



Dynamics of Mother's Psychological Condition As a Caregiver For Thalassemia Children

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ABSTRACT

Globalization and the monetary crisis, apart from providing opportunities, also presented big challenges, because they could change the map of health services which could result in the development of service quality and accelerate technology transfer. Most of the female adolescents experience psychological disorders due to the complex attributes of adolescent women due to physiological changes in the body either expected or due to age, one of which is the biggest factor of psychological problems on the arrival of the menstrual period. This research is an exploratory case study with a cross sectional approach on psychological disorders of menstrual periods in teenage girls of SMAN 4 Baturaja. The research subjects are 383 students of grade X, XI and XII students. From the univariate results of menstrual period psychological disorders, mild, namely 223 respondents (58.2%) and heavy 160 respondents (41.8%). Age at first menstruation without risk was 369 respondents (96.3%) and at risk was 14 respondents (3.7%), weight without risk is 276 respondents (72.1%), and at risk is 107 respondents (27.9%). menstrual cycle, regular was 203 respondents (53%) and irregular were 180 respondents (47%). During menstruation, mild pain was 70.2% of respondents and severe pain was 114 respondents (29.8%). Based on the bivariate results of the first menstrual period, the p-value was 0.050, body weight obtained a p-value of 0.004, the menstrual cycle was obtained p-value of 0.002, the menstrual period obtained a p-value of 0,000. There is a relationship between age at first menstruation, body weight, menstrual cycle and menstrual pain with psychological disorders in teenage students

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1. INTRODUCTION

Thalassemia, often known as sickle cell disease, is the most prevalent single gene abnormality in the world. It is a hereditary condition that manifests clinically and hematologically differently in various ethnicities. (Inati et al., 2007) . There were 600,000 cases of thalassemia in Indonesia in a period of ten years with 40% of the population being carriers, and these individuals run the risk of passing on thalassemia (Prasomsuk et al., 2007). Almost all patients have a history of inbreeding (Inati et al., 2007).

Thalassemia is a group of inherited disorders or genetic diseases characterized by a decrease or absence of globin synthesis (Surapolcha et al., 2010), which is inherited so that the affected individuals cannot synthesize sufficient hemoglobin and is one of the disorders caused by hematological disorders (Steiner, 1995). Thalassemia is classified according to the severity of its effects, patients with thalassemia major need regular blood transfusions to survive (Nahalla & FitzGerald, 2003). Thalassemia major is a public health problem in the world including

Mediterranean, Middle East, Asia, Tunisia (Bejaoui & Guirat, 2013) with large populations from these countries (Clarke et al., 2010). Thalassemia major poses considerable challenges to the health-related quality of life in children (Clarke et al., 2010). Based on the study of (De Sanctis et al., 2018), it was found that thalassemia major will cause various difficulties with the endocrine system like central hypothyroidism. Latent hypocortisolism, growth hormone insufficiency, and thyroid cancer. In addition to having an endocrine effect, thalassemia can cause hemolytic anemia (Al-Samkari et al., 2020; Iolascon et al., 2017), Congenital Morgagni hernia which is characterized by swelling of the liver caused by splenectomy for -thalassemia major causing blunt trauma (Al-Salem, 2007), it is necessary to consider the treatment of thalassemia with splenectomy procedures because of the possible consequences happened (Iolascon et al., 2017).

Patients with thalassemia major have to undergo blood transfusions to the hospital regularly to survive, this is an experience that causes concern and creates a psychosocial burden (Sapountzi-Krepia et al., 2006). Not only does it carry a psychological burden on people with thalassemia, it affects children's lives and family health due to the seriousness of the condition, the cost of ongoing treatment and care, as well as the strain and stress associated with providing care for children who have major chronic conditions like thalassemia (Wacharasin et al., 2015). The quality of life and health of children with thalassemia is determined by the severity of the disease and treatment as well as the family's finances to care for the child (Surapolcha et al., 2010). The high cost of hospitals, health insurance, blood transfusion costs, the use of iron chelation drugs is an economic burden for families who care for thalassemia children (Clarke et al., 2010; Esmaelizadeh et al., 2016; Riewpaiboon et al., 2010). In addition, based on research of Chong, parents who care for children with thalassemia who depend on transfusion will experience psychological stress (Chong et al., 2019).

Parents who have raised or cared for a child with an autosomal genetic disorder will have a profound impact on their perception of being a reproductive being. Parents who have children with cognitive disorders will be aware of the risks that occur, but there is an emotional unpreparedness in the diagnosis given to children. In this case it is clear that the self-concept can change according to the existing situation (Pisnoli et al., 2016). In addition, parents of children with thalassemia will face various challenges when caring for them. Starting from worrying about children in the future, stigmatization and social death, inadequate information (Sapountzi-Krepia et al., 2006), nothing support, experiencing psychological pressure, frustration with treatment, ethnic minorities in getting treatment (Atkin et al., 1998) and the need for good coping strategies (Prasomsuk et al., 2007; Punaglom et al., 2019). Positive and negative religious coping methods have a significant relationship on the psychology of parents of children with thalassemia (Chong et al., 2019). Based on the results of a study in Bangladesh, poor knowledge about thalassemia including diagnosis and challenges faced when caring for their children. This requires planning and designing effective prevention and intervention strategies (Hossain et al., 2021).

Family empowerment programs can provide support (Punaglom et al., 2019) and help families share experiences and beliefs about caring for kids who have thalassemia, can help make decisions about family By exchanging different types of knowledge, people can better understand one another's issues, needs, and opinions while also fostering social support. and learning processes for parenting as a function, management and family relations (Wacharasin et al., 2015). As parents who have a parenting role, on average, mothers have good family management in caring for children. Indirectly, easy family management allows for accepting care for children with chronic diseases and contributing to improving the quality of life (Sutthisompohn & Kusol, 2021). In addition, many parents would like to be given the opportunity to discuss care and treatment as well as support from health professionals (Sapountzi-Krepia et al., 2006).

2. RESEARCH METHOD

This qualitative research uses a phenomenological method, which is a qualitative methodology to understand an individual's life experience using an idiographic approach. This method aims to gain a deeper understanding of the individual experience through description and interpretation.

Research Sample

Using a purposive sampling technique, nine mothers who provided care for children with thalassemia in 2020 were chosen among patients receiving thalassemia therapy at the Palembang City Hospital. Each interview was examined separately during the initial analysis stage in order to extract information about the phenomenon of maternal psychosocial challenges. This information was then compared with information from other interviews, and after exchanging opinions with the author, consensus was reached. With the help of 9 individuals, data saturation was attained. The inclusion criteria included not being a single parent, having a kid with thalassemia major, the mother



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being the primary caregiver, not having a chronic physical ailment, and the mother having a history of psychological illnesses.

Data Collection

All participants were interviewed in-person using semi-structured questions in-depth. The women chose the calm location for the interviews, which were held adjacent to the kids. Each interview lasted between 40 and 60 minutes, depending on the participants' willingness, tolerance, and amount of information provided. The first author pre-conditioned each interview.

The study's primary interview questions are "How did you feel when you were first told that your child had thalassemia?" and "How did your child's illness affect your life?" Then, the reasons are examined in depth. According to the participants' responses, other questions such as "What part of your life has changed since you found out about your sick child?" and "Which part is causing you trouble?" also asked. In fact, the mother was questioned about the idea in each interview, and subsequent questions were based on her responses. The author wrote down the lines from tape-recorded interviews, utilizing them to discover how people understood the phenomenon.

Data Analysis

The process of data analysis was carried out using the van Manen phenomenological methodology. This technique includes listening to every recording to get the researcher connected with the participant's experiences. They then made a verbatim transcription of the digital recording. Following the transcribing stage, thematic sentences that directly related to the fen sign and added to the participant's experience were retrieved using the van Manen highlighting method. Statements provide context, which is subsequently gathered into themes shared by all participants. We also use the research activity proposed by Van Manen, as a method of geological structure, to guide research on hermeneutical phenomenology.

3. RESULTS AND ANALYSIS

The involvement of researchers with research questions has always been one of the needs of interpretive phenomenological studies. Constant questions "What are the experiences of psychosocial challenges in mothers of a child with thalassemia?" provides for the extraction and interpretation of themes throughout the entire study. Finally, well-organized ideas result in a thorough explanation of the phenomenon. Van Manen's thematic analysis method was applied to the transcription and analysis of interview data. Concurrently with data collection and analysis, initial coding was completed, and it was decided to conduct a number of further interviews.

Rigidity

Credibility, Reliability, Confirmability, and Transformability are suggested by Strauss and Corbin to assess the robustness of qualitative data, citing Lincoln and Guba. The study's findings were submitted to the participants for approval, and they provided the authors with feedback on how well the findings fit with their personal experiences. The findings were discussed in a conference with the professors of qualitative studies, and in several instances, they examined portions of the interview transcript. Other professors who specialize in qualitative research were provided access to the interview text and the method used to extract the topic for their feedback. Additionally, the corresponding authors of this study contribute to the topical reflection of the research team and analyze the analysis of qualitative studies specialists to provide research reliability. Additionally, the context is set up for analyzing and critiquing others with thorough details.

Ethical Considerations

This research was approved by the Palembang Health Polytechnic Ethics Committee No..... The informed consent document provided to each participant explains the purpose of the study, details the potential risks, and provides a confidentiality statement about how participant information will be handled safely.

Result

Nine mothers of children with thalassemia participated in this study. The demographic characteristics of the participants are presented in Table 1.

Participans	Age	Used	Qualification	Blood relation with Spouse	Number of children with thalassemia
Participant 1	38	No	Secondary school	Yes	One Child
Participant 2	33	Yes	Senior High School Certificate	No	One Child
Participant 3	43	No	Secondary school	No	One Child
Participant 4	45	No	Secondary school	No	Satu anak
Participant 5	31	Yes	Secondary school	Yes	More than one child
Participant 6	34	No	Senior High School Certificate	Yes	One Child
Participant 7	38	No	Senior High School Certificate	No	More than one child
Participant 8	28	Yes	University	Yes	One Child
Participant 9	50	Yes	University	No	One Child

534 key topics were retrieved in the first stage. Based on similarities and variances, the major themes were combined and then whittled down to 290. 24 subsidiary themes were derived by classifying the core themes according to similarity. The next step in thematic analysis is to separate the subthemes from the main themes to get at the ultimate outcome, which is 4 main themes and 7 subthemes [Table 2]. The study team made this decision in accordance with the advice of professionals. Here are the themes that were found :

Psychological Stress

Repeated hospitalizations of the child during long-term, taxing care lower the tolerance threshold and leave the mother mentally confused. When they witness their child suffer, they experience intense suffering. In addition, many moms experience sadness and some even consider suicide because they feel bad about having these kinds of kids. They are also scared and worried about the future of their children's marriage, careers, and education. They have lost motivation as a result of their unfavorable psychological experiences and the shame that comes with having a sick child among others. The following three sub-themes are part of this major theme:

a. Shocked in receiving the verdict

The mothers claimed that they lacked the strength and tolerance to care for the other children and spouses because of the high levels of psychological stress. Some of them are so scared and stressed out from the pressure of their child's illness that they can't even be bothered to take care of them. Some of them even have nightmares.. A mother of two thalassemia children said, "Blood transfusions and Dysfrol were so excruciating that I was nervous and bored. I couldn't stand it at all. I was so upset to see my children's suffering that I didn't sleep well at night and most of the time I woke up screaming and I was always impatient at daytime" (Participant Number. 7)

b. Deep sadness over suffering

Mothers have a lot of tremendous problems and can't fully perform their regular activities. These mothers' guilt over their marriage and self-blame for their children's suffering are two of the most significant issues that preoccupy their brains and perplex them. A mother said, "After my son's spleen surgery, I was afraid and I was constantly worried that he might catch a new disease. When I saw the gradual death of my child, I suffered a guilty conscience, because I caused it with my marriage. I want to kill myself because I damaged my baby with a diseased gene" (Participant Number 5).

c. Afraid of facing the worst impact

Another thing that The unintentional criticism of moms' children by others pisses them off. The mothers were devastated by this and broke down in tears during the conversation. Mothers stated that because other people only knew that their child received blood, they thought that the situation must be bad limiting the mother's interactions with those around her leading to isolation. Regarding this, a mother said, "People in my family have told me that our children may get sick while playing with yours. When the parents in the family



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wanted to talk about me, they told each other that this poor man had a baby with cancer. Because of that, I couldn't go to parties. They are strangely looking at me" (Participant Number 1).

Hopelessness treats chronic conditions

The findings showed that mothers frequently have several acute and chronic psychosomatic reactions in the body, which can significantly worsen the physical health of the offspring and lead to exhaustion. Due to their extreme weariness, these moms have developed a wide range of acute and chronic ailments, including cancer, diabetes, open heart surgery, hysterectomy, diabetes, heart difficulties, and tension headaches, all of which worsen their situation. The following two subthemes are part of the main theme:

a. Severe psychosomatic symptoms

Due to the numerous challenges of caring for a thalassemic kid, moms have experienced severe psychosomatic issues. In addition, the youngster continues to experience frequent attacks of severe headache, bone, and abdomen pain due to their extreme care, grief, and discomfort. Said a mother, "I don't have the time and ability to look after myself at all. I became weak from within. I used to be active, but now I have hand and foot pain, migraine headaches, and so on. My stomach hurts when I see that my son is behind his peers and other people his age" (Participant Number 2)

b. Long term psychosomatic Consequences

Giving care to a child who has thalassemia has adverse long-term effects and permanent psychosomatic effects on the mother. Each participant had a physical condition that made it harder for them to care for the child while simultaneously making their medical condition worse. The majority of women experience so many physical issues that they worry about losing their health and how their sickly children will survive without them. said one participant, "When I found out my son was sick, I was so stressed that I started bleeding profusely and had a hysterectomy. I have all kinds of chronic diseases like high blood pressure and diabetes, because of this pressure. I also had heart problems recently. I am always worried about who will take care of my sick child if something happens to me. " (Participant Number 8).

Mother's need for empathy and support

According to mothers, raising thalassemic children is a challenge they will never be able to handle alone. They complained about all forms of physical, psychological, and financial incapacity. In their first-hand accounts, participants spoke of a supportive urge to maintain their health, which manifested itself in many ways. Even if other family members or relatives merely listen to them to help them calm down and decompress is enough for those who are responsible for providing care alone, are no longer able to handle all these issues without assistance, and require others' help. One of the worst issues for mothers is often economic hardship. They claimed that the Relief Foundation should pay for them. The following two subthemes relate to the primary theme:

a. Hope for family support

All members of the family must work together to help mothers care for sick children. They claimed that because their spouse was engaged in earning money, they were left to handle care on their own and endured significant physical and mental harm. Families, according to mothers, ought to provide both material and emotional support. A mother remarked, "Nothing helps me and I live alone with this predicament now that my own issues, such hypertension and back pain and a thousand other calamities, have risen. "If my husband and children had helped, I wouldn't be so sick now. At least, if they listened to my hurt, I would be at ease.". (Participant Number 9)

b. Support needs outside the family

Participants also require financial, spiritual, and social support from the health care system in addition to providing for their families. To care for their children, most mothers should be knowledgeable about thalassemia. Additionally, it will actually assist them and the youngsters will experience fewer issues if the care team educates and supports them. The mothers also indicated that she was in dire need of financial support to provide drugs and deferoxamine, requiring assistance from certain disease organizations. A mother said, "The cost of treatment has increased so much that I only take one deferoxamine for my two sick children, and sometimes I don't even have the money to provide it. I don't know much about my children's problems. I took them to the local clinic and to someone when they were sick but no one guided me. I wish there was a doctor to help us. I need help myself now" (Participant Number 10).

4. DISUSSION

Researchers have always been interested in the health and quality of life of mothers of children with thalassemia. Studies have shown that mothers' quality of life can be altered by disease and a stressful lifestyle. The mother's feelings of sadness and pain are linked to the child's suffering. Psychological stress was one of the most significant miseries experienced by the mothers in this study. Mothers are said to suffer from things like exhaustion, insomnia, and physical and psychological issues, according to other studies. According to a study by Abu Shosha and Al Kalaldehy, mothers of thalassemic children have a wide range of psychological issues. Shahraki Vahed also highlights the numerous issues that parents of thalassemia-affected kids face in terms of various emotional, psychological, social, and family elements. Additionally, Pouraboli et al., Heidari, and Ahmadiyah's findings from a different study showed that parents of thalassemic children experienced psychological stress due to the challenges of caring for them. In order to lessen mothers' suffering, services for proper psychological care should be made available to moms of children who have thalassemia. Despite the crucial role that psychologists and psychiatrists play in identifying and treating psychological issues, their contribution to problem-solving has not been taken into account. As a result, it is essential to conduct activities like radio and television education and counseling programs, as well as introducing available centers, to raise understanding of maternal self-care. The assistance of psychiatric nurses working in the care facility under their direction might be used by thalassemia patient support organizations to address maternal psychological issues.

Mothers in this study experienced acute (headaches and backaches), chronic (diabetes and heart disease), and incurable psychosomatic disorders as a result of the pain and challenges of child care as well as numerous worries for their children's present and future well-being. Mothers claimed that the psychological strain brought on by their child's condition, which decreased their physical strength, was the root of their disease. Furthermore, many have said that they lack the time necessary to take care of their health. These issues may significantly worsen the mother's physical condition and cause weariness in their bodies. According to Saldanha's research, 1.5% of mothers of children with thalassemia experienced various psychosomatic diseases throughout the first two years of their kid's therapy and need assistance from others to continue taking care of the child. With the right education, these mothers should be helped to choose suitable emotional regulation methods, adaptation strategies, and physical health. Teaching cognitive emotion regulation strategies and adaptive strategies has been found to significantly reduce maternal psychosomatic illness. To solve this problem and continue the treatment process, mothers require the support of their family and friends. The care team should also put in place particular measures to help them and these mothers continue the childcare process by giving them the required self-care training.

Participants underlined the importance of empathy and support both inside and outside the family as well as their impact on their health condition while speaking about their experiences. The demands of moms who are helpful in many ways include the need for assistance from their spouses, other family members, medical organizations, and suitable insurance services. Dahnil et al.'s research demonstrated that women, in particular, were more prone to experience physical, emotional, and social problems than other parents of children with thalassemia and required all-encompassing support for child care. In a qualitative study, Qada Abu Shosha et al. shown that providing support and health education by members of the care team is an effective way to lessen the difficulties, stress, and issues faced by mothers of children with thalassemia. The most pressing need of mothers is financial support. The cost of treating children with chronic genetic illnesses because they require ongoing care and numerous visits is a topic covered by Vahab et al. Women who are raising children with thalassemia major have significant financial challenges. Financial issues were also brought up by participants in the survey. In order to address these problems, the government must work to lift restrictions, take into account old drug allowances, and mobilize public benefactors. It also requires the virtue of society not to rush to assist these women.

Limitations and Recommendations

This study's limitations include the small sample size, the contextual nature of the results, and the inability to generalize the findings to mothers of thalassemic children in other geocultural situations. We made a concerted effort to properly choose our participants in order to maximize the representativeness of our sample. In order to verify the findings of this qualitative study, comparable research should be carried out in other nations. Interpretation bias is a potential issue in this qualitative study. To overcome this and avoid losing any themes, two researchers independently examined the data for theme development. Another limitation is taking in consideration the bias of study participants when collecting data and conducting interviews. However, the researcher has no influence over how each participant decides to respond to the research topic.



5. CONCLUSION

Thalassemic children face numerous difficulties in a variety of areas, according to mothers' life experience. The need for financial, social, and emotional support as well as psychological stress are the three main maternal pains. As a result, family members and medical professionals should take specific steps to help moms of children with thalassemia.

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