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Navigating Hope and Complexity: Turkish Parents' Experiences with Savior Siblings

Eker İ. et al.: Savior Sibling Path: Parental Insights

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Abstract:
Background/Aims: Preimplantation genetic diagnosis (PGD) with human leukocyte antigen (HLA) typing represents a significant advancement in treating inherited hematological disorders, particularly thalassemia major. This technology enables the birth of healthy children who can serve as compatible stem cell donors for their affected siblings.
Turkey is a world leader in both PGD+HLA typing technology and hematopoietic stem cell transplantation from savior siblings born through PGD+HLA typing.
Aims: This study investigated the experiences of Turkish parents who underwent successful savior sibling procedures using preimplantation genetic diagnosis (PGD) with human leukocyte antigen (HLA) typing and then successful hematopoietic stem cell transplantation, from this savior sibling, for the treatment of their thalassemia major child. The research aimed to understand the medical, psychological, and socio-cultural dimensions of this complex process within the Turkish healthcare context.

Materials and Methods: A qualitative study using descriptive phenomenological approach was conducted. In-depth interviews were performed with 16 parents, who successfully completed PGD+HLA matching and subsequent successful stem cell transplantation process from this savior sibling to their thalassemia child. Data were analyzed using Colaizzi's seven-step method and MAXQDA 20.0 software.
Results: Analysis revealed six main themes: Disease Stage, Treatment, Recovery Process, Social Family, Support Systems, and Recommendations. Parents reported significant emotional challenges but demonstrated unexpected resilience. Religious and cultural factors played nuanced roles, with most parents viewing the process as compatible with their beliefs. Economic burden, prolonged hospitalizations, and geographical access to treatment centers emerged as key challenges. Extended family support and healthcare professional guidance were identified as crucial support mechanisms.
Conclusion: The study highlights the complex interplay between advanced medical technologies and traditional values in Turkish society. Findings emphasize the need for comprehensive, culturally sensitive support systems and long-term follow-up for families. Results suggest implementing multidisciplinary care teams and developing specialized support programs for families undergoing savior sibling procedures.
Keywords: Savior siblings, preimplantation genetic diagnosis, stem cell transplantation, qualitative research, Turkish families, medical ethics

Öz:
Giriş: İnsan lökosit antijen (HLA) eşleştirmesi ile birlikte preimplantasyon genetik tanıyı (PGD) içeren tedavi yöntemi, özellikle talasemi majör gibi kalıtsal hematolojik hastalıkların tedavi edilmesinde önemli bir ilerleme sunmaktadır. Bu teknoloji, hasta olan kardeş için potansiyel uygun kök hücre bağışçısı sağlıklı kardeşin doğmasını sağlar. Türkiye hem PGD+HLA eşleştirme tedavisinde, hem de PGD + HLA eşleştirme tedavi yöntemi kullanılarak dünyaya gelen kurtarıcı kardeşten hematopoietik kök hücre nakli konusunda dünya lideridir.
Amaç: Bu çalışmayla preimplantasyon genetik tanı (PGD) ve insan lökosit antijen (HLA) eşleştirmesi tedavi yöntemi ile doğan çocuklarından, hasta olan çocuklarına başarılı kök hücre nakli yapılan, talasemi majör hastası çocuk sahibi Türk ebeveynlerinin deneyimlerinin araştırılması amaçlanmıştır. Araştırma bu kompleks süreci, ebeveynler üzerindeki etkilerini, ebeveynlerin yaşadıklarını medikal, psikolojik ve sosyo kültürel açıdan anlamayı amaçlamaktadır. Ayrıca bu tedavi yöntemini alacak ailelere ve uygulayacak sağlık hizmeti sunucularına önerilerde bulunmak hedeflenmiştir.
Materyal ve Metod: Tanımlayıcı fenomenolojik yaklaşımı kullanılan niteliksel bir araştırma tasarımı kullanılmıştır. Bu çalışma da başarılı bir PGD+HLA eşleştirmesi yöntemi ile doğan kurtarıcı kardeşten talasemi majorlü hasta çocuklarına, başarılı kök hücre nakli gerçekleştirilmiş 16 aile ile derinlemesine görüşmeler gerçekleştirildi. Veri analizi için Colaizzi'nin yedi aşamalı yöntemi ve MAXQDA 20.0 yazılımı kullanılmıştır.
Bulgular: Analiz altı ana tema ortaya çıkartmıştır: Hastalık evresi, tedavi, iyileşme süreci, sosyal aile, destek sistemleri ve tavsiyeler. Ebeveynler önemli duygusal zorluklar bildirmiş ama beklenmeyen dayanıklılık göstermişlerdir. Dini ve kültürel faktörler ince bir role sahip olup çoğu aile bu süreci inançlarına uygun değerlendirmiştir. Ekonomik yük, uzun hastane yatışları ve tedavi merkezine coğrafi erişim önemli zorluklar olarak öne çıkmaktadır. Yoğun aile desteği ve sağlık profesyonellerinin liderliği önemli destek mekanizmaları olarak dikkat çekmektedir.
Sonuç: Bu çalışma ileri medikal teknolojiler ve Türk toplumunun geleneksel değerleri arasında kompleks ilişkiyi vurgulamaktadır. Bulgularımız; aileler için kültürel hassasiyetlere sahip detaylı bir destek sistemine ve uzun süreli takiplere ihtiyaç olduğunu ortaya koymaktadır. Sonuçlarımız, kurtarıcı kardeş sürecinden geçen aileler için özelleştirilmiş destek programlarının geliştirilmesini ve multidisipliner bakım ekiplerinin uygulanmasının önemini göstermiştir.
Anahtar Kelimeler : Kurtarıcı kardeş, preimplantasyon genetik tanı, kök hücre nakli, niteliksel araştırma, Türk aileler, tıbbi etik

Introduction and Aim

Preimplantation genetic diagnosis (PGD) with human leukocyte antigen (HLA) typing represents a significant advancement in treating inherited hematological disorders, particularly thalassemia major. This technology enables the birth of healthy children who can serve as compatible stem cell donors for their affected siblings [1,2].

Turkey is a world leader in both PGD+HLA typing technology and hematopoietic stem cell transplantation from savior siblings born through PGD+HLA typing. In the multicenter study by Kurekci et al., transplantations from PGD/HLA-matched siblings achieved a 96% success rate in 52 patients between 2008-2014 [3]. This represents the largest case series reported in the literature. The procedure, covered by Turkey's social security system since

2009, offers a promising option for patients without suitable donors. The study of Kurekci et al demonstrates Turkey's pioneering role in successfully implementing this technology for treating various hematological disorders.

In Turkey, where thalassemia is prevalent and Islamic perspectives influence medical ethics, PGD and HLA matching have gained acceptance within medical necessity frameworks. While existing literature focuses on medical outcomes and ethical analyses [4-6], there is limited research on families' lived experiences navigating this complex process.

This study addresses this gap by investigating the experiences of Turkish parents who have successfully completed the savior sibling process, offering unique insights into how this advanced medical procedure is experienced within a predominantly Muslim society that combines traditional values with modern medical practices.

Materials and Methods

Research Design: In this study, the descriptive phenomenological research model, one of the qualitative research methods, was used [7].

Research Team: The research team consisted of four people. Two were faculty members in the medical school, one in the faculty of health sciences, and one was a qualitative research expert.

Sample: The study sample consisted of parents who had a savior sibling child to be a hematopoietic stem cell transplant donor for their sick child. In the phenomenological model, participants selected for the sample group must have experienced the phenomenon in all its aspects. Therefore, parents who were 18 years of age and older, whose sick children had undergone hematopoietic stem cell transplantation, and who had a savior sibling child were included in the study. Using homogeneous purposive sampling, the study sample was selected so that all the sick children of families who had transplants from their savior sibling children had thalassemia major (e.g., a group that had experienced the same process from start to finish). This type of sampling tends to ensure that the final sample is adequately representative [8]. Data saturation and homogeneity were considered in determining the number of participants for the sample [9]; it was anticipated that data saturation could be achieved with 16 parents.

Data Collection Process and Participant Selection: The study included 16 families (16 mothers and 14 fathers) who had successfully undergone the savior sibling process for their children with thalassemia major. Individual interviews were conducted with only mothers and fathers and separately, not together to ensure they can give responses and maintain privacy. Interviews with savior sibligns, sick children or other family members were not conducted. The average interview duration was 38 minutes (range: 30-45 minutes). All interviews were conducted online via secure video conferencing software between October 2022-February 2023.

Participant Demographics: The mean age of mothers was 36.4 years (range: 28-44) and fathers was 39.2 years (range: 31-48). Educational background varied: 37.5% had university degrees, 43.8% had high school education, and 18.7% had primary school education. Families were from diverse geographical regions of Turkey: Marmara (31.25%), Central Anatolia (25%), Aegean (18.75%), Mediterranean (12.5%), and Eastern Anatolia (12.5%). The mean age of sick children was 8.3 years (range: 4-14) and savior siblings was 3.2 years (range: 1-6).

Data Collection Tools: The study data were collected between October 2022-February 2023 using a semi-structured interview form. To collect data, semi-structured interview forms consisting of five questions were used, prepared in light of demographic information and current literature knowledge on the subject:

1. What did you feel when your child was first diagnosed with the disease?
2. What were your initial thoughts when you were told that bone marrow transplantation (Hematopoietic Stem Cell Transplantation) was needed for your child's treatment?
3. How did you decide to have a savior baby as a bone marrow transplant (Hematopoietic Stem Cell Transplantation) donor?
4. How did you feel when making this decision?
5. What did you experience during this process?

Additional questions were asked to deepen the interview as needed, depending on the course of the conversation and extracting other questions from the family's conversation.

Data Collection Process: Data were collected online using the individual in-depth interview technique. Before starting the study interviews, a pilot interview was conducted with two participants outside the current participants. The interview questions were modified based on the pilot interview. Verbal consent was obtained from the participants before starting the interview. All interviews were conducted individually with mothers (n=16) and fathers (n=14) who participated. Mother and father were not taken into the interviews together, they were taken separately so that they could express themselves comfortably. The average interview duration was 38 minutes (range: 30-45 minutes). Additional questions were asked based on participants' responses to gain deeper insights into their experiences. All interviews were recorded with consent and transcribed verbatim. Transcripts were sent to participants and approved.

Data Analysis: The data from the qualitative interviews were analyzed using the MAXQDA 20.0 statistical software package and Colaizzi's seven-step phenomenological analysis steps, and thematic coding was created [10].The analysis process included the following steps:
- Reading the transcripts and taking notes;
- Selecting significant statements;
- Formulating meanings;
- Grouping meanings into categories, themes, and sub-themes;
- Integrating results into a comprehensive description of the phenomenon;
- Formulating the fundamental structure of the phenomenon;
- Returning to participants for validation;
- Examination of themes and codes by an expert.

Reliability of the Study: The reliability of this study was carried out according to the criteria of credibility, dependability, transferability, and confirmability [11]. Participant approval was obtained, the examined phenomenon was described in detail, researchers discussed the process, direct quotations of participant statements were made between texts, inter-coder consistency was ensured, and multiple data collection methods were used.

Limitations of the Study: Due to the qualitative design and limited sample size, definitive and generalizable results were not reached. Retrospective sharing may cause some details to be forgotten or misremembered. The data of the study reveal the short-term experiences of the participants; investigating and defining the long-term experiences of the participants may be useful for future studies. Our study only includes families who have successfully had a savior sibling child and have experienced a successful transplant from this savior sibling child to their sick child. Future studies may offer a broader perspective by including families whose processes have not been successful.

Ethical Aspects of the Study: The study was carried out with the approval of the Clinical Research Ethics Committee of Afyonkarahisar Health Sciences University dated 05.08.2022 and numbered 2022/9. The principle of confidentiality was adhered to, pseudonyms were used, data were stored securely and will be destroyed after 3 years.

The authors report there are no competing interests to declare.

Results:

Demographics and Clinical Characteristics: The study included 16 families who had undergone successful savior sibling procedures for their children with thalassemia major. The mean age of mothers was 36.4±5.2 years and fathers was 39.2±5.8 years. Most families (81.3%) had at least high school education, with 37.5% having university degrees. Families were from diverse geographical regions of Turkey, with the majority from Marmara (31.25%) and Central Anatolia (25%). The mean age of patients at diagnosis was 1.2±0.8 years, and the mean time from diagnosis to HSCT was 4.1±1.9 years. Detailed demographic and clinical characteristics are presented in Table 1.

Thematic Analysis Results: Analysis of the interview data revealed six main themes regarding parents' experiences throughout the savior sibling process: (1) Disease Stage, (2) Treatment, (3) Recovery Process, (4) Social Family, (5) Support Systems, and (6) Recommendations. The detailed breakdown of these themes, their categories, and associated codes are presented in Table 2. In qualitative research, the term 'code' refers to frequently repeated expressions identified in interview data and textual content during the analysis process. Codes help researchers systematically organize and interpret the data, facilitating the identification of underlying meanings and relationships.

Table 1. Demographic and Clinical Characteristics of Study Participants (N=16 families)

Characteristics	n (%) or Mean±SD
Parent Demographics	
Maternal age, years	36.4±5.2
Paternal age, years	39.2±5.8
Education Level	
University	6 (37.5%)
High school	7 (43.8%)
Primary school	3 (18.7%)
Geographic Region	
Marmara	5 (31.25%)
Central Anatolia	4 (25%)
Aegean	3 (18.75%)

Mediterranean	2 (12.5%)
Eastern Anatolia	2 (12.5%)
Monthly Income Level	
High	3 (18.75%)
Middle	9 (56.25%)
Low	4 (25%)
Patient Characteristics	
Age at diagnosis, years	1.2±0.8
Current age, years	8.3±2.9
Gender	
Male	9 (56.25%)
Female	7 (43.75%)
Time from diagnosis to HSCT, years	4.1±1.9
Savior Sibling Characteristics	
Current age, years	3.2±1.4
Gender	
Male	7 (43.75%)
Female	9 (56.25%)
Age at donation, years	2.1±0.6

Table 2: Themes and categories

THEMES	CATEGORIES	CODES and NUMBERS OF REPEATS
Disease Stage (1)	Learning the Diagnosis	Rejection (8) Feeling guilty (8) Seeking treatment (17) Anxiety/ Worry (14) Wondering about the results (5) Feeling bewildered(5) Devastated (7)
	Searching for Different Treatment Methods	Searching for Alternatives (5) The lack of information (13) Donor search (10) Difficulties in decision-making (2) Getting ideas from other families (8)
	Motivations for having a savior sibling	Saving a sick child (23) Having no alternative (26) Reading from the newspaper (2) Doctor's advice (27) Decision-making tools (3) Planning a new child (17)
	Religious and Cultural Factors	No effect (2) Community pressure on father to have savior sibling child (1) Forbidden of any pregnancy termination in religion (6)
Treatment (2)	Challenges	Protecting the sick child from prejudice (3) Economic Difficulty (11) Prolonged hospitalisations (17) The need to travel frequently for treatment (16) The need to migrate for treatment (3)

Treatment (2)	Having an IVF Baby	Expectations during pregnancy (5) Mother's Burden of Duty (18) Feeling Under Pressure (26) Restriction of movement during pregnancy (11) Consequences of an unfavorable termination of pregnancy (5) IVF Process (2)
	Emotional State	Being Worried About Bad Results (3) Consider the Good (15) Falling into Despair (19)
	Preparation for Surgery	Waiting with Hope (5) Worrying about the Health of the Savior Sibling (4) Maintaining Operating Conditions (16)
Recovery Process (3)	Emotional Changes	Positive Emotions (14) Deficiency of New Child Fuss (2) Relaxation (3) Excitement of Having a New Baby (11) Thinking About the Next Step (1) Anxiety about relapse (3)
	Caring for the sick child after the bone marrow transplantation	Hair Loss (2) Caring for a Child (12) Chemotherapy (4) Isolation (17) Resistance of the Sick Child to Treatment (3) Concurrently Having The Duty To Look After The Savior Sibling (3)
Social Family (4)	Perspective of Family Members	Views of Family Members (11) Normal Family Relationship (11)
	Having a Savior Sibling Child	Wish to Get the Opinion of the Savior Sibling Child (9) Having Difficulty in Behaving Equally Among Children (4) Considering That The Savior Sibling Will Accept / Being Small (4) Being Aware of the Transfer Process (3)
	The Meaning Attributed to the Savior Sibling	Giving Meaningful Names (6) Considering the Purpose of Coming to Earth Sacred (11) The hope of curing the sick child (9)
Support Systems (5)	Coping Mechanisms	Religious Motivation Sources (4) Do not Want to Remember (7) Do Not Think Negatively (5) Sources of Self Motivation (3) Getting worn out/tired (15) Psychological Effects (10) Abandoning Life (7) Burnout (15) Post-procedural Illness of Parents (3) Do Not Reflect the Process (5)
	Social Support Systems	Marital Support (7) Support from Extended Family/Near Neighbourhood Support (35) Psychological Support (7)

		Doctors' Support (12) Interactions with different families who have gone through the same process (15)

Under the Disease Stage theme, four categories were identified: "Learning the Diagnosis", "Search for Treatment Methods", "Motivations for Having a Savior Sibling Child", and "Religious and Cultural Factors". Parents reported initial fear and anxiety upon diagnosis, followed by active treatment research. One participant noted: "My biggest regret was when I learned about the disease... We are both university graduates, my wife and I, because I also have two children who are carriers. Why didn't we notice this before and take precautions." (P1)

“Community pressure on father to have savior sibling child (1)” code in the “Religious and Cultural Factors Category” referred specifically to pressure to have a savior sibling child who could potentially be a donor for their sick child. The religious views about pregnancy termination were independent of fetal health status. All families were informed by their physicians about the risk of having another child with thalassemia major without PGD. Two parents reported no religious/cultural influence on their decision, six mentioned religious prohibition of pregnancy termination, while others were primarily focused on saving their sick child without considering religious implications.

The Treatment theme revealed four categories: "Difficulties", "Having an IVF Baby", "Emotional State", and "Preparation Process for Surgery". Key challenges included transportation issues, economic burdens, and social stigma. The IVF process particularly affected mothers, as expressed by one participant: "All the responsibility was on me again, if something happens, so I spent most of the time lying down." (P3)

The Recovery Process theme comprised two categories: "Emotional Changes" and "Caring for the sick child after bone marrow transplantation". Parents reported positive emotional transitions post-successful transplantation, though concerns about disease recurrence persisted. The isolation period proved challenging, as one participant described: "He had a lot of pain... he stayed in the hospital for two months without going out, in a separate room where no one saw him, he only saw his father through the glass." (P8)

The Social Family theme included three categories: "Family Members' Perspective", "Having a Savior Sibling Child", and "The Meaning Given to the Savior Sibling Child". Families maintained normal relationships with the savior sibling, who were aware of their role but too young for informed consent at the time of donation.

Under Support Systems, participants emphasized the importance of professional help and social support networks. Some experienced delayed psychological effects, with one mother sharing: "I guess because your world is that child, I always put myself in second place... I always felt like I shouldn't be happy while my child is sick." (P11)

The Recommendations theme highlighted the importance of trusting medical professionals, seeking psychological support, and maintaining determination throughout the process. Being determined/persistent and seeking psychological support were the most frequently repeated recommendations, mentioned seven times each.

Figure 1, the code map, illustrates the interconnections between frequently mentioned codes. Codes are frequently repeated expressions identified in the interviews and textual contents during the analysis process and expressed with numbers in parentheses in the figure. For example, “Doctor’s Recommendation (27)” means, this expression was repeated 27 times by the participants across all the interviews conducted within the scope of the study. And again for example “Saving the Child (23) means, this expression was repeated 23 times by the participants across all the interviews conducted within the scope of the study. The code map is particularly highlighting the relationships between healing the sick child and factors such as doctor’s recommendations, lack of alternatives, economic difficulties, travel requirements, burnout, extended hospital stays and family support. The code map illustrates the interconnections between frequently mentioned codes with line thickness representing the frequency and strength of relationships.

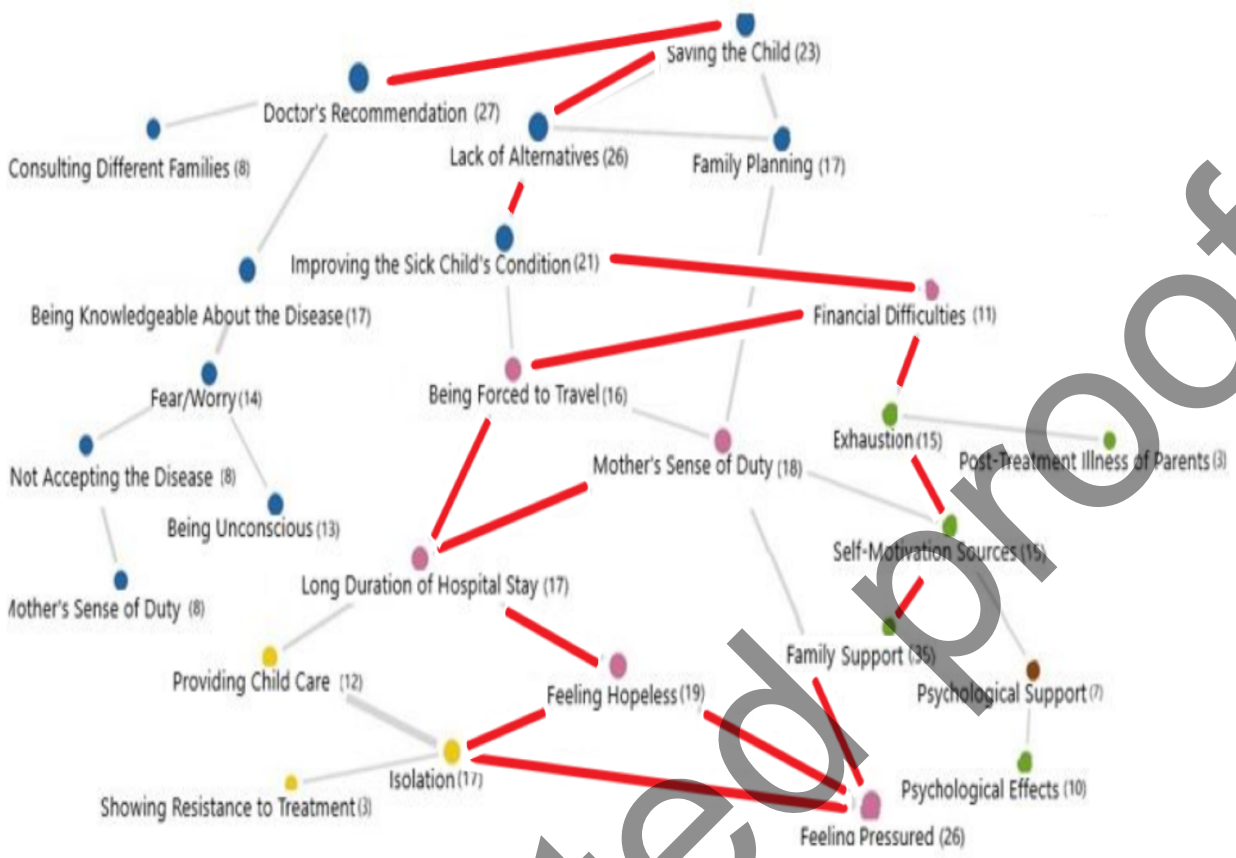

Figure 1. Code Map

Discussion:

Our study provides significant insights into the experiences of Turkish families who have successfully finished the savior sibling process for treatment of their child wtih thalassemia majör. Analysis of demographics revealed that participating families represented diverse geographical regions and socioeconomic backgrounds of Turkey. Analysis of demographics revealed that participating families represented diverse geographical regions and socioeconomic backgrounds of Turkey. This heterogeneous distribution of participants across different regions and socioeconomic strata significantly enhances the study's representational validity and provides a more comprehensive perspective of the national landscape regarding savior sibling experiences. The inclusion of families from various geographical and socioeconomic contexts strengthens the generalizability of our findings and offers valuable insights into the challenges and experiences faced by families across different settings within the Turkish healthcare system. This demographic diversity particularly enriches our understanding of how varying resources, cultural contexts, and healthcare accessibility influence the savior sibling journey in different regions of Turkey, thereby providing a more objective and holistic view of the national situation.

The mean time from diagnosis to HSCT (4.1±1.9 years) reflects the complex nature of the process, including decision-making, PGD+HLA procedures, and preparation for transplantation. The findings of this study provide crucial insights into the complex journey of Turkish families through the savior sibling process for thalassemia major treatment, revealing several key implications for clinical practice and healthcare policy. The phenomenon of the savior sibling, which has medical, psychological, sociological, bioethical and health policy perspectives, reveals the complexity and multifaceted nature of this process.

Medical perspectives: Our study sheds light on the medical aspects of the savior sibling process. The use of preimplantation genetic diagnosis (PGD) and human leukocyte antigen (HLA) matching technologies represent significant advances in the field of medical genetics. These technologies are promising for diseases that previously had no chance of cure. However, our study also revealed some concerns about the use of these technologies. Most parents expressed concerns about the complexity and potential risks of the PGD and HLA matching process. However, the willingness of parents to take these risks shows how strong their desire to save their children is. Our study also emphasizes the importance of long-term follow-up of the health status of children born with the savior sibling method. There are still important gaps in the literature on this subject. For example, Kahraman et al. showed that the short-term health status of savior siblings was normal [2].However, their long-term effects are still unclear.

Our findings confirm Turkey's leading position in PGD+HLA technology implementation. The successful outcomes of transplantation in our cohort (all 16 cases) align with previous reports of high success rate in transplantation of children wtih thalassemia major in Turkish pediatric hematopoietic transplantation centers. The mean age at donation for savior siblings (2.1±0.6 years) indicates careful timing of transplantation, balancing urgency with donor safety. This timing aligns with current recommendations for optimal transplant outcomes in thalassemia major [2,3].

Psychosocial Perspectives: The emergence of burnout as a significant theme emphasizes the need for systematic psychological support throughout the process. This finding corresponds with recent literature on caregiver burden in chronic pediatric conditions [12]. The strong role of extended family support reflects the unique cultural context of Turkish society and suggests potential benefits of formally incorporating family support systems into treatment protocols.

Sociological Perspectives: Our study illuminates the social and cultural context of the savior sibling process in Turkish society. Similar to Gürtin's study, we observed that family structure, gender roles and cultural norms shape this process [13]. In particular, the importance of extended family support in Turkish society is noteworthy. Many parents stated that the support of the extended family was critical in this challenging process. This finding is in line with other studies conducted in collectivist cultures [14]. However, this support can sometimes be a double-edged sword. Some parents also reported that the intrusive behaviour of the extended family can be a source of stress. The centrality of the maternal role is another important finding of our study. Mothers generally stated that they bear the main burden of the process. This reflects the traditional gender roles in Turkish society. However, in some families fathers were also observed to play an active role, which may be an indicator of changing family dynamics in Turkish society. Unexpectedly, we observed that traditional values and modern medical practices can coexist harmoniously. This finding shows how traditional and modern values are blended in the modernisation process of Turkish society.

Bioethical Perspectives: Our study reveals the ethical dimensions of the savior sibling process. Issues such as child autonomy, intended pregnancy and genetic selection bring important ethical debates.These findings overlap with the ethical debates in study of Pennings et al [15]. However, an unexpected finding in our study is that parents attach more importance than expected to the future autonomy of the child who will be born as a savior sibling. Many parents stated that the child would be able to make his/her own decision about whether or not to donate stem cells when he/she grows up. This reflects the increasing awareness of children's rights and autonomy in Turkish society. Our study also provides interesting findings on the role of religious beliefs in the savior sibling process. Unexpectedly, most of the parents stated that they did not seek approval in their religious beliefs when deciding on this treatment method. This finding reflects the complex relationship between the acceptance of modern medical practices and religious beliefs in Turkish society.

Healthcare Policy Perspectives: Our study reveals the relative ease of access to savior sibling treatment in Turkey. This reflects the strengths of Turkey's healthcare system. However, factors such as economic difficulties and geographical distribution of health services stand out as barriers faced by families. In particular, it was observed that families living in rural areas had difficulty in accessing treatment centers. This finding is similar to the study conducted by Fluchel et al. in the United States of America [16]. This situation indicates that the geographical distribution of health services should be improved. Our study also revealed the inadequacy of psychosocial support services provided to families during the savior sibling process. Many parents stated that they wanted to receive professional psychological support during this process, but they had difficulty in accessing these services. Ensuring a more balanced distribution of savior sibling treatment centers across the country, developing comprehensive psychosocial support programmes for families and facilitating access to these services, establishment of special financial support programmes for families in the savior sibling process are our recommendations for these issues.

Although premarital thalassemia screening was initiated in 41 provinces in Turkey in 2003 and expanded nationwide in 2018 [17,18], the presence of thalassemia major births continues to be a significant concern. The first hematopoietic stem cell transplantation in Turkey from a healthy HLA-matched sibling born through PGD and HLA matching was performed on November 29, 2005, at Akdeniz University Hospital. The donor was a 9-month-old male sibling born on February 28, 2005, and the recipient was his 6-year-old sister with thalassemia major. In our study group, the youngest thalassemia major patient who received transplantation from a savior sibling was born on January 27, 2018. Despite mandatory nationwide premarital screening since 2018, new cases of thalassemia major continue to emerge. For instance, the lead author currently follows two 2-year-old thalassemia major patients with pathogenic mutations whose parents did not undergo premarital screening, and these patients are currently awaiting transplantation. This situation clearly demonstrates that the premarital thalassemia screening program has not yet achieved full effectiveness throughout the country.

Future research may offer a broader perspective by including families whose processes have not been successful. Long-term studies should examine savior siblings' health status, identity development, and self-perception, alongside the medical and psychological impacts of PGD and HLA matching technologies. Investigation of socioeconomic factors, gender roles, and family dynamics within Turkish society would

enhance sociological understanding. Further bioethical analysis should focus on balancing child autonomy with parental decisions and examining the ethical implications of genetic technologies.

Conclusion: This qualitative study of Turkish families' experiences with savior sibling procedures reveals the complex interplay between medical advancement, psychological resilience, and cultural adaptation. Our findings demonstrate that successful implementation of PGD+HLA matching requires both technical expertise and robust support systems. The study's insights suggest establishing comprehensive support programs, enhancing geographical access to specialized centers, and implementing culturally sensitive care protocols. These findings have significant implications for hematopoietic stem cell transplantation in Turkey and similar cultural contexts, demonstrating that advanced genetic technologies can be successfully integrated into traditional societies when supported by appropriate medical and psychosocial infrastructure.

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