Managing Body Image Difficulties of Adult Cancer Patients

Lessons From Available Research

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BACKGROUND: Body image is a critical psychosocial issue for patients with cancer because they often undergo significant changes to appearance and functioning. The primary purpose of this review article was to identify empirically-supported approaches to treat body image difficulties of adult cancer patients that can be incorporated into high-quality comprehensive cancer care.

METHODS: An overview was provided of theoretical models of body image relevant to cancer patients, and findings were presented from published literature on body image and cancer from 2003 to 2013. These data were integrated with information from the patient-doctor communication literature to delineate a practical approach for assessing and treating body image concerns of adult cancer patients. RESULTS: Body image difficulties were found across patients with diverse cancer sites, and were most prevalent in the immediate postoperative and treatment period. Age, body mass index, and specific cancer treatments have been identified as potential risk factors for body image disturbance in cancer patients. Current evidence supports the use of time-limited cognitive-behavioral therapy interventions for addressing these difficulties. Other intervention strategies also show promise but require further study. Potential indicators of body image difficulties were identified to alert health care professionals when to refer patients for psychosocial care, and a framework was proposed for approaching conversations about body image that can be used by the oncologic treatment team. CONCLUSIONS: Body image issues affect a wide array of cancer patients. Providers can use available evidence combined with information from the health care communication literature to develop practical strategies for treating body image concerns of patients with cancer.


KEYWORDS: body image, cognitive-behavioral therapy, doctor-patient communication, psychosocial oncology, quality of life.

INTRODUCTION

A woman with breast cancer tells her treatment team she can no longer stand to look at herself in the mirror or show her body to her husband after a mastectomy.

A man who underwent an orbital exenteration rarely leaves the house because he does not want others staring or making comments about his appearance. He is particularly scared of what his grandchildren think of him when they see him.

A patient with diffuse large B cell lymphoma undergoing chemotherapy recently lost her hair and a significant amount of weight. She experiences daily crying spells about her body changes and is preoccupied with whether her hair will grow back differently.

A male patient with rectal cancer is refusing to undergo treatment due to concerns that he will not be able to conceal his colostomy bag from others and that his spouse will no longer find him sexually attractive.

A woman who underwent partial glossectomy and radical neck dissection has debilitating anxiety about returning to work and being around others because of her unclear speech and difficulties with eating.

Body image is recognized as a critical psychosocial issue for patients with cancer. The brief vignettes above provide examples of how cancer and its treatment can profoundly affect one’s body image and create major challenges that must...
be addressed by the oncology treatment team. Body image is a complex construct that extends well beyond how one views his or her physical appearance. It has most consistently been defined as a multifaceted construct that involves perceptions, thoughts, feelings, and behaviors related to the entire body and its functioning.\(^1\)\(^-\)\(^3\) We point to a broad range of bodily changes a patient with cancer can undergo due to the disease and treatment that can affect body image. These include but are not limited to appearance alterations (eg, hair loss, scarring, swelling), sensory changes (eg, pain, numbness), and functional impairment (eg, dysphagia, dysarthria, impotence).

In this article, we synthesize findings from the body image and cancer literature for the purpose of identifying empirically-supported intervention strategies to treat body image difficulties in the oncology setting. We focus exclusively on adults, because psychosocial care of children and adolescents differs significantly from that of adults. We can, however, glean some insights from body image research conducted on children and adolescents with cancer to lend a developmental perspective to this review article. Body image difficulties emerge during various stages of treatment even for young patients with cancer, and have strong implications for psychosocial adjustment as well as social functioning with peers. Further information about body image issues in children and adolescents with cancer can be found in a systematic review by Fan and Eiser.\(^4\)

Our objective is to delineate a practical approach for assessing and treating common body image concerns of adult cancer patients. We discuss intervention approaches for the oncologic health care team, including strategies for conversations with patients experiencing body image distress. We also discuss indications for referrals to mental health providers and types of interventions used by those providers. Because research supporting body image treatment for cancer patients is in a relatively early stage of development, we incorporate evidence-based intervention strategies from the doctor-patient communication literature as well as knowledge gleaned from our clinical experiences. We start by highlighting prominent theoretical models of body image relevant for cancer patients. We also draw attention to key findings from observational and intervention studies on body image and cancer.

**THEORETICAL MODELS OF BODY IMAGE**

Cash’s cognitive-behavioral model of body image\(^5\) has received widespread recognition and forms the basis of empirically-supported treatment interventions for body image difficulties in the general population and for patients with eating disorders.\(^6\) At the heart of Cash’s model are 2 primary types of body image attitudes theorized to drive thoughts, feelings, and behaviors related to one’s appearance: body image evaluation and body image investment. Body image evaluation refers to the degree to which one is satisfied with his or her appearance, and whether there is a discrepancy between self-perceived physical characteristics and desired characteristics. Body image investment refers to the value or importance one places on appearance and physical attributes. Both of these attitudes are routinely assessed in the body image literature.

Consider a patient with breast cancer who presents for follow-up to the reconstructive surgeon, and expresses considerable dissatisfaction with her treatment outcome (negative body image evaluation). This patient strongly values her appearance (high body image investment) and complains she does not like how her scar looks and that her breasts are smaller than what she desires. She is highly distressed that her clothes no longer fit properly, and prefers to stay at home rather than go out in public.

Cash’s model highlights the influential role of cultural socialization, interpersonal experiences, and personality traits on the development of body image attitudes. Cash further recognizes that body image attitudes are affected by changes that occur in physical functioning and appearance. This is particularly relevant for cancer patients, who can undergo extensive bodily changes from their illness and its treatment. Cash specifically distinguishes between historical factors, or past experiences that shape body image attitudes, and proximal factors, which pertain to current life experiences. Others have discussed cancer and its treatment as a critical proximal event that activates self-evaluations of one’s physical appearance and bodily functioning.\(^2\)\(^,\)\(^7\)

There are several theoretical models of body image specifically developed for patients with cancer. White delineates a cognitive-behavioral model, based on the work of Cash, focused on how patients experience perceived or actual changes to appearance resulting from cancer and its treatment.\(^8\) White highlights the subjective nature of body image and suggests it is vital to consider the patient’s perspective regardless of whether appearance changes are noticeable to others. Cancer-related appearance changes are expected to result in negative reactions if one has high body image investment and there is a discrepancy with one’s body image ideals. Returning to the vignette of the breast cancer patient who is dissatisfied with her treatment outcome, there is clearly a perceived
discrepancy between her current breast size and what she desires. Furthermore, she is experiencing negative emotions (ie, distress) and problematic behaviors (ie, social isolation) due to her body image concerns.

Fingeret conceptualizes body image concerns of patients with cancer on a continuum. This model distinguishes treatment considerations for cancer patients with normal and extreme levels of body image concerns. For example, patients with mild to moderate difficulties adjusting to body image changes may engage in social situations even though they feel somewhat self-conscious. In contrast, those with extreme body image concerns avoid social situations nearly altogether and become isolated. This model posits that many patients minimize body image difficulties due to shame, embarrassment, or guilt. Within this framework, a patient’s body image concerns are not necessarily considered to be pathological in nature, but in most cases a normative experience.

Recently, disease-specific theoretical models of body image have emerged. Two such models pertain to patients with head and neck or breast cancer. The study by Rhoten et al focuses on adjustment to treatment sequelae of head and neck or breast cancer. The study by Rhoten et al focuses on adjustment to treatment sequelae of head and neck cancer (ie, disfigurement and dysfunction), whereas Fingeret et al considers various disease and treatment-related factors specific to breast cancer reconstruction (eg, tumor characteristics, genetic risk, type of ablative surgery, type, timing, and stage of reconstruction, and complications) that can influence body image outcomes.

OVERVIEW OF BODY IMAGE RESEARCH WITH CANCER PATIENTS

In reviewing available research on body image and cancer, we primarily focused on findings published within the last 10 years. We conducted a literature search using Ovid MEDLINE, PubMed, SCOPUS, and Web of Science with the search teams “body image” and “cancer” and “treatment/intervention/therapy/counseling programs” from 2003 to 2013, excluding studies with adolescent and children samples. This search yielded a total of 92 studies. We focus here on discussing relevant findings from observational and intervention studies.

Observational Studies

Although the largest amount of research on body image in the oncology setting has been conducted with patients who have breast cancer, these issues have been examined in a wide array of cancer patients. We found research including patients with cervical, colorectal, head and neck, hematological, melanoma, ovarian, prostate, renal, and testicular cancers. Most studies were conducted within disease-specific samples, which allowed researchers to consider unique illness-related issues associated with body image.

Few studies evaluated the prevalence of body image concerns. However, some evidence suggests that patients with head and neck cancer treated with surgery are highly likely to have such concerns. Two studies found that up to 75% of patients with head and neck cancer who are undergoing surgical treatment acknowledge concerns or embarrassment about 1 or more types of bodily changes at some point following diagnosis. Other research documents the prevalence of body image concerns in patients with breast cancer. One study conducted with women less than 7 months after diagnosis found that 17% to 33% experienced body problems some or much of the time. Taken together, these findings indicate that body image concerns affect substantial numbers of breast and head and neck cancer patients, with these issues persisting into long-term survivorship. Body image concerns are also associated with a large number of adverse psycho-social consequences. Across numerous disease sites, body image concerns are significantly correlated with higher levels of anxiety and depression (breast, colorectal), worse quality of life (breast, head and neck, prostate), and sexual functioning difficulties (breast, gynecological, testicular).

Patients are found to be most concerned about body image in the immediate postoperative period and soon after completing other forms of treatment. Body image issues, at least for breast cancer patients, appear to subside and stay relatively stable after approximately 2 years, although issues may persist in some patients. Some studies have reported that younger patients, patients with higher body mass index (BMI), patients who experience postsurgical complications, and patients who undergo certain types of surgical, hormonal, and reconstruction treatment are more likely to experience body image issues. The influence of cancer treatment type on body image outcomes has been extensively studied with breast cancer patients, with the literature generally reporting more favorable outcomes for patients who had undergone breast conservation therapy (as compared to mastectomy), immediate reconstruction (as compared to delayed reconstruction), and autologous tissue-based reconstruction (as compared to implant-based reconstruction), although findings are equivocal.

Although the relationship between cancer treatment type and body image has been studied in other cancer samples,
research is limited. For instance, 2 studies with patients with colorectal cancer reported that placement of a stoma (compared to those with no stoma) was a significant predictor of body image concerns that worsened over time. 21,23 One study in the prostate cancer literature reported that patients receiving androgen deprivation therapy compared to those without androgen deprivation therapy endorsed greater body image dissatisfaction. 31 To summarize, although the literature is starting to show a preliminary pattern of predictors, further evidence is needed to identify demographic, illness, and treatment-related factors that elevate a cancer patient’s risk of experiencing body image concerns.

### Intervention Studies

We searched all available articles, regardless of year published, testing a psychosocial intervention targeting body image difficulties of adult cancer patients. We found a total of 13 studies, 12 of which were conducted with breast cancer patients. Nine studies used a randomized controlled trial design. These studies provide a preliminary basis on which to make treatment recommendations for patients with cancer who are struggling with body image concerns. We summarize key aspects of these intervention studies in Table 1.

With regards to the type of intervention used, cognitive-behavior therapy (CBT) was the most frequently employed, and was used in 4 studies. CBT is a goal-oriented, time-limited psychotherapeutic approach delivered by a trained mental health professional that targets dysfunctional thoughts, emotions, and behavior through techniques which include goal-setting, cognitive restructuring, systematic desensitization, and skills training. 5 CBT is an established, empirically validated treatment for various mental health disorders, including eating disorders and depression. 33 Three interventions consisted of 6 sessions, and one intervention consisted of 14 sessions. All 4 CBT-based intervention studies reported improvement in body image outcomes after intervention: 3 studies 34-36 reported statistically meaningful differences compared to controls, whereas one study 37 reported improvements in body image that were not statistically significant. These interventions were delivered in either a group or couples format. For the 2 studies that conducted follow-up assessments, improvements in body image outcomes were maintained at 6 months 36 and 12 months 34 follow-up.

With regards to other types of psychological interventions, Kalaitzi et al 38 evaluated the effectiveness of a 6-session, couples-based psychosexual intervention. Significant improvements were found in body image scores, relationship satisfaction, and other sexual adjustment outcomes. Fobair et al 39 evaluated the effects of a supportive-expressive therapy intervention for lesbians with early-stage breast cancer, but found no significant changes in body image or sexuality. This was a small study (n = 20) evaluating the effects of a 12-session intervention without comparison to a control group.

Helgeson et al 40 conducted the largest randomized intervention study that evaluated the effectiveness of an education-based intervention for 312 patients with breast cancer. Patients were randomly assigned to one of 4 group conditions: control, education, peer discussion, or education plus peer discussion. Consistent positive effects on body image, self-esteem, and thoughts about illness were seen in the education group compared to the other groups at posttreatment and 6 months follow-up. In this study, education was defined as lecture-type presentations by health care professionals on information about breast cancer, adverse effects of treatment, and how to manage the disease. Other types of interventions found to improve body image outcomes include cosmetic rehabilitation for patients with flap reconstruction due to oral cancer, 41 beauty treatments for patients in the first week after breast cancer surgery, 42 massage therapy, 43 strength-training, 44 and physical exercise. 46

To summarize, current evidence supports the use of CBT-based interventions for addressing body image concerns of patients with breast cancer. All CBT interventions employed either a couples or group format. Educational

### TABLE 1. Highlights of Body Image Intervention Studies

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<thead>
<tr>
<th>Cognitive-Behavioral Therapy Interventions</th>
<th>34-37</th>
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<tr>
<td>• Therapeutic approach that targets dysfunctional cognitions, emotions, and behavior by alteration of cognitions</td>
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<tr>
<td>• Components included psycho-education, stress management, problem-solving, cognitive reframing, and communication skills training</td>
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Other Psychological Interventions

| • Psychosexual therapy focusing on communication training, sensual focus, and body image exposure |
| • Expressive-supportive therapy focusing on expression of thoughts and emotions, receiving and offering support, coping skills |

Education Interventions

| • Information disseminated in lecture formats to increase knowledge on disease and treatment with the aim of increasing self-efficacy |

Cosmesis-Focused Interventions

| • Education on using cosmetics to improve appearance |
| • Provision of beauty treatment regimens (manicure and pedicure, hairdressing, make-up) |

Sensate-Focused/Physical Fitness Interventions

| • Massage therapy with the aim of stress reduction |
| • Hatha yoga focusing on changing patient’s perceptions about physical constraints imposed on their body |
| • Strength training and physical exercise to regain physical fitness |

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To summarize, current evidence supports the use of CBT-based interventions for addressing body image concerns of patients with breast cancer. All CBT interventions employed either a couples or group format. Educational
interventions and other types of interventions also show promise in mitigating body image concerns, although results are preliminary. Future research is needed to determine how best to treat body image concerns in patients with cancer other than breast cancer.

**Other Studies and Limitations**

Our literature review has a few limitations. First, we may have missed relevant intervention studies targeting body image of cancer patients if the key term “body image” was not used to index the articles. For instance, we may have missed studies in which body image was considered under a more general construct, such as patient satisfaction or quality of life. Second, we found that investigators used a wide variety of instruments to measure body image concerns in cancer patients, which makes it difficult to compare results across studies. This lack of standardization can be partially explained by the fact that some researchers used a generic measure of body image relevant for various cancer types, whereas others used or developed disease-specific instruments capable of capturing nuances for a particular cancer type. This issue is reviewed in greater detail elsewhere.47

**PRACTICAL RECOMMENDATIONS FOR THE ONCOLOGIC HEALTH CARE TEAM**

In the remainder of this article, we propose practical strategies for the oncologic health care team when addressing body image concerns. We are aware of only one study48 that focuses on patient-physician communication about body image changes related to cancer. However, the health care communication literature supports certain key skills and strategies that are undoubtedly as applicable to body image concerns as they are to other emotional issues. Strong evidence suggests that we can help our patients overcome fear, embarrassment, anxiety, and other negative emotions by following patient-centered approaches to challenging conversations.49 We discuss these approaches below.

**With Whom Should We Discuss Body Image Concerns?**

Because body image concerns are widespread among cancer patients and associated with significant adverse psychosocial outcomes, it would be ideal to discuss body image with every patient during each encounter in the same way we reconcile medications. However, such a universal approach is not feasible in busy clinical practices. We therefore recommend that clinicians focus on patients who are most likely to develop body image concerns, namely those whose disease or treatment cause significant self-perceived changes in physical appearance or function.

Available research points to patients who undergo mastectomy and head and neck surgery as having a high prevalence of difficulties adjusting to body image changes.10,15 In addition, patients who undergo ostomy placement also develop body image issues.21–23 We should discuss body image with patients who undergo treatment for gynecological, testicular, or prostate cancer, because surgery and other treatments affecting sexual organs have both functional implications and strong symbolic significance related to masculinity/femininity.32–34 Limb amputation resulting from cancer treatment is also likely to result in significant body image issues, with research demonstrating heightened body image difficulties especially for patients undergoing late amputation (that is, after a failed limb-salvage procedure).50

Regardless of a patient’s diagnosis, we should address body image concerns with those who voluntarily raise concerns or who behave in ways that indicate body image difficulties. Each indicator listed in Table 2 corresponds to dysfunctional thoughts, maladaptive behaviors, and/or negative emotions, according to the cognitive-behavioral framework discussed throughout this article. Some patients may develop body image concerns that interfere with treatment, such as the patient who declined treatment for rectal cancer described briefly at the beginning of this article. Other body image difficulties become evident following treatment, such as the breast cancer patient who avoids viewing herself postoperatively and refuses to allow her husband to view her breasts. Body image problems can also persist into survivorship, as reflected by ongoing distress, anxiety, or depression. If left untreated or unrecognized, the patient with debilitating anxiety about returning to work and engaging in social situations following a partial glossectomy may ultimately

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<th>TABLE 2. Potential Indicators of Body Image Difficulties</th>
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<tr>
<td>• Unrealistic expectations about treatment outcomes for appearance and functioning</td>
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<tr>
<td>• Preoccupied with concerns about upcoming appearance changes</td>
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<tr>
<td>• Difficulties making treatment decisions due to concerns about appearance/body changes</td>
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<td>• Difficulties with or avoidance of viewing oneself after treatment</td>
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<tr>
<td>• Highly dissatisfied with appearance outcome following treatment</td>
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<tr>
<td>• Preoccupied with perceived or actual physical flaws resulting from cancer and/or its treatment</td>
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<tr>
<td>• Avoidance of social situations due to appearance/body changes</td>
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<tr>
<td>• Romantic relationship distress due to body image changes</td>
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<tr>
<td>• Considerable time and effort spent in appearance-fixing behaviors</td>
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<tr>
<td>• Persistent distress, anxiety, or depression due to body image changes</td>
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TABLE 2. Potential Indicators of Body Image Difficulties
become reclusive and be unable to resume routine activities. Considering the subjective nature of body image, even a patient whose functioning and appearance changes seem minimal can still experience significant body image difficulties. Many patients are embarrassed or ashamed to voluntarily mention their body image concerns. We should therefore proactively inquire about body image if we suspect an issue, even if the patient does not mention it.

**A Framework for Discussing Body Image Difficulties: The Three C’s**

Fingeret proposed a conceptual framework for approaching conversations about body image, which is referred to as *The Three C’s.* This strategy encourages patients to discuss their body image concerns, thereby allowing the health care team to identify emotional difficulties and problematic behaviors associated with these concerns and develop a plan to address them. At the beginning of a clinical encounter, providers should remind patients that body image difficulties are very common as a result of cancer and its treatment. Normalizing concerns in this way reduces shame, embarrassment, and stigma. We should then ask patients what specific concerns they have related to body image. These may include concerns about effects of impending treatment or about recent or prolonged changes to appearance and/or functioning. This step is accomplished with open-ended questions that elicit patient narrative. Finally, we should ask patients about consequences of their body image difficulties, or impact on daily functioning. We should be especially attuned to problems with social, emotional, and occupational functioning.

Principles of patient-centered communication are critical for addressing body image concerns. Open-ended questions and phrases, such as “Tell me more” and “What is that like for you?” encourage expression. Many people think of communication as talking and educating, but listening well is arguably the most powerful aspect of effective communication. Creating space in the conversation by allowing for silence encourages expression and often yields highly significant if not profound information about patients’ values, fears, and goals. Interjecting brief phrases without actually interrupting shows patients we are tuned in (e.g., “What else?”, “I see...”). Listening is highly therapeutic, because all people have a need to be heard, especially those who are scared and vulnerable, such as cancer patients. Health care providers, especially doctors, tend to do most of the talking in an attempt to “educate” patients, pose a series of closed-ended questions, and interrupt patients after only a few seconds. Many doctors worry that allowing patients to express themselves takes too much time. However, encouraging expression typically adds only a few minutes to the encounter and greatly increases the value proposition. In other words, the meeting may take a few minutes longer, but the time investment pays huge dividends in trust, rapport, and patient satisfaction in the short and long term.

Encouraging patients to express themselves invariably creates emotional moments that lead to empathic opportunities. Emotional moments can be explicit, such as when a patient cries, says “I’m scared,” or displays anger. Emotional moments can also be implicit, such as when a patient looks sad or anxious without saying so. Many doctors are uncomfortable during emotional encounters, because they become emotional too or do not know how to respond to emotion. Medical training overemphasizes biomedical knowledge at the expense of psychosocial skills, so we tend to try to “fix” problems. Many health care providers offer premature reassurance by saying things like “You look great!” or “Stop worrying, in a few months you will look completely normal.” Others offer a treatment plan rather than simply staying with emotions for a few moments. We should offer reassurance, education, and further treatment options only after patients have had the chance to express their concerns. Table 3 presents a summary of key communication skills and phrases useful for addressing body image concerns.

In addition to *The Three C’s,* there are 4 additional recommendations for the oncologic team to effectively address body image issues. These include: 1) educate patients about what to expect in terms of appearance and functional outcomes, 2) connects patient with relevant community resources, 3) refer patients to a mental health specialist for brief or intensive therapy if needed, and 4) follow up with patients with known body image issues about their concerns at each clinic visit. There are numerous community resources to assist cancer patients in dealing with body image. Two examples of community-based organizations with dedicated programs for cancer patients struggling with body image are the American Cancer Society (the Look Good, Feel Better Program) and Changing Faces. Other organizations such as CancerCare, Cancer Support Community, and Livestrong also provide national support programs that can help address body image issues. Further details about these types of community resources has also been summarized elsewhere.

With regards to referring patients to a mental health specialist, Table 2 offers potential indicators to signify the need for a referral. There are various intervention
techniques that well-trained mental health specialists can use to treat body image difficulties of patients with cancer beyond those discussed in Table 1. Further work describes, for example, the use of mindfulness-based therapy, acceptance and commitment therapy, expressive writing, and sensory approaches (eg, art, music, and dance therapy) to treat body image dissatisfaction.66,67 Such approaches have not been evaluated with cancer patients experiencing body image distress, and thus warrant further study.

Conclusions

Our review of available research on body image and cancer revealed that body image issues affect a wide array of cancer patients and adversely impact quality of life and psychosocial functioning. Body image difficulties appear to be the most prevalent in the immediate postoperative and treatment period. Some research suggests that these difficulties may subside and stay relatively stable after approximately 2 years. However, continued body image problems have been found with long-term survivors, specifically within the breast cancer literature. Several tentative risk factors of body image disturbance have been reported (eg, younger age, higher BMI, specific cancer treatments), but further studies need to be conducted. Intervention research is also limited in this area; however, current evidence supports the use of time-limited CBT interventions delivered by a mental health professional. Other interventions, such as psychosexual therapy, educational-based, cosmesis-focused, sensate-focused, and physical fitness interventions also show some promise but require further study. We identified a number of potential indicators of body image difficulties to facilitate referral to a mental health specialist for body image therapy. However, we also presented key communication skills and strategies that can be used by all members of the oncologic health care team to address body image difficulties during a clinic visit.

We identify a number of future directions for research in the area of body image and cancer. Further data are needed on the prevalence and trajectory of body image concerns as well as on predictors of body image difficulties for patients with different types of cancers. Additional evidence is also needed to support interventions targeting body image difficulties of adult cancer patients. Particular attention must be paid to evaluating
interventions delivered in an individual format, because existing work focuses largely on couples or group formats. Finally, significant concerns have been raised about assessment tools currently being used in the literature to evaluate body image outcomes. Moving forward, it will be critical to use validated tools with established clinical cut-off scores that are responsive to change over time with treatment.

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