



Self-care in Patient with Major Thalassemia: A Grounded Theory

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ABSTRACT

Introduction: Self-care is the core concept of health care and may be considered as one's stabilization, and restoration as well as the improvement of his/her health and well-being. Looking at the process of Self-care from patients' perspective who suffer from thalassemia may assist the nurses and health care providers to facilitate the health process. Thus this study was conducted to discover the process of self-care in patients with major thalassemia.

Methods: This qualitative study was conducted with grounded theory approach. 21 patients with major thalassemia from a Medical Research Center, supervised by Kerman Medical University, were selected through purposeful and theoretical sampling. Data were collected by unstructured interviews which lasted 30-60 minutes. These data were analyzed using the method of Corbin and Strauss.

Results: The main theme of "struggling to improve life quality" that included the sub-themes of "focus on needs of illness, "activating resources" and "restoring a new identity with thalassemia" were extracted from the data. This theme implies that participants endeavor to strengthen their self-efficacy via thalassemia. "Looking for strengthening self-efficacy in light of thalassemia" was the core theme in this study.

Conclusion: Facilitating the process of self-care in patients with major thalassemia requires that they be helped so that their self-efficacy, influenced by real life conditions, might be strengthened in light of thalassemia. Increasing public awareness and social support may affect the recognition of individual, family and society.

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Introduction

Thalassemia is the most common hereditary blood disorder and about 240 million people Carry Beta thalassemia worldwide.¹

Approximately 200,000 patients with major thalassemia have been reported in the world and each year about 60 thousands people will add to this figure.² In Iran, Thalassemia is the most common genetic disease and about³ 3 million people are carriers of this disease, and about 26,000 people have major thalassemia and about 800 people added to this figure annually.³ These patients require lifelong care, regular blood transfusions, and iron chelation, and they suffer from anemia, fatigue, and lack

of tolerance toward physical activity.⁴ In addition, bone marrow hyper activity causes observable changes in the face and skull.

Moreover, growth failure, bone tissue loss, and an enlarged liver are common. The most important factor underlying the effects of such disorder is lack of self-care activities.⁵ Self-care is defined as behaviors "engaged in over time, performed by persons in stable or changing settings and within the context of their patterns of daily life".⁶ In a self-care process, an individual's engagement in self-care behaviors is linked to prevention of complications.⁷

Within the self-care process, recognizing and regulating behaviors are learned and

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performed with a person's stages of growth, development, health, and environment.⁷ Self-care behaviors occur within a context of time sequences and they support life and healthy functioning. Nursing research has shown that self-care changes over time.⁸ When people perceive "a threat to life or health, they assume responsibility toward themselves" by applying self-care behaviors.⁶

Promoting self-care has become a central concern of nursing interventions for patients with chronic illnesses.⁹ Individuals diagnosed with a chronic disease have to deal with complex tasks in order to manage their illness and to prevent related complications. Modifications of diet and activities are typically recommended as a means of reducing these symptoms. Such actions, undertaken by an individual to improve their health and limit the progression of the disease, are termed self-care and they are important factors in the prognosis of chronic diseases.¹⁰ Self-care refers to the process in which patients play an active role in their health and well-being, a process that encompasses the skills, attitudes, and abilities needed to master the settings in which individuals with a chronic illness function.¹¹

Self-care behaviors are influenced by various factors like experience, education, culture, scientific knowledge, learning, sex and race.¹²

Since cultural and racial aspects could be significant factors in determining caring approaches in thalassemia¹³, it is important to briefly discuss the Iranian context. Iran is a part of the Middle East region and it is the eighteenth largest country in the world. Its population exceeds 80 million¹⁴, and culture has a prominent impact on all aspects of Iranian's lives.¹⁵ A chronic disease like thalassemia is considered as a taboo in the Iranian culture accompanied by families' shame and suffering which influence the afflicted child's and family's views on a threatening disease and the related cure.¹⁶

Kerman is one of the ten provinces known for high incidences of thalassemia in the country, which is assumed to have resulted from the humid tropical climate of certain regions in the province, and a high frequency

of β thalassemia Gene, as well as numerous consanguineous marriages.¹⁷

The Iranian thalassemia association which is a part of thalassemia international federation (TIF) is a non-governmental organization (NGO) and all financial resources are provided by the charity and some revenue of running project is provided with collaboration of governmental and non-governmental organizations. This association provides a number of services for thalassemia patients, including paying for the required medical equipment, supporting patients who are not covered by insurance, providing educational programs to prevent the birth of children with thalassemia as well as covering the accommodation and transportation costs of patients who travel from remote areas.¹⁸

Yang et al., conducted a qualitative study in China, exploring illness knowledge, social support and self-care behaviors in adolescents with major beta-thalassemia. The results showed that regarding illness knowledge, the best score belonged to treatment knowledge, and the worst score to the knowledge of complications and symptoms. As for the social support the family was found to be the major source of support, with classmates/friends providing the least support for thalassemia adolescents. Regarding self-care behavior, the best score was given to the medical and chelate therapy while the worst score was given to the management of problems and coping. These findings could provide referential materials for nursing research and nursing practice.¹⁹

In a content analysis in Iran, Pouraboli et al., explored the experiences of self-care in patients suffering from thalassemia. The results showed that thalassemia is very stressful for patients in the physical, psychological, social, and spiritual aspects. Moreover, culture was found to be playing an important role in shaping the patients' experiences of the suffering.¹⁶

In Iran, no study has explored experiences of patients' with thalassemia during self-care process. The results from studies in other countries where this issue has been directly or indirectly taken up cannot be generalized to

Iran due to structural, cultural, social and economic mismatches. For this reason, the present study intended to gain more knowledge about self-care process of Iranian thalassemia patients and how they handle the self-care process. We used a qualitative method to attain these goals and grounded theory methodology was employed to generate a substantive theory and acquire that experience.

Materials and methods

This qualitative research has been conducted in the paradigm of qualitative research based on the grounded theory method suggested by Corbin and Strauss (2008). Grounded theory is rooted in symbolic interactionism which focuses on dynamic relationships between meaning and actions.²⁰ It increases our understanding of human behavior in a particular situation where understanding is lacking, such as determining the thoughts, activities and feelings of patients with thalassemia that occur at self-care time. We have used grounded theory to understand self-care process from the perspective of thalassemia patients in Iran.

Twenty-second interviews were conducted with 21 participants (participant n: 1 was interviewed twice for clarifying certain points that were not so obvious) who were selected through purposeful sampling. The research was performed at the thalassemia ward in a hospital in Southeast of Iran. The main inclusion criteria were: understanding and speaking Persian, wishing to participate, and signing informed written consent.

Participants were approached by the first author for an interview and provided with a written consent form to sign. Initially, the participants were chosen purposefully. As the study progressed, however, the method of selection changed to theoretical sampling. Theoretical sampling was conducted either to select participants for the next interview or to increase knowledge.

We attempted to select participants with different experiences in order to comply with

maximum data variation. The participants were selected according to their age, sex and professional experiences. Theoretical saturation was a criterion to finish data collection. After each interview and according to the memos and interviews, the interviewer added new questions which were more conducive to achieving the research goals.

These questions focused more on thinking, behaviors and feelings of the thalassemia member during the self-care process and how they might change. Comparisons were made between the interviews and the evolving categories, thus the interview questions were subsequently focused on particular categories that required additional information.

The participants consisted of 12 patients, 4 family members, and 5 healthcare providers and there was also one focus group with 5 participants. The patients were between 14 and 32 years of age and their level of education varied from illiterate to university graduates. Health provider team was between 32 and 44 years of age and their level of education varied from Bachelor to fellowship degree. The parents were between 37 and 46 years old and their level of education varied from illiterate to Bachelor¹ (Tables 1, 2, 3).

This study was approved by the Ethics Committee of Kerman University of Medical Sciences (record number K91/93). The aims and methods of the study were explained to all participants. They were assured of the confidentiality of their information and it was explained that participants could withdraw at any time without the need to explain their refusal or withdrawal from the study. This information was a part of the consent form and it was explained verbally to each participant, as well. Participation was voluntary and all participants signed the consent forms before we proceeded with tape recording.

Data were collected through in-depth unstructured interviews. As agreed, the interviews were conducted in an isolated room specified for this purpose. Interviews were tape-recorded. All interviews were directed by a researcher (the first author). The duration of the interviews depended on the patient's

desire and each interview lasted from 30 to 60 min. The interview questions began with open ended questions such as 'Please tell me about your experience of self-care?', 'How are you doing?', as the interviews progressed, however, the questions were modified based on their analysis. For example, the following questions were added, 'Why do you think self-care is hard?', and 'What might reduce this hardship?'. The interviews were subsequently transcribed word by word by the researcher.

Data analysis began with the paradigm of Corbin and Strauss (2008) for data analysis. The paradigm consists of four stages.

Analyzing data for concepts: Researchers began with open coding. The transcripts of sound files were read and reviewed several times in order to obtain an overall understanding of the concepts within the transcripts. Next, the data were initially broken down and the participants' exact phrases or substantive codes were used as primary codes. At this stage, the researchers also utilized axial coding. Comparative analysis was utilized with the first transcribed interview and subsequent transcriptions. Codes were revised and, if necessary, the previously coded data were re-coded based on co-author discussions. After that, we did data analysis for context and focused on the conditions and factors that influenced self-care for the patients, trying to find issues that governed the study subject. We used MAXQDA 2007 software (VERBI GmbH, Berlin, and Germany) to manage and sort the coding. For bringing the process into analysis, the strategies used by the participants to overcome difficulties and reach their goals were identified.

Integrating categories: we determined the core category in the final stage Rigor. To reinforce credibility, excerpts from interview transcripts with emerging codes and categories were presented to several co-authors experienced in the grounded methodology in order to evaluate the analysis and provide comments on its accuracy. Several sessions were held for presenting the reporting and receiving experts' opinions. The research stages and decisions were carefully recorded

and reported to provide for the possibility of a follow up for others if necessary, which allowed for both data dependability and conformability and also we did member check. In order to increase the generalizability of the findings to other situations and groups, different participants were used in terms of age, gender, socio-economic status and patient status in order to comply with maximum data variation.

Results

A theory to guide families and care providers of the patient with major thalassemia For the purpose of the study, 3 categories were generated from the data and the relationships between the categories were identified, using the paradigm model recommended by Corbin and Strauss (2008). The basic components of the paradigm model are "Concentration on illnesses needs" "activation of the resources and "Recreation of a new identity with thalassemia. "Looking for strengthening "promotion of self-efficacy in light of thalassemia" was the core category in the following study (Table: 4).

The first category: "Concentration on illness's needs": this category consists of subcategories of illness acceptance, getting information about self-care, and behaviors of health promotion as described below.

Illness acceptance, All participants tried to hold a positive view on the illness, accepting and coping with the illness. Some believed that the illness was a divine gift. Others accepted their illness when comparing their illness with those who had more severe illnesses.

P5 said: "I accepted my illness and I am really glad and thank God for this illness"

Getting information about self-care, Participants tried to get information from different sources for monitoring their health. Parents, especially mothers, were the first people who were informed. Some part of information was given by nurses. The role of physicians was remarkable. They believed that doctor is the main source of responding to all questions. They also talked about the role of

those who had the same illness as theirs. They received a lot of instructions from their peers.

P11 said: "my mother was the first person who answered my questions about self-care."

P5 said: "we are friends with other thalassemia patients in this clinic, we educate each other.

P12 said: my doctor is the best source of my self-care information.

Behaviors of health promotion:

They tried to care for their physical health. Blood and des feral injection was very important for them. They believed that the blood is a vital factor that supplies energy and blood circulation was assumed to be flow of life. Caring for and controlling Iron was very important for them, too. They tried to take supplementary pills regularly, exactly as prescribed and they were determined to go Tehran for a checkup once a year, especially for T2 STAR MRI, osteoporosis. Thus they tried to prevent it by drinking milk, eating yogurt, dairy products and taking medications such as calcium. They were well informed about the importance of cardiac health. Diabetes is the side effect of iron precipitation in Pancreas and thalassemia patients were afraid of diabetes and emphasized its prevention.

P16 said: "I take my pills regularly at nights."

P9 said: "my doctor is (A) in Tehran. I go to Tehran for checkups once in six months. We will go under ultrasound of belly, size of liver, spleen, and kidney. The ovary is checked for its size, cysts and bone mineral densitometry." Mental health was important for them, and they tried to maintain it. Some of the patients talked about lack of peace of mind in their lives as a result of loneliness and some of them became angry or aggressive when they were dissatisfied with the treatment and care. Reduction of hemoglobin, lack of calcium and vitamins were the likely causes of aggression. Some of them were afraid of death; some believed that poor culture of society in facing with thalassemia brings about mental stress.

P7 said: "the psychologist of the ward believes that: some parents of clients complain about their children's aggression. When the hemoglobin reduces, children start to shout. Some children are

humiliated due to their short heights and are not accepted by the society so they become reserved"

P13 said: "the students nicknamed me 'Mrs. Pepper pot' in the school."

They tried to use certain methods for getting relaxation: they had used medicinal methods, high risk behaviors, and distraction techniques to get relaxation.

Some of the patients referred to doctors for stress and anxiety and were on anti-anxiety medications.

P16 said: "I have experienced an increase in my heart rate several times because I am afraid of death and the doctor has prescribed medications for me"

Some of them had developed high risk behaviors for getting relaxation: smoking, taking narcotics, drinking alcohol.

P16 said: "I used to smoke cigarette and opium with my friends because it is palliative.

Some of patients had used distraction techniques of all kinds including listening to music, wearing makeup and beautiful cloths, dancing, painting, reading books, going to cinema, avoiding negative thinking, presence in the society, doing exercise, travelling, playing chess, crying, and gazing at a wall in a silent place.

P8 said: "I sing the song when the music is being played. I feel relaxed. Sometimes I manicure my nails or buy new clothes in order to get positive energy.

P5 said: "sometimes the stigma of thalassemia makes me sad and disappointed with my life. I wash my face or watch flowers or read books to get rid of this negative thought.

Most of the patients agreed that one of the most important activities for the promotion of their health was participation in social activities: most of the participants were present in different places and contexts of the society such as, schools, religious places and thalassemia association. They even participated at congresses of global thalassemia federation and exchanged their views and experiences with others. Presence at society makes them spiritually relieved.

P2 said: "I try to increase my social activities and to interact with others. A patient with thalassemia will not be disappointed if he/she is socially active."

Activating resources: This category was reduced to six sub-categories

Family sources: patients with thalassemia assumed that parents were their main supporters and they took away from the fear of self-care. The patient who'd married a healthy person talked about the support of her husband's.

P9 said: "*my parents, my husband and my husband's parents were beside me all along and supported me.*"

Sources of therapeutic-healthy services

The first self-care source of patients was physicians; they thought that they were the best support in case of making decisions about marriage, delivery, cesarean, taking medications and bone marrow transplantation. They believed that nurses are an important source in self-care and they were great supports that facilitated their self-care.

P11 said: "*physicians especially doctor (A) facilitated my self-care, encouraged me to keep going and not to stop my treatment. He also advised me to marry and continue my studies.*"

Social sources:

Participants pointed to the role of society as a powerful source. The self-care attempts had increased in those who were valuable for the society. Those who had a job talked about the support of work place for giving them sick leaves for self-care and treatment, so that it causes regular cares.. Thalassemia patients also talked about the support of school and teachers for self-caring in schools.

P2 said: "*I was a kind of person who did not pay attention to my health because I felt it was pointless, but when I was valued by society I decided not to ignore myself.*"

Spiritual sources:

Some participants believed that thalassemia was a divine test and appreciated it. They thanked God for things which are not appreciated by normal people and things that have been ignored by healthy people.

They trust in God and manage their self-care, life stresses, and important events such as marriage and pregnancy. They believed that they'd become closer to God by thalassemia

and praying, avowing, retraction, Salavat (greeting Muhammad and his descendants).

P11 said: "*I start to pray when I am being injected the blood so that I will not show any sensitivity to the blood*".

Recreation of new identity with thalassemia: This category consisted of these subcategories: feeling of pride, being special, being capable and being normal.

Feeling of pride: participants feel proud because they could be successful in great decisions of life and they could reach their goals with thalassemia.

P11 said: "*I feel proud because I could reach whatever I wanted with thalassemia*"

Being special: some participants believed that thalassemia is a special illness .They thought they had something more than other people did and they liked to be special and enjoyed it. They tried to use their capacities in order to prove their uniqueness and to make an individual identity."

P8 said: "*always my thought is we are special; a special patient can do something more than other people and this view makes me success.*"

Being capable: most participants believe that they were capable persons and expressed some evidences for their claim such as studying in difficult conditions, going to university, memorizing Quran, sport successes, writing poems and some even believed that they stood higher and were superior to normal persons. Those who were married said that their spouses and families confessed to their capabilities.

P9 said: "*I can do so much work which cannot be done by normal people. My husband believes that I am more capable than some people around us.*"

Being normal: all participants emphasize that if the patient with thalassemia is completely treatable, she/he will be as same as a healthy person. Thalassemia is not an obstacle for doing every day routines and thalassemia people are like other people in the society.

P11 said: "*I am the same as healthy persons regarding school and house work.*"

Promotion of self-efficacy in light of thalassemia Participants spoke about the

difficulties of self-care, and the factors that influenced it. They endeavored to promote self-efficacy in light of thalassemia which was selected as the core category of the study. Interactions, actions and emotions were all in line with this aim. This was called 'Promotion of self-efficacy in light of thalassemia' and included the patterns of 'focusing on the needs of the illness', 'Activating resources' and 'Restoring a new identity with thalassemia'.

Discussion

The results of this study raised our understanding of the emotions, thoughts, and strategies used by thalassemia patients in

their self-care. According to the findings, a patient's acceptance is the starting point for the promotion of self-efficacy in light of thalassemia. The acceptance of thalassemia promotes life quality of patients and their self-efficacy. Sham et al., concluded that thalassemia adolescents wanted to have a normal life by self-care, illness acceptance, and changing themselves. They accepted and dealt with the illness.²¹

One of the patterns used by patients was getting information about caring that was necessary for the promotion of life quality. They tried to understand how to beat thalassemia and to have the best care for self-efficacy.

Table 1. Individual features of parents of thalassemic patients

| No | Gender | Age | Job | Education | Relationship with patient | Living place | Interview duration |
|----|--------|-----|-----------|------------|---------------------------|--------------|--------------------|
| 12 | Woman | 45 | Housewife | Primary | Mother | Town | 40 min |
| 15 | Woman | 37 | Housewife | Illiterate | Mother | Kerman | 32 min |
| 17 | Man | 46 | Retired | Primary | Father | Town | 55 min |
| 18 | Man | 38 | Teacher | Bachelor | Father | Town | 36 min |

Table 2. Individual features of participants (patients)

| No | Gender | Age | Starting point of illness | Residential place | Education | Married status | Job | No. of interviews | Interview duration |
|----|--------|-----|---------------------------|-------------------|---------------------------------|----------------|------------------------------------|-------------------|--------------------|
| 1 | Woman | 31 | 6 months old | Kerman | Diploma | Single | Unemployed | 2 | 60 min |
| 2 | Man | 31 | 6 months old | Kerman | B.A student | Single | Manager of thalassemia association | 1 | 55 min |
| 3 | Woman | 22 | 6 months old | Kerman | B.A student | Married | Teacher in kindergarten | 1 | 60 min |
| 4 | Woman | 29 | 6 months old | Kerman | Associate degree | Divorcee | Housewife | 1 | 52 min |
| 5 | Woman | 24 | 6 months old | Kerman | Student of Persian literature | Single | Student | 1 | 60 min |
| 6 | Woman | 18 | 6 months old | Kerman | Diploma | Single | Unemployed | 1 | 59 min |
| 8 | Woman | 28 | 6 months old | Kerman | Associate degree | Single | Employee | 1 | 60 min |
| 9 | Woman | 31 | 6 months old | Kerman | Bachelor | Married | Unemployed | 1 | 60 min |
| 11 | Woman | 14 | Eight years old | Kerman | Elementary school (third grade) | Single | Student | 1 | 54 min |
| 13 | Woman | 16 | Four months old | Town | High school (third grade) | Single | Student | 1 | 30 min |
| 14 | Woman | 22 | 6 years old | Town | Bachelor | Single | Student | 1 | 30 min |
| | Woman | 25 | | Town | Diploma | Single | | | |
| | Woman | 21 | | Town | Associate | Single | | | |
| | woman | 23 | | Town | degree | Single | | | |
| | | | | dipoma | | | | | |
| 16 | Man | 32 | One year old | Kerman | diploma | Married | Employee | 1 | 54 min |
| 21 | Man | 25 | four years old | Kerman | Diploma | Married | Employee | 1 | 30 min |

Table 3. Individual features of other participants of health team members

| No | Gender | Age | Job | Education | Job background | Work place | Interview place | Interview duration |
|----|--------|-----|----------------------|--------------------------------------|----------------|-----------------------------|-----------------------------|--------------------|
| 7 | Woman | 38 | Psychologist | Bachelor | 9 years | Center of special illnesses | Center of special illnesses | 58 min |
| 10 | Man | 38 | Physician | Subspecialists of infective diseases | 5 years | Center of special illnesses | Office | 45 min |
| 19 | Woman | 43 | Nurse | Bachelor | 17 years | Center of special illnesses | Center of special illnesses | 45 min |
| 20 | | 32 | Nurse | Bachelor | 9 years | Center of special illnesses | Center of special illnesses | 30 min |
| 22 | | 44 | General Practitioner | Medical doctor | 20 years | Thalassemia association | Thalassemia association | 60 min |

Table 4. Core category, categories, and subcategories

| Subcategories | Category | Core category |
|---|---|--|
| Illnesses' acceptance Getting information about self-care Behaviors of health promotion | Concentration on illness's needs | Promotion of self-efficacy in light of thalassemia |
| Family sources Sources of therapeutic-healthy services Social sources Spiritual sources | Activating resources | |
| Feeling proud Being special Being capable Being normal | Recreation of a new identity with thalassemia | |

Willingness to learn was the common feature in all patients with thalassemia. Pauisri et al., believes that getting more information improves self-care.²¹ The mothers who participated in the study of Shosha wanted to get information to help their children and one of their needs was to get information and they were aware of their effective role on thalassemia children.²² Those who participated in Shosha'a study stated that they needed the nurses and physicians to show them how to care and treat their children²² In the study done by Wilson, unlike present study, most of participants rarely received their knowledge from health care providers.²³ Perhaps the reason was because other informational sources such as media programs were available. Participants emphasized on getting information from their peers. In the study done by Hasani et al., hemo-dialysis patients established relationships with their peers, compared

their status with their peers', learned from them, encouraged them, and were, in turn, encouraged by them.²⁴

The illness requires promoting health care behaviors and paying attention and concentrating regularly on a set of monitoring. Management of medications and continuous and on time consumption of main medications such as Desferal and Osveral were the most important and effective measures of self-care. In the study of Yunak et al., participants took medications such as Folic acid and multivitamins based on their doctors' orders.²⁵

Higher quality care provided in a well-equipped center was found to be an important factor. There were not enough health care facilities in small cities of Iran. In the study carried out by Shosha (2014), these services were offered to thalassemic patients in Jordan free of charge.²² As thalassemia is included in the list of special

illnesses in many countries, the services are given freely to promote cares.

All participants acknowledged the significance of regular and on time blood injection. It is a normal requirement for them and makes them energetic, just as gas is essential for automobiles. Participants of the study done by Wahab et al., emphasized the continuous blood injection.²⁶ In the study of Yunak et al., participants believed that the blood is the source of their power.²⁵

In health promotion behaviors, spiritual health care was an important principle. Participants talked about mental stresses. In the study conducted by Shaligram, 44% of thalassemic children had low life quality and mental problems. Symptoms of anxiety (67%), emotional problems especially depression (62%) and relational problems were and 49% respectively²⁷. Participants of the present study wanted to find peace by smoking cigarette or opium due to wrong beliefs and common superstition in the society. Elkins et al., believed that 42% of young people use narcotics and alcohol against life problems.²⁸

Participants wanted to get relaxation from allowable (medications and techniques of distraction such as listening to music) and unallowable methods (cigarette, opium and alcohol). The study of Haun et al., showed that listening to music is effective on the reduction of anxiety in patients who are waiting for breast biopsy.²⁹

Most participants attended different social places such as school, religious places. The process of socialization is one of growth aspects in human beings. Establishing relationships with others is one of basic needs for human beings. Unlike the present study, the study done by Gharibeh et al., showed that adolescents with thalassemia had problems with social interactions and social relationships with their friends, sisters, and brothers and they faced social isolation.³⁰ Also, in the study of Ismail et al., children with thalassemia were reported to have lower social performance than their healthy peers.³¹ The results were

not in agreement with those of the present study. This discrepancy may be due to lower number of the participants and the difference in the social climate which was different from that of other researchers.

Self-efficacy is facilitated by using spiritual sources and having a relationship with God. In the study done by Taleghani et al., women with breast cancer believed that their illness was dependent on God.³² Muslims believes in the role of praying, and religious beliefs in making relaxation and promoting cares.

According to holy Quran "hearts will be calm by remembering God". Religious beliefs and spirituality can be effective in other health dimensions and in promoting them.²⁴

Paying attention to spirituality, identifying, and reinforcing spiritual behaviors can promote self care.³³ Participants in the study of Abdoli benefited from praying to beat the illness.³⁴

The results of this research indicated that support plays an important role in the patients' self care and it can increase their self efficacy. Gallant believes that social support is an effective factor on the management of self care behaviors of chronic patients.³⁵ In the study done by Jussila, the power of family for emotional support required by the patients has been emphasized on.³⁶ In the study of Shosha, the mothers of the participants talked about social, financial, and professional supports and caring needs.²² They were in agreement with results of the present study.

The participants of the present study pointed to the role of society as a motivational source. They said that if they are valued by the society, they will try hard for their self-care. In the study done by Hasani, socio-personal factors were facilitative factors for transition from hemodialysis and socio-spiritual and mental features (from personal factors) along with specialized support of medical and nursing team, support of social organizations, family and relatives (from social factors)

were facilitative factors for transition from dialysis.²⁴

In the present study, the effective relation between therapeutic team and spiritual support of patients is another requirement that was important for the participants. In the study of Gibson et al., children and young people with cancer referred to the role of personnel for supporting them in addition to support of family and friends.³⁷ They were in agreement with present results.

Thalassemic patients redefined this illness in process of life quality promotion. Most of them believe that thalassemia is an opportunity for changing and reaching success. The majority of them had a positive interpretation of thalassemia and took on a new identity easier than those who did not have such an interpretation.

Participants used all their capacity and ability to recreate a new identity with thalassemia and they reached considerable successes. Fighting against the illness was the key for the creation of a powerful identity. Participants felt proud when they became successful in great tasks and life decisions.

They believed that they were special patients and they thought that they had something more than normal people and thus tried to use their capacities to prove this uniqueness. In this stage, they tried to deal with thalassemia and enjoy a normal life with self-care. Weiss believed that there are people who choose effective responses and individually creative ways to handle crisis in life.³⁸ This positive achievement has appeared in five different areas, including appreciation of life moments, a more significant personal relationship, understanding individual talents, changing life priorities, the development of spiritual dimensions of life.³⁹

The small number of participants associated with this grounded study and the focus on one health center were the limitations of this study which could limit applicability of the results. Thus,

conducting similar studies could help clarify this subject and the affecting factors.

Conclusion

Self-care experience in chronic patients is an important parameter for nurses in order to improve self-management in chronic patients and enable them to move beyond medical concept and go towards a holistic approach for nursing care. Nurses can change life of thalassemia patients but certainly they will face some challenges and the easiest way for solving such challenges is to listen to the voice of the patients and check their needs. The voice of the clients is often forgotten in the process of health care and health care providers do not understand correctly the way people respond to and manage the illness. Therefore, silent cries of the clients should be listened to and heard and we should endeavor to make them feel valuable and respectful.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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