

A Thematic Analysis on an Exploration of Concerns of Cancer Patients and their Caregivers in the Context of the COVID-19 Pandemic

Bindu Menon K¹, Padmaja Gadiraju², Nethagani Jayalatha³

¹Doctoral research student in Psycho-oncology at the Centre for Health Psychology, University of Hyderabad, ²Head and Associate Professor, Ph.D. in Psychology at the Centre for Health Psychology, University of Hyderabad, ³MD, PDCC, Director of MNJ Institute of Oncology & Regional Cancer Centre, Hyderabad.

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Abstract

Background: COVID-19, a pandemic prevalent for a long time presents a multistep crisis; the first stage is an acute health crisis, followed by a healthcare recovery crisis in the second stage and a socio-economic crisis in an indefinite period. The study explores the challenges and specific concerns among patients diagnosed with cancer and their caregivers during the pandemic.

Materials and Method: Qualitative research employs specific research methods such as in-depth interviews, content analysis, observation methods, and life histories or biographies to examine people's experiences in detail. In the present study, a semi-structured questionnaire was developed and interviews were conducted to understand the experiences of cancer patients and their caregivers with health care and their daily challenges during the pandemic. A Non-random sampling method, involving males and females, within the age group of 18 to 65 years, and their primary care providers from the Regional Cancer Centre and other cancer hospitals are followed. Semi-structured interview responses were collected from cancer patients and their caregivers., illustrative quotes were summarised and key themes from the interviews were extracted.

Results and analysis: 9 Key themes with 20 subthemes were extracted in the content analysis. Difficulty having access to medical care, fear of infection transmission, lack of social support, loss of income source, drastic lifestyle changes, uncertainty about disease cure, and apprehension about the future, which result in cumulative disease burden have been frequently reported in the study.

Conclusion: The current research is relevant in describing the experiences and perspectives of cancer patients and their caregivers, throwing light on the psychosocial issues and challenges during the pandemic situation, thus emphasizing the need for developing a supportive psychosocial intervention.

Keywords: Psychosocial issues, Health care challenges during pandemic, Cancer, and Corona, Psychosocial intervention

Introduction

The pandemic-coronavirus disease (COVID-19)

profoundly affected all aspects of life, such as health care, family dynamics, finance, social life, and the surrounding environment. The research

Corresponding Author: Padmaja Gadiraju, Head and Associate Professor, Ph.D. in Psychology at the Centre for Health Psychology, University of Hyderabad.

Email: gpadmaja.psychology@uohyd.ac.in

explored the challenges during a pandemic crisis and closely examined the difficulties faced by patients diagnosed with chronic diseases like cancer who may need long-term medication and regular health assessment.^[1,2] The lockdown has hindered the delivery of specialized medical services, drugs, and other healthcare needs to these patients.^[3,4] While it disrupted the lives of all in many ways, patients with chronic health problems and those who needed regular healthcare checks or procedures were the most affected. The caregivers of such patients also have to withstand the impact owing to the uncertainties and outcomes.

A study on the impact of COVID-19 on cancer patients (Zhang et al., 2020) found that 28.6% of study patients contracted the coronavirus due to nosocomial infection while hospitalized for their cancer treatment. This article describes cancer treatment given within 14 days of the COVID-19 diagnosis was reported as a risk factor for developing medical complications such as acute respiratory distress syndrome (28.6%), septic shock (3%), and acute myocardial infection (3.6%).^[5] Thus, knowing the challenges and dilemmas, Tsamakis et al., 2020 emphasized the screening for COVID infection and strict infection control measures in oncology units.^[6] Self-isolation and quarantine are the first strategies recommended worldwide to slow down the spread of pandemics, but the restrictions also impose deliberate social isolation.^[7] With little support, caregivers faced serious challenges in caring for their loved ones struggling with chronic diseases like cancer during the pandemic period (Shankar et al., 2020).^[8]

The rationale of the study:

Chronic diseases like cancer present challenges in accessing medical care for ongoing treatment regimens like chemotherapy, radiation, or surgical procedures during the pandemic. Any delay in medical procedures could lead to disease progression, resulting in complications and a cumulative disease burden. On the other hand, a caregiver's dilemma is having to attend to their medical and other day-to-day needs without any social support to add to their woes. An attempt is made to explore the impact of the pandemic on cancer patients and caregivers in the present study.

Objectives of the Research

The present study focuses on the COVID-19 Pandemic, discussing psychosocial issues and challenges faced by patients diagnosed with cancer and their primary caregivers. The objectives of the research are:

1. To investigate cancer patients' difficulties and psychosocial issues during the COVID-19 pandemic phase.
2. To study caregivers' challenges and coping strategies during the pandemic period

Materials and Methods

One-on-one interviews were conducted with 18 cancer patients and their caregivers to capture in-depth information about their experiences and challenges during the prevailing pandemic period. An attempt was made to understand the psychosocial factors that play a significant role in providing quality care to cancer patients. This study also explores caregivers' challenges in coping with the prevailing pandemic situation.

Participant recruitment for qualitative interviews

A total of 36 participants, including 18 patients and their caregivers, both male, and female, within the age group of 18 to 65 years, from the Regional cancer center were recruited for the present study. Interviews facilitated by a semi-structured interview guide, lasting approximately 20–30 minutes were conducted for both groups (cancer patients and caregivers) and field notes and their responses were recorded.

Questionnaire Development

Interaction with health care providers, including doctors, nurses, and social workers, and the researcher's own experience as a medical professional attending to queries and concerns from cancer patients and their families helped to develop a semi-structured interview questionnaire. A total of twenty-four questions were included and when the tool was administered to 3 cancer patients along with their caregivers, whatever questions were not properly understood were reframed. Wherever necessary, spontaneous secondary and relevant questions were asked for better exploration. There are no positive

or negative answers and therefore, no marks were allotted. Instead, all the participant's responses to the questions were carefully noted.

Collection of Data

Interviews were conducted by the researchers during the pandemic period. Participants were informed about the purposes and format of the interview as well as their rights, and informed consent was obtained. Socio-demographic and health questions included were direct and closed-ended, whereas open-ended questions were asked to explore their challenges and experiences during the pandemic period. The impact of the pandemic on health care, personal aspects (physical, emotional, and social), lifestyle changes, crisis if any, and their coping methods were noted. Any other factors that are important and have an impact on their lives were also included in the study.

Analysis of Data

The characteristics of the participants were summarized. The interview transcripts were reviewed and given numbers to maintain patient confidentiality and ensure transcript completeness and accuracy. The data underwent "thematic analysis" following a prescribed coding framework involving the extraction and review of excerpts, with new codes added as themes and concepts emerged from the data. Key themes and sub-themes related to patient experiences and caregivers' challenges during the pandemic were summarised and illustrative interview quotes were used to support the key findings identified from the interview transcripts.

Results

Sample characteristics: qualitative interviews

Interviews were conducted with 18 cancer patients from the regional cancer center and private hospitals along with their caregivers. There are 10 female and 8 male cancer patients in the given sample. The majority of participants in the caregiver's group were female, with the formal education of tenth or twelfth grade only, from a lower or middle socioeconomic status, and rural (12) as well as urban (6) areas. The mean participant age of cancer patients is 46 years old, and that of caregivers is 58 years old.

Despite common responses by the participants, there were differences found in symptoms, contributors, coping, and progression of illness among cancer patients and their caregivers.

The transcribed data (semi-structured interview) was segmented, and responses were carefully analyzed and coded into sub-themes (20) and themes (9). Below are the illustrative quotes that describe the Interview participant's experiences and verbal responses on the impact of COVID-19.

Key themes (Subthemes) are derived from the Illustrative Quotes. Here, (P) refers to cancer patients and (C) refers to Caregivers.

1. Healthcare needs & availability

(Access to medical information, Access to treatment, and Availability of drugs & healthcare resources during the pandemic)

(P) 'I have no idea when I will have my next treatment.

(P) 'It was miserable and I couldn't tolerate the pain and wanted to go to the hospital,' said a patient.

(C) 'We were trying to connect to the hospital several times, but they didn't answer.

(C) 'Where would we get medicine from during lockdown? Medicines for pain (morphine) are not available outside.

(C) "Buses or other transport were not available to travel to the hospital," remarked a caregiver.

2. Fear of infection

(Fear of corona infection, Expressed anxiety/worry, Distress)

(P) One lung cancer patient anticipated the risks. I think all the treatment will go to waste if I get infected with the coronavirus. It may lead to serious complications and I may infect others too.

(P) Another participant commented, "If not for COVID, cancer would kill me."

(C) A lady expressed her fear of infection to her son as he is undergoing chemotherapy for cancer at a private hospital. She said, "What if he gets a Corona from the hospital itself?" I am tense and don't know what is right and what could go wrong at any time.

(C) "My parents are very old and there is always a risk of infection transmission to them."

(C) Another caregiver was anxious and upset about hospitals' not taking enough precautions and allowing the mixing of staff from the COVID Ward to the Oncology Block. "The hospital having a COVID block in the nearby premises is a threat to my family," he said.

3. Social challenges

(Lack of social interaction, reported lack of social support)

(P) "Sitting alone all day without even seeing someone and having nothing to do is very frustrating", a young cancer patient responded.

(C) 'I can't even get my parents home for some support due to the pandemic situation.'

(C) Due to the pandemic, even my helper is not coming and I can't seek any relative's help. I am so tired and left with no time for myself".

(C) 'Having no help from anywhere during a pandemic is tough', said a caregiver.

4. Financial challenges"

(Loss of business /income source/Loss of job)

(P) "I have applied for long-term leave and have had no salary for the past 4 months, said a cancer patient who is undergoing radiation treatment".

(C) A caregiver said, 'owing to a pandemic, our Kirana shop is closed and my elder son gets only half his salary.'

(C) 'We are left with very little money having no daily wage work and worried about my wife's treatment for breast cancer, a caregiver expressed.

5. Work-life balance"

(Challenges of working from home, online classes for children, managing office work and domestic chores)

(C) A caregiver expressed her woes that 'working from home and managing things at home is a double challenge'.

(C) 'Attending children having online classes and me working from home and taking care of my husband diagnosed with Prostate cancer is somewhat difficult.

6. Lifestyle disruption

(Procurement of Items,Lifestyle changes, Absence of Leisure activity)

(P) One cancer patient expressed his difficulty, 'I can't go out to buy any essentials even from nearby shops.

(P) Another patient said, 'I can't go out with my friends for my regular walks. I am always sitting at home.

(C) "There is no leisure activity when you work from home and it's like full-time work", remarked a caregiver.

7. Difficulty in adaptation to pandemic protocols

(Using face mask & sanitizer)

(P) One elderly patient diagnosed with lung cancer expressed anguish over the pandemic situation. He said 'I feel suffocated using masks all the time and even seeing others in masks makes me feel anxious.'

(C) "It is difficult to wear a mask and sanitize premises now and then".

8. Strategies of management

(Dealing with the changes and adjustment, self-care regime)

(P) 'I take precautionary steps such as using a mask, sanitizer very often and strictly avoids public places which are very crowded' as told by a breast cancer patient.

(C) A caregiver expressed, 'We regularly do self-care practices like yoga and breathing exercises. Also, we eat a nutritious diet and herbal supplements to boost our immunity.'

9. Fear of uncertainty

(Uncertainty & dilemma about the future)

(P) A lung cancer patient asked, 'What's more deadly Cancer or Corona? When will it get in control?'

(C) Caregiver expressed their concern, 'I have no idea whether the situation will improve or worsen with time?'

Apart from these responses, two of the patients

reported that they had received a phone call from a private Cancer Hospital and there was no delay in their scheduled chemotherapy session. "My treatment went smoothly, and the hospital had taken screening as well as proper safety measures." "Our medical records were sanitized and the premises were disinfected," said a caregiver.

Key themes that emerged in the study are

health care needs and availability, fear of infection, social & financial challenges, work-life imbalance, lifestyle disruption, difficulty in adapting to covid protocols, strategies of management, and fear of uncertainty.

Figure 1. Themes from the Interview participant's responses (N=18)

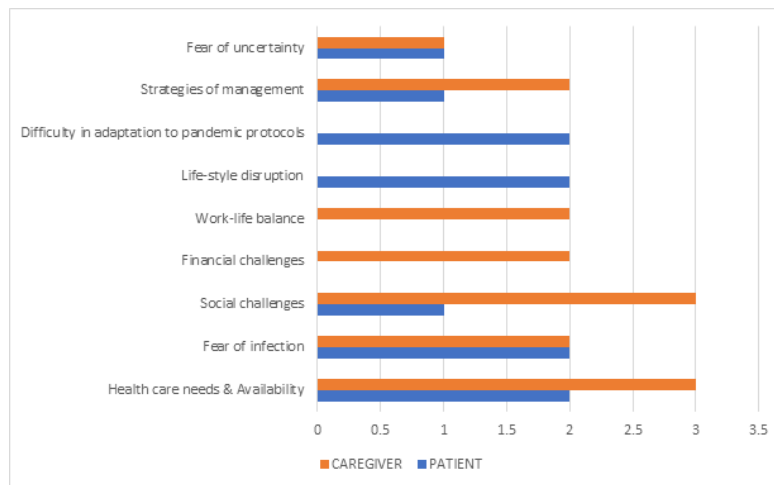


Figure 1: Represents nine key themes that emerged in the study (comparing the verbal quotes from cancer patients and caregivers).

Discussion

The present study provided valuable insight into patients' and caregivers' perspectives on dealing with the dual challenges of cancer and corona. Healthcare needs, availability, and lack of social support are the most commonly reported symptoms by 6 cancer patients and their caregivers (33.3%). Difficulties in transport, procurement of medicines, and delays in treatment are the main difficulties reported by 10 caregivers, most of whom are located in remote or rural areas (55%). On the other hand, 6 patients reported having symptoms of pain and fatigue (33%), 2 patients reported disruption in lifestyle (11%), as well as difficulties adhering to COVID protocols (11%). Fear of infection, as well as fear of uncertainty, is expressed by 2 cancer patients and 3 caregivers (14%). Lack of social support and loss of an income source is burdensome, creating anxiety and deep worry, majorly reported by 6 caregivers (33%) in the present study.

Research provides supportive evidence that the potential mental health effects of COVID-19 might be

associated with the primary effects of epidemic disease outbreaks as well as secondary effects of economic recessions and depression, loneliness, quarantine, and social isolation.^[9-11] During the pandemic, the World Health Organization and most governments strongly advised people to stay at home and be safe. As a result, a large proportion of the population who lived alone had mental health concerns during this period. Prolonged periods of domestic confinement can lead to an increased prevalence of post-traumatic stress disorder, loneliness, boredom, and anger during and after quarantine.^[12] Research (Matias, Dominski, & Marks, 2020) largely supports and rationalizes human needs in COVID-19 isolation.^[13] Williams, Morelli, Ong, & Zaki, 2018, describes in their study that being connected with others fulfilled self-affiliation, thus helping people to regulate their emotions, cope with stress and remain resilient.^[14] It is evident that during the lockdown, unmet self-protection needs may cause systematic frustration of a deep-seated need to ensure the protection of self and family. It may induce fear, anxiety, and distress, and is also associated with insomnia, irritability,

and aggression. A sense of loss experienced in society due to the loss of direct social contact in multiple forms, such as loved ones, employment, education opportunities, social support, relaxation, and recreation, is reported.^[15-16] The present study describes the challenges of having no social support and the psycho-social impact of Corona on cancer patients and their families.

Working in a lockdown phase during a pandemic from home had its challenges, according to research (Kumar, Kumar, Aggarwal, & Yeap, 2021) on COVID-19-induced work stress, job performance, distress, and life satisfaction.^[17] Ashforth, Kreiner, & Fugate, 2000 explain in their study that employees who worked from home, shared household responsibilities, and switched from one role to another while being distracted by thoughts, emotions, or demands associated with another role be extremely frustrating.^[18] According to the responses of the caregivers, this appears to be primarily a concern (Table 1). In the present study, caregivers majorly reported complaints of working from home, facing challenges sharing household responsibilities, family obligations, and work commitments, and missing work-life balance during the lockdown phase of COVID-19. Role overload, family distraction, changes in lifestyle choices, and occupational discomfort were significant predictors of distress during the lockdown. Life satisfaction has been reduced due to a significant increase in distress levels and lowered job performance. Pfefferbaum & North, 2020 reported in their study that it is important to monitor vulnerability such as pre-existing physical or psychological conditions for medical evaluation, and supportive intervention such as psychoeducation and cognitive behavioral techniques to enhance coping is emphasized.^[19]

Conclusion

Research studies suggest that interventions include online psychological support and psychological first-aid, imparting education through Telepsychology. This also explains that interventions based on technological tools and programs to mitigate the effects of the pandemic are the 'new normal'.^[20] Telemedicine emerging as the new perspective

of well-being to address the several psychosocial concerns of patients and caregivers,^[21-22] and psychosocial interventions designed to meet the needs of the patients and caregivers need to be focused.^[23] Practical approaches such as educating people and creating awareness about the current pandemic situation, creating access to medical care and psychological support, and information from reliable sources are emphasized in the study.

Conflicts of Interest: There are no conflicts reported for the study and the research is not funded by any source.

The study fulfills the ethical guidelines and has taken permission from the parent institution and hospital authorities. Necessary information was provided and informed consent was given to the participants.

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