

## PRESENTATION

### Experience and Supporting Needs of Family with Children with Thalassemia $\beta$ Mayor

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#### Abstract

Concept of Well-being and sick explained that human being is in health condition in one point and sick in another point. However, once people get sick, people will do any treatment, as visiting hospital, either inpatient or outpatient. Thalassemia is the most common hereditary blood disorder in thalassemia belt, which known as a malaria endemic area as well, include Indonesia. One of the chronic illness impacts, including thalassemia, toward family is guilty feeling (children or parents) which affect to children lack of self-care, distressful, physical disorder, powerless, and helplessness. Parents of school-age children with thalassemia  $\beta$  mayor show varied respond toward this circumstance. This qualitative method research with phenomenology descriptive approach aims to explore parents' experience on taking care of school-age children with thalassemia  $\beta$  mayor. By using descriptive phenomenology, the study observes every problem through place it on natural circumstance. Data were collected through in-depth interview. 5 participants were recruited purposively, included 4 mothers and 1 father, with range in age from 38 – 54, elementary to university educational background and come from Sunda, Java and Betawi tribe. The study identified 7 themes consists of 5 themes described parents' experience on take care of children with thalassemia  $\beta$  mayor and 2 themes described family support needs on taking care their thalassemic children.

**Keywords:** Parent's experience, School-age children, Thalassemia  $\beta$  mayor

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## INTRODUCTION

Concept of Well-being and sick explained that human being is in health condition in one point and sick in another point. All age people include children expect healthy live and protected from any disease. However, once people get sick, people will do any treatment, as visiting hospital, either inpatient or outpatient. Pediatric nursing practice include contract to the children itself as a patient and family. Pediatric nursing aims to prevent, assess, delivery intervention and improve welfare through nursing process according to ethic and legal aspect. Therefore, as a part of family, children should be involved on nursing care, hence agreement among family, children and health professional should be developed.

As one of development stage, psychosocially, children on school age develop creativity, get recognized through skill demonstration, create things and develop self-esteem by achieving goals. Their behavior are influenced by peer group, physical, social and cognitive growth, ideas development and surrounding exploration (Hockenberry& Wilson, 2007). Unfortunately, school age children with chronic illness may face significant impediment on this development stage.

Thalassemia is the most common hereditary blood disorder in thalassemia belt, which known as a malaria endemic area as well, include Indonesia. It is

supported from Yunanda (2008) stated that carrier prevalence in Indonesia was varied from 1- 10%. According to preliminary study in National Referral Hospital in Indonesia, Rumahsakit Dr. Cipto Mangunkusumo Jakarta (RSCM) found that until December 2010, patient number in thalassemia unit reached 1.495 people with highest number was on 0-5 years children 43,68 % (653 people), 6 -10 years 30,97% (463 people), 11 – 15 years 16,79 % ( 251 people) and rest of them were more than 15 years 8,56 % (128 people). It also revealed that number of man with thalassemia 56,25 % (814 people) is higher than woman.

One of the chronic illness impacts, including thalassemia, toward family is guilty feeling (children or parents) which affect to children lack-of self-care, distressful, physical disorder, powerless, and helplessness. Once child get chronic illness, family acquire the impact, hence support is needed for family and the child itself. Fundamental family needs consist of: emotional support or convenience, cognitive support through information and advice, and material support (Jacobsen, 1986 on Cadman, et.al, 1991).

## PURPOSE

### Main Purpose

This research aims to acknowledge family experience and support needs on taking care of children with Thalassemia  $\beta$  Mayor.

### **1.1. Specific Purpose**

#### **The specific purposes of this research:**

- a. Description of parent's experience on delivering care to school-age children with thalassemia
- b. Description of support needsof parent with school-age children with thalassemia

### **1.2. Research Question**

"How does family feel during taking care school-age children with thalassemia and what kind of support they need?"

## **METHOD**

### **Design**

This study employed phenomenology method on qualitative approach. Phenomenology method was commonly employed to investigate a phenomenon deeply, critically and systematically (Streubert& Carpenter, 2003). By using descriptive phenomenology, the study observes every problem through place it on natural circumstance. It explored and defined every family experience during taking care of school-age children with thalassemia. This approach benefits to deeply explore the complexity of family experience during taking care of school-age children with thalassemia.

#### **a. Participant**

Participants in this study were parents of children with thalassemia  $\beta$  mayor. Purposive sampling technique

was employed to acquire appropriate population and sample. Five participants were chosen according to these criteria: 1) Provided consent for the study 2) Cooperative 3) Agreed to reveal their experience in Indonesian language.

#### **b. Data Collecting Instrument**

Instrument in this study was the researcher itself. Data were collected through in-depth interview to participants. Supporting equipment was tape recorder to record information from participants. Field report was used to write down non-verbal respond from participants and surrounding circumstance during interview.

#### **c. Data Analysis**

Collected data consist of interview recording and field report as an observation result. Data were analyzed using the 9 steps Colaizzi (1978 on Streubert& Carpenter, 2003). All interview were tape-recorded and transcribed verbatim by the researcher. Double check for these transcripts was. The researcher read each trascript several times to ensure the transcript accuration. Participant's non-verbal respond written in field report was also integrated in transcript.

Furthermore, keywords were identified through selecting participants' statement. Keywords whose relatively closest meaning were formed into one category. Same categories were grouped

into one sub-theme. Theme was created through classifying sub-themes with similar meaning. Hence, the researcher referred theme appropriateness into specific purpose of study. Last data analysis process was writing down narration of research finding. It was written according to structure of specific purpose and each theme. Category and sub theme were conducted in form of description to describe mechanism of each theme formation on each specific purpose.

## RESULT

### Participant Characteristic

Participants in this study were five parents who mostly were mother. They were range in age from 38-54, one man and four women. Education background was varied as well from elementary to university graduate and came from different tribes as Sunda, Java and Betawi.

### Theme

#### Theme 1: Parent's Knowledge Regarding Thalassemia

Theme of parent's knowledge regarding thalassemia was supported by sub-theme of definition, cause and treatment.

Sub theme of definition was identified through participants' statements as below:

*"Thalassemia is not infectious disease..." (Participant 1). "What I know*

*from this disease is it can't produce red blood cell, though she consume vitamin or anything else..." (Participant 2). "...That is a blood disorder... Lifelong disease..." (Participant 3). "...I heard it such a lack of blood..." (Participant 4) "...Thalassemia is a hereditary disease..." (Participant 5).*

Sub-theme of cause of thalassemia was identified through participants' statements as below:

*"...Parents were carrier of this disease..." (Participant 1). "Thalassemia caused hereditary from parents, means both of them..." (Participant 5).*

Whereas sub-theme of treatment was identified through respondents' statements as below:

*"...Every month need blood transfusion. That's thalassemia..." (Participant 1). "What I know is transfusion is needed in order to provide sufficient blood for body, blood transfusion should be carried out..." (Participant 2). "...It needed ongoing blood transfusion every month." (Participant 3).*

#### Theme 2: Apply Normalization Process

Theme of normalization process was identified through sub-themes of arrange normal lifestyle, improve physical condition, support from peer group and overcome emotional respond. Participants reported to arrange normal lifestyle some people show nothing different, same action, while others were

more careful and patient, as statements below:

*“...should be patient to take care of him. Because he was quite stubborn nowadays...” (Participant 1). “...Nothing different, just like take care of other children...” (Participant 2). “...Nothing special to take care of him...” (Participant 3). “...I took care of her carefully at home, pay attention to her food, her toys...” (Participant 4). “...It was quite long time because I had been taken care of two children with thalassemia. But praise to God this child was not difficult to handle since he was four years old...” (Participant 5).*

Sub theme of improving physical condition was identified through these participants' statements:

*“...Yes, I pay attention to his medicine. Ensure he took his medicine...” (Participant 1). “Going to school was depending on his condition. If he was not fit, I couldn't force him to leave because his school was quite far...” (Participant 3). “...If he wants to play around, he was not allowed to be so exhausted, even for studying...” (Participant 4) “..”I avoid him to do physical exercise outside. Prevent from unexpected thing, because playing outside will make him out of energy, decrease immunity, so make him get sick easily, like the child A whose hemoglobin never be normal...” (Participant 5)*

To improve physical condition, participants provided alternative activities, as the statements below:

*“...He understand that my prohibition for his goodness, but I didn't forbade whole activities, I gave him alternative like not going to “Dufan” (Amusement Park), but visiting “Kidzania” (Edutainment Hall)...” (Participant5).*

Whereas sub theme of peer group support was identified through participant's statement as below:

*“...Honestly, I was sad for having child like this, verysad. It was so terrible. But after I visited RSCM Hospital and saw many people on the same condition, I just let it flow...” (Participant 2). “...as the physician said, I have several people on same condition. So it make me bit relaxed. My child was not the only one suffer from this illness...” (Participant 3).*

Then, theme of overcome emotional respond was described through these participant's sentences:

*“Probably he was stubborn after lot of transfusion episode, so I should be patient. We should eager and want to persuade. After all nothing difficult as long as I stay warm...” (Participant 1). “...Probably because of thalassemia, he tend to hard. Then we should give way to, can't be hostile to him” (Participant 2). “This child has difficult behavior, frequently get upset. If he was upset, I should calm him. However, as parent, sometime I was angry. Then I feel*

*so sorry...” (Participant 3). “...In the beginning, it was difficult to make him understand about my prohibitions, he got angry, protest. Sometime he cheated me to break the rule. But the time goes on; he realized I did it for him...” (Participant 5).*

### **Theme 3: Adequate Nutrition**

Theme of adequate nutrition supply was identified through sub themes of nutrition types and its pattern. These participants mentioned nutrient types which are allowed to consume and which one is forbidden:

*...If the food contain vegetables it couldn't be eaten, but he may consume beef or liver in small amount, then chicken, fish, soup were allowed...” (Participant 1). “...He couldn't eat food high in iron as spinach, water spinach...” (Participant 2). “...Vegetables were not allowed, like cassava leaves, spinach...” (Participant 4). “...He was prohibited to consume food high in iron, so he would read the food label first before bought it, I tell him iron was written as Fe, so if he found something with it, he would tell me or his mother first. It means meal should be free from Fe...” (Participant 5).*

Sub theme of nutrition pattern was described on participants' statements as below:

*“...Eat like usual. More important thing was he eager to eat. Breakfast with rice, lunch as well, depend on his mood...” (Participant 3). “...Same treated. But*

*limit the food high in iron, minimize it...” (Participant 2). “I fed him very carefully. If I was cooking green vegetables, I wouldn't feed him with it...” (Participant 4). “...Generally, I didn't differ anything, but for meal, these two children have some prohibition...” (Participant 5).*

### **Theme 4: Perceived Changes**

Theme of perceived changes was identified through sub themes of family economy alteration, psychology problem and surrounding responds. Sub theme of family economic alteration was described through category of expense improvement and income source alteration. Below are participants' statements describing expense improvement:

*“...Medical bill was helped through public insurance, but transportation cost and meal during hospital visit were high...” (Participant 2). “...Financial problem was number one. I had difficulty regarding financial because his father was only newspaper man, hospital bill was paid by relatives, but for transportation cost, meal and photocopy, his dad only received twenty-five thousand rupiahs a day, so if I didn't have money to go, I delayed hospital visit...” (Participant 3). “...The problem was financial. As his dad had gone, I had no idea what to do. Don't know what to do. How to pay hospital bills if I seek for medical treatment...” (Participant 4).*



Contrast to previous statements, this participant stated that public insurance from government was very helpful to pay hospital bill, like this statement:

*“...From financial point, it is as what you see... Not difficult at all... because I was helped through government public insurance for poor family..”(Participant 1).*

Whereas, the change of pattern and resource of family income was described in this statement:

*“...I used to work; but now I leave my work and be a housewife because no one could take care of the children. Financial problem aroused. Income was less than before, one child was sick, others was grown up so they need higher needs for school...” (Participant 2).*

Sub theme of psychology problem was described in sad and frustration category. These were participant's statement regarding that category:

*“...I was shock in the beginning, but then I feel pity to A...” (Participant 1). “...Emotionally, I was so sad for having this child, very upset. It seems only happen to me... Poor the child...” (Participant 2). “When the physician told me that my child got thalassemia... I feel sad...” (Participant 3). “Absolutely I was sad, but we couldn't bring back time...” (Participant 5).*

Category of frustration was described through these statements:

*“...I didn't want to think about that, what would going to happen, but when I saw older people, I thought my child would be like that...” (Participant 2). “...I get upset sometime. How could this child be like this...” (P3). “Well, so much problem, but then... How tiring... confusing... I just poor people...” (Participant 4).*

Respond to others was described in category of social interaction and how to react of it. These were participants' statements explained category of social interaction:

*“...Sometime I told to his friends. Please do not bully this child, because he used to experienced that.” (Participant 1). “This child couldn't be touched. Low-confidence, to avoid that, I always accompany him since he was on elementary school, so I was the one who interacted with his friend, not him, he was indifferent...” (Participant 3).*

Then, category of how react to others was stated like these:

*“...Other people did not understand my child condition. I interacted to his friend so they wouldn't trait bad to my child...” (Participant 3). “I communicate properly and intensively to school, either to security or headmaster. I told them that my child was like this and that...” (Participant 5).*

## **Theme 5: Over-protection**

Theme of over-protection was identified through sub theme of no

chance to have new skill, then that sub theme was described through physical, psychology, maturity and discipline category. These were participants' statement of each category.

These statements described physical over-protection:

*"...His sister more care to him... like... more protect to him... sometime I avoid to let him play outside, I worried he get so tired..." (Participant 2). "This child tend to be sweaty... sohe couldn't be over exhausted, his school often missed as well..." (Participant 3). "... if he want to play, he was avoid to be so tired, even at home just like this... even for studying he couldn't be overexhausted..." (Participant 4). "...I avoid he do physical exercise outside, especially when the weather like this... believe it or not, until now AG never going to DuniaFantasi (Amusement Park)..." (Participant 5).*

Then, other participants stated psychology overprotection through these statements:

*"...If the child with thalassemia want request something, we need to follow that, otherwise he could be fierce... I should put effort to do that. I am afraid because his special condition... If children with thalassemia get anger, it just like something..." (P1). "...He was quite stubborn, if he requests something, it should be done..." (Participant 2). "...Child like this had particular behavior, this child... tend to get angry... Anything should be served..." (Participant 3).*

Other participants mentioned that they limit child independency, through these statements:

*"Regarding school, he want to join with this course and another one, many requests, but we worried of him." (Participant 1). "Did my child independent enough? He was the only child, everything would be served for him, even once he got sick, I always accompany him since he was on elementary school, now he had been in junior high school, if he asked, I would accompany him..." (Participant 3).*

Some participants were not put discipline to their children, like these statements:

*"Sometime he didn't want to go to hospital, probably because, bored or anything." (Participant 1). "If he was fit, he would go to school, if not; we wouldn't force him because his school was far away..." (Participant 3). "...Even for studying couldn't be so exhausted, so school often missed..." (Participant 4).*

## **Theme 6: Support from Others**

Theme of support from others was identified through sub theme of safe and convenience feeling and knowledge and cognitive support. Sub theme of safe and convenience feeling was described through category of healthcare facility, supporting facility and healthcare professional attitude. Participants shown



positive perspective regarding healthcare facility:

*“...We didn’t expect much... if it possible, keep going like this... free charge for medical treatment...” (Participant 2). “...bloodsupply was always available... easy for anything, like blood, medicine and forms...” (Participant 3). “...I wish nothing bad happen, nothing worse ahead...” (Participant 4). “...good cooperation among trained healthcare professional will ease the treatment...” (Participant 5).*

In other hand, some participants mentioned importance of support from school and workplace institution which parents get to work, like these statements:

*“...His father worked far, he should absence frequently. Some institutions were understand, some were not, so I quit from my job...” (Participant 2). “...One more institution that should care was place where parent work, because not all office seemed understand that every month the child need extra attention which asked his parent to absent from office so he can accompany the child for blood transfusion...” (Participant 5).*

*“...School environment, especially class teacher should be educated to recognize symptoms when child get dropped, sport teacher was also need to know children condition so he wouldn’t force them to get involved in vigorous activity... One more that should care was security officer...” (Participant 5).*

These participants explained their testimony regarding healthcare professional behavior during care delivery:

*“...Do not put pharmacist on afternoon shift, because it was difficult to get the medicine. All nurses were kind. So far so good, once we came they served us directly, then if something happen, nurse would be coming immediately, so did the physician.” (Participant 1). “...Nurse used to help us attach this equipment, so please do not get so hostile. Do not be so mean to patient, to parent as well.” (P2). “Do not ignore us, pay attention, once I asked what they did, no respond.” (Participant 3).*

In contrast with previous participants, these participants said positive behavior on healthcare professionals:

*“...Healthcare professional in here were kind. Good relationship among them like nurse, physician, administration officer and blood supplier really helpful, so once my child need blood transfusion, they handle it in time. All staffs in this unit were care, if I contact by phone, they respond properly. The physician was good as well.” (P5).*

Needs of family support mentioned in these statements:

*“...I still capable to take care of him, together with his father. Both of us working together. Husband’s support means*

emotional and financial support...” (Participant 1). “...Medical treatment was funded by relatives...” (Participant 3). “...He didn’t have father anymore... I didn’t know what to do. What should I do...” (Participant 4). “.. In my opinion, all people should care, especially family, father, mother, brother, sister...” (Participant 5).

Sub theme of cognitive and knowledge support was described through category of anticipation assistantship, care and complication prevention. Needs of anticipation assistantship were stated in these statements:

“...I understand a little bit... but, I still have no idea for many things. The survivor like this would find more obstacle once he grown up, I still no information regarding this. Knowledge about something ahead, what it would be like...” (Participant 2). “...Did it possible to heal? Then what about his future... Could he acquire same education with others? Is he going to get married? His development... could he survive? Would his health get better or worse...” (Participant 3). “...I think we need education about what going to happen in the future...” (Participant 4).

Category of care and complication prevention was stated by these participants:

“...We didn’t know the impact ahead...If his stomach get bigger, what should be done, I didn’t know that. then, he

become adult, some more question arose. What going to happen for man, for woman, we didn’t know yet...” (Participant 2). “...I didn’t know what to do with this children. I worried there would be complication to his heart...” (Participant 3). “...How to ensure N keep healthy, so he could acquire blood transfusion every month if he is health.” (Participant 4).

## **Theme 7 Realistic Expectation**

Theme of realistic expectation was identified through sub-theme of life continuity and healing process, here participants’ statements:

“I hoped he get well soon, but it depends to God...” (Participant 2). “...I wished he can survived, get recovered was God’s miracle... we couldn’t force that...” (Participant 3). “...I hoped I could stay health so I can bring him here... I also wished N keep health so nothing bad happen again...” (Participant 4). “...I wished more research were conducted to find how to cure thalassemia...” (Participant 5).

“...If it always could be like this... free, support was available... that was number one...” (Participant 2). “...yes, It would be like this... blood stock always available... easy for everything...” (Participant 3). “...I expected nothing bad happen in the future, like usual, nothing get complicated...” (Participant 4).

## DISCUSSION

Family with chronic illness included thalassemia respond to the illness by trying to figure out chronic illness diagnosis which suffered by their children. Seeking information was carried out by parents while recognizing the child get problem, but no information available from healthcare professional yet (Hockenberry & Wilson, 2007). It was supported by result found that parent, especially mother seek information regarding the illness through conversation with other parents of children with thalassemia and read poster, so information was limited into what thalassemia is, nature and treatment.

Normalization was revealed in creating normal lifestyle. According to Shepard and Mahon (2000) in Hockenberry and Wilson (2007) normalization refer to children with chronic disease' daily activities integrate into family and society daily activities. These activities include school, doing hobby, recreation and maturity development. It is similar with research finding that parent keep trying to maintain children daily activities without any significant changes and difference with other children. This study revealed that most participants had tried to apply normalization principle for children with thalassemia, although not as whole. Normalization process occurred by most participants in form of school activity, in

which most participants supported their children for keep going to school. It is similar with Robinson (1993) who explained that family with chronic disease undergo dramatically change in life, however family should decide to focus on normal life aspect for children and family.

According to Friedman, Bowden and Jones (2010) one of family function was health care protection. This function was accomplished by parents providing meal, home, clothes and health care. Family must put effort to ensure their family member safe from any harm included illness, once illness appear, family should prevent this disease would not get worse and make complication.

Participants in this study stated that they had accomplished health care function through gave adequate nutrition for their children with thalassemia. Nutrition needs was accomplished by giving appropriate type and pattern of nutrition to children needs, as low iron nutrition. Although no study yet to prove that low iron diet benefits for patients with thalassemia, food with high in iron should be limited. It means liver, cereal, leafy green vegetables (Arijanty & Nasar, 2003).

Having children with thalassemia may require ongoing medical treatment, which affect to family and children. Chronic illness influence family by giving new task and responsibility, ensure school and healthcare service

available, deal with uncertainty, grieving, face social stigmatization and increasing expense (Hockenberry & Wilson, 2007). That theory support finding on this study which revealed that most participants need more financial resource to bring their children for visiting healthcare service. Even though medical treatment for thalassemia was funded by government through universal coverage, parent still need more money for transportation cost, meal and photocopy on each hospital visit, either for physician consultation or blood transfusion. This also supported by National Jewish Health (2008) that every family with chronic illness will have problem regarding financial, sibling rivalry, parent attention and spouse conflict.

Participants were also feel sad and frustration. This feeling appear because uncertainty of his children recovery. More frustration comes up in family with more than one child with thalassemia. Sad and frustration was begun from injustice feeling, why it happened to him and his family (Hockenberry & Wilson, 2007). Another change was others' respond, as question why she must accompany and wait during school time. It arose because of overprotective, like three parents who always accompany and wait during school time. They did that due to worry of their children condition, either physically, socially and emotionally. This finding support Gray

(1993) stated mother receive more negative stigma from society because mother seen to have main responsibility for taking care children and get socialized daily.

Hockenberry and Wilson (2007) mentioned that in adaptation phase, there were four parenthood type: 1) over-protective 2) refuse 3) denial 4) accept in some steps. Over-protective appear because parent was afraid to make their children get frustrated so they were not allowed their children fostering new skill, avoid discipline and follow their request. This finding supports Hockenberry and Wilson (2007) statement that participants avoid or limit some physical activity. In addition, participants were also over-protective in psychology, maturity and discipline aspect. Physically, parents forbid their children doing physical activity outside home, playing, even for school and study. Another study revealed similar finding by Logothetis at all (1971) that psychological change in children with chronic disease influence their parent to become so worry of illness which shown in prohibit, talkative and over-protected.

Over-protective parenthood characteristic means keep helping the children although the children have capability to do by themselves. This circumstance also appear in participants who always obey their children willingness to be served, accomplish any children request in order to prevent the

children get angry, however they realize it will lead the children become dependent. Avoiding discipline was also carried out by participant as they didn't motivate the children for school or blood transfusion schedule.

Another finding in this study was family need support from others as save and convenience feeling. It was expected to be found from healthcare care service, supporting facility as workplace, positive attitude from healthcare professional and support from spouse or other family member. This finding sound same with Hockenberry and wilson (2007) that resource from family, social, peer-group, healthcare professional relation with parenthood and society support was great supporting network for family of children with chronic illness.

Beside support from surrounding, participants in this study also need knowledge or cognitive support in form of anticipation assistantship, care and complication prevention. It is supported by Jacobsen (1986 in Cadman, at.al, 1991) stated that support for family with chronic disease basically consist of three points: emotional support or convenience, cognitive support through information and advice and material support.

Finding in this study also similar with Johnson and Kastner (2005) statement that family of children with chronic disease not only need support for children condition, but also structural

and functional support like coping strategy and external support such as working schedule. Family of children with chronic illness had different perspective with general family because they acquire higher psychosocial stressor. This study found theme of family expectation regarding life continuity and ease of medical treatment for children.

## **CONCLUTION**

Parents' experience of taking care school-age children with Thalassemia  $\beta$  Mayor was described by five themes as acknowledge thalassemia disease, apply normalization process, adequate nutrition supply, perceived changes and over-protective. Parent supporting need was describe on two themes as support from others and realistic expectation. Parent need support from other in form of secure and convenience feeling from healthcare officer, family or spouse. Another supporting need was in form of education like anticipation assistantship, care and complication prevention.

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