

PREDICTORS OF FAMILY MANAGEMENT BEHAVIOR FOR CHILDREN WITH THALASSEMIA

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Abstract. Children with thalassemia can thrive with quality care by their families. The purpose of this study was to examine predictors of family care behavior by family caregivers of children with thalassemia. Eighty-eight family caregivers for children with thalassemia aged 1-16 years were recruited by purposive sampling from in-patient and out-patient clinics in an eastern regional hospital in Thailand. Research instruments were 5 self-administered questionnaires: 1) demographics of family caregivers, 2) perceived family management, 3) medical adherence, 4) health literacy, and 5) family management behavior. Data were analyzed by percentages, means, standard deviations, Pearson's product moment correlation and multiple regression. The strongest predictor for family management behavior was perceived family management ($B=0.550$, $p<0.001$), it accounted for 26.3% of the variance. Health literacy ($B=0.337$, $p=0.024$) accounted for 4.5% of the variance. When these two dependent measures were combined, they accounted for 30.8% of the variance ($R^2=0.308$, $F=18.933$, $p<0.001$). Within the three subscales of family management behavior (medical, role, and psychosocial management), medical adherence, health literacy and perceived family management, together accounted for 22.6% of the variance for medical management. Perceived family management and health literacy together accounted for 30.3% of the variance in role management. Perceived family management accounted for 20.9% of the variance in psychosocial management. These findings suggest a tailored intervention program should emphasize promoting family management and increasing health literacy to improve the quality of family management behavior for children with thalassemia.

Keywords: family management, family caregivers, behavior, thalassemia, children

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INTRODUCTION

Thalassemia is a chronic childhood disease found throughout the world. In the Middle East β -thalassemia predominates while many Asian countries have a high prevalence of both β -thalassemia

and hemoglobin E. Thalassemia affects the ability to produce normal hemoglobin, and can result in either moderate or severe anemia (Weatherall, 2005). Affected children suffer in all dimensions of their lives: physiologically (anemia, weakness, fatigue, shorter stature, large abdomens and delayed puberty), psychologically (poor self-image and peer group rejection), socio-culturally (limited participation in peer/social/athletic activities, isolation, and school absenteeism) and spiritually (feelings of aimlessness, powerlessness, hopelessness and worthlessness) according to their developmental stage (Aydin *et al*, 1997; Gorree, 2001).

Approximately 5% of the world's population, 250 million people, have abnormal genes that can transmit thalassemia; about 300,000 children are born with thalassemia each year (WHO, 2006). In Thailand, 1% of the population (630,000) has thalassemia (MoPH, 2006). Approximately 30% to 40% (20 to 24 million) are carriers of the genes that transmit thalassemia. The number of infants born with thalassemia has increased by 12,125 cases per year for the past 16 years (MoPH, 2006).

Until the 1970s, most children with thalassemia died in early childhood. As a result of advances in scientific knowledge and technology, thalassemia is no longer a hopeless disease. Children with thalassemia can now look forward to a long and productive life. Family caregivers are important persons in the child's care of this chronic condition. Family caregivers provide direct care for the child's medical condition and monitor the child's well-being and developmental/academic progress.

Consistent with previous studies on family caregivers of children with thalassemia, Wacharasin and colleagues (2006)

studied mothers in Chon Buri Province, Thailand and found most had no experience in caring for a chronic illness and needed up-to-date information about the treatment of thalassemia. Additionally, mothers had insufficient knowledge about the condition, such as the rate of occurrence or reoccurrence, the inheritance pattern, the indications for a splenectomy and parenting concerns. Support from family and health care professionals is important (Disayabood, 1994; Prasomsuk *et al*, 2007). The few studies published on the impact of thalassemia on family caregivers, specifically mothers, have reported the impact psychosocially, emotionally and financially (Tsiantis *et al*, 1996; Prasomsuk, 2005; Wacharasin *et al*, 2006). However, little research has focused on examining factors contributing to family management behavior. Thus, it is necessary to describe family management behavior and the related factors.

Conceptual framework

This study was guided by the Family Management Framework of chronic conditions described by Grey *et al* (2006). Over the past 20 years, the family management framework has described the family response to care of childhood illness and developed details of conceptual, empirical and methodological work (Knafl *et al*, 2008; Deatrick *et al*, 2009). Several factors impact a family's ability to manage care according to this framework. Factors that may impact family management behavior include family demographics, health literacy, medical adherence and perceived family management. This study focused on factors of the framework that impact the family's ability to care for children with thalassemia.

Family demographics include age, marital status, education, occupation and family income. The impact of these

variables on family management behavior was demonstrated in a study on diabetics by Fisher *et al* (1998). The study revealed lower socioeconomic status is associated with poorer disease management and higher socioeconomic status is related to better care management.

Health literacy is the ability of family caregivers to understand basic health knowledge about thalassemia in order to make appropriate health decisions for affected children (Ratzan and Parker, 2000). Several studies have demonstrated low health literacy is associated with poorer health outcomes and is a barrier to active participation and self-management (Schilling *et al*, 2002; Coleman and Newton, 2005; Paasche-Orlow *et al*, 2005).

Medical adherence, as described by Sabate (2003), refers to the family caregivers' adherence to medical advice, such as blood transfusions, administration of medication, diet and exercise. A review of the literature shows medical adherence is associated with better health outcomes and quality of life (Feldman *et al*, 2007; April *et al*, 2008).

Perceived family management refers to the family caregiver's perspective on the management of the child with thalassemia. Knafl and Deatrck (1990, 2003), utilizing the family management style framework, described how family management influences family functioning that then affects the family life of the child with a chronic illness. For example, families with floundering management had significantly lower satisfaction with family life than families with thriving, enduring, and struggling management. Higher family functioning was associated with better family management of chronic conditions (Fisher *et al*, 1998; Grey *et al*, 2006).

The dependent variable for this study was family management behavior. Family management behavior refers to the family's ability to care for a child with thalassemia by reducing the physical symptoms and maintaining health. Family management behavior consists of three basic tasks: 1) medical management-- direct care of the child's treatment regimen, scheduled doctor appointments and symptom assessment; 2) role management-- maintaining and encouraging the routine daily family activities of the child's health care, managing the burden of caring and environmental and financial concerns; and 3) psychosocial management-- support of family interaction and social life (Coleman and Newton, 2005; Lorig *et al*, 2006).

This study examined variables (family demographics, health literacy, medical adherence and perceived family management) contributing to family management behavior of children with thalassemia. The conceptual framework was based on the Family Management of a Chronic Condition, and is illustrated in Fig 1.

MATERIALS AND METHODS

Study sample

The participants were family caregivers of children with thalassemia who were recruited from the out-patient departments (OPD) and/or in-patient departments (IPD) of thalassemia clinics from April to November 2010 from an eastern regional hospital in Thailand. Family caregivers were recruited purposively into this cross-sectional study. The inclusion criteria were: the participant must be either a mother, father or relative who is the primary caregiver living in the same house with a thalassemic child who assumes the primary responsibility for the

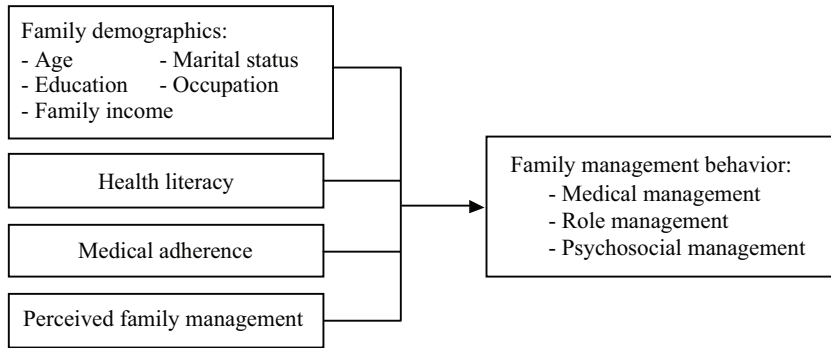


Fig 1–The conceptual framework.

regular and continuous care of the child, is able to communicate verbally and willing to participate in the study. Families were defined as the group which included at least one child with thalassemia and a responsible caregiver plus other family members, such as parents, siblings, grandparents or cousins. Families with primary caregivers who were ill were excluded from this study.

The sample size estimation for multiple regression with 4 independent variables with a power of 0.80, an alpha level of 0.05, and a medium effect size of 0.15, was 82.32 (Cohen, 1988). The actual collected samples included 88 family caregivers.

Data collection

This study was the first phase of a research project to develop a family management program for children with thalassemia. Data were collected after this study was approved by the Mahidol University Institutional Review Board (MU-IRB 2010/038.2801) and the Research Ethics Board of Chon Buri Hospital (No. 16/2010). After consent was obtained from participants, they completed 5 self-administered questionnaires. Two caregivers needed assistance to read the questionnaire due to visual problems.

Questionnaires

The Family Demographics (FD) questionnaire. The FD questionnaire obtained socio-demographic data about the caregiver, including age, marital status, educational level, occupation, and family income.

The Perceived Family Management (PFM) questionnaire. The PFM questionnaire was modified from the Family Management Measure questionnaire (FaMM) (Knafl *et al*, n.d.), which assessed perspectives of the caregivers regarding managing a child with a chronic illness. The researcher tailored the wording to be applicable to children with thalassemia. It consisted of 46 questions with six subscales: the child’s daily life, the impact of the condition on family life, the difficulty of family life, efforts to manage the condition, the ability to manage the condition, and parental mutuality (for partnered parents only). A 5-point Likert scale (1=strongly disagree to 5=strongly agree) was utilized. The total score ranged from 46 to 230 points. The higher the score, the higher the perceived family management. The mean score was categorized into three levels: low (46-107.32), moderate (107.33-168.67) and high (168.68-230). The Cronbach’s alpha coefficient was used to test internal consistency yielding the value of 0.77.

The Family Management Behavior (FMB) questionnaire. The FMB questionnaire was developed specifically for children with thalassemia (Coleman and Newton, 2005; Lorig *et al*, 2006). It consisted of 57 items with three content areas: 14 items on medical management, 27 items on role management, and 16 items on psychosocial management. The answers to the questionnaire were on a 5-point Likert scale (1=never to 5=always) with the total score ranging from 57 to 285 points. The higher the score, the better the family management behavior. The mean total FMB scores was categorized into low (57-132.99), moderate (133-209) and high (209.01-285). The three subscales (medical management, role management and psychosocial management) were divided into low (14-32.66, 27-62.98, and 16-37.32), moderate (32.67-51.33, 62.99-99.0, and 37.33-58.67) and high (51.34-70, 99.01-135, and 58.68-80). The Cronbach's alpha coefficient of FMB was 0.88.

Medical Adherence (MA) questionnaire. The MA questionnaire is specific for children with thalassemia (Leickly *et al*, 1998; De Civita *et al*, 2005). It consisted of 18 items with four subscales: 4 items on blood transfusions, 8 items on medication, 3 items on exercise, and 3 items on diet. Participants were asked to respond on a number scale (0=never to 100=always; or 0=not difficult to 100=most difficult). Because of no response on some items (taking medicine, injecting Desferal), raw scores were converted to scaled scores that ranged from 0-100. The higher the score, the greater the medical adherence. The mean score was divided to three levels: low (<59.99%), moderate (60%-79.99%) and high (>80%) (Bloom *et al*, 1971). The Cronbach's alpha coefficient was 0.76.

The Health Literacy (HL) questionnaire. The HL questionnaire was based on the

Test of Functional Health Literacy in Adults (TOFHLA) (Parker *et al*, 1995). The HL questionnaire measured knowledge of thalassemia, medication and treatment regimens by family caregivers. The instrument had 33 multiple-choice questions, each with three possible choices and one correct answer. Because of no response on some items (taking medicine, injecting Desferal), raw scores were converted to scaled scores that ranged from 0-100. The higher the score, the higher the health literacy. The score was used to categorize the results: inadequate health literacy (<59.99%), marginal health literacy (60-74.99%) and adequate health literacy (>75%) (Parker *et al*, 1995). The Cronbach's alpha coefficient was 0.66.

Validation of the questionnaires

The questionnaires were checked for content validity by a hematologist, nursing instructor, pediatric nurse, and two experts experienced in family health. Following the experts' recommendations, the questionnaires were modified and piloted with 30 family caregivers who had children with thalassemia similar to the study subjects.

Data analysis

Data were analyzed using SPSS for Windows (version 18). All variables met assumptions of normality except family demographics where only age had a normal distribution, while other family demographics did not follow normality. Therefore, logarithm transformation that reduced the positive skew of family income was employed to obtain normal distribution. The Pearson's product moment correlation was used to analyze relationships among age, family income, perceived family management, health literacy, medical adherence and family management behavior. The χ^2 test was

Table 1
Perceived family management, health literacy, medical adherence and family management behavior (*n*=88).

Variables	Possible range	Actual range	Mean (SD)	Level
Perceived family management	46 - 230	120 - 206	167.25 (16.17)	Moderate
Health literacy	0 - 100	29.7 - 82.8	63.74 (11.25)	Moderate
Medical adherence	0 - 100	41.4 - 98.6	75.08 (13.46)	Moderate
Family management behavior:	57 - 285	163 - 260	221.30 (17.88)	High
Medical management	14 - 70	42 - 70	59.38 (6.33)	High
Role management	27 - 135	69 - 120	98.02 (8.17)	Moderate
Psychosocial management	16 - 80	35 - 80	63.89 (6.83)	High

Table 2
Relationships among family caregiver age, family income, perceived family management, health literacy, medical adherence and family management behavior (*n*=88).

Variables	<i>r</i>	<i>p</i> -value
Age	-0.129	0.230
Family income (log)	0.234	0.028
Perceived family management	0.513	<0.001
Health literacy	0.243	0.022
Medical adherence	0.284	0.007

used to test associations for categorical variables. Multiple regression analysis, using the significant predictors, was used to examine the best model to predict family management behavior. Backward regression techniques were used to remove non-significant variables; only significant variables remained in the final model.

RESULTS

Family caregivers ranged in age from 22 to 64 years old with an average age of 35.9 ± 7.7 years. There were more mothers (78.4%) than fathers (18.2%). The majority of participants (80.7%) were married and members of the family (61.4%). Most family caregivers were employed (80.7%); 31.8% were employees and 26.1% were

in business/traders. Seventy point five percent of families earned enough; 42.1% earned enough but had no savings. The average family income was 20,365.9 Baht/month. Thirty-eight point six percent had an income of 10,000-20,000 Baht/month and 28.4% had an income of 5,000-10,000 Baht/month. Thirty-six point three percent of caregivers had a secondary school and 34.1% had a primary school education.

The descriptive statistics for four questionnaires are provided in Table 1. The results illustrate moderate levels of perceived family management, health literacy, medical adherence and a high level of family management behavior. Within the family management behavior questionnaire subscale, both medical manage-

Table 3
Final multiple regression with backward analysis of predicting factors and overall family management behavior ($n=88$).

Variables	B	SE	Beta	T	p-value	R ² change
Perceived family management	0.550	0.099	0.500	5.530	<0.001	0.263
Health literacy	0.337	0.143	0.213	2.360	0.021	0.045
Constant = 107.737, R ² = 0.308, R ² _{adjust} = 0.292, F = 18.933, $p < 0.001$						

Table 4
Final multiple regression with backward analysis of predicting factors for each aspect of family management behavior ($n=88$).

Variables	B	SE	Beta	T	p-value	R ² change
Medical management						
Medical adherence	0.128	0.046	0.273	2.768	0.007	0.106
Health literacy	0.150	0.054	0.267	2.778	0.007	0.078
Perceived family management	0.082	0.039	0.210	2.123	0.037	0.042
Constant = 26.377, R ² = 0.226, R ² _{adjust} = 0.198, F = 8.155, $p < 0.001$						
Role management						
Perceived family management	0.250	0.046	0.495	5.452	<0.001	0.258
Health literacy	0.155	0.066	0.214	2.355	0.021	0.045
Constant = 46.345, R ² = 0.303, R ² _{adjust} = 0.287, F = 18.479, $p < 0.001$						
Psychosocial management						
Perceived family management	0.193	0.041	0.457	4.768	<0.001	
Constant = 31.563, R ² = 0.209, R ² _{adjust} = 0.200, F = 22.735, $p < 0.001$						

ment and psychosocial management were at a high level and role management was at a moderate level.

Table 2 shows positive relationships among income, perceived family management, health literacy, medical adherence and family management behavior. There was no relationship between age and family management behavior. For categorical variables, there was a significant difference for education and family management behavior ($\chi^2=6.472$; $p=0.039$); marital status and occupation showed no significant difference ($\chi^2=0.001$ and 4.642,

respectively; $p>0.05$).

Table 3 shows predictors of family management behavior. Perceived family management and health literacy together accounted for 30.8% of the variance in overall family management behavior. The strongest predictor for family management behavior was perceived family management ($B=0.550$, $p<0.001$), accounting for 26.3% of the variance, followed by health literacy ($B=0.337$, $p=0.021$) accounting for 4.5% of the variance.

The predictive equation is expressed as follows:

Family management behavior = $107.737 + 0.550$ (perceived family management) + 0.337 (health literacy)

This equation states that a mean score of 167.25 points on the perceived family management questionnaire and a mean score of 63.74 points on the health literacy questionnaire predicts a family health behavior score of 221.21 points, indicating a high level of family management behavior.

Table 4 shows the relationships between the three subscales of family management behavior and the other measures. Medical management was significantly associated with perceived family management, health literacy, and medical adherence. Together they accounted for 22.6% of the variance. The strongest predictor was medical adherence, which accounted for 10.6% of the variance. Health literacy and perceived family management accounted for 7.8% and 4.2% of the variance, respectively. Role management, perceived family management and health literacy together explained 30.3% of the variance. The strongest predictors were perceived family management, which accounted for 25.8% of the variance, and health literacy, which accounted for 4.5% of the variance. Psychosocial management and perceived family management only accounted for 20.9% of the variance.

DISCUSSION

Perceived family management had a positive relationship with family management behavior at a moderate level ($r=0.513$); medical adherence, health literacy and family income impacted family management behavior positively but on a low level ($r=0.284$, 0.243 , and 0.234 , respectively).

Higher perceived family management

scores were associated with greater family management behavior. Item analysis was performed from the information provided by family caregivers, particularly mothers, who assured that follow-up treatment/evaluation was complete, they kept appointments, set goals for prevention of complications and addressed concerns about the child's opportunities in the future (employment, complications). Caregivers scored only moderately high on perceived family management of a child's normal life (the child's everyday life and learning were similar to other children), their ability to manage their child with thalassemia (willpower, going to the hospital due to severe anemia), their time and work to manage the illness (close care all the time, taking time to go to hospital), life difficulties in dealing with thalassemia (difficulty in balancing the illness and family life), receiving support from their partner and working together to manage their child's conditions (family working closely together to manage care and consult with each other before making decisions). This finding is consistent with a previous study of family management of chronic conditions that revealed higher family functioning was associated with better family management of chronic conditions (Grey *et al*, 2006).

Medical adherence led to better family management behavior. Item analysis of the questionnaire's results revealed family caregivers maintained good adherence to blood transfusions and iron chelation injections. However, they had only moderate medical adherence for medications, exercise and nutrition. Children with thalassemia require blood transfusions every 4-6 weeks, medication every day and iron chelation injections 3-5 days/week. The questionnaire results suggest medication regimens should be followed

more closely than exercise and nutrition because they are necessary to maintain the child's health and reducing complications (pallor, iron overload). These results are similar to a previous study of childhood chronic illnesses in that better medical adherence was associated with better health outcomes in diabetes (Davis *et al*, 2001), weight loss (Wrotniak *et al*, 2005) and juvenile idiopathic arthritis (Feldman *et al*, 2007).

Health literacy also led to better family management behavior. Itemization of the questionnaire's results reveals family caregivers had an adequate understanding of thalassemia and blood transfusions, but not oral medications and injections for iron chelation. Family caregivers could read and understand medical instructions and information (leaflets, labels, medical forms, research questionnaires), since two-thirds were educated to at least at the primary school level. Increasing health knowledge and skills can lead to improved family management and successful management of chronic illness related decision-making (Nutbeam, 2009). This finding is congruent with previous studies which found the higher the level of health literacy, the higher the active participation with care and better health outcomes (Schillinger *et al*, 2002; Coleman and Newton, 2005).

Education was significantly correlated with family management behavior; higher education levels contribute to better family management behavior. Low literacy is a barrier to patient participation in their care, and causes problems with understanding health care instructions, resulting in poor health outcomes (Coleman and Newton, 2005; Nutbeam, 2009). Age, marital status and occupation were not significantly associated with family management behavior ($p>0.05$).

Family income was associated with family management behavior. Family caregivers had an average family income of 20,365.9 Baht/month and more than two thirds of the families reported sufficient income. The finding is congruent with prior studies that revealed lower socio-economic status was associated with poorer self-management (Fisher *et al*, 1998; Grey *et al*, 2006).

Regression model analysis demonstrated family management behavior can be explained by two predictors ($p<0.001$). Perceived family management had a moderate positive relationship with family management behavior, whereas other factors were less related. Perceived family management was the only predictor of family management, both overall and in each subscale (medical management, role management, psychosocial management). Thus, perceived family management was a key determinant of enhancing a family's ability to manage a child with thalassaemia (Knafl *et al*, n.d.). Family caregivers also took responsibility on a day-to-day basis for management and making decisions about thalassemia. Adequate health literacy is necessary for the family to understand and use information to promote and maintain child health outcomes, such as monitoring symptoms, taking medication and selecting healthy food.

The medical management provided by primary caregivers included symptom assessment (observing for severe anemia and other symptoms), providing treatment (giving medicine, sponging for high fever) and attending doctor appointments. Other roles performed by family caregivers included general child health care, such as hand washing, avoidance of iron-containing foods, brushing teeth and providing high protein foods. Caregivers also provided a clean house

with adequate ventilation and a safe environment. Family caregivers understood these roles as important in children with chronic conditions and a higher level of health literacy is required to perform such skills (Knafl *et al*, n.d.; Nutbeam, 2009). Perceived family management and health literacy both impact family management behavior. Psychosocial management was correlated with perceived family management. Family caregivers have positive family interactions and play with their children, encourage their children to play with other siblings and children and reinforce positive self-esteem in their children. Perceived family management describes how families respond to children with a chronic condition in everyday family life (Grey *et al*, 2006; Knafl *et al*, n.d.). The findings show promoting perceived family management and increasing health literacy can improve family management behavior for children with thalassemia.

There were several limitations of this study. Generalizability to other chronic illnesses and settings is limited. Random selection sampling was not possible due to limited access to family caregivers of children with thalassemia. This cross-sectional study was limited since it is a picture of one point in time with a developing, ever-changing child with chronic disease. Future research should include a larger sample size and various contexts for representativeness. A longitudinal design would better capture changes in behavior.

The results are useful for the next phase of development of a family management program for children with thalassemia. In order to enhance family management behavior, an effective intervention program should focus on the two significant predictors of family

management behavior: perceived family management and health literacy. Promoting perceived family management should be recognized and integrated into the program. An intervention program to teach families how to better balance daily life with thalassemia and to keep their child stable and healthy is indicated. Health literacy can be increased with simple, clear, attractive educational materials (Kobylarz *et al*, 2006), such as handbooks and posters in in- and out-patient departments.

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