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ORIGINAL ARTICLE / ARAŞTIRMA YAZISI

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"Ours Is A Hopeless Disease": A Qualitative Study On The Supportive Care Needs Of Women Under Treatment For Gynecological Cancer

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Abstract

Background/Purpose: Identifying and managing unmet supportive care needs while caring for a patient with gynecological cancer is an important component of healthcare. The purpose of this study is to determine the supportive care needs of women receiving gynecological cancer treatment.

Methods: This study, using a qualitative research design, was conducted with 15 women diagnosed with gynecological cancer. Face-to-face interviews were conducted with the participants determined by the purposive sampling method until reached the saturation point. The interviews were held between January and May 2022.

Results: The mean age of the participants was 53.5±11.14, five of them were primary school graduates, nine of them had a medium income and 10 were married. Seven of the participants had endometrial cancer and the mean diagnosis period was 10.4±2.5 months. As a result of the analysis of the data, five themes were determined. These themes; the continuity of the need for care, lack of social support, lack of sense of control, the desire to cope with uncertainty, and the lack of communication in the health institution.

Conclusion: It was determined that women who were treated for gynecological cancer had care needs that were not met and needed to be supported due to individual, economic, social and medical reasons. Supportive care needs of women receiving gynecological cancer treatment should be evaluated within the framework of a multidisciplinary team approach, and counseling and rehabilitation programs including symptom management and psychosocial support should be organized in order to improve coping methods with their diseases.

Keywords: gynecological cancer, qualitative study, supportive care, need, woman

Özet

Giriş/Amaç: Jinekolojik kanserli hastaya bakım verilirken karşılanmamış destekleyici bakım ihtiyaçlarının belirlenmesi ve yönetilmesi sağlık hizmetlerinin önemli bir bileşenidir. Bu çalışmanın amacı jinekolojik kanser tedavisi gören kadınların destekleyici bakım gereksinimlerini belirlemektir.

Gereç ve Yöntem: Nitel araştırma desenin kullanıldığı bu çalışma, jinekolojik kanser tanısı alan 15 hasta ile yürütüldü. Amaçlı örnekleme yöntemiyle belirlenen katılımcılarla doyum noktasına ulaşıncaya kadar yüz yüze görüşmeler yapıldı. Görüşmeler Ocak-Mayıs 2022 tarihleri arasında gerçekleştirildi.

Bulgular: Katılımcıların yaş ortalaması 53,5±11,14, beşi ilkokul mezunu, dokuzu orta düzeyde geliri sahip olup ve 10'u evlidir. Katılımcıların yedisinin tanısı endometrium kanseri olup tanı süresi ortalaması 10,4±2,5 aydır. Verilerin analizi sonucunda beş tema belirlendi. Bu temalar; bakımın gereksiniminin sürekliliği, sosyal destek eksikliği, kontrol duygusu eksikliği, belirsizlikle baş etme isteği ve sağlık kurumunda iletişim eksikliği olarak belirlendi.

Sonuç: Jinekolojik kanser tedavisi gören kadınların bireysel, ekonomik, sosyal ve tıbbi nedenlerden dolayı karşılanmamış ve desteklenmesi gereken bakım gereksinimlerinin olduğu belirlendi. Jinekolojik kanser tedavisi gören kadınların destekleyici bakım gereksinimleri multidisipliner bir ekip anlayışı çerçevesinde değerlendirilmeli, hastalıklarıyla baş etme yöntemlerini geliştirmek için semptom yönetimi ve psikososyal destek konularını içeren danışmanlık ve rehabilitasyon programları düzenlenmelidir.

Anahtar Kelimeler: jinekolojik kanser, niteliksel çalışma, destekleyici bakım, gereksinim, kadın

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Introduction

Gynecological cancers are one of the diseases that should be given importance due to the serious consequences they cause. Gynecological cancers are among the top 10 most common cancer types in women, and these are endometrial, ovarian, and cervical cancers (1). According to Globocan 2020 data, when the most common cancer in women is examined; cervix cancer ranks 4th, endometrial cancer 6th, and cancer ranks 8th (2). Women undergoing gynecological cancer treatment go through a process that includes different treatment methods such as surgical treatment, chemotherapy and radiation therapy. During the treatment process, women's physcial functions, social life and quality of life are adversely affected. Among these effects, common physical complications, psychological distress, changing body image and changing personal relationships increase the psychological burden of cancer (3-5).

As gynecological cancer patients transition into survival, inappropriate management of disease process and cure sequelae increases the challenges they face. In order to eliminate these problems and meet the needs of the patients, women with cancer need supportive care (6). Addressing the effects of gynecological cancer multidimensionally requires a comprehensive supportive care service. Supportive care is a person-centered approach that provides basic services to people, living with or affected by cancer to meet their physical, sexual, psychological, spiritual, social and informational needs during cancer pre-diagnosis, treatment and survival process (7). As advances in the treatment of gynecological cancers contribute to increasing survivors, it becomes increasingly important to meet the care needs of women living with cancer to be supported (6).

Health professionals are in an important position to provide professional care to reduce the symptoms and complications for gynecological cancers on life quality. In order to meet the supportive care needs of patients, healthcare professionals should prevent complications, symptoms or side effects caused by cancer and the treatment process, as early as possible and throughout the treatment period. It is a primary component of providing care that health professionals identify the supportive care needs of women undergoing gynecological cancer treatment. This approach, which includes evaluating the patient and her family at all stages of cancer, provides a holistic perspective and contributes to the improvement of the patient's quality of life (2,8-10). This study is designed to assess the various aspects of the supportive care needs of women receiving gynecological cancer treatment and to provide basic information for the policy makers, health professionals and researchers toward the appropriate planning that in turn help to promote the health of women undergoing gynecological cancer treatment. Most of the researches about supportive care needs of women receiving gynecological cancer treatment have been conducted with a quantitative approach (5,7-9), and limited qualitative data are available on women's experience of supportive care needs (6,10). Unlike previous studies, the present study points to the different challenges and changing needs of women throughout the treatment process. Thus the impact of the treatment process on needs was the primary focus of the present study. In addition, the qualitative approach adopted in this study sought to understand the reasons, concerns and contradictions underlying the failure to meet women's specific needs. In line with this information, the present study was conducted to determine the supportive care needs of women receiving gynecological cancer treatment.

Materials And Methods

Design

In this study, a qualitative research method was applied. Adopting a qualitative design allows researchers to explore context and details regarding participants' needs (11). This study was carried out between January 2022 and May 2022 within a city center located in the Southeastern Anatolia Region of Turkey.

Sample

Female patients diagnosed with gynecological cancer registered in the chemotherapy unit of the training and research hospital in the city center were included in the study. The study sample consisted of 15 participants. The participants, who were determined by the purposeful samples method, were interviewed until they reached the saturation point (n=15). Inclusion criteria for the study; being diagnosed with gynecological cancer, being over 18 years old, currently undergoing cancer treatment, and volunteering to participate in the study. The exclusion criterion was determined as having any comprehension that communication problems.

Instruments and Data Collection

Data of the study were collected by using an sociodemographic characteristics form and semi-structured interview form designed by the auther in line with the literature (5,6,9,12). The sociodemographic characteristics form consists of six questions to determine age, income status, education level, marital status, and how many years they have taken. The structured interview form, which consists of three open-ended questions, is as follows: "What are your needs that you cannot meet to provide your care during the treatment? Which needs for your care were met by the health institutions you applied to? In which aspects would you like to receive support from the health institution during the treatment?". Data

collection forms were evaluated by experts (two nurse academics).

The interviews were conducted face-to-face in a room in the hospital where the study was conducted, in a room where confidentiality could be ensured. The duration of the interviews varied between 30 minutes and one hour. With the consent of the participants, the interviews were audio recorded. During the recording of the data, the participants were coded by giving numbers from one to fifteen.

Statistical Analysis

The sociodemographic charecterisitcs of participants were evaluated by number, mean, percentage, and standard deviation. Expressions of the participants were analyzed by content analysis method. The data recorded with the audio device were converted into written text as raw data after listening immediately after the interviews and transferred to the Nvivo 11 package program. In line with the purpose of the research, the statements were read many times and the data were coded. Views were combined according to their semantically similarity and code names were created to represent these views. After the generated codes were grouped according to the integrity of meaning, the sub-theme representing these codes and finally the themes of the study were obtained. The data obtained at the end of the analysis were transferred to the participants to confirm the results. Themes, sub-themes and analysis results. It was evaluated by three different academics who were not involved in this study, who are experts in qualitative research and women's health for counseling.

In the study, credibility, consistency and confirmability criteria were provided in order to ensure validity and reliability. In order to increase the credibility of the study, while the personal information form and in-depth interview questions were created, a conceptual framework was created by reviewing the relevant literature and expert opinion was sought. In the content analysis, the themes and the relationship between the sub-themes forming the themes and the relationship of each theme with the others were checked and integrity was ensured. In order to increase the consistency, all the findings are given directly without comment. In-depth data collection, expert review strategies, and participant consent were adopted to ensure reliability.

Results

When the sociodemographic characteristics of the participants shown in Table 1 are examined, the mean age of participants was 53.5±11.14. Five of the participants were primary school graduates, nine of them had middle level and 10 of them were married. Seven of the participants were diagnosed with endometrial cancer and the mean diagnosis time was 10.4±2.5 months. Nine of the participants were being treated with both chemotherapy and surgery.

As a result of the analysis of the interview data, five main themes were created that reflect the supportive care needs of the participants (Fig. 1). These themes were; continuity of care, lack of social support, desire for a sense of control, inability to cope with uncertainty, and lack of communication in the health institution.

Continuity of Care

All participants stated that they needed the support of someone else while meeting the need for care during the treatment process and that this should be continuous. Subject-oriented life two sub-themes were determined as change of lifestyle and financial hardship. All of the participants stated that there were changes in their lives after the diagnosis of cancer and during the treatment process, that they had difficulty in adapting to this process and that they needed the support of someone else during the adaptation process. 12 participants stated that their economic expenses related to cancer treatments were constantly increasing, they had difficulty in meeting this, and they needed to be supported financially by their family members.

Lack of Social Support

10 participants reported that they needed the support of family members or friends during the treatment process.

Desire for a Sense of Control

Six participants stated that they needed to develop a sense of control to adapt to changes in their body during the treatment process and to be respected in order to shape the treatment plan.

Inability to Cope with Uncertainty

Five participants stated that they experienced uncertainty about the future and needed support to improve their coping skills. Two sub-themes were determined for the subject: time of death and treatment process. Four participants expressed concern about the uncertainty of the time of death. Four participants stated that they needed support to cope with the uncertainty of the treatment process.

Lack of Communication in the Health Institution

Seven participants stated that they had communication problems in health institutions and that this problem should be solved. Two sub-themes were identified, the desire for information and the lack of trust. Six participants stated that they needed information about the diseases, symptoms and treatment process. Four participants

stated that there were problems about the treatment plans due to gaps in interdisciplinary communication, and therefore they did not trust health institutions. The same participants stated that they needed support from the health institution to resolve this problem.

How these supportive care needs were expressed by the participants is shown below with direct quotes from their responses (Table 2).

TABLE 2: The data structure for expressions of participants

Theme	Subtheme	Examples of illustrative quotes
Continuity of care	Change of lifestyle	"Our life has completely changed. I have to adjust everything according to my disease. Now I get tired quickly, especially after chemotherapy for a week, I cannot recover, someone has to be by my side all the time" (P3, 62 years old, endometrial cancer) "Yes, I got cancer and I accepted it. After that, it is not really easy. I have to think about everything from food to the my trip. This is not easy either. Someone needs to accompany me" (P5, 45 years old, cervical cancer)
	Financial hardship	"The money flows like water during the treatment and it bothers me very much that I had to constantly make calculations. Someone from my family has to transfer money to me" (P6, 48 years old, endometrial cancer) "It is a fact that I have financial hardship. I do not know where to transfer the money. Sometimes we make a loan. Yes there is insurance but it only covers part of my treatment. I have special medicines that come from abroad and they are very expensive. My husband even took out a loan. It's hard for me to be a burden to him like this." (P10, 55 years old, ovarian cancer)
Lack of social support		"My family tells me that if I had not smoked, I would not have cancer. Let alone asking for support, I am also blamed for having cancer. This situation embarrasses me" (P1, 48 years old, cervical cancer) "My children always tell me to be strong, you will beat cancer, you will succeed. Actually, they have good intentions. It seems boring to say this all the time. It backfires. But I guess ours is a hopeless disease, I'll embarrass them. Having so many surgeries and taking drugs doesn't give a person that power anyway. I expected them to understand this" (P9, 50 years old, ovarian cancer) "I need my friends and family in this process. You ask why? because they are my reason for survival and we must achieve this together. If they were in my place (God forbid), I would give all kinds of support"(P2, 50 years old, cervical cancer)
Desire for a sense of control		"Someone decides about me, yes for me to be well, but no one asks me if it's appropriate. For example, this drug that is right, I have to accept it. Or you will come to the hospital today. I surrender myself to the treatment helplessly and without question. I have cancer. but I can still decide, at least it will make me feel better. I need to control the process" (P15, 40 years old, cervical cancer) "My body has changed after the surgery, I have already entered menopause. I can't stand the heat anymore, they call it hot flashes. Or I vomit after taking my medications. But I used to have no stomach complaints. My body was not like that" (P13, 53 years old, overian cancer)
Inability to cope with uncertainty	Time of death	"Yes, everyone will die one day, but it is difficult to know that I will die of cancer. It is harder to predict when it will happen. I wonder when death waits for the right time? It cannot be said that my illness is going well. But my children have not married yet, I have no grandchildren. Mine should not be an unquestioned surrender, I have to cope, I need this, I'm so sorry" (P4, 52 years old, endometrial cancer) "I have a lot of things to do before I die. I am very worried in case I die suddenly without doing these things. When I get cancer, I keep thinking about when I'm going to die" (P12, 55 years old, endometrial cancer)
	Treatment process	"There are cancer patients around me. They beat cancer but reappeared. Mine can too. I have not recovered from cancer yet, but every time I give a tests, I am waiting for my results and I am afraid that there will be a worse result at any moment. This situation makes me very uncomfortable and I need support in this regard" (P7, 33 years old, endometrial cancer) "It is unclear how long my treatment will continue. I had surgery first, now chemotherapy. This uncertainty is very sad" (P13, 53 years old, overian cancer)

TABLE 2: The data structure for expressions of participants

Theme	Subtheme	Examples of illustrative quotes
Lack of communication in the health institution	Desire for information	"When I go to the hospital, I wonder what was my test result, how is my illness going, what should I do at home? Sometimes health experts give missing answers. In general, they are very busy people, it is okay, but if they spend me a little more time, I would know what to do" (P11, 43 years old, ovarian cancer)
	Lack of trust	"You have to be your own lawyer in the hospital, because I receive heavy treatments and a mistake can throw away everything. I prefer this way to trust the health personnel. I have been treated in larger hospitals and I realized this. When I do not question, I cannot access enough information and services. It is uncomforting to be in this situation, hospitals should deal with this issue " (P8, 30 years old, endometrial cancer) " We do not expect much from hospitals. I want to trust the hospital we go to. For example, let them not do anything wrong because of intensity. They should make us feel that we can trust them " (P14 , 47 years old, endometrial cancer)

Discussion

Women undergoing treatment for gynecological cancers have unmet needs that need to be supported. It is important to continually assess, anticipate and meet the needs of women living with gynecological cancers (13). The supportive care needs stated by the participants in this study are the fields of continuity of care, financial difficulties, psychological, communication and social support. In the literature review, it was determined that the main unmet needs of women treated for gynecological cancer were related to psychological, symptom management, economic and daily life problems (8,14–17).

The theme of "continuity of care needs" determined in this study is an important indicator in terms of increasing the quality of daily life of the participants. In a study conducted in Indonesia, it was reported that daily life changing among the most frequently unmet physical needs of women diagnosed with gynecological cancer (18). In a study conducted in Turkey on this subject, it was determined that 46% of women had needs for daily life changes (9). Thus, the fact that the needs of women who are treated for gynecological cancer to continue care in daily life are not met, shows that it continues as an important problem that prevents individuals from improving their quality of life.

The themes of "desire to cope with uncertainty", "sense of control", and "lack of social support" identified in this study revealed the importance of organizing counseling and rehabilitation programs that include symptom management and psychosocial support for women who are in treatment, and their families and relatives. In the study of Lopez et al., patients treated for gynecological cancer reported needs for social support, isolation, uncertainty, escape from illness, and advocacy. In the same study, participants reported the need for symptom management of regarding the impact of surgical treatment-induced menopause (10). In a study conducted in Turkey on the subject, it was determined that women had problems in meeting the symptom management requirements diagnosed with gynecological cancer (19). Providing support to patients diagnosed with gynecological cancer and their relatives on how to manage the treatment process will make it possible to reduce these concerns. Furthermore, participants needed help coping with family members' expectations of being a "cancer survivor", and strengthening social support in this study. Similarly, other studies reported that many gynecological cancer patients experience increased distress about family members' perspective on cancer and lack of social support (20,21). For these problems, nurses can facilitate open discussions with family members, elicit their fears and concerns, and provide education about common concerns faced by the gynecological cancer patients.

In this study, the sub-themes of "request for information", and "lack of trust" revealed the importance of healthcare professional-patient communication and the fact that these expectations are often not met. A study conducted in Indonesia confirms that 98% of patients with gynecological cancer have at least one unmet need for supportive care, and the need for information is the most widely reflected topic (5). In a study conducted in Sweden, it was defined that the service provided in a health institution is a desire for consistency and continuity in order to improve the quality of life of patients with gynecological cancer (22). The attitude of health professionals is important in terms of reducing communication and information concerns of women who are treated for gynecological cancer. Therefore, health professionals should pay special attention to the problems originating from health institutions in the process of evaluating the supportive unmet needs of gynecological cancer patients.

Several limitations were determined for the present study. Firstly, it was used a small purposive sample that included

a diverse group of gynecological cancer types. The sample was heterogeneous and consisted of endometrial, ovarian, and cervical cancers and diagnosis period ranging from 6 to 10 years. Although most of the participants were treated with both surgery and chemotherapy, their treatment regimens and sociodemographic characteristics were variable and this may affect the type of needs expressed by the participants. Finally, each participant was interviewed only once. More interviews over a period of time could have provided a more complete picture of knowledge on their needs to be supported.

Conclusion

In this study, within the scope of the unmet and to be supported needs of women receiving gynecological cancer treatment; knowledge of continuity of care, psychological, financial, communication, and social support needs were obtained.

A multidisciplinary team approach is needed to meet the supportive care needs of the patients, including oncologists, gynecological oncology nurses, social workers, dietitians, and physiotherapists. A systematic screening process is recommended to identify women undergoing gynecological cancer treatment who need and want support, and to ensure appropriate and timely assistance or referral. In addition, the results of the study showed that research involving large sample groups is needed to determine to what extent these needs are met in health institutions.

Declarations

Ethical Approval: This study was performed in line with the principles of the Declaration of Helsinki. It was obtained Ethics committee approval from Siirt University Non-Interventional Clinical Research Ethics Committee (Application date: 26/11/2021 and, Approval number: 2021/26.11.08), and written informed consent from all participants.

Conflict of interest: The author reported no conflict of interest.

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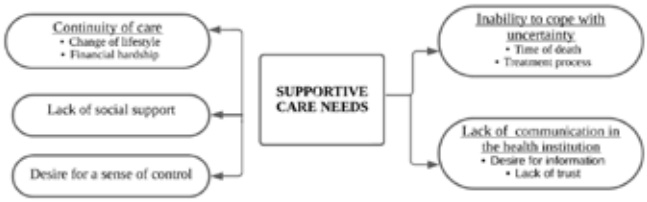

Figure1 Themes and sub-themes emerging from the data analysis

TABLE 1: Sociodemographic characteristics of participants

Characteristics	n	%
Education level		
Illiterate	2	13.3
Literate	3	20.0
Primary school	5	33.4
High school	3	20.0
University	2	13.3
Perceived income level		
Good	2	13.3
Moderate	9	60.0
Poor	4	26.7
Marital status		
Married	10	66.6
Single	5	33.4
Diagnosis		
Endometrial	7	46.6
Ovarian	4	26.7
Cervical	4	26.7
Treatment received*		
Surgery	14	
Chemo	10	
Radiation	3	
Age	X±SD 53.5±11.14 (Min: 40 Max: 62)	
Diagnosis time	X±SD 10.4±2.5 Min: 6 Max: 20	

X: Mean; SD: Standart Deviation; Min: Minimum; Max: Maximum; * Multiple options select

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