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Doing facial difference

The lived experiences of individuals with facial limb absence

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Doing facial difference

The lived experiences of individuals with facial limb absence

Dissertation

to obtain the degree of Doctor at the Maastricht University, on the authority of the Rector Magnificus, Prof. dr. Rianne M. Letschert in accordance with the decision of the Board of Deans, to be defended in public on Friday 8 June 2018, at 12:00 hours

by

Gili Yaron
For my grandparents

Moshe and Ahuva (Luva) Cohen
&
Hillel and Dora Yaron
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Chapter 1

Introduction

An empirical-philosophical study into the everyday meaning of facial limb absence

Parts of this chapter appear in a manuscript that is currently under review with an international, peer-reviewed journal.
Gabriel lost most of the upper left part of his face to cancer. He is the 16th participant I interview for my study into facial difference, and when we first meet, I am almost used to seeing partly amputated faces. It all started ten years ago when a small white dot appeared on the tip of his nose, Gabriel tells me after I turn on the recording device. Although his physician surgically removed that part of his nose, the cancer kept spreading. Multiple rounds of medical treatment followed, during which his left eye socket and parts of his temple and forehead were amputated as well. Eventually, the growth stopped coming back: Gabriel has been ‘cancer free’ for over four years now. But he still has to deal with the effects of his disease—and its treatment—on a daily basis. Having but one eye, Gabriel has a limited visual field and problems with assessing depth and distance. In addition, parts of his skin are insensitive due to damage to his facial nerves. His appearance has also changed radically. He now wears a prosthetic device that closely resembles his lost facial areas, but has a somewhat artificial look. Gabriel’s ‘eyelid’ cannot blink, his glass ‘eye’ does not move, and the silicone ‘skin’ occasionally stands out against his ruddy complexion. When he removes his prosthesis, I find it hard to interpret what I see—and to fully focus on our conversation. Gabriel puts his prosthesis back on, and mentions he keeps older, worn-out devices in a box under the sink. He puts his collection on the table between us, arranging the items according to their size: from the smallest nose nibs he started with to the elaborate prostheses he uses today. It seems as if his face has gradually transferred from his head to the devices, I observe. While discussing the various effects of his facial difference, Gabriel repeatedly assures me that he “handles everything quite easily”. His cheerful manner and many jokes affirm his positive approach. And yet, I cannot escape thinking that having to live with a face that lacks parts must be a formidable challenge. 

(Field notes, March 2012)

As Gabriel’s story illustrates, the amputation of part(s) of the face is associated with the loss of various physical functions. Affected individuals’ outward appearance, too, is radically altered: a face that lacks parts presents an unusual image. These changes have a significant impact. After all, the face is vital for our ability to perceive the world, eat and drink, communicate with others verbally and non-verbally, breathe, display and experience ‘inner’ states (e.g. emotions, judgements), recognize ourselves, and be recognized as such. It is therefore hardly surprising that losing one or more facial limbs and/or areas forms a life-altering and often deeply distressing event. Those
who, like Gabriel, have undergone the amputation of part(s) of the face must contend with this loss for the rest of their life. But how exactly do these drastic alterations feature in the daily life of those who have a different face—a face marked by ‘disfigurement’—due to the absence of facial limbs and/or areas? In this thesis, I address this question by drawing on the experiences of individuals who have lost part(s) of their face, interrogating the role this loss plays in their everyday life. As I will discuss in the conclusion, such examination may offer a fresh perspective on what it actually means to live with a different face to both patients and health care professionals.

To investigate the impact of facial limb absence in affected individuals’ everyday life, I adopt an empirical-philosophical approach. As such, my argument relies on qualitative data acquired through interviews with individuals who lack one or more parts of the face, while also engaging with various scholarly sources ranging from phenomenology, the philosophy of technology, and (critical) disability studies. This introductory chapter outlines the background to the research underlying this thesis. In the following pages, I first discuss current medical and psychological approaches to facial difference, highlighting the need for an experience-oriented, qualitative study into facial limb absence. Next, I provide an overview of the theoretical literatures this study draws upon, and indicate how these might be used to gain insight into the embodied, technological, and social-cultural dimensions of facial difference. I then present my methodology, describing how I recruited participants, interviewed them, and analyzed the interview data. Finally, I briefly introduce the three chapters that present the study’s findings. Before laying out my theoretical and methodological approach, however, it is expedient to offer more information about the condition I came to define as ‘facial limb absence’.

A. FINDING THE RIGHT WORDS: FACIAL LIMB ABSENCE AND FACIAL DIFFERENCE

The absence of a facial limb or area can be traced back to various causes. First, affected individuals may have a congenital, craniofacial condition that results in their being born without one or both ears, or the nose (e.g. Treacher Collins syndrome, anotia/microtia, arhinia). Second, the loss of part(s) of the face may have resulted from exposure to acid, an explosion or fire, an attack by an animal, or an accident involving a sharp object. Finally, facial limbs or areas may be amputated in the course of the treatment of cancer occurring in the face, such as head and neck cancer (HNC), cancer of the eye and orbit, or skin cancer, as is the case for Gabriel.1

1 Head and neck cancer refers to a group of cancers that arise in the head or neck region, namely the nasal cavity, sinuses, lips, mouth, tongue, salivary glands, throat, voice box/larynx, skin of the head and neck or salivary glands (source: Dutch Head and Neck Society (Nederlandse Werkgroep Hoofd-HalsTumoren), available from: http://www.nwhht.nl).
Each of these conditions has its own distinct diagnosis, treatment, and rehabilitation trajectory. Thus, a congenital craniofacial anomaly may pertain to absent facial limbs, but also lead to an atypical development of facial bone structure. This means that an affected individual’s forehead, cheekbones and jaws may be shaped irregularly, leading to various functional problems (e.g. difficulties with chewing and swallowing, hearing impairments). While most people who lack part(s) of the face due to a congenital condition or an accident receive reconstructive surgery as part of their rehabilitation, many cancer patients also undergo radiation therapy and chemotherapy. The effects of such treatments may extend to organs and structures inside the head (e.g. radiation damage to saliva glands or the olfactory system, bone porosity). These variations matter. The cause of the condition resulting in the absence of part(s) of the face; specific functional issues; the type, number, and degree of intrusiveness of medical procedures; possible side-effects of these treatments; the location and size of the missing facial area—all of these are linked to particular types of experiences for the person involved. The same applies, of course, to various contextual factors, such as the age at which the condition became apparent or the accident took place, the responses of parents, partners, or friends, and the availability and quality of (prosthetic) rehabilitation.

Despite these differences, however, individuals who lack part(s) of the face tend to run into similar issues in their daily lives. These similarities pertain not so much to the specificities associated with their condition, but to the way it manifests in the context of their day-to-day existence. Thus, most affected individuals will have to deal with various functional problems. In addition, they need to cope with a sometimes radically altered appearance. This visible difference follows from the absence of part(s) of the face, as well as from the conspicuousness of various medical appliances worn to hide this absence from view, including gauze dressings, Band-Aides, eye-patches, or facial prosthetic devices. These functional and appearance-related issues arise as affected individuals go about their everyday activities, tasks, and projects, regardless of their specific condition or medical trajectory. This thesis, then, focuses on the various implications of facial limb absence in a day-to-day context, rather than on the specific condition underlying this absence or on the particulars of its diagnosis, treatment, and rehabilitation.

To denote these similarities in the situation of people who have lost part(s) of the face, I have chosen to refer to the participants in this study by using the phrase ‘individuals with facial limb absence’, which serves as shorthand for ‘individuals who lack one or more facial limbs and/or areas’. My choice for this term is also motivated by another consideration. In this dissertation, I explicitly avoid terms with derogative

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2 In fact, medical treatment of cancers occurring in the face does not always involve the amputation of facial areas: some patients can be treated successfully by means of radiation therapy or chemotherapy alone, or only undergo surgical removal of inner tissues.
associations such as ‘deformity’, ‘defect’, ‘malformation’, or ‘disfigurement’. Throughout their long and often unpleasant history, these terms, and others like them, have been used to demean persons who have an atypical appearance, and in particular, an atypical face. Their usage is not innocent, because they imply that there is something intrinsically flawed or diminished about the individual involved. Such language is part of a persistent, age-old tendency to regard people with facial and bodily variance as freaks, monsters, or lesser humans. Facial difference especially, according to commonly held views, marks the affected individual as possessing some undesirable character trait, represents a manifestation of past sins (either their own or those of forbears), or denotes immoral inclinations (Elks, 1990; Rumsey, 1997; Shaw, 1981; Thompson & Kent, 2001).

This way of framing visible difference is by no means a relic of the past; in fact, the face of many a villain in contemporary (Western) movies, books, or cartoons is scarred, atypically formed, or at least plain ugly (e.g. the Joker in the Batman movies; Voldemort the evil sorcerer in the Harry Potter book series). And when facially different persons depicted in popular media do not feature as antagonists in the story (for instance, when they are portrayed in television shows about ‘disfiguring’ conditions or on websites of international medical relief organizations), they are often presented as tragic, suffering figures. Such ubiquitous representations of facial difference converge into a ‘disfigurement imagery’, as sociologist Heather Laine Talley has argued (2014). A collection of widespread images of, and storylines about, people with facial variance, the ‘disfigurement’ imagery typically positions visible difference as “inherently horrific” (Talley, 2014, 30). Because it supposedly condemns affected persons to the unbearable fate of social death, ‘disfigurement’ requires a medical fix at all costs, no matter the risk. However, the assumed, intrinsic awfulness of facial difference is in fact exacerbated by the pervasiveness and availability of medical and technological interventions that target faces and images of faces in contemporary societies (e.g. ‘corrective’ rhinoplasty (nose job), photoshopping in advertisement and social media). Significantly, by making ordinary faces more beautiful—or, rather, more average—these interventions simultaneously render atypical ones less common and acceptable. In accordance with the (often implicit) biases imbuing the ‘disfigurement’ imagery, people with an uncommon face have long confronted—and indeed, still confront—various forms of ‘lookism’: appearance-related discrimination and exclusion in their personal and professional lives (Houston & Bull, 1994; Minerva, 2017; Stone & Wright, 2013; Tartaglia, Mcmahon, West, & Belongia, 2005).

My usage of ‘facial limb absence’ as a more neutral, descriptive term is by no means intended to somehow erase or gloss over this ideological history. Much of this thesis is in fact devoted to an interrogation of the ways in which negative assumptions about

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3 Historically, the pseudo-science of physiognomy ‘studied’ the supposed link between facial features of particular shapes and sizes and the character traits and morals these were assumed to reflect (Twine, 2002; Wegenstein & Ruck, 2011).

4 The link between appearance and virtue or character goes both ways: as many scholars have pointed out, individuals considered attractive are often regarded more positively—morally better, more accomplished, more honest and hardworking—than those with a less appealing appearance. For more on the so-called ‘physical attractiveness stereotype’, see (Dion, Berscheid, & Walster, 1972).
facial difference affect the person involved, profoundly shaping the way she inhabits her (social) world. As many have argued, the life of those who have atypical faces is actually complicated by these beliefs, rather than by the ‘disfigurement’ itself. Instead of neglecting these issues, the terminology deployed in this dissertation seeks to articulate life with facial difference in a less stereotypical, demeaning, and judgmental way. By closely attending to various factual situations encountered by the participants in my study, I aim to open up a space for discussing facial limb absence in its multifaceted and often quite mundane and practical nuances.

For these reasons, when indicating the particular condition of the respondents featuring in this dissertation, I use descriptive phrases such as ‘facial limb absence’, ‘loss/absence of part(s) of the face’, or ‘loss/absence of facial limbs and/or areas’. Referring to the general condition of having an unusual face, I use such phrases as ‘facial difference’, ‘atypical face’, or ‘facial variance’. When I cannot avoid using ‘disfigurement’ or ‘disfigured’, the single quotation marks serve to denote the problematic status of these words. In this, I follow guidelines provided by the Dutch ‘Stichting eigen gezicht’ [One’s Own Face Foundation] and the UK-based charity organization ‘Changing Faces’. These guidelines echo wider debates on appropriate language when referring to people who somehow differ from the norm. Activists associated with various social movements in Western countries of the past century (such as women’s liberation, civil rights, disability rights) have sought to critique and dismantle linguistic conventions that debase and set apart marginalized groups. Scholars and advocates within the disability rights movement, for instance, have promoted the usage of such terms as ‘mobility impairments’, ‘neurodiversity’, and ‘unusual bodies’, or the more general ‘people with disabilities’. These and other phrases serve to avoid stigma and stereotyping — while also unmasking commonplace normative assumptions about disability as a form of inferior embodiment that permeate common language (Garland-Thomson, 2005).

B. FACIAL DIFFERENCE IN THE MEDICAL AND PSYCHO-SOCIAL LITERATURE

Research on facial difference—including facial limb absence—generally takes either a medical approach or a psycho-social one. Medical studies typically focus on a specific condition’s etiology (cause), pathogenesis (development), as well as diagnosis, prognosis, and prevention (Murray 2002; Trainor, Dixon, and Dixon 2009). Often, such

5 These are both organizations for those who live with a broad range of conditions that affect the face. For the guidelines mentioned, see the websites of Changing Faces (www.changingfaces.org.uk/news-and-media/media-guidelines) and Stichting een eigen gezicht (www.eigengezicht.nl/components/documents). Although Changing Faces retains the use of the term ‘facial disfigurement’ because it is a “succinct general term” that is “widely understood”, it promotes the usage of neutral, descriptive language such as ‘facial difference’ or the name of a specific condition (source: www.changingfaces.org.uk/news-and-media/media-guidelines).

6 In order to underscore the humanity of those who live with disabling conditions, US-based activists have sought to ‘put people first’ by embracing the term ‘people with disabilities’. In the UK, the term ‘disabled people’ has become the norm because it indicates that people with impairments are effectively disabled by various societal and environmental barriers rather than by their difference (Martin, 2012).
studies also provide an analysis of a condition's incidence (the number of new cases over a given period), prevalence (the total number of cases at a given point in time), possible dysfunctions (problems with chewing, swallowing and speaking, sensorial impairments, chronic pain, facial paralysis), and preferred treatment options (Aarabi, Longaker, & Gurtner, 2007; Lowes, Bowcock, & Krueger, 2007). Other medical studies assess the quality of life (QOL) associated with specific conditions in quantitative terms, indicating how respondents score on such parameters as pain, mental health, and social functioning when compared to the general population (Murphy, Ridner, Wells, & Dietrich, 2007; Rasmussen, Ekholm, Prause, & Toft, 2012).

By including psychosocial issues, QOL studies point to the way facial difference impacts more than the physical capabilities of affected individuals. These psychological and social issues may be unrelated to individuals’ looks (e.g. depression and anxiety due to chronic pain or loss of good health, problems with communication), but more often than not they also involve appearance-related concerns. Medical and nursing journals target these concerns through publications devoted to how visible facial difference affects QOL (Djan & Penington, 2013; Dropkin, 1999; Vickery, Latchford, Hewison, Bellew, & Feber, 2003). These venues also publish studies examining specific appearance issues such as body image (Rhoten, Murphy, & Ridner, 2013) or coping strategies (Dropkin, 1989). In this way, healthcare scholarship on conditions that affect the face has in fact incorporated what has come to be called ‘the psychology of appearance’: a body of literature that investigates the psychological and social repercussions of living with visible (facial) difference.

The psychology of appearance can be traced back to the work of Frances MacGregor, a pioneering sociologist who was the first to systematically explore the psychosocial needs and concerns of ‘disfigured’ patients before, during, and after reconstructive cosmetic surgery (Macgregor, 1953, 1970, 1974, 1979). In the past twenty years, scholars and advocates have worked to establish the psychology of appearance as a field of inquiry that highlights psychological and social issues (e.g. social anxiety, avoidance behavior, psychosocial adjustment and coping, depression) confronted by those whose looks deviates from the norm (Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997; Macgregor, 1990; Rumsey & Harcourt, 2004, 2012; Thompson & Kent, 2001). This has resulted in a body of qualitative and quantitative studies exploring the psychosocial impact of such conditions as psoriasis (Kent & Keohane, 2001), vitiligo (Thompson, Kent, & Smith, 2002), cleft lip and/or palate (Stock, Feragen, & Rumsey, 2016), and facial paralysis due to HNC (Valente, 2009). In addition, scholars working within this field also review, develop, and test psychometric scales to measure appearance-related psychological distress in individuals with visible facial difference, meant to gauge patients’ suitability for cosmetic and reconstructive surgery, and evaluate surgery outcomes (Djan & Penington, 2013; Harris & Carr, 2001). Stressing the need for more support for affected individuals, appearance researchers also propose and evaluate various professional interventions (e.g. self-help, psychotherapy, social skills train-
CHAPTER 1

ing) that may address the psychological challenges they encounter (Bessell & Moss, 2007; Callahan, 2005; Jaspal, 2012; Muftin & Thompson, 2013; Newell & Clarke, 2000; Robinson, Rumsey, & Partridge, 1996).  

Medical and psychosocial studies on conditions that affect the face offer important insights into facial difference. The experiences of individuals with an atypical face involve more than the issues addressed in these studies, however. Impairments and visible differences can both severely impact the ways in which these individuals experience and relate to their own body, everyday objects, other people, and their surroundings. In other words: the meaning of facial difference takes shape in the context of everyday life. Although a number of qualitative studies about conditions that affect the face attend to the lived experiences of affected individuals (see, for example, Henry et al., 2014; McLean et al., 2015; Thompson & Broom, 2009; Thompson, Kent, & Smith, 2002), studies focus only on psychological issues and concepts (e.g. the attitudes, cognitive patterns, and behaviors of affected individuals; psychological pathologies). As a result, the full range of the day-to-day, lived experiences associated with facial difference—and, in particular, facial limb absence—is yet to be explored.

How, then, do individuals with facial limb absence experience and relate to their altered body and world in the context of their everyday life? In this thesis, I address this question by drawing on a qualitative study into the lived experiences of individuals who have lost part(s) of the face. The study’s design and my analysis of the empirical material are both informed by a range of theories on embodied meaning-making, the role of (assistive) technologies therein, and the social and cultural dimension of disability. In the next section, I introduce each of the theoretical bodies of literatures applied: phenomenology, postphenomenology, and disability studies.

C. EMBODIMENT, TECHNOLOGICAL MEDIATION, AND DISABILITY: A THEORETICAL FRAMEWORK FOR STUDYING FACIAL LIMB ABSENCE

To gain insight into the impact of facial limb absence in the everyday life of the participants in my study, it is necessary to investigate how they experience their difference. This includes the various ways in which this difference becomes present in their daily lives, and how they subsequently relate to this presence. By providing an account of the ways in which subjective experiences are endowed with meaning, phenomenology is uniquely suited for such an investigation. Emerging at the end of the nineteenth century, this philosophical tradition is still very much relevant today. Although its dif-

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7 Parallel to these medical and psychosocial approaches, there also exists a body of literature on the prosthetic rehabilitation of individuals who lack part(s) of the face. This literature includes technical studies on the construction of artificial facial limbs, but also studies that investigate patients’ satisfaction with their facial prosthetic devices (Chang, Garrett, Roumanas, & Beumer III, 2005; Jani & Schaaf, 1978; McBain, Ezra, Rose, & Newman, 2014; Parel & Tjellström, 1991).
ferent exponents highlight disparate aspects of human experience, they all share some central notions (Aydin, 2007). One such common idea is captured by phenomenology’s founding father Edmund Husserl’s call to ‘return to the things themselves’. By this, he means that phenomenology must consider the way human beings experience various phenomena that appear in awareness (Husserl, 1989). When approaching various phenomena that appear to us, Husserl claims, we ordinarily view them through commonly held prejudices, judgments, and beliefs informed by common-sense realism, positivistic science, or some other explanatory framework. Instead of falling back on such ‘filters’, phenomenology asks about the meaning of this thing for the experiencing person, and the way this meaning comes into being. This meaning is not given, but is rather constituted through a continuous process of sense-making (Sinngebung) in which human subjects relate to their lifeworld. By ‘bracketing’ our preconceived notions regarding objective reality, phenomenology enables us to return to the thing as it is experienced and interpreted at a primordial level, and simultaneously lay bare the process through which meaning-making itself emerges.

According to Husserl, the meaning of phenomena is constituted by the consciousness of the experiencing subject. However, consciousness is not just the passive capacity of receiving and assembling sensations and information. Rather, consciousness inherently involves an active directedness, an orientation towards something. This so-called ‘intentional’ structure of consciousness implies a certain relation between a subject’s capacity for experience (i.e. consciousness), and that what she experiences, be it a sensorial perception, a sensation, a thought, an emotion, or some other ‘content’. To be conscious, in other words, is always to be ‘consciousness of’, suggesting that ‘consciousness’ is better understood as a verb (bewusstsein) than as a noun. However, it is important to stress that phenomena are always already endowed with meaning. The particular meaning a phenomenon receives in the subject’s experiences inevitably stands in relation to a wider (personal, historical, social, cultural) context. Experiences are always already interpreted in relation to the meaningful context of a person’s lifeworld: subject and world cannot be thought apart, and indeed emerge together through this process of sense-making.

Drawing on Husserl’s work, Maurice Merleau-Ponty has shown that experience, intentionality, and sense-making are inherently corporeal (Merleau-Ponty, 2014). Human subjectivity is in essence an embodied subjectivity. Being the ground or ‘zero-point’ of our sensory-motor capacities, the body forms the here-and-now from which human beings reach out to their lifeworld, move through it, and involve themselves in all manner of activities. The body, in other words, both enables and structures meaning-making. As researchers working in the phenomenology of illness and disability have shown, (chronic) medical conditions may disrupt subjects’ formerly easy engagement with their life-world in various ways (Carel, 2012, 2016; Svenaeus, 2001; Toombs, 1988, 1995). The ill, disabled body ceases to be the self-evident basis for experience of and engagement with the world (Leder, 1990). No longer ‘passed over in silence’
The body then becomes the focal point of awareness. Phenomenological accounts of illness and disability tend to focus on disruptions brought about by bodily dysfunctions (e.g. impaired mobility, debilitating pain). But illness and disability may also be accompanied by an atypical appearance. The ways in which visible difference may trouble affected individuals’ everyday relationship to their body, others, and the world remain virtually unaddressed in this literature. In this thesis, I apply insights from phenomenology to investigate the meaning of both functional and appearance-related issues in the everyday experiences of those affected by facial limb absence.

The participants in my study, however, do not only deal with an altered face but also with various medical appliances such as facial prostheses, bandages, or eye-pads. What role do these aids play within their daily lives? As indicated by Merleau-Ponty, the body may incorporate different supplements and instruments, such as reading glasses or a walking stick, as it engages with the world (Merleau-Ponty, 2014). Philosopher Martin Heidegger, too, has famously discussed the way human beings relate to material objects in *Being and time* (1967). As he points out, we mostly do not notice our physical environment and the everyday artefacts within it, nor do we consciously reflect upon them. Instead, we mindlessly navigate spaces and handle various objects while directing the bulk of our attention elsewhere. Tools, in particular, appear as ‘ready to hand’ rather than ‘present to hand’. These artefacts will demand conscious awareness only when they break down or do not function as expected.

Taking up and expanding Heidegger’s analysis of tool usage, philosopher of technology Don Ihde explores several modalities of human-technology interactions, discussing how various everyday artefacts may ‘mediate’—interfere with—the relationship between body and world (Ihde, 1990). His approach, which has come to be called postphenomenology, has proven influential in contemporary philosophy of technology, inspiring a wide range of publications on the ways in which modern-day technologies affect our existence (Rosenberger & Verbeek, 2015; Verbeek, 2005). Recent contributors have discussed how human beings and intimate technologies, such as cochlear implants or implanted neuromodulation devices, may ‘hang together’ (Besmer, 2012; Dalibert, 2016). But how do postphenomenology’s insights regarding technological mediation translate into an analysis of facial prostheses? In this dissertation, I use postphenomenological concepts to examine how these devices affect the relationship between their users, other people, and the world.

Any effort aimed at better understanding the ways in which atypical embodiment—including facial difference—impacts affected individuals, must include a broader, disability studies perspective on the meaning of societal disability. Accordingly, my analyses of my respondents’ experiences are informed not only by phenomenology and postphenomenology, but also by key concepts from (critical) disability studies. The disability movement originated in the 1970s, when activists inspired by the civil rights movement of earlier decades started claiming the same
right to participation, equal treatment, and nondiscrimination demanded by other marginalized or oppressed groups such as women or people of color (Meekosha & Shuttleworth, 2017). Since that time, disability activism has been accompanied by a growing body of academic literature found under the heading of ‘disability studies’, most notably in the UK and US but also elsewhere (Blume and Hiddinga 2010, Hoppe, Schippers, and Kool 2011). Rejecting what came to be called ‘the medical model of disability’, activists and scholars alike protested the ways in which medicine and policy reduce disability to an essentially individual, physical fact. By viewing disability as a ‘problem’ belonging squarely in the field of health care, however, this approach neglects the agency and autonomy of people with disabilities and fails to address the widespread oppression of the disabled. This critique included calls for more voice for people with disabilities in research and policy, as is expressed in the movement’s slogan ‘nothing about us without us’.

To address how these social, cultural and economic issues shape the meaning and experience of disability, disability scholars introduced an alternative explanatory model termed ‘the social model of disability’ (Oliver, 1990, 2013). Distinguishing between ‘impairment’ and ‘disability’, this model proposes that the limitations experienced by persons with variant physical, cognitive, or psychological functioning flow mostly from society’s failure to accommodate the needs of all its members. This means that a disability is no longer seen as an individual problem residing in the atypical person’s body, mind, or psyche, but rather as a consequence of the way modern societies are organized. Such societies, as disability scholars and activists argue, are infused with ‘disabilism’: implicit and explicit stigmatization, discrimination, and oppression of the disabled. As a result, individuals with various impairments are barred from fully participating in modern-day societies. Barriers to participation are twofold. First, widespread negative beliefs about disability represent disabled persons as essentially faulty and inferior, both for the impairments they have and their dependency on assistance. Second, disabilism is materialized through the organization of everyday, modern life. Thus, the lay-out of the built environment renders it accessible only for the typically embodied (e.g. buildings that are accessible only by stairs cannot be entered by wheelchair users). In addition, the standardized procedures and schedules that govern the day-to-day operation of contemporary life are not accommodating to people with disabilities (e.g. work meetings planned in short succession do not take into consideration the amount of time a visually impaired person may need to get from one location to another). Both of these types of barriers make it difficult for disabled people to navigate everyday life and take part in meaningful activities.

The social model of disability has opened the way for a variety of critical analyses of the societal and cultural meanings accorded to disability. As such, disability studies promises to offer a distinctive take on the everyday impact of that facial limbs absence. Disability scholars have only just started to investigate the issue of visible facial difference, however, as is testified by the small number of publications devoted to atypical facial appearance as a disability issue (see, for instance, Garland-Thomson,
2006, 2009; Talley, 2014). In particular, the lived experiences of those who have an unusual face have not yet been explored systematically from a disability studies perspective. In this thesis, I make use of ideas developed by disability scholars to critically interrogate the meaning of visible difference in everyday social interactions.

Phenomenology, postphenomenology, and disability studies each offer tools to understand the experiences of the participants in this study as they experience and relate to their facial limb absence in the context of everyday life. Phenomenology, and in particular, the phenomenology of the body and of illness and disability, allows for insights into the ways in which these individuals’ being-embodied-in-the-world has changed after they have lost part(s) of their face. Postphenomenology helps grasp the role of the facial prosthesis herein. Disability studies, finally, brings into focus the role of disablist societal norms in their exchanges with others. As will become clear in the following chapters, I do not only draw on these three scholarly traditions to analyze facial limb absence, but also use empirical data to stretch the boundaries of each. Before diving into the ways in which my findings resonate with and build upon these theoretical frameworks, I will first discuss my methodological approach in the qualitative part of this study.

D. INTERVIEWING, ANALYZING, WRITING: FROM DATA TO THESIS

Study design & participants
The empirical study underlying this thesis took the form of a qualitative study into the experiences of individuals who have lost part(s) of their face. In the course of this study, I interviewed twenty individuals (eight women and twelve men, ranging in age from 42 to 84) who lack one or more facial limbs or areas. Of the participants in the study, six have had their nose amputated, ten lost their orbita (the eye socket, including the eye and sometimes part of the brow), three lack a larger facial area (nose and orbita, as well as the temple, parts of the forehead, parts of a cheek, or the upper lip), and one misses a small segment of the upper cheek. In the case of nineteen individuals, the lost part of the face was amputated in the course of medical treatment for cancer occurring in the face. One interviewee experienced a fireworks accident. The individuals in my sample all make use of a facial prosthetic device to cover the amputated area. This so-called facial prosthesis is an artificial facial limb made from silicone, tailor-made for its users by specialized prosthetists. It is attached to the amputation site by means of medicinal glue, magnets, or by locking into the cavity. Next to the facial prosthesis, most participants also use other medical aids to hide the missing facial area from view, including such appliances as bandages, Band-Aides, gauze dressings, and eye patches.

Recruiting the participants & conducting the interviews
The respondents were recruited through a prosthetics service facility operating within a specialized cancer medical center in a large city in the Netherlands. This facility,
one of several in the Netherlands, caters to the needs of approximately 140 patients throughout the country. The clinic’s clients were first approached through a quantitative study into the quality of life of individuals who wear a facial prosthesis, initiated by the hospital’s HNC department. This study, conducted in 2011, consisted of a standardized questionnaire that was sent to each of the service facility’s clients, and that also included an additional item asking the receiver to indicate whether they would be willing to be interviewed about their experiences with their facial prostheses. Of the 71 participants that submitted a completed questionnaire, forty had consented to being interviewed. In the fall of 2011 and the winter of 2012, I approached them all by telephone to set a date for the interview. By that time, a number of the respondents could no longer be reached, and others decided to withdraw from the study. I interviewed the twenty remaining participants in two rounds: in late 2011, and early 2012.

Most of the interviews were conducted in respondents’ homes, but in one case I met a participant at a café in the village where this person was living. Many of the interviews also included the respondents’ spouse, who added observations and anecdotes on what it means to live with facial limb absence. In the beginning of each interview, I explained the purpose of the study, and indicated that interviewees would be anonymized in any publication resulting from the research to protect their privacy. I also asked each participant to read and sign an informed consent form, and stressed the fact they could interrupt or terminate the interview at any time, and could opt to retract their participation in the study retrospectively. During the interviews, I made use of a topic list compiled in advance. This topic list was designed in consultation with my daily supervisor, to prompt participants to discuss how their facial difference and the usage of the facial prosthetic device affected their everyday life. After having gained a basic understanding of the issues encountered by the respondents following the first three interviews, I adapted the topic list to better reflect my growing insight in the challenges associated with facial limb absence. I revised the topic list again after the tenth interview, to focus more on the usage of medical aids other than the prosthesis. The interviews lasted between 45 and ninety minutes each, and were all tape-recorded and transcribed verbatim.

While preparing for the interviews, I visited the medical center itself, accompanying one of the specialists as he discussed the diagnosis, prognosis, or treatment trajectory with several patients. During the data collection and analysis phase of the study, I also visited three different prosthetics service facilities in the Netherlands and Belgium. Here, various resident prosthetists told me about the field of (facial) prosthetics and its history, demonstrated how different types of facial prosthetic devices are constructed and attached, and discussed their approach to new and returning clients. In 2014, I also attended an appointment with a returning client who was outfitted with a new nasal prosthesis at one of these facilities. In 2016, I spoke to an oncology nurse working with HNC patients at another medical center in the Netherlands, who told me about her work with these patients from the moment of diagnosis and well into their
treatment and rehabilitation. Although I did not formally record and analyze these conversations and observations, they enabled me to form an impression of the clinical trajectories traversed by individuals with facial limb absence.

**Analyzing the data & writing up the findings**

Having completed the interviews, I proceeded with analyzing the results. In this, I followed the method of thematic analysis (Braun & Clarke, 2006) while also taking direction from interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009). Inspired by the phenomenological tradition, this method for the narrative analysis of interviews puts special emphasis on the ways interviewees make sense of their own subjective experiences, in particular those following a life-changing event. Accordingly, my analysis focused on participants’ stories about how they experience and relate to their radically altered face and lifeworld.

I started the analysis by carefully reading and summarizing the first five interviews, in order to get an overall sense of what it can mean to live with facial limb absence (Smith et al., 2009). As I found, two distinct themes recurred throughout these five interviews, forming an initial entry point into respondents’ experiences. The first theme pertained to the various new bodily habits participants developed as they gradually adjusted to their different face following the amputation. The second theme involved the different ways in which interviewees adapted (filed, cut, dyed, etc.) their facial prosthesis. I then set out to expand my analysis of these themes, a process I will detail below. While further developing the second theme, I identified a third theme in the interviews: the various ways in which respondents’ facial difference manifested visibly when they use different medical appliances to cover their absent facial area, or refrain from doing so. This initial analysis was heavily influenced by my ongoing reading of what would become the theoretical frame of this thesis: key texts in the philosophy of the body, illness, and disability, in postphenomenology, as well as in disability studies. Thus, the phenomenological literature offered me a particular lens to explore how people with facial limb absence relate to their own body and, through their body, to their lifeworld. Postphenomenological research provided me with a frame to investigate the mediating role the facial prosthesis plays in the relationship between humans and their world. Disability studies scholarship, finally, allowed me to critically interrogate the role of visible facial difference in everyday social interactions.

After having identified the three main themes in the first five interviews, I turned to the next stage of analysis: looking for more specific patterns underlying each theme (Braun & Clarke, 2006). To this end, I read, reread, and summarized all of the interview texts, highlighted quotes relevant to the particular theme and grouped together similar quotes. Thus, for the first theme—respondents’ new bodily habits—I identified three distinct types of habits which they had developed while adjusting to various challenges presented by their altered faces. For the second theme—the adaptations participants made to their prostheses—I categorized different adaptations, and pon-
dered the rationale behind them. For the third theme—the particular visibility of the different ways in which interviewees display their face—I mapped out four ways in which they displayed their faces to others. By systematically ordering the interviews in this way, I was in effect looking for similarities within each interview (horizontal analysis) and between interviews (vertical analysis) for each theme, and reflecting on what these similarities revealed about the meaning of facial limb absence in respondents’ everyday life. In the process, I was careful to remain attentive to experiences that did not fit easily with these patterns, and thereby preserve the particularities and tensions present in respondents’ accounts. Writing draft upon draft of interpretation, I gradually developed an understanding of the ways in which participants’ facial difference impacted their everyday life. Although my presentation of the analysis process here may suggest otherwise, this was hardly a smooth, linear procedure: much of the work actually involved a great deal of groping around, not always in a very deliberate or straightforward manner.

The following pages contain the results of my analysis: three chapters exploring what it means to live with a face that lacks one or more parts, and to use various medical aids to hide this absence. In the second chapter, I look into the embodied aspects of facial difference by highlighting the various bodily habits that the participants in my study develop as they gradually adjust to their altered face. In the third chapter, I examine the role of the facial prosthesis—essentially a ‘cosmetic’ device—in the everyday life of my interviewees. In the fourth chapter, I investigate respondents’ ‘visibility experiences’ by zooming in on the distinct ways in which they display their face to others in different social contexts. In the discussion chapter, finally, I assemble the common threads recurring in the three empirical chapters—embodiment, disability, the usage of assistive devices, functionality, ‘disfigurement’, everydayness, materiality, visibility, social interaction, the cultural meanings of visible difference, and normativity—by demonstrating how they all involve the ‘doing’ of facial difference in affected individuals’ everyday lives. Throughout these chapters, I provide an answer to the question driving this study: what is the meaning of facial difference in the everyday life of individuals who lack one or more facial limbs and/or areas?


REFERENCES CHAPTER 1


Chapter 2

Facing a disruptive face

Embodiment in the everyday experiences of ‘disfigured’ individuals

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A. 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, Ridner, Wells, & Dietrich, 2007), on the treatment of these conditions, or on the rehabilitations of affected individuals (Leon-Villapalos, Jeschke, & Herndon, 2008; van der Molen, van Rossum, Burkhead, Smeele, & Hilgers, 2009). By contrast, researchers working in the emergent field of the psychology of visible difference aim to address the appearance-related concerns of individuals with atypical facial (Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997; Rumsey & Harcourt, 2012). They investigate such topics as body image and self-esteem (Dropkin, 1999; Rumsey & Harcourt, 2004), coping strategies and the merits thereof (Dropkin, 1989; Jaspal, 2012; Koster & Bergsma, 1990; Stock, Feragen, & Rumsey, 2016); and the efficacy of (professional) interventions such as self-help, social skills training and psychotherapy (Callahan, 2005; Konradsen, Kirkevold, McCallin, Cayé-Thomasen, & Zoffmann, 2012; Muftin & Thompson, 2013; Robinson, Rumsey, & Partridge, 1996).

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; Leder, 1990; Merleau-Ponty, 2014). 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 (Aho & Aho, 2008; Carel, 2012; Leder, 1990; Toombs, 1995). But how does such disruption manifest itself in the case of facial difference?1 In this article, we seek to answer

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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 (Levinas, 2003). For Gilles Deleuze and Felix Guattari, the face produces faciality: a mechanism that signifies and subjectifies the body (Deleuze & Guattari, 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 (Goffman, 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.
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.

B. 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 lifeworld. 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 (Carel, 2012; Merleau-Ponty, 2014: 70). 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 (Leder, 1990: 13, 22; Merleau-Ponty, 2014: 96-97, 150-151). 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 (Leder, 1990: 20-22; Merleau-Ponty, 2014: xvii). In its outward orientation, the body may incorporate different supplements, tools, and extensions (Leder, 1990: 33-34; Merleau-Ponty, 2014: 139, 144-145; Murray & Harrison, 2004). Embodiment thus denotes the simultaneous constitution of the (extended) body-subject, and the meaningful, material environment in which she finds herself.

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: 20-22, 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 (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 health care 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 aids 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 (idem, 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 (idem, 1990: 83, 70, 81). For Fredrik 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, 2014; Slatman & Yaron, 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 (Sartre, 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 (Dolezal, 2015; Sartre, 2007: 347-350). 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, 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).

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.
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.

C. 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 twenty 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 aids 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 ninety 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.

To interpret respondents’ accounts we applied a thematic analysis to the interviews (Braun & 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 consulta-
tion 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, valuates 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.

D. 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. (…) You 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. (Lisa)

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’ (Schütz, 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: 175-176.). 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

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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.
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 buildup of vapors in his workroom. 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
CHAPTER 2

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 unhome-like and strange (Svenaeus, 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 lon-
ger 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 nine degrees Celsius can be quite painful. Going outside, she experiences a sharp ache in the lower area of her face:

Yes, from nine 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 Dora’s 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 sever 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:

*[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. (John)*

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 aids they use to cover their facial difference can be more or less conspicuous. Due to their color and
placement, such covers as gauze dressings, eye patches, or Band-Aides 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 (Goffman, 1963). 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). 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

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4 See Yaron, Widdershoven, & Slatman (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 endeavor to maintain each other’s social face (Goffman 1967: 10-11).
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 (Leder 1990: 93; Sartre, 2007: 347-350), 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, 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:

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\text{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:

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\text{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:
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. (Walter)

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 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.

E. 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 inter-

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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.
fers 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 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). 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-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

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.
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. 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 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

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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.
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 (Garland-Thomson, 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, spatiotemporal 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 disruptions individuals with other forms of facial difference confront will vary in accordance with the

9 For similar calls for a return of the body and materiality in disability studies, see (Paterson & Hughes, 1999), (Shakespeare & Watson, 2002), (Scully, 2008), and (Hoogsteyns & 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).
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 along 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 skepticism (Black, 2011; Edkins, 2015). 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.

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).


REFERENCES CHAPTER 2


Chapter 3

Recovering a ‘disfigured’ face

Cosmesis in the everyday use of facial prostheses

A. INTRODUCTION

Prosthetic devices that replace an absent body part are generally considered to be either functional or cosmetic. According to the function-cosmesis divide, functional prostheses aim to restore (some degree of) physical functioning to the user—her ability to walk or grasp, for instance. Cosmetic prostheses, by contrast, set out to emulate the missing body part’s looks. Cosmesis, in this regard, denotes the attempt to restore a ‘normal’ appearance to bodies that lack (one or more) limbs. As anthropologist and prosthesis user Steven Kurzman writes: “In a social context, artificial limbs are ideally invisible in order to facilitate mimicry of nonamputees and passing as able-bodied” (2001, 379). Despite the term’s associations with make-up and aesthetic surgery, cosmesis in prostheses is anything but frivolous or trivial—indeed, the importance of cosmesis for users of artificial limbs suggests the function-cosmesis division may be problematic.

But how do cosmetic prostheses establish a normal appearance? Remarkably, the majority of studies on prostheses do not engage with this question: authors routinely mention cosmesis as one of the possible features associated with artificial limbs, and, like Kurzman, often link cosmesis to users' ability to ‘pass as normal,’ but rarely offer in-depth explorations of this issue. In this paper, we aim to further investigate cosmesis by examining a specific type of artificial limb: the facial prosthesis. Such artificial noses and eye sockets are clearly cosmetic par excellence—they do not compensate for lost abilities or senses, but (attempt to) restore normal facial appearance. As such, these devices form a perfect case study for our investigation. Even though they are worn merely for the sake of appearing ‘normal,’ it is quite clear that these artifacts are nevertheless indispensable for the people who use them. These are people who lack an ear, eye socket, or nose due to trauma or disease, and wear a facial prosthesis to cover and conceal this absence.

In order to gain insight into how cosmetic prostheses establish normal appearance, we draw on the stories of users of facial prostheses. Given that these prostheses are first and foremost devices worn on the body, an adequate analysis of their cosmetic role requires an understanding of the ways in which bodies and technologies are bound up together. We thus interpret users’ stories against the background of the work of disability researcher and Actor-Network theorist Myriam Winance, as well as of postphenomenology—a field of inquiry within the philosophy of technology focusing on the embodied aspects of human-technology relations. Informed by these sources, our

1 Although we use both Winance’s ANT-approach and postphenomenology in accounting for the experiences of people with facial limb absence, the two theoretical endeavors do not always sit well together. In particular, there is an ongoing and important debate between ANT and postphenomenology regarding the status of first-person experiences. Whereas scholars in postphenomenology roughly follow classical phenomenology in departing from and analyzing first-person subjective experiences, ANT researchers prescribe a radically symmetrical approach to subjects and objects, which precludes attributing experiences any special status. For more elaborate discussions of this point, see, for instance, (Ihde, 2002; Lettow, 2011).
analysis will shed light on the meaning of ‘cosmesis’ and ‘passing’ in the use of facial prostheses, while ultimately also complementing the postphenomenological theoretical framework.

B. ON TECHNOLOGICAL MEDIATION: CONCEPTUALIZING THE USE OF ‘INTIMATE’ TECHNOLOGIES

Facial prostheses can be considered a kind of ‘intimate technology.’ Intimate technologies are artifacts that are worn in close proximity to the body, are embedded within it, or involve the personal life of their users. Within Science and Technology Studies (STS), researchers such as Annemarie Mol (Mol, 2002; Mol & Law, 2004), Nelly Oudshoorn (Oudshoorn, 2015), and Jeanette Pols and Ingunn Moser (Pols & Moser, 2009) have recently all applied an empirical approach to their explorations of the co-constitution of such technologies and the embodied, situated selves that use them. Myriam Winance’s work on the ways by which this co-constitution is achieved in the case of wheelchairs resonates with this scholarship. As Winance shows, these devices and the bodies of the people who use them must be adjusted to each other during a process of ongoing, laborious negotiations, which involve not only the chair and its user, but also family members, partners, and friends, various experts and knowledges, the users’ environment, and so forth (Winance 2006, 2010). As they share the adjustment work, both the wheelchair and its user can be said to take each other’s shape.

Understanding how the usage of devices impact upon users’ lives, however, also requires an understanding of technology’s role in shaping human experience. In his well-known work, Don Ihde has explored several ways by which human beings relate to technologies (Ihde 1990, 2002). Among other things, Ihde’s postphenomenological analyses show how technological artifacts become incorporated into the body of their users. Technologies, when embodied in this way, in fact extend their user’s sensorial capacities: their sense of sight, hearing, etc. In this so-called ‘embodiment relation’, the technology can be said to mediate between user and world. Ihde’s ideas have proven fruitful for many who seek to understand the relationship between humans, technologies, and the world. His concepts of technological ‘extension’ and ‘mediation’, in particular, have proven influential in contemporary philosophy of technology. To name but a few recent contributors using these notions: Susanne Lettow addresses the body’s absence in the philosophy of technology (Lettow, 2011), Kirk Besmer analyzes the ways in which Cochlear implants are incorporated by their users (Besmer, 2012), and Lucie Dalibert discusses the difference between incorporation and embodiment by examining a neuromodulation technology called ‘spinal cord stimulation’ (Dalibert, 2016). Indeed, the fact that the postphenomenological framework has proven fruitful for current analyses of the role of technological devices in human life, is evidenced by the recent publication of an edited volume dedicated to new scholarship on human-technology relations (Rosenberger & Verbeek, 2015).
CHAPTER 3

At present, one of the most notable proponents of postphenomenology is Peter-Paul Verbeek, who has expanded the scope of Ihde’s work in order to examine how artifacts mediate not only the perception of (aspects of) the world, but also praxis or action. Having done so, Verbeek draws out the implications of technological mediation for technology design (Verbeek, 2005). In his latest work, this author uses this distinction between perception and action in order to expound upon the inherently ethical dimensions of such mediation: using the concept of ‘nudge’ introduced by Richard Thaler and Cass Sunstein (Thaler & Sunstein, 2009), Verbeek explores the ways in which technologies subtly influence users’ behavior in ways deemed desirable by designers (Verbeek 2006, 2011). Yoni Van Den Eede, finally, has used Ihde’s work to examine the ‘in-between’ nature of technologies (Van Den Eede, 2011). Specifically, Van Den Eede has argued that Ihde’s notion of ‘transparency’ in the use of an instrument—the fact that objects ‘disappear’ from a user’s experience as she focuses on the task at hand—is an inherent feature of technology as such.

The conceptual tools provided by Winance, Ihde, Verbeek, and Van Den Eede prove instrumental for our goal of making sense of how artificial facial limbs establish normal appearance. Before we apply their insights to the topic of cosmesis in prosthetics, we first set the stage by providing some background information about these devices, as well as a short exposition on the study upon which this article is based. We then proceed by analyzing respondents’ stories about their experiences with facial prostheses, focusing on their attempts to achieve a proper fit between their face and their prostheses, the technological transparency such a fit enables, and the ways in which transparency comes to play in users’ everyday interactions with others. Our findings, as will become clear, resonate with the work of the scholars discussed above, but also challenge several common assumptions about the ways in which users and technologies interact.

C. THE FACIAL PROSTHESIS

Facial prostheses are silicone devices that are worn in order to replace an absent facial limb or area. In most cases, the original facial limb was amputated in the course of the medical treatment of head and neck cancer (HNC) or due to an accident. Facial prostheses are designed to closely resemble the appearance of the missing facial part. Most commonly, these prostheses substitute for an absent nose or ‘orbita’ (the eye-socket, including a ‘shell’ or glass eye, and perhaps an eyebrow as well). In some cases, so-called ‘complex prostheses’ will replace a larger facial area, consisting of several facial limbs. Rarely, facial prostheses will replace (part of) the cheek. Facial prostheses are usual-

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2 Facial prostheses are referred to differently throughout the literature, and the various practitioners interviewed used different terms. The most common alternatives are ‘maxillofacial prosthesis’ and ‘epithesis.’ For reasons of clarity, we will use the most straightforward term, ‘facial prosthesis.’
DOING FACIAL DIFFERENCE

ly attached to the face by means of medicinal glue or magnets that adhere to metal pins implanted into the face. Facial prostheses are custom-made at specialized service facilities which operate within or in conjunction with hospitals and medical centers or centers for (special care) dentistry. When outfitting a prospective user with a facial prosthesis, prosthetists aim to achieve as close a fit as possible between the user’s face and the device. This means that the prosthesis’ attachment to the face is secure, that its color and texture match the user’s skin, that it is comfortable and that its shape resembles the replaced facial limbs as closely as possible. During intake at the service unit, a cast is made of the prospective user’s face in order to determine the shape of the amputated area. The prosthetist then models a prototype of the missing limb upon this cast. This prototype is used in order to make a mold—the ‘negative’ used in the production of a series of facial prostheses. The prosthetist then mixes together silicone, colorants, and fibers (which mimic small capillaries in the facial skin) in order to approach the shade of the prospective user’s complexion, and presses this mixture into the mold. If the device is to be attached by means of magnets, metal pins are also inserted into the silicone. Next, the silicone mixture is baked in an oven. Once it is finished, the now firm prosthesis receives some final tweaking on the user’s face. After a period of usage of about six to twelve months, prostheses become worn-out: they become stiffer, discolored or frayed. Users will then receive a new prosthesis from the same cast. When the cast itself is worn-out, the design process is repeated from the beginning.

D. PARTICIPANTS, RECRUITMENT AND ANALYSIS

This article is based on a qualitative study of how people who lack a facial limb and use a facial prosthetic device experience and make sense of their altered appearance and their prostheses. After receiving ethical clearance for the study (file number NL35486.031.11), the first author interviewed twenty individuals who wear a facial prosthesis (eight women and twelve men) who were recruited through the Dutch service unit from which they receive their prostheses. In this group, six respondents make use of nose prostheses, ten carry orbita prostheses, three wear complex prostheses, and one uses a cheek prosthesis. Of the interviewees, nineteen have undergone the amputation of (a) facial limb(s) due to HNC and one had an accident that damaged his face.

The participants in our study were all interviewed at home or in another familiar setting by the first author, sometimes together with their partners. The interviews all lasted between 45 and ninety minutes, and were tape recorded and then transcribed verbatim. Analyzing the interview texts, the first author performed a thematic analysis in order to understand how respondents experience and make sense of their faces and prostheses. In the process, she received feedback from the other authors. In addition to these interviews, the first author also performed observations in three different prosthetics clinics in both the Netherlands and Belgium, and talked with the prosthetists.
working in these clinics. These observations and conversations served to further our understanding of the rehabilitation trajectory on which the users of artificial facial limbs embark, and yielded insights into the nature of different types of prostheses, their design, manufacturing, and maintenance.

Leaving the clinic with a facial prosthesis does not so much mark the end to the story but rather its beginning: the prosthesis will start playing its role in the life of its user within the context of their ongoing projects and daily activities. It is in this context that the facial prosthesis appears as a cosmetic device. In order to understand how cosmesis establishes a normal appearance, it is thus necessary to explore how prostheses are put to use within these everyday settings. In the following sections, we explore this usage by presenting users’ stories about their daily lives with their facial prostheses.

E. ACHIEVING A PROPER FIT

By emulating the lost facial limbs it sets to replace, facial prostheses do not merely shield the amputated facial area from view. The gauze dressings, Band-Aid, or eye-patch many users wear to bed or in the privacy of their own home would be more than adequate in this regard—and are more comfortable to boot. The people interviewed for this study nevertheless prefer to wear a facial prosthesis, because this device allows for a semblance of facial normality that is unavailable when using a bandage. Normal facial appearance, however, is no done deal, easily accomplished by the simple act of putting on the prosthesis. It is a hands-on, ongoing outcome that requires users to monitor, tinker with, and adjust to their prostheses in order to make sure the device fits their face properly. Gaining insight into how facial prostheses facilitate normal facial appearance, therefore, requires an understanding of how users attain a good fit. In this section, we make use of the work of Winance in order to explore what we call the ‘fitting practices’ of the participants in our study.

The different ways by which respondents accomplish a good fit between their artificial facial limb and face can be clustered into three groups: (a) fitting practices that target the prosthesis itself, (b) fitting practices that require the use of different props, or (c) fitting practices that involve adjustments to users’ own face and body. The story of

3 Achieving a good fit does not only involve the visible body, but also requires that the prosthesis is felt to be comfortable when worn upon the skin. Many users report that, especially after a period of prolonged usage, the prosthesis tends to chafe or press into their face, due to the device’s tight fit. It is beyond the scope of this article to discuss this tactile dimension to fit, as we focus on the visual aspect of the fit between the device and its wearer. The issue of comfort and tactility in prosthetics, however, remains an important one.

4 It is important to offer a qualification as to the outcome of these endeavors: some users of artificial facial limbs manage to achieve a good fit, while others do not. Moreover, whether they manage to establish such a fit depends not only on their own efforts, but also on factors they cannot control (e.g. the form and size of the amputated area, lighting conditions). This means that even those users who are adept at accomplishing a good fit are not always able to guarantee it.
Timothy, a man who wears a prosthesis over the hollowed-out area of his left cheek, serves to illustrate how the prosthesis itself is targeted in users’ efforts to facilitate a good fit:

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\[I\]\text{ often touched my face with my left hand, just to feel whether it was still there (..); since we have been talking, I’ve probably done this [presses the prosthesis into place] twice already. (..) Because I’m afraid that it, now that I’m talking a lot, will somehow come off. (Timothy)\]
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Touching the prosthesis regularly, for Timothy, serves to ascertain the device adequately hides the amputated area in his face—something he considers extremely important:

\[
\text{When I’m at a restaurant and I feel that it is [coming] loose (..) well I find it awful when that thing is just dangling there. That is terrible, I feel horribly self-conscious. (Timothy)}
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Timothy’s monitoring finger forms a part of his efforts to avoid baring his scarred and dented cheek to others. Similarly, other respondents check their device’s hold visually by repeatedly checking their mirror image. One respondent, for instance, uses a small mirror attached to a strap on the inside of his wrist for this purpose. Fitting practices that target the prosthesis itself ensure the wearer’s facial difference is successfully hidden from view.

But a proper fit involves more than the prosthesis’ secure hold on the face. A misaligned, gaping, or discolored device, although not actually revealing the amputated area underneath, will still refer to the ‘disfigurement’ by betraying the prosthesis’ artificiality. For this reason, many users also strive to conceal the prosthesis’ artificiality, so that the device does not ‘stand out.’ Their efforts include caring for and maintaining the prosthesis, which keeps it from deteriorating, but users also tinker in different ways with the device. One respondent, for instance, always makes small horizontal cuts along the lower corners of older nasal prostheses that have lost their suppleness. These cuts divide the stiff borders of the prosthesis into two flaps, somewhat resembling a fishtail, which are able to independently follow his facial movements when he speaks animatedly, laughs or eats. In this way, this man prevents the device from gaping at the sides. Such tinkering serves to conceal the concealing device itself: it aims to make sure that the prosthesis does not give itself—and its wearer’s very need for cover—away.

The second cluster of fitting practices consists in the usage of different props that serve to conceal the prosthesis’ artificiality and thereby help establish a good fit

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5 The name ‘Timothy,’ like all the other names we use below, is fictitious, so as to guarantee respondents’ privacy.
between the prosthesis and the face of the wearer. Some respondents, for instance, make use of thick-framed (sun)glasses in order to hide the edges of the device, where the difference between skin and silicone is most apparent. Others strive to realize a color match between the prosthesis and their skin tone, either by applying make up to their prosthesis, or by maintaining a constant skin shade throughout the seasons by using a sun lamp. As Leon, a participant carrying a nasal prosthesis says:

"I bought a sun lamp to retain the color of that nose. It’s quite important that I do that. [Otherwise] you’ll really get color differences, right. I always take the prosthesis in a shade slightly darker than my skin, because when summer arrives I’ll be sitting out here on the balcony, and, well, I get a tan very quickly (...), meaning I would have to get another prosthesis."

(Leon)

Fitting the prosthesis to the face, then, does not only involve the prosthesis itself, but also different objects that help wearers to make the device less noticeable.

A third way by which respondents set out to accomplish a good fit between their face and their prostheses is through adjustments they make to their own face and body. One woman, for instance, spoke of having her hair cut in a specific way in order to camouflage the borders of her orbita prosthesis. Several of the men interviewed mentioned growing beards for the same purpose. Leon’s story about his tan is another example of a bodily adjustment geared to ensuring a proper fit. Such adjustments, however, may also involve bodily postures and the body’s spatial positioning. One participant refrains from laughing or yawning too widely in order to keep her nasal prosthesis from coming off. Others minimize their blinking in order to maintain a semblance of symmetry between the artificial and organic eye. A number of respondents also mention their embodied preference for specific lighting conditions. Timothy, for instance, prefers to walk in the shade when going out in public: when shadowed, his prosthesis will not stand out as much, nor will it appear more matted than his own slightly shiny skin.

Winance’s work on the use of wheel chairs is instructive for understanding the achievement of proper fit between the device and its user as a two-way undertaking: the artifact is adjusted to its user, but the user also has to adjust herself to the device. As Winance writes when describing the process of wheel chair tests, in which patients receive a chair that fits their needs: “The actors [involved in the test] act on the materiality of the person and the chair in an attempt to make them suit together” (Winance 6). Leg amputees who use an artificial leg mention similar embodied efforts such as adjusting their gait in order conceal their amputation and thus pass as able-bodied (Murray, 2009). Interestingly, this ability to pass often plays a paradoxical role in the lives of users. Capturing this paradox, cinema and media theorist Vivian Sobchack, who is an above-the-knee amputee, describes “(...) the great delight that I take (...) in the way my prosthetic leg can pass as real and the desire I have to show it off” (Sobchack, 2006).
The human and the nonhuman in various fitting practices can thus be said to mutually constitute each other in the process of finding an optimal fit. They literally take on and make each other's form. The user of the prosthesis is no longer the same person when wearing the prosthesis, nor is her body the same body. The prosthesis, in turn, receives its ultimate shape and meaning in and through users’ attempts to find a good fit with their face. Forms and meanings may vary, of course, as particular users and prostheses meet each other in particular situations. A nasal prosthesis, for instance, may be experienced and ‘practiced’ differently, and it may have different effects in the context of a user's private house than in a public location, such as a restaurant.

Some of the efforts towards ensuring a good fit will soon become ingrained, automatic habits. Consider in this regard Timothy’s tracing finger, for instance, or his tendency to walk in the shade. The habitual entrenchment of such familiar bodily routines, for postphenomenologist Robert Rosenberger, is an important characteristic of many human-technology relations (Rosenberger 2012, 2015). Adopting and elaborating on the phenomenological notion of ‘sedimentation’ to describe the process leading to such entrenchment, he writes: “This term (...) refer[s] to the way that our past experiences build up (like sediment solidifying into rock) to provide a pre-set context of significance through which our experiences occur” (Rosenberger 2015, 127-28; see Rosenberger 2012 for a more detailed discussion of sedimentation). Sedimented bodily routines, in other words, form a ‘pre-conscious’ or implicit structure of meaning through which human beings relate to the world. And in our technology saturated world, this relationship often involves the use of everyday technological devices.

The automatic nature of such sedimented fitting practices means that respondents’ efforts to achieve a good fit are often no longer consciously experienced. Other fitting practices, however, cannot be ‘forgotten’ in this way, because they require conscious attention and take up time and effort:

I used to find it troublesome, and I still find it troublesome. (...) I need to take it out every evening, clean it; I find it laborious. I have to put it in again in the morning; well, sometimes it goes well in just one try, but I may also have to press ten times before it [is] in place, because it has to fit perfectly against my ear (...). Well, I’m always messing about with it, so I find it an inconvenient thing. (Timothy)

Not all prostheses require the same amount of fuss. Still, the hassle that comes with

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7 The efforts involved in these various fitting practices imply that the prosthesis regularly takes on quite a ‘presence’ in its user’s daily dealings and bodily awareness. As a result, many users find that their ability to fully immerse themselves in their everyday projects and activities is disrupted by their constant efforts to achieve a proper fit. More importantly, the fear that drives these practices—the fear of being exposed as visibly different and prosthetic—can be severely disrupting in its own right.
the attempt to achieve a good fit is a recurrent theme in the lives of the participants in our study. In many cases, achieving a proper fit also requires a measure of planning and preparation, as well as access to a private area with a mirror and the necessary appliances (i.e. running water, the adhesive, the cleaning solution for removing dried out glue, a surface to put everything on). The very act of leaving the house can thus become something of a project, which keeps some wearers from running a quick errand or staying the night elsewhere. Indeed, Leon has ceased going on vacation due to his fear of the possibility of a prosthesis emergency. The fuss and hassle associated with some fitting practices, therefore, does not only result from users’ attempts to find a good fit between their artificial facial limbs and their face and body; it also involves users altering their schedule, priorities, routines and (social) activities. Users adjust both their bodies and their life projects in order to achieve such a fit.

F. TECHNOLOGICAL TRANSPARENCY

The aim of the various fitting practices described above is to make the facial prosthesis look like an integral part of its user’s original face, rather than an artificial object placed upon that face. Understanding how artificial facial limbs facilitate normal facial appearance, however, requires more than an adequate grasp of the different ways by which users attain a proper fit: it also demands further insight into what such a fit enables. In this section, we use Ihde’s theory of technological mediation in order to pursue this issue. As we show below, a good fit enables the prosthesis to become transparent and thereby ‘retreat’ into the user’s face. This, in turn, allows the device to simultaneously cover the amputation and recover the face.

Being directly confronted with a severely ‘disfigured’ face can be tremendously disturbing for people unaccustomed to this sight. As soon as the cavity resulting from the amputation leaps into view, it will dominate the face and evoke a sense of disjointedness in the viewer, who cannot manage to make sense of what she sees. But the image the amputated face presents may be disturbing not only for others who gaze upon it, but also for the amputee. Describing the way his face looks after having undergone a nasal amputation, one respondent says:

Well, no, you don’t have to put that on display; that is such a horrible... For yourself, too, when you’re standing in the bathroom in the morning, and well, you simply shouldn’t think about it. If you do, then, uh, you just might start feeling sorry for yourself [chuckles]. (John)

Dora, who wears a nasal prosthesis, describes a similar attitude towards her amputation as something that is best kept hidden:
[M]y biggest fear is, that when I'm no longer on top of it all, later, that I would forget [to put] that thing [on] (...) [and] walk outside just like that all of a sudden. (Dora)

The amputated, ‘broken-up’ face, in this sense, is quite literally dis-figured: it lacks the form and coherence of a face. In extreme cases, a face may look so distorted or even grotesque that it is no longer recognizable as a human face for an unsuspecting onlooker. This may lead not only to an inability to interpret the face as a face, but also to repulsion if not outright fear. As David Le Breton writes in a recent paper on personal identity and facial transplantation: “the disfigured person recalls, with a force that comes solely from his presence, the imagery of the dismantled body that haunts many nightmares” (Le Breton 2014, 14).

By disrupting the face, the amputation in fact disturbs the effect of ‘faciality’, which, according to philosophers Gilles Deleuze and Felix Guatteri, allows human beings to recognize faces and attribute them to (particular) individuals (Black, 2011; Deleuze & Guattari, 1988). Faciality occurs whenever a viewer encounters the ‘white wall/black hole system’: an even background that is interrupted by two (or more) foregrounded dots. Together, the white wall and the black holes conjure the illusion that there is ‘someone’ within the whiteness, someone who is peeking outwards. This, then, is an illusion of subjectivity and personhood. As Daniel Black puts it: “the interaction of plane and hole produces [a visual] experience of self-contained interiority, of there being a unified someone ‘behind’ the face” (Black 2011, 6). This mechanism is at work not only whenever a viewer encounters a perforated white surface (e.g. the surface of the moon); it also presents itself in everyday face-to-face exchanges. Here, faciality ensures that one is able to see through and beyond the material facial features of one’s interlocutor. When perceiving another person’s face, that is, one does not perceive a fragmented collection of facial features and organs. Instead, one sees the person one is interacting with. It is this illusion that is disrupted by the amputation.

In replacing the lost facial limb, the well-fitting facial prosthesis recovers faciality: it re-establishes a viewer ability to ‘look through’ the face and see the person ‘behind’ it. The device is then no longer seen as a separate object covering the face but retreats into it, thereby allowing for a semblance of facial completeness. As Winston, who uses an orbita prosthesis, explains: “[The prosthesis] was an entirely different sight that

8 When confronted with a bandage or dressing rather than the amputation, onlookers may not respond as strongly. Such a cover, however, often has the effect of confusing onlookers, and leads them to question what is hidden underneath.

9 Of course, no matter how good the fit between the prosthesis and its user, artificial facial limbs never disappear from view entirely. This means that the viewer may shift back and forth between seeing the prosthesis as a separate object placed upon the face, and seeing the face as a whole. As in the famous images in which the old woman becomes a young lady, or the rabbit a duck, it is possible to switch between the two gestalts, but impossible to see them both at the same time.
that bandage, right, now [my face] is really kind of entirely complete again”. Asked to clarify what he means by ‘complete’, his wife adds that, when looking at a face, “you expect two eyes”. The prosthesis does more than merely covering the amputation site, as a bandage or patch would do—it conceals the very need for cover. As a result, respondents’ appearance often no longer attracts others’ attention. As Laura, a woman wearing an orbita prosthesis indicates:

> Yes, I can just tell that since I have gotten my prosthesis, that less people really stare or something (...) Yes, really. I could tell instantly, immediately in that first week already. Yes, [it’s different] than when you’re wearing a Band-Aid. (...) Especially out in the street or at the mall, with the glasses on, yes, people don’t notice it as much. (Laura)

When it successfully recovers the face in this way, the facial prosthesis returns a recognizable, legible human shape to the face: it ‘re-figures’ the ‘disfigured.’

In order to understand how the prosthesis retreats into the face, we now turn to Ihde’s post-phenomenological analyses of how technologies extend the body. As indicated in the introduction, Ihde’s work explores different ways by which humans relate to technologies (Ihde 1990; Verbeek 2005, 2006). One such way is the ‘embodiment relation’: here, artifacts extend users’ sensorium and thereby ‘mediate’ their access to the world. A telescope, for example, enables its user to see things that are far away by extending her visual capacities. As it mediates sense perception, the device itself retreats from its user’s focus, while the phenomena it reveals take center-stage. Thus, when a user adjusts the focus of her binoculars, she may alternate between seeing specks of dirt on the lens or seeing the bird she set out to spot. The lens itself, however, disappears from view. Indeed, as the device becomes incorporated into the user’s bodily experience, it becomes transparent. Van Den Eede (2011) elaborates on Ihde’s account of technological mediation by pointing out that transparency necessarily has its counterpart in opacity: as the device through which users perceive becomes transparent, the object perceived becomes very much present, or rather, opaque.

The framework of technological mediation provided by Ihde and Van Den Eede makes it possible to view the prosthesis’ retreat into the face as an instance of transparency. Thus, when wearer and prosthesis fit together properly, the complete(d) face—and the person ‘within’—is foregrounded (or opaque) while the device recedes to the background (or becomes transparent). This means that the prosthesis extends the visual perception of the person looking at the wearer, rather than the wearer’s own sense of sight. In this sense, both the wearer of the prosthesis and her observer can be said to embody the artificial facial limb. We will return to this point below. For now, it is sufficient to note that a well-fitting prosthesis becomes transparent, thereby facilitating a semblance of facial completeness and recovering its wearer’s face.
G. THE PROSTHETIC MEDIATION OF (INTER)ACTION

Respondents’ attempts to establish a good fit between their prosthesis and their face, as we argue above, is driven by their desire to achieve a normal appearance. Such a fit enables the device to become transparent, and thereby recover the face. But what do the users of prosthetic devices gain from such recovery? In this section, we explore how the prosthetic recovery of participants’ face permits them to ‘pass as normal’ in public spaces, and discuss what such passing entails.

As wearers of prosthetic legs imply, passing as normal means that they can avoid being marked by others as being an ‘odd-bod’ (Murray, 2009, 577. See also Murray, 2004, and Murray, 2005 for an analysis of the personal significance of artificial limbs). Resonating with this account, many participants in our study indicate that their prostheses recover not only their face, but also their inconspicuousness. In fact, for some respondents the device retreats to such an extent that being marked as different in public is hardly ever an issue. As one man who wears a complex prosthesis that replaces his nose, left eye and part of his forehead says: “I say, when I walk along at a brisk pace, then nobody sees it” (Gabriel). Thanks to both his well-fitting prosthesis and the fleeting nature of the street encounter between strangers, Gabriel manages to remain an anonymous ‘anybody’ for passers-by, instead of being noticed as an unusual ‘somebody.’

This anonymity means that users of facial prostheses can evade the unwanted attention of others—the staring gazes, remarks, and questions that people with a visibly different appearance encounter in public and that make many of them feel uncomfortable and unwelcome (Garland-Thomson, 2009). As Thelma, a participant who carries an orbita prosthesis says: “I can just go outside again, I can just cycle again. (…) I still get compliments like, ‘Gosh, you almost cannot tell (…) [the prosthesis] is so well-made’”. Oliver, an interviewee who wears an orbita prosthesis, phrases this ability to not stand out in a crowd in terms of freedom: “[Wearing the prosthesis] gave me feeling of greater freedom, indeed (…) it’s people’s staring that makes you realize you’re different than others”. In (re)covering the face, the prosthesis thus enables its wearer to traverse and occupy public spaces which would otherwise remain inhospitable. Passing as normal, in short, allows the prosthesis wearer to pass by others unnoticed, which in turn enables her to pass through public spaces unhindered by unwanted attention. Passing thus allows its wearer access to the public domain, thereby facilitating inclusion in it.

By (re)covering the face, however, the facial prosthesis does more than just granting access to a public context characterized by transitory encounters: it also accomplishes (a larger measure of) ease in lengthier interactions. As established above, the confrontation with an atypical face, whether caused by the amputation itself or by a conspicuous cover, may be quite disturbing for an unwary onlooker. Indeed, it may also disturb people who are already familiar with the amputation site. Describing her
discomfort when looking at her husband’s uncovered face when he sleeps without his prosthesis, John’s wife says:

Yes, I prefer it [when he leaves the prosthesis on at night] (…) [t]’s a very strange sight, really. (…) [A] big hole you’re looking right into. The septum is no longer there, you just look all the way into the throat, you can actually see the uvula hanging there. (John’s wife)

Being confronted with such a sight is not only unsettling; it can also hamper the onlooker’s ability to enter into and maintain straightforward face-to-face exchanges with their visibly different conversational partner. By simultaneously drawing in and repelling the onlooker’s gaze, a facial difference holds the onlooker’s attention, and this will disrupt the flow and ease that normally characterize ‘live’ interactions. As such, the facial difference disrupts the onlooker’s ability to focus on the conversation and approach their interlocutor as a full-fledged partner in the interaction. Indeed, such ‘interaction uneasiness’ has been reported in other cases of facial difference, such as facial immobility due to Parkinson’s Disease (Nijhof 2009, 2011).

It is this disruption that Kurzman alludes to when claiming that his prosthesis allows him to “be treated like a fully human being” (Kurzman 2001, 381). By returning the appearance of facial wholeness to its wearer, the properly fitting prosthesis keeps its user’s conversational partner from becoming side-tracked by the unexpected image of the amputated or bandaged face. Moreover: this also keeps the wearer herself from feeling awkward about her interlocutor’s unease. By (re)covering the amputated face, then, the artificial limb enables both parties to the encounter to maintain (some measure of) interactional ease in face-to-face exchanges, thereby restoring the possibility of a social exchange. Again, the prosthesis could thus be said to (re)cover not only its user’s physical face, but also their public, social face.

As they recover their users’ face, artificial facial limbs enable users to move anonymously through public spaces and facilitate interaction ease. This means that such devices mediate not only perception, but also action. Although Ihde refers to such mediation of praxis, it is Verbeek (2005, 2006) who offers a more systematic analysis of how technologies mediate users’ capacity to act. Doing so, Verbeek draws on Bruno Latour’s Actor-Network Theory, which offers many examples of the ways in which technologies invite their users to behave in specific ways, and inhibit them from acting.

10 This concept was first introduced by Goffman in his well-known study on stigma and its management (Goffman, 1963), and developed further in some of his later works.

11 Again, due to the fact that prostheses do not disappear entirely from view, they may still attract attention and thereby disrupt face-to-face interactions. This happens, for instance, when an interlocutor notices the artificial eye does not move, or when a child, looking from a lower vantage point, notices a gap between the nasal prosthesis and the wearer’s upper lip. All in all, however, prostheses that fit well are often less conspicuous and thus less disruptive than the image presented by the bare, partly amputated face, or the bandaged face.
in other ways. Similarly, when it (re)covers the damaged face, the facial prosthesis in fact invites others to—literally—disregard the wearer’s facial difference, and thereby makes possible both unhindered access to public areas and flowing face-to-face exchanges.\footnote{As we show above, the fuss and anticipation that accompany some users’ efforts to achieve a proper fit imply that activities like running an errand or going on vacation may be less easy to manage. Although it enables these users to pass unnoticed and thereby grants them access to public areas, the prosthesis may thus constrict users’ ability to enter public spaces as well. As Winance writes when describing the process of mutual adjustment between users and wheelchairs: “(…) this process of adjustment is ambivalent. Through adjustment, some possibilities of action emerge, but also some impossibilities” (Winance 2006, 55).} Using Verbeek’s terminology, the device mediates not only perception but also action. This mediation of (inter)action, however, takes place by virtue of the mediation of perception. One and the same technology, apparently, mediates on different levels simultaneously. In fact, one could argue that perception, action, and interaction are all aspects of mediation which cannot be seen in isolation. After all, a pair of glasses, too, will mediate a user’s sense of sight, which enables her to read an e-mail and keep in touch with her faraway friend.

But such mediation requires work, as Winance shows. Mediation is not the given, straightforward effect of putting a device to use. Rather, as the stories of our interviewees reveal, ensuring that the prosthesis appears as an integral part of the face and thereby becomes transparent is the result of ongoing efforts. On a more general note, many within STS have argued that technologies are never just functional, instrumental tools that fulfill human desires, assist differently abled or ill human beings, or replace human labor, but always require new forms of work and new skills to fulfill their promise. While Winance focuses primarily on the work experts put in in order to make the wheelchair optimally suit its user, the fitting practices we describe illuminate the continuation of this work beyond the institutional context of the prosthetist’s clinic. The work involved in these fitting practices is performed primarily by users themselves. It becomes a central part of users’ lives, targeting not only the device and their own body, but also their life projects. Moreover: this work may serve to disable these users in different ways than their functional impairments or atypical appearance do, as it requires them to constantly monitor their prosthesis’ fit, fuss with it, and adjust their priorities.

Both the mediation of perception and the invitation of action, however, are not restricted to the facial prosthesis’ wearer. Essentially, these two types of mediation take place in a social setting: the relationship between user and viewer. Although it would go too far to say that both partners in the encounter use the technology, it is nevertheless clear that it is not only the user who makes use of this device’s capacity to (re)cover the face. When the facial prosthesis is worn, it is the viewer’s visual perception of the wearer’s face that is mediated by the device, not the wearer’s sense of sight. When wearers work to achieve a proper prosthetic fit through their various fitting practices, they approach their face from the ‘outside,’ as an image in the eyes of
an external viewer. This, as Sartre calls it, is a modus of ‘being for the other’ (Sartre, 2007): a perspective on the self that incorporates the other’s gaze. Fitting practices thus form the embodied, materialized internalization of this gaze of the other. For this reason, when an artificial facial limb facilitates passing as normal and interactional ease, it acts upon the relationship between user and passerby and user and interlocutor, respectively, affecting the way they interact. Facial limbs do not mediate between their wearer and (aspects) of the world, as Ihde and Verbeek would have it, but between this wearer and others.13 The wearer of the prosthesis does not gain access to physical reality by means of (scientific) instruments, as Ihde would have it. Nor is she Verbeek’s actor in a practical world. Instead, the prosthesis’ user is first and foremost a social creature who carries the device in order to—quite literally—face others. In the case of cosmetic prostheses, technology mediates between users in a principally social world, a world inhabited by people, both strange and familiar, whose interactions with and relationship to each other are tremendously affected by the usage of technologies.14

H. CONCLUSION

In this paper, we have explored the meaning of cosmesis in the everyday use of facial prosthetic devices by drawing on interviews with users, as well as on different bodies of literature. The facial prosthesis, as we have shown, restores normal facial appearance to people with facial limbs absence by emulating the missing limb’s look. This requires a proper fit between the device and its wearer’s face. Using the work of Winance, we have discussed respondents’ various fitting practices as a continuous process of mutual adjustments between users and their prosthesis. When these practices succeed, the facial prosthesis not only covers its wearer’s amputation, but also

13 This mediation of social relations does not only involve the wearer and the perceiver, but may also include the wearer’s partner, family, and friends as they help this wearer to (re)cover his or her face. One respondent’s wife, for instance, reminds him to put on the prosthesis when going outside when he neglects to do so. Another respondent often asks her friends whether her prosthesis is still aligned when they go out together. For more on how ‘insiders’ who are ‘wise’ to the disabled or visibly different person’s condition help this person to pass, see (Lingsom, 2008).

14 Of course, many scholars have pointed out the fundamentally relational aspect of human existence. Ike Kamphof, for instance, has recently drawn attention to the way in which a newly introduced tele-monitoring in Dutch Homecare led to the reinterpretation of the relationships between caretakers and patients, in particular with regards to patients’ privacy (Kamphof, 2017). As already mentioned above, Winance, Mol, Pols, and others, too, have explored the way in which technologies mediate within networks of people, devices, animals, markets, knowledges, bureaucracies, and so forth. Instead of focusing on the user/world relationship as Ihde and Verbeek do, these authors all focus on a network of relations constituting both. However, these scholars rarely explicate the significant ways in which such technologies mediate human relationships (e.g. dependency, ways of being together). Winance, for instance, mentions but does not expound on the ways in which wheelchair usage comes to play within social relationships, changing users’ ability to walk together with others, the way in which different chairs produce different forms of dependence and independence for users and others, or how users’ choice for a sportive model allows them to appear in a certain way—i.e. sporty, young, able despite their disability—to others.
reovers her faciality. Drawing on Ihde’s notion of technological mediation (or more precisely, the embodiment relation), we have then demonstrated how facial recovery hinges on the device’s transparency. Finally, elaborating on Verbeek’s work, we have shown that transparent facial prostheses mediate not only perception and action, as he indicates, but also social interaction. By helping its wearer to pass as normal, this device enables her inclusion in public spaces and participation in social exchanges. Revolving, as it does, around the navigation of precarious social environments, cosmesis serves a most important function in the everyday lives of users of prosthetic devices.

Ultimately, our findings serve to complement postphenomenology’s traditional focus on the first-person experiences of the users of technological devices. By inquiring into the social role of facial prostheses, we illustrate how technologies affect the second-person perspective typical of relationships between subjects. These insights are relevant for theorists working in postphenomenology and STS, and merit further research into the role of ‘the other’ in the use of technologies. Another important venue for inquiry suggested by our work concerns the social repercussions of the interplay between disability, visible difference, and assistive technologies. In addition, our findings regarding the role of medical aids in the social lives of their disabled users are relevant for scholars in the sociology, philosophy, and psychology of health and illness. In a more practical vein, our work is also pertinent for health care professionals who are interested in the different roles assistive devices play in the lives of their users (see for a similar point in the context of prosthetics: Hoogsteyns and Van der Horst 2012). Finally, scholars working in disability studies may gain from our analysis of passing as involving a set of material, embodied, and situated practices, which are accomplished rather than given.

In the end, however, one conclusion cannot be overlooked: the function-cosmesis binary is quite a problematic one. Functional prostheses, as Murray suggests, are not principally approached by users as a means to restore ability, but rather as aids that enable them to fulfill various social roles such as breadwinner or dancing partner (Murray, 2009). And as our own work illustrates, cosmetic prostheses serve a similar purpose in allowing their users to encounter and interact with others in public spaces. Both function and cosmesis in prosthetics, it appears, revolve around users’ ability to meaningfully relate to others, and cannot be understood in isolation from this manifestly social role.
REFERENCES CHAPTER 3


Chapter 4

Recognizing difference

In/visibility in the everyday life of individuals with facial limb absence

A slightly revised version of this chapter is published as:
A. INTRODUCTION

People who have lost part(s) of their face have a visibly different appearance, due to the facial difference itself, but also the medical aids that they use in covering it. Thus, as part of their rehabilitation trajectory, individuals with facial limbs absence will commonly receive a so-called facial prosthesis: a ‘cosmetic’ device that replaces the lost part of their face. Although this device closely resembles their lost facial area, its artificiality remains (potentially) discernible. In addition, they may regularly make use of visible covers such as bandages, eye patches, or Band-Aides to hide the absent facial area—or refrain altogether from covering it. How does the visibility of their atypical face feature in the everyday experience of these individuals? Answering this question is complicated for three reasons. First, the small number of studies that investigate this particular population take a quantitative approach by measuring quality of life, without engaging with the experiential aspects of living with facial limb absence (Dropkin, 1999; Murphy, Ridner, Wells, & Dietrich, 2007; Rasmussen, Ekholm, Prause, & Toft, 2012). Second, visible difference as a broader category has been taken up as a research topic in disability studies and the emerging field of the psychology of appearance (Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997; Rumsey & Harcourt, 2012), but scholarship on facial variance is still limited. Third, this scholarship tends to focus on the psycho-social repercussions of being visibly different (Koster & Bergsma, 1990; Macgregor, 1970; Rumsey & Harcourt, 2004; Stock, Feragen, & Rumsey, 2016; Thompson & Kent, 2001; Valente, 2009). As this literature shows, visible facial variance may be associated with various psycho-social issues, (e.g. depression, social anxiety, avoidance behavior). These issues all take shape within the context of affected individuals’ everyday life, as they encounter and interact with others in various formal and informal contexts. Surprisingly, however, there is very little by way of empirical, qualitative investigations into the way facial difference come into play within this daily context—and nothing on the particular challenges encountered by individuals who lack part(s) of their face. How, then, does facial difference manifest visibly in the everyday experiences of individuals who have lost one or more facial limbs and/or facial areas?

In this paper, we answer this question by exploring what we call the ‘visibility experiences’ of people with facial limb absence—experiences that, as we show below, are shaped by both the visibility and invisibility of their atypical appearance. This exploration is informed by our qualitative study into the role and meanings of facial difference in people who have lost facial limbs and/or areas. Before we zoom in on the visibility experiences of the participants in our study, however, we first offer a short review of existing scholarly literature on the meanings of visible difference—and in particular facial variance—and the way it affects social interactions. Next, we discuss our approach and methods, after which we turn to our respondents’ visibility experiences. Finally, we draw out the implications of our findings. As will become clear, this article
does not only provide insights into the particular visibility experiences of people with facial limb absence, but also demonstrates the various ways in which the in/visibility of difference impacts affected individuals’ ability to be recognized by others in their various (social) identities. As such, our study illustrates the need for a well thought-out social recognition perspective in debates on in/visibility within disability studies.

B. STIGMA MANAGEMENT, STARING, AND THE IN/VISIBILITY DEBATE

To gain insight in the role of visible difference in the daily life of individuals with facial limb absence, it is important to acknowledge the fundamentally social aspect of visibility. The work of sociologist Erving Goffman has been key in exploring the social mechanisms at play during every day social interactions in public spaces (Goffman 1963b; 1963a; 1967). A fundamental aspect of social interactions in public, for Goffman, is ‘face work’: social actors’ shared, ongoing attempt to maintain a positive self-image or ‘face’ in public social interactions by conversing, dressing, carrying their body, etc., according to norms prescribing acceptable behavior. As he demonstrates in Stigma, notes on spoiled identity (1963), stigmatizing traits threaten this work, because their association with negative stereotypes serves to discredit an individual. If they wish to avoid censure, the stigmatized must therefore extensively manage their stigma, for instance by trying to ‘pass as normal’ (1963b, 42; 73-91). Many of the empirical examples of stigma management Goffman analyses revolve around some form of visible difference, often due to a disabling condition, but the issue of visibility remains secondary to his work.

Drawing on and developing Goffman’s ideas, disability scholar Rosemarie Garland-Thomson recasts stigma management as a visibility issue. People with a visible difference who enter the public realm, as Garland-Thomson demonstrates in Staring: How we look (2009), receive predominantly visual attention from non-conspicuous others. She writes: ‘Staring (...) stigmatizes by designating people whose bodies or behaviors cannot be readily absorbed into the visual status quo’ (2009, 44). The stigma associated with visible difference, in other words, takes shape within the daily context of the staring encounters that occur between those who are visibly different and those who come to notice this difference—staring encounters that mark and set apart the visibly different person. Garland-Thomson’s analysis, then, sets out to reframe scenes of staring as potentially productive and transformative, rather than solely oppressive (10; 87). Experienced ‘starees,’ she argues, can thus help ‘starers’ to overcome their initial astonishment and recoil in the face of visible difference. Arrested stares then become engaged beholding, in which both partners in the interaction meet on an equal basis. Garland-Thomson offers unique insights into the way visible difference affects social interactions in public. But because she mostly analyzes various representations of disability in art, photography, and film, her observations do not form a systematic
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exploration of the ways in which people affected by visible difference experience and make sense of their difference within the context of their everyday lives.

In recent years, a number of scholars have used the concepts provided by Garland-Thomson as a starting point for discussing the lived experiences of people with various types of visible difference. This emergent ‘in/visibility debate’ provides empirically-based, qualitative analyses of these individuals’ visibility experiences in various (social) contexts. Thus, Olney & Brockelman (2003) discuss the experiences of students with apparent and invisible disabilities due to (mostly) cognitive and mental issues. Zitzelsberger (2005) portrays the way women with various disabling conditions and differences experience their in/visibility in relation to normative standards governing what counts as ‘acceptable’ embodiment. Lourens & Swartz (2016) explore how South African students with visual impairments cope with the visibility of their disability and negotiate their identities. Finally, Hammer (2016) discusses Israeli blind women’s encounters with others’ gazes, and how they position themselves within such encounters. Still, the experiences of people with visible facial difference—and, in particular, of people with facial limb absence—have remained all but uncharted within this debate. In the following sections, we attempt to fill this void by exploring the role of visible difference in the everyday life of the participants in our study. In the discussion, we will evaluate the way our findings relate to both Garland-Thomson’s insights, and the visibility debate. First, however, we introduce our approach and methods, and provide more information on our respondents.

C. APPROACH AND METHODS

This article is based on a qualitative study of how people living with facial difference experience their atypical face. In the course of this study, the first author interviewed twenty individuals who have lost a part of their face as a result of disease or trauma. We recruited our respondents through the Dutch service unit from which they receive their prostheses, approaching the clinics’ 140 clients by mail about participating in the study. Of the forty respondents who consented to be interviewed, twenty were eventually interviewed by the first author. The other potential participants could either no longer be reached once the study commenced, or declined their participation. The study received ethical clearance beforehand (file number NL35486.031.11).

Of the twenty participants, eight were women and twelve were men, between ages 42 and 84. Nineteen of them had undergone amputation of one or more facial limbs (nose, eye socket) or parts of their face to treat their head and neck cancer (HNC). One respondent suffered an accident that resulted in the loss of his eye socket. These individuals all carry a prosthetic device to cover the amputation site, while most also make use of other medical appliances (see Table 1 for an overview of the interviewees). The interviews, which all took place at the respondents’ home or in another setting
familiar to them, lasted between 45 and ninety minutes each, were tape recorded and subsequently transcribed verbatim. In order to prompt respondents’ stories on their visible difference, the first author made use of an interview schedule, which served as a basis for asking questions during the interviews (Braun & Clarke, 2006). The first item on this schedule, ‘diagnosis, treatment and rehabilitation’, was intended to provide the interviewer with a basic understanding of participants’ everyday life after amputation. Subsequent items such as ‘facing the mirror after the amputation’, ‘interactions with relatives and friends’, and ‘interactions with strangers,’ aimed to encourage the respondents to articulate the role of their visible difference in their everyday life.

To analyze the data, we relied on the method of thematic analysis (Braun & Clarke, 2006). The first author first read and summarized the interview texts. In the process, she identified common themes in the stories of respondents, such as their response to staring behavior by others in public, their feelings about their own image while wearing a prosthesis, another type of cover, or baring their face, and family members’ attitude toward their atypical face. By focusing on the particular range of experiences associated with our participants’ covered, partly prosthetic, or bare face, we gradually established patterns in how their visible facial difference plays out in their everyday life. In this way, we gained insight in how respondents experience the in/visibility of their unusual face as they encounter and interact with others in various social contexts.

D. RESULTS: IN/VISIBILITY IN EVERYDAY INTERACTIONS

Individuals with facial limb absence, as we found during the interviews, have three options in ‘displaying’ their unusual face: a) covering the amputation site with various types of bandages; b) carrying a prosthetic device that emulates the missing limb’s looks; and c) baring their amputation for others to see. In this section, we analyze the stories of our participants to identify four clusters of visibility experiences afforded by each of these ways of displaying the face. As we show, such visibility experiences always take shape in encounters with others. It is within the context of such social interactions that the meaning of visible difference is negotiated, as interviewees relate to others’ reactions to their unusual looks.

Covering facial difference
The participants in our study all make use of a variety of covers, such as a gauze dressing, eye patch, pad, or Band-Aides to hide their absent facial area. These medical appliances are highly visible because they are placed over part of the face, and present an uncommon image. Due to this visibility, respondents often deal with unwanted attention in public:
I walked around wearing a patch on my eye, and that generated a lot of, yes, stares and questions and comments. (...) I wasn’t anonymous anymore, I was always the center of attention, yes, attention I found to be negative. (Ralph)

Interviewees not only lose their anonymity, but are also (implicitly) asked to account for their difference: “[The patch] was something they wanted to know more about, something I needed to explain” (Ralph). As a result, some feel obliged to satisfy others’ curiosity even if they do not really want to repeatedly share their story:

[You get those questions (...) like, ‘What did you do?’, and ‘Why are you wearing that over [your eye]?’ (...) And then you have to tell the entire story again (...) Then I’d be done, and they’d be satisfied (...) I hated that, actually. (Winston)

Some strangers, apparently, feel entitled to interfere with individuals whose face is visibly different—even though they might never approach someone whose looks do not diverge from the norm. This implies that implicit norms prescribing respectful distance and mutual inattention between strangers in the public realm are not quite as binding in encounters with those who are visibly different.

Many respondents deeply resent the unwanted attention they receive. Others report to feel overly self-conscious and even ashamed when others stare at them, ask questions about their cover or comment upon it: “[I] felt ashamed about [wearing the patch] (...) I would have rather skipped that couple of months before I received my prosthesis” (Ralph). He links these feelings of shame to negative evaluations of disability: “I felt really deficient, really disabled. Visibly disabled”. Or as another respondent puts it:

I walked around with a Band-Aid for almost two years (...). Well, I was quite fairly (...) a wreck then (...); that’s how you feel, incomplete, so to say (...); you feel really disabled. (Walter)

Others relate their experiences of being the object of others’ scrutiny to a sense of inadequacy: “Most often that mental [part] is even worse than the physical. (...) It’s a sort of feeling of shame regarding other people. (...) You feel yourself to be inferior” (Gregory). Such feelings most often arise in the period directly following the amputation. Although some participants reported that they have grown used to others’ unwanted attention over the years and were no longer very much bothered by it,

1 Like all the other names we use below, this name is fictitious in order to safeguard the privacy of the participants in our study.
however, most remain uncomfortable about such attention. The fact others repeatedly take notice of interviewees’ facial difference, then, serves to diminish their sense of self-worth, which continues to negatively affect respondents’ experiences in public throughout their everyday lives.

Participants’ reactions to unwanted attention take three distinct forms: (a) ignoring, (b) actively challenging, or (c) engaging in conversation. Most respondents choose to ignore (and thus implicitly tolerate) casual or ‘benign’ stares, because they see such responses as a natural human reaction to an unexpected sight. Forms of attention that are hostile (rude questions and comments) or invasive (blatant staring, repeated ‘double-takes’) are largely tolerated passively as well. A small number of participants, however, opt for a more confrontational approach:

[T]otal strangers (…) would say (…): ‘Well you’ve had some rap on the nose, haven’t you?’ (…) and ‘You’ve got a weird noggin’, you know. Then you get, in the beginning you’d get real angry, so I’d sometimes yell, like, ‘well! I’ll show you something, and I can guarantee that you won’t be so cheerful anymore the rest of the day!’ (Dora)

Dora takes a combative approach to her being scrutinized by threatening to reveal what is underneath the bandage. Using the contrast between her visible cover and that which is hidden underneath to shock and scare her detractors, she subtly turns the table on them. Most respondents who actively confront to persistent stares, rude questions or comments do not take such a ‘combative’ stance. Instead, they pointedly stare back, or politely remind the other person to mind their own business. In this way, they simultaneously challenge the right of others to interfere with and condemn their appearance, resist being positioned as an object of one-sided curiosity, and reclaim their self-worth.

The third response to unwanted attention is engaging in conversation, for instance by answering polite questions about their covered face: “I prefer they ask [about] it. Honestly. (…) Yes, it allows me to explain (…) that I can’t help it. It was an accident, pure and simple” (Gregory). For him, being asked respectfully about his facial difference is a form of ‘sympathetic interest’, which provides an opportunity for a reciprocal exchange:

People start perceiving you differently. (…) [Y]ou can tell that they look at you in a fresh way. It becomes a matter of sincere interest, you know; it’s not plain curiosity anymore. (…) And then you can grow closer together. (Gregory)

In cases of benign staring, too, many participants act to defuse awkward situations by politely initiating dialogue. Such respectful exchanges reconstitute respondents
as equal partners in an encounter based on genuine mutual interest. The visible facial difference is no longer merely a stigmatizing attribute, but serves as a starting-point for dialogue, in which the affected individual can be recognized as a fellow human being.

**Recovering the face**

Aside from various visible covers that hide their amputated facial area, the participants in our study all carry a silicone facial prosthetic device. Many respondents indicate that their facial prosthesis is very life-like, both in color and texture. In their case, this device appears as a genuine part of the face, and the face itself seems complete rather than lacking parts: “[The prosthesis gives me] a entirely different look than a bandage, right. Now [my face] is really kind of entirely complete again” (Winston).\(^2\) Clarifying what he means by ‘complete’, his wife adds that, when looking at a face, “you expect two eyes”. A well-fitting artificial limb thus does not merely cover the amputation, but also conceals the very need for cover: by emulating interviewees’ lost facial area, the device serves to undo the appearance-altering effects of the amputation. This means that respondents’ facial difference is often no longer very obvious. Indeed, most respondents have a ready supply of stories about acquaintances who fail to notice the prosthesis despite their repeated close proximity to the wearer:

> **We were painting the wall downstairs, at one time, when Peter—that’s another [neighbor]—says, ‘Well, John, look out that you don’t lose [your nose]. And the upstairs neighbor was looking at me stupidly; he didn’t get it. I said, ‘Yeah, man, I’ve got a prosthesis’. ‘I never noticed’, he replied.** (John)

Successfully concealment is by no means guaranteed, because it depends on the degree to which the device fits its wearer’s face. We will elaborate on conditions that determine proper fit, and on the consequences of poor fit, in the next section. In this section, we focus on those instances in which prosthetic concealment allows participants to become more unremarkable.

The ability to conceal the amputation site, for some respondents, is closely connected with being liberated of their disability—a label they consider to be negative:

> [T]hat’s a very pleasant feeling. (…) Well, then I could accept it entirely. I didn’t feel like someone with a disability anymore, then. (Walter)

> This was really a relief, actually (…) I felt a lot less disabled due to this prosthesis. (Oliver)

\(^2\) For more on how facial prostheses establish concealment, see (Yaron, G., Widdershoven, G., & Slatman, J. (2017)).
This sense of relief about being able to no longer identify as a disabled person has to do with being able to elude others’ unwanted attention:

[I]t’s the other people who make you feel as if you’re disabled. Because you don’t experience that yourself so much; it’s people’s staring that makes you realize you’re different (...) I am different, but I myself do not feel disabled. (Oliver)

When it enables participants to elude others’ notice, successful concealment allows participants to remain anonymous in public areas: “[I thought], ‘Now I would probably be rid of the questions when I go somewhere, too’, and, indeed, you’re all done with the questions. Nobody asks anything anymore”. (Winston) A properly fitting prosthesis enables respondents to ‘pass as normal’ and regain their anonymity in public: passing by others unnoticed, they can pass through public spaces unhindered by stares, questions, and remarks.

In addition, in those cases in which interviewees’ artificial nose or eye makes their facial difference less conspicuous, this difference ceases to matter in interactions with others. As a result, respondents are able to perform their everyday duties unhindered by others’ unwanted attention:

I spend a lot of time behind the microphone, [covering] all kinds of [live] sports events, and now, well, now I am noticeable through my voice, not through my appearance anymore. (Walter)

When the visible marker of their difference is concealed from view, interviewees can move beyond the stigma of visible difference. The device permits them to fulfil various social roles (being a handy neighbor or an announcer in sports events, as in the situations described by John and Walter) that would otherwise be complicated by their visible difference. In making their facial difference invisible, the prosthesis, in a sense, also renders its wearer invisible.

The ability to pass as normal takes on different meanings in respondents’ accounts. Successful concealment may be a source of pride: like John, many participants speak gleefully about acquaintances who have never noticed the artificial limb, even after long periods of close association. Told in a joking spirit, such anecdotes position the teller as someone who has managed to trick unsuspecting others and get away with it. But the ability to conceal their facial difference may also give rise to a sense of alienation: “[I]t’s fake. It’s not mine, it’s not real (...) It’s also meant, I think, to fool other people, in some way” (Leon). The ability to pass as normal, in other words, can be experienced as a form of deceit. Interviewees then feel uncomfortable about ‘fooling other people’ by means of a fake façade of facial wholeness, which makes prosthetic concealment much less desirable. For Leon, this unease translates into an unwilling-
ness to wear the artificial limb. At the same time, he does not feel equal to going outside barefaced, for fear of shocking others. Leon deals with this dilemma by remaining at home, where he can go about uncovered.

Discovering the prosthesis
Facial prostheses do not always manage to recover facial wholeness successfully: at certain times, the device will stand out as an artificial object that merely ‘covers’ the face. Indeed, most participants in our study reported instances in which their prosthesis failed to appear as a natural part of the face, thereby giving their facial difference away: “Sometimes at the cash register, because you’d be standing close to people, it happens that the ‘nose’ is suddenly discovered. [Their] gaze is like, ‘Wait a minute.’” (Stella). Such discovery is made more likely by particular spatiotemporal circumstances. Thus, locations such as public transportation, cafés, and queues facilitate a type of ‘slow’ encounters that are characterized by proximity and sustained exposure. Similarly, harsh neon lights make subtle differences in color and sheen between the prosthesis and its wearer’s skin more noticeable. Proximity, prolonged exposure, and specific lightening conditions all render participants’ prosthesis conspicuous, making their facial difference apparent again. But being discovered as partly prosthetic is also associated with a poor fit between the prosthesis and the user’s face. Such a poor fit may occur when the prosthesis fails to follow along with facial movements. A prosthetic eye, for instance, cannot close, which may give away its fakeness. Adjusting to this, one interviewee has come to restrain her blinking, in order to maintain a symmetrical appearance. In a similar vein, another respondent mentioned an incident in which the immobility of his artificial eye gave rise to comments when he took a nap during a flight. Others spoke of poor fit due to misalignment, a loose or gaping device, or because of seasonal and temperature-related variations in skin tone.

When the prosthesis is discovered to be fake, the participant’s facial difference becomes apparent again. As in the case of a visible cover such as a bandage, Band-Aid, or eye patch, passing as normal becomes impossible. Discovery, in other words, translates into unwanted attention from others. Interactions that flow from such discovery, however, take on a particular form:

[T]here was this girl once, and she said, ‘Mister, take that nose off’. (...) Look, a kid can be very spontaneous, of course. And they say, just like that, ‘You have a fake nose’ [laughs]. (John)

The child John encountered realized that the ‘fake nose’ replaces a lost limb. Her
desire to see what is underneath was not motivated by an expectation to see a burned, peeling, or otherwise ailing nose, but by a desire to see what a face that lacks a nose looks like. In response, John reaffirms the girl’s discovery:

Well, you just laugh about it, and then I repeat [what the child said] and then I do a bit like this [grabs his nasal prosthesis between thumb and finger and moves it, which causes it to make a clicking sound]. (John)

The clicking sound John makes serves to underscore the fact his prosthesis is not a real nose but an artificial one. Similarly, requests and attempts to touch the prosthesis operate on the assumption that the touching finger can discern what the eye almost cannot:

Yes, a child [would ask me], ‘May I touch it?’; ‘Yes, you may for a little bit’. Well, they do so very carefully, with one finger, because they do find it a bit creepy, too. (Timothy).

Or as another respondent recounts:

And then the first time I entered [my sister-in-law’s] home wearing the prosthesis—before I knew it her finger was already on my nose. Well, I really had to restrain myself not to give her a swipe! (Stella)

When the eye is fooled by the fact the prosthesis so closely resembles the missing limb, other senses must be brought into play in order to assuage fakeness: hearing and touching serve to tell silent, warm, and supple skin from noisy, cold, inflexible silicone. Others’ responses to the discovered prosthesis, in other words, operate on the realization that, although the prosthesis is eerily real, it is nevertheless fake.

Interviewees’ responses to their being discovered vary in a way similar to how they deal with unwanted attention when they wear a visible cover. Thus, overt staring, rude questions and hostile comments about the prosthesis may give rise to feelings of shame, embarrassment, anger, etc. Accordingly, respondents react by either ignoring or confronting the offending person. Consider in this regard Stella’s attitude during the incident in which her sister-in-law touched her artificial nose without asking permission. Mild staring behavior is mostly seen as inevitable and thus ignored. Respectful inquiries, on the other hand, are mostly seen as innocuous, and answered politely. In particular, children who stare at, inquire, or comment about their prosthesis—even if they do so rather rudely—are often allowed more leeway in transgressing the social imperative not to interfere with others, as John’s good cheer and Timothy’s gentle manner in their interactions with children illustrate. As in the case of visible covers, interactions elicited by discovery exhibit a dynamic in which participants are
positioned as an object of others’ curiosity, and manage this attention by ignoring, challenging or engaging others who notice their difference.

There is one exception, however, to this similarity between the social interactions afforded by the visibility of the covered and the discovered face. The visibility of the covered face makes for immediate responses from others. When respondents wear the prosthesis, however, discovery may occur only after a while. This means that the risk of being discovered as partly prosthetic grows as participants interact with others at close range and for prolonged periods of time. Responding to this risk, some interviewees take measures to anticipate belated discovery during extended interactions—for instance when teaching a class, participating in an organized trip, or giving a business presentation to clients:

> When I had to do a presentation or something, (...) I would start out by [saying], ‘Well (...) you can all see that I have a somewhat irregular something with my face. Well I’ve had a tumor and I am very happy that it all went well, and that I now have a prosthesis there.’ (...) This helped me tremendously, because I noticed that, well, if I didn’t say it [up front] people would just stay fixated on [my] face for quite some time. (Timothy)

By explaining about their facial difference in this way, respondents make sure their audience does not become side-tracked by the unfamiliar sight presented by a prosthetic facial limb. Anticipatory self-disclosure helps their audience understand the confusing visual, effectively closing off the issue. In this way, participants ensure social identities afforded by their professional or leisure activities (e.g. teacher, fellow tourist) are not overshadowed by their facial difference.

**Uncovering the amputation site**

Participants’ visible difference does not only manifest as a covered or discovered face; their partly amputated facial area, when it is uncovered, also presents an unusual sight. Respondents’ attitudes to their own altered appearance vary. Some are comfortable with looking at the amputation site in the mirror, while others indicate that they experience their own image as disturbing, using such terms as “really deformed”, “monstrous”, “very weird”, or “a horrible sight” when referring to their face. As a result, some participants find it hard to look in the mirror:

> I really very much dreaded [facing the mirror]. And I really found it horrible to see it, that disfigurement. I still do. (...) I turn my gaze away, I had rather not see it. (Ralph)

The image of their uncovered face in the mirror can be so discomforting that interviewees experience a sense of detachment.
Whether or not they are comfortable with their bare face, however, respondents all prefer not to be seen by strangers while uncovered. Indeed, many recounted episodes in which they felt embarrassed upon finding out they had either forgotten to put on their prosthesis or lost it somehow. They described how they would immediately cover the amputation site and rush home to attach the device. Some participants discussed the possibility of taking the device off in front of others or going about without it in terms of nudity. As one respondent, a teacher, commented: “When students ask, ‘Will you take off your prosthesis?’, I say, ‘Well, you take off your pants, and come stand here butt naked’” (Oliver). Another participant’s words evoked the impropriety involved in both uncovering and being asked to do so:

> In my opinion, well, you just do not go strolling outside with two of those holes [exposed]. (...) I would never do that (...) [W]hat people have under their clothes (...) you don’t see that either. I mean, they wouldn’t ask me, ‘Come, let me see what your hip looks like’. Would they now? (Audrey)

Others indicate the bare face would form a source of shame in public. The possibility of remaining uncovered is also associated with a lack of dignity:

> One thing I worry about is growing older. (...) I am afraid that (...) I’ll end up in a home and that [the nurses] will not know how to attach such a thing. Or that they would leave me sitting there without (...) my prosthesis, thinking, ‘Whatever’. (...) That’s my biggest fear. (Thelma)

One respondent, by contrast, reported that he does remove the prosthesis when asked by curious others to do so, but takes care to ask whether they are really up to seeing his amputated orbita. All in all, respondents consider their bare face as something not to be displayed in public, both because it is a private matter, and because it might frighten and shock others.

When they are at home, many respondents do not constantly cover or conceal their amputated facial area. They remain barefaced when sleeping, for instance, because this is more comfortable:

> At night, I used to wear a bandage (...) but I stopped that at some point because it’s really not necessary (...), [my wife] can handle it just fine, so I just don’t put on anything at night, it’s just open. (Winston)

Others remove their prosthesis or cover in the evening, when they wish to relax in the company of their partner: “In the evenings (...) when we’re playing cards, I take out my eye sometimes. (...) It feels pleasant, letting it breathe” (Oliver). Similarly, many interviewees remove their prosthesis or cover in the bathroom to take care of the
amputated area in the morning or at night, and then walk around the house barefaced. As in the case of sleep and relaxation, it hardly seems an issue that family members and partners see their amputation at such moments: “[W]hen I walk around here without wearing the prosthesis, (...) that’s normal for the kids (...). They just enter the bathroom” (Gregory). Although some respondents do not fully display their face because they or their loved ones do not feel comfortable about such exposure, most consider the domestic environment to be one in which they do not have to be on guard at all times and (literally) put on their ‘social face’. Instead, it is a place to sleep, relax, play, groom, and take care of their body, without worrying about their appearance.

It may take some time before participants feel comfortable about uncovering in the presence of intimates. In the period following the amputation surgery, or in the early stage of a new relationship, many interviewees said they try to hide the amputation site: “In the beginning I didn’t want to show anything at all. Whatever I’d do with the prosthesis, I didn’t want to have [my wife] anywhere near me” (Ralph). Partners, (grand)children, or close friends may try to convince respondents that they do not need to hide their facial difference in their presence. Discussing her husband’s effort to cover his bare face when going to his bedroom at night after having removed his prosthesis in the bathroom, John’s wife said:

*He would walk like this [covers her nose] (...); he kind of had to hide [for the kids] (...). Because, well, one of them could walk in any minute. (...) So at one point, all three of them said, ‘Dad, you don’t have to hide, just act normally because we’re okay with seeing it’. (John’s wife)*

Ralph’s partner, too, regularly asks to see his uncovered face, assuring him she will not be frightened or repulsed by the image it presents. In response Ralph began to create opportunities that allow for spontaneous revelation.

*It goes in small steps. (...) But gradually it’s like I, if I am busy with my prosthesis, that I wouldn’t mind her being around. (...) it’s not like I steer towards it happening, but (...) more and more, I consciously run the risk of her seeing [the amputated eye socket], for instance in the bathroom (Ralph)*

In some cases, their loved ones’ open attitude means that participants feel free to keep the amputated area uncovered when moving about the house, both during the day and at night. Many indicated that they nevertheless make use of a visible cover or their prosthetic device—even when they are completely alone. They remain uncomfortable with their unusual appearance in the context of daytime activities, and are conscious of the possibility of unexpected visitors. Others only uncover at night, for the sake of comfort. Regardless of their own preference, however, respondents cherish
the fact their partners, family members and close friends are comfortable with their uncovered face:

*I never wear it at home, right, when I’m alone with my girlfriend. (…) I feel happier when people know about me. (…) I don’t need to hide anything anymore, then, and they know what it’s like.* (Leon)

*[I]*t’s really great that she wants [to see] it and that she would dare that. That she apparently accepts me with that disability. That she doesn’t walk away from that. (Ralph)

The fact they do not need to cover up while in the presence of their intimates gives rise to a sense of relief: respondents feel cared for and accepted for who they really are, regardless of their atypical appearance.

E. DISCUSSION

In this article, we investigated the role of visible facial difference in the everyday life of twenty individuals with facial limb absence. As we demonstrated, the participants in our study cover the amputated facial area using various visible appliances, conceal it with a facial prosthetic device, or go about barefaced. Each of these ways of displaying the face makes for particular manifestations of visible difference. When it is covered by a medical aid, respondents’ facial difference is instantly visible to others, although the underlying nature of their atypicality remains hidden. When it is prosthetically recovered, participants’ face does not immediately appear to be different, because the prosthesis not only covers but also conceals the amputation site. When the device is discovered to be an artificial facial limb, interviewees’ facial difference becomes apparent again. When it is uncovered, respondents’ amputated facial area is available for others’ gaze.

These different modes of in/visibility entail a range of distinct ‘visibility experiences’ - experiences that take shape mostly within their social interactions with others who notice their atypical appearance, or fail to do so. When using a visible cover or when their prosthesis is discovered to be fake, interviewees’ atypical looks ‘snag’ others’ eyes, as Garland-Thomson puts it (2006, 33; 2009, 174). Like more explicit forms of unwanted attention such as questions or remarks, staring forms an inquiry, ‘(…) an interrogative gesture that asks what’s going on and demands the story’ (Garland-Thomson 2009, 3). Respondents have no choice but to somehow relate to these (non) verbal interrogations, which effectively means that their formerly taken-for-granted anonymity is lost. By contrast, prosthetic recovery, although it remains precarious, enables participants to evade notice and regain their anonymity. Both their facial dif-
ference and they themselves then become ‘invisible’ to others, and they are able to assume other social roles than that of ‘the disabled person’. Finally, the bared face of those interviewees who—eventually—feel equal to uncovering their face in the presence of their significant others does not merit special attention. After they themselves and their significant others grow accustomed to the appearance of the amputation site, the facial difference no longer appears unusual, becoming irrelevant—and indeed, invisible.

Respondents do not undergo the unwanted attention they receive in encounters with strangers passively. Instead, they actively develop various ways to manage both innocuous and hostile responses, thereby co-determining the meaning of their visibility and working to influence the way others’ perceive them. Often, interviewees opt for evasive maneuvers by ignoring others’ stares, questions, or remarks. Sometimes, they choose to confront others’ responses, thereby resisting being positioned as an object of one-sided curiosity. At other times, participants engage in dialogue. This strategy in particular, as we showed above, sets out to invite the noticing other to a respectful exchange. As Garland-Thomson also points out, the staring encounter can then transform into a meeting characterized by reciprocity and equal regard (Garland-Thomson 2009, 10). By engaging others who respond to their visible difference, participants actively set out to negotiate a public presence that suits their purposes in specific times and places. Such negotiating, as we showed, is not limited to the public realm investigated by Goffman and Garland-Thomson. Several respondents work to come to terms with visible difference in their private lives, as well, by working towards fully displaying their bared face to their intimates, and thereby gaining a sense of being fully accepted despite of their atypical face.

Such active management provides a much more varied picture than that painted by popular beliefs about facial variance. As Heather Laine Talley persuasively argues in Saving Face: Disfigurement and the politics of appearance (2014), these popular beliefs coalesce in what she calls a ‘disfigurement imagery’ (Talley 2014, 18; 28-30). This is a collection of popular, stigmatizing beliefs that represent facial difference as a type of social demise: a fate worse than death (idem, 19-20; 37-42). As Talley demonstrates, this imagery is (re)produced through contemporary medical practices that set out to fix the faces of individuals deemed ‘disfigured’ (e.g. extreme makeover television shows, facial feminization surgery marketed to transwomen, medical missions to repair cleft lip and palate in developing countries). Such ‘surgical facial work’, Talley demonstrates, is routinely presented as vital and lifesaving, although it is risky and not always medically necessary. Moreover: it effectively reinstates the status quo according to which the life of individuals with visible facial deviance is not worth living (idem, 38). But as our findings indicate, visible facial difference does not, in fact, form a social death sentence. Instead, the visibility experiences of the participants in our study might more adequately be understood as instances in which they navigate their social life. Unlike the disfigurement imagery would have it, interviewees mostly do
not retreat from the social realm, nor are they excluded from taking part in it—either in public or in private. Instead, they manage various others’ responses to their facial difference, thereby negotiating the meaning of visible difference in social interactions.

In these negotiations, respondents actively position themselves as social actors striving for and worthy of social recognition. Social recognition, as explored in the writings of such prominent philosophers as Charles Taylor, Axel Honneth, and Nancy Fraser, entails being acknowledged as an intrinsically worthwhile human being (Fraser & Honneth, 2003; Taylor, 1994). Indeed, Garland-Thomson repeatedly alludes to staring as a recognition issue. But how, exactly, does visible difference undermine being recognized as fully human? Writing that ‘by definition, of course, we believe the person with a stigma is not quite human’ (1963b, 5), Goffman points out that the dehumanization involved in stigma is bound up with the fact stigmatized persons are generally seen as subhuman, deficient, or inferior beings. However, the misrecognition of individuals whose appearance diverges from the norm is not merely a representation issue. As we demonstrated above, strangers often feel they have the right to interfere with visibly different persons, for instance by means of blatant stares, questions, and remarks. Such ‘uncivil attention’ (Garland-Thomson 2006, 178; 2009, 35, 45) operates on the assumption that one is entitled to breach the etiquette governing polite conduct in face-to-face interaction and freely stare at, question, and comment on the visibly different. Although Garland-Thomson does not describe it as such, this breach of etiquette is not only an invasion of privacy—it is also a form of misrecognition. When visibly different individuals are denied the same ‘civil inattention’ typically accorded to the ordinary-looking, they are effectively treated as if they are public property instead of sovereign beings. The ability to be politely disregarded in public, in other words, comes down to being implicitly recognized as social actor deserving of equal treatment and respect. Accordingly, stigma is a threat to a person’s social ‘face’ exactly because it undermines the stigmatized person’s fundamental right to be treated equally and respectfully by others. This means that our participants’ negotiations of their in/visibility in encounters with others in fact form micro-level ‘struggles for recognition.’

But visible difference does not only interfere with the ability to be recognized as fully human. It also impacts the ability to be recognized as a competent agent who fulfills of various valued (social) roles. Indeed, the authors in the ‘in/visibility debate’ referred to above all stress this issue. As Olney and Brockleman (2003) point out, the perception management strategies employed by disabled individuals are not necessarily motivated by fear of rejection or shame, but may also aim to ensure they are treated as competent rather than deficient. In a similar vein, Ziltzelberger (2010) write that visibly different women feel that their ‘bodies are highly noticed, yet their capacities, lives and desires [remain] unseen’ (394). Lourens and Swartz (2016), too, indicate that visually impaired students often feel as if others do not validate and affirm their entire personhood: ‘(...) [T]hey mostly felt that only their visual impairment, which was
only part of their identity, was seen’ (6). Only when non-disabled others understood these students’ situation, or when they associated with disabled friends, did they feel seen in their entirety—acknowledged for who they really are. Finally, Hammer (2016) describes the difficulties blind Israeli women encounter as they strive to be perceived by others as women—sexual beings, potential girlfriends, or mothers—rather than discounted as disabled. The participants in our study, too, value being acknowledged as capable, versatile individuals. As our findings show, however, their visibility experiences are not simply about asserting their misrecognition by others, or expressing a need for more recognition by these others. Instead, respondents actively resist being reduced to their difference in face-to-face interactions, and invite being perceived and approached as capable member of their communities (a handy neighbor, announcer, teacher, fellow traveler, family member or partner). By negotiating their invisibility in social encounters, these individuals actively work towards being recognized by the various others in their lives.

The mis/recognition encountered by people with disabilities, of course, forms a common theme in the disability literature. Indeed, the disability movement is clearly a larger-scale, political struggle against the exclusion and marginalization of disabled individuals in various societal domains (e.g. legislation, education, the labor market). However, the mis/recognition disabled individuals face takes place on more than one level (Danemark & Gellerstedt, 2004). As our findings suggest, mis/recognition also takes shape on a more mundane level of everyday, face-to-face social interactions. Such interactions are profoundly shaped by the invisibility of difference: apparently, mis/recognition hinges upon the extent to which a person’s body conforms to norms that prescribe proper appearance. Recognition, in other words, is a profoundly embodied and material affair, involving not only the body’s visibility, but also the usage of various—more or less visible—medical aids. This is due to the fact the body (and in particular, the face) stands at the very base of our ability to recognize others and be recognized by them, thereby forming the very condition of possibility for mutual acknowledgement (Varga & Gallagher, 2012). In order to fully understand what it means to have an atypical body in a disablist society, it is important to take into account this embodied, material and interactive dimension to the struggle for social recognition, as it is undertaken by persons with disabilities—activists as well as ordinary citizens.

In presenting the invisibility experiences of individuals who have lost a part of their face, this article contributes to the growing body of research on visible facial difference. Our findings also highlight what it means to live with facial limb absence: a condition that has until now remained mostly unexplored in the disability literature. In addition, this article clarifies the way social recognition issues play a role in the everyday life of people with visible disabilities. But our findings are also relevant

4 As Linda Martin Alcoff (2006) argues, this also applies for the in/visibility of race and gender.
for the in/visibility debate discussing the meaning of visible difference, in general. Presumably, the experiences of the participants in our study will cohere with those of individuals who have others types of visible difference, due to the fact that living with an atypical appearance often involves unwanted attention from others. Relating to such notice may require actively negotiating the social meaning of visible difference from the part of the variant person, and thus entail some kind of struggle for social recognition. Facial limb absence, of course, also affords visibility experiences that are unique to this condition, such as the fact that our respondents’ visible difference becomes manifest in four distinct ways, each accorded with particular meanings in various social settings. Being visibly different, we therefore argue, can mean different things in different contexts, and distinct types of visible difference make for specific experiences. Articulating these particularities matters, because it provides affected individuals and those who support and study them insights into the wider range of lived experiences associated with their condition—insights that may well foster a better understanding of the challenges involved in facing visible difference, as well as of the way these challenges can be actively dealt with.
REFERENCES CHAPTER 4


Chapter 5

Discussion

Doing facial difference

Parts of this chapter appear in a manuscript that is currently under review with an international, peer-reviewed journal.
In the previous chapters, I have explored the experiences of individuals who lack one or more facial limbs and/or areas, in order to provide insights into what it means to live with facial limb absence. In this final chapter, I first summarize the main findings of my study, discussing what these findings reveal about the everyday impact of facial difference. As will become clear at this point, living with a face that lacks one or more parts involves much practical, ongoing work. Affected individuals, in other words, need to ‘do’ their facial difference in various ways. I then proceed to further develop this concept of doing, demonstrating how it may be used to account for the social, embodied, and material dimensions of everyday life with facial difference. I conclude the chapter by elaborating on the practical implications of my findings.

A. SUMMARY

As already specified in the introduction to this thesis, the loss of part(s) of the face is associated with various physical impairments and dysfunctions, as well as an unusual appearance. The latter is due both to the atypical look of the amputated facial area itself, and the usage of various, more-or-less visible medical aids that cover the amputation site. In the second chapter of this thesis, I focused on both these issues by investigating the embodied aspects of facial limb absence through the lens offered by the phenomenology of the body, and of illness and disability. Applying key concepts proposed by scholars working in this field, I examined the ways in which the participants in my study gradually adjusted to their altered face. This adjustment is prompted by the different ways in which respondents’ face disrupts their ability to simply go about their everyday tasks and activities and thereby becomes present in their awareness. This happens when sensorial impairments associated with facial difference (e.g. loss of sight, smell, or skin sensitivity) interfere with their ability to engage with their material and social environment. Another source of disruption lies with the occurrence of unpleasant sensations (e.g. (phantom) itch in the lost facial limb, chronic pain around the amputated area). Again, these sensations can constrain interviewees’ ability to pursue their everyday projects. Finally, others will sometimes notice participants’ facial difference, and this unwanted attention may disrupt respondents’ ability to inhabit and traverse the public realm. All these disruptions inhibit everyday activities such as pouring tea, playing music together with others, enjoying meals, going outside on cold winter days, travelling by means of public transportation, or sitting in a café. In this way, facial difference interferes with affected individuals’ ability to immerse themselves in their lifeworld. Still, the participants in my study do not passively undergo these problems, but develop all kinds of new habits that set out to anticipate, avoid, manage, confront, and endure the disruptions caused by their different face. In this way, they attempt to keep their (potentially) disruptive face from appearing in their awareness, and relate to its disruptive presence when they cannot
avoid it. Adjusting to facial difference thus comes down to the—gradual and intuitive—development of new, habitual ways of being-embodied-in-the-world.

But dealing with the appearance-altering effects of facial limb absence encompasses more than the development of new bodily habits. In order to further examine the role respondents’ changed appearance plays in their everyday life, the third and fourth chapters of this thesis zoomed in on the visibility of facial difference. As these chapters illustrated, the people I interviewed ‘display’ their face to the world in three ways. First, they may choose to present their exposed amputated facial area as it is. They may also opt to cover this area by means of visible covers such as bandages or eye-patches. Finally, they may make use of a custom-made, facial prosthesis made of silicone, which is somewhat less conspicuous. In chapter three, I investigate the facial prosthesis through the theoretical framework offered by postphenomenology, analyzing how this so-called ‘cosmetic’ device re-establishes normal facial appearance to faces that lack limbs. Because it closely resembles the looks of the missing part(s) of the face, the facial prosthesis allows participants to restore a semblance of completeness to their partly amputated face. However, this requires continuous monitoring and management, so as to assure the prosthesis ‘fits’ the face and vice versa. To this end, some respondents repeatedly touch their prosthesis throughout their day to guarantee it remained aligned. Others use make-up, particular haircuts, beards or thick-framed (sun)glasses to camouflage its borders. Some maintain their tan in winter to match the device’s color. A number of interviewees also control their face’s movement to prevent the prosthesis from gaping. And others file or cut its edges to ensure they remained attached to their skin. These ‘fitting practices’ are all intended to make the artificial facial limb seem like a natural part of the face. A well-fitting prosthesis can be said to ‘retreat’ into the face and become ‘transparent’. This allows onlookers to see the wearer’s face in its entirety. By enabling them to disregard—quite literally, to ‘unsee’—the user’s facial difference, the device allows onlookers to simply see the person ‘within’ or ‘behind’ the face. Facial prostheses, therefore, not only cover, but also recover their wearer’s faces. As I demonstrated in this chapter, prosthetic recovery has two main advantages: (a) it allows participants to avoid unwanted attention in public, and thereby regain their anonymity and freedom of movement in a crowd; (b) it keeps the facial difference from disturbing face-to-face interactions with others.

The participants in my study, however, also reported other experiences associated with the three modes in which they display their face. In chapter four, I explored the diverse ‘visibility experiences’ afforded by these modes, discussing the way the visibility—and invisibility—of difference affects respondents’ social interactions. The visibly covered face regularly attracts others’ (unwanted) attention in public. This attention mostly takes the form of staring behavior, but others may also ask questions about interviewees’ uncommon face, or make (offensive) remarks about it. The partly prosthetic, recovered face, by contrast, allows participants to ‘pass as normal’. As indicated in chapter three, such passing not only restores their anonymity in pub-
lic, but also their ability to maintain conversational ease during close encounters. Prosthetic recovery also enables others to view respondents in a variety of ways (e.g. as a handy neighbor, as an announcer), rather than as ‘disfigured’. But recovery is by no means given: sometimes, the recovered face may also be discovered as partly artificial. Discovery takes place in particular circumstances, for instance when an interviewee is waiting in close proximity to others at the check-out, or when her skin tone does not match the device’s hue (e.g. due to fluctuations in temperature). Again, the discovering person may then sneak glances at the affected individual’s face or stare outright, ask questions about the prosthesis, or make offensive remarks. Sometimes, others request that it is removed, or ask to touch the device. Most participants indicate they dislike being the object of such notice, and report that it makes them feel self-conscious, ashamed, or even inferior. Respondents’ reactions to unwanted attention take three distinct forms: (a) ignoring, (b) actively challenging (e.g. pointedly staring back, asking a starer to behave with more civility, getting angry), or (c) engaging in conversation (e.g. explaining about the visible cover or prosthesis). When they expect potential discovery, interviewees may also opt for anticipatory self-disclosure. They then choose to tell acquaintances (e.g. colleagues, students, or fellow travelers) about the device before these acquaintances actually discover it, in order to prevent mutual awkwardness. Finally, the altered appearance of the participants in my study also plays a role in their interactions with partners and family members in the privacy of their own home. Here, a number of respondents choose to uncover their amputated facial area when in the presence of their partners or family members. Being able to bare their face, they indicate, gives them a sense of being fully accepted despite of their atypical looks, which simply cease to matter. In the end, the diverse visibility experiences all revolve around interviewees’ attempts to negotiate the meaning attached to their visible facial difference in social interactions. Using insights provided by critical disability scholars, I concluded this chapter by showing that these negotiations basically revolve around social recognition. The participants in my study resist being reduced to their difference in face-to-face interactions with others, while encouraging these others to instead perceive and approach them as fully human, ordinary and capable actors, worthy of respect and equal regard.

By zooming in on the day-to-day experiences of individuals with facial limb absence, and interpreting these experiences through the theoretical frameworks provided by phenomenology, postphenomenology, and critical disability studies, my study has explored what living with an atypical face entails. But how do the different chapters hang together? At first glance, each chapter focuses on distinct aspects of participants’ everyday experiences, namely the embodiment of facial difference, the usage of facial prosthetics devices, and the meaning of in/visible difference in social interactions. There are, however, a number of common threads running through the entire thesis. First, all three chapters investigate how respondents’ relationship to their own body, spatiotemporal environment and material objects within it changes due to their differ-
ence. In addition, they all discuss the various medical aids interviewees use. Finally, all the chapters touch upon the ways in which living with an atypical face impacts participants’ social interactions with others, in particular with regards to visible difference. In fact, when taken together, the chapters can be seen as pursuing a coherent line of enquiry. Chapter two sets the stage by exploring how respondents’ facial difference becomes present in their awareness through the functional and appearance-related disruptions it engenders. Chapters three and four zoom in on these particular disruptions and discuss the meaning of different forms of in/visiblity in social interactions.

But there is another common thread running throughout the thesis as a whole. As each chapter shows, facial difference calls for an active approach. In experiencing and relating to their altered face and world, the participants in my study can be said to ‘do’ their facial difference in various ways. As I demonstrate in chapter two, individuals who lack part(s) of the face develop new bodily habits in tackling everyday activities, thereby anticipating and responding to various (potential) disruptions associated with their unusual embodiment. These habits revolve around the doing of difference, including alternative ways of walking, driving pouring beverages, stacking objects, maintaining eye-contact with others, playing music together, eating, painting, chewing, doing errands, enduring phantom sensations, scratching, displaying one’s appearance to others, and kissing. Doing facial limb absence, as I show in chapter three, also involves various practices that aim to make the facial prosthesis fit its user’s face, and vice versa. In this way, individuals who lack part(s) of the face work to regain their anonymity in public and minimize interactional unease in close encounters with others. Doing facial difference, therefore, includes the usage and manipulation of medical aids, as well as a new way of inhabiting and moving through public spaces. And as I discuss in chapter four, doing facial difference also takes place through interactions with others. Affected individuals must anticipate and negotiate moments in which their face attracts unwanted attention in (semi)public areas, and develop a way to display their face to loved ones in the privacy of their home. Living with facial limb absence, apparently, involves much practical work. But how to understand the doing involved in this work?

B. DOING FACIAL DIFFERENCE

The notion of doing facial difference proposed above can be advanced by investigating how it addresses social, embodied, and material dimensions. To this end, I now discuss three comparative concepts: (a) ‘interactional accomplishment’ as introduced by sociologists Candace West, Don Zimmerman, and Sarah Fenstermaker; (b) ‘gender performativity’ as developed by philosopher Judith Butler; and (c) ‘enactment’ as found in the work of phenomenologist Iris Marion Young, and science and technology
Applying these concepts to my empirical findings, I show how each elucidates distinct aspects doing facial difference is done in everyday life. It is only by taking the social, embodied, and material dimensions of this doing in concert, I conclude, that it becomes possible to understand the impact of facial limb absence in affected individuals’ everyday lives.

Accomplishing facial difference through display and conduct

In social situations, people who lack part(s) of the face do their facial difference by working to pass as normal, or by managing situations in which they either cannot or do not pass as such. The doings involved in their attempts to pass as normal resonates with what Candace West, Don Zimmerman, and Sarah Fenstermaker call the ‘interactional accomplishment’ of difference (West & Fenstermaker, 1995, 2002; West & Zimmerman, 1987). Social categories like gender, race, and class, for West and her collaborators, do not refer to static phenomena that precede social exchanges. Instead, they are mutually achieved by members of society in the course of these exchanges. Discussing the accomplishment of gender, West and Zimmerman describe it as “a routine, methodical and recurrent accomplishment (...) an achieved property of situated conduct” (1987, 126). Concretely, the accomplishment of these social categories takes shape through the repetition of typical speech patterns, acts, and displays associated with, for example, femininity, blackness, or ‘poshness’.

Achieving gender, race, and class is no small matter. Rather, the interactional accomplishment of these social categories lies at the very heart of human sociality, structuring each and every social situation (e.g. sex-segregated public bathrooms, organized sports, mating practices). In such situations, members of society continuously (though mostly unconsciously) evaluate whether they themselves and others establish their relevant social identity appropriately. To accomplish difference, therefore, necessarily means to stand the risk of assessment. This assessment has real consequences: individuals are held accountable for the way in which they accomplish gender, race, or class, and they are awarded or penalized accordingly. Because members of society tend to comply with dominant social norms, however, the hard work involved in achieving social categories is mostly overlooked. As a result, features typical of particular groups receive the status of essential, natural traits. This serves to validate structural inequalities and oppression, as well as reaffirm their perceived inevitability.

1 West and her colleagues use the terms ‘accomplishment’, ‘achievement’, and ‘doing’ interchangeably. Butler, Young and Mol, too, use ‘doing’ as a synonym for ‘performative’ and ‘enactment’, respectively. For reasons of clarity, I have chosen to reserve the word ‘doing’ in the text below to distinguish my own approach from that of these authors.

2 West, Zimmerman, and Fenstermaker stress that individuals always accomplish gender, race, and class simultaneously. The particular ways in which these categories take shape together may result in highly specific, situated, and shifting configurations of difference.
West, Zimmerman, and Fenstermaker’s analysis of the ways difference is accomplished in social interactions offers a useful frame to understand the role practices of passing play in facial difference. Individuals who have an unusual face, as my findings show, often meet with unwanted attention from others. Such attention in effect holds these individuals accountable for deviating from the norm prescribing typical facial appearance: they are (implicitly) expected to answer to others’ curiosity. However, when they manage to pass as normal, individuals with visible facial difference can avoid notice. This means they can avoid being held accountable—and indeed, penalized—for their difference.\(^3\) Passing practices and the doing they involve can thus be seen as a form of interactional accomplishment. In the case of facial limb absence, passing may be achieved by means of a range of fitting practices that aim to make the prosthesis and its wearer’s face fit together well. These practices may target either the device or the face. They may also involve particular ways of positioning the body in relation to particular spaces (avoiding central spots in restaurants), objects (table arrangements), others (averting the visibly different part of the face face), and lighting conditions (walking in the shade). Similar to the notion of the interactional accomplishment of difference, the doing of facial difference in social interactions therefore includes both display and conduct.

In the end, however, passing as normal revolves around doing normalcy rather than doing difference. This is due to the fact that disability and disfigurement do not provide well-rounded patterns of stylized speech, demeanor, and display. As such, these categories of difference are inherently different from other social identities. Let me clarify this point by drawing on anthropologist Marcel Mauss’ concept of ‘body techniques’. Body techniques are the typical ways in which individuals who belong to particular groups (societies, professions, generations, genders) “know how to use their bodies” (Mauss, 1979: 70). Cataloguing different body techniques, Mauss considers various examples, including cultural and generational variations in swimming techniques, and differences between how British and French soldiers dig and march (Crossley, 2005, 2007; Mauss, 1979: 71-72). These and other body techniques are acquired through a process of socialization, in which bodies are trained and dressed in various educational and institutional contexts. Broadening the scope of Mauss’ analysis, it is possible to see how other social categories such as race, class, and even sexual orientation prescribe distinctive body techniques. Individuals who identify as members of these or other groups position themselves as such by adopting a sometimes subtle though very much recognizable stylistic ‘signature’.

\(^3\) As in the case of gender, race, and class, the (negative) meanings attributed to bodily differences are social constructs rather than intrinsic traits. Having an atypical face, in other words, is not shameful in itself, but only becomes so in relation to others’ disapproving gaze. Moreover: these meanings, as West, Zimmerman, and Fenstermaker emphasize, do not reside solely in the interactional situation, but are descended from the past, key institutions, etc. I will elaborate on this point in the next section.
Unlike other categories of difference, however, disability and ‘disfigurement’ are not accompanied by a more or less coherent pattern for using the body. Given, visibly disabled and visibly different individuals are often identifiable as such, which leads others to categorize them as belonging to a specific group, namely ‘the disabled’. Popular representations, too, portray disability in particular, often stereotypical ways (cf. the passive, suffering victim versus the persevering, triumphant survivor). In this, disability and ‘disfigurement’ clearly form distinctive social identities. However, typical ways of appearing and moving that mark certain individuals as ‘different’ are not body techniques. In the case of disability, in particular, these ways of using the body do not result from a process of socialization, but rather from the impairment itself, as well as from instances in which the impaired body and its material surrounding ‘misfit’ (Garland-Thomson, 2011). Individuals with visible differences simply do not exhibit characteristic behaviors, mannerisms, bearings, etc. Instead, they internalize disablist norms, by attempting to suppress or conceal atypical ways of moving and speaking in favor of ‘normal’ manner and appearance. Trying to pass as normal is about coming across as able-bodied and unblemished as possible. Therefore, those who have atypical bodies endeavor to do normalcy rather than difference.4

The interactional accomplishment of disability and ‘disfigurement’ as social categories of difference does not entirely cohere with the model presented by West, Zimmerman, and Fenstermaker. Nevertheless, their analysis of the way gender, race, and class are accomplished in social interactions still offers a useful frame to understand how facial difference is done through practices of passing. First, this account underwrites the role of accountability in these practices. It also highlights that this

4 It is beyond the scope of this chapter to fully unpack this line of argument, but there are two noteworthy differences between visible differences on the one hand, and other social categories of difference on the other hand. First, the bodily dimension of disability (the impairment) forms a much bigger part in the disability identity than is the case for other social categories (although gender, age, and to a much lesser extent, race, also have some physical basis). I address this bodily dimension of disability and visible difference below, in section 2c. In addition, there is a radical difference between how visible difference is contrasted with ablebodiedness, and the way other oppositional social identities function. Femininity, blackness, or ‘working-class-ness’, for instance, are arguably each defined in contrast to masculinity, whiteness, or ‘middleclass-ness’ (including various possible intersections in which black, middleclass femininity, for instance, stands in opposition to white, working-class femininity). These oppositional identities are nevertheless each accompanied by a fleshed out, recognizable style. Of course, in particular contexts (work, public life), women or people of color may internalize sexist and racist norms by downplaying distinctive behaviors, displays, or ways of speech (e.g. voice pitch, ‘black’ vocabulary) in favor of styles associated with masculinity or whiteness. They nevertheless do not opt for fully accomplishing masculinity or whiteness—and are indeed often penalized when they do (e.g. criticized for being mannish, or an ‘oreo’: a black person who exhibits predominantly ‘white’ interests and mannerisms). This is not the case for disability and ablebodiedness. Neither of these categories can in fact be said to form anything resembling a recognizable style. In everyday contexts, people, whether they are disabled or able-bodied, both try to accomplish ‘normalcy’ in interaction, and are held accountable when they do not manage to do so (e.g. when stumbling or stuttering). Normalcy, I would argue, functions as an implicit ‘master category’, prescribing a style of conduct that all members of society are expected to enact irrespective of any other social category they may identify with. Disability and ‘disfigurement’, then, operate as undesirable counterpoints to ‘ablebodiedness’ and ‘unblemishedness’ in social exchanges, rather than as distinctive, full-fledged styles in their own right.
DOING FACIAL DIFFERENCE

doing involves displays as well as various forms of conduct. Finally, following this account through helps establish that it is the accomplishment of normalcy, rather than deviance, which is at stake in the doing of facial difference. Accomplishing difference in social interactions, as West, Zimmerman, and Fenstermaker show, does not only take place merely through display and conduct: language also plays a vital part in the achievement of social categorization. And indeed, as I show in chapter four, facial limb absence is regularly done by verbal means, for instance when affected individuals ask others to stop staring. For a sophisticated analysis of the way in which language works to produce difference, I now turn to Judith Butler’s notion of gender performativity.

Performing facial difference through language

Like the notion of interactional accomplishment proposed by West and her collaborators, Butler’s theory of gender performativity aims to challenge the common distinction between sex and gender (Butler, 2007, 2011). The material body, for Butler, exists beyond language but can never be approached outside of it: since every human experience is necessarily mediated by signs, we can have no direct access to some type of ‘pre-’ or ‘extradiscursive’ bodily reality (Halsema 2000, 30-31; Noland 2009, 178). For this reason, the various meanings we attribute to particular bodies cannot be said to reside within these bodies, but are rather produced by the discourses that endow that body with meaning. Human beings, for Butler, “come into being” in language: it is only through their assimilation into the order of signification that they emerge as subjects (Butler 2007, 8; Noland 2009, 172-173, 177). This means that the sexed body is always already gendered: immediately after birth (and nowadays often before), the newborn’s body is classified as either female or male on the basis of certain anatomical features (e.g. genitalia), and she is received into a system of social and cultural meanings. In Butler’s words: “Consider the medical interpellation which (...) shifts an infant from an ‘it’ to a ’she’ or a ‘he’, and in that naming, the girl is ‘girled,’ brought into the domain of language and kinship” (Butler 2007, xvii).

Butler’s analysis of how language constitutes subjectivity incorporates and combines ideas originating with several philosophers working in (post)structuralist traditions. With Michel Foucault, Butler argues that subjects are produced as such through the repetition of the patterns of expression available to them. When they speak or write, individuals are neither the authors nor the origins of the various statements they make. Instead, these statements are drawn from established discourses—repositories of historically rooted, possible linguistic forms (e.g. phrases, jargons, plotlines) that organize communication. Importantly, discourses are inherently normative. Mobilizing forms of scientific knowledge about (the bodies of) specific social groups—psychiatric patients,

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5 For an overview of overlaps and divergences between the views of West, Zimmerman, and Fenstermaker on the one hand, and Butler on the other, see chapter 10 ‘Performance and Accomplishment: Reconciling Feminist Conceptions of Gender’ in (West & Fenstermaker, 2002).
prisoners, children, women—discourses simultaneously produce them as collectives with distinct, recognizable characteristics. Thus, when subjects internalize and reproduce specific styles of speech and writing, they in fact assert their own and others’ membership in a particular social group. Many statements, for Butler, are ‘performatice’: they establish speakers and addressees as particular types of subjects. ‘Hello, I’m Mrs. Smith, nice to meet you,’ for instance, positions the speaker as a married woman. Likewise, ‘Ladies and gentlemen, we have arrived at our destination, please do not forget to check out before you exit the train station’ produces addressees as gendered consumers. Gendered subjectivity is performed through the reproduction of common, normative linguistic patterns that constitute certain individuals as members of a characteristic (and often devalued) identity category. Adopting a Derridean strand into her thought, Butler asserts that the repetition of established patterns of discourse is in fact a form of citation. But every citation necessarily runs the risk of altering the meaning of the utterance it echoes, sometimes radically so. The fundamental ‘citability’ of language—the fact signs must be repeated in order to communicate meaning—opens up a space for difference. Applying this insight to her theory of gender performativity, Butler argues that speakers not only emulate discursive patterns, but may also improvise upon them, for instance through parody or out-of-context usage. By troubling conventionalized forms, subversive citations, in particular, may undermine and resist oppressive categorizations.

Applying Butler’s concept of performativity to my findings, it becomes possible to understand the role of language in everyday exchanges between individuals with facial limb absence and others. West, Zimmerman, and Fenstermaker’s account of difference as an interactional accomplishment, as I discussed above, helped frame passing practices as forms of conduct and display that allow those who have an atypical facial appearance to do normalcy. However, passing is not always possible or successful. If so, the uncommon appearance of affected individuals attracts others’ notice, which may be expressed through more or less obvious staring, as well as through questions or (offensive) remarks. These utterances, from a Butlerian perspective, position the visibly different person as simultaneously extraordinary and deviant. They also implicitly cast this person as less entitled to civil inattention accorded to those who have a more typical appearance. More specifically, questions and remarks constitute visibly different individuals as suffering victims (‘What happened to you?’), objects of ridicule (‘You have a weird noggin’, ‘Been in a fight?’), unworthy of (social) life (‘How do you find

6 Of course, one’s claim to any type of identity must be appropriate: one must (appear to) be an adult female to be able to creditably introduce oneself as a Mrs.

7 Interestingly, Dutch railway company NS has recently reverted to the usage of the gender-neutral ‘travelers’ instead of ‘ladies and gentlemen’ in public announcements. This form of address is part of a heavily contested, global effort to make public spaces and institutions more inclusive to non-binary or gender fluid people.

8 Nonverbal gestures such as pointing fingers, stares, and laughter may fulfil a similar role.
the courage to go on?; ‘You should just put an end to it all’), and requiring a medical fix (‘can’t [doctors] do something about your face?’; ‘[The prosthesis] is such an clever solution!’). This type of everyday language reflects and reiterates stereotypical meanings commonly attributed to deviant bodies in books, movies, websites, and other venues. Blending into a ‘disfigurement imagery’ (Talley, 2014), these representations depict disability and ‘disfigurement’ as contemptible states.

Using Butler, it becomes possible to understand such representations as part of a normative discourse on visible facial difference, which produces affected individuals as extraordinary, tragic, ridiculous or, alternatively, (heroic,) spectacles—regardless of the fact they most often manage their lives quite well.

Next to the utterances made by others, people with facial limb absence themselves also sometimes talk about their atypical appearance. They explain about their visible difference, verbally confront unwanted attention, or joke about their prosthesis to family and friends. In such situations, these individuals can be said to be doing difference by emphasizing their underlying normalcy. When they address others’ unwanted attention or offer explanations, these individuals in fact position themselves as ordinary human beings, despite their uncommon appearance, and as deserving of the same civility accorded to other members of society. Similarly, the jokes they make invariably follow situations of discovery, in which it becomes clear that the prosthesis is in fact artificial (e.g. when their silicone ‘eyelid’ remains open while taking a nap; while searching for a lost prosthesis). Joking serves to construe the person in question as being at ease with her facial difference, and thereby help defuse others’ potential tension and awkwardness. More importantly, jokes also establish rapport, signaling that the facially different person is a fundamentally normal human being, just like her interlocutor. Ultimately, these utterances are all performative in that they constitute facially different individuals as ordinary in despite their facial difference, allowing them to do difference by doing normalcy.

To summarize: applying Butler’s concept of performativity to the case of facial limb absence helps to clarify a number of key issues in how facial difference is done through everyday language. First, this doing clearly involves not only the affected person, but also others. Others’ questions and remarks in such exchanges constitute those with an atypical face as extraordinary and deviant. Second, Butler account sheds light on

9 My respondents also reported a more benign type of jokes made by friends, acquaintances, or family members. This type of language serves to defuse possible social awkwardness by lightly or indirectly acknowledging the facial difference. As I will argue below, such jokes—especially when made by the affected person themselves—also casts people with an atypical as essentially the same as others, despite their different exterior.

10 Such representations of ‘disfigurement’ also inform the accomplishment of normalcy through appearance and conduct, as discussed in the section on West and her collaborators. Trying to pass as normal implicitly enacts visible difference as something shameful that must be hidden or concealed from others. The social and cultural meanings accorded to visible difference are then literally inscribed upon the deviant body.
the discourses informing these responses. Third, the concept of performativity also illustrates how individuals with facial limb absence themselves do their difference discursively when they respond to others’ (potential) notice, namely by positioning themselves as essentially normal despite their difference.

The notion of performativity and that of interactional accomplishment focus on the way bodies are done through spoken and written language, as well other types of signification (behaviors, acts, or gestures). Nevertheless, it remains unclear how the experienced, experiencing body figures in these accounts. As Carrie Noland writes when discussing performativity: “Butler has a meagre account of both embodiment and interoception. (...) [S]he neglects to theorize the performing body’s proprioceptive, kinesthetic, even affective experience of moving in prescribed ways” (Noland 2009, 171). This point, I would argue, applies with equal force to the work of West and her collaborators. Like Butler’s performativity, the concept of interactional accomplishment they propose does not allow for an analysis of the doing of difference as it is embodied. Moreover: neither approach accounts for the ways in which this doing is structured by the materiality of assistive devices, everyday objects, and the environment with which the (atypical) body is in constant interaction. In order to conceptualize the embodied and material dimensions of the doing of facial difference, I will now discuss the notion of ‘enactment’ as found in the work of Iris Marion Young and Annemarie Mol.

**Enacting facial difference through bodies, objects, and environments**

As demonstrated by Iris Marion Young in *On female body experience: “Throwing like a girl” and other essays* (2005), how women inhabit and use their bodies has both a social dimension and a material one (2005: 5-6). The physical possibilities and limitations offered by most female bodies call for distinctive ways of ‘enacting’ the body. Breasts, for instance, may produce mother’s milk or hamper one’s ability to perform yoga exercises. Menstruation is often accompanied by cramps and bouts or irritability, and requires the management of flow. Pregnancy involves adjusting to one’s growing girth, and may cause tiredness and nausea. Women live through the materiality of their bod-

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11 Various interpreters seem to disagree on whether behaviors, acts, or gestures are indeed performatives. Silvia Stoller (2010) claims that Butler includes corporeal expressions of gender within her theoretical framework. Noland (2009) argues that Butler sometimes seems to restrict her analysis of performativity to language alone, while at other times treating acts, gestures, and behaviors as a specific type of performatives. Annemie Halsema (2000) explains gender performativity as a matter of linguistics.

12 Young’s usage of the terms ‘enactment’ in order to describe the particular ways women shape and are shaped by their embodiment is almost incidental: she never systematically explores or develops this notion as an analytical concept. Nevertheless, she repeatedly uses the term ‘enactment’ to describe the typically feminine mode of moving and performing tasks, for instance when writing: “The more a girl assumes her status as feminine, the more she takes herself to be fragile and immobile, and the more she actively enacts her own body inhibition” (2005: 44). Gail Weiss discusses Young’s analysis of the inhibited ‘I cannot’ characterizing feminine comportment and motility as a ‘doing’ of the body (Weiss, 2015: 78-82). For a more on Young’s notion of ‘I cannot’, see chapter two.
ies—a materiality that inevitably affects how they relate to themselves, others, and the world. Of course, women’s embodied capacities are not solely determined by this materiality. Like West, Zimmerman, and Fenstermaker on the one hand, and Butler on the other, Young stresses that enacting femininity also takes shape through social and cultural norms. These norms prescribe some ways to act, speak, and display the gendered body while invalidating others. As Young demonstrates, the way many women inhabit spaces and use everyday objects is characterized by an inhibited type of bodily motility: a demure, cautious way of moving that reflects sexist norms. Gender, however, is shaped through more than these social and cultural meanings. It also involves the material vicissitudes of female bodies. Indeed, the novelty of Young’s account lies in the fact she successfully draws together the way various gendered norms are inscribed upon the body, as well as the material im/possibilities of real bodies.

Applying Young’s ideas to my findings, it becomes possible to recognize the embodied dimensions of facial limb absence. The social and cultural meanings of visible difference intimately inform how the bodies of those who have unusual faces are lived through. The need to monitor and manage their looks, that is, colors affected individuals’ entire existence, altering how they experience and relate to their own body, others, and the world. The atypical face becomes something that must be carefully minded; social interactions become risky; central spots in cafés become disagreeable. The doing of visible difference, in this sense, is very much embodied. But this doing, as Young would stress, is not limited to the visible body. Individuals with facial limb absence also live through the altered capacities of their face: the sensory impairments and unpleasant sensations they confront. The new im/possibilities signaled by the atypical face, too, deeply affect how affected individuals inhabit their body and life world. The impaired face becomes a source of potential calamities; partners become sensory extensions; cold weather becomes painful. Importantly, the altered looks and bodily capacities of individuals who lack part(s) of the face both translate into new bodily habits—new ways of doing their altered face. By using Young’s notion of enactment, it becomes possible to understand how this doing simultaneously embodies affected individuals’ altered appearance and physical capacities.

As the examples provided in the former paragraph illustrate, doing facial difference takes place in various spatiotemporal environments, and involves the usage of various assistive devices and everyday artefacts. Young’s account of female embodiment, too, alludes to the way in which material settings and objects inform how bodies are enacted. In one striking passage, for instance, she describes her deeply felt inability to step over a small stream while hiking with friends (Young, 2005: 34). Other examples discuss typically feminine modes of handling objects such as balls and books. The role contexts ad artefacts play in the way bodies are enacted, however, is not the primary focus of Young’s analysis. To gain insight into the roles material environments and everyday objects play in how chronically sick, technologically extended bodies are done in practice, I now turn to the concept of enactment as developed by Annemarie Mol.
Mol introduces the term ‘enactment’ in *The Body Multiple: Ontology in Medical Practice* (2002). Here, she investigates how medical knowledge is mobilized—enacted—in hospital settings, through various practices involving human as well as non-human actors. As she writes: “The “disease” that ethnographers talk about (...) depends on everything and everyone that is active while it is being practiced. The disease is being done” (2002, 32). The term ‘enactment’, Mol argues, allows her to evoke associations with scripts that require interpretation but leave room for improvisation. It also captures the fundamental materiality of practices, their dynamic, emergent character, and the way they assemble disparate elements (Mol, 2002: 32, 37-43). But how do patients enact diseases in their everyday lives? In ‘Enacting bodies, Embodied Action: The example of Hypoglycaemia’ (2004), Mol and long-term collaborator John Law turn to the experiences of patients, investigating various ways in which hypoglycaemia, a condition whereby blood sugar levels sometimes drop to a dangerously low point, is done in practice.

Some ways of enacting hypoglycaemia involve knowing it, for instance by measuring blood glucose, or by learning to sense dangerously low glucose levels. These doings, however, are geared less towards the knowledge yielded than towards anticipating and counteracting an oncoming hypo: “In the daily lives of people with diabetes, hypoglycaemia is something they know about, but the point of their dealings with it is not to gather knowledge but to intervene” (Mol and Law 2004, 49). Patients do hypoglycaemia by using special instruments to monitor their blood sugar levels, remaining attentive to faintness, carefully managing food intake and exercise, injecting insulin, and remembering to always have access to snacks that can help offset dropping blood sugar levels. As the disease is enacted, the patients’ body ‘incorporates’ measuring instruments, foods, and the alertness of others who help keep track of an oncoming hypo. The patients’ body also ‘excorporates’ itself in various ways, “shifting out” or transferring some of its actions outwards (idem, 53). Such excorporations include falling back on partners and colleagues who know how to act when the condition manifests, and on snacks kept in strategic locations. The body, in other words, has semi-permeable boundaries: enacting disease, it incorporates its surroundings, while also excorporating into it. Doing hypoglycaemia, however, brings along inescapable tensions. Patients must navigate between the conflicting interests of different organs affected by fluctuating blood glucose levels, between the need for control and the capriciousness of the disease, and between their life projects and the requirements of disease management. Ultimately, enacting hypoglycaemia is about the work required in managing both the disease itself and the tensions it brings: “Keeping yourself whole is one of the tasks of life. It is not a given, but must be achieved, both beneath the skin and beyond, in practice” (idem, 57, emphasis in the original). Bodies are not only

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13 Although Mol does not provide a definition for this term, ‘script’ is a concept developed by Madeleine Akrich (1992) to capture the way artefacts are inscribed with designers’ expectations about the way users will and ought to use them, as well as the way these artefacts prescribe particular usages.
known, either from within or externally—they are primarily done as patients manage their medical conditions.

Mol’s descriptions of how chronically ill bodies are enacted in practice are quite similar to my own findings with regards to facial limb absence. Affected individuals’ new bodily habits, as I described in chapter two, revolve around the anticipation and prevention of instances in which sensorial impairments, unpleasant sensations, or others’ observations disrupt their everyday activities. Mol’s point regarding the need to negotiate conflicting priorities in the enactment of chronic disease can also be extrapolated to the case of facial limb absence. The chronically ill body, as Mol shows, is multiple: it may be enacted in various, overlapping or conflicting, ways. As my findings illustrate, possible ways of doing the different face, too, may either coexist harmoniously or clash. When affected individuals find new ways to engage in everyday projects despite their sensory impairments, are not bothered by unpleasant sensations, and manage to pass as normal all at once, distinct modes of doing act in concert. Different bodily modalities, however, may also prove incompatible. As I showed in chapter three, facial prostheses allow their wearers to pass as normal, but may also cause unpleasant itching and irritation. As a result, users must sometimes choose between their observable face (i.e. being inconspicuous) and their sensed face (i.e. feeling comfortable). This conflict is negotiated in various ways. Some wearers develop ways to scratch surreptitiously. Others reserve the use of the device for outings or visits, prioritizing social comfort over physical comfort for the duration of the activity. Furthermore, as I show in chapter three, achieving a proper fit between the prosthesis and the face requires much fuss, planning, and access to a private location. This may hamper a wearer’s ability to just hop outside for an errand or go on vacation. Here, the need to pass clashes with the need to pursue activities that involve spending time away from home. Such conflicts between different bodily modalities call for careful negotiation, asking that affected individuals choose one way of doing the atypical face over others.

Most important for my purposes here, however, is Mol’s analysis of the incorporations and excorporations involved in the enactment of disease. Those who have facial limb absence, too, incorporate prostheses and other appliances, as well as all manner of everyday objects such as shades, make-up, or protective shawls. They also incorporate others’ potential observations. Finally, they incorporate their physical environments, for instance when inhabiting public locations strategically or minding lightening conditions.\(^\text{14}\) In addition to these incorporations, individuals with facial limb absence can be said to excorporate their sensory impairments onto others, for instance, by positioning others to their unimpaired side, or by delegating sensory per-

\(^{14}\) Physical environments and objects are imbued by (disablist) social and cultural norms, as several scholars working in disability studies, postphenomenology, and science and technology studies have pointed out. These materialized norms, I would add, call for particular ways of doing the visibly different body. A checkout, for instance, forces people to form queues and thereby enables staring. Busy streets compel people to move along, which preclude unwanted attention. The way individuals with facial limb absence do their body, therefore, takes shape in relation to normatively-laden artefacts and contexts.
ception to these others. And they excorporate into various objects and environments as well, altering these to compensate for sensory impairments. These incorporations and excorporations are all part of the doing of facial limb absence, part of a newly developed, practical relationship to the altered body and its context. As Mol rightly observes, bodies have semi-permeable boundaries: inside and outside, self and other, biology and artefact are not so easily distinguished. The body, moreover, is essentially unfinished. It keeps requiring work in order to maintain its wholeness. The enacted body is an open project, its integrity a continuous achievement rather than a given point of departure.

Mol’s concept of enactment helps understand important issues involved in the doing of facial limb absence. First, this concept highlights that this doing is essentially oriented towards the anticipation and prevention of mishaps and discomfort. In addition, it underwrites that different ways of doing facial difference may either conflict or run parallel. Finally, Mol’s analysis underscores how this doing incorporates and excorporates into objects, others, and environments. Doing facial difference, however, is not limited to the practical, functional concerns that form the focus of Mol’s analysis. This doing unavoidably takes shape in relation to the social and cultural meanings accorded to illness, disability, visible difference, and assistive technologies. People with facial limb absence tinker with their prosthesis to better conceal their disfigurement. Similarly, they try to increase their chances of passing as normal by inhabiting and traversing public spaces strategically. These types of doing are not aimed at the avoidance of minor calamities or unpleasant sensations, but at circumscribing awkwardness, shame, and bias. Any account describing how visible difference is done in everyday practices, I would argue, must do justice to the cultural meanings and social norms associated with atypical embodiment.

In this section, I set out to examine how facial difference is done through every day, practical work. Approaching my findings through the concepts of interactional accomplishment, performance, and enactment, made it possible to highlight the social, embodied, and material dimension of this work. The meaning of facial difference in the everyday lives of individuals who lack part(s) of the face, to return to the question motivating this dissertation, is best approached by zooming in on these multifaceted doings. Living with facial difference is an ongoing endeavor that requires much work. Through the doing involved in this work, affected individuals continuously and actively relate to their altered face and lifeworld. Having come to this conclusion, I am nearing the end of my interrogation of facial limb absence. The next section will conclude this chapter by discussing some practical implication of my findings.

C. PRACTICAL IMPLICATIONS

The seemingly mundane practicalities associated with facial limb absence encompass more than medical concerns on the one hand, and psycho-social issues on the
other. By interviewing affected individuals, and interpreting their accounts through the frameworks offered by phenomenology, postphenomenology, and disability studies, I sought to pinpoint this ‘more’. The impact of losing part(s) of the face, as I showed, takes shape mainly within the context of everyday life. It is within this context that affected individuals do their facial limb absence in various ways. Through this doing, they actively relating to their radically altered face, various medical appliances, everyday objects, others, and the world. But how can this perspective on facial difference be of use for affected individuals themselves, as well as for those who treat and support them? In this section, I elaborate on some implications of my findings.

Learning to relate to one’s altered face and world begins within the clinic, when individuals with facial limb absence are diagnosed, often after a series of referrals. The radical and invasive treatment trajectory they follow is physically and emotionally draining. After its completion, affected individuals will return home, where they must deal with the challenges presented by their facial limb absence beyond medical settings. In the context of daily life, individuals who lack part(s) of the face are required to develop alternative ways to work, care for and associate with others, maintain their household, travel, pursue leisurely activities, and more. The work involved in doing facial difference therefore does not only revolve around physical and psychological healing and rehabilitation. And although it includes the development of various practical and social skills, this work exceeds beyond mere ‘coping’. Indeed, the many ways in which affected individuals do facial difference signal a radical shift in how they inhabit their body and world—both of whom have changed irrevocably.

During the interviews, many respondents in my study were quite interested in what I could tell them about other participants’ experiences, and in particular, the solutions other interviewees found to various challenges. This suggests that individuals who lack part(s) of the face could benefit from experience-based information and support not only during the period in which they recuperate from their condition and its treatment, but long after. As they learn to do their facial different, however, these individuals can often only draw upon their own experiences. Conditions that affect the face are relatively rare, which means they have no access to others who have undergone a similar path. Moreover: the health care professionals they meet in the course of their clinical trajectory, I noticed during observations at the hospital, are often unaware of the everyday impact of facial difference. Indeed, in the case of facial limb absence, the clinical trajectory is still very much oriented towards curative treatment rather than rehabilitation. Despite publications that advocate the need for social skills training in the rehabilitation of individuals with atypical faces (Robinson, Rumsey, & Partridge, 1996), new patients are not yet routinely referred to such trainings. And practical challenges, too, are mostly unaddressed in the clinic.

More importantly, health care professionals in general rarely appreciate the extent to which facial difference impacts affected individuals’ everyday existence, and the ongoing work this difference requires. Facial difference, as highlighted in this thesis, asks
that affected individuals learn to relate anew to both their changed body and lifeworld. This relating-to is a never-ending project. The ongoing character of the work involved in this, however, is not only due to the fact their face is permanently altered. As they live their lives, individuals with an atypical face continuously enter into new (social) situations: they grow older, change jobs, gain and lose friends, partners, and family members, move house, find new hobbies, or go through other life events. These changes may bring along new challenges, new needs, and new priorities—and consequently, new ways of doing facial difference. As a result, people with facial limb absence are never quite done with this doing.

To adequately inform and support individuals who lack part(s) of the face, health care professionals are advised to acquaint themselves—and even become fluent—with what it means to live with an atypical face. These professionals are therefore advised to gain an intimate understanding of how living with a face that lacks one or more parts affects a person's entire existence. They should also come to grips with the fact that this doing requires ongoing work that will feature throughout this person's entire life span in ever-changing ways. This will enable these professionals to inform prospective and new patients about what they can expect beyond the clinical settings, and offer them with first-hand support as they start confronting everyday challenges. Access to experiential knowledge regarding the lifeworld issues and ongoing work associated with facial limb absence should therefore become part and parcel of the treatment and rehabilitation trajectories offered to those who have a different face.

Another way to provide individuals who lack part(s) of the face with experienced-based support could be through contact with others who have undergone a similar ordeal. More seasoned (ex-)patients, after all, are ‘hands-on experts’ on what it means to live with a face that lacks one or more parts. Accordingly, the task of providing information and guidance with regards to the ongoing management of various (chronic) conditions often falls to patient organizations and charities. In the UK and North America, charity organizations ‘Changing Faces’ and ‘AboutFace’ fulfil this role for people who have visible (facial) difference. In the Netherlands, ‘Stichting eigen gezicht’ [One’s own face foundation] and ‘Patiëntenvereniging HOOFD-HALS’ [Patients’ association HEAD-NECK] provide a similar function. People who have lost part(s) of the face, however, do not always find their way to these organizations. What is more, new as well as more veteran patients both stand to gain from access to others’ experiences, and from scholarly perspectives on visible difference and disability. By discussing the stories of individuals with facial limb absence and connecting these with various academic literatures, this thesis may offer patients new insights regarding their own experiences.15

UK charity ‘Changing Faces’ is a particularly active organization, taking a leading role in the battle against ‘lookism’ (prejudice and discrimination against people who have

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15 For some concrete ideas on how to provide health care professionals and (prospective) patients with access to the lived experiences of individuals with facial limb absence, see the valorization chapter of this thesis.
visible difference) by vocally responding to stereotypical media representations of visible facial difference. In addition, this organization maintains close ties with scholars of the psychology of appearance and medical centers specializing in reconstructive surgery for conditions that affect the face. Together, these stakeholders work to fully integrate psychosocial care into treatment and rehabilitation trajectories for those who live with visible difference. As I argued above, it is important that these trajectories address not only the practical and appearance-related concerns of individuals with facial difference, but also their lived experiences associated with facial difference, and the work it requires. In the UK, such collaborations that cross institutional and professional divides are still very much under development. In the Netherlands, they are all but non-existent. I would therefore urge medical professionals, researchers, patients, charity organizations and disability activists to strike new partnerships and together ensure that all people with visible facial difference receive the support they need as they continuously relate to their altered face and lifeworld.
REFERENCES CHAPTER 5


Valorization

Doing more than research

Disseminating knowledge, developing clinical interventions

Parts of this chapter appear in a manuscript that is currently under review with an international, peer-reviewed journal.
By highlighting the lived experiences of individuals who have lost one or more parts of the face, this dissertation investigated the everyday impact of facial difference. This impact, as I showed in the previous chapters, takes shape mainly within the setting of everyday life. As they move through spaces, eat, practice hobbies, travel, use everyday objects, work, and interact with others, affected individuals experience various disruptions due to their physical dysfunctions and atypical appearance. It is also within this daily context that individuals who lack part(s) of the face actively relate to the disruptions associated with being amputated by developing new ways to inhabit their changed body and world. Adjusting to a radically altered face therefore involves more than physical and psychological healing: it requires the development of a new way of being-embodied-in-the-world.

As indicated in the discussion chapter, this perspective on facial limb absence can be of practical use for affected individuals themselves, as well as for the healthcare professionals working with them. This section briefly sketches out what shape this practical use may take. I start by reviewing the typical clinical trajectory patients go through. Next, I point out in what ways this trajectory is insufficiently oriented towards the lived experiences of individuals who have lost part(s) of the face, and why this is problematic. I then discuss several concrete measures to make these experiences count in the information, care, and support provided to patients throughout their treatment and its aftermath. In this way, I hope to pinpoint how this empirical-philosophical dissertation on patients’ lived experiences may have value beyond the production of a PhD degree and academic publications.

The typical clinical trajectory is primarily oriented towards curative treatment rather than the everyday impact of treatment on patients’ everyday life. As part of the process surrounding the decision to amputate, doctors and nurses typically inform patients about the expected outcome of the procedure (i.e. possible dysfunctions and facial ‘disfigurement’) and possibilities for prosthetic rehabilitation. After the surgery, when they recuperate in the hospital’s ward, patients receive further information and support by the resident nurses. The focus here lies mainly on monitoring patients’ healing, helping them establish self-care routines in treating the wound, and offering guidance as patients and their families first confront their altered appearance. In addition, nurses watch for signs of poor psychological coping, and may refer patients to mental health practitioners. After about two weeks, most patients are able to return home. A limited number of check-ups at the clinic then follow, after which the treatment comes to its conclusion. Once the amputated facial area has healed sufficiently, patients are also outfitted with a facial prosthesis at a prosthetics service unit (in the Netherlands and Belgium, these are most often affiliated with medical centers for cancer care). Because a typical device lasts for three to six months, most patients regularly return to the prosthetics unit for periodical adjustments.

This focus on curative treatment and postoperative healing within the clinical context means that the long-term adjustment of patients does not receive much attention.
Thus, patients are not informed about the practical, everyday challenges associated with physical dysfunctions and an altered appearance—including the ongoing work involved in managing these—before the amputation surgery. Likewise, the information, care, and support they receive while recuperating from the procedure are mostly geared towards their immediate recovery. And although nurses routinely monitor for poor psychological coping and body image disturbances, the protocols they follow focus only on the isolated individual’s psychological difficulties. Consequently, problems emerging within the affected person’s broader social context (most commonly due to the burden of managing unwanted attention) are not recognised or addressed. Moreover: physicians and nurses only incidentally refer patients to a mental health professional, and patients themselves rarely ask to see one. In addition, those who struggle emotionally after their return home remain undetected, and therefore do not receive a referral. Possible physical dysfunctions, too, are often not taken up in the clinic. Patients are not informed about the practical, everyday repercussions of these dysfunctions, nor do they receive professional support as they learn how to tackle everyday activities that are rendered more difficult by them. Indeed, individuals who have lost part(s) of the face seem to be somewhat of a ‘forgotten group’ within the clinic.

Of course, the fact this clinical trajectory is insufficiently oriented towards the context of everyday life cannot be attributed to ill-will or lack of professionality of healthcare professionals. Rather, the extent to which the amputation impacts affected individuals’ daily existence has until now simply remained uncharted. Because care practitioners do not have a sufficiently fleshed-out understanding of patients’ lived experiences, they are unable to articulate how ‘dysfunction’, ‘sensorial impairments’, or ‘disfigurement’ translate into practical, everyday issues. Likewise, they remain unaware of the extent and nature of the continuous work involved in the management of these issues. As a result, practitioners are unable to convey the impact of the procedure to (prospective) patients, or address issues that may arise in its aftermath. Despite the efforts of the various professionals involved in their care, therefore, patients remain unprepared for the challenges they will confront after returning home, and do not receive enough support in managing these. As a result, individuals who have lost part(s) of the face are mostly on their own as they try to come to terms with their altered face after the amputation surgery.

The three empirical chapters of this dissertation demonstrate that these individuals all run into similar problems—and devise similar solutions—as they adapt to their amputation. Each in fact reinvents the wheel, as it were. Although the work involved in doing their facial difference remains significant, most find their way eventually. They nevertheless cannot learn from others’ experience as they do so. As I mention in the discussion, many participants in my study were quite interested in others’ experiences. This interest, I surmise, is due to the vacuum they find themselves in while adjusting to their altered body and world. Hearing about others’ stories...
offered respondents insight in and recognition of the various everyday challenges they themselves confront, and the work involved in managing these. Accounts that detail affected individuals’ lived experiences, in other words, can provide an intimate and practical understanding of what it is like to live with a partly amputated face. Such an experience-based understanding could be of use to patients as well as healthcare professionals. Indeed, sufficient adequate in the lived experiences associated with the loss of part(s) of the face may help patients prepare for and handle the challenges they encounter upon their return home. It may also allow healthcare professionals to better inform, care for, and support these patients in different stages of their clinical trajectory and beyond. But how to ensure patients and care practitioners acquire an experience-based understanding of the day-to-day meaning of facial limb absence? I suggest there are three main paths towards achieving this end: (1) adjusting the clinical trajectory; (2); educating primary care practitioners; and (3) establishing close collaborations between medical centres, patients’ organisations, and researchers. In the remainder of this chapter, I will briefly discuss each of these options.

Table 1: Publications for a lay audience

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<th>Title</th>
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<tr>
<td>Onderzoek: Leven met een afwijkend gezicht</td>
<td>HOOFD-HALS magazine, issue 9, February.</td>
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<tr>
<td>Summaries of research findings</td>
<td>Public website of the research project ‘Bodily integrity in blemished bodies’ (<a href="http://www.mindthebody.eu">www.mindthebody.eu</a>).</td>
</tr>
<tr>
<td>Leven met een ander gezicht</td>
<td>Nieuwsbrief van de Vereniging Oog in Oog, issue 49, volume 14.</td>
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Adjusting the clinical trajectory to ensure it is better attuned to the everyday impact of the loss of part(s) of the face can take place through two concrete measures. First, written handouts informing patients about their condition and its treatment prior to and after the amputation surgery could be adapted to discuss the meaning of the amputation in daily life. Specifically, patients should be offered clear descriptions of various practical issues they can expect to confront due to their physical dysfunctions and altered appearance. These descriptions would ideally avoid medical jargon and normatively laden terms (e.g. ‘defect’, ‘disfigurement’). In addition, it is important to discuss the ongoing work that is involved in the management of these issues. The topic of visible difference, in particular, should be addressed not only in terms of possible body image disturbances, but by highlighting the unwanted attention (stares, questions, comments) affected individuals stand to confront. To clarify how these issues take shape in affected individuals’ daily context, it may be useful to offer concrete examples and even anonymized quotes. A list of secondary sources for further reference could also be included (e.g. websites of patient organizations, biographies of people who have various conditions that affect the face, accessible academic publications). In particular, patients could be directed to several texts presenting the
findings of this dissertation in an accessible manner to gain insight in the lived experiences associated with the amputation of part(s) of the face (see table 1 for an overview of these texts).

A second way to adjust the clinical trajectory requires more fundamental changes to its setup. These may include the revision of the aforementioned protocols currently used by nurses working in the head and neck ward. Changing the clinical trajectory may also involve the provision of standard-issue multidisciplinary rehabilitation and more elaborate aftercare. Thus, patients in the last phase of their hospital stay could routinely receive occupational therapy to help them adapt to possible physical dysfunctions. These patients could also receive customary referrals for social skills training in order to help them develop strategies for dealing with unwanted attention. In addition, patients’ long-term adjustment could be monitored through regular follow-up appointments scheduled in the first two years after the amputation surgery. During these appointments, healthcare professions can explicitly address possible everyday challenges associated with the loss of part(s) of the face, and offer referrals to further rehabilitation or support. To reach patients who have undergone the procedure long ago, it may be helpful if the prostheticians affiliated with a particular clinic become more involved in the aftercare trajectory as a whole. Because they are the practitioners whom former patients see most often, prostheticians are in a unique position to identity those who experience long-term difficulties and refer them to further support. To do so, prostheticians would not necessarily require special training, but could simply use quantitative questionnaires to measure health-related quality of life or adjustment to ‘disfigurement’.

Next to these proposed adjustments to the clinical trajectory, it is also important that healthcare professionals acquire a better understanding of the everyday impact of losing part(s) of the face. One way to foster such an understanding patients’ experiences could be through presentations on affected individuals’ experiences. In the last phase of my PhD trajectory, I have spoken about my findings for a number of different groups involved with these patients, including surgeons, nurses, prostheticians, rehabilitation practitioners and social workers (see table 2 for an overview of these talks). These groups were often surprisingly interested in the phenomenological approach to health and illness. Nurses, in particular, indicated that they should do more to better prepare and support their patients. Rehabilitation practitioners, too, were keen to find ways to ensure patients receive the aftercare they require. Indeed, such presentations not only inform healthcare professionals about the everyday impact of facial limb absence, but also persuade them that the information, care, and support they provide ought to become more attuned to this impact.

However, to ensure care practitioners become truly familiar with the lived experiences associated with facial limb absence, it would be best to develop more participative and practical forms of learning. Nurses, in particular, stand to benefit from further training in the daily challenges associated with sense-impairments, pain and other
uncomfortable sensations, and an altered appearance. Such additional training can take the form of workshops on the everyday impact of illness and disability, so-called ‘mirroring meetings’, or small-scale qualitative research projects. One way to make sure these sessions yield concrete outcomes, for instance, could be to ask nurses to improve the protocols they use in their work to reflect what they have learned about patients’ experiences. But rehabilitation practitioners and even physicians may benefit from such further training. These healthcare professionals could then use their newly-gained insights to the benefit of patients who have recently lost part(s) of the face—as well as that of other groups in the HNC ward who confront similar issues.

A final way to ensure patients and care practitioners gain access to lived experiences associated with facial limb absence would be through close collaborations between medical centres, patients’ organisations, and researchers. Thus, healthcare professionals could inform (prospective) patients about the existence of patient organizations for individuals with HNC, and facilitate meetings with so-called ‘patient informants’. Patient organizations, from their side, could do more to bring the everyday, practical challenges accompanying life with a different face into focus. These organisations often offer educational material on various types of facial difference, but could also include feature articles and testimonials on affected individuals’ lived experiences. Such stories would do much to ensure prospective and more seasoned patients gain access to others’ experiences—which they can hopefully relate to and learn from. Researchers could contribute to this effort by providing accessible texts on their findings to a

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<th>Table 2: Presentations for healthcare professionals</th>
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<tr>
<td><strong>Leven met een afwijkend gezicht: De geleefde ervaringen van individuen die een deel van het gezicht missen naar aanleiding van kanker in het aangezicht</strong> (2018). Paper presented at the 232th Dutch congress for ENT specialists</td>
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<tr>
<td><strong>Leven met een zichtbaar veranderd uiterlijk naar aanleiding van de behandeling van hoofd-hals kanker</strong> (2018). Presentation for medical social workers, Netherlands Cancer - Institute - Antoni van Leeuwenhoek</td>
</tr>
<tr>
<td><strong>De patiënt centraal? Ervaringen rondom een veranderd lichaam naar aanleiding van de behandeling van hoofd-hals kanker</strong> (2018). Presentation for the head &amp; neck rehabilitation team, Netherlands Cancer Institute - Antoni van Leeuwenhoek</td>
</tr>
<tr>
<td><strong>Leven met een veranderd gelaat: Een kwalitatieve studie naar de ervaringen van patiënten bij wie een deel van het aangezicht is geamputeerd</strong> (2018). Presentation for head &amp; neck oncology nurses, Netherlands Cancer Institute - Antoni van Leeuwenhoek</td>
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<tr>
<td><strong>Een afwijkend gezicht doen: De ervaringen van individuen die een deel van het gezicht missen</strong> (2017). Presentation for the working group ‘tumors of the head and neck’, Netherlands Cancer Institute - Antoni van Leeuwenhoek</td>
</tr>
<tr>
<td><strong>Living with facial difference: A qualitative study</strong> (2017). Presentation for dentists, nurses and prostheticians, Center for Special Dentistry, University Medical Center Groningen</td>
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A wider public (see also table 1), instead of focusing solely on academic publications. And clinics, patient organisations, and researchers together could lobby for a more patient-centred approach in the information, care, and support offered to individuals with facial limb absence.

Some of these measures can be easily implemented. Others require more time and effort. In my current position as postdoctoral fellow at the Netherlands Cancer Institute - Antoni van Leeuwenhoek, I am now working together with various healthcare professionals to re-evaluate the information provided to (prospective) patients, and rewrite the complement used by nurses working in the head and neck ward. Embedding patients’ experiences more fully within the head and neck (rehabilitation) rehabilitation trajectory, however, will require more fundamental measures. The next step is to develop a research project that explores implementation options—not only targeting those patients who have lost facial limbs and/or areas, but the entire HNC population.
Samenvatting

Een veranderd gezicht doen

De geleefde ervaringen van individuen met een gedeeltelijke aangezichtsamputatie
Wat betekent het om een ander gezicht te hebben—een gezicht dat is getekend door een afwijking? In dit proefschrift onderzoek ik deze vraag door middel van een empirisch-filosofische studie naar de geleefde ervaringen van mensen met een deels geamputeerd gezicht. Deze studie is empirisch in de zin dat ze uitgaat van interviews met twintig individuen die een of meerdere delen van het gezicht missen. De studie is filosofisch omdat haar ontwerp en de erin uitgevoerde analyses vertrekken vanuit een reeks geesteswetenschappelijke en sociaalwetenschappelijke theorieën over het lichaam, technologische hulpmiddelen en de sociaal-culturele betekenis van beperking.

In de voorgaande hoofdstukken heb ik de studie en mijn bevindingen gepresenteerd. De komende pagina’s geven een korte samenvatting van mijn onderzoek.

_Hoofdstuk een_ introduceert het onderwerp van de studie, positioneert haar ten opzichte van bestaand onderzoek naar gelaatsafwijkingen, bespreekt het gebruikte theoretische kader en gaat in op de toegepaste methode. Zoals ik in dit hoofdstuk laat zien, is er vooralsnog weinig onderzoek gedaan naar de ervaringen van mensen met een deels geamputeerd gezicht. Er bestaan wel studies naar de bredere categorie ‘gelaatsafwijkingen’, maar deze hebben over het algemeen een medische of psychosociale insteek. Medisch onderzoek belicht doorgaans de onderliggende oorzaken, diagnose, typische ontwikkeling, behandeling en verwachte uitkomsten bij aandoeningen die het gelaat aantasten. Daarnaast geven zulke studies meestal ook schattingen van het aantal nieuwe gevallen in een bepaalde periode (incidentie) en het totale aantal bestaande gevallen (prevalentie). Om de impact van dergelijke aandoeningen te bepalen, meten medische studies de kwaliteit van leven van aangedane individuen door parameters als pijn, functiestoornissen, ervaren ziektelast en geestelijke gezondheid in kaart te brengen. De psychosociale benadering van gelaatsafwijkingen zoomt verder in op de geestelijke gezondheid en sociale positie van mensen met een zichtbaar andere uiterlijk. Met name de psychologie van het uiterlijk heeft zich in de afgelopen twintig jaar ontwikkeld als een sociaalwetenschappelijke discipline die de psychische gevolgen (zoals sociale angst, psychosociale coping mechanismen en depressie) van een zichtbare afwijking onderzoekt.

Medische en psychosociale studies naar aandoeningen die het gezicht aantasten geven inzicht in een aantal zaken die samenhangen met gelaatsafwijking. Maar leven met een ongewoon gezicht behelst meer dan: mensen met een ander gezicht hebben namelijk te maken met uitdagingen die vooral tot uiting komen in hun dagelijkse leven. Zo kampen ze met de gevolgen van allerlei functiestoornissen en hun soms radicaal veranderd uiterlijk. Om te achterhalen wat het betekent om te leven met een ander gezicht is het dus noodzakelijk om te onderzoeken welke rol deze uitdagingen spelen in het dagelijkse leven van aangedane individuen. Het gaat dan om hoe mensen met ander gezicht hun eigen lichaam en de wereld ervaren. Vooralsnog zijn de alledaagse, geleefde ervaringen van mensen met een afwijking in het gezicht amper in de wetenschappelijke literatuur verkend. In dit proefschrift vul ik deze leemte.
Om dit te doen, heb ik semigestureerde diepte-interviews gehouden met twintig individuen (acht vrouwen en twaalf mannen tussen de 42 en 84 jaar oud) die een gedeeltelijke aangezichtsamputatie hebben ondergaan en een gelaatsprothese dragen. De respondenten zijn geworven via de prothetiekafdeling van een ziekenhuis in een grote Nederlandse stad. De interviews werden uitgevoerd in hun eigen huis of op een andere vertrouwde locatie. Vaak nam ook de partner deel aan het vraaggesprek. Gedurende de interviews maakte ik gebruik van een topiclijst om deelnemers aan het onderzoek te laten vertellen over de rol van hun veranderde gezicht in hun dagelijks leven. Naast de interviews bezocht ik herhaaldelijk het ziekenhuis zelf, evenals drie verschillende prothetiekateliers in Nederland en België. Via de observaties die ik in deze locaties uitvoerde kreeg ik om een indruk van het klinische traject dat wordt doorlopen door de participanten.

Bij het analyseren van de interviews paste ik een zogeheten ‘thematische analyse’ (TA) toe. Daarnaast liet ik me leiden door de benadering die centraal staat in ‘interpretatieve fenomenologische analyse’ (IPA), een methode voor de narratieve analyse van interviews die voortkomt uit de fenomenologische traditie. IPA legt bijzondere nadruk op de subjectieve manier waarop mensen betekenis geven aan hun ervaringen, vooral met betrekking tot een ingrijpende, levens-veranderende gebeurtenis. Mijn analyses richtten zich dan ook op de manier waarop respondenten hun soms radicaal veranderde lichaam en wereld belevend, en hoe zij zich tot deze veranderingen verhouden. Bij het duiden van interviewdata gebruikte ik specifieke inzichten vanuit drie geesteswetenschappelijke en sociaalwetenschappelijke theorieën, te weten fenomenologie, postfenomenologie en disability studies. Elk van deze kaders kan namelijk worden ingezet om kenmerkende aspecten van de ervaringen van respondenten te belichten. De fenomenologie, en dan vooral de fenomenologie van ziekte en beperking, verleent inzicht in de manier waarop het belichaamd-zijn-in-de-wereld van mensen verandert door een medische aandoening. De postfenomenologie wijst op de rol van technologische hulpmiddelen hierin. Disability studies onthult hoe allerlei discriminatoire sociale normen en aannames rond lichamelijke beperking tot uiting komen in het dagelijks leven. In de drie empirische hoofdstukken van dit proefschrift gebruik ik deze theoretische kaders om de ervaringen van de participanten te verkennen.

In hoofdstuk twee zoom ik in op de manier waarop gelaatsafwijking belichaamd is. Het aanpassen aan een veranderd gezicht is immers niet alleen een psychosociale aangelegenheid, maar omvat ook een lichamelijke dimensie. Ik begin door te vragen hoe de fenomenologie van het lichaam kan worden toegepast op de casus van mensen met een gedeeltelijk geamputeerd gezicht. De fenomenologie van het lichaam neemt als uitgangspunt de betrekkelijke afwezigheid van het gezonde lichaam. Fenomenologen Maurice Merleau-Ponty en Drew Leder laten zien dat mensen in het dagelijks leven normaal gesproken niet hun eigen lichaam, maar veeler de wereld ervaren—een ervaring die echter wel mogelijk wordt gemaakt door de zintuigelijke capaciteiten en het bewegingsapparaat van dat lichaam. Deze uitwendige oriëntatie wordt gekarakteriseerd door een impliciet vertrouwen in het eigen vermogen om allerlei taken en activiteiten aan te pak-

Door deze inzichten toe te passen op de interviews laat ik zien dat het ongewone gezicht van de deelnemers in mijn studie regelmatig verschijnt in hun bewustzijn wanneer het aanleiding geeft tot verstorende percepties, sensaties of observaties van anderen. Dit gaat ten koste van hun vermogen om zich volle wikken. Zo leren zij op een nieuwe manier te bewegen en handelen om ongelukjes te voorkomen, leren zij om onprettige sensaties zoals (fantoom)pijn of jeuk te managen en vinden ze manieren om zich te verhouden tot de aandacht van anderen. Deze lichamelijke gewoontes hebben als doel om de afwezigheid van het lichaam te herwinnen of vormen een manier om met de verstorende aanwezigheid ervan om te gaan. Via deze gewoontes ‘belichamen’ de deelnemers aan mijn studie als het ware hun ongewone gezicht. Door de lichamelijke dimensies van een gedeeltelijke aangezichtsamputatie te belichten, vult dit hoofdstuk de gangbare medische en psychosociale benaderingen van gelaatsafwijkingen aan. Bovendien laat dit hoofdstuk zien dat er geen strikte grens te trekken is tussen functionele aanpassingen en aanpassingen gericht op het uiterlijk, omdat beide vorm krijgen via lichamelijke gewoontes. Het hoofdstuk demonstreert ten slotte ook hoe de fenomenologie van het lichaam niet alleen fysieke beperkingen kan adresseren, maar ook kwesties die samengaan met de afwijkende aanblik van zieke en beperkte lichamen.

Maar omgaan met een veranderd uiterlijk naar aanleiding van een gedeeltelijke aangezichtsamputatie behelst meer dan de ontwikkeling van nieuwe lichamelijke gewoontes. Om de invloed van het veranderde uiterlijk op het dagelijkse leven van respondenten verder te verkennen, onderzoekt ik in hoofdstuk drie wat gelaatsprotheses voor hun gebruikers betekenen. Dergelijke ‘cosmetische’ protheses stellen geamputeerde mensen in staat om voor ‘normaal’ te kunnen doorgaan. Maar hoe gebeurt dit precies en wat hebben gebruikers hiermee te winnen? Om dit beter te begrijpen neem ik de verhalen van de deelnemers aan deze studie onder de loep. Ik maak daarbij gebruik van verschillende techniek-filosofische benaderingen om de ervaringen van respondenten te duiden. Zo laat het onderzoek van Myriam Winance zien hoe er samenhang ontstaat tussen technologische hulpmiddelen en de lichamen van gebruikers met een lichamelijke beperking. En het werk van de postfenomenologen Don Ihde en Peter-Paul Verbeek illustreert hoe technologie de relatie tussen lichaam en wereld bemiddelt, omdat het gebruik van allerlei alledaagse apparaten invloed heeft op de manier waarop mensen waarnemen en handelen.

Om te begrijpen welke rol de gelaatsprothese in het dagelijkse leven van de deelnemers aan deze studie speelt, onderzoek ik eerst hoe dit hulpmiddel het normale uiterlijk herstelt. Een gelaatsprothese bootst de aanblik van de ontbrekende onderdelen van het
DOING FACIAL DIFFERENCE

gezicht na, waardoor het weer compleet—en dus normaal—lijkt. Of dit ‘lukt’ is echter
sterk afhankelijk van de mate waarin de prothese en het gezicht van haar drager bij elkaar
passen. Uit de interviews blijkt dat een dergelijke samenhang niet zondermeer gegeven is,
maar inspanning vergt. Respondenten maken dan ook gebruik van wat ik ‘paspraktijken’
noem om een goede samenhang te laten ontstaan. Paspraktijken behelzen het monitoren
of aanpassen van de prothese (voelen of de kunstmatige neus goed vast zit, gerafelde ran-
den bijvijlen). Ze kunnen ook het gebruik van allerlei hulpmiddelen (een bril, make-up)
omvatten, die de randen van de prothese camoufleren. Paspraktijken kunnen ten slotte
ook betrekking hebben op de beweeglijkheid en ruimtelijke positionering van het gezicht
zelf (de schaduw opzoeken). Een goede samenhang van gezicht en hulpmiddel vraagt dus
om aanpassingen aan zowel de gebruiker als de prothese. Sommige paspraktijken worden
uiteindelijk ingesleten, automatische gewoontes. Andere blijven om bewuste inspannin-
grenen vragen. Participanten geven dan ook aan dat ze deze aanpassingen, en vooral ook het
plannen en ‘gedoe’ dat erbij hoort, soms lastig vinden.

Waarom blijven respondenten dan toch werken aan een goede samenhang? Dit, zo toon
ik aan, komt omdat een goed passende prothese ‘transparant’ wordt; zij trekt zich als het
ware terug in het gezicht van de drager. Hierdoor oogt zij als een natuurlijk onderdeel
van het gezicht in plaats van een kunstmatige toevoeging. Anderen zijn dan in staat om
het gezicht van de gebruiker in zijn geheel te zien. Zij kunnen weer de persoon ‘in’ of
‘achter’ het gezicht zien, in plaats van gefixeerd te raken op diens anders-zijn. De prothe-
se herstelt dus het effect van ‘facialiteit’ bij gezichten die minder goed te herkennen zijn
als zodanig. Dit levert twee cruciale voordelen op: (a) respondenten slagen erin ander-
mans starende blikken, vragen en opmerkingen te ontwijken, waarmee hun anonimité
gewaarborgd blijft. Niet langer belemmerd door ongewenste aandacht, herwinnen ze
hun bewegingsvrijheid in openbare ruimtes; (b) directe interacties tussen geïnterview-
de deelnemers en anderen verlopen vloeiender. De prothese leidt immers minder af dan
de amputatie zelf of een meer zichtbare bedekking. Een normaal uiterlijk, wanneer het
wordt hersteld met behulp van cosmetische protheses, stelt geamputeerde mensen dus
in staat om zich staande te houden in een precaire sociale omgeving. Door het alledaagse
gebruik van kunstmatige gezichtsdelen te verkennen, geeft dit hoofdstuk inzicht in de rol
van het uiterlijk in de prothesetiek. Daarnaast belicht het hoofdstuk hoe intieme technolo-
gieën niet alleen onze waarneming en ons vermogen tot handelen bemiddelen, maar ook
onze sociale omgang.

De deelnemers in mijn onderzoek rapporteerden echter ook andere ervaringen rond-
on hun veranderde uiterlijk—ervaringen die samenhangen met de zichtbaarheid van
hun anders-zijn. In hoofdstuk vier onderzoek ik dergelijke ‘ervaringen van zichtbaarheid’. Deze
ervaringen, zoals ik laat zien, hangen samen met de drie verschillende manieren
waarop respondenten hun amputatie tonen in sociale situaties, namelijk verborgen onder
een zichtbare bedekking, verhuld door middel van de gelaatsprothese, of open en bloot.
Deze verschillende manieren waarop zij hun gezicht tonen leiden tot verschillende types
interacties met anderen. In dit hoofdstuk bespreek ik ze alle drie. Om de zichtbaar-
heidservaringen van participanten te duiden, gebruik ik het werk van socioloog Erving Goffman en van disability studies-onderzoeker Rosemarie Garland Thomson. Dit kader geeft inzicht in het stigma rondom lichamen die afwijken van de norm en de aandacht die deze lichamen ten deel valt in openbare ruimtes.


Uiteindelijk draaien de zichtbaarheidservaringen van de deelnemers aan deze studie om de betekenis die hun ongewone uiterlijk krijgt in interacties met anderen. Via de positie die ze hierbij aannemen, onderhandelen ze in feite over deze betekenis. De inzet van deze onderhandelingen is niets minder dan de mogelijkheid van sociale erkenning. Participanten verzetten zich immers op verschillende manieren tegen andermans pogingen om hen te reduceren tot hun zichtbare verschil. Daarnaast moedigen zij deze anderen aan om hen als ‘gewone’ mensen te benaderen—veelzijdige actoren die recht hebben op respect en een gelijke behandeling. Dit betekent dat de strijd voor de sociale erkenning van mensen met een beperking zich niet alleen voltrekt op het macroniveau van politieke en maatschappelijke actievoering, maar ook op het microniveau van alledaagse sociale interacties.

In hoofdstuk vijf breng ik de verschillende strengen die door de drie empirische hoofdstukken lopen bij elkaar. Ik stel vast dat leren omgaan met een ongewoon gelaat om een activieve benadering vraagt. Dit noem ik ook wel het ‘doen’ van verschil. Om te begrijpen wat
dit doen behelst, neem ik in dit hoofdstuk een aantal gerelateerde concepten in ogen-
schouw. Zo laat het werk van de sociologen Candice West, Don Zimmerman en Sarah
Fenstermaker zien dat mensen hun sociale identiteiten tot stand brengen in interacties
met anderen. Taalfilosoof Judith Butler toont aan dat dit veelal gebeurt via performa-
tieve taaluitingen—taaluitingen die de sociale realiteit produceren. Fenomenoloog Iris
Marion Young wijst op het feit dat de manier waarop mensen hun lichaam ervaren,
bewonen en gebruiken wordt bepaald door sociale normen, maar ook door de fysieke
(on)mogelijkheden van het lichaam zelf. Wetenschapsfilosoof Annemarie Mol, ten slot-
tte, belicht de rol van materiële artefacten en de omgeving in de manier waarop (zieke)
lichamen vormkrijgen. Door deze inzichten toe te passen op mijn bevindingen wordt
het mogelijk om recht te doen aan de sociale, belichaamde en materiële dimensies die
samenkomen in het dagelijks doen van het veranderde gezicht.

Een veranderd gezicht ‘doen’ is dus: allerlei manieren ontwikkelen om de uitdagingen
die samengaan met het hebben van een gelaatsafwijking aan te gaan. Op deze wijze ver-
houden mensen met een ongewoon gezicht zich actief tot hun radicaal en onomkeerbaar
veranderde lichaam en wereld. Dit betekent dat leven met een gedeeltelijk geamputeerd
gezicht veel dagelijks werk vergt—werk dat herhaaldelijk uitgevoerd moet worden en
bovendien nooit af is. Dit inzicht, concludeer ik, is van onschatbare waarde voor zowel
patiënten als professionals in de gezondheidszorg. Nieuwe en bestaande patiënten kun-
nen baat hebben bij toegang tot de geleefde ervaringen van lotgenoten. Ze kunnen zich
dan in anderen herkennen, erkenning krijgen voor wat ze zelf hebben meegemaakt en
leren van de manier waarop anderen omgaan met uitdagingen. Zorgprofessionals, van
hun kant, kunnen deze geleefde ervaringen gebruiken om te begrijpen hoe ziekte en
beperking betekenis krijgen in het dagelijks leven van hun patiënten. Dit inzicht kunnen
ze inzetten bij het bieden van voorlichting, (na)zorg en begeleiding. Patiënten kunnen zich
dan beter voorbereiden op het voortdurende werk dat ze te wachten staat, en meer steun
ondervinden bij het omgaan met dit werk.
# Appendix: Overview of respondents

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

Publications in International journals:


Book chapters:


Publications for a general audience:


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I feel incredibly fortunate to be able to close this book, consider everything that went into its production, and celebrate a midway moment of contentment. Yay.
About the author

Gili Yaron (August 18th 1981, Groningen) spent her childhood in the Netherlands and Israel. After completing her high-school education at the H.N Werkmancollege in Groningen (diploma 2000), she trained as a philosopher at the University of Groningen and Tel Aviv University. Upon obtaining her Bachelor in the Arts in 2005 and Master in the Arts in 2009 (cum laude), Gili taught and assisted with a number of first-year courses at her home faculty. She also worked as a research assistant for a qualitative project at the University of Toronto Mississauga, exploring politicians’ views on honor related violence and the integration of immigrants in the Netherlands.

In 2011, Gili moved with her family to the south of the Netherlands, to pursue a PhD in medical humanities at the department of Health, Ethics, and Society of Maastricht University. Her research project explored the lived experiences of individuals who lack part(s) of the face by means of an empirical-philosophical approach. As part of her PhD studies, Gili completed the Graduate Program of the Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC). In addition, she served as a PhD representative for CAPHRI (Care and Public Health Research Institute), one of the graduate schools affiliated with Maastricht University’s Faculty of Health, Medicine, and Life Sciences. In this period, Gili also worked as a senior lecturer and researcher for the Research Centre for Arts, Autonomy, and the Public Sphere (AOK) at Zuyd University of Applied Sciences. Here, she used the findings of her study into facial difference to teach and learn about artistic research.

Gili currently works as a postdoctoral fellow at the Netherlands Cancer Institute - Antoni van Leeuwenhoek in Amsterdam, where she leads a research group studying women’s lived experiences after surgical treatment for throat cancer. In addition, she seeks to improve the information, care, and support offered to head and neck cancer patients by drawing on her dissertation’s findings. Gili lives in Heugemerveld, Maastricht with her partner Ferdie Derveld and their daughters Aya (10) and Mimi (4).