# THE PERCEIVED ROLE OF GOD IN HEALTH AND ILLNESS: THE EXPERIENCE OF JAVANESE MOTHERS CARING FOR A CHILD WITH THALASSEMIA

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## Abstract

Thalassemia is recognized as one of the major health problem in Indonesia. It is estimated that about 10% of Indonesian population are carrier of the mutated gene. Nevertheless Thalassemia is not well-understood by communities. This paper addresses how Javanese mothers view the role of God in Thalassemia. Semi-structured interview was employed to five mothers having a child with Thalassemia residing in Semarang, Central Java. Most mothers with Thalassemia children stated that Thalassemia was a result of bad consequence in the past, known as *karma* which they held at present. Having Thalassemia children would be perceived as 'destiny' and God's trial to the family. All mothers agreed that acceptance *(nrimo ing pandum)* of the child's condition without questioning to God was essential as a way to cope with.
This result points to the cultural awareness that exits in community, to the need for health care providers to be sensitive to the health-related religious beliefs of patients and their families.

**Key words:** Javanese mothers, Thalassemia, beliefs, *nrimo ing pandum*

## INTRODUCTION

Thalassemia is a hereditary blood disease which is common to happen in a place where malaria becomes epidemic such as in Indonesia. It is caused by mutated gene that influences the ability of produce haemoglobin, which the component of the red blood cells that is responsible to circulate oxygen all over the body (WHO, 2006).

Thalassemia may caused patients get pale, fatigued, and suffer tachycardia, that is the abnormally rapid heartbeat, enlarged spleen, slow physical growth, difficult to carry out physical activities, weak, lethargic, and irritable. It was found there have been 13 mutations of beta-Thalassemia identified, of which the HbE, IVS-nt5, and Cd 35 mutations are the most prevalent (Setianingsih, et al. 1998). Thalassemia is passed on to generation through autosomal recessive pattern. When both parents are carriers, a one in four or 25% chance the child will be affected by Thalassemia major, a one in two (50%) will be affected as carrier of Thalassemia, and one in four (25%) chance the child will not be affected in which there is 1 in 4 chance (25%) of being affected in every pregnancy. The quantity of individuals suffering from this severe, life shortening, disorder tends to show increased rate. It is estimated that the prevalence of being carriers vary between 6% to 10% (Timan et al, 2002).

Most of Thalassemia patients are children. Patients come at least every month to the hospital or the Red Cross to get blood transfusion in order to stay alive, moreover some of them may also need additional supportive drugs necessary. Because of the treatment received, the children will be absent for school at least for a day. During the treatment, mothers usually accompany their

affected children than fathers. In Javanese culture, mother is the main caregiver for upbringing and caring for the child (Albert et al., 2005; Zevalkink & Riksen-Walraven, 2001). Mothers tend to involve in all aspects of their children's life, including when their children were sick. Chronic illness such as Thalassemia in a child may influence the psychological responses of parents and other family members. Parents have intense burden of providing the child for their daily living. Researchers have found that mothers may experience burden for taking care of their Thalassemia child for long time periods (Sapountzi et al., 2006; Rao, Pradhan & Shah, 2004). The burden is currently associated with the consequences of the disease since the treatment is expensive and everlasting (Sapountzi, et al 2006; Rao, Pradhan & Shah, 2004).

Having a child with chronic illness, such as Thalassemia may impede the caregiver as well as the family dynamics. Feeling of anger, shock, guilt, and relief are some of wide spectrum of emotions families developed. They wonder whether the child's condition will improve or even get worse, ask whether the child will die and try to figure out how much they can expect from the child (Clarke-Steffen, 1997; Parker, 1996 in Packman et al., 2007).

Coping strategies play an important role in maintaining caregiver well being (Rafiyah, Suttharangsee & Sangchan, 2011). Researchers suggest that religious beliefs may influence overall health and/or coping with an illness (Idler, 1997; McFaden & Levin, 1996 in McAuley, Pecchioni & Grant, 2000). Religious beliefs may directly influence health behavior by avoiding negative health-related activities (Ellison, 1991) and indirectly influence health by providing and maintaining the social support in order to manage stressful condition (Lazarus & Folkman, 1994 in Rafiyah, Suttharangsee & Sangchan, 2011).

There are about 88% muslims in Indonesia (http://www.asiarooms.com/en/travel-guide/Indonesia/Culture-of Indonesia/Religion-in-Indonesia.html). Showing that Islam is the most dominant religion, which is also the larger population than any other country worldwide. This religious value is embedded in their daily life, integrated into their life experiences and personal identities amongst the Indonesian people.

This aim of the study is to describe how mothers' religion and God are incorporated into their health belief systems and how they perceive the relationships between God on their health and illness by learning from Thalassemia case.

## METHOD

### Design

Semi structured interview was run to five mothers living in Semarang, Central Java. It consisted of mothers having affected children. The questions were about their knowledge about Thalassemia and how they handled the situation when they dealt with it and how they perceived the role of God in this disease.

### Participants and Procedure

Mothers of children affected with Thalassemia were invited to participate in the study. They were recruited at the waiting rooms for Thalassemia patients at either the paediatric ward of Dr. Kariadi Hospital Semarang, or at the Red Cross, branch Semarang. Qualitative data was obtained through interviews that lasted between 45 and 100 minutes. The written consent was given prior to the study. The subjects were explained about the detailed research was all about, and convinced mothers that any personal data would be confidential therefore their identity could not be traced back.

The interviews were conducted with discussion focusing on three main areas:
1. History of the disease
2. Personal Experience and understanding about the disease
3. External control about the disease

The semi structured enabled the interviewees to discuss interest of theirselves and questions were kept deliberately open, providing cues to talk with minimum interruption from the interviewer. The interview would be audio-taped and transcribed.

**Data Analysis**

The transcribed would then be analyzed using IPA (Interpretative Phenomenological Analysis) outlined by Jonathan A. Smith (1999). This approach was used to create a comprehensive account of themes which had significance within the original texts. Thus, connections were made from the dialogue. Initially interviews were transcribed. Transcripts were analyzed individually in sequence, by marking relevant items, identifying emergent themes, noting connections, and ordering into preliminary lists.

**RESULTS AND DISCUSSION**

**Results**

*Description of subjects*

The mean age of mothers was 42 respectively. All of them were Javanese. Mostly were married (60%), 80% were Muslims and 20% were Christians. The average numbers of children was 2, and had a low and middle range of socioeconomic status.

Two emergent themes are: 1) Cause of Thalassemia; 2) Coping strategy

*Cause of Thalassemia*

Some of the respondents thought that thalassaemia could be caused by several possible triggers. It could be from internal and external factors, such as food, young married. And there was participant who related the disease as a 'curse' or 'bad luck' from their ancestor or themselves for doing bad behavior in the past (known as '*karma*') as said below:

R2 (mother of Thalassemia child):

*"……because of food or young marriage…but I also thought would it be because of my mistake or whether I was against my parents."*
*"An attempt of Allah….karma…the possibility of my ancestor making a mistake…"*

*Coping strategy*

Religion was used as key resource for mothers, enabling them to deal with Thalassemia as enhancing their own spiritual growth and through prayers helped them to cope with the symptoms of the disease, such as these statements:

R1 (mother with Thalassemia child)

*"I am more to religious, Ya Allah… had a special child….My religiosity influences me to accept the condition as the way it is. Accepting or declining depends on religiosity. I really concentrated on my religiosity then I started accepting my child's condition."*

Having an affected child also been remarked by mother that if God gave one condition, He also gave the strength to cope with it, therefore relying their faith in God was the only way to adjust with the child's illness.

R5 (mother with Thalassemia child)

*"….God warned me…. I think it is like a hit so that…it's like a warning. I think when we are given a disease then it means that God loves us…….I rely on Him. ….It is better to be like this……..What we only could do just pray so that we would not get more affected child. Praying was the only way. ….the only way to accept the condition as the way it was. It was his destiny to be given such disease like this. What we could do was praying to Gusti Allah (God).*

R2 (mother with Thalassemia child)

*"We pray to Allah everything is running well. I am not alone even though I have a child like this. I cannot imagine if I am all alone, it can be stressful."*

Realizing that Thalassemia was a cronic illness, acceptance was perceived as a way to adapt and remain positive towards their child's condition.

R4 (mother with Thalassemia child)

*"Just accept the condition as the way it is. All children are worth whatever their condition is."*

Meanwhile, keeping active was used for mothers with an affected child in order to deal with their child's condition by using supportive agents that will maintain the life of their child. Whereas mothers without Thalassemia child suggested that many efforts needed to be tried, such as using alternative medicines.

R2 (mother with Thalassemia child)

*"I make it easy because we already have Jamkesmas so it will not develop into a burden."*

*"We also ever tried for alternatives ingredients from Aceh and consume it every mornings and evenings but until now still get transfused."*

R4 (mother with Thalassemia child)

*"I used gingseng. It was three times a day for 50 thousand for a month and he survived with stable Hb for three months without transfusion."*

**Discussion**

Religious approach as a way of coping was common among person with chronic disease, such as Thalassemia. According to Seibert et al (2003) religion was used as a reference framework to understand what was happening in the external world and then to relate to it. In turn it would affect the individual's perception of disease, disability and suffering, the individual's degrees and concerns, responses to treatments, and the connection between the physicians to health care system.

Their awareness of God made them to be in control and motivated them to be active in rituals, such as praying since through it they could find relief and strength to carry on life with their affected child. Positive thinking is more likely used in mothers to face the problems arise because of Thalassemia since it could interrupt family in routines, finances, separate families, assemble conditions of dependency, and then escort to existential and spiritual concerns.. Examining the relationships, mothers' perceptions of God became the adaptive beliefs within the health and illness context.

The study showed that 80% of the subjects were Muslims whereas 20% were Christians. All of the subjects put their trust in God through praying and other religious practices. Praying itself as a means of coping was found to be effective since it enabled mothers to express emotion and made meaning in light of

traumatic events, and also a way of confession about the presence of God in their life. Moreover, through praying there was an expression of Javanese values such as surrender (*pasrah*), willing (*rila)*, and remember (*eling)* therefore mothers could enhance their identity, meaning and purpose of life, hope, and reassurance. For mothers with Thalassemia child, living close to God is the way out to understand that being health is a matter of a gift from God and being ill is a way of God's test. This finding was in line with Robinson's study (in McAuley et al., 2000) stated that religious beliefs influenced the health beliefs of the African Americans.

This finding supported other studies that stated strong religious faith may cause them to see negative life experience as a chance for the growth of spiritual life (Ellison, 1991). Believing in God made them realize that God is in control of their health. The study of Hathaway and Pargament (1991) described three coping types related to the interpretations of perceptions of God and self as active or passive: 1) a deferring style, meaning that the self was passive and responsibility for coping was placed under God's control; 2) a self-directing style, marked by the activeness of the self whereas God was perceived as passive; and 3) a collaborative style, in which both God and the self were active, working together to deal with the difficult events.

It was interesting to note that mothers developed collaborative style. Both God and mothers were seen to be active agents to encounter the child's condition. Especially in Javanese culture, concept of *nrima ing pandum* taught them to accept all condition as a gift of God therefore they can lightly face (*ikhlas)* the situation and effectively cope with the illness of their child. Destiny, devotion, and *karma* is an existence unity that become the standard on how life should be run. Moreover, people would be succeed in terms of their ability to adjust with the reality of their life. *Nrimo in pandum* had a meaning of being active to make something work using their maximum efforts and let God decide the result. Endraswara (2006) stated that in *nrimo* there was a link between horizontal and vertical path, showing the relationship that what they did would be resting in God's will.

The study showed that belief systems influenced the way mothers viewed things, including health and illness. Their belief systems functioned as a filter in order to balance their life. Mothers' understanding that God had a role in all circumstances helped them to realize that there was a mighty source in the universe that controlled for everything, including the life of their child. Supporting mothers' religious beliefs as caregivers therefore might enrich the patient-physician relationship because the goals of medicine were to cure disease when possible and to lessen suffering always, since religious beliefs influences their expectations about the outcomes of various medical treatments and also enhanced their compliance with recommendations.

## Limitation and Further Direction for Research

Mothers with Thalassemia child must be considered that their spiritual health and physical health are equally important. Therefore they would develop both their awareness about the presence of God which gave strength whereas they would also be active on trying as hard as possible to keep their child's health. A relationship with God might influence their appraisal towards the illness itself.

The limitation of the study revealed the importance of involving fathers as a part of significant person of the child, since this study did not. It was imperative to get father's impression on how they perceived their

child's illness so that it might enhance a better way of coping for parents related to the child.

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