ORIGINAL ARTICLE

Experiences of Iranian Patients with Thalassemia Major Regarding Their Palliative and Supportive Care Needs: A Qualitative Content Analysis

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ABSTRACT

Background: Due to the long-term and progressive nature of β-thalassemia major (β-TM), patients need comprehensive palliative and supportive care covering physical, mental, social, and spiritual aspects. The first step in providing palliative and supportive care is identifying the patients' needs. This study aimed to explore the palliative and supportive care needs of patients with β-TM.

Methods: A qualitative study was conducted from April 2019 to December 2019. The study involved in-depth semi-structured individual interviews with 20 individuals living with β-TM at a university hospital in Ahvaz, Iran. The participants were selected through purposive sampling. Interviews continued until the saturation of data. All interviews were recorded, transcribed, and analyzed with conventional content analysis following the steps recommended by Elo and Kyngäs using MAXQDA software version 10.

Results: Five overarching categories, each with multiple subcategories, were identified: "physical health needs," "sexual and reproductive health needs," "mental and emotional health needs," "social needs," and "need for access to comprehensive health services."

Conclusion: According to the results of this study, unmet needs are prevalent throughout the thalassemia journey. Patients with β-TM require individual, psychosocial, and comprehensive healthcare support to address their needs. Therefore, further research is necessary to develop a nursing care plan for β-TM patients focusing on supportive-palliative care needs.

Keywords: Needs Assessment, Palliative Supportive Care, Qualitative Study, Thalassemia Major

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INTRODUCTION

β-Thalassemia major (β-TM), an autosomal recessive inherited disorder due to decreased or the absence of β-globin chain production, is one of the most common genetic disorders worldwide, including in Iran.[1] This hematological disorder has a high prevalence among Asian, Indian, Middle Eastern, and Mediterranean populations. Due to a high level of relatedness within the population, it is believed that there are approximately two to three million individuals in Iran who carry the β-TM gene, with around 25,000 of them being sick.[2] β-TM is more prevalent in the Northern and Southern regions of the country, where the carrier rate for β-TM is above 10% around the Caspian Sea (Mazandaran, Gilan, and Golestan) and the Persian Gulf (Bushehr, Hormozgan, Sistan and Baluchistan), Khuzestan, Fars, and southern Kerman, and about 4–8% in other areas.[3]

β-TM is characterized by severe anemia that requires frequent blood transfusions.[1] It can lead to severe and life-threatening complications, such as changes in bone structure, reduced height, slowed growth, and delayed sexual development, posing numerous challenges for affected individuals.[4] These effects can impact self-perception, diminish self-worth, and instill feelings of hopelessness in patients.[5] Additionally, complications arising from iron accumulation in vital organs and conditions like chronic limb pain that worsens with age result in frequent hospitalizations for these patients.[6, 7] These complications impose significant physical and psychological constraints on patients' lives, making this disease potentially life-threatening.[5-8]

Studies have shown that patients with β-TM and their families have a lower quality of life than the general population and suffer from multiple psychological disorders such as depression, anxiety, and stress.[9-13] Furthermore, the progression of β-TM symptoms and resulting disabilities has led to physical fatigue; behavioral, emotional, and spiritual disorders; reduced self-confidence; and negative emotions in patients.[14, 15] On the other hand, young adults with β-TM face additional challenges such as social problems related to starting a family, continuing education, and finding a suitable job.[13] Therefore, patients require a comprehensive support network, and the lack of it adversely affects the quality of life of patients and their families.[14, 15]

Palliative and supportive care is a comprehensive approach that enhances the quality of life for patients dealing with issues related to life-threatening illnesses through early identification and treatment of pain and other problems, whether physical, mental, spiritual, or social.[16] Providing palliative and supportive care through specialized services leads to improved symptom control, pain management, reduced patients' and their family's anxiety, and the delivery of quality care.[17] By offering such services, the burden of disease on individuals, families, and communities is reduced, unnecessary hospitalizations are prevented, and costs are saved.[16]

Despite significant efforts to offer healthcare services to individuals with β-TM, there are still shortcomings in the quality of care provided to these patients.[5, 8] Studies in Iran have shown that nurses focus more on providing physical care to these patients, while patients and their families usually do not receive services such as necessary care and training in self-care, consultations with doctors and psychologists, and other care related to their social, psychological, physical, or spiritual needs.[8, 18] Supportive and palliative care are considered integral parts of nursing care, so all nurses should be able to provide adequate care in these areas.[19] However, most care providers are not sufficiently prepared to provide this type of care.[20] One of the contributing factors is the lack of awareness regarding patients' palliative and supportive care needs.[20, 21]

Although some studies in Iran have evaluated the supportive and palliative care needs of cancer patients, examining these needs has been less considered in other chronic patients, especially in β-TM patients. Most studies on issues of patients with β-TM have utilized a quantitative approach, and limited qualitative data are available on patients' experiences of care needs.[8, 12, 14] Given the significance of identifying the needs and issues to enhance patient-centered strategies, and to identify potential gaps and opportunities for planning and delivering quality services, this study utilized qualitative content analysis to explore the needs and expectations of patients with β-TM regarding the necessary support.

MATERIALS AND METHODS

This study, a part of a larger mixed-methods study as a PhD thesis in nursing, utilized a qualitative content analysis. This study was conducted in the thalassemia referral center affiliated with Jundishapur University of Medical Sciences in Ahvaz, Khuzestan province, in southwest Iran, as one of the areas with a high prevalence of thalassemia in Iran.

The participants were over 18-year-old patients suffering from β-TM, who were selected through purposive sampling. Inclusion criteria were the ability to speak Persian, no history of mental disorders based on the cases documented in their file, no other disease in the family besides thalassemia, and willingness to participate in the study and share their experiences with the researcher. Acute physical conditions were also considered as the exclusion criteria due to their influence on the presentation of information. They were selected based on various criteria, including age, sex, education, job, marital status, existence of specific complications of the disease, such as diabetes, or heart disease, and a sibling with thalassemia to ensure maximum variation.

Data were collected via semi-structured, in-depth face-to-face individual interviews from April 2019 to December 2019. The interviews were conducted by the first author based on the interview guide and using open-ended questions. With the consent of the participants, the interviews were conducted in a private room in the thalassemia center in Ahvaz, Iran. Interviews started with general questions such as, "What problems have you experienced in your life with thalassemia?" and "Please tell me how you take care of yourself?" The interviews were then continued based on the expressed materials and with more specific and exploratory questions to achieve the research objectives: "What experiences did you have about care in the clinic or inpatient ward?" "What are your healthcare problems?" "What are your healthcare needs?" "What support do you need?" "Could you explain more about it?", or "Could you give an example?" Each interview lasted between 60 and 90 minutes. Interviews were conducted until the data were saturated. This happened after 22 interviews with 20 participants. Two participants were interviewed twice. All interviews were recorded using an MP3 recorder with the participants' permission and then transcribed verbatim.

Data analysis was done simultaneously with data collection. Data management was done using MAXQDA software version 10, and qualitative data analysis was carried out based on the conventional content analysis following the steps recommended by Elo and Kyngäs, which have three main phases: preparation, organization, and reporting.[22] In the preparation phase, after each interview, it was transcribed immediately. Then, the transcripts were reviewed to obtain an overall understanding. For immersion in data, the researcher listened to the interviews several times. After that, an abstract was written for each interview, and the hidden meanings were extracted. The organizing phase included open coding, creating categories, and abstraction. In the organization phase, the initial codes were extracted; then, similar initial codes were categorized into sub-categories and the main categories were specified. The reporting phase includes a detailed description of the data analysis process and the enumeration of findings.

Credibility, dependability, confirmability, and transferability criteria were used to assess trustworthiness.[23] Prolonged involvement with data and checking created codes and categories by the research team were used to ensure credibility. Participants' confirmation of the accuracy of the transcript interview was also collected to enhance data credibility. To reach dependability, we provided the results of the study to four external observers to investigate the process of the data analysis. All the data were also kept for auditing purposes. To determine confirmability, we requested four external reviewers, who had experience in qualitative research, to evaluate all stages of the research, especially the process of data collection and analysis, as well as the formation of the main categories. To enhance transferability, we applied a thick description of the phenomenon under investigation and sampling with maximum variation.

The research project was approved by the ethics committee of Ahvaz Jundishapur University of Medical Sciences of IR.AJUMS. REC.1397.538. The objectives of the study were explained to the participants, and they signed a written informed consent form before the interview to indicate their willingness to take part. The confidentiality of the participants' information was assured, and they were informed that they could withdraw from the study at any point without consequences. Before the interviews, the participants gave both written and verbal consent to have their interviews recorded. They were also assured that any data collected would be analyzed and published anonymously.

RESULTS

Most participants were female (60%), with a mean age of 29.3±8.84 years and the range of 22–38. Participants' characteristics are presented in Table 1. Five main categories, each with multiple subcategories, were identified: "physical health needs," "sexual and reproductive health needs," "mental and emotional health needs," "social needs," and "need for access to comprehensive health services." These, together with subcategories and quotations, are presented in Table 2. The results are discussed in the following section.

1. Physical Health Needs

Physical health needs include the those related to pain control and any limitation or physical disorder associated with β-TM

Table 1: Socio-demographic of participants (n=20)

Participant number	Age (year)	Sex	Marital status	Education level	Occupation
1	36	Female	Single	High school diploma	Unemployed
2	29	Female	Married	Graduate	Unemployed
3	30	Female	Single	Postgraduate	Employee
4	28	Female	Single	High school diploma	Unemployed
5	30	Female	Single	Graduate	Shop owner
6	38	Male	Married	Primary school	Unemployed
7	27	Female	Single	High school diploma	Shop owner
8	28	Male	Single	Primary school	Unemployed
9	29	Female	Single	High school diploma	Employee
10	23	Female	Single	High school diploma	Student
11	32	Male	Married	Graduate	Employee
12	29	Male	Single	Graduate	Shop owner
13	32	Male	Single	High school diploma	Employee
14	22	Female	Single	High school diploma	Student
15	32	Male	Married	High school diploma	Shop owner
16	34	Male	Married	High school diploma	Unemployed
17	29	Female	Single	Secondary school	Unemployed
18	32	Female	Married	High school diploma	Unemployed
19	26	Female	Single	High school diploma	Shop owner
20	30	Male	Single	High school diploma	Unemployed

Table 2: The subcategories and categories generated from the data

Subcategories	Categories
Need for pain management Need for fatigue management Need for control of physical complications	Physical health needs
Need for information to control sexual and puberty problems Need for information on fertility and assisted reproductive methods Need to support for childbearing	Sexual and reproductive health needs
Inability to cope with uncertainty Need to control emotional exhaustion	Mental and emotional health needs
Need for social awareness Need to receive support from family and friends Need for financial support	Social needs
Need for accessibility of healthcare services Need for continuous care Need for access to reliable information resources Need to respect patients' rights in providing services	Need for access to comprehensive health services

and its treatments that have to be managed by patients to achieve physical health. This category consisted of three subcategories:

1.a. Need for Pain Management

Almost all the patients mentioned different pain intensities as one of the problems they had experienced and the strategies they used were not effective. They expressed that they needed support to manage their pain:

"I'm not very good at pain control. Sometimes, I feel severe pains all over my body, particularly in my shins and waist. I try to reduce my pain by using a hot water bag, massage, or painkillers, but sometimes these do not have any effects due to the severity of my back pain. I need someone to guide me, or at least provide me with a brochure that I can read about how to manage pain!" (P7).

1. b. Need for Fatigue Management

Fatigue was another common complaint among the study participants that impaired the ability of patients to undertake daily living activities. They expressed a need for guidance in managing their fatigue. A patient said:

"I am tired most of the time. While doing household chores like vacuum cleaning, I usually feel exhausted, and I can't go on. I wish I had received some guidance on how to deal with this fatigue." (P1)

1. c. Need for Controlling Physical Complications

The participants also stated that complications of the disease caused numerous problems. They believed that to control these physical problems, they needed further information regarding the disease, its complications, pharmacological complications, and self-care. A participant said:

"I have recently realized that I have osteoporosis, which has progressed. If I had enough information, I might not have osteoporosis, or it might have been diagnosed earlier, and it wouldn't have progressed this much!" (P7).

Another one said: *"I took L1 pills for a while, but they disturbed my stomach. I didn't know what to do, and I discontinued the pills. I needed to know about the drug and its complications, but the doctors and nurses didn't explain what we had to do!"* (P15).

2. Sexual and Reproductive Health Needs

Three subcategories emerged under the main category of sexual and reproductive health needs:

2.a. Need for Information to Control Sexual and Puberty Problems

One of the main complaints among participants was inappropriate or insufficient information about sexual relations, sexual maturity, and actions required for sexual development, which required support from healthcare professionals.

A married man stated, *"I have problems establishing a sexual relationship. You know, I need the help and support of my doctor to learn how to solve this problem!"* (P6).

A single woman stated, *"I didn't get my period until I was 21-22 years old. But really, neither I nor my family knew that I should take pills! You know, I say that it should be informed that when we should start taking medicine. In my opinion, these are not talked about at all, nor are they taught! While we need to be informed about these puberty problems!* (P3).

2.b. Need for Information on Fertility and Assisted Reproductive Methods

The participants stated that since they are facing the problem of infertility due to the nature of the β-TM disease, they have a great desire to obtain information on fertility and use assisted reproductive methods.

I heard that there are various assisted reproductive methods, but I don't know much about them. I wish there was a counselor available at the clinic, so I could ask my questions! (P18).

2.c. Need to Support for Childbearing

The participants also emphasized that the disease hurt their sexual growth and development. Therefore, they required assisted reproductive technology.

A married woman stated, *"The doctor told me that my sexual organs were not mature enough and I could not have children. I wish we could receive financial support to be able to make use of assisted reproductive methods."* (P2)

3. Mental and Emotional Health Needs

Many participants indicated that they suffered from lots of emotional and mental issues. This category included two subcategories:

3.a. Inability to Cope with Uncertainty

The inability to predict the disease outcomes resulted in fear, concern, and stress among the patients. Almost all the patients imagined an unpredictable future for themselves. The patients' worries included fear of the incidence or progress of disease complications, the ambiguity of the future of treatment, thinking about death, and concern about the future of one's family. Patients stated that they needed support to get rid of confusion and insecurity.

A woman stated, *"I always have anxiety about diabetes or heart problems. I'm afraid of facial changes. I always think about what is going to happen to me. These continuous blood injections may have complications, or I may be infected with HIV or hepatitis! I need support in this regard! I feel insecure!"* (P9).

3.b. Need to Control Emotional Exhaustion

Patients expressed various degrees of psychological problems. Disease complications and fatigue resulting from complex and continuous treatments led to emotional exhaustion among the patients. The negative psychological experiences included disappointment, worthlessness, lack of interest in doing activities, fatigue, impatience, and a tendency toward death, which required help and support on the part of the treatment team.

A participant stated, *"I'm tired of this disease! I'm tired of blood transfusions! I'm not interested in doing anything. I feel that my life is monotonous and meaningless! I don't know how to deal with these feelings. I need support in this regard!"* (P5).

4. Social Needs

The study participants complained that many social needs were left unmet.

4.a. Need for Social Awareness

According to the patients, the stigma

associated with thalassemia led to various social restrictions. The participants stated that disability or early death stigma caused them to encounter lots of problems with employment. In other words, they were deprived of appropriate occupations most of the time. Moreover, the exaggeration of the disease in society and rejection by others provided the ground for the patients' isolation and deprived them of their social needs, including marriage and having a family. Patients stated that there was a need to change the public attitude towards thalassemia:

A married male stated: *"Wherever I refer for work, they don't accept me because of my disease. They fear that I may not be able to do the job or die soon! I wish TV networks would strive to inform people by broadcasting appropriate programs, or that the government would create conditions for employing individuals with thalassemia."* (P16).

A single woman stated: *"I had many suitors, but due to ignorance of the disease, they all left me because they were afraid of my disease or they thought I could never have a child. I wish people would understand that our disease is not as scary as they think!"* (P17).

4.b. Need to Receive Support from Family and Friends

The participants emphasized that they needed the support of family members or friends to overcome the disease challenges and develop conformity with the disease. Nevertheless, some patients mentioned that they did not receive the needed support from their families:

"My family does not even accompany me to the hospital when I feel bad; they do not even help me buy medications or do checkups! I need my family's support; I expect them to understand this" (P8).

4.c. Need for Financial Support

Nearly all the participants mentioned that they were not able to pay for foreign drugs such as supplements or iron-chelating. Besides, insufficient insurance coverage and high costs of annual checkups created numerous problems for the patients, causing some of them to discontinue treatment. Participants reported that they needed financial support from the government and charities:

"I just do some checkups and experiments. For example, I can't do MRI, CT scan, and bone densitometry because they are costly and aren't covered by insurance! I wish the government would require insurance companies to cover the costs of our tests." (P2)

5. Need for Access to Comprehensive Health Services

Comprehensive healthcare services refer to healthcare for all patients through expanding healthcare services. This category included four subcategories:

5.a. Need for Accessibility of Healthcare Services

The need for easy access to treatment centers was one of the frequently mentioned issues among the patients. In this regard, the patients faced problems accessing healthcare centers and hematology specialists due to the distance between the treatment center and the city center, and the lack of thalassemia centers in villages and small cities. The patients considered themselves in need of support to access treatment in health centers near their residences. A participant said:

"I can't often refer for blood transfusion or visit because it is difficult for me to go to the thalassemia clinic! I wish this were possible; at least we could obtain the blood we need at the health centers in our village or doctors came to health centers at specific times for our visit." (P16)

Moreover, the patients emphasized that they needed to have access to an equipped team and a comprehensive clinic so that they would be able to refer to dentists, internal medicine specialists, psychologists, nutritionists, traditional medicine specialists, etc., in addition to hematologists. A participant said:

"We need a dentist in the thalassemia clinic because not all dentists accept us due to our disease!" (P12).

Another point raised by the patients was the need for a timely supply of medications and blood. The patients considered these two as their basic needs for survival:

"Sometimes, iron-chelating drugs are not available. Sometimes, blood is not available. Without blood and drugs, we cannot survive. We expect that our concerns will be understood, and blood and medicine will be delivered to us on time." (P7)

5.b. Need for Continuous Care

Continuous care and following up on patients' health status by healthcare teams was another need mentioned by most participants.

"I haven't used iron chelating agents for a while. My iron level has increased a lot. I feel that there should be a person to follow my treatment up!" (P20).

5.c. Need for Access to Reliable Information Resources

The participants said that because of lack of access to reliable sources of information, they had to use unofficial resources like other patients or general searches on the Internet, which finally led to their confusion and reception of unreliable information. They emphasized that they were relieved by acquiring information from the physicians and nurses in the *thalassemia ward:*

"I receive information from other patients or the Internet most of the time, but I don't know whether it is right or wrong! I would like to ask doctors and nurses my questions. I believe that no one can provide us with the correct information as they can, but unfortunately, they aren't available!" (P18).

5.d. Need to Respect Patients' Rights in Providing Services

Some participants stated that the healthcare team was inattentive to their moral and legal rights. They emphasized their need to respect some of their legal rights, including appropriate relationships between them and physicians and nurses, allocation of sufficient time for visits and examinations, and receiving the required training. A participant said:

"Here, patients are visited in groups. I need to be alone with my doctor, so I can express my problem!" (P13).

Another one stated: *"I talk to doctors during the visit session, but they don't listen at all. They see the experiments, and I am waiting for them to tell me how my test went. What should I do? But they say nothing!"* (P1).

DISCUSSION

This study explored palliative and supportive care needs in patients with β-TM. Patients implied the needs in the area of physical, sexual and reproductive health, mental, social, and access to comprehensive health services. In the current study, physical health needs were among the extracted needs. Patients with β-TM need to manage their physical symptoms and complications due to physical disorders caused by the disease and its treatments. Previous studies conducted on patients with β-TM and other chronic disorders showed that symptom management such as pain, fatigue, difficulty managing day-to-day activities, and uncontrolled physical complications were primary palliative care needs among these patients.[12, 14, 15, 24, 25] However, the participants in our study stated they did not receive any professional support for managing these issues, and they had difficulty controlling the disease and its complications. Although pain is a frequently reported concern among patients with β-TM,[7] and many individuals in this study identified it as a persistent issue, they were not referred to a pain specialist. Chronic and severe pain associated with thalassemia has been linked to a decline in quality of life, as well as increased levels of anxiety and depression, highlighting the importance of providing patients with timely pain management assistance.[5, 7] Furthermore, specialists in palliative care and pain management can provide significant help with alleviating pain. In our study, the patients expressed that they were unable to manage their pain and needed support, highlighting the necessity for improved access to palliative care for this group. Likewise, fatigue was recognized as a continuous problem for numerous patients with β-TM, hindering their ability to perform daily activities. Various strategies, including physical exercise, complementary and alternative therapies, psychosocial support, and pharmacological treatments, have been found effective in alleviating fatigue.[26] Therefore, patients must receive the necessary guidance and support in this field. Receiving adequate and clear information about the disease and its complications was another need expressed by patients with β-TM. This finding aligns with the results of previous studies involving these patients, as well as those with other conditions, highlighting the significance of this need in the realm of supportive and palliative care.[8, 27, 28] Therefore, healthcare professionals should assess the patients' information needs about the management of disease symptoms and complications during treatment and over time.

Patients with β-TM in the present study needed support in sexual and reproductive health. It is highly advisable to conduct careful clinical assessments of growth and puberty, along with suitable hormonal tests in patients with β-TM, to identify and address any endocrine issues early on. Additionally, establishing an effective chelation therapy from a young age is vital to avoid significant iron accumulation and lasting harm to the endocrine glands, especially those that regulate reproductive functions.[29, 30] Furthermore, recent advancements in treating sexual maturity issues and assisted reproduction methods highlight the importance of providing patients with information about new medical techniques that can help address or minimize patients' sexual problems instill hope for fertility and enhance their ability to bear children.

Another category extracted in this study was mental and emotional health needs, which included the need to prevent and manage uncertainty and emotional exhaustion. Uncertainty about the disease consequences and ambiguity of future resulted in the feelings of fear, concern, and insecurity among the patients. Previous studies also indicated that due to the chronic nature of their disease, patients with β-TM were highly afraid of the incidence and progress of the complications associated with the disease and its lengthy treatments, which led to a feeling of helplessness and disappointment.[14, 18, 31] Nonetheless, there is no integrated, comprehensive system for supporting patients with β-TM in Iran's healthcare system.[18] The need to prevent and manage emotional exhaustion was another mental and emotional health need among the patients in the present study. Prior studies have also demonstrated a high prevalence of depression, anxiety, and stress related to the disease and its associated problems among patients with β-TM, which negatively affected their quality of life and increased their reliance on the support of the treatment team.[12, 13, 32] Emotional support plays a crucial role for patients during their illness and can come from various individuals and services. Research has shown that psychosocial interventions can assist patients in managing difficult circumstances and enhance their emotional well-being.[33] Therefore, healthcare teams are required to consider planning and implementing supportive, social, and consultation services in the form of a comprehensive, multidisciplinary approach for these patients.[34]

Social needs, which include the need for social awareness and the need to receive social support, were other findings of this research. Participating patients suffered from social stigma, negligence of their capabilities, and deprivation of their social rights. In addition, they were concerned about being rejected by society, losing their social status, and the stigma of not being able to marry and work. In Iran, stigma is associated with negative psychosocial consequences among patients with β-TM, highlighting the importance of social awareness as a supportive need among these patients.[35] The patients also expressed the need for social support. Evidence demonstrated that social support provided by various social networks like family, friends, and healthcare staff could exert a positive effect on the mental health of patients with β-TM, eventually improving their hope and increasing their self-care behaviours and self-efficacy.[12, 31, 34, 36, 37] Moreover, patients with β-TM in other Iranian studies reported that they were mostly supported by their families and to a smaller extent by their friends and other sources.[12, 34] Although family is considered an important source of support, patients need financial, professional, and educational support on the part of governmental and non-governmental resources and social institutions.[12, 15] Therefore, governments must issue laws for these patients' employment, housing, and education. Besides, public and private policymakers and social institutes have to consider financial support and occupational opportunities for patients with β-TM.

The need for access to comprehensive health services, including the need to access health care services, the need for continuous care, the need for access to reliable information resources, and the need to respect patients' rights in providing services, were among the other needs reported by the patients participating in the present study. In accordance with the findings of the current study, a similar investigation involving patients with β-TM revealed that the need for easy access to treatment centers and comprehensive clinics is a significant support requirement for individuals with β-TM. This accessibility plays a crucial role in enhancing the patients' adherence to treatment.[31] Also, the participants in the current study stated a need for a timely supply of medications and blood. This finding is consistent with those of similar studies in Iran.[14, 15] Although thalassemia associations and treatment centers strive to facilitate easier access to blood and medication for patients with β-TM, there are instances where this access proves challenging, necessitating thorough planning by the treatment centers. Furthermore, similar studies performed in Iran and other countries revealed that need for reliable information resources was among supportive care needs in patients with chronic diseases and their families.[27, 38, 39] However, this need remained unmet in most cases due to the lack of educational and supportive centers and unavailability of reliable information resources including physicians and nurses.[31, 40, 41] The availability of a reliable information resource such as a trained nurse could assist in addressing this need. On the other hand, respecting patients' independence, involving them in treatment decisions, establishing effective relationships with patients, allocating sufficient time for visits and examinations, honoring clients and their needs, and following up on their health status can play a critical role in identifying their problems and implementing effective care measures.[31] These practices can also enhance the clients' willingness to adopt healthy behaviors and improve adherence to their treatment, ultimately leading to greater patient satisfaction with healthcare services.[42, 43]

Findings of the study provided new insight into palliative and supportive care in patients with β-TM. This study had some limitations. The selection of the participants from only one center could affect some of their needs related to shortage in the center. Another limitation is that the study illustrated palliative and supportive care needs from the perspective of patients and not from the experiences of nurses and family caregivers.

CONCLUSION

Findings showed that unmet needs are prevalent throughout the thalassemia journey. Patients with β-TM require individual, psychosocial, and comprehensive healthcare support to address their needs. Therefore, further research is recommended to develop a nursing care plan for β-TM patients focusing on supportive-palliative care needs.

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Authors' Contribution

MA and MGh were responsible for the conceptualization and design of this study. The interviews were conducted by MA, with assistance from MGh. The data analysis and interpretation were carried out collaboratively by MA, MGh, MR, AE, and MAs. MA drafted the initial manuscript. All authors critically reviewed and revised the manuscript and approved the final version for publication. All authors take responsibility for the integrity and accuracy of the data analysis. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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Declaration on the use of AI

We acknowledge the use of WORDVICE.AI (https://wordvice.ai/proofreading/) to proofread some sentences of our work.

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