

# Parents Supportive Care Needs: One Day Service for Thalassemia Patients

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**Abstract—** *Indonesia is one of the countries included in the thalassemia belt. A total of 4,710 people with thalassemia are individuals in the age group of less than 15 years. Thalassemia that occurs to children will affect the parents because children with thalassemia need regular blood transfusions throughout their life so that they will be repeatedly hospitalized. The ineffectiveness of health services can make parents absent from work, from social activities, and even have to stop working because they have to accompany the child in the hospital. This study aimed to explore deeply the supportive care needs of the parents of children with thalassemia. The research design was qualitative with a phenomenological approach. The semi-structured interview technique was carried out on five participants who had children with thalassemia. The theme finding obtained was one day service. Hospitals as health service providers are expected to be able to improve services provided especially one day service for people with thalassemia.*

**Keywords:** *parents, thalassemia, one day service*

## INTRODUCTION

Thalassemia is one of the most genetic diseases in the world. It is a global health problem. Data from the World Bank shows that 7% of the world's population is a carrier of thalassemia. Around 300.000-500.000 newborns are accompanied by severe hemoglobin abnormalities, and 50.000 to 100.000 children die from  $\beta$ -thalassemia; 80% of this amount comes from developing countries every year [1]. Indonesia is one of the countries included in the thalassemia belt with a high rate of thalassemia [2]. Data from RISKESDAS (2015), states that since 2014 there has been an increase in the incidence of thalassemia in Indonesia. Based on data from the Indonesian Thalassemia Foundation and the Indonesian Thalassemia Sufferers' Association in 2014, from the results of screening to the general public from 2008-2017, it was obtained a nature carrier of 699 people (5.8%) out of the 12.038 people examined; while the screening results in the Thalassemia family in 2009-2017 found 1.184 people (28.61%) out of 4.137 people. While based on data from RS Cipto Mangun Kusumo, in October 2016 there were 9.131 thalassemia patients registered throughout Indonesia [3]. According to the Ministry of Health (2018), 4.710 people with

thalassemia are children in the age group of less than 15 years [1].

Thalassemia is a chronic condition that requires lifelong care. Therefore, children with thalassemia will experience changes both physically and psychologically. The physical conditions that will affect the child include the buildup of iron due to blood transfusions that are carried out and then it accumulates in several organs which can damage its organs. Meanwhile, the psychological conditions that will be experienced by children with thalassemia include feelings of anxiety, depression, hopeless and disappointed with the conditions. The child will often be in and out hospital because they must undergo regular transfusions. It will hamper a child's education process and social interaction with other children of the same age [4].

The impact of thalassemia treatment is not only experienced by children but also by parents because the parents being fully responsible for the children's care. Each parent will show a different response to thalassemia's children [2]. The parents have to bear the costs of childcare which includes blood transfusion and iron chelation drugs, operational costs during treatment in the hospital, and the expenses when the child needs further medical services [2]. The impact on parents can occur physically, psychologically, socially, and financially [5]. The other impacts on parents are anxiety, lack of medical services, and the need for assistance [4]. The life experiences of mothers of children with thalassemia major revealed the less effectiveness of health services [6]. The parents who accompany the child undergoing thalassemia treatment require the fulfillment of supportive care so that they can support the thalassemia care. If the supportive care needs of parents of children with thalassemia cannot be identified, it can cause a drop out of the treatment process that the child must undergo. This certainly has an impact on children and parents because of the care they undergo. In this study, the researchers aimed to explore the supportive care needs of parents of children with thalassemia.

## METHOD

This qualitative study investigated the supportive care needs of parents of children with thalassemia. The research participants were taken by the snowball method involving key informants, where the next participant was obtained from the previous participant. The parents who are being able to speak Indonesian, cooperative, not experiencing

health problems and can tell their experiences were some of the parents' concerns. In this research, the age range of participants was between 24-29 years and 1 participant aged 64 years. The timeframe of accompanying the child with thalassemia undergoing treatment was in the range of 2-4 years. Using a semi-structured questionnaire, the researchers interviewed 5 parents (1 male and 4 female) having children with thalassemia. The number of participants taken in this study was determined based on data saturation that had been obtained. Data analysis used was the Colaizzi method [7]. The interview process was carried out by researchers to participants approximately 30-60 minutes using a recording device. Then, the results of the recording were made into transcript using researcher verbatim. This research took place from May-July 2019 in the District of Purbalingga, which includes Kalikajar, Mrebet, and Kemangkon village.

Data triangulation and member checks were used to see the validity (validation) of the data, while the transferability was done by completing the research report in a clear, detailed and systematic manner. Confirmability in this study was carried out with presenting the research results in oral presentations at international conferences, and accountability was carried out by representing joint reviews with other research members and reviewers.

#### FINDING AND DISCUSSION

The theme of the results of the analysis found related to the supportive care needs of parents of children with thalassemia was a one-day service. The results of this study indicated that parents disclosed the effectiveness of time and standard operating procedures which unmet the needs.

##### **The effectiveness of treatment time**

The following are participants' expressions related to the effectiveness of treatment time:

*"... if the house is far away in Cilacap, Pemalang, if there is a transfusion once a month, it means that in one month there are 2 wasted ... 1 for transfusion, 1 taking the medicine." (P2)*

*"... have to wait for one or three days at the hospital ..." (P1)*

*"... come then check Hb then enter blood I wait for a few hours then check Hb again then wait again then if you don't wait longer ... the formula is, not all hospitals are like that." (P5)*

*"... if the child takes the transfusion, if he does not work, then after 5 days of transfusion, he will return to take medicine, and he will also take a day off from work ..." (P3)*

*"... need fast service ..." (P4)*

##### **The Standard Operating Procedures related to one day service**

Whereas the participant's statement stating the Standard Operating Procedures related to one day service are as follows:

*"... thalassemia patients are different from general patients when receiving blood, there is a path of its own." (P1)*

*"go there directly to the TPPRI list, not on the general list, ..." (P2)*

*"... not wordy ..." (P3)*

*"... take medicine, take care of it again ... Take care of the queue in the registration first, the queue is given a prescription, the queue is waiting for the medicine." (P4)*

*"... still lining up even though it has been pruned not through the front." (P5)*

Parents in this study revealed about health services, especially blood transfusions and iron chelation drugs that has not been effective yet. The five parents stated that when the child gets a blood transfusion 2 times in a month, then the parents must be absent from their work for 4 days because the parents must take the child to the hospital and 5 days after they must return to the hospital to ask for prescription iron chelation. Parents revealed that sometimes they had to accompany their children 1-3 days in the hospital because of the children still anemic after the transfusion and had to undergo another transfusion. Parents need speed in the services provided, including in determining the amount of transfusion that children must receive so that they do not need to be hospitalized for days. These results have in common with thalassemia problems in Bangladesh, India where the number of Thalassemia sufferers is increasing every year and the unavailability of iron chelator drugs and the need for convenient transfusion facilities are the main problems raised by families [8].

The need for effective health services must also be supported by Standard Operating Procedures related to the treatment of thalassemia. Parents revealed that thalassemia patients were given ease in administrative matters both when they were about to undergo transfusion and when they were going to get iron chelation drugs. Even so, parents also still complained about the referral procedure that had to be taken care of again to get iron chelation drugs, the same as when arranging for a referral to get a transfusion. This is felt by parents only as wasting time. Hossain *et al* in their study revealed that the management practice in Bangladesh for Thalassemia Patient is Thalassemia Foundation Centre (TFH). This one daycare service was established by the Thalassemia support group and families of the patient. In this place, the patient will get a unique ID to maintain further in documentation [8].

Based on the domain in supportive care needs, the needs revealed from the resulting theme are the practice domain. The practice domain focuses on financial worries. Parents express financial problems as a source of stress and difficulties for parents. Financial difficulties experienced by

parents were related to ongoing care that must be endured by children [9]. Parents reported that to undergo childcare in hospital, the parents need to be absent from work, leave, or even quit from their jobs. This automatically would add to the burden on the head of the family as a single service provider in terms of household finances. The results of research conducted by Abu (2014) state that the participants showed their worries resulting from frequent absenteeism from school, body image changes, puberty delay, fear of death, and uncertainty about their children's future. They also expressed their needs for more information about thalassemia and its treatment, social and professional support, and financial support [10].

In the study of mothers' participants did not report much of this, but for male participants stated that when taking the child to the hospital, parents will rest for a while from work. For participants whose work was paid according to work time, this will have an impact on not earning income if they have to accompany the child in the hospital. Related to the length of time of the treatment, it was considered necessary to plan and coordinate the care and treatment services for children with thalassemia. The planning and coordination which are not optimal in providing care for thalassemia patients is a constant source of parental stress conditions [9]. A daycare that children need to undergo in the treatment of thalassemia in the hospital will waste the parents' working time. Besides, taking iron chelation drugs at other times also increased the time needed during undergoing treatment. Based on these facts, the need for integrated services and a maximum of one day service was felt to be a slight solution to solve the financial problems experienced by parents. Although several hospitals in Indonesia have already had One Day Care service for thalassemia patients, the problem is the process of registering patients which is still one by one. One Daycare service should have been complemented by the service process from the start, including registration to the patient's return. This certainly can slightly alleviate the problem complained of by the patient, namely the complexity of the registration process until the queue to take medicine.

Thalassemia patients needed a multidisciplinary care. So, it will take a lot of process during the treatment. In many hospitals, patients with thalassemia are managed in general hematology, pediatric and oncology inpatient departments and day care units, alongside a heterogeneous groups of patients with a variety of unrelated disorders [11].

#### CONCLUSION

The need for supportive care in parents of children with thalassemia focuses on optimal health services. This can be achieved by the realization of a one-day service for people with thalassemia. Effective services accompanied by Standard Operating Procedures will minimize the parents' time of visiting the hospital so that they can use better time to work and meet financial needs which are also the

supportive care needs of parents who feel heavy while providing care to children. Hospitals as the main service provider for people with thalassemia are expected to improve the quality of services by providing a one-day service for people with thalassemia. The Indonesian Thalassemia Sufferers' Association can cooperate with the hospital to determine the appropriate Standard Operating Procedures to provide effective services for persons and parents related to blood transfusion and access to get iron chelation. The government has to make sure that the One Daycare service should have been complemented by the service process from the start, including registration to the patient's discharge.

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