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## Recognizing difference: in/visibility in the everyday life of individuals with facial limb absence

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### ABSTRACT

People who lack part(s) of their face have a visibly different appearance both due to their facial difference itself and the medical aids that they use to cover it (e.g. prostheses, bandages). In this article, we draw on interviews with affected individuals in order to investigate how visible difference features in their everyday experience. The visibility of their facial difference, we show, comes into play as they interact with various others in the contexts of their daily life. However, respondents' visibility manifests in different ways, depending on whether they cover or uncover their facial difference. These different modes of visibility make for distinct 'visibility experiences', as participants meet others who notice – or fail to notice – their atypical appearance. By exploring these experiences, our article provides insights into the role of visibility in interviewees' everyday life, and demonstrates how they actively negotiate their social recognition within encounters with various others.

### ARTICLE HISTORY

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### KEYWORDS

Visible difference; facial disfigurement; facial prosthesis; medical aids; social recognition

### Points of interest

- The experiences of individuals who lack part(s) of the face – and, generally, the experiences of individuals who have a visibly different face – have not received much attention in disability scholarship.
- Individuals who have lost part(s) of the face can display their faces by either uncovering the missing facial area or covering it with various medical aids. In encounters with others, these different displays produce different experiences.
- People who have an unusual face may actively negotiate the meaning their appearance receives in social interactions. In this way, they try to avoid being reduced to their difference.

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- The unwanted attention disabled people often confront rests on the (implicit) assumption that it is acceptable to intrude on their privacy.
- The struggle for the social recognition of people with disabilities is not limited to large-scale activism and advocacy. It may also include ongoing negotiations about the meaning of difference in everyday social interactions.

## 1. Introduction

People who have lost part(s) of their face have a visibly different appearance due to their facial difference itself, but also due to the medical aids that they use to cover it. During their rehabilitation trajectory, these individuals commonly receive a so-called 'facial prosthesis' that replaces the lost part of their face. Although this device closely resembles the absent facial area, its artificiality remains (potentially) discernible. In addition, they may regularly make use of visible covers such as bandages, eye patches, or Band-Aids 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. The few studies investigating 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 et al. 2007; Rasmussen et al. 2012). Of course, visible facial difference as a broader category has been taken up as a research topic in the emerging field of the psychology of appearance (Lansdown et al. 1997; Rumsey and Harcourt 2012). Research conducted under this heading, however, tends to highlight the psycho-social issues associated with facial variance, for instance depression, social anxiety, or avoidance behavior (Koster and Bergsma 1990; Macgregor 1970; Rumsey and Harcourt 2004; Stock, Feragen, and Rumsey 2016; Thompson and Kent 2001; Valente 2009). By focusing on the psychological condition of those who have a different face, this approach has a rather narrow view on the social context informing their experiences.<sup>1</sup> This omission is exacerbated by the fact that the psychology of appearance offers very few empirical, qualitative investigations into the way facial variance comes into play in the daily life of affected individuals, as they encounter and interact with various others. In other words: the current literature on visible facial difference rarely takes a disability studies perspective when approaching this topic.

In this article, we seek to amend this hiatus by exploring what we call the 'visibility experiences' of people who lack facial limbs and/or areas. These experiences are shaped by both the visibility and invisibility of affected individuals' atypical appearance. Invisibility experiences are therefore inherently social, taking place in relation to others who perceive affected individuals' difference – or fail to do so. Our exploration is informed by a qualitative study into the everyday experiences of people who have lost part(s) of the face.<sup>2</sup> Before we zoom in on the visibility experiences of the participants in our study, we first offer a short review of existing

scholarly literature on visible (facial) difference, and the way it affects social interactions. Then, 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 experiences of people with facial limb absence, but also demonstrates the various ways in which the in/visibility of difference impacts their 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 visible difference.

## 2. Stigma management, staring, and the in/visibility debate

To gain insight into 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 in everyday social interactions in public spaces (Goffman 1963a, 1963b, 1967). An important aspect of these social interactions, 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, and so forth, in accordance with societal norms. As he demonstrates in *Stigma: Notes on the Management of Spoiled Identity* (Goffman 1963b), stigmatizing traits threaten face work, because their association with negative stereotypes effectively discredits affected individuals. If they wish to avoid censure, the stigmatized must therefore extensively manage their stigma, for instance by trying to 'pass as normal' (1963b, 42 and 73–91). Importantly, although many of the empirical examples of stigma management Goffman analyzes revolve around some form of visible difference, 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 visible difference who enter the public realm, Garland-Thomson (2009) demonstrates in *Staring: How We Look*, 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 staring encounters between those who are visibly different and those who come to notice their difference – encounters that mark and set apart the visibly different person. Garland-Thomson's most innovative move is to reframe scenes of staring as potentially productive and transformative, rather than solely oppressive (2009, 10 and 87). Experienced 'starees', she argues, can help 'starkers' overcome their initial astonishment and recoil in the face of visible difference. Arrested stares then become engaged beholding, in which both interactional partners meet on an equal basis. Garland-Thomson offers unique insights into the way visible difference affects social interactions in public. Still, she mostly focuses on representations of disability in art, photography, and film. As a result,

her observations do not form a systematic exploration of the lived experiences of those affected by visible difference.

In recent years, a number of scholars have used the concepts provided by Garland-Thomson to discuss the 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. Olney and 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 and 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 these women position themselves within such encounters. The experiences of people with visible facial difference – and, in particular, of people with facial limb absence – remain 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 the visibility scholarship introduced here. First, however, we present our approach and methods, and provide more information on our respondents.

### 3. Approach and methods

This article is based on a qualitative study into the experiences of people living with facial difference. In the course of this study, the first author interviewed 20 individuals who have lost a part of their face as a result of disease or trauma, and wear a prosthetic device.<sup>3</sup> We recruited these respondents through the Dutch service unit from which they receive their prostheses, approaching its 140 clients by mail about participating in the study. Of the 40 respondents who agreed to take part in the study, 20 were eventually interviewed by the first author in 2011 and 2012. The others could no longer be reached, or declined retrospectively. The study received ethical clearance beforehand (file number NL35486.031.11). Of the 20 participants, eight were women and 12 were men. Their ages were 42–84 years at the time of the interview, although many acquired their facial difference years before. Nineteen interviewees' facial limbs or areas (nose, eye socket, part of the cheek) were amputated in the course of treatment for head and neck cancer. One respondent had an accident resulting in the loss of his eye socket (see Table 1 for an overview of the interviewees).

The interviews were conducted in Dutch (the quotes presented in the following were translated by the first author), tape recorded, and subsequently transcribed verbatim. They all took place at the respondents' home or in another familiar setting, and lasted between 45 and 90 minutes each. To prompt participants' stories

**Table 1.** Characteristics of the interviewees.

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

on their visible difference, the first author used an interview schedule, which served as a basis for asking questions during the interviews (Braun and Clarke 2006). The first item on this schedule, 'diagnosis, treatment and rehabilitation', was intended to provide the interviewer with a basic understanding of interviewees' medical history. Subsequent items ('facing the mirror after the amputation', 'interactions with relatives and friends', 'interactions with strangers') aimed to encourage the respondents to articulate the role of their visible difference in everyday life. While analyzing the data, we relied on the method of thematic analysis (Braun and Clarke 2006). The first author started by reading and summarizing the interview texts. Next, she identified common themes in participants' stories, including their response to staring behavior by others in public, how they think about their appearance, and family members' attitude toward their atypical face. Focusing on the particular range of experiences associated with interviewees' covered, partly prosthetic, or bare face, we gradually established patterns regarding how they experience their visible difference in social situations. In this way, we gained an understanding of the role their unusual face plays in everyday social life.

## 4. 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: covering the amputation site with various types of bandages; carrying a prosthetic device that emulates the missing limb’s looks; and baring their amputation for others to see. In this section, we analyze the stories of our participants to identify four distinct types of visibility experiences following from 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 – and the norms that permeate them – that interviewees relate to others’ reactions to their unusual looks, and negotiate the meaning accorded to visible difference.

### 4.1. Covering facial difference

The participants in our study all use various covers to hide their absent facial area, including gauze dressings, eye patches, pads, or Band-Aids. These medical appliances are highly visible, and present an uncommon image. As a result, respondents regularly encounter 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)

Staring can take the milder form of stealthy glances, but may also include arrested gazes, pointing fingers, and laughter. Also, some comments and questions are offensive and distressing. One participant reports having been told repeatedly by passersby that they would commit suicide if they looked the way he did. Other interviewees were asked whether they could not be ‘fixed’ by their physician, or how they muster the courage to get out. Respondents’ visible difference means they lose their anonymity in public, and are the object of undermining rudeness.

Unwanted attention (implicitly) positions participants’ difference as something they must account for: ‘[The patch] was something they wanted to know more about, something I needed to explain’ (Ralph). They may feel obliged to satisfy others’ curiosity, but nevertheless feel uncomfortable when fulfilling this expectation:

[Y]ou 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 people, apparently, feel entitled to interfere with individuals whose face is visibly different – although they might never approach someone with more conventional looks in this way. This indicates that norms prescribing respectful distance and mutual inattention between strangers in the public realm are not quite as binding in encounters with those whose appearance diverges from the norm. In the face of difference, interactional conventions are exempted. By positioning persons with a visibly different face as objects of others’ normative gaze,

unwanted attention forms one way in which the stigmas surrounding atypical appearance act up in everyday life.

Many respondents resent the staring gazes, questions, and comments they encounter. Others report feeling self-conscious or ashamed due to unwanted attention: '[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 to widespread, 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' (disapproving) 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' notice over the years and were no longer very much bothered by it, most remain uncomfortable about stares, questions, and comments. By embodying disablist bias, unwanted attention serves to diminish respondents' sense of self-worth, which continues to affect their everyday experiences in public.

Participants' reactions to unwanted attention take three forms: ignoring; actively challenging; or engaging in conversation. Most respondents choose to ignore (and implicitly tolerate) casual or 'benign' stares, viewing these 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 as well. A small number of participants 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 uncover her face. 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 unwanted attention do not take such a 'combative' stance. Instead, they pointedly stare back, or politely remind the other person to mind their own business. Through these responses, they challenge the right of others to interfere with and condemn their appearance, and resist being positioned as an object of one-sided curiosity, thereby reclaiming their agency.

The third response to unwanted attention is engaging in conversation, for instance by answering (politely phrased) questions: '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 Gregory, being asked respectfully about his facial difference 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 initiating conversation. When respectful, such exchanges reconstitute respondents as equal partners in an encounter based on genuine mutual interest. The visible facial difference then no longer functions as a stigmatizing attribute, but serves as a starting point for dialog, in which the affected individual can be recognized as a fellow human being.

#### **4.2. Recovering the face**

Aside from various visible covers, the participants in our study all carry a silicone facial prosthetic device. Many 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:<sup>4</sup>[The prosthesis gives me] a entirely different look than a bandage, right. Now [my face] is really kind of entirely complete again' (Winston). Clarifying what he means by 'complete', his wife adds that 'you expect two eyes' when looking at a face. A well-fitting prosthesis thus does not merely cover the amputation, but also conceals the very need for cover: by emulating interviewees' lost facial area, the device revokes 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 others who fail to notice their prosthesis:

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)

Successful 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)

This sense of relief about being able to no longer identify as a disabled person has to do with being able to elude unwanted attention. Feeling diminished due to one's visible difference, in this sense, arises from negative attitudes toward difference that are implied by others' stares, questions, or comments:

[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 notice, successful concealment allows them 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, when 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 better accomplish their everyday activities: 'I spend a lot of time behind the microphone, I do all kinds of [live] sports events, and now, well, now I am noticeable through my voice, not through my appearance anymore' (Walter). Face-to-face interactions apparently proceed less smoothly when one of the partners in the exchange has an unconventional face. The difficulty, however, does not necessarily lie in the visible difference itself, but in the pervasiveness of appearance norms in everyday social exchanges. 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 fulfill social roles (being a handy neighbor or an announcer in sports events, like John and Walter) – something that is less self-evident when their face remains visibly different.

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 others and get away with it. But the ability to conceal their facial difference may also evoke 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 deceitful. Interviewees then feel uncomfortable about 'fooling other people' by means of a fake façade of facial wholeness. For Leon, this unease translates into an unwillingness 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.

### 4.3. *Discovering the prosthesis*

Facial prostheses do not always manage to recover facial wholeness: sometimes the device will stand out as an artificial object placed on top of 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). Discovery is made more likely by particular spatiotemporal circumstances. Locations such as public transportation, cafés, and queues facilitate ‘slow’ encounters characterized by proximity and sustained exposure. Similarly, harsh lights make subtle differences in color and sheen between the prosthesis and its wearer’s skin more noticeable. Next to proximity, prolonged exposure, and specific lightening conditions, discovery can also take place due to a poor fit between the prosthesis and its user’s face. This may occur when the prosthesis fails to follow along with facial movements. A prosthetic eye, for instance, cannot close, which may betray its fakeness. Adjusting to this, one interviewee restrains her blinking to maintain a symmetrical appearance. The effort involved in curbing the impulse to blink underscores the degree to which difference is apparently socially unacceptable. Similarly, 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 gaping device, or temperature-related variations in skin tone.

When the prosthesis is discovered to be artificial, participants’ facial difference becomes apparent again. As in the case of visible covers such as bandages, Band-Aids, or eye patches, passing as normal then becomes impossible. Discovery, in other words, translates into unwanted attention from others.<sup>5</sup> Interactions flowing from discovery, however, take 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). This child realized that the ‘fake nose’ covers an absence. Her request 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 affirmed 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)

This clicking sound underscores the fact his nose is artificial. Likewise, requests and attempts to touch the prosthesis operate on the assumption that the touching finger can discern what the eye 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). Because the eye is fooled by an ingenious device that so closely resembles the missing limb, other senses must be brought to bear 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.

The dynamic characterizing social interactions in which the interviewees’ prostheses are discovered to be fake exhibit some similarities to what happens when they wear a visible cover. Discovery regularly makes for unwanted attention, which may elicit feelings such as shame, inferiority, or anger in participants. They react to such notice by ignoring, confronting, or engaging the person in question. Again, respondents mostly view mild staring as inevitable and therefore ignore it, while addressing more rude forms of unwanted attention. Consider in this regard Stella’s attitude during the incident in which her sister-in-law touched her artificial nose without asking permission. Respectful inquiries, by contrast, are mostly seen as innocuous, and answered politely. As John’s good cheer and Timothy’s gentle manner in interactions with children illustrate, children are often allowed more leeway in transgressing the social imperative not to stare, ask, or comment upon visible difference – even if they do so rather rudely. More fundamentally, this social dynamics highlights common bias against those who are visibly different: unwanted attention positions the atypical person as an object of others’ curiosity, and justifies intrusion where none is warranted.

There is one exception to these similarities between how the visibility of the covered and the discovered face operates in social interactions. The obvious difference of the covered face makes for immediate responses from others. When respondents wear the prosthesis, however, discovery may occur only after a while. Responding to the risk of being discovered as partly prosthetic, 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:

[W]hen 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 atypical face – or more precisely, by bias surrounding visible difference.

#### 4.4. *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. A number of 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, "Would 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 that 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 and 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 this does not apply to all respondents, many 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 around like this [covers her nose] [...]; Because, well, one of [the kids] 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 during the day or 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.

## 5. Discussion

In this article, we investigated the role of visible facial difference in the experiences of 20 individuals with facial limb absence, as they interact with various others in everyday life. 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 a particular mode of visibility. 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, the 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 visibility entail a range of distinct 'visibility experiences' that take shape within social interactions with various others. 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, 174; 2009, 33). 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. 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 difference 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 dialog. This strategy in particular, as we showed earlier, effectively invites the noticing other to participate in a respectful exchange. As Garland-Thomson (2009, 10) points out, the staring encounter can then transform into a meeting characterized by reciprocity and equal regard. 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 have shown, 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 life, as well, by working toward fully displaying their bared face to their intimates, and thereby gaining a sense of being fully accepted despite 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 argues in *Saving Face: Disfigurement and the Politics of Appearance*, such beliefs coalesce into a 'disfigurement imagery' (2014, 18 and 28–30). This is a collection of popular, stigmatizing representations of facial difference, in which it is presented as a type of social demise: a fate worse than death (2014, 19–20 and 37–42). This imagery, for Talley, 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' 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 (2014, 38). Indeed, such beliefs inform much of the unwanted attention encountered by the participants in our study. 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 – 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 and 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? Goffman, writing that 'by definition, of course, we believe the person with a stigma is not quite human' (1963b, 5), 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 earlier, 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 and 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 a 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 various valued (social) roles. Indeed, the authors in the 'in/visibility debate' referred to earlier all stress this issue. As Olney and Brockelman (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 writes that visibly different women feel that their 'bodies are highly noticed, yet their capacities, lives and desires [remain] unseen' (2005, 394). Lourens and Swartz, 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' (2016, 2015). Only when non-disabled others understood these students' situation, or when they associated with disabled friends, did they feel seen in their entirety, and 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 a capable member of their communities (a handy neighbor, announcer, teacher, fellow traveler, family member, or partner). By negotiating their in/visibility in social encounters, these individuals actively work toward being recognized by the various others in their life.

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 (Danermark and 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 in/visibility of difference: apparently, mis/recognition hinges upon the extent to which a person's body conforms to norms that prescribe proper appearance.<sup>6</sup> 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 acknowledgment (Varga and 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 in/visibility 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 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.

## Notes

1. To be sure, scholars working within the psychology of appearance do acknowledge the stigmas surrounding 'disfigurement', and some also investigate common normative beliefs about 'disfigurement'. This, however, is not the same as considering how the stigmas surrounding visible facial difference operate in the day-to-day context of social life.
2. Facial limb absence is not only associated with an atypical appearance, but may also involve various physical impairments. In this article, we focus on visibility, but see Yaron et al. (2017) for a discussion that approaches these aspects in concert.
3. In the Netherlands, people generally have access to good-quality prosthetic rehabilitation, the cost of which is covered by Dutch health insurance plans. Often, this is not the case in other countries. As a result, those who may need facial prostheses cannot always afford them.
4. For more on facial prostheses, see Yaron, Widdershoven, and Slatman (2017).
5. Because participants generally dislike being the objects of others' attention due to their facial difference, they not only worry about potential discovery but also go to considerable lengths to avoid it. Again, see Yaron, Widdershoven, and Slatman (2017) for more on these issues.
6. As Linda Martín Alcoff (2006) argues, this also applies for the in/visibility of race and gender.

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