

## Indonesian Mothers' Needs and Concerns about Having a Thalassemic Child and Its Treatment: An Exploratory Qualitative Study

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### ABSTRACT

*Thalassemia is a major genetic blood disorder that considered as a public health problem in Indonesia. Yet, little is known about affected individuals thalassemic children and parents overall experiences with and perceptions of thalassemic mayor in Indonesia. This study aimed to explore the concerns, beliefs, feelings and needs of mothers' who have a thalassemic child. A total of (N=24) mothers' were chosen as participants. Focus Group Discussion (FGD) was carried out to better elucidate the mothers' perceptions of their needs and concerns. A semi-structure focus group moderator's guide corresponding to the research questions was developed. To gain in-depth understanding, questions were divided in four major domains which were (i) Perceptions about child disease, (ii) Knowledge about thalassemic and its treatment, (iii) Thalassemic impact on child and family, and (iv) Needs and future concerns. Transcripts were thematically coded according to the research themes that emerged from the data, and the themes were further sorted into subthemes. The finding of this study indicates significant impact of thalassemic children on their families in terms of emotional well-being, financial burden and social impact. Mother's education level was very low about Thalassemic. Mother also expressed their needs for more information about thalassemic and its treatment, social, professional support, and financial support. Results of this study provided a portrait of the reality that thalassemic has a significant impact on children and their families. A holistic approach should be carried out while caring with thalassemic children and their families. Nurses and health care professionals should explore the feelings, concerns and needs of mothers' who have thalassemic children and eventually provide appropriate care plans that alleviate their suffering.*

### Keywords

Children, Indonesia, Mothers' Concerns and Needs, Thalassemic mayor.

### Introduction

Thalassemic major is an inherited hematological single gene disorder leading to anemia in affected children in the world that represents a major public concern in Southeast Asia, including Indonesia [1-2]. It characterized by a defect in the genes responsible for production of hemoglobin. This defect causes an abnormal development of red blood cells and ultimately anemia, which is the main characteristic symptom of the thalassemic [3-4].

Thalassemic major is classified as a chronic disease that manifests

so early in life. Children with thalassemic mayor require lifelong blood transfusion, usually started within 6 to 12 months of birth of the patient and extensive medical treatment in order to live. Thalassemic poses tremendous physical problem in the affected children, as thalassemic children depend on blood transfusions and need to be treated the rest of their lives [2-5].

In Indonesia thalassemic mayor, is more prevalent and as a serious health problem; approximately 3-10% people are carrying the genes of thalassemic due to abnormal production of hemoglobin [6]. Over 3000 thalassemic homozygotes are born every year [1]. These numbers are alarmingly growing due to lack of awareness, insufficient educational campaigns, as reported by Bulan [6] that most of the mothers with thalassemic traits never come to know