Needs and Concerns of Jordanian Mothers with Thalassemic Children: A Qualitative Study

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Abstract: Thalassemia is a genetic blood disorder that considered as a major public health problem. It is a challenge for patients, their families and health care system since it requires a life-long treatment of blood transfusion and chelating drugs. **Aim**: This study aimed to explore the needs and concerns of Jordanian mothers who have thalassemic children. **Methods**: A qualitative approach was employed to better elucidate the mothers perceptions of their needs and concerns. Twenty five mothers were recruited purposively from two major thalassemia clinics in The Ministry of Health in Jordan. Semi-structured, face-to-face interviews were conducted. These interviews were transcribed verbatim and then translated into English. Data were analyzed using the process of thematic analysis. **Results**: The study revealed two major core themes. These themes were: "exaggerated worries and fear", and "supportive care needs". Participants showed their worries resulting from frequent absenteeism from school, body image changes, puberty delay, fear of death, and uncertainty about their children's future. They also expressed their needs for more information about thalassemia and its treatment, social and professional support, and financial support. **Conclusion**: Thalassemia has a significant impact on children and their mothers. A holistic approach should be used while caring with patients and their families. Nurses and health care professionals are invited to explore the feelings, concerns and needs of mothers who have thalassemic children and eventually design appropriate care plans that alleviate their suffering.

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1. Introduction

Thalassemia is the most common inherited single gene disorder in the world that represents a major public concern. It characterized by a defect in the genes responsible for production of hemoglobin (WHO, 2012). Hemoglobin is a protein that consists of two alpha and two beta chains. If the genetic mutations prevent any formation of beta chains then beta-thalassemia major occurs which involves abnormal development of red blood cells and eventually anemia (Ali et al., 2012; WHO, 2012).

In Jordan, thalassemia comprises a carrier rate of 2-4% (Hamamy et al., 2007). Consanguineous marriages which are the most preferred in Jordan contribute to increasing the incidences of genetic disorders (Hamamy et al., 2007). Children with beta-thalassemia major need a life-long treatment of regular blood transfusion and iron chelation therapy (Pillitteri, 2010, Prasomsuk et al., 2007). This illness particularly causes major social and financial burdens on patients, families, and health care system (Prasomsuk et al., 2007).

Thalassemia also poses a remarkable impact on children's lives; patients become anemic and thus have exhaustion and intolerance toward physical activities. The overstimulation of bone marrow leads children to manifest changes in the facial features and the character of the skull. Patients also have slow growth, osteoporotic tissue, ascites and enlarged liver. Arrhythmias and heart failure are also cause death (Pillitteri, 2010). These negative changes make patients with thalassemia more susceptible to anxiety, stress and depression (Yahia et al., 2013).

In addition, previous studies revealed that parents of thalassemic children expressed feelings of worry, frustration, despair, and helplessness regarding their affected children (Liem et al., 2011; Ammad et al., 2011). Empirical studies also found that parents have numerous physical, psychosocial, and financial concerns regarding thalassemic children (Ali et al., 2012; Liem et al., 2011; Prasomsuk et al., 2007). These concerns are relatively connected with the chronic nature of thalassemia and its chronic strenuous treatment (Liem et al., 2011; Prasomsuk et al., 2007).

Unfortunately, mothers of thalassemic children have demonstrated lack of knowledge about the occurrence of thalassemia, genetic issues, and caring with children (Prasomsuk et al. 2007). Ghazanfari et al. (2010) also argued that parents of thalassemic children have low knowledge and high educational needs. The knowledge gap about thalassemia was described by the parents as a major source of frustration (Liem et al., 2011).

Despite the fact that thalassemia is a major health problem in Jordan that challenges children, parents and health care system, no studies have addressed the needs and concerns raised by parents

regarding their thalassemic children in Jordan. Therefore, it is a crucial to establish an understanding of how mothers perceive their needs and concerns toward thalassemic children which will be the basis for creating appropriate educational programs and nursing care. In eventual, these strategies would minimize the psychosocial complications resulting from poor dealing with stressors and other difficulties.

This study aims to explore the feelings, problems and needs experienced by Jordanian mothers of thalassemic children in relation to the disease and its treatment, and examine the current and future concerns expressed by Jordanian mothers toward their children. Thus, this study answers the following questions:

1. How do Jordanian mothers whose children have thalassemia perceive their feelings?
2. What problems, concerns and needs do Jordanian mothers have regarding the disease, its treatment, and caring with children?

2. Methodology

Research Design

A qualitative exploratory design was employed to understand the needs and concerns of mothers who have thalassemic children. A qualitative research design is required when the aim of a study is exploratory. That is, when insufficient number of studies has been conducted in that area of research (Creswell, 2009; Polit & Beck, 2008; Speziale & Carpenter, 2007; Creswell, 2003). The intent of qualitative researcher is to understand, describe, and interpret some human phenomenon (Creswell, 2009; Polit & Beck, 2008; Speziale & Carpenter, 2007; Creswell, 2003).

Setting and Sample

The eligible participants were recruited purposively from two major thalassemia clinics in The Ministry of Health in Jordan. Twenty five participants who agreed to reveal a maximum description about their experiences of having thalassemic children were participated in this study. The sample size was determined according to data saturation which is reached when no more new information about the phenomenon emerged from the participants (Polit & Beck, 2008; Speziale & Carpenter, 2007). Mothers who participated in the study were; Jordanian mothers who have children diagnosed with beta thalassemia major for at least six months, their children are receiving thalassemia treatment including blood transfusion and iron chelation therapy. On the other hand, mothers of children who are diagnosed with other medical illnesses or mental disorders, and mothers who are not totally engaged and oriented in their children treatment were excluded from the study.

Ethical Considerations

To conduct this study, ethical approvals were obtained from the Faculty of Nursing-Zarqa University ethical committee and from The Jordanian Ministry of Health. Informed consent was obtained from each participant during the face-to-face meeting. Participations were voluntary and without any coercion. All participants had the right to conceal any private information, or terminate the interview at any time. However, they were encouraged to ask any questions or seek any clarification from the researcher. Participants were informed about the use of an electronic tape-recorder to record the interviews and they also were informed about their right to refuse the tape recording. Each participant was given a code to be used for writing up. Finally, participants were informed that quotes from the interviews will be included in the study report.

Data Collection Method

Semi-structured, face-to-face interviews were conducted using researcher-made questions derived from studies that discussed similar issues. These questions were organized into two parts; the first section included demographic information of the mothers, such as age, educational level, number of children suffering from thalassemia, and the time of diagnosis. The second section included the interview questions which are open-ended questions related to the feelings, problems, needs and concerns about beta-thalassemia major. The content of these questions were validated by a panel of experts in qualitative studies. Translation of the interview questions into Arabic language was done by the researcher and then was validated by a bilingual translator. Participants were encouraged to voice their experiences of having thalassemic children. This allowed the researcher to garner rich information about the topic. Questions were asked in an appropriate and understandable manner considering the participants' educational level and their emotional status. Finally, the researcher asked the participants about a second contact by telephone calls to discuss the study findings. All interviews were tape-recorded and transcribed verbatim by the researcher. Double check for these transcripts was conducted then they were translated into English by the researcher and confirmed later by a bilingual translator. Each interview lasted for around one hour. Data collection was started on April 2012 until June 2012.

Data Analysis

Data were analyzed concurrently with data collection. Transcripts were analyzed using the process of thematic analysis established by Marshall and Rossman (1999). Thematic analysis is the

process where the researcher recognizes themes and patterns within data. The researcher read each transcript several times to feel, understand and organize the data. The researcher then coded the data according to the type of needs, concerns, and feelings of participants. The relationship between these codes were identified and subsequently categorized into themes that represent the data. Finally, the researcher described each theme exhaustively and wrote the final relationship between themes. Themes were internally convergent and externally divergent meaning that each code falls only into one theme making that theme distinct from other structures (Silverman, 2005).

Demonstrating Trustworthiness of the Study Findings

To enhance rigor and trustworthy findings, the researcher employed the following techniques: In-depth interviews were conducted with participants to obtain rich information about the needs and concerns of mothers; independent investigator had reviewed the transcripts and the whole process of data analysis; rich and thick description of findings was provided; and member checking was done to verify the accuracy of findings.

3. Results

Twenty five Jordanian mothers ranged in age from 25-48 participated in this study. Their children have diagnosed with thalassemia major for more than six months and undergoing thalassemia treatment. Data analysis revealed two major core themes expressed by mothers. These themes included: "exaggerated worries and fear", and "supportive care needs".

Exaggerated Worries and Fear

Mothers in this study expressed their feelings and attitudes toward having a child with thalassemia. Mothers spoke about a wide range of concerns that influenced their psychosocial lives. These concerns were expressed as worries resulting from frequent absenteeism from school, worries about continuing education, body image changes, puberty delay, worries about marriage and occupation, fear of death, and uncertainty about future.

Most mothers described their children's suffering resulting from being absent from school. One mother reported:

"My daughter has to visit the clinic every month. Also, she visits doctor frequently because of fever and pain and so she leaves the school frequently…I hope her school achievement will not affected". (Participant 3).

In addition, one mother said:

"My son gets tired very easily, he cannot walk for a long distance…sometimes, he cannot play with his friends…he also cannot go to school every day because of his condition. I am very anxious about his classes. He did not take most exams; I am really worried about his study". (Participant 7).

As a result of frequent absence from school, most mothers expressed their worries about their children's future of continuing education. One mother said:

"My child goes to school for few days every month, he does not study well, he always tired and weak, I am afraid about his education". (Participant 1).

On the other hand, body image changes were a major concern for mothers. Most mothers complained of the slow growth, pale color, and bone changes associated with thalassemia and its treatment.

One mother reported:

"I am very anxious…my baby has a slow growth…he looks shorter…he looks smaller than his peer...this is very frustrated". (Participant 12).

Another woman showed her concern about physical changes associated with thalassemia, she said:

"My daughter's face changed a lot, I am very sad because of this…she was more beautiful. Now, her color became yellowish, her brow is now very wide, her jaw is protruded…I am very defeated because of these changes". (Participant 5).

Moreover, mothers spoke extensively about their worries regarding puberty delay, they complained of the delay in the maturation of secondary sexual characteristics including breast buds and menstruation. One mother said:

"My daughter is not growing as her peers…all of them have puberty signs…I am afraid that she will not have menstrual cycle as her normal peers". (Participant 16).

Uncertainty about children's future was a distressing factor reported by mothers. All mothers wanted their children to grow well and live with optimal health. They showed their wondering about their children's ability to continue their lives, find occupation in the future, and get married as others do. One mother said:

"I am always thinking about my son's future…is he going to live a normal life? Is he going to find a job or get married in the future? I am so upset". (Participant 10).

Worrying about marriage was exaggerated more among mothers of female patients. One mother complained:

"I know that no one will marry a girl with such disease like thalassemia, even if the girl is only carrier for the disease…boys need healthy and beautiful girls and not girls with such illness…I am very hopeless". (Participant 25).

Finally, fear of death was a major concern discussed in most interviews. Mothers expressed their fear from the life-long treatment of thalassemia. They wondered whether their children will live with the strenuous requirement of blood transfusion, iron chelating therapy, and splenectomy. One participant reported:

"I am afraid that I will lose my child…thalassemia is a very bad disease…I feel panic every time he becomes tired. I am always asking God to keep him in a good condition and alleviate his suffering". (Participant 20).

Supportive Care Needs

All participants spoke about their major needs to care effectively with their children. These themes were organized into three categories encompassed the need for information, social and professional support, and financial support.

Informational Needs

Participants reported that they need information about the nature of thalassemia, its pattern of inheritance, the chance of its occurrence, and dealing with the side effects of treatment. One mother reported:

"I know that thalassemia is a blood disorder, but I do not understand how it happens? Why do children need blood transfusion continuously? (Participant 13).

Another mother stated:

"I know that thalassemia is a disease of shortage of blood, but there are many diseases with shortage of blood such as anemia, I really cannot understand the differences between these diseases". (Participant 18).

However, all mothers recognized that thalassemia is a genetic disorder, but they did not understand the pattern of its occurrence. One participant reported:

"When my son was diagnosed with thalassemia, doctors told me that this disease is caused by a genetic problem where there is a defect in the gene, but I do not understand what's actually happen…what's going on with the gene". (Participant 22).

Managing the side effects of thalassemia treatment was another important issue raised by participants. Most women complained of iron overload and continuous blood transfusion. One mother said:

"I want to learn how to deal with the side effects of blood transfusion, every time after blood transfusion my daughter complains of headache, dizziness, and tiredness. I feel very sad because of this…how could I help". (Participant 24).

Another woman expressed her suffering with the use of the infusion device that used to remove the excessive iron. She said:

"This device is used to remove iron from my son's blood; nurses put a medication inside it. I do not understand how it works…it seems very painful to insert a needle into my son's abdomen, I am very sorry for that". (Participant 11).

Social and Professional Support

Social and professional support was regarded by participants as a significant factor that alleviates the suffering of mothers and their children. Accepting the disease by others and dealing with mothers and their children normally were important factors. One participant described her friends and neighbors' support as:

"When my friends knew about the disease of my son, they stayed with me, talked to me, and prayed for me…They are very kind…They always take care of my kids while I am being in the hospital". (Participant 1).

Another woman described teachers' support as:

"The school administrator and teachers gave my son the permission to be absent from the school during the period of blood transfusion…They understand his condition…They are very kind". (Participant 9).

Another participant stated:

"Teachers in the school treat my daughter very carefully…They encourage her to fight the disease and to continue her life normally, they also encourage us to cope with our condition" (Participant 14).

On the other hand, support given by nurses and doctors was very effective for helping mothers to cope with the burden of the disease. Most mothers suggested having one nurse or doctor with whom they can talk about all aspects of care, treatment, and follow up care. One mother said:

"Doctors and nurses are very kind; they helped us a lot…They always joking with us and treating our children carefully…I wish to talk with them every day and discuss my child's condition". (Participant 2).

Financial Support

Despite that thalassemia treatment is free in Jordan, most participants in this study complained of the financial cost associated with thalassemia and its treatment. This includes the cost of transportation, the cost of admission to hospital when the child becomes sick, in addition to leaving the work for the employed mothers.

One participant reported:

"I have to leave my work because of my child's illness. He must visit the clinic every month and I have to stay with him to receive blood and take his medication. Our income is now less than before…the

life of my son is more important than money". (Participant 23).

Another participant reported:

"The cost of transportation is expensive…we have to pay for taxi every time…we have to buy special diet for my child. This is really very costly". (Participant 9).

4. Discussion

The aim of this study was to explore the needs and concerns of Jordanian mothers who have thalassemic children. The study employed a qualitative approach to better illuminate the mothers' needs and concerns. Generally, the needs, feelings, and concerns identified by participants were congruent with those documented in previous studies. The study findings revealed that thalassemia has a substantial effect on the emotional and social lives of mothers. Mothers perceived thalassemia as a serious and distressing disease that required lifelong treatment of blood transfusion and iron chelation therapy. Mothers extensively discussed their areas of concerns associated with thalassemia and its strenuous treatment. The most significant concerns were related to frequent absenteeism from school, academic performance, and worries about continuing education. Mothers expressed their hope for their children to have a good academic achievement and to continue their education despite their frequent absenteeism from school. Previous studies have shown that poor academic level was related to absence from school (Yahia et al., 2013; Jantan et al., 2011; Ismail et al., 2006; Canatan et al., 2003). In addition, a study conducted by Jantan et al. (2011) revealed that parents considered thalassemia as a factor that makes their children slow learners. Thus, it is vital to assess if thalassemia itself causes any cognitive impairment or learning difficulties among patients. Consequently establish appropriate interventions and educational programs.

Physical changes in thalassemic children were another major issue that has a great impact on mothers' emotions. Mothers expressed their worries about changes in facial features, color changes, and slow growth in their children. These changes may negatively affect the psychosocial lives of children and their mothers. Previous studies have showed that physical changes associated with thalassemia have led to feeling of oddness, low self-esteem and feeling of insufficiency among thalassemic patients (Yahia et al., 2013, Jantan et al., 2011; Messina et al., 2008; Khurana et al., 2006; Georganda, 1998). Therefore, it is indeed imperative to explore the impact of physical changes on thalassemic children and how do they perceive their body image. In addition, Jordanian mothers showed their frustration and depression due to puberty delay in their children. Thus, health care providers have to provide psychological support for parents and patients to better cope with the distress resulting from thalassemia and its consequences.

Participants also revealed their uncertainty and worries about the future of their children. Marriage and occupation were major concerns reported by participants. All participants hoped for their children a better future, to get married, find a job and become independent. Previous authors have found similar concerns (Jantan et al., 2011).

Furthermore, fear of death was reported frequently by mothers as a main concern. Mothers revealed their fear about early mortality in children with thalassemia. This fear may aroused from the bad prognosis and complications associated with thalassemia and its treatment. Same findings were found by Liem et al. (2011).

On the other hand, participants showed their needs for information; they spoke extensively about their educational needs. Consistent with previous studies (Ghazanfari et al. 2010; Prasomsuk et al 2007) mothers need information about the nature of thalassemia, its pattern of inheritance, the chance of its occurrence, and dealing with the side effects of treatment. Lack of knowledge about thalassemia and its treatment may cause unnecessary anxiety and emotional distress among parents (Wong et al., 2011). Therefore, educational programs that are built based on educational needs of parents is suggested.

Social and professional support was considered as a crucial factor that helped in reducing the emotional burden associated with thalassemia. Mothers appreciated support given by their neighbors, friends, and teachers. All mothers wanted their children to be accepted and treated normally by others. This will not cause stigmatization and social isolation associated with a chronic disease like thalassemia. Moreover, psychosocial support provided by doctors and nurses was vital to alleviate the suffering of mothers and their children. Thus, health care providers should always include psychological support as a part of their care plan for thalassemic patients.

Finally, financial issues were another major concern that added to the burden of thalassemia. Increased expenses associated with transportation costs, admission costs, and living costs were the most cause of burden for families. Previous studies have found similar findings (Jantan et al., 2011; Prasomsuk et al., 2007). Financial support should be considered by policy makers and administrators to help families cope with the financial burden of thalassemia. Additionally, The Jordanian Ministry of Health should continue supporting free treatment for thalassemic patients.

5. Conclusion and Recommendations:

Thalassemia is a burden to mothers that greatly affects their lives. The study concluded that mothers have major needs and concerns related to the complications of a life-lasting disease and the challenges associated with chronic blood transfusion and iron chelation therapy. A holistic approach including nursing, medical, educational, financial, and psychosocial support should be used while caring with patients and their families. Further studies are needed to explore the needs, concerns, and the lived experiences of mothers caring with thalassemic children.

Limitations:

Lack of generalization to overall population is the major limitation in this study.

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