



The Relationship Between Psychological Distress and Religious Practices and Coping in Malaysian Parents of Children with Thalassemia

Li Tsu Chong^a, Mei Chan Chong^{b,*}, Li Yoong Tang^b, Vimala Ramoo^b, Ping Lei Chui^b, Nant Thin Thin Hmwe^c

^a Department of Nursing, Faculty of Medicine and Health Sciences, Universiti Malaysia Sabah, Kota Kinabalu, Sabah, Malaysia

^b Department of Nursing Science, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

^c School of Nursing and Midwifery, Faculty of Health and Medicine, The University of Newcastle, Australia

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ABSTRACT

Study purpose: This study was conducted to examine the relationship between religious practice, religious coping methods and psychological distress among parents caring for children with transfusion-dependent thalassemia.

Design and methods: This is a cross-sectional survey. Data were collected on 162 parents of children diagnosed with thalassemia aged 12 years and younger in thalassemia day care centers of three public hospitals in Sabah, Malaysia. Data were collected using questionnaires, including General Health Questionnaire-12 (GHQ-12), Duke University Religion Index (DUREL) and Brief RCOPE.

Results: Forty-two percent of parents had psychological distress with GHQ score ≥ 3 (mean score of 2.85 ± 3.17). Ninety-five percent of parents used positive religious coping methods (mean P-COPE score 22.35 ± 2.33) more than negative religious coping methods (mean N-COPE score was 12.19 ± 5.23). They used Organized Religious Activities (mean ORA score of 4.20 ± 1.27), and Non-Organized Religious Activities (NORA, the mean was 4.17 ± 1.37). Positive and negative religious coping methods were significantly related to parents' psychological distress (P-COPE and GHQ-12 scores (r_s (df) = 0.19, $p < .05$; N-COPE and GHQ-12 scores r_s (df) = 0.38, $p < .001$)).

Conclusion: The study findings showed the parents experienced psychological distress. They used positive religious coping methods more than negative religious coping methods. Psychological distress was significantly related to organized religious activities, non-organized religious activities and positive and negative religious coping methods.

Practice implication: The study findings facilitate understanding of psychological distress and how parents use religious coping strategies to deal with the stress caring for their child.

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Introduction

Thalassemia is an inherited hemoglobin disorder that affects children globally. In the US, approximately 1000 individuals from those affected by β -thalassemia major and an unknown number of others are carriers who have the genetic trait and can pass it on to their children (Centers for Disease Control and Prevention's CDC, 2013).

According to Modell and Darlison (2008), β -thalassemia major causes profound anemia that is life-threatening to children before the age of 3 years if they are untreated. A meta-analysis by Lozano et al. (2012) found that about 18,000 anemia-related deaths occurred globally in 2010. In Malaysia, thalassemia is one of the most common public health problems. Approximately 4.5% of Malaysians are carriers of β -thalassemia, affecting an estimated 2.1 per 1000 births annually, with an estimated 5600 patients with transfusion-dependent β -thalassemia (George, 2001). Medical advances have resulted in the development

of several treatments to improve the prognosis and prolong the lives of children with thalassemia major. However, these are lifelong treatments and require full commitment from the patients and their parents or caregivers to adhere to the treatment program.

Parents and caregivers of children with thalassemia are affected by many socioeconomic burdens during the treatment process, and they experience psychological distress. Parents often experience feelings of guilt, frustration, sorrow, sadness, helplessness, hopelessness and desire to give up (Liem, Gilgour, Pelligra, Mason, & Thompson, 2011, Sapountzi-Krepia et al., 2006). Other studies investigating psychological distress among parents of children with hemoglobinopathies, such as thalassemia and sickle cell anemias, reported that parents caring for their affected children experienced mild to severe levels of depression (Ali, Sabih, Jehan, Anwar, & Javed, 2012, Aziz, Sadaf, & Kanwal, 2012, Brown et al., 2010, Shaligram, Girimaji, & Chaturvedi, 2007). These negative feelings lead to other negative effects, which cause a withdrawal of effort from ensuring the child is receiving optimal treatment and care. Therefore, effective coping strategies are needed in order to handle their emotional issues.

* Corresponding author.

E-mail address: mcchong@um.edu.my (M.C. Chong).

Several coping mechanisms are used to deal with psychological discomfort, such as negative or positive coping strategies or using religion and cultural beliefs (Ali et al., 2012). In studies on Asian Indian and Pakistan populations, religion is the most commonly reported coping mechanism used by parents experiencing emotional disturbances (Ali et al., 2012; Liem et al., 2011; Shaligram et al., 2007). These parents believe and have faith that God gives them the strength to cope with stressful events or emotions (Atkin & Ahmad, 2000; Liem et al., 2011). According to Koenig (2007) religion is often used to help people cope or adapt to stressful circumstances, such as crying out for help from God or performing religious rituals when in high-distress situations. By identifying whether religious practice can help reduce parents' psychological distress, nurses and health care professionals can provide support to parents to help them cope with their distress.

Psychological distress and coping

Psychological stress and distress describe subjective feelings of unpleasantness. Lazarus and Folkman (1984) refer to psychological distress as a specific relationship between the individual and the environment that is appraised by the individual as being "taxing and exceeding his or her resources and endangering his or her well-being" (p. 19). The way a person evaluates the situation may affect his or her response, as interpretations and reactions are different between people and groups with different levels of sensitivity and vulnerability to certain types of events.

Parents who experience psychological distress may react differently. In the Lazarus and Folkman's model, cognitive appraisal and coping processes significantly influence both the quality and intensity of the stress response of the person in a stressful situation (Lazarus & Folkman, 1984). The level of psychological distress of parents, then, depends on how they appraise the situation as it happens. Lazarus and Folkman (1984) also defined coping as a dynamic interchange between a person and the environment as the individual endeavors to manage a difficult problem or situation.

Koenig (2007) suggested that religious beliefs can influence the cognitive appraisal of negative life events in a way that makes them less distressing. Thus, religion enters the coping process when religious practices, beliefs, and rituals become ways of coping with the problem or situation as it takes place (Pargament, 1997), whereby their religious beliefs may affect their understanding of the situation in order to cope with it.

Religious practices and coping

Religion provides resources for coping with stress that may increase the frequency of positive emotions and reduce the likelihood that stress will result in emotional disorders such as depression, anxiety, suicide, and substance abuse (Koenig, 2007). According to Kaplan and Blaze (1995, as cited in Cardella & Friedlander, 2004), religion plays a unique role in coping with chronic illness in three ways: as part of the coping process (which makes people become involved in religious activities), as contributors to the coping process (which influences people to overcome the stressful situation), and as an outcome of the coping process (which makes the role of religion important in people's lives).

Koenig (2007) defined religion as beliefs, practices, and rituals related to the sacred. Religious coping method is defined as attempts to understand how to deal with stressors in ways related to the sacred. The term coping referred to ways of dealing with distress according to their religious beliefs (Pargament, 1997). Previous studies on psychological adjustment using religious activity by parents of children with chronic illness, such as cancer, sickle cell disease or cystic fibrosis, reveal that parents adopt more religious behaviors to cope with stress. (Cotton et al., 2009; Elkin et al., 2007; Grosseohme et al., 2011; Wu & Liu, 2013).

Religious practices are used as coping devices or sources of support for parents dealing with stressful events. Several studies that examined

the effects of religious activities on distress levels of parents who have children with chronic illness, such as thalassemia, cancer, sickle cell disease or cystic fibrosis, demonstrated that parents who practice prayer, read religious scriptures, and attend public religious services show reduced distress levels (Cotton et al., 2009; Elkin et al., 2007; Grosseohme et al., 2011; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). In a qualitative study of parents (N = 64) of children receiving palliative care, religious practices (prayer and Bible reading) gave them a greater sense of peace and calm, as they felt more connected to God or had an enhanced sense of spirituality (Hexem et al., 2011). Some parents gain control over their situation by seeking comfort from God (Grosseohme et al., 2011). Therefore, religious beliefs and practices can change one's cognitive appraisal of negative events and directly or indirectly reduce painful feelings and promote positive emotions and development of human virtues (Wu & Liu, 2013).

Pargament, Smith, Koenig, and Perez (1998) indicated that religious coping follows two patterns or methods: positive and negative religious coping. Positive religious coping is a more optimistic style of coping, which involves forgiveness, seeking spiritual support, collaborative religious coping, spiritual connection, religious purification, and benevolent religious reappraisal. Negative religious coping patterns are a more pessimistic style of coping, involving spiritual discontent, punishing God reappraisals, interpersonal religious discontent, demonic reappraisal, and reappraisal of God's powers.

Parents of children diagnosed with chronic illnesses use positive religious coping styles more frequently than negative styles (Cardella & Friedlander, 2004; Grosseohme et al., 2010; Thombre, Sherman, & Simonton, 2010). Parents believe God gives them the strength to cope with life events, and therefore, based on their faith in God, religion is the only way for them to adjust to their child's illness (Widayanti, 2011). Studies have shown that positive religious coping strategies are related to perceptions of positive life changes (Cardella et al., 2004; Thombre et al., 2010). Negative religious coping strategies are related to more burdens, poorer quality of life, less satisfaction, and increased likelihood of major depressive and anxiety disorders (Grosseohme et al., 2010; Pearce, Singer, & Prigerson, 2006).

The literature has shown many parents of children with chronic illnesses experienced poor quality of life and psychological distress (Ali et al., 2012; Aziz et al., 2012; Brown et al., 2010). Religious practices and coping methods have been reported as coping strategies for negative life events and are associated with each variable (religious practices and religious coping methods) (Elkin et al., 2007; Cotton et al., 2009; Grosseohme et al., 2011; Hexem et al., 2011). However, these relationships were found in various populations, such as parents of children with cancer, sickle cell anemia, and cystic fibrosis. Parents of children with transfusion-dependent thalassemia may experience different levels of psychological distress due to different restrictions imposed by their child's treatment modalities.

Information on psychological distress and religious coping methods in parents of thalassemia children is limited. Furthermore, the relationships among psychological distress, religious practice, and coping methods have not been explored extensively. Thus, additional work is needed to investigate the influence of religious practices and coping methods on psychological distress in parents of children with transfusion-dependent thalassemia. This study was conducted to examine the relationship between religious practice, religious coping methods and psychological distress among parents caring for children with transfusion-dependent thalassemia.

Methods

Design

A cross-sectional study design was used for this study. We sought to examine the relationships among parents' religious practices, religious

coping methods, and distress who have children with transfusion-dependent thalassemia.

Sample and setting

In total, 162 parents were recruited using convenience sampling from the thalassemia daycare centers of three public hospitals in Sabah, Malaysia. These centers have the highest prevalence of pediatric thalassemia patients. Parents who met the following eligibility criteria were included: (1) had a child/children 12 years or younger receiving treatment at the daycare center; (2) had no known medically diagnosed psychiatric problems through family history records from the child medical report; and (3) were Malaysian citizens and able to understand verbal or written English, Malay or Chinese.

Prior to the data collection process, the researcher made an appointment with the nurse in charge of the day care center to identify the number of patients scheduled for transfusion and reviews. Then, the potential participants were shortlisted according to the age of the children with thalassemia from the clinic's appointment book who met the study inclusion criteria. That is, the parents of patients ages 12 years and younger who were willing to participate in the study. It was noted if any parents met the inclusion criteria and they were then approached by the researcher for voluntary participation in the study.

Data collection

Data collection was performed between April and May 2014. The researcher approached potential participants in the daycare center while they were waiting for their child to complete a transfusion or attend a doctor's appointment for review. Informed consent was obtained from eligible participants and self-administered questionnaires were administered.

Instruments

The General Health Questionnaire (GHQ-12) was used to evaluate psychological distress among parents. The English version of the questionnaire was adapted from Goldberg and Williams (1988) and the Malay (Malaysian national language) version was adopted from Yusoff, Fuad, and Yaacob (2010). The GHQ-12 items are rated on a Likert scale using the binary scoring method. The GHQ-12 scores range from 0 to 12; higher score indicates a higher level of psychological distress and lower score indicates lower levels of psychological distress. Based on the mean score of a sample suggested by Goldberg and Williams (1988) the cutoff point 3 was used to determine the level of psychological distress, thus the score of three and higher was considered as psychological distress.

The GHQ-12 has been used widely in primary care settings for screening of psychological distress and psychiatric morbidity, and its internal consistency and reliability is well established internationally and locally. The Cronbach's alpha ranges from 0.77 to 0.93 (Yusoff, Fuad & Yaacob, 2010). The Cronbach's alpha of the GHQ-12 was above 0.80 for both language versions in the current study.

Religious practice was measured using the Duke University Religion Index (DUREL), developed by Koenig, Meador and Parkerson (1997). It consists of five items contained within three subscales, including three major dimensions of religious commitment: organized religious activity (ORA; one item), non-organized religious activity (NORA; one item), and intrinsic religiosity (IR; three items). ORA includes public religious activities, for instance, the frequency of attendance at religious services or participation in other group-related religious activity. NORA consists of religious activities performed in private, such as prayer or reading religious scriptures. IR is the degree of personal religious commitment or motivation. Each subscale score in this section is examined independently (Koenig & Bussing, 2010). The Malay version was validated, which showed good parallel-forms reliability ($r = 0.70$), test-retest

reliability (Spearman's $\rho = 0.68$, $p < .01$), and fair internal consistency (Cronbach's $\alpha = 0.45$). For the current study, test-retest reliability was $r = 0.71$, with a Cronbach's alpha of 0.90 (Nurasikin et al., 2013).

Religious coping mechanisms were assessed using the Brief RCOPE, adopted from Pargament, Feuille, and Burdzy (2011), who used and validated the scale across different samples, including different sample demographic data and religions. This section contains questionnaires assessing the religious coping methods of parents, consisting of 14 questions. The questionnaire contains two subscales, divided into positive (P) and negative (N) religious coping. The total score for each subscale ranged from 7 to 28. Higher scores reflect greater adoption of methods measured by that subscale. The validated Malay version was adopted from Nuraskin et al. (2013). P-COPE and N-COPE had high internal consistency in that study (for P-COPE and R-COPE, Cronbach's $\alpha = 0.87$ and 0.88, respectively). In the current study, the Cronbach's alpha for P-COPE and N-COPE was 0.81 and 0.91, respectively.

Ethical considerations

Ethical clearance was obtained from the National Institute of Health, the Medical Research and Ethics Committee, and the Ministry of Health. Before signing the consent form, each participant received an oral explanation of the study purposes, procedures, risks and benefits of participation, and the right to withdraw at any time. Using identification numbers instead of real names for the data records protected participants' confidentiality.

Data analysis

Data analysis was conducted with SPSS version 21. Descriptive statistics were used to describe demographic data, psychological distress level, religious practice, and religious coping method. Spearman's rank-order correlation was used to examine the relationships among religious practices, religious coping methods, and psychological distress. The non-parametric test was used because the data were not normally distributed.

Results

Parents' characteristics

The calculated sample size was 179 (at a 5% margin of error and 95% confidence interval) but 200 questionnaires were distributed to parents who were eligible during the period of sampling considering parents who may withdraw, and incomplete or unanswered questionnaires. One hundred sixty-two parents volunteered to participate and completed the questionnaires, there, the response rate was 81% from the calculated projected sample size. In total, of 162 parents, 79% ($n = 128$) were mothers and 21% ($n = 34$) were fathers. In terms of race, majority of them were Dusun (52.5%, $n = 85$), followed by 14.8% ($n = 24$) other indigenous (i.e.: Suluk, Sungei, Brunei and Rungus), 13.6% ($n = 22$) Kadazan, 13% ($n = 21$) Murut, and the minority race in this sample were other races (i.e., Malay and Chinese) comprising 6.2% ($n = 10$). The majority of participants were Christian (73.5%, $n = 119$), whereas 25.9% ($n = 42$) were Islam, and only 0.6% ($n = 1$) was Buddhist.

Psychological distress, religious practice and religious coping methods

The mean score of psychological distress was 2.85 ± 3.17 . Almost half of the parents (42%, $n = 68$) had psychological distress with GHQ score ≥ 3 .

In parents' religious practice, the mean ORA score was 4.20 ± 1.27 ; indicating high practice of attending public religious services or meetings; 56.8% ($n = 92$) of the sample showed high practice of the ORA. For NORA, the mean was 4.17 ± 1.37 , and 64.2% ($n = 104$) practiced NORA. While IR scores ranged from 3 to 15, with a mean score of

13.97 ± 1.24, the majority had high IR (n = 158, 97.5%), indicating high religious faith and motivation.

Regarding religious coping, the mean P-COPE score was 22.35 ± 2.33 with the majority, with 95.1% (n = 154) of the sample scoring high. The mean N-COPE score was 12.19 ± 5.23, and 70.4% (n = 114) of the sample used negative religious coping methods. The psychological distress and religious practices, and religious coping of the participants are presented in Table 1.

Relationship between religious practice and psychological distress

Table 2 shows the correlations among religious practices subscales (ORA, NORA, and IR), religious coping method (P-COPE and N-COPE), and psychological distress (GHQ-12) using Spearman rank-order correlations. There was a weak positive correlation between ORA and GHQ-12 scores (r_s (df) = 0.18, $p < .05$), with high ORA activities associated with a high level of psychological distress. There was a weak negative correlation between NORA and GHQ-12 scores (r_s (df) = -0.17, $p < .05$), with high NORA associated with low psychological distress. There was no correlation between IR and GHQ-12 (r_s (df) = 0.04, $p > .05$).

Relationship between religious coping methods and psychological distress

There was a weak negative correlation between P-COPE and GHQ-12 scores (r_s (df) = 0.19, $p < .05$); high P-COPE was associated with low psychological distress. There was a moderate positive correlation between N-COPE and GHQ-12 scores (r_s (df) = 0.38, $p < .001$), with high N-COPE scores associated with high psychological distress.

Discussion

Parents' psychological distress

In this study, almost half of the parents caring for children with transfusion-dependent thalassemia (42%, n = 68) had psychological distress, with scores of 3 and above on the GHQ-12. This could lead to

Table 1
Parents' scores on psychological distress, religious practices, and religious coping.

Variables	n	%	M ± SD	Possible range
Psychological distress (GHQ-12)				
<3 scores	94	58	2.85 ± 3.17	0–12
≥3 scores	68	42		
Religious practice (DUREL)				
ORA				
Low	14	8.6	4.20 ± 1.27	1–6
Moderate	56	34.6		
High	92	56.8		
NORA				
Low	25	15.4	4.17 ± 1.37	1–6
Moderate	33	20.4		
High	104	64.2		
IR				
Low	0	0	13.97 ± 1.24	3–15
Moderate	4	2.5		
High	158	97.5		
Religious coping method				
P-COPE				
Low	0	0	25.73 ± 2.79	7–28
Moderate	8	4.9		
High	154	95.1		
N-COPE				
Low	114	70.4	12.19 ± 5.23	7–28
Moderate	34	21.0		
High	14	8.6		

Note. GHQ-12 = General Health Questionnaire-12; DUREL = Duke University Religion Index; ORA = organized religious activities; NORA = non-organized religious activities; IR = intrinsic religiosity; P-COPE = positive religious coping; N-COPE = negative religious coping.

Table 2
Correlations among religious practice, religious coping methods, and psychological distress.

Variables	Values	GHQ-12 scores
Religious practices		
ORA	ρ	0.18*
	p	0.02
NORA	ρ	-0.17*
	p	0.04
IR	ρ	0.04
	p	0.64
Religious coping method		
P-COPE	ρ	0.19*
	p	0.02
N-COPE	ρ	0.38**
	p	<0.001

Note. ORA = organized religious activities; NORA = non-organized religious activities; IR = intrinsic religiosity; P-COPE = positive religious coping; N-COPE = negative religious coping.

* $p < .05$ (2-tailed).

** $p < .01$ (2-tailed).

psychological instability if they are not coping well. This result is comparable in study done by Shaligram et al. (2007) that only slightly >50% of their participants had identified psychiatric problems. However, in the other study, 67.5% (27 out of 40) of parents of children with thalassemia were found to have psychological distress (Ali et al., 2012). This variation might be due to small sample size and demographic differences. On the other hand, most of the parents (58%) scored below 3 on the GHQ-12, indicating low level of distress or no distress. Perhaps this is due to adaptation to the routine treatments. The result is consistent with a study in Nigeria on parents of children diagnosed with sickle cell anemia, where few parents felt depressed over the course of treatment, which relieved the tension (Brown et al., 2010).

Religious practice and religious coping methods among parents

Parents frequently performed religious practices, as they scored high on ORA (56.8%, n = 92) and NORA (64.2%, n = 104). The mean scores showed a high use of ORA and NORA, reflecting that parents do participate in public religious activities and practice religious teaching privately. This contradicts with Hexem et al. (2011) who found that parents practiced more prayer and reading religious scriptures, but not on a regular basis. According to Banerjee et al. (2011), attending places of worship is a form of community support whereby friends provide support and strength by praying for their ill child. The mean IR score reflects that the parents have high intrinsic religiosity, indicating that these parents have strong faith and find motivation through religious teaching. Perhaps this can be explained by Hexem et al. (2011) who found that parents who were not regular attendees for public religious services still felt a connection with God or a sense of spirituality. This is supported by previous studies in which parents agreed that religion is important (Atkin & Ahmad, 2000; Cotton et al., 2009).

The mean score for P-COPE suggested a high use of positive religious coping methods by parents, while negative religious coping methods were moderately used, suggesting that positive methods are more common compared to negative methods. This finding is consistent with previous studies indicating that positive religious coping methods are preferred by parents (Cardella et al., 2004; Cotton et al., 2009; Grosseohme et al., 2011). Moreover, the use of positive religious coping methods could be due to the belief in God and faith giving them strength to cope (Atkin & Ahmad, 2000).

Relationship between religious practice and psychological distress

Although this study showed a weak positive correlation between ORA and parents' psychological distress [r_s (df) = 0.18, $p < .05$], the

results suggest that high ORA activity is associated with a high level of psychological distress. This finding probably indicates that parents who have high level of psychological distress are trying to attend more public religious services in order to get connection and support with the community. Previous studies also concluded that the increased religious activity is probably due to a need for emotional support from their God or the transcendent (Cotton et al., 2009; Grosseohme et al., 2011; Hexem et al., 2011). In contrast, the study finding showed that NORA is negatively associated with parents' psychological distress; parents who frequently practiced NORA (such as prayer, meditation, or reading religious scriptures) had lower psychological distress. As the correlation was weak, the result might have occurred by chance. Future research with longitudinal study would further explain the relationship between religious practices and psychological distress.

There was no significant association between IR and psychological distress, suggesting that neither high nor low scores in religious motivations were related to parents' psychological distress. This might be due to individual differences in the degree of psychological distress among parents who experience the stressors (Cardella & Friedlander, 2004). The experience of psychological distress depends on how the individual appraised the situation through their religious teaching. The quality and amount of the individual's stress response during stressful situations depends on the person's intellectual evaluation and coping method (Lazarus & Folkman, 1984).

Relationship between religious coping methods and psychological distress

This study showed that positive religious coping methods were related to lower levels of psychological distress. This finding is supported by Thombre et al. (2010) suggesting that religious coping efforts were significantly related to higher levels of growth and perceptions of positive life changes. On the other hand, the findings indicated that parents who often used negative religious coping methods tended to have more psychological distress than did parents using positive religious coping methods. This is comparable to a study of patients with advanced cancer (ages 21 years and older) and their non-related caregivers (N = 162), which suggested that negative religious coping strategies were correlated with an increased likelihood of major depressive and anxiety disorders (Pearce et al., 2006).

Negative religious coping methods reflect the struggle that grows out of a perception of a tenuous relationship with God, a more worrying view of life, and a sense of disconnectedness with a religious community (Nurasikin et al., 2013). Therefore, it is a challenge for nurses to be more sensitive and aware of the parents' religious coping pattern during everyday nursing care. However, nurses can complete a spiritual and cultural assessment upon admission that will help them gain prior information to support parents who need religious support. Some level of screening for religious coping method among parents and caregivers may helpful to identify those parents at risk for psychological wellbeing, and to provide spiritual support to gain control of their situation (Thombre et al., 2010).

Limitations

This study has several limitations. First selection biases might have occurred, as convenience sampling was used. Accordingly, some parents with psychological distress might have been over- or underrepresented. In the future, random sampling is recommended to avoid biases in sampling. As this study used questionnaires, and participants were requested to answer on the spot, some parents may have been unable to concentrate due to the need to calm their child if in distress. The researchers observed that parents might have answered quickly just to complete the questionnaire, which might cause recall bias. Hence, appropriate time and space should be given to parents to answer the questionnaire, especially when they are calming their children.

Besides that, the power of the study was affected due to the inability to reach the projected sample size. It was due to the availability parents who attend the day care centers for their child's transfusions and review appointments. Approximately 10–15 parents would visit the center with their children ages 15 years old and younger by appointment date (every two–three weeks) and the availability of donor's blood for transfusion. Due to the limitation of the number per visits, it limits the number of volunteer participants.

There was also a possible existence of self-report bias which limited the accuracy of information given by the parents, thus the generalizability is limited. Future study with a longitudinal design is recommended to determine the relationship between religious coping methods and psychological distress among parents caring for children with thalassemia. Lastly, parents may have felt pressured to participate in the study as all recruitment was completed by the researcher.

Practice implication

Parents in this study faced multiple challenges which affected their psychological wellbeing. Although results showed weak correlation, there are still some implications for practice. When parents are in distress, religious coping can be one of the choices of coping methods that can be suggested to parents other than non-religious coping methods. Nurses can introduce other religious colleagues to parents who need support. Helping parents to gain confidence and control of their psychological wellbeing helps to improve child health outcomes. Grosseohme et al. (2010) stated that religious supportive efforts not only help parents to find comfort through religious beliefs but also helps them gain control of their situation and find meaning in their experience.

Nurses are educated to respect every individual's culture and religious practices. Religious coping can be one of the choices to facilitate parents cope with their distress. Whereby, nurses understand and respect each cultural or religious belief in providing nursing care. Moreover, continuous nursing education on this aspect plays an vital role in reinforcing the nurses understanding in their coping method. Furthermore, nurses may work in collaboration with a religious leader such as the pastor, monk, imam, or other religious leaders to facilitate parents in coping with the stress and facilitate nurses a better understanding of religious perspective. Many major health organizations (such as the US Joint Commission for Accreditation of Healthcare [JCAHO] and American Psychological Association) require their members assess and provide spiritual care (Pearce et al., 2006). Lastly, attention should be given to parents who do not hold religious beliefs. These parents may need support in terms of counseling, learning coping skills or joining a support group for those dealing with thalassemia.

Conclusions

This study finding showed parents (42%, n = 68) caring for children with transfusion-dependent thalassemia experience psychological distress. They used positive religious coping methods more than negative religious coping methods. Organized Religious Activities, Non-Organized Religious Activities, and positive and negative religious coping methods were significantly related to parents' psychological distress.

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Declaration of Competing Interest

The authors declare no conflicts of interest.

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References

- Ali, S., Sabih, F., Jehan, S., Anwar, M., & Javed, S. (2012). Psychological distress and coping strategies among parents of Beta-Thalassemia Major patients. *International Conference on Clean and Green Energy*, 27. (pp. 124–128).
- Atkin, K., & Ahmad, W. I. (2000). Family care-giving and chronic illness: How parents cope with a child with a sickle cell disorder or thalassaemia. *Health & Social Care in the Community*, 8(1), 57–69.
- Aziz, K., Sadaf, B., & Kanwal, S. (2012). Psychosocial problems of Pakistani parents of Thalassaemic children: A cross sectional study done in Bahawalpur, Pakistan. *Biopsychosocial Medicine*, 6, 15. <https://doi.org/10.1186/1751-0759-6-15>.
- Banerjee, A. T., Watt, L., Gulati, S., Sung, L., Dix, D., Klassen, R., & Klassen, A. F. (2011). Cultural beliefs and coping strategies related to childhood cancer: The perceptions of South Asian immigrant parents in Canada. *Journal of Pediatric Oncology Nursing*, 28(3), 169–178. <https://doi.org/10.1177/1043454211408106>.
- Brown, B. J., Okereke, J. O., Lagunju, I. A., Orimadegun, A. E., Ohaeri, J. U., & Akinyinka, O. (2010). Burden of health-care of carers of children with sickle cell disease in Nigeria. *Health & Social Care in the Community*, 18(3), 289–295. <https://doi.org/10.1111/j.1365-2524.2009.00903.x>.
- Cardella, L. A., & Friedlander, M. L. (2004). The relationship between religious coping and psychological distress in parents of children with cancer. *Journal of Psychological Oncology*, 22(1), 19–37. https://doi.org/10.1300/J007v22n01_02.
- Centers for Disease Control and Prevention's CDC (2013). Thalassaemia. Retrieved from: http://www.cdc.gov/ncbddd/blooddisorders/documents/bbv_pnv_c0_1159_thalassaemia_r2mtr.pdf.
- Cotton, S., Grosseohme, D. H., Rosenthal, S. L., McGrady, M., Roberts, Y. H., Hines, J., & Tsevat, J. (2009). Religious/spiritual coping in adolescents with Sickle Cell Disease: A pilot study. *Journal of Pediatric Hematology/Oncology*, 31(5), 313–318.
- Elkin, T. D., Jensen, S. A., McNeil, L., Gilbert, M. E., Pullen, J., & McComb, L. (2007). Religiosity and coping in mothers of children diagnosed with cancer: An exploratory analysis. *Journal of Pediatric Oncology Nursing*, 24(5), 274–278. <https://doi.org/10.1177/1043454207305285>.
- George, E. (2001). Beta-thalassemia major in Malaysia: An on going public health problem. *Medical Journal Malaysia*, 56(4), 397–400.
- Goldberg, D., & Williams, P. (1988). *A users guide to the General Health Questionnaire*. Slough: NFER-Nelson.
- Grosseohme, D. H., Jacobson, C. J., Cotton, S., Ragsdale, J. R., VanDyke, R., & Seid, M. (2011). Written prayers and religious coping in a paediatric hospital setting. *Mental Health, Religion & Culture*, 14(5), 423–432. <https://doi.org/10.1080/13674671003762693>.
- Grosseohme, D. H., Ragsdale, J., Cotton, S., Wooldridge, J. L., Grimes, L., & Seid, M. (2010). Parents' religious coping styles in the first year after their child's cystic fibrosis diagnosis. *Journal of Health Care Chaplaincy*, 16, 109–122. <https://doi.org/10.1080/08854726.2010.480836>.
- Hexem, K. R., Mollen, C. J., Carroll, K., Lancot, D. A., & Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Medicine*, 14(1), 39–44. <https://doi.org/10.1089/jpm.2010.0256>.
- Koenig, H. G., Meador, K., & Parkerson, G. (1997). Religion index for psychiatric research: A 5-item measure for use in health outcome studies. *American Journal of Psychiatry*, 154, 885–886.
- Koenig, H. G. (2007). Religion, spirituality and psychotic disorder. *Journal of Clinical Psychiatry*, 1, 40–48.
- Koenig, H. G., & Bussing, A. (2010). The Duke University Religion Index (DUREL): A five-item measure for use in epidemiological studies. *Religions*, 1, 78–85. <https://doi.org/10.3390/rel1010078>.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.
- Liem, R. I., Gilgour, B., Pelligra, S. A., Mason, M., & Thompson, A. A. (2011). The impact of thalassemia of South East Asian and Asian Indian families in the United States: A qualitative Study. *Ethnicity and Disease*, 21, 361–369.
- Lozano, R., Naghavi, M., Foreman, K., Lim, S., Shibuya, K., Aboyans, V., & Murray, C. J. L. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: A systematic analysis for the Global Burden of Disease Study 2010. *Lancet*, 380(9859), 2095–2128.
- Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, 86(6), 417–496.
- Nurasikin, M. S., Khatijah, L. A., Aini, A., Ramli, M., Aida, S. A., Zainal, N. Z., & Ng, C. G. (2013). Religiousness, religious coping methods and distress level among psychiatric patients in Malaysia. *The International Journal of Social Psychiatry*, 59(4), 332–338. <https://doi.org/10.1177/0020764012437127>.
- Pargament, K., Feuille, M., & Burdzy, D. (2011). The Brief RCOPE: Current psychometric status of a sort measure of religious coping. *Religions*, 2, 51–76. <https://doi.org/10.3390/rel2010051>.
- Pargament, K. I. (1997). *The psychology of religion and coping: Theory, research practice*. New York: Guilford Press.
- Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion*, 37(4), 710–724.
- Pearce, M. J., Singer, J. L., & Prigerson, H. G. (2006). Religious coping among caregivers of terminally ill cancer patients: Main effects and psychosocial mediators. *Journal of Health Psychology*, 11(5), 743–759. <https://doi.org/10.1177/1359105306066629>.
- Sapountzi-Krepia, D., Roupas, 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), 142–152. <https://doi.org/10.1016/j.pedn.2005.06.017>.
- Shaligram, D., Girimaji, S. C., & Chaturvedi, S. K. (2007). Quality of life issues in caregivers of youngsters with thalassemia. *Indian Journal of Pediatrics*, 74(3), 275–278.
- Thombre, A., Sherman, A. C., & Simonton, S. (2010). Religious coping and posttraumatic growth among family caregivers of cancer patients in India. *Journal of Psychosocial Oncology*, 28(2), 173–188. <https://doi.org/10.1080/07347330903570537>.
- Widayanti, C. G. (2011). The perceived role of god in health and illness: The experience of Javanese mothers caring for a child with thalassemia. *Undip Psychology Journal*, 9(1), 50–56.
- Wu, C. S., & Liu, Y. J. (2013). Religious coping in life difficulties: A case study of Taiwanese folk religion female believers. *Mental Health, Religion & Culture*, 17(2), 210–218. <https://doi.org/10.1080/13674676.2013.787976>.
- Yusoff, M. S. B., Fuad, A., & Yaacob, M. J. (2010). The sensitivity, specificity and reliability of the Malay version 12-items General Health Questionnaire (GHQ-12) in detecting distressed medical students. *ASEAN Journal of Psychiatry*, 11(1), 36–43.