

Facing a Disruptive Face: Embodiment in the Everyday Experiences of “Disfigured” Individuals

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Abstract In recent years, facial difference is increasingly on the public and academic agenda. This is evidenced by the growing public presence of individuals with an atypical face, and the simultaneous emergence of research investigating the issues associated with facial variance. The scholarship on facial difference approaches this topic either through a medical and rehabilitation perspective, or a psycho-social one. However, having a different face also encompasses an embodied dimension. In this paper, we explore this embodied dimension by interpreting the stories of individuals with facial limb absence against the background of phenomenological theories of the body, illness and disability. Our findings suggest that the atypical face disrupts these individuals’ engagement with everyday projects

The term “disfigurement” may carry derogative associations which serve to stigmatize those who have an atypical (facial) appearance. In order to prevent such associations in this article, we mostly opt for neutral, descriptive terms such as “visible (facial) difference,” “atypical face,” “facial limb absence/loss,” or “amputated (facial) area” when referring to the condition and looks of the participants in our study (see for guidelines on non-offensive language as formulated by UK-based charity organization Changing Faces: <https://www.changingfaces.org.uk/about-us/press-media/media-guidelines>). When we cannot avoid the term “disfigurement,” we use quotation marks to denote its problematic nature.

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when it gives rise to disruptive perceptions, sensations, and observations. The face then ceases to be the absent background to perception, and becomes foregrounded in awareness. The disruptions evoked by facial difference call for adjustments: as they come to terms with their altered face, the participants in our study gradually develop various new bodily habits that re-establish their face's absence, or relate to its disruptive presence. It is through these emergent habits that facial difference comes to be embodied. By analyzing the everyday experiences of individuals with facial limb absence, this article provides a much-needed exploration of the embodied aspects of facial difference. It also exemplifies how a phenomenological account of illness and disability can do justice both to the impairments and appearance issues associated with atypical embodiment.

Keywords Facial difference · Disfigurement · Disability · Embodiment · Phenomenology · Dys-appearance

Introduction

Conditions that manifest in the face (e.g., head and neck cancer, facial burns, or cleft lip and palate) can severely impact the lives of affected individuals. In recent years, disability activists and charity organizations have worked to put this impact on the public agenda by drawing attention to the challenges confronted by those living with an atypical face (Partridge 1990; Piper 2011). This trend is accompanied by a growing body of research into facial variance, in which this subject is typically approached through a medical perspective, or a psycho-social lens. Medical and nursing studies focus on the quality of life of individuals who have various conditions that manifest in the face and head (Murphy et al. 2007), on the treatment of these conditions, or on the rehabilitations of affected individuals (Leon-Villapalos et al. 2008; van der Molen et al. 2009). By contrast, researchers working in the emergent field of the psychology of visible difference (Lansdown et al. 1997; Rumsey and Harcourt 2012) aim to address the appearance-related concerns of individuals with atypical facial. They investigate such topics as body image and self-esteem (Dropkin 1999; Rumsey and Harcourt 2004) coping strategies and the merits thereof (Dropkin 1989; Koster and Bergsma 1990; Jaspal 2012; Stock et al. 2016); and the efficacy of (professional) interventions such as self-help, social skills training and psychotherapy (Robinson et al. 1996; Callahan 2008; Konradsen et al. 2012; Muftin and Thompson 2013).

Having an atypical face, however, encompasses more than medical-clinical or psycho-social concerns: facial difference is also *embodied*. As prominent phenomenologists such as Edmund Husserl, Maurice Merleau-Ponty, and Drew Leder have argued, embodiment is an essential characteristic of human subjectivity (Husserl 1989; Merleau-Ponty 2014; Leder 1990). The body is the “ground” or “zero-point” of sense perception and motor skills: it is the center from which experience radiates outwards (Husserl 1989; Merleau-Ponty 2014). Through their bodies—and their faces—human beings reach out into the world and involve themselves in all manner of meaningful activities (Merleau-Ponty 2014). Illness and

disability can disrupt this involvement (Leder 1990; Toombs 1995; Aho and Aho 2008; Carel 2012). But how does such disruption manifest itself in the case of facial difference¹? In this article, we seek to answer this question by analyzing the experiences of people who have an atypical face due to their having lost one or more facial areas, against the background of phenomenological theories on human embodiment, illness and disability.

To understand the embodiment of facial difference, we first offer an exposition of phenomenological theories on the embodied aspects of human existence, and of illness and disability. We then describe the empirical study upon which this article is based, the participants in this study, and our methodology. Next, we present our findings regarding the various ways by which the different face appears as disruptive in the experience of our respondents. We conclude by discussing the relevance of our results.

Phenomenology of the Body, Illness, and Disability

Phenomenology typically focuses on the subjective way in which human beings understand and make sense of various phenomena within the context of their life-world. Phenomenological theories on embodiment highlight the role of the body herein. What Merleau-Ponty calls the *lived body* is not perceived as just another object in the world, but rather forms the very condition of possibility for perception and action (2014: 70; Carel 2012). Embodiment, however, does not simply refer to the body's sensory-motor capacities. Rather, the condition of being embodied involves an intimate experience of my body's "ownness". This includes the preconscious sense I have of being here-and-now, and of being immersed in my body (Merleau-Ponty 2014: 96f., 150f.; Leder 1990: 13, 22). In addition, embodiment encompasses my meaningful engagement with my lifeworld. As the locus of perception and action, the body is fundamentally oriented towards—*intends*—all manner of goals, activities and projects (Merleau-Ponty 2014: xvii; Leder 1990: 20f.). In its outward orientation, the body may incorporate different supplements, tools, and extensions (Leder 1990: 33f.; Murray and Harrison 2004; Merleau-Ponty 2014: 139, 144f.). Embodiment thus denotes the simultaneous constitution of the (extended) body-subject, and the meaningful, material environment in which she finds herself.

¹ Philosophical and sociological approaches to the face typically consider this body part in abstract or transcendental terms, rather than investigating real faces. For Emmanuel Levinas, the face (and in particular, the eyes) is the evocation of the others' ethical claim upon the self (2003). For Gilles Deleuze and Felix Guattari, the face produces *faciality*: a mechanism that signifies and subjectifies the body (1988). For Erving Goffman, *face* is a metaphor for a person's social image as it is negotiated in encounters with others through commonly shared *face-work* (1967). In exploring the embodied aspects of facial difference, we take a different approach to the face, focusing on the role actual faces play in everyday human life. This article thus not only complement medical and psycho-social approaches to facial difference by means of an embodiment perspective, but also remedies the lack of real faces (and more specifically, atypical faces) in the philosophical and sociological literature.

A person's being-in-the-world is usually characterized by a self-forgetfulness, an absence of the body (Leder 1990). As it reaches outwards in perception, the body itself disappears from awareness, rather than featuring in it as a distinct, thematic object (Leder 1990: 20f., 30–35). Similarly, the body's inner workings mostly recede from conscious experience (Leder 1990: 36–68). This disappearance extends to the human capacity to move and act. Many of the everyday activities human beings engage in are mastered to such an extent that they become mindless routines. Such pre-reflexive habits do not require conscious attention, which allows their executor to direct her attention elsewhere. The absent, habitual body is characterized by a basic, confident attitude of *I can*. This is an implicit assurance in one's physical capabilities, expressing a smooth, seamless interaction between bodies, objects and their surroundings (Leder 1990: 20; Merleau-Ponty 2014: 139).

S. Kay Toombs (1988; 1995) was one of the first to propose phenomenology as a framework to better understand how people subjectively experience their being ill and disabled (Carel 2012). This is necessary, she argues, because the biomedical model common in healthcare does not sufficiently address the way patients experience and give meaning to their altered body and world.² Illustrating this point, Toombs offers a phenomenological analysis of her own experiences with multiple sclerosis. As she demonstrates, her diminished motor skills disrupt her ability to perform everyday tasks (e.g., taking the stairs to teach a class on a different floor). While the different devices she uses to get around compensate for some of the mobility challenges she confronts, these aides also pose new challenges (e.g., reaching upper shelves while sitting in a wheelchair). Because her formerly self-evident, pre-reflexive bodily routines no longer suffice, Toombs now inhabits an obstructive, non-accommodating lifeworld. Leder discusses the disruptive implications of pain and disease for a person's sense of her own body (1990:70–83). When it is painful or dysfunctional, the body no longer forms the absent, “transparent” basis for perception and action (Leder 1990: 82). Instead, it draws attention to itself, appearing in awareness as dysfunctional. The body then *dys-appears*, in Leder's terms, and thereby interrupts the ill person's immersion in her lifeworld (1990: 83; 70 and 81). For Svenaeus (2000, 2009, 2015), the fact illness and disability disrupt the subject-body's implicit, habitual relation to her lifeworld, means that both body and world become *uncanny*: they lose their familiar, home-like quality.

As we have argued elsewhere, phenomenological accounts that focus on illness and disability tend to neglect the fact pathological conditions may also affect individuals' outwards appearance (Slatman and Yaron 2012; Slatman 2014). Of course, the body's visibility is not a new theme within phenomenology at large, as is evident in, for instance, Jean-Paul Sartre's discussion of the gaze of the other (2007). The realization that she is being looked at by another, for Sartre, may cause a person to become aware of her body's outward appearance, which can give rise to feelings of self-consciousness and shame (2007: 347–350; Dolezal 2015). The body's phenomenological presence in awareness then amounts to a *social dys-appearance*, in Leder's words (1990: 96). As Iris Marion Young demonstrates,

² See Toombs (1988), Svenaeus (2009), and Aho and Aho (2008) for more on the specificity of subjective illness experiences as opposed to objective disease states.

women, in particular, often internalize such an outside perspective on their body (2005). This internalization is embodied, in that it is expressed by an inhibited *I can*—or rather, an *I cannot*: women in Western societies are socialized into adopting restrained modes of comportment such as holding their arms close to their upper body or sitting close-legged (Young 2005: 148). Societal norms that govern appearance do not only inscribe gender onto bodies, however. As Frantz Fanon and, more recently, Sarah Ahmed have shown, the spatial orientation and capabilities of bodies are affected not only by sexism, but also by racism (Ahmed 2006: 111, 126, 129–142).

The phenomenology of illness and disability offers a unique understanding of the way various (medical) conditions disrupt a person's embodied being-in-the-world. Likewise, phenomenological scholarship that addresses the body's visibility offers important clues into how a person's being-in-the-world is affected by her embodied internalization of the other's gaze. But how can these insights be brought to bear in an analysis of facial difference? In the following pages, we aim to answer this question by considering the experiences of individuals who lack facial areas. This, as will become clear, involves highlighting how these individuals' embodied relation to their lifeworld becomes disrupted by both their impairments and visible difference, and discussing the ways they bodily adjust to these disruptions.

Exploring Facial Limb Absence

This article is based on a qualitative study into how people living with facial limb absence experience and give meaning to their facial difference. During this study, the first author conducted in-depth, semi-structured interviews with 20 individuals who lack one or more facial limbs and/or areas (see Table 1 for an overview of the respondents). Of the participants in our study, eight are women and twelve are men, ranging in age from 42 to 84 years old. Six of these individuals have lost their nose, ten lack one orbita (eye and eye socket), three have had their nose as well as other facial limbs amputated, and one has lost part of his cheek. In nineteen cases, the absent facial areas were amputated in the course of the medical treatment of cancer occurring in the face. One interviewee was the victim of an accident. In order to cover their amputation, each of these individuals makes use of a facial prosthesis, which is a silicone device that resembles the missing facial limb. Most also use other aides such as bandages, gauze dressings or eye patches for this purpose. The respondents were recruited through the Dutch service unit from which they receive their prostheses. The study received ethics clearance (file number NL35486.031.11), and informed consent was discussed with and obtained from the participants at the beginning of each interview. The interviews all took place at the respondents' home or in another familiar setting, lasted between 45 and 90 min each, and were tape recorded and then transcribed verbatim. In order to prompt participants' stories of their experiences with facial limb absence, the first author made use of an interview schedule which served as a basis for asking questions during the interviews. Topics included diagnosis, treatment trajectory, (prosthetic) rehabilitation and everyday life after the amputation.

Table 1 Facial difference embodied

Interview	Name and age	Absent facial limb/ area	Cause	Aides used
1	John, 65	Nose	Cancer	Nasal prosthesis (on implants), gauze dressing
2	Timothy, 65	Part of the left cheek	Cancer	Cheek prosthesis (glued)
3	Dora, 65	Nose	Cancer	Nasal prosthesis (glued), dressing
4	Laura, 45	Eye socket	Cancer	Orbita prosthesis (on implants), band-aid
5	Stella, 47	Nose	Cancer	Nasal prosthesis (glued), dressing
6	Walter, 65	Eye socket	Cancer	Orbita prosthesis (locks into the amputated area)
7	Arnold, 72	Eye socket	Cancer	Orbita prosthesis (on implants), band-aid
8	Ray, 66	Right part of the nose	Cancer	Nasal prosthesis (glued), dressing, band-aid
9	Lisa, 73	Eye socket	Cancer	Orbita prosthesis (on implants), eye patch
10	Bertha, 76	Nose and eye socket	Cancer	Complex prosthesis (glued)
11	Gregory, 81	Eye socket	Accident	Orbita prosthesis (glued)
12	Oliver, 60	Eye socket	Cancer	Orbita prosthesis (glued), eye patch
13	Harry, 79	Nose and eye socket	Cancer	Complex prosthesis (glued), dressing, band-aid
14	Audrey, 84	Nose	Cancer	Nasal prosthesis (glued)
15	Leon, 52	Nose	Cancer	Nasal prosthesis (glued)
16	Gabriel, 70	Nose, eye socket and part of forehead/ temple	Cancer	Complex prosthesis (glued), dressing
17	Christine, 72	Eye socket	Cancer	Orbita prosthesis (glued), dressing, band-aid
18	Ralph, 42	Eye socket	Cancer	Orbita prosthesis (on implants), band-aid
19	Winston, 63	Eye socket	Cancer	Orbita prosthesis (on implants), dressing
20	Thelma, 57	Eye socket	Cancer	Orbita prosthesis (glued), dressing

To interpret respondents' accounts we applied a thematic analysis to the interviews (Braun and Clarke 2006). The first author first familiarized herself with the data by reading and summarizing the interview texts. Next, she identified and attributed codes to recurring issues (e.g., "taking care of the amputated area," "adapting to sense impairments and dysfunctions," "relating to others' staring behavior"). In consultation with the other authors, she then refined the analysis by focusing on participants' descriptions of how they gradually—and often intuitively—bodily adjusted to their changed face and lifeworld. This focus allowed us to get at the embodied dimensions of our respondents' experiences. "Experience," of course, can mean different things. On the one hand, this term denotes how a person *perceives* her lifeworld and *senses* her body. On the other, this term refers to how she immediately *interprets* her world and her body as both become available through her perceptions and sensations—the ways she (consciously and unconsciously) understands, values and frames the sensations and perceptions that

appear in her awareness. Such sense-making, in turn, has both a discursive dimension and an embodied one: interpretations can be told, but they can also be performed. For instance, an interviewee may narrate how she interprets the image of her noseless face when looking in the mirror, namely as a horrible sight that must be hidden. The same interviewee may simultaneously embody this interpretation by covering the amputation site. Both these interpretations are forms of sense-making. But where the first constitutes meaning through propositional storytelling, the second establishes meaning through an habitual, embodied relation to a person's lifeworld. By foregrounding participants' descriptions of their adjusted, bodily ways of being-in-the-world, we gained insight in the non-discursive dimensions of their sense-making as they come to terms with their altered face.

The Present Face

Our respondents' bodily process of adjustment is prompted by instances in which their atypical face appears as a distinct phenomenon in their awareness. The face becomes present in this way when it disrupts interviewees' formerly unproblematic involvement with their various everyday activities. Such disruptions arise due to (a) faulty or lacking sense perceptions, (b) uncomfortable bodily sensations, or (c) observations by others. In this section, we explore the stories of the participants in our study, in order to investigate how they come to adjust to their face's disruptive presence.

Disruptive Perceptions

Due to their condition or its treatment, respondents all experience changes to or the complete loss of one or more of the sensorial capacities that originate in sensory organs located in the face and head. Accordingly, all participants who lack an eye report problems with their vision, some interviewees who lost a nose experience issues with smell and taste, and many respondents no longer have skin sensitivity in parts of their face. In this section, we discuss how these sense impairments cause the face to appear in participants' awareness, as well as the way in which they adapt by anticipating, avoiding and managing such appearance.

The visual impairment confronted by respondents who have lost an eye takes the form of the loss of parts of their field of view:

You can never look straight ahead when walking; you must always watch the part you're walking on. (...) [Y]ou don't want to always walk in that manner only. You want to see a shop window; you also want to see the greenery when you're walking. But you consciously look in front of you, to see if there are no obstacles. (...) I look up [from the ground], and then, automatically, I would look down again after having walked that stretch. (Lisa³)

³ Like all the other names we use below, this name is fictitious in order to safeguard the privacy of the participants in our study.

The restriction of Lisa's visual field means that she cannot attend her surroundings while walking, but must focus on the ground she walks upon. Losing an eye thereby forms a disruption of a person's formerly effortless, implicit relationship to her environment, and calls for a much more conscious approach to the navigation of spaces.

Problems with visual field may also interfere with the impaired person's ability to interact with others:

In the car it is also very tedious (...) I prefer driving myself and having somebody at my right side, than sitting [in the passenger's seat] (...) that's more tiring [moves his head left and right vigorously, illustrating the effort of making eye contact with an interlocutor situated to his blind left side].
(Walter)

Walter's impairment presents him with similar issues while playing music with his band, when he tries to maintain eye contact with his fellow musicians, the sound technician and the audience. This calls for a considerable amount of head-turning. Playing music together, as Alfred Schütz illustrates, involves the musicians' "mutual tuning-in relationship" (1971: 161): their shared orientation towards each other, and in particular, towards the way the other performers approach the composition's rhythm, duration, and timing (1971: 175f.). Such tuning-in occurs through a reciprocal visual assessment of and response to other musicians' facial expressions and gestures. This means that "(...) participants [in the musical piece's performance] are sharing not only a section of time but also a sector of space" (Schütz 1971: 176). Visual impairments can complicate the delicate temporal and spatial choreography that characterizes face-to-face interactions, both in conversation and in social exchanges that involve being together in non-verbal ways.

Next to a restricted visual field, losing an eye also means that participants experience problems with seeing depth and gauging distance, an issue that mainly comes up when they use everyday objects. As Lisa says while pouring tea for the interviewer: "And here I must really pay attention, (...) to make sure it really ends up in the cup". Another interviewee mentions accidents that occurred during his work as a farmer:

In the first year I kind of fumbled around (...) I would for instance have to lift something and put that on top of something else, and that then, because I couldn't see depth anymore, I wouldn't put it far enough on top, and (...) it would fall off. (Arnold)

Respondents' visual impairment means that they cannot use objects like they did before. Their sensory impairment has led to a number of accidents or mishaps. As a result, everyday tasks like pouring tea or stacking boxes become potentially hazardous.

Participants do not passively undergo these problems and mishaps, however: they compensate for their sensory impairments through the gradual development of new bodily habits. Discussing her attentive mode of walking, Lisa says: "You adjust, after having stumbled badly a couple of times, yes". As already illustrated, she adapts by developing a different, more careful way of strolling and pouring. Walter

adjusts by insisting on keeping others on his right side—the side of his healthy eye. Arnold has developed a new method of stacking boxes:

I work a lot with a fork-lift truck; I use it for piling up boxes and sometimes (...) I put a mark with a crayon, right, so that I know by looking that the one fork is positioned right, I can drive straight ahead, and then I can put the box on top of it. (Arnold)

Because interviewees' old bodily repertoires no longer suffice, they develop new bodily habits such as “navigating spaces and pouring carefully,” “interacting with others one-eyed,” and “using crayons to gauge distance”. Some of these habits become automatic over time, while others keep requiring a measure of explicit attention. Such new routines, however, are not part of a deliberate, purposeful endeavor to cope with sense impairments, but rather emerge without much overt thought or discussion, as part of respondents' intuitive attempts to anticipate, circumvent and manage recurring accidents and problems.

The perceptual disruptions participants encounter as they approach everyday tasks and activities not only arise due to visual impairments: other registers of sense-perception such as smell and touch may also be involved. Accordingly, some respondents who have lost their nose report issues with their sense of smell, due to radiation damage to their olfactory system. These issues arise when the sensory impairment interferes with mundane, formerly uncomplicated activities that involve a person's sense of smell. Speaking of his changed approach to eating after his nasal amputation, one man says:

[Food] has to feel good in my mouth. (...) A steak or something, I just can't process that. And meatballs, that's too mushy, in my mouth. That doesn't feel good. (John)

John's ability to distinguish between different foods that have the same basic tastes has become crude because he can no longer perceive their aroma. Or as his wife puts it: “He can't tell whether it's endive or spinach or leek”. As a result, the structure of dishes has become more central in the way John approaches eating: mushy foods now elicit disgust.

Like respondents who contend with visual impairment, participants who have lost their sense of smell must adjust to the fact that formerly taken for granted activities like eating become problematic. Such adjustments take the form of new habits. In responding to his altered experience of eating, for instance, John now avoids mushy meat and has developed a preference for ‘stringy’ dishes. John's inability to perceive smells also affects his ability to practice his hobby of making furniture. When applying varnish to carpentry projects, he cannot detect the build-up of vapors in his work room. To prevent the risks associated with prolonged exposure to chemicals, John has developed the habit of keeping the door to his hobby room open. This allows his wife to keep an eye (or rather: a nose) on his wellbeing:

He counts on me, then [laughs]. (...) He'll be painting and I'll say: “Don't close the door, you have to leave it open”. Well, the whole house will smell of

[varnish] then (...) but that's not as bad as you sitting all locked up in that cubby-hole with all those vapors in the air. (John's wife)

John's changed face calls for the development of a new bodily repertoire, in which "enjoying meatballs" and "painting indoors" are replaced by "avoiding mushy dishes" and "painting while delegating smelling to my wife".

In a way similar to problems with sight and smell, respondents' sense of touch can also be affected by their facial limb loss. Most participants report a complete lack of perceptions in and around the amputated area due to damage to nerve endings in the face. One interviewee describes this lack:

I could cut off my left ear with a pair of scissors and not notice a thing. It's really numb, that ear. (...) The front part of my cheek, that's also numb (...) [and] when I eat I don't feel or taste anything inside [my mouth]. (Timothy)

The fact Timothy's inner cheek no longer provide tactile feedback can be unnerving:

[I]t's as if I'm doing something outside of myself. That's how it feels, when I'm [chewing on the] left [side]. "What am I doing," I ask myself, "this is no taste; this is nothing". (Timothy)

Paradoxically, this absence of perception where perception is expected means that Timothy's inner cheek becomes all the more present in his consciousness. The ensuing sense of alienation Timothy expresses in the quote above is reminiscent of Svenaeus' analysis of the way pain renders a person's body *uncanny*, making it seem unhomelike and strange (2000, 2015). Apparently, perceptual absence can evoke a similar sense of self-estrangement. As in the cases described above, this disrupts Timothy's ability to fully immerse himself in the activity of eating. In order to avoid such disruption, he approaches eating and chewing differently than before: "I never eat [on the] left [side]". Timothy's former bodily habit of "just chewing," no longer acceptable due to the eerie non-perception it evokes, is abandoned. "Chewing only on the right side" takes its place, becoming an automatic routine that no longer requires conscious deliberation.

As we show in this section, the different types of sensorial impairments respondents confront cause various accidents and problems, thereby complicating formerly straightforward activities and tasks such as strolling, interacting with others, stacking boxes, pouring tea, eating and painting. Their different face can then be said to disrupt participants' ability to fully immerse themselves in everyday projects: they are unable to focus on the task or activity at hand, because the accidents or problems caused by faulty or lacking sensorial perception take center-stage. Or in phenomenological terms: the accident or problem appears as a distinct phenomenon in interviewees' awareness, which disrupts their previously unproblematic orientation towards their lifeworld. In responding to such disruptions, participants develop an array of new bodily habits that set out to anticipate, avoid, and manage disruptions. As we demonstrate in the next section, respondents develop such repertoires not only when dealing with faulty or lacking sensorial feedback, but also when they confront unpleasant sensations.

Disruptive Sensations

Next to causing sense impairments, losing a facial limb or area can also result in the experience of various uncomfortable sensations. In this case, it is not the faulty perception of the world, objects and others that gives rise to problems, but rather the occurrence of sensations arising in respondents' own bodies. Such sensations typically take the form of pain, itch or prickling. In this section, we elaborate on the ways in which unpleasant sensations cause the face to appear phenomenologically in the awareness of participants in our study. In addition, we discuss how they respond to such appearance by not only anticipating, avoiding and managing disruptive sensations, but also by enduring and confronting them.

In the case of some interviewees who have lost their nose, the amputation has exposed the roots of their upper front teeth. Because their teeth nerves are no longer fully embedded in their jaw, these individuals are extremely sensitive to cold. For one interviewee whose nose was amputated due to cancer, leaving her house once the temperature drops below 9 degrees Celsius can be quite painful. Going outside, she experiences a sharp ache in the lower area of her face:

Yes, from 9 degrees and below (...) [going outside] is still very uncomfortable. Yes, yes: cramped tooth and gums, and pain in your nose. (...) It is one of those "at the dentist's" type of pain (...) [that] has everything to do with those exposed teeth roots. (Stella)

As this quote illustrates, the severe pain she experiences when going outside in cold weather imposes itself on Stella's awareness. Everyday activities and tasks that require leaving the house—activities such as cycling to town to do grocery shopping—become severely uncomfortable. For this reason, respondents who experience pain due to cold exposure tend to avoid going outside once the temperature drops. As Stella says: "Well, I actually stay mostly at home (...). In winter I basically don't ride my bicycle [to town], it comes down to that". Drawing on Elaine Scarry's work on pain, Myriam Winance, too, shows that pain affects individual's ability to move: "illness, through pain (...) affects a person's mobility, his/her capacity to move and be moved" (2006: 1112). Although the participants in our study only experience pain in specific times and places, this sensation nevertheless effectively disrupts their ability to pursue everyday projects that require going outside, and thereby disrupts their link to the world.

But anticipating and avoiding pain is not the only option participants have: sometimes, they consciously choose to undertake an out-of-doors activity despite the discomfort. For John, a shawl proves helpful on such occasions by dampening the pain. According to his wife, "[John] does continue feeling [the pain] then, of course, but because he keeps something in front [of his nose], he can still go outside". In Stella's case, shawls and other covers do not help to make the pain more manageable. However, when she sets her mind on engaging in an outdoor activity in cold weather, she willingly chooses to confront the pain head on:

So once the weather gets a little bit colder, I'll be at the intersection [of two options], like, "I just want to take my bicycle!" [versus] "Well actually I

shouldn't..” And when I hop on my bicycle anyway, I start thinking, “Oh it hurts! (...) well, too bad, then”. Simply because I want to go to the market.
(Stella)

When they anticipate, avoid and manage painful sensations—and when they confront such sensations head on—respondents in fact adjust to their altered face: they adapt their bodily repertoire of “going outside” to accommodate potential disruption.

In addition to pain, some participants report the occurrence of phantom sensations post amputation. As Dora, a nose amputee, says: “My [lost] nose itches. (...) It’s like those weird phantom pains or some such. (...) Yes, it’s very strange”. Such phantom sensations can vary from mild prickling, as in Dorás case, to severe itch. Such severe phantom sensations can be quite overwhelming:

I experience a terrible amount of itch. Really bad itch. (...) It’s the [severed] nerves (...) I’ll never be rid of that. [it’s as if] a bunch of little ants (...) are walking in your head. (...) I get that three or four times a day. (...) It’s nasty.
(Thelma)

Such sensations impose themselves on respondents’ consciousness and thereby keep them from attending to things other than their sensed face. In this way, intense phantom sensations severs their formerly taken-for-granted connection to their lifeworld. As Winance writes about pain: “Through the links they weave with the world, subjects acquire their abilities to act. By causing a person to withdraw from his/her body and world, pain causes these links to be broken and the person loses his/her capacities” (2006: 1113). And being phantom phenomena, sensations such as tingling or itching cannot be relieved by scratching:

I can’t scratch, because I can’t come through [the skin]. (...) Sometimes [I do] scratch all over and bang my head [against something] and occasionally I will take [the prosthesis] out and put a cold tea bag (...) in the cavity. (...) That helps a little. (Thelma)

Unlike pain related to cold exposure, respondents cannot avoid the appearance of phantom sensations, but can only endure them. Both types of sensations, however, disrupt a person’s ability to move and act—to fully inhabit her lifeworld.

Next to pain and phantom experiences, several respondents report (severely) uncomfortable sensations that arise due to a prolonged usage of their prosthetic device. As John says: “[the prosthesis] is quite a tight fit (...) Yes, I feel that now as well, just the pressure, and when I do this [moves his face], I feel it chafing somewhat”. The sensation of itch Stella encounters is more bothersome:

The borders [of the prosthesis] itch sometimes, yes, that is very uncomfortable, because, of course (...) the prosthesis now covers [that area]. (...) So you cannot reach [in order to scratch]. (Stella)

Again, such sensations draw participants’ attention to their sensing face, thereby disrupting their ability to focus on their activities. Because virtually all the respondents in our study prefer to wear their prostheses when going outside in

public, this type of unpleasant sensations cannot be avoided altogether. Unlike phantom itch, ordinary itch does not have to be simply endured: it can also be managed. Stella, for instance, has developed a new way of scratching that involves carefully moving her upper lip from side to side: “I will do this [moves her upper lip] with my face, making weird facial expressions”. This surreptitious way of scratching saves her the hassle and embarrassment of removing and reapplying her nasal prosthesis—and remaining barefaced meanwhile. It also prevents the prosthesis from coming loose due to actual scratching, which would be equally troublesome. Stella’s repertoire of relieving itch thus comes to include “scratching without dislodging the prosthesis”. There is an important difference between managing unpleasant sensations, and confronting or enduring them, however. Habits that involve the management of unpleasant sensations may become automatic responses after a while. By contrast, habits that involve confronting and enduring intensely uncomfortable sensations never become mindless routines, both because these sensations cannot be alleviated, and because enduring them requires conscious deliberation and action.

The unpleasant sensations respondents experience, as we have demonstrated in this section, cause their different face to become phenomenologically present in their consciousness. This foregrounding of the sensed face serves to disrupt participants’ ability to partake in everyday activities such as going outside for grocery shopping. Indeed, the more severe the sensation, the more disruptive it is, fully commanding an individual’s awareness and keeping her from focusing on anything else. In relating to these bodily sensations, respondents develop various new bodily repertoires. As in the case of the disruptive perceptions discussed in the previous section, these habits allow participants who experience disruptive sensations to actively anticipate, avoid, and manage these sensations. Relating to disruptive sensations, however, may also entail confronting or simply enduring them. In the following section, we discuss yet another source of disruption that our respondents encounter due to their facial difference: the observations of others.

Disruptive Observations

Facial limb absence does not only involve possible sense impairments and unpleasant sensations, but also leaves affected individuals with a different appearance. Accordingly, one of the most common topics that participants raised during the interviews was the way others responded to their unusual looks in (semi)public locations. In this section, we discuss how others’ attention causes the face to become present in interviewees’ awareness, and the ways they respond to this presence by anticipating, avoiding, and managing situations in which their facial difference is observable to others.

As mentioned above, respondents generally do not venture outside without covering their amputation; they do not want to be seen “barefaced”. The various aides they use to cover their facial difference can be more or less conspicuous. Due to their color and placement, such covers as gauze dressings, eyepads or band-aids tend to attract others’ notice. Dora speaks of her experiences when wearing a bandage that hides the area where her nose used to be:

Well you can imagine what a “party” that was, right. (...) you’d get those remarks like, “Well, you’ve had a hefty blow” you know. (...) I would get mad sometimes. Because people would make comments and look and look again. You don’t wanna know. (Dora)

Facial prostheses are much less obtrusive than such visible covers—many respondents report they regularly manage to avoid others’ attention when wearing one. By concealing their facial difference, the prosthesis allows participants to *pass as normal*, in Goffman’s terms, and thereby elude the censure associated with having a stigmatizing trait (1963).⁴ As Goffman writes: “Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent” (1963: 74).⁵ But such passing is not a given: participants all recall instances in which others notice there is something unusual about their partly prosthetic face:

Yes, last week we were in Germany, we went on one of those little trains (...) and there was this grandpa with his grandchild sitting opposite from me, and that child kept on looking at me. And then each time again like this [looks at interviewer] and then outside, and then again back at me. (John)

Being conspicuous, then, means that interviewees commonly confront unwanted attention in public, in the form of staring gazes, questions and remarks.

The unwanted attention generated by their atypical face makes participants aware of their own looks: others’ staring gazes, questions and remarks inevitably draw interviewees’ own attention to the unusual, unexpected image their face presents. This awareness of their appearance comes down to the internalization of the other’s gaze. Indeed, Leon, a man who lost his nose to cancer says: “[W]hether it’s true or not [that people actually stare], those stares, I feel them in my head”. As they focus on their own looks, respondents are unable to fully focus on their present activities (walking home, travelling by train). Instead, they must attend to the way their outer appearance comes across to others, and deal with others’ responses. In close approximation of Sartre’s discussion of the gaze of the other (2007: 347–350; Leder 1990: 93), participants’ awareness of the (potential) onlooker’s “outside” perspective on their visibly different exterior disrupts their ability to immerse themselves in their everyday projects.

Participants evaluate others’ responses to their unusual appearance differently: generally, mild staring and genuinely interested questions are seen as inoffensive, while comments and blatant staring are considered rude. Regardless of how they receive the unwanted attention they encounter, however, respondents must nevertheless relate to such attention. As disability scholar Rosemarie Garland-Thomson argues in her analysis of the staring behavior elicited by visible difference,

⁴ See Yaron et al. (2017) for a more detailed analysis of the way the facial prosthesis allows its wearer to *pass as normal*, as well as a discussion of the way this device enables its user to minimize what Goffman (1963) terms *interaction uneasiness*.

⁵ Of course, in face-to-face interactions in public, others may well hide the fact they notice interviewees’ facial difference. This is due to the fact both interactional partners may be invested in a mutual endeavour to maintain each other’s social face (Goffman 1967: 10f.).

staring “is an interrogative gesture that asks what’s going on and demands the story” (2009: 3). Implicit as they may be, such interrogative gestures must be dealt with in some way. Thus, many interviewees indicate they deliberately ignore gazes. Elaborating on the incident in the train described above, John says:

I don’t react. And I won’t deliberately look at him [either], so I just look out the window. But when I turn my head, he will be at it again [laughs]. (...) I think, “Well kid, just look your fill”. (...) Yes, that happens so often; it’s part of the drill. (John)

Curious children—and this is a recurring theme in the interviews—can apparently count on a lenient reception. Staring adults are not always so readily excused:

When an adult is staring at me, I just stare back. But what I think is: “Come on!” [speaks in an exasperated tone]. (...) [I]f you see something about me, and you want to know [about it], then you’re big enough to [approach me and] say, “Mister...?” (Timothy)

Many participants share Timothy’s preference to be openly approached about their atypical face, though they stress such expressions of curiosity should be polite. In response, they often provide information about their amputation, visible cover or prosthesis. Witticisms and rude remarks, by contrast, are mostly ignored, though some respondents opt for a more confrontational approach by calling the offending person into account.

But interviewees do not only respond to others’ unwanted attention: they also try to avoid it altogether. Leon, for instance, mostly refrains from going outside: “I mean, I hardly ever go out on the street anymore”. The effort associated with going out into an inhospitable social world then results in what Toombs terms *existential fatigue* (1995: 15), which may translate into a tendency to just give up and withdraw. As Toombs writes: “The person with a disability is tempted severely to curtail involvement in the world” (1995: 15). Nevertheless, Leon also makes use of a more active approach to circumvent unwanted attention, for instance by using sunglasses to camouflage his prosthesis:

I’m always happy in the summer, then I’ll be outside more often, because I wear sunglasses then. (...) Yeah, you don’t see [that I wear a prosthetic nose] then at all. You almost don’t see it. (Leon)

Other participants also develop ways to conceal their atypicality. Dora uses theater make-up on her artificial nose to achieve a smooth transition from silicon to skin. Timothy inhabits public spaces “strategically,” as he calls it: he takes care to always sit in the left-most corner when he eats out with friends. In this way, if his prosthesis comes loose, he can remove it surreptitiously. Laura, a woman who lost her orbita in childhood, closely monitors the blinking impulse in her residual eye while interacting with others: “I try to blink as little as I can when I’m talking to someone (...) or else there is only one eye blinking, right”. By controlling her blinking, Laura strives to ensure her eyes appear symmetrical to her conversational partner.

Respondents' efforts to render their facial difference inconspicuous and thereby avoid unwanted attention extend beyond the visual to include the full range of others' senses. Stella, for example, refrains from welcoming her grandmother with a kiss while wearing her prosthesis:

[W]ith my grandmother (...) I would be wanting to give her a kiss on her forehead and well, you wouldn't do that, because your nose gets in the way (...). A hard thing on someone's face (...), would obviously not give a warm feeling, which a kiss should actually be doing, really. (Stella)

This adjusted mode of kissing aims to keep Stella's inflexible, hard nasal prosthesis from pressing into her loved one's skin. Stella's consideration of the way her atypical face appears to others apparently ranges beyond the gaze to encompass the other person's sense of touch. Harry, a nasal amputee, provides a similar example:

[W]hen there's a droplet coming out of my nose (...) I don't feel that (...). Often I dry my nose, yes. In advance. Because (...) at a birthday party [when] you come in, you know, you give [the hostess] (...) a kiss or three kisses, and then I will blow my nose [beforehand]. (Harry)

This awareness of the face as an observable bodily structure may also include others' sense of smell. As Walter says: "Normally you would have 'sleep' in your eyes or some such (...) there behind [the orbita prosthesis]. I clean it with a swab (...) because I don't want it to smell". As they strive to keep their atypical face from being observable to others, respondents take into account different ways by which they are perceived by these others.

Interviewees' ways of dealing with their potentially observable difference all revolve around the development of new habits. Thus, they manage situations in which their visible difference is noticeable to others by relating to others' unwanted attention in various ways.⁶ In addition, they also set out to keep their face inconspicuous and thereby elude others' notice. These routines all become part of their newly developed repertoire of "appearing to others"—a repertoire that allows them to manage, anticipate and avoid notice, and thereby deal with the (potentially) disruptive presence of their visibly different face. Again, some of these habits keep requiring purposeful action (e.g., pointedly staring back at starers, curbing the impulse to blink), whereas others may become ingrained, intuitive routines (e.g., situating oneself to the left of others, wiping one's artificial nose before kissing).

To summarize this section: Participants' atypical face becomes present to them when it attracts others' attention. Such unwanted attention causes interviewees to become acutely aware of their different appearance, as they adopt a third-person, external perspective upon their face. This focus upon their observable face serves to

⁶ The fact respondents explicitly address others who stare at them, or who ask about or comments upon their appearance means that the way they adjust to their visible difference extends beyond the development of new bodily habits. It is beyond the scope of this article to discuss the various—verbal and non-verbal, explicit and implicit – ways in which respondents' visible difference acts up in exchanges with others. We investigate this issue in more detail in an upcoming paper on the role of the visibility and invisibility of facial difference in social interactions between individuals with facial limb absence and others who notice their facial difference—or fail to do so.

disrupt respondents' outward orientation towards their daily projects. The various bodily repertoires participants develop in response to such unwanted attention aim to manage others' responses to their atypical face, and to keep their difference from being observed by others. These habits do not target only the visual face, but also the face as it appears through other senses such as smell or touch.

Facing a Disruptive Face

Due to their facial difference, the participants in our study must repeatedly relate to various disruptive sensory impairments and sensations, as well as a disruptive observability to others. As a result of these disruptions, respondents' face becomes foregrounded in their awareness, while simultaneously ceasing to be the absent background to their engagements with the world. The fact their disruptive face *disappears* in this way interferes with interviewees' ability to perform daily tasks and activities. Their impairments and "disfigurement" render problematic participants' formerly taken for granted way of being-in-the-world, thereby undermining the familiarity of their lifeworld. Their body and world, to speak with Svenaeus, both become uncanny (2000, 2015). But the participants in our study do not undergo the disruptions engendered by their altered face passively. Instead, they develop an array of new bodily habits that serve to anticipate, avoid, manage, confront and endure disruptions. This newly-developed bodily repertoire does not consist in deliberate, conscious attempts to cope with facial difference, but rather forms a gradual recalibration of perception and (inter)action that emerges intuitively as respondents come to adjust to their "new" face.

Through their new bodily habits, interviewees effectively incorporate their face's disruptiveness. Encompassing an understanding of facial difference that resides within the body rather than in the mind, these habits form new way of being-in-the-world: an altered *I can*. But this *I can* simultaneously involves the inability to perform tasks as one did before. As Leder argues, being disabled by a medical condition means that a the sick person cannot engage the world as she once did: her *I can* then manifests as an *I no longer can* (1990: 81). Respondents' modified *I can* reflects both *actual* disruptions and *possible* ones. Indeed, many of respondents' new routines can be said to embody the very real risks posed by their disruptive face. It is both this risk and the disruptions themselves, then, that influences the range of options open to them. Drawing on Sartre, Toombs makes a similar point: "[I]t is important to recognize the *lived body* as possibility, potentiality for action in the world. (...) Permanent loss of function represents a modification of the existential possibilities inherent in the *lived body*" (1995: 16, emphasis in the original). The habits participants develop as they adjust to their impairments, debilitating sensations and altered appearance embody disability as well as new forms of ability, and incorporate both actual and possible disruptions.

Respondents' changed *I can* takes different forms. Some of their newly formed routines—for instance, their new way of walking, pouring, stacking objects, chewing, scratching, or kissing—become automatic and mindless. Although they initially may take some getting used to, these habits eventually become sedimented:

they are embedded seamlessly within interviewees' preconscious way of being-in-the-world. Other bodily repertoires, however, do not become embedded in this way, but rather keep requiring an attentive attitude towards the (potentially) disruptive face. Respondents' monitoring of the impulse to blink, their avoidance of cold weather, and the way they deal with (phantom) sensations, for example, are recurring, practiced actions. Nevertheless, they cannot be considered automatic, because they require some manner of explicit attention. Expressing a new, more vigilant attitude towards the unruly face, these habits form a conscious way of dealing with (the possibility of) disruptions.

Respondents' newly-developed bodily habits are all driven by a common purpose: to somehow relate to the face's (potential) *dys-appearance*. As Leder points out, the painful or sick body does not only demand attention, but also calls for the relief of pain and the removal of illness. He writes: "Pain exerts a *telic demand* upon us. While calling us to the now, its distasteful quality also establishes a futural goal: to be free of pain" (1990: 77, emphasis in the original). Complying with this *telos* (objective or end) involves a *pragmatic moment*, in which the sufferer attempts to cope with, master or eliminate her suffering (Leder 1990: 77)⁷. The newly developed habits of the participants in our study can be understood as embodied manifestations of this pragmatic moment, although they differ in the degree to which they succeed in reestablishing the face's absence. Although they initially arise in response to the face's disruptive presence in awareness, fully sedimented bodily habits ultimately enable respondents to anticipate and avoid its *dys-appearance* by ensuring disruptions rarely take place anymore. Those habits that require an ongoing, attentive attitude towards the potentially disruptive face, however, do not afford a similar return to bodily absence. Although they prevent the different face from appearing in awareness through various disruptions, such habits simultaneously make the face all the more present through the monitoring involved. In other words: these more attentive habits involve not only the face's disappearance, but also its re-appearance. Finally, newly-formed routines that require explicit attention in order to endure or confront disruptions cannot be said to involve any form of regained disappearance. Thus, despite the fact some of respondents' routines allow them to regain a degree of bodily absence, their altered way of being-in-the-world remains uncanny and precarious, requiring an explicit, attentive relationship to their face, lifeworld, and the disruptions occurring in both.

Drawing on the theoretical foundation provided in Leder's work, our analysis provides an empirical exploration of the various ways by which ill and disabled people pursue their body's disappearance, and relate to its unavoidable *dys-appearance*. But our findings complement Leder's work in another way: they highlight the ongoing, everyday character of the work involved in regaining the body's absence. In his brief discussion of the pragmatic moment induced by the *dys-*

⁷ Curiously, Leder does not explicitly frame his discussion of the telic demand of pain and the pragmatic moment in which the sufferer tries to get rid of this sensation in terms of a desired return to bodily absence. Being theoretically motivated, he also does not provide a comprehensive investigation of the different ways in which human beings respond to and negotiate their body's (recurring) disruptive presence. By offering detailed accounts of everyday embodied experiences, empirical-phenomenological investigations such as ours can add to more theoretically oriented undertakings.

appearing body's telic demand, Leder focuses on patients' health-seeking behavior (obtaining professional help, making use of therapies and taking drugs). Our participants' work as they relate to their face's *dys-appearance*, however, has a more mundane dimension as well. Their efforts to anticipate, avoid, manage, confront, and endure their face's disruptive presence take place within daily settings and beyond the treatment and rehabilitation context. It is this type of practical bodily work that forms the heart of Young's phenomenology of female embodiment: her analysis departs from her observations regarding "bodily comportment, physical engagement with things, ways of using the body in performing tasks" in the context of everyday existence (2005: 144). This approach is novel exactly because it approaches the body as it is *done* in daily life (Weiss 2015). Following Young, we, too, highlight the mundane, continuing bodily work involved in respondents' efforts to make their *dys-appearing* face disappear.

This *doing* takes a particular form in the case of disruptions due to others' observations. As Young points out, the (internalized) awareness of the others' gaze may translate into an inhibited intentionality: a constrained manner of moving, interacting with objects, and occupying spaces that expresses a fundamental *I cannot*. As our findings regarding the different face as an observable bodily structure illustrate, this may also occur due to atypical facial appearance. The participants in our study conceal their visible difference in various ways, in order to evade others' unwanted attention. This suggests they simply *cannot* display their face outright in public—even though they are physically perfectly able to refrain from covering up. Interviewees' implicit, corporeal awareness of the other's gaze is enacted through the ways in which they carry their body, occupy spaces and orient themselves towards others. And although the way they *do* their gazed body may at times become habitual, this *doing* often remains very much self-reflexive.

Focusing on the body as it is *done* in everyday life, makes it possible to account for the full range of bodily experiences associated with facial variance. The atypical face (and often, the atypical body as well) is not either functional or visible. It is both—and in a fundamentally embodied way. Individuals with a facial limb absence confront various impairments (e.g., problems with skin insensitivity, uncomfortable sensations). At the same time, they also contend with their visibly different appearance.⁸ Both their impairment and "disfigurement" have the potential to disrupt their formerly easy, bodily connection with their world. These disruptions, whether due to physical impairment or visible facial difference, have a disabling effect, because both affect a person's *I can*. As we have discussed above, respondents develop bodily habits that target both their impairments and their visibly different appearance. By focusing on the ways in which the perceiving, sensed *and* observable face are all *done* in practice, our phenomenological exploration of the embodied aspects of facial difference makes it possible to address

⁸ The first- and third-person perspectives on the face can overlap and even conflict. For instance, respondents continue to wear tight and itching prostheses despite the discomfort involved, as illustrated by the quotes in the section "[Disruptive Sensations](#)". Taking both these perspectives on the body together, therefore, gives rise to new questions about the way individuals prioritize the atypical body's appearance over its capacity for perception and sensations, or its ability to act over its appearance. It is beyond the scope of this article to address these questions, but they may inform future research.

the functional as well as visible dimension of embodiment in concert, and thereby do justice to both these aspects of human existence.

This *doing* concerns not only the body's social, but also its physical context. Material objects and the material environment, from a phenomenological perspective, are not independent, objective entities, but rather appear as meaningful only within a person's lifeworld. This person, in turn, is constituted by her embodied involvement in her lifeworld. The body-subject and her lifeworld emerge simultaneously, as it were. The role of embodiment and materiality in co-shaping disability experiences is increasingly taken up in disability scholarship, signaling a move beyond the so-called *social model of disability* that focuses on the way the organization of society, rather than the impairment itself, effectively disables individuals. As Garland-Thomson has recently argued, for instance, disability cannot be reduced to either the body's physical make-up or an environment that fails to accommodate difference (2011; Weiss 2015). Instead, Garland-Thomson conceptualizes disability as a *misfit* between the body and its material context. By discussing both body and context in her analysis, Garland-Thomson's approaches disability as an inherently relational phenomenon, which involves shifting interactions between individuals' physical bodies, their spatio-temporal settings and the material objects they use.⁹ Accordingly, the disruptions the participants in our study encounter can all be seen as instances in which their facial difference (visual impairment, pain), environment (a hobby room, a cold winter day) and the various objects they use (teapots, prostheses) do not fit together well. But embodiment, as we demonstrated above, also includes a third-person perspective on the body. This means that *misfitting* occurs not only due to a mismatch between the body's physical capabilities and its environment, but also when the atypical body's unusual looks do not fit with social expectations and norms concerning appearance. Respondents' adjustment to facial difference through the development of new bodily routines can thus be seen as a process in which a new fit emerges between the body/face, various objects, spatio-temporal environments, and social contexts.

But how do our findings relate to other cases of facial difference? Of course, any answer we provide will be speculative, because studies into other conditions that affect the face generally do not consider the issue of embodiment. We nevertheless believe that, as in the case of facial limb absence, other forms of facial difference will likely cause an affected person's face to appear in her awareness due to various disruptions. Similarly, this person will most probably adjust to her atypical face by developing a new *I can*—mirrored by a new *I cannot*. This *I can/not* will take the form of a set of (implicit and explicit) bodily habits that aim to anticipate, avoid, manage, endure or confront her face's disruptive presence. The particular

⁹ For similar calls for a return of the body and materiality in disability studies, see (Paterson and Hughes 1999), Shakespeare and Watson (2001), Scully (2008) and Hoogsteyns and Van der Horst (2013). However, such calls do not involve recasting impairment as some sort of objective, straightforwardly physical state. In fact, nowadays most disability scholars—including those who argue for a return of the body in disability studies—dispute the very distinction between disability and impairment, and critique the social model for failing to adequately address the way the latter is socially and culturally constructed. For a recent outline of a sociology of impairment that takes into account the experiences of impaired individuals, the social and cultural construction of impairment, the role of diagnosis in the constitution of impairment, and the politics of impairment, see Sherry (2016).

disruptions individuals with other forms of facial difference confront will vary in accordance with the way their condition impacts the various roles the human face plays in everyday life. In Western societies, the face is the body part that is most associated with personhood and personal identity (Cole 1997). Facial appearance also forms a marker of a person's social position, enabling others to classify her such axes as gender, race, age, and ability, among others (Talley 2014: 13). In addition, in many cultures the face is vital for verbal and nonverbal communication, playing a central role in people's ability to experience and display emotions and so-called "inner" states such as happiness or scepticism (Black 2011; Edkins 2015).¹⁰ Finally, various sensory organs are located in the face and head, which are also the bodily seats of (vital) functions like chewing, swallowing and speech. Facial "disfigurement"—and its treatment—can interfere with all of these roles, although most conditions will presumably compromise some facial roles while leaving others unaffected. It is therefore important to further investigate the particular ways other forms of facial variance impact affected individuals' embodied being-in-the-world. Such investigations will not only add to our understanding of facial difference, but also allow for novel insights regarding the complex, elusive body part that is the human face.

Acknowledgements First and foremost, we wish to thank the participants in our study for sharing with us what it means to live with facial difference. The first author would like to thank Sara Rodrigues and Marjolein de Boer for their unflinching support—both in doing and writing philosophy, and in navigating academia and life in general.

Funding This study is funded by the Netherlands Organization for Scientific Research—NWO (VIDI-Grant 276-2Y16).

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¹⁰ For a discussion of the impact of facial paralysis due to Parkinson's disease in face-to-face communication, see Nijhof (2009, 2011). An account of the ways paralysis due to Bell's palsy and Mobius syndrome influences affected individuals' ability to express and experience emotions can be found in Cole (1997, 1998: 115–130, 2001).

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