



Asian Journal of Scientific Research

ISSN 1992-1454

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Research Article

Profile and Psychological Burden in Caregiver of Children with Thalassemia Dependent Transfusion

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Abstract

Background and Objective: Thalassemia is one of the most prevalent hereditary diseases in West Java, Indonesia. Children with thalassemia need care from the first years of their life owing to the physical and psychological effects of their disorder. Thalassemia is a concern not only for the children's health but also for the quality of life of both the children and their caregivers. This study investigated the relationship between the burden of care giving and the psychological conditions. **Materials and Methods:** In this analytical cross-sectional study, a total of 60 parents of children with thalassemia dependent transfusion (11 fathers and 49 mothers) aged 19-73 years ($M = 38.12$, $SD = 9.80$) were included, of whom 83.33% of caregivers lived with their spouses. All participants completed 2 different questionnaires to assess their knowledge about thalassemia and their psychopathological symptoms (SCL-90). All participants consented to undergo screening and voluntarily participated in the screening tests. **Results:** Caregivers had high knowledge of thalassemia, but their education levels were rather low. The major finding of this study was that their psychopathological symptoms were significantly associated with their occupation ($p = 0.039$, $OR = 0.309$, $95\% CI = 0.099-0.965$). Those with no occupation showed a higher prevalence of psychopathological symptoms. **Conclusion:** Thalassemia affects not only the persons with the disorder but also their caregivers in several aspects, including their psychosocial well-being. This study emphasises the role of a supportive group in the psychological well-being of caregivers, which could be used to prevent the pathological effects of caregiver burden and enhance their psychological well-being through counselling.

Key words: Burden, psychopathological, thalassemia dependent transfusion, caregiver, counselling

Citation: Lulu Eva Rakhmilla, Shelly Iskandar, Susi Susanah, Enny Rohmawaty and Sjarif Hidajat Effendi, 2020. Profile and psychological burden in caregiver of children with thalassemia dependent transfusion. *Asian J. Sci. Res.*, 13: 29-35.

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Competing Interest: The authors have declared that no competing interest exists.

Data Availability: All relevant data are within the paper and its supporting information files.

INTRODUCTION

Thalassemia is a component of haemoglobinopathy, a haemoglobin disorder caused due to changes in the composition of amino acids that form globin chains, which are characterised by a decrease or an absence of synthesis of normal globin chains¹. The primary symptoms are often pallor, the abdomen appears to be enlarged due to swelling of the spleen and liver and if not treated properly, progression to a change in the shape of the facial bones and a darkened skin colour². Thalassemia is primarily inherited as a recessive trait. As an autosomal recessive condition, heterozygotes with either alpha or beta thalassemia are generally asymptomatic and do not require treatment. The WHO has estimated that 7% of the world's population are carriers of haemoglobinopathy and an estimated 300,000-400,000 babies born will be affected by this disease each year³. The highest carrier frequencies of beta thalassemia have been reported in the Maldives (16-18%), Cyprus (14%), Sardinia (10.3%) and Southeast Asia (3-5%)^{4,5}. The high gene frequencies in these regions are probably associated with selective pressure from malaria caused by *Plasmodium falciparum* infection. However, population migration and marriage between different ethnic groups render thalassemia a disease that can be found in almost every country in the world, including Northern Europe where thalassemia was previously absent³.

In Southeast Asia, the prevalence of thalassemia is quite high, which implies that this condition will become a health burden due to its hereditary nature and the mortality rate in the first few years of life, which is still quite high. The number of new case births in Southeast Asia has been estimated at 20,420 annually⁶. The high probability of a marriage between fellow carriers in Indonesia is illustrated by an estimated 6-10 of 100 residents carrying beta thalassemia traits. However, in general, carriers are not aware that they carry the thalassemia trait because the condition is asymptomatic (silent carrier) or has only mild anaemic symptoms (thalassemia minor)¹. Due to the inheritance characteristic of autosomal recessive traits, there is a high probability that the thalassemia gene could be found in the family tree of thalassemia. Therefore, in this study, family members, especially families who are still in a direct lineage, are considered as high-risk populations⁷.

The complexity of the problem in patients with thalassemia is related not only to biological aspects but also to psychological, social and spiritual aspects. Qualitative studies with a phenomenological approach have shown that the bio-psycho socio-spiritual aspects are extremely important and interrelated in the adjustment of the life of patients with thalassemia and their families. Case studies have reported that

the factors that influence the bio-psycho socio-spiritual adjustment of children with thalassemia include parental knowledge and parenting and family support. Therefore, patients with thalassemia and their families must have good adaptability to survive⁸. Children with major thalassemia require serious attention, commitment and struggle of family members to care for them. A mother who has a child suffering from thalassemia must be able to accept it by adjusting to the situation and condition of the child⁹. This study was conducted to support a screening programme in Indonesia in the context of preventing the occurrence of new thalassemia cases through screening approaches to major thalassemia family extended.

MATERIALS AND METHODS

This analytical cross-sectional study included 60 parents of children with thalassemia dependent transfusion (11 fathers and 49 mothers) aged 19-73 years ($M = 38.12$, $SD = 9.80$), of whom 50 participants lived with their spouses. Among parents who came to seek treatment for their children, only those whose children were aged <18 years and received routine blood transfusion as a treatment were selected. Caregivers with incomplete or missing data and those who had ever undergone any psychopathological examination were excluded. Literate participants were recruited to participate in the thalassemia screening programme at the Research Centre of Medical Genetics, Padjadjaran University, Bandung, Indonesia in 2017. Since 2016, our research centre developed an ideal thalassemia prevention program as the most viable strategy to reduce the burden of the thalassemia patients on families and to manage a sustainable healthcare system. The participants were recruited consecutively from the Thalassemia Clinic at Dr. Hasan Sadikin General Hospital, Bandung. All participants agreed to undergo screening and voluntarily participated in the screening tests.

A sociodemographic form was developed by the researchers to assess the following demographic features of the participants: sex, gender, occupation, formal education, income, ethnicity, marital status, history of anaemia and blood transfusion.

The questionnaire used to evaluate knowledge about thalassemia was a 20-item construct. It has 8 subscales assessing knowledge about the magnitude of the problem, cause of the disease, concept of genetic disease, individuals at potential risk due to inheritance concept, identification of important symptoms, management, complication and prevention strategies. Responses to the questions were true or false options. Subjects who scored equal to or higher than

the mean score were classified as those with high knowledge about thalassemia. The Cronbach's alpha value for this study ranged from 0.69-0.78% for the 8 subscales¹⁰.

The Symptom Checklist-90 (SCL-90) is a self-reported questionnaire. It measures both the presence of psychopathological symptoms in general and the dominant psychopathological symptoms experienced by respondents in the past 1 month. The SCL-90 consists of 90 Likert-scale questions with scores 0-4 (i.e., '0' indicates 'Not At All'). These questions addressed depression symptoms, anxiety, obsessive-compulsive disorder, phobic anxiety, somatisation, interpersonal sensitivity, hostility, paranoid ideation, psychoticism and additional symptoms. Scores from those questions then were totalled generating a raw score. The raw score was converted into a total T-score. Respondents were considered to be having psychopathological symptoms when their T-score was ≥ 61 . Another output of the SCL-90 questionnaire was the dominant psychopathological symptoms experienced by the respondents. This was assessed by grouping the questions based on each of the above-mentioned psychopathological symptom. The raw score was converted into a T-score and when the cut-off psychopathological score was >70 , the respondent was considered as experiencing that symptom. The questionnaire used in this study was the one translated into Indonesian language and tested in terms of validity and reliability with¹¹ $r = 0.67$.

RESULTS

After data collection, all the 60 caregivers fulfilled the inclusion criteria and were classified based on ethnicity into Sundanese (42 subjects, or 70%) and Javanese (11 subjects, or 30%) groups. Considering the availability of the participants, we enrolled either the mother or the father of the child depending upon their willingness to participate and their availability to answer the questions. Among the participants, 42.9% of Sundanese and 61.1% of Javanese did not graduate high school. All other participants had varying degrees of education. The study sample was represented by a lower socioeconomic status (Table 1) based on the family income proportion of the participants (Sundanese 61.9%; Javanese 55.6%). Among the participants, 25% had a history of anaemia throughout their life and only 5 participants had a history of blood transfusion.

Table 2 shows the percentage of correct answers regarding thalassemia among the participants who had heard of the disorder. The participants answered correctly to the majority of the questions on thalassemia. For example, the majority (90%) identified the cause of the disease, individuals at risk due to inheritance and the prevention strategies of the disease. Only 68.3% of them were aware of the magnitude of the problem. Although the majority identified thalassemia as being an inherited disease, only 71.6% were aware that it required two defective genes to be transmitted. Among the

Table 1: Demographics of the participants based on ethnicity (n = 60)

Characteristics	n	Sundanese		Javanese		p-value
		Number	Percentage	Number	Percentage	
Sex						
Male	11	10.00	23.80	1.00	5.60	0.94
Female	49	32.00	76.20	17.00	94.40	
Age of caregivers years, Mean (SD)						
Mother	49	38.34	9.918	39.35	11.911	0.753
Father	11	34.90	4.841	1.00	-	0.195
Educational level						
Not graduating high school	29	18.00	42.9	11.00	61.10	0.428
High school graduates	17	13.00	31.0	4.00	22.20	
University graduates	14	11.00	26.1	3.00	16.70	
Occupation						
Unemployed	39	24.00	57.1	15.00	83.30	0.051
Employed	21	18.00	42.9	3.00	16.70	
Family income						
Low	36	26.00	61.9	10.00	55.60	0.645
High	24	16.00	38.1	8.00	44.40	
Marital status						
Married	50	35.00	83.3	15.00	83.30	0.657
Divorced	10	7.00	16.7	3.00	16.70	
Having history of anaemia	15	10.00	23.8	5.00	27.80	0.745
Having history of blood transfusion	5	3.00	7.1	2.00	11.10	0.610

Table 2: Frequency (f) and percentage (%) of participants who correctly answered the 8 questions on thalassemia subset knowledge dimension and had psychopathological symptoms (n = 60)

Variables of interest	Frequency	Percentage
Knowledge dimension, respondents who answered correctly		
Magnitude of problem	41	68.3
Cause of the disease	54	90.0
Concept of genetic disease	43	71.6
Individual at risk due to inheritance	54	90.0
Clinical manifestation of the disease	48	80.0
Management of the disease	53	88.3
Complication of the disease	51	85.0
Prevention strategies of the disease	54	90.0
Psychopathological symptom distribution*		
Psychopathology group (n = 28)		
Depression	10	35.7
Anxiety	13	46.4
Obsessive-compulsive disorder	12	42.8
Phobic anxiety	13	46.4
Somatisation	12	42.8
Interpersonal sensitivity	5	17.8
Hostility	1	3.5
Paranoid ideation	4	14.2
Psychoticism	6	21.4
Additional	8	28.5
Non-psychopathology group (n = 32)		
Phobic anxiety	1	3.1
Somatisation	2	6.2

*Sum of percentages is >100% because there are participants who had more than one symptom

participants, 28 (46.66%) experienced psychopathological symptoms in general. The most common psychopathological symptoms experienced by the participants were anxiety and phobic anxiety (46.4%), followed by obsessive-compulsive disorder and somatisation (42.8%). There was no difference in the distribution in the non-psychopathology group. The most common psychopathological symptom was somatisation (6.2%).

Table 3 presents the associations between the sociodemographic variables and psychopathology among caregivers who had children with major thalassemia. The knowledge about thalassemia was equal in proportion between the groups (p = 0.628). Sex, age, family income, marital status and education level were not associated with psychopathological symptoms (p = 1.000, 0.379, 0.864, 0.737 and 0.746, respectively). A significant association was found between occupation and psychopathology ($X^2 = 0.425$ and $p = 0.039$).

DISCUSSION

Our study was a part of a roadmap Medical Genetics of Padjadjaran University research that was aimed to collect information about the history of the same disease in families

Table 3: Association between socio-demographic features and psychopathology groups (n = 60)

Variables	Psychopathology		Non-psychopathology		X^2	OR (95% confidence Interval)	p-value
	Number	Percentage	Number	Percentage			
Sex							
Female	23	46.9	26	53.1	0.008	1.062 (0.286-3.945)	1.000
Male	5	45.5	6	54.5			
Age							
≤30 years old	5	35.7	9	64.3	0.880	1.8 (0.523-6.199)	0.379
>30 years old	23	50.0	23	50.0			
Occupation							
Unemployed	22	56.4	17	43.6	0.425	0.309 (0.099-0.965)	0.039*
Employed	6	28.6	15	71.4			
Family income							
Low	7	35.0	13	65.0	0.029	1.114 (0.725-7.510)	0.864
High	9	37.5	15	62.5			
Marital status							
Married	24	48.0	26	52.0	0.214	0.722 (0.181-2.875)	0.737
Divorced	4	40.0	6	60.0			
Education level							
Not graduating high school	15	51.7	14	48.3	0.586	1.882 (0.500-5.120)	0.746
High school graduates	7	41.2	10	58.8			
University graduates	6	42.9	8	57.1			
Knowledge of thalassemia							
Low	14	43.8	18	56.3	0.234	1.286 (0.464-3.559)	0.628
High	14	50.0	14	50.0			

with thalassemia dependent transfusion to construct a complex medical and psychosocial relationships diagram as a part of a family genogram. Some researchers have also proven that a three-generation pedigree can identify a thalassemia carrier higher than other approaches¹². This screening is also appropriate for regions that have very large populations and lack health infrastructure to support large-scale screening. Families with a history or family members who have thalassemia tend to be more afraid of getting thalassemia, so family members will find it easier to screen for carriers. Therefore, after the index case is identified cascade screening is more cost effective. In this study, knowledge about thalassemia, demographic factors and psychopathological symptoms were investigated among caregivers in West Java, Indonesia. The majority of caregivers were female respondents who had a parental relationship with the child. This finding may be attributed to the Asian culture of parenting in which mothers tend to stay at home and take care of their child. A weak association was found between sex and caregiver psychopathology in this study, which is consistent with previous findings¹³.

Our findings indicate a high level of knowledge about thalassemia, with more than half of the participants having an experience of the disease. Even those who had an experience of the disease demonstrated inadequate knowledge of the basic concepts of thalassemia. The knowledge is considerably higher than that reported in other countries, including India (47.6%), Pakistan (60%) and Iran (49.5%)¹⁴⁻¹⁶. The majority of participants had misconceptions about abnormality of hemoglobin production, leading to anemia with high accumulations of iron. Previous studies have shown the level of awareness of thalassemia parents possibly cause unnecessary knowledge, like blood transfusion is the only treatment for this disease¹⁷. Parents should be more aware about complications of iron accumulation, because it can lead to life-threatening and increase risk of poor prognosis. Less than a fifth of the caregivers knew that thalassemia leads to high iron levels and more than half recognized that thalassemia causes anemia. The majority of caregivers recognized that thalassemia is a hereditary disease, few caregivers understood its pattern of inheritance. This condition is an important issue, especially in a country with a high prevalence of thalassemia. Physicians have contributed a greater role to the caregiver's knowledge about thalassemia. Caregiver's knowledge is important since it contributes to the caregiving process and quality. Past research support providing psychosocial support such as informal education to caregivers to improve both the patients' and their caregiver's quality of life¹⁸. The education level of caregivers in this study

was rather low. Any association between educational level and knowledge about thalassemia cannot be concluded completely. The caregivers had a better understanding of the problem because they had experience in caring for children with thalassemia. The willingness to participate in screening was very high; in this study, all caregivers volunteered for screening. However, one of the major difficulties encountered in convincing the parents to participate in thalassemia screening was the fact that they were obviously healthy and felt well, so that it was difficult for them to understand that even obviously healthy parents could have a very ill child. Even well-educated caregivers might not be familiar with hereditary issues and genetic problems¹⁸.

Another interesting finding in this study was that anxiety and phobic anxiety were the most common psychopathological symptoms experienced by caregivers of patients with thalassemia. The caregivers were constantly worried about their children's physical health and future. Furthermore, they faced several financial burdens due to the expensive treatment of thalassemia, which included regular transfusion of blood according to the severity of the disease and medicines to remove excess iron, constant care and fulfilment of the parental responsibilities. These factors may contribute and play a major role towards an increase in the prevalence of psychopathological symptoms of the caregivers and hinder them from achieving psychological well-being¹⁶. The major finding of this study was that psychopathological symptoms were significantly associated with occupation ($p = 0.039$, $OR = 0.425$, $95\% CI = 0.099-0.965$). The prevalence of psychopathology increases in people without any occupation. This is consistent with the studies of Beutel *et al.*^{19,20} in German men and women of all ages, which showed previous unemployment as a predictor of anxiety ($p < 0.001$). According to Jahoda's theory, employment provides a manifest function (salary) and a latent function such as broader social activities with less emotional charge, clear identities and participation in a purpose and effort together²¹. It is also said that employment offers reality in one's life. This supports the Freudian theory of personality that ego development and its control require balanced pleasure and a reality principle to have a satisfying life. These needs are lost because of unemployment²². Furthermore, unemployment makes people lose their control over their environment and reduce the demand trusted on them. It is said that health can be improved by having a reasonable amount of demand. Caregivers of children with thalassemia did not plan their unemployment. Their unemployment was undesired and beyond their control because of the impact from having children with thalassemia^{22,23}. There are several

coping styles exhibited by parents of children with chronic illness. There are some parents who have learned to accept their condition as the new normal⁸. On the other hand, poor coping mechanisms such as avoidance can lead to poor psychological well-being of the caregiver. Meanwhile, caregivers with psychopathological symptoms may show reduced quality of care to the patient, which can decrease the patient's survival rate^{8,24}. Therefore, it is important to provide psychosocial intervention for caregivers of children with thalassemia, as well as those with other chronic diseases.

The primary problems that arise in caregivers include difficulty in providing optimal care, difficulties in having to move places, impact on family size, changes in knowledge and attitudes, perceived prejudice due to conditions from the immediate environment and divorce. In this study, it was found that the consequence of giving birth to children with major thalassemia was a challenge and life had changed for the majority of participants. Most of the challenges were related to caring for these children and the simultaneous emotional difficulties they experienced. The impact of religion still appeared to be a part of consideration in every decision at every stage of their lives, which was considered as positive. This study has several limitations. The self-reported questionnaire may have resulted in a response bias and the results might not be generalizable to the entire population in West Java. Consecutive sampling technique was used for this study, which is not a representative of the population.

CONCLUSION

The study demonstrated an association between occupation and psychopathology. This condition affects not only the persons with the disorder but also their caregivers in several aspects, including psychosocial well-being. Therefore, it is important for physicians to provide health care management not only to the patients but also to their caregivers. Counseling and psychotherapies for caregivers of the patients with thalassemia can be provided using the findings of this research.

SIGNIFICANCE STATEMENT

This study discovers the importance of caregiver's psychological well-being in determining the survival of children with thalassemia. This study will help the researcher to find effective thalassemia caregiver counselling methods to reduce psychological burdens that are still not widely published. Thus, new theories about guidelines for assessing the supportive care needs of caregivers of thalassemia

children to design interventions through providing education and information that provides general and specific information, regarding facts about thalassemia, caregiving skills and symptoms management both when thalassemia is diagnosed, as well as during transfusion or treatment in hospital and when returning home and possibly other methods may be arrived at.

ACKNOWLEDGMENT

We would like to thank all the participants who took part in this study and all the staff of Research Centre of Medical Genetics, Padjadjaran University, Bandung, Indonesia for all the help they provided during this study.

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