

# Body Image Distress Among Primary Brain Tumor Patients: Implications for Clinical Coping Strategies

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## RESEARCH

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## ABSTRACT

Women diagnosed with primary brain tumors (PBTs) face unique challenges related to body image distress, stemming from both visible and invisible treatment-related changes such as scarring, hair loss, weight fluctuations, and neurological impairments. This narrative review examines the psychosocial impact of altered appearance in women with PBTs, highlighting the gender-specific dimensions of body image distress and underscoring the need for tailored, evidence-informed coping strategies. While existing literature on cancer-related body image concerns has extensively addressed breast and head-and-neck cancers, research on body image among women with brain tumors remains limited. Factors influencing distress, including age, ethnicity, tumor characteristics, and treatment course, intersect with gender

norms and societal expectations of appearance. Psychological consequences such as anxiety, depression, social isolation, and diminished quality of life are explored in depth. Integrating insights from psycho-oncology and neuro-oncology, this review offers clinical recommendations for early identification and intervention, promoting holistic and patient-centered care. Specific strategies are presented for healthcare providers to validate experiences, offer anticipatory guidance, and embed body image support into survivorship planning. This work lays a foundation for future research and interventions aimed at improving psychosocial outcomes among women affected by brain tumors.

**Key words:** Primary brain tumors, body image distress, cancer survivorship, women's health, quality of life.

## INTRODUCTION

Primary brain tumor (PBT) patients experience appearance changes that impact their body image, treatment selections, and overall quality of life. Body image concerns and its correlation with physiological and psychosocial outcomes have been studied in patients with many cancer pathologies, however, no data currently is evident regarding body image issues in patients with PBT [1]. Pikler and Winterowd [2] mentioned that body image has often been overlooked as a secondary problem by healthcare providers; thus, the significance of body image in the lives of PBT patients has been underscored. Patients with PBT warrant further investigation of potential body image concerns due to unique issues related to neurologic



dysfunction, including facial asymmetry, hoarse voice, dysarthria, and cognitive changes. While some may adapt to these changes easily, others have a harder time coping which results in a longer treatment process and recovery period.

In addition, treatment-related alterations can leave scars, craniofacial deformity, alopecia, steroid-related weight gain, and cushingoid appearance [3]. Studies have contended that cancer patients who have more positive perceptions of their body image exhibited greater self-confidence in battling cancer. Therefore, the overview of PBT patients' body image distress is developed as a foundation to design and influence the development of interventions that can alleviate body image disturbance in a vulnerable population. Consequently, this study aims to conceptualize body image in a broad range of PBT patients to mitigate body image distress and promote positive health outcomes.

The most frequent side effect of treatment, alopecia (chemotherapy-induced hair loss), can cause stress and discouragement in PBT tumor patients, impacting their long-term health outcomes. Hair loss is a significant side effect that may deter PBT patients from undergoing cancer treatment due to the fear of a decreased body image [4,5]. Hair loss induced body image distress can be further amplified through the use of tumor-treating field devices, which typically require frequent head shaving. PBT patients are encouraged to wear wigs or headdresses that camouflage their hair loss. However, no research has determined the best interventions to address appearance-related concerns to mitigate body image distress and accompanying quality of life (QoL) issues among various subsets of PBT patients, including those suffering from weight and appearance changes. As body image distress is a subjective experience [6,7], a better understanding of PBT patients' body image experiences will identify "best practice" mitigation strategies.

This study is significant because it can help the public health community bridge the gap between the psychology of PBT patients and the clinical care they need. Body image concerns in this population of patients lack

literature research, thus, addressing the gap present between the two branches of knowledge will assist healthcare providers, clinicians, and support organizations in understanding, recognizing, and creating interventions that targets the issues that arise for PBT patients. Overall, the psychological burden that is a direct result of appearance-related changes can be further addressed, where strategies can be formed to aid these patients in a faster and more efficient recovery.

## **Primary Brain Tumor and Physical Change Characteristics**

Body image-related distress is a multifaceted issue that is influenced by various factors such as cancer type, diagnosis, pre-existing body image concerns, body weight, and other demographic characteristics and personality variables. Accumulated evidence research studies indicates that body image distress experienced by cancer patients influence their treatment choices during the first year of survivorship [8]. Tiggemann and Lacey [9] established that cancer patients can cope with physical changes brought about by treatment through fashion and accessories to manage and improve their appearance and presentation. Rudd and Lennon's [10] qualitative study on body image indicated that clothing was used as a strategy to camouflage some bodily flaw or as a means of self-expression. The psychological and psychosocial needs identified in this study will help in the formation of integrative care methods including social support, counseling, and patient education that promote not only physical care but emotional welfare as well. Therefore, healthcare professionals need to effectively inform PBT patients about the possible effects of physical changes and effective coping strategies when the treatment is planned to better serve PBT patients.

## **Visibility of Characteristics**

The patients' perception of their disease is drastically altered by the visibility of their physical changes to others [11]. The most noticeable physical change resulting from radiation therapy is hair loss. With the desire to maintain their physical appearance, cancer patients



consider hair loss a significant problem that impacts their treatment selection [5]. For example, most brain cancer patients express desire to disguise their hair loss [12]. Scars and body weight changes were also sources of frustration and embarrassment for patients [13,14]. Cancer patients have a heightened awareness of their bodies during social interactions when they experience noticeable changes in appearance (e.g., alopecia). They may become alienated from their bodies and personal identity if their appearance-related symptoms disrupt how they interact with others during their hair loss period or if their hair grows back differently. Due to this, clinicians should conduct a routine assessment solely based on patients feelings and well-being in order to acknowledge their mental and psychological health at the same time.

### **Permanency and Speed of Physical Changes**

Whereas gradual hair loss gives patients time to adjust to changes to their bodies, the surgical loss of a body part happens suddenly. The speed and permanency of such change may have short-term or permanent effects on one's self-image. Many patients desire immediate surgical reconstruction when these changes are reversible or minimizable [15]. Even if appearance changes are not visible, the psychological effect of an undesired physical change may negatively impact one's body image and influence clothing choices [15]. Chemotherapy-induced alopecia typically occurs within three weeks of the first chemotherapy exposure [16]. The rapid changes in appearance experienced by PBT patients can significantly impact their stress levels and treatment decisions. A study on the frequency of appearance-related symptoms and distress among cancer patients revealed that the majority of female patients were worried about alterations in their appearance [17].

### **The Severity of Body Image Distress**

#### **Coping Strategies**

Although some cancer patients are not given adequate information to accommodate for cancer-related hair loss [18], healthcare professionals often attempt to

address this issue. Under typical current practice, women who are scheduled to have chemotherapy that causes alopecia are introduced to a wig supplier as a form of preparation. A study by Frith et al. [19] found that most female cancer patients felt better prepared for the onset of alopecia by trying out and purchasing wigs or scarves as an accommodation. Female cancer patients may also have access to programs that instruct them on how to utilize makeup, wigs, scarves, and hats to hide the effects of chemotherapy and ultimately, boost body image [20,21]. Additional studies have found that participating in such programs may help women cope with alopecia and other appearance changes by distracting them from treatment [22,23]. Although wearing wigs and other headwear allows some women to feel control over their appearance, such strategies make some patients even more self-conscious about their cancer status because items such as wigs and headscarves come to symbolize their cancer treatment [24]. Many patients do not prepare prior to addressing appearance issues.

### **Psychosocial Impact**

Physical changes can profoundly affect social interactions, especially for individuals who place extra value on physical appearance and body image [25]. Cancer survivors who place high levels of importance on appearance experience more difficulty in psychosocial adjustment [26-31]. Some young patients have coped with these concerns by restricting social activities and refusing to go out in public without covering their heads [32]. The diagnosis and treatment of cancer directly affects dating, marital, and couple relationships. Physiologically, cancer patients often experience sexual dysfunction, including losing sexual desire and not finding sex pleasurable [33,7].

Concerns about changes in the body can cause emotional distress, leading to greater social isolation and changes in behavior in response to perceived or actual reactions from others [34,35]. In a study of 23 Danish cancer survivors, Rasmussen et al. [36] found that people tend to focus on the cancer patients' altered appearance, therefore, some patients focus on hiding hair loss to prevent being

pitied by others and to affirm that they look like they are not PTB patients [37]. The support of a spouse or partner has been identified as playing a significant role in psychological well-being and positively influencing patients' coping abilities [38]. A supportive relationship is a significant source of resilience in breast cancer patients [39]. Borstelmann et al. [40] found that women without a supportive partner had higher anxiety symptoms than women with a supportive partner.

## **Anticipatory Coping as Conceptual Framework**

### **Anticipatory Coping and Control**

Anticipatory coping is a term used to define the action of preparing to manage the stressful consequences of an upcoming event. The idea typically involves using a routine to manage complex events related to illness and stressful circumstances [41]. According to Kaiser [42], clothing serves essential social and physical human needs and offers cultural representations and aesthetic value. Frith et al. [19] found that most female cancer patients felt better prepared for the onset of hair loss by trying out and purchasing wigs or scarves. Wearing wigs and other forms of headwear allows some women to feel control over their appearance. Healthcare professionals may miss the opportunity to develop effective interventions if they cannot identify effective coping strategies.

Thompson et al.'s [43] study on cancer patients with various diagnoses found a strong correlation between perceptions of control and successful adjustment to cancer treatment. From a psychological perspective, control is fundamental to emotional well-being, adjustment, and coping [44]. Cancer patients may have no control over their disease, however, when they wear wigs and scarves, a sense of control is established and helps them healthy and confident in their appearance [43].

Patients engage in activities to manage and cope with their physical changes to provide themselves with control over their situation [19]. Clothing and other appearance-management behaviors may become increasingly important for cancer patients, providing a means of secondary or cognitive control over an inevitable

and largely uncontrollable disease. Indeed, perceived control over daily emotions and physical symptoms is perceived as more important by the patients than controlling the disease, relationships, or medical care [19].

Frith et al. [19] suggested that cutting and shaving off one's hair may help patients prepare themselves as well as others for the potential loss of hair, thus, making the patients feeling more proactive in the treatment process. The self-confidence of cancer patients in dealing with the disease is greatly influenced by their perceptions of their body image [45]. Women who have a more positive view of their bodies are more likely to believe in their ability to stay healthy despite the illness and its treatments, and to maintain physical and emotional closeness with others.

## **Personality Variables**

### **Body Investment**

Cash [46] categorized appearance investment into self-evaluative salience and self-motivational salience. Self-evaluative salience refers to the importance of physical appearance in defining one's self-worth and self-concept. Self-motivational salience refers to one's efforts to engage in appearance-management behaviors to improve attractiveness. Moreira et al. [26] found that higher self-evaluative salience predicted negative consequences of treatment, including lower QoL, higher levels of depression, and increased fear. However, higher levels of self-motivational salience predicted the opposite. If patients are high in self-evaluative salience, their negative evaluation of their appearance will be more significant due to the increased fear of others' negative evaluations of their physical appearance. On the other hand, patients with higher self-motivational salience will make more effort in their behavior to manage their appearance. These findings by Moreira et al. emphasize the need for tools and assessments that can guide healthcare providers to provide patients with resources and support strategies based on their experiences. It also highlights the distress that can be caused when excessively focusing on physical appearance as well as how patients' individual coping methods can differ to a great extent.



A self-evaluative component of body investment is frequently associated with clothing or camouflage among cancer patients [6,7]. Cancer patients who are unsatisfied with their body changes may feel the need to cover up what is perceived as imperfection; therefore, they tend to put more effort into camouflaging their bodies. Strategic apparel shopping would benefit cancer patients who are conscious about their appearance and experience physical changes that differ from a societally prescribed “normal” appearance. The impact of such body investment requires the consideration of additional factors, including cancer type, diagnosis, body weight, other demographic characteristics, and body investment in one’s appearance.

## Demographic Variables

### Age

The severity of cancer treatment on body image is likely to depend on the patient’s chronological age [15]. According to Can et al., [47], body image is lower in younger (vs. older) cancer patients because they are more likely to focus on appearance than older patients. Possibly due to the fear of receiving judgement from others as well as the incentive to seek a future partner. Hopwood et al. [48] conducted a study with breast cancer patients younger than 55 and older than 55 to explore the effect of age on body image. Results showed that younger patients had more concerns about their body image. Nozawa et al. [17] found that younger patients experienced greater body image distress levels than older patients for gastrointestinal and lung cancer. However, Fan and Eiser [49] identified nine studies that assessed the relationships between the cancer patient’s body image and age; no significant associations were found in seven of these studies. Thus, it is not conclusive that older patients have a more positive body image and cope better with physical changes.

### Gender

Gender strongly predicts body image dissatisfaction.<sup>46</sup> Due to more rigid cultural beauty ideologies, females in the United States experience higher levels of body dissatisfaction than males [50]. Distress

related to hair loss, for example, is felt more strongly by female participants. The more significant distress experienced by female participants relative to appearance symptoms may be an extension of their awareness and concern, in general, relative to beauty and cosmetics [51]. However, men encounter a social pressure and expectations causing them to mask their distress in terms of body image. Additionally, males place greater importance on physical attractiveness in their mate choice than females, leading them to feel less satisfied with their physical abnormalities [52]. Following cancer treatment, the removal of female symbols such as long hair and large breasts can negatively affect one’s body image. Tekkis et al. [53] conducted a study on patients who had undergone rectal cancer excision and discovered that women reported a poorer body image and were less sexually active compared to men.

Fan and Eiser [49] identified 12 studies that investigated gender differences. Five studies indicated that males rated their body image more positively than females [54-58]. Six studies found no differences [59-64]. Only one study found that females rated their body image better than males [65]. However, Fingeret et al. [11] suggested that gender fails to contribute to body image scores due to the unique experiences of patients’ body image concerns when facing life-threatening illnesses. It appears reasonable to be concerned that male body image difficulties are perhaps more undetected.

### Ethnicity

Schlebusch and van Oers [66] compared body image among Black and White female cancer patients in South Africa and found significant variation in disease experience across ethnicity. Black patients were found to experience higher levels of depression and body image dysphoria and used less adaptive coping strategies compared with White patients [2]. Researchers emphasized the importance of further studies, as body image has not been investigated in other people of color, such as Native Americans, Asian/Pacific Islanders, or multiracial patients in the United States.

## Socioeconomic Class

Breast cancer patients who report higher body image concerns tend to be more educated and have higher household incomes than patients who report lower body image concerns [45]. This is likely due to the fact that higher-income cancer patients can purchase products that tend to benefit from mood-regulatory functions. For example, women who are not satisfied with their appearance can afford to purchase more clothing, fashion accessories, jewelry, and body care products to alleviate their body image distress. Such coping activities may inadvertently help remind patients of the discrepancy between their perceived and ideal body image, amplifying their body image concerns. Socio-economic status significantly impacts patients' appearance-related concerns [67].

One study conducted by Dean et al. [68] studied the effects of financial burdens on treatment and aftercare including but not limited to monetary strain, lost income, and out of pocket medical expenses. The same study found that many patients and families may experience out of pockets cost in the tens of thousands of dollar range despite having insurance [68]. The financial distress individuals in lower socioeconomic groups face will often disincentivize any spending individuals may want to allocate towards cosmetic concerns.

## Overview of Body Image among Cancer Patients

White and Hood [69] developed a multidimensional model of body image in oncology. This model displays the value that patients put on body image and how they view themselves beyond the disease itself. Clinician and researchers are recommended to acknowledge the value that patients attach to the body part affected by cancer to obtain a more refined understanding of the patient's perspective. Considering the body image model in oncology by White and Hood [69], the conceptualization of cancer patients' body image is developed based on a literature review concerning cancer patients' body image accounting for cancer type, personality, and demographic variables.

Cash's [46] cognitive-behavioral model of body image highlights the influential role of personality traits in developing body image attitudes. To expand on this, White [15] delineated a cognitive-behavioral model based on Cash's work, investigating the impact of cancer treatment on how patients experience perceived or actual changes to their appearance. By building on Cash's work, White explores how these processes influence how patients perceive themselves and in what ways they respond to these physical changes. Considering the subjective nature of body image is important in understanding the patient's perspective, regardless of whether physical changes are noticeable to others. Cancer patients often feel concerned about reactions from others when they perceive a large discrepancy between their current selves and their ideal body image. On the other hand, cancer patients with great body investment tend to be more resilient when they need to camouflage their appearance.

The severity of body image distress differs based on the type of cancer and physical changes. Visible physical changes are expected to result in negative reactions from others. Moreover, cancer patients' body image experiences are significant when these changes are rapid and permanent in the body. Disturbances of physical functioning also affect cancer patients' body image. Patients who must decide whether to undergo appearance-changing cancer treatment need support when evaluating their thoughts, beliefs, and feelings related to appearance changes so that they can make an informed decision. Developing effective coping strategies using fashion items is one way to enable patients to adjust to the resulting changed appearance from cancer treatment [70].

## CONCLUSION

Body image assessment among cancer patients is significant because treatment-caused physical changes affect cancer patients' attitudes toward their bodies. There is evidence that body image-related distress is subjective and is not solely based on the severity of illness. Developing effective coping strategies helps cancer patients adjust to changes in their appearance during treatment. Healthcare





professionals currently have a limited understanding of the distress related to body image experienced by cancer patients. This limitation hinders their ability to personalize communications with patients and their families. Patients who must decide about appearance-changing cancer treatment need support when evaluating their thoughts, beliefs, and feelings about appearance changes to make an informed decision. Clinicians and researchers need to understand the value cancer patients put on altered appearance.

The relationship between QoL, body image, and social relationships would vary among different demographic groups, especially related to PBT patients. It would be beneficial to clarify how demographic factors such as age, ethnicity, gender, body weight, and height as well as concerns about appearance changes, impact the actual decision-making process regarding treatments among PBT patients. Body image of cancer patients has been recognized to have a major impact on many aspects of QoL due to the physical presence of the tumor and the patient's response to treatment [71,11]. PBT patients experience rapid appearance changes due to hair loss and surgical treatment involving the head. However, earlier studies of cancer patients' body image often ignored PBT patients' cancer treatment and QoL assessment which resulted in a lack of understanding and care for the patients.

Cancer patients' self-efficacy in coping with cancer is significantly impacted by higher or lower body image perceptions [45]. In particular, women who felt better about their bodies had a stronger belief in their ability to keep healthy in spite of the disease and its treatments (including continuing physical and nonphysical intimacy with others), and could cope better with hair loss or lack of energy, remained more hopeful and optimistic, and felt more confident in asking questions of nurses and physicians. This research suggests that the QoL of PBT patients can be improved by helping them build or maintain a positive body image. Medical professionals can provide better-coping strategies to these patients by understanding the factors that significantly impact body image and being aware of effective mitigation strategies. They are best

positioned to foster conversations about the impact of treatment options and strategies to mitigate body image distress.

## FUTURE DIRECTIONS

Further research is needed to develop effective intervention strategies that demonstrate the effectiveness of apparel use among cancer patients in a clinical setting and compare control and non-control groups to confirm the efficacy of appearance-related behaviors. Utilizing various methods such as personalized questionnaires, body image tracking devices, and assessment tools tailored to PBT patients can help us obtain a deeper understanding of the situation and the strategies that can be used to ease patient distress and improve quality care. It is particularly beneficial to investigate patients from diverse ethnic groups and all income levels as this can also address the patients' needs as well.

Due to the lack of existing research in primary brain tumor patients, this review looks at body image distress among PBT patients. There is established literature addressing other cancer populations such as breast cancer, however, these papers don't address the unique challenges and side effects faced by PBT patients. This review is based on secondary evidence from previously established literature which may limit the generalizability of this study's findings. Addressing this limitation is vital for the interpretation of this study as it provides a basis for a conceptual framework as well as a need for a more focused research approach. For example, this research should focus on developing mitigation strategies using appearance-related behaviors and products for patients with permanent visible physical changes, regardless of gender.

This review introduces body image as an area where psychotherapy can integrate appearance-related behaviors to benefit patients regarding their appearance. In the future, therapists could utilize fashion as a reference for counseling. It is especially significant because the outcome of appearance-related behaviors can improve cancer patients' body image. Highlighting the concept of therapy via fashion can contribute to apparel studies in other



academic fields, including oncology, psychotherapy, and counseling. Fortunately, some of these developments have already occurred. This therapy is highly effective at improving the attitudinal and behavioral dimensions of body image [72]. The publication of cancer-specific body image assessment tools [48] will likely assist in establishing validated models that can be used to guide assessment, psychological and medical treatment, and outcome evaluation within cancer care settings.

The study must include factors such as perceived control, hopes, and fears regarding the treatment and the potential impact or burden of appearance change. Coping skills and strategies have been explored predominantly in women with breast cancer, including cognitive coping, minimization or avoidance, reliance on social support, humor, acceptance, self-efficacy, and perceived control [45, 73-76]. Breast cancer patients were less fearful, better adjusted, and reported improved QoL when they possessed higher self-efficacy and perceived control over situations [45]. Applying these findings to the population of cancer patients can initiate psychological interventions which can be used to acknowledge the necessary components of recovery and healing. These previous research projects are highly suggestive that understanding body image distress of PBT patients may help them improve their social QoL and improve their long-term health outcomes, however there is still a significant amount of aspects that can be studied in terms of body image in breast cancer patients.

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