

## The Burden of Care: Experiences of Parents of Children with Thalassemia

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Received date: March 15, 2017; Accepted date: March 28, 2017; Published date: April 5, 2017

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### Abstract

**Introduction:** Parents who care for Thalassemia children tolerate a great burden. Understanding these sufferings seems necessary in order to provide appropriate care. This study was aimed to explore the experiences of parents who have children with thalassemia.

**Method:** A qualitative approach was used to obtain rich data. Twenty-two parents were recruited purposefully from one charity clinic in South East of Iran. Semi-structured interviews were used. Data were analyzed by Lundman and Granheim's content analysis method.

**Results:** Data analysis led to form one main theme including "Parents' Burden of care". Within this theme the following categories created: immersion in suffering, stigma and social death, uncertainty about future, and absence of a support network.

**Conclusion:** The findings of this study showed that Caring for children with thalassemia have a significant impact on the lives of caregivers and alleviating caregivers' burden is critical to managing parents. This research may be useful in terms of increasing information about thalassemia and raising consciousness of nurses and other health care providers.

**Keywords:** Burden of care; Parents; Thalassemia; Qualitative study; Iran

### Introduction

Major thalassemia is a genetic disease. This defect may cause an abnormal development of red blood cells and ultimately anemia [1]. Furthermore Thalassemia is a common disorder worldwide with a predominant incidence in Mediterranean countries and Southeast Asia [2]. Approximately, 240 million people are estimated as carriers for  $\beta$ -thalassemia throughout the world while 100,000 children with thalassemia major are born annually [2]. In Iran the prevalence of thalassemia is approximately 3-4% in general population and there are over three million  $\beta$ -thalassemia carriers [3]. Almost 26,000 patients with major thalassemia and 800 infants with thalassemia are born annually in Iran [4].

Children living with  $\beta$ -thalassemia major need a life-long treatment of regular blood transfusions and iron chelation therapy [5], which cause major social and financial burdens on patients, families, and health care system [6]. According to Pillitteri thalassemia poses a remarkable impact on children's life; patients become anemic and thus physical activities are exhausting and intolerable for them. He added that the overstimulation of bone marrow leads children to manifest changes in their craniofacial features as well as delayed growth, osteoporotic tissue, ascites and enlarged liver and finally arrhythmias as well as death resulted from heart failure [5].

Parents suffer from weakness and disability of their ill child. They feel worried, frustrated, despaired and helpless [7]. Also they have numerous physical, psychosocial and financial sufferings [6,8] which are relatively connected to the chronic nature of the disease and strenuous treatments. Recognition the nature of parent's burden is curtailed because it enables nurses to intervene effectively and reduce parental burden [9]. During recent decades, there has been a substantial increasing concern and attention given to the phenomenon of suffering in healthcare literature [10,11]. Rodger et al. used the method of concept analysis and defined the concept of suffering as an individualized, subjective and complex experience [12]. Nahalla et al. in a phenomenological study showed the impact of regular hospitalization of children with thalassemia on their parents. Ten parents were interviewed. Three themes were used to present the participant's experience: worries, medical services, and helping and being helped [13]. Also, Prasomsuk et al. [6] in a qualitative study in Thailand explored the lived experiences of mothers of children with thalassemia major by conducting semi structured interviews. Six themes were identified including: lack of knowledge about thalassemia, psychosocial problems, and concerns for the future, social support systems deficiencies, financial difficulty, and effectiveness of healthcare services. Sapountzi et al. in Greece conducted a qualitative study on the experiences of mothers caring for their children with thalassemia and interviewed with 19 mothers that had children with thalassemia. Emotional distress, fear of death and difficulties in dealing with feelings were some of the mothers' concerns [14].

Iran is one of the countries with the high rate of thalassemia [4] where the parents play the key role in caring for their sick children [15]. They have to take care their sick child and perform other responsibilities for their professional, social and familial roles simultaneously. Since they have to spend more time for a sick child, the quality of their social, professional and familial roles may be greatly influenced by this issue [15]. Although above studies have investigated some dimensions of this disease on the parents. However culture and healthcare service system can have an influential impact on this experience. As a result, regarding the particular rules and culture of Iran, in this qualitative study, we addressed the question “what are the experiences of caregiver having a child with thalassemia?”

Qualitative content analysis is one of the methods of qualitative researches and also qualitative data analysis [16]. Content analysis method contains techniques for systematic text analysis [17] because it is an unobtrusive technique of analysis that can simply accommodate a great amount of data [18]. Thus, this approach could help understand the meaning of Living with suffering as voiced by parents of children with thalassemia. Moreover, a cultural-based understanding may help healthcare policy makers establish effective context-based interventions. This study was aimed to explore the experiences of parents who have children with thalassemia.

## Materials and Methods

### Study design and setting

This study was a conventional qualitative content analysis with a descriptive-explorative approach. Content analysis is a qualitative method for analyzing written, verbal or visual communication messages. The aim at Content analysis research is to attain a condensed and broad description of the phenomenon. According to Graneheim et al., content analysis can be performed with various degrees of interpretation. They added that in each text, there are manifest messages to be described and latent meanings to be interpreted, although both manifest messages and latent meanings require interpretations which may vary in depth and level of abstraction [19].

This qualitative study was conducted from March 2012 to September 2013 in Kerman, a south-eastern city in Iran. In Kerman, Kerman Province is located in southeast of Iran; with an area of 11% of the whole country and more than 2.5 million populations [20]. This province is among ten provinces in the country where incidences of thalassemia are high due to humid tropical climate of some regions of the province, high frequency of  $\beta$ -thalassemia Gene as well as numerous consanguineous marriages [21]. There is one educational charity hospital with thalassemia disease centers which are affiliated to Kerman University of Medical Sciences. The majority of children suffering from thalassemia who reside in the south-east of Iran are referred to this hospital.

### Participants

The main inclusion criterion was: parents who had a child diagnosed with thalassemia that required regular blood transfusions and experienced at least 1 year of caregiving their child.

The qualitative research interview was semi structured, participants were asked to narrate their experiences of caring from their child with thalassemia and related disease. As in qualitative researches, no absolute rules determine the estimated number of participants, sampling continued and data were saturated, until no new information

was extracted. In the present study, the saturation was achieved after interviewing with 22 participants. There were 11 mothers and 11 fathers in the study. Also each of the parents in the study has 1-3 children with thalassemia. Purposive sampling was used to select participants. To reach rich and divers information, individuals with different and rich experience about the research concept were invited to do the interviews. In addition, individuals with different characteristics such as age, role, and work experience were chosen by the first researcher to provide a wide range of information. The characteristics of the participants are shown in Table 1.

Participant	Age (year)	Level of education	Experience of caring of children with thalassemia (year)	Job/relative to parents
Fathers	37-46	Uneducated: 2	2-18	Pensioner: 1
		Diploma: 8		Employee:9
		B.A: 1		Teacher: 1
Mothers	37-45	Uneducated:3	9-12	Housewife: 8
		Diploma: 8		Employee: 3

**Table 1:** Characteristics of the participants (n=22).

### Data collection

Data were collected through semi-structured, face-to-face interviews. A nurse who was trained for deep interviews performed them (the first author). First, she introduced herself as a nurse and researcher and explained the research aims and the interview process for the parents. Then, she asked them if they were willing to participate, and then they signed a consent form. . In the cases the participant did not sign the consent form, it was read loudly and his/her permission was taken orally due to the cultural structure of Iran. Sometimes, the participant did not trust on giving an informed written consent. Afterwards, the suitable time and place for interview was determined for each participant based on her comfort. The interview was done in a room in thalassemia clinic. At the beginning of conversation, the interviewer explained the study aims and the benefits of the study and reminded the interviewee that they can withdraw the interview Session whenever they did not want to continue. Then, the primary questions were asked. For Example, “What is your perception of caring for your child?” And please describe your experience of one day of caring about your child.” The interview was conducted using follow up questions such as: “Please tell me more about it”, “How do you feel about them”, “Please give me an example”. Every interview lasted at least 20 and at most 60 min. All interviews were recorded with previous permission of participants. Also, the key points were written during the interview.

### Data analysis

The first author recorded, transcribed, and analyzed the audio responses verbatim, read the transcripts interviews repeatedly and allocated codes to recurrent themes. The MAXQDA 2007 software (VERBI GmbH, Berlin, and Germany) was used to manage and sort the coding. The analytical process was guided by qualitative content analysis, as described by Granheim and Lundman. Content analysis is initially interpretative; the narratives were read several times to obtain a comprehensive view of the attributes associated with a meaningful

encounter. After that, words and sentences that applied to the attributes which were related by content and context were broken into meaning units without losing the content of the text, meaning units were condensed and labeled with codes at a low level of abstraction. After rereading and understanding the coded, they were sorted into preliminary categories representing similarities and differences. Finally, the preliminary categories were formulated as categories and subcategories according to the manifest content at a higher level of abstraction. During the analysis process, focus moved between the whole and parts of the text to ensure that interpretations were made at a high level of abstraction [19].

### Ethical considerations

The study was approved by the ethical center committee, in Medical Research at the Faculty of Nursing and Midwifery supervised by Kerman University of Medical Sciences (ethical code 91/93). All participants provided informed consent and some oral information was given to them including the goals and objectives of the study. They were assured of anonymity and confidentiality of the data. Also they were informed about their rights to withdraw from participation in the study at any time. Furthermore, they could refuse to answer any unfavorable question.

### Rigor

Trustworthiness is a criterion which constitutes rigor in qualitative researches. Usually four issues use to describe various aspect of trustworthiness: credibility, conformability, dependability, and transferability [19,22]. Several techniques were used to enhance trustworthiness of the following study. Peer checking has done by researcher's supervisors through frequent sessions between the first researcher and the supervisors, the study's progress and process was reported and discussed. Member-checking was completed with some of participants for validation of interpreted findings (codes and categories). Some of the faculty members checked the encoding process and access to categories (external checks). In addition, a clear and detailed description of culture, context, selection and characteristics of participants, data collection and process of analysis were provided. Interviews lasted between 35-60 min. The interviews were audio taped and then the transcripts were written out verbatim by the first author (B.P).

### Results

In total, 22 parents were interviewed: 11 mothers and 11 fathers. The age of the participants ranged from 37 to 46 years. Their level of education ranged from illiterate to bachelor and had different jobs. 8 mothers were housewives and 3 were full-time employees. 10 fathers were full-time employees and 1 was retired (Table 1).

According to data analysis, the main theme was "Parents Burden of care" was emerged. Through this theme, we created the following categories: 1- immersion in suffering, 2- stigma and social death, 3- uncertainty about future 4- absence of a support network.

#### Immersion in suffering

The mothers faced multiple problems in care process. They endured a lot of sufferings. This category was extracted from the following subcategories: exhaustion with the past, tensions of caring, new-age sufferings, and concerns about transplant, psychological tension.

#### Exhaustion with the past

Suffering of these parents has been started since the past; however, this suffering has continued and reformed. Parents complained about lack of pre-marital tests, preventive methods for birth of thalassemia children, and lack of diagnostic tests of thalassemia in the past. Some families blamed this factor for having three or four children with thalassemia. They complained about some difficulties including: spending extended periods of time due to lack of diagnostic facilities in the past, the untimely diagnosis of their child's disease and endured suffering of purchasing blood for required frequent transfusions as well as lack of desferal pump and medications. Due to these shortages, some patients received ineffective treatment because they forced to share one desferal pump with other siblings with thalassemia.

A father with two children with thalassemia said: *"I was always searching for someone to donate blood. I donated my own blood several times. Some soldiers were ready to sell their blood. I had to find them to pay for and purchase their blood. I myself had to take them to the blood transfusion center to receive their blood."*

Some patients who lived in remote districts had to commute frequently to receive treatments. In order to be close to an equipped center, they moved to another city and their problem was unfamiliarity with their residential place.

The father of two thalassemia boys (one of whom was dead) stated:

*"We forced to move in this city (Kerman). I remembered the terrible night when we arrived Kerman. We were chased by some stray dogs. I carried two of my children on my shoulders to get rid of those animals."*

#### Caring tensions

Parents suffered from uncooperative of their thalassemia children for self-care for example non-cooperation of children with Deferoxamine injections. Some parents living in remote area lost their spouses in road accidents due to frequent commuting to an equipped center to provide treatment for their sick child. These participants stated that they had to follow-up treatments for their ill child lonely. They tolerated insomnia and fatigue due to the fortnightly journey to charity center for blood transfusions. Also parents stated that the child's treatment program interfered with their routine life and severely restricted parents' activities.

A father said: *"One of the most annoying days of the week is the day I come here. I miss a lot of my plan and have to take a day off to come here."*

Children's high iron levels (Hemosidrosis), Deferoxamine injections, insertion of IV lines and withdrawing blood, in addition to the potential complications of hepatitis C left parents distraught and exhausted during caring for these children.

A mother who cared for her two daughters and a son with hepatitis C stated:

*"I was hurting more than my ill children. Their disease stressed me a lot. Once they had fever I stayed awake all the night to care for them."*

In addition, the comparison of the child's growth with other children and having no answer to their childish questions about these differences was a heavy burden of parents.

A father stated: "My child asks me why Mr. X's son is taller than me. Why has he grown more than me? Why do I have to receive frequent injections and my sister not? These questions really hurt me."

Also parents were worrying about their children being called by 'offensive names' and teased by their peers for their shorter height.

A mother stated: "Children at school bother my daughter and they call her MRS.PEPPERPOT."

### New-age sufferings

The history of having a thalassemia child imposed pregnant mothers to great stress of amniocentesis and possible mandatory abortion. A positive result of a thalassemia test in a pregnant mother reminded them bitter memories of the operating room, abortion and surgical complications. In some cases, the false answer led to the birth of a child with thalassemia. Also lack of technology required patients to travel to Tehran to receive services such as T2 star Magnetic resonance Imagine that is a new device for assessment Iron in heart and liver and a fully equipped laboratory with polymerase chain reaction (PCR) tests that is a laboratory test for detecting hepatitis in thalassemia patients in their province.

The mother of two daughters and one son with thalassemia and hepatitis C (they should do a test for hepatitis C due to effective treatment) stated: "Their treatment will be finished here but I have to carry them to Tehran for Echo and laboratory tests. It is very difficult for me, I always think about it and I cannot sleep at night."

### Concerns about transplant

Parents sought for certain treatment of their children's diseases that is transplant of stem cells. At first, the donor of stem cells should be searched for. In addition, it is not possible in small cities and patients should refer to an equipped center. Therefore, lack of a bone marrow transplantation center in their province, lack of a suitable donor and unaffordable expenses concerned parents.

A father said: "The most important challenge is that I only think about my child's health and I try my best to treat him/her even if I die in direction of my goals. I will sell all my properties and spend them for his/her treatment (even for transplant)."

A parent stated: "The biggest suffering is that, since foundation of this charity clinic in 1998, a transplantation center has not been established in the province."

### Psychological tension

Parents suffered psychological tensions due to the difficulties of caring for the thalassemic child. They stated that they were distressed and grieved to see their upset child. Also, they expressed concern about birth of next children with thalassemia too. Furthermore, parents narrate their experiences of receiving abrupt diagnosis of thalassemia, which caused despair, sadness and they did not believe their child disease. A father of two children with thalassemia stated: "When we were informed about our children disease, we were distraught and disheartened. Our life became bitter."

The next reaction of parents was denial; disbelief in the diagnosis which led them to change medical team or hospital. One father living in a village near to Jiroft (a city in Southern Kerman) said: "After receiving the thalassemia test result, Dr. F informed us about our child

diagnosis. We went to Jiroft to confirm the result by another doctor. We could not trust him too; therefore, we went to Kerman."

Parents believed that the diagnosis of thalassemia for their child impacted their mental and emotional status, family relationship as well as love and affection between couples. Fearing from birth of a thalassemia child, some of the mothers underwent tubal ligations surgery which led to separation and divorce in a number of families.

One of the fathers stated: "We liked to have at least four children. With this happening, we do not want any more children. This matter bothered us and family problems appeared. This was not the woman I used to love. My love for this child is gone."

### Stigma and social death

This category was extracted from three subcategories: 1- poverty of the society, 2- concealment, 3- censure.

#### Cultural poverty of society

Parents suffered from cultural poverty, misconception and lack of knowledge and insufficient information about the disease in the society. A father said:

"People treat unwisely. They talk about my child disease unfairly when they speak together."

The false beliefs and superstitions about thalassemia also troubled parents." A parent stated that:

"People stigmatize us. Unfortunately, that is how they perceive thalassemia and blame this disease."

#### Concealment

In order to escape from other people's reproach, a number of parents followed their child treatments and care secretly which annoyed them. One of the interviewed mothers who concealed her child's disease expressed:

"I swear to God, that we annoy of secret living. We are scared of our own shadow. We cannot tell anyone; therefore, we have to do everything alone." On the other hand, more parents worried about their child's marriage which causes them to reveal their child disease. A mother said: "some men proposed marriage to my daughter but I had to refuse. I'm worried and this bothers me."

#### Censure

Censure was another reaction experienced by participants, in verbal or non-verbal forms (a blaming look). Despite some parents were bothered by their relatives' reproach, they had to ignore their behavior, suffer or terminate the relationship with these relatives. A mother of two daughters with thalassemia said:

"Everybody reproaches us, including relatives and strangers. They allow themselves to talk about our child disease in an unfair and unreasonable manner. Well, it's a small town and the news spreads quickly. Thus it is not wondering if a mother is hurt by these behaviors." Another father described people's reproach:

"I married to a non-relative woman and my relatives blamed me for it. They believe that my child disease is a consequence of my marriage and my suffering is a punishment and torture from God."

### Uncertainty about future

Uncertainty about their children future, job prospects of children, education of children, marriage of children, and definite treatment of their children caused another stress. A father of two children with thalassemia whose daughter was attending the university this year expressed his concerns: *"We worry about their future and their work prospects. "Can they get a job? Will they be able to manage themselves? I have butterfly in my stomach"*

### Absence of a support system

Participants complained about lack of effective management of thalassemia. High expenses of treatments transportation and hospitalization, besides the living costs imposed a heavy burden for families. They mentioned some deficiencies in health care system such as lack of expertise among the medical team, absence of an equipped team and lack of experienced nurses in IV (intra venous) lines administration. A father said:

*"There is effective management for all diseases except this disease; there is no stable management. It is annoying when you realize no one cares about this disease"*

In spite of free medical treatments for thalassemia, most interviewees complained of the financial treatment costs of thalassemia. Financial burden of expensive costs of the disease caused economic consequences on families which they could no longer afford it. Most parents considered these as the most important suffering. This includes the cost of transportation, accommodation, and child's hospitalization. A father stated:

*"Our main problem is financial costs and that's all.' One of the fathers whose child took iron chelating pills said: "I like to buy "Exjade" pill manufactured in foreign countries for my child to stop more nausea and vomiting caused by Iranian pills, but I can't afford it. This is really bothering."*

Parents complained about medication shortage and lack of insurance support. Due to recent sanctions in Iran, providing Deferoxamine and Exjade is difficult and this torments parents.

A father said:

*"To provide pills we have to search everywhere. But they are not easily available and this is so distressing."*

### Discussion

In this study, the parents considered their care experiences of children with thalassemia. The

Burden of the child care by parents was found as the main theme of this study.

According to the findings, four categories for the main theme were found: immersion in suffering, - stigma and social death, uncertainty about future, absence of a support network.

All categories existed in their experiences of parents. In this part, the scientific documentations on the significance of codes are explained. Although there were few qualitative studies, it was tried to use both quantitative and qualitative literature.

### Immersion in suffering

One of significant results of this study was difficulties that participants buckled with and did not forget their unpleasant memories during the years. These difficulties profoundly impact their mental and physical conditions. This finding is agreed with the study of Pouraboli et al. that revealed lack of social support and health insurance, lack of a regular program for thalassemia treatment and lack of fixed custodians were the most burdens of participants [3]. However, in a study conducted in Italy, the authors reported extremely lower difficulties faced by parents of thalassemia children [23]. These differences could be associated to the lower incidence rate of this disease in such countries resulting in a better well-being and effective management of the disease. Also, this discrepancy may be related to cultural differences and different social attitudes toward this disease in western countries compared to Iranian context. Fortunately, recent requirements of thalassemia patients and their families have taken more concentration than before with cooperation of non-governmental organizations and charities.

In the current study, participants reported suffering when comparing their child's physical features with healthy children; furthermore they were tormented by questions asked by their ill child. This result is in agreement with findings of a study conducted by Wahab et al., which stated that not attaining the average height compared to their peers was perceived as a major problem by both parents and patients. Also, patients were being called by 'nick names' and teased by their peers for their shorter stature. Participants in their study reported that these children were compared to other siblings at home regarding their height and thus they were not respected by younger siblings [24].

According to the findings of the following study, interviewees experienced great psychological tensions and emotional distress caused by thalassemia and its treatment. In a similar study conducted by Åstedt-Kurki et al., they reported various emotional symptoms and feelings of shock induced by illness of a family member in 50% of cases; negative psychological symptoms such as depression and grief were reported in 71% of families [25]. Widayanti stated that parents of children with thalassemia suffer tremendously from provision of daily life-long care for their child [26]. Also Mashayekhi et al. reported that psychological problems annoyed families more than other problems [27]. Also Liem et al. reported feelings of concern and despair experienced by these parents [28]. Despite numerous psychological problem experienced by parents unfortunately effective psychosocial consulting services which lead to a healthy mind and sense of well-being, are not available properly for these parents in the context. Furthermore, the important role of psychologists and assistance of psychiatric nurses has not been considered in identifying and resolving such problems.

In this study, parents also reported that they were angry and shocked when being informed about their child diagnosis. They felt guilty. This finding is in congruent with the other studies which reported that parents described the shock of being informed about their child's disease and reluctantly accepted the diagnosis of disease and sought the possibility of misdiagnosis [15,29].

Insomnia and fatigue reported by parents as caregivers also are confirmed by other studies. Mashayekhi et al. reported that families had experienced Insomnia and fatigue more than other problems [27].

## Stigma and social death

Concealment and censure reported by interviewees were other significant findings of the present study which both are rooted in cultural beliefs, stigma and inadequate knowledge about thalassemia in the society. In a similar research, Furness et al. reported people's comments and verbal taunts as one of the parents suffering [30]. According to Pouraboli et al., in Iran patients with thalassemia conceal their illness as a result of stigma [3]. Also In the study by Shum et al., participants also considered thalassemia as a reason for shame and stigma leading to social isolation and reduction of their communications [31]. In study of Else et al breast cancer patients had experienced shame and stigma [32] however, in a study conducted in Greece acceptance of these patients by the society was reported [23]. The reason for this difference may be related to lack of knowledge and favorable attitude toward this illness which result in lack of a social position and poor acceptance of these patients by the society.

Also according to the results, interviewees experienced stigma. This finding is disagreed with the finding of Wahab et al.'s study in which stigma is not mentioned by participants [33]. Chenard stated that Stigma is a socially constructed concept that identifies a person or social group that has aberrance from some norms, ideals, or expectations. He goes on that Stigmatized persons are viewed negatively for having violated certain rules or for possessing traits that are negative or socially devalued [34]. According to Chenard, stigmatized persons to preserve themselves from the shame, embarrassment, blame, and social rejection, consistently struggle with the decision of whether to conceal or disclose their stigmatizing attributes [35].

In the following study all mothers wished 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. False beliefs in Iranian Culture are main reason of related problems. This challenge may be overcome through educating people in order to change the society misconception.

Based on the results, parents suffered from uncooperative children under medical care which was in congruent with the study conducted by Wahab et al. The authors reported that parents complained about non-cooperative children with deferoxamine injections, which was attributed to the presence of rashes at the injection site [33]. Patients with thalassemia major must receive at least 150-350 mL of packed red cells every two or four weeks. Although blood transfusion is lifesaving, it causes painful IV line insertion and loads body with excess iron. Iron accumulation eventually may result in hemosiderosis and its associated complications [36]. Prognosis for survival will be greatly improved if the serum ferritin level is kept below 2,000 mg/L by regular chelation by deferoxamine (DFO) [37]. However to achieve a satisfactory result, DFO has to be administered via painful subcutaneous infusions, for 8-10 hours each day and five to seven days a week [36].

## Uncertainty about future

Participants also revealed their uncertainty about the future of their children. Marriage and employment were major concerns reported by participants. All participants hoped for their children to get married, continue education, find a job and become independent in future. Parents in Previous studies have similar concerns about their children [27,33] Concern about children's marriages was not reported in some studies conducted in other countries [10]. This concern reflects the importance of marriage in the Iranian/Islamic culture. In this respect,

people's perspective toward thalassemia patients' marriage should be changed through educating and informing via mass media. However, in recent years more attention has paid to marriage of these patients. The health care system accompanied by some charities support them by paying the cost of their wedding celebration, housing and furniture. Therefore marriage of two thalassemia patients or even marriage of a patient with a non-thalassemia person has increased.

## Absence of a support system

Absence of a support system was among the most important concerns stated by interviewees which are in disagreement with mothers' statements reported in Shosha's research. They appreciated the support given by their neighbors, friends, and teachers. Moreover, Shosha reported psychosocial support provided by physicians and nurses which was vital to alleviate the suffering of mothers and their children [10]. This supportive behavior was not reported by parents in the following research. Despite available psychosocial support and services for patients with thalassemia in recent years in the Iranian context, some parents' needs are ignored to a large extent. Some services have offered by health care system, non-governmental organizations and charities, but mostly are focused on patients welfare including: providing these patients with some pilgrimage and recreational trips, performing some celebrations in some special days such as thalassemia day in May 8, dedicating some foods, clothes, stationery and toys. Lack of supportive behaviors in health care and lack of a holistic care system for families may reflect many challenges that require effective strategies to be overcome in the Iranian context

Finally, financial issues were another major concern that participants expressed. High expenses of treatments, transportation and hospitalization, besides the living costs imposed a heavy burden for families. Previous studies found similar findings [6,33,38]. According to Sattari et al., the cost of therapy in thalassemia as well as any other disease does not only include medication cost. They stated that these extra costs include the cost of medical consultation, laboratory tests, diagnostic tests, cost of treatments, side effects of therapies and many other indirect costs. They added that indirect costs include travel expenses, the impairment of well-being. Concerning high costs of this disease as well as poor economic condition of most thalassemia patients in this region of the country, effective strategies are required to reduce the financial burden [39]. More financial support and favorable insurance should be considered by national health care policy makers and administrators. Additionally, The Iranian Ministry of Health should continue supporting free treatment for thalassemia patients. Sattari et al. stated that almost all medications in Iran are subsidized by the government and a small fraction of the total cost of treatment/care is paid by the patients such as iron chelating therapies in thalassemia treatment. Also they added there is insurance coverage for these patients. Despite coverage of most costs of therapy, parts of the cost are not paid by the government or the insurance companies and are paid by the patients themselves [39]. Also overcoming this challenge is required charity and non-governmental organizations support because the numerous expenses of this disease burden significant financial load to the health care system annually. According to Habibzadeh et al., about 350,000 blood bags are needed annually for thalassemia patients costing about US \$3 apiece. This is equal to US \$1,000,000 per year. Also DFO is an expensive drug, and US \$40,000,000 should be spent annually to provide the adequate amount for thalasseemics in Iran [21].

## Limitations of the Study

Despite the strategies we applied to enhance the rigor of this study, some limitations may be inherent. The sample size was small and the context confined to a particular geographic location. However, the study provides some valuable insights for the parents suffering from children with Thalassemia. But we believe that these findings would support further research of wider scope. The findings of this study can be generalized to other mothers, families and special professional in health services.

## Conclusion

According to the findings of this study, parents of children with thalassemia face many problems when caring their child. Results of this study showed that some parents manage their problems alone. Also, deep cognition of parents' needs was obtained considering the experiences of parents. Thus, it is necessary that health provider provides support and education by appropriate planning. Nurses are recommended to help these parents by appropriate interventions. Training life skills to them can be very helpful in reducing the severe difficulties imposed on these parents in Iran. Furthermore, it is helpful to determine the parents' burden of care to improve the family function.

## Acknowledgement

Special thanks to all parents who took part in this study. This study was undertaken in part fulfillment of the degree of nursing doctoral by the first author.

## Conflict of Interests and Funding

There is no conflict of interest to be declared. The authors received no financial support for the research and publication of this article.

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