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The experiences of parents with a child born after preimplantation genetic testing



OBJECTIVE

Little research has explored family experiences after preimplantation genetic testing (PGT) for monogenic disorders (PGT-M) or PGT for structural rearrangements (PGT-SR), particularly regarding how parents discuss the condition with their children. The objective of this study was to understand whether parents tell their children about PGT-M or PGT-SR and their reflections on the advantages and disadvantages of the treatment.

STUDY DESIGN

A total of 47 parents with a child born after PGT-M or PGT-SR completed a survey between December 2019 and May 2020. Parents were asked open-ended questions about telling or not telling their children about PGT, how their children understood and reacted to being conceived using PGT, whether parents had any worries about their use of PGT, and 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 of children born after PGT (1). The 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 analyzed using qualitative content analysis and frequency counts and percentages were computed. Illustrative Quotations are provided in the tables (see methods in [Supplementary Material](#), available online). 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 children to be truthful, and they saw no reason not to do so. For parents who had not yet told their child, this was predominantly because the child was too young. Two respondents anticipated that disclosure would be difficult. A total of 23 parents gave responses for how their children 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 told their child to be truthful 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 ($n = 2$), whether the child will be able to access PGT when they need to ($n = 2$) and feeling unsure of their decision to use it ($n = 1$). All parents stated that they would recommend the treatment method to others. A total of 38 (80.9%) parents 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 the advantages of PGT, the main advantage was the ability to have a healthy child ([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 infant was healthy. The main disadvantage involved the adverse effect of the treatment, specifically in response to the hormonal treatment received, and it is a lengthy and invasive process that also took a toll on mental health ([Table 2](#)).

CONCLUSIONS

To our knowledge, this is the first study to examine the experiences of parents raising a child born after 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 after the treatment.

CRedit Authorship Contribution Statement

Vasanti Jadva: Writing – review & editing, Writing – original draft, Methodology, Investigation, Conceptualization. **Kate Shaw:** Writing – review & editing, Methodology, Formal analysis. **Bjørn Bay:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Michelle Poulsen:** Writing – review & editing, Formal analysis, Data curation. **Hans Jakob Ingerslev:** Writing – review & editing, Data curation. **Morten Rønn Petersen:** Writing – review & editing, Data curation. **Jens Fedder:** Writing – review & editing, Data curation. **Ulrik Schiøler Kesmodel:** Writing – review & editing, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

Declaration of Interests

V.J. has nothing to disclose. K.S. has nothing to disclose. B.B. has nothing to disclose. M.P. has nothing to disclose. H.J.I. has nothing to disclose. M.R.P. has nothing to disclose. J.F. has nothing to disclose. U.S.K. has received funding from Gedeon Richter Nordic, IBSA, and Merck for studies outside this work; honoraria for teaching from Merck and Thillotts Pharma AB; and travel support and conference expenses covered by Merck.

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 the child's feelings at the time and currently.

	n	%	Illustrative quote
Reason for telling the child			
To be truthful and open	11	42.3	It is the truth. We figure that way he will not look at it in the wrong way
No reason not to/no shame about it	10	38.5	...there is nothing shameful about it.
Because the child will/may need help or to use PGT when having their own children	9	34.6	One is carrying a disabled chromosome (chromosome that causes disability) and must go through the same when they are to have children.
So, the child understands that they do not carry their parents' disease	8	30.8	It is important that my child knows the truth about himself and that he does not have to fear inheriting my illness.
The child is interested or has asked questions	7	26.9	it was only natural to tell her when she herself asked "how she was born"
So, the child understands they may carry their parents' disease	7	26.9	One of them is a carrier and they need to know that so that one day we can find out who is a carrier.
Part of the child's story	6	23.1	Both because it is also her story, and then you never know if it is information that can be used for something later.
The child has the right to know	5	19.2	I think she has a right to know. It is no secret.
To avoid taboo	3	11.5	It should not be a taboo and seem wrong.
The rest of the family already know	3	11.5	To be honest, since everyone in the family/friends knows.
Other	5	15.3	
How did you explain PGT to your child?			
Parents needed help so the child would not have the condition their family member has	11	42.3	... the hospital helped so he would not get the disease mom and grandma had.
Parents needed help to have a child	5	19.2	that some couples need help to have children
Doctors chose the healthy/"best" gametes	5	19.2	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 old)
IVF process described: egg and sperm selection and mixing	5	19.2	That they took eggs out of me. Put them in a bowl and mix in Dad's sperm... And the eggs that could be used, we kept, and the rest we put in the garbage bin.
PGT details not yet explained	4	15.4	We have not told specifically about PGD - but we told that we had difficulty having children and that's why we got help at the hospital
Other	8	30.8	
How did your child react to finding out about their birth using PGT?			
Neutral/Indifferent	9	34.6	They (she) are indifferent. To them (her) it is natural.
Felt special and/or excited	5	19.2	Think he just found it a little exciting and felt special
Curious, interested	5	19.2	No big feelings about it - informative and interested/curious.
Glad not to inherit the condition	3	11.5	Glad not to have to fear illness and disability.
Other	7	26.9	
How does your child currently feel about their birth?			
Neutral/indifferent	14	53.8	Feels completely normal and indifferent about it.
Do not think about it	7	26.8	They do not think about that.
Other	6	23.1	

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

IVF = in vitro fertilization; PGT = preimplantation genetic testing; PGT-M = preimplantation genetic testing for monogenic disorders; PGT-SR = preimplantation genetic testing for structural rearrangements.

Jadva. Parent's experiences after PGT-M or SR. Fertil Steril 2024.

TABLE 2

Recommending PGT-M or SR to others and the advantages and disadvantages of having a child after PGT-M or SR.

	n	%	Illustrative quote
Reasons for recommending PGT to others			
Enabled genetically related children without disease	12	25.5	It is amazing that you can get help to have the children you want despite congenital chromosomal abnormalities.
Helps eradicate diseases	6	28.2	I do not think you should impose avoidable diseases on children when you can avoid them, and you can with PGD.
To have a healthy child	6	28.2	When they have fertility problems, the only solution is to have their own biological child.
Gives the child a normal life	4	8.5	It makes sense to give your children the best conditions for a good and "normal" life.
Helps avoid miscarriages/abortions	3	6.4	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.
Felt safe/professional	3	6.4	Very professional treatment we went through at (the Hospital).
A challenge, but worth it	3	6.4	The inconveniences have been small compared with creating healthy genetics.
Other	8	17.1	
Advantages of using PGT			
Can have a healthy child free from a genetic condition	19	40.4	You are sure to have a fine and healthy child.
Can end generations of disease	12	25.5	We avoided a hereditary disease in the rest of our family, which has afflicted the family for generations!
May not have had a child otherwise	7	14.9	We have healthy children—twins. Otherwise, we would not have had children.
Avoid miscarriage	5	10.6	We were spared more unsuccessful pregnancies.
Able to enjoy pregnancy more	5	10.6	It gave a greater peace and a joyful pregnancy.
Other	3	6.4	
Disadvantages of PGT			
Adverse effects of the treatment process	18	38.3	I got some adverse effects from hormonal treatment.
Long process	11	23.4	It takes time and effort to carry through PGD treatment.
A psychologically difficult process	7	14.9	All the attempts were hard, both physically and mentally. A long period with many "ups and downs."
The disadvantages were outweighed by the positive outcome	6	12.8	Hard with the hormones, but worth it.
Uncertainty and worry during treatment	5	10.6	Tough process. Years of uncertainty about success. Adverse effects of medication include pain during oocyte pick-up, bloating, and sickness after the pick-up. Keeping family and friends updated on the process when you are unsure of yourself.
Long wait time for treatment	4	8.5	The waiting time between treatments and especially up to the start of the process. OHSS with fluid in the lungs and hospitalization after treatment in 2017.
Felt like an unnatural way to conceive	4	8.5	The process itself was a bit alienating, and it is an unnatural way to have children. But that does not matter when you are sitting with a newborn, healthy infant.
Inconvenience involved in accessing treatment	3	6.4	Long and extensive treatment and many hospital visits. Overstimulation.
Other	6	12.8	

Note: OHSS = ovarian hyperstimulation syndrome; PGD = preimplantation genetic diagnosis; PGT = preimplantation genetic testing; PGT-M = preimplantation genetic testing for monogenic disorders; PGT-SR = preimplantation genetic testing for structural rearrangements.

Jadva. Parent's experiences after PGT-M or SR. *Fertil Steril* 2024.

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REFERENCE

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;106:1363–9.e1.