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RUNNING TITLE: Parent's experiences following PGT-M or SR

TITLE: The experiences of parents with a child born following pre-implantation genetic testing

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Attestation Statement:

- Data regarding any of the subjects in the study has not been previously published unless specified.
- Data will be made available to the editors of the journal for review or query upon request.

Data sharing statement: Data from this study cannot be shared to protect the identity of participants.

Capsule: The findings show that overall, families who have used PGT have positive experiences of the treatment after the birth of the child.

Research Article

Objective: Little research has explored family experiences following PGT-M or PGT-SR, particularly regarding how parents discuss the condition with their children. The objective of this study was to understand whether parents tell their child about PGT-M or PGT-SR and their reflections on the advantages and disadvantages of the treatment.

Study Design: 47 parents with a child born following PGT-M or PGT-SR completed a survey between December 2019 to May 2020. Parents were asked open ended questions about 1) telling or not telling their child about PGT, 2) how their children understood and reacted to being conceived using PGT, 3) whether parents had any worries about their use of PGT and 4) parents' general reflections on the advantages and disadvantages of using PGT. The sample was drawn from a previous study examining the obstetric and neonatal outcomes for children born following PGT¹. Sample response rate was 47.19%. Children were aged 4-18 years (Median = 9.9, 25th/75th percentile = 8.5/12.50). Data from the open-ended questions were analysed using qualitative content analysis and frequency counts and percentages were computed. Illustrative Quotations are provided in the tables (see methods in supplementary material). The Danish Data Protection Agency (File number 1-16-02-298-15) approved the data collection. Questionnaire studies do not require approval from ethical committees or institutional review boards in Denmark.

Results: Reasons for telling or not telling the child about their use of PGT-M or PGT-SR are shown in Table 1. Most parents told their child to be truthful and they saw no reason not to tell. For parents who had not yet told their child, this was predominantly because the child was too young. Two respondents anticipated disclosure would be difficult. 23 parents gave

responses for how their child responded to finding out about the use of PGT-M or PGT-SR.

The most common reaction was indifference, followed by feeling excited, special, or curious.

Most parents reported their child to feel indifferent about it at the time of the study.

For the 10 parents who said they worried about the child, the reasons for their worry included whether the treatment will cause other medical problems given that it is a relatively new treatment method (n = 5), whether their child will have trouble conceiving in the future (2), whether the child will be able to access PGT if they need to (2) and feeling unsure of their decision to use it (1). All parents stated that they would recommend the treatment method to others. A total of 38 parents (80.9%) explained why they would recommend PGT to others, with the most common reason being that it enabled parents to have a genetically related child. In terms of advantages of PGT, the main advantage was the ability to have a healthy child (See Table 2). Seven of the participants mentioned that PGT allowed them to have children where they otherwise may have chosen not to. Other advantages included avoiding miscarriage and being able to enjoy the pregnancy knowing that the baby was healthy. The main disadvantage involved the adverse effect of the treatment, specifically in response to the hormonal treatment received, and it being a lengthy and invasive process which also took a toll on mental health (See Table 2).

Conclusion: To our knowledge, this is the first study to examine the experiences of parents raising a child born following PGT. The findings from the study are reassuring and show that families who have used PGT have positive experiences of the treatment, and children are reported to feel either neutral or positive about having been born following the treatment.

References

1. Bay B, Ingerslev HJ, Lemmen JG, Degn B, Rasmussen IA, Kesmodel US. Preimplantation genetic diagnosis: a national multicenter obstetric and neonatal follow-up study. *Fertil Steril* 2016;**106**:1363-1369.e1. Elsevier Inc.

Table 1: Reasons for telling the child about PGT-M or PGT-SR, how parents explained PGT-M or PGT-SR to their child and child's feelings at the time and currently.

	n	%	Illustrative Quote
Reason for telling the child			
To be truthful and open	11	42.3	<i>It is the truth. We figure that way he won't look at it in the wrong way</i>
No reason not to/no shame about it	10	38.5	<i>...there is nothing shameful about it.</i>
Because child will/may need help or to use PGT when having their own children	9	34.6	<i>One is carrying a disabled chromosome [chromosome that causes disability] and must go through the same if they are to have children.</i>
So child understands that they do not carry their parents' disease	8	30.8	<i>It is important that my child knows the truth about himself and that he doesn't have to fear inheriting my illness.</i>
Child is interested or has asked questions	7	26.9	<i>it was only natural to tell her when she herself asked "how she was born"</i>
So child understands they may carry their parents' disease	7	26.9	<i>One of them is a carrier and they need to know that so that one day we can find out who is a carrier.</i>
Part of child's story	6	23.1	<i>Both because it is also her story, and then you never know if it is information that can be used for something later.</i>
Child has right to know	5	19.2	<i>I think she has a right to know. It's no secret.</i>
To avoid taboo	3	11.5	<i>It should not be a taboo and seem wrong.</i>
The rest of the family already know	3	11.5	<i>To be honest, since everyone in the family/friends knows.</i>
Other	5	15.3	
How did you explain PGT to your child?			
Parents needed help so child wouldn't have the condition their family member has	11	42.3	<i>... the hospital helped so he wouldn't get the disease mom has and grandma had.</i>
Parents needed help to have a child	5	19.2	<i>that some couples need help to have children</i>
Doctors chose the healthy/"best" gametes	5	19.2	<i>As a chromosome error and therefore the doctors must find the best sperm and the best egg - namely to make the best child (he was 5 years)</i>

IVF process described: egg & sperm selection and mixing	5	19.2	<i>That they took eggs out of me. Put them in a bowl and mixed in dad's sperm... And the eggs that could be used, we kept, and the rest we put in the garbage bin.</i>
PGT details not yet explained	4	15.4	<i>We haven't told specifically about PGD - but we told that we had difficulty having children and that's why we got help at the hospital</i>
Other	8	30.8	

How did your child react to finding out about their birth using PGT?

Neutral/Indifferent	9	34.6	<i>They (she) are indifferent. To them (her) it's natural.</i>
Felt special and/or excited	5	19.2	<i>Think he just found it a little exciting and felt special</i>
Curious, interested	5	19.2	<i>No big feelings about it - informative and interested/curious.</i>
Glad not to inherit condition	3	11.5	<i>Glad not to have to fear illness and disability</i>
Other	7	26.9	

How does your child currently feel about their birth?

Neutral/indifferent	14	53.8	<i>Feels completely normal, indifferent about it.</i>
Doesn't think about it	7	26.8	<i>They don't think about that</i>
Other	6	23.1	

Note: Percentages calculated of those who had told the child (N = 26)

Table 2 Recommending PGT-M or SR to others and the advantages and disadvantages of having a child following PGT-M or SR

	n	%	Illustrative Quote
Reasons for recommending PGT to others			
Enabled genetically related child without disease	12	25.5	<i>Amazing that you can get help to have the children you want, despite congenital chromosomal abnormality</i>
Helps eradicate diseases	6	28.2	<i>I don't think you should impose avoidable diseases on children if you can avoid it, and you can with PGD</i>
To have a healthy child	6	28.2	<i>if they have fertility problems and it is the only solution to have their own biological child</i>
Gives the child a normal life	4	8.5	<i>It makes sense to give your children the best conditions for a good and "normal" life.</i>
Helps avoid miscarriages/abortions	3	6.4	<i>I have also tried to conceive without PGD, which led to a placental biopsy, which subsequently induced a miscarriage. It was not a good experience.</i>
Felt safe/professional	3	6.4	<i>very professional treatment we went through at [Hospital].</i>
A challenge, but worth it	3	6.4	<i>The inconveniences have been small compared to creating healthy genetics</i>
Other	8	17.1	
Advantages of using PGT			
Can have a healthy child free from genetic condition	19	40.4	<i>that you are sure to have a fine and healthy child</i>
Can end generations of disease	12	25.5	<i>We avoided a hereditary disease in the rest of our family - which has afflicted the family for generations!</i>
May not have had a child otherwise	7	14.9	<i>We have healthy children - twins. Otherwise, we wouldn't have had children.</i>
Avoid miscarriage	5	10.6	<i>That we were spared more unsuccessful pregnancies.</i>
Able to enjoy pregnancy more	5	10.6	<i>It gave a greater peace and joyful pregnancy.</i>
Other	3	6.4	
Disadvantages of PGT			

Adverse effects of treatment process	18	38.3	<i>I got some adverse effects from hormonal treatment.</i>
Long process	11	23.4	<i>It takes time and effort to carry through PGD treatment</i>
A psychologically difficult process	7	14.9	<i>All the attempts were hard both physically and mentally. A long period with many "ups and downs"</i>
Disadvantages were outweighed by the positive outcome	6	12.8	<i>Hard with the hormones, but worth it.</i>
Uncertainty & worry during treatment	5	10.6	<i>Tough process. Years of uncertainty about success. Adverse effects of medication - pain during oocyte pick-up and bloating/sickness after the pick-up. Keeping family/friends updated on process when you are unsure yourself.</i>
Long wait time for treatment	4	8.5	<i>The waiting time between treatments. And especially up to the start of the process. OHSS with fluid in the lungs and hospitalisation after treatment in 2017.</i>
Felt like an unnatural way to conceive	4	8.5	<i>The process itself was a bit alienating, and it's an unnatural way to have children. But that doesn't matter when you're sitting with the new-born, healthy baby.</i>
Inconvenience involved in accessing treatment	3	6.4	<i>long and extensive treatment many hospital visits. Overstimulation.</i>
Other	6	12.8	

Supplementary material: Methods

Materials and Methods

The sample for this study was drawn from a previous study examining the obstetric and neonatal outcomes for children born following PGT-M and PGT-SR ¹. The original sample consisted of all children born in Denmark from January 1, 1999 to December 21, 2013 (see Bay et al., 2016, for further recruitment details). The sample for the present study comprised of 47 parents with a child born following PGT. All children ranged in age from 6-18 years (Median = 9.9, 25th/75th percentile = 8.5/12.5 see Table 1 for participant characteristics).

The data for the study were collected by survey between December 2019 to May 2020. The survey formed part of a larger study examining the socio-emotional development of the children born following PGT in Denmark. The present paper reports on data from the survey that was designed to assess the experiences of parents who had used PGT-M or PGT-SR. This section included multiple-choice questions alongside free text boxes to explore parent experiences of 1) telling or not telling their child about PGT, 2) how their children understood and reacted to being conceived using PGT, 3) whether parents had any worries about their use of PGT and 4) parents' general reflections on the advantages and disadvantages of using PGT. The questionnaire was developed with the input of professionals working in the field of PGT and parents who had used PGT. The study was piloted to ensure the questions were clear and relevant and to assess feasibility and functionality. The questionnaire used the term PGD rather than PGT to reflect the terminology used by patients.

Whilst some parents reported on more than one child, only data for one child (selected at random) per family were included in the analysis. One case was excluded due to insufficient responses to the questions. Most of the questionnaires were completed on paper (80.9%, 38). The Danish Data Protection Agency (File number 1-16-02-298-15) approved the data collection. Questionnaire studies do not require approval from ethical committees or institutional review boards in Denmark.

Analysis

Free text responses to open ended questions about family experiences of PGT were translated into English by professional translators. For validation, the text was then back translated to Danish to ensure no loss of meaning. Any sentences that were not grammatically correct, or that presented problems with translation, were discussed with the authors. To understand how parents felt about talking with their child and others about having used PGT treatment, and to explore their general reflections on the process, this qualitative data were analysed according to the principles of qualitative content analysis²,³. The open text responses were carefully read by the second author (KS) and text-driven categories were produced to capture the content of the responses. These were then checked by a second coder (VJ) to ensure the categories accurately reflected the content of the responses. Frequency counts and percentages were then calculated and are presented alongside illustrative quotations.

Table I: Sample characteristics

	PGT N = 47	
	N	%
Child sex		
Male	22	46.8
Female	25	53.2
Questionnaire age category (years)		
6-10	24	51.1
11-18	23	48.9
Child age (years)	Median 9.9	25th/75th percentile 8.5/12.5
Maternal age at birth (years)	Mean 32.2	SD 3.6
Maternal parity	N	%
Nulliparous	28	59.6
Multiparous	19	40.4
Indication for PGT		
<u>PGT-M</u>	24	52.2
Autosomal recessive inheritance	4	8.7
Autosomal dominant inheritance	16	34.8
X-linked disease	4	8.7
<u>PGT-SR</u>		
Chromosomal translocations/inversions	22	47.8

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