WALAILAK JOURNAL
http://wjst.wu.ac.th Health Sciences

Influencing of Family Management in Families with Thalassemic Children on Health Related Quality of Life and Family Functioning: SEM approach

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Received: 12 March 2017, Revised: 17 October 2017, Accepted: 10 November 2017

Abstract

Purpose: To predicate the way in which families incorporate the work of managing a child with thalassemia within family life and its outcomes. **Methods:** A correlational design with a structural equation modeling (SEM) approach was used. A total of 309 parents of children with thalassemia from 4 tertiary care hospitals in Thailand completed our questionnaires. **Results:** Family life difficulties had a negative influence on the child's health-related quality of life (HRQOL) ($\beta = -2.23$, $p < 0.05$) and family functioning ($\beta = -0.27$, $p < 0.05$), whereas the child's daily life ($\beta = 5.06$, $p < 0.05$) and condition management ability ($\beta = -1.86$, $p < 0.05$) had a negative influence on the child's HRQOL. In the final model, 3 variables including the child's daily life, condition management ability, and family life difficulty could explain 33 % of variance in the child's HRQOL ($R^2 = 0.33$). This model showed that only family life difficulty could explain 2 % of variance of family functioning ($R^2 = 0.02$). **Conclusions:** The study suggests that nurses should design interventions to support families in managing their child's conditions in order to achieve a good child and family outcomes.

Keywords: Family management, family functioning, health related quality of life, children with thalassemia, parental perception

Introduction

Thalassemias are genetic disorders. There are many types of thalassemic syndrome. In each type, there is a decreased production of one or more of the globin chains that make up hemoglobin. Without sufficient amounts of alpha-and beta-globin, sufficient hemoglobin cannot be formed resulting in a decrease in the amount of oxygen in body tissues, which ultimately results in the individual experiencing poor growth, organs damage and many other health issues. Individuals with thalassemia come from all ethnic groups and almost every country in the world. The common thalassemia diseases found in Thailand are homozygous β-thalassemia disease and β-thalassemia/Hb E disease [1]. However, the incidence of thalassemia is higher in certain countries. The incidence of hemoglobin [Hb] E approaches 60 % of the population in many regions of Southeast Asia, and also has high prevalence in Thailand [2]. It has been estimated that 30 - 40 % of the population in Thailand are carriers of alpha-or beta-thalassemia [3]. According to thalassemia foundation website, in Thailand, with a population of 65 million, about 40 % have thalassemia traits or are carriers, while 1 % of the population is afflicted with this disease [1]. This disease is mostly incurable and treatment procedures incur high costs such as stem cell transplantation.

Blood transfusion and infusion of iron chelating agents are basic treatments for improving both patient survival and quality of life [3]; children experience less health problems; and are able to live within the family unit rather than in hospital or special care clinic. Children depend on their parents to take care of their condition. Thus, thalassemia not only affects the child's lifestyle, but it also affects the family's life [4]. Families of children with thalassemia are especially important to know that a healthy lifestyle for the affected child means "managing the disorder", as well as healthy functioning family. Therefore, the day-to-day management of these children is the issue and concern of families. The routine care for an affected child may disrupt a parent's work life such as missing work. Family management with a child with thalassemia refers to parents' perception on the work of managing a child with thalassemia. For example, they bring a child with thalassemia regularly to the hospital for blood transfusions. Additional expenditures that families receive are due to increased use of special equipment, special medical services as well as transportation. Moreover, parents worry about their children's condition and future health such as school absentee, and suffering caused by their condition. Families that can manage well will have different outcomes, and this can be indicated by good quality of life and smooth family functioning. However, families who have a child with thalassemia need to change their daily life. For example, the family needs to manage the condition so that while at school the child can be included in activities with classmates such as playing football and they must carefully manage iron consumption through food [5]. As a positive result, families can achieve higher functioning with less negative effects on all members of the family despite caring for a chronically ill child [6]. Healthy functioning of the family is defined as "members with clear roles and structure; those whose family members are supportive each other and demonstrate open communication; and those who do not create family conflict" [7]. Families of a child with thalassemia may not only focus on defining parenting roles and structure to promoting their child's physical health, but also assist their child in developing psychosocial health. Good health and related quality of life in children with thalassemia depends on the medical care they receive which can significantly influence their psychosocial functioning. This issue may be a concern for their families to manage.

Nowadays, most studies in children with thalassemia have indicated that the severity of the disease and treatment has a negative impact on health-related quality of life [3,8], and the same results were reported in a study by Storch [9]. The family is most responsible for managing their child's conditions at home including the symptoms of the disease, and the side effects of any treatment. HRQOL is associated with the severity of the disease as well as family factors. Therefore, HRQOL in a child with thalassemia and family functioning are impacted by family management. The literature related to caring for a child with thalassemia shows it is increasingly evident that nurses needed a deeper understanding of how families respond to a child with thalassemia because understanding this provides knowledge for the health care professionals towards the way the family manages the chronic condition of their child, and the effect it has on the family. However, existing studies in exploring the relationship among influential factors on health have been primarily on children with thalassemia. Few studies have addressed the family management styles of families who have a child with thalassemia that focus on family and child functioning (such as HRQOL). Therefore, this study attempts to describe the influence of family management on families of a child with thalassemia on the HRQOL of a child and family functioning.

Conceptual framework

The theoretical framework guiding this study was the family management style framework [FMSF]. Knafl and Deatrick [6] explained that the FMSF is used to describe family response to health-related challenges. The FMSF was developed to enhance understanding of how families incorporate the work of managing a child's chronic condition within family life. The framework is composed of 3 major components: definition of the situation, management behaviors, and perceived consequences. Each component is composed of conceptual dimensions that reflect more specific aspects of the component. The dimensions of the FMSF consist of; 1) the family's view of the child's daily life, 2) the impact of the condition on family life, 3) the difficulty of family life, 4) the family's effort in managing the child's condition, 5) the family's ability in managing the child's condition, and 6) parental mutuality, that influence family management. FMSF classifies the outcomes into 2 groups including individual

functioning (HRQOL of a child with thalassemia) and family functioning. The continuing condition management to family life such as adherence to treatment regimens, has been associated with improved condition outcomes and HRQOL of children with thalassemia.

Hypothesis: The 6 dimensions of family management styles in families of a child with thalassemia influences on family functioning and HRQOL of a child.

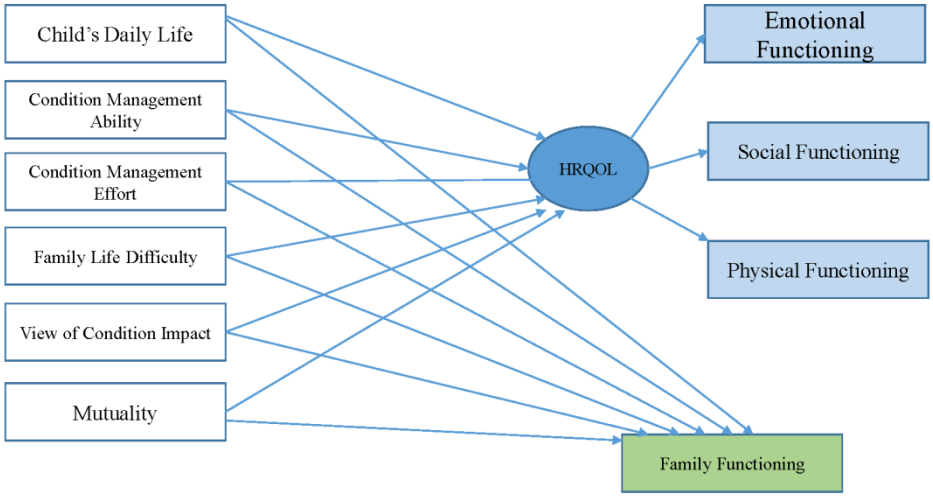

Figure 1 A hypothesized model of family management of families of children with thalassemia.

Materials and methods

Research design

A correlational design with random sampling was used. This study focused on parents of children with thalassemia (aged 1 to 15 years old) attending the hematology clinic and the pediatric unit. The samples of parents of children with thalassemia were recruited from tertiary care hospitals in the central region, the east and north-east of Thailand. A parent should be a primary caregiver of a child with thalassemia, at least 18 years of age, and able to read and communicate in Thai. The sample size: the main analysis method used in the study was structural equation modeling. A sample size of 87 was needed to detect a medium effect size of 0.15 [10] with a statistical power of 0.80 at 0.05 alpha level with 1 latent variable and 7 observed variables. Taking into account the possibility of 10 % missing data, the desired sample size was set at least 100.

Protection of human subjects

Approval was obtained from the ethical approval committee, Burapha University and reviewed by the hospital system. Participants were also informed that their information was kept confidential. Names of participants were replaced with study identification numbers. A logbook linked participant names with study identification numbers and the completed questionnaires were kept in a password protected computer. Although there were no physical risks or harms anticipated for this study, parents who become emotionally stressed while completing the measures were encouraged to contact the researcher. Then, they were referred to appropriate counseling or psychological services.

Measures

1) Background information: This form consists of questions about parental age, gender, and educational level, as well as a question about family income and type of universal coverage scheme.

2) Family Management Measure (FaMM) [6,11] was used to assess parental perspectives on how the family is managing the care of the child with thalassemia and the extent to which they are able to incorporate thalassemia into everyday life. FaMM consists of 53 items and there are 6 scales: 1) child's daily life (5 items), 2) condition management ability (12 items), 3) condition management effort (4 items), 4) family life difficulty (14 items), 5) view of condition impact (10 items), and 6) parental mutuality (8 items). The parental mutuality scale is not used with non-partnered parents. Parents are asked to respond to statements using a 5-point Likert scale. Scores are calculated for each of the 6 FaMM scales using the scoring instructions found on the FaMM webpage. According to Knafl [7], internal consistency reliability for the 6 scales ranged from 0.72 to 0.90. Test-retest reliability based on the responses from 65 parents who were retested within 2 - 4 weeks, ranged from 0.71 - 0.94. Construct validity was supported by significant correlations with related constructs in established measures. (e.g. family functioning by the McMaster family assessment device). In this study, Cronbach's alpha for 6 dimensions of family management measure ranged from 0.26 to 0.82 (**Table 1**).

3) Brief Family Assessment Measure-General [BFAM-G]: the BFAM-G is a 14-item measure developed by Skinner [12], to provide an overall rating of family functioning. Respondents are asked to respond to each item using a 4-point Likert scale (0 = strongly agree; 1 = agree; 2 = disagree; 3 = strongly disagree). The BFAM-G is based on the general scale of the family assessment measure [FAM III], a self-report measure designed to assess concepts in the process model of family functioning. According to Skinner [12], the alpha coefficient for the general scale is 0.93. Correlations between the BFAM-G and the longer FAM-G have ranged from $r = 0.49$ to $r = 0.64$ with a median item total correlation of $r = 0.59$. With regard to validity, the general scale has significantly differentiated between clinical and non-clinical families [12]. A total score is calculated for BFAM-G by doing the following. First, responses to the 7 negatively phrased statements were reverse coded. Then, the positive item responses and the negative reverse coded items were summed to calculate a total score. The total score is then converted to a t-score or percentile using the conversion table provided for the scale. T-scores have a mean or average of 50 and a standard deviation of 10. If an individual's raw score converts to a t-score of 50, the individual is responding at the average of the response group. Overall, the interpretation is as follows; t-scores of 65 or above indicate problematic family functioning; t-scores between 56 and 64 indicate increasing problem in family functioning; t-scores between 45 and 55 indicate average; t-scores between 36 and 44 indicate increasing strengths; t-scores 35 and below indicate excellent family functioning. Cronbach's alpha for BFAM-G was 0.80. This indicated an acceptable value of the internal consistency.

4) PedsQL™ parent proxy-report (PedsQL™ 4.0) [13]. This measure was developed by Verni [13] to assess parent's perception of their child's HRQOL in children and adolescents aged 2 to 18 years. The 23-item measure includes: 1) physical functioning (8 items), 2) emotional functioning (5 items), 3) social functioning (5 items), and 4) school functioning (5 items). Parents were asked to indicate how much of a problem each item was for their child during the past month. A 5-point response scale is utilized across the parent report (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0 - 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate a better HRQOL. Reliabilities for the parent proxy report total scale score have been reported to be 0.90 or above across all ages groups [13]. Alpha values for the majority of the individual parent proxy report scales were above 0.70 for most age groups. PedsQL™ Parent proxy-report was used to better understand the child's HRQOL by obtaining a parent's perspective to provide an adequate normalization of family life with thalassemia. Children who are less than 6 year of age, are not attend in school. Therefore, this study focused on three dimension of HRQOL, except school functioning for all. Cronbach's alpha in this study for the total scale was 0.85 and ranged from 0.82 to 0.86 for the subscales.

Data collection

Data collection began once approval was received from the ethical approval committee and reviewed by the hospital system. The researcher sent a letter to the directors of the 4 hospitals to see if participants could be recruited from the hematology clinics located in their hospitals. Once the permission letter was signed, the researcher arranged a meeting with clinicians (e.g. hematologist, directors of nursing departments, head nurses, and staff nurses) who were leading or working in the hematology clinics and the pediatric units located within that hospital. The purpose of the meetings was to provide information about the purpose of the study, inclusion criteria, the recruitment process and the process of informed consent. All 4 of the hematology clinics were staffed by a hematologist and hematological nurses. Annually, the age ranges for the children were between 2 - 15 years. The hematology clinics were held 2 days per week. For each visit, the children usually spent 30 to 60 min in the thalassemia clinic. Then, the children and their parents were moved to the pediatric unit so the child could receive his/ her transfusion. The transfusion process took between 4 - 5 h to complete. Parents remained with the child during the transfusion process. Nurses from the 4 hematology clinics and the pediatric unit were asked to share information about the study with parents. Once a parent expressed interest in learning more about the study, they had the opportunity to ask questions and express concerns about study participation. Then, if the parent agreed to participate in the study, the parent was asked to sign a consent form and was given a packet of study materials. Parents were encouraged to complete the packet prior to leaving the hospital. Given that the transfusion process took between 4 - 5 h and the packet of questionnaires took approximately 20 - 30 min, most parents had adequate time to complete the packet of questionnaires before leaving the hospital. However, if this was not possible, parents were given a pre-stamped, pre-addressed return envelope or they were given the opportunity to bring the completed packet of measures with them during their child's next visit to the clinic.

Table 1 Study variables and Cronbach' alphas.

Observed variables	Items	Possible range	Actual range	Cronbach's alpha
FaMM				
Daily life of a child	5	5-25	10-25	.26
Condition management ability	12	12-60	28-58	.71
Condition management effort	4	4-20	8-18	.60
Family life difficulty	14	14-70	18-55	.82
View of condition impact	10	10-50	19-41	.63
Parental mutuality	8	8-40	19-40	.60
BFAM-G	14	0-42	5-37	.80
PedsQL™ parent proxy-report				
Physical functioning	8	0-800	21-100	.82
Social functioning	5	0-500	35-100	.75
Emotional functioning	5	0-500	25-100	.58

Data analyses

Descriptive statistics were used to analyze the demographic characteristics. Each variable was screened for missing data, univariate, multivariate outliers, and normality. The data were screened for normality using skewness, and kurtosis scores divided by its standard error. Multivariate normality of data was tested by Mardia's test. A normalized multivariate kurtosis value not much larger than 10 is regarded as satisfactory [14]. A bootstrapping procedure was applied; the bootstrapping is an option for

small samples, or sampling with replacement from an original data set to a desired sample size [15]. This study used the structure equation model. Indicators of the overall fit of the model with the data used in this study were Goodness-of Fit Index (GFI), the Adjusted Goodness of Fit Index (AGFI), and Comparative Fit Index (CFI). Values above 0.90 were regarded as adequate and above 0.95 reflected a good model fit. A Root Mean Square Error of Approximation (RMSEA) was used to determine the parsimonious fit of the model. A RMSEA value of less than 0.05 indicates a good fit with a value between 0.05 and 0.08 showing a moderate fit and values 0.08 to 0.10 indicate a fair fit, while values greater than 0.10 indicate a poor fit.

Results and discussion

Demographic data of the participants

A total of 309 parents, who met the inclusion criteria, consented to participate in the study. The majority of participants (73.8 %) were mothers. For parents' age, most parents (39.5 % of mothers, 43 % of fathers) were aged between 26 to 35 years with a mean of 34.8 years (*SD* = 6.6 years) for the mother, and 38.06 years (*SD* = 7.6 years) for the father. Most parents were Buddhists. Nearly three-fourths of the parents (72.2 %) were married followed by those who lived with their partner (27.8 %). Regarding educational attainment, parents (50.4 % mothers, 45.6 % fathers) had received at least a secondary school in comparison to parents having received a bachelor's degree or higher (14.4 % mothers, 12.3 % fathers). Over half of parents were labor workers (71.6 % fathers, 47.8 % mothers). Parents had a monthly family income ranged from 15,000 to 50,000 Baht (*M* = 21,268.18 Baht, *SD* = 20,204.4). Nearly half of the parents (48.2 %) had sufficient family income for living. No families were identified as lacking health insurance; they were covered by Universal Health Care coverage (**Table 2**).

Table 2 Demographic characteristics of families of children with thalassemia.

		n	**%**
Parents	Father	81	26.3
	Mother	228	73.8
Marital	Married	221	71.5
Partnered/ Living together		88	28.5
Family income: Range = 200000-0, *M* = 21268.18 Baht (*SD* =20204.42)			
	< 15,000	68	22
	15,000-35,000	176	44.7
	35,001-50,000	34	11
Sufficiency: Insufficient		142	46
Sufficient for living		149	48.2
Sufficient for living and saving		18	5.8
Health Insurance Universal health care coverage		309	100

The descriptive statistics of variables

The study variables including the family management measure (FaMM), family functioning (BFAM-G), and health related quality of life (PedsQL™ 4.0 parent proxy report) are described as follows (**Table 3**). Child's daily life scores ranged from 10 - 25 with a mean of 18.3 (*SD* = 3.5). Condition management ability scores ranged from 28 - 58 with a mean of 42.6 (*SD* = 5.8). Parental mutuality scores ranged from 19 - 40 with a mean of 29.9 (*SD* = 4.5). Condition management effort scores ranged from 8 - 18 with a mean of 12.9 (*SD* = 2.4). Family life difficulty scores ranged from 18 - 55 with a mean of 34.3 (*SD* = 8.6). View of condition impact scores ranged from 19 - 41 with a mean of 30.2 (*SD* = 4.5). Parental perception of physical functioning ranged from 21 - 100 with a mean of 66.3 (*SD* = 17.9), on emotional functioning ranged from 25 - 100 with a mean of 62.4 (*SD* = 16.2), and ranged from 35 - 100 with a mean of 66.3 (*SD* = 14.5) for social functioning.

Table 3 Descriptive statistics of observed variables.

Observed variables	No. of items	Possible range	Mean	SD
Child's daily life	5	5-25	18.3	3.5
Condition management ability	12	12-60	42.6	5.8
Parental mutuality	8	8-40	29.9	4.5
Difficulty of family life	14	14-70	34.3	8.6
View of condition impact	10	10-50	30.2	4.5
Condition management effort	4	4-20	12.9	2.4
PedsQL™ 4.0				
Physical functioning	8	0-100	66.3	17.9
Emotional functioning	5	0-100	62.4	16.2
Social functioning	5	0-100	66.3	14.5

The brief family assessment measure-general (BFAM-G) assesses parent's perception of strength and weakness in their role and structure in the family of a child with thalassemia. The BFAM-G has a potential score range from 0 - 42. Scores on BFAM-G are given in **Table 4**. Parents had a score ranging from 5 - 37 for mothers, and 6 - 36 for fathers. The total score is converted to a t-score using the conversion table provided for the scale. T-scores of 35 and below indicates excellent family functioning. The study results showed approximately 69.7 % of the mothers and 64.2 % of the fathers were in the problematic level group and only 4.4 % of the mothers and 3.7 % of the fathers were in the increasing strengths group.

Table 4 BFAM-G score of the study variables.

BFAM-G	**T-score**	**Mother (*n* = 228)**	**Father (*n* = 81)**
Problematic	≥ 65	159 (69.7 %)	52 (64.2 %)
Increasing problem	56-64	35 (15.4 %)	19 (23.5 %)
Average	45-55	24 (10.5 %)	7 (8.6 %)
Increasing strengths	36-44	10 (4.4 %)	3 (3.7 %)

Model testing: The influence of the 6 dimensions of family management style in families of a child with thalassemia on family functioning and HRQOL of a child was tested**.** Before the full model was examined, measurement models used to assess the relationships among observed variables and the latent variables were examined. HRQOL of children with thalassemia was assessed using PedsQL™ parent proxy-report including its 3 subscales physical functioning, emotion functioning, and social functioning. All of the indicators were loaded on their particular factor at 1.00 or greater (**Table 5**). Higher loadings indicate a stronger relationship between the indicator and latent variables [16]. Thus, the measured variable and latent variable were identified as adequate for the structural model testing.

Table 5 Factor loading for the measurement.

	Estimate	**S.E.**	***t***	***p***	R^2
Physical	1				.4
Emotional	4.73	.92	5.12	< .05	.4
Social	3.35	.63	5.33	< .05	.3

Data analysis revealed non significant Chi-square (X^2) value for the hypothesized model of 27.47, $df = 23$, $p = 0.23$. The values of GFI = 0.98 and CFI = 0.99 were greater than 0.90, and RMSEA = 0.025 was less than 0.10 (**Table 6**). These indicate that the overall fit indices for the initial hypothesized model testing were acceptable and that the hypothesized model was fit with the actual data of this study. The final model indicated that family life difficulty had a direct negative influence on HRQOL ($\beta = -2.23$, $p < 0.05$) as well as family functioning ($\beta = -0.27$, $p < 0.05$), whereas the child's daily life ($\beta = 5.06$, $p < 0.05$) and condition management ability ($\beta = -1.86$, $p < 0.05$) directly influenced the HRQOL of the child (**Figure 2**). In the final model, 3 variables including the child's daily life, condition management ability, and family life difficulty could explain 33 % of variance in the HRQOL of a child ($R^2 = 0.33$). In addition, this model showed that family life difficulty only could explain 2 % of variance of family functioning ($R^2 = 0.02$).

Table 6 Statistics of model fit index between the hypothesize model and acceptable score.

Model fit criterion	Acceptable score	Hypothesized model
CMIN	$0.05 > p \leq 1$	27.47 (p = .23)
CMIN/ df	< 3	1.2
AGFI	≥ .90	.96
GFI	≥ .90	.98
CFI	≥ .95	.99
RMSEA	≤ .05	.025

Note: CMIN = minimum Chi-square, AGFI = Adjusted goodness-of-fit index, CFI = Comparative Fit Index, GFI = good-of-fit index, RMSEA = root-mean-square error of approximation, Normed Chi-square (CMIN/ df)

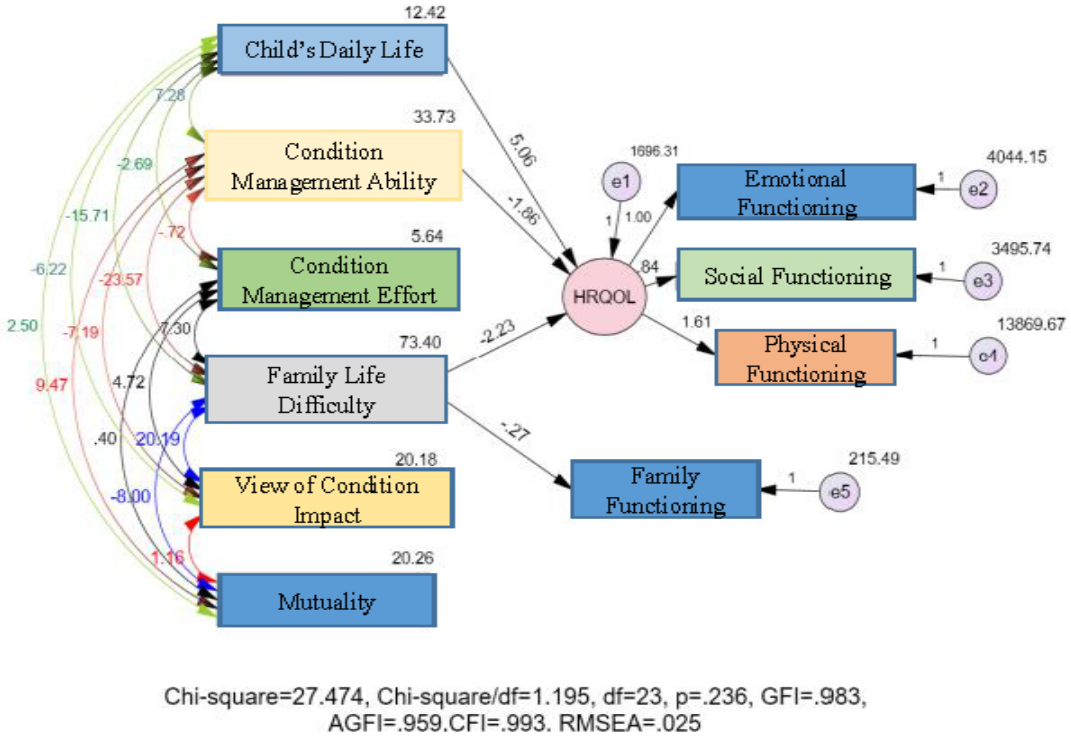

Figure 2 The final model of family management in families of a child with thalassemia.

Discussion

Based on the theoretical model proposed in the present study, 3 variables including the child's daily life, condition management ability, and family life difficulty could explain 33 % of variance of the HRQOL of a child (R^2 = 0.33). In addition, this model showed that family life difficulty only could explain 2 % of variance of family functioning (R^2 = 0.02). In this study sample, there was low internal consistency reliability on the daily life of a child dimension (Cronbach's alpha = 0.26) of the FaMM, which depicts the child's ability to have a normal daily life despite their illness. However, parents who participated may have had concerns about their child's condition in transfusions that prompted them to respond.

Children with thalassemia require blood transfusions every 4 - 6 weeks, medication every day and iron chelation injections 3 - 5 days/week. They come at least every month to the hospital to get a blood transfusion. The children with thalassemia do not complain of difficulty in their daily life such as studying, playing with classmates, hygiene care, taking medicine, or eating [7]. It was found that the children with thalassemia still have normal IQ scores and normal intellectual development when compared with healthy children [17]. Most studies in children with thalassemia have shown that the medical care they received not only improved HRQOL, but also life expectancy. Parents perceived that having a child with thalassemia did not make it difficult to balance their child's condition and family life, or fit with family routine, and also their perception on the seriousness of thalassemia and its implications would not make it harder to take care of the child and the family in the future. Parents tried every possible treatment option to save their child's life, like parents of children with any other chronic condition. In a survey of 59 children and 129 parents, the results showed 86 % of parents believed that their child would not have a shortened life [18]. There are enormous costs when they are living with sickle cell disease. In developing countries, it has a high cost in lives and morbidity and cannot be treated appropriately because of a lack of resources [19]. However, transfusions for thalassemia in Thailand are supported under the Universal Health Coverage scheme [UC] in the fiscal year 2007 [3]. The empirical evidence reveals an improving trend in health equity in terms of both access and financial protection of the use of health services is in favor of the poor within the district health system, which includes health centers and district hospitals as the contractor providers. These institutions play a crucial role in pro-poor health service provision, due to their geographical proximity to the rural population, which is mostly poor [11].

This study also demonstrated a relationship between family management style and family functioning. Contrary to expectations, family management style had a partial influence on the family functioning. Lower scores in family life difficulty were related to a greater perception of family functioning ($\beta = -0.27$, $p < 0.05$). SEM analysis also demonstrated that family life difficulty could explain 2 % of variance of family functioning (R^2 = 0.02) in this study. There are several explanations of this finding in terms of the strong adherence to family values. Thai parents have parenting responsibilities, and expressed concern about the importance of their caring responsibilities. Thus, a family's duties that help parents work together toward their goals included child health outcomes. Parents have an alternating duty, for example when they accompany with their child to hematology clinic, they may have support from family and kinship. Consistent with Zhang [21], Chinese and other Asians prefer direct family members to be their primary source of support. Chinese mothers depend extensively on the knowledge and skills of their extended family members for advice and assistance in condition management. Another characteristic of Thai family's is the influence of religious beliefs, family relationships, and societal values [22]. Especially, Buddhist values have a strong influence on Thai health beliefs [23] and the management of the condition. The parents of children with thalassemia in this study were recruited from tertiary care hospitals in the central region, the east and north-east of Thailand. They are different in the geographic context. However, the value of taking care of a family member is similar and strong. Parents are more likely to spend time at home, and they live close to their extended family. Hence, their condition management is more subject to family functioning. Moreover, parents usually take an important role in decision-making of what they believe to be the best for their child [8]. Parents have responsibility for any of the child's problems. Parents are continuously in control of their children's daily lives and children are expected to obey their parents. Therefore, parents receive support not only from

family members, but also from extended family and neighbors to maintain care roles. Moreover, Thai culture, especially Buddhist tradition in which parents are respected, promotes a positive attitude and a friendly concern to other families. Parents wish other families to not experience the same problems they have faced [4].

Importantly, parents who are Buddhists believe in karma and in a previous existence. The concept of karma is used to explain cause and effect. The laws of karma teach that if people do well, they will experience well and if they do evil, they will experience evil, but may not be able to explain the balance because the effects may be the result of actions done in a prior incarnation. These findings are consistent with those of Tedsiri [4] that the mothers believed that good karma must be repaid throughout good care.

Conclusions

Health care professionals should facilitate and encourage family members or caregivers to promote thalassemia management behaviors. Multidisciplinary teams consisting of nurses, physicians, pharmacists, dietitians, and school health nurse should work with families and pay focus on enhancing their perceptions of a child with a normal life to promote their children's health. This result provides basic information for primary, secondary, and tertiary hospital administrators and school administrators to determine the health care policy and strategic plan for improving HRQOL in children and their families by promoting parental focus on the daily life of the child to reduce difficulties in family life.

Implications for nursing practice

Nurses should incorporate the comprehensive assessment of parental perception on the child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact and parental mutuality as an integral part of the routine assessment process in the nursing care plan for improving HRQOL in children and their families by promoting parental focus on the daily life of the child to reduce difficulties in family life.

Limitations of the study

There are some limitations in this study. First, the daily life of a child with thalassemia changes over time, and depends on the view of thalassemia impact, family adaptation and their life experiences. Therefore, the child's daily life items in the family management measure in this study had low internal consistency reliability which might limit generalization of the study results. In addition, the parents may have had concerns about their child's condition so they may have been distracted while completing the questionnaire. It is postulated that the length of the instrument may have been burdensome in an environment with limited time and distractions.

Acknowledgements

The author would like to express a special recognition to Suan Dusit University for providing scholarship for doctoral study and the National Research Council of Thailand for research funding.

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