

Experiences of Thai Children Living with Thalassemia Major : A Qualitative Study

Suksiri Prasomsuk

R.N., Ph.D.

Community health Department, Siam University

E-mail: suksiri_drko@yahoo.co.th

Waraporn Kamrot

R.N., M.Sc.

Community health Department, Siam University

E-mail : wara_au@hotmail.com

Abstract

Thalassemic patients must be taken care of throughout their life including a helping hand from their families and ongoing medical treatment. As a result, this disorder has a continuous physical and psychological effect on the patient and his or her family. To date, only limited research has been conducted in regards to this problem. The purpose of this qualitative study was to explore the problems of thalassemic children. Fifteen mothers with children diagnosed with HbE?-thalassemia major were given semi-structured interviews and the data was analyzed utilizing content analysis. Four categories were examined including: 1) the perceiving thalassemic knowledge in the patient, specifically in regards to the disease's process and awareness of the related pathology, 2) the impact of her child's education, such as issues participating in school activities because of the physical condition of the patient, 3) the impact of school absences due to blood transfusion in the hospital, and 4) children s' behavior prior to and during blood transfusions in regards to their stress and anxiety levels. The findings of this study provided insight into the experience of thalassemic children and suggest that a holistic nursing approach should be considered in caring for these children.

Keywords : Children's behaviors, Thalassemia, Qualitative study

I. INTRODUCTION

Many of psychosocial reactions found in children with thalassemia are not unique. General problems of anxiety, fear of treatment and problems in social functioning are shared by children affected by other chronic diseases. Similar coping behaviors are observed. Specific or characteristic coping tasks and strategies facing patients vary from condition to condition in that they are dependent in part on the manifestations and management of the disease. Different patterns of illness place different psychosocial demands on the child. Also, there is a wide range of responses and behaviors exhibited by patients suffering from a particular chronic children disease (1).

While we know a great deal about thalassemia as a disease, including its physical manifestations and appropriate treatment, we know little of what it is like to be a child with thalassemia. For instance, what it is like for a young child bewildered by the necessity for blood transfusions, because he or she does not understand what is wrong? What is it like for the older thalassemic patient who is suffering chronic discomfort from symptomatic heart failure and numerous endocrine and liver problems? What is it like knowing or suspecting that death is near? What is it like going to school or the hospital when you are a thalassemic child (2)?

It is difficult to imagine, even with the copious medical literature, what it is like to be a thalassemic child and what impact the treatment described has on the patient's ability to function normally in society. It is also challenging to imagine what it is like to the intellectually normal child who falls behind peers in growth and physical maturity. The protection of the interests for the "disabled or handicapped" is

virtually unknown in terms of special accommodations for treatment scheduling or special sensitivity (3).

Parents are recovering during their child's preschool years because they are still uncertain and unsure of their child's future. The child has become able to actively resist unpleasant treatment. The parents' submission to the whims and demands of their frightened child, caused by their guilt and inability to positively support the child, added to the development of difficult behavior problems. It also signaled to the child and siblings that something was different about the thalassemic patient. Literature and empirical findings in western countries indicate that thalassemia major, as a chronic illness, causes negative impacts on the thalassemic child (4, 5, 6).

Thus, effects of thalassemia major on Thai children's behaviors are an increasing concern to society and health care professionals. However, there is little theoretical information and empirical research regarding the behavior of thalassemic children. The purpose of this study was to explore experiences of Thai children living with thalassemia major in the context of Thai society. It was expected that, with a clear understanding of this information, health care professionals who care for these patients and their families could support them as effectively as possible while keeping the child healthy and maintaining an optimal quality of life along with social standards and culture in the Thai community.

II. METHODOLOGY

Design

A qualitative design was used to investigate the problems of these children, how they think and feel about their lives, how they perceive thalassemia major and what impact the disease had on their

lives. This study adopts a qualitative method because "qualitative research is especially useful where little known about the area of study and the particular problem, setting or situation, because the research can reveal processes that go beyond surface appearances" (7,8).

Participants

The study participants consisted of 15 mothers of 15 thalassemic children and aged 6-14 years. The inclusion criteria included families who had a mother whose age ranged from 25-50 years and were the primary caregivers for their hemoglobin (Hb) E β -thalassemia major child for at least one year. The mothers were given an in-depth interview and signed a consent form. Their level of education ranged from elementary to secondary school level (14 elementary, 1 secondary). The ages of their children when diagnosed ranged from 2 to 10 years. The children who were diagnosed by Hb typing as having Hb E β -thalassemia major problem were receiving blood transfusion therapy at the study site.

Setting

In-depth interviews took place in a comfortable setting chosen by the participants. All participants preferred to be interviewed in the pediatric ward at Khon-Kaen Center hospital in Northeastern Thailand.

Procedure

Ethical approval was obtained for the interviews from the ethics committee of the faculty of Medicine at Khon Kaen University. Data collection was guided by processes specific to the qualitative method (9) and an interview guide was developed. Following the pilot interviews, questions were revised. The areas covered in the interview guide included: a) questions

about the family's first experience taking care of the child diagnosed with HbE beta-thalassemia major, b) the feelings of the family in regards to caring for the thalassemic child, c) information they had receive related to the disease, d) how helpful this information was, e) life experience since the child's diagnosis and f) factors influencing their quality of life. A phenomenological approach, using semi-structured conversational interviews, was used with the aim of enabling participants to voice their own experiences (10). In each interview, permission was given to record, transcribe and translate the session. A code was created to preserve the anonymity of the participants. Each transcript was read line-by-line and summarized by the researcher to obtain a complete overview of the interview and identify the topics discussed. Methodological rigor was ensured by double checking the researcher, independent text coding and triangulation of data analyses (11).

Data analysis

A process of content analysis refined the raw data (completing data collection, tape recording, field note taking, recording of all evidences of feeling, emotion and facial expression.) The data processing methods included an interview transcription, data grouping, key words linkage and identification, and summaries (11). The significant statements that were relevant to the life experiences of the mothers were extracted from each individual transcription. These themes served as a basis for defining categories.

III. FINDING

Fifteen mothers with children diagnosed with HbE β -thalassemia major participated in the study. All of the mothers were married. Their ages ranged

from 24 to 47 years old with a mean age of 35. The participants included 12 housewives and 3 who worked full-time. The age of their children when diagnosed ranged from 2-10 years old. We identified four core categories encountered by mothers with their children. Generally speaking, all participants agreed that Hb E β -thalassemia major affected their lives. The four categories were perception of thalassemic knowledge, impact of thalassemic education, school absences and children's behavior during blood transfusions.

Perceiving of thalassemic knowledge

Each children was knowledgeable about the disease process and the impact it has on her live. A child felt that, *"Having thalassemia means I cannot have kids...And I am sad about that."* They were aware that strenuous activity with results in pain and that when they have pain, treatment needs to be administered. One child said, *"Sometimes when I am playing basketball, I have to stop and go into my house and get a drink, or lay down so I will feel better."* (Interview 1) Another child stated that *"You have to take care of yourself until you feel better or it just gets worse."* (Interview 2) This participant also hoped that, *"You get better at dealing with this as you get older."* (Interview 3) Recorded statements reflected that the children were aware of the pathology and self management related to thalassemia. They were often asked to explain different aspects of their disease to other people.

One child stated, *"Sometimes people keep asking me 'how come you have yellow eyes?'"* (Interview 4) Another child has been asked to explain the implanted catheter *"...because it's so big and it's round and people can see it sticking out of your shirt."* (Interview 2) A third participant educated

others because, *"I don't want them to treat me like I have a contagious disease."* (Interview 1)

Impact of child's education

Nearly half of the families with school-age children stated that their child's education had been disrupted by the illness. In six cases, prolonged absences of 6 weeks or more were reported. Two of these involved long hospitalizations for removal of the spleen and the others pertained to hospitalizations for unspecified severe respiratory problems associated with high fever.

Many families reported that their child had problems participating in school activities because of physical conditions. They reported that "tiredness" prevented their child from partaking in or keeping up with physical activities such as playing football, gymnastics or was responsible for their falling behind in lessons. These families identified the physical symptoms of weakness and tiredness as a significant factor affecting their child's ability to function normally in a school setting. Interviewee comments included:

"She gets very tired going to school but she still does not want to shy so she feels bad about it and cries." (Interview 1)

"He gets tired and cannot study for long. He feels dizzy." (Interview 2)

"At first he was avoiding the difficult exercises and then he stopped participating in gym." (Interview 3)

"When he had low hemoglobin he did not feel like studying. He could not understand his lessons. Since the splenectomy, he does not get so tired." (Interview 4)

"He feels tired in school when blood transfusion time approaches. His legs hurt him." (Interview 13)

A less sympathetic mother noted:

"He does not participate more in school because of his teacher's fear and his own laziness than his health earlier it was because of his spleen." (Interview 14)

Impact of school absences

School absences among thalassemic children varied considerably for a number of reasons and treatment was particularly disruptive for those children coming from the villages. A hemoglobin test might involve a day-long trip. Given the transfusion requirements and current scheduling of pre and post-blood transfusion test, it was impossible, even for people in Khon-Kaen, to avoid some school absences each month. In some cases, absences were viewed by teachers as affecting school performance. In other cases, due to successful family-initiated efforts to make up assignments, it was shown not to affect school performance. One family observed:

"Because of absences, even though she was a good student and was studying, she could not cover the entire syllabus and had to repeat a class." (Interview 15)

Parents also indicated missing school for treatment was upsetting to their child:

"She is very upset because of the transfusion related absence. She cries and does not want to leave school to come to the hospital for treatment." (Interview 13)

Each mother also identified the impact that thalassemia major has had on her child's school attendance. These statements were both positive and negative. Positive statements related to "getting to miss school" and "getting treated

differently by teachers and classmates." The participants viewed these situations as gains from having this disease. Negative statements also surrounded missing school, such as "today I wanted to go to school but instead I had to come here (to the hospital)." Another participant stated,

"Sometimes you just miss the work and they just go on to something else and sometimes you get there right in the middle of a thing and you don't get to finish what you were working on and that gets very complicated." (Interview 12)

Two mothers could identify the fact that thalassemia and blood transfusion were having an impact on their educational process.

One participant clarified this as, *"Thalassemia has a lot of impact, a huge impact on my life because I miss so much school."* Three of the participants mentioned the school that is available at the hospital and that there are *"Special people who are around to help you keep up."* (Interview 11)

This substitution was not viewed as the ideal and schoolwork did not appear to be a priority for these children while receiving monthly blood transfusion. Nearly all of the school-aged children missed some schools. Three days per month was standard, given the treatment. In cases where special arrangements for treatment were made, absences did not occur. In another case, a mother utilized private physicians for hemoglobin testing to avoid long waits at the provincial hospital.

Children behavior toward blood transfusions

A child's tolerance of treatment is another factor of overall adjustment. The dynamics between

a child, his or her parents and the medical personnel in the treatment settings were at times extremely hostile and volatile and at other times friendly and jovial.

In general, it can be said that each clinic and transfusion day was emotionally draining. This was due to the extreme disturbance of some children and to the short tempered parents who had been waiting for hours to see the doctor or begin a transfusion. Doctors themselves grew worried of the routine treatment and one physician stated that he was beginning to have nightmares about blood. Other physicians were observed bowing their heads in despair at yet another diagnosis of thalassemia in an infant during a regular clinic day. All of these factors added to the stress of what could have solved with more effective organization and routine office visit for the children and parents.

All of the children in this study were observed in the treatment setting at least four times over a 6-month period. There was a considerable range of behavior displays by children in response to various aspects of the treatment program. The following notes taken during clinic observations illustrate children who tolerated examination very well.

"She cried a little while the nurse drew her blood. She tried to control herself though. She was watching the procedure all the time. She asked for the empty syringe (needle removed) and went after the nurse for it as she went to rinse it out in the sink." (Observe 1)

Another brave 5-year-old child displayed the same behavior during a particularly difficult blood drawing session.

"The nurse began to tie his arm for blood drawing. She made absolutely no fuss and watched

the whole procedure without alarm, as did her mother. The nurse left the needle in the arm removing the syringe, and the nurse was collecting the dripping blood in a vial. The nurse squeezed the boy's arms to get more blood. He watched quietly." (Observe 3)

The next examples illustrate cases where children did not tolerate examinations or blood drawing well. In one case, the child began protesting the visit to the clinic the night before and began crying the minute he awoke.

"He cried vigorously during the venous blood drawing, shouting, "My arm is hurting me, mother, mother." He began calling for his father and the nurse asked him where his daddy' was. He responded through his crying, "At work." The boy continued crying, saying "Stop it, it's enough, you hurt me." He then asked his mother, "Why does he pierce me?" The mother responded, "Well, how was he going to take the blood?" Afterwards, his cousin said to the doctor, "You better give her syringe." The nurse responded, "No, I will not, since he cried like this." He was angry then because he thought he was not going to be given the empty syringe. The nurse handed it to him as he left." (Observe 2)

Other children were not happy with the venous puncture to draw blood but controlled themselves fairly well.

"When who came to get blood drawing, who was not happy. Her mother held her with her head back so that she wouldn't see the procedure. She cried during the blood drawing. Afterwards she was fine and in good spirit again." (Observe 4)

The observations of the children's behaviors during office visits to the hospital showed that over

half of the children resisting treatment were less than 3 years of age. The majority of the others were preschoolers with three in elementary grades. The pediatric ward was an upsetting scene during blood transfusions, particularly for their mothers. Their infants were tied to the beds, both arms and legs fasten to the bed corners with cloth strip, to restrain their protests and keep them from disengaging the transfusion. The transfusion apparatus was attached to the infant's temple. These youngsters were sedated; often so they did not awaken easily and appeared very drugged afterwards. One mother was observed kissing and caressing her baby's hand or feet and staring with a blank white face at the blood dripping from the bottle.

Transfusion scenes tended to be even more traumatic in cases where the child's fears were aggravated by bad experiences with inexperienced personnel. Even for those who accepted the need for transfusions, recognizing that they felt much better afterwards; violent reactions on the part of other children disrupted the entire group. The following two scenes depict transfusion days at center hospital. In each case, one child's resistance to a transfusion promoted uneasiness among the other children and parents.

Anxiety prior to transfusions was reported by mother who observed behavior changes as the transfusion approached. Here is an example of a typical comment from a mother:

"He wants to be very punctual with the dates of his transfusions and insists on it. When the date approaches he is very anxious to get over and done with it." (Observe 6)

"Dum was scheduled for a transfusion in the evening but felt so weak in the morning that he didn't go to school and come for a transfusion

instead. Both Dum and Deang were receiving two bottles of blood. Dum began crying when the nurse began to hook up the infusion of the bottle. The nurse had difficulty in getting him hooked up and was trying to do it in his ankle. This upset Dum a great deal. Deang's mother told him it's the same in the arm, that it wouldn't hurt any more, which calmed the boy down a bit. Dum's mother held his hand and head in her arms. This scene was also upsetting the others." (Observe 1)

IV. DISCUSSION

Thalassemia is a chronic illness causing serious symptoms to children and a burden to families that can profoundly affect their quality of life. The present exploratory study focused on the qualitative accounts of Fifteen mothers of children with thalassemia. The main aim of the study was to elicit a series of individual accounts regarding the impact of thalassemia on quality of life and to determine what commonality lay between these families and the life domains they reported were affected. In this study, most families of the thalassemia group interviewed lived in northeastern Thailand and were of low to middle socioeconomic status with an educational level of elementary school. Finding showed that thalassemia was a burden to the child and their family in regards to his or her quality of life. Factors included frequent absence from school, discomfort at the time of transfusion, physical limitation and complications of the illness itself. The families also felt negative impacts on their economic status, occupation, time for parenting and general family functioning. More support for these families is imperative and necessary to provide a more comprehensive management program which would include information, psychosocial and economical support

for those affected by thalassemia.

One of the biggest concerns of these families were the misunderstandings regarding thalassaemic knowledge, such as understanding splenectomy, occurrence of thalassemia, genetic issues and prevention. Although they came to visit the doctor for blood transfusion therapy nearly every month, it seemed that the amount of information received from the health personnel was inadequate and unclear for applicability in real life situations. Therefore, the families needed a better understanding of thalassemia, its triggers, treatments and preventive strategies in order to become successful home caregivers. If these needs were not met, it would cause a great deal of stress to most families. As a result of minimal information, they developed their own coping strategies to fit their family lifestyle until they found better methods. The findings of this study could help all health care providers better understand the family's perspective of symptom management and other factors related that affected their lives. The way information about thalassemia is provided to family members should be adjusted for each family's unique circumstance including education programs and decisions regarding these programs. As a result of better information, it would directly enhance the sense of mastery and control by empowering family members.

On the other hand, this study revealed that families perceived the psychosocial impacts of thalassemia in regards to worries about image, illness, treatment (especially splenectomy), blood transfusions as well as concern for the future of their child and the impact on their life. These problems affected every aspect of their lives. In striving for a higher quality of life, these families took care of themselves as a whole person in the context of

their culture, including their values and beliefs. In addition, the influence of Thai culture, especially Buddhism, in respect of Thai thalassaemic families who performed their respective role with a positive attitude and a friendly concern to other families (14). They wished that other families would not face thalassaemic problems as they had. These findings are consistent with those of Tedsiri (3). Therefore a "family-based" approach should be considered in caring for this group because such as an approach values holistic health, well-being and self-help. "Family-based approaches" were recommended in the literature on chronic illness as the preferred method for helping families cope. This involves meeting with both parents, following up a short time after diagnosis with all relevant family members and caregivers, enquiring about day-to-day management, emotional aspects, giving all medical information required and adding written material for review (2).

Some families reported that to get treatments and blood transfusions they needed access to private clinics to save money and time. These kinds of experience revealed that the health care system in Thailand did not provide the same standard of care for people in rural areas. Community hospitals did not have some drugs or blood transfusions for children. The families spent time and money for transportation to the provincial hospital. Therefore, families with a child diagnosed with thalassemia in rural areas experienced inequity in accessing quality care. They also needed more money to support their child for monthly hospital visits.

V. IMPLICATION FOR PROFESSIONAL PRACTICE

The first issue that generates from this study for professional practice is education. An accurate understanding of the experiences of each individual would help health professionals to think about teaching strategies and the nature of health education among the public

A second issue is psychosocial care. Effective psychosocial care requires recognition that each family needs to prevent or lessen psychosocial complications. In order to achieve this, health personals should educate and inform the families clearly about thalassemia.

The third issue is to enhance family support services by establishing community support by organizing family groups with thalassemia. The sharing of information and brain storming during group meetings that often occurs in support groups, may also lead to a greater sense of empowerment (12). This will have the potential to enhance the use of cognitive coping strategies, to the extent that they may reduce stress enough to allow families to engage in calm reflection to their immediate need.

The fourth issue is the recommendation for a Thai national thalassemic policy planning. This policy plan should be provided to health personal on thalassemia services in rural hospitals. Genetic counselors should be trained by qualified personnel and standard guidelines should be established for the whole country(13). Thalassemia support groups should be officially established in regional hospitals and also in rural hospitals for the psychological support and emotional support, other than the basic knowledge on thalassemia (15).

The last issue is a suggestion for further research. Other researchers should continue to define the concept in real life situations from a different contexts in each region. Due to generalizability to the family who have a children with thalassemia, which was limited by the participant demographics and study setting.

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