

The Unseen Challenges of Cancer Survivorship

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Abstract

While the physical challenges of cancer treatment are widely known, there are secondary challenges and barriers that get placed on the patient and families which are overlooked and impact the treatment, and quality of life (Wagner & Lacey, 2004; Wang et al., 2025). Patients face extra expenses and career slowdown or loss (Wagner & Lacey, 2004), ongoing care that's not equal to all (Munday & Tansley, 2026), and psychological struggles ("Bladder Cancer Care," 2024; Londoudi et al., 2024). Unfortunately, many people will experience a cancer diagnosis without fully understanding the unexpected challenges that may follow ("Bladder Cancer Care," 2024; Wagner & Lacey, 2004). This paper explores the less recognized challenges that can arise following a cancer diagnosis, focusing on the three core areas: Financial strains and career setbacks (Wagner & Lacey, 2004), systemic healthcare inequalities faced by disabled and neurodivergent patients (Munday & Tansley, 2026), and psychological struggles and anxiety (Wang et al., 2025). Although studies have been conducted to address some of these barriers, healthcare settings and standard oncology care need to give greater emphasis to these matters to reduce stress and burden ("Bladder Cancer Care," 2024; Munday & Tansley, 2026).

The Unseen Challenges of Cancer Survivorship

When someone receives a cancer diagnosis, they mentally prepare to face the challenges associated with the disease including chemotherapy, radiation, and surgery. However, there is an aspect of the cancer journey that often goes unrecognized at first and eventually catches patients off guard and unprepared. These overlooked challenges can add an additional burden to cancer and impact the patients overall quality of life. Among these concerns are unexpected expenses that emerge during treatment, unequal access to care for individuals with disabilities, and the emotional effects of living with cancer.

The Overlooked Expenses of Cancer Care

Advancements in medicine have improved cancer treatment; however, it also creates a financial burden for the patient and their families (Wagner & Lacey, 2004). While cancer patients are actively battling the disease, unexpected expenses and obligations accompany it. In addition to the standard out-of-pocket medical expenses, the unforeseen indirect expenses related to treatment include transportation, food, lodging, childcare, elder care, housekeeping assistance, wigs, medical supplies, prosthesis, and assistive devices. These expenses can become especially challenging when patients must pay upfront without any reimbursement options (Wagner & Lacey, 2004). “Transportation is consistently named as a significant source of out-of-pocket expenses and a barrier to care” (President’s Cancer Panel, 2002, as cited in Wagner & Lacey, 2004, p. 280). Also, the workplace can become another source of strain and conflict. For example, even though taking time off for treatment and recovery is anticipated, there is a deeper issue within:

Lost wages are somewhat measurable, but estimating the cost of lost promotion and career advancement possibilities for patients and their caregivers is nearly impossible. In

addition, the effect of “job lock” which Glajchen (1994) defined as the inability to leave a position for fear of losing insurance coverage, is not easily calculated. If the unpaid labor of family caregivers was included in cost estimates, the cost of caring for a patient with cancer at home would approximate that of nursing home care (Stommel et al., 1993, p. 280, as cited in Wagner & Lacey, 2004, p. 280).

In a one-time survey assessing the hidden financial impact on 30 patients with breast cancer, Moore (1999, as cited in Wagner & Lacey, 2004) recognized a wide array of expected out-of-pocket expenses, which included transportation, meals, lodging, clothing, medications, insurance premiums, telephone, child or elder care, home assistance, lost wages, and quality-of-life costs. Every single participant reported incurring transportation costs, 80% reported increased insurance premiums and telephone bills, and 60% suffered a loss of income.

Similarly, a survey by Lloyd et al. (2001, as cited in Wagner & Lacey, 2004) discovered that all patients and even caregivers experienced out-of-pocket lost wages with transportation, lodging, lost wages, and prosthetics being the main factors. These examples show that cancer can create financial difficulties that go beyond the cost of medical treatment and possibly continue to financially affect patients after treatment.

Inequality in Cancer Care for People with Disabilities

Everyone deserves equal access to quality healthcare, regardless of a disability or other personal circumstances. Unfortunately, this is not always the case, as people with disabilities with cancer often face disadvantages when accessing cancer screenings and the correct treatment options. “Cancer is more likely to be underdiagnosed and undertreated in people with disabilities compared to non-disabled people, as shown by the Cancer Patient Experience Survey” (Munday & Tansley, 2026, p. 44). “Disabled people are more likely to experience stigma, discrimination,

and inaccessibility in healthcare, including inequalities within cancer services such as physical inaccessibility and invalidation of needs” (Sakellariou et al., 2019; World Health Organization [WHO], 2023). Munday & Tansley, 2026, p. 44) points out another difficulty experienced by patients with disabilities. Healthcare settings can be overwhelming to autistic patients due to sensory challenges and from the assumption that they can easily manage multiple appointments. However, a lack of empathy and understanding by the healthcare staff can further contribute to patients feeling overwhelmed and unsupported. They also emphasize that disparities must be addressed to produce preventable illnesses and death.

Cuypers et al. (2020, as cited in Munday & Tansley, 2026) demonstrated that systemic disparities lead to lower care satisfaction and substandard cancer treatment for patients with disabilities. The patients also frequently experience major delays in getting diagnosed and starting treatment (Cuypers et al., as cited in Munday & Tansley, 2026). In addition, they are less likely to receive standard care options. For example, “Disabled patients are offered curative blood cancer transplants much less often, and are far more likely to undergo aggressive radial mastectomies instead of the minimally invasive breast cancer procedures recommended by treatment guidelines” (Gross et al., as cited in Munday & Tansley, 2026, p.45).

Munday and Tansley (2026) investigated the specific barriers that disabled and neurodivergent people experience when trying to access cancer care. They created a project known as ‘What I would Like to Say...’ By conducting interviews and gathering data, this allowed participants to vocalize potential solutions that the disabled and neurodivergent communities in cancer care face. After gathering data, they learned that patients commonly ran into systemic issues such as unhelpful attitudes from providers, rigid scheduling, and environments that ignored their sensory and physical needs. Many participants also reported

feeling dismissed, unsafe, or treated as a burden because of their pre-existing conditions.

Munday and Tansley (2026) identified four key recommendations that can improve patient experience: Support patients' understanding, take a holistic approach, ensure the accessibility of practice, and expand knowledge of disabled people.

Munday and Tansley concluded that addressing these gaps requires healthcare professionals to provide more empathetic care while being more mindful of their patients' unique needs. Moreover, the workshop provided insights that can help address the challenges, such as improving communication between the healthcare team and patients, increasing accessibility to screenings and appointments, and spreading awareness of the limitations that disabled patients experience in healthcare settings.

Fear of Cancer Recurrence

For many cancer survivors, the end of treatment marks the beginning of fear and anxiety about the possibility of cancer recurrence. According to a definition given by the American Cancer Society, fear of cancer recurrence (FCR) or progression is “fear, worry, or concern associated with the possibility that the cancer will return or progress” (as cited in Londoudi et al., 2024, p.317). A substantial concern is the correlation between FCR and insomnia because it is a road block for cancer survivors that are trying to adjust to life after treatment. FCR can lead to insomnia and insomnia can eventually develop abnormal sleeping patterns This disruption prevents cancer survivors from returning to a normal life or gaining a sense of normalcy. Sleeping problems can heighten anxiety and create a cycle for FCR and insomnia to influence one another. “Continuous anxiety can lead patients to worry that their treatment may not be fully completed” (Londoudi et al, 2024). According to Londoudi et al. (2024):

It is widely accepted that FCR is recognized as the most common psychological burden

experienced by cancer patients and survivors. According to the previous studies, 39-97% of cancer survivors experience a distressing experience of cancer recurrence, and the range of manifestation of fear that this will occur varies from fear as a natural response to behavior disturbances, depression, and anxiety (p.318).

Following are some examples of the emotional and psychological effects experienced by a variety of cancer patients and survivors. “Research shows that social constraints from family and friends directly increase insomnia in African American breast cancer survivors, which is an effect mediated by fear of cancer recurrence” (Loudoudi et al., 2024). In a cross-sectional study of 217 Greek cancer patients receiving chemotherapy, Loudoudi et. al (2024) discovered that there was a higher fear of cancer recurrence, which was associated with anxiety, depression, and insomnia. Approximately 47% of the patients reported experiencing a significant fear of recurrence. In another study, bladder cancer survivors often experience “scanxiety,” a specific type of distress marked by increased levels of anxiety and intensifies during waiting periods between medical appointments, tests, and screenings. Other factors that can contribute to psychological distress include changes in body image, sexual dysfunction, pain, side effects from surgery and chemotherapy, and changes in urinary control serve as a psychological distress (Dunn, 2024).

Research indicates that meaning-centered interventions (MCIs), such as Managing Cancer and Living Meaningfully (CALM), can help cancer patients and survivors experience psychological and emotional challenges (Wang et al., 2025). A meta-analysis conducted by Wang et al. (2025), which included 25 randomized control trials, found that these interventions can benefit the overall quality of life by improving fatigue, decreasing the sense of distress, and helping patients feel more confident in managing their illness. In addition, meaning centered

interventions can also help caregivers in making positive changes and cope with their caregiving experience.

Conclusion

Although modern medicine has made significant progress in cancer treatment, surviving the disease is only one part of the journey. Unfortunately there are other difficult challenges that are often overlooked. Cancer affects more than just a patient's medical care and immediate expenses. It creates additional financial strain from unanticipated expenses and career setbacks, such as "job lock." Cancer also creates inequalities, as disabled and neurodivergent patients may experience physical barriers, delayed diagnosis, and even equitable care and treatment. Lastly, the transition into life after cancer treatment can be affected by ongoing psychological challenges, especially fear of cancer recurrence and insomnia. This matter needs to be approached by the healthcare systems and recognize these hardships in order to improve the quality of life during and after treatment. Providing patients with support that addresses these barriers can help them better manage the difficulties of their cancer journey.

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