ORIGINAL ARTICLE

Level of Knowledge and Awareness Among Parents Regarding the Care of Children with Thalassaemia

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ABSTRACT

Background This study assessed parental knowledge and awareness of children with thalassemia. Thalassemia care among 65 parents at a Kota Kinabalu hospital focuses on parental knowledge and awareness of children with thalassemia. The objectives were to identify parents' level of knowledge of thalassemia care and assess their awareness of specific care needs.

Methods: This was a descriptive, cross-sectional study of the thalassemia families of patients at Likas Women and Children's Hospital, Kota Kinabalu, Sabah. Using random sampling. The study involved 65 respondents from Sabah Women and Children in Kota Kinabalu, Sabah. Data from questionnaires and tests were processed using SPSS version 24, with descriptive statistics analysing frequency and percentage, expressed as mean ± standard deviation.

Results Most respondents had a high level of knowledge about thalassemia, an inherited disease caused by insufficient red blood cell supply. They understood that untreated conditions could deteriorate thalassemia patients but could lead normal lives with proper therapy. They also knew that thalassemia could be detected through blood tests and that blood donation could be beneficial. However, they had moderate knowledge of the connection between thalassemia and anaemia, blood transfusions as the only treatment, and their ability to identify and avoid thalassemia during pregnancy.

Conclusion This study emphasises the need for education, community engagement, and healthcare involvement to enhance the understanding and support of individuals with thalassemia, suggesting that comprehensive strategies, including education programs and collaborations with local organisations, can be implemented.

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Introduction

Thalassemia is a genetic disease or inheritance that occurs worldwide. Thalassemia remains one of the diseases for which there is no cure or treatment. Therefore, the incidence of thalassemia shows a significant increase in this country because of marriage, especially among individuals categorised as minor carriers.[1] When both couples marry and have children, they can potentially have a child with thalassemia primary disease.[1,2] This situation will significantly impact couples and challenge the Malaysian Ministry of Health, particularly in providing exceptional care. Based on statistics from the Malaysian Ministry of Health, thalassemia cases in this country, especially in Sabah, have consistently increased yearly. This situation causes the annual incidence rate of thalassemia in the state of Sabah to increase.

Researchers have proposed and discussed various theories and assumptions regarding the significant increase from year to year. Although not explicitly discussed, what factors caused this increase, especially in Sabah? The possibility that this situation occurs because of knowledge of and exposure to thalassemia still needs to be discovered by the community in this state.[3] Based on a study[3,4] one of the factors that cause an increase in the number of thalassemia patients in this country is marriage between individuals who are both minor carriers.

The result of their marriage will give birth to a child who is prone to thalassemia. The interviews conducted by the researchers found that most of these couples did not know they would have a child at a high risk of giving birth to a child with thalassemia if both were carriers of thalassemia minor.

The most prevalent monogenic diseases worldwide are inherited haemoglobin abnormalities. In Malaysia and other tropical nations, thalassemia is one of the most prevalent autosomal recessive diseases, causing faulty haemoglobin formation. This was caused by a decrease in the production of one or more haemoglobin subunits composed of both globin chains.[5]

According to the World Health Organization (WHO)[6], thalassaemia is a major public health concern. Accurate data on the impact of the disease on health in nations with a high thalassemia prevalence is required. Although thalassemia is the most prevalent hereditary haemophilia in Malaysia, there still needs to be more information regarding the geographic distribution of patients, socioeconomic data, and clinical data, including treatment outcomes. 4.5 per cent of Malaysians were carriers. As various molecular abnormalities cause thalassemia, each ethnic group has a unique set of mutations. While uncommon among Malaysian Indians, thalassemia is more common in Malay and Kadazan-Dusun populations. Most cases of haemoglobin (Hb) Bart's hydrops fetalis have been recorded in Malaysian Chinese individuals.[7]

Methods

This was a descriptive cross-sectional study. The population of families of patients who came for treatment at Likas Women and Children's Hospital, Kota Kinabalu. Random sampling was used as the sampling method. Sample size calculation was performed using the Krejcie and Morgan 1970 table.

Respondents were 65 respondents. This study was conducted in Sabah Women and Children, Kota Kinabalu, Sabah. Data were collected from February to March 2023. Questionnaires were filled out for 15–20 minutes. The validity of the questionnaire was calculated using Cronbach's alpha to test the reliability and internal consistency of the responses obtained from the respondents.[8] Random sampling techniques were used in this pilot study. A questionnaire was created and pilot-tested using Cronbach's alpha reliability test, which yielded a value greater than 0.84.

The questionnaire was divided into two parts. The first part about the respondents' background included gender, age, marital status, living with someone and educational background. The second part was a question about respondents' awareness and knowledge of thalassemia. The questions were rated on a Likert-type scale. The questionnaire was administered with a brief description by the researcher regarding its purpose and stating. Respondents were given 20 min to respond.

Data collected through questionnaires and written tests were processed using the Social Science Statistics Package, namely SPSS version 24, to obtain results from the data obtained. Descriptive statistics were used to analyse the frequency and percentage of the data. Descriptive data are expressed as the mean ± standard deviation. An independent sample t-test was conducted to compare variables. Ethical Consideration: Permission to collect data from the hospital director was the approval to conduct the research from NMRR 124/2023.2

Results

Table 1 shows the representation of parents' demographic with 52.3% aged 31-40, 33.8% aged 31-40, and 13.8% aged 21-30. The study revealed a balanced sex distribution, with a slightly higher percentage of females (53.8%). Most participants (95.4%) were married and had a secondary or diploma education, with a smaller proportion (21.5%) having tertiary education. Most families (49.2%) had a family income below RM 2000, followed by those between RM 2000 and RM 4000 (30.8%). Most individuals (76.9%) resided with their families, while a smaller percentage (23.1%) resided with their parents and siblings.

Table 1 Demographic Data

Criteria	(N) Frequency	Percentage
Age		
21 – 30 Year	9	13.8
31 – 40 Year	34	52.3
> 41 Year	22	33.8
Gender		
Male	30	46.2
Female	35	53.8
Marital Status		
Married	62	95.4
Divorced	3	4.6
Education		
Secondary	23	35.4
Tertiary	14	21.5
Diploma	21	32.3
Degree and above	7	10.8
Family Income		
< RM 2000	32	49.2
RM 2000 - RM 4000	20	30.8

> RM 4000	13	20.0
Living With Who		
Own family	50	76.9
Parents & sibling	15	23.1

The findings of this study, referring to Table 2, that assessed parents' knowledge of how to care for children with thalassemia, revealed some significant findings. Most respondents indicated a high level of knowledge about numerous thalassemia-related topics. They constantly and firmly understood that thalassemia is an inherited disease (mean = 4.52, SD = 0.867) caused by insufficient red blood cells (mean = 4.63, SD = 0.574). Additionally, respondents demonstrated a clear understanding that thalassemia patients' conditions are likely to deteriorate if untreated (mean = 4.76, SD = 0.424) and that thalassemia patients can lead normal lives with the right therapy (mean = 4.64, SD = 0.570).

Additionally, many participants knew that thalassemia could be detected using a blood test (mean = 4.52, SD = 0.589) and that individuals with thalassemia could benefit significantly from blood donation (mean = 4.78, SD = 0.450). There were also differences in knowledge levels. The respondents' knowledge of the connection between thalassemia and anaemia was moderate (mean = 3.78, SD = 1.023), and they had a moderate comprehension that the sole available form of treatment was blood transfusions (mean = 3.35, SD = 1.351). Most respondents also showed high levels of knowledge about their capacity to identify thalassemia during pregnancy (mean = 4.12, SD = 0.760) and avoid it through genetic counselling and prenatal screening (mean = 4.44, SD = 0.750). The results showed that parents generally had a high level of knowledge of thalassemia, with only a few areas requiring additional education or awareness to improve their understanding.[9]

Table 2 Knowledge of parents regarding the care of children with Thalassemia

Item	N	Mean	Std Deviation	Interpretation
Thalassemia is due to not having enough Red Blood Cells	65	4.63	.574	High
Thalassemia is an Inherited Disease	65	4.52	.867	High
If thalassemia is left untreated, the person will get worse	65	4.76	.424	High
Individuals who have Thalassemia can lead normal lives with appropriate treatment	65	4.64	.570	High
Individuals who have Thalassemia are anaemic	65	3.78	1.023	Medium
A blood test can identify thalassemia	65	4.52	.589	High
Blood donation can help Thalassemia patients	65	4.78	.450	High
Blood transfusion is the only treatment for Thalassemia patient	65	3.35	1.351	Medium
Thalassemia can be detected during pregnancy	65	4.12	.760	High
Thalassemia can be prevented by genetic counselling, pre-marital and prenatal screening	65	4.44	.750	High

Bast on Table 3 Findings of Parents' Awareness regarding the care of children with Thalassemia. Parents showed various levels of Awareness of several thalassemia and related topics. With a mean score of 4.40 and a standard deviation of 0.932, they generally understood that thalassemia can occasionally be recovered with blood transfusions, showing a " high " level of awareness. With mean scores of 3.78 and 3.27, with various standard deviations, knowledge regarding the use of drugs and surgery as treatment options for thalassemia was moderate, reflecting a "Medium" degree of awareness.

However, there were some areas in which Awareness needed to be improved. With a mean score of 2.83 and a higher average deviation of 1.364, parents showed only a " low " degree of awareness regarding the genetic risk for thalassemia when one parent was a carrier. The average score was 4.72 out of a possible 5.00, with a relatively small standard deviation of 0.599, indicating a "High" degree of awareness regarding the hereditary risk when both parents are carriers. Additionally, parents had a "High" level of awareness, as shown by a mean score of 4.33 and a standard deviation of 0.776, regarding preventing Thalassemia by avoiding marriage with carriers or sufferers. With a mean score of 4.44 and a small standard deviation of 0.613, they also demonstrated a high awareness of the availability of screening tests for thalassemia gene detection before marriage, again demonstrating a "High" level of awareness.

In addition, there was moderate awareness that even if neither parent was a carrier, they could still have a child with thalassemia disease, with a mean score of 3.09 and a high standard deviation of 1.800, indicating a "Medium" level of understanding. Finally, with a mean score of 4.58 and a small standard deviation of 0.658, indicating a "High" level of awareness, parents demonstrated a high comprehension that thalassaemia can be treated via bone marrow transplant. Unfortunately, they had a "Low" level of awareness, with a mean score of 2.93 and a larger standard deviation of 1.356, about the requirement for frequent blood transfusions in Thalassemia carriers.

Table 3 Awareness of parents regarding the care of children with Thalassemia

Item	N	Mean	Std Deviation	Interpretation
Thalassemia can sometimes be treated with blood Transfusion	65	4.40	.932	High
Thalassemia can sometimes be treated with medications	65	3.78	1.256	Medium
Thalassemia can sometimes be treated with surgery	65	3.27	.875	Medium
If one parent has the Thalassemia carrier, the couple has a chance of having a child with Thalassemia disease	65	2.83	1.364	Low
If both parents have the Thalassemia carrier, there is a chance of having a child with Thalassemia disease	65	4.72	.599	High
Thalassemia can be prevented by not marrying a Thalassemia carrier or	65	4.33	.776	High

Thalassemia patients				
Screening tests for Thalassemia gene detection can be done before marriage	65	4.44	.613	High
If neither parent has the thalassemia carrier, they can have a child with thalassemia disease	65	3.09	1.800	Medium
Thalassemia can be treated by bone marrow transplant	65	4.58	.658	High
A person with thalassemia carrier requires frequent blood transfusion	65	2.93	1.356	Low

Discussion

The majority of respondents showed a good understanding. For example, a sizeable proportion strongly concurred that thalassemia is inherited. It showed that the participants understood thalassemia's genetic basis and possible effects.

The participants also demonstrated a high awareness of the requirement for routine blood transfusions in thalassemia patients. Most respondents strongly agreed that patients with thalassemia need frequent blood transfusions, consistent with the fact that transfusions are a frequent and important treatment option for thalassemia management.[1]

Findings indicate that the participants thoroughly understood the therapeutic approaches required for thalassemia patients. The importance of genetic counselling and premarital screening tests was well understood by participants in terms of preventive measures.[10] Many firmly believe that premarital screening and genetic counselling effectively prevent thalassemia.

Determines the significance of identifying carrier status and the role of informed decision-making in family planning to prevent thalassemia transmission to future generations.

However, there were also aspects where participants showed a small quantity of uncertainty or knowledge gaps. For instance, many individuals questioned had misunderstandings or divergent opinions about their ability to spot thalassemia in pregnant women.[11v]This finding suggests the need for further education and awareness regarding prenatal testing and its role in identifying thalassemia in unborn children. Furthermore, some participants disagreed about treating thalassemia with medication, surgery, or bone marrow transplant. Indicates a potential knowledge gap regarding available treatment options for thalassemia.[12] Therefore, it is important to publish accurate information about various therapeutic approaches and their applicability in various thalassemia cases.[13]

Most respondents recognised that thalassemia is an inherited disease, emphasising the importance of genetic factors in its development. This understanding is crucial for providing appropriate care for children with thalassemia, as it enables healthcare providers to identify and support at-risk families, provide genetic counselling, and offer early interventions.[14]

Furthermore, participants' awareness of the need for frequent blood transfusions in patients with thalassemia is vital for caring for affected children.

Regular blood transfusions are essential for managing thalassemia symptoms and preventing complications. The participants' recognition of this aspect indicates a level of knowledge that aligns with the established medical guidelines for thalassemia treatment.[15]

However, there were areas where participants demonstrated uncertainty or a lack of knowledge. For example, some participants expressed uncertainty regarding detecting thalassemia during pregnancy. This knowledge gap can have significant implications for the care of children with thalassemia, as early detection during pregnancy allows for timely interventions, including specialised prenatal care, genetic counselling, and informed decision-making regarding the child's future.[16]

Moreover, the participants' varying levels of knowledge regarding the treatment options for thalassemia can impact the care provided to affected children. While the majority agreed or strongly agreed that thalassemia can be treated with interventions, such as medications, surgery, or bone marrow transplantation, a notable number expressed uncertainty or disagreement. Highlights the importance of ensuring accurate information dissemination to healthcare providers and families to facilitate informed decisions regarding the most appropriate treatment modalities for individual cases.[17]

It is crucial to address these knowledge gaps to improve the care of children with thalassemia. Education and awareness programs can be pivotal in providing accurate information about thalassemia, its management, and available treatment options. These programs should target healthcare professionals, parents, and the general public, foster a comprehensive understanding of thalassemia, and promote best practices in care.[18]

Additionally, healthcare providers should prioritise genetic counselling services and facilitate access to premarital and prenatal screening programs. Increasing awareness and promoting these preventive measures can minimise the risk of thalassemia transmission, and parents can make informed decisions regarding family planning.

Data analysis also sheds light on parents' awareness regarding caring for children with thalassemia. The participants' responses provided insights into their awareness and understanding of the specific needs, challenges, and considerations involved in caring for children with thalassemia. One aspect of parental awareness is their understanding of the need for regular blood transfusions in children with thalassemia.[19]

Most participants agreed or strongly agreed with the statement that individuals with thalassemia require frequent blood transfusions. Indicates heightened awareness among parents about the critical role of blood transfusions in managing thalassemia and ensuring the well-being of the affected children.

Also, the fact that most people who took part agreed or strongly agreed that people with thalassemia can live normal lives with the right treatment shows that they are optimistic about the chance for children with thalassemia to have fulfilling and important lives. This awareness is crucial in empowering parents to provide their children with the necessary support, care, and opportunities, promoting their overall well-being and quality of life.[20]

However, it is important to note that there were areas where participants expressed uncertainty or disagreement, indicating potential gaps in their awareness and understanding. For instance, some participants were unsure or had mixed opinions regarding their ability to detect thalassemia during pregnancy. It suggests a need for further education and awareness regarding prenatal testing and the importance of early diagnosis and intervention in improving outcomes in children with thalassemia.[21]

People in the study had varying knowledge and agreement about treatment options such as drugs, surgery, or bone marrow transplantation. This could mean they did not know about or did not understand the different ways to treat thalassemia.[22] The importance of providing comprehensive information and support to parents, ensuring that they are well informed about the different treatment modalities and their potential benefits for their children.

Targeted educational initiatives are essential for enhancing parents' awareness of caring for children with thalassemia. Healthcare providers and organisations should provide comprehensive information to parents, address common misconceptions, and highlight the importance of early diagnosis, regular medical follow-up, and adherence to treatment plans.

Empower parents to actively participate in their child's care actively, promoting better health outcomes and overall well-being. Furthermore, support groups and counselling services can play a vital role in raising awareness and providing emotional support to the parents of children with thalassemia. These resources can facilitate sharing experiences, exchanging information, and developing coping strategies, empowering parents to navigate the challenges and complexities in caring for children with thalassemia.[23]

The study examining how parents care about kids with thalassemia found that most parents knew much about it. Parents knew that their kids would need regular blood transfusions and that, with the right care, they could live normal lives. However, there are areas where awareness and understanding can be improved, such as prenatal testing, treatment options, and holistic care for children with thalassemia.[24] By implementing targeted educational programmes, providing comprehensive information, and fostering support networks, we can enhance parental awareness and empower parents to provide the best care for their children with thalassemia.

Parental awareness is crucial in ensuring that children with thalassemia receive appropriate and timely medical intervention. With an understanding of the need for regular blood transfusions, parents can actively collaborate with healthcare providers to ensure their child receives the necessary transfusions at the recommended intervals. This awareness can contribute to better management of thalassemia-related symptoms and complications, ultimately improving children's overall health and quality of life.[25]

Moreover, awareness of treatment options such as medications, surgery, or bone marrow transplantation allows parents to have meaningful discussions with healthcare professionals. They can weigh different interventions' potential benefits and risks and make informed decisions regarding their children's most suitable treatment course. This level of awareness empowers parents to advocate for

their children's health, ensuring they receive the best available care and treatment options.[26]

Parental awareness extends beyond medical intervention. It encompasses a holistic understanding of the daily challenges and unique needs of children with thalassemia. Includes awareness of the importance of regular monitoring, adherence to medication schedules, dietary considerations, and children's emotional well-being. By recognising and addressing these aspects, parents can provide comprehensive care that supports their children's overall development and quality of life.[27]

Additionally, parental awareness influences the support network available to children with thalassemia. When well-informed, parents can seek resources, connect with support groups, and access educational materials that provide guidance and assistance.[28] This network offers valuable emotional support, practical advice, and opportunities to share experiences with other families who face similar challenges. Parental awareness creates a strong foundation for building a supportive community around the child, fostering a sense of belonging, and reducing the feelings of isolation that sometimes accompany thalassemia.[29]

Collaboration among healthcare providers, advocacy groups, and educational institutions is crucial to enhance parents' awareness regarding the care of children with thalassemia.[30] These stakeholders can collaborate to develop and implement educational programmes addressing parents' needs and concerns. Such initiatives should provide accurate information, practical guidance, and opportunities for support and engagement. [31] Furthermore, healthcare providers should prioritise open and effective communication with parents, ensuring that information is compassionate and culturally sensitive.[32] This approach can build trust and empower parents to participate actively in decision-making processes related to their child's care.

Conclusion

This study stresses the importance of education, community, and healthcare involvement to understand and help people with thalassemia. It suggests that broad strategies, such as education programmes and working with local groups, can be implemented.

Conflict of Interest

The authors declare no potential conflicts of interest or competing interests. The authors received no financial assistance or grants from public, private, or non-profit funding agencies.

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