Living with an upper- or lower-limb prosthesis: The material remaking of the body through the prosthesis's presence and absence

Lucie Dalibert

University of Lyon

Valentine Gourinat ⁶

Paul-Fabien Groud ⁶

University of Lyon

Corresponding authors

Lucie Dalibert University Claude Bernard Lyon 1, University of Lyon, S2HEP Research Centre, 43 boulevard du 11 Novembre 1918, 69622 Villeurbanne Cedex, France ⊠ lucie.dalibert@univ-lyon1.fr

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Abstract

University of Lyon

Prostheses are complex, ambivalent, and non-uniform objects. Even before it "exists" as a material entity, the prosthesis, and more specifically the future body-prosthesis relation, is already present in one's amputation and rehabilitation trajectory. It is indeed integrated by healthcare professionals in amputation surgical protocols as well as during care in the pre-fitting rehabilitation phase. Not there yet, it still shapes, materially, amputees' bodies. Likewise, while amputees wait for its arrival, the prosthesis is an object they imagine and possibly fantasise about. Then, once manufactured and materially present, prostheses become part of a long, uncertain, and ever-changing process of creating a body-prosthesis alliance. Spanning from rehabilitation to daily-life at home, this process oscillates between adaptation and dis-adaptation, embodiment and rejection, capacities and limitations, hopes and disappointments.

Based on ethnographic fieldwork conducted with amputees and healthcare professionals in France, the purpose of this article is to delve into amputees' daily experiences, in order to grasp the complexity of the alliance that is woven between amputees' bodies and prostheses over time. More precisely, we will use the dialectic of absence and presence as a guide for our analysis, since these two notions are enlightening to understand the complex embodiment and collaboration between the amputee, his/ her body, and his/her prosthesis. They shed light on the temporalities, the spaces, and the issues of the body-prosthesis relationship in the process of embodiment and appropriation throughout the life course.

Keywords

amputation; prosthetic devices; presence/absence; embodiment; materiality; representation.

1. Introduction

Limb prostheses are complex and ambivalent objects (Sobchack 2004). Their ambivalence manifests insofar as the prosthesis is not only a material device but also an imagined and fantasised one, be it positively or negatively. That is, a leg or an arm prosthesis is indeed there to recover a motor function, but it can also serve as symbolic repair, insofar as prosthetic devices and the bodies fitted with them are enmeshed in social and cultural representations and imaginaries. However, the collective imaginary of the prosthetic body is quite far from the material reality of prosthetic bodies. Highly robotic, the prosthetic devices that are covered by the media and present in the collective imaginary are quite unlike the arm and leg prostheses actually fitted on amputees (Sobchack 2006; Dalibert 2015; Gourinat 2018), which are less shiny and harder to handle. Likewise, amputees shown in the media are mostly young and healthy, whereas in the actual population amputees are a lot older and suffering from various illnesses. *How are these tensions played out in the experiences of amputees?*

In this article, we will answer this question by focusing on a particular dimension of prosthetic devices in their relations with their "users". We will show how prosthetic legs and arms are always already both present and absent. We do not need to own a prosthesis to be entangled in a particular imaginary surrounding this type of technological device: while materially absent, prosthetic devices are present in our imagination. What's more, even though they are not there yet in one's amputation and post-amputation trajectory, prosthetic devices are already present in the surgical and rehabilitation protocols. Their simultaneous absence and presence also play out at the experiential level. That is, prostheses are hardly used constantly. Quite fundamentally too, as one may strive and work for his/her prosthesis to become "transparent", i.e., absent or in the background of one's attention, one's artificial leg or arm can become a cumbersome and highly present object when it malfunctions, when it is not adjusted properly and/or when it interacts with the wider socio-material context. The latter may have disabling effects; it may not only render the prosthetic device highly present for oneself and others but also affect the way one can live well with his/her prosthesis.

After introducing our conceptual and methodological frameworks, we develop the empirical analysis in four stages: we attend to how prosthetic devices' absence-presence is enacted in collective discourses and imaginaries (paragraph n. 4.1), before the amputation and/or the fitting of the prosthesis (paragraph n. 4.2), during the rehabilitation process and the learning/embodiment of the prosthesis (paragraph n. 4.3) and in amputees' long-term experiences, especially in their daily life and social contexts (paragraph n. 4.4). Finally, we offer our conclusions and final remarks.

2. Analytical perspectives

Being able to walk and live well with a leg or arm prosthesis is an intricate endeavour, as philosophers, anthropologists and Science and Technology Studies (STS) scholars have emphasised (Sobchack 2004, 2006; Dalibert 2014; Crawford 2015; Shew 2017; Gourinat 2018; Groud 2020). Not only are limb prostheses complex objects, composed of different elements, such as a custom-made socket that welcomes the stump, a (hip, knee, ankle or shoulder, elbow, wrist) joint, an appendage (e.g., foot or hand), an adapter (e.g., a tube that connects these main components together), and eventually a liner (that envelops the stump) and a cosmesis (that covers the prosthesis), but they are also material entities that are at once present and absent, enmeshed with imaginaries and expectations. While STS scholars and philosophers of technology have attended to the ways in which tools, technical artefacts and technological

objects mould and influence our actions and intentions (Ihde 1990; Latour 1994; Verbeek 2005), they have given less attention to more intimate human-technology relations, such as those involving prosthetic devices. In fact, the very notion of use might be problematic when attending to the specificity of the interactions between an amputee and her prosthetic limb, for instance her prosthetic leg, inasmuch as one does not so much *use* her prosthesis but rather sits, stands on, walks and more generally moves with it. What's more, for the prosthesis to enable her wearer to accomplish such activities, its presence needs to take on a particular dimension: as Vivian Sobchack, herself an above the knee amputee since 1993, remarks when she tells of her relationship with her prosthesis,

[o]bviously, transparency is what I wish – and strive – for in my relation to my prosthetic leg. I want to embody it subjectively. I do not want to regard it as an object or to think *about* it as I use it to walk. [...] Insofar as the leg remains an object external to me, a hermeneutic problem to be solved, a piece of technology to "use," I cannot live it and be enabled by it to accomplish those intentional projects that involve it but don't concern it. So, of course, I want the leg to become totally transparent. (Sobchack 2004, 172; emphasis in original)

To be enabling, the prosthesis must become transparent: in one's subjective experience, it must not draw attention to itself. That is, its presence must be marginal in one's consciousness; it must be an absent presence.

The notion is reminiscent of phenomenological understandings of bodies and technologies. At the phenomenological level, bodies oscillate between presence and absence. That is, when one is healthy and/or pain-free, one's attention is hardly ever directed toward one's body but rather towards the world. One's body is experienced as absent – it is an absent presence, writes Drew Leder (1990) - while one's being-in-the world is characterised by intentionality and agency ("I can"). Conversely, when one suffers from (chronic) pain and/or illness, one's body is not experienced as transparent but rather attracts and may even engulf one's attention. In these circumstances, the body "dys-appears", dys-appearance¹ denoting the body's absent absence, which is marked by discomfort (Ibid). Furthermore, Sobchack's account resonates with particular appreciations of one's relationship with technologies. In his attempt to map human-technology-world relations and illuminate our technologically mediated lifeworld, philosopher of technology Don Ihde (1990) characterises as embodiment relations the configurations where technological devices both extend and are integrated into one's perceptual field or one's sensory-motor schema - one's bodily schema. In such relations, one experiences the world through the artefact while perceiving the latter as transparent, as a "quasi me". A typical example is the relation between the blind man and his white cane found in Maurice Merleau-Ponty's *Phenomenology of Perception* (1962): when he walks with the cane, it is not the cane that the blind man perceives. Rather, the cane is integrated in his body schema – it is embodied - all the while it extends it, and it is through the cane that he perceives the world. Similar conceptualisations are offered by material culture anthropologists who not only underscore that material objects can become integrated or incorporated into one's body schema, but also emphasise how, once embodied, they shift from a position of exteriority to a relation of evidence or obviousness (Rosselin 2006; Nourrit and Rosselin-Bareille 2017).

Successful relations with or embodiment of a limb prosthesis thus require the latter to be transparent or an absent presence. As aforementioned, this is what Sobchack wishes and strives for in her relation to her prosthetic leg. However, such an achievement is neither immediate, nor definite, nor absolute: rather, it demands work, and the status of the prosthesis may change depending on the broader socio-material context (Sobchack 2004; Rosselin 2006; Winance 2010, 2019; Dalibert 2014, 2016; Gourinat 2018; Groud 2020). More precisely, similar to Myriam Winance's analysis of wheelchair users' experiences, walking with a prosthesis is the result of a dual learning process: a highly reflexive and iterative one wherein, in light of the effects of the technological device, one assesses one's sensations and adjusts one's bodily movements and, both simultaneously and successively, a more embodied process wherein one learns to "do with" the technological device, progressively incorporating know-hows (Winance 2010; see also Dalibert 2016; Groud 2020). When such a dual process is successful, one's prosthetic device becomes an absent presence. Nevertheless, due to disabling stares and material arrangements, the artificial limb that was experienced as being a part of oneself can convert into an object that is rather experienced as part of the world (Sobchack 2006; Winance 2019; see also Garland-Thomson 2009). Here, one's prosthesis becomes dramatically present or an absent absence for oneself and eventually others.

A prosthetic device oscillates between absence and presence or, rather, it is always already both present and absent in a second respect. A prosthetic limb does not need to be used or even materially there to affect its wearer. To account for the ways in which technological devices shape or mediate our experience of ourselves, of others and of the world, not only in their actual use but also in their potential or virtual action, Asle Kiran (2012) has proposed to extend the concept of technological mediation (Verbeek 2005) with that of technological presence. Even though it is not being worn, handled, or employed, a technological device such as a prosthetic leg or arm will affect the way one perceives oneself and the world, it will influence how one envisions one's future and projects oneself in it. Even though it is not there yet, that is, even though it is not fitted or not even fabricated yet, the limb prosthesis is already present in the healthcare and rehabilitation protocols, in the therapeutic and life goals, as well as in care and social relationships. Where virtuality is "the potentiality of the actual" in Kiran's account (2012, 86), prostheses' (technological) presence takes on two particular dimensions: a material and an imaginary one. First, prosthetic devices have been the object of intense media coverage and "spectacularisation" (Marcellini et al. 2010; Dalibert 2015; Goffette 2017, 2019; Gourinat 2018, 2020; Holt and Murray 2019; see also Sobchack 2006). In so doing, as material objects, they are inseparable from a particular (visual) imagery and imaginary, one that is mainly built around efficiency and performance (Gourinat et al. 2020), and one that is inextricable from ableism. Indeed, this discriminatory ideology towards people with disabilities values healthy, efficient, and autonomous bodies. Ableism, as Fiona Campbell (2001, 44) defines it, is a

network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.

The (de)valuation inherent to ableism is further exposed by Gregor Wolbing who explains that "[t]his preference for certain abilities over others leads to a labelling of real or perceived deviations from or lack of 'essential' abilities as a diminished state of being" (2008, 253; see also McRuer 2006). Which amputated bodies with prostheses are present in and, reciprocally, absent from media coverage and representations is undoubtedly affected by the systematic devaluation of disabled bodies. Second, prosthetic devices are prescribed and worn to compensate for the loss of a limb, but even though they are still materially absent, their projected presence in amputees' daily life informs and guides amputation procedures. That is, the prosthesis' virtual presence guides the way the limb is cut as well as the way the body, its postures and motor conducts (Warnier 2005) are remoulded through physical therapy – the latter not being exempt from ableist standards either (Gardien 2016; Williamson 2019).

Finally, a prosthetic device is always already present-absent in a third respect: even when it is worn, it is not worn constantly. Rather, it can be "used" very pragmatically (depending on the context and the task to accomplish) or hardly ever. Even in rehabilitation centres, when amputees are encountering and getting acquainted with their limb prosthesis, the latter is seldom here and disappears/dysappears often. Yet, few analyses in the humanities and social sciences, including those rooted in STS, have addressed the issue of non-use and/or abandonment of technological devices. It is in relation to information and communication technologies, and to the notion of the digital divide more specifically, that the issue of non-use has been raised (Wyatt et al. 2002; Wyatt 2003, 2010). In this context, it has been emphasised that non-use should not merely be apprehended in terms of deficit or failure, but that it may be due to resistance, lack of interest or disinterest after an initial use. What this work highlight is that, like use, non-use shows different degrees and forms of engagement and needs to be contextualised. Use, non-use and, as we would add, partial use can be transformed according to different temporal and social trajectories all the while they are neither absolute nor definitive; rather, they can shift and reverse (Wyatt 2010). To understand non- or (very) partial use, Fabien Granjon (2004) invites us to investigate "ordinary sociability", that is, to look at everyday practices in order to appreciate the usefulness of technologies, in this case limb prostheses, in such practices and to explore the way they are perceived and make sense to (non- or partial) users. This is what we intend to do in this article.

3. Methodological framework

Our analysis is informed by two different fieldworks. Firstly, we realised a multi-site ethnography (Marcus 1995) in two French rehabilitation centres, at amputees' homes and within an association for amputees from September 2020 to January 2022. In the first rehabilitation centre, which is a large one, we were able to observe and interview a wide variety – with respect to the causes and levels of amputation as well as the types of prostheses that were fitted there – of amputees. With fewer amputees being cared for, the second centre is smaller and located in one of the French regions most affected by diabetes and vascular diseases, which are the main causes of amputation in France. This enabled us to meet (often) elderly amputees. In both centres, we spent 4 months in four full hospitalisation units, where we interviewed 39

caregivers and observed the rehabilitation trajectories of 29 newly amputated patients, from the beginning to the end of their stay. We also interviewed them as they progressed through the prosthetic fitting process. After they returned home, we undertook a longitudinal follow-up. More precisely, we did interviews and home visits one month, six months and one year after the end of the rehabilitation stay.

Then, after the end of the ethnographic fieldwork in full hospitalisation units, we moved to outpatient care for 7 months: in both aforementioned rehabilitation centres, we observed about a hundred follow-up consultations with 93 experienced amputees. The aim was to account for the experiences of people who have been amputees for a while and to examine the ways in which medical follow-up takes place during their life course. We conducted semi-structured interviews with 31 of them, mostly at home in order to observe their daily environment, as well as with 27 healthcare professionals working in these outpatient units. Furthermore, we observed the peer support practices initiated by an association for amputees, which ranged from coming to rehabilitation centres to meet new amputees, to organising sports activities and events or moderating the Internet forum. We interviewed 21 members of the association to get their feedback on peer support.

Throughout our ethnographic fieldwork, we recorded our observations by writing in various notebooks and by making photos as well as videos. All interviews were transcribed. We coded our data thematically using NVivo. We triangulated our analysis with all three authors reading each interview transcript and all the field notes (see also Olivier de Sardan 1995, 2008). To respect the participants' confidentiality, we use pseudonyms throughout the article.

On the other hand, our analysis stems from the study that one of us, Valentine Gourinat (2018), undertook from 2010 to 2016: relying on a diachronic perspective, she examined the content of more than 1000 search results on Google and Google News, by using keywords such as "amputee", "amputation" and "prosthesis". Following Bronner's methodology for identifying the state of a "cognitive market" (Bronner 2013), she listed the first 30 search results for each year and each keyword, both in the press results (Google News) and in generalist results (Google, including image and video results). This number relies on the assumption (*Ibid.* 68) that a large majority of Internet users (65%) will be satisfied with the first 10 results proposed by the search engine, while almost all of them (90 to 95%) will take note of no more than the first 30 results. Thus, the first three pages of the Google search results allowed her to identify the state of knowledge, beliefs and information available to the public. On this basis, Gourinat classified in Nvivo the results by theme, which she developed both inductively and deductively, in order to identify the structures of occurrences and their recurrences, hence, to map the state of information available to the general public on the prosthetic issue (see also Gourinat 2018).

4. Empirical Analysis

4.1 Presence/absence of the prosthesis in collective discourses and imaginaries

The dialectic of absence and presence of the prosthesis can already be observed ahead of the prosthetic fitting process, in fact before limb amputation and the moment amputees discover their prosthesis. In industrialised countries at least, the prosthetic limb is an object that already exists in the imagination of the public, whether or not the latter is directly concerned with the problem of amputation3. In the context of cultural productions for example, several heroes of science fiction are amputees fitted with high-tech limb prostheses (Goffette 2019). Furthermore, part of amputation's media coverage, especially in the press, is about technological advances in prosthetic devices. The analysis of the structure and contents of these discourses has shown a high and almost exclusive presence of the prosthesis (Gourinat 2018). In most media coverage, the prosthesis is the main object of the discourse. Through the idea that the limb prosthesis enables to "repair" the damaged body, it is conceived as "the" solution in every situation and to all the problems encountered by amputees (Alan 2013; Smith 2016). In a sense, the prosthesis is presented as the outcome of every amputee's destiny. Amputees are almost never represented without a prosthetic device. Even more so, they are almost always represented behind or through their prosthesis. They cannot be understood nor identified without it: they appear, as it were, "ancillary" to their prosthesis (see also Sobchack 2004). Such media and cultural representations of prosthetic bodies are likely to impregnate amputees' imagination long before the amputation process.

Conversely, as our research on thematic occurrences in Google and Google News search results has shown, amputees' bodies are the great absentees from cultural and media productions and the imaginary (see Gourinat 2018). Amputees' bodies, and more particularly the stump, are rendered invisible or at least "euphemistic". A striking example of this dynamic might be that of Oscar Pistorius, whose athletic body and the spectacular physical skills he has developed over a lifetime of training are surprisingly not foregrounded in collective discourses. Only his prostheses are at the heart of media considerations and analyses of his sporting performances (Marcellini et al. 2010): they alone sum up his identity and his abilities. The first (and only) irruption of his body into the media occurred when he stood trial for the murder of Reeva Steenkamp as, in his defence, he bared his stumps to highlight the vulnerability of his bodily condition. The general shock caused by the appearance of the amputated body, of the stump, within a collective imagination entirely built around the prosthesis, shows quite clearly the disruption such an image was generating. In fact, the amputated body has no place in the collective discourse around prostheses. The publicised body cannot be a fragile or vulnerable body; it must not only be "repaired" but also camouflaged, and even at times enhanced by prosthetic technology. Equipped with prosthesis, it must appear as a "bionic" or "cyborg" body. Similarly, when it is present in the collective imagery, this body is always normalised, euphemised, sanitised: young, white, healthy, it is devoid of scars, disease, and weakness (Dalibert 2015). Yet, the actual bodies of amputees are rather old, ill, and fragile (Quesnel 2013; Varma et al. 2014). In fact, such imagery and imaginary are ableist: while disabled bodies and disability are shown, they simultaneously appear as something to be vanquished, with prosthesis being displayed as the innovation for doing so. The narrative hence becomes about ridding the imaginary and social world of disability⁴. With normative beauty, (technological) performance and self-determination being the values that it convenes and conveys, ableism and techno-enchantment (Gourinat et al. 2020) go hand in hand.

The narratives surrounding the prosthesis in collective discourses are essentially built around the dimensions of efficiency, performance and spectacularisation (Marcellini et al.

2010; Goffette 2017; Gourinat et al. 2020). Prostheses are presented as objects that are either effective in their performance or spectacular in their use or appearance. This staging makes certain types of prosthesis particularly present, all the while they are largely absent from rehabilitation trajectories: sports prostheses (e.g., racing blades), "mind-controlled" bionic arms, and artistic or designer prostheses. These types of prosthesis are, to a great extent, inaccessible to amputees, insofar as they are not reimbursed, nor can they be prescribed for everyone (a specific physical condition or motor skills are required to obtain a prescription). Some prostheses are not even available on the market, as is the case of several high-tech prostheses shown in the media, which are still in the research stage. In this respect, Nabil, a 32-year-old upper-limb amputee with a shoulder disarticulation⁵, explains how he is not satisfied with his myoelectric arm, which does not function as easily as he would like. He is interested in new perspectives regarding prosthetics, and he does not understand why the medical team did not let him choose his arm:

Like this one [he points to a prosthesis in a magazine photo], I saw, it's being produced now. I wasn't asked about it. I just have this one, it's...When you ask, they say directly: "This one is reimbursable, the other one is not", but still.

As the prostheses displayed in the media might generate idealised and unachievable expectations from amputees, the latter are likely to be disappointed by the prosthetic devices that they will ultimately get (see Figures 1-2 and 3-4). This is the case of Miroslav, a 40-year-old transhumeral⁶ amputee. As he is talking to his occupational therapist during a consultation, he points to his prosthetic glove and expresses that:

I can't go out with this: this is horrible. I don't want to. There, it makes bumps, it's not nice! It's horrible. The fingernails too, it's not beautiful. It's not natural. What the hell is this? I don't like it: I don't want to wear it outside.

Several interviewees indeed complained about the ugliness of the prosthesis' appearance. Such a feeling is particularly strong at the beginning of the rehabilitation journey when the provisional prosthesis has a "cobbled together" appearance. Amputees find it difficult to project themselves into wearing it. As Claude, a 51-year-old transtibial amputee, explains:

There is a criticism that I make [...] and I have often heard it repeated by people who are fitted for the first time, it is that when a preparatory prosthesis is made, it looks like nothing! It's, it's... horrible! [...] [W]hen you try on a preparatory [leg] prosthesis, with the casting tape around it, with a translation adjuster that is oversized, and that makes big lumps on the side [...]. When you see that on yourself, you are distorted... That's not good. It's too violent.

The negative evaluation of the prosthesis, its perception as ugly, also persists later: not only can its uncanny dimension – i.e., it is real-looking while still visible as not real – be experienced as disturbing, but the appearance of the prosthesis itself can also deteriorate with use: the coating can get stained, crumpled, or damaged (see Figures 5-6).





Figure 1. Figure 2.

Media representation of lower and upper limb prostheses
(respectively Pexels Cottonbro studio and Pexels Mart Production)





Figure 3. Figure 4.

Lower and upper limb prostheses as they are delivered for a permanent use (pictures by Valentine Gourinat)





Figure 5. Figure 6.

Lower and upper limb prostheses worn and damaged after months or years of use (pictures by Valentine Gourinat)

Finally, the modalities of what it means to be living with a prosthesis are absent from media discourses: the issues regarding learning and actual use, the difficulties of using a prosthesis and the possibilities of non-use are never addressed in the collective representations. Passed over in silence, they become hard to anticipate for amputees entering the rehabilitation process; they might even prevent them from projecting themselves towards what awaits them in practice. This process wherein prosthetic devices are idealised and highly present in the media and cultural productions all the while amputees' bodies and experiences are absent, might lead to particular (high) expectations from future prosthetic "users" (and their relatives), which may complicate the care journey.

4.2 Presence/absence of the prosthesis before amputation or prosthetic fitting

Further away from the prosthetic imaginary, in the reality of what it means to be an amputee and to be fitted with a prosthetic device, the prosthesis is still inscribed in a dialectic process of absence and presence, but one that takes on a different form. The dual dimension of the prosthesis impregnates and influences the way amputees' bodies and living as an amputee is conceived.

Before amputation, the prosthesis is an object that already has a central place in the discourses of caregivers and the testimonies of amputated peers. When amputation is inexorably required following the critical development of a pathology⁸ or when it is a therapeutic and functional option9, healthcare professionals mention the positive aspects and the benefits of the prosthesis to show the person who must be amputated that it is possible to live with the loss of a limb. The medical-functional gains and the psychosocial benefits offered by the prosthesis are elements that are evoked to enable the person to project herself into a post-amputation future. Even before it is manufactured and thus before it exists as a material entity, the prosthesis is already (omni-) present in the intentions of care, the rehabilitation, and the autonomy of the (future) amputee. To a certain extent, amputees' bodies are not apprehended outside of their relation with a prosthesis. The latter, which aims at compensating for the loss of the limb, also becomes part of an ableist endeavour to overcome disability and to restore the body's integrity and normalcy. In fact, as Ève Gardien has shown, rehabilitation protocols tend to "slavishly reproduce able-bodied gestures" (2016, 109, our translation) rather than to utilise the singular potential of each corporeality. While amputation protocols aim at avoiding future medical issues (e.g., being upright contributes to functional cardiac and vascular systems and prevents bedsores), bodies are nonetheless moulded, hence constrained, to achieve a particular shape and gait in order to comply with ableist conceptions of what a body is and should do (e.g., standing up and walking on two legs).

In this respect, the prosthetic device's absence-presence continues during the surgical act of amputation. Surgical protocols define the prosthesis not as a simple object that is added to the amputated body, but as intrinsically tied with the body. The objective of surgical techniques, which have been perfected over the years through collaboration between surgeons, physical medicine and rehabilitation (PMR) physicians and prosthetists, is to shape the stump in order to allow for the absence of pain and for the future presence of the prosthesis. As Ambroise, an experienced 62-year-old PMR physician, explains it:

Patients are much better taken care of before, during and after amputation. Surgeons ask our opinion when they amputate someone [...] Inter-team communication protocols... there are many things like that that we didn't know before, everything is standardised [protocolise] [...] It is important that the person is amputated well, with a stump that has a good length as well as good and painless skin coverage so that it can be adapted to prosthetic fitting.

In the search for the person's future well-being with the prosthesis, surgical protocols rely on various techniques and standards, such as a particular level of amputation, covering the stump with the preserved soft tissues, or shortening the tibia with abrasion of the Farabeuf angle (transtibial amputation). The resection of the patella at the level of the stump in order to obtain an efficient "terminal support" (Gritti-type femoral amputation) is another illustrative example of the integration of the prosthetic device and its eventual challenges in the shaping or moulding ("formatage") (Gardien 2008) of the amputated body. In this sense, if the prosthesis is not "incorporated" yet into the person because it is materially absent at the time of amputation, it is nevertheless present and incorporated into surgical protocols. The amputated body is designed and shaped to accommodate the prosthesis.

The surgical act is only the first step in the long process of shaping or moulding (*formater*) the amputated body in connection with the future wearing of the prosthesis. Post-surgery, the first phase of re-education, which is tellingly called "pre-prosthetic" in rehabilitation centres, aims to heal the stump and to train the person at the functional level in order for her to regain autonomy as well as to prepare for the arrival of the prosthesis. Caregivers use different techniques and practices to shape amputees' bodies during this phase. The stump is the part of the body that is quite central in these procedures. Despite the absence of the prosthesis, the stump is prepared for its future alliance with it (Groud and Perennou 2022), especially its socket, by various compression techniques and via the use of anti-oedema bands and elasto-compressive socks¹⁰. As Adrien, a 30 year-old physiotherapist expresses it:

Compression [contention] is necessary. As soon as you want to fit someone with a prosthetic device, in terms of the first fitting, you need to set a compression as early as possible. [...] Because we need to prepare for the fitting. The difficulty is that if we don't put such a compression in place, we will have variations in [the stump] volume during the day because the patient will walk during the day, which will chase away the oedema, and then at night with the fact that we don't have a compression, the oedema will reappear. And so afterwards, the prosthesis will be too big or too small [...] If a patient does not have good compression, the prosthesis may be abandoned because the patient will never feel comfortable and will consider that the prosthetists are doing their job badly, and that in any case he does not have a comfortable prosthesis.

While waiting for the prosthesis, the main challenge of this compression and moulding work is to obtain and maintain a pain-free stump, one that is also stable in shape and volume: at stake is to have an optimal fit with the prosthetic device. As we observed in rehabilitation centres, physiotherapists, nurses, and care assistants explain very early on to amputees why and how to bandage their stump or put on their compression sock. From the beginning of the "pre-prosthetic phase", and despite its material absence, the prosthesis is continually present in the minds and practices of

amputees and carers. It is as much the beacon of the rehabilitation journey as the goal to achieve.

Besides the stump, the shaping process also focuses on the whole body. Caregivers use several techniques to mould it, such as muscle reinforcement exercises for amputees to be able to wear and bear their prosthesis, and making them stand up – which caregivers call making them vertical (*re-verticalisation*) – in the physical therapy parallel bars and walk monopodally with a crutch in the perspective of walking with the prosthesis. In this process, healthcare professionals are particularly attentive to what they call the body's "improper positionings" ("*attitudes vicieuses*"), such as a flexed knee or hip, which may be harmful when the prosthesis is used. Assuredly, it is also able-bodied gestures and norms, hence an ableist conception of what a body is and should do, that are enacted here. The consideration and influence of the prosthetic device are decisive and reveal close ties between shaping amputees' bodies and the perceived functionality of the latter with the prosthesis, even before it is present. Long before the prosthesis is manufactured, this approach highlights the dialogical links and the process of organic-material compatibility that are woven between bodies and prostheses and that will become essential elements of amputees' future daily life.

4.3 Presence/absence and embodiment of the prosthesis during the rehabilitation journey

Whereas the prosthetic device is materially absent in the first phase of re-education, the manufacture and arrival of the first temporary prosthesis have amputees enter a second phase in their stay at a rehabilitation centre, called the "prosthetic" phase. Although it is impatiently awaited, the prosthesis is also the source of interrogations (What will it be like? How will I use it?) as well as uncertainty (Will I manage to walk with it?), all the while it raises hopes (I may walk again!). The first day one "encounters" or "meets" his/her prosthesis, that is, the day one is fitted with the prosthesis in the parallel bars of the rehabilitation room, is a particularly "strong" moment as Omar and Odile recall:

When I first put on the prosthesis [...] it was really... It's strong... I'm telling you it's strong... Very strong... I was pleased to be able to stand up again, to see... The fact of standing up, it's important. (Omar, 43 years old, transtibial amputee)

I was afraid that I wouldn't walk again. I was told: "Here, you will walk again. We're going to give you a prosthesis." I didn't know what a prosthesis was. And it's true that when I had the prosthesis, when I was walking between the bars, I cried a little because I was happy. (Odile, 66 years old, tibial and transmetatarsal¹¹ amputee)

Because of the possibility of standing up again and of being able to walk a few steps, the first trial with the prosthesis generates intense emotions and high expectations. Many amputees expect to learn quickly and to use the prosthesis regularly and easily. However, this learning process turns out to be more disenchanted than they had imagined. As the sessions and days of rehabilitation progress, amputees realise that the materialisation of the prosthesis does not mean a permanent presence and use of the prosthetic device. On the contrary, the prosthe-

sis is only intermittently present during the first days or even weeks of the prosthetic phase, which may cause some disappointment, such as that described by Hubert:

The time spent with the prosthetists was not unpleasant in itself. The problem is that it was beyond our control. But what is very frustrating and taboo is the length of the work. [...] I'm not criticising that they don't do their job well, but I mean that... when they say, "Here, we'll take your prosthesis," but in fact they give it back to you 10 days later. (Hubert, 63 years old, femoral amputee)

The adaptation process is often long and uncertain (see also Sobchack 2004; Winance 2010). Amputees first wear the prosthesis for a few minutes, then for 15 minutes, 30 minutes and an hour, so that the stump gradually becomes accustomed to the socket and does not get injured. In addition to the progressive wearing of the prosthesis, its tweaking by prosthetists over one or more days, the constraints linked to certain pathologies and the possible risks of injury to the stump are other elements that can lead to a prolonged absence from wearing the prosthetic device. As André expresses it:

I got blisters, these I got because I insisted on walking. That was a mistake at the beginning, but I think it's a mistake everyone makes: I mean, we're so happy to be standing. [...] So as a result, well, you get injured easily. So sometimes it's 15 days without wearing a prosthesis. (André, 62 years old, double tibial amputee)

Emma, a physiotherapist we interviewed, concurs with André as she explains that:

You have to explain that for some of them, it will be very quick, they will integrate it [the prosthesis] quickly and for others, well, there will be arteritis pain which means that they won't be able to keep it on for very long [...] [They won't be able to keep it] on the stump because it creates constraints in spite of everything. (Emma, 26 years old, physiotherapist)



Figure 7.

Dressing worn after a stump wound with the prosthetic socket (picture by Paul-Fabien Groud)



Figure 8.
Prosthesis removed after 30 minutes of walking in rehabilitation centre (picture by Paul-Fabien Groud)

In the so-called prosthetic phase of rehabilitation, the accommodating process (Winance 2010) between body and prosthesis is therefore complex for most people. It fluctuates in a fragile balance between the search for progressive wear and periods of stoppage. Thus, if the prosthesis is materially present, and often within reach, it is nevertheless frequently absent, worn little or not at all during the days of re-education while waiting for an efficient entanglement between the organic and the prosthetic.

In fact, the presence/absence dialectic is at the centre of the embodiment processes of the prosthetic device. Initially, and especially at the beginning of rehabilitation, amputees perceive the presence of the prosthesis as an unknown material object, one that is external to the body, that involves a counter-intuitive use and that absorbs their attention. One of the main challenges of the prosthetic phase is to get used to and embody, if not completely, at least partially, the prosthesis – that is, to experience it as marginal in one's consciousness and field of perception, to experience it as "transparent" or a "quasi me". Accompanied by caregivers, the posture exercises and the experimentation with the prosthesis are here to help amputees discover and learn (to master) motor conducts and prosthetic bodily techniques.



Figure 9.

Exercises on a rehabilitation treadmill as part of the accommodating process necessary to embody the prosthesis

(picture by Valentine Gourinat)



Figure 10.

Exercises, accompanied by caregivers, that consist in going up and down stairs and that are part of the accommodating process necessary to embody the prosthesis (picture by Valentine Gourinat)

In so doing, through increasing familiarity with the prosthesis, the embodiment process leads to a progressive blurring of the boundary between the organic (the body) and the material presence of the prosthetic device, that is, to an alliance between the two entities (Groud 2020; see also Oudshoorn 2020). Synonymous with embodiment and with a balance found between (subjective) absence and (material) presence, it is when motor behaviours and walking with the prosthesis become fluid and "natural" that the body-prosthesis alliance is enacted: the materiality of the prosthesis and the amputated body becomes experienced as transparent (Sobchack 2006; see also Ihde 1990). This embodiment process and search for

a "becoming one" ("faire-corps") (Warnier 2005) with the prosthetic device also combines, with the prospect of returning to a daily environment, with a desire to efface the social stigma (Goffman 1975) that is linked with ableist norms and that, in the eyes of others, is associated with the prosthesis and the amputation. As voiced by Pascaline:

I also told the physiotherapist, I don't want to limp. I don't want to limp. (Pascaline, 72 years old, femoral amputee¹²)



Figure 11.

Pascaline standing up
(picture by Paul-Fabien Groud)

However, if the embodiment and transparency of the prosthesis, which is then lived as an "absent presence", are objectives of the rehabilitation course, such a process is not linear. Various elements may come to thwart it and to interfere with the precarious balance between (subjective and material) absence and presence of bodies and prostheses. A source of disappointment and frustration, these obstacles mark out the rehabilitation journey and interfere with the learning process of the prosthesis. In this respect, Bernard and Valentin recall that:

[You have] to get used to the weight, to the weight. It [the prosthesis] is 3.5 kilos. That's it! [...] According to the prosthetist, it's important to train yourself, you must train so that the stump can accept, that's it, support this weight, otherwise there's no... there's no, there's no other solution. (Bernard, 85 years old, transtibial amputee)

For many people, it is the prosthesis that makes them walk, not the patient who walks with the prosthesis. That's an element that's quite difficult for us physiotherapists, and that's why we must adapt our discourse. [...] [T]hey have the impression that it's a robot that will make them walk, whereas this is not the case. (Valentin, 30 years old, physiotherapist)

Depending on their sensations and level of fatigue, amputees often feel that the prosthesis is a heavy and massive presence. Intermittently or regularly, they perceive the prosthesis as

impractical, difficult to control and to integrate at the sensory-motor level. For example, the heaviness and the consequent cognitive effort required for upper-limb myoelectric prostheses to function correctly cause great difficulties in use and embodiment, the opposite of what amputees had imagined, namely a prosthesis capable of rehabilitating motor functions. Furthermore, the omnipresence of the body, in its painful side, is also likely to resurface at any time during the prosthetic phase. For various reasons, the presence of pain (bone pressure, redness) and/or injuries (blisters, opening of the scar) can disturb and greatly slow down the appropriation and embodiment of the prosthetic device. That is, the absent absence of the body (it hurts, it is injured) interacts with the absent absence of the prosthesis (it is heavy, it is cumbersome, it is painful, it requires a lot of energy and attention) - they both dys-appear - making the embodiment of the prosthetic device, i.e., its becoming transparent in one's perceptual field, very precarious. For the prosthesis to be experienced as part of oneself, both the body and the prosthesis must be lived as absent presences. Moreover, because the temporary prosthesis is devoid of any aesthetic cosmesis, amputees tend to perceive the device as a visually unattractive object, as opposed to the high-tech prostheses displayed in the media. The overall appearance of the prosthesis and its negative appreciation can further hinder its embodiment.

Throughout their prosthetic journey in a rehabilitation centre, amputees (and their caregivers) deal with the absence/presence dialectic of the body and the prosthesis. The end of the rehabilitation stay does not mean the end of this dialectic, however. It will indeed continue and be enacted in other ways when returning home and experiencing one's everyday environment.

4.4 Presence/absence of the prosthesis through the long-term experience of amputees, in daily life and social contexts

The confrontation of the prosthesis with one's actual and multifaceted environments, which is often not the right "fit" (Garland-Thomson 2011), will bring about challenging situations within which the presence of the prosthesis becomes cumbersome or problematic. In the protected environments of the rehabilitation centre, the prosthesis can slowly start to be experienced as transparent. Yet, with daily environments and activities revealing its functional and/or social limitations, the (hard-won) absent presence of the prosthesis can fade away. There, the prosthetic device dys-appears: too visible, too cumbersome, too painful, too obstructive, it becomes highly present in one's actions and practices – in one's subjective experience. As Luc bemoans it, when comparing his wheelchair with his prosthesis:

I have much more autonomy in the wheelchair than with the prosthesis. With the prosthesis, I must use crutches. The crutches mean that I no longer have the use of my hands. At least in the wheelchair I have the use of my hands. If there is something on the floor, from the wheelchair, I can reach it. If I have the prosthesis, I can't bend down anymore. I can't... even to eat at the table, I'm already far from the table and I'm putting [food] on my chest. (Luc, 82 years old, femoral amputee)

In everyday life at home, the prosthesis can either be absent (not worn) because it is not very useful, or too "present" to be comfortable or effective. Indeed, the transparency of the prosthe-

sis, the fact that it can be experienced as an absent presence or, conversely, as an absent absence, is not static: rather, it is enacted in concrete situations. Therefore, for the sake of comfort or ease, amputees may prefer to remove their prosthetic device when at home, as James tells it:

Like when you have shoes and you feel more comfortable taking them off, once you're at home. (James, 36 years old, double tibial amputee who walks on his knees in his house)

In fact, at home, amputees might rather manage with a wheelchair, crutches or "simply" their stump(s) to realise their daily activities, because it is both easier and more comfortable for them. Vice-versa, outside the reassuring home environment, where the material absence of the prosthesis, hence the exposure of the amputation, might allow for greater comfort, the situation proves to be quite different. Firstly, as they are conceived for able-bodied people, urban environments are still not sufficiently adapted to wheelchairs (Borioli and Laub 2006). Therefore, they make it difficult for amputees, be they fitted or not with a prosthesis, to move around in everyday actions and movements. This is how Asma experiences and expresses it:

Outside, there are still... There are subways, there are pavements... And nothing is made for the disabled... We have nothing. You have pavements everywhere, things everywhere, stairs everywhere... No automatic doors and all that. We don't think about the disabled. (Asma, 69 years old, femoral amputee)

Secondly, besides the difficulties linked to the built environment, the social dimension is a weighty factor in the balance between presence and absence, visibility, and invisibility, of the prosthesis (Gourinat 2019). The way people look at disabled bodies is still far too stigmatising: the missing limb(s) and/or the prosthesis, when they are visible to others, may not only become an obstacle or a major constraint in social interactions, but they may also have an impact on amputees' psychological well-being (Rybarczyk et al. 1995). In this respect, Asma shares how:

I don't like the way others look at me because, especially in Algeria [where she lives half the time], it's people who are not discreet. They look at you in a way that says: "Oh poor girl, I feel sorry for her, she has a prosthesis... What happened to her?" And there are others... those who are mean: "But her husband, he kept her? It's not possible...". (Asma, 69 years old, femoral amputee)

When it becomes visible to others, the prosthetic body becomes present in one's consciousness: it can no longer be experienced as transparent. As Myriam Winance (2019) aptly encapsulates it regarding the disabling experiences of wheelchair users, an object that I perceive as part of me can suddenly become not part of me and part of the world in my encounters with the socio-material environment, which includes people's stigmatising and disabling gaze and stares. Here, the disappearance of the social presence of disability is revealing of collective values and norms, i.e., what we collectively want to be absent, which are informed by ableism. As such, in order to become an absent presence for oneself, the prosthesis must also become invisible to others. That is, the transparency of the prosthetic device and the related

absent presence of the prosthetic body, namely the "smoothness" with which one experiences his/her body fitted with prosthesis, is intimately bound to being able to pass as able-bodied, hence, to achieve absence or invisibility in the public sphere. Pascaline's fear of limping (see paragraph n. 4.3) can be reminded here.

Therefore, in order to avoid and/or remove the stigma, a whole game of presence and absence through clothing (large or loose-fitting clothes) and/or postural strategies (attenuating the limp or moving the prosthetic hand(s) while speaking in order to look natural) can be put in place. Indeed, as Youssou recalls:

Until I was 23, I didn't want to be without my prosthesis. [...] This means that I used to buy only long-sleeved clothes [so that the socket junction would not be visible]. Even if it was 60°C, I was wearing long-sleeved clothes. When I went on holiday abroad, whether to the Comoros or anywhere else, I always wore long sleeves and it was embarrassing, but at least I wasn't being looked at and I liked not being looked at. That was my thing, that I wasn't being looked at. It was more... no one came to ask me questions. (Youssou, 43 years old, transradial agenesis 13).

The aim of these strategies is therefore to make the prosthesis disappear from sight and social interaction, to make it absent and enable oneself to experience it as such, even though its (discreet) presence is also the guarantee of the invisibility of the stigma. Conversely, but less commonly, in an attempt to remove the stigma, some people will prefer to make the prosthesis particularly visible, and even highly present, in order to use it as a tool for asserting or enhancing their self-esteem and body image (Tamari 2017). This is reminiscent of the way in which the media expose prosthetics as the main attribute of amputees (see 4.1).

5. Conclusion

Throughout this article, we have sought to analyse the absence/presence of the prosthesis and the prosthetic body, in its multiple enactments. Several levels of this dialectic may emerge from our ethnographic observations and content analysis.

Firstly, the prosthetic absence/presence dialectic relates to the field of the imaginary and media productions and representations. There, whereas bodies and disability are absent, prostheses are highly present: they take centre stage. That is, in the collective imagination, supported by media representations and discourses, amputees' bodies are hardly shown. Rather, they are often erased behind prostheses. Prostheses are displayed as being beautiful, easy to use and immediately efficient and enabling (that is, as easily embodied, as transparent). However, this does not correspond to the reality of most prosthetic users; it is, in fact, informed by ableist ideals which evacuate disability in favour of (technologically) performant bodies. Secondly, if from an unknown and strange object that is external to oneself, the prosthesis becomes experienced as transparent, as an absent absence, it is the outcome of a long and difficult learning and training process. While, because of compression and rubbing, the prosthesis, or rather, the body fitted with a prosthesis can be experienced as painful, thus

as an absent absence, the amputated body itself also tends to be damaged, weakened and sometimes vulnerable, making embodiment, i.e., experiencing one's body with prosthesis as absent presence, all the more difficult. Therefore, transparency cannot be understood solely from the perspective of the prosthesis. While becoming one with the prosthesis requires the latter to be experienced as transparent, transparency is not only transparency of the device but also transparency of the body and, in fact, of their alliance. If one experiences his/her body as painful, sore, or itching, hence as an absent absence, it will be all the more complicated to embody the prosthetic device and achieve a body-prosthesis alliance. Prosthetic embodiment thus relies on the fragile combination of absent/presence of both prosthesis and body. Finally, we have shown that the use and non-use of the prosthesis can constitute a third level of the absence/presence dialectic. The material and subjective presence and absence of the prosthesis, and the desired transparency of the prosthetic body, are not linear nor fixed in space and time. Prosthetic embodiment cannot be separated from one's capacity for action or one's intentionality, which can be encapsulated in "I can". It is in action and through the particular tasks it enables its wearer to realise that the prosthesis can become experienced as a "quasi me". Such an experience is, however, affected by one's embeddedness in ableist environments and subjection to ableist norms. Be it when the body is shaped or moulded during rehabilitation to (be able to) be fitted with a prosthesis or when one must pass as able-bodied to avoid stigmatising stares, amputees and what their prosthetic body can do are intimately linked to ableist injunctions. In fact, subjected to the injunction of performing public invisibility, amputees' subjective experience of transparency is intimately linked to their performance of able-bodiedness. Furthermore, while ableism informs all the levels of transparency (or embodiment) and the possibilities thereof, it also shapes the way prosthetic devices and bodies are perceived and apprehended by healthcare professionals and amputees' loved ones. For able-bodied healthcare professionals and the able-bodied relatives (as well as the broader social group) of amputees, the prosthesis might be seen as an obvious and necessary object in the amputees' existence. And indeed, while the future presence of the prosthesis informs surgical and rehabilitation protocols and practices, non-fitting tends to be seen as a failure: the absence of prosthesis is not an option. Nevertheless, for amputees who experience the prosthesis' limitations and its dys-appearance (i.e., its absent absence in one's field of perception), its constant presence and use might not be essential. They modulate how and when to wear the prosthesis. They may even not feel the need to be fitted at all – but then, they tend to be pushed by their family or dragged into the rehabilitation process by healthcare workers and protocols.

Such an issue allows us to ask a final question, which relates to the issue of prosthetic use and non-use, and the relevance of a use paradigm in the context of prosthetic embodiment. Assuredly, limb prostheses are removable devices: as such they can be handled and worn to realise particular actions. In so doing, they appear to be usable objects and one could indeed say that they are used. Yet, embodiment seems to involve a deeper relation between oneself and the prosthetic device than, say, between oneself and a fork or a hammer (see also De Preester and Tsakiris 2009). Such tools also require to be embodied to be efficiently handled: they are experienced as transparent when they extend the body and enable it to complete the task at hand. Prosthetic devices, however, are introduced into amputees' lives and bodies in order to compensate for the loss of a limb. In so doing, not only are they inextricable from disability

and its affective, existential reality, but they can also become experienced as part of one's body, as becoming one with oneself: as we have shown, a successful embodiment entails such a subjective experience. Nevertheless, prostheses might be worn not to realise specific tasks but to hide one's missing limb, their aesthetic and social dimensions thereby eclipsing their functional ones and further questioning the relevance of a use framework. But more fundamentally, when from amputation onwards, the body is cut in a particular way, worked on and trained, that is, shaped or moulded to be fitted with a prosthesis, to what extent can one actually *choose* to use or not to use a prosthesis? To use or not to use a particular device involves and requires choice. The very nature of choice might be at stake in one's prosthetic fitting and eventual embodiment.

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Notes

- ¹ From Ancient Greek δυσ-, the prefix "dys-" refers to what is difficult, bad, ill or impaired.
- ² According to Bronner, "[t]he *cognitive market* is an image that makes it possible to represent the fictitious space in which the products that inform our view of the world are disseminated: hypotheses, beliefs, information, etc." (2013, 23-24, our translation). It is from this informational offer that the knowledge and beliefs of individuals and the community are constructed.
- ³ Whereas some future amputees will research what to expect and will look for information on the Internet before their rehabilitation, hence will arrive with ready-made images, others will have fewer or no idea regarding what to expect at the time of their hospitalisation.
- ⁴ We thank one of the reviewers for inviting us to further develop the intrinsically ableist dimension of cultural and media representations.
- ⁵ A shoulder disarticulation means that the amputation was done at the level of the shoulder joint (between the humerus and the scapula).
 - ⁶ A transhumeral amputation corresponds to an above the elbow amputation.
 - ⁷ A transtibial amputation is also called a below the knee amputation.
 - ⁸ For example, in case of limb necrosis due to vascular causes or in case of development of a cancerous tumour.

- ⁹ For instance, in case of severe chronic pain and consequent functional loss in a limb after an accident or agenesis.
 - 10 Compression is also used to reduce the pain linked to swelling and to prevent phlebitis in the stump.
 - ¹¹ In transmetatarsal amputations, all or part of the forefoot is removed.
 - ¹² A femoral amputation corresponds to an above the knee amputation.
- ¹³ Transradial agenesis refers to the fact that part of the arm, the part below the elbow (i.e., transradial), did not develop during embryonic growth (i.e., agenesis).

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