

Body Image and the Female Adolescent Oncology Patient

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Abstract

Female adolescent oncology patients undergo many physical changes throughout treatment that have challenging psychological, emotional, and social implications. Body image for this population is a subject that tends to be overlooked in the midst of the cancer experience. This article will examine the complex concept of body image and discuss why female adolescent patients are at such high risk for negative body image. Assessment and care strategies are needed to foster a positive body image, resiliency, and overall well-being. Although survivorship studies may offer insightful information about the effects of the cancer journey on long-term body image, focus should be on prevention and holistic care as part of the treatment itself. The health care team, especially nursing professionals, should acknowledge, recognize, and address this vital issue as a critical part of oncology care.

Keywords

body image, adolescent, female, oncology, cancer

Literature Review

Several studies have explored the psychosocial implications of cancer and cancer treatment on adolescents. It is generally accepted that adolescents have unique qualities and needs that require exceptionally holistic and sensitive oncology care. However, only one study focused on female adolescents and the impact of cancer and its treatment on body image (Puukko, Sammallahti, Siimes, & Aalberg, 1997). In this study, survivors indicated a normal body image when compared with a healthy control group. However, through clinical interview, it was found that 36% revealed an impaired body image and 36% revealed diffuse answers, meaning they were unable to answer or evaded the question. Total body image scores revealed only 28% of female leukemia survivors had an appropriate body image versus 90% of the healthy control group.

Additionally, Larouche and Chin-Peukert (2006) presented case studies that identified body image perceptions of adolescents with cancer and how these perceptions affected their daily lives. The overall theme identified was that they do not look normal. Coping strategies included avoidance, attempts to maintain normalcy, gradually reentering the social scene in secure and nonthreatening environments, and protection of friends. Authors recommend that nurses initially assess body image perceptions of their adolescent patients and assist them with exploration of safe social activities and coping strategies.

In 2010, a study done by Williamson, Harcourt, Halliwell, Frith, and Wallace explored adolescent and parental perceptions of appearance throughout cancer treatment. It concluded that appearance changes cause major concern, anxiety, and low self-esteem. This affected social activities and compliance to treatment. Parents felt unprepared to support their children with these negative psychological implications. However, some displayed impressive resilience through the support of friends and family. The authors concluded that practical and social skills are necessary for management of well-being so adolescents can develop healthy coping strategies to manage their altered appearance and its social impact.

Background: Concept of Body Image

Several terms are associated with body image including weight satisfaction, appearance orientation, body schema, and size perception accuracy among many others, which illustrate the complexity and multidimensionality of body image. One's perception of his or her body and its interactions with the external world is an individual and subjective experience. Thomas F. Cash (2002), a clinical and

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Table 1. Physical Changes of the Female Adolescent Oncology Patient.

	Physical Change	Causal Agents
General	Weight loss: Less breast development and shapeliness, facial gauntness	Rapid metabolism from oncological process, extreme nausea, vomiting, undernutrition from chemotherapy, and/or radiation therapy
	Weight gain: Edema, fat deposition, and/or mass in the facial, neck, chest, and/or abdominal regions	Corticosteroid therapy, solid tumor masses
	Remarkable disfigurement, asymmetry	Surgical manipulation or resection, radiation therapy
Skin	Discoloration, visible irritation, dryness, burns, exacerbation of acne, pallor, bruising, petechiae, and/or stretch marks	Chemotherapy, radiation therapy, corticosteroid therapy, anemia, thrombocytopenia, weight fluctuations
	Intravenous access: Implanted port, tunneled central venous catheter, peripherally inserted catheter	Need for long-term infusions
Hair and nails	Brittle, ridged, discolored, and/or cracked fingernails and toenails	Chemotherapy
	Alopecia or thinning of hair on head, eyelashes, and/or eyebrows	Chemotherapy and radiation therapy
Function	Sensation, musculoskeletal, cognitive, and/or sexual dysfunction	Chemotherapy, radiation therapy, corticosteroid therapy, central nervous system tumors, neurotoxic and ototoxic medications, reproductive system tumors

research psychologist who has extensively studied the phenomenon of body image, defines body image as “the multifaceted psychological experience of embodiment” (p. XV). He also prefers to use the term “body images,” expressing the plurality of body image even within each individual. The body image goes beyond one’s physical appearance and delves into the subjective body experience. Furthermore, Annunziata, Giovannini, and Muzzatti (2011) define body image as a “combination of physical, cognitive, emotional and relational elements that, when well integrated in one’s self-development as a whole, allow for the growth of a stable and coherent sense of identity” (p. 902). They convey that body image is non-static, evolves over time, changes with different events and human experiences, and is intertwined with self-perception, self-esteem, relationships, and sexuality.

The Female Adolescent Oncology Patient

For the female adolescent, body image is a central part of psychological and intrapersonal development. Young women tend to define themselves by the appearance of their bodies, which puts them at high risk of insecurity and limited confidence, especially when their bodies do not meet the considered norm. When compounded with body changes that occur with the cancer experience, these risks exponentially increase. Side effects of many adolescent-type cancers, such as leukemias, lymphomas, central nervous system tumors, and soft tissues sarcomas and their treatments can be physically traumatic and have long-term sequelae (see Table 1).

Implications of an Altered Appearance

Annunziata et al. (2011) state, “Oncology patients not only have to face a life-threatening disease; they also have to undergo treatments that, by modifying the body image, add more distress to an already compromised emotional situation” (p. 903). Because of this, treatment decisions and adherence can become compromised. As these authors explain, studies have consistently found that adherence to treatments negatively correlate to body image disturbances. The value of normalcy for this population can override optimal treatment strategies and directly affect everyday choices, potentially interfering with progress and even chance of survival. Even so, most of the literature about body image in female adolescents focuses on the period following treatment.

A study by Larouche and Chin-Peukert (2006) identified common themes of adolescent perceptions while undergoing active cancer treatment. The primary theme articulated through interview was, “I don’t look normal,” which was split into 2 themes of “I look ugly” and “I look sick.” All adolescents explained that looking in the mirror constantly reminds them of the fact they are sick and have cancer. The second perception was, “People look at me.” All participants felt vulnerable and exposed, and these impressions have a strong connection with their emotional well-being. The goal of “fitting in” is a familiar and fairly universal adolescent ideation, and this social hope is greatly jeopardized by their outward appearance.

These emotionally detrimental body image perceptions profoundly affect physical and social well-being. Williamson et al. (2010) found that if adolescents think

they look bad, they feel bad physically. Outward appearance contributes to even further physical harm on top of the tremendous toll of cancer and its treatment, which is a very telling phenomenon.

The social implications are also significant. When body image is unhealthy, adolescents tend to ultimately avoid social situations. Larouche and Chin-Peukert (2006) further analyzed consequences of social avoidance. They explain that friendships, intimate/romantic relationships, school life, and leisure activities are all negatively affected. Many are hesitant about establishing new friendships or even maintaining current friendships due to insecurities about the way they look. Most are neither involved nor have a desire for a boyfriend or girlfriend due to perceptions of unattractiveness or thoughts that a significant other could never understand what they go through. The routine of school is interrupted not only because of the fatigue and time consumption of treatment but also due to negative body image. A 17-year-old told the authors, "I don't want to go back to school until my hair grows back" (p. 205). Finally, leisure activities are commonly neglected, especially activities that involve body exposure such as swimming. By avoidance of these social situations that help mold a healthy adolescence, the innate quest for connection with peers, self-identification, and independence can be sabotaged.

Social Media

With the overuse of social media, few adolescent girls are without a Facebook, Twitter, and/or Instagram account. Although this may seem to broaden one's support system, the downfalls and risks of social media must be recognized. People post photos on their profiles, which range from the everyday self-taken portrait to fancy events with friends and family. Additionally, filtering these photos is an effortless way to appear tanner, thinner, and overall more alluring. The instinct for girls to compare themselves with others can be damaging enough in real life, but when this comparison is against another's embellished and unrealistic image, the effects are exhausting, deleterious, and potentially endless.

Little research has been done on the correlation between social media and body image, and none on oncology patients. One study by Furgeson, Muñoz, Garza, and Galindo (2014) examined television, social media, and peer competition influences on body dissatisfaction, eating disorder symptoms, and life satisfaction. Results suggested that social media "may provide a new arena for peer competition" (p. 12). The ability to observe at any time what one's healthy peers look like and what activities he or she is missing out on offers harsh reminders of the unfair life that comes with being a cancer patient. This growing issue is one of great concern and it must be further explored.

Preventative Care

Assessment

Initial assessment of the female adolescent's body image is key. Annunziata et al. (2011) identify 3 aspects of body image assessment in the oncology setting: "1) the time elapsed since diagnosis, 2) the visibility of body changes, and 3) the permanence of changes in body image" (p. 902). The authors explain that emotional impact also varies with disease stage, completed treatments, and the value or symbolic meaning behind the affected body part. In-depth discussion about individual values, concerns, and risks is the only way to appropriately measure and provide holistic care. Pruzinsky (2004) outlines benefits of individualized body image assessments. They include more effective screening for body image distress, however uncomfortable or unskilled the provider may be, specification of body image concerns, and refinement of health outcomes from a unique and holistic perspective. By addressing these needs, integration of body image assessment into routine oncology care can be accomplished. Because of the personal sensitivity of body image, it is oftentimes necessary for the health care provider to introduce this issue in an explicit, empathetic manner. In the midst of the cancer experience, an adolescent may perceive that body image is somewhat of a superficial topic and less of a priority. Therefore, it is the health care team's responsibility to initiate this conversation on diagnosis and regularly throughout treatment no matter how resilient the adolescent may seem.

Given the complex and subjective nature of the human body experience, accurately measuring body image is a difficult task. A single tool may not serve as a reliable or valid indicator of one's mental body image, but certain points can help direct the assessment of someone undergoing changes from a medical illness and treatment. In his discussion, Pruzinsky (2004) mentions these points, and they will be discussed in terms of the female adolescent oncology patient. He explains that when measuring body image, one must consider whether or not a general or a disease-specific assessment is necessary. It may be appropriate at time of diagnosis to perform a general body image assessment of the teenager or young woman with dialogue such as, "Describe your thoughts when you look in the mirror" and "Share with me likes and dislikes about your body." Throughout treatment, questions may be more directed based on particular issues at the time: "Tell me how you feel about your hair thinning" or "What are your concerns about your body as it feels weaker?"

Also, the assessment should touch on the multidimensional nature of body image itself. Although numbers and ratings may be an adequate start, there is limited ability of a scale alone to capture the full picture of one's bodily experience. Patients need to be given the chance to express feelings about their body in his or her own words

through open-ended questions and discussion topics. Last, cultural sensitivity is essential when it comes to body image assessment. Pruzinsky (2004) states, "The specific cultural meaning assigned to specific types of illness, body parts, body appearance, sexual functioning, etc. may have a dramatic (if often underappreciated) influence on the individuals' body image related quality of life" (p. 76). For a female adolescent, her culture may encompass her ethnicity, group of peers, extracurricular activity involvement, and so forth, and may shape her self-perception.

There have been limited body image assessment tools researched in the oncology setting. The Body Image Instrument discussed by White (2000) has been the only tool developed with and sensitive to adolescent cancer patients. It includes items about general appearance, body competence, others' reactions to appearance, and value of appearance and body parts (see the appendix). Based on the findings of Kopel, Eiser, Cool, Grimer, and Carter (1998), this tool "exhibited moderate to high internal reliability and concurrent validity," and could contribute to clinical care by identifying "adjustment problems related to body image disturbance" (p. 141). Although these conclusions were made from studies with childhood cancer survivors, many of the same issues assessed are relevant for those undergoing active treatment, and this tool could help guide and structure special needs that are present or may arise throughout therapy. Annunziata et al. (2011) mention other tools included in cancer care such as the Body Image Scale, Body Image and Relationship Scale, and Sexual Adjustment and Body Image Scale, although these have only been included in adult cancer care and levels of consistency, reliability, and validity are variable.

Regardless of the assessment approach chosen, these discussions require an established, therapeutic relationship between the health care professional and the patient. They should take place in a private and uninterrupted space, with or without family present, depending on the patient's preference. Essential skills needed for a quality assessment include patience, active and compassionate listening, and provision of a therapeutic environment.

Education and Anticipatory Guidance

Adolescent females have the ability to acquire complex knowledge and understanding about their disease and its implications. Therefore, it is the health care team's ethical and professional responsibility to give honest and thorough education when deemed appropriate as routine, holistic care. Hedström, Skolin, and Essen (2003) state, "Information helps adolescents to become active participants in their care, and may as clinical competence, promote a sense of security and control" (p. 16). However, adolescent girls maintain a certain emotional

vulnerability that requires, as with assessment, sensitive and empathic explanations of these matters.

One key element is anticipatory guidance regarding the bodily changes that will occur with treatment. This allows the female adolescent to have time to mentally prepare for what is to come as well as help her avoid some of the shock that occurs when these changes start to take place. She may more likely process these changes as natural and expected, rather than feel as though her body is acting against her.

First, anticipatory discussion should include managing the altered appearance itself. This is a very patient-specific issue and one that is dependent on the personal value of the affected body part. For example, if losing her hair produces the most anxiety, focus should be on perhaps finding suitable wigs, scarves, or hats that she selects as most representative of her style and the person she is. Other efforts to conceal illness and maintain normalcy such as jewelry, colorful clothing, and makeup are sometimes helpful to avoid unwanted sympathy or attention. These options should be introduced and discussed before the actual changes occur so that she has time for practical tasks such as shopping or practicing makeup techniques as well as emotional adjustment to this new set of needs in the midst of a cancer diagnosis. Additional anticipatory guidance discussions should revolve around practical tips for managing reactions of others. Williamson et al. (2010) mention necessary techniques such as judging when it is safe to reveal appearance changes, warning friends, responding with confidence and information, and incorporating humor. These strategies help instill control and confidence while confronting others.

Peer and Family Support

A quality group of friends contributes to a sense of normalcy for the female adolescent and strongly promotes well-being. Larouche and Chin-Peukert (2006) introduce the concept of peer-shielding, a term used to describe the protection friends can offer against negative reactions in school, social events, and/or out in public. One adolescent shared with authors, "My friends, it's like my mental shield, like a bubble on top of me, if somebody will say something about me, they won't be scared to defend me" (p. 205). Friends may also prevent or halt rumors by serving as intermediaries in situations where others have questions or cruel criticisms and by doing so, the peer-shield promotes feelings of security, support, and safety.

Furthermore, Larouche and Chin-Peukert (2006) suggest that adolescents with cancer appreciate the importance of quality relationships with friends rather than a large quantity. Adolescents perceive their peer-shield as a bidirectional, supportive relationship that is often established before the time of diagnosis. One may hypothesize

this helps with feelings of negative body image since quality friends recognize inner beauty past the alopecia, weight changes, and so forth, and offer a shield against the hurtful reactions toward these changes.

Another source of shielding discussed by Williamson et al. (2010) involves parents and their strategies to protect their child against negative social reactions. This may involve promoting the peer-shield by organizing events and visitations as well as intervening with and diffusing awkward social interactions. A strong sense of partnership between a mother and her daughter can help tackle emotional hardships. For example, by a mother shaving her head, a daughter may discern an even stronger bond and a sense of unconditional support and comfort despite these distressing physical changes.

Physical Activity

Many studies have shown the benefits of physical activity on psychological well-being. Multiple activities that the adolescent girl oncology patient enjoys participating in, and can tolerate, may diminish insecurities regarding physical appearance due to feelings of control and empowerment over her body. They may foster the thought that her body is not cancer or a product of chemotherapy, but rather a vessel that is capable of strength and one that she can care for and cherish.

Physical activities that promote the mind–body experience, such as yoga or tai chi, may especially stimulate and enrich the inner self. For cancer patients, proper safety precautions must be taken and professional guidance is recommended. However, when practiced correctly, these activities have been proven to have several physiological and psychological benefits, many of which target side effects of cancer and treatment. Additionally, yoga and tai chi may promote a sense of control and kindness to the self, a sense of community, and also serve as a gateway to healthy choices and improved quality of life. Although not outwardly evident, they enrich one's inner body experience, which is considered a large dimension of body image concept.

Support Groups

Support groups with other adolescent girls with cancer or other chronic illnesses can offer an invaluable sense of camaraderie. Oftentimes, these girls feel as though it is helpful for them to ask questions, raise concerns, and share deep and personal thoughts with someone who is undergoing or has undergone similar experiences. A study done by Shama and Lucchetta (2007) found that teenagers and young women who attended support groups “received information, understanding, empathy, and acceptance from peers with cancer that could not be provided by a healthy peer” (pp. 102-103).

Rehabilitation and Treatment

The goal is for the female adolescent to return to optimal functioning of the body experience. As noted by Pruzinsky (2004), the term “rehabilitation” is preferred over “treatment” to describe the concept of disrupted body image management since the latter term often implies a pathology or disorder. Rehabilitation may involve physical activities such as yoga or tai chi as described above, or psychological intervention such as cognitive–behavioral therapy or somatic techniques (ie, massage). Should the adolescent girl's body image interfere greatly with activities of daily living or quality of life, treatment through professional psychodynamic or cognitive–behavioral therapy, or pharmacological management with antidepressant or antianxiolytic agents may be necessary.

Future Research

There is a need for further research regarding the female adolescent oncology patient and body image. Specifically, larger sample sizes of females would be very beneficial to broaden the identification of needs for this population. In addition, it would be valuable to gather data and perform research on those newly diagnosed and undergoing active treatment so that the focus can remain on prevention and rehabilitation of all patients.

Nursing Implications

Nurses should be aware of the compounding factors that contribute to the female adolescent oncology patient's risk of negative body image and their consequential social, physical, and psychological implications. After a therapeutic relationship has been established, nurses have the opportunity and responsibility to accurately and sensitively assess and educate the patient on her disease and treatment. Anticipatory guidance should include discussion of strategies to manage the symptoms of altered appearance and/or function and to manage the reactions of others. Nurses should take an individualized, holistic approach to care by helping the female adolescent identify and harness support from friends and family, encourage physical activity, and suggest support groups of girls with cancer or other chronic illnesses. Resilience is possible with reliable and unconditional support from the health care team. Therefore, close collaboration with clinicians, physical therapy, child family life services, integrative medicine specialists, social work, and perhaps psychology is imperative. This care should be provided before and throughout treatment as well as survivorship since body image is a serious, fluid, and complex issue that will be permanently affected by the cancer experience.

Appendix

The Body Image Instrument

General Appearance

1. I am very satisfied with my height
2. I find it difficult to look at myself naked
3. I think I look good in a swimming costume
4. I am very satisfied with my weight
5. I think my body is well proportioned
6. I am as well developed physically as my friends
7. I don't mind changing my clothes in front of other people
8. I am happy with the way I look
9. I cannot always wear the clothes I like because of how I look

Body Competence

10. I wish I was more physically fit
11. My body is strong enough for all I want to do
12. I am too badly coordinated to take part in games or sport
13. I worry about knocking things over
14. I worry about falling over
15. I think I get tired more easily than my friends
16. I am not able to move as quickly as I would like

Others' Reaction to Appearance

17. I feel people stare at me in the street
18. I feel people avoid me because of the way I look
19. I feel my appearance makes it difficult for people to like me
20. I am afraid people will laugh at me because of the way I look

Value of Appearance

21. How popular you are depends to a great extent on the way you look
22. Whether people of the opposite sex find you attractive depends on how you look
23. There are many things I care about more than how I look
24. It is the person who counts not what they look like

Body Parts

25. I feel self-conscious about the way my hair looks
26. I feel self-conscious about the way my face and neck look
27. I feel self-conscious about the way my arms and shoulders look
28. I feel self-conscious about the way my stomach looks

Items 2, 9, 10, 12-22, and 25-28 are reversed before scoring.

Kopel, S. J., Eiser, C., Cool, P., Grimer, R. J., & Carter, S. R. (1998). Brief report: Assessment of body image in survivors of childhood cancer. *Journal of Pediatric Psychology, 23*, 141-147. Reproduced by permission of Oxford University Press.

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