Parents of Children with Sickle Cell Disease Are Interested in Preimplantation Genetic Testing

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Objective To evaluate awareness of and attitudes toward preimplantation genetic testing (PGT) for sickle cell disease (SCD) among parents of children with SCD.

Study design Parents of children with SCD were given an educational handbook on PGT before a routine SCD clinic visit. After their clinic visit, parents were asked to complete an anonymous survey.

Results Of 83 patents approached, 67 (81%) completed the survey. Only 16 of the 67 parents (24%) were previously aware of PGT for SCD. After our clinic-based education, 65 of the 67 parents (97%) indicated that it was important or very important for parents of children with SCD to know about PGT. Among parents interested in having more children, 29 of 32 (91%) would personally consider using PGT if covered by insurance.

Conclusions Parents of children with SCD are generally not aware of PGT. When educated in clinic, parents viewed information on PGT as valuable. Pediatricians and other health care professionals should inform parents of children with SCD about this reproductive option. *(J Pediatr 2020;223:178-82)*.

Although current supportive care has greatly decreased childhood mortality from sickle cell disease (SCD),[1–4] individuals with SCD experience many problems secondary to sickle-related complications and life expectancy is lower in adults with SCD compared with adults without SCD.[5–8] Although active clinical trials of gene therapy for SCD are promising, the only well-proven cure for SCD is hematopoietic stem cell transplantation (HSCT). HSCT for SCD with an HLA-identical sibling donor has a >90% event-free survival, but is limited to patients who have a full sibling who is healthy and HLA identical.[9]

Hemoglobinopathy trait screening of adolescents or young adults before childbearing could theoretically help to inform individuals' reproductive choices and decrease the incidence of SCD. One such program in Jamaica, however, failed to decrease the number of babies born with SCD.[10] In the US, all newborns are already screened for sickle cell trait, but this information may not be consistently passed on to families, and there are no guidelines for counseling by pediatricians.[11,12] Parents of children with SCD must decide if they want to have another child who could also have SCD. To further complicate this decision, having another child could potentially help to cure their existing child with SCD if the new child is unaffected and HLA identical.

Prenatal testing early in pregnancy is problematic because it is invasive, carries a risk of complicating the pregnancy, is time sensitive, is ethically unacceptable to many, and cannot practically be used to test for both SCD and HLA.[13] Another option is preimplantation genetic testing (PGT). PGT involves the use of in vitro fertilization (IVF) to test embryos before transfer into the uterus. Although PGT does not involve abortion, it raises its own ethical issues, particularly for individuals who regard embryos as living persons.[14,15] PGT for SCD has been available for more than 20 years, but few parents of children with SCD use this technology.[16]

We previously conducted a pilot study involving 19 parents of children with SCD who attended a SCD family education symposium.[17] Most parents in this group had not previously heard of PGT, suggesting that at least part of the low uptake of this technology for SCD may be owing to providers' failure to educate parents. All parents in this pilot study indicated that it was important for parents of children with SCD to know about PGT, with most specifying that this education should occur during infant SCD clinic visits. Given these results, we sought to develop educational material on PGT that could be used in the SCD clinic setting. With this education, we aimed to describe views on PGT from a larger, more general cohort of parents of children with SCD.

Methods

Based on feedback from a multidisciplinary team (hematology, reproductive endocrinology and infertility, social work, and psychology) and parents of a child with SCD who underwent PGT, a 5-page educational handbook was created on PGT for SCD (**Appendix**; available at www.jpeds.com). This booklet was

HSCT	Hematopoietic stem cell transplantation
IVF	In vitro fertilization
PGT	Preimplantation genetic testing
SCD	Sickle cell disease

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reviewed and critically edited by an expert in health education. The booklet covers the following topics: sickle cell genetics, what is PGT, IVF and PGT steps, PGT risks and benefits, and is PGT for my family. During certain hematology clinic days in which multiple providers were seeing patients with SCD, all parents of children with SCD were approached in the waiting room by a member of the study team and given this PGT educational handbook. Parents were encouraged to read the handbook and ask their provider questions related to its content during their clinic visit. Although this study was not limited to parents attending an infant SCD clinic, based on the results from our initial study, it was intentionally administered on days that included our program's infant SCD clinic.[18] Nonbiological and non-English-speaking parents were excluded. Patients being seen for a sick visit or for their initial hematology appointment were also excluded.

After the patients' clinic visit, a member of the study team asked parents to complete a 24-question, anonymous survey on a computer. If 2 parents were present, each parent was asked to complete the survey independently. During the study, 2 additional multiple choice questions were added to evaluate parents' understanding of PGT before the questions concerning their views on PGT. After answering each of these 2 knowledge questions, the survey automatically generated a message if the response was correct or incorrect with an explanation (**Table I**; available at www.jpeds.com). This study was approved by the Children's National Institutional Review Board and a waiver of consent was granted because no personal health information was collected. All demographic and child SCD data were from parent report.

Study data were collected and managed using REDCap hosted at Children's National Hospital.[19,20] Categorical data were analyzed with the χ^2 test. Statistical calculations were performed with SAS University Edition (SAS Institute Inc, Cary, North Carolina).

Results

A total of 83 biological parents of children with SCD were approached and 67 parents (81%) completed the questionnaire. Regarding the 16 nonparticipants, 8 expressed that they did not have time to complete the questionnaire, 3 declined to participate because they indicated that they did not care about the topic or it upset them, 2 did not participate owing to technical problems with administering the computer survey, and 3 did not participate for other or unknown reasons. **Table II** summarizes the parent participant demographics. Three parents had SCD themselves.

Eighty-nine percent of parents had only 1 child with SCD; and the median age of their oldest child with SCD was 3 years (IQR, 1-11 years). By parent report, their child's genotype was 71% HbSS, 18% Hb SC, 3% S beta zero thalassemia, 2% S beta plus thalassemia, and 6% unknown or other; 76% of parents reported that their child had been hospitalized because of their SCD, 47% reported that their child was on hydroxyurea, and 8% indicated that their child was on chronic transfusion therapy.

Understanding of PGT after Brief Education in Clinic

Fifty-seven parents were given the 2 questions to check their understanding of PGT (**Table I**). Forty-one parents (72%) answered the first question correctly, selecting that "PGT involves creating embryos in the laboratory and testing them for sickle cell disease." For the second question, 23 parents (40%) answered correctly, choosing the statement "PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease," and 27 parents (47%) selected the incorrect statement "PGT is strongly recommended for all couples who have a chance of having a child with sickle cell disease." Twenty parents (35%) answered both of these questions correctly.

Awareness of PGT

Among the entire group of 67 parents who completed the questionnaire, 53 (79%) indicated that they had previously heard of HSCT for SCD before their visit, but only 16 (24%) answered that they had heard of PGT for SCD ($P < .0001$). Three parents (4%) indicated that they had actually met with a fertility doctor about PGT, with 2 of these parents having had or currently undergoing PGT for SCD.

Table II. Demographics of parents (n = 67)

Characteristics	
Sex	
Mother	52 (78)
Father	15 (22)
Age (y)	35 (30-42)
Race	
Black or African American	60 (90)
Hispanic or Latino	5 (7)
Other	2 (3)
Place of birth	
US	34 (51)
Outside of the US	33 (49)
Highest education level	
Some high school	3 (4)
High school/GED diploma	26 (39)
College diploma	20 (30)
College and graduate school diploma	18 (27)
Religion	
Catholic	16 (24)
Other Christian	36 (54)
Muslim	6 (9)
None	9 (13)
Total household income	
<$25 000	13 (19)
$25 000-34 999	10 (15)
$35 000-49 999	10 (15)
$50 000-74 999	12 (18)
$75 000-99 999	3 (4)
$100 000-149 999	3 (4)
≥$150 000	10 (15)
No answer	6 (9)
Total No. of biological children	2 (1-3)
Total No. of biological children with SCD	1 (1-1)

GED, General Education Development.
Values are number (%) or median (IQR).

Views on PGT for SCD

Sixty-five parents thought educating parents with SCD about PGT was important or very important, which represents 78% of all approached parents and 97% of parents who completed the questionnaire (Table III). Forty-six parents (69% of those surveyed) felt that this education should occur very early (at the first hematology visit) (Table III).

Only 9 parents (13%) indicated that they could pay $20 000 for PGT (an estimate of the cost of 1 cycle of IVF/PGT), and 65 (97%) thought it should be covered by health insurance. Among parents who indicated that they might want to have more children (n = 32), 29 (91%) answered that they would be interested in using PGT if covered by insurance. Sixteen of these 29 (55%) stated their primary interest in PGT was to avoid having another child with SCD, and 11 (38%) were primarily interested in PGT to have a child who could be a HSCT donor for their existing child with SCD.

Views on SCD Prognosis

When asked if they believed their child's SCD will get better, worse, or stay the same when they are older, 65% of parents selected better, 26% the same, and 9% worse. When asked if they believed if their child's life will be shorter than other people without SCD, 20% of parents answered yes and 80% no.

Qualitative Responses

At the conclusion of the survey, parents were asked if they had any comments about the survey, educational material, or the general topic of PGT. Eight parents wrote comments that were all positive (Table IV; available at www.jpeds.com). One parent expressed that more information needed to be provided, particularly for individuals who are pro-life, regarding what happens to embryos created during the process of IVF and PGT that are not selected for implantation.

Table III. Parent views regarding education on PGT for SCD (n = 67)

Views	No. (%)
How important do you think it is for parents of children with SCD to know about PGT?	
Not important	1 (1)
A little important	1 (1)
Important	20 (30)
Very important	45 (67)
When do you think doctors should talk to parents of children with SCD about PGT?	
At the very first hematology visit (newborn)	46 (69)
During the first year, but not at the first visit (before age 1 year)	8 (12)
Sometime in childhood, but not during the first year (after age 1 year)	10 (15)
Doctors should not routinely talk about PGT; they should only talk about it if asked	1 (1)
Never	2 (3)

Discussion

Our study demonstrates the interest in PGT and the attitudes toward this technology in parents of children with SCD. Almost all surveyed parents (97%) indicated that learning about PGT as an option is important or very important for parents of children with SCD, and more than 90% of parents wanting to have more children would consider personally using PGT. Our study involved an unbiased sampling of parents of children with SCD attending our SCD clinics. Although this study group involved parents from only 1 SCD center and thus may not fully represent the views of all parents of children with SCD across the country (in particular non-African Americans), the study group was diverse and included parents of children with SCD with varied educational, economic, and immigrant backgrounds (Table II).

All parents in our study received the same PGT educational booklet before their clinic visit, but the amount of time they had to read it and additional education (if any) during their actual clinic visit was not structured and likely varied depending on the hematology physician or nurse practitioner. This design can be viewed as a study limitation because we do not know how much of parents' knowledge and views on PGT were shaped by the booklet vs any follow-up interaction with their clinical provider. Conversely, this design can also be viewed as a strength of the study because it demonstrates how this education can occur in the real-world, time-constrained clinic setting when an educational booklet is given to parents immediately before their clinic visit. The results of our brief knowledge assessment suggest that through this approach a majority of parents understood the basics of PGT, but misconceptions persisted for some. It is notable that almost one-half of parents chose the incorrect statement that "PGT is strongly recommended for all couples who have a chance of having a child with sickle cell disease," because PGT is an option, not a recommendation. Parents may have selected this statement because of their personal views that PGT is beneficial. A limitation of this study is that it did not include a preintervention knowledge assessment. Future work should more rigorously study different educational interventions to improve parents' understanding of PGT. Educational interventions that incorporate clinically relevant vignettes or involve multimedia may be more effective.[21] It is also important to acknowledge that our survey has not been validated; future work should develop validated tools to measure knowledge and attitudes toward PGT.

In a survey exploring parents' interest in HSCT for SCD, Roth et al previously found that 66% of parents believed that their child's SCD will get better and 86% did not think SCD will shorten their child's lifespan.[22] We included the same 2 prognosis questions in this survey and obtained very similar results. We agree with Roth et al that 1 interpretation of this finding is that providers fail to adequately educate parents that SCD is progressive and causes premature mortality.

Alternatively, given exciting recent advancements in new drugs and curative therapy for SCD, most parents' reported optimism regarding their child's future may be realistic.[23-27] Regardless, it is an important finding that, even with this optimism regarding their child's SCD prognosis, parents are still interested in PGT for SCD.

Most parents of children with SCD are not aware of PGT for SCD; approximately 3 out of 4 surveyed parents had never heard of this option. We suspect this lack of awareness is not specific to our center; other studies have also found that few patients with SCD and parents of children with SCD knew about PGT.[13,28] This lack of awareness is a barrier to PGT use that can be overcome with education. Although many surveyed parents indicated that this education should occur at the very first hematology visit, this may not be feasible because parents already need basic SCD education on topics like penicillin prophylaxis, fever, and spleen palpation at this time to ensure the health of their newborn. If not at the first visit, however, this education should occur at one of the first follow-up visits.

A more difficult barrier to PGT use is its cost; studies have reported a cost of approximately $20 000 per IVF-PGT cycle.[29,30] Although some national health systems provide coverage for PGT for SCD, insurance in the US generally does not.[31] Cost significantly affects parents' decision to use genetic screening in the setting of IVF.[32] Previous work has shown that African Americans use assisted reproductive technology less frequently; this apparent disparity is driven largely by economic factors and can be overcome with improved access to care.[33-35] Further underscoring the importance of access, states with a comprehensive insurance mandate requiring insurers to cover assisted reproductive technology have higher assisted reproductive technology use per capita.[36] Although a formal economic analysis of PGT for SCD has not been done, others have concluded that PGT for cystic fibrosis, another autosomal recessive chronic disease, is cost effective.[29,30] Given the very high health care costs associated with SCD as well as the added potential benefit of conceiving a HSCT sibling donor through PGT for SCD, PGT for SCD is likely to also provide net economic benefits.[37,38]

The education conducted as part of this study on PGT for SCD was intentionally brief to simply introduce the topic. Parents interested in PGT need additional education that likely is best provided by a fertility specialist. With more counseling on the procedures involved with IVF and the risk of a single IVF cycle often failing to succeed in the birth of a newborn (1 center reported a live birth rate of only 13% per PGT cycle initiated), some of the surveyed parents who expressed interest in PGT may actually decide against it.[39] In addition, further consideration of the discarded or extra embryos created with IVF may cause some parents to not use PGT; this ethical concern has been raised as a major problem for some health care professionals.[15] Finally, our educational booklet contained very little information regarding the cost of PGT.

In conclusion, most parents of children with SCD seen in the hematology clinic did not know about PGT, but, when educated about this option, viewed this knowledge as important. Routine hematology clinic appointments in early childhood may be opportune times to educate parents about PGT. Cost may be a major barrier to the use of PGT, but providers should discuss PGT with parents of children with SCD to help ensure access to this option. ■

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Table I. Checking your understanding of PGT questions and automated answers

Answer	Response shown immediately to parent if answer was selected	Number of parents who selected answer (n = 57)
Question 1: Which ONE of the below statements is CORRECT regarding PGT for sickle cell disease?		
PGT is medicines a woman takes during pregnancy so that a baby will not have sickle cell disease.	INCORRECT. PGT does NOT involve taking medicines during pregnancy. PGT is done BEFORE a woman is pregnant, not after. PGT is a series of steps, including meeting with a fertility specialist, IVF (in-vitro fertilization), and testing of embryos to select an embryo without sickle cell disease. The correct answer is: PGT involves creating embryos in the laboratory and testing them for sickle cell disease.	9 (16%)
PGT is testing after a woman is pregnant to decide if she wants to end the pregnancy (have an abortion).	INCORRECT. PGT does NOT involve a woman having an abortion. PGT is done BEFORE a woman is pregnant, not after. PGT is a series of steps, including meeting with a fertility specialist, IVF (in-vitro fertilization), and testing of embryos to select an embryo without sickle cell disease. The correct answer is: PGT involves creating embryos in the laboratory and testing them for sickle cell disease.	4 (7%)
PGT involves creating embryos in the laboratory and testing them for sickle cell disease.	CORRECT. PGT is a series of steps, including meeting with a fertility specialist, IVF (in-vitro fertilization), and testing of embryos to select an embryo without sickle cell disease.	41 (72%)
PGT is a major surgery done during pregnancy so that a baby will not have sickle cell disease.	INCORRECT. PGT is NOT a major surgery. PGT is a series of steps, including meeting with a fertility specialist, IVF (in-vitro fertilization), and testing of embryos to select an embryo without sickle cell disease. The correct answer is: PGT involves creating embryos in the laboratory and testing them for sickle cell disease.	3 (5%)
Question 2: Which ONE of the below statements is CORRECT regarding PGT for sickle cell disease?		
PGT is strongly recommended for all couples who have a chance of having a child with sickle cell disease	INCORRECT. PGT is NOT strongly recommended for ALL couples. PGT is an OPTION. Before beginning PGT, families meet with a fertility specialist to determine if this is the right option for them. Multiple cycles of IVF/PGT may be needed and may still not work despite the time, energy, and money invested. Correct answer: PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease.	27 (47%)
PGT can be done directly at Children's National	INCORRECT. Children's National does NOT do PGT/IVF. PGT is done by a fertility specialist. Correct answer: PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease.	3 (5%)
PGT is a one-time procedure that offers a 100% guaranteed birth of a child without sickle cell disease	INCORRECT. PGT does not have a 100% success rate. PGT is a series of steps, and multiple cycles of IVF/PGT may be needed and may still not work despite the time, energy, and money invested. Therefore, before starting this process, families meet with a fertility specialist to determine if this is the right option for them. Correct answer: PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease.	4 (7%)
PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease	CORRECT. PGT can be used to try to have a child who can be a bone marrow donor for a current sibling with sickle cell disease. Multiple cycles of PGT may be needed and may still not work in some cases despite the time, energy, and money invested. Therefore, before beginning this process, families meet with a fertility specialist to determine if this is the right option for them.	23 (40%)

Table IV. Parent comments

Parent demographics	Comment
Do you have any comments about this survey, the educational material on PGT, or the topic of PGT that you would like to share?	
A 30-year-old mother	I didn't know about PGT until I had him and he had sickle cell. I didn't even know it was an option. I would have definitely gone through PGT initially.
A 51-year-old mother	I am proud to know about this because, even though I am not having another baby, I can share this with other people. I do not want other people to make the same mistake as me and can avoid this disease. It is very important to know about this.
A 35-year-old mother who identified as Catholic	I feel that the PGT option should be first discussed with women prior to being pregnant. Especially women who are likely to give birth to a child with the trait and/or disease. There needs to be more information about what would happen to the remaining embryos for women and families who are pro-life.
A 25-year-old mother	I think this is a good brochure with a lot of details. I like the way that there are people like you (survey proctor) to answer questions and help administer the survey.
A 47-year-old father	It is a very important information provided by the physician and I look forward to recommending it to people who have families with sickle cell trait or disease to ensure future children without the disease.
A 52-year-old mother with a high school diploma	Good teaching.
A 33-year old mother	I believe this procedure could help reduce sickle cell.
A 40-year-old mother with an annual household income of $35 000-$49 999	If the cost of the PGT is too expensive, then there is no point for parents who are low income. It is an option that should be discussed with anybody that has sickle cell trait. Insurance should cover it. It is a fantastic idea. We should lead this with people with traits should NOT HAVE KIDS TOGETHER and if they have to, PGT is an option for them.