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Aged; Healthcare service needs and demands; Healthcare services for the aged; Oncology nursing; Supportive care needs

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# Experiences and views of nurses about unmet needs of older cancer patients receiving chemotherapy: A qualitative study

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### **Abstract**

**Objective.** The aim is to understand the experiences and views of oncology nurses about the unmet care needs of older cancer patients receiving chemotherapy. Nurses play the key role in evaluating and determining the needs of this special group.

**Method.** A phenomenological descriptive qualitative study with convenience sampling was used. Participants were referred by the Turkish Oncology Nursing Society. The study participants were 12 nurses aged 34–53 years, with oncology experience between 5 and 27 years. The data were collected using semi-structured face-to-face interviews. Interviews were transcribed verbatim with concurrent analyses and data collection. Thematic content analysis was used to determine common domains.

**Results.** The study data were categorized into 3 contexts, 12 themes, and 37 subthemes. The first context, "unmet needs", includes physical care, psychological care, and social care themes. The second context, "barriers to meeting those needs", comprises the theme of patient characteristics, attitude of family, attitude of the nurses/healthcare team, health system, and culture. The last context is "suggestions for meeting needs". Nurses play an important role in identifying and meeting unmet psychosocial needs.

**Significance of results.** The study indicated that older cancer patients had problems in identifying, expressing, and making demands for their needs and that their culture contributed to this situation. Nurses serving in the outpatient chemotherapy units should conduct a holistic assessment of older cancer patients, be aware that these patients may not be able to express their needs, be more sensitive toward them, and ensure that the voice of the older patients is heard.

# Introduction

As the world population ages, cancer is affecting more and more older people (White et al., 2014). Sixty percent of cancer cases and 80% of cancer-related deaths are observed in people >65 years old (Cancer research UK, 2020); however, physical, psychological, and social changes and losses that come with aging overlap the challenges of cancer, which makes it difficult for the older people to cope with the health challenges (Perez-Zepeda et al., 2016; Aunan et al., 2017; Lang-Rollin and Berberich, 2018; Dumitrache et al., 2018a, 2018b). Factors, such as fragility (Perez-Zepeda et al., 2016; Carandang et al., 2019), low health literacy, and economic problems, can prevent older cancer patients from accessing the healthcare services that they need (Özdemir and Bilgili, 2014; Sao Jose et al., 2019). The older population is a disadvantaged group in terms of both high cancer incidence and prognosis (White et al., 2014; Aunan et al., 2017; United Nations, 2017). Because of their physiological and cognitive changes secondary to aging, the presence of comorbid medical conditions, and psychosocial factors, older cancer patients have unique and complex needs (Bond et al., 2016; Aapro, 2018; Boyle et al., 2019; Tsubata et al., 2019). Especially, the chemotherapy process can be extremely challenging for the older patient and may result in more complex needs. These unique and complex needs bring out the supportive care needs.

Supportive care is anything one does for the patient that is not aimed directly at curing his disease but rather is focused at helping the patient and family get through the illness in the best possible condition (Eduardo Bruera, 2021). Supportive care needs of cancer patients is that physical, psychological, socioeconomic, information, and spiritual needs of individual patients should be identified, considered in the treatment plan, and satisfied (Nipp et al., 2021). The supportive care needs must be met to help the older people manage cancer, which is an extremely challenging process, make it easier for them to adapt to this extraordinary situation, and maintain their quality of life (Lopez et al., 2019; Zhang et al., 2019; National Comprehensive Cancer Network, 2019b). The need for supportive care may increase, especially for those older patients who receive outpatient chemotherapy and must actively manage treatment and its side effects (Puts et al., 2012).

There is evidence that older cancer patients are not always able to access the care they need (Colussi et al., 2001; Koll et al., 2016), and nurses play an important role in meeting those



needs. Oncology nurses can meet the supportive care needs by evaluating the patients and their families, determining their priorities, taking precautions against risks, and improving the quality of life because of these proactive activities (Koll et al., 2016; Yates et al., 2020).

It has been stated in the literature that these unmet needs may vary according to technology, the healthcare system, time, culture, and age (Pehlivan et al., 2013). A study conducted by Ayvat (2019) within the Turkish culture reported that the supportive care needs of the patients may differ depending on their age and emphasized that healthcare professionals should consider that older people may have problems when expressing their needs (Ayvat and Atli Ozbas 2021). Determining the views and experiences of nurses regarding the supportive care needs of patients who have cancer and are older people, two special circumstances, can gather important data that will provide the information they need to enable them to determine the care and services for these patients.

The aim of the study was to understand the experiences and views of oncology nurses, who are the first contacts of older cancer patients, about meeting their unmet care needs and the differences between the needs of older and younger cancer patients' needs. This study sought the answers to this question "What are the experiences and views of oncology nurses working in chemotherapy units regarding the needs of older patients?"

#### **Methods**

## Study design

The present study was based on the phenomenological approach to qualitative research. Data were collected using one-on-one, in-depth interviews with the oncology nurses, as is the protocol for this research method. The data were gathered and reported according to the checklist created by the Consolidated Criteria for Qualitative Studies (COREQ) (Tong et al., 2007; Creswell and Poth, 2016).

## Participants and setting

The study used convenience sampling of nurses who were members of the Turkish Oncology Nursing Society. These nurses responded to an announcement of the study posted in the Society's WhatsApp Group. The inclusion criteria for the study were as follows: (1) care of older cancer patients and (2) at least 6 months' experience in oncology. The sample size of 12 was determined to reach data saturation.

# Data collection, analyses, and synthesis

Both researchers, trained in qualitative methods, conducted the interviews (RN/PhD and RN/PhD, student) used in the present study. Based on a literature review, we developed a semi-structured questionnaire (Güner et al., 2018; Chan et al., 2019; Cox-Seignoret and Maharaj, 2020) and conducted the interviews from July 2020 through January 2021 using video conferencing because of COVID-19 restrictions at that time. Data were analyzed by two researchers. First, all audio records of the interviews were listened at least three times before being transcribed. The transcripts were then read several times by the researchers. Each researcher created separate codes that reflected the interview answers, after which they shared, discussed, and divided the codes into meaningful groups and 3 contexts, 12 themes, and

37 subthemes. All data analyses were conducted and reported in Turkish (Holloway and Wheeler, 1995).

# Ethical approval

The study protocol was approved by the ethics committee from the Non-interventional Clinical Researches Ethics Board within which the study was conducted. The protocol conforms to the provisions of the Declaration of Helsinki. In addition, all participants gave their informed consent to participate, and the researchers ensured that patient anonymity was preserved. Verbal consent was obtained from the participants in the study with the Ethics Committee approval number 2020-16/63. Only the researchers could access the data, and the interview videos were encrypted and stored on their personal computers.

### Results

Table 1 shows the nurses' sociodemographic variables. All participants were women with a mean age of 43.25 years. The participants had worked in the oncology for a minimum of 5 and a maximum of 27 years. All participants stated that they were happy and satisfied with working at the chemotherapy unit.

Table 2 shows the study's contexts, themes, and subthemes. The data were categorized using the following three contexts: unmet needs, barriers to meeting these needs, and suggestions for meeting these needs.

## Context 1: unmet needs

# Theme 1: physical care

The participants remarked on the high care needs of older patients. Three subthemes — self-care, nutrition, and comfort — are included within this context.

The participants indicated that the patients were dependent on others to meet self-care needs and, if these needs were not met by their relatives, became unmet needs. Nutrition came to the forefront as one of the ways of relatives shows attention to and give care for the patient; however, for several reasons, such as failure in symptom management, financial insufficiency, and lack of information, the nutritional needs were not sufficiently met. In addition, the physical conditions of some chemotherapy units were not suitable for the older patients. For example, they expressed that chemotherapy chairs were not suitable, patients felt tired after the treatment, but they had to go immediately after receiving chemotherapy because there was no place where they could rest, and patients with low socioeconomic status and coming from out of town had problems in transportation. Briefly, that patients' needs for comfort, such as rest and transportation, were not met.

"To say the truth, we have some seriously fragile patients. When I look at them and I must administer the chemotherapy ....Sometimes I don't have the heart to do it. You say to yourself: "He is already fragile. When he receives chemotherapy, he will collapse completely." P10

# Theme 2: psychological care

The subthemes were (1) being noticed, (2) expressing oneself, and (3) emotion management. The nurses commented that older cancer patients wanted to be noticed by their family, healthcare professionals, and the healthcare system; wanted to be remembered and paid attention to; and wanted their preferences considered

Palliative and Supportive Care 241

Table 1. Sociodemographic characteristics of the study participants

Study participant	Age	Oncology experience (years)	Working experience outside oncology	Views on oncology nursing	Elderly cancer patient in the family
P-1	45	10	Intensive care, chief nurse	The unit where she was assigned as punishment An area that nurses do not want to work in An area that nurses want to work in	N/A
P-2	45	10	Mixed service, general internal medicine, pediatric surgery clinic, and neurosurgery intensive care	The unit where she was willingly transferred A harsh and difficult workplace	N/A
P-3	34	6	Cardiology intensive care	Loves and willingly works in the unit	Father — lung CA
P-4	39	6	Neurology, physiotherapy	Temporary assignment Found it scary at first then got used to it	N/A
P-5	39	12	Internal medicine, chest diseases, cardiology service, and reanimation intensive care	Likes to work in the unit Does not want to work in another unit	Father — lung CA
P-6	43	10	Medical oncology service, bone marrow transplant unit, and outpatient chemotherapy unit	Loves to work in the unit and finds it important A sensitive work area Fear of dealing with psychological damage and not being able to serve enough	N/A
P-7	41	8	Family health center, maternity ward operating room, outpatient clinic, and chemotherapy unit	Working in oncology is among her taboos Fears oncology Had difficulty learning while working in oncology	N/A
P-8	52	27	Case management nurse, pediatric oncology, and adult oncology	Tries to take care of patients by touching them Providing care by putting herself in the patient's shoes Showing a positive attitude toward elderly and pediatric patients	Yes Father — prostate CA
P-9	45	5	Chest diseases, psychiatry, neurosurgery, cardiovascular surgery, palliative, and general surgery services	Area where one witnesses how the patient slowly disappears	N/A
P-10	45	18	Pediatrics and oncology	A busy, hard, and difficult area A unit where one witnesses the patient's demise step by step A unit that provides satisfaction A unit that requires meticulous work	N/A
P-11	38	18	Intensive care, gynecological oncology, and radiation oncology, and chief nurse for pediatric and adult oncology	Desire to seek satisfaction in the profession and to be a role model Are where one witnesses how the life of the patient changes	N/A
P-12	53	20	Hematology, oncology, radiation oncology, and nuclear medicine	An area where processes vary according to cancer types	Yes Grandmother — lung CA

when they were not able to express themselves and could not make demands. The data revealed that older patients experienced feelings of death fear, dependency, abandonment, anxiety, anger, shame, and loss, but that they were unable to receive the needed support for handling and managing those feelings. Two nurses commented as follows:

"Young people are able to express themselves better, they can say things like "I need this, and I want this" but older people feel sad because they feel that they are dependent on somebody or feel like they cannot do things themselves anymore, so they do not want to show these feelings." P10

"People tell them about somethings all the time, but nobody listens to them." P5  $\,$ 

"When their relatives don't come, they get annoyed and angry: "Why didn't he come, did he forget me?". There are also they have fears of abandonment." P12

# Theme 3: social care

This theme had the following two subthemes: (1) social activity and (2) contact with others. The fact that the patient and family were isolated because of the fear of infection, lack of information, cultural expectations for the older people to stay at home,

**Table 2.** Views and experiences of nurses on the care needs of elderly cancer patients

Context	Theme	Subtheme
Unmet needs	Physical care	Self-care Nutrition Comfort
	Psychological care	Being noticed Expressing oneself Emotion management
	Social care	Social activity Contact with others
Barriers	Patient characteristics	Dependency Weakness Not being able to demand
	Family attitude	Not having a relative who can provide care Overprotection Difficulty in care
	Nurse/healthcare team attitude	Attitude toward elderly cancer patient Lack of information
	Healthcare system	Problem in accessing the service Problem in providing the service Failure to ensure the continuity of the service
	Culture	The elderly being expected to withdraw socially The elderly being accepted in the dependent role Negative attitude toward elderly sexuality Gender
Suggestions	Nurse and healthcare professionals	Sensitivity Hearing the elderly's voice
	Institution	An integrated approach philosophy Multidisciplinary team Psychosocial support for healthcare workers Improvements in physical conditions
	Healthcare system	Making the elderly visible Providing economic support for the elderly Improving home care services Cultural care Ensuring social justice Facilitating the access of the elderly to healthcare services
	Academic community	Scientific studies Experts in the field

increasing the protective approach by the family after cancer, and the healthcare system not providing the patients with the opportunity to meet social needs. Participants stated that their patients need to communicate with others were at the forefront, and they observed that patients had a need to talk with nurses on social issues and to interact with people.

"I can see that they are lonely, want to communicate, and need someone to talk to. They want to share. They want to talk about daily and routine stuff, about simple things of life. But there is something strange. It is like they are in a spiral, which they cannot escape. So, their ties with the outside world are severed ... They can be very lonely." P2

"They also want to talk about social issues. The famous questions "Are you married?" and "Do you have children?" (laughing)." P4

"They need to talk a lot, as far as I have observed. They even need us to sit next to them and even touch them." P12

# Context 2: barriers to meeting needs

# Theme 1: patient characteristics

The "dependence," "weakness," and "not being able to demand" were categorized as factors that led to an increase in unmet

needs. The increase in dependence after a cancer diagnosis was frequently stated. Dependence, which is explained by both cultural factors and deterioration in the physiological functions, was expressed not only as fact but also one of the biggest fears and feelings of shame for the older cancer patient. The participants remarked that older cancer patients experienced psychological as well as physical weakness from factors such as loss of their roles, economic losses, and low levels of functionality. The patient's low sociocultural level, dependency, and powerlessness were expressed as barriers that prevented them from making demands. The participants emphasized that older patients did not request information themselves and did not express their problems, and that their needs could be determined only when questioned by healthcare professionals.

"Because they think that they are already a burden, they do not tell their relatives or us what they need. They already are grateful to those caring for them. Hence, I think they do not express themselves, even when they really need it." P8

"We have a lot of patients like they can't get up to the toilet frequently, they can't walk. He finds that insulting to have a diaper tied under him because my feet are not holding, so he doesn't want to drink water and go to the toilet." P10

## Theme 2: family attitude

Three subthemes were determined: (1) not having a relative that could provide care, (2) overprotection, and (3) difficulty in care. The long duration of cancer treatment and the burden of care for the older cancer patient may cause difficulties for the family. Conflicts may occur in these cases within the family and the older cancer patient may be exposed to neglect or abuse.

"First, they create a protective shield over the patient because the patient is old, and the family does not know what to do. They take care of all his affairs. Therefore, the patient feels like he cannot do anything, just sitting in the corner...Then, they undertake even simple self-care tasks. It is like the family even decides what the patient has to say." P5

# Theme 3: healthcare team/nurse attitude

There were two subthemes: (1) attitude toward the older cancer patient and (2) lack of information. Healthcare professionals were also affected by the social negative attitudes toward the older people. They underestimated the coping potential of the older cancer patient and prioritized their dependent roles. As a result of this attitude, it was revealed that older cancer patients were excluded from the decision-making mechanism, and health information was given to the patients' relatives.

"What I have observed with all my colleagues, whether physician, nurse, or other staff members .... is that they are left between concepts such as "he is already at the end of the road, he can be left to his destiny, he can also sit in a corner at home, he could just not receive the treatment and he could just not do this." P5

Nurses feel more knowledgeable and equipped to manage physiological care but had difficulties managing psychosocial care. They considered psychosocial care outside of their nursing functions and competencies, or they were not able to provide it because of their over workload. The participants' statements on the lack of information and especially on meeting sexual care needs drew attention.

"Of course, our perspective on sexuality is also important. We still do not know how we can talk amongst even with each other, so we do not know what to say or how to say something on this subject." P1

# Theme 4: healthcare system

There are three subthemes: (1) problem in accessing the healthcare service, (2) problem in providing the service, and (3) failure to ensure the continuity of the service. Patients had difficulties reaching the healthcare, using technological devices, web applications, and to make appointments. There are not any special assessment tools for the older patients, and that there were no special procedures for them. Sometimes, returning home after treatment could be a problem, and continuing care at home is a big challenge.

"They need care at home but do not know how to afford it, they do not know how to pay for everything, they become desperate when the family is not enough in these times, they have difficulties in reaching care services when they go to the hospital for any reason or that they experience difficulties in reaching a doctor, nurse or caregiver when going to another hospital." P5

"... the system is completely automated ... The electronic hospital system requires good computer or smartphone skills and older people only

have limited knowledge about technology ....We expect them to get support from a device that they have not seen their whole life." P7

#### Theme 5: culture

There are four subthemes: (1) the older people being expected to withdraw socially, (2) the older people being accepted in a dependent role, (3) negative attitude toward older people's sexuality, and (4) gender are sub themes. There is an expectation by the older people to accept their dependent role and surrender to it, which leads to the older people being steadfast in not expressing their demands.

"...they are mostly described as grumpy or easy-going elders. Elders who do what they are told to or elders who do not do what they are told to. There are those sweet old people, who you find cute and are right in the middle of life, they say "Ok, I am ok with it, it comes from God"." P1

## Context 3: suggestions for meeting supportive care needs

There are four subthemes: (1) nurses and healthcare professionals, (2) institution, (3) healthcare system, and (4) academic community. Participants drew attention to the importance of healthcare professionals being more sensitive, asking the patient about needs, and learning the patient's expectations. They recommended developing a holistic-care philosophy, multidisciplinary teamwork, provide psychosocial support services to healthcare professionals, and plan for the older patients regarding the physical conditions of the institution.

## **Discussion**

The data were examined within three contexts. The first comprised views on the unmet needs of older cancer patients. Nurses statied that the self-care, nutrition, and comfort needs could not be met, and reported that the needs of the older patients increased with increasing dependency because of both decreasing functions because of old age and the side effects of chemotherapy. In the Turkish culture, the care of the older people and patients is generally provided within the family, and the lack of family members to provide that care results in being unable to meet care needs.

The nurses have observed that patients' relatives were constantly attempting to feed the patient. Culturally, feeding an individual is associated with good care practices; however, the study's results indicated that because of the lack of information, problems with symptom management, or the patient's insufficient economic situation, the older people could not be enough fed. Parallel to studies on the nutritional needs of older cancer patients receiving chemotherapy (Caillet et al., 2017; Forbes et al., 2020), the present study has also emphasized the problem in meeting nutritional needs.

Psychosocial care, an important component of holistic care, has serious effects on meeting the physical needs (Aldaz et al., 2017); however, this study indicated that nurses had difficulty in providing psychosocial care and needed support. The lack of providing psychosocial care was related to the lack of knowledge and skills of psychosocial care, limited time, over workload, and insufficient staff. Understanding the interaction between physical and psychosocial care and providing both are important factors in terms of compliance with treatment, symptom management, quality of life, comfort, and decreasing of stress level (Güner et al., 2018; Chan et al., 2019; Warth et al., 2019). Thus, the

Comprehensive Geriatric Assessment can be an effective method for to remove disruptions in the field (Mohile et al., 2018; Blanquicett et al., 2019). Distress thermometer, Barber questionnaire, Fried Frailty Criteria, G8, Groningen Frailty Index, Triage Risk Screening Tool (TRST), Vulnerable Elders Survey (VES-13), and Lachs' screening test are other recommended methods for holistic care of older cancer patients (Aapro, 2018; National Comprehensive Cancer Network, 2019a, 2019c).

As in previous studies (Colussi et al., 2001; Nelson et al., 2019), the study participants stated that older cancer patients were better able to cope with cancer psychologically and that some cultural factors had placed older cancer patients into specific categories. It is expected that older patients "accept their faith, because it comes from God," and to be grateful for the care and treatment they receive. It was inevitable that the study participants were affected by the culture in which they live. As in studies conducted within other cultures (Schroyen et al., 2016; Sao Jose et al., 2019), data results also indicated that older cancer patients were labeled with descriptions such as "grumpy," "cute," "adorable," "will die anyway," and "will not tolerate chemotherapy." Other studies have reported that older cancer patients exposed to the double stigma by both society and their families of being both older people and a cancer patient internalizes this situation (Chasteen and Cary, 2015; Bulut and Cilingir, 2016; Schroyen et al., 2017). Those who accept this stigma and internalize these cultural expectations are then not able to express their wishes or make any demands in

Nurses observed feelings of anxiety, fear of death, anger, and shame in older cancer patients but that these patients were unable to express their feelings. Hong et al. (2015) have reported that 43.8% of older cancer patients described high levels of distress and that emotional problems were the leading cause of that distress (Hong et al., 2015). Ayvat and Atli Ozbas 2021 has found in the study, conducted within the Turkish culture, that older cancer patients have levels of psychological needs like those of younger cancer patients; therefore, the widespread acceptance by the study participants that older cancer patients can better cope and accept the process may be because the older patients do not express the psychological difficulties that they experience. In fact, the participants in the present study also observed that older cancer patients do not express themselves.

Although the overprotective attitude of the family is defined as "putting a protective shield over the older people," it later turns into the incapability of the family to cope with the situation because they get weary as the disease progresses. Some nurses believed that the older people cancer patients should surrender themselves to their children during this process and that this point of view is also supported by society. This makes the older people cancer patient more dependent, and this increasing dependency brings much more responsibility to the patient's caregiver. This increased responsibility, knowledge deficiency, and ineffective family communication create family conflicts (Fjose et al., 2018; Wittenberg et al., 2018; Wang et al., 2021). As a result, the older people cancer patients are literally put into a corner of the home and not asked what they want or even listened to. Do not want to participate in the care increases dependency and affects them bio-psychosocially (Schroyen et al., 2016). It is important for nurses to support the patients' independence by asking them about their wishes and including them in the care.

Another issue that drew attention in the present study was that no theme for the information and sexual needs of older people patients was identified. The need for communication of older people cancer patients found its place under social care; however, answers to the questions about the needs regarding sexual care and information were that the older people did not make any demands for these subjects. Participants stated that they had difficulty evaluating the sexual needs of older people cancer patients, and sexuality was a taboo for both the patient and the nurse. It is also stated in the literature that nurses experience difficulties providing psychosocial care (Güner et al., 2018). The negative attitude toward the sexuality of the older people is present in many parts of the world, and that healthcare professionals have difficulty discussing it (Leung et al., 2016; Albers et al., 2020).

The results of this study found that an important factor that results in the interruption of care is access to services by older people cancer patients, especially for those with low socioeconomic status and who have problems using technology. Even though it is believed that the older people have saved their money and not have economic problems, there is still the possibility of economic problems because of cancer treatment (Erden and Boz, 2018). In addition, older people cancer patients who are trying to adapt to developing technology encounter technological infrastructures or computers with which that they are not familiar when they enter the hospital. Glomsas et al. 2021 have reported in their study with older people patients on telehealth applications that the participants need more training and information on their use.

The continuity of healthcare increases the compliance of both the patients and their relatives with the disease and treatment, which can result in them feeling safe (Colussi et al., 2001; Steven et al., 2019). The nurses stated that the care was provided only in the hospital, and that there were problems in ensuring continuity. It is believed that regular follow-up by healthcare workers would support both the family and older people cancer patients in adapting and coping with the disease.

# Limitations

Because of the COVID-19 pandemic, the present study was conducted online because it was presumed that there would have been problems reaching the participants face to face. This may be considered as a limitation of this study conducted using the phenomenological method; however, because the study was conducted through the Turkish Oncology Nursing Society, the participants were provided the opportunity to participate without any institutional connection and physically outside of their institution. The study participants stated that they were able to express themselves freely and were selected from very different regions within Turkey, which could be considered as the strength of the study.

## Conclusion

Nurses play an important role in identifying and meeting unmet psychosocial needs. The results of the present study indicated that older people cancer patients had problems in identifying, expressing, and making demands for their needs and that their culture contributed to this situation. It is recommended that nurses serving in a chemotherapy unit do a holistic assessment of older people cancer patients, have perspective on transcultural care, be aware that these patients may not be able to express their needs, be more sensitive toward them, ensure that they can hear their voices.

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