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TOWARD A PHENOMENOLOGY OF DISFIGUREMENT

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> Recovering from facial injuries is, in the end, about how well you can communicate with the rest of humanity, in spite of your tarnished face.
>
> —James Partridge, *Changing Faces*

Introduction

Bracketing fixed beliefs and naturalized views, phenomenology aims at an unprejudiced analysis of individuals' lived experience. A phenomenology of disfigurement will thus concentrate on the way disfigured people experience their bodies. Another basic assumption of phenomenology, however, is that one needs the other (the others' gaze) to become fully conscious of one's embodied self. It is only because of one's "being for the other" (*pour autrui*) that one can be "for oneself" (*pour soi*).[1] Hence, from a phenomenological perspective, embodied self-experience and embodied agency is at once an *individual* and a *social* affair. This double view on embodiment, as we will argue, is constructive to gain both theoretical and practical insight into the meaning of disfigurement.

Our current research project, in which we explore the meaning of bodily integrity in cases of disfiguring cancer, aims to make this phenomenological approach productive in medical practices.[2] Indeed, we believe that this approach may support medical professionals in

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attaining a suitable and desirable attitude toward people with disfigurement. In this chapter, we will present some of our preliminary findings as well as the theoretical program that underlies and directs our research. Here, we will discuss only facial disfigurement, since this type of disfigurement, which is hard to conceal, almost always immediately affects social interaction. This focus will thus allow us to address the social as well as the individual, lived, aspects of disfigured embodiment.

Taking into account the privative meaning of the prefix *dis*-, disfigurement literally means that one's "figure" or "form" has fallen apart, that it has become formless. Hence its exclusively negative connotations: defacement, deformity, blemish, deficiency, defect—the negation of bodily wholeness and beauty. However, regardless of the obviousness of its anatomical markers, the (negative) meaning endowed to disfigured bodies cannot simply be derived from anatomical differences or deficiencies as such. As Nick Crossley (2001, 152; emphasis added) aptly argues: "Differences and deficiencies are not intrinsic properties of bodies [. . .] they are inevitably *social constructions.*"

In social (and historical) studies of science, as well as in (medical) sociology of the body and feminist philosophy, it has become virtually commonplace to think of the body in terms of "social construction." Although the usage of this term is rather disparate (Hacking 2001), generically, it refers to the idea that bodies (and their deviances) have no intrinsic (universal) meaning. Social constructivism can thus be seen as a way out of naturalistic essentialism: for its general claim is that biologically (and phenotypically) varying bodies (male, female, young, old, healthy, sick, disabled, disfigured, black, white, etc.) are not simply naturally occurring. Instead, bodily variance is ordered along social and cultural axes valorizing some qualities and rejecting others.

Although naturalistic essentialism has thus been criticized fiercely in theoretical debates, it still resonates in the dominant medical-biological view on embodiment in medical practices that endorse the medical-biological view according to which disfigured bodies are reduced to individualistic entities that deviate from biological norms and subsequently aims at restoring biological intactness. Social constructivist approaches, by contrast, consider the impact and value of bodily difference against the background of prevailing social and cultural norms, thus underlining that disfigurement is more a social than an individual issue.

Despite the fact that we sympathize with the idea that the body's meaning and value should not be understood as something naturally occurring, we believe that "social constructivism" is not the most adequate answer to medical-biological reductionism in health and medicine. In its emphasis on the powerful force of social and cultural classifications, relations, and categorizations, social constructivism loses sight of the lived nature of both suffering and enjoyment: physical pain, distress, and discomfort or, conversely, pleasure, the corporeal confidence and delight derived from physical capacities, comfort, and so forth. Thus, rather than offering a sound alternative, social constructivist approaches to embodiment seem to share the same ontological premises that underlie the mainstream medical-biological view. According to phenomenological vocabulary, both presuppose the idea of the body as a thing that appears; that is, an "intentional object."[3] They both neglect the fact that the body is not only given in its capacity to be sensed but also as a "sensing thing."

As we will argue here, the meaning of disfigurement is not only about the appearance of the disfigured body as an exposed thing or image to oneself and to others but also about how one's disfigurement is lived through and how it may, or may not, inhibit one's bodily intentionality. To clarify and justify this double view on embodiment in disfigurement, we will present four sections in this chapter. First, we will briefly discuss the gains and the limits of social constructivist approaches to embodiment. In the second section, we will, on the basis of the example of disfigured war veterans, discuss how a focus on social norms and relations can explain the positive social value attributed to some physical scars and blemishes, but, at the same time, still fails to address the body's double ontology. In the third section we will present phenomenology as an approach that amends this hiatus. In the last section, we will explore the meaning of this double body ontology in practice by discussing the story of "Leah," a facially disfigured woman wearing a facial prosthesis.[4]

Embodiment as Social Construction: Liberating and Unsettling

As is well known, "the body" has gained enormous theoretical interest in the last two decades both in the humanities and in the social sciences. In the humanities, most prominent examples are to be found

in (medical) history and feminist philosophy. In the social sciences, a genuine "sociology of the body" has developed since the 1990s (Featherstone, Hepworth, and Turner 1991; Turner 1992, 1996; Shilling 1993; Crossley 2001; Williams 2003). Within science studies, more and more attention is paid to the way embodiment is "produced" and "manufactured" in scientific and medical practices (Hirschauer 1991; Mol 2002; Latour 2004). Typical for this interest in the body, generally speaking, is the focus on its social, cultural, and historical meaning. As this focus implies that the body's specific meaning is mainly considered in relation to others, we call it the social approach to embodiment.

To grasp the theoretical meaning and scope of this social approach to the body, we will start with a short exposition of how it was developed in feminist studies. One of the first and most famous statements about the female body's social meaning is probably Simone de Beauvoir's (1949) claim: *on ne naît pas femme, on le devient* ("one is not born but becomes a woman"). Since Beauvoir, the distinction between (biological) *sex* and (sociocultural) *gender* has become generally accepted. Accordingly, the project aiming to free women from the presumed biological fact of their womanhood has placed much emphasis on the sociality of gender (Witz 2000). The distinction between sex and gender has made it very clear that being a woman is not (only) a biological fact and that social inequalities between men and women cannot be justified on the basis of biological, anatomical features. Nevertheless, this distinction is not an uncomplicated one.

Judith Butler, for instance, argues in *Bodies That Matter (*1993) that the sex-gender distinction still presupposes a certain biological substrate on top of which gender pops up as a social construct. In her view, the idea of social construction is not useful since it suggests that "sex" is something biological that precedes construction; as such it becomes a sort of prelinguistic fantasy to which we have no access (1993, 12). Butler, therefore, rejects the idea of social constructivism and replaces it by the concept of materialization. A body is a "body that matters," that is, a body that is socially meaningful and comprehensible (as opposed to being socially abject) if it is materialized through a certain discursive practice. Inspired by Austin's idea of performativity in language and Foucault's theory on discursive power and normalization, she claims that there is no matter independent of or prior to language or to discourse in general. Sex is always already gendered (Butler 1993). Butler thus suggests that biology and

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biological knowledge are produced by discourses on the body. This implies that not only gender-related differentiation (such as preferred division of roles) but also "hard," "factual" biological and anatomical differences between the sexes are only intelligible against the background of social and cultural norms.[5]

Although Butler criticizes the idea of social construction and replaces it with the idea of materialization, we believe that she implicitly still endorses social constructivism at least in her early work.[6] She indeed reduces sexual markers (and the body) to a passive surface to be inscribed by social signifiers only, thus reducing materiality to signs and considering anything meaningful in our world as the outcome of social and discursive processes. Indeed, from a Butlerian perspective, the social and cultural meanings of bodies are inseparable from their material, physical manifestations. In the next section we will explore how this view on embodiment can explain the valorization of some forms of facial disfigurement.

The Social Value of Disfigurements

A visual disfigurement is a social marker. It can only be valued as a difference in relation to normal others. Indeed, a disfigured person only recognizes her own disfigurement while seeing herself through the eyes of others, while comparing herself to these others. But why are some differences valued in a negative way and some in a positive way? This question, obviously, requires a social approach.

A clear analysis of the body such as it is exposed to others—and how this exposure yields social meaning—is provided by Michel Foucault's early work. According to Foucault (1979) the body's social value is the result of normalizing power; people discipline their bodies to "normalize" them. Submitted to a constant watchful eye, whether actually present or not, modern people live in a *panopticon*—which literally means everywhere (*pan*) visible (*opticon*)—by means of which they are constantly aware of their own visible bodies and, subsequently, constantly measure and manage their visible bodies against prevailing standards and norms. According to this view, a certain physical marker can have both a positive and a negative meaning dependent on the specific situation. In a society that respects old age, an old body will be positively valued. In a society that, by contrast, adores youth, an old body becomes a "nonnormative" body.

The question is now whether this also holds for disfigurement. Is it possible to read the physical marker of disfigurement in a positive way? This question is pertinent, since, as mentioned in the introduction, disfigurement has a thoroughly privative and thus a negative meaning. From time immemorial, disfigured people have been frequently stigmatized and thus excluded from social groups. However, not all physical blemishes function as excluding social stigmas (Goffman 1963). A disfigurement or scar might even have a positive social value; a form of "cultural capital" perhaps.[7]

A telling example of this is the representation of the so-called Guinea Pig Club in the United Kingdom. This club consists (consisted) of former RAF aircrew members who survived severe burn injuries during World War II. These men did not have to hide their damaged faces since they were signs of bravery; their faces expressed the honor of having served their country. In addition, these men also served medical sciences; they were real guinea pigs for the plastic surgeon Archibald McIndoe, who, at that time (rather successfully) experimented with new kinds of medical technologies (Mayhew 2004). Although his treatment could not wipe out the horrible traces of burns, he did give these men a socially faceable face. Pictures of these men show disfigured but happy and almost smiling faces.[8] One could therefore argue that the exposition of these faces to the gazes of others did not result in a social devaluation. In the context of the social value attributed to heroism, bravery, and patriotism, their marked appearance could be read as socially valuable.

Such a reading of facial disfigurement can be rather *liberating*, since it frees the person with disfigurements from the idea of being a deviant, abnormal individual, and thus from stigmatization. Yet it might be *unsettling* as well: if one interprets the meaning of one's appearance solely against the background of social norms and discourses, one fails to recognize possible personal tragedies against the background of individual and shared stories. The British Guinea Pigs may have found comfort in the positive social meaning of their disfigurements. But if their bodies are really reduced to signifiers of "bravery" and "patriotism" then these men are deprived of the possibility to express how they actually experience their being facially disfigured. Facial disfigurement, indeed, involves often more than a social valuation of visible defects. As we will discuss in the last section of this chapter, disfigurements habitually go together with a variety of disturbances in sensory perception and motor capacities. These

disturbances may indeed result in a modification of one's embodied intentionality and habits.

If we frame social constructivists approaches, such as they are advocated by Foucault and Butler, in ontological terms, we can say that they, on the one hand, *liberate* the body from its being an individual, biological, and genetic entity, but on the other hand, they are *unsettling* since they share the same Cartesian ontological premises that haunted biologically essentialist accounts of the body. While biology understands the body as an object in the sense of Descartes' *res extensa* or machine, social constructivism reduces the body to a malleable thing at the mercy of certain social practices, relations, and discourses. Focusing on its visibility and its malleability, social constructivism, indeed, still endorses a Cartesian view on the body (Hacking 2007), thereby ignoring the body's own intentionality—its experienced subjectivity and agency.

Since it fails to recognize the reality of bodily experiences and embodied self-experiences, we believe that a social constructivist view on disfigurement does not offer an adequate reply to the medical-biological view on the body prevailing in current medical practices. In order to do justice to individuals' lived (embodied) experiences as they take form against the background of their lifeworld, we need to shift to a phenomenological account of embodiment.

Embodied Self-Experience: An Individual and a Social Affair

In this section, we will clarify how the perception and experience of one's own body always takes place within a social field and simultaneously opens up such a field, while referring to some ideas of Maurice Merleau-Ponty. Although Merleau-Ponty is well known (and praised) for the idea of the lived body (*corps vécu*)—thus criticizing the Cartesian view on embodiment—we should not forget that, for him, this lived body always remains attached to its "object-side." In other words: the lived body is not just a perceiving subject, it is also a perceived object among other objects in the world. This double view on the body is most clearly articulated in Merleau-Ponty's later work, in which he replaced the notion of lived body by a double-sided "subject": a seer who is seen (*voyant-vu*) or a sensing subject who is sensed (*sentant-senti*) (Merleau-Ponty 1993; Merleau-Ponty 1968).

As the body appears to oneself, it is an intentional object. It is a *noema* that correlates with a certain intentional act or a *noese*. At first glance, we can stick to an uncomplicated phenomenological model to describe self-appearance. For, indeed, one's own body can explicitly appear as an object to which certain qualities can be attributed; one can observe, for instance, the color and texture of one's own feet while cutting one's nails. Yet, the fact that one's self-observation goes together with an explicit sense of ownership reveals that the body is not simply an intentional object. While perceiving my own body I may think "this is my body." However, the actual *experience* that this is my body involves more than an observational content. The experiential affirmation that this perceived body is *mine* is provided by nonintentional localized sensations, or "sensings." Examples include touch sensations, pain sensations, proprioception, and kinesthetic sensations. Instead of constituting an intentional object, they constitute the body as a "sensing thing."

One's own body can thus appear in two different modes: either as a thing or intentional object or as a localized lived-through experience of oneself. This double-sided experience can be explained along the lines of the Husserlian distinction between *Leib* (body as mine, based upon nonintentional sensations) and *Körper* (body as intentional object). We must stress here, however, that the phenomenological distinction in two modes of appearances does not imply a separation between two forms of embodiment. As argued elsewhere in more detail, the experience of *Leib* both presupposes and affirms the experience of *Körper* (Slatman 2005, 2008).

In his early work, Merleau-Ponty (1962) argues that the body as lived (*corps vécu* or *Leib*) forms the zero point of intentionality. As such it does not appear to oneself in the same way as everything around us appears to us but conditions that very appearance. The body as intentional object, by contrast, appears within the horizon such as it is constituted by the lived body as zero point. The double-sidedness of body appearance can thus also be explained in terms of distance: whereas the lived body is an experience of "here," the body as object appears "there" (Slatman 2009).

It is on the basis of this difference in "distance" to oneself that the social dimension within embodied self-experience comes to the fore. In the sense that my body appears as an object—for instance, in the mirror—it appears "there" and does not totally coincide with my "here" and therefore is not fully owned. As Merleau-Ponty writes: the

moment I recognize my own mirror image, "I am no longer what I felt myself, immediately to be [. . .]. I am torn from myself, and the image in the mirror prepares me for another still more serious alienation, which will be the alienation by others" (Merleau-Ponty 1951, 136). It is because of one's outside, one's physical appearance, that one is delivered to (the gazes of) others, and is a social being. This phenomenological view on embodiment thus teaches us that the experience of one's own body, according to the two interdependent modes of *Leib* and *Körper*, always already involves a social dimension. Moreover, it teaches us that the social body, that is, the body as intentional object with a readable surface, is always interlaced with the body as a lived-through zero point of intentionality.

Phenomenology of Disfigurement in Practice

In order to address the double-body ontology that is at stake in facial disfigurement, we will now discuss the case of "Leah." Leah's face was severely disfigured during the treatment of cancer, which consisted in extensive radiotherapy and the amputation of the affected area (her entire nose, parts of her palate, and parts of her upper jaw). After a period of recovery, she received a silicone facial prosthesis that hides and protects her now-exposed nasal cavity. Leah's story not only illustrates the body's double-sided ontology, but also reveals that it is by no means a given, static condition. Leah does not endure her disfigurement passively: coping with her condition means that she develops various ways of "doing" her body anew—ways that operate both on her body as image and on her body as lived through the condition of appearance.

At first sight, Leah's story underlines the major role physical appearance plays in interaction with others. Very often she has to face people in the street or in shops staring at her, commenting on her unusual appearance ("what happened to you, girl?"), giggling, and pointing. Also, some of her own friends recurrently ask to see her face without the prosthesis despite her explicit refusal. These examples underline how Leah's disfigured face appears primarily as an object of the others' gaze—an object that is labeled as strange, different, fascinating, or repulsive and receives a discursive, symbolic meaning in relation to valorized, opposing terms such as "acceptable," "normal," "common," or "attractive."

Next to these more obvious, social aspects of her disfigurement, however, Leah is also confronted with loss of and damage to several bodily functions. These changes, accessible only to Leah herself, affect both her perception of the world and of her own body. One example is her altered sense of smell. Since her treatment, there is a distinct lag in Leah's perception of scents, and sometimes she does not notice odors at all. As a result she can no longer pursue her profession: nurses must to be able to smell patients, drugs, and other scents. Radiation has also affected the functioning of Leah's tear ducts, which no longer drain her eye fluids effectively. Consequently, Leah's eyesight has become blurred, which sometimes causes her to lose her balance.

But Leah also deals with other bodily changes, changes that affect her perception of world and body and that cannot simply be labeled as "loss of function." One example is the fact that Leah can no longer expose her face to the warm water while taking a shower, as she used to do. This would result in her drowning in the water entering her unprotected windpipe. In order to cope with this very real danger, Leah has developed a new way of showering. The removal of parts of her upper jaw dictates yet other adjustments. Due to the fact that the sensitive roots of her teeth are no longer enclosed within tissue, Leah can only go outdoors when the temperature is about twelve degrees Celsius. Colder weather causes pain comparable to root-canal treatment, and the cold air entering her nasal cavity unwarmed and unfiltered often gives rise to acute colds. In a similar manner, Leah can no longer take big bites of food. This is simply too painful; it causes a sensation similar to breaking her front teeth.

Another issue in coping with her disfigurement is Leah's daily concerns and dealings with her prosthesis and bandage, which affect both the public and private aspects of disfigurement. A silicone "nose," for instance, is not very flexible: it does not budge when kissing someone, which is rather unpleasant for the person being kissed. This is why Leah prefers to hug her loved ones instead of kissing them. Also, the prosthesis can be quite uncomfortable: it sometimes feels quite "tight" and pressing, and the adhesive gluing it to her face irritates the much-abused skin around the cavity. At home Leah thus prefers to wear a bandage. Going out, however, she always wears the prosthesis. The bandage (she calls it her "emergency triangle") does not only generate more attention than a prosthesis, but it can also be easily blown away by the wind and gets wet in the rain. This is not to say that she has full confidence in the prosthesis remaining fixed. Leah

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avoids crowds for fear of having her prosthesis knocked off. She no longer goes to her favorite department store, for example.

The bodily changes caused by the radiotherapy and amputation have not only left Leah with a different exterior and numerous impairments and handicaps, however. It has also changed the way in which the world appears to her. A delayed perception of smells and diminished sight mean that Leah registers her world in an altered way: as odorless, vague, and less stable. The appearance and meaning of her world have also changed in a more subtle way, however. Eating and walking outside on a winter day have become potentially painful experiences. Showering can be lethal. As a result, sandwiches, errands, and showerheads now call for a cautious, calculating approach and cannot be handled thoughtlessly. The activities of eating, walking outside, and showering have all become cumbersome affairs. Since her amputation, Leah's world and body have become much more fragile: her world now appears as threatening and disruptive, her body as a site of pain, irritation, and hindrance. Leah's former, taken-for-granted confidence in approaching her everyday projects—projects in which world and body coincide—has thus turned into a careful, attentive attitude.

A similar point can be made with regard to Leah's relationship to her now exposed nasal cavity, her prosthesis, and the bandage. Getting rid of mucus now involves manually cleaning her nasal cavity in front of the mirror. And both the prosthesis and the bandage call for an extensive regime of caring and minding: they must be cleaned, prepared, glued to the face, and adjusted to circumstances (a windy day, for instance). Whether she wears her prosthesis or bandage or neither, Leah's altered face now appears as an object of care, calling for a careful and calculating approach. These particular regimes, based upon an explicit attentive attitude toward her own body, are not only geared toward fending off potential pain and discomfort, but also toward meeting the others' gaze. The adjustments to her body, of course, also involve changes in Leah's relationships with others (eating and shopping are often social affairs governed by strict standards regulating one's conduct and appearance). But, in this case, the caring and minding are much more obviously done not only for the sake of comfort and hygiene but also in order to present the world with an adequate, acceptable exterior.

Leah's facial disfigurement and subsequent usage of prosthesis and bandage has thus resulted in considerable changes in the way she is

directed and geared toward her world, and the way she engages in her everyday projects. Some activities she undertakes in much the same way as before; other pursuits call for different doings. We could therefore say that Leah's bodily changes call for new ways of "doing" her body, in the sense that her embodied intentionality, her being engaged in projects—or her "I can" (Merleau-Ponty 1945)—goes together with the development of a host of new, embodied habits: habits that pertain to her body as image seen by others as well as to her lived body.

Intentionality and habit are constituted and inscribed in one's body, yet, at the same time, they are conditioned by the social order. This has been aptly described by Iris Marion Young in her analysis of feminine movement. Young (1990) 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 that 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. The way girls (and boys) move and how they use their bodies is not simply the result of following social norms and rules. With reference to the work of Pierre Bourdieu (2000), we could call this (social) practice a *habitus*: a set of habits that are literally incorporated, that is, habits that are physically produced (in gestures, movement, expression, manners, etc.) and become part of one's body scheme. With this, they form a person's (prereflective) stance in the (social) world. Girls do not only move differently than boys. The environment and its objects appear to them differently: they literally do not inhabit the same world. A *habitus* is thus formed by given social structures but, at the same time, is inscribed throughout an individual's body and subsequently bodily experience.

The inhibitions Leah experiences originate both in the physical limitations she deals with and in incorporated, normalizing (and sometimes sexist) standards. These two, however, cannot always be seen apart. Going outside has become problematic not only due to physical constraints such as pain, discomfort, and the possibility of catching a cold: Leah avoids crowds in fear of losing her prosthesis, and favors her prosthesis over a bandage in public because of prevailing cultural ideals regarding normalcy, wholeness, and beauty—ideals that, in our society, have a much larger impact on women than on

men (Grealy 1994; Shannon 2012). Likewise, Leah does not refrain from kissing her granddaughter only in order to avoid physical discomfort to both of them—she also feels very strongly about others seeing her exposed face.

Leah's story thus illustrates how the disfigured body operates not only as a symbolically charged image for the (internalized) gaze of the other but also as an experiencing agent. Both these sides to the disfigured body's ontology matter to disfigured people. Both play a major part in their altered lives. And both, rather than being static, final terms, are in fact starting points that call for new ways of "doing" the body.

Concluding Remarks

Having discussed the case of Leah against the background of a discussion on body ontology, the purpose of this chapter has been a rather theoretical one. One of our aims has been to show how the phenomenological double-sided body ontology can complement the one-sided Cartesian ontology underlying both social constructivist and medical-biological approaches. We believe, however, that this theoretical challenge of the idea of the body as an object—either as a material and readable surface of inscribed norms (social constructivism) or as a biological (and genetic) entity that can be fixed and designed (medical-biologism)—can also have its impact on medical practices. We thus hold the view that the phenomenological approach to embodiment can be applied to and implemented in the actual practice of treatment and care of people with disfigurements.

In addressing the individual, lived side to embodiment, as well as the ways it is "done," a phenomenological approach to disfigurements can help medical professionals—including ENT specialist and surgeons, prosthetic technicians and designers, speech (and swallow) therapists—to adequately adjust treatment, care, and rehabilitation programs to individual patients' ailments and subsequent needs. In their intention to help and support people with a disfigurement, medical professionals are surely guided by the idea of moral imagination or empathy, that is, the possibility of putting oneself in the place of another. Endorsing norms of biological (and social) normalcy, they naturally strive toward healing disfigurements by repairing them as much as possible.

However, moral imagination is limited as a practical guidance (Mackenzie and Scully 2007): Medical professionals, like all other nondisfigured people, cannot simply presume that they know what it means to be disfigured. They may see, for instance, someone without a nose and instantly find that this defect needs to be covered up with the best lifelike prosthesis possible. This response is understandable, but it forecloses the focus on other aspects the person with disfigurement has to deal with. A person with an amputated nose may need a prosthesis to camouflage her open face, but, as Leah's case shows, such a camouflage is only a starting point for regaining one's (social) life after having acquired facial disfigurements. What medical professionals thus can learn from a phenomenological approach is that embodiment is a multilayered phenomenon that calls for multilateral attention and care. We thus suggest that medical practices could be improved if medical professionals could incorporate a wide range of questions about embodied self-experiences in their patient interviews, and if they subsequently could use patients' "body-stories" while counseling them. We hope that our currently ongoing research on facial disfigurements will result in findings that can serve as handles for medical professionals to accurately inform patients about the variety of impacts that a disfigurement can have and about the possible benefits and shortcomings of different prosthetic devices.

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Notes

1. Already in his *Ideas II*, Husserl observed that the body as *Leib* appears as "a remarkably imperfectly constituted thing" (1989, 167) See also Merleau-Ponty's (1962) remark that a cripple or

invalid man only experiences himself as a cripple or invalid "through the eyes of another."

2. Our five-year research project, Bodily Integrity in Blemished Bodies, started in the spring of 2011. In this empirical-philosophical project we examine the meaning of experiences of bodily identity or integrity in disfiguring breast, head, and neck cancer—forms of cancers that, beside the constant fear for relapses, leave manifest traces in the survivors' material bodies. Whereas head and neck disfigurements immediately disturb one's feeling of self-identification from a social perspective, disfigurement of the breast may affect self-identification more from a cultural perspective (Slatman 2012). The entire project comprises four subprojects and is carried out by four researchers. This chapter solely discusses some findings in the subproject on facial disfigurements and facial prostheses.
3. According to phenomenology the intentional object is the correlate of intentional consciousness; it is never fully given but always given in adumbrations (*Abschattungen*). For instance, if we perceive a table, the rear sides of the table are not actually present to our consciousness, but still our "consciousness of" the table also includes its rear sides and as such constitutes the table as an object. As Husserl and Merleau-Ponty have explained, and as we will underline in the third section of this chapter, one's own body can also appear to oneself in a nonintentional way. This nonintentional appearance constitutes the body as a lived body (*Leib* or *corps vécu*).
4. "Leah," a pseudonym, is one of the respondents interviewed by the second author. In the scope of her current research project, she interviewed twenty-four people who wear a facial prosthesis. All respondents were recruited through the department of facial prosthetics of the Dutch national cancer institute, Antoni van Leeuwenhoek hospital in Amsterdam. Ethical clearance for this study was provided by the ethical committee of this hospital (file number NL35486.031.11). In this study we will limit ourselves to the case of Leah and will not yet provide a systematic analysis of all the data we have collected to date.
5. A nice example of how cultural and social norms "produce" biological facts is provided by Thomas Laqueur's (1992) study on sexual embodiment and, more specifically, on female orgasm. On the basis of a meticulous analysis of historical sources (medical

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textbooks, biological textbooks, etc.), he argues that during the eighteenth century a radical turn took place in the biology of sex: from a one-sex model to a two-sex model. This shift in model illustrates that the presumed plain facts of sex, sexual pleasure, and sexual difference are not universal, nor ahistorical, but rather are "contextual" and "situational" (Laqueur 1992, 16).

6. "To return to matter requires that we return to matter as a *sign* which in its redoublings and contradictions enacts an inchoate drama of sexual difference" (Butler 1993, 49; emphasis in the original). In later work, Butler shifts to a less radical position. See for instance her work on narrativity and self-narrating (Butler 2004), which, interestingly, have been positively cited by leading scholars in narrative medicine (Charon and Wyer 2008).
7. Bourdieu considers physical qualities such as fitness, strength, and stamina and aesthetic qualities as a form of cultural capital (Crossley 2001, 107). These qualities are socially valuable since they can be used to produce ends in a certain situation or in a certain social group. The Guinea Pigs' blemishes can be seen as socially valuable since they yield honorable social recognition.
8. The positive meaning attributed to the disfigured faces of the British Guinea Pigs is exceptional, mainly thanks to the extraordinary efforts McIndoe took to treat these wounded soldiers, to encourage them to still wear their military uniform, and to go to public places, as well as to encourage other "normal" people to socially interact with them in a normal way. For this see also the documentary *Guinea Pig Club: The Reconstruction of Burned Airmen in WWII* (2005). We should of course not forget that most disfigured war veterans were not treated in this way and had (and some still have) a difficult time in readjusting to society. Their disfigurements were and are hard to interpret in a positive way (see Van Ells 2001).

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