

Phenomenology of Bodily Integrity in Disfiguring Breast Cancer

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In this paper, I explore the meaning of bodily integrity in disfiguring breast cancer. Bodily integrity is a normative principle precisely because it does not simply refer to actual physical or functional intactness. It rather indicates what should be regarded and respected as inviolable in vulnerable and damageable bodies. I will argue that this normative inviolability or wholeness can be based upon a person's embodied experience of wholeness. This phenomenological stance differs from the liberal view that identifies respect for integrity with respect for autonomy (resulting in an invalidation of bodily integrity's proper normative meaning), as well as from the view that bodily integrity is based upon ideologies of wholeness (which runs the risk of being disadvantageous to women). I propose that bodily integrity involves a process of identification between the experience of one's body as "Leib" and the experience of one's body as "Körper." If identification fails or is not possible, one's integrity is threatened. This idea of bodily integrity can support breast cancer patients and survivors in making decisions about possible corrective interventions. To implement this idea in oncology care, empirical-phenomenological research needs to establish how breast cancer patients express their embodied self-experiences.

Integrity, stemming from the Latin *integrum*, literally signifies "wholeness" or "intactness." In many ethical discussions, the wholeness of either the person or the body involves the normative counterpart of actual vulnerability. With regard to the body, integrity refers to the vulnerable body's inviolability, which should be respected and not infringed upon (*in-tangere*) (Rendtorff and Kemp 2000; Rendtorff 2002). Various feminist phenomenologists have argued that in Western society, bodily integrity is habitually—yet not always appropriately—measured against the norm of physical intactness.¹

In this essay, I explore the meaning of bodily integrity in "non-normative embodiment" (Scully 2008)—that is, bodies that deviate from the norm of physical intactness—while focusing on a specific and socially-culturally urgent case:

disfiguring breast cancer. Although disfigurement caused by mastectomy or lumpectomy is specific to the female body, my approach of analyzing disfiguring breast cancer can also be applied to non-gender related issues.² My broader concern circles around the question of how to deal with non-normative embodiment in a society that is dominated by ideal images of young, slim, able, and strong bodies and that reinforces the normalization of this ideal by encouraging us to indulge in easily accessible cosmetic interventions.

The aims of this essay are more modest and limited. Here I present an initial outline of what I call an “ethics of non-normative embodiment” while discussing bodily integrity in disfiguring breast cancer. In current bioethics and health care ethics, bodily integrity is habitually related to issues like organ donation, reproductive autonomy, pregnancy and abortion, tissue engineering, and circumcision. In these discussions the emphasis is placed on the question of whether it is morally desirable to intrude, be it medically, cosmetically or ritually, upon an intact body. The case of disfiguring breast cancer raises a different normative question. Here the choices between mastectomy and breast-saving surgery, choices for or against breast reconstruction, nipple banking, prostheses, or specially adapted clothes concern interventions on bodies that are no longer intact.

To explore the ethical dimension of this typical case of “non-normative embodiment” I will use a phenomenological approach, drawing on the work of Scully and Mackenzie.³ They argue that the appreciation of “non-normative” or “deviant” embodiment cannot simply be based upon moral imagination, that is, the possibility of putting oneself in the place of another (Mackenzie and Scully 2007). Normative evaluations of “non-ideal” embodiment should rather be based on the experience of it as it is lived, thus demanding a phenomenological approach (Scully 2008). The normative claim of this paper is that processes of (shared) decision-making in *mammae* oncology care should be led and informed by a focus on a patient’s embodied experience of bodily integrity rather than privileging medical and cultural norms of bodily intactness. To substantiate this claim I take the following steps. First, I discuss the differences between a phenomenological and “principlist” approach to bodily integrity. To show that the extent of disturbed embodied self-experience does not automatically correspond to the extent of biological or functional intactness, I then draw on the example of *Body Integrity Identity Disorder* (BIID). In indicating some limitations in the current practice of body experience evaluation, I finally show how the idea of bodily integrity based upon embodied self-experience can be used to support oncology care.

BODILY INTEGRITY IN CONTEMPORARY HEALTH CARE ETHICS

Contemporary medical and health-care ethics are predominantly guided by a so-called “principlist” approach. This “principlism,” founded by the work of

Beauchamp and Childress (1994), proposes that moral reasoning about health-care issues should be ruled by a set of four *prima facie* principles: autonomy, non-maleficence, beneficence, and justice. Compared to standard medical ethics prior to the 1970s—which were primarily based upon the Hippocratic “*primum non nocere*” (“first, do no harm”)—this “principlist” approach implied a shift from a beneficence-based model to an autonomy-based model that incorporates a set of social concerns, notably the issue of distributive justice (Beauchamp 2007). Emphasizing respect for autonomy, this approach presupposes a rather liberal stance in ethical reasoning.

From this liberal point of view, respect for bodily integrity is mostly identified with respect for personal autonomy. Accordingly, respect for bodily integrity mainly implies that one may touch or intervene in another person’s body only if this person has consented to this intervention. Hub Zwart convincingly argues that the current identification of bodily integrity with autonomy effectively wipes out the ethical dimension of bodily integrity (Zwart 2000). For, indeed, as a normative principle in its own right, bodily integrity is not just about giving permission to intervene. Since it is a *normative* principle, it does not simply refer to one’s actual (vulnerable) body, but to the inviolability in this vulnerability that *should be* secured (Zwart 2007). This inviolability or wholeness is not necessarily something that can be pointed at in an actual body but is more likely an “ethical fiction.” This “fictional” aspect of bodily integrity becomes clear if we look at, for example, preconceived ideas of wholeness such as those postulated by various religions, for example, metaphors such as “temple” or “sacrament” (Ashley 1985; Campbell 1998). It is also against the background of a certain preconceived idea (and ideal) of bodily wholeness that the practice of male circumcision in Judaism, for instance, becomes understandable and morally justifiable. According to Judaism, the foreskin indicates an imperfection of the male body. The removal of this body part thus means, among other things, a restoration of perfection and wholeness rather than its violation (Dekkers, Hoffer, and Wils 2005; 2006).

Noting the ways that the normative dimension of bodily integrity is directly related to images or fictions of wholeness shows us that bodily integrity is always embedded in a certain ideology of wholeness. These kinds of ideologies are very forceful in the public domain, and can have unforeseen, undesirable, or counter-productive consequences. Perpich, for instance, explains that bodily integrity is not necessarily something good or morally desirable if it is considered to be related to a certain ideology of physical intactness (Perpich 2005): the (mythical) idea of an intact virginal membrane—intact virginity—for instance, easily runs counter to the right of sexual autonomy. Needless to say, ideologies of wholeness are also operational in practices that claim to approach the body from a “neutral,” scientific point of view. As I will go on to discuss, the biomedical norm of “fixing” an “incomplete” body disregards some women’s decision to

refuse a breast reconstruction even if they meet all the (medical) criteria for such an intervention.

As has been stressed by various researchers, especially in the field of disability studies, biomedical claims about bodily wholeness, ability, and health are not neutral, and are not simply based upon scientific “facts,” but rather reflect contemporary medical discourse assumptions that equate norms of health with ability and wholeness.⁴ In that sense, one could also say that the use of the term *disfigurement* still involves a negative ideology of wholeness. Indeed, disfigurement is the negative counterpart of being whole and undamaged. To prevent this negative connotation, other authors use terms like bodily *difference* (Lansdown et al. 1997; Shildrick 1999), or the already mentioned “non-normative embodiment” (Scully 2008). I, nonetheless, use the term *disfigurement* to avoid concealing that something has happened to one’s body. Disfiguring breast cancer implies an undesired, involuntary modification of one’s body. Rather than presuming that disfigurement automatically results in a loss of bodily wholeness, however, I provide a phenomenological description of *experiences* of wholeness or loss of wholeness in women with this medical condition that challenges medical practices that consider disfigured bodies to be less than whole.

I will not linger on the role of ideologies, fiction, and images in relation to the normative dimension of bodily integrity. Instead, I would like to shift the focus from *images* of wholeness to *experiences* of wholeness.⁵ This shift in focus also prevents us from throwing away the proverbial baby with the bathwater, that is, if one concentrates too much on ideology and prevailing social norms, one runs the risk of both losing the “lived body” and the normative principles that morally regulate social interaction between vulnerable embodied individuals. Ingunn Moser has claimed, for instance, that most theories of the body that analyze the meaning of embodiment from the perspective of social norms and (power)relations reduce the body to a social-cultural construct that is opposed to the individual biological-genetic body in biomedicine (Moser 2009). Trapped in this dualistic reality, the meaning of individual “lived bodies” (*corps vécu*) against the background of a social-cultural ideal of embodiment is not approachable, let alone analyzable. My phenomenological approach of analyzing embodied experiences thus supports the present call (in, for instance, disability studies) to “reclaim” the lived body (Shakespeare 2006; Scully 2008; Moser 2009).

We may lose a valuable moral principle if we think of bodily integrity only in terms of “ideologies of wholeness.” Therefore, I believe that Diane Perpich does away too hastily with the notion of bodily integrity (Perpich 2005). Following Jean-Luc’s philosophy, which involves a radical critique of traditional and humanist discourses that stress the unity and “ownness” of one’s own body, she suggests that we would be better to think of the body in terms of “des-integration.” Despite the fact that I share her concern about violent myths, fictions and images of bodily integrity, I would still like to defend the ethical significance of

bodily integrity. Although I also sympathize with Nancy's philosophy of the body, I will draw another lesson from it (as I will explain in more detail below). Even if one's own body is never fully *owned* (thus denying an autonomous liberal stance toward one's own body) and never fully *one* (thus rejecting an ideology of intactness), *it can still be considered as a whole that needs to be respected.*⁶ This wholeness is not a united and self-coinciding substance but rather an experience of oneself as non-identical. To explain this, I will now shift from the liberal and ideological view of bodily integrity to a phenomenological view.

To understand bodily integrity from a phenomenological perspective, most interpreters—rightly—draw on the idea of ambiguous embodiment presented by de Beauvoir (1948) and Merleau-Ponty (1945/1962). On this view, human existence implies simultaneously having (embodied) possibilities of being engaged in one's world ("I can") and being limited in one's possibilities because of one's vulnerable body. Zeiler, for instance, claims that not just any physical change will threaten the integrity of one's body (Zeiler 2009). One's bodily integrity is affected only if a physical change affects one's engaging in the world. In the same vein, Bergoffen argues that one's bodily integrity is threatened if one's ambiguous embodiment is neglected, if one's embodied possibilities are frustrated or annulled and one's body is used by others as a mere thing (Bergoffen 2009). According to this phenomenological view, then, bodily integrity is directly related to the intactness of embodied *possibilities*.

Although I go along with this view, I believe that it can be further developed while looking at the phenomenology of bodily self-experience that underlies the idea of the embodied "I can." It is true that the question of whether embodied possibilities are modified or decreased is crucial in many cases of non-normative embodiment. Since he emphasizes the role of motor intentionality in his analysis of embodiment, Merleau-Ponty notably analyzes (pathological) cases in which bodily potentiality (the "I can") is impaired (Merleau-Ponty 1945). But he does not teach us much about changes in physical appearance that do not affect one's physical functioning, but that may nonetheless disrupt one's experience of wholeness and integrity. In disfiguring breast cancer, women do not necessarily experience a limitation of their "I can," while their experience of bodily integrity might be affected.⁷ To understand how one's experience of wholeness and integrity can be affected while one's "intentional arc" remains "undiluted" (Merleau-Ponty 1945/1962), I will concentrate here on the phenomenological analysis of bodily self-experience instead of focusing on the idea of "being bodily engaged in the world."

BODILY INTEGRITY AND EMBODIED SELF-EXPERIENCE

It is well-known that contemporary medicine and health-care practices are predominantly based upon a (neo-)Cartesian conception of the body (Hacking

2007). Criticizing the one-sidedness of this conception, phenomenologists draw attention to the ways in which patients and care receivers experience their own bodies and contrast this to the Cartesian conception of one's body as corpse or machine. They thus stress that we *are* our bodies, instead of just *having* them. Toombs (1999) and Leder (1999), for instance, argue that the integrity of the body, which is at stake in organ donation, must be understood on the basis of the subjective embodied experience of oneself (Leder 1999; Toombs 1999).

To secure patients' bodily integrity, health-care professionals should indeed pay more attention to the body as it is lived, the "body-subject." Yet, I suggest that a full-fledged phenomenological conception of bodily integrity must also take into account that the experience of one's body as lived cannot be separated from the experience of one's body as a thing. My phenomenological analysis of bodily integrity, therefore, starts from the assumption that the experience of our own body is principally double-sided. To illustrate this, I turn to Husserl, whose phenomenological analysis forms the basis of Merleau-Ponty's and Beauvoir's idea of embodied ambiguity.

Husserl claims that in self-perception, one experiences oneself not just as a thing or *Körper* but also as a lived-through body or *Leib* (Husserl 1952/1989).⁸ Self-perception thus involves two experiences. He describes these experiences while analyzing what happens when one touches one's left hand with one's right. First, the left hand can be experienced as a thing with a certain extension and with certain properties. As such, the left hand is experienced as the "physical thing left hand." This is the experience of having a *Körper*. Second, however, the left hand is also experienced as the localization of sensations. These sensations do not constitute physical properties such as smoothness or roughness and thus they do not constitute the physical thing "left hand." Rather, they constitute the experience that one feels *in one's* left hand that it is touched; the touched hand senses its being touched. It is by means of these localized sensations that the body as physical thing "becomes" the body as *Leib*—*es wird Leib, es empfindet* (Husserl 1952/1989, 152). We can thus say that the Body (*Leib*) is constituted in a double way: first it is a physical thing or matter with extension and real properties, and second, "I find on it, and I sense 'on' it and 'in' it" (153). Or, as Husserl concludes, "Obviously, the Body (*Leib*) is also to be seen just like any other thing, but it becomes a *Body (Leib)* only by incorporating tactile sensations, pain sensations, etc.—in short, by the localization of the sensations as sensations" (158–59).⁹

At first sight, Husserl's analysis seems to head straight for a new kind of dualism: the experience of *Körper* versus the experience of *Leib*. However, if we look a bit closer at the example of the two touching hands, we see that things are more complicated. As said, the experience of *Leib* is constituted by localized sensations, which means that the touched hand feels itself being touched. Feeling one's own touchability is only possible if the hand is also experienced as some-

thing that can be touched, and this is possible only if the hand is also experienced as a touchable thing or *Körper*. Hence, the experience of *Leib* presupposes and affirms the experience of *Körper* (Slatman 2005). To phrase it differently, there is no such thing as a pure experience of *Leib*. If that were the case, *Leib* would be something disembodied, similar to Descartes's idea of mind or *res cogitans* (Waldenfels 2004).

The relation between *Leib* and *Körper* can be translated into the relation between experiences of ownness and experiences of strangeness. Whereas the experience of *Leib* is an experience of "mine-ness" or "ownness," the experience of *Körper* lays bare the experience of being at a distance from one's own body. Since *Leib* experience presupposes and affirms *Körper* experience, the analytic distinction between ownness and strangeness should not be understood as an actual separation. In fact, one always experiences a certain strangeness at the very moment one experiences oneself.

This interpretation of Husserl brings us to Nancy's conception of bodily identity and integrity. Although he does not mention the Husserlian distinction between *Leib* and *Körper*, it is quite possible to explain Nancy's view along the lines of this distinction. His basic claim is that one's (bodily) self is always already intruded (*intrus*) by something strange (*étranger*) (Nancy 2000). One's own body is never fully one's own: it is always differing from itself; it does not coincide with itself. It is "*différent*" (Nancy 1993, 58). Consequently, Nancy maintains that identity should not be seen as $I = I$ (I am I because I coincide with myself) (Nancy 2000, 11). Leaving behind the conventional idea of identity as "adequation," we should rather say $I \neq I$ (I am I because I differ from myself).

In view of this idea of "differential identity," Nancy writes about himself after his own heart transplant and subsequent treatment: "*I am* the cancer cell and the grafted organ, *I am* the immuno-depressive agents and their palliatives, *I am* the bits of wire that hold together my sternum, and *I am* this injection site permanently stitched in below my clavicle, just as I already *was* these screws in my hip and this plate in my groin" (Nancy 2000, 13; my emphasis) Instead of saying "I have," he says "I am," making the identification at stake here explicit. Nancy thus identifies himself with replaceable parts (and extensions) of his body. I interpret this process of identification as the possibility of *being* the body one *has* (Slatman 2008). The phrase "having a body" refers to the dimension of the *Körper* experience, and this entails an aspect of strangeness. "Being the body one has" involves bodily identity and integrity in which the aspect of strangeness is not annulled but remains present. Taking the permanent character of the body's inherent difference seriously, bodily identity rather implies a never-ending process of identification instead of a self-coinciding substance. Precisely because the *Leib*-experience affirms and presupposes the *Körper*-experience, the process of identification remains open, enabling constant ex-corporation and incorporation.

To summarize: the experience of bodily integrity presupposes the possibility of being the body one has. Accordingly, respect for bodily integrity first of all means acknowledging the difference between *Leib* and *Körper*. Translated to health-care practices, it requires that professionals must try to make explicit whether (and how) a patient is able to identify with her body. This, indeed, calls for an interpretation and investigation of how a patient values her modified body. Instead of simply presupposing that a disfigured body should be fixed, medical professionals should first examine patients' experiences of wholeness (or loss of wholeness).

EXPERIENCES OF DISTURBED WHOLENESS

It is a widespread conviction in medicine as well as in society that experiences of bodily wholeness correspond to the extent of the body's biological and functional intactness. From the phenomenological perspective I have presented, experiences of lost wholeness in bodies that are biologically or functionally affected can be explained in terms of a disruption between *Leib* and *Körper* by means of which an experience of strangeness can dominate and displace the experience of ownness. A telling example of such a disruption is provided by Paul Rayment, the chief personage in Coetzee's novel *Slow Man* (2005), a man of middle age who lost his right leg in a traffic accident and who has a hard time adapting to his blemished body: "To himself he does not call it a stump. He would like not to call it anything; he would like not to think about it, but that is not possible. If he has a name for it, it is *le jambon* [the ham]. *Le jambon* keeps it at a nice, contemptuous distance" (29). At this point, Paul Rayment describes his own leg as something strange to himself; it has become a mere *Körper* that he does not want to experience as part of himself. It is nonetheless true, even in this case, that the leg has not been totally alienated, since Rayment obviously knows that it is not a ham. This is also a reason for why a re-identification with his blemished body remains possible, and this eventually happens in the novel.

Although some breast-cancer patients experience mastectomy as an operation that frees them from an "intruder," that is, a malign tumor, and, therefore, sometimes prefer this operation over a breast-saving operation (Collins et al. 2009), the amputation of a breast can also result in a certain alienation from one's body. Similar to the experience of Paul Rayment, mastectomy and the subsequent cicatrizing can result in an experience of one's own body (part) as mere *Körper*. In one of the pilot interviews I have carried out, Mrs. Janssen (age 69)—who had undergone a mastectomy six years ago—replied to my question "do you find it difficult to look at yourself naked in the mirror?": "I find it difficult. I have, eh ... it was in the hospital that was already a long time afterwards: I didn't dare to touch my own armpit. There is a big hole and I did not dare to

touch that.”¹⁰ In her case, the surgical modification of breast and armpit resulted in experiences of distance and alienation toward her own body. The surgical knife, while literally making one’s body less whole, caused the experience of being a mere *Körper* and thus an experience of disrupted bodily integrity.

The phenomenological view I am presenting thus clarifies the biomedical idea of bodily integrity as being physically intact and undamaged. More interestingly, however, it can also significantly add to the current biomedical view, for it is quite possible that the relation between *Leib* and *Körper* is disturbed while biological and functional bodily integrity is unaffected. An extreme example of this is the rare disorder *Body Integrity Identity Disorder* (BIID); people suffering from BIID strongly desire to have an amputation of one (or more) of their healthy limbs. One explanation for this disorder is that there is a “mismatch” between one’s experience of the body and the actual body (Bayne and Levy 2005; Sorene, Heras-Palou, and Burke 2006). BIID is an example of how people with a “normal” and “intact” body may have the experience of an unacceptable strangeness in their body so that they do not experience it as a real *integrum*: they are not able to be the body they have (Slatman and Widdershoven 2009). One of the participants in Melody Gilbert’s documentary on BIID, who introduces himself as someone who “became a person late in life,” says that it was only after having his left leg amputated that he had become “whole” (Gilbert 2003).

This example of BIID, obviously, has nothing to do with breast cancer. I make reference to this disorder only to make clear that experiences of bodily integrity cannot simply be derived from the body’s biological and functional intactness. My claim is that the evaluation of experiences of wholeness should take into account both aspects of embodiment: (1) the body as *Körper*, that is, the body that appears as an intentional object to oneself, and (2) the way one values this object and is able to identify with it. I will now turn to a discussion of the way in which bodily experiences are evaluated in oncology care and how this evaluation—from a normative ethical viewpoint—can be improved.

EVALUATION OF BODY EXPERIENCES IN BREAST-CANCER CARE

Oncology care and aftercare evaluations of quality of life, including psychic and bodily well-being, are becoming increasingly important. The evaluation of bodily experiences is one of the central issues in the medical-psychological discipline of psycho-oncology.¹¹ Although this attention to bodily experience in breast-cancer care is only to be welcomed, these medical-psychological evaluations, for the most part, fail to address the normative dimension inherent in the valuation of one’s own body. As I have explained elsewhere in more detail, this is, to a large extent, due to the limitations of quantitative evaluation tools (Slatman 2011).

Another problem that needs to be recognized is that in medical discourse and practice, the idea of bodily integrity seems to be totally reduced to actual and biological intactness. 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 breast reconstruction if their physical condition allows it (Woerdeman 2005). To rehearse a term I have used earlier, medical discourse, in fact, proposes an idea of bodily integrity based upon the "ideology" of physical intactness, perhaps foreclosing other "ethical fictions" of the body's inviolability.

The same kind of ideology seems to be presupposed in many studies that aim at evaluating the embodied self-experience of breast-cancer survivors. If we look at the designs of these studies, we see that that the inclination to find correlations between physical mutilation and negative embodied self-experience is often immanent, for example, studies that suggest that patients who received breast conservation have a more positive "body image" than those who received a mastectomy (Arora et al. 2001; Figueiredo et al. 2004), or that reconstructive surgery may restore a woman's "body image" (Andrade, Baxter, and Semple 2001). These studies suggest a direct, and perhaps causal, correlation between the degree of physical mutilation and the degree of negative valuation of the body one has.

It goes without saying that the actual state of one's physical body can be crucial for the way in which one experiences and values it, and therefore, I do not want to minimize these types of studies. However, I would like to stress that these studies run the risk of overlooking the possibility that the restoration of physical wholeness does not automatically yield the experience of bodily wholeness. Fortunately, there are also studies that point to this possibility and establish, for example, that breast reconstruction does not always increase "body image" satisfaction (Harcourt et al. 2003), or that women sometimes even experience 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 (Sheehan et al. 2008). It is quite possible, then, that women with a body that is less whole feel more whole than expected. The experience of bodily wholeness is not based simply upon having a physically intact body. Rather it is based upon the ability to identify with the body one has, whether it is physically intact or not.

It is, however, not my intention to trivialize the importance of a physically intact (female) body. I therefore do not agree with the radical feminist claim that women should abstain from an idea of bodily wholeness that is a construction of male biology and medicine, and, should therefore renounce reconstructive surgeries and adaptive prostheses and/or fashion (Lorde 1980). Like the biomedical discourse, this radical discourse also implies a limited and one-sided normative

claim. In fact, both discourses focus only on the body that appears as an intentional object (*Körper*): whereas biomedicine seems to suggest that the body needs to meet the standard of physical intactness, radical feminism tends to neglect the claim that bodily well-being presupposes the possibility of identifying with one's body. To facilitate good decision-making, and thus good care, one should suspend both these discourses to concentrate first of all on patients' embodied experiences. In sum, a phenomenological ethics of bodily integrity primarily implies an evaluation of bodily experiences that can account for their double-sidedness (Slatman and Widdershoven 2010).

PHENOMENOLOGICAL ETHICS: A POSSIBLE SUPPORT IN DECISION-MAKING

A first step for making this phenomenological approach applicable to health-care practices such as oncology care requires that professionals become more sensitive to the ways in which patients experience their bodies and the ways in which they express this experience. In particular, professionals need to be provided with certain signs to enable them to recognize and interpret these experiences. Endorsing the hermeneutical idea that bodily experience expresses itself in life-stories (Ricoeur 1991; Widdershoven 1993), I argue that the phenomenological approach goes together naturally with a narrative approach. The interpretation of patients' stories should be part of counseling prior to interventions such as breast reconstruction, nipple banking, and tattooing. As has been claimed by Rosalyn Diprose, ethics should start from the assumption that the lived body is the very "fabric of the self" (instead of its appendage) and that bodily identity (and integrity) can be derived only from a person's "specific corporeal history" which "will vary in each case" (Diprose 1994, 108). By focusing on life stories instead of on the actual state of one's body, the temporal horizon against which people construe their identity becomes more visible. Indeed, it would be inadequate to just ask a patient about her bodily experiences. One should rather ask about these experiences in relation to the patient's earlier experiences, her expectations, her situation, values, and so on.

Let me return here to the interview I had with Mrs. Janssen to illustrate how such a process of failed or successful self-identifying can be experienced and narrated. She told me that initially she had no real problems with her breast being amputated: it was just something that had to be done. "It is just like (eh) ... like being in a carrousel. Going from one doctor to another—a busy schedule. Yes, I knew that my breast would be amputated, but, well yes, ... in a way I did not really realize... ." At the time of the interview, six years after the mastectomy, she had more problems with her modified body: "if I look nowadays into the mirror I have more problems than before [just after the operation].... I am more aware of it." In this respect, time did not heal all wounds or, to be more precise,

it did not contribute to a process of successful self-identification. It seems more likely that, in this respect, she had distanced herself further from herself over time. Together with a persisting agonizing pain in her breast and shoulder—which was caused by the fact that the surgeon had cut into one of the nerves during the operation—her overall embodied self-experience was dominated by a negative and objectified experience of her own body. She continues to find it difficult to live with such a painful and marked body.

Interestingly, however, in the same interview she also mentioned some experiences that indicate that from another perspective she did succeed in re-identifying with her modified body. As pointed out earlier, Mrs. Janssen had a hard time touching her own armpit because of the scar tissue. In some respects, she was becoming afraid of her own body. She told me that, eventually, a physician helped her overcome this fear by literally taking her hand and putting it on her scar: “I didn’t dare, but he did, eh, he made me touch it consciously—I didn’t dare myself,” and, “Now, I do not mind touching it, no, now it’s okay.” Touching consciously her own scar tissue, she learned to “reunite” with it. Another experience she reported was when her grandson (seven years old) joined her while taking a shower:

A while ago, it was quite funny, I really liked that ... it was when I was taking a shower and Jason entered the bathroom—“so that’s, eh, it is taken away now, there just the one side grandma?” At that moment, I did not really know what to say, but then I simply said: “yes my boy, it is away.” “Okay granny,” he said, and went away, and that’s that. It made me laugh.

By expressing a simple affirmation of his grandmother’s modified body, the young boy helped his grandmother to realize that, although she might have problems identifying with her modified body, he had no problems whatsoever with it.

These fragments of what I would call Mrs. Janssen’s “body-biography” reveal how the experiences of blemished embodiment, in their temporal perspective and against the background of a specific life-world, are narrated. It is my hypothesis that the expression and interpretation of these kinds of biographies, on the basis of a phenomenology of embodied self-experiences, can add to practical knowledge and tools. As part of clinical trials, in which a treatment’s effectiveness is examined, body experience valuation is very useful. From a normative point of view, however, this kind of evaluation is even more important *prior* to interventions; for, as such, it can be used to support processes of decision-making. As I see it, a phenomenological-narrative approach to bodily integrity fits the goals of current ideas on shared treatment decision-making (STDM) quite well. Moreover, a phenomenological-narrative approach may enrich the practice of STDM, which, currently, is mainly understood as a process based upon mutual *information* exchange, *shared* discussion about pros and cons of a

treatment, and the physician's *recommendation* (Charles, Gafni, and Whelan 1999; Charles et al. 2003). In addition to these aspects, a phenomenological-narrative approach can explicate implicit, pre-reflective aspects that habitually are not recognized as "information" but that nevertheless *inform* the process of decision-making.

If we look at commonly used decision-making aids, we see that they, first of all, aim at making visible estimated benefits and risks of (optional) treatments. Women suffering from a certain type of early breast cancer, for instance, may benefit from adjuvant (additional) therapy after surgery. To help women in choosing a therapy—chemotherapy, hormone therapy, a combination of both, or no adjuvant therapy at all—the expected effects of these optional therapies are calculated and discussed. The support in these decision-making processes thus concentrates on already articulated knowledge and the processing of this information. An interpretive approach, by contrast, will enable one to articulate aspects that are not (yet) cognitively recognizable. As I have maintained, the way one experiences one's body and values it is crucial for one's bodily integrity. Normatively speaking, patients' decisions should be informed and guided by their actual ability to re-identify with their bodies or not (or, at least, by their belief whether they will be able to regain an experience of bodily wholeness or not in due time). To put it plainly, a woman who is able to re-identify with her one-breasted body after mastectomy, and thus has regained an *experience* of embodied wholeness, probably will not greatly benefit from a breast reconstruction. Conversely, a woman who is not able to re-identify with her wounded body, and who experiences a severe loss of bodily wholeness after mastectomy, needs to be supported in choosing an intervention that will enable her to regain an experience of wholeness.

I thus still employ the term *wholeness* even though I criticize "ideologies of wholeness." As discussed earlier (cf. footnote 6), I hold that it is ethically desirable to strive for wholeness in one's embodied self-experience. People who lack an experience of wholeness may suffer severely from it (as is very clear in cases of BIID). Identifying and possibly decreasing this kind of distress by means of an adequate evaluation of embodied self-experience will improve care and aftercare. In medical and health-care practice, respect for bodily integrity—protecting another's vulnerable body against harm—should indeed result in *good care*.

Since the way one experiences one's own body is not always completely transparent to oneself, a process of self-interpretation is required. A crucial starting point for this self-interpretation is the patient's "body-biography." Health care professionals need to support patients in constituting body-biographies, while interpreting what they, and their relatives, say against the background of their life world. To be able to recognize and to discuss bodily experiences of wholeness or loss of wholeness, professionals need a suitable vocabulary and a "catalogue" of examples. Presumably, patients will not articulate their own bodily experiences in terms of "wholeness" or "being the body one has." To gain awareness of the

ways that patients express their experiences, an in-depth empirical-philosophical investigation of the actual care practice is needed. Indeed, to effectively implement a phenomenological-narrative view of bodily integrity into the biomedical practice of breast cancer care, we need to learn how to listen to and understand breast cancer patients' expressions of their experiences of wholeness, lost wholeness, and regained wholeness. A systematic analysis of data collected through a manifold of structured (and in-depth) interviews (similar to the interview with Mrs. Janssen), through diary research, and through homogeneous and heterogeneous focus groups will provide insight into the way in which cancer patients and survivors relate to their own body over time.¹²

My hypothesis is that the articulation and interpretation of body experiences can help identify those interventions that are best for each patient. This is so because a "body-biography" is not an account of actual experiences alone; it rather gives voice to the identity and integrity of one's body over time. Although one can never totally oversee how future interventions may affect one's embodied self-experience, a body-biography still has some predictive value. It expresses how past and present experiences are linked to each other, as well as whether and/or how former bodily modifications have been fit in one's narrative identity (Cf. Hilhorst 2002). As a filigree that connects one's past and present self-experiences, a body-biography invites us to envisage which threads will persist in the face of future events. Incorporating this phenomenological-narrative approach of embodiment as a decision aid will complement the statistical probability of one's future bodily well-being with a probability inscribed in and "derivable" from one's embodied life story.

NOTES

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1. See, for example, Grosz (1994); Perpich (2005); Scully (2008); and Weiss (1999).

2. My concern here is the disease's disfiguring effect on female bodies. We should not forget, however, that breast cancer can also affect men, albeit rarely. Male breast cancer accounts for less than 1% of all breast cancer cases (Weiss, Moysich, and Swede 2005).

3. In this essay, I set aside political and legal questions concerning breast cancer treatment such as fair distribution of health care and the right of women's own voices in this "medical" matter (Lorde 1980; Duncker and Wilson 1996; Bazell 1998; Kopelman 2006; Lerner 2006; Sherwin 2006; Tong 2006; Kendrick 2008). I would like to place the questions related to politics and justice on hold to create a venue to discuss issues that

need to be clarified and specified before entering the political arena. Without neglecting the fact that breast cancer treatment involves political choices, I would like to focus here on a normative dimension that is directly related to the way in which survivors experience their bodies.

4. See for this, for example, Fuss 1989; Oliver 1996.

5. This shift in focus does not mean that I deny the intrinsic relation between the fiction of wholeness and the experience of wholeness. In fact, I endorse the view that embodied experience of wholeness is part of an “ethical fiction” precisely because this experience may refer to an inviolability that is not present in the actual vulnerable body. In the research project I am currently setting up, I intend to examine how cultural representations of bodily (im)perfection affect the experiences of bodily wholeness of breast-cancer survivors. In this essay, however, I limit myself to an explanation of the subjective dimension of this kind of experience.

6. To summarize my position: I do not defend the ideals of either biological intactness or those of humanistic (or religious) ideals of wholeness; I also do not presume that experiences of wholeness are experiences of a substantial wholeness. As I see it, an experience of wholeness is based upon *difference* rather than upon *identity*. In the light of this philosophy of difference, one might perhaps wonder why I still want to preserve the term *wholeness*. The reason for stubbornly sticking to this term is that, from time immemorial, wholeness refers to the moral dimension of the vulnerable body. Indeed, to prevent mutual harm, we need to respect one another’s bodies. More specifically, we need to respect this specific bodily dimension that refers to a person’s experience of being one and whole (even if one never really is one and whole).

7. Needless to say, although survival rates have increased enormously in the last decade, (breast) cancer remains a life-threatening disease. This evidently means that most breast cancer survivors are not only concerned about their bodies but even more so about their lives (Cohen, Kahn, and Steeves 1998). The fear of death surely affects one’s “being in the world,” both for oneself and one’s relation with others (Weiss 2006). In this essay, I leave aside this existential experience of breast cancer and limit myself to the way in which survivors value their modified bodies.

8. I prefer to use the original German terms here since the common English translation (“Body” for *Leib* and “body” for *Körper*) fails to differentiate between the experience of what is “lived through” (*Leib, leben, life*) and the experience of thinghood or even unanimated matter (*Körper, corpse*).

9. This double-sided experience is typical for *self*-experience. As Husserl has indicated, however, it is not limited to the appearance of oneself (Husserl 1931/1970). To a certain degree, it also applies to the appearance of others. On the basis of a process of “coupling” (*Paarung*), one perceives the other not just as a *Körper*, but also as a *Leib*. However, I would like to stress here, encapsulating what I have explained in more detail elsewhere (Slatman 2009a), that the appearance of another individual’s *Leib* presupposes another form of intentionality than the appearance of one’s own *Leiblichkeit*. Whereas the appearance of one’s own *Leib* is based upon the presence (or presumed presence) of localized sensations in one’s own body, the appearance of the other as *Leib* is based upon

apperception. Whereas the former implies a non-intentional experience, the latter implies an intentional experience. To put it simply, whereas the other, however close to me, always appears over “there,” my own body can appear both “here” and “there.” One “couples” with another’s *Leiblichkeit*, not because one literally locates the other in one’s own body, but rather because one shares the same world. One, for instance, immediately “understands” another’s embodied gestures—that is, without cognitive reflection—because one “recognizes” them as a way of disclosing one’s shared world.

10. As part of my initial empirical research, I administered two pilot interviews with breast-cancer survivors. Though the data has not yet been formally analyzed, I have used some material from my interview with Mrs. Janssen (a fictional name for one of my interviewees) to illustrate my theoretical approach.

11. As is now standard in medical psychology (and psycho-oncology), bodily experience is operationalized in terms of “body image.” Note that this understanding of “body image” may differ considerably from philosophical and psychoanalytical conceptions. In contemporary medical-psychological theory and practice, body image refers to the way one conceives of one’s own physical self. This may imply either perceptual aspects (such as accuracy of size estimation) or attitudinal aspects, including cognitive, affective, and/or behavioral factors (Pruzinsky and Cash 2002a; 2002b). Most current body image research concentrates on the attitudinal aspect. Elsewhere I have discussed the meaning of body image in phenomenology, neuroscience, and psychoanalysis (Slatman 2007; 2009a; 2009b), and have explained how the medical-psychological understanding of body image is related to these other conceptions (Slatman 2011).

12. In the spring of 2011, I began a 5-year research project, *Bodily Integrity in Blemished Bodies*, which includes the collection of firsthand data. This project is being carried out with two PhD students and is funded by The Netherlands Organization for Scientific Research (NWO). We are collecting data by means of interviews, diary research and focus groups from two Dutch Academic Hospitals: Maastricht University Medical Center (MUMC) and Antoni van Leeuwenhoek Hospital-Dutch Cancer Institute in Amsterdam (NKI-AVL).

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