Visual Embodiments of Bodily Sensations and Their Individual Conditionality

A Visual Phenomenology

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Abstract This paper gives insight into the exploration of perception, visual representation, and mediation of physical symptoms using methods of artistic research. A crucial question is what experiences and languages can serve to re-present the invisible. The cultural and individual context through which perception is first constituted plays an essential role. Bodily sensations are everyday experiences, but become even more explicit through symptoms of illness. Lived experiences are deeply subjective and require a language in order to be conveyed. This investigation is based on self-experienced incidents caused by multiple sclerosis (MS). Many individuals afflicted with MS experience paresthesia due to a signal-transmission disorder in the central nervous system. The symptoms are not perceived as occurring at the actual location of the damaged nerve cells; in addition, there is no external stimulus associated with the sensations. Such sensations include that of socks covering the feet or balls of textile material underneath the feet. This material is perceived as foreign. These illusions seem perfectly real and are irritating. The process of making bodily phenomena visual is preceded by introspection and leads to externalization, these phenomena acquiring, in this process, an additional existence outside the body. The transfer to a sheet of paper can bring relief and help in the process of regaining possession of an alienated body. The drawings are also a means of conveying the invisible to other affected persons, their relatives, and persons in the clinical field. In the process of sensation–perception–representation, a double question arises: What pre-existing images occur during perception and to what extent do the visual representations allow the recipient to begin to comprehend a sensation? Does legibility depend on similarity of experiences and cultural contexts?

Keywords: lived experience – phenomenology – visual embodiment – illness – introspection– externalization

Artistic research approach and context

The artistic exploration of bodily sensations, and the processing of the project,[1] also corresponds to the structure of this text. In addition to the drawings and their accompanying descriptions and reflections, I refer to texts that are an important source for my questions. Most of these texts are from the disciplines of philosophy, medicine, and medical humanities. As a visual artist I do not want to claim to have understood these texts only approximately in their complexity. Rather, this interweaving of different references indicates something of my working approach. If questions arise in the practical artistic work, I try to look at the problem more closely by researching other disciplines. In doing so, new questions are raised—sometimes affirmatively encouraging, but also contradictory and challenging—and I follow them up in the artistic process.

Point of view and use of terms

This text is written from the first-person perspective, since it is about own lived experiences. Writing in the third-person would contradict the methodological artistic approach, which I also understand as a micro-phenomenology. This concept arises from the neurophenomenological program of Francisco Varela (cf. Varela *et al.* 2002) as a study method of lived experiences and was further developed substantially by Claire Petitmengin (Petitmengin *et al.* 2018: 691ff).

In order not to get entangled in complex terminologies, I would like to say in advance that the use of terms "representation"[2] and "visualization" can be misleading, as they can be understood quite differently, also depending on the discipline. Michael Taussig would probably replace how I understand representation with the term "mimesis": "I, however, am taken in by mimesis precisely because, as the sensate skin of the real, it is that moment of knowing which, in steeping itself in its object…" (Taussig 1993: 44). I understand representation as re-presenting in the form of another corporeality through a material existence. The process of drawing responds to a physical sensation and by transferring it to a visual medium it can never correspond; however, it gains a life of its own. The process rather resembles a recording. This depends essentially on the practice of drawing and its materiality. Nevertheless, if there is some kind of correspondence, the drawings may evoke something that is relevant to the lived experience, in its similarity but also difference.

And the term "visualization" is no less complex. Beside visible images, it can also refer to inner—conscious or unconscious—images. Moreover, it is a tricky matter since inner and external images are interdependent. When I use the notion of "visual representations" with respect to my drawings, I understand it as a material embodiment of sensory perception. This is certainly an inadequate simplification and embodiments depend not only on the cultural background of the producer, but also on the context in which the recipient of the drawing interprets and co-forms it. Nonetheless, I would understand the drawings as an articulation of embodied knowledge, which is individually and culturally[3] shaped.

Further, I speak of "disease" when it comes to diagnosis and "illness" when it is about the lived experience of the disease. And I call the experienced symptoms "sensations," even though they cannot be sharply distinguished from "feelings," because as soon as a physical phenomenon appears and becomes a perception, there is already an emotional interpretation involved.

In lived experiences there is no "pure" sensation

To distinguish sensation from perception clearly seems to be a futile endeavor, since they depend inseparably on each other and are intermingled. To assume that first a stimulus triggers a sensation, which subsequently appears mentally processed as perception, does not correspond to lived experiences since at the very moment a sensation appears at least a part of this perceptual processing has already taken place. It is experienced simultaneously, although physiologically there may be a temporal sequence. To leave a trace in memory, the process may be conscious or unconscious and is recalled in the next experience. This is also relevant to the process of introspection and externalization as it relates to memory, interests, and the production of meaning. In *The Primacy of Perception*, Maurice Merleau-Ponty writes about the process of introspection:

"This is an internal perception, the noting of an event with which I coincide. But reflection is not at all the noting of a fact. It is, rather, an attempt to understand. It is not the passive attitude of a subject who watches himself live but rather the active effort of a subject who grasps the meaning of his experience" (Merleau-Ponty 1964 [1946]: 64).

The (un)conspicuous body and alienation

The project of investigating bodily sensations took its departure in the moment when I felt that my body had become another. The reality that we are constantly transforming was irrelevant at that moment. The diagnosis of MS and the accompanying symptoms, also the knowledge that it is not a temporary disease, was drastic. In the relapse that led to the diagnosis, movement limitations were involved as well as incomplete numbness from the soles of the feet to the hips, which later partially remitted. Strange bodily sensations appeared, or rather imposed themselves by their unpleasant or painful character. While some of these resemble everyday incidents, such as the tingling sensation of a hand falling asleep, they are distinguished by their duration and the knowledge that the symptoms may never completely disappear. The body previously taken for granted has become conspicuous, longing for what Drew Leder calls the "ab-

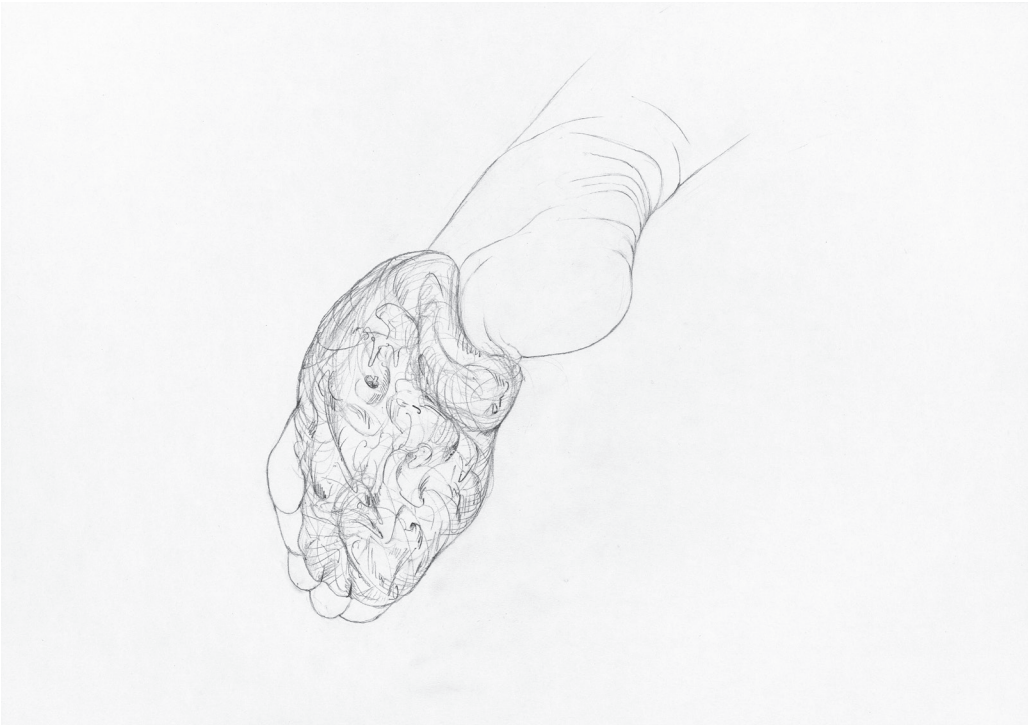

Fig. 1 Barbara Graf, *Drawing 190*, 2017, graphite pencil on paper, 29.7 × 42 cm.

sent body," the body that is always there, through which we perceive, but is not always the subject of perception. He describes the paradox of simultaneous presence and absence in the following way:

"Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at the time of disfunction; we then experience the body as the very *absence* of a desired or ordinary state, and as a force that stands opposed to the self" (Leder 1990: 4). The conspicuousness and presence of the body can become evident in pleasant or ecstatic moments, but also in discomforting experiences and the symptoms of illness. This is explored by Havi Carel in *Phenomenology of Illness* (2016) and underscores the relevance of phenomenology as a resource for patients, healthcare professionals, and different disciplines such as anthropology and the medical humanities, and focuses on experience and perception: "So far I have suggested that phenomenology can be used to describe illness by focusing on first-person accounts of what it is like to suffer from a particular condition. On Merleau-Ponty's view, our experience is first and foremost an embodied experience, an experience of fleshly sensual existence" (ibid. 40).

When strange phenomena suddenly appear as a bodily experience, it means a disruption in sensual existence. For example, due to the nerve disorder, I perceive extra tissue on the sole of my foot (see Fig. 1). I perceive it somehow belongs to me, but at the same time it is a foreign body. This leads to insecurity and the difficulty of understanding one's own body. Carel claims "that we have a tacit sense of bodily certainty that only comes to our attention when it is disrupted and replaced by bodily doubt" (ibid. 5). Alienation in relation to one's own body can be understood in broader terms and not only by the alien sensation of a specific body part. It is not only a disturbed perception of corporeality, rather, it is a disconnectedness. Frederik Svenaeus also uses the term "unhomelikeness":

"One of two *a priori* structures of existence—not being at home and being at home—wins out over the other: unhomelikeness takes control of

our being-in-the-world. The basic alienness of my being-in-the-world, which in health is always in the process of receding into the background, breaks forth in illness to pervade existence" (Svenaeus 2000: 93).

These fundamental questions of human existence come to the fore, especially in special life situations, during drastic experiences such as illness. Further, in *The Hermeneutics of Medicine and the Phenomenology of Health,* Svenaeus refers to Sigmund Freud's concept of the "uncanny" ("*unheimlich*"), which is related to "unhomelike" ("*unheimisch*") (Freud 1970 [1919]: 241ff): "Illness is an uncanny (unhomelike) experience since the otherness of the body then presents itself in an obtrusive, merciless way" (Svenaeus 2000: 111).

The feeling of alienation was strongest in the first period after the diagnosis of the chronic disease; however, this feeling fades into the background when symptoms are less pronounced and other perceptions come to the fore or are partially directed by attention or non-attention. It becomes ordinary that something alien is constantly present, like the sensation of fibrous knots being fused with the soles of the feet (see Fig. 2). Now I ask myself to what extent my drawings influence my current perception of sensations? At the beginning of the project, it was my intention to give a visual language to these weird sensations. As an artist who works with textiles frequently and is well trained in drawing, it is almost obvious that such images emerged, as inner visualizations that I only had to bring to a sheet of paper with a pencil. But now, I doubt, if I perceive the physical phenomena simply as they appear, or in the way as I had recorded them before? Do the drawn physical sensations tell me, so to speak, how I should feel? If this were the case, they could also be partially changed by drawing or assigning them differently and would be more flexible than they seem to be at the moment.

Since I have always approached the body as a subject of artistic exploration, it was almost inevitable I make my own body, in its alteration, the subject of investigation. It was not possible for me to simply continue working as before. Visu-

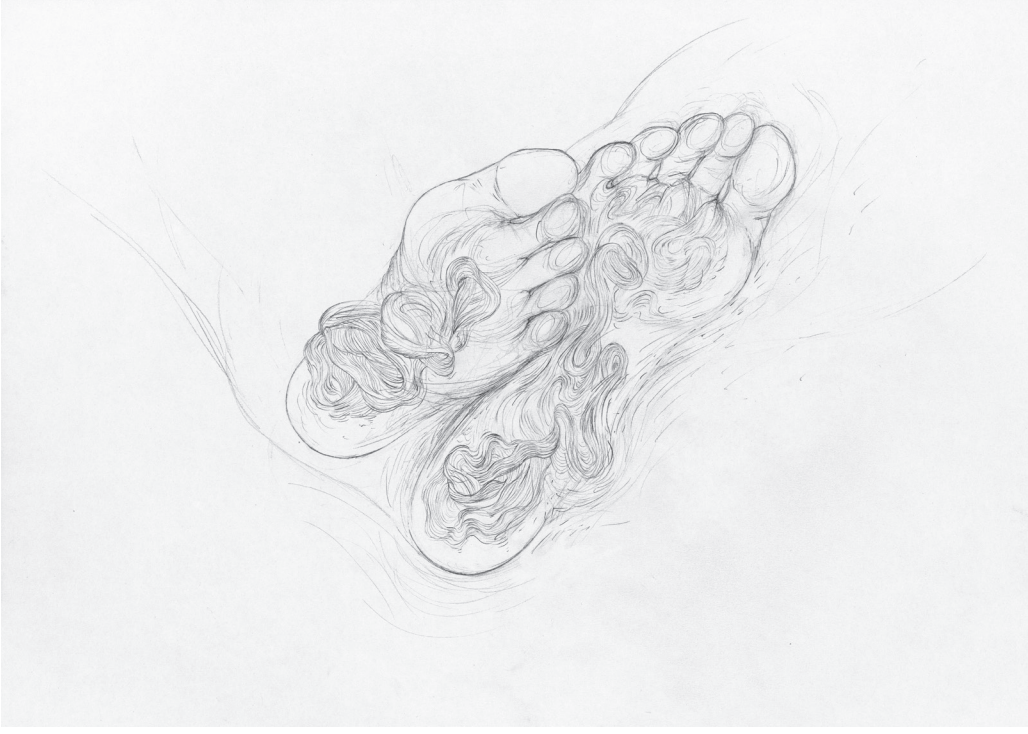

Fig. 2 Barbara Graf, *Drawing 202*, 2019, graphite pencil on paper, 29.7 × 42 cm.

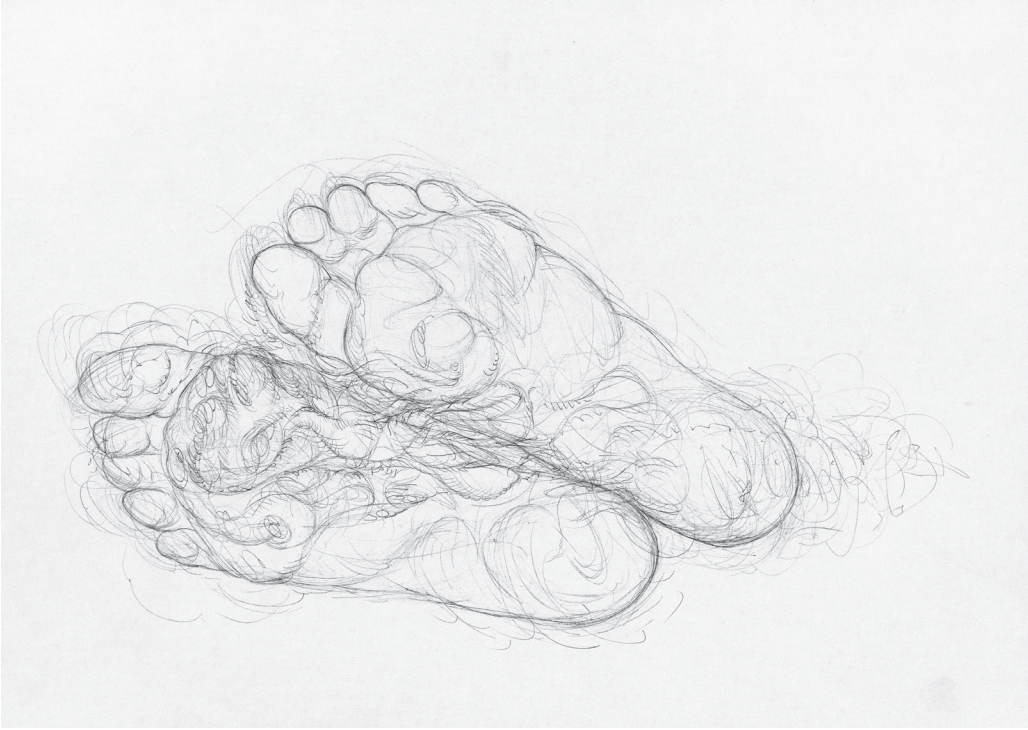

Fig. 3 Barbara Graf, *Drawing 196*, 2018, graphite pencil on paper, 29.7 × 42 cm.

al representations of strange bodily phenomena not only help to investigate the representability of invisible lived experiences, they also engender a coping process, one that leads to accepting, and actively re-appropriating, the alienated body. In relation to the "uncanny" (Freud's "*Das Unheimliche*"), this is a strategy to banish the uncanny, even if it remains, as it were, background noise.

Presence and absence

Numbness is an interesting perceptual phenomenon, as it is more than the absence of bodily sensation. Especially when the numbness is not complete, I ask myself if I am comparing this sensation with the state before the sensory disorder or if a new quality of sensation is present, such as a fibrous addition as a reduction of sensitivity (see Fig. 3). Interestingly, the German term for numbness, "*Taubheitsgefühl*," includes a sensation and not only an absence. The first part of the word "*Taubheit*" ("deafness") refers to another sense, that of hearing, and the second part to "*Gefühl*" ("feeling"): a description of an in-between condition of presence and absence.

The situation is different in the case of a complete loss of sensation, in which the alienation is not only more explicit and radical, but results in a complete disconnection, thus even more irritating when the affected body part is visibly present. In his book *A Leg to Stand On*, Oliver Sacks describes how an accident altered his corporeality. He could no longer move his leg, but above all had no sensations in it and felt alienated because this part of his body no longer belonged to him. What makes his descriptions particularly interesting for narrative medicine is that he was a neurologist and narrates what it means to be a patient, changing positions from neurologist to patient. He writes:

> [T]he leg suddenly assumed an eerie character—or, more precisely, if less evocatively, lost all its character—and became a foreign, inconceivable thing, which I looked at, and touched, without any sense whatever of recognition or relation. It was

> only then that I gazed at it, and felt, I don't know you, you're not part of me, and, further, I don't know this "thing," it's not part of anything. […] I had lost the inner image, or representation, of the leg. There was a disturbance, an obliteration, of its representation in the brain—of this part of the "body-image," as neurologists say (Sacks 2020 [1984]: 84f).

Questions of visual representations: touched by textiles

In my artistic exploration and reflection of physical sensations, perception, and depiction, I am concerned with the following questions that can already be affirmed: If I often have a textile perception of paresthesia, is it because, as a visual artist, I regularly work with textiles and have a textile alphabet at my disposal? Or is the everyday experience of being touched by textiles a reason why images of clothing often appear? Does my drawing experience merge with my sensations, and does it, together with other works of art I have seen, such as Leonardo Da Vinci's drawings of tempests or Raphael's depictions of hair, serve as my repertoire of pictorial possibilities? This exploration also concerns questions that I cannot yet confirm: Can there be legibility when the recipient's cultural context differs significantly from mine? Can an image convey the feeling of wearing socks (see Fig. 4) or gloves (see Fig. 5) to a person who never wears them? What can my drawings of bodily phenomena convey when similar experiences on the part of the recipient cannot be assumed?

Verbal and visual recordings

During my research, I noticed that visual artists and other people living with MS rarely visualize physical symptoms, although some do refer to their illness through art. It is more common in verbal formulations, and emotional uncertainty and anxiety occupy a larger place in literary expressions than a detailed description of physical sensations. For example, in *The Journal of a Disappointed Man,* writer W.N.P. Barbellion describes

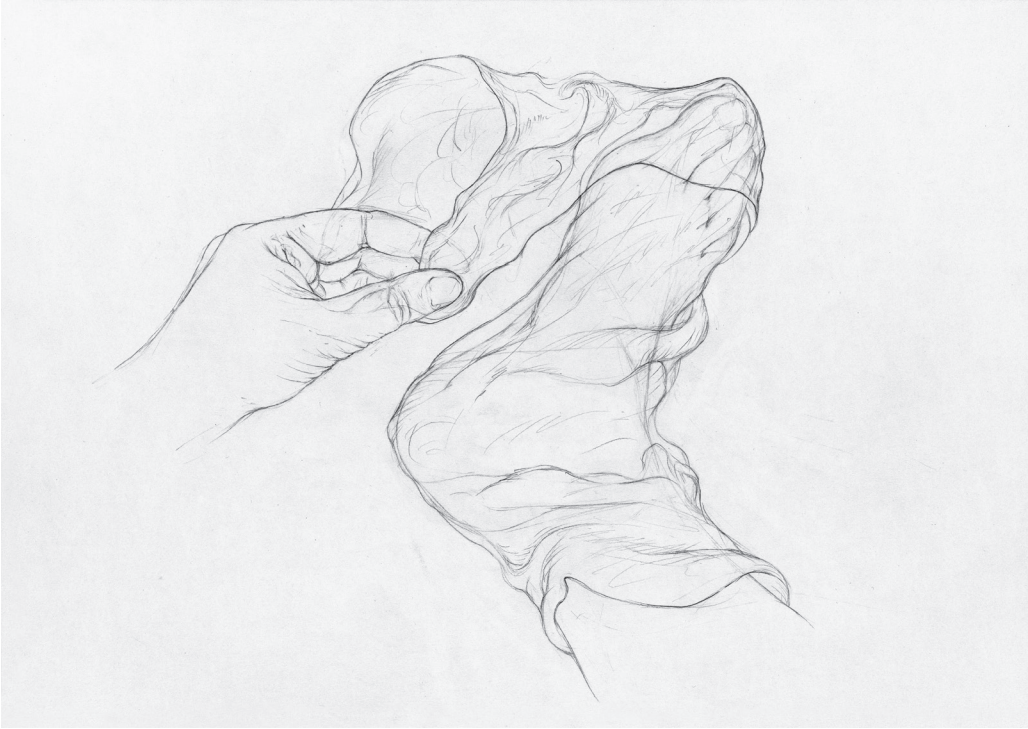

Fig. 4 Barbara Graf, *Drawing 193*, 2018, graphite pencil on paper, 29.7 × 42 cm.

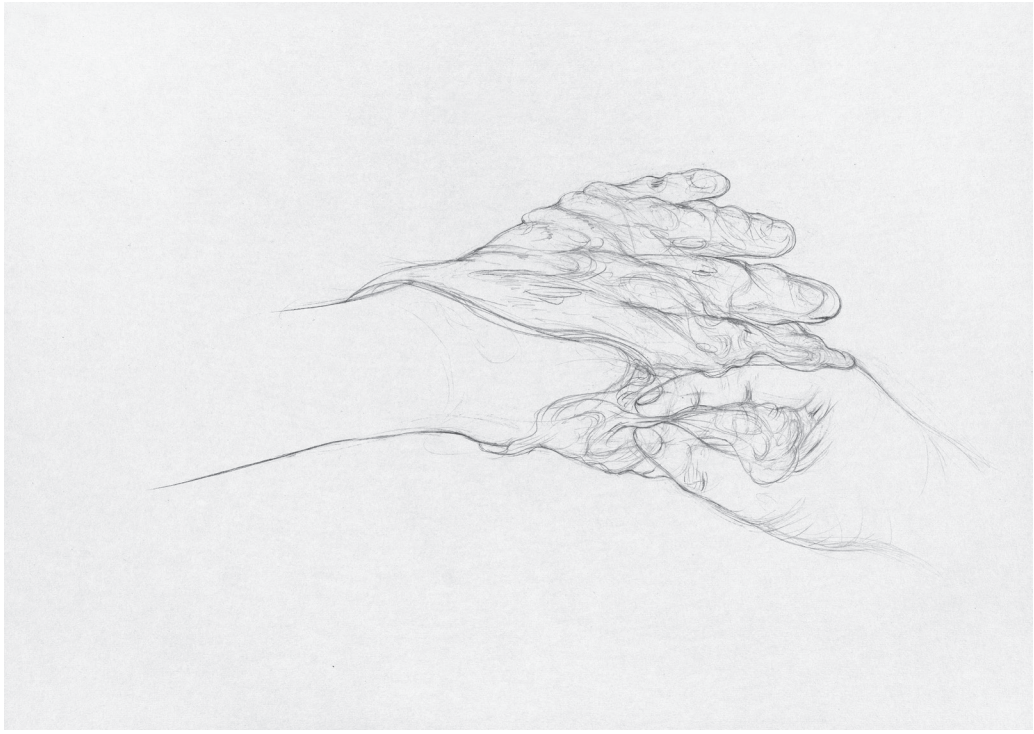

Fig. 5 Barbara Graf, *Drawing 218*, 2019, graphite pencil on paper, 29.7 × 42 cm.

his life struggles, the bodily uncertainty and unclear diagnosis, but also bodily symptoms:

> My nerves are giving way under the strain[.] One leg (the left) drags abominably. […] The numbness in my right hand is getting very trying… […] "I've a tingling in my right hand," I said, "that drives me nearly silly" (Barbellion 2017 [1919]: 251ff).

According to the descriptions of the physical phenomena, he had a progressive form of MS. But the detailed diary tells more about his life circumstances and disappointments and he had left the text passages of the diagnosis blank. Furthermore, the term "MS" did not become established until the 1950s. This chronic disease had previously been named by numerous different descriptions. In *Multiple Sclerosis: The History of a Disease*, T. Jocks Murray writes that in most early names "sclerosis" was part of the terminology (Murray 2005: 7f).

Early symptoms of MS are often sensory disorders: different types of paresthesia, such as numbness, hypersensitivity, sensation of pain, tingling, itching, pins and needles, burning, altered sensation of temperature, feeling of largeness, banding (band-like) (see Fig. 6), tightness, or Lhermitte's sign (electric sensation). Medical professionals name these symptoms based on patients' experiences. But how to think of the phenomena as an experience and what does it actually feel like?

Affected individuals often describe the strange perceived phenomena with narrative comparisons, for instance: socks rolled up under the feet, towel-like sensation over feet and legs, cotton balls underneath the feet or between the toes, extra pads on the soles of the feet, and many other phenomena related to textile materials (see Fig. 7).

MS groups on social media, where affected individuals share their experiences, are a good source of verbal formulations of the phenomena. Normally, when someone posts describing a phenomenon, there are direct responses sharing similar experiences. So far, however, I have not discovered any images of visually recorded symptoms. MS includes many other symptoms than

sensory disorders. And not every person living with MS is affected by them, or not to the same intensity, or may experience other, more severe, symptoms such as limitations or loss of mobility. My project focuses on the depiction of irritating and disturbing sensory disorders. Fibrous layers, that seem to grow together with the feet, can add uncertainty to a step on the ground but do not significantly limit walking (see Fig. 8).

Sensing sensations: being inside/outside

However, when I formulate the phenomena graphically and represent them through a supposed material touching the skin, I am not drawing the sensation itself. Rather, it is the combination of a visually perceived body and a material that can evoke sensed phenomena. Sensing a sensation, I do not feel the body boundaries as they are shown in the drawings as contours, except the body is in touch with an external object. And I do not sense as if looking at my body from the outside. So, I attempted to draw only what I sense. Following the conspicuous sensations with a pencil, the visual representation (see Fig. 9) shows that perception can go beyond the physical and visual boundary of the body, in a fluid transition into the surrounding space. Although I did not focus on the visual appearance of feet, they became visible in the drawing.

This led to going one step further and forgetting about the visual appearance of the body as much as possible. But how can I actively forget what is stored unconsciously? And don't the very effort of forgetting draw attention to the thing to be forgotten? For this attempt it is not very helpful, even a complication, that I have been drawing bodies, as an artist, for many years and able to do it by heart.

In addition, there is an unconscious bodily awareness, what PAUL SCHILDER calls the "body schema" ("*Körperschema*"), which concerns the spatial perception of body parts in relation to each other, formed by sensations from previous impressions (SCHILDER 1923: 2f). He shaped, among others, the concept of the "body schema," but he

Fig. 6 Barbara Graf, Drawing 189, 2017, graphite pencil on paper, 29.7 × 42 cm.

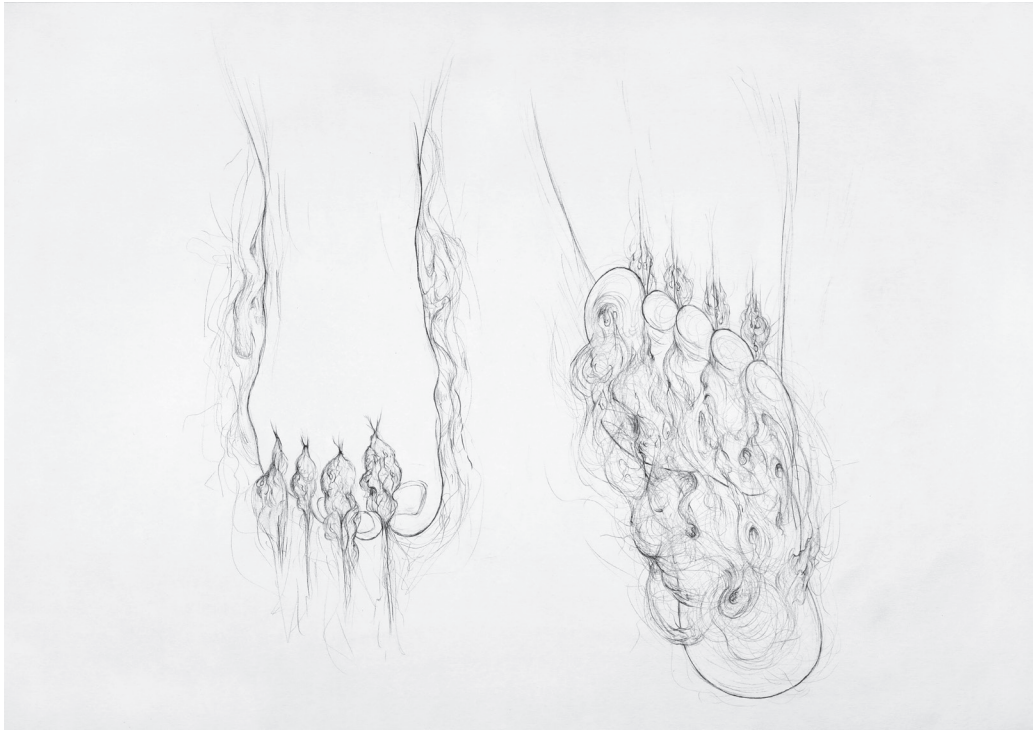

Fig. 7 Barbara Graf, Drawing 250, 2021, graphite pencil on paper, 29.7 × 42 cm.

did not clearly distinguish it from the (inner) "body image." This different use of terminologies, or translations, contributed to an ongoing dispute. The discussion on "body schema" and "body image"—a relevant, or even main, topic of EDMUND HUSSERL (1950), MAURICE MERLEAU-PONTY (2002 [orig. 1945], 1994 [orig. 1946/47]), JEAN-PAUL SARTRE (1985 [orig. 1943), FRANÇOISE DOLTO (1987 [orig. 1984]), JUAN-DAVID NAISO (2011 [orig. 2007]), SHAUN GALLAGHER (2021), and many others—is far too complex to even consider particular aspects in detail here. Nevertheless, I would like to mention them because their concepts support some of the thoughts, questions, and contexts of this artistic research. In addition, HUSSERL, MERLEAU-PONTY, and SARTRE are the main authors referred to by the phenomenology and medical humanities experts quoted in this text.

Quasi-seismographically recording

Back to the drawing, in which I tried to ignore both the proportion of the physical body and its external appearance (see Fig.10). I only record what deviates from ordinary body sensation and draw these deviations in the size and intensity they are sensed—in LEDER's words, everything that goes beyond the "absent body"—however, this poses insoluble problems. Already, the attempt to create a veritable mapping of these striking sensations gives attention to even previously inconspicuous parts of the body. So, I try to record the conspicuities quasi-seismographically, but the "tool" and the subject of the recording are the same. MERLEAU-PONTY points out that the very expression "with senses," already targets the core of the problem. "The sensible is what is apprehended with the senses, but now we know that this 'with' is not merely instrumental, that the sensory apparatus is not a conductor" (MERLEAU-PONTY 2002 [1945]: 11).

It cannot be overlooked that the observing body is identical with the observed, but this is pre-

cisely inevitable in the case of introspection as a practice of lived sensations. This is why I call the procedure "quasi-seismographic." The notion of the seismograph points to an external recording body and "quasi" relativizes the separation of inside and outside.

Another problem is, since a drawing is created over a certain duration, it cannot be a snapshot of sensations at the very moment, and I do not know whether fine sensations become stronger through the recording process itself or change independently in the meantime. And a crucial question is: How decide on a structure that should embody, for example, tingling, stinging, or a tension?

Intuition and unconscious language

Forgetting is nevertheless a relevant strategy, but it can only be a partial fading out of pre-knowledge, since I still need a language that enables the transition from sensation to perception to visual representation. To better describe the process of temporary forgetting, I propose a setting of two brackets that embrace the practical drawing process. Reflection and analysis are outside of these brackets. Doing the pencil lines is characterized by an intuitive process to maintain the flow of drawing at all. Intuition is the basis for accessing past experiences and previous thoughts. They are individually and culturally shaped, and this intuitive approach allows them to appear and embody themselves in the drawings by accessing a kind of alphabet of articulations of lived experience. It is not necessary that they take the path of verbal formulation. This seems paradoxical since it is precisely a certain pre-knowledge that should be forgotten and regulation is needed to exclude at least some of it. Of course, this is a flawed construction because the intention of this setting already influences the intuitive recording and thoughts that occur during the process of drawing, which would actually be intended for outside the bracket. If I concentrate on the movement of the hand and the touch of the pencil on the paper, tracing inner-bodily sensations as if the paper were an alternative body, I can suspend at least some of the

Fig. 8 Barbara Graf, *Drawing 215*, 2019, graphite pencil on paper, 29.7 × 42 cm.

Fig. 9 Barbara Graf, *Drawing 208*, 2019, graphite pencil on paper, 29.7 × 42 cm.

pre-knowledge. When I am outside this bracket, I can think about what has unconsciously arisen and by what my repertoire of structures might be influenced, such as the studies of water, thunderstorms and deluges by Leonardo Da Vinci.[4]

Sensory microscope: quality-intensity scale

In another approach and in order to trace the intensity of sensations I isolate them from the sensed body part. I choose a kind of visual representation like a view through a microscope. Based on the well-known pain scale, I limit the intensity levels to five and focus on the quality and how it transforms as intensity increases (see Fig. 11) (Graf 2021: n.p.).

Pain scales are not entirely without descriptive explanations in order to function as a self-assessment tool. They are usually scaled from 1-10, or 0-10 (0 means no pain). Level 1 is usually described as "mild pain" and the last level as "worst pain possible." Sometimes they include descriptions of how much an intensity limits everyday activity. They are often supplemented by pictograms indicating a facial expression under a certain intensity of pain. Sometimes there are complementary graphs with the localization of a pain. If the intensity levels are color coded, in addition to numbering numbers, it is usually from green to red. If the number 0 is also part of the scale, it is marked with blue or cyan. In any case, the progression is from a cold, calm color to a warm, alarming color.[5] Today's numerous popular pain scales are often highly simplified compared to the historical one from 1970 and focus on intensity. This also aimed at the quantifiability of pain, but contained essential and detailed qualitative descriptions. Known as "The McGill Pain Questionnaire," it was developed by Ronald Melzack, from descriptions of pain experiences, to make them measurable in intensity. One of Melzack's scales is the affective scale consisting of levels 1–5: "nagging, nauseating, agonizing, dreadful, torturing" (Melzack & Warren 1970: 50 ff).

Visual representations that address the quality of pain are rare. *Dolography* is a tool to facilitate

the communication of pain, developed by communication designers Sabine Affolter and Katja Rüfenacht (2018) in close collaboration with different pain experts and patients. It is a set of 34 cards from which patients can choose what corresponds to the quality of their pain. The visual representations are non-objective (non-figurative) and allow an associative approach. Aspects of the pain experience that are not verbalized can be addressed by acting with the cards and making it possible to differentiate qualities of pain.

Different from most of the pain scales, I have chosen five levels for my graphic representation that, however, does not correspond to the aforementioned affective scale of Melzack. My intention is to show how the character of a sensation changes with increasing intensity. The first field shows a very subtle first appearance of a sensation that is so vague that it can be overlooked and is perceived only by giving attention. In the following fields, the peculiarity of the sensation is formed gradually. The fifth level shows a sensation in which the character of the sensation is clearly recognizable and pronounced before it transforms, through over-intensity, into a sensation that can no longer be clearly characterized. They would be characterized by the pain being dominant over the peculiarity or by a dullness that would no longer be characterized by a specific quality.

In the first field, the pencil lines are very fine and barely visible, and develop over various levels into a clear, pronounced formation embodying, for example, a star-shaped, slightly vibrating and burning pain (see Fig. 11). In another drawing, it ranges from minimal disturbances to the perception of fibrous structures to tangle-like agglomerations (see Fig. 12).

What is omitted in these drawings is the dimension that chronic (pain-)sensations, even though they may be less intense than acute symptoms, are annoying. The drawings represent only the possible degrees of specific sensations, leaving out their duration and emotional interpretation—of course, they are not completely free from the emotional, since they are hand drawings.

Fig. 10 Barbara Graf, *Drawing 210*, 2019, graphite pencil on paper, 29.7 × 42 cm.

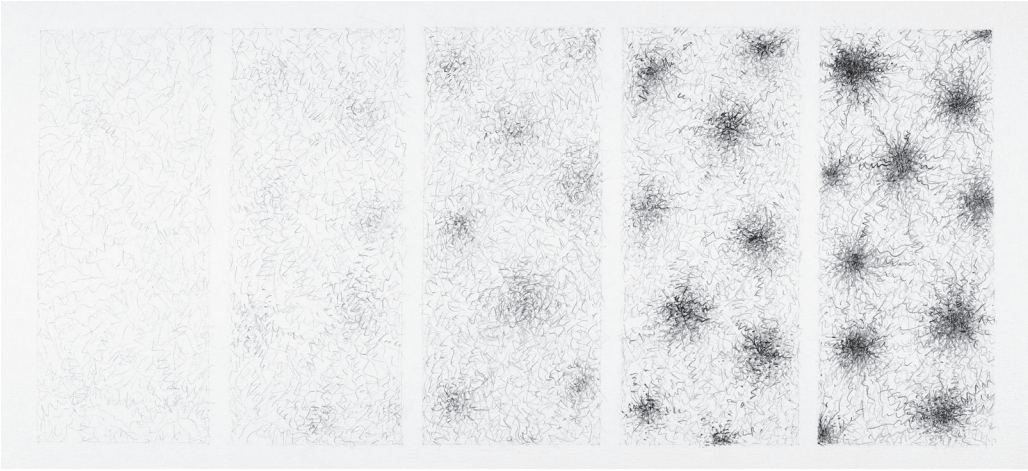

Fig. 11 Barbara Graf, *Drawing 231*, 2020, graphite pencil on paper, 13 × 28 cm.

Previous experience and expectations

In the experience of bodily symptoms, not only are immediate physical sensations decisive, but previous experiences and expectations are involved. S. Kay Tooms examines this in detail in *The Meaning of Illness*:

"This is simply to note that the manner in which illness is apprehended and the suffering which accompanies illness, is integrally related to the whole pattern of a person's life. […] Cultural definitions of illness can also be a source of suffering to the sick person. Such definitions influence the behavior of others toward the person who is ill and the behavior of the sick towards themselves" (Toombs 1992: 43).

The knowledge of a diagnosis also influences the experience of bodily incidents. When a symptom appears or intensifies, I associate it with the diagnosed disease, even though it could also have another reason. The diagnosis can easily become part of the illness as an interpretation of lived experiences. And the anxiety of how the chronic disease could worsen, but has not yet, can disturb the relationship with one's body integrity in the present. In *The Analysis of Sensations*, Ernst Mach emphasizes that traces of the past become effective in the perception of sensations: "Sensational stimuli can be partly or wholly replaced by memory-images. All memory-traces that remain behind in the nervous system co-operate with the sensations to set free, to assist, to inhibit and to modify the reflexes" (Mach 1914 [1903]: 172). Consequently, sensations are flexible in their perceptual meanings and could also be modified or overwritten. Nowadays, neuronal plasticity is used therapeutically for the modulation or transformation of psychical/physical traces, such as pain memory (Sandkühler & Lee, 2013). Similarly, in *Transformative Experience*, L. A. Paul describes the influence of past experiences on present ones and thinks them into the future. From the present, possible futures can be modeled by setting values and making various decisions (Paul 2014: 105ff). In chronic illness, the speculation of possible subjective futures is very crucial, not because we know how it will be, but in order to have an active part in the modelling of future experiences. Even if it seems paradoxical to decide for the future, it is important for the present and future, and PAUL emphasizes the potential of the choice:

"When you consider what might happen in your future, your consideration involves an imaginative reflection on what it will be like, from your point of view, to experience the series of future events that are the mostly likely outcomes of whatever it is that you choose to do" (ibid. 106).

Legibility and reception

Since my research is not based on a quantitative study of the reception of visual representations, but I have nevertheless collected numerous re-

actions, reflections, and responses, I would like to summarize some aspects of the feedback.[6] The drawings could also be read quite differently if there were no information that they embody physical sensations. All the people who responded know the context. The reactions are based on oral and written subjective responses. For most individuals, the drawings evoke the idea of bodily sensations and can empathize well through the visuals. In terms of empathic access with the visual embodiments, no significant differences emerged between individuals who are, or are not, affected by MS. Many of the respondents can draw on similar experiences, such as restless leg syndrome, polyneuropathy, conditions caused by accidents, other diseases, or other temporary everyday experiences. However, almost all of those affected by MS have reacted very emotionally and been relieved to see the symptoms visualized in front of them. They see it as a good way to communicate this strange phenomenon. Individuals from the clinical field see a potential to use visualizations of symptoms as an addition to verbal articulation. Some people find these evocations extremely unpleasant. And few persons, while seeing visual explorations of the body, do not relate them to their own corporeality.

Coping and healing: Instead of a conclusion

Many writers and artists—among them many women—have made records of their experience of illness and the process of dealing with it. In *The Cancer Journals*, Audre Lorde writes about her experience with breast cancer, surgery, pain, and loss, and about the importance of articulation: "Some of what I experienced during that time has helped elucidate for me much of what I feel concerning the transformation of silence into language and action" (Lorde 1997 [1980]: 23). As a format, the book is a combination of diary notes and reflections on them. A life-threatening disease certainly cannot be compared to a chronic disease like MS. In acute severe diseases, it is a question of surviving. In chronic progressive diseases, it is a matter of fear of relevant disabilities in the future. Nevertheless, the ways of articulating experiences and coping may be similar. For example, Lorde also writes about the essential difference between fear and anxiety:

"One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness[7]. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to namelessness, formlessness, voicelessness, and silence" (ibid. 14).

In *Performative Autopathographies,* Tamar Tembeck describes the approaches and articulations of artists who deal artistically with their

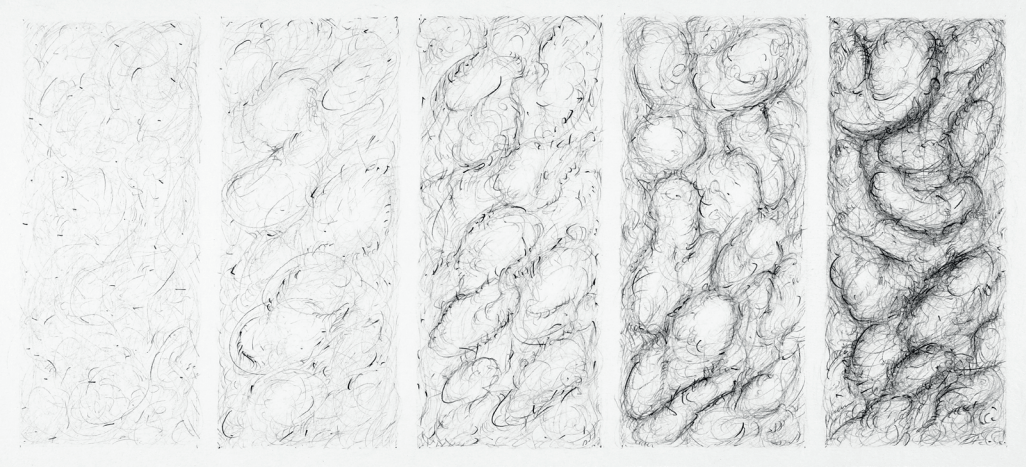

Fig. 12. Barbara Graf, *Drawing 228*, 2020, graphite pencil on paper, 13 × 28 cm.

Fig. 13. Barbara Graf, *Drawing 245*, 2021, graphite pencil on paper, 29.7 × 42 cm.

life-threatening diseases. She refers especially to the performative photographs of Hannah Wilke or the photographic archive of Jo Spence. In different ways, these works embody intimate self-representation through experience and suffering (Tembeck 2009). Acute disease, hospitalization, vulnerability, loss, and the visibly altered body are the subject of artistic explorations of these two artists. In chronic diseases, there are similar strategies of transforming lived experience into aesthetic processes, but in a fundamentally different context, as it is not an exceptional situation to live with the altered body and uncertain progression.

To convey the strange sensations of chronic illness to others and myself, I search for visual formulations. Exploring subjective experiences is challenging because the "tool" of observation is the same as that of the subject of investigation. It reminds me of how Niels Bohr describes the essential position of the tool as an integral component of observation in quantum physics (1963: 3f) as "the interaction between the objects under investigation and our tools of observation, which in ordinary experience can be neglected or taken into account separately, forms in the domain of quantum physics, an inseparable part of the phenomena" (ibid. 18).

In artistic explorations, it is not only the tool in hand or the medium of investigation that is essential, but also and above all, the person who undertakes it, including the individual and cultural conditions. And the involvement of the observer is not a disturbance, but makes the process and actual work possible. This becomes even more explicit in phenomenological research, since lived experience is both subject and tool. Furthermore, artistic processes not only refer to reflected experience, but also have the potential to access pre-reflective, tacit self-consciousness even before conscious introspection starts (Zahavi 2005). The slow process of drawing allows for different accesses at the same time: a kind of self-forgetfulness in doing a pencil line, conscious and unconscious knowing taking place, remembering and reflecting on past experiences, analyzing modes

of representation, and a reflection on the matter that what is visually embodied stands in similarity but also difference to the starting point. Externalization supports coping with a chronic illness and enables to understand the alienated body as one's own again. Taking the experienced fibrous sensations into my own hand (Fig. 13), as self-empowerment, changes the perception and emotional position of what is physically experienced and does a reassessment and emotional reinterpretation of symptoms. It means a process of healing without the disappearance of the disease and enables—in spite of experienced symptoms—one to feel healthy.

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Notes

1 This text is an insight into my artistic research PhD "Stitches and Sutures: Phenomenological Archive of Body Sensations" (2018–2024) at the University of Applied Arts Vienna (https://phaidra.bibliothek.uni-ak.ac.at/view/o:72623).

2 For the fundamental problem of representation and the gap between representation with the entities to be represented, Karen Barad, in her critical reflection on representationalism, introduces performative approaches and proposes terminologies such as "performativity" (Barad 2007).

3 When I speak about cultural and individual conditions, I mean the whole spectrum of socio-cultural, gender, and economic imprints. This is not only relevant for the perception of sensations, but also for the vocabulary that is available to me (belonging to Western culture) for the articulation of sensations.

4 In the Royal Collection (UK) there are a large number of drawings by Leonardo Da Vinci Showing the movement of water, as well as studies of various weather situations. If I think of them not as an external incident, but as internal bodily phenomena—the graphic structures can well be understood as bodily sensations. They can be found under "Studies of Water," "Deluges," and "Tempests" and were created c. 1510-18. Royal Collection Trust, United Kingdom. https://www.rct.uk/ [12.06.2024].

5 There are a large number of pain scales. They contain not only the numerical scale, but are equipped with further descriptions, pictograms, or colors. This is also the base of their readability and accessibility. Depending on the age, culture, or gender of the person affected by pain, some are more suitable or accessible than others and require further explanation in use since not every person has the same verbal or visual preconditions. A few are listed here, named according to the person or place of creation: McGill Pain Questionnaire, Mankoski Pain Scale, Wong-Baker Faces Scale; or scales according to their visual form or category: VAS (Visual Analog Scale), CAS (Color Analog Scale), NRS (Numerical Rating Scale), CS (Categorical Scale), SAS (Smiley Analog Scale), FLACC (Face, Legs, Arms, Crying, Consolability).

6 The responses are woven into a polyphonic textual fabric in the chapter "Resonating Voices" of the PhD project. I had asked over forty persons to react to my artistic works. These responses include feedback in the form of resonance, evocations, reflections, expectations, associations, questions, as well as reactions indicating affective or intuitive approaches. In addition, I include feedback that came from lectures, talks, and the colloquia of the PhD in artistic research. Six feedbacks are from persons who are also affected by MS. The respondents are active in various disciplines such as the arts, art history, anthropology, medicine, medical humanities, psychiatry, philosophy, and other professions.

7 Black lesbian feminist Audre Lorde—as she calls herself—was half blind since childhood. After the mastectomy, she refused to wear prostheses. This is also consistent with her political position in other contexts. She was for the visibility of otherness. She died of cancer in the year 1992.

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