

# Supportive Care Needs: External Support for Parents of Children with Thalassemia

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**Abstract**—Deficiencies in the social support system are most often expressed by parents who have a child with thalassemia. Parents need to be able to adapt to changes in children's conditions. If parents do not get adequate social support there will be obstacles in the social interaction. In the end, this condition will also affect the emotional condition of parents in providing care for children with thalassemia. The purpose of the study was to obtain in-depth information about the supportive care needs of parents with young children with thalassemia. This study used a qualitative design with phenomenological studies. The characteristics of the participants were: being able to speak Indonesian, cooperatively and openly, not experiencing health problems, and being able to tell their experiences well. 5 participants in total were involved in this study through a snowball sampling method. The interview guide was used as a research guide in gathering data. Based on the results of data analysis, 5 participants obtained the theme of external support including the category of peer support among parents who had children with thalassemia, support from the environment around the home, and support from the school. These findings were expected to improve the fabric of love and communication among fellow thalassemia facilitated by the Association of Parents of with Thalassemia Children.

**Keywords:** *parents, thalassemia, external support*

## INTRODUCTION

Thalassemia is a type of hemolytic anemia and is an autosomal inherited disease. If a married couple is a thalassemia gene carrier, then their children will possibly suffer from thalassemia (25%), thalassemia gene carriers (carriers) (50%), and normal (25%). Most people with thalassemia are children aged 0-18 years. This disorder is inherited recessively according to Mendel's law [1].

In thalassemia, the body produces several healthy red blood cells and hemoglobin whereas hemoglobin functions to carry oxygen throughout the body so that it can trigger anemia. In patients with thalassemia major, severe anemia can occur so that one of the actions taken is by giving blood transfusions. Blood iron (ferritin) levels can continue to increase due to the effects of repeated blood transfusions and there is no iron chelation therapy to remove iron from the body [2].

Riset Kesehatan Dasar (Riskesdas) in 2015 estimated that thalassemia patients will reach 20 to 25 thousand people in 2028. This makes Indonesia as one of the countries in the Southeast Asia region that includes the thalassemia belt [harsono]. Thalassemia major is more commonly experienced by Indonesian people [3].

Thalassemia major can cause various problems in pediatric patients. One of them is organ dysfunction as a result of the condition of thalassemia itself or the care given. Medical problems experienced by children with thalassemia including changes in the child's facial bones, pale skin, weakness, and the inability to do activities require a lot of energy [3].

Thalassemia experienced by children not only affects children but it also affect parents, especially in social life [4]. Also, a qualitative study in Thailand explored that the lived experiences of mothers of children with thalassemia major indicated inadequate social support system [5].

Parents of children with thalassemia require the role of nurses who can increase the empowerment of parents for the child's developmental needs such as health conditions themselves, social identity, education, self-care skills, relationships with family and social interactions, emotional development and behavior. It also includes the capacity of parents themselves about guidance and handling from family and environmental factors such as the role and function of the family, work, income, social and family integration, and community resources [4].

These conditions require the fulfillment of supportive care needs needed by parents. If this cannot be fulfilled, the condition of stress and even depression can be experienced by parents, and the quality care of parents will decrease. Based on this problem, it is important to understand deeply about the needs of parents for thalassemia conditions experienced by their children [6]. This can be the basis of creating appropriate health education programs and optimal care for children. Previous studies had been conducted, but the results of the study only indicated the level of supportive care needs of parents in caring for children with thalassemia. This study was conducted to explore in-depth information to get the essence of the experience they had.

## METHOD

A qualitative method with a phenomenological approach was used in this study. The sampling technique used was snowball technique obtained from key informants. The next participant was introduced by the previous participant. The number of samples was determined by data saturation indicating that there was no more new information about the phenomenon of research from participants [7]. Participants involved were parents of children with thalassemia who were undergoing routine treatment for thalassemia, could communicate well, and were cooperative.

Data was collected using semi-structured interview. Structured interviews were used to obtain participants' demographic data including name, age, level of education, number of children who had thalassemia, and the first time a child diagnosed with thalassemia.

The interview process for all participants lasted about 30 minutes to 60 minutes recorded using a recording device. The results of the interview were then transcribed by the researcher verbatim. The data was analyzed using the Colaizzi method because it was considered as the easiest method to provide an opportunity for the researchers to validate the data from the analysis [8]. The study was conducted from May to July 2019 in the Kalikajar, Mrebet, and Kemangkong districts of Purbalingga.

The researcher repeatedly read the transcript that had been compiled to feel and understand the keywords intended by the participants. The researcher then determined keywords of the participant's statements. Keywords that had similarities and relationships were grouped in categories and then interrelated categories were grouped in themes.

In research, credibility was done by triangulating data sources and member checks; transferability was done by compiling reports on research results in a clear, detailed and systematic manner; confirmability was done by presenting the results of research in oral presentations of international seminars; and dependability was carried out with an audit inquiry together with other research members as well as reviewers.

## FINDING AND DISCUSSION

The themes related to the supportive care needs of parents with children diagnosed with thalassemia were peer support, support from the environment around the home, and support from the school environment. The following is an overview of the themes that have been produced:

### Support other parents

Parents expressed happiness because meeting with parents who also had children with thalassemia. The followings are the statements:

*"... some cheer up like that." (P2)*

*"... so sometimes we chat, what do we want to share with the transfusion, share it." (P1)*

*"My child sometimes doesn't want to be left alone even though I'm the one who takes care of it, so I take all of it. That blood is like for us to take, so if there are friends, we can take all at once, so it will change, right, who can?" (P5)*

### Support from the surrounding environment

The statements expressing the need for environmental support around the house are:

*"If a layman is a way to get rid of it, if the lack of blood is handled, this is handled, ... it doesn't feel good like that, but it's hard to explain, it's hard to explain, finally shut up." (P2)*

*"It's normal if people here like to talk about it because of this disease, they like to pretend not to understand..." (P5)*

### Support from the school environment

The support of the school environment was expressed by several participants. The followings are expressions stated by participants:

*"... the teacher memorized it if F doesn't leave oh it recharges, so what's the charge if transfusion..." (P2)*

*"The teacher knows I explained it so if my child does not go to the hospital, the teacher will understand." (P4)*

*"... my friends, I already understand, miss, if you don't enter, why is that normal?" (P5)*

The parents in this study revealed that not everyone around their home understood about thalassemia. Parents said that there were some people who considered thalassemia as a contagious disease, a disease that does not allow sufferers to get married and have children, and so forth. On the other hand, parents did not consider this to be a problem. Parents still tried to interact with people around the home environment such as participating in social gatherings or recitation activities.

Parents also expressed their joy at the knowledge that other parents had the same case of having children with thalassemia. Moreover, they felt grateful because they had only one child diagnosed with thalassemia, unlike other parents. Parents also said that they helped each other when they were in the hospital.

When children underwent treatment in the hospital, it means that for children who were already in school child must have permission not to participate in school activities. Parents felt supported when the school could understand the condition of the child and give permission not to go to school. This can indirectly reduce parental concerns about children's education.

The parents' statements also showed the need for supportive care related to the psychosocial domain. According to a research, it was mentioned that social support is an important factor that can help parents in minimizing the emotional burden associated with the treatment of thalassemia that children undergo. In addition to social support, professional support in childcare is also very influential. Parents appreciate the support in which children receive from neighbors, friends, and teachers. Appropriate social support will give parents comfort in the absence of stigmatization and social isolation that children can accept [9].

In this study, participants revealed the lack of understanding of people in the surrounding environment against the condition of thalassemia experienced by their children. Although sometimes it irritated parents, parents tried to understand this. This statement showed that there was a negative stigma in society about thalassemia that parents felt difficult to explain the knowledge of thalassemia and to get empathy from people around them.

Parents felt bored because the interactions did not support or help parents to get social support. Based on this case, parents should get support from the surrounding environment [10].

Social and emotional support is needed by parents to respond to psychological changes and stresses that result from the effects of thalassemia conditions experienced by children. Efforts can be made to provide emotional and social support for parents, one of which can be done through socialization about thalassemia by using mass media such as television [3].

The communication with other parents who have children with thalassemia has an important meaning because parents can have a more positive outlook on the child's condition. In this study, the five participants stated that they were happy to have a fellow parent who had a child with thalassemia because they could talk to each other about the child's condition. Also, communication was established in adults with thalassemia. Parents felt so confident that children could continue to live to adulthood and build households like other adult patients with thalassemia encountered by parents [11].

Many parents complained about the lack or missing social life. However, in this study all participants did not state any obstacles in social relations with others. One participant stated that the mother continued to carry out activities in the environment around the house such as social gathering, recitation, and other social activities. Those activities are useful for parents to eliminate feelings of social isolation, shame, or a one-sided view of the community in the environment around parents. Positive social support received by parents had an impact on reducing the emotional burden experienced by parents [10]. The limitation in this study was on characteristics of participants, and different experience of caring a child with thalassemia.

#### CONCLUSION

Support for the psychosocial domain for parents is an important thing that needs attention and must be met to reduce the emotional burden felt by parents. Based on this study, parental psychosocial support was surely related to external support including support from fellow parents who had children with thalassemia, support from the environment around the house, and support from the school where children got a formal education. Based on this study, we recommend Association of Parents of Children with Thalassemia improve communication between fellow parents and other thalassemia patients to share experiences and knowledge related to thalassemia.

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