Caring Challenges of Family Caregivers of Cancer Patients in the COVID-19 Pandemic: A Qualitative Study

Abstract

Background: Caregivers of cancer patients experience significant challenges that affect their physical, psychological, and social well-being. This qualitative study aims to explore the specific challenges faced by caregivers of cancer patients during the COVID-19 pandemic. Materials and Methods: The present study is a conventional qualitative study based on the Graneheim method for content analysis. Data were collected through semi-structured individual interviews with 11 family caregivers of cancer patients in Isfahan, Iran. Results: The challenges faced by family caregivers of cancer patients are classified into three main categories: 1) caregiver burnout which includes, "non-cooperation of the patient with the caregiver," "funding the costs of care and treatment," "lack of support for the family caregiver by the family and society," and "lack of knowledge and proper care skills." 2) Health threats to the family caregiver which include, "imbalance of self-care versus patient care," "disruption of a healthy lifestyle," and "occurrence of psychophysical symptoms caused by stress in caregivers." 3) Work-family-care conflicts which include: "conflict between patient care and family" and "conflict between patient care and work." Conclusions: This study provides additional insights into the personal and societal challenges faced by family caregivers of cancer patients during the COVID-19 pandemic. Based on our findings, health policymakers can take concrete steps to address these challenges and enhance the support for family caregivers, who play a crucial role in public health.

Keywords: Caregiver burden, caregivers, COVID-19, neoplasms, qualitative research

Introduction

COVID-19 has infected over 700 million people and caused around seven million deaths worldwide as of April 2024. In Iran, this number is 146,811 deaths out of almost 7,627,186 infections at the time of writing this article.[1] Each year, over 18 million new cancer cases are reported globally. Due to their compromised immune systems, cancer patients are susceptible to experiencing more severe infections and potential complications from viral illnesses.^[2,3] Therefore, continuous care, early diagnosis, and therapeutic interventions are essential for this patient group. However, the diagnosis of cancer creates painful psychosocial problems and consequences for patients, their families, and caregivers. Heightened emotions, such as uncertainty about the future, fear of death, and changes in interpersonal relationships, have been further intensified by government-imposed quarantines during the COVID-19 pandemic.[4]

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Caregiving is a crucial component of public health, significantly contributing to the enhanced quality of life for many individuals who require assistance with their social or health needs. In certain cultures, including Iran, most cancer patients are cared for at home by their immediate family members due to the strength of family ties. Research has demonstrated that these caregivers frequently experience psychosomatic symptoms, such as stress, depression, and anxiety, as well as limitations in their social roles and daily activities. Additionally, they often face problems in their marital relationships and physical health issues due to the high demands of their caregiving responsibilities.^[5] Previous reports have highlighted the significant negative impact that caring for cancer patients can have on the physical, psychological, social, and economic well-being of their caregivers. Considering such pressure, both the patient and the caregiver require social support from the public health system. Increased

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Mohammad Reza Sharbafchi¹, Seyed Mohammad Hossein Mousavi², Ghazaleh Sheikhani³, Mahmoud Keyvanara⁴, Sima Ani³

¹Department of Psychiatry, Behavioral Sciences Research Center and Khorshid Hospital, Faculty of Medicine, Isfahan University of Medical Sciences, Isfahan, Iran, ²Department of Psychology, Faculty of Educational Sciences and Psychology, University of Isfahan, Isfahan, Iran, ³Department of Psychiatry, Isfahan University of Medical Sciences, Isfahan, Iran, ⁴Department of Health Services Management, Social Determinants of Health Research Center, Isfahan University of Medical Sciences, Isfahan, Iran

Address for correspondence: Dr. Sima Ani, Department of Psychiatry, Isfahan University of Medical

Sciences, Isfahan, Iran.
E-mail: sima84a@gmail.com

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caring stress can have consequences such as family withdrawal, frustration with social support, or poor family relationships, which could eventually result in abandonment of the job and inadequate patient care.^[6-8]

With a rise in cancer cases and the added burden of the COVID-19 pandemic, family caregivers are under increasing stress and pressure. It is crucial for health managers to recognize these challenges and offer the necessary support. Therefore, we conducted this qualitative research study using structured interviews to identify and clarify the specific challenges faced by caregivers of cancer patients during the COVID-19 pandemic, with the aim of providing valuable insights for administrators and health officials.

Materials and Methods

The present study is a conventional qualitative study based on the Graneheim method for content analysis. From January to September 2021, 11 family caregivers of cancer patients were interviewed at the "Iranian Cancer Control Center (MACSA)" in Isfahan through face-to-face and telephone interactions. Inclusion criteria were: 1) first-degree family members of patients with any type of cancer in the acute treatment phase (chemotherapy or radiation therapy) or up to 6 months post-therapy, 2) those who lived with the patient, and 3) individuals aged 18 to 65 who were willing to participate in the study. Data were collected through purposive sampling and semi-structured interviews. The duration of telephone interviews was from 20 min to 45 min and face-to-face interviews from 60 to 90 min. The content of each interview was recorded with the participant's permission and then transcribed for qualitative analysis. The interview questions were: "What were your concerns during patient care?" "What challenges did you face in COVID-19?" and "What did you do to deal with the challenges?" Also, questions such as "why," "how," requests for further explanation, and prompts for examples were employed to elaborate on responses and achieve data saturation.

The data analysis process was carried out simultaneously with data collection, using conventional qualitative content analysis following the steps proposed by Graneheim and Lundman. The processed interviews were analyzed sentence by sentence, and the main and conceptual messages were extracted and recorded. Similar codes were grouped into subcategories, which were then organized into categories based on their conceptual homogeneity. This process continued until saturation was reached. To ensure data validity, participants were allowed to review the analysis and provide feedback on the accuracy of the data. Two qualitative research experts reviewed the transcripts to validate the coding and made necessary corrections, which were then re-evaluated by the same experts.

The accuracy and reliability of the data were ensured by applying the criteria from Guba and Lincoln.^[10] We employed various methods to ensure the validity and reliability of data. The acceptability of the data was evaluated by sharing the

manuscript with the participants for review and maintaining contact with them over an extended period. Maximum variability sampling was used to enhance the validity of the data. The verification process proceeded smoothly due to the researchers' impartiality, agreement on coding and thematic frameworks, and the review of transcripts by two faculty members. Dependability was ensured through prompt note-taking, consultation with project partners, and multiple thorough re-readings of the entire dataset. Additionally, transferability or fittingness was enhanced by conducting interviews with a diverse group of participants and including direct quotes and examples, thereby offering a comprehensive understanding of the data.

Ethical considerations

This study was performed in accordance with the Declaration of Helsinki. Ethics approval was given by the Ethics Committee of Isfahan University of Medical Sciences (IR.MUI.MED.REC.1400.197). All participants provided written informed consent and no personal information was disclosed to protect their anonymity.

Results

Eleven family caregivers, consisting of eight females and three males responsible for taking care of a cancer patient, enrolled in the study. Demographic characteristics of the participants are presented in Table 1. After collecting and analyzing the data, 77 primary conceptual codes were classified into three categories and nine sub-categories [Table 2]. Statements from caregivers are presented in italics and enclosed in quotation marks, with the caregiver's number indicated in parentheses.

Caregiver burnout

Caregivers have reported that the nature of caregiving challenges has remained consistent both before and during the COVID-19 pandemic, with only the severity of these challenges intensifying. The physical and psychological care of cancer patients could be linked to challenges known as "caregiver burnout," which includes four sub-categories as outlined below.

Non-cooperation of the patient with the caregiver

Patients not following caregivers' instructions, such as discontinuing their treatment, not following diets, or missing medication doses, can lead to critical situations. For example, one of the caregivers stated that: "Sometimes he is bored and says that I won't continue chemotherapy... What is the use of these drugs... I do not know how to deal with him... I am worried that it will get worse." (M6)

"Our patient was not wearing a mask and we were worried that he would be infected with Covid-19..." (M10)

Funding the costs of care and treatment

Caring for a cancer patient involves numerous demands

	Table 1: Demographic characteristics of family caregivers							
Code	Gender	Age	Education	Job	Caring duration (years)	Cancer type	Relationship with the patient	Patient's gender
M1	Female	65	HG*	Housewife	13	Melanoma	Daughter	Female
M2	Male	65	PhD**	Retired	3	Breast cancer	Husband	Female
M3	Female	40	BS***	Researcher	3	Colon cancer	Daughter	Male
M4	Female	38	BS	Housewife	1	Breast cancer	Daughter	Female
M5	Male	42	BS	Self-employed	7	Breast cancer	Husband	Female
M6	Female	50	HG	Retired	4	Breasts and colon cancer	Daughter	Male
M7	Female	35	BS	Legal institute	2	Colon cancer	Daughter	Female
M8	Female	45	PhD	Lawyer	3	Lung cancer	Daughter	Male
M9	Female	45	HG	Self-employed	3	Lymphoma	Daughter	Female
M10	Female	45	HG	Retired	6	Breast cancer	Daughter	Male
M11	Male	48	BS	Self-employed	5	Breast cancer	Husband	Male

^{*}HG=High School Graduate. **PhD=Doctor of Philosophy. ***BS=Bachelor of Science

Table 2: Main challenges experienced by caregivers of cancer patients during COVID-19 pandemic

Category	Subcategory			
Caregiver	Non-cooperation of the patient with the caregiver			
burnout	Funding the costs of care and treatment			
	Lack of support for the family caregiver by the family and society			
	Lack of knowledge and proper care skills			
Health threats	Imbalance of self-care versus patient care			
to the family	Disruption of healthy lifestyle			
caregiver	Occurrence of psycho-physical symptoms caused by stress in caregivers			
Work-family-	Conflicts between patient care and family			
care conflicts	Conflicts between patient care and work			

and costly nutritional needs. The burden of these expenses, compounded by inadequate insurance support, has created significant challenges for caregivers. "I have to sell our house to cover the treatment costs..." and "My monthly income does not cover the treatment costs..." (M5)

"All the drugs are expensive and the insurance is of no use... when will the insurance be used?..." (M1)

Lack of support for the family caregiver by the family and society

In COVID-19, to prevent the transmission of the virus to the patient, the family caregiver is responsible for all care inside and outside the home. Some caregivers have expressed the lack of adequate behavioral support from other family members. For example, "Indeed, all tasks are also entrusted to me...for example, making an appointment for a doctor...buying medicines and etc." (M4)

Also, due to the extreme attention of all family members to the patient, the family caregiver is ignored and the caregiver's wishes and needs are ignored. For example, "They pay a lot of attention to the wishes of my mother {the patient}, but my needs and wishes are ignored... as if I am not a person at all..." (M9)

Inadequate knowledge and skills of the family caregiver about the patient's treatment and medications

Family caregivers reported that they do not have enough knowledge and skills to perform medical and emergency care at home. For example, "We didn't have a nurse to help and I had to take care of everything... or if my patient was in severe pain, I didn't know whether to give painkillers or not... I was confused..." (M3)

Some family caregivers tried to access online training resources or seek information from various sources. For example: "The nurse only taught me very briefly, but it wasn't enough for me...I had to search everything over the internet" (M11)

"My patient has symptoms of pain and lethargy, but I don't know if he is infected with Corona or not... I do not know what to do in such situations... The doctor's office is crowded and I cannot take the patient for a visit... This is bothering me a lot..." (M1)

Health threats to the family caregiver

Caregiving has resulted in various physical and psychological consequences for the caregivers, jeopardizing their overall health.

Imbalance of self-care versus patient care

Family caregivers noted that the prolonged and stressful patient care during COVID-19 has limited their time for self-care. Consequently, there has been an imbalance between self-care and patient care. For example, "I don't have time to do my work at all… because I have to take care of my sister more and she needs my presence…" (M9)

Due to the quarantine conditions and the fear of cancer patients contracting COVID-19, family caregivers did not have enough time to attend sports and recreation centers. As a result, health-related activities such as sports were decreased in family caregivers. For example, "I do not have enough fum... I have less contact with my friends...

because we have to take care of my father {cancer patient} so that he doesn't get infected with COVID-19..." (M8)

Disruption of healthy lifestyle

Caregivers also found that their own healthy lifestyle is disrupted. The caregivers struggled with the patient's irregular sleep and eating schedules due to round-the-clock care. They also encountered inconsistencies between the patient's dietary regimen and their meal plan. "I have to prepare the foods that are prescribed for the patient... I cannot consume many of these necessary foods myself... I don't feed at regular times either..." (M1)

"I used to sleep at 11 p.m.... now I sleep much later at night... so, many times I wake up late in the morning..." (M9)

In addition, several health-related behaviors have been affected due to the quarantine conditions of COVID-19 and the care of cancer patients. COVID-19 has caused caregivers to take care of themselves in a compromised and more limited manner. "I was afraid that I would go to the gym and be a virus carrier for my mother {cancer patient}...My weight has increased..." (M4)

"I don't get enough rest... My sleep is affected... I feel fatigued and weak but I had no choice and couldn't change the situation" (M3)

Occurrence of psychophysical symptoms caused by stress in caregivers

The feeling of fear and worry about the patient's health and future has led family caregivers to experience significant stress. This stress can manifest as functional symptoms, posing threats to the physical and psychological well-being of caregivers. "Sometimes I want to hit my head against the wall because of a severe headache..." (M11)

"The back of my shoulders hurts and I always need someone to massage me..." (M8)

Work-family-care conflicts

Family caregivers frequently face conflicts stemming from the overlap of their caregiving responsibilities with other familial and work obligations. These conflicts present an additional challenge in caring for cancer patients, and can be categorized into two subtypes "conflict between patient care and family" and "conflict between patient care and work."

Conflict between patient care and family

Prioritizing the needs of the cancer patient and not having enough time to address the needs of other family members was another experience for family caregivers. For example, "During the day, I have to deal with my wife's treatment so much that I don't have time to play with my daughter... My daughter is at a sensitive age and needs my presence...I cannot be with her because I have to take care of his mother {cancer patient}... I'm so tired..." (M5)

Another challenge for family caregivers was the reduction in time spent with their immediate family due to social distancing measures and efforts to prevent the spread of COVID-19. For example, "During COVID-19, to maintain social distance and prevent my father {cancer patient} from getting infected, I am less present at our house and I cannot do my previous duties such as shopping, taking care of children, etc." (M2)

Conflict between patient care and work

Another challenge for family caregivers is that their job and academic duties have been affected due to caring for a cancer patient. For example, one caregiver, who was a student, faced disciplinary problems at the university. For example, "Our classes were online and I was in the doctor's office at the same time...I didn't answer the teacher's questions and I was faced with the teacher's reaction... Well, they don't know what condition I am in..." (M3)

Other employees were severely criticized for poor performance and numerous absences at work. "I asked the manager to change my workplace and not be in crowded places...because I take care of my mother {for prevention}...the manager didn't pay attention and I had to leave my workplace..." (M7)

"The number of my vacations has increased... I was absent from work several times and my case has been submitted to the disciplinary committee... I have to be with my wife for treatment sessions..." (M5)

"My clients have decreased because my hours in the office are not regular..." (M11)

Some caregivers stated that they lost their work and educational opportunities due to full-time patient care. "I spent the capital that I had prepared to buy a shop to cover treatment costs... now I don't have the capital to expand my business..." (M11)

"I have to go to Tehran to continue my education, but my mother needs me to be in Isfahan... I cannot participate in the doctoral course because I have to go to another city..." (M4)

Discussion

This study aimed to identify and classify the care challenges faced by family caregivers of cancer patients during the COVID-19 pandemic. Most families cared for their sick loved ones at home to protect them from COVID-19. This care was the responsibility of the main caregiver, which is called the family caregiver in this study. After analyzing the data, three main challenges for family caregivers were identified.

The primary challenge identified was "caregiver burnout" defined in this study as the circumstances and environment in which family caregivers bear the responsibility of caring for the patient entirely on their own. This challenge primarily stemmed from four subcategories:

"non-cooperation of the patient with the caregiver," "funding the costs of care and treatment," "lack of support for the family caregiver by the family and society," and "lack of knowledge and proper care skills."

Caregivers need the patient's cooperation in the treatment plan to follow the treatment. One of the challenges of family caregivers in COVID-19 was "non-cooperation of the patient with the caregiver." This means that the patient did not adhere to the treatment and created caregiver burnout for the family caregivers. Due to the COVID-19 pandemic, a significant decrease in the adherence of cancer patients to intravenous chemotherapy has been reported.[11] Contrary to our findings, one study reported that cancer patients showed greater adherence to protective behaviors compared to non-cancer participants.[12] However, consistent with our results, adherence to chemotherapy declined, and the rate of CT postponements increased after the onset of COVID-19.[13] There is a lack of information regarding the psychosocial factors influencing cooperation between cancer patients and caregivers during the COVID-19 pandemic. We believe that this reduced cooperation is due to both the patient's frustration and fear of contracting COVID-19 in the hospital.[14]

Another challenge for family caregivers was "funding the costs of care and treatment." The economic burden of cancer worldwide is still substantial, at around US\$470 billion per year, and is increasing rapidly.^[15] Caring for a cancer patient during COVID-19 is a time-consuming responsibility that can prevent caregivers from fulfilling their professional duties, resulting in lost income and reduced financial resources. This concern has also been raised by COVID-19 monitoring agencies in other countries.[16,17] Additionally, the absence of insurance support during COVID-19, for numerous healthcare and medical services has placed a significant financial strain on family caregivers of cancer patients.[18] Given the economic pressures caused by the COVID-19 pandemic, more attention is needed to cover treatment costs for family caregivers. In Iran, various private or public institutions, as well as charities provide financial support to families with cancer. However, this support is often insufficient to meet the needs of these families.[19]

This study has also identified "lack of knowledge and proper care skills" as a significant challenge. Caregivers may not have the necessary skills or knowledge to provide adequate care or to adjust their caregiving role in COVID-19. This lack of knowledge about COVID-19 is often compounded by a lack of guidance from medical professionals and access to scientific resources, leaving them unsure of treatment plans and medications.^[20] The lack of provision of necessary information and knowledge by medical professionals about the disease and the basic needs of family caregivers in COVID-19 has been discussed before.^[21] Consequently, they use empirical knowledge that may be wrong and could negatively affect the patient's health. In contrast, providing timely and credible information about the COVID-19

pandemic to health officials is associated with a subsequent reduction in anxiety and emotional distress. Accurate information sources are essential for family caregivers who encounter difficulties while providing care to relatives diagnosed with cancer during the COVID-19 pandemic.^[22]

Another challenge was the "lack of support for the family caregiver by the family and society." Caring for cancer patients often requires multifaceted support and the cooperation of others in various domains, including physical, mental, and emotional support. However, in many cases, other family members and society fail to provide the necessary support, which adds to the burden of the caregiver. Observance of social distancing has led to the separation and lack of support from other family members for caregivers. A study highlighted that the lack of support for family caregivers of children with medical disorders during COVID-19 has been particularly challenging. [13] In another qualitative study on COVID-19, family caregivers reported feeling lonelier during hospital admissions and clinic visits due to restrictions on visitors in medical centers. [14]

The second major challenge for family caregivers of cancer patients was "health threats to the family caregiver." The demands of caring for a cancer patient necessitate the caregiver's full-time presence. Therefore, the physical and psychological health of caregivers is exposed to different risk factors. They experience worse health status and a higher risk of death compared to other family members.^[23] This challenge can be explained in sub-categories of "imbalance of self-care versus patient care," "disruption of a healthy lifestyle" and "occurrence of psycho-physical symptoms in the caregivers caused by stress."

One of the threats related to the health of family caregivers is the "imbalance of self-care versus patient care." Caregivers have weaker self-care than non-caregivers. [23] Family caregivers usually spend most of their energy and time taking care of the patient, leaving them with less desire and opportunity to take care of themselves. As the primary care providers, this often results in a lack of self-care. Observations have also been made regarding family caregivers of individuals with dementia, where a lack of social connections and a decrease in enjoyable social pursuits have had a detrimental impact on their mental well-being. [24] Self-care is crucial for preventing disorders; so, it is recommended to implement educational measures aimed at improving the self-care practices of family caregivers.

Disruptions in a healthy lifestyle (such as improper diet, sleep disturbances, and physical inactivity) have been identified as significant health threats for many family caregivers of cancer patients. The lifestyle changes following COVID-19 pose risks to their physical, mental, and social health. Issues with maintaining a healthy lifestyle among family caregivers have been reported both during and before the COVID-19 pandemic.^[25] This problem has been documented in various studies, highlighting its persistence over time.^[26-28]

Another health threat identified was the "occurrence of psycho-physical symptoms caused by stress in caregivers." The findings revealed that both physical and psychological stress can jeopardize the health of family caregivers. The current pandemic has exacerbated these challenges, potentially leading to more severe health problems in the long term. Similar to our findings, psychological issues in caregivers, such as anxiety, emotional distress, mood disorders, guilt, panic disorder, post-traumatic stress disorder, and unresolved grief, have been previously reported in Iran^[29-31] and other countries.[32] In this regard, emotional distress was expressed as one of the major problems by family caregivers, which can be considered a threat related to both their mental and social health.[33] It is also reported that even under normal circumstances, family care is associated with reduced health^[34] and caregivers are more stressed than non-caregivers.^[23] In COVID-19, these stresses may be beyond the capacity of family caregivers, putting them at further risk of illness due to chronic stress and delayed self-care.[35]

The third main challenge for family caregivers during COVID-19 is "work–family care conflicts." The role of family caregivers has shifted from being just a family member to becoming the primary caregiver for the patient. They assist their loved ones with daily activities and tasks, which often leads to conflicts between their caregiving responsibilities and other family or work obligations. In previous studies, it has been reported that family caregivers put the role of patient care as their priority and postpone their occupational, academic, and family roles.^[25,36] Providing care for a cancer patient is a responsibility that requires a significant time commitment, thereby impeding the caregiver's ability to fulfill their professional obligations, ultimately leading to a loss of income and a reduction in financial resources.^[37-39]

This study provides new insight into the challenges of taking care of cancer patients during the COVID-19 pandemic. Our results indicate that caregivers are facing deep-rooted challenges and problems that have been exacerbated by COVID-19. Considering that this viral infection could be part of our daily life in the coming years, our result creates an opportunity for health policymakers to plan to manage caregiving challenges in family caregivers as an essential part of the public health system. Health authorities should provide support to caregivers across different aspects of their lives. For example, by organizing caregiving workshops to increase their required knowledge and skills. Clear and continuous medical information should be provided to both caregivers and their families. Psychosocial empowerment can be implemented to promote emotional, mental, and social well-being.

In contrast, the findings of this study may have limited generalizability to different regions and time periods because the data were collected within a specific psychosocial context during the COVID-19 pandemic. Future studies are also necessary to explore the long-term effects of the

pandemic on the health and caregiving capacity of family caregivers. Additionally, this study specifically examined family caregivers of cancer patients, whereas caregivers of individuals with other chronic illnesses may face distinct challenges. Therefore, further research is required to address this limitation by broadening the scope and including a more diverse range of caregivers and medical conditions.

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Conflicts of interest

Nothing to declare.

References

- COVID Live Coronavirus Statistics Worldometer [Internet]. Available from: https://www.worldometers.info/coronavirus [Last accessed on 2024 Aug 18].
- Duan L, Zhu G. Psychological interventions for people affected by the COVID-19 epidemic. Lancet Psychiatry 2020;7:300-2.
- Guan W-J, Liang W-H, Zhao Y, Liang H-R, Chen Z-S, Li Y-M, et al. Comorbidity and its impact on 1590 patients with COVID-19 in China: A nationwide analysis. Eur Respir J 2020;55:2000547.
- Chen W, Zheng R, Baade PD, Zhang S, Zeng H, Bray F, et al. Cancer statistics in China, 2015. CA Cancer J Clin 2016;66:115-32.
- 5. Khanjari S, Oskouie F, Langius-Eklöf A. Lower sense of coherence, negative religious coping, and disease severity as indicators of a decrease in quality of life in Iranian family caregivers of relatives with breast cancer during the first 6 months after diagnosis. Cancer Nurs 2012;35:148-56.
- Chang H-Y, Chiou C-J, Chen N-S. Impact of mental health and caregiver burden on family caregivers' physical health. Arch Gerontol Geriatr 2010;50:267-71.
- Milbury K, Badr H, Fossella F, Pisters KM, Carmack CL. Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. Support Care Cancer 2013;21:2371-9.
- Park B, Kim SY, Shin JY, Sanson-Fisher RW, Shin DW, Cho J, et al. Prevalence and predictors of anxiety and depression among family caregivers of cancer patients: A nationwide survey of patient-family caregiver dyads in Korea. Support Care Cancer 2013;21:2799-807.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004;24:105-12.
- Guba EG, Lincoln YS. Fourth generation evaluation. Thousand Oaks, CA, US: Sage Publications, Inc; 1989. p. 294.
- Guven DC, Aktas BY, Aksun MS, Ucgul E, Sahin TK, Yildirim HC, et al. COVID-19 pandemic: Changes in cancer admissions. BMJ Support Palliat Care 2024;14:e376-9.
- 12. Kassianos AP, Georgiou A, Kyprianidou M, Lamnisos D, Lubenko J, Presti G, et al. Mental health and adherence to

- covid-19 protective behaviors among cancer patients during the covid-19 pandemic: An international, multinational cross-sectional study. Cancers (Basel) 2021;13:6294.
- Karacin C, Bilgetekin I, B Basal F, Oksuzoglu OB. How does COVID-19 fear and anxiety affect chemotherapy adherence in patients with cancer. Future Oncol 2020;16:2283-93.
- 14. Tsamakis K, Gavriatopoulou M, Schizas D, Stravodimou A, Mougkou A, Tsiptsios D, *et al.* Oncology during the COVID-19 pandemic: Challenges, dilemmas and the psychosocial impact on cancer patients. Oncol Lett 2020;20:441-7.
- Bradley CJ. Economic burden associated with cancer caregiving. Semin Oncol Nurs 2019;35:333-6.
- Dhumal T, Siddiqui ZA, Kelley GA, Harper F, Kelly KM. Systematic review and meta-analysis of randomized controlled trials of interventions addressing caregiver distress and burden among cancer caregivers. PEC Innov 2023;2:100145.
- Csaba DL. Caregiving burden and other psychosocial considerations. In: Informal caregivers: From hidden heroes to integral part of care. Cham, Switzerland: Springer Nature Switzerland AG; 2023. p. 13-32.
- Williams CP, Rocque GB, Caston NE, Gallagher KD, Angove RS, Anderson E, et al. Health insurance and financial hardship in cancer survivors during the COVID-19 pandemic. PLoS One 2022;17:e0272740.
- Hashemi M, Irajpour A, Taleghani F. Caregivers needing care: The unmet needs of the family caregivers of end-of-life cancer patients. Support Care Cancer 2018;26:759-66.
- Thomson MD, Genderson MW, Siminoff LA. Understanding cancer caregiver burden over time: Dyadic assessments of family cohesion, conflict and communication. Patient Educ Couns 2022;105:1545-51.
- Rao PT. A paradigm shift in the delivery of physical therapy services for children with disabilities in the time of the COVID-19 pandemic. Phys Ther 2021;101:pzaa192.
- 22. Jin Z, Zhao KB, Xia YY, Chen RJ, Yu H, Tamunang Tamutana T, et al. Relationship between psychological responses and the appraisal of risk communication during the early phase of the COVID-19 pandemic: A two-wave study of community residents in China. Front Public Health 2020;8:550220.
- Van Houtven CH, Smith VA, Stechuchak KM, Shepherd-Banigan M, Hastings SN, Maciejewski ML, et al. Comprehensive support for family caregivers: Impact on veteran health care utilization and costs. Med Care Res Rev 2019;76:89-114.
- Savla J, Roberto KA, Blieszner R, McCann BR, Hoyt E, Knight AL. Dementia caregiving during the "stay-at-home" phase of COVID-19 pandemic. J Gerontol B Psychol Sci Soc Sci 2021:76:e241-5
- 25. Tolbert E, Bowie J, Snyder C, Bantug E, Smith K. A qualitative exploration of the experiences, needs, and roles of caregivers during and after cancer treatment: "That's what I say. I'm a

- relative survivor." J Cancer Surviv 2018;12:134-44.
- Barrera M, Solomon A, Desjardins L, Chung J, Hancock K. Predicting quality of life in caregivers of children with cancer within one year post-diagnosis. J Child Fam Stud 2021;30:2215-24.
- Simón MA, Bueno AM, Otero P, Blanco V, Vázquez FL. Caregiver burden and sleep quality in dependent people's family caregivers. J Clin Med 2019;8:1072.
- 28. Page BF, Hinton L, Harrop E, Vincent C. The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. Health Expect 2020;23:1144-54.
- Iranmanesh S, Hosseini H, Esmaili M. Evaluating the "good death" concept from Iranian bereaved family members' perspective. J Support Oncol 2011;9:59-63.
- Sajjadian AS. Evaluation of care problems in family caregivers of breast cancer patients. Iran J Breast Dis 2015;8:7-14.
- 31. Bahrami M, Sadeghi A, Mosavizadeh R, Masoumy M. Challenges of meeting the palliative care needs of colorectal cancer patients in Iran: A qualitative research. Iran J Nurs Midwifery Res 2022;27:325-30.
- Kim Y, Baek W. Caring experiences of family caregivers of patients with pancreatic cancer: An integrative literature review. Support Care Cancer 2022;30:3691-700.
- 33. Sousa H, Frontini R, Ribeiro O, Paúl C, Costa E, Amado L, et al. Caring for patients with end-stage renal disease during COVID-19 lockdown: What (additional) challenges to family caregivers? Scand J Caring Sci 2022;36:215-24.
- Irani E, Niyomyart A, Hickman Jr RL. Family caregivers' experiences and changes in caregiving tasks during the COVID-19 pandemic. Clin Nurs Res 2021;30:1088-97.
- von Känel R, Mausbach BT, Dimsdale JE, Ziegler MG, Mills PJ, Allison MA, et al. Refining caregiver vulnerability for clinical practice: Determinants of self-rated health in spousal dementia caregivers. BMC Geriatr 2019;19:18.
- Yang WF, Liu J, Chan YH, Griva K, Kuparasundram S, Mahendran R. Validation of the needs assessment of family caregivers-cancer scale in an Asian population. BMC Psychol 2020;8:84.
- 37. Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, *et al.* Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. JAMA 2016;315:272-83.
- 38. Abbasnezhad M, Rahmani A, Ghahramanian A, Roshangar F, Eivazi J, Azadi A, *et al.* Cancer care burden among primary family caregivers of Iranian hematologic cancer patients. Asian Pac J Cancer Prev 2015;16:5499-505.
- Hashemi-Ghasemabadi M, Taleghani F, Yousefy A, Kohan S. Transition to the new role of caregiving for families of patients with breast cancer: A qualitative descriptive exploratory study. Support Care Cancer 2016;24:1269-76.