

Factors Related to The Needs of Parents Having School Age Thalassemic Children

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Abstract

Thalassemia is a major genetic blood disorder that has negative impacts on thalassemic children and their family. The needs of parents while caring for thalassemic children are important matters because the failure of meeting needs of parents may affect their mental and physical health. Yet, little is known about factors that meeting the needs of thalassemic child parents. The study aim was to identify factors that correlate with the needs of parents having a school age thalassemic child in west java province. This research used correlational analytic with cross sectional approach. The population in this study were parents of school-age children with thalassemic major totaling 136 people using the total sampling method. Data were analyzed with bivariate using chi square and biserial points. Then a multivariate analysis used logistic regression. The results showed the age of parents related to information ($p = 0.005$) and professional ($p = 0.004$), parent gender related to information ($p = 0.000$), professional ($p = 0.017$), social ($p = 0.035$), financial ($p = 0.023$) and spiritual ($p = 0.009$). Parental education is related to information ($p = 0.000$), social ($p = 0.005$), emotional ($p = 0.000$), financial ($p = 0.016$) and spiritual ($p = 0.001$). Parent income is related to information ($p = 0.000$), social ($p = 0.006$), emotional ($p = 0.000$), financial ($p = 0.003$) and spiritual ($p = 0.004$). The number of thalassemic major children is related to emotional ($p = 0.015$) and financial ($p = 0.013$). Parental needs are related to several factors. The importance of increasing the role of nurses as educators and consultants and helping parents find sources of spiritual, emotional and financial support for parents of school-age children with thalassemic.

Keywords: Needs, parents, school-age children, thalassemic major.

Introduction

Thalassemia 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 (Galanello & Origa, 2010; Mediani, Nurhidayah, Mardhiyah & Panigoro, 2017; Viprakasit Origa, & Fucharoen., 2014). According to the Indonesian Thalassemia Foundation-the central association of parents of thalassemia children that Indonesia is one of the countries with a high prevalence of thalassemia with the carriers of thalassemia around 5–10% and it is estimated that every year 500-600 babies are born with thalassemia. In 2015, thalassemia cases in Indonesia reached 7,029 cases. Meanwhile, cases of thalassemia in west java is the highest in Indonesia, it reaches 42% cases or 3,300 in early January 2016 (Kemenkes., 2017).

Thalassemia consists of minor thalassemia or the carrier and thalassemia major (Galanello & Origa, 2010; Regar, 2009). Thalassemia major is obtained genetically which is characterized by the reduction or absence of beta globin synthesis which results in the destruction of red blood cells in the bone marrow or spleen therefore, decreasing Hb, red blood cell production and anemia (Galanello & Origa, 2010; Marcdante, Kliegman, Jenson & Behrman, 2011).

When a child is diagnosed with thalassemia, parents start a new routine, are preoccupied with scheduling treatment, seeking information and learning about the treatment process, changing patterns of work, income, and responsibilities in the family and providing emotional support to children and other family members (Klassen et al., 2011; Pelentsov, Fielder & Esterman., 2015). Parents as caregivers should fulfil their duties of caring for school-aged children with thalassemia who need care for life (Astarani & Siburian., 2016; Pouraboli et al., 2015; Potts & Mandleco, 2007), but on the other hand they also need to meet the other children's needs, family members' needs and their own needs so that it requires great time, efforts and sacrifice (Astarani & Siburian, 2016; Klassen et al., 2011).

Need is an important thing and satisfaction

is an indicator when needs have been fulfilled or not, in other words, someone will feel satisfied once they met their needs (Kim, Kashy, Spillers & Evans, 2010). Failure to fulfil needs results in an imbalance in one's condition that will affect mental and physical health (Asmadi, 2008; Winstanley, Simpson, Tate, & Myles, 2006). The health problems occurred in parents will affect the care of their children with thalassemia and lead an impact on children's health (Mediani et al., 2017; Wacharasin, Phaktoop & Sananreangsak, 2015), besides that, children also spend more time at home with parents compared to hospitals so parents can provide care better for their children (Wilder, 2010). The needs of parents in school-aged children with thalassemia are associated with long-term complications, blood transfusions and iron chelation (Mediani et al., 2017; Shosha, 2014).

The needs of information that needed by parents related to congenital blood disorders (carrier) in parents and how the scheme devolves to children, the vulnerability of thalassemia and managing side effects of transfusions such as iron overload. The needs of support are expected to come from family, friends, neighbours, teachers, nurses and physicians' supports regarding care, treatment and follow-up care (Mediani et al., 2017). Then the needs of financial are needed relating to thalassemia treatment: transportation costs, hospital admission costs when the child is sick, and costs while leaving his job to accompany his child (Mediani et al., 2017; Shosha, 2014). The needs of emotional of parents are related to the children's health condition, the severity of the disease and the responsibilities of parents. They live in fear and helplessness because their child's illness will worsen over time (Pelentsov, Dip, Laws & Esterman, 2015). The needs of spiritual are another urge for parents (Pelentsov, Dip, Laws & Esterman., 2015; Sujana, Fatimah & Hidayati, 2017). The needs of spiritual of parents concerned about the urge for meaning and purpose while caring for the child. Some parents feel unable to get involved with religious rituals and practices because of their child's illness, resulting in a crisis of faith.

Sociodemographic characteristics are strong predictors of not meeting the needs of

parents and must be considered in developing interventions to help parents meet their needs (Kim, Kashy, Spillers, Evans, 2010). Sociodemography means a description of the population as a whole or group and is categorized based on certain characteristics, such as age, socio-economy and distribution of residence (Adioetomo, 2010). Some literature showed that the sociodemographic characteristics of parents related to the needs of parents including age, gender, education level and income (Kim, Kashy, Spillers & Evans, 2010) and the number of children with thalassemia (Habeeb et al., 2015; Ishfaq, Naeem & Ali, 2013). According to Kerr (2008) and Pelentsov, Dip, Laws and Esterman (2015) based on the concept of supportive care needs, this needs are influenced by age, gender, education, economic status, family support, culture and religion. The Child's characteristic related to parents' needs is time period of being diagnosed (Golics et al., 2013).

Family involvement in nursing care is part of the philosophy of pediatric nursing, namely family-centred care (Kyle & Carman, 2014). Family-centred care is able to improve the quality of life of children with thalassemia (Nafafi, Borhani, Rabari & Sabzevari, 2011). Family-centred care is used as a standard of pediatric nursing practice that involves families/parents in caring for children (Kuo et al, 2012; Suza, 2017).

As a pediatric nurse who provides nursing care, it is necessary to understand the factors related to the needs of parents in order to provide appropriate interventions according to the parents' needs of school-aged children with thalassemia. If the nursing interventions provided are not in accordance with the parents' needs, parents will experience emotional distress and have difficulty caring for their child (Fitch, 2008).

The Aim Of The Study

The aim of the study was to analyze factors that relate to the needs of parents having school age thalassemic children at 4 government hospitals in West Java Province.

Method

This study used a quantitative method with

correlational analytic research design and a cross-sectional approach. The cross-sectional study is observing the subject of the study once and carrying out the variable measurement at the same time (Keller & Kelvin., 2012). The study used the total sampling method to choose the overall sampling of the population (Sugiyono, 2013). The sample in this study were all 136 parents of school-aged children (6–12 years) with thalassemia major: 40 respondents from Distric Hospital 45 Kuningan; 20 people from Gunung Jati Cirebon Hospital, 23 parents from Majalengka Distric Hospital and 53 people from Sumedang Distric Hospital. Sample selection based on inclusion criteria that were parents who accompany their thalassemic children for having thalassemic treatment in those hospitals, parents who can read and write, parents with children who undergo transfusions and iron chelation treatment. While, the exclusion criteria in this current study was parents with children who have undergone splenectomy.

Data collection was carried out in 4 government distric hospitals in West Java Province for five weeks starting on July 3rd, 2018 until August 21st 2018. Data collection method used in this current study was questionnaires which focused on the needs of information, emotional, and spiritual using supportive care need instrument modified from Kerr et al. (2007) and the needs of professional from Pelentsov et al. (2016) while social and financial needs using the family need survey instrument. Meanwhile, the factors studied were the parents' age, gender, education, parent income, number of thalassemia major children and the time period of being diagnosed.

Data analysis were processed by using the computer software. Several data analysis techniques used in this study: 1) Univariate analysis was performed to obtain the frequency from each variable, 2) Bivariate analysis was conducted to determine the significance of the relationship between each independent variable and one dependent variable using the chi-square test and biserial points, and 3) Multivariate analysis used logistic regression due to variables in this study is categoric.

This study was approved by the Health

Research Ethics Committee of the Faculty of Medicine, Universitas Padjadjaran. The ethics committee has reviewed the study protocol and determined that it adheres to ethical principles. Ethical approval number is 514/UN6.KEP/EC/2018. Permission for conducting this study was obtained from dean faculty of nursing and directors of the hospitals. All participants were asked to

complete a consent form. Confidentiality was warranted by restricting access to the names of participants and demogarpahic details were separated from other data to ensure that respondents could not be identified. Only the researchers can access to the raw data.

Results

Table 1 Characteristics of Parents of School-Aged Children with Thalassemia Major in West Java

Variable	f(%)
Age (years old)	
Late Adolescent (17–25 years old)	42 (30.1)
Adults (26–45 years old)	71 (52.2)
Early Elderly (46–55 years old)	24 (17.6)
Gender	
Male	34 (25.0)
Female	102 (75.0)
Education	
Primary (Elementary School/Junior High School)	79 (58.1)
Middle (Senior High School/of the same level)	36 (26.5)
High (College)	21 (15.4)
Income	
< Regional Minimum Wage (IDR 2,250,000)	97 ((71.3)
> Regional Minimum Wage (IDR 2,250,000)	39 (28.7)
The Number of Thalassemia Major Children	
1 child	110 (80.9)
> 1 child	26 (19.1)

Table 2 Characteristics of School-Aged Children with Thalassemia Major in West Java

Variable	mean ±SD	min	max
Length of time diagnosed	7.5 ± 2.85	1.00	12.0

Table 3 The Needs of Parents of School-Aged Children with Thalassemia Major in West Java

The parent’s needs	Low		High	
	f	%	f	%
Need of Spiritual	56	41.2	80	58.8
Need of Social	57	41.9	79	58.1
Need of Information	60	44.1	76	55.9
Need of Emotional	63	46.3	73	53.7
Need of Finansial	69	50.7	67	49.3
Need of Professional	74	54.4	62	45.6

Table 4 Relationship of Parents' Age, Gender, Education, Income, the Number of Thalassemia Major Children with Parents' Needs of School-Aged Thalassemia Major Children in West Java

Variable	The parent's needs					
	Information	Emotional	Professional	Financial	Social	Spiritual
	P-value	P-value	P-value	P-value	P-value	P-value
Age	0.005	0.213	0.004	0.683	0.320	0.168
17-25 years old						
26-45years old						
46-55 years old						
Gender	0.000	0.136	0.017	0.023	0.035	0.009
Male						
Female						
Education	0.000	0.000	0.794	0.016	0.005	0.001
Elementery						
Midle						
High						
Financial	0.000	0.000	0.103	0.003	0.006	0.004
< UMR						
≥ UMR						
The Number of Thalassemia Major Children	0.670	0.015	0.246	0.013	0.052	0.924
1 child						
>1 child						

Table 5 Length of Time Diagnosed with the Needs of Parents of School-Aged Children with Thalassemia Major in West Java

Variable	Needs of Information	Needs of Professional	Needs of Social	Needs of Emotional	Needs of Financial	Needs of Spiritual
Length of Time Diagnosed	r = 0.170 p = 0.047	r = 0.127 p = 0.142	r = 0.222 p = 0.010	r = 0.265 p = 0.002	r = 0.202 p = 0.018	r = 0.157 p = 0.069

Table 6 The Significant Factors Related to the Needs of Parents of School-Aged Children with Thalassemia Major in West Java

Factors	Needs	B	Wald	p-Value	OR (CI 95%)
The Number of Thalasemia Children	Emotional	1.385	6.038	0.014	3.995(1.324-12.060)
	Financial	1.153	3.383	0.024	3.167(1.165-8.607)
Gender	Information	2.639	22.090	0.000	13.997(4.657-42.069)
	Professional	1.332	7.943	0.005	3.790(1.500-9.572)
	Social	1.288	7.865	0.005	3.625(1.474-8.918)
	Spiritual	1.411	9.790	0.002	4.100(1.694-9.922)

It can be seen from the table 1 above more than a half of parents are 26-45 years old (52.2%). Mothers tended to accompany children more during thalassemia (75.0%) compared to fathers (25.0%). The majority of parents' education is on the elementary level (58.1%). Most of the parents get income less than Rp 2,250,000 or below the West Java RMW (71.3%). The majority of parents have

one child with thalassemia (80.9%).

The time period diagnosed is an average of 7.5 years with only a year diagnosed and a maximum of 12 years with an average and standard deviation of 7.5 ± 2.85 .

Based on the table 3 above, the needs of spiritual (58.8%) and social (58.1%) were the two highest of the parents' needs, follows the need of information (55.9%),

emotional (53.7%) and for the two lowest of parents' needs were financial (49.3%), and professional (45.6 %).

Based on the table 4 above shows that the parents' age is related to the needs of information and professional with ($p < 0.05$). The gender has a relationship with each domain of parents' needs except emotional needs. Moreover, education and income factors have a relationship to each domain of parents' needs except professional needs ($p < 0.05$). Interestingly, the number of having a thalassemic child is the most related factor to emotional and financial needs, while others: the needs of information, professional, social and spiritual are significantly related to the gender of parents.

It can be seen from table 5 above there is a relationship between the length of time diagnosed with the needs of parents of school-aged children with thalassemia major, except for professional and spiritual needs.

Table 6 The Significant Factors Related to the Needs of Parents of School-Aged Children with Thalassemia Major in West Java

The table 6 above illustrates result of multivariate analysis which indicates the variables that most related to the needs of parents of school-aged children with thalassemia major, based on the p-value and the Odd Ratio (OR) value: more than one thalassemia children who need emotional support more than 3,995 times and needs of financial more than 3,167 times compared to only one child thalassemia. Furthermore, female parents tend to need of information support was about 13,997 times, professional needs of 3,790 times, social needs of 3,625 times and spiritual needs 4,100 times compared to male parents.

Discussion

So far to our knowledge, this is the first study conducted in multisites in West Java to explore predicting factors that correlated to the needs of thalassemic child parents. The findings of this study found that the highest needs of parents are spiritual needs. Thalassemic children need a life-long of treatments such as regular blood transfusions and iron chelation therapy (Mediani et al, 2017; Pillitteri.,

2010). This such long treatments may cause negative impacts on thalassemic children and their families (Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, 2007). Fulfilment of spirituality in parents provides strength and helps them in controlling the problems and their burdens that occur which are related to their children's illness (Mediani et a.l, 2017; Pillitteri., 2010; Sujana, Fatimah & Hidayati, 2017). Spirituality is a source for someone who is religious as his coping (Frey, Daaleman., & Peyton., 2005).

The meaning of spirituality is finding out whether parents can find the meaning and purpose of life when their children are sick. If parents cannot find the meaning and purpose of their life, as a nurse, they can help parents find the meaning of spirituality and encourage parents to use their spirituality as a strength in facing problems (Nur'aeni, Ibrahim & Agustina, 2013). The conditions faced by parents make their lives not as normal as before children suffering from thalassemia, thus, by these conditions parents can actually take wisdom in their lives (Hexem et a.l, 2011). Previous research conducted by Nuraeni, Nurhidayah, Hidayati, Sari and Mirwanti (2015) showed that almost all respondents in this study chose and knew the spiritual needs by finding the meaning of pain and suffering.

Age affects a person in expressing feelings and using coping through illness (Viedebeck., 2008). Usually, anxiety at a young age is easier to emerge from at an older age, but can also occur otherwise. The anxiety that occurs in the elderly can arise due to past experience of the same thing before (Kaplan & Saddock, 2010). Research conducted by McKenna, Collier, Hewitt and Blake (2010) found that older parents want more information support from health professionals in making decisions. The older the age of parents will experience a physical decline so that it has an influence in providing information (Fahra, Widayati & Sutawardana, 2017; Kaplan & Saddock, 2010). Therefore, the parents' physical decline limits parents in seeking information so that it requires information support, in contrast to young age who can seek information from various sources.

Fathers are more responsible for family finances, this is related to the culture that

the main breadwinner is a father (Handian, Widjanto & Sumarni, 2017). In this study, most mothers did not work or as housewives and rely solely on income from their husbands. This makes the fathers have a greater financial burden so the financial support is more needed for the fathers than the mothers (67.6%). Meanwhile, mothers have a more sensitive feeling to their emotions that affect their emotional and psychologically status, they will easy to get anxiety and stress (Kaplan & Saddock, 2010). As Mediani et al. (2017) indicated that all mothers in their study experienced more fear and sadness because they felt worries and uncertainty about the future of their thalassemic child. Similarly, Oers et al. (2014) found that parents who have children with chronic diseases, especially mothers report high levels of anxiety and depression.

Interestingly, this current study is different from previous research conducted by Mundy (2010) that indicated the needs of mothers were not significantly different from fathers. In Asian culture, especially in Indonesia, fathers are required to remain calm in an emotional state and must control their emotions, so they are not free to express emotions (Kati, Opod & Pali, 2018). Although the gender in this study did not relate to emotional needs, the results of cross-tabulation showed that mothers needed high emotional needs (57.8%). Children with thalassemia pose an emotional burden to mothers because they are pregnant and raise children so they have stronger relationships with children.

Education is foundation for people to drive their ability in improving their health status; it enables people to be more productive to earn a better quality of life (Mediani, 2014). Low educated people tend to be less able to use effective and constructive coping compared to higher education levels so that they need the support of other coping sources (Davies et al, 2011; Notoatmodjo, 2007). Higher education will influence the thinking of parents so it is more rational in dealing with problems. People with having adequate knowledge and education tend to have effective and constructive coping when facing problems that will more easily overcome anxiety and fulfil their emotional needs (Mediani, 2014; Notoatmodjo, 2007). Results of this current

study showed that some parents had low level education background, they finished their study from primary education (elementary/middle school) only and the need of emotional support as much as 67.1%. This study finding is in line with research conducted by Cheah, Ling and Chang (2015) which identified that low education background (elementary school education) was significantly associated with non-fulfilment of needs ($p < 0.01$).

Literature reveals that people who have low basic education are more often faces spiritual distress (Caldeira, Cservalho & Viera., 2014). Meanwhile, previous study found that people with having higher education tends to have more experience with spiritual needs (Forouzi, Tirgari, Safarizadeh, & Jahani, 2017). Findings of this current study indicated that parents with having higher education are more effective in using spirituality than people with having low education. This current research is concurrent with earlier study conducted by Rezaei, Fatemi, Givari and Hoseyni (2009) which showed that the level of education is related to spirituality, the lower the level of education, the greater the spiritual needs.

High income tends to get good tools in finding information to increase their knowledge (Thavorncharoensa et al, 2010; Novrianda, Yeni & Asterina., 2014). Results of study by Thavorncharoensa et al (2010) stated that income affects information needed by parents, both from visual audio or print media. According to Darmojo and Hadi (2006) people who did not work showed little change in the level of knowledge compared to people who work because they are more active outside so they get a lot of information from friends in their work environment. Previous study conducted by Novrianda, Yeni and Asterina (2014) showed that income has a meaningful relationship with knowledge ($p = 0.006$). High economic status has better opportunity to get whatever is needed including information networks, while parents with low economic status must think about spending money because basic needs are more important to them. Health professionals also tend to assume that low-income parents are able to understand and use information properly (Gallo, Knafel & Angst., 2009). Another study conducted by

Alam (2007) found that parents with low economic status are associated with not meeting financial needs, especially medical expenses. In this study, parents said that even though the cost of treating thalassemia was borne by the Social Security Organizing Agency (BPJS), but parents with low income said they had to bear other costs such as transportation because they used motorcycle taxis, public transportation and minibuses to the hospital.

Social support is very important for low-income individuals because it helps them overcome financial problems (Documet et al, 2015; Mediani et al, 2017). The family financial burden on health care can be reduced by family support (Golics, Khurshid, Basra, Salek & Finlay, 2013). The research conducted by Mashayekhi, Jozdani, Chamak and Mehni (2016) found that low income can significantly influenced social support. Results of this study is concurrent with this current study that parents with low income required higher social support. This current study fundings are supported by otherprevious study conducted by Norberg, Lindblad and Boman (2006), which showed that income was related to social support received by parents ($p = 0.012$). Parents who care for children with chronic diseases and also low-income people will greatly influence their social life, such as interaction with other people in daily activities will be carried out quickly or immediately abandoned even though these activities have not been completed (Golics et al, 2013).

The more number of children, the stress level of parents would be higher because the role that must be done is increased as parents who care for children (Alam, 2007; Mirbehbahani, Salehi, Jahazi, & Karimi, 2014). Research conducted by Mirbehbahani, Salehi, Jahazi and Karimi (2014) showed that having more than one child thalassemia was associated with depression in the elderly ($p = 0.01$). Parents who have two thalassemia children feel sad and disappointed hoping that their other children will not suffer from thalassemia. Parents with two or more thalassemia children have greater pressure than parents who have one child with thalassemia major (Sultana, Humayun, Humayun & Zafar, 2016).

The financial burden becomes a problem in the family when treating children with chronic diseases, especially genetic diseases (Mediani et a, 2017). This means parents who have more than one child are influential in the family, especially low socio-economic groups (Wahab et al, 2011). The number of children affects the family finances because more and more children are cared for causing greater costs.

Based on bivariate tests showed there was no relationship between the number of thalassemia children and the spiritual needs of parents but the results of cross-tabulation showed that parents who have more than one thalassemic child need spiritual support. Everyone depends on spiritual and religious support in controlling their emotions (Golics et al, 2013). In this study, the mothers always cried while praying and wondered why their child must suffer from thalassemia and be different from other children.

The longer caring for children with thalassemia, the more obstacles faced by parents and that such barriers must be overcome during caring for thalassemic children because parents will often feel anxious about the uncertain condition of the child (Mediani et al, 2017; Rachmawati, Ranuh & Arief, 2016). Infact the treatment of thalassemic children need a life-long treatments of regular blood transfusion and iron chelation therapy, however there is no certainty of recovery also makes parents feel anxious (Mediani et al, 2017; Pouraboli et al, 2015). Similarly, Norberg and Boman (2008) found that anxiety and depression that occur in older people still occurred after 2.5 years since being diagnosed and 12% of parents with having children diagnosed of cancer more than five years continue to report the same thing. This is due to parents's coping was not effective in overcoming their psychological distress and fear knowing their child illness. In addition, long treatments of thalassemia such as routine transfusions cause negative impacts on thalassemic children. Changes in face shape, skin colour, splenomegaly and growth delay in their children and delaying puberty in children as common problems faced by thalassemic children as side effect of long routine transfusion that will cause concern to parents (Kahouei, Kazemzadeh,

Zadeh & Ahmadi, 2016; Mediani et al, 2017; Norberg, & Boman, 2008; Shosha & Kalaldehy., 2017; Shosha, 2014).

Parents need information not only at the beginning of the diagnosis but continue during childcare (Mediani et al, 2017; Ririnisahawaitun, Prabandari, & Gamayanti, 2015). Research conducted by Lee, Nelson, Thompson and Donovan (2016) showed that the length of time diagnosed is related to information needs. According to Dahnil, Mardhiyah and Widiyanti's study (2017) that more than half of respondents need information regarding thalassemia, treatment and side effects of therapy. Similarly, Mediani et al. (2017) found that all participants in this study needs a lot information regarding the disease and its treatments. Parents still want the latest information about thalassemia such as new treatment options related to chelation and transplantation (Liem et al, 2011).

According to Shosha and Kalaldehy (2017) after one year since diagnosis of disease, perceived social support tends to decrease. The immediate family and people provide supports at the beginning of the diagnosis but from time to time the perceived support begins to decrease (Banovcinova & Baskova, 2014). The longer suffering from the disease makes a person resigned to treatment different from the time span of the sick who still have high expectations of treatment (Satari et al, 2012). Therefore, parents who have long treated thalassemia children need spiritual support because without hope it will cause a loss of enthusiasm and surrender that affects the care of their children (Mediani et al, 2017).

The longer the child is diagnosed, the treatment that has been carried out has been going on for a long time, this makes parents have financial difficulties because of the repeated costs to the hospital (Rijen, Spreeuwenber, Schippers & Groenewegen, 2013; Satari et al, 2012). Research conducted by Rijen, Spreeuwenber, Schippers and Groenewegen (2013) indicated that the longer the duration of illness is associated with lower opportunities to seek economics, especially parents of thalassemia children in this study some of whom have self-employment such as drivers, farmers and labourers whose income is not fixed monthly.

Based on result of multivariate analysis in

this current study to see the most influential variables on the needs of parents thalassemic children can be seen from the value of the Odd Ratio (OR) to the variable p-value <0.05. Results of multivariate analysis indicated that there are three highest of the parents' needs were related to professional, emotional and financial needs. Interestingly, the most related to gender needs were information needs, professional support, social and spiritual support.

Literature identifies that parents who have more than one child with thalassemia major complain of financial problems in the family (Shosha & Al Kalaldehy, 2017). This happens because of changes in the family economy and impact on the quality of parents in caring for children (Mediani et al, 2017; Shahraki-vahed et al., 2017; Retnaningsih & Dini, 2016). Some parents with low-economy have problems with the cost of hospital transportation for routine care and the problem is escalating as the number of thalassemia children increasing (Mediani et al., 2017; Shahraki-vahed et al., 2017).

Parents who have more than one child with chronic conditions feel their welfare is lower, less optimistic, distress and even depressed (Ekas, Whitman & Shivers, 2009; Saldanha, 2013). For instance, Saldanha (2013) found that parents who have more than one thalassemic child are significantly experienced stress. Similarly, Ismail et al (2013) identified that parents with more than one child with thalassemia faced more problems due to increased physical and mental stress that affect their quality of life.

The next one, gender was also identified as the most related factor to the needs of parents of thalassemic children in this current study. Spending time with friends and talking with parents of thalassemia is the most important thing for mothers compared to fathers. Emotional support is usually obtained from friends and family, while information support involves health professionals (Mediani et al, 2017; Requena, Arnal, & Gil, 2015). This current research is in line with the research conducted by Maunder (2012) which showed that in a multivariate manner, parent gender is the factor most related to parental needs (OR 3.6). Mothers said she wanted to get more support than fathers. As the primary

caregiver, the mother's responsibility to bring her child to undergo treatment for a long time and the mother must also care for other children so that they need a source of support, both emotional, mental and social.

Limited information obtained by parents and poor communication from the nurses causes delays in parents' ability to care for children (Pelentsov, Fielder, Laws & Esterman, 2016). Support of physicians, nurses, psychologists/psychiatrists and nutritionists is the most important source for parents during treatment (Baer, 2013; Requena, Arnal & Gil, 2015). During the treatment is the right time to receive emotional support and information as one of the interventions of health professionals (Mediani et al, 2017; Requena, Arnal, Gil, 2015). It is therefore nurses as patient advocate should more aware about the patients and their family needs. Nurses need to maintain a good communication and provide continuous supports to their thalassemic patients and their family. Furthermore, it is necessary to provide a consultation room in thalassemic clinic so parents will feel more comfortable and that it can guarantee its privacy and be more open to nurses.

Conclusion

According to findings of this current study can be concluded as follows:

1. The parents' age is related to the needs of information and professional. The gender has a relationship with each domain of parents' needs except emotional needs. Furthermore, education and income factors have a relationship to each domain of parents' needs except professional needs. The number of children with thalassemic major is related to social, emotional and financial needs. The time period of being diagnosed is related to information, social, emotional and financial needs but is not related to professional and spiritual needs.

2. The number of children with thalassemic major is the most related factor to emotional and financial needs, while others: needs of information, professional, social and spiritual are significantly related to the gender of parents.

The results of this study are expected to be input as consideration in providing nursing care to parents who have children with thalassemic.

1) Nurses are expected to play an active role as educators or consultants because most parents of children with thalassemic really need information and emotional support in child care. Therefore, consultation at any time is needed to support the parents' role by providing appropriate knowledge about treatment and care that is being undertaken. In addition, there are specialized nurses who can provide genetic counselling. Nursing services can also provide education on safe contraceptive methods. The implementation of prenatal diagnosis can also be considered in the prevention of thalassemic.

2) Providing spiritual, emotional and financial support to foster a sense of optimism and expectations of parents is needed by empowering parents in finding various sources of support that can strengthen coping strategies, both family and fellow parents who have children with thalassemic and other support groups, and looking for various family financial resources related to treatment, both formal and non-formal institutions such as those provided by the government with the use of BPJS and thalassemic foundations.

For the management of hospitals

It is expected to increase the role of nurses as educators and consultants who are directly faced with every parent who has children with thalassemic by socialising the importance of meeting the needs of parents of children with thalassemic major as an intervention in implement appropriate nursing care so parents can provide caring for their children with thalassemic optimally.

For Further Researchers

Future research is needed to examine other factors in each domain of parents' needs such as marital status, family form, coping, age of the child, and conduct further research by comparing differences in needs between fathers and mothers of school-aged children with thalassemic in helping meet their needs to improve the quality of services, especially pediatric nursing.

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