## **Research** Paper Stakeholders' Perceptions of Home-based Palliative Care for Cancer Patients During the COVID-19 **Pandemic: A Qualitative Study**

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### ABSTRACT

Background: During the COVID-19 pandemic, care for cancer patients may be disrupted for several reasons, leading to disease progression. Home-Based palliative care, if properly managed, can provide easy and safe access to care services for these patients. This study aimed to explore stakeholders' perceptions of home-based palliative care for cancer patients during the pandemic.

Methods: This qualitative study was conducted using conventional content analysis in Tehran, Iran, in 2021. By purposeful sampling, 19 participants, including cancer patients receiving home-based care services from the Iranian Cancer Control Center (MACSA) and their families, as well as the homecare providers, were recruited. The study data were generated by conducting 19 semi-structured interviews and a focus group session and analyzed based on the method proposed by Lundman and Graneheim.

Results: Qualitative analysis of the data revealed 5 main categories: "need for remote services", "disease transmission reduction", "management requirements", "burnout", and "reducing hospital workload."

Conclusion: The use of telemedicine, the existence of call centers, and the designing of appropriate guidelines, along with the help of qualified personnel, prevent the transmission of COVID-19 to cancer patients in-home palliative care and lead to the provision of comprehensive care to these patients. This approach to care helps avert staff burnout and reduces the number of occupied beds in hospitals.

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#### Highlights

• Cancer patients are more vulnerable to COVID-19 disease.

• Home-based palliative care can improve the quality of life of patients and caregivers by reducing the length of hospitalization.

• The participants believed that home-based palliative care for cancer patients is better provided by recruiting qualified staff, the use of telemedicine, the existence of call centers, and appropriate guidelines.

• This approach to care helps prevent disease transmission to cancer patients and reduces staff burnout.

#### Plain Language Summary

The experiences of people caring for cancer patients during the COVID-19 crisis can help plan homecare for those with advanced cancer during the pandemic. The findings of this study showed that to prevent the transmission of CO-VID-19 to cancer patients in home-based palliative care, telemedicine should be employed. This type of care should be done using appropriate guidelines and qualified care providers. Providing home palliative care to cancer patients during the pandemic could lead to the reduction of care staff burnout as well as vacant hospital beds.

#### **1. Introduction**

OVID-19 was first reported on December 31, 2019, in Wuhan, China, and shortly after turned into a pandemic. By July 1, 2021, the number of infected patients and dead bodies of the disease reached 182996268 and 3963152 worldwide

(WHO, 2020). The patients with cancer are more vulnerable to COVID-19 due to chemotherapy, surgery, and a suppressed immune system (Liang et al., 2020; Wang and Zhang, 2020; Kamboj and Sepkowitz, 2009; Li et al., 2014; Longbottom et al., 2016; Sica and Massarotti, 2017) and more likely to die (Garassino et al., 2020). Because of the high infectivity and pathogenicity of CO-VID-19 in patients with chronic diseases and those with compromised immune systems, caring for cancer patients during the pandemic has faced serious challenges (Lewis, 2020). Cancer patients may not refer to health centers during the pandemic for various reasons, such as fear of being infected, overcrowded hospitals, and lack of empty beds. This condition leads to delayed diagnosis, screening, and treatment which eventually leads to disease progression (Cannistra et al., 2020). The limited number of hospital beds, especially intensive care beds, and insufficient protective equipment for medical staff have created serious difficulties in providing care to these patients (Mohseni Afshar et al., 2022). To be able to provide care to cancer patients during the pandemic, many studies have accentuated the need to pay attention to home-based care to avoid hospitalization and ensure continuous care (Costantini et al., 2020).

Likewise, the prevalence of cancer in Iran is on a progressive rise, and the disease is the second leading cause of death in the country (WHO, 2021). The prevalence of the COVID-19 disease and its mortality rate in Iran also rose progressively during the pandemic, and until July 25, 2021, the number of infected and deceased people was 3691432 and 88800, respectively (Timeline CO-VID-19., 2020). Cancer patients in Iran, similar to other parts of the world, are vulnerable to COVID-19 disease.

The World Health Organization (WHO) has declared palliative care as an approach to upgrade the quality of life of end-stage cancer patients (WHA67, 2014). Palliative care has a holistic view of patients and includes different physical, psychological, social, and spiritual dimensions of human beings (Heydari et al., 2019; Hojjat-Assari et al., 2021). Home-based palliative care can improve the quality of lives of patients and caregivers, reduce the length of hospitalization and referrals to the emergency departments (Owens et al., 2012) and also enable the occurrence of more deaths at home (Kim and Tarn, 2016).

In Iran, home-based palliative care is rarely provided to end-stage cancer patients, and these patients occasionally receive care services from several scattered centers (Nasrabadi et al., 2019; Heydari et al., 2017). The Iranian Cancer Control Center (MACSA) is a charity center that has been the first and largest provider of specialized palliative care services to cancer patients in Iran since 2009. The services provided at MACSA across the country include medical, nursing, and rehabilitation services, as well as spiritual, psychological, and nutritional counseling and casework. Because of the novel nature of COVID-19, different care and therapeutic needs of people with chronic diseases, especially those with advanced cancer, are still unknown during the pandemic (Young et al., 2021). Considering the limitations of home-based palliative care in Iran (Hojjat-Assari et al., 2021) and the various problems of cancer patients in the face of this disease (Mohseni Afshar et al., 2022), understanding home-based palliative care for cancer in this particular context can help develop effective strategies and therapeutic plans for them.

The experiences of people engaged in palliative care of cancer patients during the Covid-19 crisis can be useful in planning home care and treatment protocols for people with advanced cancer during the pandemic. Qualitative research can be a suitable approach to understanding the different dimensions of care in the COVID-19 disease and to identifying the care needs of patients with advanced cancer and its dimensions in the specific cultural, economic and political context of each region. Accordingly, this study explored stakeholders' perceptions of home-based palliative care for cancer patients during the COVID-19 pandemic.

#### 2. Materials and Methods

This qualitative study was conducted using the conventional content analysis method from April to October 2021.

#### Study participants

The participants were 19 people consisting of cancer patients receiving home-based care services from the MACSA, their families, and the home care providers. The participants were recruited by purposeful sampling. The patients had been under MACSA care for at least one month. Other inclusion criteria were as follows: at least 18 years of age, orientation to time and place, not having COVID-19 disease at the time of the interview, lacking scheduled chemotherapy at the time of the study, and consent to participate. Family members were primarily responsible for patient care. Doctors, nurses, rehabilitation experts, and managers involved in providing homecare services to these patients were also included. The exclusion criteria for all groups were as follows: suffering from psychological disorders, being diagnosed with COVID-19, or any other acute illnesses during the study period.

#### Data collection

The study data were collected through 19 semi-structured face-to-face or telephone interviews and a focus group session during the COVID-19 pandemic. The interviewer was a palliative care physician knowledgeable in cancer, COVID-19 disease, and qualitative study. For telephone interviews, the patient's information was initially obtained by referring to MASCA. After explaining the aims of the study to the participant, the time of the interview was set. The duration of the interview ranged from 15 to 40 minutes. In face-to-face interviews, cautions related to COVID-19 were observed. The main

query of the study was, "Would you please share your experiences with palliative care at home during the pandemic?". Using probing questions, the interviewer guided the direction of the interviews to achieve the research objectives, such as "Would you please tell me about your experiences on receiving advanced home-based cancer care during the pandemic?" and "How did you receive cancer care?". The questions were slightly modified depending on the participant's position as a patient, a family member, or a member of the health care team. The interviews continued until no new information was discovered in data analysis (i.e., data saturation).

To use the opinions of experts and to understand better the dimensions of the phenomenon, a focus group session was also held. The focus group questions were focused on the ambiguities that arose during the individual interviews. Some participants in this session were the same ones who were interviewed in person. The main researcher modified the session. The data were recorded with the participant's consent.

#### Data analysis

In this study, the collection and analysis of the data were conducted simultaneously based on Lundman and Graneheim method (Graneheim and Lundman, 2004). Immediately after each individual and focus group interview, audio files were listened to several times and were transcribed verbatim. Then the written texts were read several times, and the initial codes were extracted. The primary codes related to each other were merged based on their similarities to form categories. Finally, the concepts hidden in the data were extracted.

#### Trustworthiness

The approach proposed by Guba and Lincoln (Nowell et al., 2017) was used to confirm the trustworthiness of the findings. For credibility, the authors engaged with the data for about 8 months. Data gathering was conducted through face-to-face and focus group interviews. For a maximum variation of sampling, participants with different ages, gender, position, knowledge, specialty, and

work experience were interviewed. Member checks were achieved by sharing the findings with some participants and obtaining their opinions. To ensure the confirmability of the data, a peer check was also done by two faculty members with expertise in qualitative research. An inquiry audit was used to ensure dependability. The interviews and analyses were shared with a professor (not involved in the study project) to verify the findings. To ensure transferability, a thick description of the study context was performed.

#### 3. Results

In total, 19 interviews were conducted with 12 women and 7 men (Table 1). The focus group session was held with the participation of 7 people, including 4 women and 3 men (Table 2). Qualitative data analysis revealed 5 main categories and 15 subcategories (Table 3).

#### Need for remote services

Data analysis showed that for delivering home-based palliative care, care providers, institutions, and caregivers should collect all their efforts to prevent the transmission of the COVID-19 disease to cancer patients and their families. These patients may be exposed to the disease when referred to health centers or when caregivers visit to deliver home care. Also, it was shown that cancer patients might be exposed to the SARS-CoV-2 virus (COVID-19 causative agent) at the time of referral to health centers for medical services. Therefore, for the safety of these patients, care programs should be remotely performed at homes as much as possible. Under this category, there were three subcategories: "changing

Table 1. Characteristics of the participants in the individual interviews

Codes	Position	Educational Level	Work Experience (y)	Sex
P1	Mother of the patient	Under Diploma		Female
P2	Patient	Diploma		Male
P3	Daughter of the patient	Bachelor		Female
P4	Daughter of the patient	Postgraduate		Female
P5	Sister of the patient	Diploma		Female
P6	Technical manager	Physician	13	Female
P7	Patient	Under Diploma		Female
P8	Wife of the patient	Under Diploma		Male
Р9	Coordinator of homecare institute	PhD in human sciences	12	Female
P10	Psychological advisor	Postgraduate psychology	8	Male
P11	Social worker	Bachelor of social work	8	Female
P12	Daughter of patient	Bachelor		Female
P13	Patient	Diploma		Female
P14	Oncologist	Physician	14	Male
P15	Patient	Under Diploma		Female
P16	Homecare nurse	Bachelor in Nursing	10	Female
P17	Homecare nurse	Bachelor in Nursing	4	Male
P18	Manager of home healthcare	Postgraduate	30	Male
P19	Homecare nurse	Bachelor in Nursing	4	Male

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Codes	Position	Educational Level	Work Experience (y)	Sex
F1	Manager of home healthcare	Postgraduate	30	Male
F2	Physician	Oncologist	28	Male
F3	Coordinator of homecare institute	PhD in human sciences	12	Female
F4	Physician	Hematologist	33	Female
F5	Educational manager of homecare institute	Palliative care physician	23	Female
F6	Homecare nurse	PhD in Nursing	19	Male
F7	Technical manager	Physician	13	Female
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Table 2. The characteristics of the participants in the focus group interviews

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the home visit schedule to telemedicine", "the need for creating electronic records for cancer patients", and "the need for a call center."

Changing the home visit schedule to telemedicine

Data analysis showed that one of the parameters that can help protect cancer patients against COVID-19

disease is providing healthcare and counseling via telemedicine. The participants' experiences showed that to reduce patients' visits to healthcare centers, homecare providers should have rescheduled in-person home-based care provision programs for cancer patients in the time of absence via telemedicine-based strategies during the early months after the onset of the pandemic. In this regard, one of the home care offi-

 Table 3. Categories and subcategories extracted from the data

Main Categories	Subcategories		
	Changing the home visit schedule to telemedicine		
Need for remote services	The need for creating electronic records for cancer patients		
	Need for call center		
	Ensuring the health of caregivers		
Disease transmission reduction	Equipment safety		
Disease transmission reduction	Commuting management		
	Providing requirements for death at home		
	The need for recruiting a competent workforce		
Managament vasuivamenta	The need for developing homecare guidelines		
Management requirements	Providing comprehensive services		
	Compliance with ethical principles		
Durraut	Manpower shortage		
Burnout	Increased workload		
Deducing beenitel workload	Reducing the number of occupied beds		
Reducing hospital workload	Reducing staff workload		

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cials noted: "...We have rearranged home visit plans according to COVID-19 instructions... face-to-face home visits were replaced with telephone visits..." (P9). Another participant about caregivers' willingness to provide services via telemedicine, despite the inevitability of some in-person visits for physical problems, mentioned: "...Caregivers are now enthusiastic about conducting online counseling... " (P10).

# The need for creating electronic records for cancer patients

The findings revealed that one factor that increases the risk of contracting COVID-19 in cancer patients or their family members is their referral to health centers to create or complete a medical profile or to receive consumable drugs and equipment. Creating patient electronic databases from admission to registration for receiving required medications and equipment could reduce the risk of disease transmission. One of the homecare physicians addressed the need for following up with patients and delivering required health services electronically: "... When an electronic prescription is issued, there should be pharmacies to receive it and insurance companies to cover its expenses..." (P6). Another participant stated: "...Prescriptions should be extended electronically..." (P9).

#### Need for call center

The participants believed that one of the ways that patients can receive cancer care services at home without needing in-person visits is to set up a call center in health care facilities. In this regard, an oncologist highlighted the importance of using telemedicine during the pandemic and future epidemics: "...In providing palliative medicine, considering that patients do not need to move much, physicians can resolve many problems through the call center...Caregivers can also perform most of their work remotely through the call center... "(F4).

#### **Disease transmission reduction**

Data analysis showed that due to the vulnerability of cancer patients to the COVID-19 disease, the caregivers providing home-based services should do their best to follow health instructions to avoid disease transmission to patients and their family members. In this category, there were four subcategories: "ensuring the health of caregivers", "equipment safety", "patients' commuting management", and "providing requirements for death at home." Ensuring the health of caregivers

It was shown that caregivers might be COVID-19 carriers and transmit the disease to patients. Therefore, the health of caregivers should be affirmed in terms of the COVID-19 disease. In addition, by observing health protocols, they should help maintain the safety of patients and family members. For this purpose, caregivers are obliged to adhere to health protocols when visiting patients at home, and also, it is required to employ vacant COVID-19 caregivers for delivering home-based services. In this regard, healthcare providers must enter the patient's home wearing protective clothing. One of the homecare managers mentioned: "...Caregivers must go to patients' homes wearing gowns and shields ... " (P6). It was also shown that the managers of homebased palliative care providing centers should recruit the personnel who have had the least contact with COV-ID-19 patients during the pandemic. In this regard, one of the participants stated: "...A number of our nurses were working in hospital ICUs...during the pandemic waves, we excluded them... "(P9).

#### **Equipment safety**

The management of the equipment provided (e.g., suction machine, oxygen generator machine, wheelchair...) to patients and families is one of the items that should be considered when providing care to cancer patients. Personal protective equipment (PPE) should be sufficiently delivered to patients and families. On the other hand, the equipment temporarily consigned to them should not be the source of contamination. It was shown that some patients do not follow health protocols for various reasons, such as poverty or ignorance. In addition to promoting satisfaction, distributing protective equipment packages among families can be considered a method for enriching the culture of using protective equipment to prevent infection with COVID-19 disease. In this regard, one of the participants shared his experience: " ... During the second wave of COVID-19, we started handing out packs of face masks and disinfectants at the same time as we visited homes... this was both culture-building and helping to prevent disease transmission ..." (P9).

The participants' experiences showed that managing home care equipment and how to translocate them, considering the possibility of disease transmission via contaminated surfaces, were challenging issues that could potentially propagate the disease. In this regard, one of the participants said: "...The tools and equipment such as oxygen generator that we carry to patients' homes should not be contaminated with COVID-19 virus..." (P18).

#### **Commuting management**

One of the aspects of disease transmission reduction was to manage their commuting to hospitals to receive therapeutic and palliative care and medications. In this regard, referral to the hospital should have been managed to reduce patients' exposure to the virus by facilitating their access to medications. Data analysis showed that to prevent being infected with the COVID-19 disease, cancer patients should refer to hospitals in a scheduled manner if needed, and hospitals should consider special beds for critically-ill patients who need urgent care. This measure can avoid their confusion and wandering in emergency departments and, therefore, their exposure to the disease. In this regard, one of the participants stated: "... Patients' referral to the hospital should be managed to avoid their wandering in emergency departments... " (P9).

According to the participants' experiences, one of the factors that could promote cancer patients' safety during the COVID-19 pandemic is to facilitate their access to required medications and narcotic analgesics. Because of COVID-19 restrictions, these patients' access to opioids should be considered for longer intervals. In this regard, one of the participants stated: ".... As for the administration of opioids...we have always given 5 pills, which during the pandemic increased to 10 pills at a time..." (P9). Another participant said: "...In my opinion, the government can cooperate with several centers to distribute drugs..." (P19).

## Providing necessary requirements for death at home

Data analysis showed that one of the measures that can restrict the spread of the disease in the community is providing the ground for a calm death at home. Data analysis showed that patients dying at home leads to a peaceful death experience, reduces visits to medical centers, prevents overcrowding of patients, and limits the spread of disease. Homecare authorities also tried to provide conditions for end-stage cancer patients to die at home and with their families so that they would not be involved in the hospital's problems in the last moments of life. In this way, the workload of hospitals and the exposure of family members to COVID-19 would also be reduced.

In this regard, one of the participants mentioned: "... you have to talk to terminally-ill patients and convince them to choose home for the last moments before death... In the hospital, they are exposed to the environment infected with COVID..."(P9). Another participant mentioned: "... If this patient died in the hospital, the family would also go to the hospital with him, and the possibility of contracting the COVID-19 disease was high for them..." (P19).

#### **Management requirements**

Cancer patients endanger their health and their companions when they go to health centers. The participants believed that conditions should be provided so that these people can enjoy the comprehensive care of the health staff at home until death. One of the things that can help in providing comprehensive and ethical services to these patients is designing appropriate guidelines for the care of these patients outside of medical centers. Four subcategories were identified under this main category: "the need for recruiting competent workforce", "the need for developing home care guidelines", "providing comprehensive services", and "compliance with ethical principles."

#### The need for recruiting competent workforces

Data analysis revealed that the Achilles' heel of home palliative care delivery is the confidence of cancer patients and their families in the professionalism of the care provided and the staff providing the care. The participants' experience indicated the necessity of providing standard healthcare services to cancer patients. They believed that professional and qualified caregivers should be employed to gain the trust of families and provide quality services. In this regard, one of the participants mentioned: "... The care team should be truly qualified..." (P9), and another participant in the focus group said, "...Nurses who provide care at home should be more capable than hospital nurses..." (F1).

#### The need for developing home care guidelines

The findings showed that healthcare providers should adhere to a set of guidelines to provide appropriate care to patients. However, since few guidelines were available at the onset of the COVID-19 pandemic, care centers should have developed such guidelines. A physician providing home-based palliative care services noted the lack of appropriate guidelines in this area during the CO-VID-19 pandemic: "...No specific guideline is available to physicians..."(P6). The same participant explained his experiences preparing such instructions by some home care centers: "... In our center, we prepared a series of instructions for this problem such as wearing foot covers when entering the patient's home" (P6). Another participant said: " .... We determined the number of required caregivers based on the size of the house or the type of the disease..." (P9).

Providing comprehensive services

It was shown that cancer patients should receive comprehensive care services and be supported physically, psychologically, and socially during the COVID-19 pandemic. The participants emphasized the need to consider parameters such as wounds on the patient's body, pain management, catheter replacement, and care of the skin and other body parts during the care process. In this regard, one of the physicians providing palliative care declared: "... their physical symptoms under the influence of the disease (i.e., COVID-19) are not easily controllable ..." (F5).

The findings indicated that patients might experience mental disorders during the pandemic for various reasons, including social isolation, disease exacerbation, and fear of death. Therefore, psychological and spiritual counseling should be considered important care dimensions. One of the homecare nurses reiterated the patients' psychological problems: "... I see the patient becoming depressed or stressed..." (P19). A patient raised concerns about developing mental issues due to home quarantine: "... You are tormented mostly by remaining at home worrying about contracting the CO-VID-19 disease..." (P1).

#### Compliance with ethical principles

The findings indicated that during the provision of home-based palliative care services, a series of ethical challenges might arise for the service provider or recipient, such as the need to consider the economic status of families in providing care, providing standard services, meeting the requirements of death in the home, keeping patients and family members safe, obtaining family and patient consent to provide services at home, as well as protecting patients and family members from COV-ID-19 during the care delivery process. One participant addressing this issue mentioned: "...Care should be provided for the patient and the family so that another problem is not added to the patient's problems... such as the family getting sick due to the carelessness of the service provider.... or an additional financial burden be imposed on the patient and family...." (P9)

#### Burnout

Data analysis demonstrated that the staff providing home-based palliative care services during the pandemic might develop exhaustion and burnout due to increased workload and manpower shortage because of illness or dismissal. Within this main category, there were two categories of "manpower depletion and increased workload during the COVID-19 pandemic".

#### Manpower shortage

Data analysis showed that during the COVID-19 pandemic, home-based palliative care centers suffered from staff shortages, and part of this shortage could be related to exhaustion, becoming ill, or fear of contamination. One of the participants said: "...Another problem is an insufficient number of caregivers. They are afraid of spending a long time with patients, so the number of available caregivers has decreased..." (P6).

#### Increased workload

The COVID-19 pandemic increased the administrative and technical workload of home care centers. These centers should have delivered their usual services with only 50% of the workforce capacity. On the other hand, since the spread of the COVID-19 disease, patients and their families' needs for care has increased, adding up to this workload. Data analysis also showed that family caregivers distanced themselves from patients due to fear of infection, increasing the workload of official caregivers. One of the participants cited this notion: "...Although the patient's daughter has been taking care of him, now because of COVID-19 ... the daughter is afraid to have direct contact with the patient, and this has made it difficult for us to communicate with the patient ..." (P6).

#### **Reducing hospital workload**

During the COVID-19 pandemic, hospitals were overcrowded with patients, and empty beds were unavailable to admit new COVID-19 cases. The data demonstrated that home-based palliative care could reduce the burden on the health system and hospitals by keeping patients at home. Under this main category, there were the two subcategories of "reducing the number of occupied beds" and "reducing staff's workload."

#### Reducing the number of occupied beds

Participants' experiences showed that delivering homebased palliative care to cancer patients at home could increase the availability of more empty beds for COV-ID-19 patients. A hematologist participating in the focus group session addressed the importance of prioritizing home-based care and the need for policymakers to pay attention to this issue: "Due to overcrowding in hospitals, cancer patients should be cared for at home as much as possible... With this, hospital beds are vacant and accessible for patients with COVID-19 ..." (F4), and another specialist mentioned: "... Hospital beds are limited ... and home-based care can be helpful ..." (F2).

#### Reducing staff workload

Data analysis showed that one of the benefits of homebased palliative care was reduced referrals to hospitals and, therefore, a reduction in hospital staff workloads. One of the participants cited this as: "...the purpose of home-based care is to obviate the need for a patient to refer to the hospital...and this can provide nurses with an opportunity to rest for a while..." (P19).

#### 4. Discussion

This qualitative study was conducted to explain stakeholders' perceptions of home-based palliative care for cancer patients. The findings indicated 5 main categories: "the need for remote services", "disease transmission reduction", "management requirements", "burnout", and "reducing hospital workload."

The participants believed that to prevent these patients from contracting the virus, homecare services should be delivered through telemedicine as much as possible. Various studies have shown that telemedicine can increase access to health care services, reduce face-to-face communication, decrease hospitalization rates, raise death with dignity at home, and finally provide the opportunity for delivering ongoing care and performing early interventions to prevent disease complications (Stowe and Harding, 2010; Tuckson et al., 2017; Steindal et al., 2020). Therefore, due to the need for cancer patients for continuous care and the necessity for reverse isolation, efforts should be made to deliver most of their services via telemedicine during the pandemic.

It was shown that during the provision of home care for cancer patients, all aspects should be considered to minimize the risk of COVID-19 transmission to these patients. Cancer patients are suggested to receive care in a separate room and, if possible, from a single caregiver apart from other family members. Moreover, care providers should also use appropriate personal protective equipment when entering the patient's room (Motlagh et al., 2020). Caregivers should also contact patients before visiting the home to be aware of the symptoms of COVID-19 in the patient and the family. In addition, they should wear protective equipment such as face masks, gloves, and disposable gowns during home visits (Porzio et al., 2020). The findings of this study highlighted the importance of providing comprehensive physical, psychological, and social support for cancer patients during the pandemic. Another study accentuated pharmaceutical and non-pharmaceutical home-based palliative care for patients with hard-to-treat diseases (Maddocks et al., 2019). Another study underlies the psychological problems of cancer patients due to fear of contracting the infection and becoming isolated (Kedia et al., 2020). On the other hand, the decrease in in-person visits by healthcare providers to patients' homes has made it more difficult to diagnose mental health problems (Peters et al., 2020), and empathy with patients has faded (Cameron et al., 2015). However, palliative care can alleviate distress in these patients (Delibegovic and Sinanovic, 2013).

Psychological counseling, as one of the most important support programs in palliative care, is required to be provided to patients to help them cope with the condition. Also, video-based communications between patients and their friends and family members can diminish the heavy burden of the isolation period on the patient (Sutherland et al., 2020; Toulabi et al., 2021). Spiritual care is another important need of cancer patients during the pandemic. Therefore, to augment patients' calm and peace, they should receive counseling by clergies in person or via social media (Organization, 2018). Our findings showed that one of the issues that should be considered during caring for cancer patients at home during the pandemic is utilizing appropriate care guidelines. In this regard, the European Society for Medical Oncology (ESMO) has developed a guideline for providing care to cancer patients during the COVID-19 pandemic, in which solving mental and psychological problems of patients and providing home care in person or by phone is highlighted (Schoenmaekers et al., 2020).

Our data showed that during the pandemic, the workload of caregivers, especially nurses, increased dramatically due to the community's excessive demand for medical services. Also, some medical staff resigned from their duties due to the fear of contamination and heavy workloads, and others were excluded from the care programs due to illness. These events have led to the exhaustion and burnout of caregivers. Also, another study pointed out the burnout of caregivers during the COVID-19 outbreak (Young et al., 2021). Medical staff is exposed to psychological problems and burnout due to extended work shifts, high workload, and fear of becoming infected (Lai et al., 2020), which can limit their capability to provide quality palliative care to patients (Maslach et al., 2001). Based on this, the National Comprehensive Cancer Network (NCCN) has published a guideline for stress management of health workers during the COVID-19 pandemic (Cinar et al., 2020). Therefore, it seems necessary that authorities support medical staff with proper planning and implementing professional health principles.

Our data showed that home-based palliative care could reduce the workload of hospitals and the number of occupied beds, which could diminish the workload of healthcare staff. According to reports, the rate of inhome mortality has increased during the pandemic (Raleigh, 2020), which, based on our findings, can shrink crowds in hospitals and the workload of medical staff.

One of the limitations of this study was that we conducted sampling amid the COVID-19 pandemic, and due to the vulnerability of cancer patients, some interviews were conducted in absentia. However, by holding several face-to-face interviews and a focus group session, it was tried to minimize the impact of this limitation on the accuracy and authenticity of the data. Like other qualitative studies, the findings should be used with caution in other contexts.

#### 5. Conclusion

The findings of this study showed that the development of home-based palliative care could be very helpful for advanced cancer patients during the pandemic. Also, our results show that the management of patients and family caregivers should be such that their visits to hospitals during the pandemic are minimized as much as possible so that hospital resources are available to other patients and the safety and quality of life of cancer patients at home is ensured. In this way, the workload of health workers is also reduced, and their burnout is prevented. Despite the many benefits of palliative care at home, the fear of contracting COVID-19 is an obstacle for these patients and their families to use home care services. The clients must make sure about the safety of visits and services. Also, healthcare services should be provided via telemedicine as much as possible, and if the presence of caregivers at home is inevitable, safety protocols must be fully observed to reduce the risk of patient exposure to the infection.

#### Ethical Considerations

#### Compliance with ethical guidelines

This study was approved by the Ethics Committee of Lorestan University of Medical Sciences (Code: IR.LUMS.REC.1400.016). All participants were assured about the anonymity and confidentiality of information and audio files. Written and verbal informed consent was obtained from the participants.

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#### Authors' contributions

Conceptualization and supervision: Suzanne Hojjat-Assari, Heshmatolah Heydari and Vahid Kaveh; Methodology: Suzanne Hojjat-Assari and Heshmatolah Heydari; Investigation, writing–original draft, and writing–review & editing: All authors; Data collection: Ghazal Razani, Kosar Hossinie and Romina Sadeqian; Data analysis: Suzanne Hojjat-Assari and Heshmatolah Heydari; Funding acquisition and Resources: All authors.

#### Conflict of interest

The authors declare no competing interests.

#### References

- Cameron, R. A., et al., 2015. In search of compassion: A new taxonomy of compassionate physician behaviours. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 18(5), pp. 1672–85. [DOI:10.1111/hex.12160] [PMID] [PMCID]
- Cannistra, S. A., Haffty, B. G. & Ballman, K., 2020. Challenges faced by medical journals during the COVID-19 pandemic. *Journal of Clinical Oncology*, 38(19), pp. 2206-7. [DOI:10.1200/ JCO.20.00858] [PMID]
- Cinar, P., et al., 2020. Safety at the time of the COVID-19 pandemic: How to keep our oncology patients and healthcare workers safe. *Journal of the National Comprehensive Cancer Network*, pp. 1-6. [PMID]
- Costantini, M., et al., 2020. Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy. *Palliative Medicine*, 34(7), pp. 889-95. [DOI:10.1177/0269216320920780] [PMID] [PMCID]
- Delibegovic, A. & Sinanovic, O., 2013. The influence of palliative care on the level of anxiety and depression in lung cancer patients. *Medical Archives*, 67(4), pp. 263–5. [DOI:10.5455/medarh.2013.67.263-265] [PMID]
- Garassino, M. C., et al., 2020. COVID-19 in patients with thoracic malignancies (TERAVOLT): First results of an international, registry-based, cohort study. *The Lancet. Oncology*, 21(7), pp. 914–22. [DOI:10.1016/S1470-2045(20)30314-4] [PMID]

- Graneheim, U. H. & Lundman, B., 2004. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), pp. 105-12. [DOI:10.1016/j.nedt.2003.10.001] [PMID]
- Heydari, H., et al., 2019. Exploring health care providers' perceptions about home-based palliative care in terminally ill cancer patients. *BMC Palliative Care*, 18(1), pp. 66. [DOI:10.1186/ s12904-019-0452-3] [PMID] [PMCID]
- Heydari, H., Rahnavard, Z. & Ghaffari, F., 2017. Exploring the position of community-based nursing in Iran: A qualitative study. *International Journal of Community Based Nursing & Mid*wifery, 5(4), pp. 386-96. [Link]
- Hojjat-Assari, S., et al., 2021. Developing an integrated model of community-based palliative care into the primary health care (PHC) for terminally ill cancer patients in Iran. *BMC Palliative Care*, 20(1), pp. 100. [PMID] [PMCID]
- Kamboj, M. & Sepkowitz, K. A., 2009. Nosocomial infections in patients with cancer. *The Lancet Oncology*, 10(6), pp. 589-97. [DOI:10.1016/S1470-2045(09)70069-5] [PMID]
- Kedia, S. K., et al., 2020. Psychosocial interventions for informal caregivers of lung cancer patients: A systematic review. *Psychooncology*, 29(2), pp. 251-62. [DOI:10.1002/pon.5271] [PMID]
- Kim, S. L. & Tarn, D. M., 2016. Effect of primary care involvement on end-of-life care outcomes: A systematic review. *Journal of The American Geriatrics Society*, 64(10), pp. 1968-74. [DOI:10.1111/jgs.14315] [PMID]
- Lai, J., et al., 2020. Factors associated with mental health outcomes among health care workers exposed to coronavirus disease 2019. JAMA Network Open, 3(3), pp. e203976. [DOI:10.1001/jamanetworkopen.2020.3976] [PMID] [PMCID]
- Lewis, M. A., 2020. Between scylla and charybdis-oncologic decision making in the time of Covid-19. New England Journal of Medicine, 382(24), pp. 2285–7. [PMID]
- Li, J. Y., et al., 2014. Selective depletion of regulatory T cell subsets by docetaxel treatment in patients with nonsmall cell lung cancer. *Journal of Immunology Research*, 2014, pp. 286170. [DOI:10.1155/2014/286170] [PMID] [PMID]
- Liang, W., et al., 2020. Cancer patients in SARS-CoV-2 infection: A nationwide analysis in China. *The Lancet Oncology*, 21(3), pp. 335-7. [DOI:10.1016/S1470-2045(20)30096-6] [PMID]
- Longbottom, E. R., et al., 2016. Features of postoperative immune suppression are reversible with interferon gamma and independent of interleukin-6 pathways. *Annals of Surgery*, 264(2), pp. 370-7. [DOI:10.1097/SLA.00000000001484] [PMID]
- Maddocks, M., et al., 2019. Holistic services for people with advanced disease and chronic or refractory breathlessness: A mixed-methods evidence synthesis. *Health and Social Care Delivery Research*, 7(22). [DOI:10.3310/hsdr07220] [PMID]
- Mohseni Afshar, Z., et al. 2022. Challenges posed by COVID-19 in cancer patients: A narrative review. *Cancer Medicine*, 11(4), pp. 1119-35. [PMID] [PMCID]
- Motlagh, A., et al., 2020. COVID19 prevention & care; a cancer specific guideline. Archives of Iranian Medicine, 23(4), pp. 255-64. [DOI:10.34172/aim.2020.07] [PMID]

- Nasrabadi, A., et al., 2019. Designing a process model of home care service delivery in Iran: A mixed methods study. *International Journal of Community Based Nursing and Midwifery*, 7(4), pp. 288-99. [DOI:10.30476/ijcbnm.2019.73934.0]
- Nowell, L. S., et al., 2017. Thematic analysis: Striving to meet the trustworthiness criteria. *International Jour*nal of Qualitative Methods, 16(1), pp. 1609406917733847. [DOI:10.1177/1609406917733847]
- World Health Organization., 2018. Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises: A WHO guide. Geneva:World Health Organization. [Link]
- Owens, D., et al., 2012. Primary palliative care clinic pilot project demonstrates benefits of a nurse practitioner-directed clinic providing primary and palliative care. *Journal of the American Academy of Nurse Practitioners*, 24(1), pp. 52-8. [DOI:10.1111/ j.1745-7599.2011.00664.x] [PMID]
- Peters, L., et al., 2020. Psychological distress in a sample of inpatients with mixed cancer-a cross-sectional study of routine clinical data. *Frontiers in Psychology*, 11, pp. 591771. [DOI:10.3389/fpsyg.2020.591771] [PMID] [PMCID]
- Porzio, G., et al., 2020. Home care for cancer patients during covid-19 pandemic: The double triage protocol. *Journal of Pain and Symptom Management*, 60(1), pp. e5-7. [PMID] [PMCID]
- Raleigh, V., 2020. Deaths from Covid-19 (coronavirus): How are they counted and what do they show. The King's Fund. Avilable from: Accessed: Accessed: 3 March 2020. [Link]
- Schoenmaekers, J. J. A. O., Hendriks, L. E. L. & van den Beukenvan Everdingen, M. H. J., 2020. Palliative care for cancer patients during the covid-19 pandemic, with special focus on lung cancer. *Frontiers in Oncology*, 10, pp. 1405. [PMID] [PMCID]
- Sica, A. & Massarotti, M., 2017. Myeloid suppressor cells in cancer and autoimmunity. *Journal of Autoimmunity*, 85, pp. 117-25. [DOI:10.1016/j.jaut.2017.07.010] [PMID]
- Steindal, S. A., et al., 2020. Patients' experiences of telehealth in palliative home care: Scoping review. *Journal of Medical Internet Research*, 22(5), pp. e16218. [PMID] [PMCID]
- Stowe, S. & Harding, S., 2010. Telecare, telehealth and telemedicine. *European Geriatric Medicine*, 1(3), pp. 193-7. [DOI:10.1016/j.eurger.2010.04.002]
- Sutherland, A. E., Stickland, J. & Wee, B., 2020. Can video consultations replace face-to-face interviews? Palliative medicine and the Covid-19 pandemic: Rapid review. BMJ Supportive & Palliative Care, 10(3), pp. 271-5. [DOI:10.1136/bmjspcare-2020-002326] [PMID] [PMCID]
- Timeline: Coronavirus epidemic. Available from: . Accessed: 3 March 2020. [Link]
- Toulabi, T., et al., 2021. Exploring COVID-19 patients' experiences of psychological distress during the disease course: A qualitative study. *BMC Psychiatry*, 21(1), pp. 625. [PMID] [PMCID]
- Tuckson, R. V., Edmunds, M. & Hodgkins, M. L., 2017. Telehealth. *The New England Journal of Medicine*, 377(16), pp. 1585– 92. [DOI:10.1056/NEJMsr1503323] [PMID]
- Wang, H. & Zhang, L., 2020. Risk of COVID-19 for patients with cancer. *The Lancet Oncology*, 21(4), pp. e181. [DOI:10.1016/ S1470-2045(20)30149-2] [PMID]

- World Health Assembly, 67, 2014. Strengthening of palliative care as a component of comprehensive care throughout the life course. Avilable from: [Link]
- World Health Organization (WHO). WHO announces COV-ID-19 outbreak a pandemic, 2020. CDC. Available from: . Accessed: 3 March 2020. [Link]
- World Health Assembly., 2014. 19. *Strengthening of palliative care as a component of comprehensive care throughout the life course.* Geneva: World Health Assembly. [Link]
- Young, E., et al., 2021. Caregiver burnout, gaps in care, and COVID-19: Effects on families of youth with autism and intellectual disability. *Canadian Family Physician Medecin De Famille Canadien*, 67(7), pp. 506–8. [PMID] [PMCID]