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Parental barriers in preventing recurrent thalassemia in children: A qualitative study

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ABSTRACT

Thalassemia is a genetic blood disorder that can cause a heavy burden on families, especially parents whose children suffer from this condition. Parental involvement in preventing thalassemia in children is key, but there are many challenges to be faced. The aim of this study was to explore parental barriers in preventing recurrent thalassemia in children. This research uses a qualitative design with a phenomenological approach. Researchers conducted interviews and focus group discussions with 15 parents of children with thalassemia at a hospital in West Java Province. Data was collected and then analyzed using a phenomenological approach to identify main themes. The results of the study show that the barrier for parents in preventing recurrent thalassemia is the belief that my bloodline is clean, because there are no plans to have more children, so lazy to do screening, busy time, fear, expensive cost, and desire to have another child. This study found that there are various psychosocial and economic factors that influence parents' decisions in preventing thalassemia in their children. Increased education and financial support can help reduce the barriers parents face. More inclusive health policies and social support programs designed to target these factors could improve thalassemia prevention efforts.

Keywords: barriers, parents' experiences, prevention, thalassemia

ABSTRAK

Thalassemia merupakan kelainan darah genetik yang dapat menimbulkan beban berat bagi keluarga, terutama orang tua yang anaknya menderita kondisi tersebut. Keterlibatan orang tua dalam mencegah talasemia pada anak merupakan kuncinya, namun banyak tantangan yang harus dihadapi. Tujuan penelitian ini adalah untuk mengetahui hambatan orang tua dalam mencegah thalassemia berulang pada anak. Penelitian ini menggunakan desain kualitatif dengan pendekatan fenomenologis. Peneliti melakukan wawancara dan diskusi kelompok terfokus kepada 15 orang tua anak penderita thalassemia di salah satu rumah sakit di Provinsi Jawa Barat. Data dikumpulkan kemudian dianalisis menggunakan pendekatan fenomenologis untuk mengidentifikasi tema-tema utama. Hasil penelitian menunjukkan bahwa hambatan orang tua dalam mencegah thalassemia kambuhan adalah keyakinan bahwa garis keturunan saya bersih, karena tidak ada rencana untuk memiliki anak lagi, sehingga malas melakukan skrining, waktu sibuk, ketakutan, biaya mahal, dan keinginan. untuk memiliki anak lagi. Penelitian ini menemukan bahwa terdapat berbagai faktor psikososial dan ekonomi yang mempengaruhi keputusan orang tua dalam mencegah talasemia pada anaknya. Peningkatan pendidikan dan dukungan keuangan dapat membantu mengurangi hambatan yang dihadapi orang tua. Kebijakan kesehatan yang lebih inklusif dan program dukungan sosial yang dirancang untuk menyasar faktor-faktor ini dapat meningkatkan upaya pencegahan talasemia.

Kata Kunci : hambatan, pengalaman orang tua, pencegahan, thalassemia

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INTRODUCTION

Thalassemia major is an inherited genetic blood disease caused by an abnormality in the synthesis of one of the two globin chains present in hemoglobin (Meiyanti et al., 2020). In the world, approximately 1.5% of the global population are thalassemia trait carriers, with varying prevalence in different regions, including in Indonesia, which has a significant number of thalassemia cases (Angane et al., 2022). This condition can lead to chronic anemia that requires regular blood transfusions and intensive medical management. Thalassemia major is a serious genetic blood disorder and one of the most common genetic diseases in the world, with a significant impact on the health and quality of life of sufferers (Valizadeh et al., 2021). The disease is mainly caused by genetic mutations that lead to abnormal hemoglobin production, causing anemia and other related disorders. Due to the hereditary nature of the disease, the role of parents is crucial in the prevention and management of this condition in children (Meiyanti et al., 2020).

The main problem in preventing recurrent thalassemia major in children lies in the lack of parental awareness and understanding related to this genetic disease. The genetic factors of thalassemia dictate the need for effective genetic screening and counseling for high-risk couples (Caocci et al., 2012). However, access to genetic health information and services is often limited, especially in areas with less health resources.

The challenges faced by parents in preventing childhood thalassemia are not only technical or informative. Economic burden, social stigma and ethical decisions are also part of the challenges. Options such as pre-implantation genetic diagnosis (PGD), embryo screening and other assisted reproductive technologies provide opportunities to prevent disease, but also raise ethical and psychosocial questions (Razzazan et al., 2015). In addition, there are cultural and social barriers that make parents reluctant or unable to seek or use such information.

There are several factors that hinder parents in their efforts to prevent recurrent thalassemia in children. First, low awareness of thalassemia and limited understanding of the mechanism of genetic transmission are often the main barriers. Many parents are unaware that they are carriers of the thalassemia trait, which unwittingly increases the risk of having children with the same condition (Bala & Sarin, 2014). Second, limited access to quality health services, including genetic screening and counseling, makes it difficult to identify and effectively manage this condition (Rehman et al., 2021). Third, economic factors play a significant role, where high treatment costs and long-term management needs can be a burden to families (Chong et al., 2019; Mariani et al., 2020). Fourth, stigma and social pressure often prevent families from seeking help or participating in screening programs for fear of discrimination or social exclusion. Finally, psychological challenges faced by parents, such as fear, anxiety, and emotional burden, can reduce their ability to make informed decisions regarding thalassemia prevention in their children (Bagul, Abhay et al., 2013). Effective prevention of thalassemia requires a holistic strategy that addresses all these barriers, involving in-depth education, social support, and the availability of inclusive and affordable health services.

Therefore, it is important to further investigate the challenges faced by parents in preventing recurrent thalassemia in their children, and identify strategies that can be taken to address these issues. The purpose of this study was to explore parental barriers to preventing recurrent thalassemia in children.

RESEARCH METHOD

Design

This research uses a qualitative design. The approach used is phenomenological which aims to explore and describe the phenomena experienced by parents of children with thalassemia from their own perspective.

Population and Sample

The study participants will consist of parents who have at least one child diagnosed with thalassemia. The sample will be purposively selected to ensure that participants have diverse experiences relevant to the phenomenon under study. The sample size in this study is 16 parents with thalassemia children. This study was conducted in one of the hospitals in West Java Province.

Data Collection

Data collection techniques in qualitative research conducted in this study were using in-depth interviews and focus group discussions with 16 parents divided into 2 groups. Through this technique, the researcher explored information about the health prevention program carried out and the obstacles in implementing the prevention program. Questions were open-ended to encourage discussion on topics such as understanding of the disease, experiences with health services, social support, and challenges in prevention. Interviews were recorded and transcribed verbatim.

Data Analysis

Interview transcripts were analyzed using phenomenological analysis methods, which may include approaches such as Colaizzi or Giorgi, to identify key themes and subthemes. This process involved repeatedly reading through the transcripts, looking for emerging insights, and developing categories that reflected the participants' essential experiences.

Research Ethics

This study was approved by the relevant Research Ethics Committee. Informed consent explaining the purpose of the study, procedures, participants' right to withdraw at any time, and measures to maintain confidentiality will be obtained from all participants.

Validity and Reliability

To ensure validity and reliability, the researcher will use triangulation, member checking, and journal reflection techniques to review the research process and data interpretation. Peer reflection and supervision will also be used to ensure critical and objective interpretation.

RESULTS AND DISCUSSION

Data collection in this study is through focus group discussion (FGD) by identifying problems of parents or families with children diagnosed with thalassemia in Thalassemia Clinic of Hasan Sadikin General Hospital, Bandung. The data that will be identified through FGDs include data on problems/barriers in preventing recurrent thalassemia (such as thalassemia screening, family planning, prenatal diagnosis, etc.) from the perspective of parents and their expectations to meet the needs in the care of children with thalassemia.

Description of Parents' Characteristics

There were 16 parents who participated in this FGD, all of whom were mothers of children with thalassemia. The FGDs were divided into 3 sessions. Each session lasted 60 minutes. Session I had 7 participants, session II had 5 participants, and session III had 4 participants. The participants' ages ranged from 27 to 46 years old. The participants' level of education varied from elementary school, junior high school, and senior high school. The participants' occupation is housewife. The monthly income of the participants' families ranged between <Rp. 2,000,000 and between Rp. 2,000,000 - Rp. 4,000,000. A total of 14 participants used various family planning methods such as injections, IUDs, implants, and pills. Meanwhile, 1 participant did not use family planning, and 1 participant was 6 months pregnant.

Thematic Analysis Results

After conducting FGDs with parents of children diagnosed with thalassemia, several themes were obtained regarding obstacles or constraints in preventing recurrent thalassemia such as thalassemia screening and family planning.

One of the preventive measures taken in overcoming the incidence of recurrent thalassemia is one of them by conducting thalassemia screening either among couples (husband and wife) or in other family members such as brothers or sisters of children diagnosed with thalassemia. The reasons or barriers of participants who did not or have not done screening are as follows.

Table 1
Thematic Analysis Results

Theme	Quotes
Confidence that my bloodline is clean	"..., at that time I was told to be screened too, because I felt that my bloodline was clean. So I thought I didn't need to check, right. Because the bloodline, in my opinion, I am clean". (R3)
Because there are no plans to have more children, so lazy to do screening	"...so the desire to have more children I think it's probably not there yet, so ah lazy, let's just enjoy what is there, lazy to want to do screening, the important thing is just the first child I screened." (R8) "The reason is that I'm afraid of having another child, and I also don't do screening." (R2)
Busy time	"...the first child again, I wanted to register, but the time was busy" (R8) "...I wanted to join the screening, but the time was not right..." (R6) "...yes, I haven't had screening yet, I planned to, but the time wasn't there. My husband will also check later, hopefully it's okay..." (R7) ".... haven't had a screening yet because there is no time, it's just not the right time, my husband will also check later..." (R15)
Fear	"..I haven't done screening yet, because I feel scared, it's better not to know at all..." (R1)
Expensive cost	"...no ah, I haven't been screened, because the cost is expensive..." (R13) "... I'll get the screening later, I want to get the screening if there is a program later...." (R16)
Desire to have another child	"in my heart, maybe there is, maybe so, but that's it" (R8) "yes..., I want to have another child because I only have one, I plan to, but I'm afraid, my husband is also afraid..." (R14)

DISCUSSION

Findings from this study indicate that parents with thalassemia children face various challenges in preventing recurrent occurrence of the disease in their children. Consistently, participants reported barriers in access to comprehensible genetic information and relevant counseling services. These difficulties correspond with previous research documenting deficiencies in communication between healthcare providers and parents regarding genetic risks and prevention options (Mat et al., 2020). Furthermore, socioeconomic and cultural factors often play an important role in the decisions made by parents. Many participants reported that cultural beliefs and social norms have a strong influence, which is consistent with findings from Septyana et al., (2019), who highlighted how social norms can hinder the adoption of genetic disease prevention practices.

On the other hand, the results of this study also revealed remarkable strength and resilience among parents. They often develop coping strategies and strong informal support networks to cope with the emotional stress associated with caring for a child with thalassemia (Fitriliani et al., 2020; Rehman et al., 2021). This confirms the importance of supporting existing social systems, found in the study by Chandra et al., (2022), which indicated the importance of community as a source of support.

This study revealed one of the main challenges faced by parents in managing the care of a child with thalassemia is their busy daily lives. Most parents work full-time, often to meet the financial needs of the family, including ongoing healthcare costs. This leads to a dilemma for many families, where limited time reduces their ability to actively participate in the prevention of recurrent thalassemia events (Chandra et al., 2022; Fitriliani et al., 2020). Similar studies have highlighted the difficulties faced by families with chronic conditions in managing their children's health care with their work responsibilities (Khanna et al., 2015; Mettananda et al., 2020).

Busy parents often rely on their social networks, including extended family and community, for support in the management of thalassemia in their children. However, this study suggests that this support is not always available or consistent, reinforcing difficulties in regular monitoring and effective medication management (Khanna et al., 2015; Artamia et al., 2019). Research by Barua et al., (2020) also suggests that lack of social support can increase emotional distress in parents, potentially reducing effectiveness in treatment and prevention.

Financial hardship is one of the major obstacles parents encounter in their efforts to prevent thalassemia in their children. The costs associated with thalassemia treatment are often significant and go beyond medical treatment, including transportation costs for routine care, nutritional supplements, and loss of income due to frequent absences from work. In this study, many parents expressed concern about the ongoing financial burden, which is compounded by the lack of insurance coverage or financial support from the government (Behdani et al., 2015; Stacy et al., 2021). Previous research has identified that access to affordable healthcare is a determining factor in the successful management of pediatric chronic diseases (Stacy et al., 2021). In the case of thalassemia, effective preventive care, including regular iron chelating therapy and blood transfusions, is important to prevent complications such as iron overload, which can lead to organ damage and other serious health problems.

Healthcare professionals play a vital role in overcoming the barriers parents face in their efforts to prevent childhood thalassemia. Medical professionals, particularly pediatricians, nurses, and genetic counselors, have a responsibility to provide accurate and up-to-date information on thalassemia management, guide parents through the maze of genetic information, and support them in making informed decisions regarding their child's health management (Mat et al., 2020). They should also be proactive in identifying families who may be experiencing financial or logistical difficulties and work with social agencies or charitable organizations to provide the necessary resources (Chandra et al., 2022). Effective education from health professionals can strengthen parents' understanding of the importance of early screening, appropriate preventive therapy, and other preventive measures to reduce the risk of complications in children living with thalassemia (Bala & Sarin, 2014).

Multidisciplinary collaboration is important to ensure that each family receives holistic and integrated support that addresses not only the medical but also the psychosocial and economic issues that accompany thalassemia treatment (Barua et al., 2020). Health care providers to recognize the need for a more holistic approach to communication and health education, which focuses not only on information delivery but also on respecting the cultural and social context of parents (Mettananda et al., 2020). The development of more inclusive and culturally sensitive educational materials could improve the effectiveness of thalassemia prevention programs.

CONCLUSION

This study adds to the existing literature by revealing that parents' experiences in preventing childhood thalassemia are complex and multifaceted. This demands an equally complex response from the health system to effectively support them in their prevention role. The findings of this study have important implications for clinical practice and policy making when it comes to supporting families at risk of thalassemia. The implications include the need for a more sensitive and personalized communication approach in genetic counselling, which takes into account the uniqueness of each family, including socioeconomic and cultural factors. Improved access to clear and comprehensive genetic information can also help parents make better decisions regarding the prevention and management of thalassemia. In addition, the development

of stronger support networks and community-based intervention programs can empower parents and improve the quality of life of affected families.

Given the limitations of this study, including a sample that may not include all cultural and economic perspectives, recommendations for future research include larger quantitative studies to test the prevalence of factors identified in this study. Future research should also explore the use of digital technologies to improve education and communication between healthcare providers and parents. In addition, there is a need for intervention research designed to test the effectiveness of new support strategies targeted to families facing thalassemia risk. In-depth research into fathers' experiences in this context would also add an important perspective that is often under-explored. A multidisciplinary approach involving psychologists, social workers and genetics specialists may provide further insights into how best to support families in dealing with the challenges associated with thalassemia.

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Conflict of Interest Statement

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