

Living in a misty marsh: A qualitative study on the experiences of self-care suffering of patients with thalassemia

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ABSTRACT

Background: Thalassemia major is the most common hereditary anemia in Iran. Thalassemia major patients require lifelong care and suffer much pain during self-care. Knowledge of the nature, meaning, and impact of suffering from the perspective of patients is needed to determine which interventions are helpful. This study was designed to understand the experience of suffering in patients with thalassemia.

Materials and Methods: This was a qualitative study conducted with content analysis method. In the present study, 21 patients with thalassemia were selected by purposive sampling. The research was performed at Kerman Samen Alhojaj Medical Center, Iran, in 2013. Data collection method was conducting unstructured interviews using open-ended questions and field notes. In addition, data were analyzed using qualitative content analysis and conventional approach.

Results: Data analysis resulted in the emergence of the four central categories of physical exhaustion, mental and spiritual restlessness, society's behaviors and beliefs, and surviving a hard life, which were the suffering themes of the patients.

Conclusions: Results showed that thalassemia in the physical, psychological, social, and spiritual aspects is very stressful for patients. Moreover, culture plays an important role in the patients' experience of suffering. Results of this study can help nurses improve nursing care to alleviate suffering based on these experiences.

Key words: Qualitative research, suffering, self-care, thalassemia

INTRODUCTION

Thalassemia is the most common hereditary blood disorder and approximately 240 million people worldwide carry beta thalassemia.^[1] Approximately 200,000 patients with thalassemia major have been documented in the world and each year about 60 million people will be added to this figure.^[2] Thalassemia is the most common genetic disease in Iran. In Iran, about 3 million people are carriers of this disease, and about 26,000 people

have thalassemia major and about 800 people are 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. In addition, bone marrow overactivity causes observable changes in the face and skull. Moreover, growth failure, bone tissue loss, and enlarged liver are common. Arrhythmias and heart failure are the leading causes of death in these patients.^[4] These negative changes cause anxiety and depression^[5] and numerous social and financial burdens for patients, families, and health systems.^[6] Suffering is a personal, mental, and complex experience,^[7] which has a historical, cultural, and social structure.^[8] The experience of suffering is often regarded as pain, while suffering is an experience that encompasses the totality of a person.^[9] Johnson believes that some of the important aspects of living with a threatening disease are how one understands its meaning, feels about his/her position, and experiences his/her suffering. However, in practice, not many studies have been performed on this experience.^[10]

Dildy, in a study on the suffering of patients with rheumatoid arthritis, found that the result of experiencing suffering, confusion, and loss of hope is the conscious reconstruction of the future and finding meaning through positive changes

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in life.^[11] Fredriksson showed how a care dialog which focused on the suffering of the patient minimized the vulnerability of the patient.^[12]

Suffering is an important concept in nursing, and the purpose of nursing is to help prevent the experience of suffering, pain relief, coping with it, and finding meaning and growth through it.^[13] In addition, understanding this experience can help in providing essential information to improve the quality of life of patients.^[9] This is why nursing researches should be performed on the experience of suffering in different groups.^[14] This experience must be expressed by those who have experienced pain.^[15] To reach a deep understanding in this respect, a qualitative approach seems more appropriate.^[16] Since in Iran's health system the thalassaemia patients' suffering was not comprehensively studied, this study was carried out to explore the experience of suffering due to self-care in patients with thalassaemia.

MATERIALS AND METHODS

In order to discover the meaning of suffering due to self-care in thalassaemia patients, content analysis technique, which seeks to understand the human emotions and implications of their life experiences, was used.^[17] Purposeful sampling method was used. Individuals who had thalassaemia and were willing to express their experiences were selected. Interview locations were selected by the participants and were mostly in thalassaemia unit. The study was conducted in 2013. For data collection, unstructured interview was used with one main question, exploratory questions, and field notes. The duration of interviews varied between 35 and 60 min and sampling was continued until data saturation, meaning that no new code or data was obtained and all the conceptual levels were completed.^[18] Data analysis was performed with qualitative analysis method with a conventional approach. In conventional content analysis, categories are extracted directly from textual data. Moreover, with this method, the hidden theme and patterns of the participants' data content can be revealed.^[19] Immediately after each interview, the interviews and non-verbal communications, such as crying, were listened to a few times and were written. Interview transcripts were reviewed several times, and then, data were broken down into meaningful units. Semantic units were reviewed and the semantic codes for each concept were written. Then, the codes were categorized based on concept similarity and were made as small and compact as possible. The declining trend of data was observed in all analyzed units, and main categories and subcategories. Finally, the data were summarized into one main theme which was more general and conceptual. The ethical permit of the study was approved by the ethics committee of Kerman University of Medical Sciences, Iran (number

K93/91). After clearly explaining the study objectives to the participants, they were asked to sign the informed consents, the permission to record their statements was obtained, and they were assured that their statements would be kept confidential. To validate the data, manuscripts, interviews, and analysis units were extracted with initial codes and were given to participants, and their opinions were taken and the necessary corrections were made. In addition, three professors in the field of qualitative research reviewed the study process. Using a combination of methods (interviews and field notes) with maximum variation in sampling, meaning interviews with various people (in terms of age, gender, education, etc.), increased data authentication and transferability.

RESULTS

Participants included 21 patients with thalassaemia and their mean age was 14–32 years. After classification and merging of codes, four main categories were obtained including physical exhaustion, emotional, spiritual, and behavioral instability, society's beliefs, and living a hard life. Moreover, "patient suffering" was the theme of the study.

Physical exhaustion

- a. Physical changes resulting from the disease
- b. suffering from self-care

a. Physical changes resulting from the disease

Some patients had deformed faces and the patients themselves and others were afraid of their faces; therefore, they had separated themselves from others and saw themselves as the burned generation. Some others suffered from growth retardation, delay in the appearance of secondary sex characteristics, low body strength, and inability to perform their favorite activities. A patient stated:
"Being deformed is painful for me; I avoid appearing in public because they show me to each other."

A teenager said:

"My strength is lower than normal kids and I cannot play football which I am interested in."

b. Self-care suffering

Care was distressful for the patients. The experience of venipuncture was painful for them. They were also tired of taking drugs, desferal injection, soreness, and sensitivity of the injection area, and were willing to die to be free of them. For some patients, hepatitis, diabetes, heart disease, and other complications had made their lives a living hell and they referred it as a misty marsh. A girl said:

"I sometimes pray to God to let me die and be free from all of this."

They talked about the impact of anemia on themselves; among the physical problems were headache and paleness of the skin, and a psychological problem was aggression. Two sisters with thalassemia said:

"When we are anemic, we get frustrated and fight with each other."

Emotional and spiritual turmoil

- a. Mental damages
- b. spiritual turmoil

a. Mental damages

The illness and experiencing negative reactions from others had different psychological consequences. Most of the participants suffered from anxiety, worry, grief, loneliness, feelings of rejection, and depression. A patient said:

"I have anxiety because of the side effects of the disease, such as changes in appearance and fear of being mocked at school."

Another patient stated:

"For me, the psychological suffering is more than the physical suffering of the disease; everywhere I go for work, they tell me I am deformed and cannot work, I am depressed and unsociable, I have repeatedly thought of suicide."

b. Spiritual turmoil

Some patients were spiritually distressed; they felt guilty and considered their illness to be the result of their or their parents bad actions and saw it as divine retribution. Therefore, life regrets and loss of hope led to depression. A patient said:

"Sometimes I regret my life and think why I should have thalassemia."

A teenager with two brothers and sisters with thalassemia said:

"I always think that may be God knew and this is retribution for our and our parents' bad actions."

Behaviors and beliefs of the society

- a. Social stigma
- b. lack of a comprehensive support network

a. Social stigma

Thalassemia patients considered the negative mindset of the society and officials regarding thalassemia, the societies' behavior toward these patients, and not believing their abilities to be unjust and the result of lack of knowledge. They were often mocked in public. The students talked about the outdated ideas of the teachers, magnifying of the illness, being considered incapable, being humiliated, and being disgraced.

A girl with a disfigured face said:

"There is not a day that they do not mock me, I cannot go out into the street and not be humiliated, when people do not have culture this is the result."

Young people felt lonely and needed a partner to rely on and they were concerned if they could ever get married. Some were annoyed by their family's lack of understanding of love and their need to get married, and not being able to marry the person they want. A teenager said:

"A person with thalassemia can fall in love and get married, but my family rejects this and tells me I am not allowed to."

Another young man said:

"We cannot propose to anyone, and cannot love whoever we want, because not everyone chooses a thalassemia patient to live with."

b. Lack of a comprehensive support network

Lack of social support and health insurance, lack of a regular program for thalassemia, not having fixed custodians, lack of up-to-date educational advertisements in the media, existence of an outdated view toward the illness in cyberspace, not being noted and visible, and being ignored were the causes of great suffering for the patients. They want to be seen not as a patient, but as a person with thalassemia in the community.

A patient who was a thalassemia custodian said:

"The most important pain we have is not having a regular program and a comprehensive protection act for thalassemia in Iran; we have requested it many times, but they say it is not a priority."

Living a hard life

- a. Financial constraints
- b. medication constraints

a. Financial constraints

Financial concerns had affected health care and irritated the patients. The majority of patients were unemployed. False ideas of the society had affected their employment. Those who were employed were dissatisfied with their job and were unable to work in their desired field. A patient said:

"The concerns of the patients are the expenses and having no money."

A teenager said:

"They do not offer just any kind of work to a person with thalassemia and this hurts."

b. Medication constraints

Shortages and high prices of drugs, due to medication

sanctions, had made care difficult, and forced the patients to use Iranian medications, and these medications caused allergies and resulted in the discontinuation of the treatment. A girl stated:

“Unfortunately we have sanctions now, I use Iranian made desferal and I am allergic to it, but to keep my iron low, I have to bear the pain and soreness.”

DISCUSSION

The findings indicated the experience of pain by patients suffering from thalassemia in various physical, mental, spiritual, and social aspects. The most important finding of the study was the deformation and the negative reactions of people toward thalassemia patients. Individuals who have appearances that differ from others experience negative reactions such as staring, rude talk, and stigmatization.^[20] In the study by Wahab *et al.*, the parents were concerned about the negative image formed in their children's mind and believed it to be the cause of their confidence reduction.^[21] This was consistent with the present study. However, studies in Italy showed a good and positive image of the patients.^[22] This was inconsistent with the present study. These differences could be due to cultural differences and the support systems in these countries. The perception of the community should be changed through culture building. Other main findings of the study were fatigue, weakness, and growth retardation. Chronic fatigue may affect the individuals' ability to concentrate and their activities.^[23] Previous studies, the results of which were consistent with this study, showed that physical changes resulting from the disease lead to feelings of being different, diminished self-esteem, and feelings of inadequacy in some patients.^[21,23] Venipuncture pain, and fatigue caused by injections and medications were the sources of stress in the participants. Shum *et al.* believed that iron chelation injection pain was the most important cause of anxiety and the most painful experience for thalassemia patients.^[22] Previous studies in this field reported pain, anxiety, fear, discomfort of venipuncture, fatigue, scarring, swelling, and redness at the injection site of desferal and wishing to be free of them.^[22,24] The nurse must use various methods to try to relieve pain.^[24]

Participants had repeatedly talked about wishing to die due to intolerance of the treatment. Cancer patients, in the study by Nilmanat *et al.*, had also felt worthlessness and wished to die; this was in agreement with the current study. In any case, when symptoms are well managed and patients feel they are in control, the wish to die will fade.^[9] The most important element of emotional turmoil of the patients was the physical changes in appearance. Moss and Carr believed that malformed individuals were

susceptible to problems such as depression, anxiety, shame, and disruption of communications.^[25] Previous studies, which were consistent with the present study, reported that the mental health problems of thalassemia patients included depression, loneliness, anxiety, fear of death, and aggression.^[21,26,27] This showed the need for psychological support of patients. Among the noticeable spiritual turmoil effects of the participants were despair, loneliness, and regret of life. Hope is a symbol of mental health,^[28] and chronic diseases have a negative impact on a person's level of hope.^[9]

In the study by Browne *et al.*, the participants had also experienced feelings of guilt and hopelessness.^[29] This is because nurses have focused more on the physical needs of the patients and the spiritual needs of patients have been neglected; moral support is also necessary.^[30] One other important finding was social stigma. Stigmatization had important mental, social, and emotional effects on the patients,^[1] and could lead to unemployment, rejection, isolation, and even suicide.^[31] In the study by Shum *et al.*, participants also considered thalassemia as a cause for shame and stigma and this matter led to social isolation and reduced their communications.^[22] This is consistent with the results of the present study. However, studies in Greece showed a good relationship between the society and the patients and no stigmatization of thalassemia patients.^[22] This result was inconsistent with the present study. The reason for this difference may be related to cultural differences and the optimal care support systems of these countries.

Other concerns of the patients were their parents' lack of understanding of the patients' love and marriage. The desire to marry is part of human nature^[32] and patients with thalassemia are no exceptions. In the study by Wahab *et al.*, the Muslim parents of the participants had concerns about finding the right partner for their children, which reflects the importance of this issue in the Islamic world.^[21] The media and the government should plan measured programs and build the culture to overcome stigmatization of the disease and facilitate the marriage of these patients.

A major concern was the lack of a safety net. Support is the most important need of people in crisis and under stress.^[22] Inadequate support can cause psychosocial problems.^[22] Studying chronic patients has shown that good social support has a positive effect on mental health.^[33]

The participants of the study by Shum *et al.* mentioned medical support, and family, social, spiritual, and peer support as their basic needs.^[22] In this study, the need for social support was highlighted. This could be because of the

strong cultural and family ties, and weak social support in Iran. The government needs to enact and implement laws protecting the employment and education of these patients.

Poverty increased the suffering of patients; increased cost of living, traveling, and doctor visits were a heavy burden for thalassaemia patients.^[21] In line with previous studies, participants of the present study had financial concerns.^[3,21] Policymakers should prioritize financial support of thalassaemia patients to reduce the financial burden on families of these patients, and the Ministry of Health should support free treatment and diagnostic facilities for thalassaemia patients. In the present study, anxiety of drug shortages doubled the experienced pain. In the study by Shosha, unlike the present study, there was no shortage of drug.^[23] The reason for this difference was medication sanctions during the period of this study. The Ministry of Health should attempt to eliminate medication sanctions.

CONCLUSION

The findings of this study indicated the different aspects of pain and its profound impact on the lives of patients with thalassaemia. A holistic and comprehensive approach including nursing, medical, educational, financial, social, psychological, and spiritual support could be designed and implemented to promote self-care and decrease the suffering of thalassaemia patients. The findings of the present study are grounds for further research in a wider range to assess different aspects of the experience of suffering.

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