

Multiple dimensions of embodiment in medical practices

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Abstract In this paper I explore the various meanings of embodiment from a patient's perspective. Resorting to phenomenology of health and medicine, I take the idea of 'lived experience' as starting point. On the basis of an analysis of phenomenology's call for bracketing the natural attitude and its reduction to the transcendental, I will explain, however, that in medical phenomenological literature 'lived experience' is commonly one-sidedly interpreted. In my paper, I clarify in what way the idea of 'lived experience' should be revisited and, subsequently, what this reconsideration means for phenomenological research on embodiment in health and medicine. The insight that the body is a condition of possibility for world-disclosing yet, at the same time, itself conditioned by this world forces us to not only zoom in on the body's subject-side, but also on its object-side. I argue that in order to render account for this double body ontology, phenomenology should include empirical sociological analyses as well. I thus argue in favor of the idea of a socio-phenomenology. Drawing on material from my own research project on embodied self-experiences after breast surgery, I show how this approach can be fruitful in interpreting the impact of disfigurements on a person's embodied agency, or a person's 'I can'.

Keywords Phenomenology of the body · Body as subject · Body as object · 'I can' · Disfigurements

Introduction

It is nearly common place that 'the body' is not a unequivocal phenomenon in medical practices. Different medical specialists and professionals, who each focus on specific parts or aspects of a patient's body, consider it in different ways, resulting in different attitudes towards a patient's body. A surgeon evidently needs a more instrumental view than a nurse or counselor, and a pathologist needs a more objectifying view than a rehabilitation specialist. What all these different professional attitudes have in common, however, is that they involve an external view on the body. Although patients can consider their own bodies also from an external perspective, it has been often claimed that their 'lived experience' of their sick or impaired body constitutes a rather different view, since 'lived experience'—so it is argued— involves an internal perspective on embodiment. To facilitate patient-centered treatment and care, it would be desirable to pay more attention to this latter aspect of embodiment in medical practices.

Proponents of a less objectifying and instrumental view typically endorse a phenomenological approach to medicine and nursing (Zaner 1981; Toombs 1992; Leder 1992b; Aho and Aho 2009; Carel 2011, 2012). From a phenomenological perspective, it has been argued, for instance, that an objectifying and instrumental view reduces the body to a spatial object ignoring its temporal dimension (Toombs 1990); that it neglects the patient's lived experiences of her or his body (Leder 1992a; Van Manen 1998); that it ignores the experience of 'being ill' (Carel 2008); and that it disregards somatic symptoms for which no clear physical causes can be identified (Bullington 2013).

In this paper, I will, by and large, join this phenomenological movement in health and medicine, yet, at the same time, I will slightly depart from its conventional line of

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attack. Instead of underscoring the difference (or opposition) between the patient's perspective and the physician's perspective on the body, I will solely concentrate on the patient's perspective, and will analyze what kind of embodied self-experiences appear from this perspective. Drawing on both phenomenological theories and a specific clinical case, I will argue that the mainstream idea of 'lived embodiment' needs adjustment, and further classification.

Instead of being an end in itself, phenomenology's focus on experience, its investigation of the 'first person's perspective' (Zahavi 2005), is a means to exploring how things appear, how subjectivity discloses the world (Gallagher and Zahavi 2012, p. 26). Therefore, lived embodiment does not simply involve subjective and individual experiences of one's body; rather it conditions the meaning of a shared world. In addition to this commonly endorsed idea in phenomenology, I will go one step further and argue that the first person's perspective is itself constituted and conditioned by the world it discloses. This means that the first person's perspective on embodied experience cannot be isolated from an external view on one's body. We therefore must not only delve into the way one's body is lived or experienced 'from within', but should simultaneously look at how it manifests itself in a world that is shared with others; how it appears 'from the outside' for other people as well as for oneself. In the field of health and medicine this is highly relevant, since most illnesses and disabilities go together with some sort of appearance-related issues, or with changes in one's perceptible manifestation in the world.

The main aim of this paper is thus to demonstrate that a phenomenology of the body can account for more dimensions of embodiment than has been acknowledged hitherto. To this end I will first discuss the relevance of phenomenology for health and medicine, both on the level of theory-development and empirical research. Then, I will make a short philosophical detour, returning to some basic phenomenological ideas, to explain that, if rigorously pursued, phenomenology brings about a double perspective on the body. Subsequently, I will draw on a case of disfiguring breast cancer to discuss the various dimensions of embodiment that emerge from such a complex perspective. Finally, I will conclude this paper by providing an initial sketch for what I call a socio-phenomenology of the body, that is, an approach to embodiment that can account for both a first person's perspective and an external perspective on one's body.¹

¹ The external view on the body is often identified with a third person's perspective on one's body (which in the field of health and medicine has become a synonym for a physician's instrumental and objectifying view). However, an external view on one's body could also imply a second person's perspective on one's body, which, indeed, implies a far less instrumental attitude. This further classification of the notion of external view goes beyond the scope of this paper. I tackle this subject in another paper.

Phenomenology in contemporary medicine

Phenomenology and phenomenological oriented approaches are nowadays widely embraced within the field of health and medicine, both theoretically and empirically. Leder (1992a) who criticizes current medicine from a phenomenological point of view, claims that medicine's body-ontology entails, in fact, the 'dead' body, the corpse. Questions about bodily ailments are not answered by the one who suffers from this ailment but are questioned by a thorough analysis of the body (by means of all kinds of imaging technologies), and are very often confirmed by a pathologist who researches body tissues, outside the living body, under a microscope. A phenomenological view on the body, by contrast, can make clear in what sense an illness affects a person's embodied being in the world. Svenaeus (2011), for instance, argues that illness may change one's entire being in the world from homelike being in un-homelike being. What phenomenology in a general way discloses is that even in cases where symptoms can be easily traced back to localizable anatomical defects, illnesses and disabilities should not simply be reduced to physically localizable bodily problems. It reveals that physical illnesses, pain, discomforts, disabilities or chronic conditions often erode a person's perception of the world, and his or her possibilities to act within this world.² Phenomenologists of medicine thus stress that illnesses and disabilities frustrate one's bodily intentionality, that is, one's possibility to endow meaning to one's life and world (Toombs 1988, 2001; Leder 1992a; Van Manen 1998).

Another thing that phenomenologists have emphasized is that illnesses and disabilities also involve a possible disturbance of one's sense of self. The reason for this is that certain experiences of one's own body may imply a form of 'self-alienation'. In most of our daily activities, we are not really aware of our own body; we do not explicitly feel it. It is like a taken for granted condition for all our actions. Sartre (1943) eloquently describes how his virtually unnoticed body, during the reading of a book, progressively turns into an object of his consciousness because of an increasing pain of his eyes (p. 355–60). Since Sartre defines human existence as freedom and having possibilities, he considers the change from being unnoticed ("passed by in silence", p. 354) to becoming the object of consciousness as a process of self-alienation. If I can no longer experience my body as a condition for having possibilities, but rather as an object, it no longer appears as

² Although the phenomenological approach is mostly used to provide insight in physical orders, it should be noted that the phenomenological conception of 'embodied being in the world' is also gaining ascendancy in the interpretation of mental disorders. See for this notably the work of Fuchs (2005, 2007), De Haan and Fuchs (2010), and Ratcliffe (2008, 2009).

my own (*pour soi*), but appears to me in the mode of being for another (*pour autrui*), so Sartre argues.

Along the same lines, Leder (1990) has underscored that pain causes an ‘alien presence’ of the body (p. 76), and more generally that experiences of physical pain, disease and discomfort constitute a rather negative appearance—*dys*-appearance—of the body, alluding to both the Greek prefix ‘*dys*’ which signifies ‘bad’, ‘hard’ or ‘ill’ (p. 84), and the Latin prefix ‘*dis*’ which signifies ‘away’, ‘apart’ or ‘asunder’ (p. 87). Others who have taken up Leder’s analysis underline that *dys*-appearance corresponds to experiences of one’s body as unfamiliar or alienated (Zeiler 2010; Groven et al. 2013; Kitzmüller et al. 2013).

Leaving here aside the question whether the term ‘*dys*-appearance’ or ‘alienation’ is always adequate to describe how people experience their sick or disabled body, a phenomenological approach to the body reveals that one can experience one’s own body in (radical) different ways, which means that it can appear according to different modes, and subsequently, that it can have different meanings.³ Indeed, a painful body which is in the foreground of one’s experience and awareness is *not* the same (thing) as the (same person’s) body when it is not explicitly noticed, or when it gives cause to enjoyable experiences despite persisting pain. Perceiving one’s own body in the mirror involves another experience than touching it. And, the experience of one’s body as strong and able appeals to yet another dimension of embodiment than the awareness of a disfiguring scar on one’s physically well-functioning body.

Phenomenology as guide and method in empirical studies on embodiment

Turning the attention to lived embodied experiences, phenomenologists thus lay bare how an illness or impairment may affect a person’s subjectivity, agency and sense of self. Because it takes the patient’s view, his or her first person’s perspective, as point of departure, phenomenology

³ As I see it, experiences of pain or of discomfort not necessarily result in experiences of self-alienation. In some situations pain can also lead to experiences of self-confirmation. Cole (2004), for instance, describes how people suffering from tetraplegia due to spinal cord injury, and who most of the time cannot feel their own body anymore, can be ‘anchored’ in their body through pain. Pain “is almost my friend” one of his interviewees said, because “it puts me in touch with my body” (p. 89). Conversely, I would not reserve the experience of alienation to negative or pathological experiences such as pain and discomfort only. From a phenomenological point of view, one could also argue that any experience of one’s own body from an external perspective involves self-objectification and thus alienation. In that sense I agree with Ingerslev (2013) who discusses external explicit body experience in terms of ‘self-distance’, and shows that this phenomenon accounts for both pathological and non-pathological bodily self-experiences.

has been cordially embraced by health and nursing studies that seek to develop a more humanistic approach to care (Carel 2012). Moreover, it does not simply consider the patient as pivot of care—which could easily result in consumer-driven care—but starts from the position of the patient in his or her context or life world (Dahlberg et al. 2009).

Because of its sensibility for the way patients experience their illness, phenomenology has been developed as a research method in its own right (Van Manen 1990; Moustakas 1994), which is increasingly used in the field of health, illness, and quality of life research. This growing interest, I think, could be partly understood as a response to the rise of ‘evidence based’ medicine and practice. For indeed, ‘evidence based’ knowledge production requires quantitative data collection and analysis, also in the case of subjectively experienced issues, including quality of life evaluation and appreciation of one’s bodily experiences. Examples of this include a huge range of ‘quality of life’ scales to quantitatively measure people’s daily functioning and their appreciation of their functioning, and more specifically so-called ‘body image’ scales to evaluate people’s satisfaction or dissatisfaction with appearance related issues in cases of eating disorders, obesity (Cash and Szymanski 1995), but also after disfigurements (Rumsey and Harcourt 2004), and disfiguring cancers (Hopwood et al. 2001).

Evidently these quantitative tools are very useful to collect data of large samples and hence to provide generalizable outcomes. Inherent to their claim of internal validity, however, these kinds of measurement tools can only handle univocal information about one’s body, and therefore they cannot account for the different ways in which one and the same body can be experienced. Also, a questionnaire always consists of a number of items, each of them asking for a specific aspect of a person’s body experience at a specific moment in time. In that way body experience is inquired while decontextualizing it: it is divorced from its temporal, social and spatial dimension. Qualitative empirical studies can obviate these drawbacks of quantitative studies and as such they can complement them. It is therefore not surprising that researchers in nursing studies are supposed to master both quantitative and qualitative methodology (Polit and Beck 2008).

Phenomenology has thus become a much used method approach within qualitative research in nursing studies (Finlay 2011), and in health and medical psychology alike (Smith et al. 2009). Most important research tool in the phenomenological approach is (multiple) in-depth interviewing. These interviews aim at revealing patients’ lived experience of their illness or condition. If we look over empirical studies based upon a phenomenological approach we will quickly notice that most of them, even if they

contain references to some basic concepts of phenomenology, do not have any philosophical pretension. Some philosophers, therefore, say that these kinds of studies should not be considered as genuinely phenomenological, since phenomenology epitomizes a certain way of doing philosophy. Earle (2010) therefore suggests to sharply distinguish between phenomenology as a philosophical movement and phenomenology as a research method. I certainly agree with the view that studies that do not (critically) reflect on used concepts could not be seen as philosophical. Yet, on the other hand, I would not simply disregard empirical studies as if their findings would be of no use to a philosophically phenomenological approach of embodiment in medical practices.

Martínková and Parry (2011) claim that empirical studies should not be considered as phenomenological exactly since these studies are *empirical* and thus lacking the transcendental shift or reduction which is central to phenomenology. Also here I agree only partly. It is true that the transcendental stance is crucial for phenomenology but, as I will discuss in the next section of this paper, if we look closely at what happens in the shift towards the transcendental, we will see that the transcendental always remains attached to the empirical. This ultimately means that a phenomenology that reveals transcendental structures of embodiment should also account for the actual worldly, mundane (i.e. non-transcendental) context in which these structures are themselves framed and conditioned. A phenomenology of the body should therefore not turn its back on (empirical) analyses of the social world.

Phenomenology of the body as a result of returning ‘to the things themselves’

As is well-known, one of the main premises of phenomenology is that it aims at a ‘return to the things themselves’ (Husserl 1900–1901). And this turn, instigated by a fundamental critique of positivistic and naturalistic approaches in the human sciences, should be achieved while breaking old and fixed thinking habits, breaking away from our ‘natural thinking-attitude’. The natural attitude has to be replaced by the phenomenological one, which requires to bracket off this belief in the existence of reality as such, and to put stop our thinking-direction towards this presumed reality. Instead of looking outside to a world to be discovered and analyzed by our faculties, we should look at things that appear to us—leaving aside the question whether these things really exist—and ask ourselves what their *meaning (Sinn)* is for us, and how this meaning has come into being. This direction in thinking is transcendental in the sense that it searches for the conditions of possibility for perception and understanding of the appearing world.

According to Husserl, the transcendental reduction reveals intentional consciousness as the irreducible condition of possibility for perception and understanding. Following the logic of transcendental, stemming from the Kantian tradition, this transcendental consciousness is not empirical and hence does not appear itself.

However, in later work Husserl (1952) explains that perception requires another condition, i.e. a transcendental ‘organ of perception’. For this he uses the German term *Leib*—which is commonly translated as ‘lived body’ or as ‘Body’. In this paper, however, I will hold on to the German term, since it is more appropriate to indicate that it differs radically from the body as a physical thing or object (*Körper*). The *Leib* is conditioning the possibility of perception since it provides a zero-point for movement and orientation, an embodied ‘here’ from which all one’s actions set off. As such *Leib* does not express one’s “I think” but as Husserl says one’s “I can” Most interesting aspect of this analysis is that the *Leib* as zero-point is not a pure or absolute zero-point that is always already given. It is itself constituted through experience. *Leib* appears or is experienced through localized, and non-intentional sensations such as they are provided by the sense of touch, proprioception, kinesthetic sensations, pain sensations, warmth and cold sensations, and constitute an experience localized in one’s body, in the sense organs. This is in contrast with other sensations that are not sensed in or on the sense organ. For instance, if I perceive a color, the color sensations are not located in my eye.

The constitution of *Leib*, or the way *Leib* appears differs clearly from the appearance of our own body as an object or *Körper*. If one perceives one’s body as an object it appears within a certain horizon and with certain adumbrations (*Abschattungen*). As such it appears as extended thing in space, and is comparable to other spatial things. *Leib*, by contrast, is not extended in space. Therefore, *Leib* involves a very peculiar way of being embodied. It is almost incorporeal since it does not entail the extended body as thing, as object. It is a ‘non-thing’ (Waldenfels 1989). Yet, it is not totally disembodied since it involves the constitution of a here and now anchored in one’s body through localized sensations.

Phenomenological literature has given much attention to the body in terms of *Leib*. It is indeed the *Leib*-experience that seems to appeal directly to the notion of ‘*erleben*’ and thus to ‘lived experience’; it is the *Leib* that Merleau-Ponty calls ‘lived body’ (*corps vécu*). The German concept *Erlebnis* indeed refers to the subjective, lived dimension of the process of experiencing. This aspect of experience, however, is not restricted to non-intentional experiences, i.e. experiences that have no intentional object (such as pain). This means that the experience of one’s own body as *Körper* (or intentional thing) also involves an *Erlebnis*. It is

thus misleading to reserve the term ‘lived experience’ to the *Leib* experience only.

Husserl’s description of *Leib* in terms of a zero-point can be seen as a first move towards a philosophy of embodied subjectivity. Most famously is Merleau-Ponty’s study on the body in his *Phenomenology of Perception* (1945). According to him the ‘I can’ expresses the body as subject, as germ of activity and agency. The world does not appear to us because we think, but because we perceptually orientate ourselves in the world. On a primordial level it is our moving, sensing and adept body that discloses the world: “The body is our general medium for having a world” (Merleau-Ponty 1945, p. 146).

Although Merleau-Ponty’s philosophy of the body certainly ties in with a kind of transcendental philosophy he explicitly does not talk about something like a transcendental world, but only about a transcendental *field*. For indeed, the subject that opens up this field is not a universal impartial beholder—it is an embodied, incarnated subject that is situated somewhere, and as such this field is related to a certain given position, in time and space. So what we see in Merleau-Ponty’s idea of transcendental philosophy is that the tendency towards revealing transcendental conditions is immediately ruptured. As he writes in his preface to phenomenology of perception: “Phenomenology is a transcendental philosophy which brackets the assertions arising out of the natural attitude, (...) but it is also a philosophy for which the world is always already there, before reflection begins...” (vii). And in the same vein he writes that “The most important lesson which the reduction teaches us is the impossibility of a complete reduction” (Merleau-Ponty 1945: 14). This means that phenomenology needs to break with the natural attitude to gain insight into what conditions the appearance of the world, yet at the same time it can never totally free itself from this natural attitude.

For a phenomenology of the body it is crucial to respond to this paradoxical call since the body itself forms an intersection between the transcendental and the mundane. On the one hand it is condition of possibility for perception because it is being directed toward the world, yet on the other; it remains part of this world. Merleau-Ponty describes our bodily being as ‘being in the world’ (*être au monde*). Whereas the French saying expresses this ambiguity pertinently, it has been lost in the English translation. For indeed, the French preposition *à* has various meanings, including relations of direction, position, destination, possession or belonging to. ‘*Je suis au monde*’ thus means that while being part of it, I am orientated and directed to my world. This double bind implies a kind of circular conditioning or foundation: the body conditions world-disclosure, whereas the disclosed world conditions the body.

This philosophical detour through the labyrinth of transcendental structures pertaining to the body enables us

to broaden mainstream phenomenology’s conception of the ‘lived body’. If we take into account the circular conditioning between body and world, we should not only look at how the body as subject discloses the world. We also have to look at how this embodied subject framed and conditioned by this very world. In Merleau-Ponty’s phenomenology, the double bind between embodied subject and world is understood in very general terms of a reciprocal relation, in which the world functions as a taken for granted background for intentional embodied actions, i.e. the world invites me to move and act in a certain way. I believe however that the way in which “the world” conditions subjectivity and agency should be directly related to the social meaning of the body, which is given with the fact that the body is not just a *Leib*, but also, and equally primordial, a *Körper*. To understand how the world, as a world shared with others, conditions embodied subjectivity, we need to take into account the body’s ‘object-side’ as well; its ‘outside’. For it is only at its outside that it is susceptible to the world it shares with others.

The ‘I can’ and the body’s perceptibility

The question for what it means that one’s body as condition of possibility is *visible, perceptible* for others and thus can be looked at, can be very important for understanding impairments and disabilities. This question is even more urgent in the case of disfigurements, because they primarily affect a person’s visible appearance. It would thus be interesting to examine in what sense an undesired change of one’s body’s outside can affect one’s bodily intentionality, one’s ‘I can’.

Up to now, phenomenology of health and medicine has not paid much attention to *disfigurements*. It has mainly focused on the meaning of *disabilities*. This is not surprising since the theory on bodily intentionality that is mostly used in health and medicine is the one that it is developed by Merleau-Ponty (1945), and which is exclusively built upon a case of disturbed motility and sensory perceptions (due to specific brain damage)—the case Schneider. Merleau-Ponty very much stresses how Schneider’s bodily ‘I can’ is impaired because of the decline of certain types of movement. He does not further discuss how Schneider’s visibly deviant appearance possibly adds to his (illness) experience. In a sense, he considers Schneider’s agency—his ‘I can’—separately from its social context. To examine how visible differences such as disfigurements may affect a person’s subjectivity and consequently this person’s ‘transcendental field’ we need to examine the interdependency between ‘I can’ and social context.

This relation between embodied agency and social context has been explicitly addressed in some phenomenological analyses on race and gender. Needless to say, the

(social) meaning attributed to perceptible aspects of race and gender cannot simply be compared to the meaning of disfigurements. I nevertheless believe that it is expedient to look briefly at these studies since they reveal how physical perceptibility affects one's embodied agency. In his classical text on his own experience of being black (*noir*) in a white society Fanon (1952) already alludes to the idea how skin color can affect one's 'I can': "In the white world, the man of color (*l'homme de couleur*) encounters difficulties in the development of his bodily schema" (p. 89). More recently, Ahmed (2007) has argued that although skin color, unmistakably, has nothing to do with biological physical capacities, it certainly determines the way one orientates oneself in the world, whereby this world is always colored—mostly 'white'—in a taken for granted way. In that sense, 'whiteness' does constitute one's 'I can'.⁴ In a similar vein, norms pertaining to either feminine or masculine behavior or movement can have a decisive impact on a person's 'I can'. Young (1990), for instance, argues that the typicality of 'feminine movement' can be explained in terms of different embodied competences and self-experience in women. These are formed against prevailing social and cultural norms. Girls who are raised in a sexist society which discourages them from employing their body in the same open and expressive way as boys, may develop an 'inhibited intentionality'; a basic embodied attitude of 'I cannot' despite their physically able bodies.

Fanon's and Ahmed's phenomenological analyses of race describe how one's embodied orientation in one's life world can be disrupted if one's external bodily manifestation 'deviates' from the taken for granted norm, i.e. 'whiteness'. Young's analysis of gendered embodiment makes clear that adopting to (and internalizing) dominant gender norms can have a literally inhibiting effect on motor capacities. In both cases, we clearly see that one's 'I can' is not simply based upon individual physical agency; one's 'I can' is indeed framed within a social context. Inhibition or enforcement of one's 'I can' is produced by social differences which, in their turn, are produced by one's body's visible manifestation. Let us now unravel how this interdependent relation between social context and 'I can' (or 'I cannot') is at stake in disfigurements.

Disfigurement: 'I can' and 'I cannot'

To show how a disfigurement can change a person's agency, I will present here a case of disfiguring cancer, and will draw from two interviews I have administered with Janet (a fictional name for one of my respondents) in the

⁴ I would like to thank Nicholas Smith for drawing my attention to this text by Ahmed.

course of my present research project.⁵ Janet (62), a well-educated, single woman, mother of an adult son, has had a mastectomy of her left breast and wears an external breast prosthesis. She nearly always wears this device, even if she is home alone. She tells me that she in fact uses the prosthesis for two reasons; she does not want others to see her as a single-breasted woman, and she does not want to be reminded of her loss. She really dislikes it if she is not wearing her bra with the device in it, because then she literally feels the empty space at her chest. If naked or not wearing her prosthesis she feels being confronted with her loss. The prosthesis thus literally restores the empty space and could therefore provide some comfort. However, after my question on feeling and being comfortable with the prosthesis, she added "[I feel comfortable] but I still find that women who dare to go out without it, just like that—I find these women very powerful. This is something I would like to do myself, but I am not sure whether I can do it"

So, on the one hand, the prosthesis facilitates her being in the world as a social being and thus empowers her 'I can', yet on the other it confronts her with her inability ('I cannot') to actively resist prevailing social norms. She admires women who challenge the norm for feminine embodiment ('being two-breasted') but, unlike activists such as Lorde (1980), she simply feels that she cannot do this. After having purchased her silicone prosthesis she was "happy like a child", she said, "it fills the void, literally and figuratively".

On another level, Janet, in spite of herself, did display a kind of activism. She was rather angry and offended about the way breast prosthetics is put in practice in the Netherlands. All women who have undergone a breast amputation receive (before hospital discharge) a temporary device consisting of a soft batting-filled pat which can be used instantly. After a couple of weeks, if the wound is well scarred over, this temporary device can be replaced by a silicone prosthesis that needs to be purchased in a specialized lingerie shop. Janet told me that she found this very strange: "Don't you think it is ridiculous that you have to shop for your breast prosthesis? If you need an artificial leg you won't go shopping but you will be referred to a specialist in the hospital", and she repeated this complain a couple of times: "It [breast prosthetics] should be taken out of the commercial circuit". She added that the local hospital should make accommodation available for breast prosthetics, and that she would even volunteer herself to run such a service.

⁵ In this project I have 'followed' 19 women who have undergone breast surgery for a period of 8–10 months by means of multiple interviews. The main question in this research is how women habituate to disfigurements and (if applicable) to the usage of a concealing prosthesis.

Her criticism on the procedure of purchasing breast prosthesis points to some typical presuppositions concerning the female breast. The breast, so it seems, is considered more like a universal symbol for femininity than a part of an individual's self-experienced body. In that sense, breasts seem to be interchangeable; indeed, nearly all breast prostheses are ready-to-wear mass produced devices. Only in very rare cases breast prostheses are tailor-made. This indeed contrasts sharply with the manufacturing of limb prostheses that are always tailor-made, and that are made fit by a medical professional, instead of a commercial shop assistant.

The most important thing about a limb prosthesis, in seemingly contrast with a breast prosthesis, is that it facilitates one's motor intentionality—this is most successful if the device can be incorporated in one's body scheme, and this in fact means that one forgets about the device while wearing it. This functional aspect is often not taken into account in breast prosthetics. This might seem logical since the breast is not a moving, acting body part like an arm or leg. Yet one can imagine that a certain degree of forgetfulness of the breast prosthesis also facilitates one's scope of action. Indeed if the prosthesis remains in the foreground of one's experience, if one constantly feels it, one will be hindered in being engaged in other activities.

Like one's own breasts a prosthesis should thus not be experienced as an obstacle, or perhaps it is even better if it is not experienced at all. This is of course only possible if the prosthesis fits well (and not only looks good). A breast prosthesis should not only support a woman's 'I can' in the sense of being able to face the normalizing gazes of others; it should also enable her to forget about her body all together. Janet told me that most of the time the prosthesis is satisfactory in the sense that it does not bother her, and that she can forget about it. But sometimes it is not. She recalls that at a certain point when she was busy cleaning her house, only wearing a singlet because it was hot, and she was leaning down to reach for her cleaning cloth in the bucket, her prosthesis did not remain attached to her body. These are moments at which the prosthesis does not satisfy, it then loses its meaning of supporting one's embodied capacities, one's 'I can'. If the prosthesis slides off the body it reinforces the feeling of being incomplete.

Janet's daily encounters with her prosthesis involve various dimensions of 'I can' and 'I cannot'. Usage of the prosthesis reinforces her 'I can' in three different ways: she can go out acting 'normally'; she does not have to put up with prevailing norms and, if fitted well, the prosthesis feels like her own breast, transferring her loss in the background of forgetfulness. But her daily dealings also appeal to experiences of 'I cannot': she is not able to ignore prevailing norms on feminine embodiment how much she

would like that; and her daily doings can suddenly be interrupted if the device does not stick correctly. In Janet's case it is very clear that her lived experiences of agency are framed within and conditioned by her social context. Her agency and subjectivity, i.e. her possibility to act within the world, to go out and see other people is dependent of the usage of a prosthesis, and thus dependent of how others perceive her, and thus of an external view on her body, her body as object. Conversely, the degree to which the prosthesis is able to fix her body as an object is dependent of the degree to which it is not explicitly noticed and thus to the degree to which it does not disturb her daily dealings and actions.

Another thing that we can learn from this analysis is that Janet's lived experience of her disfigured body involves different relations to her own body. She feels her body 'from within', for instance, when she literally feels a void when not wearing her prosthesis, and reaching with her arm along her chest. This experience of asymmetry thus implies a lived experience from within yet, at the same time, it also has to do with how it looks 'from the outside'. Her experience of being complete or not is also constituted by the fact that she herself also adopts an external, perhaps even objectifying or instrumental, view on her own body. This, I think, illustrates very well that phenomenology should not concentrate exclusively on the non-objectifying experience of one's body (*Leib*) to the detriment of experiences of one's own body as a thing, an object (*Körper*).

Towards a socio-phenomenology of the body

I believe that a phenomenology of the body that proceeds from the body's double ontology can enlarge the perspective for treatment and therapy. In the practice of disfigurement treatment and care there is a strong focus on the individual. Whereas physicians consider disfigurements as a physical problem for the person in question, psychologists tend to understand the difficulties that people have to face due to disfigurement, and the possibility to overcome them, as something that is predominantly related to this very person's capacities. As a result of a sole focus on the 'deviated' individual, medical assistance is directed towards the issue of how to restore or camouflage this visible difference (through reconstructive surgery or cosmetic prosthetics), or the issue of how to support the individual in coping with his or her difference (through counseling and therapy).

Janet's wish to fill up and to conceal the void on her chest seems to affirm this focus on fixing 'deviating' individuals. In my analysis of her case, however, I have interpreted Janet's change in agency against the background of her social context, and thus have attempted to

put individuality in perspective of the social. In that sense, my approach is partly motivated by theorists, mainly in disability studies, who have disputed the strong and sole focus on the individual by medical professionals, also known as the ‘medical model’. Some even claim, thus embracing a strong ‘social model’ that it is rather society than a person’s individual body that is producing disability (Oliver 1990).

Comparable to the meaning of disabilities we can argue that the meaning of disfigurements cannot simply be reduced to an individual’s physical problem, but is related to social context. Especially since we are dealing with disfiguring breast cancer here, it may be very tempting to apply a ‘social model’. In particular feminist-oriented studies have shown how norms pertaining to feminine embodiment influence the management of the female body’s disfigurement (e.g. Lorde 1980; Crompvoets 2012; Shannon 2012).

I certainly believe that it is very important to make explicit what prevailing (gender) norms are, and to analyze how, on the basis of these norms, female bodies are treated in society and medicine alike. Yet, I think that we should go one step further and should also explore what individual women do or don’t, what they can or cannot while being entangled in a network of social norms on (feminine) embodiment. Since the ‘social model’ tends to disregard embodied agency and experience, I do not think that it is a good alternative for the ‘medical model’. In that sense I totally agree with Moser (2009) and Scully (2008) who have made clear that the social model in disability studies has silenced completely lived experience; it has in fact set the scene from which the lived body has utterly vanished. In line with their request to reclaiming the body in disability studies by means of phenomenology, I also suggest that a phenomenology of the body can bridge the gap between the individual’s agency and experience, and societal norms including medical ones.

As I have shown in this paper, the so-called ‘lived body’ involves experiences of one’s body both as subject (*Leib*) and as object (*Körper*). For that reason phenomenology in the field of health and medicine should abandon its unilateral criticism on the ‘body as object ontology’. The kind of phenomenology I propose here has nonetheless critical aspirations. Medical professionals’ instrumental view on the body can be problematic, not because it involves a ‘body as object’ ontology, but rather because professionals often consider this bodily object as an individual entity, separated from a social context. To ensure that phenomenologists do not forget about the body’s object-side, its outside and hence its social embedding, I would like to suggest here a broadening of phenomenology into a socio-phenomenology. As I see it, a socio-phenomenology of the body involves an analysis of embodiment both on the level

of the individual and on the level of this individual’s social group. It is thus a phenomenology that is engaged in (medical) sociology.

A socio-phenomenological approach also makes evident at once what the difference between phenomenology and psychology is or, at least, it can ward off an always imminent methodological jeopardy. Empirical phenomenological studies easily fall prey to becoming psychological, which means that they erroneously result into accounts on inner feelings and experiences. If it is clear, however, that phenomenology involves an exploration of ‘*contextualized* lived experience’ and not of experiences *tout court*, research interviewers are explicitly encouraged to put the emphasis on an exploration of what people do and what the context of this ‘doing’ is. They should thus *not* literally ask respondents for their experiences or, at any rate, they should not start with questions of experience, such as ‘how do you feel about your body?’, ‘how do you experience it?’ Rather they should pose questions about actions, situations, habits, and events: ‘what happened?’, ‘what did you do?’, ‘how did that go?’, ‘who else was involved, and in what way?’, ‘in what kind of situation do you feel confronted with your disfigurement?’, ‘are there moments at which you forget about your disfigurement?’. I thus suggest that in order to explore the various dimensions of the ‘lived body’, phenomenology should carry out another, yet gentle, shift in thinking-attitude and research-attitude, and should explore more intensively the ‘doing of the body’ instead of the ‘experiencing of the body’.⁶

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⁶ In that sense my approach to embodiment is close to the way Mol (2002) analyzes the multiplicity of body ontologies while concentrating on the question how a ‘disease is done’, how a ‘body is done’ in various practices. However, there remains a considerable difference between her ethnographical approach to embodiment and my socio-phenomenological one. Whereas she holds the view that a ‘practice’ is something local, and not generalizable, I believe that a phenomenological exploration of embodiment can identify generalizable forms of embodied self-experiences. This difference amounts to the fact that my philosophy of the body still adheres to the request of bracketing the natural attitude, the call for the reduction, even though a complete reduction or bracketing is never possible.

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