

Exploring Patients' and Caregivers' Perception of Healthcare Provision to Cancer Patients During the COVID-19 Pandemic: A Qualitative Study

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Abstract

Background: Patients with cancer are among the groups that are vulnerable to the COVID-19 crisis. Identifying the factors affecting the process of healthcare provision can improve the health services provided to cancer patients. Therefore, this study aimed to explain stakeholders' perception of the healthcare services provided to cancer patients during the COVID-19 pandemic.

Methods: The present qualitative study was conducted using the conventional content analysis method in Iran in 2021. Participants included cancer patients, their families, and healthcare providers, who were selected via purposive sampling. Data were collected through 19 individual interviews and two focus groups and then analyzed using the method proposed by Graneheim and Lundman.

Results: Qualitative data analysis revealed seven main categories, including the disruption of care continuity, reduced quality of health services, poor provision of community-based services, lack of comprehensive care, lack of public education, predicting changes in cancer incidence and mortality trends, and ethical challenges.

Conclusion: The COVID-19 pandemic has exposed cancer patients to many challenges, including limited access to health services. Therefore, there is a need to facilitate these patients' access to safe healthcare services.

Keywords: COVID-19 pandemic, Cancer patients, Healthcare delivery, Qualitative study

Citation: Kaveh V, Pirjani P, Heydari H, Hossini K, Razani G, Sadeqian R, et al. Exploring patients' and caregivers' perception of healthcare provision to cancer patients during the COVID-19 pandemic: a qualitative study. *J Qual Res Health Sci.* 2023;12(3):120–128. doi:10.34172/jqr.2023.18

Received: February 10, 2022, **Accepted:** October 12, 2022, **ePublished:** September 30, 2023

Introduction

The COVID-19 is a transmissible disease ravaging the globe which has turned into a pandemic (1). Until July 25, 2021, the disease infected 194 616 521 people, leading to 4 171 983 deaths worldwide (2). Among those infected by COVID-19, cancer patients are more vulnerable to severe disease secondary to the debilitating impacts of chemotherapy, surgeries, and immunosuppressive medications (3-5), leading to a higher mortality rate among them (6).

In Iran, the incidence of cancer is on the rise, and the disease is known as the second leading cause of death in the country (7). Until July 25, 2021, the number of confirmed COVID-19 cases and related deaths in Iran stood at 3 691,432 and 88 800, respectively (2). Cancer patients in

Iran, similar to other parts of the world, have been exposed to COVID-19-related problems and damages.

As COVID-19 is a newly emerging disease, many of its care dimensions and therapeutic requirements are obscure, especially in patients with advanced cancer (8). The COVID-19 disease, directly and indirectly, causes inequalities in cancer patients' access to diagnostic and therapeutic modalities, as well as to specialists, leading to adverse physical, psychological, social, and financial consequences and reducing the quality of life of patients and their families.

Healthcare providers are in contact with cancer patients on a daily basis and therefore, can help recognize the needs and problems faced by patients amid the pandemic more than anyone else.



The experiences of cancer patients, their families, and their caregivers during the COVID-19 crisis can help develop effective healthcare strategies and therapeutic plans for these patients. Qualitative studies can help achieve this goal by identifying various dimensions of cancer patients' needs (9), especially during the COVID-19 crisis. Regarding the researchers' experiences in providing care for patients with advanced cancer and their expertise in performing qualitative research, this study aimed to explore stakeholders' perception of healthcare provision to cancer patients during the COVID-19 pandemic.

Methods

This qualitative study was conducted using the conventional content analysis approach. The study started on April 20, 2021, and continued for two months. In this study, data were collected through 15 semi-structured telephone and 4 face-to-face interviews, followed by two focus group sessions. Participants included cancer patients and their family members. The patients should have either received home care services from the Iranian Cancer Control Center (MACSA) for at least one month from the start of the COVID-19 pandemic in Iran (i.e., from January 29, 2020) or had a history of hospitalization during this period. The physicians, nurses, rehabilitation experts, and managers who were involved in providing healthcare services to these patients were included as well.

The participants were recruited using purposive sampling and by visiting the MACSA Charity Institution, where patients and caregivers with rich information about the phenomenon were selected.

The inclusion criteria were being at least 18 years old, having consciousness, not being infected with COVID-19 at the time of the interview, and willingness to participate in the study. The patients should have been diagnosed with advanced cancer, have received either home-based or hospital-based care for at least one month, and have had no scheduled chemotherapy during the study. For family members, those who were the main home-based care providers were included. Finally, the caregivers who provided home health services to cancer patients for at least two months and the managers who have been managing this process during the COVID-19 pandemic were also included. Developing any acute illness during the study was regarded as an exclusion criterion.

Regarding the urgent need for collecting the data to improve the care provision process for cancer patients, limitations for face-to-face contact, and the vulnerability of cancer patients to the COVID-19 disease, semi-structured telephone and in-person interviews were chosen for data collection. The interviews were conducted by a palliative care specialist and a medical student. For conducting telephone interviews, the participant's

contact information was obtained from the MACSA Charity Institution. After explaining the objectives of the study to the participants, the time and place of the interview were arranged according to the participants' preferences. The main interview questions were: "Could you please tell us about your experiences of receiving care for advanced cancer during the COVID-19 pandemic?", "How and where did you receive care for your illness?", and "How do you perceive the health system's response to cancer patients' needs?" The questions; however, were tailored according to the participant's role (i.e., a patient or a family member). The probing questions were further asked to guide the direction of the interview toward research objectives. The interviews continued until no new information was obtained. To increase the richness of the information, two focus group sessions were held with experts in the field.

In this study, data analysis was performed simultaneously with conducting the interviews using the method proposed by Graneheim and Lundman. The proposed method comprises the following five steps: 1- Transcribing the interviews immediately after their completion, 2- Reading the texts for acquiring a general understanding, 3- Determining meaning units and primary codes, 4- Classifying similar codes into categories, and 5- Discovering the content hidden in the data (9). Accordingly, immediately after each interview, the text was transcribed verbatim, and then read in detail several times to extract initial codes. Next, the relevant initial codes were merged to form categories based on their similarities. Finally, the concepts hidden in the data were extracted.

Credibility, dependability, confirmability, and transferability were checked as described by Lincoln and Guba to confirm data accuracy and reliability (10,11). To ensure data acceptability, participants were recruited with maximum diversity in terms of age, gender, income, literacy, type of cancer, and other demographic variables. After the initial analysis and the emergence of initial codes, the participants were requested to confirm the interpretation of the codes and the accuracy of the data. If the codes were inconsistent with the participants' experiences and opinions, they were reviewed to make necessary amendments in the data coding process. For confirmability, two faculty members who were experts in qualitative research were asked for their opinions to reach an agreement on the selected codes and classifications. For transferability, it was attempted to accurately report the whole research process.

Results

A total of 19 participants, 15 (63.16%) females and four (36.84%) males, were interviewed. Seven experts, four (57.14%) females and three (42.86%) males, participated in each focus group session (Tables 1 and 2). Qualitative

data analysis led to the emergence of seven main categories (Table 3).

1. Disruption of care continuity

Data analysis showed that some cancer patients were less inclined to follow their treatment during the COVID-19 crisis due to the fear of COVID-19 transmission, difficulty in commuting, and poor access to medications and equipment. In this main category, three categories emerged, including delay in receiving treatment due to the fear of COVID-19 transmission, difficulty in accessing

health services, and problems in commuting.

1.1. Delay in receiving treatment due to the fear of COVID-19 transmission

According to data analysis, some cancer patients were less inclined to follow up their treatments due to the fear of contracting the COVID-19 disease, leading to cancer progression, losing the golden time for treatment, and the exacerbation of the patient's condition. Data analysis showed that virus transmission could have occurred in healthcare centers due to not observing health

Table 1. The characteristics of the participants in interviews

Code	Role	Education level	Type of Interview	Gender
1	Patient's mother	Lower than diploma	Telephone	Female
2	Patient	Diploma	Telephone	Male
3	Patient's daughter	Bachelor's degree	Telephone	Female
4	Patient's daughter	Master's degree	Telephone	Female
5	Patient's sister	Diploma	Telephone	Female
6	Technical manager	Physician	Telephone	Female
7	Patient	Lower than diploma	Telephone	Female
8	Patient's wife	Lower than diploma	Telephone	Male
9	Coordinator of the home care institute	Ph.D. in human sciences	Telephone	Female
10	Psychological advisor	Master's degree in psychology	Telephone	Male
11	Social worker	Bachelor's degree in social sciences	Telephone	Female
12	Patient's daughter	Bachelor's degree	Telephone	Female
13	Patient	Diploma	Telephone	Female
14	Oncologist	Physician	Telephone	Male
15	Patient	Lower than diploma	Telephone	Female
16	Cancer center manager	Master's degree in nursing	Face-to-face	Female
17	Home care nurse	Bachelor's degree in nursing	Face-to-face	Male
18	Manager of the home health care center	Master's degree	Face-to-face	Male
19	Home care nurse	Bachelor's degree in nursing	Face-to-face	Male

Table 2. The characteristics of the participants in focus group sessions

Focus groups	Codes	Role	Education level	Work experience (year)	Gender
Focus group 1	1	Manager of the home health care center	Master's degree	30	Male
	2	Physician	Oncologist	28	Male
	3	Coordinator of the home care institute	Ph.D. in human sciences	12	Female
	4	Physician	Hematologist	33	Female
	5	Educational manager of the home care institute	Palliative care physician	23	Female
	6	Home care nurse	Ph.D. in nursing	19	Male
	7	Technical manager	Physician	13	Female
Focus group 2	8	Manager of the palliative care center	Master's degree in nursing	30	Male
	9	Oncology group manager	Oncologist	21	Male
	10	Physician	Emergency medicine specialist	12	Female
	11	Physician	Hematologist	33	Female
	12	Educational manager of the home care institute	Palliative care physician	23	Female
	13	Cancer care nurse	Bachelor's degree in nursing	22	Male
	14	Manager of the home health care center	Master's degree in nursing	18	Female

Table 3. The categories and subcategories extracted from the data

Main categories	Categories	Subcategories
Disruption of care continuity	Delay in receiving treatment due to the fear of COVID-19 transmission	Difficulty in accessing specialists
	Difficulty in accessing health services	Problems associated with the provision of medications and equipment
	Problems in commuting	
Reduced quality of health services	Crowded healthcare centers	Increased staff workload
	Interruption of treatment	Shortage of hospital beds
	Interruption of diagnosis	
Poor provision of community-based services	Telemedicine gaps	
	Necessity of providing home care	
Lack of comprehensive care	Lack of palliative care	
	Lack of spiritual care	
	Poor social support	
Lack of public education		
Predicting changes in cancer incidence and mortality trends		
Ethical challenges		

protocols during patient transfer. In this regard, one of the oncologists participating in the focus group session addressed cancer progression in patients during the COVID-19 pandemic, “...During the first six months of the pandemic, many of my patients were scared of coming to the hospital, which led to the progression of cancer from stage II to III, and from stage IV to advanced cancer...” (Focus-Participant 2).

1.2. Difficulty in accessing health services

Data analysis showed that cancer patients should have had easy access to health services to continue their treatment during the COVID-19 pandemic. According to the data in the present study, patients had difficulty in accessing specialists, physicians, some medications, and equipment during the pandemic. In this category, two subcategories were identified, including difficulty in accessing specialists and the problems associated with the provision of medications and equipment.

1.2.1. Difficulty in accessing specialists

Data analysis showed that one of the factors that could delay healthcare provision to cancer patients during the COVID-19 pandemic was difficulty in accessing specialists. One of the family caregivers addressed the difficulty of access to physicians, “...we actually encountered problems in having access to a doctor...” (Participant 8).

1.2.2. Problems associated with the provision of medications and equipment

Data analysis showed that during the COVID-19

pandemic, some professions were closed because of quarantine regulations, resulting in unemployment and financial problems for families and difficulty in providing medications due to either financial issues or the lack of access. Therefore, such problems could have affected the quality of the health services provided to cancer patients. The participants’ experiences indicated that cancer patients paid high costs for their required consumables, equipment, and drugs during the COVID-19 period. One of the participants highlighted the shortage of some medications and their unavailability even at high prices, “... Apalutamide... is not covered by any insurance company...we are in debt all over...” (Participant 8).

One of the participants mentioned the loss of the family income and the difficulty in providing medications, “... my husband is self-employed...and the pandemic had a great impact...there was no business during the pandemic...” (Participant 13).

The participants’ experiences revealed that during the COVID-19 pandemic, cancer patients had difficulty in accessing a number of chemotherapeutics. An oncologist mentioned, “A number of chemotherapy drugs became unreachable...” (Participant 14).

1.3. Problems in commuting

Data analysis showed that patients were deprived of receiving timely healthcare services as they would avoid traveling to treatment centers due to the fear of COVID-19 transmission. In this regard, one of the participants expressed the fear of ambulances being contaminated with the COVID-19 virus and their staff not observing health protocols during transferring the patient to the

hospital, "...we were afraid of the ambulances carrying patients..." (Participant 4).

2. Reduced quality of health services

Data analysis showed a reduction in the quality of the services provided to cancer patients during the COVID-19 period. Amid incessant waves of the COVID-19 disease across the country, hospitals faced crowds of COVID-19 patients who needed to be hospitalized. Oncology beds were dedicated to COVID-19 patients, exaggerating their shortage. Moreover, care provision to the growing number of COVID-19 patients demanded a sharp increase in the workload of health providers, all of which could have contributed to reducing the quality of the comprehensive care provided to cancer patients. This main category covered three subcategories, including crowded healthcare centers, interruption of treatment, and interruption of diagnosis.

2.1. Crowded healthcare centers

Data analysis disclosed that one of the factors affecting the quality of the services provided to cancer patients was the overcrowding of hospitals following multiple COVID-19 waves. In this category, two subcategories were identified, including Increased staff workload and shortage of hospital beds.

2.1.1. Increased staff workload

Participants' experiences indicated that an increase in the number of patients admitted to hospitals disturbed the balance between patients and healthcare providers, intensifying the workload of the staff providing health services to cancer patients. In this regard, one of the participants declared, "... the workload of medical staff increased; cancer patients were occasionally contracting the COVID-19 infection..." (Participant 14).

2.1.2. Shortage of hospital beds

Regarding the vulnerability of cancer patients at the time of the COVID-19 pandemic, they should have been taken care of in septic conditions with sterile equipment and hospitalized in isolation rooms. In this regard, one of the oncologists noted, "...our patients were receiving chemotherapy in the same hospital and the same environment with COVID patients ..." (Participant 14).

2.2. Interruption of treatment

Based on data analysis, no specific guidelines were available for providing care to cancer patients simultaneously infected with the COVID-19 disease, and these patients were treated and cared for as other COVID-19 patients. On the other hand, amid recurrent COVID-19 waves, the excessive admission of patients to hospitals disturbed the balance between hospital beds and patients. Besides, oncology wards were dedicated to COVID-19 patients,

disrupting the therapeutic courses of cancer patients. In this regard, one of the oncologists participating in the study shared his confusion about the course of the COVID-19 disease in cancer patients, "...They were very worried about when we would start COVID treatment, ... or whether or not chemotherapy could weaken the patient's immune system and exacerbate COVID complications..." (Participant 14).

2.3. Interruption of diagnosis

Data analysis revealed that being infected with COVID-19 could change some blood indices in cancer patients, complicating the diagnosis and care provision to these patients. Addressing this issue, an oncologist mentioned, "... We had patients who might develop thrombocytopenia following being diagnosed with COVID-19, but we might attribute it to chemotherapy side effects..." (Participant 14).

3. Poor provision of community-based services

The data highlighted that it was better to provide healthcare services to cancer patients in absentia and at their homes as much as possible. Patients should also be acquainted with the structure of the health system so that they can participate in deciding how to access healthcare services. Under this main category, two subcategories were discovered, including the telemedicine gaps and the necessity of providing home care.

3.1. Telemedicine gaps

The participants noted not using telemedicine for providing care to cancer patients during the COVID-19 pandemic. The data showed that the use of telemedicine could facilitate providing therapeutic and care services to cancer patients. Addressing the fear of patients from visiting medical centers and the necessity of using telemedicine, one of the participants mentioned, "...it would be highly beneficial if their therapeutic services be delivered via telemedicine at their homes..." (Participant 10).

3.2. Necessity of providing home care

Data analysis showed that providing home-based care was a beneficial approach for cancer patients during the COVID-19 pandemic. Accordingly, home-based care can help reduce the disease burden and boost the satisfaction of patients and family members due to avoiding unnecessary traveling. The participants believed that home-based care provision should have been employed by health policymakers during the COVID-19 period. The data showed that this approach could increase patient satisfaction by facilitating access to health services, reducing the need for visiting medical centers, properly managing patients' referrals, providing more empty hospital beds, and reducing the workload of hospital staff. Data analysis showed that during the COVID-19

pandemic, compared to the pre-pandemic time, cancer patients were more willing to receive home care due to commuting problems and their fear of going to a hospital. In this regard, a home-based palliative care physician highlighted the willingness of cancer patients to receive care services at home after vs. before the pandemic, "... Patients were more willing to receive care services at home ..." (Focus-Participant 7).

4. Lack of comprehensive care

Data analysis showed that cancer patients, as a vulnerable group of society, were more prone to psychological problems secondary to the fear of contracting the COVID-19 infection and obligations to adhere to numerous disease prevention regulations. These patients needed to be cared for in different health dimensions. The data showed that the care provided to cancer patients was not comprehensive in terms of the physical, mental, and social dimensions. In this main category, three subcategories were identified, including the lack of palliative care, lack of spiritual care, and poor social support.

4.1. Lack of palliative care

Data analysis indicated there was negligence in providing home-based palliative care to cancer patients during the COVID-19 pandemic, and the health system seemed to fail to adequately deliver palliative care services to cancer patients during this critical time in Iran. In this regard, one oncologist in the focus group session emphasized the importance of providing home-based palliative cancer care to boost hospitals' capacities for inpatient admission and prevent the burnout of medical staff, "...Providing home-based palliative care would have saved the lives of many who died of cancer and other incurable diseases during the pandemic..." (Focus-Participant 11).

4.2. Lack of spiritual care

Data analysis illuminated a gap in cancer care provision during the COVID-19 pandemic, and that was the lack of psychological counseling. One of the oncologists attending the focus group session referred to the need of cancer patients for psychological support and the necessity of providing them with psychological counseling, "... Psychological counseling can have a remarkable role in optimizing care provision during the pandemic..." (Focus-Participant 4).

4.3. Poor social support

Data analysis showed that one of the basic needs of cancer patients during the COVID-19 pandemic was the need for communicating with the family, friends, and the community. The data showed that cancer patients, especially those with end-stage disease, had only relative independence before the pandemic, and the COVID-19

disease disrupted the support that they used to receive from relatives and friends. Therefore, this gap should have been compensated for by the health system during this critical time. In this regard, one of the participants highlighted the necessity of providing emotional support to cancer patients by relatives, "...My mother really needed to see relatives..." (Participant 4).

5. Lack of public education

Data analysis showed that one of the gaps during the COVID-19 outbreak was over-focusing on treatment, while neglecting the pandemic-related educational needs of patients with chronic diseases. One of the participants accentuated the importance of training cancer patients in preventive measures during the COVID-19 pandemic, "...The whole focus of the country's health system was directed towards treatment..." (Focus-Participant 1). Another participant stated, "... there was a gap in the training of patients with chronic conditions and related government notifications..." (Focus-Participant 11).

6. Predicting changes in cancer incidence and mortality trends

Cancer patients were deprived of many of their diagnostic and therapeutic opportunities during the pandemic to avoid exposure to the virus, leading to gradual changes in the identification and survival of cancer patients compared to the pre-pandemic era.

In this regard, one of the oncologists stated, "...For some cancers, such as multiple myeloma, the mortality rate was much higher during the pandemic... we expected a growth in cancer incidence due to the mutations and inflammation caused by the COVID..." (Participant 14).

7. Ethical Challenges

Amid the COVID-19 pandemic, cancer patients and their families faced inappropriate behaviors of medical staff and the reduced quality of the care provided. The volunteers employed during the pandemic could have inflicted harm on patients because they were unfamiliar with the treatment process and protocols. One of the participants whose mother was injured during hospitalization stated, "...my mother's hand bruised because of medical negligence..." (Participant 12).

Discussion

This qualitative study was conducted to explain the stakeholders' perception of healthcare provision to cancer patients during the COVID-19 pandemic. The findings showed that cancer patients encountered many challenges in accessing health services during the pandemic.

Parallel with the findings of the present study, the results of a qualitative study showed that the COVID-19 pandemic was a threat to cancer patients and disrupted the process of care provision to these patients (12).

In this study, the data showed that one of the threats to cancer patients was the delayed delivery of treatments. Consistently, other studies showed that cancer patients were inflicted by the discontinuation of specific cancer treatments (13,14). The American Society of Clinical Oncology proposed that an appropriate plan should be in place for cancer patients who are not currently under treatment to ensure an integrated therapeutic course (15). Moreover, chemotherapy plans were recommended to be reviewed to minimize doctor visits, and oral therapeutic regimens should be prescribed as much as possible to mitigate immunosuppression. For cancer patients infected with COVID-19, cancer treatments should cease until the patient recovers from the infectious disease (16).

The findings of this study showed a reduction in the quality of the health services provided to cancer patients during the COVID-19 pandemic owing to various reasons. The results of other qualitative studies have shown that although virtual care is now a viable option to ensure public safety and protection, such models may not adequately meet the complex care needs of people with cancer (17,18). The findings of another study showed that most of the centers delivering services to cancer patients had to cut their routine services to these patients, some due to precautionary and preventive measures and others due to the shortage of resources, overwhelmed systems, inadequate manpower, and unavailability of medications (13). The global mobilization of pharmaceutical companies towards producing COVID-19 drugs played a role in the global shortage of some chemotherapeutics, urging health systems to amass adequate pools of these drugs (19). A number of reputable global pharmaceutical agencies started to issue initiatives and guidelines to obviate drug shortage during the COVID-19 pandemic (19,20). Taking into account the economic and pharmaceutical ramifications of COVID-19 and the health system's structure (21), these measures can be employed by drug suppliers in each country, besides implementing creative measures, to prevent shrinkage in the resources of cancer drugs.

The data showed that one of the needs of cancer patients during the COVID-19 pandemic was to promote community-based care, which could preferably be provided in absentia (22,23). The findings of another study showed that the COVID-19 pandemic hurdled the provision of community-based health services (24). Telemedicine can be used to communicate with patients and provide them with psychological and physical counseling to avoid unnecessary referrals and admissions to hospitals (25,26), which can boost patients' and caregivers' satisfaction (27).

The findings of this study showed that during the COVID-19 pandemic, one challenging task was to accurately characterize and manage the clinical condition of cancer patients infected with the COVID-19 disease.

This is due to the overlap between the symptoms of the COVID-19 disease and cancer. In line with the findings of the present study, it was noted that patients with lung cancer might reveal pneumonia-like lesions in lung CT scans, interfering with the diagnosis of COVID-19 via this procedure (28,29). On the other hand, cancer patients treated with immunosuppressive drugs may show symptoms mimicking the COVID-19 disease (30), which can disrupt diagnostic and therapeutic procedures in these patients (31). Therefore, in accordance with the type of cancer, these patients should receive appropriate education about the symptoms of COVID-19 (32-34). Such patients should also undergo a more thorough clinical examination (30).

According to the findings of this study, there were increasing trends in cancer incidence and mortality in Iran during the pandemic. In line with the observations of this study, another study predicted that the disruption of cancer care amidst the COVID-19 pandemic could increase cancer-related deaths by 2.0% in Canada from 2020 to 2030 (35). The advanced age of cancer patients (36) and their compromised immunity owing to immunosuppressive therapies (37,38) expose them to a higher risk of COVID-19. According to statistics, 6% of COVID-19 patients also suffer from cancer (39), which is much higher than the global rate of cancer (0.2%) (40). During the COVID-19 pandemic, most health resources were directed towards treatment, ignoring preventive measures which are as important as therapeutic plans for controlling the disease outbreak among the public and patients with chronic disorders.

One of the limitations of this study was that sample recruitment was conducted amid the COVID-19 crisis. Thus, because of the vulnerability of cancer patients, some interviews were conducted in absentia. However, by holding focus group sessions and some face-to-face interviews, it was attempted to minimize the impact of this restriction on the accuracy of the data.

Conclusion

The findings of the present study revealed several challenges faced by cancer patients in accessing care services, complicated by delayed diagnosis, as well as delayed therapy initiation and continuation. Providing community-based care services and strengthening the infrastructure for virtual counseling can help reduce the need for traveling to healthcare centers. This approach can also help keep more empty hospital beds and reduce the workload of medical staff. Health policymakers must direct their attempts toward establishing the necessary infrastructure to ensure the adequate provision of drugs to cancer patients and the continuation of screening programs for early cancer diagnosis.

Acknowledgements

The authors would like to profusely thank all individuals who

supported and helped us to conduct this study.

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Competing Interests

The authors declare that they have no conflict of interest.

Ethical Approval

This study was approved by the Ethics Committee of Lorestan University of Medical Sciences "IR.LUMS.REC.1400.016". The objectives and protocol of the study were explained to all participants. Verbal and written informed consent was obtained from the participants.

Funding

This study funded by the Lorestan University of Medical Sciences, Iran, and grant number is 1742.

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