Body Image and Adolescent Cancer Patients: The Need for Psychosocial Support

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ABSTRACT

Objective: A cancer diagnosis in adolescence can be extremely distressing. It brings with it a number of physical changes which can have a significant impact on body image (BI). The purpose of this review was to examine the concept of BI in adolescent cancer patients (ACPs).

Methods: A systematic review was conducted. 18 journal articles were included. BI was discussed under the headings: the body reality, the body ideal, the body presentation, coping strategies and social support.

Results: Cancer-related physical changes include hair loss, weight changes and scarring. Patients employ a range of coping strategies such as concealment, self-imposed isolation, fatalistic coping strategies and self-love. Social support is an imperative component of BI. Concepts such as a “peer shield” and “testing the waters” can be explored with ACPs by healthcare professionals (HCPs).

Conclusions: BI should be routinely addressed by HCPs beginning at diagnosis. HCPs must be proactive in providing support.

Keywords: Adolescent, Cancer, Body Image, Psychosocial Support

1. BACKGROUND

The World Health Organisation defines adolescents as individuals in the 10–19 age group (WHO, 2021). For the purpose of this review, this is the age range focused on. Adolescence is a challenging time due to the central role physical appearance plays in overall self-esteem, confidence, self-evaluation and identity formation of the individual
(Drew, 2007; Wu & Chin, 2003). The disruption of some physical, cognitive and psychosocial developments in adolescence by cancer can impact heavily on patients.

Schilder (1950) defined body image (BI) as “The way in which our body appears to ourselves” (p. 11) and noted that BI reflects attitudes and interactions with others. Price (1990) expanded on this idea, stating that BI is made of five components: the body reality, the body ideal, the body presentation, coping strategies and a social network of family and friends. BI can be seen as a treatment outcome variable and an indicator of psychological adjustment.

This review explores the five components of BI set out by Price (1990) and how they relate to adolescent cancer patients (ACPs). The role of healthcare professionals (HCPs) in ACP’s BI is discussed and relevant psychosocial supports are analysed.

1. Materials and Methods

The PUBMED database was searched using key words such as: body image, self-image, self-esteem, adolescent, adolescence, paediatric, pediatric, cancer, tumour, tumor and oncology. There were no restrictions on age or type of cancer to facilitate more results. The reference list of retrieved articles were searched for additional studies.

2. Results

88 articles were identified from the database. Titles/abstracts were read to decipher the appropriateness of studies. 9 studies were critically appraised. A further 9 studies were retrieved from reference lists and critically reviewed. A total of 18 studies was included.

3. Discussion

THE BODY REALITY

The first aspect of BI is the body as it really is. As an adolescent the body is already going through a series of changes which can distort BI resulting in feelings of self-consciousness (Somerville, et al., 2013). When an adolescent is diagnosed with cancer the body undergoes further shifts in function and physical appearance due to the cancer itself and the subsequent treatment. This includes scarring, amputation, dermatological changes, hair thinning or loss, fluctuations in weight and muscle tone, and the presence of a central venous catheter or stoma (Brierley, Sansom-Daly, Baenziger, McGill, & Wakefield, 2019). These changes can leave adolescents feeling less like themselves and more like a stereotypical cancer patient.

It has been well documented that changes to the body are upsetting for ACPs. Responses to cancer-related body changes include shock, sadness and fear that these changes may be permanent (Moore, et al., 2020). There is a strong link between patients perceiving that they look “ill” or “ugly” and feeling vulnerable (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

A common theme throughout the literature is that hair loss and weight changes are the most distressing physical changes for female ACPs (Brierley, Sansom-Daly,
Baenziger, McGill, & Wakefield, 2019; Drew, 2007; Kinahan, et al., 2012). Hair loss can be associated with a loss of identity and self-expression (Brierley, Sansom-Daly, Baenziger, McGill, & Wakefield, 2019). Weight issues are a common BI concern for many adolescents. Although when cancer and its treatment are the propellants of weight changes this can be especially distressing. One mother described her daughter’s experience of weight gain as “nightmarish”: “She threatened to stop taking steroids and didn’t go out for 3 weeks. That’s when she got depressed” (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010, p. 170).

From the limited research available on male ACPS’ perception of BI it appears that loss of muscle tone and reduced physical fitness are primary concerns for this group (Drew, 2007). Further research with larger sample sizes is warranted to ascertain if this is representative of the wider population.

The presence of scars attract both positive and negative responses (Drew, 2007; Brierley, Sansom-Daly, Baenziger, McGill, & Wakefield, 2019; Kinahan, et al., 2012). The data on the number, location and severity of scars isn’t recorded in the studies which may have an impact on patients’ perception of them.

**The Body Ideal**

For adolescents with cancer the ideal body type is a healthy one. When undergoing cancer treatment adolescents report that they feel “unattractive”, “abnormal”, “weak” and “ugly”. Patients often speak of their pre-cancer bodies in terms of body ideals (Brierley, Sansom-Daly, Baenziger, McGill, & Wakefield, 2019; Drew, 2007). They envy their peers’ “normal” bodies and feel stigmatised by their illness (Larouche & Chin-Peuckert, 2006; Moore, et al., 2020; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

However, the media is changing perceptions of what is “normal”. Individuals are challenging conventional beauty standards by posting positive pictures of their non-conforming bodies online (Rademacher, 2018). Photos of colostomy bags, alopecia and amputated limbs are becoming more prevalent on social media. Models for popular beauty and clothing brands are also becoming more diverse. Individuals hope to destigmatise medical issues often with an outcry of positive responses. With time, it is hopeful that this body positive movement will improve ACP’s BI by giving them the confidence to accept their bodies.

**The Body Presentation**

The body presentation is the way we adjust our BI through dress, presentation, grooming etc. (Price, 1990). In several studies adolescents were innovative and proactive in concealing physical changes and creating the illusion of a pre-cancerous body. Various methods were used such as wearing a wig, scarf or hat to hide hair loss, using makeup and clothes to conceal differences in appearance, and wearing baggy clothes to cover a central venous catheter (Lee, et al., 2012; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

**Coping Strategies**
Coping strategies can be conscious or unconscious. Effort to conceal changes in B1 is one of the common coping strategies adopted by adolescents on treatment. Concealing changes for this patient group may give them the confidence to socialise with friends without attracting attention. However, for the wider population camouflaging physical “flaws” is associated with greater B1 dissatisfaction (Cash, Santos, & Williams, 2005), suggesting that this coping strategy may not be sustainable for patients long-term.

“I just wouldn’t go out” is a common behavioural response to B1 changes. Self-consciousness, low self-esteem and fear of ridicule can lead to self-imposed isolation (Moore, et al., 2020; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010, p. 171). Frequent absences from school are common particularly during the first year after diagnosis. This can put a strain on friendships as the patient and their school friends go through very different life experiences. Some patients report that they lose touch with their friends (Mattsson, Ringner, Ljungman, & Von Essen, 2007) which may contribute to these periods of isolation. This avoidance-type coping strategy can lead to feelings of loneliness and demoralisation.

Alienation from a body that patients feel has betrayed them can result in fatalistic coping strategies. One patient described her body as something separate to her over which she has no control. “I feel like my body is an object to be injected, poked, tested on. Like it’s not mine, like it’s just a thing. It’s not me” (Drew, 2007, p. 285). Patients should be encouraged to take an active role in treatment decisions to help reduce this.

Some adolescents respond with positive coping strategies such as self-love and not caring what others think (Moore, et al., 2020). With time, some patients can look back on their cancer experience positively and feel proud of themselves for what they’ve been through. They see their scars as a talking point or evidence of an experience which has made them more resilient (Drew, 2007). For some, cancer can put things into perspective and give them a more mature, positive outlook on life. (Mattsson, Ringner, Ljungman, & Von Essen, 2007; Wallace, Harcourt, Rumsey, & Foot, 2007).

**Social Network**

Numerous studies highlight the need for social support from family and friends as well as from HCPs (Lee, et al., 2012). A social network, whether it be limited or extensive, helps ACPs cope with the rapid changes that engulf them when undergoing cancer treatment. They help them to make sense of these changes and to integrate them back in society following periods of low self-esteem and isolation.

This group of patients strive to be treated as “normal people” and require reassurance that they are still beautiful from both family and friends (Wallace, Harcourt, Rumsey, & Foot, 2007; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010). Patients exhibit negative emotions when receiving special treatment from family, friends or acquaintances in school. They perceive this attention as further confirmation that they are not “normal”.

Support from friends was explored with the concept of a “peer shield” (Larouche & Chin-Peuckert, 2006). ACPs described how they relied on their group of friends to shield
them from negative criticism and act as a buffer between the patient and the outside world. The idea of socialising or going out in public can be intimidating for patients. They fear stares and ridicule from people they might meet. With a close-knit group of friends they felt safer knowing their friends would answer any uncomfortable questions that may arise and support them if they were teased or stared at. Friends can act as a comforting and protective agent.

How others perceive an individual’s appearance can play a role in a person’s own BI. For ACPs, others’ reactions and opinions can mitigate or amplify their own BI concerns (Moore, et al., 2020; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010). “Testing the waters” is a method through which ACPs begin to show others their true physical appearance (Larouche & Chin-Peuckert, 2006). Patients reveal their body changes in safe environments with people they trust. Removing a wig or showing another an amputated leg is no small feat. A positive or encouraging response from their chosen confidant may inspire confidence in the adolescent. In completing this exercise, patients may slowly begin the journey of reintegrating themselves back into their social lives (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

A recent study describing the effects of social media on ACPs showed predominantly positive results. They viewed social media as an important communication tool for them and their peers. They felt supported when posting updates and receiving positive comments and “likes”. It mitigated feelings of isolation caused by missing school and other regular activities (Daniels, Yang, Toohey, & Willard, 2021). It allowed them to post images of themselves on their own terms regaining some control over their BI, a possible virtual method of “testing the waters”. Given the vulnerability of this patient group to negative comments, which can be widespread on social media, more research is advised in this area.

**TOOLS TO MEASURE BODY IMAGE IN ADOLESCENTS**

Although it has been reported that ACPs have comparable BI to the healthy population (Fan & Eiser, 2009), the reasons for this may be explained by inappropriate measures of BI. Commonly used questionnaires include the Offer Self-Image Questionnaire, Piers-Harris Self-Concept Scale, Body Image Instrument, Physical Impairment Rating Scale, Body-Esteem Scale for Adolescents and Adults and Self-Perception Profile for Children. All of the above questionnaires have been designed for children or adolescents. The Body Image Instrument has the advantage of being the only tool designed specifically for paediatric and ACPs. However, this tool neglects to determine the patient’s level of social support which is a key element of BI.

BI can be measured in terms of resilience. When ACPs are shown to have a more positive BI than the healthy population, it is possible that resilience plays a role (Mattsson, Ringner, Ljungman, & Von Essen, 2007). Resilience is described as the ability to “bounce back” from adversity, stress and challenges and minimise the negative effects (Patterson, 1995). Resilience outcomes include improved self-esteem, self-confidence, self-transcendence and quality of life. The Adolescent Resilience Model (Haase, 2004) revolves around concepts that are classified as either protective, risk, or outcome factors. Protective
elements include family, social and healthcare supports, derived meaning and courageous coping. Risks include uncertainty in illness, disease and symptom-related distress and defensive coping. Outcomes include resilience and quality of life. Questionnaires and interventions can be constructed around these concepts to promote resilience and improved quality of life. This model is useful in addressing the possible areas where patients could improve their support and coping mechanisms in relation to BI. However, the Adolescent Resilience Model places emphasis on deriving meaning from the cancer experience which may not be universally salient. It is counter-productive to assume that every adolescent must have a positive outcome from the cancer experience.

**Recommendations for Practice**

The variation in opinions, responses, perceptions, thoughts and feelings in the literature reinforces the idea that there is no one-size-fits-all strategy for recognising, measuring and improving BI. BI is not static in nature and must be continually addressed throughout treatment and survivorship periods.

The patient must be actively involved in the consent/assent process to provide holistic treatment. It is important for consultants to consider that although treatments may improve functioning of the body or lead to an extension of life, they may have a negative effect on BI. This must be communicated to patients in an explicit, empathetic manner (Pruzinsky, 2004). For patients, knowledge is power. ACPs report that at diagnosis they fear altered appearance, loss of friends and activities (Hedström, Skolin, & Von Essen, 2004). When HCPs don’t broach these subjects, patients find it difficult to ask for information. They worry that they will be perceived as superficial or vain. One patient “wanted to know more, but the doctors don’t tell you anything like that, it’s difficult to ask then” (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010, p. 173). It is the HCPs responsibility to initiate this conversation regardless of how resilient they perceive the adolescent to be.

A common theme in the literature is that BI is not routinely addressed by HCPs. According to HCPs there is a high variability in patients’ need to discuss BI and there are no set guidelines of how and when to approach it (Moore, et al., 2020). HCPs reluctant to address these matters may feel uncomfortable or unskilled and so routine questionnaires, or prompts are warranted (Pruzinsky, 2004).

In Ireland, according to the Health Service Executive (HSE) Model of Care, HCPs should be continually screening patients for psychological distress using general scoping questions such as “How are you coping?” (Greally, Love, & Mullen, 2020, p. 34). The report stipulates that patients must be assessed for distress at a minimum of two points during the cancer journey. However, information on how to ensure this has been completed is lacking. To rectify this, a questionnaire containing prompts could be completed to ensure no patient has been forgotten.

The HSE Model of Care divides psychosocial support into 5 levels. There is a multitude of resources available to patients at Level 1 such as information booklets, lectures, events, peer support programmes and online media. HCPs and cancer centres must actively promote these resources as patients report that lack of awareness of programmes is the greatest
obstacle for accessing support (Barakat, Galtieri, Szalda, & Schwartz, 2016). Online support groups are popular among this age group particularly for those who are reluctant to talk about BI issues in person (Barakat, Galtieri, Szalda, & Schwartz, 2016). Some studies which included online questionnaires found that participants were more open to discussing BI challenges anonymously online (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

Level 2 intervention is for patients with more significant morbidity and should be managed by a clinical nurse specialist (CNS) or other HCPs with appropriate psycho-oncology training. In Ireland, patients are assigned a CNS who is a direct point of contact for the patient and their family. There is a clear benefit in assigning one CNS to each patient who accompanies them through their cancer journey. Patients and parents appreciate continuity (Vindrola-Padros, et al., 2016). They form a connection with the patient and are more likely to recognise shifts in BI and subsequent psychological distress.

For HCPs providing Level 1 and 2 support, previously mentioned topics such as “the peer shield”, “testing the waters”, social media and family dynamics can be explored with patients to assess the extent of their social support. The self-isolation coping mechanism can have profoundly negative implications for patients. Therefore, HCPs should encourage more positive coping strategies such as building confidence and self-love (Abrams, Hazen, & Penson, 2007). They can provide practical information on using wigs, hats and scarves to mask body changes. HCPs should be trained to recognise when a patient requires a referral for more advanced levels of support which can be delivered in the form of cognitive behavioural therapy, psychotherapy, counselling or psychiatry services. These are available at Level 3, 4 and 5. The Model of Care discussed is focused on adults as there currently are no existing guidelines on ACP models of care in Ireland.

Adolescents must be recognised as a group distinct from children and adults in healthcare settings. Care should be tailored to their explicit needs (NICE, 2005). Adolescent-specific cancer centres are required globally for this purpose. An environment which doesn’t have a hospital feel to it, with a variety of activities and amenities, and healthcare provided by a specialised multidisciplinary team all under one roof has been shown to be valued by ACPs, parents and HCPs alike (Vindrola-Padros, et al., 2016).

Attending an adolescent-specific hospital can give patients a social outlet as they meet others who they can relate to. Patients describe being more comfortable with their BI around people who look like them (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010) and it can provide a unique sense of camaraderie. In one study, participants felt they would benefit from meeting other ACPs and hearing “success stories” (Wallace, Harcourt, Rumsey, & Foot, 2007). However, it is salient to note that other adolescent cancer survivors may not consider themselves a success story. Adolescent-specific cancer centres are not available in many countries due the relatively low incidence of adolescent cancer and the cost constraints. Nonetheless, it is hopeful that with further research that the advantages of such centres will be acknowledged.

4. Limitations of Studies
Many of the studies included children and adolescents, or adolescents and young adults up to the age of 39. Failing to isolate adolescents from this wider age group is to ignore the unique challenges faced during this important developmental stage.

Sample size is a limiting factor in many studies due to the lower incidence of adolescent cancer compared to adult cancer. Some studies with larger sample sizes included data from surrogates who completed surveys on behalf of patients who were cognitively impaired, <18 years of age or deceased. The validity of these results on the subjective, highly personal topic of BI must be considered.

Qualitative studies have a strong advantage for getting in-depth descriptions of BI from cancer patients compared to quantitative studies. However, many of these qualitative studies use self-selection which introduces bias. It is reasonable to speculate whether those who refuse to participate in the study may have entirely different perceptions of BI compared to those willing to get involved. In one study, vulnerable patients who may have found the topic of BI upsetting were intentionally excluded (Wallace, Harcourt, Rumsey, & Foot, 2007).

Studies show a bias towards English speaking Caucasian participants. It is known that patients from culturally and linguistically diverse groups are more likely to experience psychological distress after cancer treatment (Harun, Harrison, & Young, 2013). One study had diversity in race and ethnicity of participants but failed to discuss the influence of culture on BI (Moore, et al., 2020). This is an area recommended for further research.

5. Conclusions

Cancer during adolescence poses unique challenges. BI of ACPs is multifaceted and must be addressed by HCPs beginning at diagnosis. HCPs must be proactive in providing the five levels of support to promote a positive BI in ACPs.

6. Bibliography


