

Integrative Review for a Family-centered Care Intervention to Promote Family Functioning in Families Living with Children with Chronic Illness

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Abstract

This integrative review aimed to synthesize a family-centered care intervention to promote family functioning in families living with children with chronic illness. This review was conducted regarding family living with children with chronic illness, and CINAHL, PsycINFO, PubMed, and Scopus databases were searched from January 1, 2011 until December 31, 2021. Eight studies involving participants were included. The following six major categories were identified as the interventions focusing on several components: communication skill development, problem-solving skill development, promoting caregiver knowledge, supporting and cognitive components, spirituality, and parent-child relationships. This integrative review was designed to provide insightful understanding of family-centered care interventions to promote family functioning in families living with children with chronic illness. According to the findings, the family empowerment program is an interesting program that can improve almost all components under family functioning. Moreover, spirituality is widely applied as the strategy promoting family functioning in the area studied. Therefore, developing a program based on the concept of family empowerment and spirituality were recommended in this study to help families living with children with chronic illness maintain family functioning.

Keywords: family-centered care, family intervention, family functioning, children with chronic illness, integrative review

The family is a significant component in the health care system for children with chronic illness and should be regarded as a partner of health care providers, because it is directly responsible for these children. The family of a chronically ill child has to face irreversible situations after the illness, which demands continuous care. This means that the entire family requires a high level of family functioning, because family functioning reflects the adaptability of the whole family.^{1,2} If the family can achieve appropriate adaptation, it not only achieves high family functioning, but also child well-being.³ However, there is widespread recognition about whether the illnesses of children with chronic illness can trigger increasing stress and distress in the family or result in destruction of family functioning.^{3,4}

Family functioning is a vigorous factor included in quality of life and well-being of chronically ill children as a whole. In particular, parenting adjustment has been associated with positive psychological functioning.³ On the other hand, degradation in family life has been linked to inferior emotional and behavioral functioning and low compliance with medical regimens. Therefore, family functioning in the surroundings of a chronically ill child is a crucial gap calling for additional study and nursing intervention.

As mentioned before, the importance of maintaining family functioning requires nursing intervention to help families build potential for their family functioning, which also leads to the promotion of child well-being. The characteristics of chronic illness and the importance of family functioning as a natural support source

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for everything to meet the high demands of children with chronic illness require further understanding.⁵ In summary, family-centered care intervention is aimed at addressing adverse family situations caused by children with chronic illness.

Family-centered care in the pediatric clinical setting is a philosophy that relates to devotedness, collaboration, adaptation, and learning for both healthcare providers and families. According to two perspectives in philosophy of care, healthcare professionals and families come into and create a reciprocal partnership that leads to promoting quality of life, positive outcomes, and good care-giving experiences.

An insightful understanding of family-centered care interventions to promote family functioning in families living with children with chronic illness has been synthesized. The recommendations about how to apply family-centered care interventions for the Thai context are also proposed in this article.

Aims

This systematic review aimed to synthesize a family-centered care intervention to promote family functioning in families living with children with chronic illness.

Method

Search Strategy

This integrative review is consistent with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist guidelines⁶ and Joanna Briggs Institute (JBI) methods.⁷ A systematic search strategy was applied to identify a family-centered care intervention to promote family functioning in families living with children with chronic illness. CINAHL, SCOPUS, PubMed, and PsycINFO were searched from January 1, 2011 until December 31, 2021. The keywords used were ‘family intervention’ OR ‘family program’ OR ‘family-based intervention’ OR ‘family centered intervention’ OR ‘family-based program’ OR ‘family-centered care program’ AND ‘family adaptation’ OR ‘family coping’ OR ‘family stress’ OR ‘family functioning’ AND ‘children with chronic illness’ OR ‘child with chronic’.

Inclusion and Exclusion Criteria

Eligibility criteria were managed by the patient/problem/population, intervention, comparison, outcome (PICO) model.⁸ Journal articles were added to this review if they

- (1) were articles published between 2011 to 2021 and available in English;
- (2) were primary quantitative research studies;
- (3) study type was limited to a family-centered care intervention to promote family functioning in families living with children with chronic illness;

- (4) targeted family functioning, family adaptation, family coping;
- (5) studies where the sample was parents or family caregivers living and caring for children with chronic illness.

Criteria for exclusion were: not written in English, no patient outcomes, commentaries, narrative reviews, full-text unavailability, editorial review, no related concepts and insufficient information for critical appraisal.

Study selection

The articles retrieved from the systematic search were evaluated by using the PRISMA flow diagram.⁶ A stepwise fashion with a team of five reviewers contributed to search selection strategies: Three reviewers independently examined all titles for inclusion criteria. All abstracts were examined independently, and also full-text versions of articles meeting the inclusion criteria and presenting an original study on the topic were obtained and randomly assigned and examined by three reviewers. The data of all eligible articles were extracted into evidence tables. To ensure that no relevant studies were left unexamined, the reference lists of all relevant studies were cross-checked by the two reviewers.

Data Extraction

Titles and abstracts were scrutinized freely to evaluate for inclusion/exclusion. Full texts were then assessed for eligibility, data were extracted and research findings were synthesized based on objectives, samples, settings, methodology, data collection, data analysis, conclusions, strengths, limitations and future implications.

Results

Search Results

The literature search was conducted using CINAHL, SCOPUS, PubMed, and PsycINFO. This paper reviews much scientific evidence and reports to explain how family-centered care interventions promote family functioning in families living with children with chronic illness. The search for related articles with the keywords yielded 121 articles, 8 of which met the inclusion criteria. The literature search tried to answer one question, “What are family-centered care interventions to promote family functioning in families living with children with chronic illness?” To state the question in terms of PICO (Population, Intervention, Comparison, Outcome), the population was children with chronic illness. The intervention was the family-centered care intervention. The type of comparison was usual care or waitlist. Outcomes included family functioning, family adaptation and family coping.

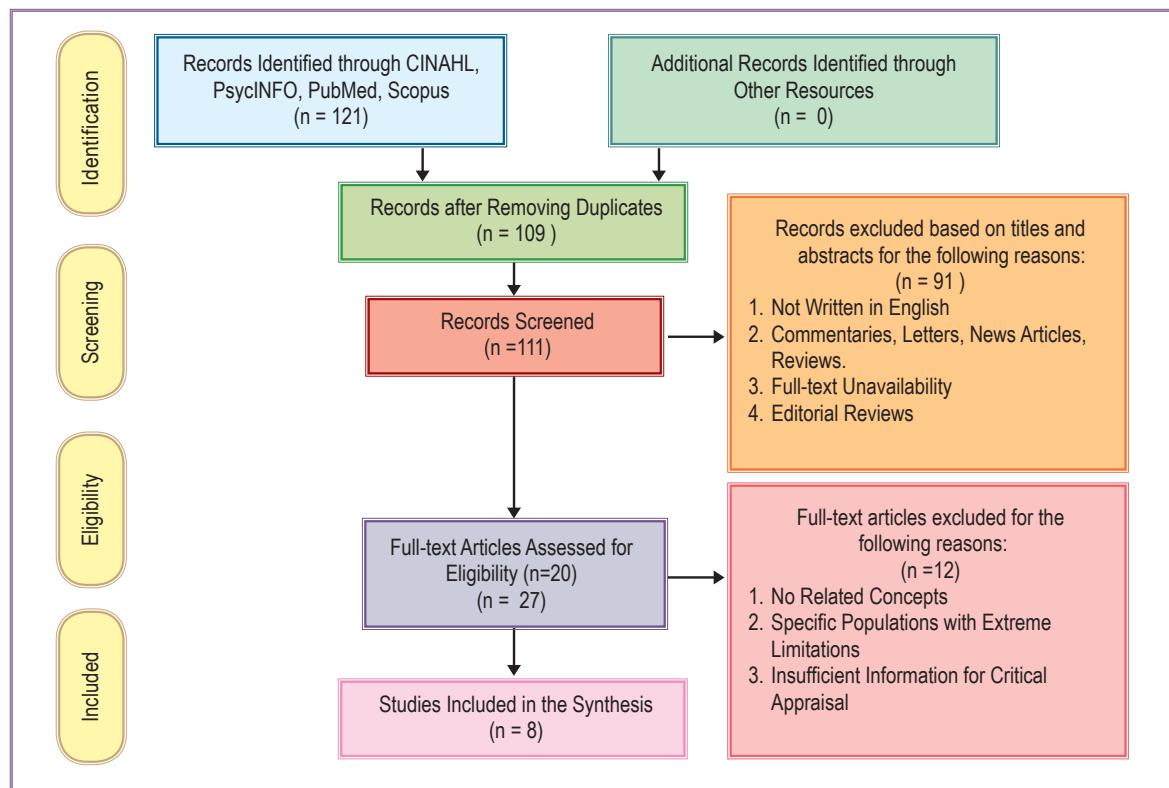


Figure 1: PRISMA flow diagram on the outcomes of search strategies.

Table 1: Studies included from systematic searches

Author, Year	Study Design/ Participants	Intervention and Control Groups	Results
Wacharasin, et al. 2015 ² Thailand	<ul style="list-style-type: none"> Quasi-experimental design n = 56 families Experimental group, n = 26 Control group, n = 30 The main primary family caregivers in both groups were mothers (73%) and ages ranged from 30-44 years. 	<ul style="list-style-type: none"> The intervention for the experimental group was the family empowerment program (FEP) that was conducted 4 days plus usual care. The control group received usual care only. 	<ul style="list-style-type: none"> The family caregivers involved in the program had significantly higher family functioning and empowerment scores over time.
Najafi et al. 2011 ⁹ Iran	<ul style="list-style-type: none"> Quasi-experimental study n = 86 mothers of children 6 to 12 years old with thalassemia that were randomly divided into 2 groups with 43 mothers in each group. 	<ul style="list-style-type: none"> The intervention for the experimental group was the family-centered empowerment model. The control group received usual care only. 	<ul style="list-style-type: none"> After the intervention, the average scores of the mothers' knowledge and attitudes were significantly increased in the intervention group and higher than control group ($p < 0.05$).
Borjalilu et al. 2016 ¹⁰ Iran	<ul style="list-style-type: none"> Quasi-experimental study. n = 42 mothers of children with cancer that were randomly selected into 2 groups with 21 mothers in each group. 	<ul style="list-style-type: none"> The intervention for the experimental group was the spiritual care training program. The control group received usual care only. 	<ul style="list-style-type: none"> The results showed that, after the intervention, the scores for anxiety and depression in the test group diminished at the post-test, and the test group also had higher total scores for the spiritual care than the control group with statistical significance ($p < 0.001$).
Yeh et al. 2016 ¹¹ Taiwan	<ul style="list-style-type: none"> A randomized control trial. n = 76 children with asthma between the ages of 6 and 12, and their families, were recruited for this study. 	<ul style="list-style-type: none"> The intervention for the experimental group was a family empowerment program The control group received traditional self-management only. 	<ul style="list-style-type: none"> The family empowerment program decreased parental stress ($p < 0.001$) and increased family functioning (cohesion, expression, conflict-solving, and independence) ($p < 0.001$).

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Author, Year	Study Design/ Participants	Intervention and Control Groups	Results
Mapiloon et al. 2016 ¹² Thailand	<ul style="list-style-type: none"> Quasi-experimental study. Experimental group, n = 14 couple of family caregivers and their children. Control group, n = 15 couples of family caregivers and their children. 	<ul style="list-style-type: none"> The intervention for the experimental group was the program to develop capacity for self-care among school-age children with thalassemia and the capacity of family caregivers in taking care of their children to promote self-care behavior among school-age children with thalassemia; the control group received usual care only. 	<ul style="list-style-type: none"> The average scores of school-age children with thalassemia's self-care behavior were significantly higher before the intervention, and significantly higher between the test group and the control group. ($p < 0.01$).
Zare et al. 2017 ¹³ Iran	<ul style="list-style-type: none"> A randomized controlled clinical trial. n = 72 mothers of CP in Bushehr and Shiraz, Iran. 	<ul style="list-style-type: none"> The intervention program was based on a self-management empowerment model for the experimental group The control group received traditional self-management intervention only. 	<ul style="list-style-type: none"> After the intervention, independent t-test reflected significant inter-group differences in terms of aggression and loneliness ($p < 0.001$).
Nagar et al. 2020 ¹⁴ Egypt	<ul style="list-style-type: none"> A quasi-experimental study design (one group pre-post test). n = 50 mothers and their children with chronic kidney disease (CKD). 	<ul style="list-style-type: none"> Family empowerment program through learning and involving mothers in providing care for their children was used as the intervention in this study. 	<ul style="list-style-type: none"> There was a positive relationship between the total level of mothers' knowledge, home care of children with CKD and level of family empowerment with statistically significant difference. The mean score of family empowerment sub-scales and total level of family empowerment were developed in the post-intervention compared to the pre- intervention phase.
Lee et al. 2021 ¹⁵ Canada	<ul style="list-style-type: none"> A non-randomized, pre-post pilot study. n = 70 parents of youths aged 8–17 years who had completed an intake assessment at an outpatient pediatric chronic pain clinic. 	<ul style="list-style-type: none"> The content of a parent group intervention for pediatric chronic pain in this study consisted of mindfulness, coping strategies for parents (maintaining family routines, social support and self-care), identifying and overcoming barriers, and school partnerships and celebrating successes. 	<ul style="list-style-type: none"> The results revealed adequate feasibility with attendance rates at 61.4% and attrition rates at 24.3%. This parent-targeted group intervention for pediatric chronic pain appears to be beneficial in decreasing maladaptive parental behaviors and increasing parents' psychological flexibility.

Results

The 8 studies yielded by the systematic literature search can be divided into 6 major categories of family-centered care interventions to promote family functioning in families living with children with chronic illness as described below.

Interventions Focusing on Communication Skill Development

This finding was shown in 3 articles.^{2, 10, 12} The study by Wacharasin et al.² was conducted in the Thai context to determine the effectiveness of a family empowerment program for families having children with thalassemia. In this program, the process of communication skill development was used to strengthen the confidence of family caregivers to express emotions, human needs, and obstacles efficiently via communication performances. For instance, communication performances in challenging events were demonstrated by asking for physicians and other healthcare providers to help with their children. The study by Borjalilu et al.¹⁰ determined

the success of a spiritual care training program in maternal caregivers of children with cancer. The program encircled seven 90-minute sessions proposed once a week. The communication skill development was one of the main skills for spiritual care in this program and was delivered through activities under the program such as brain storming, model presentation, group discussion, encouraging family caregivers to express feelings, engagement in active listening, and encouraging family caregivers toward positive thinking. And the study by Mapiloon et al.¹² revealed that the program provided communication skill development through three group discussions among family caregivers. Sharing information about the problem of caring, caring experiences both of successes and obstacles, and also the strategies to solve problems were organized in this program to enhance the communication skill of family caregivers.

Interventions Focusing on Problem-solving Skill Development

This finding appeared in 6 articles.^{2,10,11-13,15} The study by Wacharasin et al.² revealed that problem-solving skill development was an important concept used in the study that aimed to exchange experiences and feelings through activities such as introduction to the group for discussions about family problems and needs, then encouraging the group to exchange their responses to family problems. Finally, the family caregivers were commended for their ability in making decisions related to family obstacles and meeting needs linked with the management of their children's illnesses. Additionally, an activity to reduce personal stress by observing stress symptoms and discovering the cause of stress was presented in this study as well. Next, the family caregivers were facilitated in changing beliefs related to stress with practice of relaxation techniques. The study by Borjalilu et al.¹⁰ found that the anxiety and depression scores in the test group diminished in the post-test with a tendency to decrease the amount of stress until 3 months after the intervention (score averages were 2.7 at pretest, 2.54 at posttest, and 2.42 three months after obtaining education). The study by Mapiloon et al.¹² showed that problem-solving skill development was used in the study through group activities to enhance the capability of family caregivers such as the "You Can, I Can Activity" or what is called in Thai "Khun Tham Dai, Chan Tham Dai". This activity was presented through using people who had children with thalassemia as with all the participants in this study as models. The models who had succeeded in caring for their children showed the group ways to care, problems encountered care and ways to manage care. The family caregivers were also offered the chance to ask any questions about family problems, personal problems related to child care, and have group discussions to share and learn together about the problems and coping methods. The activity, "Jub Khao Khooy" was an activity to facilitate family caregivers in having chances to share experiences together, help one another find ways to deal with problems and give mutual mental support together. The study by Yeh et al.,¹¹ proposed an asthma family empowerment program that was conducted in 4 sessions comprising identification of the family, posing family problems and conflicts, discussions about problem-solving, and applying knowledge and acting out. This program was able to decrease parental stress ($p < 0.0001$) and increase family function in the experimental group ($p < 0.0001$). This finding was congruent with the study by Zare et al.¹³ who revealed that the parents in the experimental group were encouraged to assess the scope of their problems in the first stage. Then the desired goals were determined with the help of the parents based on their problems. Finally, a plan was devised in accordance with the domains of the self-management empowerment model. And the study by Lee et al.,¹⁵ showed the benefits of interventions in terms of decreasing maladaptive parental behaviors and increasing parents' psychological flexibility among the parents in experimental group.

Interventions Focusing on Promoting Caregiver Knowledge

This finding has been shown from 4 articles.^{2,9,12,14} The study by Wacharasin et al.² found that family empowerment programs (FEP) can be biopsychosocial education programs since these programs are designed to provide necessary knowledge for family caregiver adaptation to the adverse effects of chronic illnesses such as thalassemia via the group process with updated information about treatment for disease, providing relaxation techniques, communication skills, offering health education by health care professionals and providing genetic counselling by a hematologist. The study by Mapiloon et al.¹² was conducted to assess the effectiveness of an educative supportive program to promote self-care among children with thalassemia. The program comprised 3 sessions at 4-week intervals. In this program, the family caregivers were provided knowledge about taking care of their children via Power Point, booklets, a question and answer contest, and sharing information among family caregivers through the group process. The study by Nagar et al.,¹⁴ aimed to evaluate optimistic outcomes on mothers' knowledge and performance concerning chronic kidney disease (CKD) management and home care. The intervention was conducted in 4 sessions on knowledge discussion about the CKD, hemodialysis, knowledge regarding home care, and conclusions about the most important points, including educational booklets given to the mothers. And the study by Najafi et al.⁹ was a semi-experimental study aimed at determining the effectiveness of a family-centered empowerment model on mothers' knowledge and attitudes about thalassemia in children consisting of 3 processes. The knowledge was provided in Steps 1 and 3. For Step 1, the family caregivers were advised in the group process to discuss by using the pamphlets and slides containing information about the disease. In Step 3, the family caregivers were provided educational pamphlets and other handouts with CD audio tracks to increase awareness and attitude for children in the care process. The results showed significant differences in knowledge and attitude in the two groups after the intervention ($p < 0.05$).

Interventions Focusing on Supporting and Cognitive Components

This finding appeared in 5 of the articles.^{2,10,11,13,15} The study by Wacharasin et al.² found that FEPs were developed based on psychosocial management and empowerment,¹⁶ so all five stages were shown in the program in this study to offer family caregivers who were introduced in the group discussion to find psychosocial support and cognitive components through the process of empowerment. The study by Borjalilu et al.¹⁰ explored a spiritual care training program in which the program created an import cognitive assessment in the coping mechanisms for family caregivers, thereby enabling them to assess negative events and enhance a strong sense of control. According to the characteristics of the program covering group discussion, the activities helped family caregivers meet the need for a sense of psychosocial support. At the same time, the research findings revealed that family caregivers were

educated on strategies to create a happy environment and gained working knowledge on how to cope with the conditions of children with cancer. Following the program (post-test), family caregivers' understanding was shown to be significantly different than before the program (pre-test) ($p < 0.01$). This finding was congruent with the study by Lee et al.¹⁵ who demonstrated that this intervention was a parent-targeted group intervention that focused on cognitive-behavioral intervention such as focusing on values, mindfulness, and self-validation. The study by Yeh et al.¹¹ revealed that, at the last step of the program in this study, the targeted families recognized the family as a whole. This resulted in shared information/resources and giving support to one another as families to maintain family functioning. And the study by Zare et al.¹³ revealed that social capacities, available support sources and limitations of mothers of children with cerebral palsy were assessed in the first step of this intervention to evaluate the mothers' self-awareness about changes and recognition of personal performance levels and expectations. In addition, the mothers were educated about how to discover and utilize social support sources or gain better insight into their children's conditions.

Interventions Focusing on Spirituality

This finding appeared in 2 articles by Borjalilu et al.¹⁰ and Zare et al.¹³ Borjalilu et al.¹⁰ explored the effects of a spiritual care training program for caregivers of children with cancer to assess the effectiveness of the program on the quality of care and mental health of caregivers. This program provided spiritual care training through group discussion. The main skills targeted for this program consisted of communication skills, encouragement, and offering hope. The research findings showed that the spiritual care training program promoted spirituality, religiosity and spiritual care as well as decreasing anxiety and depression in mothers of children with cancer. And the study by Zare et al.¹³ revealed that the spiritual domain was assessed in the first step of this intervention to evaluate mothers' self-awareness, which was an important concept used in self-management empowerment programs to manage anger and overcome the social isolation of mothers of children with cerebral palsy.

Interventions Focusing on Parent-Child Relationships

This finding appeared in 3 articles.^{10,11,13} The study by Borjalilu et al.¹⁰ stated that the program consisted of the following 5 sessions: 1) providing concepts of spirituality including religious coping strategies; 2) understanding spirituality in healthy and sick children; 3) exploring interactions between mothers and children; 4) understanding the excitement of children with illness, and how to deal with their feelings; 5) enhancing reality, hope and future for their children, creating fun by maintaining appropriate play environments for children. Therefore, this program not only helped the family members strengthen their sense of control through important skills under the spiritual care model, but helped the family caregivers develop the ability to recognize

children's spiritual needs to enhance parent-child relationships. This finding is congruent with the study by Yeh et al.¹¹ who revealed that improving the relationships between parents and children was an important concept used in the intervention by asking questions without obvious answers and engaging in conversation. And the study by Zare et al.¹³ stated that the mothers who were involved in the program reflected themselves as lacking knowledge and awareness about the changes occurring in their lives in having disabled children and learning to manage the situation. Thus, the mothers often treated their children with a sense of aggression and hostility, so this program tried to introduce resolution conflict between the parents and their children.

Discussion

The McMaster Model of family functioning is used for discussion in this study to understand which components of family functioning have been corrected and which have not. The six components under this model illustrate the enormous effects on the emotional and physical health of family members comprising problem-solving, communication, roles, affective responsiveness, affective involvement, and behavior control.¹⁷

Problem-solving: Interventions focusing on problem-solving skill development appeared in 6 studies^{2,10-13,15} and interventions focusing on the promoting of caregivers' knowledge appeared in 4 articles^{2,9,12,14} showing the results on improving the problem-solving component under family functioning. The finding can be explained in that, because the family is acknowledged as a vital natural support resource for each family member, when family members are faced with crisis situations such as when some of the family members are faced with chronic illness, the entire family will be triggered to adapt themselves to meet the high demand of needs of their children. The characteristics of chronic illness include incurability, requirements for long-term care for the lifetime of the children, uncertainty, a tendency toward uncertainty and irreparability etc. The above findings reflected the difficulty of both instrumental and affective problems in addition to the voice of family members in asking for help from the health care system to help them maintain family functioning.

When we determine the interventions in these categories, the common features emerging from all of the studies were the group process interventions. In this regard, the group process helps family members in expressing feelings and emotions, learning and sharing information about the disease, advanced treatments, new ways to manage their problems, and so on through the group process to apply in dealing with their problems. This finding was congruent with studies on the effects of educational care programs via group discussion on parents' quality of life in caring for children with leukemia.¹⁸ Such a study stated that group discussion was a useful strategy enabling these parents by empowering them to deal with the problems caused by taking care of their children more systematically and leading to promoting the parents' quality of life. Similarly, the study by Plumridge et al¹⁹ stated that

support groups can play a useful and vital role in supporting family members to learn and share necessary information about the genetic conditions of their children. The group process as an intervention is appropriate as it fits with the natural characteristics of people, furthermore, these interventions are useful in improving problem-solving skills. A study on the nature of family-centered care in Thailand²⁰ stated that peer-to-peer support happened spontaneously between family caregivers when their children attended the same hospital or were from the same community. Family caregivers shared information and experiences with one another and the main topics that were frequently discussed were strategies for dealing with their children's nutritional needs.

Moreover, one in four of the studies¹⁰ explored spiritual training through the group process. This intervention can be explained in that mothers who had children with cancer were triggered to use spiritual coping strategies such as belief, endurance and leaving the problem to God, because people who are confident in God's trust and have faith in His wisdom, agree with God's will, establishing a good relationship and love between God and humanity to be independent from any suffering, fear, or distress.²¹⁻²³ Similarly the study by Efe et al.,²⁴ found that 82.5% of the parents reported using complementary and alternative medicine (CAM) methods, while prayer/spiritual practice was chosen by most of the parents at 61.8%. The important reason for a decision to use CAM was the belief that it is possible to help improve their children's conditions and symptoms. Although the parents knew prayer might not cure the children's disease, prayer gave them peace for the family that everything possible was being done for their children. Similarly, the study by Nabors et al.²⁵ found that faith or religion like a prayer was perceived by caregivers as a strategy to express emotion and feelings in addition to finding support for expressing their hopes and wishes for their children. This reflected the role of spirituality in creating opportunities for individuals who are anxious, in doubt or experiencing a sense of conflict to control, routinely portrayed psychological distress. This finding is congruent with the study by Anum and Dasti²⁶ who stated that the role of spirituality in the psychological well-being of family caregivers could be employed to prevent the pathological influences of family caregiver burden and enhance psychological well-being via spiritual counseling.²⁷⁻²⁹

In the Thai context, Buddhism is the professed faith of 93.9% of the population.³⁰ It is the foundation of Thai society and follows parental and ancestral traditions. A statue of Buddha is placed in a prominent area of hospital grounds to give family caregivers easy access for worship, prayer and merit-making to reduce suffering. Congruent with the study on the nature of family-centered care in Thailand,²⁰ it was revealed that the parents of children with thalassemia believed that illness was caused by karma. The family members did not know whether the practice of religious doctrines would cure their children's illness, but they remained aware that the children's illness required medical treatment. However, the family members and their children usually performed spiritual and religious practice to ease suffering, find peace of

mind and reduce any distress. The family caregivers reflected on their feelings after studying religious doctrines, stating that it was very useful to calm down and help them accept their children's illness. The family caregivers understood the suffering as natural and something everyone has to learn and understand. This reflected the importance of religious doctrines in terms of alternative coping methods that integrated into Thai family member lifestyles.

Communication: Interventions focusing on communication skill development were found in 3 of the studies included^{2,10,12} and showed the results on improving the communication component under family functioning. Family caregivers of children with chronic illness are faced with communication problems both among family members and with outsiders such as neighbors, relatives, and health care providers.³¹ For instance, if the children needed to go to hospital for admission, due to an exacerbation of their disease, one family caregiver needs to stay with the sick child in the hospital while the other family caregiver organises care for the healthy children and household chores. In addition, families are not only confronted with communication problems and negotiation within their families, but also continue to struggle when they have to communicate with healthcare providers due to lack of communication skills, lack of self-confidence, little to no knowledge about they ways to convey their thoughts or needs, etc. These situations reflect the suffering within families and can lead to poorer family functioning. Therefore, interventions on family-centered care can promote the capability of family caregivers concerning communication skills through the group process with communication practice and ways to convey their thoughts or needs in addition to promoting self-confidence, encouraging family caregivers to express emotions, and promoting engagement in active listening. This is congruent with a study on the nature of family-centered care in Thailand²⁰ stating that parents are reluctant to ask questions or seek more information from nurses as they do not want to add to the nurses' workloads.

Roles: The entire family requires adaptation to maintain family homeostasis or health. The family needs to reconstruct and reorganize. For example, the assignment of a main caregiver taking care of an ill child means that someone in the family must change his/her job, or possibly even quit a job to have enough time to respond to high demands in health care for the ill child. This topic can lead to other problems such as economic distress due to someone in the family having role overload in earning money to support numerous treatment expenses and so on. These situations show the caring burden caused by and related to role problems.¹ In this regard, one study by Lee et al.¹⁵ developed a cognitive-behavioral group intervention for parents of youths with chronic pain by providing coping strategies for parents to maintain their family roles. These findings were congruent with those of a study by Golfenshtein et al.,³² who said that easy ways to support family members included respite child care services for several hours a week, facilitating family caregivers in managing their time for other activities.

Affective Responsiveness and Affective Involvement:

Interventions focusing on spirituality were identified as interventions capable of improving affective responsiveness and affective involvement. This finding can be explained through a study by Borjalilu et al.¹⁰ who conducted a spirituality training program referring to supporting people exploring for meaning and goals in life. This concept encompasses religious support, communication skills, and empathic relationships with patients. In this regard, spirituality creates an opportunity for individuals who are anxious, in doubt or experiencing a sense of conflict to control, routinely portrayed psychological distress, which can be applied to families living with children with chronic illness. This program helps families to have good relationships and communication with their children and others. Families can also express appropriate emotions and behavior in response to the needs of affective responsiveness and affective involvement of their family members as a whole leading to sick children and entire families having feelings of love from their families as a part of spiritual needs. Moreover, it helps decrease the problem of behavior control between sick children and family caregivers due to the differences in the expectations on both sides.

Behavior Control: Interventions focusing on the parent-child relationship^{10,11,13} were identified as interventions able to improve behavior control. This finding can be explained in that even children with chronic illness require effective care from parents. Nevertheless, as children transition into adolescence or young adulthood, the parent's traditional caring style in terms of over protection may no longer suit the developmental needs of children. This can lead to relationship problems between parents and sick children.³³ The interventions in this category can facilitate family members to recognize the developmental and spiritual needs of sick children. It will lead to family members being able to create appropriate interactions with their children with reciprocal connectedness, enjoyable parent-child interactions, and family members' knowledge about the ways to manage the aggressive behavior of their children with techniques to enhance child compliance. In the Thai context, a study by Yuennan²⁰ found that the practice of religious doctrines could not only be useful for family members in terms of helping them accept the facts of their illness but was also helpful for chronically ill children in many ways. This is because religious doctrines about karma are a way to understand life and the idea of living the middle way, without being either too rigid or too loose in any practice. This responds to the developmental needs of sick children by family members and can create proper activities, environments and interactions with sick children.

Implementation Challenges

The included studies demonstrated that family-centered care is a necessary and important intervention in promoting the utmost ability of the entire family that will lead to the family's ability to maintain family functioning in the context of living with chronically ill children.³⁴ In this regard, developing necessary resources for family-centeredness by conducting

learning programs for all healthcare providers, sick children, families, and staff from other areas of the hospital are essential. Enhancing the collaboration of sick children and their families with health care providers can lead toward the achievement of optimized quality of care. Promoting the ability of family members and family support groups and empowering them in providing care for their children can be done while building networking to allow participation without interference from a hierarchical system. Empowerment of family members from low socio-economic backgrounds can be included in the care process.

This review points out the role of the Thai cultural context and its influence on the way families applied to promote family functioning in families living with children with chronic illnesses. Interestingly, belief in spirituality and the principles of religious doctrines can facilitate family members in easily accepting the realities of problems caused by chronically ill children and family members can also learn from the principles of religious doctrines to help them cope with suffering. Healthcare providers who work under these circumstances, therefore, need to be equipped with essential knowledge for developing a program base on the concept of family empowerment integrating with beliefs in spirituality and the principles of religious doctrines (e.g., merit-making, prayer, performing the belief traditions, and spiritual counseling) to help families living with children with chronic illnesses in maintaining family functioning.

Importantly, an insightful understanding of the family-centered care intervention to promote family functioning should be integrated into healthcare policy to provide appropriate nursing guidelines. In this regard, healthcare providers and families should come into and create a reciprocal partnership in the nursing care process to promote family functioning that will lead to good caregiving experiences as well as improved family functioning and child well-being eventually.

Further research is recommended to explore a family-centered care intervention to promote family functioning in families living with children in other conditions to expand the body of knowledge in this area.

Limitation of the Study

As this review included only quantitative studies, any qualitative or mixed methods studies were not incorporated and compared to determine if such methods promoted or distributed a counterpoint to the quantitative findings.

Conclusion

Family functioning is a complex phenomenon describing the organization of a family and the patterns of interactions between family members. In addition, it includes how families manage their daily routines, fulfill their roles within the family, and communicate and connect emotionally. Unfortunately, families living with children with chronic illness have

encountered inevitable difficulties resulting in poorer family functioning compared to families with healthy children. Thereby, an insightful understanding of the family-centered care intervention to promote family functioning in families living with children with chronic illness is a vital and challenging issue for health care providers. This understanding

will guide healthcare providers in tailoring appropriate interventions based on the concept of family-centered care to enable families living with children with chronic illnesses in maintaining family functioning.

References

1. Adanir AS, Taskiran G, Fettahoglu EC, et al. Psychopathology and family functioning in adolescents with beta Thalassemia. *Adolesc Psychiatry* 2017;7(1):4-12. doi:10.2174/221067660666161115143217.
2. Wacharasin C, Phaktoop M, Sananreangsak S. A family empowerment program for families having children with Thalassemia, Thailand. *Nurs Health Sci* 2015;17(3):387-94. doi:10.1111/nhs.12201.
3. Herzer M, Godiwala N, Hommel KA, et al. Family functioning in the context of pediatric chronic conditions. *J Dev Behav Pediatr* 2010;31(1):26-34. doi:10.1097/DBP.0b013e3181c7226b.
4. Keshvari M, Ebrahimi A, Abedi H. Relation between children's well-being and family function in children with thalassemia major in Isfahan in 2013. *Glob J Health Sci* 2016;8(12):170-7. doi:10.5539/gjhs.v8n12p170
5. Yunak R, Chontawan R, Sripichayakan K, et al. Living with the differences: Thai adolescents' experiences of living with transfusion-dependent Thalassemia. *Thai J Nurs Res* 2009;13(4):318-31.
6. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71
7. Santos WM, Secoli SR, Püschel VAA. The Joanna Briggs Institute approach for systematic reviews. *Rev Latino-Am Enfermagem* 2018;26:e3074. doi:10.1590/1518-8345.2885.3074.
8. Yensen J. PICO Search Strategies. *Online J Nurs Inform* 2013;17(3). Available at <http://ojni.org/issues/?p=2860>
9. Najafi K, Borhani F, Rabari D, et al. The Effect of Family-centered Empowerment Model on the Mothers' Knowledge and Attitudes about Thalassemia Disorder. *Iran J Pediatr Hematol Oncol* 2011;1(3):98-103.
10. Borjalilu S, Shahidi S, Mazaheri MA, et al. Spiritual Care Training for Mothers of Children with Cancer: Effects on Quality of Care and Mental Health of caregivers. *Asian Pac J Cancer Prev* 2016;17(2):545-52.
11. Yeh HY, Ma WF, Huang JL, et al. Evaluating the effectiveness of a family empowerment program on family function and pulmonary function of children with asthma: A randomized control trial. *Int J Nurs Stud* 2016;60:133-44.
12. Mapiloom P, Ratchanagul P, Muensa W. The effect of the program to develop capability of self-care of school-age children with thalassemia and capability of family caregiver for taking care of their child to self-care behavior of school-age children with thalassemia. *J Nurs Sci* 2016;31(2):52-68.
13. Zare N, Ravanipour M, Bahreini M, et al. Effect of a self-management empowerment program on anger and social isolation of mothers of children with cerebral palsy: A randomized controlled clinical trial. *Evid Based Care J* 2017;7(3):35-44. doi:10.22038/ebcj.2017.26072.1598.
14. Nagar SA, Lawend JA, Elbilgahy AA. Empowering mothers caring for their children with chronic kidney disease through engagement and education. *IOSR-JNHS* 2020;9(4):12-9.
15. Lee S, Edwards K, McMurtry CM. A cognitive-behavioral group intervention for parents of youth with chronic pain: Development, feasibility, and preliminary effectiveness. *Clin Pract Pediatr Psychol* 2021;9(2):145-55. doi:10.1037/cpp0000385.
16. Gibson GH. The process of empowerment in mothers of chronically ill children. *J Adv Nurs* 1995;2:1201-10.
17. Epstein NB, Bishop DS, Levin S. The McMaster model of family functioning. *J Marital Fam Therapy* 1978;4(4):19-31.
18. Noughabi FA, Iranpoor D, Yousefi H, et al. Effect of instructing care program through group discussion on the quality of life of parents of children afflicted with leukemia. *Glob J Health Sci* 2016;8(5):197-204. doi: 10.5539/gjhs.v8n5p197.
19. Plumridge G, Metcalfe A, Coad J, et al. The role of support groups in facilitating families in coping with a genetic condition and in discussion of genetic risk information. *Health Expect* 2012;15(3):255-66. doi: 10.1111/j.1369-7625.2011.00663.x.
20. Yuennan C. The nature of family-centered care in Thailand: A case study. A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in the School of Health Sciences, Faculty of Medicine and Health Sciences, the University of East Anglia.2015 (Accessed January 10, 2022, at https://ueaprints.uea.ac.uk/id/eprint/59197/1/Choosak_Yuennan_Thesis_Final.pdf).
21. Bonab BG, Koohsar AAH. Reliance on God as a core construct of Islamic psychology. *Procedia Soc Behav Sci* 2011;30(1):216-20. doi:10.1016/j.sbspro.2011.10.043.
22. Mousavi FS, Bonab BG, Karimi JP. The role of trusting in God in predicting mental health of Tehran university students. *Health Spirituality Med Ethics* 2014;1(4):2-9.
23. Gaudette H, Jankowski KR. Spiritual coping and anxiety in palliative care patients: A pilot study. *J Health Care Chaplaincy* 2013;19(4):131-9. doi:10.1080/08854726.2013.823785.
24. Efe E, Isler A, Sarvan S, et al. Complementary and alternative medicine use in children with thalassaemia. *J Clin Nurs* 2013;22(5-6):760-9. doi: 10.1111/j.1365-2702.2012.04210.x.
25. Nabors LA, Kichler JC, Brassell A, et al. Factors related to caregiver state anxiety and coping with a child's chronic illness. *Fam Syst Health* 2013;31(2):171-80. doi:10.1037/a0031240.
26. Anum J, Dasti R. Caregiver burden, spirituality, and psychological well-being of parents having children with Thalassemia. *J Relig Health* 2016;55(3):941-55. doi:10.1007/s10943-015-0127-1.

27. Ali S, Sabih F, Jehan S, et al. Psychological distress and coping strategies among parents of beta-Thalassemia major patients. International Conference on Clean and Green Energy 2012;27:124-8. Retrieved from <http://www.etlibrary.org/?m=fbook&a=details&aid=5151>.
28. Heo GJ, Koeske G. The role of religious coping and race in Alzheimer's disease caregiving. *J Appl Gerontol* 2013;32(5):582-604. doi:10.1177/0733464811433484
29. Ivtzan I, Chan CP, Gardner HE, et al. Linking religion and spirituality with psychological well-being: Examining self-actualization, meaning in life, and personal growth initiative. *J Relig Health* 2013; 52(3):915-29. doi: 10.1007/s10943-011-9540-2.
30. National Statistic Office. The economic and social survey of the house crutcher BE. 2555. Bangkok: National Statistic Office.2013 (Accessed December 2, 2021, at http://web.nso.go.th/en/stat_theme_eco.htm).
31. Zaheer Z, Wazir S, Hameed B, et al. Psychological burden in β-thalassemia affected families. *J Postgrad Med Inst* 2015;29(4):260-3.
32. Golfsenstein N, Srulovici E, Deatrick JA. Interventions for reducing parenting stress in families with pediatric conditions: An Integrative review. *J Fam Nurs* 2016;22(4):460-92. doi:10.1177/1074840716676083.
33. Trachtenberg FL, Gerstenberger E, Xu Y, et al. Relationship among chelator adherence, change in chelators, and quality of life in thalassemia. *Qual Life Res* 2014; 23(8):2277-88. doi: 10.1007/s11136-014-0671-2.