



FEELING AS A BULLYING VICTIM” PERCEPTIONS OF ADOLESCENT FEMALE WITH THALASSEMIA MAJOR: A QUALITATIVE STUDY

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ABSTRACT

Adolescent female with thalassemia major disease experience various psychological, emotional, and social behavioral problems that affect their perceptions of being a woman in the future. The purpose of this study was to explore the perceptions of female teenagers with thalassemia major about being woman. This study uses a descriptive phenomenological approach. The method used was in-depth interviews using semi-structured interview guidelines, and data was analyzed using the Colaizzi method. There were 12 participants selected using a purposive sampling technique. The results was based on the theme, fear of ill- treatment, with the sub-themes, fear of bullying from friends and fear of physical violence from men. Adolescent female with thalassemia major in this study experienced bullying both verbally and physically. Verbally, adolescents receive various kinds of negative labels that are often said by their friends. Three teenagers in this study received physical abuse (physical violence) from their friends and their father. Adolescents with this disease experience fear and worry about their future as women, especially with the experience of treatment from those around them.

Keywords: adolescents female; bullying victim; thalassemia major; woman roles

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INTRODUCTION

Thalassemia is a group of congenital blood disorders, caused by defects in the genes that are responsible for producing globin chains in haemoglobin (Lippi & Mattiuzzi, 2020). This genetic disease is the most common blood disorder in the world caused by the rapid aging of red blood cells (hemoglobin, especially in the globin chain) therefore the age of red blood cells becomes shorter (about 20-30 days), and this is one of the causes of anemia (IDAI, 2016). This disorder is inherited recessively according to Mendel's law (Wahidiyat et al, 2022), and is passed down from both parents who carry thalassemia traits. According to World Bank data, 7% of the world's population are carriers. Every year, there are about 300,000-500,000 newborns with severe hemoglobin disorders. Furthermore, about 50,000-100,000 children died from β thalassemia, of which about 80% are from developing countries including Indonesia, an indicator of the high frequency of thalassemia carrier genes. The epidemiological research in the country proves that the number of thalassemia major genes ranges from 3-20% (Kementerian Kesehatan Republik Indonesia, 2018), and based on data, as at October 2018, there are 9,131 patients with this disease registered in all Indonesia.

Moreover, till now, this disorder does not have a cure, especially thalassemia major, which requires continuous treatment, such as blood transfusion by maintaining hemoglobin levels above 10g/ dl. However, the harmful impact on children is the accumulation of iron in the child's organs, I.e., the liver, heart, endocrine glands, and others (Wahidiyat et al, 2022). Thalassemia major also causes psychological, emotional, and behavioral problems in children and their families. This challenge is more severe in adolescents who are seeking autonomy for themselves (Hassan & Azzab, 2016). In general, teenagers with thalassemia also face emotional feelings such as sudden mood swings, which have an impact on decreasing the quality of life of adolescents so that they affect physical, emotional, social, school, psychological and cognitive functions that can interfere child development (Nurhidayah, Hendrawati, Mediani, & Adistie, 2016). According to the research results conducted by Behdani et al (2015), adolescents who suffer from this disease experience worse psychological, emotional, and social behavior problems than healthy adolescents ($p < 0.001$). This is in line with the results of research conducted by Az-zahra, Mardhiyah, and Nurhidayah (2019) that as many as 54.3% of adolescents with thalassemia major experience depression.

The negative effects of major treatment of thalassemia also affect the adolescents' appearance, such as bone deformities and short posture (Yacobovich & Tamary, 2014). Also, facial bone deformities, namely cooley facies (slanted eyes, a protrusion on the forehead, between both eyes and hypertrophy of the maxilla, dental malocclusion) (Kementerian Kesehatan Republik Indonesia, 2018). Therefore, it affects body image, which has an impact on psychosocial psychosis and decreases the adolescents' quality of life (Behdani et al., 2015). The research results conducted by Mariani, Rustina, and Nasution (2014) stated that the quality of life of children with thalassemia major was on average 58.6 with the lowest score of 26.6 and the highest at 93.8. The social and physical quality of life domains were above the average quality of life score, where the social domain was the highest, the emotional was below the average quality of life score, while the school domain was the lowest. This is in line with the research conducted by Behdani et al (2015) using the PedsQL, SDQ, and CDI questionnaires showing that there was a significant relationship between thalassemia major and healthy adolescents' depression, anxiety, quality of life, and behavioral screening. These problems interfere with interpersonal relationships, reduce self-esteem, and lead to depression (Mohamadian, Bagheri, Hashemi, & Komeili Sani, 2018).

Furthermore, adolescents with this disease experience various problems as described above. Therefore, nurses have a role as counselors to deal with the psychological aspects such as ways to accept their conditions, which are not the same as their peers. The study conducted by Behdani et al (2015) showed that 80% of children with thalassemia major had at least one mental disorder, the most common experienced being depression, and approximately 26.7% of thalassemic adolescents experience depression. This problem significantly affects their adherence to treatment, self-management, and expected results. Therefore, they need counseling to prevent psychological problems and mental disorders (Mohamadian et al., 2018). This problem is also a result of an individual's ability to adapt to situations, because humans are a holistic and adaptive system. Therefore, this study uses the adaptation theory approach proposed by Sister Calista Roy, to determine the perceptions of female adolescents with thalassemia major as women in the future. This was intended because the needs and feelings of adolescents are different from adults, and each age group has unique problems according to their stage of growth and development. Therefore, knowing who they are as women is important, because it affects their lives and the treatment that they continue to undergo. This study reveals in-depth the perceptions of thalassemic female adolescents about

themselves as women in the Jakarta, Depok, Bekasi, Bogor, and Tangerang (Jabodetabek) areas, which is useful as basic data in caring for them. Therefore, the psychological needs of adolescents are met and this reduces their worries as women in the future.

METHOD

The study used a descriptive phenomenological approach to explore the perceptions. The participants were chosen through a purposive sampling technique. The researcher also performed bracketing, a process by which the researcher “suspends” any preconceived opinions and beliefs about the phenomenon being studied. Therefore, the results obtained are from the point of view of the individual studied. The informants in this study were female adolescents with thalassemia major. The informants criteria were aged 17-19 years, had regular blood transfusions, not married, and willing to express themselves. The number of participants in this study was based on data saturation. Data collection is performed by sampling until a point of saturation where no new information is obtained, and experience has been gained. Data saturation was reached at twelve informants.

The data collection procedure began with obtaining the ethical clearance letter. After obtaining permission from the authorities, the researcher sent a research permit to YTI (Yayasan Thalassemia Indonesia), and then directed them to contact POPTI (Persatuan Orang Tua Penderita Thalassemia Indonesia) in Jabodetabek. Then the prospective participants and their parents were contacted, and a trusting relationship was fostered. Afterward, the researcher explained the purpose, benefits and the rights of the participants, as well as the research procedures. The researcher asked for the address of potential respondents, willing to participate in the study. The informants met in person with the researcher at their homes according to the prior agreement, and a consent form was signed. The interview process was conducted until saturation was achieved in each participant. The total interview time was 30-90 minutes. Data was collected using instruments: the Sony ICD-UX71 recording device, smartphones, semi-structured interview guidelines, and field notes. Data collection was conducted in February-Mei 2020. The interview results were analyzed by writing down the interview transcript and recording important information.

This study used Colaizzi's (1978) phenomenological method for the data analysis stage. According to Colaizzi's method, the researcher first had to obtain a clear picture of the phenomenon under study. The observations and interviews with all participants were recorded and transcribed. The researcher made a transcript of each participant after each interview. After all participants were interviewed, the researcher re-read the transcripts repeatedly to understand and interpret the participants' answers and be able to take keywords from each participant's statement. Important statements are marked to be grouped. Then, the researcher looks for the meaning of each important statement from all participants, then the data is grouped into several themes and the main theme will appear. After that, the researcher logically integrated the results into a narrative form and returned it to the participants for clarification. This provides an opportunity for the participants to add information or choose information that they did not want to be published in this study. Finally, the researcher concluded the analysis results with the data obtained during the validation process.

RESULTS

Participants characteristics

There were twelve adolescents female with thalassemia major in this study. All of them were single with an average age of 18 years, i.e., 7 respondents, 2 participants were 17 years old, and the remaining 3 participants were 19 years. There were 2 of the respondents were still in

school, 9 had graduated, and 1 was in college. Furthermore, all have experienced delays in their first menstruation, and are still taking iron chelation drugs till date. Moreover, 3 of the respondents undergo transfusions once a week, 5 have theirs every 2 weeks, and 4, every 3 weeks. Five of the adolescents had thalassemia carriers, and the remaining seven sibling are not.

Table 1.
Participants characteristics

Age	Education
18	Graduated school
18	Graduated school
18	Still in school
18	Graduated school
18	Graduated school
17	Still in school
19	Graduated school
18	Graduated school
17	Graduated school
19	High school
19	Graduated school
18	Graduated school

Themes

The study results showed the theme was fear of ill-treatment, with the sub-themes were fear of verbal bullying from friends and people around them and of physical violence from men. All the teenagers reported that many unkind words were directed at them by their friends, and this made the adolescents sad and became increasingly inferior in their relationships.

"...I dislike being called arrogant, never going to school, "you own a school" they said. Also, I dislike it when someone asks me why I am still in elementary school..." (P1)

"...friends often ask why I always go to the hospital. It does not matter. Sometimes some also like to say that my skin is black. Then, the one that I really felt the most was a lot of male friends who wanted to talk badly about me. I think about it all day long because they seem to want to say that I am ugly (teary eyes)..." (P2)

"...my height is often teased by my friends from elementary to high school. Some say mini, pororo, nyinying because my voice is also small. My cheeks are referred to as chubby. Then, the nose problems. That is what they discuss most often. They say how come you do not have a nose bone (teary eyes)..." (P4)

"...I am often told by friends that my face was different because it was pale. Sometimes some do not want to be friends with me because I am sick. Some even told people to stay away from me, because the disease spreads. There are also those who say that I would not live long (crying) ... " (P5, P11)

"... I was bullied by a friend using dirty words, saying I am big, black, pretentious..." (P6)

"... my body is small, therefore my friends often tease me (face looks sad) ..." (P7, P8)

"... at school, I dislike being teased because my stomach is fat, like a thalassemic child in general. Therefore, in the past, they ridiculed "you are bloated and short because you are not tall enough". Then, when I was in high school in grade 1, I was bullied all the way by my classmates, my bags and books were thrown into the trash, and my stool was covered with glue. Then, every morning, there is teasing..." (P10)

"... sometimes they say 'you are black..." (P12)

Adolescent females with thalassemia major are also afraid of physical violence from male figures in their lives, making them traumatized and worried about having a relationship with their partner. As reported, a male classmate beat one of the participants who lost consciousness for a week. Another reported being beaten by the father. This makes adolescents afraid and worried that it is bound to happen again. This feeling is illustrated by the participant's statement as follows:

"... At that time, I was playing around, suddenly there was a male friend who hit the back of my neck. After that, I was in a coma, and was afraid (teary eyes) ... "(P2)

"... I'm afraid of violence, because when I was discharged from the hospital, my father punched me in the face until my nose was bleeding (crying) ... "(P6)

DISCUSSION

The label "sick child" is difficult adolescents, even when opposed, verbally or physically. The teenagers reject this name not only because of its negative connotations, but also because it shows how different they are from others. However, this resistance is further weakened by low self-esteem which causes, in confidence and inability to challenge what others think about them. This leads to conflicts which further causes depression in social settings (Mufti et al., 2014). Furthermore, female adolescents with thalassemia major who were involved in this study reported bullying from their friends. Bullying comes in various kinds of violent behavior that includes elements of coercion, both psychologically and physically. Therefore, the victim feels depressed, traumatized, and helpless. This is usually done by people who feel more powerful, and it is always in two forms, physical or verbal. Verbal bullying comprises nicknames, insults, accusations, sharp criticism, and offensive statements that are sexual, while physical bullying is in the form of punches, kicks, scratches, and so on (Zakiyah, Humaedi, & Santoso, 2017). The Indonesian Minister of Education and Culture, Anies Baswani said that 84% of children in Indonesia have experienced violence. However as many as 70% of children in the country have also been perpetrators of violence in schools (Setyawan, 2016). This data is a high number, which apparently also occurs in female adolescents with thalassemia major, who experience bullying both verbally and physically. Various kinds of negative labels are received by the subjects from friends. Some were said to be black, had snub noses, short, tiny, small, short-lived, pale faces, bloated stomachs, and some were being addressed with dirty words. Three adolescents in this study received physical abuse from friends and fathers. The physical bullying committed by the friend was in the form of hitting the back of the neck, which led the subject into a coma (decreased consciousness) and she had to be hospitalized for one week. Furthermore, other adolescents also experienced physical bullying, such as books and school bags secretly thrown into the trash by friends and putting glue on their school benches. Meanwhile, the physical bullying done by the father of the third adolescent was a punch to the face which caused bleeding. The participant said that it occurred suddenly, having just returned from the hospital. This has

made a deep impression on the teenagers, which eventually traumatized them, in the area of having a relationship with males, for fear of getting the same treatment.

Zakiah, Humaedi, & Santoso (2017) said that the impact of bullying is very broad, and adolescent victims are more at risk of experiencing various kinds of health problems, both physically and mentally, as well as feeling sad. The sadness felt by teenagers is part of an internal problem. Internal problems are problems that are directed at oneself through the feelings that exist within a person. This can have an impact on the emergence of feelings of guilt, feelings of rejection, and feelings of low self-esteem. Research results prove that as many as 40.3% of thalassemia children experience this internal problem. One of the factors that greatly contributes to the emergence of these internal problems is the disease factor, which can have an impact on internal psychosocial problems related to the treatment routine that adolescents must undergo and the length of illness experienced by adolescents (Nurvitasari, Mardhiyah, & Nurhidayah, 2019). Behdani et al (2015) also stated that thalassemia major adolescents had more psychological, emotional and social behavioral problems than healthy adolescents ($P < 0.001$). The same is the case with the participants in this study who received physical abuse from their fathers. The adolescents become afraid to meet new people even when the person is a female. This was evident when the researchers first met the participant, who would not leave the room and only stayed in the corner of the room with a blank face and full of fear. However, after slowly developing a trusting relationship and encouraging the adolescents, they finally opened up. Hatta (2018) also stated the same condition that bullying does not only hurt the victim physically, but also makes them depressed, traumatized, fearful, and sometimes causes death. All the participants involved in this study were Muslims, and were victims of bullying. When the problem of bullying is observed from the aspect of Islam, it is inferred that this occurs because of the loss of religious value lessons at school. Therefore students no longer respect differences, tolerance, and mutual respect. Even though in the teachings of Islam, all humans are ordered to do good and have a noble character to all creatures created by Allah, because the religion clearly states that "humans are created from different ethnic groups to know each other and do good" (Hatta, 2018).

CONCLUSION

This study has explored the perceptions of adolescent females with thalassemia major about themselves as women, which was mainly on the theme of fear of ill-treatment, further grouped into fear of bullying from friends and physical violence from men. All the participants in this study are afraid and worried about experiencing this same treatment in the future.

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