

Emotional and Behavioral Aspects of Children with Thalassemia in Banda Aceh, Indonesia

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Abstract: Thalassemia is an inherited disorder that can hardly be cured. A thalassemia patient needs blood transfusion for a lifetime. A child with thalassemia might experience emotional and behavioural changes due to some changes in his or her physical function which might lead to particular psychosocial effects. The purpose of this research was to identify the overview of emotional and behavioural aspects of children with thalassemia in one of the public hospital in Aceh. This descriptive-quantitative research was conducted with a cross-sectional study approach. There were 117 respondents participated in the study by using consecutive sampling technique. The data collected by utilising the 'Strengths and Difficulties Questionnaire' (SDQ) assessing the emotional symptoms, behavioural issues, peer relations, hyperactivity disorder, and prosocial behaviour as the five sub-variables. The result of univariate data analysis showed that children with thalassemia had the emotional and behavioural aspects (89.7%), and the five sub-variables – emotional symptoms (74.4%), behavioural issues (76.9%), peer relations (59.0%), hyperactivity disorder (84.4%), and prosocial behaviour (69.2%). Hence, it is suggested that the medical workers keep educating the parents in order to maintain the emotional and behavioural aspects of children with Thalassemia.

1 INTRODUCTION

Thalassemia is a hereditary disease characterized by a disturbance in the synthesis of haemoglobin (Hb) resulting from a change in the level of globin chain production. In 2011 the World Health Organization (WHO) stated that about 5% of the world's population carries haemoglobin-carrying genes, especially sickle cell disease and thalassemia. However, in some regions shows the percentage of carriers is 25%, with an estimated more than 300,000 babies born with haemoglobin abnormalities every year and mostly in low and middle income countries. WHO also states that this condition is mostly common in the tropical region, but the migration of residents has spread this disease to most countries (Fatmasyithah & Rahayu, 2014).

Thalassemia International Federation (TIF) (2011) reported that Indonesia is included in the group of countries with high risk of thalassemia. According to the Indonesian Ministry of Health (2013) the prevalence of thalassemia's carrier in Indonesia is estimated around 3-8%. If the percentage of thalassemia reaches 5%, with a birth

rate of 23 per 1,000 of the 240 million population, it is estimated that there are around 3,000 babies with thalassemia born every year. The results of the 2007 Indonesian Basic Health research (RISKESDAS) showed the national prevalence of thalassemia was 0.1%. Currently, thalassemia is still a global problem that requires special attention. Thalassemia is found throughout the world with the highest prevalence of thalassemia genes in several tropical countries (TIF, 2008).

Data from the Indonesian Ministry of Health in 2010, Aceh province was recorded as a province with the highest percentage of thalassemia in Indonesia with a figure of 13.4% (Fatmasyithah & Rahayu, 2014). According to WHO global incidents, 1 in 5 children aged less than 16 years' experience emotional and behavioural problems. In Singapore for example, 12.5% of children aged 6 -12 years have emotional and behavioural problems (Wiguna et al., 2010). Research conducted in one of hospitals in Surakarta, Indonesia in 2013 found that the prevalence of emotional and behaviour problems in Thalassemia children is 26% (Nurhaeni, 2015).

Emotional and behavioral problems in children lead to difficulties in learning since it is difficult to focus and concentrating, poor ability to remember, behave inappropriately in the school environment and will increase delinquency and crime in adulthood (Blanchard et al., 2006). Emotional and behavioral problems are one of the several problems that cause barriers to a child's development such as psychosocial problems, depression in children, and other mental disorders. Emotional and behavioral problems in children are a serious problem since they affect the children development and cause a decrease in productivity and quality of life (Wiguna et al, 2010). Various bio psychosocial stressors are often associated with the occurrence of emotional and behavioral problems in children, such as physical illness, domestic violence, inadequate peer relationships and parenting (Wiguna et al., 2010). Inadequate parenting will have an impact on children development, namely parents who are authoritarian children will tend to be hostile and rebellious. Children whose parents are permissive tend to behave freely or uncontrolled and in children whose democratic parents tend to avoid anxiety chaos (Yusuf, 2009).

This study aimed to assess the major chronic thalassemia pain conditions which include: emotional and behavioral disorders by using the standard instrument in order to detect psychosocial problems of children aged 4 - 17 years. The instrument called the 'Strength and Difficulties Questionnaires' (SDQ). SDQ has become one of the most widely used standard measurements in child psychology to evaluate behavioral and emotional problems. Research conducted by Riyana & Riza (2017) mentioned that there is a behaviour disorder in major thalassemia children. It was found there were 22 children (73.3%) with disrupted categories from children with internal behavioral disorders. Whilst for children with external behaviour, there were 12 children (40.0%) from 30 children with major thalassemia is classified as a normal category.

2 METHODS

2.1 Study Design

This is a descriptive quantitative study with cross sectional design. The respondent in this study is 117 parents who have children with thalassemia aged 4 - 17 years. The data was collected consecutively in the provincial referral public hospital in Banda Aceh.

2.2 Instrument

Data collection tools used in this study is SDQ instrument consisting of three parts; parent demographic data, child demographic data, and an existed questionnaire "Strength and Difficulties" Questioner consists of 25 questions and divided into 5 sub-variables namely, 1) Emotional symptoms, 2) Behaviour changes, 3) Peer relationships, 4) Hyperactivity, and 5) Prosocial behaviour. Each sub-variable consisted of 5 questions (Goodman, 2010). This SDQ questionnaire has been translated to 87 languages around the world including Bahasa Indonesia.

2.3 Data Analysis

The scoring template is available on the SDQ website. The total score of each aspect also the overall result of the 5 sub-variables are classified with normal, borderline, and abnormal categories. Demographic data is analysed with the univariate analysis.

3 RESULTS

Based on the research conducted on 117 respondents, the following results were obtained:

Table 1: Demographic Data of Parents of Children with Thalassemia.

Demographic Data	Percentage N=117
Age	
17-25	2.6
26-35	38.5
36-45	59.0
Gender	
Male	33.3
Female	66.7
Education	
Elementary -Junior High School	25.6
Senior High School	64.1
University	10.3
Occupation	
Farmers	51.3
Labourers	2.6
Housewives	41.0
Entrepreneur	2.6

Based on table 1, it can be concluded that most respondents who have children with thalassemia are generally in the late adults with the average age of

38 to 45 years old (59.0%). Most children come to hospital with their mother (66.7%). Parent education level is on senior high school (46%). Most parents (51.3%) work as farmers.

Table 2: Demographic Data of Thalassemia Children.

Demographic Data	Percentage (%) N= 117
Age:	
Toddler	20.5
School Age	46.2
Early teenage	30.8
Late teenage	2.6
Gender:	
Boy	43.6
Girl	53.8
Education:	
No Education	41.0
Elementary School	48.7
Junior High School	10.3
Family order:	
First child	51.3
Second child	7.7
Third Child	30.8
Fourth child	7.7
Fifth child	2.6
First Diagnosed	
0-1 years old	66.7
2-3 years old	30.8
4-5 years old	2.6

Based on table 2, it can be concluded that 46.2% thalassemia children are in the school age and come to do the treatment at the provincial referral public hospital in Banda Aceh. 53.8% of the children who were doing the thalassemia therapy are girls. Most of them are in elementary school (48.7%). More than 50% of the children with thalassemia are the first children in the family. They were first diagnosed on the age below 1 year old (66.7%).

Table 3 shows the result of each aspects of the emotion and behaviour of children with thalassemia in Aceh. For emotional symptoms shows that 74.4% children are in abnormal category and 76.9 % children with thalassemia has abnormal behaviour issues. In regards with peer relations with other children, 59% are in abnormal category. 84.6% children with thalassemia have hyperactivity disorder and lastly 69.2% of the children have problems with prosocial behaviour in abnormal category.

Table 3: Distribution of each Aspect of Emotions and Behaviour of Thalassemia Children.

Aspects Category	Normal	Borderline	Abnormal
	(%)	(%)	(%)
Emotional symptoms	15.4	10.3	74.4
Behavioral issues	12.8	10.3	76.9
Peer relations	33.3	7.7	59.0
Hyperactivity disorder	10.3	5.1	84.6
Prosocial behaviour	7.7	23.1	69.2

Table 4: Total distribution of total score of emotional and behaviour aspects children with thalassemia in Aceh.

Category	(%)
Normal	4.1
Borderline	6.2
Abnormal	89.7
Total	100

From 117 respondents, total score of all aspects measured namely emotional symptoms, behaviour changes; peer relation, hyperactivity and prosocial behaviour, 89.7% of the children with thalassemia in Aceh is in abnormal category.

4 DISCUSSION

Emotions are responses or reactions of individuals to stimuli, feelings and desires both positive and negative. The cognitive theory view states that emotions are more determined by the results of individual interpretations of an event, and then emerge changes internally in the body. Such changes, for example, changes in facial expression, tears out, and reddened eyes (Notoadmodjo, 2013).

The results of the study found that many children had restless responses, fast breathing and banging during blood transfusions. This is in line with the research conducted by Putri, Mardhiyah & Widiyanti (2015) who said that the results of the response most frequently indicated by patients with thalassemia at the time of transfusion took place were that almost all of them showed a response requesting significant emotional support in people (84%).

This is also related to research by Mazzona et al. (2009), which says that thalassemia children tend to experience high emotional temperament and poor socialization. Researchers argue that emotional symptoms in thalassemia children do tend to be more emotional, as evidenced by research showing an abnormal category of 74.4%, because sufferers feel different from others, and there are still people who think thalassemia is an infectious disease.

Based on table 3 it was found that behaviour problems in children with thalassemia in Aceh are in an abnormal category (76.9%). It is on-going opposing behaviour without serious violations of social norms or the rights of others. This behaviour problem is a difficult problem often shown by children such as hitting, fighting, mocking, refusing to obey other people's requests (Istiqomah, 2017). According to Rescorla et al. (2007) as cited in Halimah, Allendekania, & Fajar T W (2016), the next behaviour change that occurs is the problem of decreasing attention. The risk of this problem is influenced by gender, ethnicity, and mother's education, adolescents with male sex increase the risk of decreasing attention.

The results of the study found that many children had behavioral changes starting from facing down when the researcher invites to speak, and looks very nervous. This is in line with the research of Riyana, & Riza (2017) which says that thalassemia children experience behavioral disorders as much as 73.3%. Another study by Halimah, Allendekania, & Waluyanti (2016) says that adolescent boys with thalassemia have a higher risk of experiencing behavioral problems such as anxiety problems, social problems, and problems with less attention. Although, it does not rule out that behavioral problems could also occur in adolescent girls. Other factors that increase the risk of behavioral changes are the ethnicity, multi transfusion, maternal education, and the involvement of next of kin and relatives.

Based on the table 3, peer relationships in thalassemia children is in the abnormal category (59.0%). Children are less able to socialize with their peers both at home and at school. The difficulty of children in socializing often makes children less accepted by their peers. This could limit the children in interacting actively within their peers (Istiqomah, 2017). The results of the study found that many thalassemia children have poor relationships with their surroundings or peers. This is inherent with the research of Maghfiroh et al. (2014), who said that almost half of thalassemia children had low feelings of being accepted in a friendship environment. Thus,

self-esteem is obtained from one self and social interaction with peers. Individuals will feel high self-esteem if they often experience success. However, there are influencing factors such as parents and peers that greatly affect the development of self-esteem. If children have good peers, they could increase their self-esteem.

Researchers argue that the social environment has a relationship with peers. Therefore, the difficulty of socializing often makes children less accepted by their peers. This study showed an abnormal category of 59% for peer relation aspect of the children with thalassemia. The most important thing about peer groups is to provide sources of information and comparisons about the world outside the family, peer interactions that have their peer to play a special role in socio emotional development.

Researchers argue that many children tend to be more silent and unwilling to play; this is evidenced by the results of the study showing 84.6% abnormal categories in hyperactivity disorder. Although thalassemia children are not allowed to overact, nurses should provide counselling about child development, starting from motoric training and playing according to their age, but within limits they do not force children to play excessively. The researcher found that many thalassemia children who are not able to move much and prefer to be quiet, if they play only briefly but not too much because the child is easily weakened. This is in line with the research of Fetriyah, et. Al (2016), which explains that most mothers regulate children's daily activities. This is so that rest and activity remain balanced, so that the mother gives direction to the child to rest because if you do too much activity and lack of rest will affect Haemoglobin levels in the blood and can affect health in general.

The condition of children with thalassemia also affected the relationship with their families. It could potentially interfere with their welfare as individuals and disrupt their functioning socially. The research conducted by Indanah (2010), found that prosocial behaviour plays an important role in psychosocial support from family and peers. The family play a role by helping to control the behaviour of children facing physical and psychological changes. Indanah said only 59% of respondents reported getting peer support. Prosocial support and behaviour are mostly indicated by the involvement of friends in social activities that do not drain the child's energy. Researchers argue that there are still many children who lack of prosocial relationships with their peers. This is evidenced by the results of this study

showing an abnormal category of 69.2% in prosocial behaviour, teachers and nurses should provide examples of behaviour, guidance and motivation to raise children's awareness of other people's feelings as well as awarding prosocial behaviour in thalassemia sufferers, situations and the hospital affects children's opportunities to develop prosocial behaviour.

The emotional and behavioral disorders in children with thalassemia have complex characteristics. These characters consist of moving a lot, fighting behaviour and sometimes being alone (Istiqomah, 2017). The researcher argues that the high number of emotions and behaviour of thalassemia sufferers that cause a decrease in self-esteem. The result of this study showed an abnormal category of 89.7% of emotional and behavioral aspects of children with thalassemian in Aceh. The description of emotional and behavioural aspects of children with thalassemia is also influenced by the demographic data of children and parents such as gender, child's age and parental occupation. This is in line with research by Aji et al. (2009) mentioned that thalassemia suffer a poor quality of life because of the changes in their psychosocial aspect. Thalassemia children have a lifelong blood transfusion where at these times medical treatment usually requires non-cheap medical expenses. In addition, long-term treatment can change all aspects of life, not only for patients but also for their families.

5 CONCLUSION

All the participated children with thalassemia, measured with the 'Strengths and Difficulties Questionnaire' (SDQ) showed that the emotional and behavioral aspect of the children with thalassemia is in abnormal category (89.7%). Besides providing physical and medical cure to the children who suffer from thalassemia, care givers should also consider the emotional and behavioural aspects of the children. Hence, it is suggested that the medical workers keep educating the parents regarding the emotional and behavioural aspect of children with thalassemia.

ETHICS APPROVAL

This study holds ethical approval from Ethics Committee of Faculty of Nursing, Syiah Kuala University in Banda Aceh, Indonesia.

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