Health Care Anal (2011) 19:295–311
DOI 10.1007/s10728-010-0153-9

ORIGINAL ARTICLE

The Meaning of Body Experience Evaluation in Oncology

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Published online: 18 July 2010

Abstract Evaluation of quality of life, psychic and bodily well-being is becoming increasingly important in oncology aftercare. This type of assessment is mainly carried out by medical psychologists. In this paper I will seek to show that body experience valuation has, besides its psychological usefulness, a normative and practical dimension. Body experience evaluation aims at establishing the way a person experiences and appreciates his or her physical appearance, intactness and competence. This valuation constitutes one's 'body image'. While, first, interpreting the meaning of body image and, second, indicating the limitations of current psychological body image assessment, I argue that the normative aspect of body image is related to the experience of bodily wholeness or bodily integrity. Since this experience is contextualized by a person's life story, evaluation should also focus on narrative aspects. I finally suggest that the interpretation of body experience is not only valuable to assess a person's quality of life after treatment, but that it can also be useful in counseling prior to interventions, since it can support patients in making decisions about interventions that will change their bodies. To apply this type of evaluation to oncology practice, a rich and tailored vocabulary of body experiences has to be developed.

Keywords Bodily integrity · Body image · Breast cancer · Change in appearance · Narrativity · Phenomenology · Quality of life

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Introduction

As a result of the rapid development of effective treatments (e.g. 'targeted therapy'), the chances of survival for various forms of cancer have increased considerably in the last decade [60]. Given that the disease is now often treatable and has become comparatively manageable, it is no longer considered a 'medical emergency' but instead a 'chronic condition' [33]. This change allows new perspectives and focus in treatments. Although oncologic safety, obviously, remains the primary focus, more and more attention is paid to quality of life related issues in the treatment and nursing care of cancer patients.

Besides a permanent (latent) fear of relapses, cancer survivors often have to deal with physical defects, as is very clear in cases of breast cancer and head and neck cancer. These may result in functional disturbances such as problems with speaking and swallowing (in the case of head and neck cancer) or limited motility of the upper limb (in the case of breast cancer) which, evidently, can be important for a person's quality of life. In addition to this, however, are the changes in appearance often brought about by these physical blemishes. These changes in appearance, which cannot simply be reduced to physical function or dysfunction, may affect a person's valuation of his or her body and thus change a person's 'body image'. It is now generally assumed that body image related issues are essential to a person's quality of life [27, 41].[1]

In contemporary (psycho-)oncology attention to body image issues is increasing [1, 8, 14, 16, 63, 64]. In the last decade specific body image self-report scales have been developed [3, 4, 7, 27]. These questionnaires are mainly used to evaluate treatment in clinical trials and sometimes to support psychotherapeutic interventions.[2]

In the context of the increasing interest for body image related issues in oncology, I would like to suggest that body experience evaluation is valuable not only from a psychological perspective. My hypothesis is that body experience evaluation can play an important role in health care practices, especially in these kinds of practices where patients have to decide (together with the medical professionals involved) about interventions which will affect their physical appearance. In this paper, I would like to make visible the practical and ethical dimension of body experience evaluation in oncology, mainly concentrating on breast cancer. I will do so by means of a conceptual and phenomenological analysis of body image and bodily integrity. This paper thus also amounts to a medico-ethical analysis from a phenomenological perspective which, as has been rehearsed

[1] Van der Steeg [59], by contrast, claims that the importance of 'body image' is overestimated with respect to quality of life in breast cancer patients. This claim, however, is based upon an inadequate conception of 'body image'. Her study starts from the assumption that body image is the same as physical appearance. As I will explain, body image implies a relation to one's physical self.

[2] Medical psychologists have established that body image disturbances are often associated with specific psychic problems such as poor self-esteem [34], social anxiety [10] and depressive symptoms [54]. Cancer survivors often suffer from these kinds of psychic troubles. Cognitive and behavioral therapy, aiming at the reinforcement of one's body image, therefore supports the general condition of one's psychic well-being [63].

recently [68], is still an uncommon, and perhaps underestimated, perspective in health care analysis as well as in medical ethics.

My analysis involves the following steps. First, I will briefly explain the meaning of what is called 'body image', drawing on philosophical and psychological literature.[3] Second, I will discuss how body image is currently evaluated in breast cancer patients. I will do so by focusing on the way questions are phrased on the Body Image Scale (BIS) questionnaire and pointing to its inherent limitations. Third, I will introduce the notions of 'bodily integrity' and 'identification' and will explain how these may be useful for understanding the impact of body experience evaluation in health care practice. In the final section, I will argue in favor of the application of body experience evaluation in counseling prior to (surgical) interventions in oncology.

'Body Image': Being Related to One's Physical Self

Since the 1990s, body image research has increased enormously within (clinical) psychology and psychiatry [40]. Having its origin in psychological, neurological, psycho-analytic, and phenomenological-existential studies of the way in which people experience their own body [20, 36, 45, 47], the concept 'body image' is far from univocal. Very often the term body image is associated with the simple idea of 'how the body looks like'. Psychologists, on the other hand, claim that it is a complex term which refers to the 'multifaceted experience of embodiment' [9].

Although my primary interest in this paper concerns the usage of body image in (medical) psychology, for the sake of clarity, I will first briefly rehearse some conceptual distinctions made in contemporary philosophy. From a philosophical perspective, body image refers to a certain form and level of consciousness, i.e. the way one's own body is an 'object' of one's consciousness. Gallagher [23] defines 'body image' as a "system of perceptions, attitudes, and beliefs pertaining to one's own body" (p. 24). This system requires a certain degree of consciousness, albeit often implicit or pre-reflective. Indeed, very often I am not fully aware of how I perceive my own body. This more or less conscious system should be distinguished from 'body schema' which, according to Gallagher, refers to "a system of sensory-motor capacities that function without awareness or the necessity of perceptual monitoring" (p. 24). One's 'body schema' is thus not part of one's consciousness. The body schema operates in a close-to-automatic way, e.g. if I reach out for a glass, my hand shapes itself for picking up the glass [23]. This intentional action is, therefore, not a reflective or conscious action. Obviously, it is possible to perceptually monitor this action. Then, the hand in movement becomes part of the body image. The distinction between body image and body schema is helpful in specifying (pre)conscious and unconscious aspects in the experience of one's own

[3] It is not my intention to provide a literature review here. While summarizing the essential features of what is meant by body image, my explanation rather aims at providing some clarity in the hotchpotch of current body image literature.

body. Normally, body image and body schema work together and form one integrated system.[4]

The philosophical interest in the notion of body image is particularly related to questions of consciousness or, more specifically, the relation between unconscious processes and (pre) conscious experiences. Medical psychology does not concern itself with these kinds of (epistemological) questions. It is primarily interested in dimensions of (bodily) experience, leaving to one side questions concerning the degree of consciousness involved in these experiences. Medical psychologists that test body image, using standard questionnaires, presuppose that body image involves a totally conscious experience of one's own body. Indeed, self-report scales presuppose that participants are aware of what is being tested [23]. Compared to its use in philosophical discussion, the concept of body image in psychology has thus been narrowed down to a simple conscious experience of one's body. Also, because of its focus on body experience and behavior, and less attention on underlying sensory-motor capacities, psychology deals exclusively with 'body image', leaving aside the 'body schema' system. In the psychological practice of clinical trials, this narrow concept of 'body image' is considered to be sufficient when testing bodily experience after medical interventions. In the last section of this paper, however, where I return to the phenomenon of the body image's preconscious edges, I will maintain that medical practice will benefit from a broader concept of body image. As I see it, it is by means of a narrative approach—which allows a "quest" for giving voice to both explicit and implicit bodily experiences—instead of a pure cognitive-psychological one, that professionals are able to articulate and interpret one's body image, including its less conscious dimensions and its temporal course.

Before criticizing contemporary psychological usage of body image, I will first explain and summarize it: 'body image' involves a conscious experience of one's own body, which, nevertheless, does not simply refer to one's physical body. It rather involves a certain *relation* to one's physical self. In what follows, I will specify the meaning of both (1) 'physical self' and (2) 'relation'.

(1) In psychological literature, "physical self" refers to one's appearance, one's physical competence, and one's physical intactness. This seems to be a rather straightforward definition, yet it includes different aspects of embodiment: whereas appearance has to do with one's own body as a certain object of perception, competence is directly related to motor intentionality and capacity and thus involves one's body as an agent. The notion of physical intactness can refer to both biological and functional intactness of one's body, and can thus include one's body as both object and agent. As I will discuss in the remainder of this paper, it is with regard to the idea of physical intactness in particular that confusion can arise. Psychologists, exploring quality of life and body

[4] Gallagher [23] notes, however, that specific neurological disorders can disintegrate the relation between body image and body schema. For instance, he describes the case of IW, a male adult who lost his sense of proprioception and touch below the neck due to an infectious mononucleosis. IW does not experience his own body from within. In fact, he has lost his body schema and compensates for this loss by means of his body image, which means that he has to consciously monitor all his movements.

image in cancer survivors, sometimes use the term integrity to refer to the body's functional or biological intactness. (Cf. [16]). In so doing, they, perhaps unwittingly, follow the biomedical discourse which makes no distinction between physical intactness and 'bodily integrity'. I find this usage of the term bodily integrity inadequate. In my view, bodily integrity involves more than biological and functional intactness. Like body image, bodily integrity implies a relation to one's physical body (which I will explain as a relation through identification). If one omits the relational aspect in body integrity one overlooks its normative dimension.

(2) According to psychological literature, the relation to one's physical self in body image can be (a) perceptual or (b) attitudinal.

   (a) The perceptual component of body image refers to awareness of one's own body. This aspect is often associated with the representations of somatic sensations in one's brain, which has indeed resulted in a more neuro-scientific connotation of 'body image' [29]. At a psychological level, the perceptual aspect refers to the ability to evaluate accurately the size, shape and position of one's body. Thus examination of eating disorders such as anorexia sometimes involves assessment of the perceptual body image [38, 55]. Explicit disturbances of the perceptual body image include the experience of a phantom limb [42, 45] or experimentally evoked illusory experiences such as the Rubber Hand Illusion [6, 49]. Although some (rare) cases of phantom breast sensations after mastectomy have been reported [53], the assessment of perceptual components is not a central issue in body image research in cancer survivors. It rather focuses on the attitudinal aspects involved in the phenomenon of body image.

   (b) The attitudinal relation to one's physical self can imply cognitive, affective and behavioral components. Cognitive aspects include thoughts, perceptions and beliefs about one's body. The affective component refers to the way one feels about one's body (ashamed, embarrassed, disappointed, satisfied, proud, etc.). The valuation of one's own body can also be related to typical behavior, such as avoiding certain situations. Although these three components are related to one another, there can be a dissonance between them. People with negative thoughts (cognitive) and feelings (affective) about their body, for instance, do not necessarily avoid mirrors.

Body image disturbances in cancer survivors are predominantly caused by actual changes in appearance, though it should be noted that the actual diagnosis 'cancer', and even the mere knowledge that one is the carrier of a gene mutation which increases the risk of breast cancer, may affect one's thoughts and feelings about one's body [18]. In what follows, I will concentrate on the impact (expected) physical damage can have on the way one experiences one's own body, and will limit myself to cases of disfiguring breast cancer.[5]

[5] It should be noted that not all bodily feelings and experiences can be related to one's body image. Feelings like nausea, fatigue and fear of death, which occur frequently in cancer survivors, refer to the experience of one's body 'beyond image' [11].

Evaluation of Body Experience in Breast Cancer Survivors

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life study group takes responsibility for the development and validation of specific QoL self-report scales for various cancers. Next to the QoL-Breast cancer questionnaire (EORTC-QLQ-BR23), it has developed a body image scale for (breast) cancer patients (BIS) [27]. Apart from literature review and discussions with health care professionals, this 10-item scale is, based upon extensive interviews (and subsequent debriefing interviews) with breast cancer patients. It is designed to provide a quick impression of the intensity of a patient's distress: ranging from 0 to 30, with 0 representing no distress and higher scores representing increasing distress.

It has often been claimed that quantitative evaluations of patients' experiences are incomplete (Cf. [13, 21]). Although I share the view that quantitative tools might be limited, I have no intention to criticize quantitative research as such. The question whether experience in itself is quantifiable or not is not my concern here. I would rather point to some (perhaps unavoidable) problems in phrasing. For this purpose, I reproduce the BIS here and, subsequently, I will single out some issues concerning language to judge its adequacy.

> BIS: In this questionnaire you will be asked how you feel about your appearance, and about changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.
> 1. Have you been feeling self-conscious about your appearance?
> 2. Have you felt less attractive as result of your disease or treatment?
> 3. Have you been dissatisfied with your appearance when dressed?
> 4. Have you been feeling less feminine/masculine as a result of your disease or treatment?[6]
> 5. Did you find it difficult to look at yourself naked?
> 6. Have you been feeling less sexually attractive as a result of your disease or treatment?
> 7. Did you avoid people because of the way you felt about your body?
> 8. Have you been feeling the treatment has left your body less whole?
> 9. Have you felt dissatisfied with your body?
> 10. Have you been dissatisfied with the appearance of your scar?.
> Reply ratings:
> Not at all (score 0)
> A little (score 1)
> Quite a bit (score 2)
> Very much (score 3)
> Hopwood et al. [27]

[6] This BIS is designed to be used with any group of cancer survivors. But it should be noted that it was developed on the basis of interviews with female breast cancer survivors only. Also, its French version is used exclusively for the assessment of women who have survived breast cancer (Brédart, Swaine Verdier and Dolbeault, 2007).

To begin with, it is notable that nearly all questions are phrased in a negative way. Up to a certain extent, it is understandable that the questions are phrased in this way; debriefing interviews have made clear that most patients normally do not describe themselves in terms like 'feeling sexually attractive' [27, p. 191]. This might be true, yet the restriction to negative phrased questions precludes a fully fledged account of body experiences, since it forces informants to negative formulations only. What does it mean if a woman replies 'not at all' to the question 'do you find it difficult to look at yourself naked?' Of course, it means that she has no difficulty with her own appearance. But this reply gives no information about the possibility of this woman being content (or perhaps surprised or fascinated) while looking at herself. The negative phrasing prevents the possibility of expressing a positive experience. Conversely, a negative reply to a positive phrased question does not simply correspond with a genuine negative experience. Consequently, a body image scale which is limited to either negative or positive phrasings does not adequately assess the wide range of possible body experiences. If one really aims at gaining insight into the experience of changes of appearance in cancer survivors, it is advisable to complement quantitative questionnaires with some open question.

My second objection with this efficient and concise body image scale – however useful it may be for a quick examination – involves another difficulty in wording. As explained above 'body image' is not the same as the physical body, rather it implies a *relation* to it; it comprises the way one experiences and values one's body. If we look at item (8) from the BIS, for instance, we see that it is rather difficult to take into account clearly the relation between physical self and the experience of this physical self in such a briefly formulated question. The issue is about the feeling of bodily wholeness: 'Have you been feeling the treatment has left your body less whole?' One can imagine that respondents might have difficulties in understanding what exactly the examiner wants to know. Given the fact that most of the questioned population literally has lost a body part this item may seem redundant. However, this item is not about physical loss in itself. It rather interrogates how a physical defect is experienced. As such it gives the respondents the possibility to express their own feeling of loss. Not everybody experiences the loss of a body part in the same way, and it is even possible to retain one's feeling of wholeness after a mastectomy. The emphasis should thus be put upon 'feeling'. It is questionable, however, whether the relation and distinction between one's physical loss and one's feelings about it are adequately formulated here.

These problems in formulation are brought out even clearer if we look at the French translation of this item: 'Avez vous ressenti le traitement comme une atteinte à votre corps ou une mutilation' [7].[7] Literally translated back into English it reads

[7] It is worth noticing that French researchers who translated the English Body Image Scale into French had quite some difficulties with item 8. Provisionally they translated 'have you been feeling the treatment has left your body less whole?' into 'Avez-vous ressenti que le traitement avez affecté votre intégrité corporelle?' This resulted in the English contra-translation 'Did you feel that the treatment affected your body integrity?' It was noted, however, that the concept 'bodily integrity' was not comprehensible enough since it involves an elevated style. Hence, the item was finally translated as 'Avez vous ressenti le traitement comme une atteinte à votre corps ou une mutilation', which harmonizes with ordinary French usage [7].

as follows 'Did you feel that the treatment has injured or mutilated your body?' Assuming that most breast surgery in actual fact results in a greater or lesser degree of mutilation, this question is rather ambiguous. Indeed, it is hard to imagine that a breast amputee will reply 'not at all' to this question. And yet, it is well possible that these patients may experience their (amputated) body as whole. We thus need another approach to make explicit the experience of wholeness (or lost wholeness) in people who have to live with a body that from a biological perspective is no longer whole.

From Body Image to Bodily Integrity

That body image does not simply coincide with one's physical appearance is clear in cases in which a person may have an extremely negative feeling or attitude towards her or his body despite an unchanged or "non-deviant" physical appearance. Such is the case in Body Dismorphic Disorder [39], Body Integrity Identity Disorder [50], and some eating disorders. Since body image disturbances in cancer survivors are caused by changes in one's physical appearance, intactness (and sometimes one's competence), one might be tempted to believe that there is a direct correlation between the degree of physical mutilation and the degree of body image dissatisfaction. Indeed, if we look at various studies on body image and breast cancer, we see that the tendency to find correlations between physical mutilation and negative body image is one that is inherent to the design of such studies, e.g. studies that suggest that patients who received breast conservation have a better body image than those who received a mastectomy [2, 19], or that reconstructive surgery may restore a woman's body image [1]. These studies suggest a direct relation between body image and physical appearance and intactness. I would like to stress here, once again, that body image does not simply imply a coincidence with the physical body, i.e. neither with the body as a physical object (appearance, biological intactness), nor with the body as an agent (competence, functional intactness).[8] Body image involves the valuation of these aspects of embodiment.

The incautious equation of physical self with its valuation is even more apparent in medical practice. For physicians, who predominantly operate from a biomedical perspective, it is almost taken for granted that the restoration of physical wholeness results in a (more) positive valuation of one's physical self. It is therefore not surprising that some physicians even suggest that all women who have to undergo a breast amputation, should be offered the option of a breast reconstruction if their physical condition allows it [67].

[8] By the same token, quality of life does not simply coincide with physical (dys)function or appearance. It rather involves a person's *valuation* of function and appearance. This implies that the restoration of physical functions does not automatically result in an increased quality of life. It is unfortunate that in the quality of life questionnaire for breast cancer survivors (BR-23), not all items reflect this aspect of valuation. Item 34 ('Have you lost any hair?') and item 49 ('Was it difficult to raise your arm or to move it sideways?'), for instance, only query appearance and function and not a person's valuation of it [17].

Without denying that the actual state of one's physical body can be crucial for the way one experiences and valuates it, I would like to emphasize here that the restoration of physical wholeness does not automatically yield the experience of bodily wholeness. Indeed, breast reconstruction does not always increase body image satisfaction [25]. Sometimes women even experienced regret concerning their choice for breast reconstruction, especially when they were not able to value the physical restoration of their body in a positive way [46].

It is not my intention to trivialize the importance of a physical intact (female) body. In that sense my view differs from radical feminist conceptions which criticize the practice of breast reconstruction and insist that women should not allow themselves to be seduced by the idea of bodily wholeness which is a construction of male biology and medicine [35, 52]. Like the biomedical discourse, this feminist discourse also implies a limited and one-sided normative claim. To facilitate good decision making, and thus good care, one should suspend both these discourses to concentrate first of all on patients' embodied experiences.

Since the 'fixing' of damaged bodies does not always simply imply the restoration of a patient's positive valuation of her body [15], health care practices that focus solely on normalizing interventions, such as a breast reconstruction, do not always show respect for a patient's bodily integrity. As a matter of fact, these types of interventions, however benevolently intended, may even violate a patient's bodily integrity. To justify this view on how medical professionals should take care of 'damaged bodies', I suggest that the phenomenon of body image—i.e. being related to one's physical self—presupposes a process of identification, and that the extent to which this process is successful is crucial for one's bodily integrity.

No doubt, the notion of bodily integrity I would like to propose here differs considerably from current normative conceptions in bioethics. Leaving aside the details of various studies on bodily integrity in health practice, I believe that my idea of integrity differs in at least two ways. First, in most current studies on bodily integrity, the emphasis is placed on the question of whether it is morally desirable to intrude, be it medically, cosmetically or ritually, upon an (intact) inviolable but vulnerable body. For that reason, bodily integrity is mainly discussed in issues like organ donation, circumcision, and self-determination in sexual reproduction. As far as I know, it has never been an issue in the care and treatment of bodies that are no longer intact, such as in oncology. Second, very often bodily integrity is understood as a pre-conceived idea of wholeness, i.e. wholeness according to biology, or wholeness according to a religious or moral system, or according to a certain ideology. In contrast with this, I consider bodily integrity first of all as an *experience* of wholeness.

As I have explained in-depth elsewhere [51], the experience of bodily wholeness, including its underlying process of identification, can be understood on the basis of a phenomenological understanding of embodiment. In that sense, my view on bodily integrity is in accordance with Zeiler's [68]. Drawing on Merleau-Ponty's philosophy, she maintains that not just any physical change will threaten the integrity of the body-subject. Rather, a physical change affects one's integrity only if it perturbs one's being and engaging in the world. I concur with this Merleau-Pontian view, yet, I would like to add that one's integrity may still be

disrupted even in cases where one's functional being in the world is not really affected. Indeed, Merleau-Ponty's philosophy of the body concentrates on motor intentionality and one's functional engaging in the world—the embodied subject as 'I can' (*je peux*) [36]—and, accordingly, he analyzes (pathological) cases in which this bodily potentiality is impaired. But he does not teach us much about changes in physical appearance that do not affect one's physical functioning, but which may nonetheless disrupt one's experience of wholeness and integrity.

Instead of focusing on the phenomenological idea of 'being bodily engaged in the world', I will concentrate here on the phenomenological analysis of bodily self-experience. This experience is so typical since it is double-sided or, to phrase it slightly differently, one can experience one's own body according to two different modes of experience: as an object (or *Körper*) and as a subject (or *Leib*) [28]; or as *corps objectif* and as *corps propre* or *vécu*, a lived body which is one's own [36]. It is especially because of the *Leib*-experience that the experience of one's own body differs from the perception of other things or objects. The *Leib*-experience is a localized lived-through experience of oneself, for instance, when in touching my left hand I have the feeling that I am touched, that it is *my* body that is touched. It is often claimed that contemporary medicine considers patients' bodies exclusively as objects, totally ignoring their *Leib*-experiences [31, 56]. As I see it, an experience of wholeness or integrity implies that both experiences of one's own body concur with one another. What I call bodily identification involves the relation between *Leib* and *Körper* experiences.

These two experiences of one's own body could also be seen as the experience of *having* (*Körper*) and *being* (*Leib*) one's body [48]. In the experience of having a body, one is distanced form oneself and does not coincide with oneself [61]. In this experience, one's body is like a thing. It is especially through the sense of vision that one can perceive oneself as a thing. Facing one's mirror image one perceives one's own objectivized body, inspecting its various qualities. Normally, one experiences this 'thing' nevertheless as one's own because one identifies with it. To explain the process of identification, it is useful to briefly discuss the phenomenon of one's mirror image. Lacan [30] has argued that the recognition of one's own mirror image immediately implies a misrecognition (*méconnaissance*) since the image is not the same as oneself; it is an externalization or alienation of oneself. Identification through mirror recognition therefore does not simply mean X = X, but rather X = Y: I *am* my mirror image though I do not totally coincide with it. According to psychoanalysis, identification not only indicates an equation of myself and my image, but also involves assimilation into it; one desires to be like one's image. This latter aspects gains ascendency if we realize that one's own mirror image is directly related to one's visibility for others.[9] Identification through mirror recognition, therefore, equally implies a desire to assimilate to dominant ideals in one's society and culture, to respond to the (normative) gaze of others. For that reason, the process of self-identification is not an isolated, individual psychological process. In this paper, I will limit myself, nonetheless, to a discussion of

[9] Or, as Merleau-Ponty [37] argues in his interpretation of the mirror stage: "the image in the mirror prepares me for another still more serious alienation, which will be the alienation by others" (p. 36).

identification on a personal, subjective level, so as not to overcomplicate my argument.[10]

Although visible and imaginary aspects are important in the process of identification, I prefer to describe this process more generally as the possibility of *being* the body one *has*. I do so because not all experiences of one's body as a thing (or *Körper*) are directly related to the sense of vision. A lame or sleeping limb, for instance, is a clear *Körper* experience in which no vision is involved. As previously mentioned, in most cases in which one experiences one's body (or parts of it) as *Körper*, one is nevertheless capable of identifying with it. Whereas the condition of a sleeping limb may temporarily and slightly interrupt this process, other conditions, such as paralysis and amputation, may disturb it in a more profound way. These conditions are caused by the absence of so-called "localized sensations". These sensations normally produce the experience of "mine-ness" and "here-ness" which are typical for the *Leib* experience. The cancelation of this experience in these conditions is due to neurological problems.

Whether one is able to *be* the body one *has* is, however, not only a neurological question. Failures in identification can equally imply psychological (or psychiatric) problems. An extreme example of not being able to *be* the body one *has* is Body Integrity Identity Disorder (BIID). This is a condition in which one experiences one's own limb as something that does not belong to one's body and therefore has to be removed. BIID patients are not able to *be* the body they *have*, and therefore they cannot experience their body as a whole or an *integrum* [50]. Only after amputation they regain an experience of wholeness. This extreme (psychiatric) example shows painfully what happens if the process of bodily identification fails. It is not for nothing that it is called a disorder of one's identity and integrity.

Negative feelings about one's own body after disfiguring breast cancer, obviously, cannot be compared to this psychiatric disorder. I believe, however, that breast cancer survivors can also have problems in identifying with their modified body, though they clearly differ from identification failure due to neurological and/or psychiatric conditions. If breast cancer survivors fail to identify positively with their modified body, they value their own body in a negative way. If, conversely, they succeed in *being* the body they *have*, it implies that they are able to experience and say: 'This body I have, however changed (and mutilated) it is, is me'. It is very unlikely that cancer survivors will express their embodied self-experiences in this way. Experiences of wholeness—or discrepancy—come to light most explicitly in certain feelings and emotions. Shame, for instance, involves a certain degree of self-discrepancy [26]. If a breast cancer survivor is (extremely) ashamed of her body, I would say that her experience of bodily integrity is affected.

[10] It goes without saying that the way one valuates his or her scarred body, the degree to which one can identify with it, is also dependent of social and cultural norms. Indeed, physical 'deviances' or 'stigma's' only come into being in social relations [24]. Social (and cultural) interaction is thus constitutive for the meaning of appearance in breast cancer survivors [58]. This paper, however, is not the place to dwell upon the social and cultural aspects implied in body image and bodily integrity. My hypothesis that bodily integrity involves a process of identification on both a personal level and an intersubjective and cultural level (and that these levels are interrelated), will be elaborated and researched in another study.

Understood in this way, bodily integrity is directly related to body image, and especially to the latter's affective dimension (although this can never be fully separated from its cognitive and behavioral components). Indeed a negative body image (i.e. a negative valuation of one's physical appearance and one's physical intactness) refers to the lack of a positive identification with one's physical self and, thus, to the loss of bodily integrity. I thus believe that the use of certain body image items can contribute to the articulation of a person's bodily integrity. In contrast with the aim of most body image evaluation—the reinforcement of a patient's psychic well-being—I suggest that body experience evaluation should not be used for psychological purposes only. Examining a patient's experience of bodily integrity, with the help of body image items, can have a practical and ethical purpose as well.

The ethical dimension of body experience valuation becomes clear if we look at moral values that are implicated in the notion of bodily integrity. Stemming from the Latin word *integrum* and the verb *in-tangere*, integrity signifies both 'wholeness' and 'not touching' [43]. Taken together it thus refers to a wholeness that should not be touched, not be hurt—a wholeness that should be respected. Applied to medical practices, this means that a patient's body should be treated with respect and prudence. Medical professionals who necessarily have to intervene in a patient's body still have to respect as much as possible the *integrum* of this person's body.

From a liberal stance, according to which a person owns his or her own body, bodily integrity more or less converges with the principle of autonomy [69]; i.e. a health professional may 'intrude upon' a patient's body only if this patient has consented to the intervention. In spite of this, respect for bodily integrity is not exactly the same as respect for autonomy, because one's body is never fully possessed, nor something of which one has total disposal. No matter whether patients have consented to certain interventions, respect for bodily integrity also prescribes that medical professionals should not treat patients' bodies as if they were just objects or a collection of organs, tissues and limbs [32, 57, 68]. In this way, bodily integrity is closely linked to human dignity and, to a lesser degree, to the medical ethical principle of 'nonmaleficence' [5]. In accordance with these conceptions, violation of bodily integrity occurs in, for example, the commercialization of human organs, disrespectful nursing and an amputation of the wrong limb.

Returning to the example of breast cancer, I would like to add something here that enlarges the moral scope of bodily integrity, namely, that benevolent treatments can also violate a person's bodily integrity. Indeed, if a breast cancer survivor has received a breast reconstruction which eventually turns out to make no contribution at all to the restoration of her experience of bodily wholeness, the treatment has been an unneeded (and irreversible) intrusion.

Body Experience Evaluation Prior to Intervention

Thus far, I have argued that medically successful treatments, even if they have been performed with prudence and professional discretion after patients have consented to it, still may result in the violation of a person's bodily integrity. One could object here that it is not fair to judge treatments with the benefit of hindsight, and that if a

physician would have known that a treatment would not have the expected result s/he probably would not have performed it. This is true. It is not at all my intention, however, to express disapproval of medical practices such as breast reconstruction. My, perhaps extreme, view on bodily integrity should rather be seen as an invitation to support oncology care practices given that the evaluation of bodily wholeness could, I believe, be employed in assessment *prior* to interventions.

Body experience evaluation, which aims at the articulation of a patient's actual experience of bodily wholeness, can help patients (who have to decide about an intervention that will change their body) to weigh up their situation more clearly. Deliberately considering their own embodied experiences (with the help of the professionals involved), may enable patients to gain a more complete idea of the impact of various interventions. As such it can also be seen as making an important contribution in helping those involved arrive at a more informed decision.

One may again raise an objection here: how could the evaluation of a person's body experience prior to intervention envisage how this person will valuate her or his body after the intervention? Of course, one can never fully foresee how a change in physical appearance and intactness will be experienced but this, in itself, does not leave the suggestion I am making here—that explicit awareness of the way one actually values one's body may be useful in weighing up different alternatives—any less compelling. I find this so mainly because the valuation of one's body—one's body image—is not something isolated. Rather, it is directly related to what is valuable and meaningful for this person in his or her life. A person's long-term body image, which does not necessarily stay the same all the time [62], parallels a person's life story. Body experience evaluation which aims at envisaging the impact of future interventions should thus take place against the background of a patient's narrative.

Endorsing the hermeneutical idea that experiences express themselves in stories [44, 65], I maintain that the interpretation of lived experience necessarily involves an interpretation of stories. The narrative stance naturally complements the phenomenological one. Also, the narrative approach can take into account the temporal aspect of the way one experiences one's own body. This temporal and narrative aspect of body image is hard, if not impossible, to frame in a quantitative evaluation tool. Indeed, measuring a specific bodily experience at a certain point in time does not provide much information about how valuation of one's body is formed over time. Body image is not an instant experience of one's body, and this is the reason that the actual valuation of one's body is not detached from a person's future. Given this, it is not totally impossible to estimate, on the basis of actual body experience valuation, how someone will eventually valuate a certain change in physical appearance, intactness and competence.

It is too naïve to maintain that a story or narrative is a simple representation of one's experiences. The way one experiences one's body—one's body image—is not always completely transparent and conscious for one self [23]. Expressing one's body experiences thus already implies a process of self-interpretation. In this sense, the telling of a story is not only about what *was* experienced, but equally about 'what *becomes* experience in the telling and its reception' [22]. In this process of interpretation and story telling, health care professionals can play an important role.

In a practice of so-called 'joint narrative work' [66], medical professionals should not only listen to stories, but also help to build them while interpreting them. This is especially so in stressful situations, such as the fearful period after having being diagnosed with a (life-threatening) cancer and during which one has to make far-reaching decisions in a short space of time. Here patients may have totally lost track, and may have great difficulties in articulating how they experience and value their own body.

Following Frank's [22] distinction between 'restitution', 'chaos' and 'quest' narratives, I believe that aspects of quest narratives will be especially helpful here. Quest narratives are not about triumphing over one's illness (restitution narrative), nor simply about being sucked into one's illness (chaos). In a quest narrative, the narrator is constantly searching for a way to deal with his or her condition. The quest narrative is indeed the story of the patient who is telling the story and not just about remedy (restitution narrative) or suffering in which the teller has lost his or her voice. A quest narrative, remaining open and never ending—let alone happily—"affords the ill person a voice as teller of her own story" [22].

Obviously, counseling prior to interventions is not the place to build extensive life stories. The only thing I would like to suggest here is that counseling could also include a short but joint orientation of what is important for a patient in his or her life with a special focus on how this patient values his or her physical appearance and intactness.[11] Needless to say, to develop (and implement) this type of assessment, further research is required. To increase health care professionals' sensitivity to the impact of body experience in health care practice, and to provide them with some practical aids to thematize this experience, it should first of all be examined how patients, both before and after treatment, put into words their experience of (loss of) bodily wholeness. These specific expressions can serve as a basis for prospective joint narrative work and can support health care professionals to initiate the process of jointly constructing the patient's 'body story'. Future research, therefore, needs to aim at the development of a rich, yet workable, vocabulary of patients' body experiences.

Acknowledgments I would like to thank two anonymous reviewers for providing constructive comments and helpful suggestions on an earlier version of this paper. This research has been funded by CAPHRI School for Primary Care and Public Health, Maastricht University Medical Center.

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[11] Although more and more attention is paid to the articulation of patients' personal values and attitudes in the process of decision making [12], a specific focus on body experiences is lacking in most conceptions of shared treatment decision making.

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