Brain Cancer: An Erosion of Identity

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Living with cancer is an often disorienting experience that affects every facet of life, including a patient's identity. The physical effects of the disease, the stress of living with it, and the societal implications that follow heavily disrupt an individual's sense of self—their perception of the physical, emotional, and social qualities that define them. Brain cancer, however, is especially detrimental to identity due to its unique impact on cognition—the processes that dictate memory, language, and behaviour. Unlike other cancers that may impact the body but leave the brain relatively unharmed, brain cancer creates a unique set of challenges in that it directly impairs cognition and emotional regulation, targeting the very organ that defines who we are. This makes discussing the relationship between brain cancer and identity particularly complex. Different tumor locations, treatment regimens, personal histories, and support systems make each patient's experience unique, and with identity being an individual and evolving concept, the ways in which brain cancer can influence it vary widely. However, by highlighting the potential the disease has to challenge identity—without making absolute claims—we can investigate its profound effects on identity while respecting the individuality of those impacted.

Cognitive Impact

Sitting at the centre of cognition, the brain dictates the processes that enable speech, decision making, and recollection. Brain cancer—whether through tumor growth, surgical interventions, or radiation or chemotherapy treatments—often impedes these processes (Coomans et al., 2019). Cognitive impairments such as memory loss, poor concentration, and language deficits can erode an individual's confidence in their abilities, forcing them to confront the unsettling reality that they are no longer the person they once were. Changes in competence have the potential to spark significant identity crises, especially for the many who derive much of their self worth and identity from their ability to perform in professional or academic settings (Anderson-Shaw, Baslet, and Villano, 2010). Behavioral and personality changes are also common, often resulting from the tumor's location or the side effects of treatment. For example, individuals with frontal lobe tumors may experience an increase in impulsivity or emotional outbursts (Loughan et al., 2023), while those with tumors in the temporal lobe may struggle with mood swings or heightened anxiety. Stark shifts in behaviour can disrupt a patient's sense of continuity, severing the alignment between "who I am" and "who I was" and creating a sense of disconnect from their former selves (Lee and Hall, 2019).

However, brain cancer treatments, such as surgery, radiation therapies, and chemotherapy, often come with their own distinct set of psychological challenges. A commonly reported side effect of treatment is chemo brain: a colloquial term for the cognitive fog that comes from chemotherapy. Chemo brain can impair memory and concentration, and, like the cancer itself, further the disease's devastating impacts on identity (Miyashita, 2023). Additionally, the longevity of treatment may lead to chronic stress and anxiety. Regular tests, scans and follow ups keep the threat of recurrence at the forefront of the patient's mind and may prompt a "hypervigilance" of any symptoms that might signal tumor progression (Loughan et al., 2023; Boccia, 2022). The constant mental and emotional stress can lead to burnout and exhaustion, which may impact the amount of energy a patient has available to invest into maintaining or expressing their sense of self. As a result, it may be more difficult to engage in the activities, roles, or relationships that previously defined who they were.

Emotional Impact

The emotional struggles brought about by a cancer diagnosis may cause significant shifts in how patients view themselves and overshadow their previous sense of self, as many of their most prominent feelings, such as fear, grief, and despair, are now defined by their illness (Madhusoodanan et al., 2015). Patients may also experience alexi-thymia, the inability to identify and describe feelings, which only exacerbates this shift (Boccia, 2022). Many of these struggles flood in immediately upon diagnosis, creating an abrupt rift in identity and self-perception pre- and post-diagnosis. The development of brain cancer is often described as rapid, with symptom onset, hospitalization and neuroimaging, and pathological diagnosis confirming a tumour—all confined within the span of a few days (Loughan et al., 2023). This process brings with it a whirlwind of emotion, among which fear is typically the most immediate and pervasive, rooted in the life-threatening nature of the disease and the uncertainty of treatment outcomes (Madhusoodanan et al., 2015). Patients often express concerns about missing future milestones, like graduations, weddings, and births, as well as personal accomplishments, like finding a life partner or having children. There may also be concerns of the disease being genetic and affecting family members in the future (Loughan et al., 2023).

The fears and anxieties surrounding brain cancer are accompanied by a sense of despair in many patients. In fact, a study by Finze et al. (2023) concluded that 87.5% of glioblastoma patients present substantial depressive symptoms, with higher rates of clinical diagnosis than other oncology demographics. This may manifest externally as irritability—an exasperation with physical and cognitive changes that come with the disease—though it much more prominently presents itself as internal despair, rooted in feelings like uncertainty and grief (Eaton Russell et al., 2016; Madhusoodanan et al., 2015). Unlike other cancers, brain cancer can be particularly unpredictable in its progression and treatment response, putting patients and their families in a state of "emotional limbo" and making it difficult to plan for the future or find a sense of stability (Randazzo and Peters, 2016). Grief often accompanies this distress, as patients mourn the life they had before their diagnosis and the abilities or roles they may lose as the disease progresses (Eaton Russell et al., 2016). For many, this distress is in constant conflict with their desire for optimism, forcing patients to regularly oscillate between hope and despair (Loughan et al., 2023). Fluctuating between these intense feelings has the potential to create a somewhat "dual identity" within the patient, as the stark contrast and lack of linearity between hope and despair often disrupt the continuity of emotional experience. This may leave patients with a sense of internal dissonance as they attempt to reconcile these conflicting aspects of their identity (Sachs et al., 2013).

Physical Changes and The Role of Societal Perception

The physical changes that accompany a brain cancer diagnosis are another significant factor impacting patient identity. Surgical procedures, such as craniotomies, may leave visible scars, while radiation and chemotherapy often result in hair loss, weight fluctuations, and visible fatigue. Though often dismissed as superficial, for many, the body serves as an outward expression of the self. These changes can carry a deep psychological weight, furthering the estrangement from life pre-diagnosis (Tollow et al., 2023). The physical symptoms of brain cancer—such as seizures, motor impairments, and chronic pain—may also contribute to this, limiting patients' ability to engage in activities that once gave them joy, individuality, and a sense of purpose (Randazzo and Peters, 2016). For example, a runner who develops mobility issues or an artist who loses fine motor skills may feel a crucial part of their identity has been taken from them. Unable to access outlets for self expression, patients are far more susceptible to feelings of isolation and grief (Slocum and Villano, 2021).

Societal perceptions of brain cancer may also challenge the identity of patients. Stigma, pity, or avoidance out of fear of saying the wrong thing are commonly directed at cancer patients, which can reinforce feelings of alienation (Boccia, 2022a). Visible markers of illness, like surgical scars or disabilities, can prompt infantilizing behaviour from peers even if it is well intentioned, stripping patients of their agency and self-worth (Knapp, Marziliano, and Moyer, 2014). This, in addition to emotional and behavioural changes, strain relationships and contribute to social isolation as patients and their loved ones navigate the altered dynamics of their interactions (Boccia, 2022a). This may disrupt how individuals feel they fit within certain groups, severing that aspect of their identity in the process (Knapp, Marziliano, and Moyer, 2014). Additionally, societal narratives around diseases like brain cancer often depict patients as either heroic fighters or hapless victims. While in some circumstances these archetypes can be constructive, patients may often struggle to align these societal labels with their own nuanced experiences and self-perceptions of their identity. This disconnect between societal labels and one's self-perception can further fragment a patient's sense of identity (Knapp, Marziliano, and Moyer, 2014).

Redefining Identity

Despite the significant challenges that come with a brain cancer diagnosis, many patients find ways to adapt and redefine their identity to accommodate their illness. Support groups and therapy can provide a space for patients to process their emotions and connect with others who share similar experiences (Magasi et al., 2022). Engaging in creative pursuits (Abu-Odah et al., 2024), mindfulness practices (Mehta et al., 2019), or advocacy initiatives (Jerjes and Williams, 2024) may also allow patients to reclaim a sense of purpose and agency.

For some, brain cancer becomes a driving force for self-reflection, prompting them to reevaluate their values and priorities in life. The disease may facilitate a shift away from identities grounded in extrinsic achievements toward those centered around relationships, spirituality, or personal growth (Magasi et al., 2022; Vonarx, 2015). This realignment of identity can both empower patients and lessen the emotional toll of the disease, enabling them to find solace and resilience in the face of adversity.

Despite these adaptive strategies, it is important to recognize that there are no perfect solutions for navigating life with brain cancer. Coping mechanisms and support systems vary greatly in their effectiveness depending on the circumstances of individual patients, and not all patients may find solace in the same approaches (Dev et al., 2024). Feelings of frustration, grief, and uncertainty are often recurring in these cases, even with the best efforts to adapt (Anderson-Shaw, Baslet, and Villano, 2010). This highlights the importance of providing flexible avenues of support that acknowledge the complexity and individuality of each patient's journey (Dev et al. 2024).

Conclusion

Brain cancer profoundly affects identity, challenging patients physically, cognitively, emotionally, and socially. Unlike other cancers, brain cancer’s unique impact on cognition and behaviour attacks the core of self-perception, disrupting the continuity between how patients see themselves before and after diagnosis. Patients are regularly faced with grief over their former selves, exacerbated by rigid societal archetypes that fail to capture the complexities of their experience. While there are strategies patients use to redefine their identity, it is important to recognize that there is no one-size-fits-all approach to coping with brain cancer. Each patient’s journey is unique, shaped by their personal history, tumor characteristics, treatment trajectory, and social support systems.

Understanding the relationship between brain cancer and identity means acknowledging both the shared struggles and the individual variability in experiences. By recognizing how profoundly complex identity is in the context of brain cancer, we can take flexible and compassionate approaches to cancer treatment to empower patients to find stability, meaning, and dignity post-diagnosis.

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