

Multiple Caregiving Role with the Novel Challenge of COVID-19 Pandemic: A Crisis Situation

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Abstract

Caregivers of cancer patients in the COVID-19 pandemics have been faced with new complexities and challenges related to their patient's care. It has added tremendous stress to the previous multiple caregiving roles. We present the journey of a caregiver of cancer survivor who had played multiple care giving roles for the past 10 years. With the added challenge of the pandemic the caregiver faced severe psychological distress concerning his caregiving role. This was addressed to a large extent with counseling and empathy. Communication is an important measure to relieve the distress and address the complexities faced by caregivers.

Keywords: Caregiver stress, multiple roles, pandemic

INTRODUCTION

The life in the era of COVID-19 has brought new complexities and stresses in the life of people. The novel virus, which is highly transmissible, has found to have varied presentations with a higher risk of complications in patients with comorbidities such as cancer.^[1] Caregivers of cancer patients have diverse responsibilities ranging from assistance in health care needs, managing treatment and associated finances, and providing emotional support to the patient. They have been further presented with the heightened responsibility of protecting their relatives from the infection from the new virus while maintaining their cancer treatment as well. Caregivers have a dynamic role that is filled with challenging situations and responsibilities. Associated with a dramatic change in their lives, the caregivers are prone to stress and caregiving burden. As it is already known that the burden of caregiving adversely affects their physical, emotional, psychological, and functional well-being.^[2] Unaddressed caregiver's symptoms might have a negative impact on the caregivers health and indirectly adversely affect the patient as well. In the present crisis situation, the caregiver's distress and fear need to be acknowledged and addressed.^[3]

In the present case report, we present the distress of a caregiver who has assumed multiple caregiving roles in his journey of life for the past 10 years. The present report highlights his distress

and helplessness in the current pandemic scenario, which he has never experienced before.

CASE REPORT

A 35-year-old educated young male is the main caregiver of his mother, who is a cancer survivor. He has two children of 3 years and 6 years old. He is the sole earning member of his family. The journey of his life has been filled with many challenges for the past 10 years.

His first complex caregiving episode dates back to the time when he was 25 years old. He had just started a new job after completing his education. However unfortunately, at the same time, his mother was diagnosed with colon carcinoma. He recalled that it seemed to him as the end of the world at that time. It was for the first time in his life that he experienced a sense of great responsibility toward his mother. He assumed the role of a parent for her and followed her up for treatments in

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Submitted: 22-May-20 **Accepted:** 26-May-20

Published: 30-Jun-20

Access this article online

Quick Response Code:



Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_165_20

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How to cite this article: Gulia A, Mishra S, Bhatnagar S. Multiple caregiving role with the novel challenge of COVID-19 pandemic: A crisis situation. Indian J Palliat Care 2020;26:S163-5.

the hospital, caring for her at home after surgery and supporting her emotionally as well. As his father was not educated and sister too young to understand, he did not share much of his loneliness and distress with anyone. After the surgery slowly over a period of a year, his mother's health improved, which relieved his distress.

The second complex caregiving episode was when his father died due to a sudden cardiac event (massive heart attack) 4 years back. This was a major turning point in his life. He felt all alone. He hardly used to discuss all his fears with his father, but still, he felt that his father was the only source of social and emotional support for him. Furthermore, seeing the mother in grief and fearing the ill effects of stress on her health. He now realized that he has to be the support system for his whole family. With responsibility came more stress, which further strained him emotionally.

He describes the present complex caregiving situation due to the pandemic as the worst experience in which it seemed to him that there is only sadness, distress without any hope of something good. He describes the present state of his mind as being filled with hopelessness and fear. He states that to add to his distress was the new symptoms of pain abdomen and bowel disturbances in his mother. The thoughts of having a recurrence terrified him for which he desperately wanted to visit the hospital. However considering his mother at high risk of complications from the COVID-19 infections, he was too perplexed to decide what to do. Another thought of his children being at risk of the infection if he visited a hospital heightened his anxiety. He recalls himself having sleepless nights wondering what is better in the current scenario for the safety of his whole family without adversely affecting his mother's health. He remembered having episodes of anger, frustration on his kids and wife over small immaterial things. However, when the situation continued and had almost felt devastated for >2 months he finally thought to visit the hospital once.

When he presented to the outpatient department to show his mother, it seemed evident that he was in great psychological distress. The mother was evaluated and suspected of an infection for which treatment was prescribed. However, we thought of communicating with him regarding his fears, distress, and anxiety. Once he was comfortable, he expressed his distress which he stated had completely ruined his life. He discussed his worries and slowly and gradually felt much better. We followed them using teleconsultation and found that his negative symptoms such as helplessness, anger, and distress had decreased and he felt good to be with his family.

DISCUSSION

The pandemic crisis had left the people across the globe startled and terrified. Caregiving is otherwise also a taxing responsibility which has great bearing on the physical and psychological well-being of the person. Caregivers of cancer patients are faced with challenges related to the health of

their patients. This is heightened in the present scenario of the pandemic. We, in this case, found that a caregiver is faced with multiple stressful situations related to caregiving from time-to-time, adding to which is the risk of infection and its complications in the present pandemic.

It has been previously documented by Girgis *et al.* that the prevalence of depression ranges from 10% to 53% in family caregivers of cancer survivors.^[4] Previous evidence also states that comparison of depression rates among caregivers has been found to significantly higher than among noncaregivers.^[5]

Hence, it becomes paramount to address the distress issues of the caregivers along with the patients.

Communication with the caregivers and patients in discussing their goals of care, delivering bad news is an important tool to allay the distress and worries of caregivers.

The role of communication holds more important in the present scenario when the caregiver is burdened with the new emotional challenge of caregiving. Caregivers are dealing with a myriad of issues faced due to COVID-19, so it becomes mandatory to take care of their mental health along with patient care. It has been previously suggested that caregivers valued communication with physicians who were focussed on experiences of patients and caregivers and sensitive to unmet information.^[6] The use of timely communication had beneficial effects on the caregiver's mental health and overall well-being of the caregiver described in the present study. We hope that more attention to communication directed at allaying the worries of the patient and his caregivers will help us emerge from the pandemic with more positive outcomes in their health.

Caregivers are the backbone of the well-being of cancer patients, so supporting them in ways such as connecting with them using teleconsultation and other helpful ways seems important. The challenge for the health-care providers in the present pandemic is to provide good communication using new tasks such as telephonic consultations. We have to reach out to the caregivers and encourage them, support them with communication and compassion to continue their journey of patient care without adversely affecting their own health.

Declaration of consent

The authors certify that all appropriate consent forms have been obtained from the patient and caregiver regarding clinical information to be reported in the Journal. They understand that their names and initials will not be published, and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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