

Experience of Uncertainty in Patients with Thalassaemia Major: A Qualitative Study

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ABSTRACT

Background: Uncertainty leads to a stressful situation in patients with thalassaemia major that can dramatically affect their psychosocial coping ability, treatment process and disease outcomes, and reduce patients' quality of life. As one of the important factors affecting the health of thalassaemia patients, understanding the concept of uncertainty is of major importance to health care providers especially nurses as the first line of exposure to these patients. The present study aimed to explore the experiences of uncertainty in patients with thalassaemia major.

Materials and Methods: The present qualitative study was conducted through in-depth face-to-face semi-structured interviews held with 18 patients with major thalassaemia selected through purposive sampling. Interviews continued until saturation of data. All interviews were recorded, transcribed and analyzed with conventional content analysis method of Landman and Graneheim using MAXQDA10 software.

Results: Two main themes, including 'living in the shadow of anxiety' and 'coping with uncertainty' emerged from patients' experiences of illness uncertainty of thalassaemia. 'Living in the shadow of anxiety' included four categories of 'fear of complications', 'contradictory views on treatment', 'unknown future' and 'stigma'. 'Coping with uncertainty' included three categories of 'spiritual coping', 'psychosocial coping' and 'knowledge acquisition'.

Conclusion: According to the results of this study, uncertainty is a major psychological stress in patients with thalassaemia major. Healthcare providers should therefore consider the challenges and concerns faced by patients and, through utilizing appropriate training and communicational practices, plan interventions and strategies to empower patients for coping with uncertainty.

Keywords: Patients with thalassaemia; Uncertainty; Qualitative study; Iran

INTRODUCTION

Thalassaemia is one of the most prevalent genetic diseases in the world including Iran¹. Based on the latest statistics in 2013, there are about 26,000

thalassaemia patients as well as two to three million thalassaemia carriers in Iran². Thalassaemia major is characterized by severe anemia that cause many

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physical and psychological limitations in the patients' lives³.

Over the recent few decades, because of significant advances in medical science and treatment of diseases, the life span of thalassemia patients has been increased to more than 50 years⁴. However, the results of the studies show that in spite of increased life expectancy, other aspects of the lives of these patients and their families⁵ such as general health, mental health, and quality of life have been affected^{6,7}. Problems such as financial constraints, reduced income or unemployment, performance-related limitations, drug restrictions, health-related problems, poor financial and family support, and the lack of a comprehensive support network can negatively affect the patients' physical and psychological health and reduce their quality of life drastically^{8,9}. These stressful problems affect different aspects of the life of thalassemia patients broadly and provide the basis for uncertainty about the future in these patients⁸⁻¹⁰. Uncertainty is defined as a cognitive state arising from inability to determine meaning or inability to predict disease-related events¹¹. The concept of uncertainty was first introduced by Mishel in the form of a nursing theory that has been widely used hitherto to explore this concept in patients with acute and chronic diseases¹². According to Mishel's theory, uncertainty is a combination of doubt, indecision, ambiguity and perplexity in an individual, and arises when people are in critical, sudden, unexpected and life-threatening situations and unable to predict future events^{11,12}. Uncertainty leads to a stressful situation in patients that can dramatically affect their psychosocial coping ability, treatment process and disease outcomes^{12,13}, and reduce patients' quality of life¹⁴.

As one of the important factors affecting the health of thalassemia patients, understanding the concept of uncertainty is of major importance to nurses as the first line of exposure to these patients. The nurses thus can be effective in reducing the patients' fears, concerns and their uncertainty about the future by better understanding of this concept and identifying the causative factors as well as the factors influencing the patients' coping with this issue¹⁵.

Uncertainty is a multidimensional concept that can be different depending on the sociocultural context and the nature of the disease. Given that the recognition of these differences can be effective in managing uncertainty, providing optimal care and improving patients' quality of life, examining the patients' experiences of the concept seems to be necessary. Although some studies in Iran have evaluated the concept of uncertainty in cancer patients¹⁶, this concept has been less considered in other chronic patients. Given the various meanings of uncertainty in different diseases, the significance of this concept in thalassemia major patients and the important effects it has on the quality of life of these patients, this study aimed to explore the experiences of uncertainty in patients with thalassemia major in order to identify the dimensions of uncertainty and pave the way for a better evaluation and management of it. Doing so, a good insight will be provided into the planning of support services, prevention of psychosocial stresses, and promotion of health level as well as physical and psychological well-being of these patients.

MATERIALS AND METHODS

Study design

In this study that is a part of a large study as a PhD thesis in nursing, the descriptive exploratory study design was used. In this qualitative study, for coming to an in-depth understanding of the experiences of thalassemia major patients with the concept of uncertainty, conventional content analysis was used.

Study setting

This study was conducted in thalassemia clinic and inpatient ward of Baqa'i hospital in Ahvaz, Khuzestan province, in the southwest of Iran, as one of the areas with high prevalence of thalassemia in Iran.

Participants

Over 18-years-old thalassemia major patients who could speak Persian, had no history of mental disorders, and were willing to participate in the study and share their experiences with the researcher were selected through purposeful sampling method. To achieve maximum variation, the participants

varied in terms of age, gender, education, job, and marital status.

Data collection

Data were collected between November 2018 and July 2019 using semi-structure in-depth face-to-face individual interviews. The interview was conducted by the first author of this article based on the interview guide and using open-ended questions. The time and place of the interviews were determined by the coordination and preference of the participants. With the consent of the participants, the interviews were conducted in a private room. Interviews first started with general questions such as: "What problems have you experienced in your life with thalassemia?" "How do you feel about living with thalassemia?" The interview was then continued based on the expressed material and with more specific and exploratory questions to achieve the research objectives: "What have you worried about in this regard?" or "Could you explain more about it?" Each interview lasted between 45 and 75 minutes. Overall, 20 interviews were conducted with 18 thalassemia major patients (two patients interviewed twice). Data saturation was achieved after 16 interviews, but to be sure, four other interviews were also conducted. Using a MP3 recorder, all interviews were recorded with the permission of the participants.

Data analysis

Data analysis was carried out in accordance with the recommended steps by Graneheim and Lundman¹⁷. After each interview, the researcher immediately transcribed it into written texts, and each interview was read several times to gain an overall understanding of its content. Meaning units were then identified and the initial codes were extracted. Next, similar initial codes were categorized into more comprehensive categories and, finally, the main themes were specified. Data collection and analysis, using MAXQDA 10 software, were done simultaneously.

Rigor

In this study, credibility, dependability, confirmability, transferability criteria were used to assess trustworthiness¹⁸. For data credibility in this study, the researcher was involved with the data during the study period for 9 months ceaselessly. The created codes, categories, and themes were reviewed and revised continuously by the members of the research team. Additionally, initial coding in each interview was returned to the interviewees and their approval was obtained. To ensure the dependability of the data, the process of the research was given to the research team to verify the validity of it. The results of the study were also provided to several external observers to investigate the process of the data analysis. In order to achieve the criterion of confirmability, all stages of the research, especially the process of data collection and analysis, as well as the formation of the main categories were reviewed and approved by external check. In order to enhance transferability, the participants were selected with maximum diversity.

Ethical considerations

The research project was approved by the Ethics Committee of Ahvaz Jundishapur University of Medical Sciences (IR.AJUMS.REC.1397.538). All ethical considerations including informed consent, information confidentiality, and voluntary participation in and exit from the study were considered in the study.

RESULTS

A total of 18 patients with thalassemia major including 12 women and 6 men, aged 22-38 (mean, 29.8 [SD, 3.84] years) participated in the present study. Participant characteristics are presented in Table 1.

Table1: Socio-demographic of participants (n=20)

Variable	Category	N (%)
Sex	Male	6 (33)
	Female	12 (67)
Marital status	single	13 (72)
	Married	5 (28)
Educational level	≤ High school diploma	12 (67)
	Graduate or postgraduate	6 (33)
	Occupation	
	Employee	4 (22.2)
	shop owner	4 (22.2)
	Unemployed	8 (44.5)
	Student	2 (11.1)

Data analysis led to the extraction of two main themes of living in the shadow of anxiety and coping with uncertainty, as shown in Table 2.

Table 2: Themes, categories and sub categories

Themes	Categories	Sub-categories
Living in the shadow of anxiety	Fear of complications	Fear of complications of the disease Fear of complications of blood transfusions
	Contradictory views on treatment'	Anxiety about the fulfillment of needs and treatment costs Hope for definitive treatment
	Unknown future	Obscure future with regard to marriage and parenting or presenting new roles Thinking about death Influencing family structure
	Stigma	Disease disclosure concerns Expected social discrimination concerns
Coping with uncertainty	Spiritual coping	Hope in God and acceptance of providence Connection with God and spiritual peace
	Psychosocial coping	Accepting the illness Use of psychosocial coping strategies
	Knowledge acquisition	Information search Knowledge as a requirement

Living in the shadow of anxiety

In describing their experiences of uncertainty, almost all thalassemia major patients expressed fears and worries. This theme included four categories of fear of complications, contradictory views on treatment, unknown future, and stigma.

Fear of complications

According to this category, fears and concerns about the complications of the disease and the complications of repeated blood transfusions are known as important factors in the occurrence of uncertainty in patients with thalassemia major.

Fear and concern over the possibility of multiple complications caused by the disease or the possibility of the progress of the complications had made the future of the disease uncertain and unpredictable for the patients. For instance, a 29-year-old woman stated, "*I always have stress! I'm always worried that I may run into trouble. I usually think something bad is going to happen to me now! I'm afraid to go for a checkup lest they tell me something is wrong, but I do it with stress*" (P9).

The patients also were afraid of the possibility of blood reactions, alloimmunization, and antibody formation in the blood, as well as viral infections through the infected blood and, hence, described their future as uncertain and unsafe. A woman stated, "*The blood we have been receiving for a while has not been checked for blood subgroups! I'm so scared of it!*"(P4). Another participant said, "*It may occur very rarely, but we are really worried about getting contaminated blood! Its likelihood may be one in a hundred or thousand, but this is also a large number. Maybe that 'one' is me. I feel there is no safety!*"(P7).

Contradictory views on treatment

While expressing concern about their treatment and being uncertain about their future, the patients in this category were hopeful of discovering new and definitive methods of treatment. This category consisted of two subcategories of anxiety about the fulfillment of needs and treatment costs, and hope for definitive treatment.

The absence of certain blood groups or the shortage of blood in some situations had led to a great deal of

anxiety in the patients, and their blood-dependent life made them afraid of the future waiting for them if they cannot receive the blood they need. A 32-year-old man stated, *"One thing I am so afraid of is that one day there will be no blood donor! No blood! What can I do then?"*(P11). The participants also maintained that the shortage of medicines and sometimes the unavailability of some needed drugs, the inadequate quality of available medicines, the non-compliance of the prices of the needed medicines with financial ability of the patients, the inadequate coverage of insurances, and the high cost of annual checkups impose a great deal of stress and anxiety upon them. A woman stated, *"I have a lot of stress with regard to my medication. Sometimes you cannot find your medicine! I'm always worry about it that what can I do if the medicines become unavailable!"*(P18). One of the patients whose wife also suffered thalassemia stated, *"Our biggest concern is the cost of medicines and the cost of our checkups that we don't know how to deal with! Well, both my wife and I suffer thalassemia. The price of medicines, especially desferal, has increased. Many medications are not supported by insurances!"* (P2). However, along with specific concerns associated with their treatment, the patients also considered another aspect of their illness and that was the hope of discovering a definitive treatment for the disease. A 27-year-old woman stated, *"My main concern is definitely treatment! What is going to happen in the future! How will we be treated? I don't like to think about future so much. I say to myself that anything may happen. But I'm always anxious that what will happen. Can there be a definitive treatment?"*(P7).

Unknown future

The patients participating in the study expressed concern about the future of their lives as well as the future of their families and, eventually, described their lives as ambiguous and wrapped in a halo of uncertainty. This category consisted of three subcategories of obscure future with regard to marriage and parenting or presenting new roles, thinking about death, and influencing family structure.

Issues such as the tendency to marry and the fear of not being accepted by society for marriage, together

with the fear of infertility and giving birth to a sick child also raised concerns among most of the participants and made them uncertain about the future. A single participant stated, *"I really would like to get married, but I'm always worried about getting married and not being accepted by the family of my future wife!"*(P14). Patients also worried about infertility or giving birth to a sick child. A married woman stated, *"My greatest concern is giving birth to a child. This is my usual concern that how my husband's family may treat me if I can't give birth to a child! On the other hand, I'm worried about giving birth to a sick child!"*(P17).

Some other thalassemia patients spoke of their waiting for death and described their future as obscure as possible. A 32-year-old man stated, *"You don't think about the future. You think that you'll die today, this month or this year. Even though you know that thalassemia can't kill you, you're not sure!"*(P13). A 22-year-old woman student said, *"I always think about death; especially when a thalassemia patient dies. I tremble and I feel that I'll meet my death very soon"* (P14).

The participants were also uncertain about the future of their family. Concern for the destiny of the spouse and children after the death, imposition of the disease costs on the family, and cancellation of the marriages of the healthy siblings caused uncertainty for the participants and added to their anxiety. Married patients were more worried about future of spouse and children, a married man said, *"Well, there is this concern that I will probably die sooner because of the disease! I But I'm not at all worry about myself! My wife and child are my main concern! How will be their future?!"*(P15). One of the girls believed that she is the barrier to the marriage of her brother, *"I wish my brother got married to someone he loves! I don't want see him as the victim of my disease! I'm very upset that his proposals of marriage are declined because of me"* (P5).

Stigma

This category expresses the patients' concerns about social stigma as an important factor in the emergence of uncertainty in thalassemia major patients. This category consists of two subcategories

of disease disclosure concerns and expected social discrimination concerns.

In this study, the majority of patients expressed concern about disclosing their illness as it might lead to social stigma. Fear of disclosing the disease in many cases had led to social isolation in patients and made them skeptical and hesitant about their social relationships. A 29-year-old woman said, *"I broke up with many of my friends to prevent them from knowing about my illness. Those who have known about it hitherto have a different look. I have always had the fear that my friends would understand and avoid me! That they may see me as a helpless patient and then everything may change between us!"*(P2). Social discrimination was one of the important subcategories of this study. Social discrimination had led to social deprivation in patients and deprived them of their social rights including proper employment. The participants of the study, especially men, expressed great concern about their employment status because of disability stigma or premature death. A married man stated, *"They don't hire us anywhere! They fear that we will die early or we can't work properly because of our physical problems! I'm married and when go somewhere for employment, they don't hire me when they know from my military service completion card that I'm thalassemia. I'm so worried about how to manage my life in this situation!"* (P16). Another patient stated, *"One of my biggest fears is that somebody in my workplace will know I have this problem! If they know it, I might get fired!"*(P11).

Coping with uncertainty

The participants used different strategies to cope with uncertainty. These strategies were classified into three categories of spiritual coping, psychosocial coping, and knowledge acquisition.

Spiritual coping

Almost all participants of the study mentioned spirituality as one of the most effective ways of coping with uncertainty when describing their experiences of uncertainty. This category had two subcategories of hope in God and acceptance of providence, and connection with God and spiritual peace.

Patients tried to endure disease-related uncertainty through spiritual beliefs such as hope, trust in God and acceptance of providence. A participant mentioned, *"I always tell myself that we are not the cause of what happens or does not happen; everything is the work of providence. We have to trust in God. Doing so, I try to take the life easy and remain hopeful"* (P6).

Many of the patients also stated that they resort to religious practices such as prayers, and taking part in religious ceremonies to cope with the fears and anxieties caused by the illness as well as the unpleasant experience of uncertainty about future. A woman stated, *"I pray when I get very worried. I ask God to help me! I usually calm down when I talk to God and become more hopeful"*. (P1)

Psychosocial Coping

Accepting the illness and coping with it, and the use of psychosocial coping strategies were other techniques used by the patients to cope with uncertainty caused by the illness.

The patients maintained that in the face of thalassemia as a chronic genetic disease with an unpredictable nature, they try to accept the disease as part of their lives and deal with the concerns caused by it. A man participant said, *"I just tried to accept it! I mean, I considered it as a part of my life. I didn't consider it something new that can prevent me from having a normal life"*(P11).

The participants used various coping strategies to deal with concerns and uncertainty in their illness. Keeping one's spirit up and distracting the thought by doing sports and listening to music, not thinking about problems, thinking positively and optimistically, and comparing oneself with those who have more severe illnesses are among the psychological strategies employed by the participants of this study. A participant stated, *"I try to escape from thinking about my problems, because thinking about them does not solve them. I always say that life is inherently difficult so I shouldn't make it any harder for myself. I try to make it easy through having more positive thoughts"*(P10). A young woman also said, *"When I'm really worried I try to get myself involved with work, music or walking. I try to*

invite myself to restaurant, cafe, and cinema at least once a month or go biking! Alone!"(P7).

The research participants also acknowledged that support from family, friends, and peers helped them cope with the disease and uncertainty as well. A participant said, *"My family always supported me; in everything they gave me confidence and treated me like a normal person. They never say no, don't do that because you are sick" (P3).* Married patients also referred to the role of their spouses as a source of hope and striving for life. A married woman said: *"I used to think about my problems and worries! I was very disappointed! But my husband has given me hope and energy since he entered my life! My life is now different!" (P17).*

Knowledge acquisition

Gaining knowledge and information about the disease and its complications, as well as medications and treatment were one of the ways by which the participants of the study coped with disease-related uncertainty.

The patients attempted to find answers to their medical questions in order to reduce this uncertainty. A participant stated, *"When I hear that now medicines have been produced for our disease I try to search the internet for more information about it. I also talk to my doctor about it. I also talk to the patients who have taken that medicine. I try to research well then use it, because I'm very afraid of side effects!"(P12).*

The participants stated that having information about the side effects of the medicines and the complications of the disease would help them to prevent and control the side effects. They also emphasized that being informed by their physician about their health status could help them to prevent the development of complications, manage their treatment and lead to the decreased uncertainty about the future. A participant stated, *"For example, I have osteoporosis! If I had enough information about how to prevent it, I probably wouldn't have it"(P7).* Another participant also said, *"I expect my doctor to tell me about my illness and, when checking my tests, tell me what is high, what is low and what should I do! I expect my doctor to explain; I'd like to know!" (P3).* In addition, the participants

acknowledged that awareness of new treatments would also increase their hope for and reduce their uncertainty about the future. A man participant stated, *"I wish doctors could at least inform us of new treatments that are coming. Even if they are not in Iran and we are unable to use them, we still hope that a new treatment has been found" (P11).*

DISCUSSION

The aim of this study was to explore the experiences of uncertainty in patients with thalassemia major. Living in the shadow of anxiety and coping with uncertainty were the two main themes discovered in this study. The results of similar studies in thalassemia patients are also indicative of concern about and hopelessness for the future in these patients¹⁹⁻²¹.

In the present study, concerns about the complications of the disease and the side effects caused by repeated blood transfusions were important aspects of future uncertainty in patients with thalassemia major. Previous studies have also shown that the likelihood of disease progression together with the disease and treatment complications leads to numerous fears and concerns in thalassemia patients^{8,10,19,22,23} and other chronic patients as well^{16,24,25}. Fear of complications can lead to either positive or negative consequences for these patients. In line with some studies²³, fear of complications functioned in the present study as a facilitating factor for accepting treatment and self-care behaviors. According to one female participant in the present study, although she was afraid of checkups as they might discover new problems in her, she did so for the fear of complications. Nonetheless, this fear can lead to anxiety and worry in patients and jeopardize their mental health²⁶. Therefore, it is necessary to control this feeling of fear in patients and to teach them how to overcome their fear and live without fear of illness²⁴.

Concern for treatment was another result of this study that was expressed by the majority of the participants. The needs and costs of treatment and the obscure treatment-related future had led to uncertainty about future in these patients. Consistent with the results of previous studies on thalassemia patients^{8,9,27} and other patients with

chronic diseases^{16,28}, the present study showed that blood deficiency, medication shortage, high medication prices, increased medical costs and inability to pay had imposed a heavy burden on the patients and made it difficult for them to take care of themselves. In line with the results of the present study, in a study in Pakistan, thalassemia patients expressed concern about the growing costs of medical practices²⁹. In Iran, thalassemia patients benefit from insurance services for specific patient, but only a limited number of laboratories and diagnostic centers, which are mainly located in the capital, have contract with this insurance and a limited number of medicines required by these patients are covered by it. Part of the financial and medical concerns of the patients was also related to the social, political and economic situation of Iran at the time of the study. Therefore, paying attention to patients' medical issues, timely blood and medication supply, free insurance services and improved insurance coverage should be among the health-related planning of government.

One of the main categories of this study was unknown future that referred to the patients' concern about their future as well as that of their families.

Concern and fear of being rejected for marriage, on the one hand, and the fear of infertility and giving birth to a sick child, on the other, has made them uncertain and doubtful of their future.

Consistent with the results of the present study, the results of a study in Malaysia showed that thalassemia major patients had a high level of concern that their marriage proposal might be declined and were afraid of being rejected by their future spouse because of their illness²². This similarity in results seems to be due to the similar cultural backgrounds of the two countries. In Iranian culture, thalassemia is considered as a taboo that entails the stigma for marriage and fertility⁸. As such, people with thalassemia will not be easily accepted for marriage. Additionally, the unknown future was associated with thinking about death and being concern for the future of the spouse, children, and family, which seems to be a common concern among all patients with chronic diseases^{16,28,30}. Factors such as the chronic and progressive nature of the disease,

poor prognosis, complications of the disease and treatment, and the expectation of early death are the major causes of these concerns in thalassemia patients³¹. Mental support for these patients and providing an opportunity for them to express their concerns and helping them to overcome their fears should be considered in supportive care of thalassemia patients.

Concern about stigma was another important category obtained in this study. Fear of disclosure of the disease and loss of social status and fear of social discrimination had forced the patients to conceal their illness and made them unsure of what they had to expect. In line with our results, Kumar et al. study in Singapore also showed that thalassemia major patients feared disclosure of their disease that was due to the concern about the stigma of the inability to marry and work as well as the fear of social and occupational discrimination (20). Stigma is associated with adverse psychosocial outcomes in patients, and the absence of supportive laws in Iran for the employment of specific patients^{8,21,23}, the lack of appropriate social status for them and poor acceptance of thalassemia patients in society have made these patients feel frustrated, fearful and uncertain about the future^{32,33}. These findings emphasize the need for social support for thalassemia major patients and the need for social destigmatization.

Coping with uncertainty was the second main theme in this study. When confronted with uncertainty and experiences of fear and anxiety, patients with chronic diseases try to employ coping strategies to cope with the current situation. Based on Mishel's theory of uncertainty, if these coping strategies are effective, adaptation will occur¹⁴. The use of coping strategies not only leads to the management of fear and anxiety and overcomes uncertainty³⁴ but also influences patients' adherence to treatment³⁵. As the results of the present study showed, spiritual coping, psychosocial coping, and knowledge acquisition were three strategies used by thalassemia patients to cope with uncertainty.

In adaptation to uncertainty and to reduce its negative effects on their lives, the patients seek spirituality. Belief in God as the superior power and trust in divine will or providence helped the patients

to cope with uncertainty more easily and to accept it as destined fate and divine expediency. Studies have shown that those who benefit from spiritual coping are more adapted to the complications and stresses of illness (36, 37). The role of spirituality in hope and coping with illness and overcoming anxiety and worry has been shown in various studies^{10,19,37}.

Psychosocial coping through employing different coping strategies was another way of coping with uncertainty in these patients. Consistent with the results of the present study, the use of different coping strategies in coping with disease and reducing uncertainty in patients have been shown in several previous studies^{10,13,15}. Moreover, in line with the results of our study, other studies have emphasized the role of social support from family, friends, and peers as one of the factors that can directly and indirectly influence coping with the disease and uncertainty as well as the disease control^{12,13,38}. Since utilizing disease coping strategies improves coping with stress and complications of the disease³⁵, healthcare providers should consider training these strategies in dealing with uncertainty in patients.

Inadequate information and poor readiness to manage the illness and its complications can prevent the patient from predicting changes and lead to uncertainty of the patient about the occurrence of mental and physical problems in the future; therefore, access to information as an effective factor is important in coping with uncertainty^{13,15,16}. Similar to the results of the present study, the results of other studies have shown that lack of information about the disease, its complications and its treatment methods is stressful for the patients and not informing them consistently leads to anxiety and frustration in them as well as uncertainty about the future of their disease and treatment. Therefore, patients seek information to overcome uncertainty and control their condition^{6,30}. One important aspect of Mishel's theory of uncertainty is the need for information. According to this theory, nurses play an important role in providing information to patients for confrontation with and management of uncertainty. Accordingly, nurses' proper assessment of the perception of patients, evaluation of patients' need for health information and providing clear and

meaningful information are effective in reducing patients' anxiety and preparing them to deal with uncertainty¹².

Clinical application

These results enable healthcare providers, including nurses as important members of the health team, to understand patients' response to uncertainty and how to adapt to it and, through utilizing appropriate training and communicational practices, plan interventions and strategies to empower patients for coping with uncertainty.

Study limitations

Selection of the participants from one center has been one of the limitations of this study which limits the applicability of the results. Accordingly, conducting similar studies can help clarify the concept of uncertainty and its dimensions in thalassemia patients.

CONCLUSION

According to the results of this study, uncertainty is a major psychological stress in patients with thalassemia major. Uncertainty about the future of the disease and the treatment, and the concern about the high costs of treatment, on the one hand, and the concern about playing a social role and the future of the family, on the other, presented these patients with uncertainty and many challenges. The patients' experiences also indicated the need for psychological, spiritual, and social support, as well as the need for information to cope with uncertainty. Therefore, it is recommended that future researchers conduct studies to investigate how information provision and teaching coping strategies can reduce uncertainty. Finally, studies are suggested to develop appropriate tools for measuring this concept in thalassemia patients.

CONFLICT OF INTERESTS

The authors declare no conflict of interest.

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