yet started sharing information about the donor conception with their 7- to 8-year-old child. Among these parents, the greater confidence they had in their ability to talk with the child about his/her genetic origin, the less they were inclined to initiate sharing this information during the coming year. This is a somewhat surprising finding as previous research has shown that parents frequently report uncertainty about how to talk with their child as a major obstacle for disclosure (Readings et al., 2011; Applegarth et al., 2016; Hershberger et al., 2019). The present results indicate that some parents had made a deliberate decision to postpone disclosure until their child was older, which might be considered to be in contrast to the message from the fertility clinics that parents should start sharing information about the donor conception with the child from an early age (The National Board of Health and Welfare, 2004). However, the perception that the child is too young and needs to reach sufficient maturity to understand donor

conception is a commonly reported reason to postpone disclosure (Indeiku et al., 2013; Hershberger et al., 2019). This finding may also be related to parents' desire to protect the family from potential stigmatization by limiting information about the donor conception to a small circle, e.g. the core family, and their assessment of the child's ability to control this information (Readings et al., 2011; Isaksson et al., 2016). However, to postpone disclosure until certain conditions are fulfilled, referred to as the 'right-time' strategy (Mac Dougall et al., 2007), has been found to be risky as the envisioned optimal time-point for disclosure may never appear (Applegarth et al., 2016) and sharing this information may become more difficult the longer parents wait (Daniels et al., 2011). Longitudinal studies also indicate that parents' intentions to disclose are only borne out in practice to a limited degree (Readings et al., 2011; Hershberger et al., 2019). Finally, while the TPB-DQ assessed parents' intention to talk about the donor conception with their child during the upcoming year, this finding may

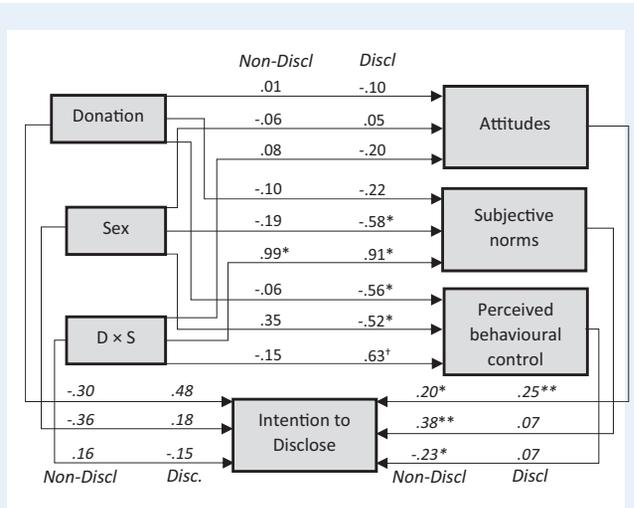


Figure 2. Path model of the associations between type of donation, parent sex, donation × sex interaction, TPB-factors Attitudes, Subjective norms, Perceived behavioural control and the TPB-factor Behavioural intention. Associations between type of donation (oocyte = 0, sperm = 1), parent sex (female = 0, male = 1), donation × sex interaction, TPB-factors (Attitudes, Subjective norms, Perceived behavioural control) and the TPB-factor Intention to disclose. Associations with type of donation, sex and their interaction (plain) correspond to Cohen’s *d* while associations with TPB-factors Attitudes, Subjective norms and Perceived behavioural control (italicized) correspond to standardized beta-weights. For each parameter, the leftmost value is for those who had not started the disclosure process (Non-Disc) and the rightmost value is for those who had (Disc). †*P* < 0.10, **P* < 0.05, ***P* < 0.01. TPB, theory of planned behaviour.

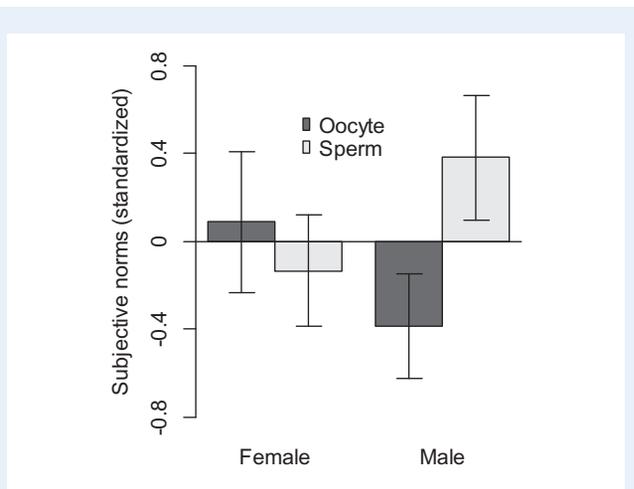


Figure 3. Mean degree of Subjective norms separately for the four combinations of type of donation × sex. The error bars indicate 95% CI.

also reflect the relation between perceived behavioural control and disclosure intentions of parents who are reluctant to ever disclose this information to their child. Overall, the mean values of indicators of the

perceived behavioural control factor indicate that parents in the present study had relatively high confidence in their ability to talk with their child about his/her genetic origin, which is a reassuring finding.

Moreover, the more non-disclosing parents considered opinions favouring disclosure in their environment, the more they intended to talk with their child about the donor conception in the upcoming year. This finding is in line with previous research from the US indicating that parents are influenced by perceived values in their community (Shehab *et al.*, 2008). In the Swedish context, all recipients of donor gametes are informed about offspring’s legal right to donor information and encouraged to share information about the donor conception from an early age (The National Board of Health and Welfare, 2004; Stoll, 2008). Reports of higher disclosure rates among parents who underwent treatment in the past two decades than during earlier periods may reflect a change in societal attitudes towards greater openness about donor conception, according to results from Sweden (Gottlieb *et al.*, 2000; Isaksson *et al.*, 2011, 2012) and Finland (Soderstrom-Anttila *et al.*, 2010; Sälevaara *et al.*, 2013).

Among those parents who already had started the disclosure process, neither subjective norms nor perceived behavioural control were significantly associated with the intention to talk with their child about the donor conception in the next 12 months. For this group, only beliefs about various consequences of talking with the child about his or her genetic origin (attitudes) were associated with their intention to continue the disclosure process. As previously described (Mac Dougall *et al.*, 2007; Blake *et al.*, 2010; Readings *et al.*, 2011; Isaksson *et al.*, 2016), disclosure to offspring generally does not occur at a single occasion but rather constitutes a continuous process, involving several layers of information.

The present findings indicate that subjective norms and perceived behavioural control may be influential primarily for the decision to initiate information-sharing about the child’s conception with donor gametes, and may have less influence on continued disclosure.

Parents’ intention to talk with their child about his or her genetic origin, whether they already had started the disclosure process or not, was not significantly related to whether parents had been treated with OD or SD. The absence of such an association could not be explained by possible differences in attitudes, subjective norms or perceived behavioural control among parents following OD or SD. This finding is in line with research showing similar attitudes and concerns about disclosure among heterosexual oocyte and sperm recipients (Golombok *et al.*, 2004; Mac Dougall *et al.*, 2007; Isaksson *et al.*, 2011, 2012). However, other results indicate that parents with 7-year-old children following OD and SD differ in disclosure intentions and behaviour (Readings *et al.*, 2011).

In addition, the existence or absence of a genetic link to the child was not directly associated with parents’ intention to talk with the child about the donor conception, neither among disclosers nor non-disclosers. This finding may reflect that (non-)disclosure most often is based on a joint decision made by both parents in a heterosexual couple (Nachtigall *et al.*, 1998; Shehab *et al.*, 2008; Daniels *et al.*, 2009). Among study participants, a vast majority were still married/cohabiting with the child’s other parent, which increases the likelihood that the couple had come to a joint agreement on when to start the disclosure process. Interestingly, parent sex and parent-child genetic linkage was found to be associated with subjective norms. While subjective norms did not differ between mothers following the two types

of donation, fathers following SD (who lacked a genetic link to the child) reported more social pressure to disclose compared to fathers in OD families. A tentative explanation of this finding is that men are more inclined to comply with societal opinions of disclosure when this involves revealing their own infertility compared to revealing their partner's lack of genetic linkage. Besides the need to validate these findings in other samples, qualitative studies may shed more light on how parents following donor conception reason around the role of societal and social network opinions for their own disclosure intentions. The present findings add to the complexity of disclosure of donor conception, involving both psychosocial and ethical concerns (Freeman, 2015). In the context of Sweden and other jurisdictions, donor-conceived offspring have the legal right to information about their genetic origin, based on the premise that this is in the best interest of the child. While technologies such as direct-to-consumer DNA testing pose new challenges to all individuals involved in gamete donation (Harper et al., 2016), the need to avoid anxiety-driven disclosure has been stressed (Zadeh, 2016). In view of the complex short- and long-term psychosocial consequences of using gamete donation, it has been suggested that psycho-educational approaches may be useful in order to increase parents' confidence in open communication within the family (Crawshaw and Daniels, 2019).

Methodological considerations

The present study has methodological strengths as well as weaknesses. The study is part of the longitudinal multicentre SSGD, which included consecutive recruitment of large samples of gamete recipient couples. One limitation of the present study is the risk of selection bias, namely that couples who favour non-disclosure opted out of the study initially or during the course of the longitudinal study, and indication of such attrition bias was reported for a previous wave of data collection of the SSGD (Isaksson et al., 2012). One strength is that we applied the validated TPB to disclosure of donor conception and developed the study-specific TPB-DQ based on guidelines for constructing a TPB-measure (Francis et al., 2004). However, it should be noted that the TPB has been criticized for investigating behaviour too much on a cognitive, rational level and not considering emotion as part of behaviour (Ajzen, 2011). In the context of donor conception, this may include fear of stigmatization (Indekeu et al., 2013) and unresolved grief related to infertility (Hahn and Craft-Rosenberg, 2002; Hershberger et al., 2019). Additional factors not addressed in the present study, such as cultural and relational aspects as well as the child's developmental stage and maturity, may also influence parents' disclosure intentions. While a CFA based on the TPB-factors Attitudes, Subjective norms, Perceived behavioural control and Behavioural intention indicated a mediocre model fit, due to theoretical considerations and acceptable reliability in the measurements we decided to retain these factors and let the structure of the TPB form the statistical analysis. A path analytical approach made it possible to add relevant associations (type of donation and parent sex) to the theoretical model. The relatively low response rates resulting in a small overall sample size, and the small sample size of non-disclosing parents are limitations of the study. With more participants, and thus higher power, it is possible that more of the analysed associations would have been significant. Finally, the cross-sectional design of the present study limits the ability to make causal inferences

regarding study variables. With these limitations in mind, the present study identified meaningful and potentially important associations between parents' attitudes, subjective norms and perceived behavioural control concerning disclosure, and their intention to disclose. Future studies using the TPB-DQ with larger samples are needed to validate this measure.

Conclusion

By applying the TPB, parents' intention to talk with their child about his/her genetic origin was found to be related to their attitudes, subjective norms and perceived behavioural control concerning disclosure. Parents' intention to start the disclosure process appears to be influenced by beliefs that disclosure would have desired consequences and a desire to act in accordance to perceived positive attitudes towards disclosure in society and their social network. The finding that parents who were confident in their ability to talk with their child about the donor conception were less inclined to start sharing this information during the upcoming year warrants further investigation. The present results suggest that interventions aimed at promoting disclosure should focus on perceived social norms and consequences of disclosure, and provide opportunities for parents to discuss and reflect about these issues. In addition, the risks of postponing disclosure should be discussed with parents. The present results add to the complexity of disclosure of donor conception, and may contribute to promote open communication and support family life following donor conception.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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Authors' roles

C.L., A.S.S. and G.S. conceived of the design and conducted the data collection. K.S. performed the statistical analyses. All authors contributed to the interpretation of results and revision of the manuscript and approved the final manuscript.

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Conflict of interest

The authors have no conflict of interest to declare.

References

- Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process* 1991;**50**:179–211.
- Ajzen I. The theory of planned behaviour: reactions and reflections. *Psychol Health* 2011;**26**:1113–1127.
- Applegarth LD, Kaufman NL, Josephs-Sohan M, Christos PJ, Rosenwaks Z. Parental disclosure to offspring created with oocyte donation: intentions versus reality. *Hum Reprod* 2016;**31**:1809–1815.
- Blake L, Casey P, Readings J, Jadva V, Golombok S. 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand. *Hum Reprod* 2010;**25**:2527–2534.
- Blyth E, Crawshaw M, Frith L, Jones C. Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence. *J Law Med* 2012;**19**:769–789.
- Bracewell-Milnes T, Saso S, Bora S, Ismail AM, Al-Memar M, Hamed AH, Abdalla H, Thum MY. Investigating psychosocial attitudes, motivations and experiences of oocyte donors, recipients and egg sharers: a systematic review. *Hum Reprod Update* 2016;**22**:450–465.
- Crawshaw M, Daniels K. Revisiting the use of 'counselling' as a means of preparing prospective parents to meet the emerging psychosocial needs of families that have used gamete donation. *Fam Relatsh Soc* 2019;**8**:395–409.
- Daniels K, Gillett W, Grace V. Parental information sharing with donor insemination conceived offspring: a follow-up study. *Hum Reprod* 2009;**24**:1099–1105.
- Daniels KR, Grace VM, Gillett WR. Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception. *Hum Reprod* 2011;**26**:2783–2790.
- Ethics Committee of the American Society for Reproductive Medicine. Informing offspring of their conception by gamete or embryo donation: an Ethics Committee opinion. *Fertil Steril* 2018;**109**:601–605.
- Francis JJ, Eccles MP, Johnston M, Walker A, Grimshaw J, Foy R, Kaner EFS, Smith L, Bonetti D. *Constructing Questionnaires Based on the Theory of Planned Behaviour*. Newcastle upon Tyne, UK: University of Newcastle, 2004.
- Freeman T. Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence. *Monash Bioeth Rev* 2015;**33**:45–63.
- Golombok S, Lycett E, MacCallum F, Jadva V, Murray C, Rust J, Abdalla H, Jenkins J, Margara R. Parenting infants conceived by gamete donation. *J Fam Psychol* 2004;**18**:443–452.
- Gottlieb C, Lalos O, Lindblad F. Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes. *Hum Reprod* 2000;**15**:2052–2056.
- Hahn SJ, Craft-Rosenberg M. The disclosure decisions of parents who conceive children using donor eggs. *J Obstet Gynecol Neonatal Nurs* 2002;**31**:283–293.
- Harper JC, Kennett D, Reisel D. The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. *Hum Reprod* 2016;**31**:1135–1140.
- Hayes AF. Beyond Baron and Kenny: statistical mediation analysis in the new Millennium. *Commun Monogr* 2009;**76**:408–420.
- Hershberger PE, Driessnack M, Kavanaugh K, Klock SC. Oocyte donation disclosure decisions: a longitudinal follow-up at middle childhood. *Hum Fertil* 2019;1–15. 10.1080/14647273.2019.1567945.
- Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equation Model* 1999;**6**:1–55.
- Ilioi E, Blake L, Jadva V, Roman G, Golombok S. The role of age of disclosure of biological origins in the psychological wellbeing of adolescents conceived by reproductive donation: a longitudinal study from age 1 to age 14. *J Child Psychol Psychiatr* 2017;**58**:315–324.
- Indekeu A, Dierickx K, Schotsmans P, Daniels KR, Rober P, D'Hooghe T. Factors contributing to parental decision-making in disclosing donor conception: a systematic review. *Hum Reprod Update* 2013;**19**:714–733.
- Isaksson S, Skoog-Svanberg A, Sydsjo G, Linell L, Lampic C. It takes two to tango: information-sharing with offspring among heterosexual parents following identity-release sperm donation. *Hum Reprod* 2016;**31**:125–132.
- Isaksson S, Skoog Svanberg A, Sydsjo G, Thurin-Kjellberg A, Karlstrom PO, Solensten NG, Lampic C. Two decades after legislation on identifiable donors in Sweden: are recipient couples ready to be open about using gamete donation? *Hum Reprod* 2011;**26**:853–860.
- Isaksson S, Sydsjo G, Skoog Svanberg A, Lampic C. Disclosure behaviour and intentions among 111 couples following treatment with oocytes or sperm from identity-release donors: follow-up at offspring age 1–4 years. *Hum Reprod* 2012;**27**:2998–3007.
- Kirkman M. Parents' contributions to the narrative identity of offspring of donor-assisted conception. *Soc Sci Med* 2003;**57**:2229–2242.
- Mac Dougall K, Becker G, Scheib JE, Nachtigall RD. Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes. *Fertil Steril* 2007;**87**:524–533.
- Nachtigall RD, Becker G, Quiroga SS, Tschann JM. The disclosure decision: concerns and issues of parents of children conceived through donor insemination. *Am J Obstet Gynecol* 1998;**178**:1165–1170.
- R Core Team. *R: A Language and Environment for Statistical Computing*. Vienna, Austria: R Foundation for Statistical Computing, 2018. <https://www.R-project.org/> (21 November 2018, date last accessed).
- Readings J, Blake L, Casey P, Jadva V, Golombok S. Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy. *Reprod Biomed Online* 2011;**22**:485–495.
- Rosseel Y. lavaan: an R package for Structural Equation Modeling. *J Stat Soft* 2012;**48**:1–36.
- Shehab D, Duff J, Pasch LA, Mac Dougall K, Scheib JE, Nachtigall RD. How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics. *Fertil Steril* 2008;**89**:179–187.
- Soderstrom-Anttila V, Salevaara M, Suikkari AM. Increasing openness in oocyte donation families regarding disclosure over 15 years. *Hum Reprod* 2010;**25**:2535–2542.
- Steuber K, Solomon D. Factors that predict married partners' disclosures about infertility to social network members. *J Appl Commun Res* 2011;**39**:250–270.
- Stoll J. *Swedish Donor Offspring and Their Legal Right to Information*. Uppsala: Department of Law, Uppsala University, 2008.
- Sälevaara M, Suikkari AM, Söderström-Anttila V. Attitudes and disclosure decisions of Finnish parents with children conceived using donor sperm. *Hum Reprod* 2013;**28**:2746–2754.

- Tallandini MA, Zanchettin L, Gronchi G, Morsan V. Parental disclosure of assisted reproductive technology (ART) conception to their children: a systematic and meta-analytic review. *Hum Reprod* 2016;**31**:1275–1287.
- The National Board of Health and Welfare. Barnets rätt att få kännedom om sitt ursprung efter en assisterad befruktning med donerade ägg eller spermier. 2004. https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/meddelandeblad/2004-1-1_200411.pdf (5 October 2020, date last accessed).
- van den Akker O. A review of family donor constructs: current research and future directions. *Hum Reprod Update* 2006;**12**:91–101.
- Williams JM, Smith LA. Concepts of kinship relations and inheritance in childhood and adolescence. *Br J Dev Psychol* 2010;**28**:523–546.
- Zadeh S. Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals? *Hum Reprod* 2016;**31**:2416–2420.