New challenges in psycho-oncology: An embodied approach to body image

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# Body image in oncology: The challenge of an embodied approach

## 1 | Introduction

Physical appearance and the image of the human body have long been relevant in a wide variety of clinical settings in medicine [1-3]. The concept of body image is of particular importance to oncology, as all types of cancer and its treatment have some impact on it. [4-7].

Body image has obvious connotations of physical appearance. However, it is complex, with multiple aspects that have important, but not always obvious, connections with cancers and their treatment problems arising from bodily changes. This presents a challenge in research and clinical care. Breast cancer has been the most widely investigated cancer in empirical research in psycho-oncology [8-11] and findings show that impaired body image can have marked negative and potential long-term effects on psychological adjustment and quality of life. However, body image outcomes and treatment effects on the body are often reported separately in quality of life outcomes. We suggest this division is problematic and the challenge is to work with a coherent framework that demonstrates interrelated body image and body changes.

Defining body image has proved elusive, but it can be approached in different ways. For example, established cognitive behavioural perspectives [12] have been adapted for cancer patients [13], foregrounding psychological assessments of body image disruption. Other models, designed for use in clinical practice, acknowledge self-perceived appearance change but emphasise different aspects, such as decreased physical and social functioning, [14]. Price includes the concept of an ideal body, influenced by socio-cultural factors [15] and Fingeret [16] presents a comprehensive management model, embracing treatment-related bodily changes and psychosocial difficulties.

We argue that body image reflects alterations in appearance *and* bodily changes and functioning. We uphold a view that body image is used to describe all the ways people conceptualise and experience their body and to acknowledge the social as well as the physical reality of the body [17]. We refer to this as '*embodied body image'*. Links to the physical body are not new, having been proposed by Schilder in 1950 [18], and are widely reported in psycho-oncology literature [6,8, 16,19-22]. However these complexities have not been fully theorised. The challenge is to understand the subjective, changing nature of body image and incorporate important connections to the altered body and social context.

In order to meet this challenge, we propose a coherent basis for understanding embodied body image in cancer patients. We present a distinctive framework rooted in social theory that embraces both appearance changes and the physical body in everyday life and activities. Taking a social practice perspective helps to go beyond the objective clinical setting and into patients' lived experiences of cancer (that is, their everyday experience of living with and beyond cancer, the choices they make, and the knowledge of themselves and of cancer that they gain). We use the example of breast cancer and illustrate application of the framework with case examples.

## 2 | Breast cancer and body image

The symbolic nature of the breast, associated with social understandings of femininity, attractiveness, sexuality and mothering, points to potential trauma resulting from breast cancer and its treatment. This is reflected in extensive body image research based on a wide variety of body image assessment scales [23-25]. These highlight different ways of understanding body image but difficulty when comparing findings (see Fingeret [16] for details of scales). Constituents of body image [23] and factors influencing body image outcomes have been identified [6,13]. These include constructs such as investment in appearance [26], coping strategies [15] and the nature of interpersonal relationships [27].

Research has also challenged some assumptions associated with the longstanding tendency to focus on distress related to breast loss. For example, appearance after mastectomy is not the most important outcome for some women [28], whilst breast reconstruction is complex, does not ensure body image satisfaction [29] and may not improve intimacy [30]. Of added importance to our thinking about embodied body image are the multiple bodily repercussions from adjuvant cancer treatments that may include radiotherapy, chemotherapy, endocrine therapy or biological agents). Their adverse effects on appearance *and* function arise, for example, from skin and breast changes, and more visible arm swelling [31] or hair loss [32]. Patients also report distress and disruptions to daily life from chemotherapy side effects that may last well beyond treatment completion [33,34] whilst Greenhalgh [35] describes her personal experience of the strangeness of chemotherapy and an altered body during treatment and recovery.

Sexual dysfunction is closely linked to body image disturbance [36] and the physical body is deemed inseparable from the intrapsychic, social and relational contexts [37]. More disturbing are life-changing but unseen effects of systemic treatments that can cause early menopause and infertility. These affect a woman's perception of her personal and societal image as woman [38] and mother [39,49]. These disruptions to the normality of the body and its activity in everyday roles impact significantly on embodied body image but may be overlooked in the medical setting.

### 2.1 | The (missing) body in body image

Understanding how *bodily* changes in breast cancer can be integrated into the concept of an embodied body image is crucial. Biomedical and psychological aspects of body image may not reflect the full complexity of women's experiences. Qualitative research offers insights into women whose concerns relate to multiple domains of their lives and whose experience of treatment and recovery are embodied in their body image. [41,42]. This helps us understand the personal meanings of an altered body, a changed sense of self [43] and feminine identity [44]. Embodied body image is also reflected in

the societal image of womanhood and self-consciousness in social interaction [19]. Furthermore, the impact of breast loss evolves over time depending on life context, and some women feel more positive about certain aspects of life. Others are neutral or experience both positive and negative changes, whilst bodily decline due to treatment effects may result in poorer quality of life [45]**.** Women discuss how it *feels* to have a changed body and of difficulty managing the menopause [46] or dealing with advanced disease [47]. Bodies may feel unfamiliar and embarrassing, affecting personal and sexual identity and female roles, by 'feeling like an outsider' [48]

Anxiety about uncertain fertility or changes in nurturing and mothering can affect a sense of self in which women can feel robbed of time and choice [49]. Such changes are also absorbed into an embodied body image and require a contextual view of illness. Socially, our bodies express who we are but the altered body may conflict with this: survivors want to look well, feel natural and normal and regain a beneficial equilibrium from everyday life [50,51] The challenge is to integrate women's bodily changes into their roles, responsibilities and activities. This can be accomplished through an embodied body image framework, underpinned by understandings of embodiment from social practice theory.

## 3 | Social practice theory and embodiment

In this section we connect principles from social practice theory with a conceptualisation of our experience as embodied humans. These are brought together in Figure 1, a framework that captures the key aspects of an embodied approach to body image in oncology.

### 3.1 | Body image is entangled with the physical body

We have described how body image is not purely a property of the mind, separate from the physical body. Social practice theory rejects such a split between mind and body. Instead the two are viewed as two entangled aspects of a whole (see Grosz [52] for further discussion). Body image then is

experienced as integral to the *physicality of the body,* whether healthy, sick, treated, scarred or altered. This principle is at the core of an embodied approach, hence its central location in Figure 1.

### 3.2 | The body and body image have a history

A patient's "body image" at any one time is not just a reflection of its present form. Social practice theory tells us that we cannot untie ourselves from our pasts, and our pasts always intrude in the present [53]. The body in question has a history comprising processes such as ageing, and events such as injury, or disease. Body image is shaped by this history, which unfolds in a social and cultural context. A patient's response to recent changes may be magnified if past embodiments render the present body image more vulnerable to insult or trauma [54]. This can reduce coping, and impede adaptation [55]. The second principle of an embodied approach to body image is therefore that diagnosis, evaluation and treatment of body image problems must attend to the patient's *embodied history*, the effects of which cannot be assumed as minimal or insignificant.

### 3.3 | The body and body image are not just personal

Bodies are not merely a private matter, they are shaped socially through patterns such as diet, activity, sexuality and interaction. Body image is similarly social; a patient's body image and experience of that image have origins in how bodies generally are represented, valued and subject to social scrutiny [56,57]. The third principle is therefore that body image must be understood in terms of the patient among other people, whether sexual partners, family, friends, or society in general.

### 3.4 | The body and body image are dynamic and malleable

Body dissatisfaction is relatively stable in older adults [58] but body image is pliable in the face of disruption, with potential for rapid changes following cancer as well as societal changes over time, Malleability suggests that

people have some capacity to influence their body image, or can be assisted by others. Body image in cancer patients changes with injury, adaptation and restitution, together with participation in everyday activities, social roles and reproduction, and the dis- and re-establishment of relationships. These emphasise the connectedness between body image and how we *use* our bodies, and to the importance of support in managing changes to body image. [16]

### 3.5 | Being, having and using a body

Our embodied approach rests on three clinically relevant dimensions of embodiment, drawing on the work of practice theorist Theodore Schatzki [53].

*Being a body* refers to our capacity to experience sensations and perceptions, move our limbs and so. We are usually aware of this – it is the body that we simply 'are', and creates our concept of self [59].

*Having a body* refers to ways in which we are reminded of our embodiment in moments of breakdown, failure, or explicit effort. We are made aware of our body, which can provoke a disruption between self and body. This can be ephemeral and unproblematic, as when we stumble on a step. But, for many cancer patients this disruption becomes a severance that produces significant psychological distress. The body that we '*have*' is the one that requires our care and attention in maintenance or restoration.

*Using a body* is to accomplish desired actions rather than what the body does automatically, as when we may move our arms to cuddle a child. An embodied approach to body image must address the fact that any patient *is* a body, *has* a body, and *uses* that body. This is represented in the three points of the triangle in Figure 1.

Insert Figure 1.

## 4 | Illustrating the framework

In this section we present and discuss three cases with significant body image disruption to illustrate how the embodied framework above helps understand: (i) variation in patients' experiences of cancer and its treatment, and (ii) apparent incongruities between what a treating team might objectively observe and what is significant for the patient. Each case history is modelled on insights from past experience of practice and research. Patients like these were assessed and treated in an established psycho-oncology service.

### 4.1 | The 'mutilated' body and its impact on mothering, marital and social behaviour

Insert Figure 2 – Case History 1

Viewed in terms of embodied body image, breast loss was catastrophic for Claudine. It disrupted the core of her embodied self. The mastectomy caused a break from her previous way of *being* a body in which femininity, sexuality and mothering were important to her. Claudine's *being a body* was greatly disrupted, as she could not 'let go' of the body she had before, which was not how her her body felt now. She avoided looking at herself, or using her body in showing affection to her children and husband. Claudine She could not be herself as a one-breasted woman. Her social difficulties were less about how others saw her (in contrast to Edith, discussed below), but rather an envy of normal-breasted women who could show a cleavage. There was a disruption to her body and her sense of body image and self, grounded in relations between her body and other people (children, husband, female friends) but inviible to health care professionals.

Psychological intervention helped restore daily life and relationships to near normal, but she remained conscious of her breast loss. It was only a physical restoration of the breast that enabled her body to feel living and fleshy again, with reunification of her sense of self with her body and physical closeness with her family. For patients like Claudine, despite adjusting to a new normal and restoring daily life and activity, a rupture between body and sense of self

can be so profound that it can only be recognised and resolved by understanding body image as embodied, i.e. historical, social, dynamic, and entangled with the physical body.

### 4.2 | Objectification and fear of being identified as a breast cancer patient

Insert Figure 3 – Case History 2

Edith had a long-standing desire to avoid attention to her body. Her cancer treatment made this difficult to achieve meaning that the change in her body and body image compromised her normal social interactons. The entanglement of the physical body and its image reflects Edith's bodily history as a larger-breasted woman (*being a body*), for whom the breasts present a prominent feature of her outward appearance, rendering her highly sensitive to her experience of the perceived gaze of others. Unlike Claudine, Edith's issues centred primarily on her body when under the scrutiny of others. *Having a body* connected with her breast asymmetry following radiotherapy in a complex way. She felt people could tell she was a breast cancer patient, even when she was fully clothed. In her mind she could only present outwardly the body of a cancer patient. *Using* her body was entwined with the fear of others knowing this.

Edith's improved body image was sustained after corrective breast surgery even though further changes to the shape and texture of the treated breast slowly continued. Here, her body did not disrupt her sense of self (*being a body*) as temporarily regaining symmetry was sufficient to 'uncouple' the association of her asymmetry from the cancer. The continuing breast changes were part of a very different body image once their connection with trauma of her cancer had been weakened. A holistic and coherent understanding of cases like Edith's can thus be reached through a conceptualisation of an embodied body image.

### 4.3 | The invisible breast and its impact on the functional body and sense self

Insert Figure 4 – Case history 3

The embodied history of body image is crucial to understanding Diane's case. Her struggles to cope with her altered breast appear less incongruous when framed in the context of her past injury. She remained very self-conscious of her changed body image and sense of self. Objectively her limp was almost unnoticeable although avoided in discussion. This past trauma may have predisposed her to a more difficult adjustment to her changed body image after cancer through prior feelings of her previous body injury extending into the experience of cancer damaging her body again. The end of her breast cancer treatment was not the end of her *experience* of breast cancer, but was connected with the history of her body. It was not the visible outward appearance of the breast, rather, fear of cancer remaining in the breast, a second trauma to her body, which inhibited her developing an image of a cancer-free body.

The breast cancer remained present in Diane's *embodied* body image. The changes in her personal behaviour and her engagement with others arose not because of fears of how others would see her, but because of this changed sense of self. This interweaving of the breast with her history of the body helps us understand the idea of her persistent cancer in an embodied body image. She responded well to intervention that helped her focus *on having a (healthy) body* and *using a body*. Diane achieved her personal goal to go on holiday with friends and wear a bikini with confidence within several months. The framework accounts for intimate connections, in cases like Diane's, between a history of body image disruption and the lived, embodied experience of having had breast cancer.

## 5 | Relevance of the framework to other cancers

Significant potential for altered appearance and bodily function in other cancers means body image remains a critical issue [6, 60]. The challenge in research and practice is to address disparate disease sites and treatment types in connection with their varying impact on the lived experience of the patient. An embodied approach to body image can provide a common platform in such work (see Fig 1).

It remains essential to consider cancer and treatment sequelae in *male bodies* and issues of *masculinity* [61]. Hence, in prostate cancer, the most common cancer in men, hormonal treatment creates similar psychological concerns and deleterious effects on the body, body image and daily life to those of women treated for breast cancer [62]. Research highlights issues of *being a male body* that echo those found in our embodied analysis of breast cancer, through distressing feminisation, sexual dysfunction and hence loss of masculine identity [61]. Such bodily changes accentuate societal expectations of men's bodies, roles and capabilities that constitute what it means to be masculine, and challenging the taken-for-granted body [63,64]. Cancer can create feelings of uncertainty and isolation in men but since they are apparently less likely to voice their body image concerns or seek help [63], researchers and health professionals should pro-actively engage with this through an embodied approach to body image.

Radiotherapy, used to treat pelvic cancers in men and women, can also disrupt bowel, bladder and sexual function [65]. An embodied approach acknowledges the potential negative impact on body image, even if appearance is uncompromised. What it means to be male or female with these sequelae may otherwise be overlooked. Potential adverse effects to *using a body*, even when unseen, can be anticipated using the framework approach.

Chemotherapy is widely used in oncology producing visible changes, notably hair loss with its conspicuous and symbolic effects for men (who speak of loosing body hair) and women (concerned with loss of hair from the head) [66]. An embodied approach to body image shows how this changes the

sense of self that is inseparable from *being a body* in society, bringing reminders of *having a (cancerous) body* which may be associated with stigma. Chemotherapy can be physically debilitating in the short and long term, which not only foregrounds *having a body*, but can disrupt *using a body* as normal roles and routines have to be adapted or curtailed. Consistently, the framework points to diverse potential indicators of the need for supportive care and for research in many aspects of cancer that would benefit from incorporating embodied body image disruptions.

A further value of the framework points to consideration of the needs of particular patient groups across cancer domains. For example, the *history of the body* is relevant to older patients who may have co-morbidities that interact with new embodied body image changes due to cancer and its treatment but who strive to maintain positive self-evaluation. Such patients may have dealt with previous body image changes in ways that are a helpful resource for present difficulties, rather than a risk factor for poor body image [54] as discussed earlier.

Permanent visible difference is the legacy of many cancers, and is associated with social disability [60] and significant psychosocial issues [*3*] as well as difficulties for health professionals addressing disfigurement in their patients [67]. Recent studies of cancers of the head, neck and mouth have highlighted high potential for difficult and distressing appearance-related consequences [68,69], together with significant functional disruptions to speech, eating and physical activity [70]. This emphasises the importance of the whole body and its functioning. This is precisely what is included in an embodied body image approach, which can accommodate impacts on personal identity, family, working life and society more generally [71]. Patients with visible disfigurement may have difficulty looking at themselves as well as being looked at, intimately or socially, as with breast cancer. The framework offers a way of understanding such significant disruption and distress and of considering factors that hinder or enable adaptation and social integration, as a person with disfigurement [72].

As discussed with respect to breast cancer, assumptions that the degree of physical change predicts body image disturbance and thus the need for additional psychological care are common in relation to a range of cancers that involve a visible bodily change [3]. However, many assumptions have no empirical support. Rather, through an embodied framework, the complex relation between the body and the mind can be conceptualised in a coherent way.

## 6 | Conclusion

A key challenge in psycho-oncology research is to improve cancer survival and explore the potential benefits of new modes of treatment [73]. In parallel there is the challenge of improving psychosocial health care delivery, which has been found wanting [74]. We have addressed a related challenge associated with a wide range of treatment effects that disrupt the quality of life of oncology patients; embodied body image lies at the heart of this. Patients may be affected by a visibly or invisibly altered body, changes in bodily functioning and the personal and social consequences of these sequelae.

The multidimensionality and complexity of body image present an ongoing challenge to better recognise and understand diverse issues underpinning the extent of, causes of, and recovery from body image disruption as described in body image literature. Complementing the ongoing value of existing models of body image and related therapeutic interventions, we offer a novel, coherent approach to understanding embodied body image through Schatzki's social practice theory [*53*].

Our *embodied body image* framework ensures that the body is conceptualised in its inseparable connection with psychological, social and functional aspects. It brings together the body as subjectively experienced historically and used in everyday activities. Through detailed examples of breast cancer, and comparable sequelae in other cancers, we have shown how this framework can explain the subjective experience of cancer treatment and its effects on

embodied body image, particularly when these are hard to understand if based only on external appearance.

The framework can provide valuable theoretical underpinning to aid the design of tools used to evaluate body image, which could be mapped to the aspects highlighted in Figure 1. It can also assist in detection of body image disruption, mindful of the patient's agenda, in a way that incorporates the patient as a whole person and the psychosocial context of illness. New research questions can be addressed with this approach, such as the specificities of body image in patients with recurrent or progressive disease, when existential factors come acutely into play.

There is increasing recognition that the interface between the physical, psychological and social realms matters for body image. Rather than splitting the mind from body, and body from society, there have been calls to 'put the mind back into bodies, bodies into minds, bodies into society, and society into bodies' [75]. Tackling these challenging interconnections, we have shown how multiple domains can be coherently theorised together, offering a new contribution to the toolkit for health professionals and researchers engaged in the important field of body image.