

Indonesian Mothers' Needs and Concerns about Having a Thalassemic Child and Its Treatment: An Exploratory Qualitative Study

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ABSTRACT

Thalassemia is a major genetic blood disorder that considered as a public health problem in Indonesia. Yet, little is known about affected individuals thalassemic children and parents overall experiences with and perceptions of thalassemic mayor in Indonesia. This study aimed to explore the concerns, beliefs, feelings and needs of mothers' who have a thalassemic child. A total of (N=24) mothers' were chosen as participants. Focus Group Discussion (FGD) was carried out to better elucidate the mothers' perceptions of their needs and concerns. A semi-structure focus group moderator's guide corresponding to the research questions was developed. To gain in-depth understanding, questions were divided in four major domains which were (i) Perceptions about child disease, (ii) Knowledge about thalassemic and its treatment, (iii) Thalassemic impact on child and family, and (iv) Needs and future concerns. Transcripts were thematically coded according to the research themes that emerged from the data, and the themes were further sorted into subthemes. The finding of this study indicates significant impact of thalassemic children on their families in terms of emotional well-being, financial burden and social impact. Mother's education level was very low about Thalassemic. Mother also expressed their needs for more information about thalassemic and its treatment, social, professional support, and financial support. Results of this study provided a portrait of the reality that thalassemic has a significant impact on children and their families. A holistic approach should be carried out while caring with thalassemic children and their families. Nurses and health care professionals should explore the feelings, concerns and needs of mothers' who have thalassemic children and eventually provide appropriate care plans that alleviate their suffering.

Keywords

Children, Indonesia, Mothers' Concerns and Needs, Thalassemic mayor.

Introduction

Thalassemic major is an inherited hematological single gene disorder leading to anemia in affected children in the world that represents a major public concern in Southeast Asia, including Indonesia [1-2]. It characterized by a defect in the genes responsible for production of hemoglobin. This defect causes an abnormal development of red blood cells and ultimately anemia, which is the main characteristic symptom of the thalassemic [3-4].

Thalassemic major is classified as a chronic disease that manifests

so early in life. Children with thalassemic mayor require lifelong blood transfusion, usually started within 6 to 12 months of birth of the patient and extensive medical treatment in order to live. Thalassemic poses tremendous physical problem in the affected children, as thalassemic children depend on blood transfusions and need to be treated the rest of their lives [2-5].

In Indonesia thalassemic mayor, is more prevalent and as a serious health problem; approximately 3-10% people are carrying the genes of thalassemic due to abnormal production of hemoglobin [6]. Over 3000 thalassemic homozygotes are born every year [1]. These numbers are alarmingly growing due to lack of awareness, insufficient educational campaigns, as reported by Bulan [6] that most of the mothers with thalassemic traits never come to know

that they are carrying the genes as thalassemia carriers are healthy and they are the source of spreading the disease. However, little is known about impacted individual parents overall experiences with and perceptions of caring for thalassemia children.

Thalassemia mayor causes a lot of problems for the pediatric patients due to defect of various organs because of the illness its self or the treatment being given. The disease also causes some other medical problems to the patients such as has thalassemia faces, pale color, exhaust and cannot do hard work [5]. Development of a disease during physical and psychosocial maturation could disturb a child's quality of life. Moreover, the disease psychologically may affect the thalassemia children such as feeling of helplessness, un-acceptance, loss and grief [7-8]. Literature identifies that thalassemia not only affects the thalassemia children's health but also affects the socio-economic condition of the families and leaves disturbing psychological and financial burden on families and complexity with social integration [5,9-11]. Previous studies revealed that parents of thalassemia children expressed feelings of worry, anxieties, frustration, despair, and helplessness regarding their affected children [9,11,12]. These concerns are relatively connected with the chronic nature of thalassemia and its chronic tireless treatment [5-6].

Despite the fact that thalassemia is a major health problem in Indonesia that challenges children, parents and health care system, no studies have addressed the needs and concerns raised by parents regarding caring for thalassemia children in Indonesia. In addition, there is little understanding of parents' awareness, and knowledge regarding the disease and its impact on patients and families. Therefore, it is a crucial to establish an understanding of how mothers perceive their needs and concerns toward thalassemia children and its treatment which will be the basis for creating appropriate educational programs and optimal pediatric nursing care. In addition, this study was conducted to fill the gaps in the literature and to contribute to it.

Objective of the study

This study was carried out with an objective to explore the belief of mothers about their child disease, awareness, knowledge and the needs about thalassemia, impact of thalassemia on patients and their families, and their future concerns regarding thalassemia mayor. Thus, this study answered the following questions:

- How do Indonesia mothers whose children have thalassemia perceive their feelings and perceptions regarding thalassemia mayor and its treatment?
- How do mothers' knowledge and awareness regarding thalassemia disease and its treatment?
- What problems, concerns and needs do Indonesia mothers have regarding the disease, its treatment, and caring with children?

Methodology Research Design

A qualitative exploratory design with using focus groups was employed to understand the needs and concerns of mothers who have thalassemia children in West Java Province Indonesia.

Qualitative methods such as focus groups are aimed to provide researchers with means for collecting data that can be used to construct a descriptive account of the phenomena being studied [14]. Focus groups also tap into subjective experiences and are an effective way to collect large amounts of data that describes, explains or compares a social phenomenon [15] because this approach allows participants to interact with one another and build on one another's comments, and they allow the facilitators to probe for details [14,15].

Setting, Participants and Procedures

The eligible participants were recruited purposively from a thalassemia clinic in a General Hospital in West Java Province Indonesia. Twenty four participants who agreed to reveal a maximum description about their experiences of having thalassemia children were participated in this study. Participants were included in this study who met the established criteria. Mothers who participated in the study were; Indonesian mothers who have a child diagnosed with beta thalassemia mayor for at least 3 year and required regular blood transfusion and iron chelation therapy. On the other hand, mothers of children who are diagnosed with other medical illnesses or mental disorders and mothers who are not totally engaged and oriented in their children treatment were excluded from the study.

Focus groups were held during February to April, 2016. Participants voluntarily participated in FGDs. The researcher as moderator conducted 2 focus group discussions (FGDs) divided equally into 3 groups comprising (n=4) participants from a thalassemia clinic. A semi-structure focus group moderator's guide corresponding to the research questions was developed. To gain in-depth understanding, researcher divided questions in four major domains which were (i) Belief and perceptions about child disease, (ii) Knowledge about thalassemia and its treatment, (iii) impact of thalassemia on parents, affected child and family, and (iv) Needs and future concerns. Before conducting FGDs, a written questionnaire was completed by participants in order to gather information about their demographic backgrounds (Table. 1). All the participants were literate, and for keeping in view the convenient for participants, FGDs were conducted in using Bahasa Indonesia. The FGDs were tape recorded with the permission of the participants. Written informed consent was obtained from all participants. The anonymity of participants in the focus groups is protected in this report. The researcher has read a brief excerpt about thalassemia and showed an illustration about the inheritance patterns at each session before the proceeding of discussion about belief and perception about thalassemia and its treatments. The excerpt that was read out to all the focus groups state that "Thalassemia is an inherited blood disorder which is passed from parents to their children. There are two types of thalassemia are called minor and mayor thalassemia". The FGDs were conducted from 60 to 100 minutes.

Data analysis of focus group discussions

Result of focus group interviews were transcribed and went through several phases of analysis. A preliminary analysis was

conducted in order to get a general sense of the data and reflect on its meaning. Next, a more detailed analysis was performed and data was divided into segments or units that reflected specific thoughts, perceptions, attitudes, and experiences of participants in caring for thalassaemic children. At the conclusion of this process of analysis a list of topics was generated, and the topics were compiled into categories that were labeled as themes. Data from across all focus groups was again analyzed so it could be organized into these categories. Then these categories or themes were analyzed to determine the interconnectedness of issues and conditions that may have given rise to the categories [14,16].

Trustworthiness of the Study Findings

To enhance credibility and trustworthy findings, the researcher employed the following techniques: focus group discussions were conducted with participants to obtain rich information about the needs and concerns of mothers regarding caring for thalassaemic children and its treatment; the researcher had reviewed the transcripts and the whole process of data analysis; rich and thick description of the result was provided.

Ethics considerations

The health Research Ethics Committee of the Faculty of Medicine Universitas Padjadjaran Bandung Indonesia has reviewed the study protocol and determined that it adheres to ethical principles.

Results

	Demographic variables	Total sample	%
Gender	Female	24	100
	Male	0	0
Marital status	Married	24	100
	Divorced	0	0
	Widow	0	0
	Single	0	0
Type of Marriage	Cousin marriage	2	8.33
	Marriage with relative	4	16.66
	Out of family	18	75
Age	<20	0	0
	21-30	1	4.16
	31-40	13	54.16
	41-50	10	41.66
	>50	0	0
Highest Education Attainment	Illiterate	0	0
	Primary school	9	37.5
	Secondary School	15	62.5
	Diploma	0	0
	Graduation	0	0
Monthly income in Rupiah	< 1.500.000	3	12.5
	1.500.000 -3.000.000	21	97.5
	3.000.000 -5.000.000	0	0
	>5.000.000	0	0

Table 1: Demographic Characteristics of Respondents (N=24).

Result of data analysis in this study four main themes have been derived from participants' perceptions and thoughts, thereby they

could draw the perceptions and belief of mothers about their child disease, awareness, knowledge and the needs about thalassemia, impact of thalassemia on patients and their families, and their future concerns regarding experience in caring for thalassemia children. These themes included:

Theme 1: Belief and perception about Child's Disease

Finding of the study identified there were various mothers' beliefs and perceptions about their child disease. Mostly mothers expressed that it is the will of GOD and a trial from GOD to their faith that how firm they are in religious teachings and how do we thank to the blessing of Allah even in times of adversity. One of the participants said:

"I think the disease of my child was written of Allah. We do not have power to do anything without the will of Allah, it's all planned and written that what is going to be happen. Everything in this world is fragile and everything has to come to its eternal end, the real world is hereafter'. I have to accept this takdir".

Some participants were blaming and perceived that their marriage with their cousins or relatives was a reason for their child disease.

"I really did not know before that a cousin marriage gives birth can cause many diseases such as thalassemia. If I wish I could know it before, maybe I will not marry with my cousin. I could have option then, but now I must except my child illness and have to take care of my child as best as I can to get him treated rest of his whole life".

Theme 2: Knowledge about Thalassemia and its treatment

Across the group discussions, a number of participants were unable to give a correct definition of the disorder although they correctly defined thalassemia as an inherited blood disorder. Interestingly, there was disbelief among several participants that thalassemia is a communicable disease and can it be transmitted from one person to another. For example one participant mentioned:

"I think thalassemia is communicable disease that can be transmitted from one person to other person. Two of my children having thalassemia".

In the data showed that lack of knowledge was emerged as another related theme. Many participants demonstrated lack of knowledge about thalassemia and its treatment. They did not know any preventive measure during or before thalassemia. Moreover, there was confusion between thalassemia major and carrier among mothers and some of them were not able to tell the difference. Data also identified there were wrong assumptions that all thalassemia major children are physically abnormal, and unable to carry out daily activities and attend school, some participants even believed that thalassemia carriers also require blood transfusion and iron chelating therapy. Knowledge about the genetics of thalassemia was also very low. Many did not know that parents must be carriers in order to produce an affected child and that carrier parents have a ratio of 1:2:1 children who are normal, carrier, and thalassemia major. One of participant in group 2 suggested:

"I have been visiting to thalassemia clinic for the blood transfusion of my daughter every month for the last 3 years.

Blood transfusion process takes 5 to 6 hours which includes blood test, cross match and blood transfusion. I realize that I am uneducated and I cannot understand the doctors or nurses words " want to know all about my child disease, what actually the disease is and what is its treatment, but they told me about my child disease and its treatment not in detail".

Data of FGD's identified that many mothers were not aware about the severity of the disease and complications associated with it. However, when they were asked about what is the treatment of their child disease. Many said that blood transfusion is the main treatment of thalassemia. As a mother in group 1 said:

"I do not know that thalassemia is connected with other diseases. I believe that blood transfusion is the real treatment of thalassemia".

Some participants believed that iron chelating agent can save the lives of their thalassemic child. However, overall the mothers did not know the consequences of the treatment and with the process of bone marrow transplantation. Findings of this study indicate that mothers tended to lack of information and awareness and it is one of the major causes of inadequate knowledge about thalassemia.

Theme III: Impact of Thalassemia on affected Child, parent and Family

When talking about impact of thalassemia on the affected child and family, in general participants in this study expressed their feelings, perceptions and attitudes toward having a thalassemic child. They described about a number of concerns that influenced their psychosocial lives. These concerns were expressed as worries resulting from frequent absenteeism of their child from school, worries about child growth and development, continuing education, puberty delay, worries about marriage and occupation, fear of death, and uncertainty about future of their children. Most mothers mentioned that their children's suffering resulting from being absent from school. One of participant reported:

"My child has to visit the clinic every month for having blood transfusion. Also, he visits doctor frequently because of fever, cough and pain so that he leaves the school frequently...I worry his school achievement will affected".

In order to know the impact of thalassemia on child and family, participants were asked to give examples of specific factors that have affected the child and their parental lives. Many participants identified a considerable impact of thalassemia on affected children and their parents. They explained that their children frequently catch fever, cough and their growth is also delayed which is affecting child overall activities and most of time they cannot play with other children and if they play, they become easy to having fatigued. One of mother said that:

"I am really pity to my child he cannot life like a normal child. I want my child to live a normal life like other children; I want him to go to school, to participate in routine activities such as playing football, swimming. I cannot see him suffering with this disease; I want him to fight with the disease' I want him to stay strong and long life".

Several participants described the difficulties of their child faced while having blood transfusion and treatment every month which directly affects their child's emotions and school regularity. They noticed that sometimes their child being upset and bored.

Impacts of child disease on parental lives were significant. The impact of thalassemia on financial state emerged as other major theme. All mothers were of the opinion that financial burden was an important issue. Although nowadays Indonesian government provide free health insurance for Indonesian people especially for the poor for having free treatment of thalasemic children. However, many mothers experienced a financial constraint including the financial expenditures, transportation, visits to hospital, and purchase of rent a room because the come from other cities. Also for some them any loss of working days meant financial loss as well.

Impact of thalassemia on emotional well-being of mothers was emerged as a related subtheme. Mothers often felt frustration, sadness and helplessness regarding their child illness.

"I am often feel sad, frustration and guilty if I thinking about my child illness and its treatment. I hope my child can have long life".

Theme IV: The Future Concerns and Needs Concern

Uncertainty about children's life was a distressing factor reported by mostly participants. All participants wanted their child can grow up well and live with optimal health. As mentioned before they worried about their child's ability to continue their lives, education, find occupation in the future, and get married as others do. As a mother said:

"I am always thinking about my daughter's future...is she going to live a normal life? Is she going to finish her education, find a job or get married in the future? I am really worries about her life".

Fear of death was a major concern discussed in FGD's. All participants expressed their fear from the life-long treatment of thalassemia. They wondered whether their children will live with the demanding requirement of blood transfusion, iron chelating therapy. One mother in Group 1 stated that:

"I am really afraid that I will lose my child...I know thalassemia is a very dangerous disease...I often feel panic every time she becomes tired. I am always asking to Allah SWT to keep her in a good condition and alleviate her suffering of thalassemia".

The Needs

Regarding the needs, all participants explained about their major needs to be able caring for their child illness optimally. These themes were organized into three sub categories encompassed the need for information, emotional, social, professional support, and financial support.

The need of information

Mostly mothers reported that they need information about the

nature of thalassemia and its treatment such as the pattern of inheritance, the chance of its occurrence, and to overcome with the side effects of transfusion. As a mother in group 1 revealed:

"I know that thalassemia is a blood disorder;... but I do not understand how it happens? Why do children need blood transfusion continuously and how to reduce the side-effects of the treatment?"

Although all participants recognized that thalassemia is a genetic disorder, but they did not understand the pattern of its occurrence. One participant mentioned:

"When my child was diagnosed with thalassemia major, doctors told me that this disease is caused by a genetic problem where there is a defect in the gene, but I do not understand what's actually happened...what's going on with the gene what is that?"

Managing the side effects of thalassemia treatment was another important issue raised by participants in FGD's. Most mothers complained of iron overload and continuous blood transfusion. As a participant said:

"I know that blood transfusion gives side effect to my child condition, but I do not know how to minimize the side effects of the treatment. I want to learn how to deal with the side effects of blood transfusion, every time after blood transfusion my son often complains of headache, dizziness, and fatigue. I feel very sad and confuse because of this.... How could I help him".

Emotional, social and professional support

Emotional, social and professional support was regarded by participants in FGD's as a significant factor that alleviates the suffering of mothers and their children. Accepting the disease by others and dealing with participants and their children normally were important factors.

A participant told that her friends supported her as:

"When my friends knew about the disease of my child, they stayed with me, talked to me, and prayed for me...They are so nice and kind...They always pay attention to my family even they take care of my kids while I am being in the hospital".

Some participants felt happy because they realized their family and friends always support them as one mother said:

"My family and neighbor always give support to our family... They encourage us to cope with our condition. It made us feel happy"

Other participants suggested that teachers' support is important for their child as one mother said:

"The school teachers gave my child the permission to be absent from the school during the period of blood transfusion...They really understand my child condition...They are very kind".

Many mothers believed that support given by nurses and doctors was very useful for helping mothers to cope with the burden of the disease. They can talk about all aspects of care, treatment, and follow up care. One mother said:

"Nurses and doctors here are very kind and helpful, they helped us a lot...sometimes, they are joking with us and treating our child carefully...I always talk with nurses whenever I have questions regarding my child illness and its treatment".

Financial Support

Despite that thalassemia treatment is free in Indonesia, most mothers in this study complained of the financial cost associated with thalassemia and its treatment. This includes the cost of transportation, the cost of admission to hospital when the child becomes sick, in addition to leaving the work for the employed mothers. It can be understood this financial cost was the important issue for them because mostly participants were not a rich people. One participant commented:

"The cost of transportation is expensive...We come from Tasikmalaya, we have to pay for the bus, public transportation every time.... We are not rich people. So this is really very costly".

Discussion

So far to my knowledge, this is the first study in Indonesia which explored the mothers' belief and perception about child's disease, their awareness to disease and its treatment, its impact on patients and parents, future concerns and needs of the 24 mothers of affected children. The focus group interviews have provided valuable insights into the perceptions, knowledge, attitudes, and needs of Indonesian's mothers having a thalassemic child.

Although the small numbers of participants in focus groups limited the generalization of outcome to larger population, this study revealed several important findings. The primary themes that emerged from data analysis were (i) belief about child disease, (ii) knowledge about thalassemia and its treatment, (iii) impact of thalassemia on child and families, (iv) future concerns and needs. The findings of this study demonstrated that mothers' belief about their child disease was firm and they all have taken their child disease as a "will of Allah". The researcher identified a number of participants understanding to disease at a low level. They did not know etiology of thalassemia. Knowledge about the genetics of thalassemia was also very low. All participants also were unfamiliar with any preventive measure during or before thalassemia. The findings of this study correlate with other studies conducted by Prasomsuk et al. [5]; Liem et al. [9]; Zaman and Salahudin [17]. For instance, Zaman and Salahuddin [17] concluded in their study that educated parents were taking preventive measures if a disease is presented in their families. But on the other hand, due to the high rate of illiteracy majority were not aware of the preventive measures. The study also highlights some fundamental misconceptions which include thalassemia is a blood cancer and blood transfusions is the only treatment for this disease. Such misconceptions clearly lead to unnecessary anxieties. Similarly, many mothers in this current study have misconceptions regarding thalassemia, they though any type of thalassemia has same prognosis and etiology. It can be understood because mostly their education level was only secondary level.

The findings of this study indicated that thalassemia has a substantial effect on the emotional and social lives of mothers. Mothers perceived thalassemia as a serious and distressing disease that required lifelong treatment of blood transfusion and iron chelation therapy. The presence of a chronic disease like thalassemia places tremendous psychosocial burden on the parents and thalassemic children. Some participants discussed their areas of concerns associated with thalassemia and its treatment. The most significant concerns were related to frequent absenteeism from school, academic performance, and worries about their child future education. Mothers expressed their wish and hope for their children to have a good academic achievement and to continue their education despite their frequent absenteeism from school. While, they have shown that their child academic level was not good. Similarly, earlier studies have shown that poor academic level was related to absence from school [18-19]. Therefore, it is essential to assess if thalassemia itself causes any learning difficulties among thalassemic patients. Consequently establish appropriate interventions and educational programs should be provided.

The study findings identified all participants felt uncertainty and worries about the future of their children. Quality of life, education, marriage and occupation were major concerns reported by participants. They hoped for their children will have a better future life, having a good education, to get married, find a job and become independent. Previous research has found similar concerns of mothers [5,20].

Other important findings of this study indicated that thalassemia was affecting parental financial status. Many of the affected children's parents were unable to afford the costly treatment. Although, government is providing blood transfusion facilities; subsidize and free medicines in public teaching hospitals which are only limited to big cities. Previous research [21] found a similar finding that disease causes financial impact on patient's families. It showed that the miseries of the poor patients are greater than the efforts made so far. If thalassemic children are not treated in time optimally, they cannot long life, they will die between the ages of 1-8 years [2]. Therefore, timely and proper treatment is essential for the survival of thalassemic children.

Thalassemia is a preventable disease and across all focus group discussions, the need for information, emotional, social and financial support exhibits. This study showed that in term of medical treatment, some problems such as inadequate information of parents and patients regarding the disease and its treatment by health care professional. This study and other previous studies, which showed the necessity for giving adequate information, rising awareness, development of trainings about the disease and providing and supply emotional and social supports throughout the family and society to fight against psychological consequences and stresses caused by involvement in disease among the given thalassemic children and their families. Making effort to provide emotional and social support, which may positively effect on life process of thalassemic children's parents, requires covering

not only a limited area, but also taking some measures in formal training course as well as employing mass media such as television regarding this disease and as some part of supportive efforts, it necessitates making some social efforts to reduce financial burdens in which the family is involved.

The limitation of this study was its nature of self- reported FGSs, although the researcher tried to gain the possible real information from participants. But all the information that has been attained from FGD's was self - reported. Thus self- report may bias towards socially desirable results might exist. However this study has identified thalassemia-related needs of Indonesian's parents and has important implications in the development of health care services provision of thalassemia in Indonesia. This study found that the current knowledge among participants regarding thalassemia and its treatment is inadequate. Therefore, knowledge regarding disease among mothers need to be improved. Health care providers need to enhance the parents' education regarding thalassemia major with respect to carrier, premarital screening and prenatal diagnosis and improved efforts of nurses staff in providing practical knowledge regarding the disease of their child should significantly improve patient quality of life and adherence to treatment.

Conclusion

The finding of this study indicated there was significant impact of thalassemia on thalassemic children and their families in terms of, emotional well-being, social, professional support and financial support. Parents' education level was very low about thalassemia. The finding of the present study also highlight the need of implementing effective public educational programs and to make premarital screening compulsory for general public to reduce the prevalence rate of the disease. Moreover, additional facilities for premarital screening and counseling should be made accessible and available to general public in Indonesia.

In this context, the researchers suggest that nurses need to understand the difficulties faced by thalassemic children and their parents, acknowledge their cultural values and support them in their therapy's different phases while working jointly with family members. Patients and parents support group during the outpatient's return visits can be an intervention strategy used by patients and parents to express and discuss their feelings concerning the disease, treatment and how these impact their lives.

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