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“Hope is the Indispensable Life Force”: A Qualitative Study of the Meaning of Hope in the Life Experiences of Lymphoma Patients

“Umut Vazgeçilmez Yaşam Gücüdür”: Lenfoma Hastalarının Yaşam Deneyimlerinde Umudun Anlamı Üzerine Nitel Bir Çalışma

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ABSTRACT
Aim
Although hope is considered to be of vital importance for cancer patients, it remains uncertain in lymphoma patients. This study aimed to examine the life experiences of patients with lymphoma and reveal the meaning of hope.

Method
A hermeneutic-phenomenological design was used in this study. 19 lymphoma patients who were receiving chemotherapy participated in interviews. Participants were selected through the purposive sampling method, and the interviews were audio-recorded. A phenomenological-hermeneutic approach was used to analyze the data.

Results
Three themes and 12 sub-themes emerged that summarized the life experiences of patients and the meaning of hope. These themes were as follows: ‘Being in existence’, ‘Hope is the indispensable life force’, and ‘There is always hope, but it varies’. Within the scope of the sub-themes, this study showed that there were changes in the physical and emotional well-being of participants and the importance of discovering the moment. This study, which reveals the meaning of hope as a “desire to return to routine, a bridge from now to the future”, emphasized that both the patients affect hope and the factors related to the disease.

Conclusion
This study revealed the changes in the physical and emotional well-being of lymphoma patients, the meaning of hope in their life experiences, and the factors affecting hope. It is thought that the findings obtained will contribute to the provision of psychosocial support and care planning by healthcare professionals to strengthen hope in lymphoma patients and may guide future studies.

Keywords
Chemotherapy, hope, life experience, lymphoma, qualitative research

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ÖZET

Amaç

Kanser hastaları için umudun hayati bir öneme sahip olduğu düşünülse de, lenfoma hastalarında umut belirsizliğini korumaktadır. Bu çalışma, lenfoma hastalarının yaşam deneyimlerini incelemeyi ve umudun anlamını ortaya koymayı amaçlamaktadır.

Yöntem

Bu çalışmada hermeneutik-fenomenolojik bir tasarım kullanılmıştır. Kemoterapi alan 19 lenfoma hastası görüşmelere katılmıştır. Katılımcılar amaçlı örnekleme yöntemi ile seçilmiş ve kayıt altına alınmıştır. Verileri analiz etmek için fenomenolojik-hermeneutik yaklaşım kullanılmıştır.

Bulgular

Hastaların yaşam deneyimlerini ve umudun anlamını özetleyen üç tema ve 12 alt tema ortaya çıkmıştır. Bu temalar: 'Var olmak', 'Umut vazgeçilmez yaşam gücüdür' ve 'Umut her zaman vardır fakat değişkenlik gösterir'. Alt temalar kapsamında bu çalışma, katılımcıların fiziksel ve duygusal iyilik hallerinde değişimler olduğunu ve anı keşfetmenin önemini göstermiştir. Umudun anlamını 'tekrar rutine dönme isteği, bugünden geleceğe bir köprü' olarak ortaya koyan bu çalışma, umudun hastalardan ve hastalıkla ilgili faktörlerden etkilendiğini vurgulamıştır.

Sonuç

Bu çalışma lenfoma hastalarının fiziksel ve duygusal iyilik hallerindeki değişimleri, yaşam deneyimlerinde umudun anlamını ve umudu etkileyen faktörleri ortaya çıkarmıştır. Elde edilen bulguların, sağlık çalışanları tarafından lenfoma hastalarında umudun güçlendirilmesine yönelik psikososyal destek sağlama ve bakımı planlamaya katkı sağlayacağı, gelecekteki çalışmalara rehberlik edebileceği düşünülmektedir.

Anahtar Kelimeler

Kemoterapi, umut, yaşam deneyimi, lenfoma, nitel araştırma

What is known about the field

- It is known that hope is an important coping mechanism.
- The meaning of hope in life experiences is important to manage of nursing care.
- Although hope is of vital importance for cancer patients, it remains uncertain in lymphoma patients.

Contribution of the article to the field

- Three main themes regarding experiences and hope were identified.
- The meaning of hope was a desire to return to routine and a bridge from now to the future.
- Hope is the first related to the moment, and the second is about the future.
- Hope was affected by disease-related factors and external sources.

INTRODUCTION

Hematological malignancies occur in immune system cells or tissues that generate blood, including the bone marrow. The three most prevalent hematological cancers are lymphoma, leukemia, and myeloma (1). Lymphoma begins in the lymphatic system, the area of the immune system that fights infection, and has two types: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL) (2). According to recent reports on cancer statistics, NHL is more common than HL (2). The estimated number of new cases of HL and NHL globally in 2020 was 83,000 and 544,000, and the estimated number of deaths was 23,400 and 260,000 respectively (3). The incidence of HL increases during adolescence and young adulthood, between the ages of 15-40, and that of NHL after 55 years of age.

In the treatment of lymphoma, chemotherapy, radiation therapy, immunotherapy, biological therapy, cell therapy, bone marrow or stem cell transplantation may be used, and chemotherapy is often shown as the main treatment option (4, 5). Individuals and their families face heavy symptom burdens during long treatment processes (6, 7). Common symptoms during diagnosis include swollen lymph nodes, night sweats, and fever. However, additional disease-specific symptoms such as itching and skin bleeding may also occur (2). Additionally, patients experience many symptoms that contribute to poor quality of life such as fatigue, mouth sores and dry mouth, nausea, vomiting and loss of appetite because of chemotherapy (8-11). Individuals also report many psychosocial problems due to physical effects (10, 12).

Quantitative and qualitative studies have also clearly demonstrated negative effects on psychosocial well-being as well as on patients' physical functions (13-17). Although lymphoma patients benefit from drug treatment, the fact that they encounter various side effects related to chemotherapy and radiotherapy (7, 13), believe that their daily lives have become immobilized and experience psychological distress with uncertain future anxiety negatively affect the quality of life of the individuals. (10, 14). Hope was found to be associated with symptom burden, anxiety, depression and quality of life, depending on the physical and psychosocial factors experienced by patients during treatment (18, 19). With the physical and psychosocial difficulties experienced during the diagnosis and treatment process of cancer, hope is seen as an important coping mechanism (19). The positive effects of hope such as less anxiety, pain, and depression, and a better quality of life been shown in various studies (19). Hope, a concept belonging to the field of positive psychology, emerges as an intangible, complex, multifaceted and dynamic phenomenon (20-22) and can be affected by many internal and external sources (19). In a study of cancer in patients, the concept of therapeutic hope was revealed and it was emphasized that hope is important in life-affirming, valuing life and connections with others, rather than rejecting death (21). In another qualitative study conducted on patients in the palliative period in cancer patients, it was explained that the use of hope showed the patient how to focus on the positive, connect with others, and continue to engage in life even while dying (20). Kylma et al. (2009), in a review of the research on hope in palliative care, revealed two themes: 'living with hope', that is, existential hope and 'hoping for something' as a future-oriented and goal-oriented phenomenon (23).

The advancement of technology and advances in diagnosis and treatment methods for lymphoma increase the recovery probability and life expectancy of individuals (24). As life expectancies increase, research on all aspects of survival and long-term quality of life has become a priority (16). Although hope is of vital importance for cancer patients (21, 22), it remains uncertain in lymphoma patients. No qualitative study has been found in the literature on the meaning of hope in the life experience of lymphoma patients, and it is thought that obtaining in-depth information about the disease experiences, thoughts, and feelings of lymphoma patients and revealing the meaning of hope in patients will be effective in providing care for the development of hope.

METHODS

Aim

This research aimed to examine the life experiences of patients with lymphoma and reveal the meaning of hope.

Design

A hermeneutic-phenomenological design was adopted in this study. The hermeneutic-phenomenological method focuses on identifying and interpreting the basic structures of patients' lived experiences (25). This hermeneutic-phenomenological method is widely used by researchers to understand lived experiences and suggests that individuals are as unique as their life stories (26). This method therefore provides an ideal platform for understanding lived experiences (26) and is only used to affect the meaning of the lived experience, that is, as understood by the interpreter (25). In line with the aims of this study, hermeneutic-phenomenological approach was chosen to examine the life experiences of individuals with lymphoma and reveal the meaning they attribute to hope in the diagnosis and treatment process. The Qualitative Research Reporting Consolidated Criteria (COREQ) was used as a guide in reporting this research (27).

Participants

This study was conducted with patients diagnosed with lymphoma in a hospital in Antalya, Turkey. The inclusion criteria were: a) having a diagnosis of lymphoma and receiving chemotherapy treatment; b) knowing the medical diagnosis; c) being over the age of 18; d) not having an auditory or cognitive disability. The exclusion criteria were lack of orientation, having undergone bone marrow transplantation, and patients' wish to leave the study. There was no specific rule in calculating the sample size in qualitative studies and it was recommended to continue collecting data until the saturation point was reached (28). Accordingly, the process was carried out by considering the focus of the research, the amount of data, and the saturation point.

Data collection

Ethics committee approval and institutional permission were obtained before the collection of the data. The patients were first evaluated in terms of inclusion criteria; the purpose and method of the study were explained before the interview, and written informed consent was obtained. The sample was determined by the purposive sampling method. The data were collected by a researcher (EÇ) through in-depth individual interviews between March and November 2022. A Personal Information Form and a Semi-Structured Interview Form were used in the data collection phase of the research. The Personal Information Form consisted of 10 questions about socio-demographic characteristics and the disease. The Semi-Structured Interview form consisted of six questions examining in more detail the feelings and thoughts of individuals diagnosed with lymphoma (Table 1). The interviewer was trained in qualitative research methods and had clinical experience in the care of lymphoma patients. The interviews were recorded with a voice recorder after obtaining the consent of the patients. An individual interview was held with each participant, and the interviews lasted between 30 and 45 minutes on average. Before the interview started, it was stated that the patients would be asked questions about their illness and hope, the interview would be recorded, the recording would be used only within the scope of the research and would not be shared with anyone else. At the beginning of the interviews, a Personal Information Form was filled out to create a warm environment with the patients. During the interviews, some individuals became emotional, cried, and wanted to take a break while sharing the process. In this situation, a short break was taken, and the interview was continued after the individual's readiness. The interviews were continued until the researchers were sure that no data could be added to the data codes related to the research questions, and the research was terminated after data saturation was achieved.

Table 1. Interview guide

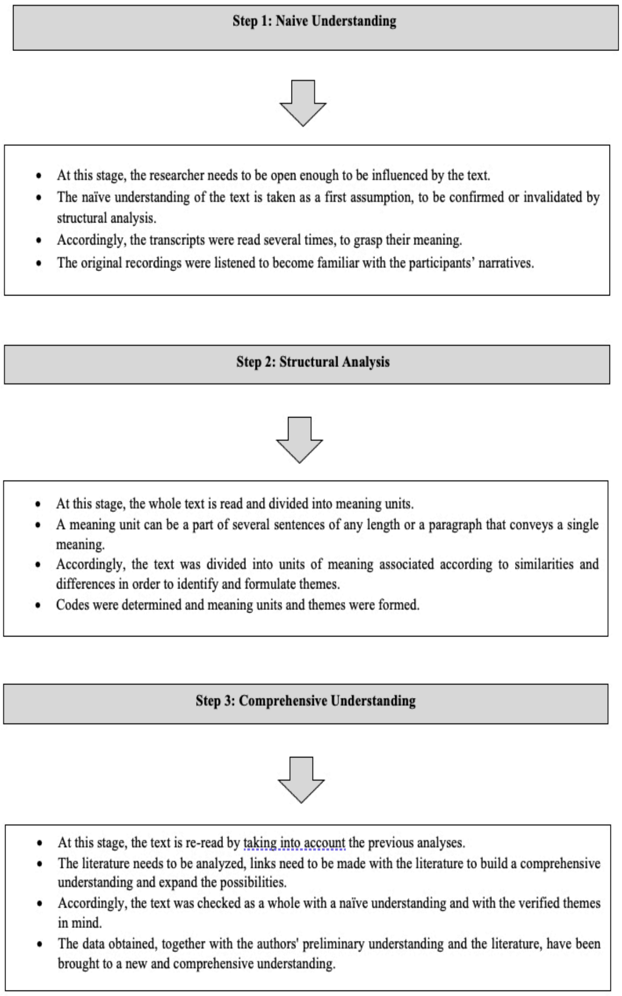
1. What are your thoughts about your disease?
   - How did you feel when you first learned about your illness?
   - What stage of your disease are you in, what did you think when you learned the stage?
   - What does being diagnosed with lymphoma mean to you?
   - If you were to liken illness to something, what would you liken it to?
2. How would you evaluate the disease process you are experiencing?
   - What are the effects of this process on you?
   - How does your illness affect your daily life?
   - What are the physical (your body) effects of this process?
   - What are the psychological effects of this process?
   - What are the social (family roles, business life) effects of this process?
   - What are the effects of this process on your family members?
3. How has the experience of illness changed your outlook on life?
   - What are you doing to cope with your illness?
4. How would you define hope? Can you talk about being hopeful?
   - What do you think hope means?
   - What is your perspective on hope in the process you are in?
   - If you were to liken hope to something, what would you liken it to?
5. Can you tell us about the factors that affect your hope?
   - What are the situations that increase your hope during the treatment process?
   - What are the conditions that reduce your hope during the treatment period?
6. If you wanted to give a message to other patients in your situation, what would you say?
   - CLOSING: Is there anything else you would like to add before we end?

Ethical considerations

The research process was carried out by the international standards and principles accepted by the World Medical Association's Declaration of Helsinki. Ethical approval was obtained from the Clinical Research Ethics Committee before collecting the research data (22.12.2021,956). In addition, institutional permission was obtained from the hospital where the participants were receiving treatment. Informed verbal and written consent were obtained from the participants, and the names of the participants were coded in the study.

Data analysis

Numerical and percentage calculations were used to interpret the distribution of the demographic characteristics of the patients. The transcribed interviews were analyzed using a phenomenological-hermeneutic method, involving three phases; naïve understanding, structural analysis, and comprehensive understanding (25). In the first phase: The data obtained from the interviews with the participants were analyzed by making a written transcript after the interview was completed. In the naïve understanding, the transcripts were read several times, to grasp their meaning. The original recordings were also listened to become familiar with the participants' narratives. In the second phase for the structural analysis, the text was divided into units of meaning associated according to similarities and differences to identify and formulate themes. Independent coding ensures validity and reliability and provides a comprehensive and objective presentation of the analysis process (29). Therefore, two researchers (STK, ZÖ) independently assigned codes and created units of meaning and themes. NVIVO software was used to enable data management (30). The last third phase for the comprehensive understanding, it is recommended to consult colleagues, examine the proposed literature, and build a comprehensive understanding by making connections with the literature, and thus expanding the possibilities (25). At this phase, comprehensive understanding was intended to generate a scientific discussion. The data obtained from the naïve understanding and structural analysis stages were brought into a new comprehensive understanding together with the authors' pre-understanding and literature (Figure 1).



Step 1: Naive Understanding

- At this stage, the researcher needs to be open enough to be influenced by the text.
- The naïve understanding of the text is taken as a first assumption, to be confirmed or invalidated by structural analysis.
- Accordingly, the transcripts were read several times, to grasp their meaning.
- The original recordings were listened to become familiar with the participants' narratives.

Step 2: Structural Analysis

- At this stage, the whole text is read and divided into meaning units.
- A meaning unit can be a part of several sentences of any length or a paragraph that conveys a single meaning.
- Accordingly, the text was divided into units of meaning associated according to similarities and differences in order to identify and formulate themes.
- Codes were determined and meaning units and themes were formed.

Step 3: Comprehensive Understanding

- At this stage, the text is re-read by taking into account the previous analyses.
- The literature needs to be analyzed, links need to be made with the literature to build a comprehensive understanding and expand the possibilities.
- Accordingly, the text was checked as a whole with a naïve understanding and with the verified themes in mind.
- The data obtained, together with the authors' preliminary understanding and the literature, have been brought to a new and comprehensive understanding.

Figure 1. Qualitative data analysis steps

The text was read again as a whole with the naïve understanding and the validated themes in mind. Themes and sub-themes were compared, and differences were discussed until a consensus was reached. In the hermeneutic approach, distanciation is defined as the process of creating the distance necessary for the interpreter to analyze the text objectively (31). Distanciation in the interpretation contributes to objectifying the text rather than subjectifying it.(32). As a result of distanciation by writing and the objectification of the structure of the work, the text achieves a new and different understanding of being-in-the-world (32). To ensure distanciation, we used verbatim transcriptions of the interviews in the naïve naïve understanding and narratives linked to each interview or text in the structural analysis.

Validity and reliability/Rigor

Credibility, transferability, dependability, and confirmability criteria should be sought to test reliability and validity in qualitative research (33). To ensure credibility, an expert on qualitative research methods examined the interview questions before the study. In addition, a mutual trust relationship was established between the researchers and the participants by having them sign the informed consent. To ensure consistency, all the results of the interview were given directly without comment and coded separately by researchers experienced in qualitative research. To evaluate the compatibility between coders, a comparison was made by the coders, and a consensus was reached by discussing the inconsistencies in the codes. Records of interviews, documents and participant observations were kept ensuring confirmability. To ensure that the results could be transferred to situations with similar participants and environments within the scope of transferability, sampling criteria were first determined, and a purposeful sampling method was preferred to obtain the opinions and experiences of the participants.

RESULTS

Characteristics of participants

Ten women and nine men completed the interviews. Eleven participants were married. The mean age of the participants was 52.26+15.85 years and ranged from 24 to 73 (Table 2). Three main themes were obtained from the interview: (I) Being in existence, (II) Hope is the indispensable life force and (III) There is always hope; but it varies, and 12 sub-themes related to these themes were determined (Figure 2).

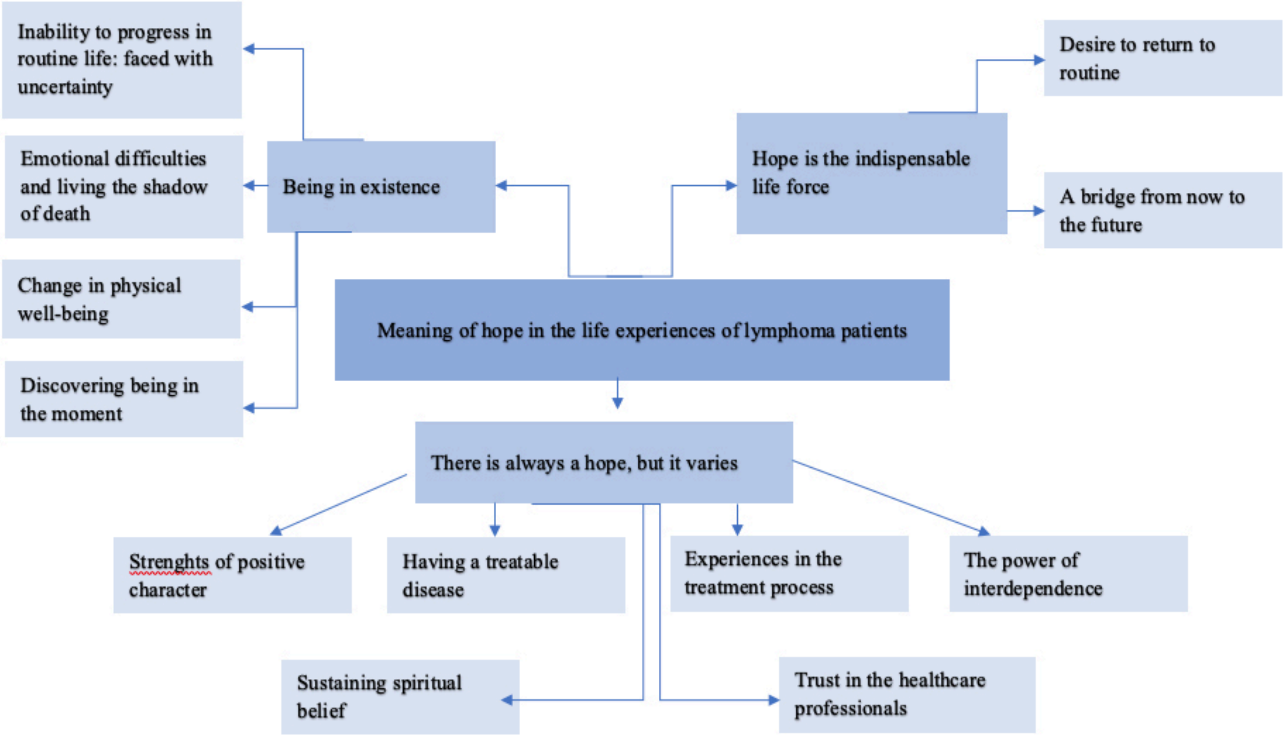


Figure 2. A framework of main themes and subthemes

Table 2. Sociodemographic and disease-related characteristics of the participants

Characteristics	N (%)
Gender	
Female	10 (53%)
Male	9 (47%)
Age (mean±SD, min and max)	52.26 ± 15.85 (min:24, max: 73)
Education level	
Primary education	12 (63%)
High school	4 (21%)
Associate/Bachelor graduate	3 (16%)
Marital status	
Married	11 (58%)
Single	8 (42%)
Working Status	
Working	4 (21%)
Not working	15 (79%)
Living with	
Family	14 (74%)
Children	4 (21%)
Friend	1 (5%)
Presence of chronic disease	
Yes	9 (47%)
No	10 (53%)
Family history of cancer	
Yes	10 (53%)
No	9 (47%)
Disease type	
Hodgkin lymphoma	6 (32%)
Non-Hodgkin lymphoma	13 (68%)
Duration of diagnosis (month) (mean±SD, min and max)	18.85 ±20.28 (min:1, max: 84)

Theme 1. Being in existence

This theme described the patients' experiences of being in existence from the beginning of the disease process, about "facing uncertainty, experiencing changes in physical well-being, emotional difficulties and living in the shadow of death, and discovering being in the moment".

Inability to progress in routine life: faced with uncertainty

Patients indicated four different uncertainties and an inability to progress in routine life. The first of these was the prolongation of the process due to the different examinations performed in the hospital and therefore the uncertainty related to the diagnosis process. "I've had an endoscopy, a colonoscopy, a laparoscopy… I was saying every day, sir, I am in this uncertainty, what will happen to my disease?" (P2). The second was emphasis on the uncertainties about the disease process and stage after diagnosis. "I've never heard of this lymphoma; I don't know more exactly." (P8). Another uncertainty experienced by the patients were related to the treatment process and the effects of chemotherapy. "Since we do not know how the treatment is administered, in how many days a result can be obtained, or in how many days it can show an effect, drugs are constantly coming in" (P10). "So how does the treatment go? Is it difficult? How much does it tire me? ....I was thinking all the time." (P5). Most of the patients emphasized that they experienced more uncertainty in the early stages of the treatment because they did not know the procedures, but this decreased with the progress of the treatment. Finally, patients stated that they experienced uncertainty about progress in routine life, maintaining life goals, and the continuity of their future lives. "I say, never mind, you have today; maybe I won't have tomorrow" (P2). "Illness inevitably disconnects people from life; I just broke away from life" (P17).

Change in physical well-being

Patients stated that they often experience pain, fatigue, loss of appetite, and sleep problems after chemotherapy "Those two courses of treatment killed me. I suffered a lot. It hurt to the marrow of my bones." (P12). "The things that try my patience are pains, dizziness, and things like numbness, lack of appetite" (P10). In this, it was seen that many patients equated their symptoms with the illness. "When I think of lymphoma, I think of tiredness, tiredness, or something that sweats a lot." (P1). The patients stated that the symptoms, especially those because of chemotherapy, affected their daily lives. "I can't walk for two days, but as the effect of chemotherapy gradually decreases, the body starts to recover slowly" (P14). Participants reported that they could not get out of bed for a long time due to the physical changes they experienced; therefore, they had difficulty performing their daily living activities, and some patients reported that they could no longer work "After that I lost all my social life. I mean, I was like the living dead. A very bad tiredness." (P17).

Emotional difficulties and living in the shadow of death

Most participants reported that they experienced anxiety and fear during the diagnosis and treatment processes. "At first I was really afraid, I was nervous. It's cancer after all – the big C. It frightens people" (P8). They emphasized that the reasons for anxiety and fear were the perception of cancer, the sudden emergence of disease and symptoms, physical changes, uncertainty, staying in the hospital for a long time and coming more often. "Now I am still afraid to come here (to the hospital); I did not want to take the medicine" (P12). They stated that the effects of daily activities, getting away from routines, isolation practices for protection from infection, and the thought of being dependent on others increased their anxiety. "It constricts you; you are in one room; an unfamiliar situation, an unexpected situation" (P10). The anxiety increased not only for themselves but also for their relatives. "Of course, when I first learned about it, my family came to my mind, ...hearing this broke me down" (P8). "When I was miserable, that made my family miserable too." (P12). In addition, most patients stated that they felt near death and had a fear of dying. "Now, with the disease, are we a little closer to death? Are we going to evil?" (P7). "I began to wait for the time of death" (P11). In addition, some patients stated that they thought about death due to the problems they experienced. "In all this, I wanted to die. No, I preferred to die than to suffer this pain." (P12). Some of those emphasized that they did not like people around them talking about approaching death. "Like they talked to me as if I was dying." (P1). Some patients stated that the disease prevented them from realizing their life goals, they became angry quickly, and this negatively affected their families. "I started shouting at people like I've never done before." (P14).

Discovering being in the moment

Most of the patients stated that they prioritized health in their lives after diagnosis. "This was a turning point for me… I understood that nothing else was important, only being healthy, and living the life in front of you" (P4). "I will sit and think about my health. I decided that about life is first, health is first" (P6). The patients emphasized that the point of life view about life is important for staying healthy and they had discovered staying in the moment, not living in the past or future. "Previously, I used to live much more future-oriented, but now I've started to focus on living in the moment a little more" (P3). "We will not worry about anything; I believe we will have a very different life" (P8). It is seen that discovering how to stay in the moment is also related to feeling like one is living in the shadow of death. "I say forget it; you've got today, maybe you won't have tomorrow. Eat, drink and be merry I say; I don't care." (P2). Patients who decided to live in the moment stated that they enjoyed life more and did not get hung up on details. "I don't know, I've started to look at everything more positively. I've started to appreciate the scent of flowers." (P19).

Theme 2. Hope is the indispensable life force

This theme revealed that hope is an indispensable life force in patients waiting for a return to routine and building a bridge from the present moment to the future and that it is difficult to have a hopeless life.

Desire to return to routine

Many patients diagnosed with lymphoma hoped that the illness would go better, the treatment would be effective, and they would recover. "Hope means recovery, the treatment always being positive" (P1). Also, it was emphasized that the meaning of hope was the wish to be freed from the difficulties brought on by the treatment. "I think this treatment will make me better; it'll be good, and I'll leave the hospital" (P17). The patients expressed the hope not only of recovery, of being freed from their difficulties, but also of returning to the old days, and of everything going back to routine. "The old days, God willing, those days will come back… anyway, that's what we dream of" (P14). One patient expressed his hope metaphorically: "It's like you're making a faded flower sprout up again. You give it water and you want it to recover like that" (P17).

A bridge from now to the future

The patients defined hope as connecting with life and being able to continue, as defining their aims for the future. "I want to see more days in the future, I want to live better… I've got hope" (P6). Hope was expressed as the belief that good things would happen in the future, life which they wanted to see in the future. "I believe I'll get better. I have a lot of hope. I never think pessimistically. I never let myself go; I mean I always think good things" (P2). Hope was emphasized by many of the patients to be the existence of a good future. "I think hope expresses a good future. A beautiful future" (P5).

Theme 3. There is always hope, but it varies

The patients' levels of hope were affected by the process of diagnosis and treatment. They said that in this process, hope was dynamic, and varied over time. "Each moment isn't the same… One moment we're overtaken by hopelessness, but sometimes there's an improvement, and our belief that things will get better increases, and we can be more hopeful" (P3). Under this theme, it was stated that hope was affected by the factors of positive strength of character, the possibility of treating the illness, experiences in the treatment process, mutual interdependence, spiritual beliefs, and trust in healthcare professionals.

Strength of positive character

Many of the patients spoke about the importance of belief and trust in oneself in the maintenance of hope. "I mean, I don't know, there's something in me for living. You do this, you're successful at that, and it's like I'm always on my feet, without being knocked down" (P8). Also, they said that focusing on the positive and thinking positively were important for maintaining hope."I've always been positive without ever being pessimistic… I've always laughed, I've been happy with my children, I mean I can say I've never cried" (P19). It was seen that positive coping experiences in the past were also effective in maintaining patients' hope. "I talked to myself each morning in the mirror, I say, 'You'll succeed in this. Look what you've got over" (P19).

Having a treatable disease

The patients stated that they were able to be more hopeful because lymphoma was treatable and could be treated more easily than other cancers. "I've got one of the easiest of cancers. In that way I'm hopeful" (P11). They emphasized that developments in technology and the treatment of patients were important in maintaining hope. "Technology is advancing, and there's nothing that can't be treated" (P10). It was also mentioned that hope varied according to the effects of treatment. "I can say that each time I start a different treatment, my hope is revived. I mean, at first, when I start the treatment, I'm hopeful. Of course, when later I see that it's not doing any good, that changes a bit" (P3). "All sorts of things make me a more hopeful person. At least you know that there are treatments" (P10).

Experiences in the treatment process

The patients stated that problems associated with the treatment process affected their hopes. "I mean, I've never been overcome by hopelessness in the treatment process, but when I'm having treatment, my values are low and the treatment is long, and that makes me lose hope a bit…" (P5). It was seen that the patient's observations and experiences with other patients affected their hope. "I've seen people much worse off than me" (P14). "A 16-year-old girl came… she was crying… she was pulling out her hair with her hands. What a morale-destroying thing! Another was vomiting. I go home with low morale. And because of that, I started not coming" (P16). In addition to this, they said that sharing their experiences in their social environment – "Sometimes a neighbor says whatever you do there's nothing that can be done; hearing that kind of talk upsets me… they put me into a difficult position, and upset me" (P1), or the presence of people who have overcome the disease increased their hopes. "When I heard of people in my circle of friends who've completed the treatment, my hope increased" (P5).

The power of interdependence

The patients' relationships with their families greatly affected their hope. "My hope is my family, I'll stand up to it because of them, God willing I'll get over it in a short time, I mean I succeeded for them" (P8). They emphasized the importance of the support of their social circle, relatives, and friends in the maintenance of hope. "I mean, first the treatment, then I couldn't be with my friends; these things affect you whether you want it or not. Staying away from social activities affect your hope, I mean as moral motivation. It makes you lose hope" (P5). They said that talking with trusted people in their family and social circle was important, but that talking did not always have a positive effect, and sometimes they did not want to talk about their condition. "My family, the people around me, even if they aren't putting pressure on me, they keep on calling to say how are you, how's it going, so that I don't want to answer the phone… They look at me as someone who's dying; talking to them or telling them about my condition lowers my motivation" (P8). Apart from the family, a patient's relationships with other living things affects their hope. "I'm still hopeful because there are reasons for me to be hopeful, things that remain for me. I need to live a bit longer, so I can place my hope in them. At least I've got three dogs, for example. That gives me hope" (P11) "I've got plants that I grow; my balcony is full of them, and I talk to them" (P19).

Sustaining spiritual belief

The participants stated that their spiritual beliefs were effective in maintaining their hope during their illness and treatment. Just as there were patients who believed that illness came from God and that it was a test – "It's something coming from God; because we know that, I say thank God, I have never lost hope" (P18), there were patients who said they believed that the cure would also come from God. "All help comes from God. Who will help us but Him?" (P10). They emphasized the importance of patience and prayer in coping in the course of the illness. "Endurance. By praying to God. By praying, by being patient" (P6). "I wait with patience. I only wish for patience from God" (P10). It was seen that during the illness, they thought that it could have been worse, and so they were thankful and submissive to the will of God. "Something which comes from God, something which He gives or takes away, I'm thankful, and I've never given up hope" (P18). Being patient is seen to be important for patients in this process. "I wait patiently, and only ask God for patience" (P10).

Trust in the healthcare professionals

The patients stated that they felt more hopeful with professional information obtained from health professionals. "He explained it to me in a very straight way there. It gave me great hope like that" (P1). "What makes me a more hopeful person? At least we know that there are treatments. We have hospitals, and doctors and nurses who have given years to understanding this business." (P10). It was seen that there were patients who did not much want to use information other than from health personnel. "It hasn't made much difference to me, but I haven't done any research on lymphoma or anything; there's so much wrong information on the internet, and it confuses you, so I haven't done any research like that" (P14).

DISCUSSION

This study adds to the existing literature by describing the patients' experiences of lymphoma and hope, thereby providing further insight into the findings from qualitative research on this group. In data obtained from our study, three main themes were determined: I) Being in existence, II) Hope is the indispensable life force, and III) There is always hope, but it varies. The meaning of these themes will provide important information to the health profession in the management of treatment and nursing interventions. Within the scope of this main theme "Being in existence", patients' experiences of being in life include the inability to progress in routine life, being faced with uncertainty, change in physical well-being, emotional difficulties and living in the shadow of death and discovering being in the moment. It has been stated in many qualitative and quantitative studies that the process of diagnosis and treatment of cancer involves uncertainty (15, 34, 35). Our study from the others because we gathered the causes of uncertainty under four headings. Limiting uncertainty only to the diagnosis and treatment process or to the future may not be sufficient to provide holistic nursing care. Studies on NHL patients (14) and hematological malignancies (15) have revealed uncertainty about the future. Living with uncertainty often causes marked ongoing emotional distress (15). Chircop et al. (2018) stated the sub-theme in their study as "fear of the unknown" (14).

Planning the interventions for the cause of the uncertainty in patients is important in combating uncertainly (35). In this direction, it is thought that providing education, peer support, blogs and content for sharing information with technological infrastructure, hope for the future (35) and gradually sharing these contents with patients at every stage from the beginning of the diagnosis and treatment process may be effective in preventing uncertainty. Increasing clinicians' clarity and patient access to information can contribute to improved patient outcomes (34). In this study, patients stated that during the treatment process for lymphoma, both physical and psychosocial changes caused them to move away from their daily lives. Quantitative and qualitative studies conducted with patients with lymphoma have also clearly demonstrated this (13-17). Chircop et al. (2018), in a study investigating the experiences of patients with NHL during the initial stages of chemotherapy, revealed three main themes: 'living an emotional rollercoaster', 'becoming dependent on others' and 'facing an uncertain future'. In their study, it was stated that patients were upset at not being able to maintain their daily routines (14). In another study examining the experiences of patients with lymphoma, six themes emerged: (I) cancer diagnosis reactions, (II) self-image altered, (III) interpersonal relationships influenced, (IV) career development hindered, (V) life philosophy changed, and (VI) personal growth achieved (17).This study revealed that the emotional difficulties in lymphoma, most deeply affects the patients is living in the shadow of death. The reasons for this include the perception of cancer, intense symptoms, and distressing periods. Ruan et al. (2020), on the other hand, showed in their study that patients accepted approaching death. In our study, this sub-theme was that death makes itself felt, and individuals stated that they felt close to death. The patients' interpretation of hope as "a bridge from today to the future" suggests that this feeling can be overcome, and the future may continue with attempts to increase hope. Of course, more information is needed to interpret this situation, and new interventional studies are warranted on this subject. While this study provided that patients moved away from routine life for the reasons mentioned above, the sub-theme "discovering being in the moment" showed that they also tried to see the positive aspects of this situation. Ruan et al. (2020) also signed that within the scope of the theme "life philosophy changed", participants prioritized their health, understood the value of their time better, and attached importance to living a valuable and meaningful life (17). It seems that the number of studies on developing a new perspective after lymphoma is limited (17). Our findings of this study may lead to the planning of interventions in line with the needs of patients with lymphoma, home support services by health care providers during treatment, and the initiation of screening programs and measures to monitor physical and psychosocial distress. Strengthening this aspect of patients by health professionals may be beneficial in coping with the disease. More interventional studies on the subject are needed.

Within the scope of the theme "hope is the indispensable life force", the patients' experiences were revealed as a desire to return to routine and a bridge from now to the future. These two sub-themes are very important in revealing the meaning of hope for patients. Here, hope has two meanings for patients, the first is that it is related to the moment, and the second is that it is related to the future. Studies on the experience of illness have shown the theme and sub-themes of return to normal or a 'new normal' (35). Another new piece of information that this study has brought to the literature is that the way of defining hope is the desire to return to routine. Nazam et al. (2021) stated that the major common themes related to hope during illness in cancer patients were the expectation of survival and the will to live (36). Many studies have also confirmed that hope contains positive expectations about the future (37, 38). Another innovation revealed by this study is that hope is about being first in the present and then being in the future. As the present moment takes place, the future will unfold accordingly.

In our study, within the scope of this theme "There is always hope; but it varies", patients' sources of hope were examined under six headings: "Strength of positive character, having a treatable disease, experiences in the treatment process, the power of interdependence, sustaining spiritual belief and trusting the healthcare professionals". It is one of the important things revealed by this study that patients' hope is affected by both the patients themselves (character and spirituality), the factors related to the disease (curability and experiences) and external resources (interdependence and healthcare providers).

The significance of the results of this study is to emphasize the importance of clinicians establishing trusting and patient-centered relationships, strengthening the positive perspective of patients, and developing interdependence. This interdependence can be not only with humans but also with plants and animals. In the literature, it has been shown that hope comes from many sources or is affected by various factors (19, 39). A systematic review of quantitative studies on hope in cancer patients shows that there is a positive relationship between hope and quality of life, social support, spiritual well-being and existential well-being. In addition, hope appears to be negatively associated with symptom burden, psychological distress, and depression. The relationship between hope and anxiety, on the other hand, remains unclear (19).

In a thematic review (39), found seven themes to increase hope including positive personal relationships, positive character traits, quality of life, setting and achieving goals, spirituality/religion, and hope after death (39). In this review, it is shown that hope is always present, even when it changes with increasing pain or poor prognosis, and that hope can still be present even when treatment fails and palliative care is provided. In addition, positive interpersonal relationships, positive character traits such as determination and optimism, setting realistic goals, improving quality of life, and spirituality and religion have been shown to promote hope (39).

Social support from loved ones and health professionals helps individuals to adapt to the situation they are going through, accept and cope with the cancer and treatment process (Chiu et al., 2017; Ruiz-Rodríguez et al., 2022). It is also stated that social support contributes to the psychological well-being and quality of life of individuals while coping with the stressful aspects of the diagnosis and treatment process (Usta, 2012). Support from loved ones may assist patients feel valued (40), while the provision of information from healthcare professionals can help increase hope by giving patients a sense of security, support, and control (41). Although it has been revealed that the support of healthcare providers, families and friends eases disease experiences in NHL, there is still a need for further studies on how this situation affects hope in patients with lymphoma. Also, maintaining a strong sense of spirituality can help in adapting to illness (34), coping, and finding meaning and peace even with treatment-related side effects (42). Disease acceptance is their destiny (14) and having a stronger faith (17) were among the themes emerging in these studies (14,17, 29). However, no qualitative study was found on the importance of spirituality in maintaining hope in lymphoma patients.

In a thematic review conducted to investigate the meaning of hope for patients receiving palliative care and to examine the themes that foster hope, it was stated that when faced with a crisis, people often turn to spirituality or religion while seeking meaning, hope, and love (39). In this review, it has been shown that believing in God and praying about spirituality were effective in maintaining hope in individuals despite their illness (Broadhurst & Harrington, 2016). Patients can be helped by using the positive power of experience through support meetings and groups. It is recommended that associations create content for experience sharing and peer-led self-management programs, and people who have just finished their treatment to help adjust to life should be beneficial to other patients.

Limitations

This study has several limitations. The first is the hermeneutic paradigm used to examine the experiences of lymphoma patients, which prevented the results from being generalizable. Other limitations may be that it was a single-center study and the participants did not review their transcripts for external validity.

Implications for Nursing Practice

This study offers a new perspective on focusing hope through the disease experience, may help to improve the understanding of hope-oriented care in healthcare professionals and develop interventions to improve hope in lymphoma patients. In line with the findings, it is recommended that clinicians focus on the factors affecting hope and sharing information on reducing uncertainty, establishing trust-based and patient-centered relationships, strengthening patients' positive perspectives, and improving mutual commitment.

CONCLUSION

This study contributes to the existing literature by describing the lymphoma and hope experiences of patients and will provide insights into the management of lymphoma treatment and nursing interventions. Healthcare professionals may utilize this data to provide care that meets the needs of lymphoma patients, to serve supportive services, and to guide new research. To monitor the distress of these patients, it is recommended that screening programs should be initiated, and programs may be developed to provide domestic, and peer support. In addition, this study may guide future studies to increase hope and improve life experiences in patients with lymphoma.

Author contributions

Idea/Concept: EÇ, STK, ZÖ; : Design: EÇ, STK, ZÖ; Supervision/Consultancy: STK, ZÖ; Data collection and/or processing: EÇ, STK, ZÖ; Analysis/interpretation: EÇ, STK, ZÖ; Literature review: EÇ, STK; Writing the article: EÇ, STK, ZÖ; Critical Review: STK, ZÖ

Conflict of interest

The authors declare they have no conflict of interest.

Informed consent

Informed consent was obtained from all the participants included in the study, and the names of the participants were coded in the study.

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