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Genetic Counseling to Reduce the Level of Depression in Parents of Children with Thalassemia Major

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Abstract: Thalassemia major is a chronic disease that the prevalence in Indonesia is increasing from 3,653 cases in 2006 to 5,501 cases in 2011. Besides having an impact on the patient's health physically, thalassemia major also gives psychological consequences, such as depression, on parents of patients with thalassemia major. The aim of the study to investigate the impact of genetic counseling in reducing depression level on parents of children with thalassemia major. This was a quasi-experimental study using a pretest-posttest group design. In total, 44 parents met the inclusion criteria. The parents received genetic counselling to better understand and cope with thalassemia major. Beck Depression Inventory II was used to measure parental depression level before and after genetic counselling was conducted. The Wilcoxon test as well as paired-sample t-test were applied for comparison analysis. The majority of participants (65.91%) reported lower depression after they received the genetic counselling session (Meanpre=16.31; Meanpost=11.50; p<0.001). The results highlight the positive impact of a genetic counselling on reducing depression on parents of children with thalassemia major.

1 INTRODUCTION

Thalassemia is a chronic disease from parent to child in an autosomal recessive inheritance (Price and Wilson, 2006). Other studies revealed parents who had children with thalassemia reported high levels of anxiety, guilt feeling, and responsibility. Therefore, the parents tend to supervise and nurture their children excessively. The complexity of these problems leads to high rates of depression in parents and children with thalassemia (Jenerette and Valrie, 2010).

In Indonesia, thalassemia is a genetic disorder which is the most common with the highest number among the group of hemolytic anemia. The prevalence of thalassemia carrier in Indonesia reached about 3-8% in March 2009. Thalassemia cases in Indonesia increased by 8.3% of the 3,653 cases recorded in 2006. As quoted from the official website of Hasan Sadikin Hospital in Bandung, Indonesian Thalassemia Foundation - Association of the Parents of the Patients with Thalassemia (YTI-POPTI) reported that the province of West Java is the most widely recorded to have thalassemia patients in 2011. From the 5,501 patients, 1,751 patients or approximately 35% originated from West Java.

Thalassemia affects physically as well as psychologically to the patients. The changes or physical impairment that may emerge such as dizziness, pale face, fatigue, insomnia, loss of appetite, as well as the enlargement of lymph glands. These conditions may impact the patient's emotional state (Wong, et al., 2009). Patients often experience psychosocial and emotional issues such as anxiety, depression and social isolation

One of the efforts to reduce the psychological burden of the parents of the children with thalassemia major is to provide health services such as genetic counseling (Stuart, 2009; Cabrera, et al., 2010). Dini (2012) stated that the more information about the disease was provided, especially in the case of genetic disease, the more individuals had certainty about their conditions (Fisher, et al., 1981; Dini, 2012; Zongrum, 2014).

Genetic Counseling is a communication process undertaken to address the issue of genetic diseases affected in the family (Joao, 2008). The Process of genetic counseling include present about definition of the disease, ethiology, clinical features,

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calculation and recurrent risk, testing dan screening in their family (Genetic Alliance, 2009).

Research on genetic counseling has been conducted include screening tests and prevention in various genetic diseases such as thalassemia (syed, 2011), but the psychological effects caused by genetic counseling, researchers have not found. In developed countries like the United States, Australia, and the Netherlands, genetic counseling is conducted as a part of the procedure to overcome the psychological problems of the parents who have children with genetic disorders, including thalassemia (Rujito, 2010; Leinalaa, 2008). In contrary, in Indonesia, studies on the intervention for the provision of genetic counseling to the acceptance of genetic disease are still lacking. Among the limited reports available, Widayanti, et al. (2011) conveyed that the awareness of the parents to receive information about thalassemia disease were low. This study is essential due to the rapid development of genetic science in Indonesia so that genetic counseling also needs to be developed.

2 METHODS

The study applied a quasi-experimental with pretest-posttest group design. All participants received genetic counseling. Evaluation on depression level was conducted before and after the treatment was given. The study protocol was approved by ethical committee of General Ahmad Yani Health Science College.

The study was conducted in the Thalassemia Room, Ciamis Hospital from April 24 until July 18, 2016 with the entire population of parents who had children with thalassemia major. Thalassemia major screening was conducted using MCH (Mean corpuscular Hemoglobin), MCV (mean corpuscular volume) and MCHC (Mean corpuscular Hemoglobin Concentration) examination (Longlouis et al., 2008). Based on medical records data, 120 patients with thalassemia major were identified. They had been diagnosed by experienced pediatrician based on the examination of MCH, MCV and MCHC in the laboratory of Ciamis District Hospital. From 120 parents of children with thalassemia major, 44 patients met the following inclusion criteria: had children diagnosed with thalassemia major whom following treatment in thalassemia division of Ciamis District Hospital, were able to write and read, experience depression due to the disease suffered by their children, and signed informed consent to participate the study.

Genetic counseling was a process to help parents of the children with thalassemia major to understand and adapt to the medical and psychological effects, family implications, and the genetic contribution to the disease suffered by their children (Resta et al., 2006). In the study, genetic counseling was given in the following three sessions: pre-counseling, preparation, and counseling sessions. In the pre-counseling session, the researcher (HS) confirmed the planned visit of participants, explained the genetic counseling plan as well as provided emotional support. In the preparation session, the socio-economic data were collected and the medical records and genetic problems were reviewed. In the counseling session, the researcher conducted genetic counseling in accordance to the modules developed for the study.

Procedures of genetic counseling include:

a. Obtaining a three-generation genetic family history (pedigree)
b. Assessing risk for thalassemia in family members
c. Identifying risk factors impacting medical management (e.g., family history of other hemoglobin traits or diseases, ethnicity, consanguinity)
d. Incorporating psychosocial information impacting the family system and relationships (e.g., location of residence, disclosure/ nondisclosure of diagnosis, reliable source of emotional/social support)
e. Assisting patients in conveying information about genetic risk to other family members
f. Providing informed consent, pre-, and post-counseling for all genetic testing

Data in the form of Beck Depression Inventory II (BDI II) questionnaires collected from respondents before and after genetic counselling Conducted. The Indonesian version of the BDI II was used to measure participants depression as pretest and posttest evaluation. The Wilcoxon Signed Ranked Test was used to examine the differences in the level of depression in parents of children with thalassemia major before and after the genetic counseling was given. Pearson's Product Moment analysis was done to determine the effects of the characteristics of participants (age, educational level, occupation, family income and the number of children with thalassemia in the family) to the level of depression.

3 RESULTS AND DISCUSSION

The participant's characteristics described the distribution of participants by age, educational level, occupation, family income, and the number of children suffered thalassemia major in one family. These characteristics were presented in Table 1.

Table 1: The participant's characteristics by age, educational level, occupation, family income, and the number of children suffered thalassemia major.

Characteristics		n	%
Age	< 35 years old	28	63.64
	≥ 35 years old	16	36.36
Education*)	Low	11	25.00
	Medium	21	47.73
	High	12	27.27
Occupation	Unemployee	22	50.00
	Have an occupation	22	50.00
Family Income	Under Minimum Wage	8	18.18
	Over Minimum Wage	36	81.82
The number of children suffered thalassemia major in family	1 child	41	93.18
	> 2 children	3	6.82

*) Education were classified into Low = Elementary School to Junior High School, Medium = Senior High School, dan High = College.

Based on the data presented in Table 1, the majority of participants (63.64%) were <35 years old, finished high school (47.73%), earned over Medium Wage of income (81.82%), and had one child with thalassemia (93.18%). Only three participants (6.82%) had two or more children with thalassemia. The number of participants who had occupation were comparable to those who were unemployee.

The results of comparison analysis on the depression level that were obtained before and after genetic counseling were reported in Table 2.

Table 2: Depression level before and after the genetic counselling.

Depression Level	*PreTest*		*PostTest*		*p*
	n	%	n	%	
No depression	0	0.00	5	11.36	<0.001
Low	3	6.82	23	52.27	
Medium	32	72.73	13	29.55	
High	9	20.45	2	4.55	
Deny	0	0.00	1	2.27	
Total	44	100.00	44	100.00	

Notes. Wilcoxon signed-rank test was used; significant at $p < 0.05$.

Based on the data presented in Table 3, it can be concluded that the majority of participants (65.91%) experienced positive change which means the depression level was lower after genetic counseling was given (Meanpre = 16.31; Meanpost = 11.50; $p < 0.001$).

Based on the results of statistical analysis, the characteristics of participants such as age, educational level, occupation, family income and the number of children with thalassemia did not reveal significant correlation to depression levels in parents of children with thalassemia major either before or after having genetic counseling.

3.1 Discussion

The study aims to investigate the impact of genetic counseling in reducing depression level on parents of children with thalassemia major. Before having genetic counseling, the majority of participants reported medium and high levels of depression. However, after having genetic counseling, the majority participants reported a low level of depression and even five participants reported no depression. Overall, the majority of participants reported positive changes indicating a reduced level of depression. The findings suggest the impact of disease education and emotional supports, which were given during the genetic counseling sessions, in reducing the depression levels of parents of children with thalassemia major.

The results of this study were different from the previous studies. Wilhelm et al. (2009) stated that genetic counseling did not give the psychological impact such as decreasing the level of anxiety, decreasing the level of depression, improving coping mechanisms, as well as increasing the adaptation process. Although participants received detailed information regarding genetic disease which cause chronic condition in the affected family member, the given genetic counseling did not bring psychological impact in short term or long term period because the social environment predominantly influence depression (Braithwaite et al., 2004; Davies et al., 2007).

Findings from the study highlight the need to implement genetic counseling in the healthcare in Indonesia, particularly those which offer care for patients with genetic disease like thalassemia. Ariani (2010) and Rujito and Anwar (2010) mentioned that Despite the increasing study on genetic counseling and its benefits, the genetic counseling was mostly

available in some hospitals located in the big cities of Indonesia. In the district hospitals, the majority of health care workers were not familiar with genetic counseling. In addition, the lack of knowledge or information on genetic diseases among lay people as well as health practitioners hindered the process of genetic counseling. As a consequence, many health practitioners were not confident in giving a genetic counseling, especially on the recurrent risk to the next descendant (Gaye et al., 2006; Metcalfe et al., 2008).

The other challenge is how to influence the policy makers to have more concern on the implementation of genetic counseling in health services of genetic disease in Indonesia. Currently, Faculty of Medicine, Diponegoro University is the only institution in Indonesia that offers formal education to become a genetic counselor. Therefore, a policy from Indonesian government to regulate the profession of Genetic Counselors and Genetic Counseling Services are necessary (Ariani, 2010; Rujito and Anwar, 2010).

The study was hindered by several limitations. The criteria of participants from social, cultural and religious aspects tend to have homogeneous background (Bonelli et al., 2012). As the study only measured a short-term impact of genetic counseling on parental depression, future studies need to examine the long-term effects of genetic counseling on the parental depression level.

4 CONCLUSIONS

Having a child with genetic disease like thalassemia major can be stressful for parents and for a longtime, it may lead to depression. Genetic counseling is hardly available in the health centers in Indonesia. Education about the disease and providing emotional support can facilitate better disease acceptance. The study confirmed the pivotal role of genetic counseling in reducing parental level of depression in the case of thalassemia major. Unfortunately, genetic counselor or genetic counseling is not available in all hospitals in Indonesia. Considering the increasing number of genetic disease reported in Indonesia, it is now important to have genetic counseling as well as genetic counselor available in the hospitals. Future studies on genetic counseling and the psychosocial impact of having genetic disease in the families should be encouraged.

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