

STRESS AND QUALITY OF LIFE AMONG MOTHERS WITH THALASSEMIC CHILDREN IN MALAYSIA

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ABSTRACT

Mothers of Thalassaemic children are often confronted with stressful life associated with the illness of the child as well as other related stressors. Consequently, these mothers' quality of life is impacted. This is a cross-sectional study involving 372 mothers who have children with Thalassaemia that undergo routine blood transfusions every month from ten government hospitals in Malaysia. Data collection consisted of face-to-face interviews using the Parental Stress Scale and SF 12v2. Medical Research Ethics Committee (MREC) ethical approval was obtained prior to conduct this study. Results indicated that the working mothers have a good quality of life compared to those who are not working. However, there are no differences in stress among mothers who are working and not working. Results also showed a significantly negative direction in the relationship between quality of life and stress ($r = -0.269$, $p < 0.001$). In summary, the findings from our study highlight the importance of coping strategies and the role of the healthcare team to develop intervention programs for decreasing stress levels and promoting better quality of life for mothers of Thalassaemic children. In addition, issues and challenges faced by primary caregivers of Thalassaemic children in Malaysia should be addressed.

Keywords: mothers of Thalassaemic children, stress, quality of life, chronic illness, Thalassaemia.

INTRODUCTION

Generally, mothers of Thalassaemic children are often confronted with a stressful life and are exposed to exaggerated worries associated with the illness of the child, as well as to other related stressors (Widayanti, 2011; Ali, Sabih, Jehan, Anwar & Javed, 2012; Baiee, Ameer, Hadi, Kamel & Alaa, 2015). Stress is usually faced by mothers who have children with chronic genetic disorders, especially when the child has to undergo blood transfusion at least once a month depending on the severity of the disease as a regime treatment for the entire life. Consequently, these mothers' quality of life is impacted by long-term diseases of childhood, especially with younger children who are dependent on their mother as the main caregiver.

Furthermore, as the child's condition worsens, there is a greater risk of infection, and lower antibody makes him vulnerable to other diseases. Correspondingly, this will affect the mother's ability to take care of the other children, and with all the household chores to do, their primary function as either a full-time housewife or as a worker affects their quality of life, including their physical and mental functioning. Hence, mothers are highly affected by the burden of this type of chronic genetic disease in our country. Moreover, the total number of Malaysia's population with Thalassaemia is high. According to the Malaysian Thalassaemia Registry, there are a total of 4,768 Thalassaemia patients registered as at August 2009. From that number, 3,310 patients are transfusion dependent β Thalassaemia Major who need blood transfusion regularly (Management of Transfusion Dependent Thalassaemia, Ministry of Health, 2009).

Previous research on children with Thalassemia have found that they have a psychosocial problem such as lower self-esteem, social isolation, depression, financial issues, psychiatric disorder, limitation of physical activity, behavioural and school performance problems, factors of maturation and common complications (Wahab, Naznin, Nora, Suzanah, Zulaiho, Faszrul & Kamaruzaman, 2011; Yaman, Isik, Yarali, Karademir, Cetinkaya, Bay, Ozkasap, Kara & Tunc, 2013; Koutelekos & Haliasos, 2013; Nasiri, Hosseini & Shahmohammadi, 2014; Khamoushi, Ahmadi, Karami-Matin, Ahmadi-Jouybari, Mirzaei-Alavijeh, Atae & Mahboubi, 2015).

Nowadays, most research on Thalassemia highlights the quality of life amongst patients, especially in countries that have a higher prevalence of these genetic blood disorder diseases (Torcharus & Pankaew, 2011; Caocci, Efficace, Ciotti, Roncarolo, Vacca, Piras, Littera, Dawood Markous, Collins, Ciceri, Mandelli, Marktel & La Nasa, 2012; Kaheni, Yaghobian, Sharefzadah, Vahidi, Ghorbani & Abderahemi, 2013; Ansari, Baghersalimi, Azarkeivan, Nojomi & Hassanzadeh Rad, 2014; Boonchooduang, Louthrenoo, Choeyprasert & Charoenkwan, 2015; Ishfaq, Shabbir, Naeem & Hussain, 2015; Dhirar, Khandekar, Bachani & Mahto, 2016). In line with this, some research have been carried out in Malaysia which focus on the quality of life amongst patients of Thalassemia or on the Thalassemia disease itself (Mary Anne Tan, Lee, Wee, Tan, Mahali, George & Chua, 2010; Wahab et al., 2011; Wong, George, & Tan, 2011; Ismail, Chun, Yusof, Shahar, Abdul Manaf, Rajikan, Latif, Ibrahim & Jamal, 2013).

However, there is a study conducted by Wahab et al. (2011) and Ismail et al. (2013) on the family of children with Thalassemia in Malaysia that shed some light on the perception from families and patients about the beliefs and feelings about Thalassemia, as well as the health outcomes impacted by this genetic disease. There only a few studies were conducted on the quality of life amongst caregivers of paediatric patients with chronic diseases and little research was done amongst mothers, parents and caregivers of Thalassemic children (Pruthi & Singh, 2010; Majid & Abidi, 2013; Anum & Dasti, 2016).

Recently, researchers have placed more focus on stress, caregiver burden, as well as psychological impact amongst parents, caregivers and mothers of Thalassemic children (Pruthi & Singh, 2010; Widayanti, 2011; Aziz, Sadaf & Kanwal, 2012; Rajput, Nadeem & Kumar, 2015). Furthermore, a few studies using qualitative research methods have been conducted on the burden of caregiving, particularly amongst mothers who take care of children with Thalassemia (Sapountzi-Krepia, Roupa, Gourni, Mastorakou, Vojiatzi, Kouyioumtzi & Van Shell, 2006; Prasomsuk, Jetsrisuparp & Silcox, 2006; Prasomsuk, Jetsrisuparp & Ratanasiri, 2007; Liem, Gilgour, Pelligra, Mason & Thompson, 2011; Widayanti, 2011; Ishfaq, Bhatti & Naeem, 2014).

Several previous studies have been conducted on stress amongst parents with children suffering from various disabilities, and findings conclude that parents with children suffering from Down Syndrome are more stressed than parents with autism children (Sabih & Sajid, 2008) especially with children at a young age wherein mothers as the primary caregiver are more likely to be stressed (Norizan & Samsuddin, 2010; Al-Qaisy, 2012) and mothers of girls with intellectual disabilities is more stress in gender differences (John, 2012). However, mothers with children suffering from chronic illnesses such as leukaemia, cancer and Thalassemia are more likely to have psychological symptoms because their children need to go through lab examinations for diagnosis, lifelong treatment, high risk of relapse and cause of death (Saifan, Masa'Deh, Hall & Collier, 2014; Zaheer, Wazir, Hameed, Zeeshan, Zaman & Iqbal, 2015). Besides that, the lifelong treatment of Thalassemia patient will cause the frequently of hospitalization especially when they have other health complications. This hospitalization often contributes the psychological impact on their parents because they always thinking about their child disease condition and may be unable to cope due to limited access to get support and accurate information.

In addition, study on the psychological well-being among parents with Thalassemia children stated that the psychological and emotional health among parents was affected because of caregiving responsibilities during the treatment process. Besides that, they feel worried, uncertainty about their child's health status in the future and also financial issues arise during the lifelong treatment (Anum & Dasti, 2016). Furthermore, mothers showed the symptoms of anxiety and depression compared to the father who has children with a blood disease. Based on the results of the previous findings showed that mother more involved in the feeling and also the care of their sick children. Therefore, mothers need more emotional and psychological support compared fathers because mothers play a more active role in the caregiving process (Ashrafzadeh, Adineh, Baraz & Darvishi, 2016). Moreover, the level of quality of life among the female caregiver is lower than male caregiver because of their involvement in the physical and psychological problem of children with hemophilia (Motaharian, Rad, Ziaee & Zade, 2015) and have a higher rates of psychiatric problem compare to male caregivers of children with Thalassemia and haemophilia (Javed & Muazzam, 2013).

Many of studies related to parents' or mothers' of children with the blood disease especially Thalassemia that experiences the stress and quality of life were conducted in Mediterranean countries, the Middle East and the Indian subcontinent. Therefore, the findings of these studies are not relevant to a culturally diverse country such as Malaysia and may not reflect the true picture in our country. Furthermore, the scenarios about the stress and quality of life among mother of Thalassemic children in Malaysia were scarce.

Although there is evidence of research on the stress and quality of life of people with Thalassemia, research that is specifically focused on caregivers, especially amongst mothers of Thalassemic children, is limited. Accordingly to the data of patient Thalassemia in Malaysia, it's indicated that the number of Thalassemia patients is increasing every year. Furthermore, based on the past literature, a limited number of studies in this area particularly in Malaysia and there has no study has been carried out in the population of Malaysia. Therefore, this study is carried out to fill the gaps in the literature and to contribute to it. This study will focus on the stress and quality of life among mothers and the aim of this study is to identify the mother's demographic background, to explain the differentiate between stress and quality of life in job status and to examine the relationship between stress and quality of life amongst mothers of Thalassemic children in Malaysia.

METHODOLOGY

This is a cross-sectional study involving 372 mothers of Thalassemic children that undergo routine blood transfusions every month from ten government hospitals in Malaysia. Data collection consisted of face-to-face interviews using the established and reliable instruments namely Parental Stress Scale (Berry & Jones, 1995) and SF 12v2 (Ware, Kosinski & Keller, 1996). Medical Research Ethics Committee (MREC) ethical approval was obtained prior to conduct this study. Descriptive statistics and bivariate analysis were used to analyse data gathered from a sample of mothers that recruited based on inclusion criteria i) have children undergo the routine blood transfusion in hospital and iron chelating therapy, ii) children below 17 years old and iii) fluent speaking and writing in Malay or English language. Written informed consent was obtained from all participants.

PARENTAL STRESS SCALE

Parental Stress Scale (Berry & Jones, 1995) was being measured to assess the stress among mothers of Thalassemic children in the present study. The PSS consists of 18 items that assess and measure the stress level among mothers that have children with chronic illness or disable children. This includes 8 positive items and 10 negative items and it is widely used in measuring stress among parents. An example of a positive item is 'I enjoy spending time with my children' and the negative item is 'The behaviour of my children is often embarrassing or stressful to me.' The selection of this instrument is that it can be applied to the respondents, concise and easily understood by respondents and it is appropriate to focus on the stress experienced by parents who play a role in protecting and educating their children (Lessenberry & Rehfeldt, 2004). Reliability analysis showed that the Cronbach Alpha value is higher 0.78 and previous research in Malaysia also uses this instrument to study the level of stress among mothers who take care of children with intellectual disabilities (Norizan & Samsuddin, 2010).

QUALITY OF LIFE

HRQOL among mothers of Thalassemic children was assessed using the Medical Outcomes Study Short-Form Health Survey version 2 (SF-12v2) (Ware. et al. 1996). The SF-12v2 is a generic HRQOL which consists of 12-items to measure the quality of life among mothers who have children suffering from Thalassemia. Similar to an instrument (SF-36), the SF-12v2 provides scores for eight health concept subscales (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health), as well as summary scores for physical and mental health status. The Physical Component Summary (PCS) scale includes physical functioning, role physical, bodily pain and general health subscales, whereas the Mental Component Summary (MCS) scale includes vitality, social functioning, role emotional and mental health subscales. Higher scores indicate better health. License for using the SF12v2 in the current study was acquired from QualityMetric Incorporated (AMD-QM019953, December 2012).

This instrument using a Likert scale where a score is analyzed and calculated from the value of 0 (lowest score) to 100 (highest) based on the manual by Ware, Kosinski, Turner-Bowker & Gandek (2002). The results of the analysis have a value of 0 indicates that poor health status and value of 100 indicates excellent health status for the mother. This indicates the highest score a benchmark that better health. In present study, respondent rate the items using as 5 point Likert type scale (1 = none of the time; 5 = all of the time). Several items are reversed scored. Scoring follows a series of formulas using a norm-based method and calibration in which scores range from 0 – 100 with a mean of 50 and standard deviation of 10. Higher scores represent better functioning (Holt, Wang, Caplan, Schulz, Blake & Southward, 2011). This instrument has been tested and used extensively not

only in this country but in other countries and the level of reliability in Cronbach Alpha is 0.70 and have the legitimacy to measure an item of the quality of life among mothers.

RESULTS & DISCUSSION

Results in Table 1 below indicate that a majority of mothers (43.3%) are aged between 31-40 years (mean = 39.21, sd = 7.188). They are mostly Malays (78.5%) and Muslims (81.2%). In Malaysia, Thalassemia disease occurs mainly amongst the Malay and Chinese population. This data demonstrates that Malays contribute mostly to the outcome of this study because the ethnic population of Malaysia consists of Malays (54.3%) followed by Chinese and Indians (25% and 7.5%, respectively), and other indigenous groups account for 13.2% (Department of Statistic Malaysia, 2010).

Table 1: Demographic background mothers and child

| Demographic background | N | % |
|---|----------|----------|
| Race | | |
| Malay | 292 | 78.5 |
| Chinese | 37 | 9.9 |
| Indian | 3 | 0.8 |
| Bumiputera Sabah & Sarawak | 40 | 10.8 |
| Religion | | |
| Islam | 302 | 81.2 |
| Buddha | 33 | 8.9 |
| Hindu | 3 | 0.8 |
| Christian | 34 | 9.1 |
| Level of education | | |
| No formal education | 9 | 2.4 |
| Primary school | 42 | 11.3 |
| Secondary school | 233 | 62.6 |
| Higher education | 88 | 23.7 |
| Job status | | |
| Working | 171 | 46.0 |
| Not working | 201 | 54.0 |
| Age of child | | |
| 0 – 6 years old | 79 | 21.2 |
| 7 – 12 years old | 170 | 45.7 |
| 13 – 17 years old | 123 | 33.1 |
| Total number of Thalassemia children in family | | |
| One | 238 | 64.0 |
| Two | 107 | 28.8 |
| More than 2 child | 27 | 7.3 |

The data also shows that majority mothers in the current study have a secondary school background (62.6%) and 54.0% are not working. Mostly they are not working due to responsibilities in taking care of their ill child. Table 1 above also demonstrates that the age of the children who participated is between 7 – 12 years (45.7%). Besides that, results indicate that the majority of mothers in this study have only one child with Thalassemia (64.0%), and based on the previous study (Ismail et.al, 2013), 69% of respondents also have only one child with Thalassemia. The present study is consistent with finding by Ishfaq et. al. (2015) in Pakistan that majority parents (69.6%) have only one child with Thalassemia in their family.

In addition, data reveals that mothers having Thalassaemic children in the family are not working (54.0%), as they are the main caregivers for the Thalassaemic child in the hospital. Furthermore, they are spending more time with their children, either at the hospital during the blood transfusion treatment or during follow-ups at the paediatric clinic, due to the cultural belief that mothers are more attached to their own children. This result is similar to previous studies on the quality of life of Thalassaemia children and their caregivers in HKL and UKMCMC which reveal that the majority of mothers (63%) are involved in the caregiving of their sick children (Ismail et al., 2013). Besides that, mothers reported that they have received the emotional support from husband (33.5%), families (22.9%), parents (21.9%) and friends (11.2%). In the present study, all participants take their child to the government hospital for blood transfusion or others treatment. This demographic data indicated that mostly mothers in present study were attending secondary school (62.6%) and only 2.4% have no formal education.

Below Table 2 and Table 3 demonstrated the differences between stress and quality of life in job status among mothers with Thalassaemic children to answer the second of research objective of this study.

Table 2: Means and standard deviations of mothers' stress with job status

| Job Status | Stress | | | |
|-------------|--------|------|---------|-------|
| | m | sd | t | p |
| Working | 1.79 | 0.49 | - 0.305 | 0.760 |
| Not working | 1.80 | 0.48 | | |

* $p < 0.05$, $n = 372$

Results in Table 2 above revealed that there have no significant differences ($t = - 0.305$, $p < 0.05$) between job status (working and not working) with stress among mothers of Thalassaemic children. This outcome was contradicted with finding from the study done by Rubira, Marcon, Belasco, Gaiva & Espinosa (2012) among mothers who have children with cancer. Mothers who are not working facing the psychological burden that contribute to stressful in their life because of the lower of economic resources for the treatment expenses purposes. In addition, the comparative study among parents of children with Thalassaemia and normal children revealed that the parents of Thalassaemic children experienced higher degrees of distress compared to another group due to the multiple problems especially the financial issues as the main problem among them (Ali & Sabih, 2012).

The current study also contrasts with previous findings among parents with Thalassaemia children in Iran. Majority of them are missed days of work because of the commitment to accompany their children in routine treatment procedure especially blood transfusion in once a month (Sattari, Sheykhi, Nikanfar, Pourfeizi, Nazari, Dolatkah & Mashayekhi, 2012). Besides that, mothers with disabilities child also reported they had a lack of income that contributes to the financial burden on their families (Geok, Abdullah & Kee, 2013). These findings contradicted with the present study because all the treatment was covered by government especially for the children in primary and secondary school and they have the letter from the school. This outcome may be a difference with other research because of the disparity of health policy from their government in different countries. Therefore, the expenses including in medical aspect or non-medical such as transportation and accommodation will contribute to financial strain especially among countries that have difficulties in accessing the government support.

However, Table 3 below indicate that there are significant differences between job status and quality of life among mothers of Thalassaemic children ($t = 2.316$, $p = 0.021$). Data confirmed that mean value for the quality of life among mothers who are working is higher 75.27 ± 14.83 compared with mothers who are not working 71.56 ± 15.86 in statistically. This finding was related to research on working mothers who have involved in caregiving their child with cancer. Most of them have a good quality of life because they have a support system to help them improves their health outcomes includes the mental and physical health (Rubira et. al., 2012). On the contrary, evidence from the existing literature on quality of life among caregivers of patients suffering from Thalassaemia major showed that they experience the psychological distress that affects their emotional health

because they have faced much concern of psychological and social adjustment of their sick children includes the financial problems and unable to afford the costly treatment (Majid & Abidi, 2013, Ishfaq et.al., 2015).

Table 3: Means and standard deviations of mothers’ quality of life with job status

| Quality of Life | | | | |
|-----------------|-------|-------|-------|--------|
| Job Status | m | sd | t | p |
| Working | 75.27 | 14.83 | 2.316 | 0.021* |
| Not working | 71.56 | 15.86 | | |

* p < 0.05, n = 372

Table 4: Results of correlation between stress and quality of life

| Correlation | | | | |
|-----------------|-------|-------|-----------|---------|
| | m | sd | r | p |
| Stress | 1.80 | 0.48 | - 0.269** | 0.001** |
| Quality of Life | 73.26 | 15.48 | | |

** p < 0.001, n = 372

Results in Table 4 above reveal that there is a significantly negative correlation between quality of life and mother’s stress (r = - 0.269, p < 0.001). The negative correlations between stress and the quality of life indicated that mothers who have higher levels of stress experience lower levels of quality of life. This finding showed that stress is associated with quality of life based on the research objective. In line with this, current results supported by research by Skok (2006) reveal that stress and entire psychological symptoms affect health outcomes, including the quality of life and wellbeing. Contradictly, Feeley, Turner-Henson, Christian, Avis, Heaton, Lozano & Su (2014) found that the greater of stress level is influence more on sleep quality than overall quality of life among mothers with bronchopulmonary dysplasia.

The present study also consistent with the previous study that showed the negative correlation between caregiver burden and the psychological well-being among parents with Thalassaemic children in Pakistan (Anum & Dasti, 2016). It revealed that higher level of caregiver burden will decrease the psychological well-being. Similarly with the present study, a higher level of stress will contribute the poor of the quality of life among mothers with Thalassaemic children. In addition, poor quality of life was related with higher in psychological burden among caregivers of Thalassaemic children compared with children with cerebral palsy in a study conducted in India (Pruthi & Singh, 2010).

As we know, raising a child involves resources but the demand is higher and often increased when caring for a child with a chronic illness, especially Thalassemia, which requires regular lifelong treatment. This will include financial strain, monitoring the drug or medical equipment for their daily medicine intake at home, accompanying them, especially for young children to get blood transfusion treatment for at least once a month depending on the severity of the disease. Besides that, this frequency of psychological distress will lead to mothers stress, especially for the mothers with young children (Majid & Abidi, 2013). Hence, the more dependent the child with the chronic illness is, the greater is the mother's distress and give an impact on their quality of life.

Most mothers in the current study are Malays and their belief and thought are influenced by Islam, which is the main religion in Malaysia. This contributes to the positive attitude in dealing with acceptance of their child's illness. Acceptance will serve as a coping strategy and the emotional support that they receive will help them to increase their quality of life and reduce their stress level. This is consistent with the study by Salehi & Morovati (2016) on religious/spiritual consulting on chronic diseases and should be emphasized in the programme of care planning for patients and their families. Moreover, acceptance the current situation is one of coping approach that can be used not only for the parent of Thalassemic children but also for the family members (Dadipoor, Haghghi, Madani, Ghanbarnejad, Shojaei, Hesam & Moradabadi, 2015).

The present study proves that the quality of life is associated with stress. According to Yengil, Aiyapayam, Kokacya, Kurhan, Oktay & Ozer (2014), parents have a poor quality of life because they feel guilty about having a child with a genetic blood disorder. However, perceived social support will help them to improve their quality of life as a part of the strategies for continuous psychological balance (Sultana, Humayun, Humayun & Zafar, 2016). Indirectly related to a good quality of life, continuous social support as coping resources will help them to face the challenges of the disease and childcare associated with the many concerns on psychological and social adjustment for lifelong diseases. Mashayekhi and colleagues in 2016 investigated the caregiver burden and social support among mothers with β Thalassemia and reported the lower social support may affect their quality of life. Although the social support can be received from their family members, mothers of Thalassemic children also can practice the self-discipline in order to help them organize their life and at the same time to manage their children in term of learning time management skills (Anum & Dasti, 2016). This will help the mother either working or not to manage their discipline lifestyle and enhance the good quality of life. Indirectly, this type of coping skills will help them to develop their own capabilities and adaptation with the sick children situation.

CONCLUSIONS

In summary, the findings in present study highlight the important of good quality of life to contribute the better health outcomes and indirectly reduce the entire psychological burden as well as the level of stress experienced by mothers. Moreover, the results of this study can contribute to the development of a screening program for decreasing stress level and promoting quality of life for mothers of Thalassemic children. As the recommendation, the stress screening should be implemented in every hospital and clinics for parents of having children with Thalassemia because with the management of stress among mothers as main caretakers it can be achieved with better treatment among children with Thalassemia. The present finding also proves that besides the medical management for the children with Thalassemia, the psychological well-being of parents should also be an area of clinical attention. Therefore, counselling and psychotherapist for mothers of the patients with Thalassemia can be provided in an intervention programme. In this kind of programme, the clinicians, nurses and another healthcare team can play a role as formal support that can help in term of information and knowledge about the disease that helps mothers to more understand about the disease, the complication and medication. Indirectly, mothers can build their self-confidence and more optimistic toward their sick children.

Furthermore, the needs of social support should be emphasized and included in the intervention programs by healthcare teams in order to maintain the mother's psychological and physical health, as well as their quality of life as a whole. Besides that, the mothers should be given a chance to learn the time management skills and another coping skills in order to improve their quality of life especially their mental and physical health. However, to ensure the mothers can explore their capabilities to manage their stressor and enhance their quality of life, the need of intervention program involving their family members that can improve the coping resources among mothers with Thalassemic children.

In future studies, longitudinal analyses would be beneficial in underlining the effects of the child's illness on maternal quality of life and stress and to identify the type of social support that can be used as a coping strategy. Besides that, future researchers should be emphasizing on qualitative and quantitative studies to ensure that healthcare societies include the healthcare team involved in the intervention programs and help them to identify the ideal healthcare, not only for mothers of Thalassemic children but also for the patient.

With regard to the limitation of this study, it is to our knowledge that this is the first study that examines the quality of life and stress among mothers who have children with Thalassemia in this country. In addition, the limitation of this study that was conducted only on mothers and future studies should be designed to explore fathers' unique experiences with a larger sample and gender differences outcomes. The fact is Thalassemia is a genetic disease and patients will need lifelong treatment and the financial aspect is an important issue, especially for Thalassemia patients amongst young children. Although some of the treatment expenditure in our country is covered by the government, especially for young patients who are still in school, they still have financial burdens during hospitalization due to other health complications. Future researchers are recommended to study the correlation between financial constraint and other additional factors also could possibly affect the mother's stress and quality of life such as marital satisfaction, family resources, perceived social support, the child severity illness and mother-child relationship.

However, the results of this study can contribute to the development of a screening program for decreasing psychological burden and promoting the better quality of life for mothers of Thalassemic children. The quality of life of mothers can be affected due to raising the child, psychological burdens, and stressors during the treatment process because Thalassemic children need lifelong treatment. Therefore, future research needs to be done to identify the type of social support that can be use as coping strategies to help mothers adapt due to the child illness especially for the genetic diseases in Malaysia and it should be highlighted.

ACKNOWLEDGEMENT

The author(s) would like to thank the Director General of Health Malaysia for permission to publish this article. Author(s) also would like to thank the patients and their mothers for their participation and the Paediatrics Department from all hospital for their contribution in this study.

REFERENCES

1. Article

- Al-Qaisy, L. M. (2012). Mothers stress in families of children with mental handicap. *Asian Social Science*, Vol. 8, No. 2 : 80-85. Retrieved from <http://www.ccsenet.org/journal/index.php/ass/article/viewFile/14611/9976>. doi:10.5539/ass.v8n2p80
- Anum, J. & Dasti, R. (2016). Caregiver burden, spirituality and psychological well-being of parents having children with Thalassemia. *Journal Religion Health*, 55:941-955. Retrieved from <http://link.springer.com/article/10.1007%2Fs10943-015-0127-1>. doi:10.1007/s10843-015-0127-1
- Ansari, S., Baghersalimi, A., Azarkeivan, A., Nojomi, M. & Hassanzadeh Rad, A. (2014). Quality of life in patients with Thalassemia major. *Iranian Journal of Pediatric Hematology Oncology*. Vol. 4, No. 2. Retrieved from www.ncbi.nlm.nih.gov/pmc/articles/PMC4083201/pdf/ijpho_4_057.pdf
- Ashrafizadeh, H., Adineh, M., Baraz, S. & Darvishi, M. (2016). Depression and anxiety among parents of children with blood disease in Ahvaz, South West of Iran. *International Journal Pediatric*. Vol. 4, N. 7, Serial No. 31 : 2193-2202. Retrieved from http://ijp.mums.ac.ir/article_7047_910.html. doi : 10.22038/ijp.2016.7047
- Aziz, K., Sadaf, B., & Kanwal, S. (2012). Psychosocial problems of Pakistani parents of Thalassemia children : A cross sectional study done in Bahawalpur, Pakistan. *BioPsychoSocial Medicine*, 6:15 Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3489523/pdf/1751-0759-6-15.pdf>. doi:10.1186/1751-0759-6-15
- Baiee, H. A., Ameer, M. A., Hadi, B. A., Kamel, M. & Alaa, H. (2015). Depression among parents of children with Thalassemia in Babylon Province-Iraq during the year 2014. *Medical Journal of Babylon*. Vol. 12, No. 4: 999-1005. Retrieved from http://www.medicaljb.com/library/paper/12_4_1116.pdf.
- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial Psychometric Evidence. *Journal of Social and Personal Relationships*, 12, 463-472. Retrieved from https://www.researchgate.net/publication/249719271_The_Parental_Stress_Scale_Initial_Psychometric_Evidence. doi:10.1177/0265407595123009
- Boonchooduang, N., Louthrenoo, O., Choeyprasert, W. & Charoenkwan, P. (2015). Health-related quality of life in adolescents with Thalassemia. *Pediatric Hematology and Oncology*. 32:5, 341-348. Retrieved from <http://dx.doi.org/10.3109/08880018.2015.1033795>. doi:10.3109/08880018.2015.1033795.
- Caocci, G., Efficace, F., Ciotti, F., Roncarolo, M. G., Vacca, A., Piras, E., Littera, R., Dawood Markous, R. S., Collins, G. S., Ciceri, F., Mandelli, F., Markt, S. & La Nasa, G. (2012). Health related quality of life in Middle Eastern children with beta-Thalassemia. *BioMed Central*, 12:6. Retrieved <http://www.biomedcentral.com/1471-2326/12/6>
- Dadipoor, S., Haghghi, H., Madani, A., Ghanbarnejad, A., Shojaei, F., Hesam, A. & Moradabadi, A. S. (2015). Investigating the mental health and coping strategies of parents with major Thalassemic children in Bandar Abbas. *Journal of Education and Health Promotion*. Vol. 4 : 59. Retrieved from jehp.ney/temp/JEduHealthPromot4159-7944498_220404.pdf. doi:10.4103/2277-9531.162375.
- Dhirar, N., Khandekar, J., Bachani, D. & Mahto, D. (2016). Thalassemia Major: how do we improve quality of life?. *SpringerPlus*, 5 :1895. Retrieved from <http://link.springer.com/article/10.1186/s40064-016-3568-4>. doi : 10.1186/s40064-016-3568-4
- Feeley, C. A., Turner-Henson, A., Christian, B. J., Avis, K. T., Heaton, K., Lozano, D. & Su, X. (2014). Sleep quality, stress, caregiver burden and quality of life in maternal caregivers of young children with Bronchopulmonary Dysplasia. *Journal Pediatric Nursing*, 29 (1):29-38. Retrieved from www.ncbi.nlm.nih.gov/pmc/articles/PMC4056670/pdf/nihms582011.pdf. doi:10.1016/j.pedn.2013.08.001
- Geok, K. C., Abdullah, K. L. & Kee, L. H. (2013). Quality of life among Malaysian mothers with a child with Down syndrome. *International Journal of Nursing Practice*, 19:381-389. Retrieved from http://umexpert.um.edu.my/file/publication/00004843_101367.pdf. doi:10.1111/ijn.12083.
- Hamidah, A, Arini, M. I., Zarina, A. L., Zulkifli, S. Z., & Jamal, R. (2008). Growth velocity in transfusion dependent prepubertal Thalassemia patients: Results from a Thalassemia center in Malaysia. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 39(5), 900-5. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19058587>
- Holt, C. L., Wang, M. Q., Caplan, L., Schulz, E., Blake, V., & Southward, V. L. (2011). Role of religious involvement and spirituality in functioning among African Americans with cancer: Testing a mediational model. *Journal of Behavioral Medicine*, 34(6), 437-48. Retrieved from <http://link.springer.com/article/10.1007/s10865-010-9310-8>. doi:10.1007/s10865-010-9310-8
- Ishfaq, K., Shabbir, M., Naeem, S. & Hussain, S. (2015). Impact of Thalassemia major on patients; families in South Punjab, Pakistan. *The Professional Medical Journal*. 2015; 22 (5) : 582-589. Retrieved from <http://eds.b.ebscohost.com/eds/pdfviewer/pdfviewer?sid=2dbfd296-2a39-4daf-a47bb0efdde4a4a8%40sessionmgr103&vid=2&hid=127>
- Ismail, M, Chun, C.Y., Yusof, N. A. M, Shahar, S., Abdul Manaf, Z., Rajikan, R., Latif, Z. A., Ibrahim, H. M. & Jamal, A. R. (2013). Quality of life among Thalassaemia children, adolescent and their caregivers. *Sains Malaysiana*, 42 (3) : 373-380. Retrieved from http://www.ukm.my/jsm/pdf_files/SM-PDF-42-3-2013/14%20Munirah%20Ismail.pdf.
- John, A. (2012). Stress among mothers of children with intellectual disabilities in urban India : Role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2011.00672.x/pdf> . doi : 10.1111/j.1468-3148.2011.00672.x.

- Kaheni, S., Yaghoobian, M., Sharefzadah, G. H., Vahidi, A., Ghorbani, H. & Abderahemi, A. (2013). Quality of life in children with β -Thalassemia major at center for special diseases. *Iranian Journal of Pediatric Hematology Oncology*. Vol. 3, No. 3. Retrieved from www.ncbi.nlm.nih.gov/pmc/articles/PMC3921875/pdf/ijpho_3_108.pdf.
- Khamoushi, F., Ahmadi, S. M., Karami-Matin, B., Ahmadi-Jouybari, T., Mirzaei-Alavijeh, M., Ataee, M. & Mahboubi, M. (2015). Prevalence and socio-demographic characteristics related to stress, anxiety and depression among patients with major Thalassemia in the Kermanshah country. *Journal of Biology and Today's World*. 2015, March; 4 (3):79-84. Retrieved from http://sdh.yums.ac.ir/uploads/Prevalence_and_Socio-Demographic_20731.pdf. doi:10.15412?j.JBTW.01040304.
- Koutelekos, J. & Haliasos, N. (2013). Depression and Thalassemia in children, adolescents and adults. *Health Science Journal*. Volume 7 (2013), Issue 3. Retrieved from <http://www.hsj.gr/medicine/depression-and-thalassemia-in-children-adolescents-and-adults.pdf>.
- Lessenberry, B. & Rehfeldt, R. (2004). Evaluating stress levels of parents of children with disabilities. *Council for Exceptional Children*, 70 (2), 231-244. Retrieved from <http://www.questia.com/library/journal/IGI-112792600/evaluating-stress-levels-of-parents-of-children-with>. doi: 10.1177/001440290407000207
- Liem, R. I., Gilgour, B., Pelligra, S. A., Mason, M. & Thompson, A. A. (2011). The impact of Thalassemia on Southeast Asian and Asian Indian families in the United States: A qualitative study. *Ethnicity & Disease*. Volume 21, Summer 2011. Retrieved from <http://www.ishib.org/ED/journal/21-3/ethn-21-03-361.pdf>
- Majid, A. & Abidi, M. (2013). Quality of life and coping styles of caregivers of patient suffering from Thalassemia Major. *International Journal Medicine Pharmacy*. Volume 3 (10). Retrieved from www.scopemed.org/fulltextpdf.php?mno=40853
- Mary Anne Tan, J. A., Lee, P.C., Wee, Y. C., Tan, K.L., Mahali, N. F., George, E. & Chua, K.H. (2010). High prevalence of alpha- and beta-Thalassemia in the Kadazandusuns in East Malaysia: Challenges in providing effective health care for an indigenous group. *Journal of Biomedicine & Biotechnology*, 2010. Retrieved from <https://www.hindawi.com/journals/bmri/2010/706872/>. doi:10.1155/2010/706872
- Mashayekhi, F., Jozdani, R. H., Chamak, M. N. & Mehni, S. (2016). Caregiver burden and social support in mothers with β Thalassemia children. *Global Journal of Health Sciences*. Volume 8, No. 12 : 206-212. Retrieved from <http://www.ccsenet.org/journal/index.php/gjhs/article/view/57841/31909>. doi : 10.5539/gjhs.v8n12p206.
- Motaharian, E., Rad, A. R. M., Ziaee, M. & Zade, N. H. (2015). Investigating the relationship between coping strategies and quality of life among the principal caregivers of children with hemophilia. *Modern Care Journal*. Volume 12 (Issue 2) : 68-73. Retrieved from <http://en.journals.sid.ir/ViewPaper.aspx?ID=469041>.
- Muazzam, A. & Javed, S. (2013). Predictors of caregiver's burden : interplay of physical and emotional health and perceived hope in children with Thalassemia and Hemophilia. *Pakistan Journal of Social and Clinical Psychology*, Volume 11, No. 2 : 36-42. Retrieved from <http://www.gcu.edu.pk/FullTextJour/PJSCS/2013b/6.aminamuazzam.pdf>
- Nasiri, M., Hosseini, S. H. & Shahmohammadi, S. (2014). Mental health status in patients with Thalassemia major in Iran. *Journal of Pediatrics Review*. 1014;2(1):55-61. Retrieved from <http://jpr.mazums.ac.ir/article-1-56-en.pdf>. doi:10.7508/JPR-V2-N1-55-61
- Norizan, A. & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down Syndrome. *Journal of Intellectual Disability Research*, Vol. 54, Part 11, pp 992-1003. doi : 10.1111/j.1365-2788.2010.01324.x
- Prasomsuk, A., Jetsrisuparp, A. & Silcox, J. (2006). Problem of caring for Thalassemia children in Thailand : A study of mother's experiences in Udornthani Province. *Thai Journal of Nursing Research*. Vol, 10, No. 2. Retrieved from http://www.tnc.or.th/files/2011/05/tnc_journal-621/thai_journal_of_nursing_research_vol_10_no_2_april_11028.pdf.
- Prasomsuk, S., Jetsrisuparp, A., Ratanasiri, T., & Ratanasiri, A. (2007). Lived experiences of mothers caring for children with Thalassemia major in Thailand. *JSPN*, 12(1). Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/j.1744-6155.2007.00085.xlpdf>
- Rajput, A. H., Nadeem, F. & Kumar, V. (2015). Depression, anxiety and stress among primary caregivers of Thalassemia patients in Hyderabad. *Journal of Pakistan Psychiatric Society*. Oct-Dec2015, Vol. 12 Issue 4, 36-39. Retrieved from <http://www.jpss.com.pk/article/1466661110490.pdf>.
- Rubira, E. A., Marcon, S. R., Belasco, A. G. S., Gaiva, M. A. M. & Espinosa, M. M. (2012). Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer. *Acta Paul Enferm*, 25 (4): 567-573. Retrieved from www.scielo.br/pdf/ape/v25n4/en_aop1712.pdf.
- Sabih, F. & Sajid, W. B. (2008). The is significant stress among parents having children with autism. *Rawal Medical Journal*. RMJ. 2008; 33(2): 214-216. Retrieved from <http://www.scopemed.org/fulltextpdf.php?mno=7753>
- Saifan, A., Masa'Deh, R., Hall, C. & Collier, J. (2014). Experiences of Jordanian mothers and fathers of children with cancer. *Journal of American Science*, 10 (8) : 29-39. Retrieved from https://ueaeprints.uea.ac.uk/51607/1/Experiences_of_mothers_and_fathers_of_children_with_cancer_in_Jordan.pdf
- Salehi, S. & Morovati, S. (2016). Coping behaviors in families with children suffering from Thalassemia major and evaluating the implementation effect of nursing intervention on these behaviors. *International Journal of Medical Research & Health Sciences*, 5, 2 : 58-63. Retrieved from file:///C:/Users/J39PF2JB/Downloads/IJMRHS-2016-5-5-58-63.pdf.
- Sapountzi-Krepia, D., Roupa, Z., Gourni, M., Mastorakou, F., Vojiatzi, E., Kouyioumtzi, A., & Van Shell, S. (2006). A qualitative study on the experiences of mothers caring for their children with Thalassemia in Athens, Greece. *Journal of Pediatric Nursing*, 21(2), 142-52. Retrieved from http://ac.els-cdn.com/S0882596305002587/1-s2.0-S0882596305002587-main.pdf?_tid=30718498-7327-11e6-b272-00000a0b0f02&acdnat=1473052463_a74dacba57093555be1b352928d56fbd. doi:10.1016/j.pedn.2005.06.017
- Sattari, M., Sheykhi, D., Nikanfar, A., Pourfeizi, A. H., Nazari, M., Dolatkah, R. & Mashayekhi, S. (2012). The financial and social impact of Thalassemia and its treatment in Iran. *Pharmaceutical Sciences*. 18 (3), 171-176. Retrieved from <http://journals.tbmed.ac.ir/PHARM/Manuscript/PHARM-18-171.pdf>.

- Skok, A, Harvey, D. & Reddihough, D. (2006). Perceived stress, perceived social support and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability*, 31(1):53-57. Retrieved from <http://www.pubfacts.com/fulltext/16766323/Perceived-stress-perceived-social-support-and-wellbeing-among-mothers-of-school-aged-children-with-cerebral-palsy>. DOI:10.1080/13668250600561929
- Sultana, R., Humayun, S., Humayun, S. & Zafar, U. (2016). Psychosocial problems in parents of Thalassemia children. *Journal Social Obstetric & Gynaecology Pakistan*. Vol. 6, No. 2. : 63-67. Retrieved from <http://jsogp.net/Volumes/Volume6-2/Psychosocial%20Problems%20in%20Parents%20of%20Thalassaemia%20Children-Online.pdf>
- Torcharus, K. & Pankaew, T. (2011). Health-related quality of life in Thalassemia treated with iron chelation. *Royal Thai Army Medical Journal*. Vol. 64, Vol. 2, January-March 2011. Retrieved from http://www.rtaimedj.pmk.ac.th/vol_64/64_1_4.pdf.
- Wahab, I. A., Naznin, M., Nora, M. Z., Suzanah, A R., Zulaiho, M., Faszrul, R. A., & Kamaruzaman, W. S. (2011). Thalassaemia: A study on the perception of patients and family members. *The Medical Journal of Malaysia*, 66(4), 326–34. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22299552>
- Ware, J. E., Kosinski, M., & Keller, S. D. (1996). *A 12-item short-form health survey of scales and preliminary construction tests of reliability and validity*. Lippincott William & Wilkins, 34(3), 2–9.
- Ware, J.E., Jr., Kosinski, M., Turner-Bowker, D.M. & Gandek, B. (2002). *How to score version 2 of the SF-12v2® Health Survey (With a Supplement Documenting SF-12® Health Survey)* Lincoln, RI: QualityMetric Incorporated.
- Widayanti, C. G. (2011). The perceived role of god in health and illness : The experience of javanese mothers caring for a children with Thalassemia. *Jurnal Psikologi Undip* Vol. 9, No.1, April 2011. Retrieved from <http://ejournal.undip.ac.id/index.php/psikologi/article/view/2903/2586>
- Wong, L. P., George, E., & Tan, J.A. M. A. (2011). Public perceptions and attitudes toward thalassaemia: Influencing factors in a multi-racial population. *BMC Public Health*, 11(1), 193. Retrieved from <http://bmcpubhealth.biomedcentral.com/articles/10.1186/1471-2458-11-193>. doi:10.1186/1471-2458-11-193.
- Yaman, A., Isik, P., Yarali, N., Karademir, S., Cetinkaya, S., Bay, A., Ozkasap, S., Kara, A. & Tunc, B. (2013). Common complications in beta-Thalassemia patients. *International Journal of Hematology and Oncology*. Number : 3, Volume : 3, Year : 2013. Retrieved from http://www.uhod.org/pdf/PDF_573.pdf. doi: 10.4999/uhod.12005
- Yengil, E., Aiyapayam, C., Kokacya, M. H., Kurhan, F., Oktay, G. & Ozer, C. (2014). Anxiety, depression and quality of life in patients with beta Thalassemia major and their caregivers. *International Journal of Clinical and Experimental Medicine*. 2014; 7(8):2165-2172. Retrieved from <http://www.researchgate.net/publication/265792808>.
- Zaheer, Z, Wazir, S, Hameed, B, Zeeshan, S, Zaman, Q. & Iqbal, M. (2015). Psychological burden in β-Thalassemia affected families. *Journal Postgraduates Medical Institution*. 2015; 29 (4):260-3. Retrieved from <file:///C:/Users/user/Downloads/1750-4930-1-PB.pdf>

2. Conference proceeding

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- Ali, S., Sabih, F., Jehan, S., Anwar, M., & Javed, S. (2012). Psychological distress and coping strategies among parents of Beta-Thalassemia major patients. Papers presented at *International Conference on Clean and Green Energy IPCBEE*, 27, 124–128. Retrieved from <http://tfp.org.pk/wp-content/uploads/2016/07/ali-psychological-distress-2012-1.pdf>
- Ishfaq, K., Bhatti, R. & Naem, S. (2014). Mothers' awareness and experiences of having a Thalassemia child : A qualitative approach. Papers presented at Proceeding of SOCIOINT 14 - *International Conference on Social Sciences and Humanities*. 8-10 September 2014, Istanbul, Turkey, 660-669. Retrieved from http://www.ocerint.org/Socioint14_ebook/paprrs/443.pdf.
- Pruthi, G. K., & Singh, T. B. (2010). Psychosocial burden and quality of life in parents of children with Thalassemia and cerebral palsy: A comparative study. Papers presented at *National Annual Conference of Indian Association of Clinical Psychologist, Hyderabad, 2009* Delhi Psychologist, 2(1), 10–17. Retrieved from <http://www.delhipsychologist.com/current-issue/delhi-psychologist--july-2010/psychosocial-burden-and-quatlity-of-life-in-parents-of-children-with-thalassemia-and-cerebral-palsy-a-comparative-study>.

3. Report/Guidelines

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-
- Department of Statistic Malaysia. *Monthly Statistical Bulletin Malaysia August 2010: Population and vital statistics*. Retrieved from <http://www.statistics.gov.my/portal/index>
- Management of transfusion dependent Thalassemia: Clinical practice guidelines MOHE*. (2009). MOH/PAK/195.09(GU). Retrieved 6/7/2011 from <http://www.moh.gov.my/attachments/4656>