

Research Article

Mother's Fortitude in Taking Care of Children with Thalassemia in Indonesia

Ria Andriani^{1*}, Nani Nurhaeni², Allenidekania², and Erna Safariyah¹¹Universitas Muhammadiyah Sukabumi²University of Indonesia**ORCID**Ria Andriani: <https://orcid.org/0000-0002-4166-6103>

Abstract. Thalassemia is the most common single-gene disorder. It affects the ability to survive due to chronic anemia and this hemoglobin disorder is inherited from parents. Having children with thalassemia can change the relationships among family members. The situation can trigger pressure and sadness for parents, especially the mother as the closest figure and generally the one who interacts more with the children. Taking care of children with thalassemia can give mothers up and down experiences and stress. Fortitude will help her to determine a series of attitudes that can assist in coping with the stress. This study used qualitative research methods to understand in-depth the mother's experiences in taking care of children with thalassemia. A phenomenological method was used with in-depth interviews with six mothers. The themes that were identified from this study were: not accepting reality, surrendering, efforts to treat children through medical and traditional means, challenges, and mother's fortitude. We can conclude that a mother's fortitude in taking care of children with thalassemia is successful if the mother can accept the reality. This can be seen and felt through the mother's actions in taking care of her children with patience, sincerity and prayer.

Keywords: thalassemia, fortitude, mother's experienceCorresponding Author: Ria
Andriani; email:
ria.andriani@yahoo.com

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1. Introduction

Thalassemia is a disease caused by an autosomal recessive gene disorder on the 16th chromosome gene in alpha thalassemia and the 11th chromosome in beta thalassemia [1]. Lifelong disorders are grouped into alpha thalassemia and beta thalassemia. Based on the severity, beta thalassemia is divided into thalassemia major and minor. Beta thalassemia major is a lifelong genetic disease which is a type of chronic disease [2]. In many cases, the presence of a new member with thalassemia in the family is usually unknown to the parents. For families who live with children as thalassemia sufferers, it is a formidable challenge in the journey of life. The impact of the birth of a child with thalassemia on a partner changes relationships with other family members. Not only that psychologically, economically, emotionally and socially family members need adjustment [2,4].

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Children with beta thalassemia major require routine blood transfusion therapy with the aim of maintaining hemoglobin (Hb) levels of about 10 g. Such a situation shows that children with this disorder certainly really need serious attention and it takes commitment and a hard struggle for family members to take care of them. However, it is not an easy job for family members because not all of them can accept and adjust quickly. Families will feel guilty, angry, tired and stressed facing these conditions [2].

The impact received by family members and the problems of acceptance and adjustment that take time from the concept of parents' thinking about the "dream" child. Parents really crave offspring who are physically and mentally healthy and this can affect the parent's reaction to the child's illness. Ygge and Arnet (2004) mention that the general reaction that occurs in. The first time parents feel shocked, experience inner shock, fear, sadness, disappointment, guilt, rejection or anger². The fact that the child is a thalassemia sufferer is difficult for parents to accept. This condition triggers pressure and sadness for parents, especially mothers as the closest figures and generally interact more directly with children [10]

The negative impact will be felt by the mother, both physically and psychologically. Psychologically, the presence of a disease that threatens the child's life is a condition that causes stress for the mother and can affect the emergence of depressive disorders. Sick conditions in children who have no cure is certainly an important factor that stimulates pressure for mothers and puts mothers in conflict situations in their lives and increases the risk of depression. On the other hand, maternal depression can reduce the sense of responsibility for child care, involvement in education and the fulfillment of proper nutrition in their children. This also causes rejection and hostility towards children [30].

Data from the World Health Organization (WHO), explains that the incidence of thalassemia in the world in 2014, around 250 million world population (4.5%) carry thalassemia genetics, while 80-90 million of them carry genetic thalassemia. Beta thalassemia³⁹. WHO states that the incidence of thalassemia carriers in Indonesia ranges from 6% - 10%, meaning that out of every 100 people, 6 to 10 people in Indonesia carry thalassemia traits. This disease is a genetic disease, so sufferers of this disease have been detected since they were babies (<http://web.rshs.or.id/>). Patients with thalassemia disease in Indonesia are classified as high and are included in high-risk countries, because every year 3,000 babies are born with the potential for thalassemia. (<http://www.puslit.kemsos.go.id>). Based on the results of an interview with the Chairperson of YTI Answers, in Indonesia in 2016 there were 7,200 people with Thalassemia major and 3,200 people came from West Java Province, increasing to 3,264 patients in 2017. 2018 was recorded and also reported as many as 9000 thalassemia major and

40% of patients were still recorded in West Java. In West Java there are 9 cities and 18 regencies, Bandung City is the city with the highest number of thalassemia sufferers, reaching 30% of the total sufferers in West Java.

There is some information about mothers who provide an overview of their situation in caring for children with thalassemia, with various kinds of needs that are not simple. Starting from routine transfusions and medication, to the pattern of fulfilling nutrition and activities that must be of particular concern. Perform blood transfusions for their children in order to maintain the child's Hb and the child's body defense is good. Alternative medicine efforts are carried out to maintain the health of children in addition to medical treatment. Research on the experience of mothers in caring for children with thalassemia in Sri Lanka, conducted by Nahla and FitzGerald (2003) found that parents experience financial difficulties to finance routine care for their children, namely routine blood transfusions to the hospital and iron chelation therapy to prevent iron buildup. It also describes the concerns of parents about neglect of other healthy children when parents care for children suffering from thalassemia.

Clarke et al (2009) research conducted on the impact of routine care of children with thalassemia major on the family economy in the UK, found an increase in the cost of caring for children with thalassemia major, related to additional hospital travel costs, consultation fees for other health problems. According to Hockenberry and Wilson, 2009 during treatment, generally children are always accompanied by their parents, and the mother is the most common. Mothers have an important role in caring for and caring for their children. In caring for children with thalassemia, mothers will experience their own ups and downs, stress, and of course this provides an experience of fortitude for the mother.

These experiences were related to mother's knowledge about thalassemia, the feeling for the first time when she found out her child had thalassemia, self-acceptance, mother's fortitude and patience towards children with thalassemia, worries about the child's future, worries about blood transfusions, efforts to cure thalassemia children, worries to add children. Mothers in caring for children with thalassemia disease which can be at risk of causing stress, depression and also health problems for family members, if it is not accompanied by a very meaningful meaning of fortitude. Resilience will help determine a series of attitudes that make him resistant and able to cope with the stress faced in caring for a child with thalassemia. The purpose of this qualitative research with a phenomenological approach is to understand in depth the picture of fortitude that focuses on the experience of mothers caring for children with thalassemia. Efforts to take care of mothers, Commitment, Control and Challenge mothers in caring for children

with thalassemia. With the fortitude possessed by mothers in caring for children with thalassemia to deal with various kinds of stressors in their lives.

2. Methods and Equipment

This research was conducted with a qualitative research method with a phenomenological approach. Qualitative research as research that is used to understand the phenomena experienced by research participants (eg behavior, motivation, and action). This is understood holistically by means of description in the form of words and language in a natural context using various natural methods²⁵. Moleong (2011) reveals that phenomenology is a thinking view that focuses on human participatory experiences and interpretations of the world. Qualitative research approach is based on perspective perception by looking at the holistic world, where there is not only one reality of life. Reality is seen based on individual perceptions that differ from one another and can change over time. The descriptive phenomenological method aims to explore individual experiences. An individual's experience of a phenomenon he experiences will be the basis for an understanding of a phenomenon that occurs. In general, the activities carried out using a phenomenological approach²¹, include intuition, analysis and descriptive: (a). Intuition stage, the researcher fully recognizes and understands the phenomenon under study, the first step in doing intuition begins when collecting data by exploring the experiences of participants. (b) In the analysis phase, the researcher identifies and analyzes the data or information found. Reading all the data that has been collected, rereading phenomena and selecting keywords (coding process), identifying the meaning of several identified keywords (categorization process), grouping several identified meanings into the form of themes (thematics), writing the pattern of relationships between these themes into a temporary narrative, returning the narrative to be validated and recognized by the participants, and describing the data from the validation results and writing them in the final narrative (research results). (c) The descriptive stage is the final activity of data collection and analysis, and the researcher compares the results of his report with the results of previous studies and provides criticism based on the pattern of theme relationships formed from the phenomena studied. The taking of participants in this study used a purposive sampling method, namely the researcher had certain considerations in selecting the participants involved in the study. This purposive sampling method in sample selection is oriented towards research objectives where the sample must meet predetermined characteristics that are in accordance with the phenomenon under study³. This qualitative study research basically poses no risk to

the participants. Researchers still have to be sensitive to ethical issues in carrying out phenomenological research. Ethical problems in research occur due to the meeting of two or more different interests at the same time. Thus, a research ethics guarantee is developed to protect participants from ethical problems that may occur. The four principles of research ethics used are: respect for human dignity, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits. The data collection method that will be used in this study is an in-depth interview using interview guidelines and field notes. The interview guide serves to direct the researcher in developing the content of the questions based on the objectives so that they do not deviate from the research objectives. The interview strategy in this study used open-ended questions [3,4]. The data collection process will be carried out through three stages, namely the preparation, implementation and termination stages.

The data analysis activity was started by listening to the participants' verbal descriptions and followed by reading the results of the verbatim transcripts over and over again. The method of inductive analysis and synthesis used in this study using Colaizzi's Method⁴

3. Discussion

The early days when children are diagnosed with chronic diseases, parents often experience emotional turmoil and the characteristics of this situation are shock, disbelief and rejection. This can be found in phenomenological research that has been carried out on parents, especially mothers who take care of children with thalassemia who feel shocked, surprised, and difficult to accept the reality. Because they feel that no family has ever had the same disease. Although the mothers felt very sad and difficult to accept in the end, the mother was able to adapt well. Grieving is an emotional response to loss that is very likely to arise, in Kubler-Ross theory the grieving process consists of 5 stages, namely rejection, anger, bargaining, depression and accepting reality. The informants in this study have gone through this process. In the metasisthesis⁹ states that parents who care for children with chronic diseases will feel worried, and it is this concern that encourages parents to act, to do something for their child's recovery. In this study, mothers who have gone through treatment efforts through alternative medicine such as prayer water, food/drink is one form of treatment that is carried out outside of medical treatment. From this research, it is known that the mother feels that treatment is not easy, such as the child's desire or the child's refusal to undergo the treatment process, but over time the child can follow the treatment like other thalassmic children.

Parents who have and care for children who suffer from chronic diseases in general must seek and learn certain knowledge needed in the treatment of these diseases. Parents are also required to be able and even proficient in caring for children without significant challenges. So far, many parents have experienced fear, frustration and doubt, and often parents express frustration, do not respect or do not recognize the role and efforts of parents²¹

4. Conclusion

The themes that have been identified in this study consist of 6 main themes, namely: 1) Characteristics of children with thalassemia symptoms 2) Not accepting the reality of children 3) resignation 4) Carrying out hospital treatment and alternative treatment actions 5) Efforts to treat children with medical and alternative 6) challenges faced by mothers 7) Mother's resilience in caring for children with thalassemia. The themes mentioned above are separated and detailed to reveal the meaning of the various experiences of the informants. Although discussed separately, these themes are still interconnected and form a unified whole, so that they can explain the essence of the picture of a mother's steadfastness in caring for a child with thalassemia.

4.1. Characteristics of children with thalassemia symptoms

Children with thalassemia have special signs and symptoms. Characteristics that are different from healthy children, conditions that distinguish healthy children from thalassemia children, one of which has a level of dependence on medical treatment, must undergo routine transfusions, because the body's physiological functions are unable to maintain hemoglobin (Hb) levels. As for the mother's perception that is seen and felt related to children with early symptoms of thalassemia, it is described that the child experiences frequent pain, decreased hemoglobin, looks pale. This was conveyed by the informants, as expressed as follows:

...when I was little, my son often had fever..it didn't go down and down..(I² and I⁴)...my child used to have fever up to 39 degrees Celsius (I¹)...my child used to look pale (I³)... ..the symptoms used to be my child is often coughing... not getting better (I² and (I⁵)...

4.2. Not accepting reality

A normal child is the hope of every parent, but if at the time the child is born it does not meet expectations, it makes parents disappointed, so sometimes parents, especially mothers, do not accept this reality. This was especially felt by the informants 1, 2 and 5. The ha was expressed as follows:

.. when I heard about the disease from the doctor, I was shocked.. sad.. disappointed... I can't describe it.. I cried (I¹)...why... I was surprised, because no family had ever had a transfusion(I³).... I've never had a family like that (I⁵)...

4.3. Efforts to care for children with thalassemia

Daily care at home and in hospital. Treatment of children with thalassemia is very dependent on medical treatment, in addition to routine transfusions every certain *period* of time, children also have to carry out certain daily care, control their health, limit activities, and take medication regularly. This can be seen from the expressions of the mother informants below:

...I am taking care of the thalassemia child. ...carrying out the same treatment as others (I⁵).. routine drug administration, but in general they do not provide different treatment (I⁴).. ways of treatment. What is recommended by the medical staff (I²)... ..I'm very protective...don't run...don't be tired...(I⁵)... exjade (I³)..

4.4. Alternative treatment

The diverse Indonesian community still believes that alternative medicine can be used as an option to try to treat the disease that is being suffered by their child. Parents try to do this for the sake of their child's recovery as revealed by the following informant

...while taking care of me, I tried alternative treatments.. ..yes, alternative..with the family, people can bring it..in other words, drink water(I⁵)... do alternative therapy...pray..pray like that (I⁴)..besides medical therapy. I do alternative therapy by feeding the child the kind of sea cucumber..what..yes..that's it (I¹) ..

4.5. Challenges faced by caring for children

Caring for thalassemia children sometimes faces challenges in the form of difficulties that must be faced so as not to become a nuisance for mothers to help and care for

their children who are disturbed. In caring for children with thalassemia there are several challenges that must be faced by mothers, including those expressed by informants as follows:

.. The challenge.. if the child doesn't want to be transfused, he has to be extra persuasive (I¹).... What's the challenge... actually, there are a lot of things.. For example, we have high desires.. we want to be like healthy children (I⁴)... ..the challenge is to give encouragement so that you can continue to do it as you wish... yes, hopefully it can be done (I³) and (I²).. .. to play a role in the mother in carrying out the routine of life with thalassemia children.. (I⁵)

Mother's steadfastness in caring for children by accepting the reality of a mother's success in caring for a child with thalassemia can be seen and felt through the mother's actions in caring for her child patiently and sincerely. Accepting the reality of the condition of a child who has a disease that is difficult to cure is a situation that is not easy to live with, but the mother and the informants gave an extraordinary picture of fortitude, as seen from the expressions conveyed by the informants below:

... in undergoing treatment now we are positive thinking ... attitude of surrender (I⁵) continue to learn to be patient.. sincere... so that everything is made easy.. (I⁴)... Pray a lot for children.. so that they are given a long and blessed life.. (I³) ...make children as a source of motivation in living life.. (I²)...Pray a lot for children..so that they are given a long and blessed life (I¹)..

Mothers who care for children with thalassemia have their own experiences. From this experience they know that thalassemia is a hereditary disease that cannot be cured, but can be prevented. Mother states that she accepts that thalassemia in children is destiny, must be patient, steadfast and sincerely accept it. Parents always try to meet the needs of children and then pray in living it always ask for the strength of Allah SWT. In the research⁵ found that religion is an important source of strength for some mothers, which gives the mother the ability to accept the child's illness can increase her faith in God and pray is one of the coping methods used.

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