HEALTH EDUCATIONAL PROGRAM FOR IMPROVING KNOWLEDGE OF PARENTS OF CHILDREN WITH THALASSEMIA: EVIDENCE-BASED NURSING

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ABSTRACT

The objective of the study was to summarize all related evidences in regard to educational programs in order to improve the knowledge of parents of children with thalassemia, and provide appropriate recommendations based on the evidences obtained. The researcher searched research articles from Mahidol University database which were published from 2008 to 2013 in English. These studies were quasi experimental studies. The PICO (population, intervention, comparison, and outcome) framework was used to select the research articles. Four quasi experimental studies were obtained. These studies were appraised by Level III for their reliability, validity, and applicability.

The health educational interventions aimed to improve the knowledge of parents of children with thalassemia. Most of the educational programs included teachings and discussion sessions. The medias used were video, booklet, pamphlets, slides, handouts, CD audio tracks, and films. The four health educational programs were determined to be able to increase the knowledge of parents of children with thalassemia. Thus, an effective health educational program should be developed for parents of children with thalassemia in the hospital in Bangladesh.

KEY WORDS: PARENTS/CHILDREN WITH THALASSEMIA/KNOWLEDGE/HEALTH EDUCATIONAL PROGRAM/EVIDENCE-BASED NURSING

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CHAPTER I
INTRODUCTION

1.1 Back ground and significance of the problem

1.1.1 Prevalence of children with thalassemia

Thalassemia is a major chronic and genetic hematological disorder worldwide (Clarke et al., 2009). It is a severe life-limiting and potentially life – aggressive disease that causes significant disorder in all aspects of life (Koutelekos & Haliasos, 2013). Thalassemia is a hereditary disorder involving hemoglobin production resulting in a reduced the globin chain. Comparative imbalance of alpha and beta globin genes produces intramedullary hemolysis and unproductive erythropoiesis (Sohn et al, 2013). The defective globin genes for thalassemia are carried in approximately 4.5% of the world's population **(**Shanthi, Balasubramanyam, & Srinivasan, 2013). Worldwide, a total of 100,000 children with major thalassemia children are born each year (Grow, Abrol, Vashist, Yadav & Sharma, 2013). In the Mediterranean, there are over 200,000 beta thalassemia patients (Mansi, Aburjai, albashtawy & Dayem, 2013). Most of these patients are in developing and low-income countries (Grow et al., 2013). In India, 10,000 children are born with thalassemia per year. For beta thalassemia carriers, there are 1-3% of children in Southern India and 3-15% of children in Northern India carry the disease (Kumari, Upadhyay, Gupta, Piplani & Bhatia, 2012). In Bangladesh, there are 123.85 million and total births are 2,477,022 newborns per year. 1,040 children are born with beta thalassemia major and 6,443 children are born with Hb E beta thalassemia each year. The total number of beta thalassemia major patients are 52,017 and Hb E beta thalassemia patients are 3, 22,137. In Bangladesh, the infant mortality rate is 46 per 1000 births (Khan et al., 2005).

In Bangladesh, thalassemia is the greatest common genetic disorder. Although there is no document registry for the number of patients with thalassemia,

the number of patients with thalassemia is very high. In Bangladesh, pediatric mortality from diarrhea, respiratory tract infection and malnutrition has decreased due to improved health services and diets. Most Bangladeshi children live with genetic illnesses such as thalassemia and are admitted to hospital more frequently. Genetic services are required due to an infant mortality of 46 per 1,000 births. In the Barisal and Rajshahi divisions, beta thalassemia trait and Hb E trait have the highest prevalence. Therefore, thalassemia is the most significant health problem in Bangladesh along with other genetic disorders (Khan et al., 2005).

1.1.2 Impact of children with thalassemia

Children are affected by thalassemia in physical, behavioral, psychological, emotional, social and learning aspects leading to decreased quality of life and hospital readmissions (Haghpanah et al., 2013).

1.1.2.1 Physical impact: Children with thalassemia are affected by many physical problems within the first two years of life. They are born healthy at birth and thalassemia develops between the ages of three to six months. This severe condition develops within the first year of life (Rani, Vijoyakumar, Kumar & Chandana, 2013). These children may have some complications such as cardiomyopathy, heart failure, arrhythmia, pericarditis, hepatomegaly and splenomegaly (Grow, Abrol, Vashist, Yadav, & Sharma, 2013). They also have some endocrine complications such as diabetes mellitus, hypothyroidism, hypoparathyroidism, hypogonadism and delayed puberty. Some children have high fevers, pneumonia and oral ulcers, etc. (Thavorncharoensap et al., 2010). Frequent blood transfusions lead to iron overload (Khurana et al., 2006), and children with thalassemia major become paler and jaundiced with shortness of breath. These children develop severe anemia with severe paleness. Sometimes, they suffer from infections causing high fever and oral ulcers. They have poor appetites and are unable to consume sufficient food. These children are short in stature. They have bone deformities, slow growth and weakness. Their faces become moon-shaped. Their bones are fractured easily. Their spleens, livers and hearts may become enlarged (Mazzone, Battaglia, Andrezzi, Romeo & Mazzone, 2009).

1.1.2.2 Behavioral and psychological impact: Children with thalassemia are at high risk for behavioral and psychosocial problems such as opposition, passiveness, anxiety, phobias and depression, all of which affect their self-confidence. These problems affect their quality of life, and compliance with therapy. These children have stress, fear and anxiety due to separation from their parents during hospitalization (Moghaddam, Moghaddam, Sadegmoghaddam &Ahmadi, 2011). They have negative thoughts, guilty senses and increasingly low self-esteem. These children frequently become sick and are unable to play with siblings or other children (Mazzon et al., 2009). These children are also afraid of intravenous line insertions and subcutaneous infusion pumps (Guha et al., 2013). They are unable to sleep due to nightly subcutaneous injections of iron chelation therapy (Siddiqui, Ishtiaq, Sajid & Sajid, 2014). In addition, they have deteriorating relationships with family members (Mazzon et al., 2009). Some children are doubtful about the future and believe they will succumb to early death (Siddiqui et al., 2014).

1.1.2.3 Emotional, social and learning impact: Children with thalassemia are frequently absent from school for hospital visits (Khurana, Katyal &Marwaha, 2006). They are excessively dependent on their parents. They miss both school and social activities (Siddiqui et al., 2014). These children receive frequent blood transfusions, chelation therapy and hospital visits and/or treatment complications. They frequently suffer from infections such as fever and pneumonia. Therefore, they are unable to go to school regularly (Thavorncharoensap et al., 2010). These children are insufficient inlanguage, attention, and memory. They had low intelligence and poor school performance (Mazzon et al., 2006).

1.1.3 Impact of parents of children with thalassemia

Parents of children with thalassemia are also affected by their children's illnesses with numerous impacts such as physical, psychological, emotional and financial impacts.

1.1.3.1 Physical impact: Children with thalassemia receive iron chelating therapy in a subcutaneous infusion over eight to ten hours. These children require hospitalization for iron chelation therapy three to five times a week. Therefore, during this period, parents are unable to find a suitable place to rest and do not get sufficient rest in hospital.

1.1.3.2 Psychological impact: Children with thalassemia frequently miss school for medical treatment. The parents are worried about their children's education. Children are not allowed to participate in certain activities such as sleepovers, school field trips or extended vacations during blood transfusions and nightly chelation therapy. Parents are worried about their children's health conditions (Liem et al., 2011). Parents would also like these children to live their lives similar to non-disabled children. Thus, these parents are anxious and depressed (Prasomsuk, Jetsrisuparp, Ratanasiri & Ratanasiri, 2007).

1.1.3.3 Emotional impact: Parents of children with thalassemia receive long-term care. Parents are involved in essential care such as giving medications, taking the children for hospital visits and blood transfusions and giving children food with low iron content (Liem et al., 2011).

1.1.3.4 Financial impact: Parents of children with thalassemia have financial problems. They bring their children to the hospital for blood transfusions every three to four weeks. These children require iron chelation therapy, routine hospital visits and emergency follow-up in some cases (Liem et al., 2011). Therefore, parents are unable to work regularly. Parents' income becomes insufficient or they lose their jobs. Parents spent more money on blood transfusions for their children. Some children needed splenectomy or stem cell transplants, which are more expensive. The financial burdens are loss of income and the high costs of treatment, transportation and living expenses during patient admission (Prasomsuk et al., 2007).

1.1.4 Treatment for children with thalassemia

Thalassemia is a chronic and lifelong disease. Children with thalassemia cannot be cured completely. These treatments might be long and children may require urgent and monthly follow-up with repeated hospital admissions. They require more health care resources, proper care and treatments, all of which are expensive (Mirbehbahani, Salehi, Jahazi, &Karimi, 2014). The lifelong treatment costs for each child with thalassemia is nearly 149,899 USD (Riewpaiboon et al., 2010).

Treatment of children with thalassemia depends on the type and severity of the disease. The oral medications include iron, multivitamins, Vitamin C and folic acid. Folic acid builds healthy red blood cells. Vitamin C increases the amount of iron

absorbed from foods. These children require blood transfusions every two to three weeks in order to keep their hemoglobin levels above the normal range (10 g/dl) within one month. This “hyper-transfusion” method enhances growth and well-being for these children. Hyper-transfusion prevents heart failure and bone deformities in the children. Blood transfusions, however, also lead to iron overload in children with thalassemia (Ghodekar, Grampurohit, Kadam &Thorat, 2014). A combination of iron chelation therapy and regular blood transfusion could reduce morbidity and increase the survival rate for children with thalassemia. The primary goal of iron chelation therapy is to control the amount of iron in the body. Deferoxamine is administered in a 8–12-hour continuous infusion at a rate of 5–7 times per week. For an alternative drug, deferiprone is orally administered three times per day when deferoxamine therapy is contraindicated or inadequate. Deferiprone, however, has better activity on removal of iron from the heart (Scalone et al., 2008). Therefore, iron chelation therapy includes deferoxamine and deferasirox. Because intravenous deferoxamin is more painful, this medicine is provided subcutaneously at a very slow rate. Iron chelation therapy takes more times and it had side effects such as loss of vision and hearing. Deferasirox is provided once a day. The side effects of deferasirox are headache, nausea, vomiting, diarrhea and joint pain. Blood transfusions and marrow stem cell transplant are the special treatments capable of curing thalassemia. However, it is hard to find a good match among donors for children with thalassemia. The complications of treatments are heart disease, liver disease, infection, osteoporosis, splenomegaly and iron overload (Ghodekar et al., 2014).

1.1.5 Special care for children with thalassemia

In addition, children with thalassemia require some special care from their parents in addition to the health care protection required by other children. The care of these children includes nutrition, growth and development, vaccinations, physical activity, medications and follow-up care, etc. (Haghpanah et al., 2013).

Children with thalassemia require sufficient nutritional support for their growth and development. Therefore, nurses should encourage parents to give normal, healthy diets containing of fresh fruits, vegetables, milk and protein (fish or meat). Children need many different foods containing a wide variety of nutrients. These kinds

of foods are needed to reduce any infection in children with thalassemia (Aimiuwu et al., 2011). Meningococcal vaccines and Hib booster vaccinations should be given to children before splenectomy. Routine vaccines should start up to the age of two months. Hepatitis A and B vaccine should also be given to children who receive long-term blood transfusions (Vichinsky et al., 2012). Physical exercise is the most important to prevent cardiac problems in these children. Healthy foods, appropriate body weight and treatment of any endocrine diseases such as diabetes, hypothyroidism and hyperthyroidism can prevent cardiac problems of these children (Baer et al., 2013).The nurses encourage parents to give medications to their children and go to hospital with their children for follow-up regularly (Sananreangsak et al., 2012).

As mentioned above, children with thalassemia require ongoing care from parents and health care providers, especially nurses. Nurses provide routine nursing care for children and parents both in outpatient and inpatient units. Nurses also provide general nursing care such as taking body weight and vital signs as well as preventing infection. For special nursing care, nurses draw blood and send blood samples to the blood bank for grouping and cross matching. They also provide proper diet and medications for children with thalassemia (Sananreangsak et al., 2012). It is necessary for nurses to provide health education to parents for taking care of children with thalassemia such as foods with low iron content, medications, exercises, follow-up visits, and desferioxamine infusions (Ghazanfari et al., 2010).

1.2 Clinical problem of the study

Parents of children with thalassemia have insufficient knowledge in caring for their children with thalassemia. They also have insufficient information about the disease and therapeutic interventions.

From the researcher's experience in the clinical setting of Bangladesh, nurses are always busy. They provide special care such as medication, diets, vital signs and oral health care, etc. They do not have enough time to give standard educational programs to these parents. Nurses generally teach parents before children are discharged from hospital. Nurses provide little information on the signs and symptoms of the illness, diet, exercise, desferioxamine infusion, disease prevention and follow-

up. The teaching session lasts for approximately 15 minutes which is insufficient for the parents. Parents are unable to clearly understand about the care of their children. Nurses do not have an appropriate teaching method. There are no any medias for providing information to the parents. In addition, the language of parents is either Bengal or English. The parents are unable to understand the information provided in complicated medical terms.

Nurses teach parents to give foods with low iron content such as Vitamins A, E, folic acid, B12 and zinc. However, they do not tell the names of foods with low iron content to parents. Nurses teach the parents to avoid iron rich foods, but do not tell the names of high iron rich foods. They do not teach parents about physical exercise, which is necessary for children's health. The nurses do not teach parents about urgent conditions or when parents should take children to hospital. They do not provide effective health education to parents about how to take care of their children.

In the researcher's clinical setting and personal experience, parents of children with thalassemia require knowledge in order to take proper care of their sick children. However, parents do not have enough knowledge about foods, follow-up visits, physical exercise, blood transfusions and iron chelation therapy, etc. Parents frequently provide iron rich foods for their children. These iron rich foods include dried beef, beef liver, egg, cake, barger, chapatti, sticky rice, spinach, peas, broccoli, kale, tomato juice, potato, figs, strawberries, watermelon, dates and prune juice, etc. Some parents avoid providing low-iron foods for their children such as fruits (apples, cranberries, grapefruits), and vegetables (lettuce, broccoli, mushrooms, carrots, cabbage). They do not give foods that inhibit the absorption of excess iron such as milk products, coffee, tea, nuts, grains, rice and beans. Some parents take their children to hospital for monthly follow-up visits. Other parents do not know that physical exercise is needed for their children. They always keep their children in bed. Parents think their children will be more sick if they move around. Parents sometimes do not take their children to hospital for blood transfusions when their children suffer from severe anemia, mouth ulcers, pneumonia or high fevers. They do not know that blood transfusions are essential for their children. Iron chelation therapy is very painful. Hence, parents feel this therapy is harmful for the health conditions of their

children and some parents do not take their children to hospital for iron chelation therapy.

Therefore, effective health educational programs need to be developed for parents of children with thalassemia in a clinical setting by summarizing health educational programs. Nurses can provide effective health educational programs in a clinical setting for improving the knowledge of parents of children with thalassemia. As a result, these parents will provide better care for their children. Hence, the researcher wanted to review the related evidence and summarize health educational programs for parents of children with thalassemia.

1.3 Purpose of the study:

To summarize all related evidence in regard to health educational programs in order to improve the knowledge of parents of children with thalassemia.

1.4 Expected benefits of the study:

1.4.1 After completion of this study, the contents summarized from all evidence will be used to develop health educational programs suitable for parents of children with thalassemia in Bangladesh.

1.4.2 In Bangladesh, nurses will have some effective educational programs for parents of children with thalassemia both inpatient and outpatient units in their clinical settings.

CHAPTER II
METHODOLOGY

The objective of this study was to summarize the research evidence on improving the knowledge of parents of children with thalassemia. The summary is based on the related evidence available at the Mahidol University electronic databases. The searching process employed search strategy to find and select the evidence. Each related sample of evidence was appraised for its quality and feasibility by considering the setting and circumstances, health care resources and caregivers' preferences and values. In this chapter, the author describes the search strategy, search framework, scope of searching, appraisal method and level of evidence, including the selection process, level, validity and reliability of the evidence.

2.1 Search strategy

The author searched and selected evidence-based practice on improving the knowledge of parents of children with thalassemia by using the PICO framework (Melnyk & Fineout-Overholt, 2005).

2.1.1 Search framework: The author searched and selected evidence on the knowledge of parents of children with thalassemia by using the PICO framework (Melnyk & Fineout, 2005) with the following details:

P (Population)	=	Parents of children with thalassemia
I (Intervention)	=	Education program
C (Comparison)	=	Routine activities
O (Outcome)	=	Improving knowledge

2.1.2 Scope of searching: The educational programs on the knowledge of parents of children with thalassemia were based on validated evidence-based practice

found be using the PICO framework and relevant keywords to discover suitable evidence:

1) Keywords used in the search according to the PICO framework: The author used a Boolean operator for each PICO element and collected any synonyms by connecting terms with "OR", then located citations relevant to all the PICO elements by linking with "AND". In the following:

Keywords used in the search according to the PICO framework:

P (Population) = Parents / caregivers/mothers of children with thalassemia

I (Intervention) = Education program

C (Comparison) = Usual care / usual teaching

O (Outcome = Knowledge / awareness

2) Databases/sources used for the search: The author used the electronic database sources of Mahidol University Library system. Cumulative Index to Nursing and Allied Health (CINAHL), Ovid Full Text, ProQuest Nursing, PubMed, Science Direct, Cochran Library, Springer Link and Google Scholar were used to search for single research studies. The author also conducted a manual search by looking for citations from reference lists from systematic reviews. For guidelines, the author searched from the National Institute for Health and Care Excellence (NICE) websites. The author searched for published articles from database beginning from 2005 to 2014.

3) Types of evidence: The author searched for guidelines, systematic reviews of randomized controlled trials (RCTs) with quasi experimental studies and high quality single randomized controlled trial studies acquired from full text studies published in English from 2005 to 2014. The author searched and collected the articles from databases.

2.2 Appraisal methods and levels of evidence

After obtaining, the author searched evidence of related to educational program on knowledge of parents of children with thalassemia. The author assessed the various types of evidence and selected few research articles with quality strength

of evidence meeting evidence classification criteria and checked for the validity with advisory professors. Next, the author described the critical appraisal and level of evidence (Melnyk, and Fineout- Overholt, 2011).

2.2.1 Appraisal method: The author read, analyzed and synthesized four experimental studies for content, objectives, research methodology, strength of evidence, setting, sample group, instrument for evaluating the intervention outcomes, research findings, and analysis of evidence-based practice by analyzing the utilization criteria. The author assessed by the appraisal method with the classification criteria of the Melnyk, and Fineout-Overholt, (2011) to appraise the quality, reliability and applicability of the evidence. The collected evidence were appraised based on the following three criteria:

1) Validity**:** Validity is vital for validating a test in order to ensure that the results are accurately applied and interpreted. It is the level to which a test measures what it claims to measure. The research process was assessed from the research design to the analysis and summary of the results in order to assess the validity of research. The systematic and comprehensive searches were conducted in line with the objective by appropriate methodology. All evidence was obtained through sound scientific methods and objectives were clearly stated. The researcher took steps toward randomly assigning the process in order to ensure that confounding variables potentially compromising the findings and bias were removed. The selection criteria for the participants in the experimental and comparison groups were explained. Randomization is significant to experimental studies such as randomized controlled trails because different outcomes are expected from two groups in the intervention and comparison. The quality assessment of the selected evidence was stated properly and the data were adequately presented from the evidence. Moreover, the evidence preferred for this study was quality support. The population of the study was composed of parents of children with thalassemia. Furthermore, it was necessary to provide an education program for parents (Melnyk and Fineout-Overholt, 2011)

2) Reliability**:** The reliability depended on accuracy, honesty, consistency, achievement and repeatability in order to ensure that anyone could perform the same experiment by using similar equipment and conditions to achieve the

same outcome. The author studied all research articles and evidence-based practice, then analyzed and evaluated for importance according to processes with satisfactory quality implementation of research results for education programs aimed at improving the knowledge of parents of children with thalassemia. The researches were reliable, significant in literature reviews and contained evidence-based practice. The studies were assessed for suitability and consistency with research designs throughout the studies in the areas of topic, variables, research hypotheses, objectives, data collection, data analysis, sample group and instrument reliability. The results were assessed to summarize the research findings, statistical significance and clinical relevance by considering the evidence discovered in the systematic review, whether or not the researches had observations of actual clinical situations and whether or not there was a reliable review literature and reliable reference documents.

3) Applicability

3.1 Transferability of the findings: The author evaluated the feasibility of applying the evidence which indicated that implementation of an intervention from the findings was useful in the author's own local clinical setting. All evidence was evaluated by the author in terms of the feasibility of implementation in the clinical setting as concerning the choices of participants, which were similar to the author's own research population, and service users in the organization. The author kept in mind that parents of children with thalassemia would benefit from the education programs.

3.2 Feasibility of implementation: The feasibility of implementation was supported by the authority measured by the organizations with the willingness of personnel, equipment, tools and instruments. Any difficulty of methods and abilities of nurses for application with regular work and low workload were also considered. Finally, the implementation could be integrated into nursing practice.

3.3 Cost/benefit ratio: The implementation of evidence was of greater benefit to pediatric patients and parents than routine practice and required no additional costs. The medical expenses were reduced, used simple equipment, reduced length of hospital stays and decreased the risks for the patients.

The cost benefits decrease burden of families and increasing the satisfaction of the pediatric patients and their families.

2.2.2 Evaluation of the strength of the evidence: The author searched and selected empirical evidence by using the level of quality recommended. The studies were assessed as practical in the clinical setting by Melnyk and Fineout-Overholt (2011). The details on classifying level are described in the table below:

Table 2.1 - Level of Evidence

Level of Evidence	Source of Empirical Evidence
Level I	Evidence from a systematic review or a meta-analysis of all studies that are RCT, or evidence from guidelines developed from a systematic review of research evidence from randomized control trials.
Level II	Evidence obtained from at least one RCT/well designed RCTs.
Level III	Evidence obtained from at least one well-designed controlled trials without randomized assignment.
Level IV	Evidence from well-designed case controlled and cohort studies.
Level V	Evidence from a systematic review of descriptive and qualitative study.
Level VI	Evidence from a descriptive or qualitative study.
Level VII	Evidence from the opinions, attitudes of experts on the issues or and/or a report written by expert committee.

Search strategy is very important to identify appropriate evidence from different websites and electronic databases. For appropriate research objectives, the PICO format is essential to determine the evidence related to target populations for designated interventions and outcomes. The author's search processes were implemented with synonyms for finding out evidence from the electronic database of

Mahidol University in line with the research objectives. Next, the author evaluated the quality of evidence in terms the strength of validity, reliability and applicability for the evidence in meeting the inclusion and exclusion criteria.

Reasoning of searching strategy: The author's search yielded 25 articles from different databases under the PICO framework that were similar to the issue of health education programs for improving the knowledge of parents of children with thalassemia. The author read these articles and selected those meeting the inclusion criteria. After analyzing all articles, the author found none of the articles to be related to the selected PICO framework concerning the study population, interventions and outcomes. The author repeated the search to find interventional studies on parents of children with thalassemia, but the author did not yield any suitable articles. Subsequently, the evidence of parents of children with thalassemia was very scarce in Bangladesh and Thailand.

Therefore, the author was only able to find four research articles. According to the PICO framework, the author included these articles due to strong validity, reliability and applicability. The selection criteria were as follows:

1) The evidence selected should only be published in English from full text studies.

2) The duration of articles was set for 10 years; hence, the studies acquired had to be published from 2004 to 2014.

3) The research articles should be systematic reviews, quasi experimental studies and clinical practice guidelines.

4) The outcomes of all the evidence should improve the knowledge of parents of children with thalassemia.

5) Health education program should be established in inpatient units, outpatient clinics and different units.

On the other hand, the author was not able to include available articles in this study. Very few articles clearly focused on outcome intervention, population and design. Some articles were not relevant to health education programs and the contents of the programs. As a result, the author selected only four articles with outcomes on improving the knowledge of parents of children with thalassemia.

CHAPTER III
FINDINGS

The results and summary of the evidence yielded by the search explained in order to specify quasi-experimental studies concerning the health educational program as well as the contents of teaching programs for improving the knowledge of parents of children with thalassemia. The aforementioned is described as follows:

3.1 Search results:

The author‘s search yielded 25 research articles primarily from relevant evidence-based practice by searching the electronic database of the Mahidol University Library system for evidence of educational programs for parents of children with thalassemia. The author selected 20 research articles meeting the inclusion criteria such as systemic reviews, randomized controlled trials and quasi-experimental studies after reading titles and abstracts. Next, the author selected 12 articles from the remaining 20 articles by matching the titles, populations, interventions, comparisons and outcomes. During the analysis, 4 articles were excluded due weak validity. Then author then synthesized 8 research articles, 4 of which were excluded for weak dates and references. Finally, the author read each sample of evidence in detail and chose 4 articles that specifically described education programs for parents of children with thalassemia in four quasi-experimental studies. All of the studies were published in English from 2008 to 2013.

Table 3.1 Level and type of evidence

Sl /No.	Authors/Year	Title of Evidence	Type of Evidence	Level of Evidence
1	Dehkordi, A. H., & Heydarnejad, M. S. /2008.	Effect of booklet and combined method on parents' awareness of children with beta thalassemia major disorder	Quasi-experimental study.	III
2	Najafi, K. M., Borhani, F., Rabari, D. E., &Sabzevari, S. /2011.	The effect of family-centered empowerment model on the mothers' knowledge and attitudes about thalassemia disorder	Quasi-experimental study.	III
3	Dehkordi, A. H., & Heydarnejad, M. S. /2008.	Enhancement of parents' awareness about beta thalassemia disorder through two educational programs	Quasi-experimental study.	III
4	Qadir, K. J., & Hussein, K. A. /20013.	Effectiveness of an educational health program on mothers' knowledge and practices of thalassemic children receive desferal therapy in Hawler thalassemia Centre /Erbil City	Quasi-experimental study.	III

3.2 Relevant contents and appraisal results of four samples of evidence:

The author selected the 4 evidence related to educational programs for parents of children with thalassemia and briefly summarized all of the evidence as follows:

Evidence No. 1

1.1 Title: Effect of booklet and combined method on parents' awareness of children with beta thalassemia major disorder.

1.2 Authors: Dehkordi, A. H. & Heydarnejad, M. S. (2008).

1.3 Publication source and year: Journal of Pakistan Medical Association, 58(9), 485-487.

1.4 Objective of the study: To assess the effects of a booklet and combined method (lecture, video, etc.) on the awareness of parents bearing children with B-thalassemia major disorder.

1.5 Methodology of the study:

Type of evidence: Quasi experimental study.

Level of evidence: Level III.

Setting: The study was conducted at Hajar Hospital, Iran in 2006.

Program researcher: The researcher.

Participants and sampling: Total participants were 60 parents who had children with beta thalassemia major who were aged 1-11 years. The participants were randomly divided into two groups of 30 parents each. The first group received booklets and the second group received combined methods including lecture and video.

Program: The author conducted the education program with booklets and combined method (lecture, video).

Method: The education was provided with lecture, booklets and a video.

Media: Booklets and video**.**

Duration: The author did not explain the duration of the teaching sessions or program.

Measurement: Parent's knowledge was measured by questionnaire. The questionnaire included 30 items in the form of multiple choice questions; each question had equal values with scores of +1 for correct answers and zero for incorrect answers.

1.6 Content: The author did not mention about the contents of the teaching program, but the questionnaire was designed to gather information about the disease.

1.7 Outcome: Both the booklets and combined groups significantly increased knowledge. The mean scores of both intervention groups were significantly different ($p<0.01$).

1.8 Evidence appraisals

1.8.1 Are the results valid? (Validity): The study was valid because the objective of the study was clearly recognized and related to the problems. The study was quasi-experimental research. For the participants of the study, 30 parents were randomly divided to a booklet group and a combined group (lecture, video, etc). The sample size and sampling method were appropriate for this study. Parental knowledge about the disease was measured by a questionnaire including 30 multiple-choice questions. Correct answer scores were +1 and zero was given for incorrect answers. However, the researcher did not mention the content validity of the instruments. Knowledge of parents in both the booklet group and the combined group increased significantly.

1.8.2 What were the results? (Reliability): The study was reliable because it was assessed for proper design in terms of topic, variables, objective, sample group and population. Moreover, the population was similar to the clinical problem. Both data collection procedures and statistical data analysis were well-defined. The researcher did not, however, mention the reliability of the questionnaire. Data were analyzed by using student's t-test and Pearson's correlation. After the program, the knowledge of the parents in both groups increased. Therefore, this study demonstrated that both booklets and combined methods can be used in teaching programs. Both the booklets and combined program increased the knowledge of these parents.

1.8.3 Will the results help me in conducting similar programs? (Applicability): In this study, the education program was provided for parents of children with thalassemia in the hospital. This program included lecture and watching videos as well as receiving booklets. Lecturing and watching videos in the hospital will be appropriate for the author's clinical setting because the parents will be able to easily understand the disease. Nurses can provide the knowledge by lecturing in groups and letting the parents watch videos. In addition, booklets will be appropriate as the parents can take them to read at home. This program will be more convenient and effective for increasing the knowledge of parents. The author can apply the methods and media of this education program to her clinical setting.

Evidence No. 2

2.1 Topic: The effect of family-centered empowerment model on the mothers' knowledge and attitudes about thalassemia disorder.

2.2 Author/Year: Najafi, K. M., Borhani, F., Rabari, D. E., &Sabzevari, S. (2011).

2.3 Publication Source: Iranian Journal of Pediatric Hematology oncology. 1(3), 98-103.

2.4 Objective of the study: To assess the effect of family-centered empowerment model on the mother's knowledge and attitudes about thalassemia disorder in children with thalassemia.

2.5 Methodology of the study:

Type of evidence: The study was a quasi-experimental study.

Level of evidence: Level III.

Setting: This study was conducted at the Thalassemia Center of Kerman**.**

Program researcher: The researcher.

Participants: Eighty six mothers of children with beta thalassemia aged 6-12 years participated in the study. All participants were randomly divided into two groups, namely, an experimental group and a control group comprising 43 mothers each.

Method: Group discussion.

Media: Pamphlets, slides, handouts and CD audio tracks.

Duration: The author did not mention the duration of the teaching sessions and the duration of the program. The author only mentioned that the outcome (knowledge) was evaluated with questionnaires before and one-and-a-half months after the intervention.

Program: Family- centered empowerment model.

Measurement: The data were collected by questionnaires, but the number of questionnaires was not mentioned.

2.6 Content:

First Step: Discussion about disease. The researcher discussed with parents about knowledge (awareness) of participants about symptoms, treatments, detection and transfer methods.

Second Step: Decoding phase for the problem - The researcher discussed the use of pamphlets and slides about the disease to increase parents' confidence. Next, parents were able to participate in the program and discuss the care of their children.

Third Step: The researcher provided educational media such as pamphlets, handouts and CD audio tracks to family members.

2.7 Outcome: The means scores for knowledge (awareness) and attitude were significantly higher in the intervention group than the same scores in the control group. Therefore, the family-centered empowerment model was able to improve maternal knowledge and attitude about thalassemia disorder.

2.8 Evidence Appraisals:

2.8.1 Are the results valid? (Validity): The research findings were valid because the objective of the study was clearly identified and related to the problem of the study. The study was based on a quasi-experimental research design. The sample size (86) was appropriate for this study. The participants were randomly divided into intervention and control groups with 43 subjects each. In this study, the data were collected by questionnaire with pre-test and post-test findings. The questionnaire was tested for the content validity and reliability (internal correlation), however, it did not show the reliability value. The data were presented adequately in

the tables. The outcomes were clearly identified. The program was offered to only the intervention group, but the researcher did not mention what the control group received.

2.8.2 What are the results? (Reliability): The study was reliable because it compared awareness and attitudes between the two groups in the study. The outcomes were different between the intervention and control groups. The variables, objective and data collection procedures were appropriate. The questionnaire was tested for content reliability. The results were analyzed with statistical software. The scores for the awareness and attitudes of the mothers in the intervention group were significantly higher than the same scores in the control group.

2.8.3 Will the results help me in conducting similar programs? (Applicability): The family-centered empowerment model of this study was conducted at a thalassemia center. This program included group sessions and discussions. The media were pamphlets, slides, hand-outs and CD audio tracks. The author can conduct the education program by using group discussions and showing slides because nurses can spend time in providing instruction to groups of mothers in the researcher's clinical setting. Moreover, nurses will give pamphlets, hand-outs and CD audio tracks to mothers and family members of children with thalassemia to read and watch at home. Group discussions, slides, pamphlets, hand-outs and CD audio tracks will be more convenient for nurses, parents and family members. Therefore, the author can apply these methods and media to the clinical setting.

Evidence No. 3

3.1 Title: Enhancement of parents' awareness about beta thalassemia disorder through two educational programs.

3.2 Author: Dehkordi, A. H., & Heydarnejad, M. S. (2008).

3.3 Publication source: Pakistan Journal of Medical Sciences, 24(2), 283-286.

3.4 Objective of the study: To investigate how education of parents by means of lectures and/ or booklets can lead to reduction of beta thalassemia major disorder.

3.5 Methodology of the study:

Type of evidence: Quasi experimental study.

Level of evidence: Level III.

Setting: This study was conducted at Hajar Hospital, Iran in 2006.

Program researcher: The education program conducted by the researcher.

Participants: Ninety parents who had a child affected with beta thalassemia major. All participants were randomly divided into three groups of 30 parents each: the control group 30 and two intervention groups (a lecture group and a booklet group of 30 subjects each.

Intervention of the program: The researchers conducted the educational program to the parents by two educational methods; booklets and lectures, but there was no method for considering the control group.

Method: Lecture.

Media: Booklets**.**

Duration: The researchers did not mention the duration of the teaching sessions or program.

3.6 Content: The researchers did not explain the content of the intervention.

Measurement: Data were collected with 30-item questionnaires containing multiple choice questions and questions with equal values. Correct answers were given scores of +1 and zero was given for incorrect answers. Scores ranged between 0-10 (weak awareness), 11-20 (fair awareness) and 21-30 (good awareness) about thalassemia.

3.7 Outcome: There were significant differences in knowledge (awareness) scores of parents among the three study groups. In addition, there were increase in knowledge (awareness) scores in both the lecture and booklet groups.

3.8 Evidence Appraisal:

3.8.1 Are the results valid? (Validity): The objective of the study was clearly recognized and related to the problem. The participants were appropriate for this study. The data were collected by 30 item questionnaires

containing multiple-choice questions, but the researcher did not mention the content validity of the questionnaire. The significance of the study was accepted at $p < 0.05$. The data, however, was reported inadequately because there was no data on the scores for the knowledge of the parents. Therefore, the two educational programs (booklets and lectures) were able to increase the parents' knowledge.

3.8.2 What are the results? (Reliability): The study was reliable because it compared the knowledge of three groups of parents (two intervention groups and one control group). The outcomes were different between the two intervention groups and the control group. The variables, objective and data collection procedures were appropriate. The data were collected by questionnaires, but the researchers did not provide the information about the reliability. Student t-test and Pearson's correlation tests were used to determine the statistical relationships, and significance was accepted at $p < 0.05$.

3.8.3 Will the results help me in conducting similar programs? (Applicability): In this study, the educational program was provided to parents who had a child affected by beta thalassemia major. This program was conducted with lectures and booklets. The lecture method was preferred by nurses because it saves their time in teaching by approximately 20-30 minutes, and it can be taught to parents in either individual or group teaching. The booklets will be convenient for parents and nurses. The parents can take the booklets home and improve their knowledge by reading. Hence, the author can apply this program in author's clinical setting in Bangladesh.

Evidence No. 4

4.1 Title: Effectiveness of an educational health programme on mothers' knowledge and practices of thalassemia children receive desferal therapy.

4.2 Author/ year: Qadir, K. J. & Hussein, K. A. (20013).

4.3 Publication source: Zanco Journal of Medical Science**,** 17 (1), 357-362.

4.4 Objective: To improve mothers' knowledge and practices with thalassaemic children aged 3- 18 years who are using desferal therapy.

4.5 Methodology of the Study:

Type of evidence: This study was a quasi-experimental study.

Level: Level III

Setting: This study was conducted in a hospital setting at Hawler Thalassemia Center in Erbil city.

Program researcher: The education program conducted by the researcher.

Participants: One hundred mothers who had children with thalassemia major aged 3-18 years were divided into two groups (experimental and control groups) with 50 mothers each. The study group received an educational health program including lectures, group discussions, films and practical observation. The control group was not exposed to the educational health program.

Inclusion criteria: Mothers who had children diagnosed with thalassemia major and were recipients of desferol therapy by attending the thalassemia center for blood transfusion and follow-up with their ages ranging from 3 to 18 years.

Duration of teaching program: Two sessions; one-and-a-half hours per day.

Method: Lecture, group discussion and practical observation.

Media: Film.

Measurement: Data were collected by questionnaires and the direct interview technique. The questionnaire evaluated the mothers' knowledge and practices. Data were analyzed by excel and SPSS version 17.

4.6 Content: The researcher did not mention the content of teaching program.

4.7 Outcome: There were significant differences in mean scores for knowledge and practice between the two study groups. The knowledge and practice mean scores for the intervention group were higher than those in the control group. Therefore, the health educational program was able to improve the knowledge and practice of mothers of children with thalassemia.

4.8 Evidence Appraisal

4.8.1 Are the results valid? (Validity): The study was valid because the objective of the study was clearly identified. This study was based on a quasi-experimental research design. The number of participants was appropriate because it was large. One hundred mothers were divided into two groups with 50 mothers each, but the researcher did not mention the sampling method. The data were collected by questionnaires and the direct interview technique. The questionnaire was tested for content validity by a panel of 15 experts. After the intervention, the mean scores for the knowledge and practices of the intervention group increased, but none of the mean scores for the control group improved. Therefore, the educational program was effective at improving the knowledge and practices of the mothers.

4.8.2 What were the results? (Reliability): The study was reliable because the reliability and internal consistency of the questionnaire and educational health program were assessed by Pearson's Coefficient Correlation. The results were 0.878 for maternal knowledge and 0.891 for maternal practices. Data were collected by the use of a questionnaire tool and direct interview techniques. The results of Pearson's Coefficient Correlation indicated excellent scale reliability. After the intervention, the knowledge and practices of the study group were improved.

4.8.2 Will the results help me in conducting similar programs? (Applicability): In this study, the health educational program was offered to parents during patient admissions in the hospital. This program was conducted by lectures, group discussions with media and film as well as practical observation. Lecture and group discussions might be possible for nurses to provide for the parents. In addition, films will be more convenient for parents because they can be watched at home to increase knowledge. Therefore, the researcher can apply this method and media in author's clinical setting.

3.3 Conclusion:

3.3.1 Summary of the evidence appraisal:

The four quasi experimental studies met the inclusion criteria on similar the issue of educational program for improving knowledge of parents of children with

thalassemia. These four studies were published in English from 2008 to 2013. According to four samples of evidence, the researcher concluded which programs/interventions /strategies were effective at improving the knowledge of parents of children with thalassemia.

Based on the selected studies, there were two types of educational programs: health educational programs and family-centered empowerment programs. From all selected studies, health educational programs were able to improve the knowledge of parents with thalassemia children. In addition, the health educational program in one study (the fourth study) also increased the practice of these parents.

Interestingly, the fourth study also added film and practical observation in its health educational program.

According to the health educational programs in the selected studies, the researchers used many methods including lecture, group discussions and practical observation. The teaching media used were booklets, videos and films. The core contents were not explained. The researcher mentioned in one study that the duration of the teaching program was one-and-a-half hours per day. Data were collected by questionnaires and an interview technique. The questionnaire was used to measure the parents/mothers' knowledge about the disease and how they behaved with their children. The results of three samples of evidence supported that health educational programs about thalassemia programs are very effective for improving the knowledge of parents.

Based on the family-centered empowerment program in one study (second study), group discussions and teaching were conducted. The media used were pamphlets, slides, handouts and CD audio tracks. The knowledge (awareness) and attitudes of these parents were assessed by questionnaires before and at one-and-a-half months after the program. The data were collected by questionnaires. The questionnaires were used to measure the mothers' knowledge and attitude. The results of this evidence supported that family-centered empowerment programs are very effective for improving the knowledge and attitudes of mothers of children with thalassemia.

Table 3.2 - Integrate Table for Four Articles

Evidence No.	Article -1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. 2008).	Najafi, K. M., Borhani, F., Rabari, D. E. &Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. 2008).	Qadir, K. J. & Hussein, K. A. (2013).
Title	Effect of booklet and combined method on parents' awareness of children with beta thalassemia major disorder	The effect of family-centered empowerment model on the mothers' knowledge and attitudes about thalassemia disorder	Enhancement of parents' awareness about beta thalassemia disorder through two educational programs	Effectiveness of an educational health program on mothers' knowledge and practices of thalassemic children receive desferal therapy in Hawler thalassemia Centre /Erbil City

Table 3.2 - Integrate Table for Four Articles (cont.)

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. &Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Objective	To assess the effect of booklet and combined method (lecture, video, etc.) on the awareness of parents bearing children with B-thalassemia major disorder.	To assess the effect of family-centered empowerment model on the mothers' knowledge and attitudes about thalassemia disorder in children with thalassemia.	To investigate how education of parents by means of lecture and/ or booklet may lead to reduction of the beta thalassemia major disorder.	To improve mothers' knowledge and practices of thalassaemic children aged 3- 18 years who are using desferal therapy.

Table 3.2 Integrated Tables for Four Articles (cont.)

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Population	Booklet group and combined group with 30 parents each. Both groups were experimental groups.	A control group and experimental group of 43 mothers each.	A total of 90 parents with 30 parents in the control group 30 and 30 parents each in two study groups (booklet group and combined group.	A study group and control group of 50 mothers each.
Setting	Conducted at Hajar Hospital, Iran in 2006 (hospital setting).	Conducted at Thalassemia Center of Kerman, Iran (hospital setting).	Conducted at Hajar Hospital, Iran in 2006 (hospital setting).	Conducted at Hawler Thalassemia Center in Erbil city (hospital setting).
Design	Quasi-experimental study	Quasi-experimental study	Quasi-experimental study	Quasi-experimental study

Table 3.2 Integrated Tables for Four Articles (cont.)

Evidence No.	Article -1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Intervention /program/ protocol	The author did not mention the contents of the teaching program, but the questionnaire was designed to gather information about the disease.	First Step: Discussion about the Disease. The researcher discussed the knowledge and awareness of the participants about symptoms, treatments, detection and transfer methods with parents. Second Step: Decoding phase problem. The researcher discussed the use of pamphlets and slides about the disease to increase parents' confidence. Next, the parents could participate in the program and discuss the care of their children. Third Step: The researcher offered educational media, pamphlets, handouts and CD audio tracks to family members.	The author did not mention the contents of the teaching program, but the questionnaire was designed to gather information about the disease.	The researcher did not mention the contents of the teaching program.

Table 3.2 Integrated Tables for Four Articles (cont.)

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Methods	Lecture	Group Discussion	Lecture	Lecture and group discussion, and practical observed application
Media	Booklets and videos	Pamphlets, slides, handouts and CD audio tracks	Booklet	Film
Duration	The author did not explain the duration of the teaching sessions or program.	The author did not mention the duration of the teaching sessions and or program, only mentioned outcome evaluation with questionnaires after one-and-a-half months after the intervention.	The author did not mention the duration of the teaching sessions and or program.	Two sessions, one-and-a-half hour per day throughout the teaching program. The author did not mention the duration of the program.

Table 3.2 Integrated Tables for Four Articles (cont.)

Evidence No.	Article -1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M.,Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Program Leader	Researcher	Researcher	Researcher	Researcher
Measurements	Parent's knowledge was measured by questionnaires. The questionnaire contained 30 items in the form of multiple-choice questions. Each question included equal values with scores of +1 for correct answers and zero for incorrect answers.	The data were collected by questionnaire; the number of questionnaires was not stated.	Data were collected by a 30-item questionnaire. Each question had equal value with scores of +1 for correct answers and zero for incorrect answers. Scores between 0-10 were interpreted as "weak awareness"; 11-20 as "fair awareness" and 21-30 as "good awareness" about thalassemia.	Data were collected by questionnaire and the direct interview technique. The questionnaire was used to evaluate mothers' knowledge and practices.

Table 3.2 Integrated Tables for Four Articles (cont.)

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K.A. (2013).
Outcomes	Both booklets and combined groups significantly increased knowledge. The mean scores of both intervention groups were significantly differenct ($p < .01$).	The mean scores for knowledge (awareness) and attitude in the intervention group were significantly higher than those in the control group. Therefore, the family -centered empowerment program could improve maternal knowledge and attitude about thalassemia.	There were significant differences in the knowledge (awareness) scores of parents among the three study groups. In addition, there were increases in knowledge (awareness) scores in both the lecture and booklet groups.	There were significant differences in the mean scores for knowledge and practice between the two study groups. The knowledge and practice scores of the intervention group were higher than those in the control group. Therefore, the health educational program could improve the knowledge and practice of parents of children with thalassemia.

Table 3.3 Collective Table of Educational Programs for Parents

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
Setting	Hospital	Hospital	Hospital	Hospital
Trainer	Researcher	Researcher	Researcher	Researcher
Type of Intervention	Educational program	Family-centered empowerment program	Educational program	Educational program
Methods of Activities	Lecture	Group discussion.	Lecture	Lecture, group discussion and practical observation
Medias of Group Activities	Booklet and video	Pamphlets, slides, handouts and CD audio tracks.	Booklet	Film .

Table 3.3 Collective Table of Educational Programs for Parents (cont.)

Evidence No.	Article-1	Article-2	Article-3	Article-4
Author & Year	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Najafi, K. M., Borhani, F., Rabari, D. E. & Sabzevari, S. (2011).	Dehkordi, A. H. & Heydarnejad, M. S. (2008).	Qadir, K. J. & Hussein, K. A. (2013).
1. Intervention	√	√	√	√
2. Length of session				√
3.Duration				√
4. Condition of disease		√		
4.1 Causes		√		
4.2 Symptoms		√		
4.3 Meaning of disease		√		
4.4 Treatment		√		
4.5 Care process		√		

3.4 Recommendations:

The researcher reviewed of the four samples of evidences, suggested recommendations about how to use educational programs effectively to improve parents' knowledge.

These four studies contained two types of educational programs: 1) health educational programs and 2) family-centered empowerment programs. Essentially, the results were as follows:

1. Health educational programs for improving the knowledge of parents/mothers:

1.1 Population Characteristics

1.1.1 All participants were parents/mothers of children with thalassemia, beta thalassemia or thalassemia major. The parents/mothers were aged from 20 to 55 years, and the children were aged from 1 to 18 years (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir K et al., 2013: Level III).

1.1.2 The mothers lived in urban and rural areas. They were house holders and employed. Their educational levels were primary and under high school (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III).

1.2 Setting: The settings used in the studies were outpatient clinics. All of the health educational programs were implemented during blood transfusions and follow-up visits at thalassemia centers in hospital settings (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III).

1.3 Duration and number of sessions: Only one study (the fourth study) mentioned the teaching period (one-and-half hours per day) (Qadir et al., 2013: Level III).

1.4 Health educational program methods: The researcher used lecture method in two studies, lecture, group discussion and practical observation in one, in health educational program *(Dehkordi* et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III).

1.5 Health educational program media: Booklets and videos were used in two of the samples of evidence, and film was used in one sample of evidence (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III).

1.6 Program Content: Most of the studies did not mention the contents. Only one study (second study) focused on disease (Qadir et al., 2013: Level III).

1.7 Outcome measurements: Parental knowledge was measured by 30 multiple-choice questions (scores of +1 were granted for correct answers and scores of zero were granted for incorrect answers). Scores between 0-10 were classified as “weak awareness”; 11-20 as “fair awareness” and 21-30 as “good awareness” about thalassemia in two of the samples of evidence (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III). In one study, data were collected through the use of questionnaire and direct interview techniques (Qadir et al., 2013: Level III).

1.8 Outcomes: Health educational programs were able to increase the knowledge of parents in two studies. One study was able to enhance the knowledge and practices of these mothers (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III).

2. Family-centered empowerment program for improving knowledge and practices of parents/mothers:

2.1 Characteristics of participants:

2.1.1 All participants were mothers of children with thalassemia. The mothers were aged less than 40 to 60 years and the children were aged 6 to 12 years (Najafi et al., 2011: Level III).

2.1.2 The mothers lived in the capital city and rural areas. The mothers were housewives and employed. Their educational levels were below the high school and vocational certificate level (Najafi et al., 2011: Level II

2.2 Setting: The family-centered empowerment program was conducted in outpatient clinics at the Thalassemia Center of Kerman (Najafi et al., 2011: Level III).

2.3 Family empowerment program methods:

2.3.1 First Step: Discussion about disease. The researcher discussed the knowledge and awareness of the participants with the parents concerning symptoms, treatments, detection and transfer methods.

2.3.2 Second Step: Decoding phase problem. The researcher discussed the use of pamphlets and slides about the disease to increase the parents' confidence. Next, the parents were able to participate in the program and discussed the care of their children.

2.3.3 Third Step: The researcher providing educational media such as pamphlets, handouts and CD audio tracks to family members.

2.4 Outcome measurements: The knowledge and attitudes of all parents were evaluated with questionnaires after intervention (Najafi et al., 2011: Level III).

2.5 Outcome evaluation: Post-test was assessed at one-and-a half months after the intervention (Najafi et al., 2011: Level III).

2.6 Outcomes: The family-centered empowerment program was able to increase knowledge (awareness) and practices among the mothers about thalassemia disorder (Najafi et al., 2011: Level III).

According to the four studies, the results demonstrated that the health educational programs and family-centered empowerment programs were about thalassemia, which made them effective in improving knowledge, attitudes and practice among parents/mothers of children with thalassemia (Dehkordi et al., 2008a: Level III; Dehkordi et al., 2008b: Level III; Qadir et al., 2013: Level III; Najafi et al., 2011: Level III).

CHAPTER IV

CONCLUSION AND SUGGESTION

4.1 Conclusion

Thalassemia is a widespread chronic and genetic hematological disorder worldwide. The parents of children with thalassemia are the key persons for the care of their children. Most parents suffer from many physical, psychological, emotional, and financial aspects. Thalassemia is a chronic and lifelong disease requiring specialized, long-term care for their children. Most of the parents are not able to understand the signs and symptoms of the disease in their children due to poor knowledge. In Bangladesh, parents have insufficient knowledge about the disease, and parents do not provide optimal care for their children. Therefore, these children are at risk for complications. Nurses provide limited information within a short period of time (approximately 15 minutes) to the parents about the disease and care of the children such as the signs and symptoms of illness, prevention of disease, diet, exercise, follow-up clinic/doctor's visits and deferoxamine infusion at home. In Bangladesh, there are no evidence-based practices for parents of children with thalassemia. Evidence-based practice is required for improving the knowledge of parents in caring for their children with thalassemia. Evidence-based practice is an important integration of scientific papers, updated information, clinical experiences and patients' performance. Therefore, evidence-based practice is useful for the parents. Based on these problems, the author is interested in summarizing both educational programs from evidence in order to increase the knowledge of these parents. Therefore, the purpose of the study was to summarize all related evidence in regard to educational programs to improve the knowledge of parents of children with thalassemia and summarize recommendations based on the evidence obtained.

The author searched for available current evidence by using the Mahidol University Library electronic database system and websites to search for related evidence-based practice. The Cumulative Index to Nursing and Allied Health

(CINAHL), Cochran library, PubMed, ProQuest Nursing, Ovid full text, Science Direct, Google Scholar and National Institute were used to search for experimental studies. The PICO framework was used to guide the keywords for the search. The keywords used were P (Population) = “parents” OR “mothers” OR “caregivers” of children with thalassemia, I (Intervention) = “Education program” OR “teaching program” OR “training program,”C (Comparison) = “Usual activities” OR “usual care” and O (Outcome) = “Knowledge.” The author used a Boolean operator for searching. For each PICO element, the author collected any synonyms by connecting terms with “OR”, then located citations relevant to all of the PICO elements by linking with “AND”.

According to these studies, the author searched the electronic database of Mahidol University for accumulated information on evidence-based practice and found relevant articles with the PICO framework. The PICO format assisted in the discovery of appropriate samples of evidence-based practice. The author evaluated the evidence-based practice by using the methods and criteria set for testing validity, reliability and applicability. The author selected inclusion and exclusion criteria, language, publication year and setting of the intervention. The author read each detail and chose four samples of evidences that specifically described both educational programs for improving the knowledge of parents of children with thalassemia.

All studies were based on quasi-experimental research designs. All studies were published in English from 2008 to 2013. The methods of teaching were lecture, group discussion, booklets, video and practical observation. The media used were video, booklets, pamphlets, slides, handouts, CD audio tracks and films. The researchers conducted studies on parents or mothers of children with thalassemia, (beta thalassemia, and thalassemia major). However, in three studies of health educational programs, the researchers did not mention the contents of the teaching sessions. Nevertheless, items in the questionnaire used for data collection mentioned information about the disease. Only one study (second study) directly mentioned information about thalassemia. All studies used the questionnaires to evaluate the knowledge (awareness), attitudes and practice of parents/mothers before and after intervention. After the intervention there was increasing knowledge for the parents/mothers in the intervention group. The results from all of the evidence showed

health educational programs to be very effective at increasing parents' knowledge. Thus, potential effective health educational program should be included in the treatment of thalassemic children.

The four research articles identified some important issues. The programs were implemented after the diagnosis in the hospital. Most of the methods used were lectures, group discussions and practical observation (fourth study). The media used were booklets (first and third studies), CD audio tracts (second study), videos (first study), film (fourth study). In most of the studies, the researchers did not mention the duration of teaching and education programs. Only one study, (fourth study), teaching programs were provided within two sessions for one-and-a-half hours (90 minutes) per day. Based on the outcomes of the studies, two studies mentioned knowledge, and the others mentioned awareness. However, the questionnaires in all of studies were used to measure the knowledge of the parents/mothers of the disease and practices.

Based on the findings, the author drew conclusions from four studies. The studies were based on a quasi-experimental design. The participants in the studies were parents/mothers of children with thalassemia/beta thalassemia/thalassemia major. The parents/mothers ranged from 20 to 60 years in age or more, and the age of children was between 1-18 years. The parents/mothers were housewives and employed. Most of the educational levels of these parents/mothers' were below high school, vocational certificates and above.

Similarities the four samples of evidence: The outcome of the four samples of evidences concerned the parents'/mothers' knowledge about the disease. Most of the methods used (3 studies) were lectures and (2 studies) group discussions. Therefore, all educational programs from the four selected studies were able to increase knowledge about thalassemia among the parents/mothers. The media used for two studies were booklets (2 studies).

Differences in the four research articles: Three studies provided health educational programs and one study provided a family-centered empowerment program.

Selected evidence focused on strategy: In these selected four studies, the parents received educational programs about the disease. Many teaching methods and media were used. However, the limitations of the evidence included insufficient

information about the contents of the teaching sessions and interventions. The researchers did not provide the details of the teaching contents, duration or frequency of the teaching programs.

In conclusion, booklets and videos/CDs/films are appropriate media for use in the clinical setting. Video and CD audio tracks can stimulate parents to understand and improve their knowledge about the disease of their children. Booklets can assist parents to understand contents more when they read them at home.

4.2 Suggestions

The author would like to implement the health educational program for parents of children with thalassemia in the author's clinical setting in Bangladesh. According to the two study types (health educational programs and family-centered empowerment programs), the implementation for nursing practice and research should be applied as follows:

4.2.1 Implication for practice: Based on these recommendations from all of the findings, parents of children with thalassemia have more knowledge about thalassemia. The nurses will implement health educational programs for parents of children with thalassemia. The program will be conducted before children are discharged from hospital. The methods of the health educational programs and family-centered empowerment programs were lectures, group discussions and practical observation. Media were booklets and videos, CD audio tracks, films, pamphlets, slides and handouts. Parents were the key persons capable of performing important roles in providing appropriate care for their children. Therefore, each parent should participate in the health educational program.

The author would like to implement a health educational program about thalassemia for improving the knowledge of parents in her clinical setting.

Recommendations practically derived from the selected four samples of evidences for implementation of a health educational program about thalassemia disorder suitable for the Bangladeshi context are as follows:

1) The author will develop effective heath educational programs in a hospital setting for inpatient and outpatient departments.

2) All participants should be parents/mothers of children with thalassemia, beta thalassemia or thalassemia major.

3) The methods of the educational programs consist of lecture and group discusion for improving the knowledge of parents.

4) In addition, the media that should be included are booklets, videos or CD audio tracks.

5) The booklets, CDs, videos and films will be written in the Bengali language.

6) Teaching session: Sessions should last one hour per day.

4.2.2 Implications for research

Experimental research should be conducted to test the effectiveness of the combination of health educational programs and family-centered empowerment programs.

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