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Life Experience of Adolescents with Thalassemia: A Qualitative Research with Phenomenological Approach

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Abstract

Introduction: Adolescents with thalassemia, an inherited blood disorder resulting in anemia, have multiple problems. Not only do the sufferers have to face developmental issues, but also the challenges that arise from their disease both physically and psychologically. This research aimed to understand the variety of difficulties or problems faced by adolescents with thalassemia in Tasikmalaya, West Java, Indonesia.

Method: This research was a qualitative study. Samples used in this research were 7 adolescents with thalassemia who were chosen by purposive sampling with inclusion criteria as follows: 1) Adolescents with thalassemia aged 11-19 years old, 2) Regularly visit Hospital dr. Soekardjo and. Prasetya Bunda for transfusion purposes, and 3) Willing to be involved in the research. For data triangulation, interviews were also conducted with 3 mothers of children with thalassemia. Data were analyzed using Creswell's 6 steps for data analysis which consist of data transcription, data reading, data coding, reducing information to themes and categories, making data and theme description into qualitative narration, and transforming findings and results into qualitative interpretations and report writing.

Results: From the interviews conducted with adolescents with thalassemia and their parents, several findings were addressed: physical problems that arise from thalassemia are slowed growth and development rate, fatigue and weakness, and pain. Meanwhile, other problems arise in psychological aspects, such as emotional burden, anxiety and sadness about the future and frustration because of feeling different from others. In addition, the research also found that adolescents with thalassemia are experiencing difficulties in social interactions because of bullying and isolation.

Conclusions: This research provides basic information to define proactive strategies for interventions in order to increase the quality of life of adolescents with thalassemia.

Keywords: *Thalassemia, adolescence, quality of life experience, bullying, social stigma.*

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Introduction

Thalassemia is a group of genetic blood disorders from synthesis of alpha or beta globin chain either totally or partially. Symptoms of thalassemia are varied based on the amount and effected globin chain type. Thalassemia is commonly found in the Mediterranean, Middle East, India Subcontinent, North Africa, Central Africa and Southeast Asia including Indonesia. The number now has the attention of the Government of

Indonesia considering that it has seen the numbers of populations with thalassemia and also the fact that Indonesia is one of the countries that has high many thalassemia carriers, with a frequency of 3-8% and up to 10% in several regions. In Indonesia, there are 9082 people with thalassemia and these patients are spread in every region of Indonesia with the highest number in West Java region with 40.3%[4,8,14].

Thalassemia is well-known as a lifetime genetic disorder. The sufferer would experience many problems not only as part of the impact of the disease itself but also from the impact of the medication. Considering the impact of the disease, it is necessary for us to put our attention to the sufferer, especially those in the age range of child to adolescent who have physical maturation and development phases which determine their quality of life[15]. Moreover, adolescents with thalassemia are the most susceptible regarding the social issues because they tend to have dual problems, both physically and psychologically. Besides the impacts from medication, they sometimes are losing control and have the tendency to involuntarily embrace the differences with their normal friends[5]. Other research about adolescents with thalassemia using the Pediatric Quality of Life (Peds QoL) instrument has shown that their QoL only 68.91, and a low rate is also shown on emotional function and school performance, while average QoL from control groups is 79.79[11].To have a better understanding about the experience of adolescents with thalassemia and how they embrace their chronic condition, it is necessary to explore these dimensions with qualitative research.

Method

This research is a qualitative study. Samples used in this research include seven adolescents with thalassemia who were chosen by purposive sampling with inclusion criteria as follows: Adolescents with thalassemia aged 11-19 years old, regularly visit for transfusion purposes, and willing to be involved in the research by completing an informed consent form. For data triangulation, interviews were also done with three mothers of children with thalassemia. Semi-structured interviews were used for the data collection. The research was conducted in 2017 in the Thalassemia Unit of Tasikmalaya Indonedsia. All participants had already been explained about the purposes of the research and completed the consent form before participating. The semi-structured interviews were done in the Thalassemia Unit when all participants were undergoing blood transfusion. The interview took approximately 60 minutes for each participant using interview guide, field notes, and tape recorder to record participants' responses. Data were then analyzed using Creswell's 6 steps for data analysis, which consist of making data transcription, data reading, data coding, reducing information to themes and categories, making data and theme description into qualitative narration, and transforming findings and results into a qualitative interpretations and report writing.

Results

From the semi-structured interviews conducted with six adolescents aged 11-19 years old with education level from elementary school to university with thalassemia and three parents, three common themes from the discussions were obtained, which were physical problems, psychological problems, and social problems.

Physical Problems: It is common that several physical problems are found in people with thalassemia. From several issues, the physical problems were categorized as follows: delayed growth and development rate, fatigue and weakness, and pain. Those categorizations are in-line with the statements of the participants as follows:

"From the physical appearance, it is can be seen that normal adolescents look normal as the way they should, but those who suffer thalassemia there is physical differences from body weight, and body height aspects." (P.5)

"In people with thalassemia, puberty is delayed, unlike normal people. We also suffer delayed growth, especially menstruation, we experienced it delayed compared to normal people, but it is relatively the same between other people with thalassemia." (P.6)

Delayed growth and development in people with thalassemia are also confirmed by parent as follows:

"For body growth, we could see from elementary school to junior high school compared to their relatives, their body looks smaller." (P.1)

Three participants explained how their thalassemia makes them fatigue easily. It is explained as follows:

"Something I feel the most is fatigue, sometimes dizzy... either I do activities at home or at school, I am easily tired." (P.1)

"If my Hb is low, I feel so dizzy, tired, exhausted and sometimes also have fever." (P.5)

"Nowadays I often feel dizzy. I was, maybe once in a month, felt exhausted, but now that I have monthly menstruation, I feel it more often" (P.6)

Physical disorders are also confirmed by parents of adolescents with thalassemia as follows:

"Since being diagnosed with thalassemia for the first time, He has always been weak, easily tired. After having transfusion, it only supports his body for 7-10 days, a week later, he becomes weak again" (P. 2)

Some of participants also experienced pain related to their disease, such as follows:

"During transfusion, I experienced back pain until I have to be treated in hospital." (P.2)

"I have never done any exercise because I could not do much of it. My body become easily exhausted, also there are no friends of mine who have the same things and have big and painful stomach." (P.4)

Psychological Problems: Psychological problems that arose for adolescents with thalassemia can be categorized as follows: emotional burden, anxiety and sadness about the future and frustration because of feeling different from others. Those categories are constructed from the explanations below from patients:

"I once was so angry when I was tired. I was so irritable." (P.2)

"It is so sad and maddening when I was mocked by other people but I cannot defend myself." (P.5)

Emotional burden of thalassemia sufferers was also confirmed by parents as follows;

"When transfusion time comes, they (sufferer) tend to be easily angered, such as when I yelled at them, they were so emotional. I think they just tired." (P.3)

"Other psychological problems experienced by adolescents with thalassemia are anxiety and sadness about the future, explained as follows:

"I am obviously slowly becoming old. I am afraid that my future children will experience the same thing with me and have a lot of friends who are not able to fully embrace my weakness." (P.3)

"I once did not disclose it to my boyfriend because I am afraid that he will not accept me and I'm also afraid of being underestimated." (P.6)

Those arguments are also supported by the statements from parents as follows:

"As my son is growing up, it is undeniable that I have my own anxiety about their future especially about their acceptance and love life in the future. I am afraid that they won't get married because no one will accept them." (P.1)

"I cannot imagine their future." (P.2)

Another psychological problem faced by sufferer of thalassemia is that they feel that they are different from normal people. It is obviously stated from the statements of the participants as follows:

"I have tried getting a job, but it was so difficult for me to get one. For a normal people, getting a proper job has been already a difficult task, then how about people like me? Of course, I feel disappointed with this. I do hope that I will get the same opportunity for job, I want to be like others." (P.4)

"I do feel different from others. If normal people can do anything they want, I have to have transfusion regularly in hospital. I also never had any exercise because I have no friends like me." (P.7)

"I have ever in a condition where I feel abandoned by other people. Maybe it was because I am just being myself, we are different physically." (P.6)

The different feelings towards others are also strengthened by statements from parent about people with thalassemia, as follow:

"In school, their friends are much bigger and taller. I told my child that maybe a miracle will come to us in the future someday." (P.3)

Social Problems: On social interaction issues, people with thalassemia also experience problems that can be categorized as follows: bullying and social interactions difficulties. Those categories are constructed from the explanations below from participants:

"It is a common for me to be mocked at school. I do hope that my friend will never bully me again." (P.5)

Bullying towards people with thalassemia are also reported by parents, as follows;

"Way back from school, they had nosebleed. At first, I think that they have fatigue or something, but when I force them to tell me, they told me that they have been bullied." (P.2)

Bullying is also corroborated by other parents, written as follows:

"Based on their explanation, they often being hit in the head and stomach. Sometimes their belongings, like book, bottle, hat are just thrown by their friends so if my child were trying to get that, they will throw it further. Maybe it is just fun for them." (P.3)

Other social problems faced by adolescents with thalassemia is social interactions difficulties. It is in-line with the explanations of participants as follows:

"I have no friends, maybe just playing around with kindergarten children." (P.5)

The argument is also supported by parents: "I am afraid that they will just be fatigued when they play with my friends, so I asked them to just directly go home to sleep and not play." (P.2)

"In the neighborhood they are only able to play around with younger children, around 5-6 years old or on the 1st or 2nd grade of elementary school. The point is that they are not able to play with their friends." (P.3)

Discussion

This research provides basic information to define proactive strategies for effective interventions in order to increase the QoL of adolescents with thalassemia, especially in physical, psychological and social aspects. The qualitative research with phenomenological approach has produced some themes, such as physical problems, psychological problems, and social interaction problems. Physical problems in adolescents with thalassemia can be categorized by several points that include: slowed growth and development rate, fatigue and weakness, and pain. Delays of sexual developments were reported by 50% of males and females. Glucose tolerance disorder, short body, hypocalcemia, and hypothyroidism also often happen to adolescents with thalassemia. It shows that the effect of excessive iron depends on disease duration and frequency of blood transfusion and slow disease development progress[1]. Other research showed frequent number of growth failures happen in children and adolescents with thalassemia causing body image disorder. The research also highlights the number of events between 30-50% [12].

Psychological problems in adolescents with thalassemia among others are emotional burden, anxiety about future, and feeling different from others. For adolescents and parents who have chronic disease, they face specific problems related to their health issues. Specific problems for sufferers and their parents are feeling of failure and despair about the future, low self-esteem and emotional burden. Adolescents with thalassemia have higher number of psychosocial problems than normal adolescents [10,13.]. Another systematic review also found that several psychosocial problems such as distress, less social function, problems in school performance, feeling guilty, rejection due to disease and/or medication impact are also experienced by adolescents with thalassemia[3].

Social interaction problems experienced by adolescents with thalassemia in this research are bullying and social interaction issue. Bullying happens as an outcome from physical problems experienced by sufferers who position themselves as a victim and an object to be bullied. Self-identity in chronic sufferers can become compromised and their dependency to others become higher than normal adolescents. Those psychosocial problems then impact on adolescents with thalassemia in many aspects such as education, playing time with friends, physical activities, and ability to adapt. Those conditions further impact on the emergence of anxiety, social isolation, and depression. The results of systematic review about bullying prediction on adolescents with thalassemia showed that most bullying is related to their physical condition. One systematic review explained that adolescents with chronic thalassemia who have physical disorders have higher risk to be the object of bullying[6].

Conclusion

The interviews with adolescents with thalassemia and parents provide several themes of physical problems which consist of slowed growth and development rate, fatigue and weakness and pain. Psychological issues consisted of emotional burden, anxiety about the future and feeling different. Social interaction problems consist of bullying, and stigma from looking different. The research provides basic information to define proactive strategies for effective interventions in order to increase the quality of life of adolescents with thalassemia.

Conflict of Interest: The authors declare that there are no conflicts of interest in this study

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Ethical Clearance: This research was approved by the Medical and Health Research Ethics Commission of the Faculty of Medicine, Universitas Gadjah Mada with Ref: KE/FK/0775/EC/2017.

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