






# Coping Strategy of Family in Treating Children with Thalassemia Mayor aged 6–12 Years in the Urban Area of Indonesia

Septian Andriyani<sup>1</sup>, Suci Tuty Putri<sup>1</sup>, Rahayu Savitri<sup>2\*</sup>, Dadang Darmawan<sup>3</sup>, Irawan Danismaya<sup>4</sup>, Novi Malisa<sup>3</sup>, Guling Setiawan<sup>3</sup>, Upik Rahmi<sup>1</sup>, Lina Anisa Nasution<sup>1</sup>, Tunggul Sri Agus Setyaningsih<sup>3</sup>

<sup>1</sup>Departement of Nursing, Faculty of Sport and Health Education, Universitas Pendidikan Indonesia, Jawa Barat, Indonesia; <sup>2</sup>Departement of Nursing, Budi Luhur Institute of Health Sciences, Jawa Barat, Indonesia; <sup>3</sup>Departement of Nursing, Akademi Keperawatan RS. Dustira, Jawa Barat, Indonesia; <sup>4</sup>Departement of Nursing, Faculty of Health, Universitas Muhammadiyah Sukabumi, Jawa Barat, Indonesia

## Abstract

**Edited by:** Ana Vucurevic

**Citation:** Andriyani S, Putri ST, Savitri R, Darmawan D, Danismaya I, Malisa N, Setiawan G, Rahmi U, Nasution LA, Setyaningsih TSA. Coping Strategy of Family in Treating Children with Thalassemia Mayor Ages 6–12 Years in the Urban Area of Indonesia. *Open Access Maced J Med Sci.* 2022 Apr 10; 10(G):509-516. <https://doi.org/10.3889/oamjms.2022.8914>

**Keywords:** Coping strategy; Family; Thalassemia

**\*Correspondence:** Rahayu Savitri, Departement of Nursing, Budi Luhur Institute of Health Sciences, Jawa Barat, Indonesia  
E-mail: ayoe.kusmayadi@gmail.com

**Received:** 07-Feb-2022

**Revised:** 29-Mar-2022

**Accepted:** 31-Mar-2022

**Copyright:** © 2022 Septian Andriyani, Suci Tuty Putri, Rahayu Savitri, Dadang Darmawan, Irawan Danismaya, Novi Malisa, Guling Setiawan, Upik Rahmi, Lina Anisa Nasution, Tunggul Sri Agus Setyaningsih

**Funding:** This research did not receive any financial support

**Competing Interests:** The authors have declared that no competing interests exist

**Open Access:** This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (CC BY-NC 4.0)

**BACKGROUND:** Thalassemia is a genetic blood disorder and has not been cured. Thalassemia children need special attention from the family as one of the efforts in treating children with thalassemia depends on coping strategies owned by the family.

**AIM:** This research aimed to discover and deeply explore coping family strategies in caring for children with thalassemia major aged 6–12 years.

**METHODS:** This study used quantitative and qualitative approaches (mixed methods). For quantitative study we used total sampling technique (66 samples). Furthermore, for qualitative study, we used six participants with in depth-interview technique. The instrument was the revised ways of coping scale questionnaire and interview guidelines.

**RESULTS:** The study showed that 62.2% of respondents had a positive coping strategy, and (37.8%) had a negative coping mechanism. Furthermore, the qualitative analysis showed that age, education, employment status, and the number of children influenced individual coping strategies. The interview results show three themes, namely the process of grieving, fear of stigma, and an increase in spiritual activity. It is recommended for families to follow health education on caring for children with thalassemia.

## Introduction

Normal growth and development are milestones in children's lives, sometimes hampered by many diseases. Illness can be obtained during life or be inherited. One of the inherited diseases is thalassemia [1]. Thalassemia refers to genetic disorders in the production of globin chains. Thalassemia is a congenital blood disorder characterized by a deficiency in the production of specific globin chains in hemoglobin [2]. Thalassemia is a congenital blood disorder with the most clinical manifestations of severe anemia globally [3].

Based on the type of globin chain that is affected, thalassemia is classified as alpha thalassemia (caused by the lack or absence of  $\alpha$ -globin chain production), beta-thalassemia (caused by lack or absence of  $\beta$ -globin chain production), and Hb E-beta thalassemia (Hb E/ $\beta$ -thalassemia which is a combination of beta-thalassemia with abnormal Hb or structural Hb type with thalassemia) [4]. More than 200 mutations of thalassemia  $\beta$ , although most are rare, it is known

that around 80% of thalassemia is worldwide. 5%–10% of the population carries the  $\alpha$  genethalassemia [1]. Worldwide, around 15 million people are estimated to suffer from thalassaemic disorders. Based on reports of WHO, approximately 300 million carriers of Thalassemia born in worldwide, it is about 1.5% of the world's population. 10% of carrier thalassemia should be the cases [5], [6]. These are born in India every year. In India alone, there are around 30 million, with 505 million in Southeast Asia [5], [6].

Thalassemia International Federation 2008 estimated that 1.5% of the global population, as many as 80–90 million people, carry the thalassemia gene with 60,000 births each year, especially in developing countries [7]. World Health Organization 2006 reported that about 7% of the world's population has carrier thalassemia, and around 300,000–500,000 babies are born with this disorder each year [8]. In Indonesia, the prevalence of carrier thalassemia reached around 3%–8%, but until March 2009, cases of thalassemia increased by 8.3% [9].

Thalassemia is a hereditary disease caused by failure to form one of the four amino acid chains

that make up hemoglobin, so that hemoglobin is not fully formed. The body cannot form normal red blood cells, so red blood cells are easily damaged or short-lived for <120 days, and anemia develops [1]. Symptoms of thalassemia major usually include growth and delayed puberty, enlarged liver, spleen, pale, jaundice, disruption of the growth of the sex glands, leg pain, fracture of the forehead, cheeks, and prominent jawbone. In patients with beta-thalassemia major and low hemoglobin levels, routine blood transfusions are needed to maintain hemoglobin levels between 9.5 and 10 g/dl. Regular blood transfusions cause iron accumulation in vital organs such as the liver, heart, and endocrine glands. They have several complications such as hepatitis, cirrhosis, carcinoma, cardiac insufficiency, hypogonadism, hypothyroidism, diabetes, and hypoparathyroidism [10].

The impact on thalassemia patients is not only for the patient itself, but it can even impact his family. Previous research on children with thalassemia found that children have psychosocial problems such as low self-esteem, social isolation, depression, financial problems, psychiatric disorders, restrictions on physical activity, behavior, schooling, maturation factors, and general complications [11]. Families also experience psychosocial, emotional, and time and energy impacts to caring for children to undergo a lifetime treatment program. The family must provide more time to accompany the child to undergo treatment and so financially for the children's medical expenses. Hence, families are very worried about their children and even very overprotective [12].

Anxiety is an unpleasant emotion that can cause symptoms of fear and fear experienced by the family [13]. Families can reduce anxiety or stressors depending on how the family uses coping. Coping is a variety of strategies used by families to overcome everyday problems. Family coping strategies function as vital processes or adaptations through processes and mechanisms so that families can carry out family functions properly [11], [13]. Families with thalassemia who need lifelong care are needed coping to overcome problems. Some families use adaptive coping in treating children with thalassemia major, but many others still use maladaptive coping [11], [13]. This research aimed to identify and explore coping family strategies in caring for children with Thalassemia Major aged 6-12 years in Indonesia.

## Methods

### Study design

The design of this study uses a quantitative and qualitative exploratory approach (explorative mixed methods). This quantitative approach is supported by

**Table 1: Family characteristics in caring for children with thalassemia major in Bandung Indonesia (n = 66)**

Characteristics	Frequency (%)
Age (years)	
17–25	1 (1.5)
26–35	28 (42.4)
36–45	36 (54.6)
46–55	1 (1.5)
Last education	
Elementary school	12 (18.2)
Middle School	20 (30.3)
High school	30 (45.4)
University/College	4 (6.1)
Job-status	
Work	34 (51.6)
Does not work	32 (48.4)
The number of thalassemia children	
1 child	29 (43.9)
> 1 child	37 (56.1)

Table 1 shows the characteristic of family who caring children with thalassemia. Overall, most of respondents in middle age group (34–45 yo). 45.4 per cent of respondent already high school level. Morethan half respondents is a worker. Furthermore, 56.1% of respondent have more than one child. Table 2 illustrates characteristics participant who included in qualitative study. There was 4 male join this study. Most of respondent has one child with thalassemia. The long of caring is 1 to 20 years.

**Table 2: Participant characteristics for qualitative study (n = 6)**

Name	Sex	Age (year)	Children suffering from thalassemia	Long caring (years)	Education	Profession
P1	Female	38	1	12	Vocational school	Home care
P2	Male	41	2	20	Middle school	Labor
P3	Female	32	1	10	High school	Housewife
P4	Male	24	1	<1	Vocational school	SPG
P5	male	42	1	2	High school	entrepreneur
P6	Male	60	1	12	High school	Bus driver

a qualitative approach resulting from interviews with participants. The qualitative narrative approach used is to explore, describe, analyze, project, and give meaning to the experience perspective of families who have children with thalassemia. The study's design was adjusted to the purpose of the study, which was to find out and explore deeply coping family strategies in caring for children with thalassemia major aged 6–12 years at POPTI (Association of Indonesian Thalassemia Parents) Bandung City, Indonesia. The study was conducted from 30 April to 16 May 2020.

### Participant

There are 66 respondents in the quantitaive study. Furthermore 6 participant was selected to qualitative study (in depth-interview).

Under this characteristic of respondents in a qualitative study as many as 6 participants.

### Instrument for coping strategy

Quantitative data collection was carried out to 66 participants with a sampling technique that is total sampling. Researchers provide application letters and informed consent. At the time of the study, all parents agreed to be respondents in the study, and

then, the researchers gave a questionnaire to fill in the research. The instrument used was the Revised Ways of Coping Scale (WCQ-R) questionnaire from Lazarus and Folkman (1984), consisting of 60 questions [14]. The instrument was tested for validity and reliability, so the questions used in this study amounted to 39 statements. The coping strategy questionnaire consists of 30 favorable questions and 9 unfavorable questions. The scoring data use 1-5 scale likert. The assessment indicators used are (1) never: If you never did, (2) sometimes: If the action was taken 3–4 times when you were worried, (3) often: If the action was done twice when you were worried, and (4) always: If the action is taken every time experiencing anxiety due to caring for children with thalassemia. As for the range of the score, the assessment questionnaire is a positive coping strategy if the assessment score is  $\geq$  mean (34.17%), a negative coping strategy if the assessment score is  $<$ mean (34.17%).

The validity test of this instrument was carried out in the same place as the research, namely at POPTI (Indonesian Paralysis Association of Parents) City of Bandung, Indonesia. The results validity show that  $r$  count was 0.516–0.882. The reliability test results showed 0.966 with the alpha Cronbach value  $\geq$ 0.6. Data analysis techniques use univariate data analysis, which results presented in percentages.

#### **Interview guidelines used in qualitative**

For collected qualitative data, we used in depth-interview with the list question guideline below:

1. How did you feel when you first learned that your child was diagnosed with thalassemia?
2. What do you do when you find out your child has thalassemia?
3. What is your experience in meeting the biological needs of children? Like eating, drinking, sleeping, and so on?
4. How are the joys and sorrows that the mother/father felt during the care period of a child diagnosed with thalassemia?
5. What forms of support have you received during the care of children diagnosed with thalassemia?
6. Whatever spiritual values mothers/fathers instill in children are related to their illness conditions.

Participants in this study are parents who care for children with thalassemia major. Parents who became participants were selected using a purposive sampling method with the criteria to communicate well and be willing to become participants. Interviews are conducted by asking open-ended questions, which refer to interview guides that have been prepared in advance. First, the researcher conducts a selection, approaches and fosters a relationship of mutual trust, and explains the purpose and method of collecting data with prospective participants. Second, after prospective

participants understand and are willing to participate in this study, participants are asked for their approval by signing a research consent letter (informed consent). Third, the interviews were conducted for 30 min with specific 5 min opening, 20 min of in-depth interviews, and the last 5 min of termination.

Interviews were conducted in the POPTI room using Indonesian. The instrument used during the interview was the researcher himself using a tape recorder as a recording device and noted the important things conveyed by the participants. After the interview is conducted, the researcher conducts member checks to participants about the data that has been submitted.

#### **Ethical clearance**

The Universitas Pendidikan Indonesia Research Ethics Committee gave their approval to this report No. 069/1534/V-2020/BPKP.

#### **Data analysis**

Data analysis techniques used in this study are both quantitative and qualitative. Quantitative data analysis uses univariate analysis to describe and produce a frequency distribution and percentage of research variables. While Qualitative data analysis uses thematic analysis (Braun & Clarke, 2006). This study consists of six stages, namely recognizing data, initializing code, searching for themes, reviewing themes, defining themes and theme names, and producing reports [15].

## **Results**

#### **Coping strategy**

Table 3 shows the coping family strategies for caring for children with thalassemia are 41 respondents (62.2%) positive, while a small proportion of respondents were 25 respondents (37.8%) negative.

**Table 3: Frequency distribution of coping strategies in families caring for children with thalassemia major (n = 66)**

Coping strategy	Frequency (%)
Positive	41 (62.2)
Negative	25 (37.8)
Total	66 (100)

Quantitative research results show that family coping strategies are based on age (Table 4). Nearly half of respondents aged 36–45 years are in the sufficient coping category (30.3%). A small proportion of respondents aged 26–35 years are in the poor category (7.5%). Almost half of the respondents in the coping category are sufficient to have a high school

**Table 4: Distribution of coping strategies of families in caring for children with thalassemia major aged 6–12 years based on characteristics (n = 66)**

Characteristic	Coping category (%)		
	Good	Enough	Poor
Age (years)			
17–25	0	1.5	0
26–35	6.0	28.8	7.5
36–45	24.2	30.3	0
46–55	1.5	0	0
Last education			
Elementary school	9.1	9.1	0
Middle School	7.5	18.1	4.6
High school	12.1	30.3	3.0
College	3.0	3.0	0
Job-status			
Work	16.7	31.8	3.0
Does not work	15.1	28.8	4.6
Number of thalassemia children			
1 child	7.5	28.8	7.5
> 1 child	22.8	33.3	0

education (30.3%). Almost half of the respondents who worked (31.8%). Furthermore, based on the number of thalassemia children, almost half of respondents who have children with thalassemia more than one are considered sufficient (33.3%).

A qualitative research report from the interviews conducted with six participants found three themes: The process of grieving, fear of stigma, and an increase in spiritual activity.

In the psychological aspect, most of the participants describe their thought related to the response to thalassemia conditions.

### Theme 1. Grieving process

Parents discussed responding to thalassemia as a grieving process such as described by some participants “...First, you will be shocked. Continue to drop...” (P3), “...really surprised. Thalassemia is a hereditary disease while I as a parent do not have such a disease...”(P4) “...shock. First don’t believe...”(P 2), “...confused. Usually a sick child is taken to the hospital to recover, that’s all. But this is different...” (P 6). Most parent agreed that they must be accepted and keep going with this situation; participant 5 said “...We tried to accept this conditions and treat her for the best treatment such as a search for information, take her to the hospital or alternative...”(P5).

### Theme 2. Fear of stigma

We found that some mothers experiences fear related to the social stigma and limiting social interaction. They explain their opinion about fear stigma, such as “... I didn’t tell the neighbors that my kids are like this, afraid they don’t understand. If I go to the hospital just say that the control isn’t explained if the child is sick with Thalassemia, how can I be afraid of that...” (P6) and “... in fact, this child and his friend like to stay away because he thinks of infectious diseases. Maybe, so I never told my neighbor...” (P1).

### Theme 3. Increase spiritual activity

Almost parents describe their experiences to respond of the sickness condition. They tend to enhance their relationship with religion and God with worship. Participant shared her experience:

*“...we will not stop praying. If there is no real right medicine to treat it according to the medical right, yes, we pray that God will lift the disease. But we like to be sure that no disease has no cure. That’s all the optimism, but maybe you haven’t found it yet...”* (P5)

*“...in addition to treatment to the hospital, ask the cleric to read al-Fatihah every Friday...”* (P6)

*“...then I like to say that all humans must die. We don’t know our age, not necessarily those who are sick die first. If for example, you first must be sincere...”* (P1)

*“...then I like to say to my child if the thalassemia child from firstborn until later called again will definitely go to heaven...”*(P3)

## Discussion

The results showed that the coping strategies used by parents who have children with thalassemia major mostly use positive coping strategies. Parents use several strategies to reduce problems and optimize child care with thalassemia major, such as eating and drinking arrangements, especially what mothers do as caregivers in children with thalassemia major. Patients with thalassemia major should avoid eating foods with high iron content [16]. This is because of the effects caused after undergoing continuous transfusion. Therefore, food management includes limiting the consumption of juice drinks and foods such as beef, liver, oranges, spinach, green vegetables, and broccoli because they contain high iron.

It is important to reduce symptoms by limiting physical activity by reminding children and encouraging children to be more at home. In addition, parents’ strategies are to regulate the rest and activity. Thalassemia major shows clinical symptoms in the form of progressive anemia, which is characterized by chronic hypoxia and causes oxygen supply to the tissues due to a lack of hemoglobin in the body [5]. Thus, children with thalassemia major cause symptoms such as decreased tolerance to exercise, lethargy, dizziness, and headaches, which impact the child’s dependence on the mother in daily activities, physical disability of children, and discomfort due to illness. According to the Developmental Theorist Havighurst, the growth and development phase of school-age children acquire physical skills to play games such



as playing ball, swimming to form healthy attitudes in themselves, learning to get along with peers, and developing self-concepts and playing roles according to gender. So, two skills are not achieved by children with thalassemia major, namely learning to get along with peers and develop self-concept.

Families with children with chronic diseases are often faced with a large burden of caregiving and many financial demands [4], [13]. Parents coping and the way they adapt to the effects of life-threatening diseases can be influenced by various factors, such as demographics, socioeconomic status, educational background, social support, culture, religion, and individual geographical location [17]. In this study, the characteristics of parents include age, education, employment, and a number of children. With increasing age, there will be changes in physical and psychological aspects (mental). The experience of life will determine parents' knowledge. This research shows changes in psychological aspects, and a person can manage his emotions well and be better equipped to deal with something that happens, including caring for children with Thalassemia that can change the quality of life. Thalassemia is a challenge for all family members that will cause emotional disturbances and changes in quality of life [13]. The family has the function of maintaining health and providing care together to care for sick family members. The level of family knowledge related to healthy sickness will affect family behavior in solving family health problems [12].

Social support can be an important aid to help families experiencing a crisis [11], [18]. Someone who does not work will have more time with children. They routinely take their children to take medication so that parents can socialize with other parents who have the same problem and with health workers so that it will allow the exchange of information and knowledge. This condition is in accordance with research by Amaral [18], in which education by health professionals is believed to be the best strategy for improving/promoting family health. The work environment can make a person gain experience and knowledge, both directly and indirectly. Someone who has a job will often meet and interact with others. Thus someone who faces a problem feels not alone, but others pay attention, want to hear all his complaints, sympathize with and empathize with the problems they face, and even want to help solve the problems they face [10].

Children with thalassemia major continue to carry out the growth and development phase, one of which is learning basic skills in reading, writing, counting, and physical skills such as sports – mother's strategies in school and children's education. A research article on Behavioral Profile and School Performance of Thalassemic Children in Eastern India by Guha *et al.* (2013) suggests that the need for psychosocial support includes relationships with teachers or school

authorities, thus providing opportunities to undergo treatment needs and continue to participate in activities, but must be informed about the disease. Thus, if completed, the task of child development will lead to happiness and satisfaction. However, it often becomes an obstacle in carrying out the next development task if it fails.

Not only routine treatment but the wishes of children who are fulfilled are also the strategies taken by mothers in providing child care. This is done as a form of maternal psychological response during treatment. Parents, namely mothers and fathers, who have the highest levels of depression and anxiety are mothers because they are emotionally more vulnerable, and mothers also have to perform the role of caregivers and nurses for children with thalassemia major [6]. Meanwhile, parents who undergo treatment for children with chronic illnesses cause feelings of worry that make parents act to do something for the children's health [19]. The role of nurses as educators and counselors for mothers is needed in implementing the strategy.

Health education can improve cognitive abilities because it contains elements to increase knowledge about the disease, teach techniques that can help families know the symptoms of behavioral disorders, and increase support for family members themselves [12].

Thalassemia is inherited by parents who are the carrier of their children. If both parents are thalassemia sufferers, they will give birth to 100% of children with thalassemia major. If one of the parents has a thalassemia carrier gene, then the child is 50% healthy and 50% thalassemia carrier. If both parents have thalassemia carrier genes, then their children's chances are 25% healthy, 25% suffer from thalassemia major, and 50% of thalassemia carriers [16].

Coping family strategy is a form of problem-solving where the goal to be achieved is the welfare of the individual concerned, which has thalassemia child. Efforts are made to maintain cognitive and behavioral conditions to reduce emotional tension.

### **Grieving process**

The initial response of participants at the time they first found out the child was diagnosed with thalassemia varied. They were starting by rejecting, being angry, and finally accepting reality. Based on the theory of Kubler and Ross, the grieving response consists of five stages, namely denial, anger, bargaining, depression, and acceptance. The five stages of grieving, commonly referred to as chronic sorrow, state that chronic sorrow is a normal grieving response due to loss that occurs in life. Grieving is an emotional response to loss. Individuals express grief in unique and individual ways based on personal experience,

culture, and religious beliefs [5]. Therefore, as long as parents experience chronic sorrow, nurses are expected to be able to provide support so that parents do not experience pathological grief or depression.

In this study, three stages of the grieving process experienced by the participants were denied, angry, and accepting. This happens because humans are unique creatures, so the initial response shown by each individual will be different. Families who have children with thalassemia seem to experience emotional distress, anxiety, fear, and difficulty in dealing with feelings. Their children are often treated for the effects of thalassemia treatment that requires a lifetime of blood transfusion and iron chelation therapy [13]. In this study, three stages of the grieving process experienced by the participants were denied, angry, and accepting. This happens because humans are unique creatures, so the initial response shown by each individual will be different. Families who have children with thalassemia often experience emotional distress, anxiety, fear, and difficulty in dealing with feelings because their children are often treated for the effects of thalassemia treatment that requires a lifetime of blood transfusion and iron chelation therapy [13]. In this study, three stages of the grieving process experienced by the participants were denied, angry, and accepting. This happens because humans are unique creatures, so the initial response shown by each individual will be different. Families who have children with thalassemia often experience emotional distress, anxiety, fear, and difficulty in dealing with feelings because their children are often treated for the effects of thalassemia treatment that requires a lifetime of blood transfusion and iron chelation therapy [20].

Thus, effective coping strategies are needed for parents to overcome the problems faced by showing a positive attitude toward the causes of stress that need to be handled well [10] so that they can provide psychological support by finding more information about the condition of the disease, screening, and conducting counseling session in handling it positively about the condition of his child's illness.

### ***Fear of stigma***

Stigma is related to social life, which is usually directed at people who are considered different, one of them is someone who has a disease such as thalassemia. This is a particular fear for parents who have thalassemia children [21], [22]. Van Brakel in Fiorillo, Volpe, and Bhugra (2016) revealed that there are five types of stigma as follows: Public stigma, structural stigma, self-stigma, felt or perceived stigma, and experienced stigma. Participants in this study fall into two categories of stigma: Felt or perceived stigma and experienced stigma. For the one category, participants felt fear of environmental acceptance due to their child's illness. In addition, two participants seemed not to be open about their child's

illness because they were afraid of rejection from the environment. For the second category, participants revealed that their children had experienced unfavorable treatment from the environment. This happens because of the lack of environmental knowledge about thalassemia so that many people still think that thalassemia is a contagious disease.

This is consistent with research conducted by Pauraboli (2017) about the experience of parents in caring for children with thalassemia major in Iran that parents feel ashamed to have children with thalassemia and think of thalassemia as a stigma that leads to social isolation, and parents do little communication [21], [22]. Parents who have thalassemia children are better off keeping their children in ill condition rather than having to accept ridicule from the surrounding environment that impacts social isolation from chronic diseases. Such conditions are certainly very detrimental, both for sufferers and caring families. Nurses and other health professionals must be able to educate the public about thalassemia. Thalassemia patients and their families have the right to get the same treatment from the community as the theory of Abraham Maslow, which mentions that one of the five human hierarchies is to respect and want to be respected. This must be met for the creation of the process of self-actualization.

In this study, the fear of stigma limits parents' social interactions. Parents feel that the environment not in accordance with their present conditions is not suitable and uncomfortable. Parents feel more comfortable in a hospital environment where many parents have major thalassemia children. Limiting social interaction in a small scope may not be a problem, but it will become a problem if the scope changes to become large. As social beings, humans should interact with others. One of the positive impacts resulting from social interaction is social support. When someone gets adequate social support, it can influence strategies to deal with stress.

Thalassemia can cause physical, psychological, and social complications in sick children, parents, and other families. The complications caused can affect the quality of life of patients and their parents in many aspects [10]. The factors that can affect the quality of life of thalassemia children are (1). physical factors such as family history, age at onset of anemia, supportive therapy, and maintaining levels of pretransfusion, (2). mental/emotional factors include chronic illness, age, anxiety/depression, and ineffective coping strategies, (3). social factors such as isolation and social conditions bad economy and (4). factors affecting school functioning include frequent absence from school and poor academic performance [1].

### ***Increased spiritual activity***

Parents who have thalassemia children have spiritual needs manifested in increased spiritual activity. This was found in participants. The form of spiritual

activities carried out is worship in the form of praying both directly and offering prayers through the mediator of the cleric, remembering death, giving thanks even though his child has thalassemia and is different from other children [23]. However, thalassemia is a disease that requires routine maintenance to sustain life. This can impact the physical changes of the child, i.e., the child is slower than his age. Children with thalassemia have distinctive physical characteristics such as mongoloid face shape, a flat nose without the base of the nose, the distance between the eyes is wide, and the forehead bones are also wide, the state of pale skin is yellowish. Illness can also affect a patient's emotional response [21].

Mothers reported more positive experiences in general than fathers. More precisely, they found that mothers indicated that their children were a source of strength and family closeness. Mothers became more tolerant, adapted to unchangeable things, were more sensitive to family problems, expanded social networks, and a source of learning as they reacted to the challenges of their children [24].

### Implication

The implications of the results of research on nursing services are to consider that mothers who have/will care for children with thalassemia for a long period of time, it is expected that child nurses, in particular, can provide nursing care that helps mothers to prevent or reduce psychosocial problems experienced by mothers. Nurses can provide relevant information and strengthen and encourage families to express their feelings and worries. Nurses can realize this by being empathetic so that despite being in bad condition, the nurse is still able to help the mother and her family achieve the goals needed relating to the disease of their children. In addition, child caregivers are expected to be able to handle the psychological aspects of children with thalassemia through communication and counseling to the family.

### Conclusion

This study shows that more than half of the respondents have positive coping strategies in the care of children with thalassemia. Parents show a grieving process when they find out their child has thalassemia and are afraid of social stigma. They tend to respond to this by increasing spiritual activity in the process of care and treatment. Family must support their children in the all aspects of social and spiritual's life to improve the quality of life.

### Limitations of the study

Apart from the strategies implemented to improve the accuracy of this study, however, there are

limitations in this study, including the small sample size, the limited context in a particular geographical location, but researchers believe that the findings of this study can support more research more about the wider scope. The findings of this study can be generalized to mothers, parents, families, and professionals specializing in health services.

### Acknowledgment

This study did not receive research funding from sponsors. The author would like to thank all the participants for sharing their experiences with the researchers, and without the cooperation of the participants of this research, it would not have been possible. In addition, the authors expressed their gratitude to the UPI WCU Program in 2020, which assisted in publishing articles.

### References

1. Kavitha K, Padmaja A. Strategies for enhancing quality of life in thalassaemic children. *BLDE Univ J Health Sci.* 2017;2(2):69. [https://doi.org/10.4103/bjhs.bjhs\\_17\\_17](https://doi.org/10.4103/bjhs.bjhs_17_17)
2. Forget BG, Franklin Bunn H. Classification of the disorders of hemoglobin. *Cold Spring Harbor Perspect Med.* 2013;3(2):a011684. <https://doi.org/10.1101/cshperspect.a011684>
3. World Health Organization. *Control of Genetic Diseases Report by the Secretariat.* Geneva: World Health Organization; 2005.
4. Li DZ. Hemoglobin New York is not a matter in prenatal screening and diagnosis for  $\beta$ -thalassaemia. *Pediatr Hematol Oncol.* 2008;25:769-71. <https://doi.org/10.1080/08880010802435435>
5. Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. *Bull World Health Organ.* 2008;86(6):480-7. PMID:18568278
6. Babu S, Tv SB, Shantaram M. An incidence of  $\beta$ -thalassaemia in South India-a review isolation of bioactive compounds and use as therapeutic drugs for neurodegenerative diseases from medicinal plants of Western Ghat region of Karnataka view project ecology and distribution of actinomycetes in nature-a review view project an incidence of  $\beta$ -Thalassaemia in South India-a review. *Int J Res Pharm Biosci.* 2016;3(5):1-6.
7. Nufer L. The gamma-globin Repressors KLF1, BCL11A, and MBD2: Knowledge Gaps in the Literature Knowledge Gaps in the Literature Downloaded from Downloaded from. Richmond, VA: VCU University Archives; 2020. Available from: <https://www.scholarscompass.vcu.edu/etd/6403>
8. World Health Organization. *Response to the Proposal for the Inclusion of Whole Blood and Red Blood Cells on the WHO Essential Medicines Lists (EML).* Geneva: World Health Organization; 2007. Available from: <https://www.thalassaemia.org.cy>
9. Ilmu Keperawatan pada Fakultas Ilmu Keperawatan M. Universitas Indonesia Pengaruh Psikoedukasi Terhadap Kecemasan Dan Koping Orang Tua Dalam Merawat Anak Dengan Thalasemia Mayor Di Rsu Kabupaten Tangerang Banten Tesis Diajukan Sebagai Salah Satu Syarat Untuk Memperoleh Gelar. Indonesia: Universitas Indonesia; 2012.

- <https://doi.org/10.7454/jki.v19i2.461>
10. Salehi S, Morovati S. Coping behaviors in families with children suffering from thalassemia major and evaluating the implementation effect of nursing intervention on these behaviors. *Int J Med Res Health Sci.* 2016;5:58-63.
  11. Miskam HM, Juhari R, Yaacob SN. Stress and Quality of Life among Mothers with Thalassaemic Children in MALAYSIA. *Int J Stud Children* 2017;1:176-84.
  12. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting family caregivers in providing care. In: *Patient Safety and Quality: An Evidence-based Handbook for Nurses*. Ch. 14. Rockville, MD: Agency for Healthcare Research and Quality; 2008.
  13. Saldanha SJ. Stress and coping among parents of children having Thalassaemia. *Int J Sci Res.* 2013;4:438.
  14. Biggs A, Brough P, Drummond S. Part four coping with stress 21 lazarus and folkman's psychological stress and coping theory. In: *The Handbook of Stress and Health: A Guide to Research and Practice*. United States: Wiley; 2017. <https://doi.org/10.1002/9781118993811.ch21>
  15. Maguire M, Delahunt B. *Doing a Thematic Analysis: A Practical, Step-by-step Guide for Learning and Teaching Scholars*. All Ireland J Higher Edu. 2017.
  16. Ault P, Jones K. Understanding iron overload: Screening, monitoring, and caring for patients with transfusion-dependent anemias. *Clin J Oncol Nurs.* 2009;13(5):511-7. <https://doi.org/10.1188/09.cjon.511-517>  
PMid:19793708
  17. Richardson EM, Schüz N, Sanderson K, Scott JL, Schüz B. Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis. *Psychooncology.* 2017;26(6):724-37. <https://doi.org/10.1002/pon.4213>
  18. Amaral MS, Reis AC, Pauna HF, Bernal SC, Massuda ET, Hyppolito MA, *et al.* *Current Topics in Medicine and Medical Research*. Vol. 6. Geneva, Switzerland: Book Publisher International; 2020.
  19. Coffey JS. Parenting a Child with Chronic Illness: A Metasynthesis. *Pediatr Nurs.* 2006;32(1):51-9.
  20. Baer K. *A guide to living with thalassemia*. Cooley's Anemia Foundation. 2013.
  21. Ahmadi M, Gheibizadeh M, Rassouli M, Ebadi A, Asadizaker M, Jahanifar M. Experience of uncertainty in patients with thalassemia major: A qualitative study. *Int J Hematol Oncol Stem Cell Res.* 2020;14(4):237-47. <https://doi.org/10.18502/ijhoscr.v14i4.4479>  
PMid:33603985
  22. Rahman SA. Thalassaemia: A study on the perception of patients and family members. *Med J Malaysia.* 2011;66(4):326-34.  
PMid:22299552
  23. Sujana E, Fatimah S, Hidayati NO. Kebutuhan spiritual keluarga dengan anak penderita penyakit kronis. *J Pendidikan Keperawatan Indonesia.* 2017;3(1):47-56. <https://doi.org/10.17509/jpki.v3i1.7480>
  24. Andriyani S, Darmawan D. Hubungan antara pengetahuan dengan tingkat kecemasan ibu tentang hospitalisasi Pada Anak. *J Keperawatan BSI.* 2020;8(1):58-67. <https://doi.org/10.17509/jpki.v4i2.13708>