

Assessing the body image: relevance, application and instruments for oncological settings

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Abstract

Purpose Body image is the sum of physical, cognitive, emotional, and relational elements that, when integrated, allow the development of a whole, healthy self-identity. Even though body image is normally studied in relation to eating disorders, it can also be influenced by other pathologies, including cancer. In oncology, an effective body image assessment is fundamental. The physical effects of cancer and cancer treatments are important and frequently irreversible also on a functional and emotional level; however, only few surveys have investigated body image in this peculiar context.

Methods An extensive literature review was carried out in PubMed and PsycINFO. We considered articles published from 1990 to 2010.

Results Two hundred sixty-three papers matched the search criteria. Assessment methodologies included clinical interviews, self-report measures, questionnaires, symptom check lists, and graphic tests and projective techniques. After excluding the instruments that referred to eating disorders, validated only for adolescents, and/or projective and graphic tests, we found 81 articles with six questionnaires specifically dedicated to body image assessment in oncology.

Conclusions From our systematic review, we could identify six instruments specifically designed for assessing body image in the oncological area. In this paper, we discuss their general characteristics, psychometrics properties and the clinical implications, and body image relevance on the quality of life in cancer patients.

Keywords Body image · Cancer · Psychometrics · Self-assessment

Introduction

The attention to body image has ancient origins and involves contributions from a range of different disciplines, beginning with philosophy: in the fourth century B.C., Plato wrote “We are bound to our bodies like an oyster is to its shell,” thus highlighting how subjective experience is strictly integrated with the body. Over time, the interest in this subject has grown both with researchers and the general public, particularly during the last 20 years, as proved by the large amount of manuals and original papers published on this topic [1].

The literature clearly demonstrates the complexity of this topic, and even though there is a well-established tradition, to this date there is a lack of an exhaustive definition of body image.

Thompson et al. [2] defined body image classification as “tricky”, because the different components of this construct have been described with interchangeable terms that may generate confusion. There are at least 15 expressions used as a synonym of body image (i.e. weight satisfaction, size perception accuracy, body satisfaction, appearance satisfaction, appearance evaluation, appearance orientation, body esteem, body concern, body dysphoria, body dysmorphia, body schema, body percept, body distortion, body image disturbance, and body image disorder), and this list could be even longer [3]. Even though many authors contributed in disentangling the terms’ interchangeability [3], to date these expressions in body image research are misused: understanding the body image construct will then be possible only if considering its multidimensionality [4].

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Cash's definition of body image as "the multifaceted psychological experience of embodiment," which is "especially but not exclusively one's physical appearance" [5] is a significant step in classifying the many complementary definitions. Although even this description does not completely grasp the complexity of this topic, Cash has largely contributed in extending the comprehension of this construct, showing its complexity and plurality; in fact, he often refers to body image as "body images" [3, 5, 6].

Even though the concept of body image is in part still related (and limited) to its importance to the female sphere and to its implications regarding eating disorders, and weight and body shape issues, clinical practice needs to extend the research on body image to medical and allied health fields [5, 7]. Physical disease can severely modify the body and its perception by patients: it is then important to consider the subjective body experience, which is not limited to physical appearance [3]. As a consequence, in an attempt to define body image some other related issues must be considered, like worries about self-perception, self-esteem, relationships, and sexuality. In particular, the concept of body image seems to refer both to the perception of the tangible physical body and to the idealized characteristics of the body (i.e. its mental image). At the same time, the constant and continuous change and adaptation over of body image must be considered [4].

Furthermore, it is fundamental to take into account the intrinsic characteristics of the body to put oneself in relation with the external world. The individual interacts with the environment and with the others through the body, and still through the body the individual is influenced in his/her image or representation of self [4, 8].

In summary, body image seems to be 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 [3, 9]. Besides eating disorders and weight preoccupation (traditionally more studied topics), other factors can dramatically influence body image: acquired physical injuries, skin disease, burns, cancer, and cancer-related treatments can alter body image and affect quality of life [10].

The purpose of this paper is to review the knowledge on body image in the oncological setting and to verify the instruments that are currently available for the evaluation of this construct in this context.

Body image and cancer

Several types of tumors have a strong impact on body image: cancer and its treatments can, in fact, significantly modify both the look and integrity of patients' bodies, causing problems on different levels. In many cases, the

physical signs of the disease or of treatment persistently evoke cancer, contributing to causing adaptation difficulties or the emergence of emotional frailty. In the oncological setting, the suffering connected to changes in body image is not always taken into adequate consideration [11]: few studies describe the consequences of the illness and treatments, like for instance how many women feel less attractive and have lower self-esteem after having had a breast tumor [12]. Similarly, it seems that male patients report a decrease in their quality of life and in psychosocial functioning after testicular cancer [13]. There are further examples in the literature of how changes in the body and in body image due to different types of tumors have a negative impact on patients' self-esteem, working status, relationships, and sexuality. Some surveys on head and neck cancer patients show that patients with poor coping skills or limited social support can become socially isolated or depressed after cancer: this seems to be linked with the difficulties in accepting their new body image [14, 15]. In a survey of 2008 on the impact of colorectal cancer on patients and families, Cotrim and Pereira [16] evidenced that stoma patients reported poorer overall quality of life, body image, health-related quality of life, and social activity, when compared with non-stoma patients. They also reported higher depression and anxiety. Studies on the quality of life in gastric cancer patients, even several years after the disease, led to similar results [17]. Body image appears restricted, focusing on the functional status of body organs and emotional aspects, in patients with haematological malignancies [18]. The authors suggest it may be a consequence of the severeness of the diagnosis: "Patients suffering a severe illness may not be able to uphold a multidimensional view of their body [19] and the restriction of body image may serve as a coping mechanism to buffer the emotional stress" [18]. Moreover, hair loss induced by cancer therapies is often associated with a loss of attractiveness, of sexuality, and a state of illness [20] that negatively impacts body image and related aspects [21, 22].

Diagnosis, prognosis and disfigurement caused by cancer and cancer-related treatments deeply impact patients' lives, so it is then necessary to identify the essential aspects for a correct evaluation of body image in cancer patients. As exhaustively described by the heuristic cognitive behavioural model of body image in oncology developed by White [11, 23], it is fundamental to know the value that each patient attaches to the body part affected by cancer.

At least three aspects have to be considered when evaluating body image in the oncological patients' experience: 1) the time elapsed since diagnosis, 2) the visibility of body changes, and 3) the permanence of changes in body image. Furthermore, the emotional impact of cancer varies also with respect to the affected organ, the undergone treatments, and the stage of disease.

Most articles on body image focus on patients' perception in the period following the completion of treatments. They report adaptation disorders—such as socio-relational and working difficulties, and decreased daily activities as well as difficulty enjoying leisure time [24], all due to changes in body image. To our knowledge, the literature does not report studies on body image during the diagnostic and therapeutic phases, when body changes have not been accepted yet due to the confusion, fears, and worry that characterize these early stages of the disease.

In addition, cancer and cancer-related treatments may induce visible or invisible changes. Appearance changes (hair loss, edema due to inadequate lymphatic drainage, cortisone-induced swelling) can cause embarrassment, influence the choice of clothes, or even cause patients to avoid any interpersonal contact. Surgery-induced changes, involving both visible and invisible organs, often trigger a sense of incompleteness [25, 26], which has a critical impact on many psychological variables [12, 27–29]. In addition, surgery often involves functional disorders (i.e. infertility, speech or hearing loss) which require aids (prostheses, catheters, stoma care devices) or that may cause communication, socio-relational and sexual difficulties [30–32].

Lastly, the consequences of cancer and body perception-related treatments are influenced by the length and persistence of changes and by the time of onset. In fact, changes can cause reversible (i.e. hair loss, temporary ileostomy) or permanent physical alterations (i.e. ovariectomy) and can appear gradually (i.e. pallor/swelling during chemotherapy) or abruptly (i.e. amputations) [3, 33, 34].

From a subjective point of view, the organ affected by cancer is also important. Even apparently “neutral” organs (i.e. the stomach) may have a particular significance in some patients [25, 26], while others (breasts, ovaries, genitourinary system), both visible and invisible, have a specific, commonly shared symbolic meaning, as they characterize sexual identity [35, 36]. This excess of meaning and its psychological importance are consequently linked to sexuality, as well as to parental and social roles [13, 37]. The loss of these organs implies a loss of attractiveness, of sexual and reproductive roles, and of power and sexual desire, and deeply influences psychological well-being, causing low self-esteem, depressive states, and social isolation [38, 39].

Body changes in their whole range of alterations (from modest and temporary to severe and permanent) have a critical impact on the quality of life. Thus, 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 [40, 41].

In oncology, many studies focus on the evaluation of women with breast cancer, both because breast cancer is more frequently diagnosed among women and because

women, presumably, are in general more concerned about their appearance and their body than men [40, 42–44]. Even though nowadays a conservative approach, when possible, is preferred [45], the outcomes may result in disfigurement and scars that usually have a negative effect on self-perception of attractiveness. Scars on breasts in particular have a strong impact on these perceptions [23, 46–51]. Post-surgery suffering is often intensified by side effects like lymphedema of the upper limbs [52]; moreover, because of these side effects, women frequently assume that they will be negatively judged and report lower self-esteem [44]. The reactions of patients usually vary from person to person, and the outcomes on body image perception are associated with a range of psychological variables that could induce problems of adaptation and emotional distress [53]. Besides, it must be considered that the effects of body image have an impact on patients' quality of life and also on the planning and choice of treatments. In particular, the adherence can be influenced by the body image perception. Many studies report that adherence to treatments negatively correlates to body image disturbances [3, 54–56]. Furthermore, some authors also suggest a predictive value of body image on survival, showing that body satisfaction was associated with longer survival 10 years after diagnosis [57]. The impact on quality of life in oncology patients, as well as the role of therapeutic adherence and the close connection with other psycho-social variables, brings us back to how important it is to evaluate body image.

Body image assessment in oncology

An extensive research was carried out in Pubmed and PsycINFO databases, using “Body Image”, “Assessment”, “Neoplasms” keywords. We considered papers in English and in Italian, published in peer reviewed journals between 1990 and 2010, when research on body image increased considerably.

Two hundred sixty-three articles met the criteria of the strategy we adopted. They included clinical interviews, self-report measures, questionnaires, symptoms checklists, graphic tests, and projective techniques.

From the selected articles, we excluded the papers with graphic and projective tests as assessment instruments (on this subject see Radika and Hayslip [58] and Eskelinen and Ollonen [59, 60]) since they are more time consuming, have a difficult scoring system, and need specific training for therapists. We also excluded the ones on body image in children and teenagers. The number of papers was consequently narrowed to 199.

We then made a further selection and considered only the papers including questionnaires, both unidimensional and multidimensional, when designed for oncological setting

and reporting statistic data. The number was thus narrowed to 81 papers that refer to six questionnaires specifically dedicated to body image in oncology patients.

Table 1 reports the principal characteristics of the six identified instruments [61–67]. Of these instruments, four were first administrated to breast cancer patients (i.e. Body Image after Breast Cancer Questionnaire—BIBCQ; Body Image and Relationship Scale—BIRS; Sexual Adjustment and Body Image Scale—SABIS; Body Image Index—BII), one to gastric–intestinal cancer patients (i.e. Body Image Questionnaire—BIQ), and one to a sample group of patients with diverse disease sites (i.e. Body Image Scale—BIS). Samples were heterogeneous and ranged from 34 units (BIQ) to 682 (BIS).

Of the six questionnaires identified, two (i.e. BII and BIS) are monofactorial, two assess two different aspects (BIQ: body image and cosmesis; SABIS: body image and sexual adjustment), while BIBCQ and BIRS assess respectively five (i.e. vulnerability, body stigma, limitations, body concerns, arm concerns) and six (i.e. attitudes about appearance, health, physical strength, sexuality, relationships, and social functioning following treatment) dimensions; the item number is between seven (BII) and 45 (BIBCQ).

All six questionnaires showed a good internal consistency, but only three of them supply data on test–retest reliability (i.e. BIS, BIRS, SABIS), which can be considered acceptable even if assessed in different temporal range (2 weeks to 3 months).

For BIRS and BIS, the factorial analysis procedures that brought to the definitive formulation of the instruments were presented. For other instruments (i.e. BIBCQ; BIQ; SABIS; BII) the factorial derivation was reported without any other detail. The content validity was verified correlating the score to the scales (and eventual subscales) with other body image measures (like in the BIBCQ) or with similar constructs like emotional distress, quality of life, depression, sexual functioning, self-esteem, and self-mastery (BIBCQ; BIQ; BIRS; SABIS). The discriminant validity was evaluated with respect to oncological subsamples, or confronting the oncological sample with a non-oncological control sample (BIBCQ).

Finally, the data on filling time (less than 10 min) were reported for BIBCQ questionnaires only, and for the BIS a good comprehension and acceptance from compilers were reported.

None of the six instruments supplied data on cross-cultural validity.

Discussion and conclusions

Cancer and its treatments have a negative impact on body image and body image-related dimensions, causing emotional suffering and coping difficulties [11]. The most frequent

Table 1 Body image assessment tools designed for and validated with oncological patients

Questionnaires (alphabetical rank)	Authors	Number of items	Population studied in original validation study (N)	Covered dimensions	Tested validity	Reliability	
						Internal consistency (Cronbach's alpha)	Test–retest validity
Body Image After Breast Cancer Questionnaire	Baxter et al. 2006 [28]	45 common items (6 or 2 optional items ^a)	Breast cancer women (164)	Vulnerability, body stigma, limitations, body concerns, arm concerns	Content, discriminant	0.77–0.87	2 weeks
Body Image Index	Lasry et al. 1987 [29]	7	Breast cancer women (123)	Single factor: body image	–	0.81	–
Body Image Questionnaire	Dunkler et al. 1998, 2001 [30, 31]	8 (+ 2)	Gastrointestinal cancer patients (34)	2 subscales: body image and cosmesis	Content, discriminant	0.80–0.83	–
Body Image Scale	Hopwood et al. 2001 [32]	10	Heterogeneous cancer patients (276) and breast cancer patients (682)	Single factor: body image	Construct, discriminant	0.78–0.85 and 0.92–0.93	1 month; 0.70
Body Image and Relationship Scale	Hornes et al. 2008 [33]	32	Breast cancer survivors patients (96)	Attitudes about appearance, health, physical strength, sexuality, relationships, and social functioning following treatment	Construct, content	0.94	1 to 2 weeks; 0.65
Sexual Adjustment and Body Image Scale	Dalton et al. 2009 [34]	14	Breast cancer women that were diagnosed up to 1 year prior to recruitment (353)	Body image and sexual adjustment	Content	0.66–0.91	3 months; 0.66–0.81

^a BIBCQ optional items are specific to women with two breasts, or missing one or both breasts

problems regard dissatisfaction with one's own body or scars, emotional distress about one's appearance, self-idea discrepancies, compensatory behavior or avoidance, and difficult adjustment to cancer. Moreover, body image seems to negatively influence patients' quality of life and therapeutic adherence: it is then crucial for researchers to consider the body image construct assessment from diagnosis to survivorship.

Body image is a multidimensional construct that concerns personal perceptions and attitudes [3, 6]. Even though this concept is thousands of years old, its definition is still not univocal, as different authors proposed many similar and partially overlapping body image definitions.

Back in 2004, Thompson [68] reported "confusion and concern about the assessment considerations from several vantage points: faulty selection of a measurement tool, misinterpretation of the construct indexed by a particular measure, mislabeling of the specific investigated dimension of body image". The aim of the present study was to highlight the centrality of the "body image construct" (traditionally examined in eating disorders and in size and weight issues) in oncology and to review the main self-report questionnaires available in the literature.

The first consideration arising from the present study, which examines the period up to 2010, confirms what was reported by Thompson [68] on the complexity of defining and measuring body image. In particular, satisfaction, self-esteem, identity, sexuality, and emotional distress are some of the dimensions related to body image that are worth considering, as they make its evaluation difficult.

In the literature, there are several measures of body image evaluation available for both experimental and clinical investigations. Nevertheless, most of these instruments deal with eating disorders [69], and only few are specific for the oncological setting. From our systematic review of literature data, we could classify only six instruments specifically designed for the oncological field. Most of them seem to be specifically conceived for addressing a particular investigation and did not yet benefit from the necessary multistep validation processes that make an instrument valid, reliable, and replicable.

It is to be observed, in fact, that even though the reported psychometric indexes sound promising in the majority of the cases we mentioned, none of the six instruments seem to have undergone a complete validation process that makes it the gold-standard for the study of body image in oncology.

The aforementioned factors (time from diagnosis, visibility of the change, over-time stability of change, organ affected, disease stage, and treatments undertaken) are all extremely important for experiencing one's body image from a clinical/qualitative point of view. They represent a fundamental challenge for creating a valid assessment tool as they introduce many variables that cannot be investigated

by a single tool. In other words, building a questionnaire on body image adapted for patients undergoing oncological treatment (as well as for long-term survivors and whoever has faced chemotherapy or surgery etc.) is not an easy task: this could explain the limited use of the instruments here reviewed in subsequent research.

Moreover, it must not be forgotten that all the mentioned instruments are in English: as cultural aspects and customs contribute to determining the ways of perceiving, thinking about, and moving one's body, the instruments that assess body image should undergo cross-cultural and cross-national validation if used in different national/cultural contexts.

Having a precise measurement of the body image construct helps in defining how the oncological disease makes an impact on body image. At the same time this would allow to prevent or treat body image-related symptoms and to ensure body image changes do not affect patients' treatment adherence. In conclusion, future oncological psychology clinical research ought to focus further on the body image construct and on developing more evaluation instruments for oncological patients, so as to improve both the evaluation and the clinical psychological intervention when an appropriate support is needed. To this end, the first step is to achieve an exact and exhaustive definition of body image. On the basis of the results of this review, we suggest defining body image as the combination of feelings, sensations and ideas that each person elaborates about his/her own body. Body image is constantly evolving, because it is influenced by all the experiences throughout one's lifetime, whether emotional, cognitive, or morphological. It is a construct that holistically considers mind, body, and their reciprocal influences, since the body is both the object and the subject of an experience. An accurate evaluation of body image, whether in the oncological or in any other clinical setting, must take all these aspects into proper consideration.

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