

EDITORIAL

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Addressing the Psychological Needs of Cancer Survivors and their Caregivers: During Treatment and Beyond

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Abstract

Cancer survivors and their caregivers face significant psychological challenges, both during treatment and in the years following recovery. The emotional toll of cancer, like fear, uncertainty, anxiety, and depression, can profoundly affect the quality of life for both survivors and caregivers. During treatment, survivors often experience emotional distress due to physical changes, treatment side effects, and fear of disease recurrence. Caregivers, too, bear emotional and psychological burdens, juggling their caregiving roles with personal responsibilities. Both groups may experience burnout, helplessness, and anxiety, necessitating structured psychological interventions such as counseling, peer support groups, and stress management techniques. Post-treatment, survivors continue to face unique challenges related to reintegrating into daily life, managing the fear of recurrence, and coping with long-term side effects, whereas caregivers may struggle to adjust to a changed dynamic. A comprehensive approach, including psycho-oncology services, mindfulness-based therapies, and resilience-building programs, will help to mitigate these challenges, improve their quality of life, and foster long-term emotional well-being.

Keywords: Cancer Survivors- Caregivers- Psychological needs- Cancer treatment- Quality of life- Survivorship

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Introduction

According to the American Cancer Society (ACS), the overall cancer death rate in the United States decreased by 32% from 1991 to 2019, leading to millions of survivors enjoying longer and more productive lives [1]. Survivors are required to navigate not only the complexities of physical recovery but also significant psychological challenges that can be profound and enduring [2]. Surviving cancer extends beyond merely overcoming the physical symptoms of the disease, it encompasses navigating the ongoing psychological challenges that many survivors face, even after completion of treatment. As many as 20% of cancer survivors experience clinical levels of anxiety and depression, with these rates often being higher for specific cancer types [3].

For many of the survivors, treatment completion does not ensure a return to normal, but it introduces a new set of challenges like managing long-term side effects, adjusting to new physical limitations, and reconstructing a sense of identity following a profoundly life-altering experience

[4]. The psychological burden is increasingly recognized as a vital aspect of survivorship, but support services in this area are still insufficient and underdeveloped [5].

Caregivers of cancer patients (family members or close friends) experience a significant psychological toll that is frequently overlooked. These caregivers play an essential role in the patient's journey, providing emotional and physical support, coordinating treatment logistics, and managing the daily realities of living with cancer [6]. As the focus is only on the needs of the patient, caregivers themselves may suffer from burnout, anxiety, depression, and feelings of isolation [7]. This review aims to highlight the psychological needs of both cancer survivors and their caregivers, an aspect often overshadowed by the emphasis on physical recovery.

Psychological challenges faced by cancer survivors Emotional distress during treatment

A study by Jones reported that 28% of newly diagnosed cancer patients experienced clinically significant levels of anxiety, with more distress in individuals with advanced

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cancer diagnosis [8]. This anxiety stems from fears of recurrence, uncertainties about the future, and concerns about treatment-related side effects, along with a lengthy and arduous course of treatment [9]. Many patients have concerns about the financial burden of cancer treatment, as out-of-pocket expenses can be substantial, adding another layer of stress, more commonly observed in LMICs [10].

Post-treatment psychological issues

Surviving cancer does not necessarily mark the end of psychological distress as it is commonly seen that many survivors report their emotional struggles after the completion of treatment, and depression is reported to affect approximately 15-25% of cancer survivors [11]. Nearly 20% of cancer survivors reported experiencing PTSD symptoms months or even years after their diagnosis, characterized by intrusive thoughts, nightmares, hypervigilance, and avoidance of reminders of their cancer experience [12]. Some survivors encounter survivor's guilt, leading to feelings of sadness, worthlessness, and even isolation, as survivors attempt to tackle reconciling their joy in surviving with their grief for those who did not [13].

Long-term survivorship issues

Fatigue is a significant issue among survivors, with approximately 30% experiencing chronic fatigue months or even years post-treatment [14]. Kashani et al reported that up to 70% of cancer patients have cognitive dysfunction during treatment, with some enduring these impairments long after therapy has ended [15].

A study found that body image distress can contribute to social isolation and difficulties in personal relationships, as survivors may feel uncomfortable with their appearance or fear judgment from others [16]. In addition to physical changes, the long-term side effects of treatment, like sexual dysfunction or infertility, can further exacerbate emotional distress and complicate intimate relationships [17].

Challenges of reintegrating into society

Social reintegration is also a challenge, and it is seen that friends and family believe that patients with cancer can return to work just after treatment, considering them as cured, overlooking the emotional and physical dimensions of the patient.

Psychological burden on caregivers

The emotional strain of caregiving

Studies reported feelings of helplessness and struggling to alleviate their loved one's pain and distress while often feeling powerless against the disease among cancer caregivers [18]. Caregivers are also affected by the uncertainties associated with treatment outcomes and the fear of cancer progression or recurrence, which can contribute to chronic stress [19].

Burnout and compassion fatigue

A study found that over 40% of cancer caregivers report experiencing burnout, which is marked by fatigue, irritability, sleep disturbances, and an overall feeling of

emotional depletion [20]. Burnout is closely associated with compassion fatigue, a condition that arises when caregivers, overwhelmed by the suffering of those they care for, begin to feel emotionally detached or desensitized [21]. Compassion fatigue may manifest as emotional numbness, diminished empathy, and a sense of cynicism, which complicates the caregiver's ability to offer effective support [22].

Balancing multiple roles

Caregivers frequently manage multiple responsibilities, including employment, parenting, and household management, alongside their role in caring for a cancer patient. The time-consuming nature of caregiving, encompassing medication management, appointment coordination, and providing emotional support, leaves little room for self-care or relaxation for caregivers [23]. Approximately 60% of caregivers continue to work full- or part-time while providing care, with many expressing challenges in balancing their professional obligations with caregiving responsibilities [24].

Psychological impact on the survivor's health

The psychological well-being of cancer caregivers is intricately connected to the health status of the cancer survivors. Caregivers often report higher levels of fear of recurrence than the patients themselves, as they navigate their anxieties while reassuring their loved ones [25].

Existing support systems and shortcomings

Survivors and caregivers engaged in support groups have reported lower levels of distress and enhanced coping strategies [26]. Psycho-oncology services are provided by a team comprised of psychologists, psychiatrists, and social workers, can help in addressing the emotional and psychological aspects of cancer care [27]. Many individuals face substantial out-of-pocket expenses for mental health services, and insurance plans often provide inadequate coverage for counseling or psychiatric care.

Strategies to address psychological needs

Psycho-oncology services should be considered a standard component of every cancer treatment [28]. Routine screening for psychological distress in both cancer survivors and their caregivers is essential for facilitating timely interventions. Telehealth interventions, including online therapy and support groups, can be as effective as in-person services in reducing psychological distress [29]. Caregivers who receive targeted support report lower levels of distress and demonstrate improved capacity to care for their loved ones [30].

Role of policy and advocacy

Policymakers should prioritize efforts to minimize disparities in access to mental health care, particularly for underserved populations such as those in rural areas or low-income communities, ensuring that psychological services are universally accessible [31]. Policymakers should also advocate for legislation that safeguards the rights of caregivers and survivors in the workplace [32].

Conclusion

The psychological impact of cancer is profound and far-reaching, affecting not only survivors but also their caregivers. Many individuals experience significant emotional distress, including anxiety, depression, and post-traumatic stress, both during treatment and after recovery. Caregivers, often overlooked, face their unique psychological burdens, dealing with feelings of helplessness and burnout. This underscores the urgent need to address the psychological needs of all individuals impacted by cancer, be they survivors or caregivers.

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