รูปแบบการจัดการในครอบครัวที่มีบุตรป่วยด้วยโรคธาลัสซีเมีย
The Styles of Management in Families Having a Child with Thalassemia

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บทคัดย่อ

ธาลัสซีเมียอยู่ในกลุ่มความผิดปกติทางพันธุกรรมที่มีอัตราความชุกสูงถึง 30%-40% ของประชากรในประเทศไทยป่วยด้วยโรคธาลัสซีเมีย คาดว่าอีก 20 ปีข้างหน้าจะมีเด็กเกิดใหม่ป่วยด้วยโรคธาลัสซีเมียถึง 900,000 คน คุณภาพชีวิตของเด็กจึงขึ้นอยู่กับบิดา มารดาที่ให้การดูแลทั้งภาวะสุขภาพ และการเจริญเติบโตตามระยะพัฒนาการ ดังนั้นการศึกษานี้มีวัตถุประสงค์เพื่อยืนยันวิธีการที่ครอบครัวใช้ในการจัดการดูแลบุตรที่ป่วยด้วยโรคธาลัสซีเมียในชีวิตประจำวันของครอบครัว

วิธีดำเนินการวิจัย: การวิจัยครั้งนี้เป็นการวิจัยเชิงพรรณนา กลุ่มตัวอย่างคือ พ่อหรือแม่ของเด็กป่วยด้วยโรคธาลัสซีเมียที่ได้รับการรักษาที่โรงพยาบาลระดับตติยภูมิของประเทศไทย (n=309) เครื่องมือที่ใช้ในการวิจัยคือ แบบสอบถามการจัดการครอบครัวทั้ง 6 มิติ นำข้อมูลที่ได้ในแต่ละมิติมาวิเคราะห์โดยสถิติเชิงพรรณนา (การแจกแจงความถี่ ค่าร้อยละ ค่าเฉลี่ย)

ผลการวิจัย: กลุ่มตัวอย่างส่วนใหญ่ (73.8%) เป็นมารดามีอายุระหว่าง 26-35 ปี (mean = 34.8 ปี SD = 6.6) มีรายได้ครอบครัวเพียงพอสำหรับการดำเนินชีวิต (48.2%) กลุ่มตัวอย่างทั้งหมดอยู่ภายใต้โครงการหลักประกันสุขภาพแห่งชาติ ด้านการจัดการในครอบครัวพบว่ามากกว่าครึ่งของพ่อและแม่ (72.8%, 82.2%) มีคะแนนการดำเนินชีวิตประจำวันของบุตร ความสามารถในการจัดการดูแล ความพยายามในการจัดการดูแล ความยุ่งยากในการดำเนินชีวิตครอบครัว มุมมองต่อผลกระทบของโรคและความร่วมมือกันของผู้ปกครอง อยู่ในระดับปานกลางมีค่าเฉลี่ย 16.2 (SD = 2.9), 43.8 (SD = 6.3), 12.4 (SD = 3.1), 39.3 (SD = 9.3), 34.8 (SD = 5.4) และ 26 (SD = 3.7) ตามลำดับ

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สรุป: ครอบครัวของเด็กธาลัสซีเมียต้องเผชิญกับภาระของการถ่ายเลือดตลอดชีวิตของบุตร บิดามารดาควรมีการปรับการจัดการในครอบครัวให้มีความเหมาะสมกับเด็ก อย่างไรก็ตามความวิตกกังวลเกี่ยวกับความรุนแรงและภาวะแทรกซ้อนของโรคธาลัสซีเมียในบุตรจะมีผลต่อการดำเนินชีวิตของครอบครัวในอนาคต ควรมีการศึกษาความสัมพันธ์ระหว่างการจัดการในครอบครัวและผลลัพธ์ทางสุขภาพเช่นคุณภาพชีวิต การทำหน้าที่ในครอบครัว เป็นต้น

คำสำคัญ: การจัดการในครอบครัว เด็กป่วยด้วยโรคธาลัสซีเมีย

Abstract:

Thalassemias are among the most common genetic disorders that have a high prevalence in Thailand. It is estimated that 900,000 babies with thalassemia are expected to be born during the next 20 years. This figure reveals that 30%-40% of populations in Thailand are living with thalassemia syndrome. Qualities of life of children with Thalassemia depend on their parents, who must deal with the intensive management of their health and conditions, together with their normal growth and development. Hence, purpose of this study was to predicate the way in which families incorporate the work of managing their children with thalassemia into their family life.

Method: Descriptive design was conducted in parents of children with thalassemia, recruited from tertiary care hospitals in Thailand (n=309). The self-reported of Six Scale - Family Management Measure (FaMM) was applied to explore family management for their children. Scores on each of the six scales of the FaMM was analyzed by descriptive statistics.

Results: Majority of participants (73.8 %) were mothers in age between 26 to 35 years (mean = 34.8 years, SD = 6.6). Nearly half of them (48.2%) had sufficient family income for their living. All of them are under Universal Health Care Scheme. The results demonstrated that over half of parents (72.8 % – 82.2 %) scored on child’s daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental maturity were at moderate level with mean of 16.2 (SD = 2.9), 43.8 (SD = 6.3), 12.4 (SD = 3.1), 39.3 (SD = 9.3), 34.8 (SD = 5.4), and 26 (SD = 3.7) respectively.

Conclusion: The findings found that families of children with thalassemia face a life-long burden with chronic disorder of blood transfusion dependent. Parents should adapt an appropriate family routine management with children conditions. They should also have more concerns about the seriousness of thalassemia and its complications for their children and their family life in the future. For further study, relationships between family management and children health outcomes ought to be deeply investigated.

Keyword: Family Management, Children with Thalassemia

Introduction

Thalassemias are among the most common genetic disorders in the world (Hassan, Ahmad, Zakaria, Zulkafli, & Abdullah, 2013). Although there are many types of thalassemia syndrome, but in every type, the production of one or more of the globin chains that make up hemoglobin is decreased. There are typically four globin chains in hemoglobin: two alpha-globin chains and two beta-globin chains. Hemoglobin will not be sufficient formed if there are insufficient amounts of alpha and beta-globin. Diminished hemoglobin will decrease the amount of oxygen in body tissues, so the individual will be in poor growth, some will have organ damage and many other have poor health conditions. Decreasing or absence of alpha-globin production will happened in individual with alpha thalassemia, whereas decreasing or absence of beta-globin production will happened in individual with beta-thalassemia (Van Riper, 2014). In Thailand, thalassemia has a high prevalence. It has been estimated that 30%-40% of the population are carriers of alpha or beta-thalassemia (Torcharus & Pankaew, 2011). With a population of 65 million, about 40% have thalassemia traits or are carriers, while 1% is afflicted with this disease (Thalassemia foundation of Thailand 2012). Thus, thalassemia is a serious health issue for Thailand.

In present, according to medical technology advancement, quality of life and life expectancy of children with thalassemia are much better. They experience less health problems and are able to live within their families unit rather than in a hospital or special care clinic. Even so, children still depend on their parents who are the key persons that manage their conditions. Thus, thalassemia affects the children’s lifestyle as well as their family’s life (McCubbin, & McCobbin 1996). Parents have to deal with intensive management of their children's conditions and have to maintain normal developmental challenges of childhood and adolescence (Beal, Grey & Doyle, 2011). Routine care for their children with thalassemia produces temporary disruption in parents' work life, such as missing work. Moreover, parents who concern about their children's illness and their family life in the future, i.e. health care cost, frequent school absentee and suffering from chronic condition, develop negative impacts on their perspective of children with thalassemia, their meaningful role in all health care decisions, and their integration of management into their routine life activities (Surapolchai et al., 2010). Parents have to quickly adapt themselves for incorporating day-to-day management, which needs appropriate care beyond a variety of treatments in order to maintain their children's health. During the vulnerable time anxiety, depression, and lack of confidence will affect their abilities, to follow the children's medical regimen (Horsch, McManus, Kennedy & Edge, 2007).

Then, it is important for families to have better understanding of treatments and preventive strategies in order to become successful home caregivers for thalassemia. If these needs are not met, that would cause a great deal of stress, so families have to develop their own strategies to fit with their family life style. Family roles and responsibilities of maintaining child health status will be reorganized after families have been successful managed (Prasomsuk et al., 2007). Literature related to caring for children with thalassemia shows increasing evidence that nurses need deeper understanding in the phenomenon of families' responses to children with thalassemia because these phenomenon provide basic information for health care professionals toward the way families can manage chronic conditions of their children, and the effects the chronic conditions put on the families.

Objective

To predicate the way in which families incorporate the work of managing their children with thalassemia within the family life through the use of the Family Management Style Framework approach in order to provide a more comprehensive understanding of family management.

Conceptual Frameworks

This study based on Family Management Style Framework (FMSF), which was used to conceptualize parents' perceptions of key aspects of family response to childhood chronic conditions and its impact on everyday life. The FMSF is recognized as a useful framework for furthering knowledge of family response to childhood chronic illness as evidenced by its inclusion in major texts on families and health care (Van Riper, 2014). Family management of childhood chronic conditions consists of: 1) family's perception of the child's everyday life, 2) family's perception of the overall manageability of the child's condition, 3) family's perception of the extent to which having a child with chronic condition makes family life difficult, 4) family's perception of the effort to manage the child condition, 5) family's perception of the seriousness of the condition and its implications for the child's and the family's future, and 6) family's perception of support, shared views, and satisfaction with how the partners work together to manage the child's condition. Family caring for a child with thalassemia views daily routines and experiences through a lens of normalcy, and engages in activities that are consistent with self - perception as normal (Knafl, Darney, Gallo & Angst 2010). The family incorporates the work of managing a child with thalassemia into daily life and adapts to challenges as they arise.

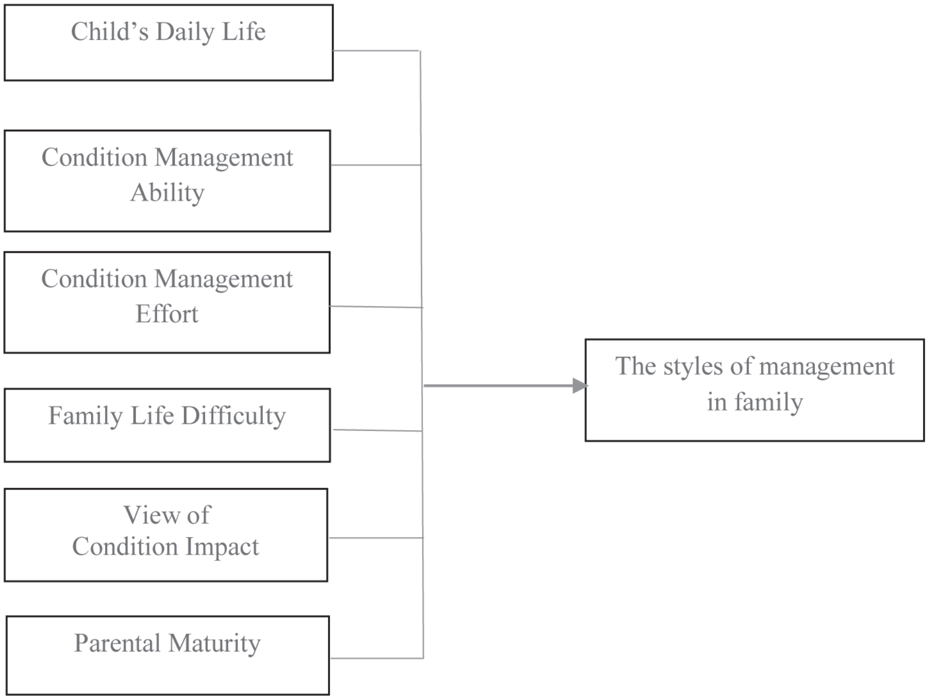

Figure 1: Family management in families of children with thalassemia based on Family Management Styles Framework (Knafl, Darney, Gallo & Angst, 2010).

Method

Population and sample: The target population in this study were parents who were primary caregivers of children with thalassemia and Continuously attended hematology clinics and pediatric units at four regional hospitals in Thailand (Sapphasitthiprasong Hospital; Ubon Ratchathani Province, Thammasat University Hospital; Pathum Thani Province, Sara-buri Hospital; Sara-buri Province, and Chonburi Hospital; Chonburi Province). 309 participants (Yamane, 1973), who were at least 18 years of age, able to read and communicate in Thai language, and willing to complete the self-report questionnaires, were recruited by simple random sampling.

Protection of human subjects: To ensure the protection of human subjects, the research proposal plan for this dissertation was submitted to the ethical approval committees. The consent form and all questionnaires were evaluated and approved by the ethical approval committee prior to the start of data collection. Although there were no physical risks or harms anticipated for this study, parents who became emotionally stressed while completing the measures were encouraged to contact the researcher. Then, they were referred to appropriate counseling or psychological services.

Instruments

1. Background information: This form consists of questions about parental age, gender, and educational level, as well as questions about family income and health insurance.

2. Family Management Measure (FaMM; Knafl & Deatrick, 2006; Knafl et al., 2009; Knafl et al., 2010) was used to assess parental perspectives on how the families managed care of children with thalassemia and the extent to which they were able to incorporate thalassemia caring into everyday life. FaMM consists of 53 items in 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 was not used with non-partnered parents. Parents were asked to respond to 5-point Likert scale statements. Reversing code for the negative item responses, the score of each six FaMM scale was the sum total and was analyzed by mean and s.d. According to Knafl, Darney, Gallo & Angst (2010), higher values of the child's daily life scale indicate it was more normal life for the child despite the condition; higher values of the condition management ability scale indicate it was more readily manageable; higher values of the condition management effort scale indicate more family effort to manage their children's conditions; higher values of the family life difficulty scale indicate more difficulties in managing their children's condition; and higher values of the condition impact scale indicate more parents' concern in managing their children's condition. As well, higher values of the parental mutuality scale indicate more shared response and greater satisfaction with how the couple works together to manage their children's condition. In this study, the reliability of measures indicated good internal consistency from the data of parents of children with thalassemia (α=0.80). Cronbach's alpha for the six dimensions of family management measure ranged from 0.26 to 0.82.

Data analysis: Descriptive statistics, mean and SD, were applied to compute scores on each of the six scales of the FaMM for each family, i.e. child daily life, condition management effort, condition management ability, family life difficulty, and view of condition impact.

Result: A total of 309 parents consented to participate in the study. The demographic characteristics of families and parents of children with thalassemia, as in Table 1 and Table 2, showed that the majority of participants (73.8 %) were mothers, the greater number of mother were aged between 26 to 35 years (mean = 34.8 years, SD = 6.6), and between 36 to 45 years (mean = 38.06 years, SD = 7.6) for fathers. Most parents were Buddhists. More than half of the parents (72.2%) were married, and lived with their partner (27.8%). In regard to educational attainment, parents (50.4% mothers, 45.6% fathers) had received at least a secondary school education in comparison to parents who 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). 44.7% of parents had a monthly family income range from 15,000 to 50,000 Baht (mean = 21,268.18 Baht, SD = 20,204.4). Nearly half of the parents (48.2%) had sufficient income for family living. No families were identified as lacking health insurance; they were covered by the Universal Health Care Scheme.

Table 1 Demographic characteristics of families of children with thalassemia (n = 309)

Demographic characteristics	n	%
Parents		
Father	81	26.3
Mother	228	73.8
Marital status: Married	221	71.5
Partnered/Living together	88	28.5
Family income: mean = 21,268.18 Baht, s.d. = 20,204.4		
< 15,000	68	22
15,000-35,000	176	44.7
35,001- 50,000	34	11
>50,000	31	10
Sufficiency with family income		
Insufficient	142	46
Sufficient for living	149	48.2
Sufficient for living and saving	18	5.8
Health Insurance		
Universal Health Care Scheme	309	100

Table 2 Demographic characteristics of parents of children with thalassemia (n= 309)

Demographic characteristics of parents	Father		Mother	
	n (81)	%	n (228)	%
Parents' age	Range = 22 - 55 years mean = 37.15, s.d. = 6.7		Range = 19 - 55 years mean =34.8, s.d. = 6.7	
≤ 25	4	5	26	11.4
26-35	32	39.5	98	43
36-45	38	46.9	90	39.5
46-55	7	8.6	14	6.1
Occupations				
Labor workers	58	71.6	109	47.8
Government officer/State enterprise	14	17.3	27	11.8
Agriculturist	6	7.4	55	24.1
Storekeeper/ vendor	3	3.7	16	7
Unemployed/Housewife		-	-	21 9.2
Educational attainment				
No-school	4	4.9	5	2.2
Elementary school	10	12.3	51	22.4
Secondary school	37	45.6	111	50.4
Vocational college/ Diploma	20	24.7	24	10.5
Bachelor's degree or higher	10	12.3	33	14.4

With the family management measure, the results demonstrated that 14.9% of the parents were at the high level in child's daily life. Approximately 15.5% of the parents had condition management ability scores at the high level, and also parental mutuality (14.2%). However, the results demonstrated that the parents were at the low level in condition management effort (8.4%), family life difficulty (17.5%), and view of condition impact (9.4%).

Additionally, over half of parents were at the moderate level on child's daily life (78%) , condition management ability (72.5%), condition management effort (87.4%), family life difficulty (65.7%), view of condition impact (5.7%), and parental maturity (72.8%) as in Table 3.

Table 3 Levels of family management (n = 309)

family management	Level		
	Low	Moderate	High
1. Child's Daily Life	6.1% (n = 19)	82.2% (n = 254)	11.7% (n = 36)
2. Condition Management Ability	11.7% (n = 36)	73.5% (n = 227)	14.9% (n = 46)
3. Condition Management Effort	9.7% (n = 30)	73.8% (n = 228)	16.5% (n = 51)
4. Family Life Difficulty	11% (n = 34)	72.8% (n = 225)	16.2% (n = 50)
5. View of Condition Impact	11.3% (n = 35)	73.1% (n = 226)	15.5% (n = 48)
6. Parental Mutuality	10% (n = 31)	73.8% (n = 228)	16.2% (n = 50)

FaMM ranges potential score for parents from 53 - 265. Scores on each dimension of the FaMM are given on Table 4, based on their mean score. A total of 309 parents presented a score range from 116 to 238. This study was evaluated into three levels such as low, middle and high by using mean ± SD for both positive and negative sides of family management. Parents' mean scores in every dimension were at the moderated level, i.e. child's daily life (mean = 16.2, SD = 2.9), condition management ability (mean = 43.8, SD = 6.3), and parental mutuality (mean = 26, SD = 3.7). Parents' mean scores were at the moderate mean score for condition management effort (mean =12.4, SD = 3.1), family life difficulty (mean = 39.3, SD = 9.3), and view of condition impact (mean = 34.8, SD = 5.4).

Table 4 Family Management Measures Score of the Study Sample (n = 309)

Dimension of FamilyManagement	Actual range	Possible range	mean	SD
1. Child's Daily Life	9 - 24	5 - 25	16.2	2.9
2. Condition Management Ability	26 - 60	12 - 60	43.8	6.3
3. Condition Management Effort	5 - 20	4 - 20	12.4	3.1
4. Family Life Difficulty	14 - 66	14 - 70	39.3	9.3
5. View of Condition Impact	20 - 50	10 - 50	34.8	5.4
6. Parental Mutuality	16 - 36	8 - 40	26	3.7

Discussion

The results demonstrated that the mean scores for parents on the six dimensions of FaMM were as follows: child's daily life (mean = 16.2, SD = 2.9), condition management ability (mean = 43.8, SD = 6.3), condition management effort (mean = 12.4, SD = 3.1), family life difficulty (mean = 39.3, SD = 9.3), view of condition impact (mean = 34.8, SD = 5.4), and parental mutuality (mean = 26, SD = 3.7), which were at the moderate level. Despite having thalassemia, parents perceived normalcy in their children's life like others at the same age, including general, educational and recreational activities. General activities or activities of general care and caring about age-appropriate growth and development were not so difficult for children to perform. Besides, parents and children became familiar with the symptoms, treatment process, and the families flexible response to ensure their children's conditions. Moreover, the finding of parents' perception in condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality were at the moderate level might not be surprising, because they faced a life-long burden with chronic disorder and blood transfusion dependency (Liem et al., 2011).

This finding was similar to many studies that identified the level of family management in families of chronically ill children. For example, a study of parents of the children with cancer by Kim & Im (2015) found that the mean scores showed child's daily life (18.3), condition ability (47), parental mutuality (30.3), condition effort (10), life difficulty (34.6), and condition impact (26.8). For the parents of children with type 1 diabetes mellitus (Rearick, Sullivan-Bolyai, Bova & Kraft, 2011), the means score of six aspects showed as child's daily life (18.7), condition ability (50.5), condition effort (13.8), life difficult (28.3), condition impact (25.5) and parental mutuality (31.3). With families with a child with asthma in the greater Charlotte, North Carolina, USA (Hines, 2011), the means score were as follows: child's daily life (22.8), condition management ability (52.6), condition management effort (8.1), family life difficulty (18.4), view of condition impact (16.6), and parental mutuality (32.4). In the study of Kim , Naomi & Hock (2016), families with children with autism, this study examined five dimensions of family management and the mean scores were child's daily (13.1), life, condition management ability (40.4), condition management effort, (14.7), family life difficulty (42.2), and condition impact (29) (Kim & Im, 2015). A study of the parents of children with asthma in asthma care clinics in southeastern freestanding pediatric facilities, USA, examined two scales, and found that the mean score of condition management ability (32.4) and condition management effort (13.0) were at the moderate level (Gibson-Young, Gerald, Vance & Lozano, 2014). These perceptions were tied to parental hope for a cure, a frequently coded coping mechanism (Liem et al., 2011). As families of children with thalassemia, this study used a modified Family Management Measure questionnaire (FaMM) (Knafl & Deatrick 2006), which assessed perspectives of the caregivers regarding managing children with chronic illness. It consisted of 46 questions with six subscales, i.e. 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. Total scores ranged from 46 to 230 points, while parents presented a score range from and 120 to 206 (167.3) and were at the moderated level (Sananreangsak et al., 2012). The children with thalassemia had no difficulties in their daily life such as studying, playing with classmates hygiene care, taking medicine, and eating foods (Palermo et al., 2014). It was also found that the children with thalassemia had normal IQ scores and normal intellectual development, compared with healthy children (Dubey et al., 2008).

Conclusion

Families, parents and children with thalassemia, should become familiar with symptoms and treatment process, so they can be flexible in their responses to ensure children's conditions. It is possible that parents were not performing intimate care all the time. Parents adapted the appropriate family routine management with their children's conditions. Even still, they had more concerns about influences, which might happen in the future, from the seriousness and complications of thalassemia.

Recommendations

Because family management changes over time, a correlation design should be carried out to determine the power of relationships among selected variables. Besides, regarding to family adaptation, some family members may engage in management of children with thalassemia.

Reerences

Beal, J., Grey, M. & Doyle, E. A. (2011). Should children with type 1 diabetes be hospitalized at diagnosis? MCN: *The American Journal of Maternal/Child Nursing,* 36(4), 214-215.

Dubey, A.P., Parakh, A. & Dublish, S. (2008). Current trends in the management of beta thalassemia. *The Indian Journal of Pediatrics,* 75(7), 739-743.

Gibson-Young, L. T. - H. A., Gerald, L. B., Vance, D. E. & Lozano, D. (2014). The relationships among family management behaviors and asthma morbidity in maternal caregivers of children with asthma. *Journal of Family Nursing,* 20(4), 442-461.

Hassan, S., Ahmad, R., Zakarla, Z. & Abdulah, W. Z. (2013). Detection of β-globin Gene Mutations Among β-thalassaemia Carriers and Patients in Malaysia: Application of Multiplex Amplification Refractory Mutation System–Polymerase Chain Reaction. *Malaysian Journal of Medical Sciences,* 20 (1), 13-20.

Hines, A. (2011). *Parental perceptions of family management styles in families with a child with asthma.* Dissertation, the University of North Carolina at Greensboro.

Horsch, A., McManus, F., Kennedy, P. & Edge, J. (2007). Anxiety, depressive, and Post-traumatic stress symptoms in mothers of children with type 1 diabetes. *Journal of Traumatic Stress,* 20(5), 881-891.

Kim, D. H. & Im, Y. J. (2015). The influence of family management style on psychosocial problems of childhood cancer survivors in Korea. *European Journal of Oncology Nursing,* 19(2), 107-112.

Kim, I. E., Naomi, V. & Hock, R. (2016). Associations between child behavior problems, family management, and depressive symptoms for mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders,* 26, 80-90.

Knafl, G. J., Dixon, J. K., O’Malley, J. P., Grey, M., Deatrick, J., Gallo, M. & Knafl, K. (2009). Analysis of cross-sectional univariate measurements for family dyads using linear mixed modeling. *Journal of Family Nursing,* 15(2), 130-151.

Knafl, K., Darney, B. G., Gallo, A. M. & Angst, D. B. (2010). Parental perceptions of the outcome and meaning of normalization. *Research in nursing & health,* 33(2), 87-98.

Knafl, K. & Deatrick, J. (2009). Family Management Style and the challenge of moving from conceptualization to measurement. *Journal of Pediatric Oncology Nursing,* 23(1), 12-18.

Liem, R. I., Gilgour, B., Pelligra, S. A., Mason, M. & Thompson, A. A. (2011). The impact of thalassemia on southeast Asian and Asian Indian families in the United States: a qualitative study. *Childhood,* 11, 12.

McCubbin, M.A. & McCubbin, H.I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crises. Family assessment: Resiliency, coping and adaptation: Inventories for research and practice, 1-64.

Palermo, T. M., Valrie, C. R. & Karlson, C. W. (2014). Family and parent influences on pediatric chronic pain: A developmental perspective. *American Psychologist,* 69(2), 142.

Prasomsuk, S., Jetsrisuparp, A., Ratanasiri, T. & Ratanasiri, A. (2007). Lived experiences of mothers caring for children with Thalassemia major in Thailand. *Journal for Specialists in Pediatric Nursing,* 12(1), 13-23.

Rearick, E.M. (2010). *Parents of children newly diagnosed with T1DM: Experiences with Social support and family management.* Dissertation, University of Massachusetts.

Rearick, E. M., Sullivan-Bolyai, S., Bova, C. & Knafl, K. A. (2011). Parents of children newly diagnosed with type 1 diabetes experiences with social support and family management. *The Diabetes Educator,* 37(4), 508-518.

Sananreangsak, S., Lapvongwatana, P., Virutsetazin, K., Vatanasomboon, P. & Gaylord, N. (2012). Predictors of family management behavior for children with thalassemia. *Southeast Asian Journal of Tropical Medicine and Public Health,* 43(1), 160.

Surapolchai, P., Satayasai, W., Sinlapamongkolkul, P. & Udomsubpayakul, U. (2010). Biopsychosocial predictors of health-related quality of life in children with thalassemia in Thammasat University Hospital. *Journal of Medical Association Thai,* 93 (Suppl. 7), 65-75.

Thalassemia Foundation of Thailand. (2012). *CPG thalassemia.* Retrieved from http://pr.moph.go.th/include/admin_hotnew/

Torcharus, K. & Pankaew, T. (2011). Health-related quality of life in Thai thalassemic children treated with iron chelation. *Southeast Asian Journal of Tropical Medicineand Public Health,* 42(4), 951.

Van Riper, M. (2014). Cross-cultural Study of Adaptation in Families of Individuals with Down syndrome. *Archives of Disease in Childhood,* 99 (Suppl. 2), A241-A241.

Yamane T. (1973). *Statistics: an introductory analysis.* New York: Harper& Row.