MEDIATING ROLE OF PERCEIVED SOCIAL SUPPORT ON THE RELATIONSHIP BETWEEN STRESS AND QUALITY OF LIFE AMONG MOTHERS WITH THALASSEMIA CHILDREN IN MALAYSIA

Hazlina M.M.1, Rumaya J.2*, Siti Nor Y.2

1Department of Human Development and Family Studies, Faculty of Human Ecology, University Putra Malaysia.
2Family, Adolescent and Child Research Centre of Excellence (FACE), Faculty of Human Ecology, University Putra Malaysia.

*Corresponding author: Assoc. Prof. Dr. Rumaya Juhari, Family, Adolescent and Child Research Centre of Excellence (FACE), Faculty of Human Ecology, University Putra Malaysia, Serdang, Selangor; Email: rumaya@upm.edu.my

ABSTRACT

Background: Mothers of Thalassemia 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. Past studies have shown that perceived social support is a part of coping strategies that can help mothers to cope with their stressful life and increase their health status.

Materials and Methods: This is a cross-sectional study involving 372 mothers whose children suffer from Thalassemia with routine monthly blood transfusions treatment from ten government hospitals in Malaysia. Data collection consisted of face-to-face interviews using Parental Stress Scale, Multidimensional Scale of Perceived Social Support and SF 12v2 measuring the respective variables. Medical Research Ethics Committee (MREC) ethical approval was obtained prior to conduct this study.

Result: Findings indicated significant negative direction in relationships between stress and social support and between stress and quality of life. Besides that, the relationship between social support and quality of life showed significant positive direction. Results also showed that when controlling for the mediating variable, stress has the strongest significant influence on quality of life (β = - 8.292, p < 0.001) and confirmed that social support is significantly mediating that relationship.

Conclusion: In sum, the findings from our study highlight the importance of social support perceived by mothers in buffering the effect of stress on their quality of life. It should be of concern of many on the issues and challenges that are faced by mothers of Thalassemia children as the primary caregiver.

Keywords: mother, stress, social support, quality of life, Thalassemia
1.0 Introduction

Generally, mothers of children with chronic genetic disorders especially Thalassemia 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). The needs of frequent monitoring of the child’s treatment every month and the medicine that should be taken by their children daily at home contribute towards an array of mixed feelings of anxiety, worry and uncertainty. In addition, the survival period, aftermath of hospitalization for the complications and the child’s pain will cause stress amongst mothers. 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.

With regard to this genetic disease, the total number of Malaysia’s population with Thalassemia is high. According to the Malaysian Thalassemia Registry, there are a total of 4,768 Thalassemia patients registered as at August 2009. From that number, 3,310 patients are transfusion dependent β Thalassemia Major who need blood transfusion regularly (Management of Transfusion Dependent Thalassemia, Ministry of Health, 2009). Previous research on children with Thalassemia have found that they have a psychosocial problem such as lower self-esteem, depression, social isolation from peers, financial issues, psychiatric disorder, limitation of physical activity, behavioural and school performance problems, factors of maturation and common complications (Wahab, Naznin, Nora, Suzanah, Zulaiho, Fasrzul & Kamaruzaman, 2011; Jain, Bagul, & Porwal, 2013; Guha, Talukdar, De, Bhattacharya, Pal, Dasgupta & Ghosal, 2013; Behdani, Badiee, Hebrani, Moharreri, Badiee, Hajivosugh, Rostami & Akhavanrezyat, 2015; Fung, Pinal & Leason, 2015; Al Ebrahimy, Al Jebory & Jehad, 2016; Obaid, 2016).

In Malaysia, limited studies have been done on caregivers of Thalassemia children. Among those documented, Wahab et. al. (2011) and Ismail, Chun, Yusof, Shahar, Abdul Manaf, Rajikan, Latif, Ibrahim and Jamal (2013) studied the family of children with Thalassemia and the quality of life amongst children and their caregivers in Malaysia that shed some light on the perception from families and patients about the concerns, beliefs and feelings about Thalassemia, as well as the health outcomes impacted by this genetic disease. Only a few studies using qualitative research methods have been conducted on the burden of caregiving and the impact of Thalassemia disease in their children towards parents emotional and social well-being, particularly amongst mothers of children with Thalassemia (Sapountzi-Krepia, Roupa, Gourni, Mastorakou, Vojiatzi, Kouyioumtzi & Van Shell, 2006; Prasomsuk, Jetsrisuparp & Silcox, 2006; Prasomsuk, Jetsrisuparp & Ratanasiri, 2007; Liem, Gilgour, Peligra, Mason & Thompson, 2011; Widayanti, 2011; Ishfaq, Bhatti & Naeem, 2014; Abu Shosha, 2014). However, these findings may not reflect the true picture in Malaysia and the scenario about the quality of life amongst mothers of children with Thalassemia in this country is scarce. Yet, there have been very few studies on stress and the quality of life amongst mothers of children with Thalassemia who need blood transfusion and iron chelation therapy for their lifelong treatment.
Several studies have been conducted in other countries on stress amongst parents especially mothers with children suffering from chronic illnesses such as leukaemia, cancer and Thalassemia indicated that those parents are more likely to have psychological symptoms because their children need to go through various health or lab examinations for diagnosis, lifelong treatment, wondering about the possibility of a cure, high risk of relapse and cause of death (Litzelman, Catrine, Gangnon & Witt, 2011, Saifan, Masa'Deh, Hall & Collier, 2014; Zaheer, Wazir, Hameed, Zeeshan, Zaman & Iqbal, 2015). Furthermore, the dependency on medicine and treatment, especially for Thalassemic patients, can cause financial strain on the family and behavioural problems amongst the children. In addition, Thalassemia is a clinical burden that contributes to psychosocial problems, not only to the patient himself, but also to other family members, especially to the main caregiver (Saldanha, 2015, Sultana, Humayun & Zafar, 2016). This is because mothers as the primary caregiver need to spend more time with their children and provide extra care from the care giving aspect.

Evidently, the Thalassemia child needs lifelong treatment and this situation will contribute to several stressors experienced by the mother as a caregiver. Nevertheless, this can be changed over time, depending on how mothers adjust to the stress because usually it is a multiple and on-going situation. This situation shows that mothers often suffer emotional and social hardship as the primary caregiver for the Thalassemic patient because they are more concerned about their child’s health, more involved in the care of their sick children, take a major responsibility in terms of decision making and they also engage in their child’s treatment. Research by Mashayekhi, Jozdani, Chamak and Mehni (2016) among mothers with Thalassemic children find that they are more burdened by the illness of their children because they are more exposed to extra care and spending more time with their children. Indirectly, it will leave an impact on their health outcomes, especially towards their quality of life as a whole.

In order to alleviate the stress, perceived social support is a resource that can help mothers to cope with their stressful life. It can be from the spouse, a close friend, family members, the community that they live in, as well as from healthcare teams such as nurses, doctors, dieticians and medical social workers. Past research on social support and knowledge of disease management amongst mothers of children with Thalassemia revealed the need for social support, as the role of a mother includes the responsibility of managing her children with chronic illness due to traditional, religious and cultural beliefs (Inamdar, Inamdar & Gangrade, 2015; Mashayekhi et. al.,2016). In addition, perceived social support can help the mother to cope better with the challenges of taking care of her sick child.

In addition, 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 that need to undergo blood transfusion at least once a month depending on the severity of the disease as a regime treatment for the entire life. This will include financial strain, monitoring the drug or medical equipment for their daily medical intake at home, accompanying them, especially for young children to get follow-up treatment. 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 chronic illness is, the greater is the mother’s distress and therefore, perceived social support becomes an important issue in overcoming care giving challenges. In addition, the social support obtained can help to reduce maternal stress and the mother’s quality of life will become better in terms of her mental and physical condition, thus improving her levels of
well-being, as observed in previous findings (Amendola, Oliveira & Alvarenga, 2011; Coyle, 2011).

In our country, the Thalassemia Association of Malaysia has an important role in helping families or parents who have a child suffer from Thalassemia. In fact, this non-government agency (NGO) actively controls programs to raise the awareness among the public about this genetic disease. In addition, the Thalassemia Association of Malaysia also helps to needy families for the assistance of medical equipment and social support not only to parents but also to the patients Thalassemia itself. As we stated previously research on children with Thalassemia has found that they have a psychosocial problem. 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. Therefore, this entire source will contribute to the stressor towards mothers and affect their quality of life as a whole.

Nevertheless, studies on the quality of life of mothers of children with Thalassemia are vague and previous studies involving mothers as primary caregivers are very limited. Although there is evidence of research on the quality of life of people with Thalassemia, research that is specifically focused on family as caregivers, especially amongst mothers of children with Thalassemia, is limited. This study focuses on the quality of life amongst mothers of children with Thalassemia and their relationship with stress and social support. Hence, the objective of this study is to identify the mother’s demographic background and to explore the relationship between stress, social support and quality of life. In addition, this study also examines the extent to which social support affects the proposed relationship between stress and quality of life among mothers of children with Thalassemia.

In doing so, a simple mediation model as proposed by Preacher and Hayes (2008) was tested. This procedure includes the criteria defined by Baron and Kenny for mediation analysis and is completed by the bootstrapping test. First, the stress should be significantly associated with the social support as a mediator, second, stress should be significantly associated with the quality of life, and third, the social support should be significantly associated with the quality of life. Bootstrapping test then addresses to testing indirect effect in order to confirm the result of mediation analysis (Preacher & Hayes, 2008).

2.0 Materials and Methods

This is a cross-sectional study involving 372 mothers who have children with Thalassemia 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), Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988) and SF 12v2 (Ware, Konsinski & Keller, 1996). For research ethical permission, the Medical Research Ethic Committee (MREC) approval was obtained prior to the study. Descriptive statistics, bivariate and multivariate 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, iii) agree to participate in this study by completing the informed consent form and iv) fluent speaking and writing in Malay or English language.

In order to test the mediation analysis, Baron and Kenny procedure was used in this study. Perceived social support is used as the mediator, mothers stress as independent and quality of life as the dependent variable. According to Baron and Kenny (1986), the conditions necessary for the mediation relation to existing are (1) variations in the independent variables account for variations in the mediator, (2) variations in the mediator account for variations in the dependent variables, and (3) when the effect of second conditions is controlled, the previously significant relation between independent and dependent variable are lessened or disappears fully. Accordingly, one regression analysis was performed for mediation model by using standard multiple regression analysis.

Although mediation analyses are most guided by the steps outlined by Baron and Kenny (1986), Preacher and Hayes (2008) noted the shortcoming of the Baron and Kenny method. They suggested the importance of directly testing the significance of indirect effects. Thus this study also examined the mediated variables by using bootstrapped confidence interval for indirect effect as suggested by Preacher and Hayes (2008).

By using bootstrapping test for indirect effect in order to confirm the result of analysis above, 5000 samples were requested and a bias-corrected and accelerated confidence interval (CI) was created for indirect effect. It stated that social support was mediating the relationship between mothers stress and quality of life. It is because of the results of bootstrapping test reveal that, the lower limit of 95% confidence interval was not include zero (-1.081, -0.005). Since the direct effect of mothers stress towards the quality of life was significance, it can demonstrate that social support was partially mediating the relationship between mothers stress and quality of life.

2.1 Parental Stress Scale

Parental Stress Scale (Berry & Jones, 1995) was used to assess stress among mothers with Thalassemia children in the current study. The PSS consists of 18 items that measured 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 ‘My child(ren) is an important source of affection for me’ and the negative item is ‘The behaviour of my children is often embarrassing or stressful to me’. 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).

2.2 Perceived Social Support

Social support was measured by using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al. 1988). The MSPSS consists of 12 items that assess individual’s perception of social support adequacy received from three sources: i) friends ‘I can talk about my problems with my friends’, ii) family ‘My family really tries to help me’ and iii) significant other ‘I have a special person who is a real source of comfort to me’. Each
item is measured on a seven-point Likert scale format ranging from 1 (very strongly agree) to 7 (very strongly disagree). A total measure of perceived social support adequacy is determined by averaging the score on the 12-items, with higher scores indicating greater perceived social support. The total scale has been demonstrated to have an internal consistency reliability of 0.88 (Cronbach’s alpha) and test-retest reliability of 0.85 and showed high internal consistency with Cronbach’s alpha of 0.93 for significant others, 0.88 for family and 0.96 for friends (Zimet et al. 1988). MSPSS was translated into the Malay language and has been validated in a previous study (Ng et al. 2010). In this study, the instrument showed the good validity in Family Division Cronbach Alpha is 0.77, the Cronbach Alpha for Section Friends is 0.89 and the value of the Significant Others is 0.95. Overall item shows the Cronbach Alpha as high as 0.88 and this value is very close to the 0.9 which showed the good value.

2.3 Quality Of Life

HRQOL among mothers of children with Thalassemia 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. 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 used 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 & (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.

Respondents rated 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 et al., 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.

3.0 Results

As depicted in Table 1, 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%). Table 1 below also demonstrates that 36.1% of mothers have more than one child with Thalassemia in their family, and the age of the children who participated is between 7 – 12 years (45.7%), and most of the Thalassemia children (87.4%) attend schools (pre-school, primary and secondary school). Results also confirmed that the majority of mothers in this study have only one child with Thalassemia (64.0%). In addition, data reveals that mothers having Thalassemia child in the family are not working (54.0%), as they are the main caregivers for the Thalassemia child in the hospital. In the present study, all respondents take their child to the government hospital for blood transfusion treatment.
Table 1: Demographic background mothers and child

<table>
<thead>
<tr>
<th>Demographic background</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Islam</td>
<td>302</td>
<td>81.2</td>
</tr>
<tr>
<td>Buddha</td>
<td>33</td>
<td>8.9</td>
</tr>
<tr>
<td>Hindu</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Christian</td>
<td>34</td>
<td>9.1</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>292</td>
<td>78.5</td>
</tr>
<tr>
<td>Chinese</td>
<td>37</td>
<td>9.9</td>
</tr>
<tr>
<td>Indian</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Bumiputera Sabah&amp; Sarawak</td>
<td>40</td>
<td>10.8</td>
</tr>
<tr>
<td><strong>Job status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>171</td>
<td>46.0</td>
</tr>
<tr>
<td>Not working</td>
<td>201</td>
<td>54.0</td>
</tr>
<tr>
<td><strong>Age of child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 6 years old</td>
<td>79</td>
<td>21.2</td>
</tr>
<tr>
<td>7 – 12 years old</td>
<td>170</td>
<td>45.7</td>
</tr>
<tr>
<td>13 – 17 years old</td>
<td>123</td>
<td>33.1</td>
</tr>
<tr>
<td><strong>Children go to school</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>325</td>
<td>87.4</td>
</tr>
<tr>
<td>No</td>
<td>47</td>
<td>12.6</td>
</tr>
<tr>
<td><strong>Total number of Thalassemia children in family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>238</td>
<td>64.0</td>
</tr>
<tr>
<td>Two</td>
<td>107</td>
<td>28.8</td>
</tr>
<tr>
<td>More than 2 child</td>
<td>27</td>
<td>7.3</td>
</tr>
</tbody>
</table>

In addition, results in Table 2 below revealed that there is a significantly negative correlation between social support and mother’s stress ($r = -0.103$) and between quality of life and mother’s stress ($r = -0.269$). This indicates that if social support and quality of life increase, there is the possibility that the mother's stress will also decrease and vice versa. However, the relationship between quality of life and social support has a significantly positive correlation ($r = 0.133$) which means that if the quality of life increases, social support also increases. Results indicate a significantly negative direction in the relationship between social support and stress, and between the quality of life and stress. However, the relationship between quality of life and social support shows a significantly positive direction. The findings revealed that there are significant relationships between social support and stress, between stress and quality of life, as well as between social support and quality of life mothers.
Table 2: Results of correlation between stress, social support and quality of life

<table>
<thead>
<tr>
<th></th>
<th>Stress</th>
<th>Social Support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
</tr>
<tr>
<td>Social Support</td>
<td>- 0.103*</td>
<td>0.046</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>- 0.269**</td>
<td>0.001</td>
</tr>
</tbody>
</table>

* p< 0.05; ** p < 0.01

Table 3 below indicated table results to explain the perceived social support as the mediator between stress and quality of life among Thalassemia mothers. According to the first step, mothers stress was negatively significantly correlated (B = - 8.645, p < 0.001) with quality of life (total effect). In this step, stress was regressed on the quality of life (R² = 0.072, F (1,370) = 28.803, p < 0.001). In addition, mothers stress also significantly negatively correlated (B = - 0.157, p < 0.05) with social support by examination in the second step. Also, stress was regressed on the social support (R² = 0.011, F (1,370) = 3.997, p < 0.05).

Table 3: Results of social support as mediator between stress and quality of life

<table>
<thead>
<tr>
<th>Variable</th>
<th>β</th>
<th>SE</th>
<th>B</th>
<th>R²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1 (Path c)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>- 8.645</td>
<td>1.611</td>
<td>- 0.269</td>
<td>0.072</td>
<td>0.000**</td>
</tr>
<tr>
<td>Quality of Life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Step 2 (Path a)    |        |      |       |      |         |
| Stress             | - 0.157| 0.079| - 0.103| 0.011 | 0.046*  |
| Social Support     |        |      |       |      |         |

| Step 3 (Paths b & c') |        |      |       |      |         |
| Quality of Life      |        |      |       |      |         |
| Social Support       | 2.247  | 1.061| 0.106 | 0.083 | 0.000** |
| Stress               | - 8.292 | 1.612| - 0.258 |     |         |

Note: β = Standardized Coefficients; SE= Standard Error. ; B = Unstandardized Coefficients. ; R² = R Square Adjusted

* p< 0.05; **p <0.001

Social support, which is the mediating variable was regressed on quality of life (R² = 0.083, F (2,369) = 16.781, p < 0.001). This mediator variable was significantly positively correlated (B = 2.247, p < 0.05) with the quality of life. While controlling for social support (mediating variable), mothers stress still have significant effect on quality of life (B = - 8.292, p < 0.001).
While direct effect reveals the amount variance from stress to the quality of life 72% and social support as a mediating variable resulted in 83% it showed that social support contributes an effect to increase the quality of life among mothers. It’s increased 11% in quality of life for R Square Adjusted value. As a result of this three regression models, it’s indicated that social support mediate the relationship between mothers stress and quality of life. It’s reveal that this model has a partial mediating effect. It can be interpreted that if the level of stress increased, the higher perceived social support by mothers will increase a better quality of life among them. This result showed that quality of life among mothers increased when they perceived social support. Below Figure 1 illustrated the details of the mediating model to showed direct and indirect effect.

**Figure 1: Mediating Model**

a) Direct Effect

![Direct Effect Diagram]

Step 1
(Path c)

\[ B = -0.269, R^2 = 0.072, p < 0.001 \]

b) Indirect Effect

![Indirect Effect Diagram]

Step 2
(Path a)

\[ B = -0.103, R^2 = 0.011, p < 0.05 \]

Step 3
(Path b and c’)

\[ B = 0.106, R^2 = 0.083, p < 0.001 \]

* p<0.05; **p <0.001

Based on Baron and Kenny (1986), Figure 1 above illustrated the mediation analysis stated that a variable functions as mediator when: (a) variations in the level of the independent variable significantly account for variations in the mediator variable (i.e path a); (b) variations in the mediator significantly account for variations in the dependent variable (i.e. path b); and
(c) when paths a and b are controlled, a previously significant relation between the independent and dependent variables is significantly reduced (i.e path c is weakened). The steps for analysis are (1) regressing the mediator on the independent variable; (2) regressing the dependent variable on the independent variable and (3) regressing the dependent on both the independent variable and on the mediator. In addition, to establish mediation, the mediator must affect the dependent variable in the third equation and the effect of the independent variable on the dependent variable must be less in the third equation than in the second.

4.0 Discussions

The present data demonstrates that Malays contribute mostly to the outcome of this study. Besides that, majority mothers reported that they have only one child with Thalassemia and this result similar to the previous study by Ismail et.al (2013), 69% of respondents also reported have only one child with Thalassemia.

In this sample of mothers with Thalassemia children, the positive correlation between perceived social support and quality of life indicates that mothers who receive social support experience higher levels of quality of life because they get the adequacy of support in their life. This finding is consistent with other studies amongst mothers of children with chronic conditions (Skok, 2006; Amendola, Oliveira & Alvarenga, 2011). Results show that there are negative correlations between stress and the quality of life, and this confirms that mothers who have higher levels of stress experience lower levels of quality of life. In line with this, current results supported by research by Skok (2006) revealed that stress and entire psychological symptoms that can affect health outcomes, including the quality of life and well-being. Furthermore, the fear of losing the child with chronic illness may lead to anxiety, frustration and sadness that impacts the parent of her life satisfaction and impairs her quality of life (Erdogan, Oto & Bosnak, 2016), and this psychological disorder is more prevalent among mothers than fathers, especially for parents who have children with blood disease (Ashrafizadeh, Adineh, Baraz & Darvishi, 2016). In line with this, Muazzam and Javed (2013) points out that the burden of care giving is experienced more by the female compared to the male caregiver.

In addition, stress amongst mothers of children with Thalassemia has been found to be ameliorated by perceived social support from a significant other, friends and family members. It consistent with finding by Meral and Cavkaytar (2012) that revealed social support resources will contribute to the increasing of social support perception among the family who has children with autism. Besides that, the perceived social support among them will reduce their stress level and indirectly improve the mother’s quality of life. However, the level of quality of life is greater when mothers of children with Thalassemia high perceived social support. This finding points out that perceived social support mediates the level of stress that can alleviate the stress level and indirectly, the level of quality of life will increase. Our findings are in line with other studies by Skok (2006) and Coyle (2011) that measure social support as a mediator of health outcomes amongst mothers’ samples.

This finding is also consistent with the findings of a study conducted by Olawale, Deih and Yaadar (2013) which reports that social support has a lesser role in mediating the impact of stress on mothers caring for children with special needs which contributes significantly
Hazlina M. M., Rumaya J., & Siti Nor Y.

113

International Journal of Public Health and Clinical Sciences
ISSN: 2289-7577, Vol. 4: No. 1
January/February 2017

Towards improvement in motor development. It shows that this type of coping strategy will help such mothers to develop their own capabilities, increase their self-confidence and adaptability to their sick children’s situation. Moreover, the present study is also similar to the finding of a research by Fidika, Salweski and Goldbeck (2013) which points out that stress and quality of life among parents of children with chronic conditions is mediated by social support and has a significant effect.

However, the demand for support may be different with the type of illness, as well as severity or level of disability (Lima, Cardoso & Silva, 2016). Findings from Babatunde (2014) show that it is neither the severity of illness or level of functioning in disabled children that contributes the stress, but rather it is the lack of social support resources from the family that is more important. In line with stress and social support in the current study, our findings are consistent with those by Shanmugam and Ramachandra (2015) that relate stress experienced by caregivers with lack of support system. This is because social support has a positive correlation with health outcomes that is more social support received will improve the level of quality of life, which will indirectly reduce the stress level.

In addition, a study by Babatunde (2014) reveals that important social support will help the caregiver manage their disabled children better compared with Thalassemia children who can be like normal children in terms of managing themselves. Moreover, social support is highlighted as a better coping resource in dealing with the care giving process. Indirectly, it assists mothers to cope adequately with all the matters related to the care of their sick children. In contrast, findings by Olawale et. al. (2013) that studied children with special needs reveal that parents of children with cerebral palsy tend to obtain knowledge and information about the disease themselves in order to assist them appropriately in terms of coping with the task of taking care of their children.

Besides that, our findings are at odds with some studies (Muazzam & Javed, 2013; Mirbehbahani, Salehi, Jahazi & Karimi, 2014 & Mashayekhi et. al., 2016) which address the problem of Thalassemia in different areas, other than the quality of life. They are focused on the care giving burden and role of social support. However, due to cultural and traditional beliefs, they are still lacking in social support resources. Research by Mashayekhi et. al. (2016) in Iran revealed that the prevalence of caregiver’s burden is higher among mothers of children with Thalassemia and they have a lower level of social support. This is contradictory with the findings of a study on mothers of children with Thalassemia in Thailand which uses a family based approach as social support perceived from family members in extended families to help them take care their Thalassemia children based on their culture, values and beliefs (Prasomsuk et al., 2006). Another research about the typical African family perspective also showed the parents appreciated the support from the members of their extended family in caring their disabled children (Olawale et. al., 2013).

In addition, some mothers use foreign workers as their helper/maid to help them in the care giving process. This commonly happens when the mother is working but still has a responsibility in monitoring and supervising their children from the healthcare aspect, especially on treatment routines and medication. According to a study by Goh, Lai, Lau and Ahmad (2013), caregivers of the elderly in Malaysia also get assistance from their foreign helper or maid and rely on them to manage the daily chores in terms of giving food and taking the elderly for physical activity during their leisure time. In contrast with the study in Hong
Kong by Chong (2014), caregivers are most likely to use the domestic helper to help them due to language barrier and cultural issues.

This current study verifies that the quality of life is associated with stress and is mediated by social support. Perceived social support from the spouse, friend and the family will also affect the stress level and quality of life. According to Yengil et. al. (2014), parents have a poor quality of life because they feel guilty about having a child with genetic blood disorder. Most mothers in the present 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 current child’s illness status that helps the mothers to cope with the Thalassemia disease condition that problematic for them (Dadipoor, Haghighi, Ghanbarnejad, Shojaei, Hamas & Moradabadi, 2015).

As a known fact, Thalassemia disease is one of the most challenging haematological diseases with no permanent cure. In addition, 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 and the hidden budget such as accommodation, transportation, and other expenses. Previous studies have also revealed that financial constraint is commonly faced by parents of children with Thalassemia (Siddiqui, Ishtiaq, Sajid & Sajid, 2014; Arbabisarjou, Karimzaei & Jamalzaei, 2015; Biswas et al., 2016). Furthermore, other additional factors also could possibly affect the mother's stress and quality of life such as marital satisfaction, family resources, the child severity illness, mother-child relationship and its impact on the quality of life among mothers of children with Thalassemia.

Moreover, another important coping strategy that can be used by mothers or parents that have a child with the chronic illness is religious coping. As Muslims, one should believe and accept the fate of having such a child and ‘redha’ with the gift from Allah s.w.t. Such beliefs could have a positive influence on mental and physical health among mothers as they try to meet the demands and challenges in the care of a child with Thalassemia. In addition, religious rituals such as performing ‘solat’, reciting the Al-Quran and praying will help them to accept the situation of their children’s illness (Nikseresht, Rassouli, Torabi, Farzinfard, Mansouri & Ilkhani, 2016).

However, perceived social support will help people who have children with Thalassemia to improve the quality of life as a part of the strategies for continuous psychological balance (Sultana et. al., 2016). Indirectly related to a good quality of life, continuous social support will help them face the challenges of the disease and childcare associated with the many concerns on psychological and social adjustment for lifelong diseases. In addition, social support will also lead to the improvement of adaptation skills, resulting in a higher quality of life effect.
5.0 Conclusion and recommendation

In summary, the findings from our study highlight the importance of social support perceived by mothers and should be included in the comprehensive intervention programmes in order to maintain the mother’s psychological and physical health, as well as their quality of life as a whole. The present study reveals that increasing levels of social support positively influences a good quality of life and reduces the psychological burden as well as the level of stress experienced by mothers. In addition, current study also provides an explanation for the association of stress amongst mothers with perceived social support, and the impact on their quality of life. This knowledge should enable healthcare providers in the identification of potential risk factors towards the lower quality of life amongst mothers. In addition, it will assist in determining when intervention may be necessary. Such intervention should particularly seek to address the maternal feelings of stress, physical pain or emotional distress, lack of parenting competence in child’s illness and acceptance of the child’s illness. Hence, the healthcare provider needs to be aware of the importance of social support as a strategy and care plan that can be used to improve the mothers’ quality of life.

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 identifying which coping patterns are more effective than perceived social support. Moreover, the need for special training of foreign helpers should be emphasized, especially for those involved in caregiving of children with chronic diseases and special needs. Besides that, the longitudinal study design would also yield valuable information on the changes in stress amongst mothers over time, and the impact on maternal quality of life on the long-term outcomes of these children. Furthermore, future researchers should be emphasizing on qualitative and quantitative studies to ensure that healthcare societies include the healthcare team involved in the intervention programmes.

As a limitation, the sample in this study is only composed of mothers and no way disregards the paternal quality of life as an outcome of raising a child with Thalassemia. Indeed, it is recognized as a real and complex construct that should be studied as a unique phenomenon. Therefore, future studies should be designed to explore fathers’ unique experiences and gender differences outcomes. 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 of mothers of children with Thalassemia in Malaysia. The quality of life of mothers of children with Thalassemia can be affected due to raising the child, psychological burdens and stressors during the treatment process because Thalassemia children need lifelong treatment. However, results from the present study confirmed that perceived social support can help mothers to cope during the Thalassemia journey with their children and help them to improve their quality of life. This is a contribution to the extent that the need for social support amongst mothers in coping with caring for their Thalassemia children in Malaysia is being highlighted.

Acknowledgement

The author(s) would like to thank the Director General of Health Malaysia for permission to publish this paper. 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.
Declaration

Author(s) declares that there is no conflict of interest.

Authors’ contribution

Author 1: Literature Review, preparing Research Proposal, conducting the research activities and analysis aspect of this research

Author 2: Main supervisor of author 1 in her graduate study, supervising the whole research process. Contributing in methodological aspects and planning the research activities

Author 3: Contributing in methodological aspects and planning the research activities
References


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.

