RESEARCH ARTICLE

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

Umudu ve Karmaşıklığı Yönlendirmek: Türk Ebeveynlerin Kurtarıcı Kardeş Deneyimleri

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Abstract

Objective: 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. Türkiye is a world leader in both PGD+HLA typing technology and hematopoietic stem cell transplantation (HSCT) from savior siblings born through PGD+HLA typing. This study investigated the experiences of Turkish parents who underwent successful savior sibling procedures

Öz

Amaç: 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 (HKHN) konusunda dünya lideridir. Bu çalışmayla PGD ve HLA eşleştirmesi tedavi yöntemi

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Abstract

using PGD+HLA typing and then successful HSCT from the savior sibling for the treatment of the child with thalassemia major. We aimed to understand the medical, psychological, and sociocultural dimensions of this complex process within the Turkish healthcare context.

Materials and Methods: A qualitative study was undertaken using a descriptive phenomenological approach. In-depth interviews were conducted with parents from 16 families who had successfully completed PGD+HLA matching and subsequent stem cell transplantation processes from the savior sibling to the child with thalassemia. Data were analyzed using Colaizzi's seven-step method and MAXQDA 20.0 software.

Results: The 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 burdens, prolonged hospitalizations, and geographical access to treatment centers emerged as key challenges. Extended family support and professional healthcare guidance were identified as crucial support mechanisms.

Conclusion: This study highlights the complex interplay between advanced medical technologies and traditional values in Turkish society. The findings emphasize the need for comprehensive and culturally sensitive support systems and long-term follow-up for families. The results suggest the value of 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

ile doğan çocuklarından, hasta olan çocuklarına başarılı HKHN 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.

Gereç ve Yöntemler: 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 Sözcükler: Kurtarıcı kardeş, Preimplantasyon genetik tanı, Kök hücre nakli, Niteliksel araştırma, Türk aileler, Tıbbi etik

Introduction

Preimplantation genetic diagnosis (PGD) with human leukocyte antigen (HLA) typing constitutes 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].

Türkiye is a world leader in both PGD+HLA typing technology and hematopoietic stem cell transplantation (HSCT) from savior siblings born after PGD+HLA typing. In the multicenter study conducted by Kurekci et al. [3], transplantations from PGD/HLA-matched siblings achieved a 96% success rate among 52 patients between 2008 and 2014. This is the largest case series reported in the literature to date. The procedure, covered by Türkiye's social security system since 2009, offers a promising option for patients without suitable donors. The study by Kurekci et al. [3] confirmed Türkiye's pioneering role in successfully implementing this technology for the treatment of various hematological disorders.

In Türkiye, where thalassemia is prevalent and Islamic perspectives influence medical ethics, PGD and HLA matching have gained acceptance within the framework of medical necessity. While the existing literature focuses on medical outcomes and ethical analyses [4,5,6], there is limited research on families' lived experiences while navigating this complex process. The present study addresses that gap by investigating the experiences of Turkish parents who 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, a descriptive phenomenological research model, as one of the qualitative research methods, was used [7]. The research team consisted of four people. Two were faculty

members in a medical school, one was a faculty member in a faculty of health sciences, and one was a qualitative research expert.

Study Sample

The study sample consisted of parents who had a savior sibling child to serve as a HSCT donor for a sick sibling. In phenomenological models, participants selected for the sample group must have experienced the phenomenon in all its aspects. Therefore, parents who were 18 years of age or older, who had a sick child who had undergone HSCT, and who also had a savior sibling child were included in this study. Using homogeneous purposive sampling, the study sample was selected so that all the sick children of the families who had received transplants from their savior siblings had thalassemia major. In other words, it was ensured that the members of the study sample had experienced the same processes 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 parents from 16 families.

Participant Selection

The study included 16 families, with the participation of 16 mothers and 14 fathers, who had successfully undergone the savior sibling process for a child with thalassemia major. Individual interviews were conducted with only mothers and fathers and separately, not together, to ensure that participants could give independent responses and maintain their privacy. Interviews were not conducted with savior siblings, sick children, or other family members. The average interview duration was 38 min (range: 30-45 min). All interviews were conducted online using secure video conferencing software between October 2022 and February 2023.

Participant Demographics

The mean age of the mothers was 36.4 years (range: 28-44) and that of the fathers was 39.2 years (range: 31-48). Their educational backgrounds varied: 37.5% had university degrees, 43.8% had high school education, and 18.7% had only primary school education. The families were also from diverse geographical regions of Türkiye, including the Marmara (31.25%), Central Anatolia (25%), Aegean (18.75%), Mediterranean (12.5%), and Eastern Anatolia (12.5%) regions. The mean age of the sick children was 8.3 years (range: 4-14) and that of the savior siblings was 3.2 years (range: 1-6).

Data Collection Tools

The study data were collected between October 2022 and February 2023 using a semi-structured interview form. The form consisted of five questions prepared in light of the relevant demographic information and the current literature on the subject:

1. How 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 (HSCT) was needed for your child's treatment?

3. How did you decide to have a savior sibling as a bone marrow transplant (HSCT) donor?

4. How did you feel while making this decision?

5. What did you experience during this process?

Additional questions were asked to deepen the interviews as needed, depending on the course of the conversation with other questions branching from the parent'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 not included among the final participants of the study. The interview questions were modified based on those pilot interviews. Verbal consent was obtained from the participants before starting the interviews. All interviews were conducted individually with the mothers (n=16) and fathers (n=14) who participated. Mothers and fathers were not interviewed together to ensure that all participants could express themselves more comfortably. The average interview duration was 38 min (range: 30-45 min). Additional questions were asked based on the participants' responses to gain deeper insights into their experiences. All interviews were recorded with the participant's consent and transcribed verbatim. Transcripts were sent to participants for their approval.

Data Analysis

The data from the qualitative interviews were analyzed using the MAXQDA 20.0 statistical software package (VERBI GmbH, Berlin, Germany) and Colaizzi's seven-step phenomenological analysis method, and thematic coding was performed [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 the participants for validation; and expert examination of themes and codes.

Reliability of the Study

The reliability of this study was established according to the criteria of credibility, dependability, transferability, and confirmability [11]. Participant approval was obtained, the examined phenomenon was described in detail, the researchers discussed the process, direct quotations from participants' statements were utilized, 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 in this study. Retrospective sharing may have caused some details to be forgotten or misremembered by participants. 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 in future studies. Our study only included families who successfully had a savior sibling child and experienced a successful transplant from the savior sibling child to the sick child. Future studies may offer a broader perspective by including families whose processes were not 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 applied, pseudonyms were used, and data were stored securely and will be destroyed after 3 years. The authors reported no competing interests.

Results

Demographics and Clinical Characteristics

The study included parents from 16 families that had undergone successful savior sibling procedures for children with thalassemia major. The mean age of the mothers was 36.4±5.2 years and that of the fathers was 39.2±5.8 years. Most participating parents (81.3%) had at least high school education, with 37.5% having university degrees. Families were from diverse geographical regions of Türkiye, with the majority being from the Marmara (31.25%) and Central Anatolia (25%) regions. The mean age of the 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 reflecting parents' experiences throughout the savior sibling process: disease stage, treatment, recovery process, social/family, support systems, and recommendations. A detailed breakdown of these themes, their categories, and associated codes is 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 data, facilitating the identification of underlying meanings and relationships.

Within the theme of "disease stage," 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... because I also have two children who are carriers, and we are both university graduates, my wife and I. Why didn't we notice this before and take precautions?" (participant no. 1).

The code of "community pressure on father to have savior sibling child" within the category of "religious and cultural factors" referred specifically to pressure to have a savior sibling child who could potentially be a donor for the

Table 1. Demographic and clinical characteristics of study participants (n=16 families).

Characteristics	n (%) or mean ± SD
Parent demographics	
Mother's age, years	36.4±5.2
Father's 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
Sex	
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
Sex	
Male	7 (43.75%)
Female	9 (56.25%)
Age at donation, years	2.1±0.6

SD: Standard deviation; HSCT: hematopoietic stem cell transplantation.

Table 2. Themes and categories.

Themes	Categories	Codes and numbers of repeats (n)
1. Disease stage	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) 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 about it in 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) Any pregnancy termination being forbidden in religion (6)
2. Treatment	Challenges	Protecting the sick child from prejudice (3) Economic difficulties (11) Prolonged hospitalizations (17) Need to travel frequently for treatment (16) Need to migrate for treatment (3)
	Having a baby by IVF	Expectations during pregnancy (5) Mother's burden of duty (18) Feeling under pressure (26) Restriction of movement during pregnancy (11) Consequences of unfavorable termination of pregnancy (5) IVF process (2)
	Emotional state	Being worried about bad results (3) Considering 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)
3. Recovery process	Emotional changes	Positive emotions (14) Lack of a fuss about the new child (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 of looking after the savior sibling (3)

Table 2. Continued.

Themes	Categories	Codes and numbers of repeats (n)
4. Social/ family	Perspective of family members	Views of family members (11) Normal family relationship (11)
	Having a savior sibling child	Wishing 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)
	Meaning attributed to the savior sibling	Giving meaningful names (6) Considering the purpose of the child's birth being sacred (11) Hope of curing the sick child (9)
5. Support systems	Coping mechanisms	Religious motivation sources (4) Do not want to remember (7) Do not think negatively (5) Sources of self-motivation (3) Being worn out/tired (15) Psychological effects (10) Abandoning life (7) Burnout (15) Post-procedural illness of parents (3) Do not reflect on the process (5)
	Social support systems	Marital support (7) Support from extended family/near neighborhood support (35) Psychological support (7) Doctors' support (12) Interactions with different families who have gone through the same process (15)

IVF: In vitro fertilization.

sick child. 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 decisions, six mentioned the religious prohibition of pregnancy termination, and others were primarily focused on saving the sick child without considering religious implications.

The theme of "treatment" contained four categories: "difficulties," "having a baby by IVF," "emotional state," and "preparation 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 happened, so I spent most of the time lying down" (participant no. 3).

The theme of "recovery process" comprised two categories: "emotional changes" and "caring for the sick child after bone marrow transplantation." Parents reported positive emotional transitions following the successful transplantation, although 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" (participant no. 8).

The theme of "social/family" included three categories: "perspective of family members," "having a savior sibling child," and "meaning attributed to the savior sibling." Families maintained normal relationships with the savior siblings, who were aware of their roles but too young for informed consent at the time of donation.

In the theme of "support systems," participants emphasized the importance of professional help and social support networks. Some experienced delayed psychological effects, with one mother sharing the following: "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" (participant no. 11).

The theme of "recommendations" 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, each mentioned seven times.

Figure 1, presenting the code map, illustrates the interconnections between frequently mentioned codes. Codes are frequently repeated expressions identified in interviews and textual contents during the analysis process and they are expressed with numbers in parentheses in Figure 1. For example, "Doctor's Recommendation (27)" means that this expression was repeated 27 times by participants across all interviews conducted within

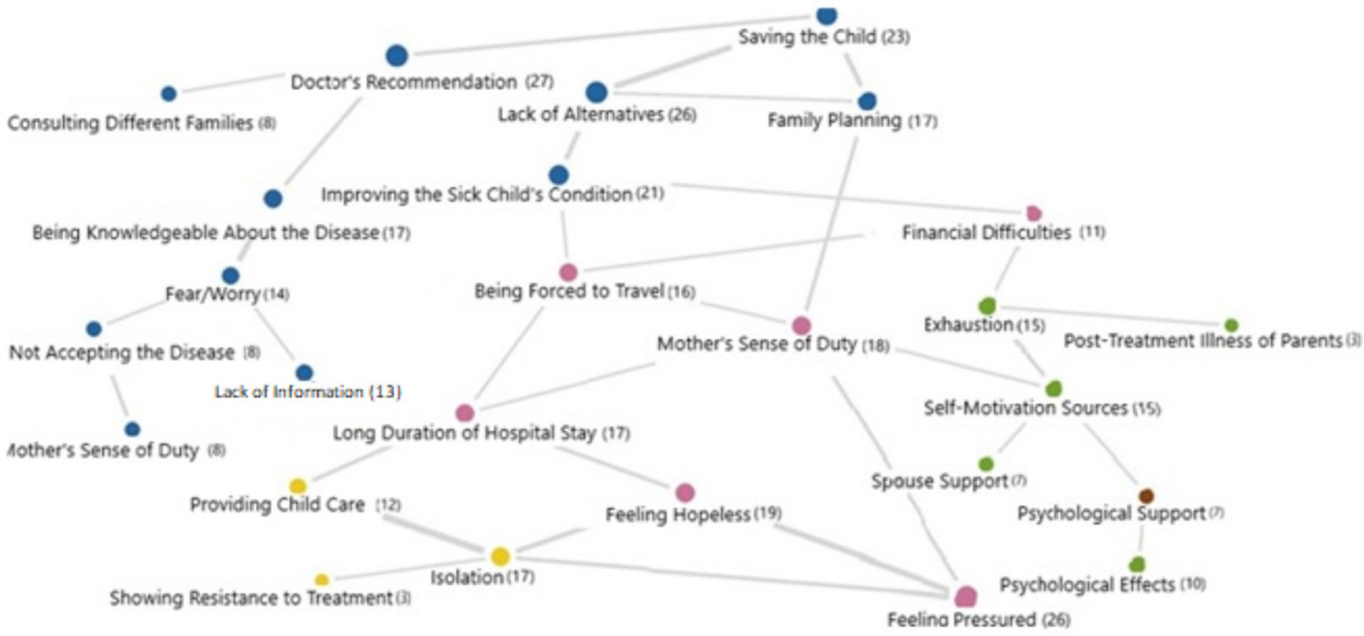

Figure 1. Code map.

the scope of the study, while "Saving the Child (23)" means that this expression was repeated 23 times by participants across all interviews. The code map particularly highlights the relationships between healing the sick child and factors such as doctors' recommendations, the 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 thicknesses representing the frequency and strength of the relationships.

Discussion

Our study provides significant insights into the experiences of Turkish families who successfully completed the savior sibling process for the treatment of a child with thalassemia major. Analysis of their demographics revealed that the participating families represented diverse geographical regions and socioeconomic backgrounds of Türkiye. This heterogeneous distribution of participants across different regions and socioeconomic strata significantly enhanced the study's representational validity and allowed for a more comprehensive perspective of the national landscape regarding savior sibling experiences. The inclusion of families from different 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 Türkiye, thereby providing a more objective and holistic view of the national situation.

The mean time from diagnosis to HSCT of 4.1±1.9 years reflects the complex nature of the process, including decision-making, PGD+HLA procedures, and preparation for the transplantation. The findings of this study provide crucial insights into the complex journeys 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 aspects, reflects 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 PGD and HLA matching technologies reflects significant advances in the field of medical genetics. These technologies are promising for diseases that previously had no chance of a cure. However, our study has also revealed some concerns about the use of these technologies. Most parents expressed concerns about the complexity and potential risks of the PGD+HLA matching process, but the willingness of the parents to take these risks shows how strong their desires were to save their children. 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. [2] showed that the short-term health status of savior siblings was normal. However, the long-term effects are still unclear.

Our findings confirm Türkiye's leading position in PGD+HLA technology implementation. The successful outcomes of all transplantations in our cohort of 16 families align with previous reports of high success rates in transplantations for children with 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 the recent literature on caregiver burden in cases of 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 the findings reported by Gürtin [13], we observed that family structure, gender roles, and cultural norms shape this process. 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 may also sometimes be a double-edged sword. Some parents reported that the intrusive behaviors of the extended family could be a source of stress. The centrality of the maternal role is another important finding of our study. Mothers generally stated that they bore 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 active roles, 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 modernization processes 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 raise important ethical debates. These findings overlap with the ethical debates addressed in the study conducted by Pennings et al. [15]. However, an unexpected finding of our study is that the parents attached more importance than expected to the future autonomy of the child born as a savior sibling. Many parents stated that the child would be able to make his or her own decisions about whether or not to donate stem cells as the child 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 a religious context 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 Türkiye. This reflects the strengths of the country's healthcare system. However, factors such as economic difficulties and the 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 results obtained by Liu et al. [16] in the United States and it 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 programs for families and facilitating access to these services, and establishing special financial support programs for families beginning the savior sibling process are our recommendations for these issues.

Although premarital thalassemia screening was initiated in 41 provinces in Türkiye in 2003 and expanded nationwide in 2018 [17,18], the birth rate of infants affected by thalassemia major continues to be a significant concern. The first HSCT in Türkiye from a healthy HLA-matched sibling born after PGD+HLA matching was performed on November 29, 2005, at Akdeniz University Hospital in Antalya. 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 the health status, identity development, and self-perceptions of savior siblings alongside the medical and psychological impacts of PGD+HLA matching technologies. Investigation of socioeconomic factors, gender roles, and family dynamics within Turkish society would enhance our sociological understanding of the process. 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 the savior sibling process reveals the complex interplay among 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 the importance of establishing comprehensive support programs, enhancing geographical access to specialized centers, and implementing culturally sensitive care protocols. These findings have significant implications for HSCT in Türkiye and other similar cultural contexts, demonstrating that advanced genetic technologies can be successfully integrated into traditional societies when supported by appropriate medical and psychosocial infrastructures.

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Ethics

Ethics Committee Approval: Clinical Research Ethics Committee of Afyonkarahisar Health Sciences University (dated: 05.08.2022 and numbered: 2022/9).

Informed Consent: Consent was obtained from all participants.

Footnotes

Authorship Contributions

Surgical and Medical Practices: İ.E.; Concept: İ.E.; Design: İ.E.; Data Collection or Processing: İ.E., H.N.Ç.Ö., F.Y.; Analysis or Interpretation: İ.E., H.N.Ç.Ö., F.Y.; Literature Search: İ.E., H.N.Ç.Ö., F.Y., A.Y., V.U., G.K., F.T.K., O.D., B.K., S.A., F.V.O., G.Ö., M.K., B.A.A., Ö.T., Z.K., B.M., A.E.K., A.B.A.; Writing: İ.E., H.N.Ç.Ö., F.Y., A.Y., A.K., V.U., G.K., F.T.K., O.G., B.K., S.A., F.V.O., G.Ö., M.K., B.A.A., Ö.T., Z.K., B.M., A.E.K., A.B.A.

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