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Indonesian parents' concerns and needs about thalassemic children and its treatment: A qualitative study

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Thalassemia is a major genetic blood disorder that considered as a public health problem in Indonesia. Yet, little is known about affected individuals and parents overall experiences with and perceptions of thalassemia mayor. A total of (N=24) mothers were chosen as participants. Focus Group Discussion (FGD) was carried out to explore the concerns, beliefs and feelings of parents having a thalassemic child. 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) Belief about child disease, (ii) Knowledge about Thalassemia and its treatment, (iii) Thalassemia impact on child and family, and (iv) Needs and future concerns of child and family. 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 identified 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 Thalassemia and its treatment. Parents also expressed their needs for more information about thalassemia and its treatment, social, professional support, and financial support. Results of this study provided a portrait of the reality that Thalassemia has a significant impact on children and their families. A holistic care 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 parents who have thalassemic children and eventually provide holistic care that alleviate their suffering.

Biography

Dr. Henny Suzana Mediani has completed his Ph.D from Curtin University Australia in 2014. She is Senior Lecturer of Paediatric Nursing and Vice Dean at Faculty of Nursing Universitas Padjadjaran Indonesia. She has conducted research more than 10 studies and has been serving as a reviewer board in Royal Collage of Nursing Publishing Company and Nursing Children and Young People Journal.

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