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Accommodating daily life with a prosthesis

Après l'unité de rééducation: l'accommodement au vécu quotidien avec la prothèse

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Accommodating daily life with a prosthesis

Après l'unité de rééducation: l'accommodement au vécu quotidien avec la prothèse

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Introduction

- 1 The amputation of one or two of a person's lower limbs constitutes a major disruption in their life, be it biologically, psychologically and socially. Following surgery and then rehabilitation, the beginning of post-amputation life necessarily involves a deep unmaking of the "world of everyday life" (Schutz, 1971; Good, 1998). Amputation disintegrates the previous feeling of physical holism and detaches the self from the body. Amputation troubles an individual's sense of commonality with the others, prompting some amputees to isolate themselves from other people. From a functional perspective, its various impacts also jeopardise the feeling of shared temporality. The various sensations and/or the pain (stump, phantom limb) following amputation challenge the feelings of sensory sharpness and of sensory awakening. Amputation blurs the feeling of an organisation led by daily actions and gives way to the feeling of a pathology that stands in for all the well-known, domestic priorities. Finally, there is a radical change from the feeling of a common, obvious knowledge of the world and its continuity to a feeling of urgency linked to the loss of a limb and where nothing can be taken for granted. With time, amputees progressively learn how to live with the loss, but also with what is being rebuilt physically with the stump and what is related to it, such as the phantom limb and the prosthesis. Facing these major changes, amputees progressively experience what we have called "the paradox of the stump" (Groud, 2017, 2019). They learn not only how to live and deal with the irreversible loss of the limb, but also with the physicality of the stump and what pertains to it, such as the phantom limb and the prosthesis.

- 2 The rehabilitation stay can be described as a critical stage during which amputees will heal, during which they learn to accept their amputated body, before learning to wear and move with a prosthesis. It is in the safe and reassuring environment of the hospital that amputees learn how to fasten and use a prosthesis. The end of the hospitalisation and rehabilitation marks the end of this learning period. Learning, however, continues at home. Out of the protective environment of the hospital, amputees must adapt and habituate to daily life with the prosthesis in their own homes and social lives. The first months adjusting to life with a prosthesis, beyond the purview of rehabilitation staff, provides the main focal point of this article.
- 3 Qualitative studies in human and social sciences have interrogated the processes of adjustment to the prosthesis (Gallagher & MacLachlan, 1999, 2001), the subjective experiences with the prosthesis (Murray, 2004, 2010; Sobchack, 2006, 2010; Crawford, 2014, 2016), and the uses and social impact of prosthesis (Kurzman, 2003; Murray, 2005, 2009; Jefferies, Gallagher & Desmond, 2017, 2018). While several studies have privileged amputated people's own experience of rehabilitation units (Warren & Manderson, 2008; Manderson & Warren 2010; Messinger, 2007, 2009, 2010; Messinger, Bozorghadad & Pasquina, 2018), only one qualitative study followed amputees leaving rehabilitation to return home, over a 18-month period (Hamil, Caron & Dorahy, 2010).¹ It is essential to focus on this time frame, which represents a significant turning point for amputees, during which the strategies, learned during rehabilitation, of living well with a prosthetic device are tested and important habits and mindsets are baked in. While Hamil, Caron & Dorahy (2010) have noted the psycho-social adaptations in the first months after amputation, the challenge of living with a prosthetic device remains overwhelmingly underexplored. Thus, the following set of questions guides our analysis: how do amputees accustom themselves to wearing one over the first eighteen months after rehabilitation? What are their experiences? Why and how do some make their prosthetic visible during social actions? Why and how do some make theirs invisible during social interactions, and what does this tell us about their perceptions of disability?
- 4 This article is based on ethnographic and longitudinal research design. The latter consisted of two interrelated phases. The first phase involved on a six-month ethnographic survey carried out in a rehabilitation unit. This approach yielded several advantages: it enabled us to observe and keep track of the rehabilitation process as it was experienced by fourteen lower limb amputees who had been equipped with a prosthesis. In addition to ethnographic observation, we conducted a semi-structured interview (I1) with each of them at the end of rehabilitation. The second phase returned to participants eighteen months after the end of the rehabilitation period for semi-structured interviews (I2) to explore their experience of post-rehabilitation life. We conducted these interviews at the rehabilitation unit when patients came for a follow-up. This article concentrates on a cross-analysis of the interviews from the second research phase (I2).² The participant sample involved 10 men and 4 women. The average age was 58,3 years old (I2 interview). The youngest person surveyed was 20 years old and the oldest was 91. As for the type of amputation, 7 people had a tibial amputation, 6 people a femoral amputation, and 1 person a bilateral amputation. Furthermore, the sample group was made of 7 people with a vascular amputation, 5 people with a traumatic amputation, and 2 people with a tumoral amputation.

- 5 This article provides the cross-analysis of what people say about their life with the prosthesis and their disability. It is divided into two parts. First, it focuses on daily life with a prosthesis and its impacts on situations of disability. Second, it attends to the strategies amputees use to navigate everyday social interaction.

Post-rehabilitation daily life and situations of disability

From the prosthesis to technical aids: a multi-faceted, changing and situational arrangement

- 6 Our focus on the everyday led the researchers to ask amputated people about the amount of time that they wore the prosthetic device on a daily basis.³ The cross-analysis of the interviews reveals that the amount of time varies⁴ from one person to the next. Young and active amputees tended to use the prosthesis most frequently, as evidenced below:

Aurélien:⁵ “During the week, I wear it all the time. The only moment when I take it off is to go to bed. In the morning, I put it on straight away.” (I2: 26 years old, tumoral, femoral amputation)

Éric: “I get up, actually, I have breakfast, then shower, then I put it on.... You know, it’s like I’m getting dressed, I put my trousers on, and bing, I put my leg on... I’ll say that my trousers are always on the prosthesis [...] From that moment on, I keep it on until the evening, until I go to bed.” (I2: 35 years old, traumatic, femoral amputation)

- 7 These participants have integrated the prosthesis into the rhythms of their daily life without much difficulty. They have accustomed themselves to the necessary everyday ritual of putting on the prosthesis every morning and of wearing it the entire day, only to take it off just before going to bed. As such, they have acquired sufficient motor skills and expertise to enable them to use the prosthetic without a break throughout the whole day, whether they are in private (at home, with a few changes depending on the people present) or in public (at work or during leisure activities). Conversely, older participants reported an entirely contrasting experience. These interviewees emphasized a more restricted use of the prosthesis, though they described significant variations in the amount of time using it:

Jean: “I put it on straight away [...]. I have breakfast [...]. And then I go for a walk, for an hour, a bit less than an hour, I take it off for lunch at midday and, after my nap, I put it back on, and in the afternoon, I do the same again, about the same amount of time as in the morning.” (I2: 85 years old, traumatic, tibial amputation)

Robert: “I use it twice a day, that is in the morning and in the afternoon, and I don’t keep it for a long time. I walk, something like, between about 50 metres or more. Together with the physio, then I walk more because he is there.” (I2: 91 years old, vascular, femoral amputation)

- 8 Some insisted that they could only bear wearing their device several hours a day, explaining that they quickly became tired by the act of walking (cf. Jean). More elderly participants reported that they wore the prosthesis for short periods of time. In these cases, limited prosthetic use can be attributed to factors related to ageing combined with a post-amputation loss of functional and physical capacities that restricted the ability of an amputee to use the prosthetic easily or comfortably. Participants such as these experience significant difficulties when putting on or taking off the prosthesis without help. Major physical difficulties with walking encourage these interviewees to

be highly apprehensive about walking with the prosthesis, with some fearing a potential fall (cf. Robert).

- 9 The prosthesis is not the only object in the post-amputation technical apparatus. Other technical aids, such as wheelchairs or environmental aids, play an important role in the lives of interviewees. Such assistive aids in many respects can complement and support the use of the limb prosthesis. But for those whom the prosthetic has little function, assistant technologies can replace the prosthetic altogether. Consider, for example, the case of the wheelchair. Wheeled assistive technology is seldom used by the young and/or active people surveyed. If it is used, interviewees emphatically emphasise that it is only sparingly, on a special occasion or at home. Once again experience diverge according to age, with older interviewees finding the wheelchair more useful for daily life. For these participants, the wheelchair provided them with a stable seating position and easy handling. These interviewees stressed that they use wheelchairs mostly for transfers (to and from bed, shower, toilet) and to move around the house and outdoors:

Interviewer: “And when you’re not wearing the prosthesis, how do you move around?”

Jean: “With the wheelchair, I don’t use crutches anymore.” (I2: 85 years old, traumatic, tibial amputation)

André: “Once I’ve taken off the leg, to watch TV, I sit down in the wheelchair in front of the TV [...]. Then I put the chair next to the bed and I climb in.” (I2: 70 years old, vascular, tibial amputation)

- 10 Although it is considered as a relatively useful technical aid in the home, elderly interviewees emphasised that using the wheelchair to get about in public was not without its challenges, emphasising that using this technology for mobility requires from users a new competence to achieve precise movement:

Geneviève: “I didn’t dare go out alone anymore [with the wheelchair] [...] Scared of making a wrong move, of veering off, of not braking in time.” (I2: 89 years old, vascular, femoral amputation)

Robert: “It’s quite heavy [the prosthesis]... When it works well, I’m really satisfied. On some days it bangs a bit. It works more or less well. But well, whether I like it or not, I put up with it. That’s it, I put up with it. I know that if I don’t do something I’ll be doomed to use the wheelchair and that’ll be it. (I2: 91 years old, vascular, femoral amputation)

- 11 Thus, as Geneviève’s and Robert’s words illustrate, the wheelchair elicits ambivalent responses from interviewees, who described the technology as both enabling and disabling.⁶ While older interviewees recognised the wheelchair as a technology that might enhance their mobility, they often reported a preference for becoming more capable with the prosthesis. Using their wheelchair to move around rather than their prosthetic often led to immense disappointment, with one interviewee describing a feeling of “doom.” Over-dependence on a wheelchair makes apparent the loss of functional capacity that the prosthetic is meant to repair and overcome. It also symbolises a relinquishing of the hope of ever walking with a prosthetic device and a preference for the prosthetic.
- 12 Crutches are also essential technical aids, but as with the case of the wheelchair, participants put these aids to different uses. Young or active participants explain that they did use crutches on some occasions, particularly at home when not wearing the prosthetic. For example, the most common situation for using crutches was for getting in and out of the shower, or when preparing for bed:

Olivier: “In the morning, I get up at 5, I take my crutches, go to the dining room – where my prosthesis is –, I put it on, I drink coffee. I go to work all day until 10pm when I take off my prosthesis.” (Olivier, I2: 35 years old, traumatic, tibial amputation)

13 For these reasons, crutches were described as a highly convenient aid to move around the house in the absence of a prosthetic. Moreover, when the prosthesis cannot be worn because of momentary physical discomfort, such as stump pain, these interviewees explained how crutches are their default option, simultaneously providing a source of security and mobility.

14 However, for other participants, such as André or Monique, using crutches had an additional role: a supporting supplement to wearing a prosthetic device with the aim of strengthening their motor skills and stability (motor behaviours or *conduites motrices*) (Warnier, 2005):

André: “At home, there are ways up and down, it gets on my nerves. So when it goes up, I use the crutches.” (I2: 70 years old, vascular, tibial amputation)

Monique: “I don’t expect a million things from walking, I want to walk well with my forearm crutches and then as time goes by use only one.” (I2: 65 years old, double vascular, tibial-femoral amputation)

15 Some participants insist on the advantages of using only one or both crutches depending on the specifics of the situation (Cf. André). According to their individual requirement, participants decide to use a single crutch as additional support to help them walk with the prosthetic device, or possibly two crutches if they need more security (Cf. Monique). The medical walker that is used by people with diminished functional capacities may further serve as an additional assistive technology. At times, crutches might not be needed, particularly at home:

Évelyne: “I walk 50 metres without crutches and that’s all. So, at home, I walk without crutches... Why? Because there’s always a piece of furniture, always something. But when I’m outside, I have to take my crutches.” (I2: 74 years old, vascular, tibial amputation)

16 Specific adaptive aids built into the home can promote ease of movement. These include the support of a banister, a piece of furniture or a wall-mounted bar, especially in the toilets and bathroom for transfers.

17 As the first post-rehabilitation months go by, thanks to an adaptation process (Winance, 2010, 2019a), interviewees describe the role of assistive equipment in their daily life and also bring into focus the important role taken on by the limb prosthesis in post-amputation life. Depending on the situations and moments of the day, this assistive equipment consists of technical aids that are not only as close to the body as possible (limb prostheses and wheelchairs), but also further away from it (crutches, medical walker), and extends up to the organisation of the immediate surroundings (wall-mounted bars, furniture, handrails). The cross-analysis of the interviews shows the meanings and the importance of these various technical aids and their influence in the involvement of people in their multiple movements and moves with the prosthesis, or by way of compensation for its absence.

Facing situations of disability

18 On leaving the rehabilitation unit, each amputated person, according to his or her individual characteristics, faces various situations of disability which may be more or

less remedied by the prosthesis. We have been able to identify two functional sides of wearing a prosthesis, as identified by interviewees, namely regained capacity and the limitations inherent to the relationship between the body and the prosthesis. These two aspects of the prosthetic experience have taken a central place in the detailed analysis of these situations of disability, and more particularly in the interviews carried out with amputees.

- 19 All participants agreed that standing up again is the most immediate advantage gained by using a prosthetic. Two excerpts from the interviews reveal how much importance people attached to being able to stand up again on both their legs, one prosthetic, the other one organic:

Patrick: “The fact of being able to say hello to someone on your feet, to finally feel like 1,85m again, hum... well it feels good, honestly, it feels good.” (I2: 56 years old, vascular, tibial amputation)

Geneviève: “Well (*pause*), the benefit is to still be able, from time to time, to stand on your feet normally (*pause*). It’s both nervous and moral, it still feels nice to be like everyone else, from time to time.” (I2: 89 years old, vascular, femoral amputation)

- 20 Standing again brought immediate pragmatic advantages. In addition to the essential functional gains mentioned by the caregivers, participants underline the fact that it allows them to stand upright again for a prolonged time, thus resembling how they had acted before amputation. Secondly, being able to stand up and to walk “normally” enabled them the opportunity to get out of the wheelchair, and to be “like everyone else,” to be *just normal* (Jefferies, Gallagher & Desmond, 2017, 2018). The standing position is normative in ableism⁷ (Campbell, 2001).

- 21 A repeated experience across the interviewees – observed in several studies (Murray & Forshaw, 2013; Dunne et al., 2015; Jefferies, Gallagher & Desmond, 2018) – is the sense that the prosthetic recovers lost physical capacities caused by amputation and heightens their sense of self-determination:

André: “You don’t have a prosthesis, you’re screwed. It’s compulsory, to move around, to go to the toilets.” (I2: 70 years old, vascular, tibial amputation)

Aurélien: “It’s just independence, I can do everything on my own and I really don’t have any problem.” (I2: 26 years old, tumoral, femoral amputation)

- 22 Here, walking with a prosthetic device allows one to regain one’s functional independence, ranging from the ability to do basic movements for old amputated people (get up, walk in one’s house) to more elaborate skills for young and/or dynamic amputated people (do active walks, go up and down the stairs). According to interviewees, one of the most important potentialities of the prosthetic-assisted amputated body lies is what can be referred to as the “virtuous circle” (Groud, 2017), which represents the positive experience of prosthetic use:

Étienne: “Let’s say when everything’s alright, when I don’t feel pain, when the settings are good and all, say I just got it... It’s all good. It’s brilliant. [...] In all those times, when I can see I walk well, I manage to do this, to run, to walk, this and that, then I’m at my best.” (I2: 34 years old, traumatic, tibial amputation)

Éric: “There are times when you really feel like you’re gaining power. Actually, it’s really linked to your autonomy... The more autonomous you are, the better you feel... Let’s say it’s normal, you know.” (I2: 35 years old, traumatic, femoral amputation)

- 23 Those interviewees who achieve “the virtuous circle” wear the prosthesis for long periods and as regularly as possible without significant problem. They maintain that

their prosthetic-assisted body confers substantial functional gain and provides them the opportunity to ‘overcome’ many challenges imposed by disability.

- 24 Nevertheless, while the interviewees stressed positive experiences, this did not mean that they did not raise negative experiences with learning to live with a prosthetic, such as pain, difficulties and constraints. Cross-analysis of the interviews reveals that all participants talked at length about the limitations of the technology. In doing so, interviewees emphasise the importance of monitoring their stump and maintaining good hygiene practices – a recommendation on which caregivers and ortho-prosthetists insist. If it remains relatively firm and stable, the stump will continue to fit comfortably within the socket. However, when the stump no longer fits the socket, problems may soon occur, such as infection and pain, making wearing the prosthetic somewhat difficult or even impossible in the worst cases:

Éric: “There is the technical limit of the device when you can... To collapse, when you can’t run, when you know that you must walk faster, you can feel that you are adapting to the device [...] when it’s not well adjusted, when you don’t really fit in, when you’re irritated, when... It’s a heavy burden.” (I2: 35 years old, traumatic, femoral amputation)

- 25 Body-prosthesis complications – anything from various wounds, feelings of pain, fluctuations or sweating – are often related to the state of the stump and to its fit with the socket. The occurrence of those phenomena is singular, depends on each person, each pathology, physiology and sensitivity / resistance of the stump (e.g. delicate nature of the skin, bone structure). Some interviewees talk about the difficulties that are due to problems with the components of the prosthesis such as socket breaks, a malfunction in the alignment of the prosthetic foot, or a dysfunction in the prosthetic knee. In these cases, an appointment with the ortho-prosthetist is required to fix the prosthetic. In cases where the stump becomes injured, the user experiences pain and might be unable to wear the prosthetic socket for quite some time. Whether it be from stump pain or prosthetic malfunction, the technology cannot be worn, and time is needed to fix the problem, leading to an inevitable temporary loss of the functional capacities gained. Significantly, the limits of prosthetic restoration, then, require amputees to face situations of disability in a radical way. In the absence of a prosthetic, they must make use of other technical aids, the nature of which we discussed earlier, but according to interviewees, these aids often fail to provide the same potentialities as the prosthesis. We can extend our discussion of the experience of becoming accustomed to prosthetics by turning our attention to one last scenario. If the complications are more serious, and it becomes impossible to wear the prosthesis for several weeks, a vicious circle may well occur, threatening to destabilise, or even create a breaking point in the balance that had been established between the body and the prosthesis. Corporeal resistance, for example, can occur when the amputee puts the prosthetic back on after a respite. When it is no longer “corseted” (*corseté*) by the socket, there is a risk that the stump might swell:

Isabelle: “It got bigger because I [...] couldn’t walk anymore. I’ve had problems with that foot (able leg), I’ve had many issues and it’s after that that I stopped walking and that my stump got bigger [...] it grew by a few centimetres, but it prevented me from putting on the prosthesis in the right way.” (I2: 66 years old, vascular, femoral amputation)

- 26 In severe cases of swelling, the body-prosthesis maladjustment requires the ortho-prosthetist to remold the socket. For the amputated person, it is impossible to wear a

prosthesis that no longer fits them, so they must now wait several weeks for the ortho-prosthetist to make a new socket. Without the prosthetic, the amputee must resort to using a wheelchair and crutches again, and to re-think and re-adjust his/her daily life to face situations of disability.

- 27 Besides potential challenges in managing the stump-prosthesis relationship, tiredness is a continuous problem. Older interviewees describe a drop in their functional capacities, as well as an inability to walk for a long time or over a long distance. Other participants stress their disappointment to do certain movements with the prosthesis, explaining that they experience problems going up or down the stairs, walking on slopes or even on loose soil (gravel, sand). Some interviewees suggested that there were limitations with using the prosthetic and developed strategies to succeed differently.
- 28 Thus far, this analysis has drawn attention to both the benefits and challenges of prosthetic use, illustrating the complex bond that is forged between the individual and the prosthesis – what is often referred to as the body-prosthesis alliance. Indeed, the term defines the relationship that develops between the amputated person and his/her prosthesis, as well as the issues underlying it. As the definition makes clear the alliance is an “action to unite, to become united” and it is “the result of that action.”⁸ An alliance between the organic and the prosthetic is progressively achieved on various levels, ranging from the relationship between the stump and the socket to that between the amputated body and the prosthesis in general but especially considered together with the elaborate motor behaviours. In the search for efficiency in the various motor behaviours, the amputated person must form an alliance with the prosthesis and reconsider his/her way of walking and moving depending on the characteristics and conditions imposed by wearing and using the prosthesis. Through the choices regarding the prosthetic components and through the various adjustments and adaptations of the socket made by the ortho-prosthetist, the prosthesis must also form an alliance with the amputated person and with his/her characteristics and specificities to be used efficiently, as described by Bernard during the interview:

Bernard: “He (*the orthoprosthetist*) put some kind of foam inside (*the socket*) and then it took me some time to get used to it, to my new socket, and then it... it... I’ve stopped feeling pain since he put foam inside, and we did a new design and since then I even thought... I even thought... I even thought of changing my prosthetist... The new socket gave us a hard time but now it’s ok.” (I2: 55 years old, tumoral, tibial amputation)

- 29 The word “alliance” thus emphasizes precisely “the union, the association, the mix of elements which at first seem incompatible” between the organic and the prosthetic, and the “common community pact”⁹ which is bound between the amputated person and the prosthesis along the person’s post-amputation life. So, as caregivers and ortho-prosthetists recommend, the device must be worn as regularly as possible if the person wishes to use it to its full potential, without pain and with the least loss of adaptability between the stump and the socket. That observation shows an attachment¹⁰ with the prosthetic device (Gomart & Hennion, 1999; Latour, 1999; Hennion, 2017, Winance, 2019a). A special relationship is established between the individual and his/her prosthesis through this attachment to the object, linked with its daily use and the benefits it provides on a functional level. Notwithstanding, some sort of reliance on the prosthetic irreversibly comes up with this attachment, related to the necessity to respect and conform to the various instructions, be they medical (be careful not to “force” and hurt the stump, keep an eye on it, have a healthy lifestyle – especially for

people amputated because of vascular problems), or ortho-prosthetic (good positioning of the prosthesis, regular use, hygiene and replacement of the prosthetic liner, regular visits to the ortho-prosthetist). The fact of not complying to some of these recommendations and the mutual reliance forged by the unstable ties between the stump and the prosthesis may cause the amputee fitted with a prosthesis to tip over to a negative situation with various complications, making the prosthesis unusable:

Étienne: “I’ve always said, ‘I’m not the one who will adapt to the prosthesis, it’s the prosthesis that will adapt to me.’ So, yes, it adapts to me, But I’ve paid the consequences of that to this day. Like, for example... I’m in a hurry, I rush down the stairs like a madman, or I lean on it all the time or I run with it or whatever.... Well, there comes a time; that’s it, the kneecap is ruined, hum... It burns, it hurts... [...] It will work a week, two weeks and then, I have to stay a week without [the prosthesis] because it [the stump] can’t take it anymore.” (I2: 34 years old, traumatic, tibial amputation)

- 30 That possible shift shows the complex and ambivalent connection and reliance between the individual and the prosthesis which the amputated person progressively becomes aware of in the months following rehabilitation.
- 31 In addition to the limit of the body-prosthesis alliance promised by medico-technological intervention, interviewees experience problems due to the interaction between various personal and environmental factors and life habits described in what Fougeyrollas (2010) calls the model of the disability creation process (*modèle de processus de production du handicap* [DCP]). During the interviews, amputees talk about the multiple situations of disability that they have experienced, and which are very common in their post-amputation life:

Bernard: “The first months, it’s not always easy. There are many things, you have learnt quite a lot of things, and you think into your head... You’re not aware of being disabled for the first few months. You still have the feeling that... I realized, it needs time, that I was... There’s stuff I can’t do like when I was able-bodied, that’s it, it needs to be put into perspective [...] Walking is ok, it’s ok except when... it mustn’t be too steep you know, or else... Overall it’s ok.” (I2: 55 years old, tumoral, tibial amputation)

Geneviève: “It’s sometimes, and on occasions when I feel like doing something and then, no, I can’t reach, it’s very high, I can’t... and then I think to myself, ‘oh, well, yes, I have lost something’.” (I2: 89 years old, vascular, femoral amputation)

- 32 The various situations of disability described refer to the impossibility to grab objects because of the use of crutches or a wheelchair (Cf. Geneviève) or to walk on steep slopes (Cf. Bernard), and to the difficulty of walking up and down stairs or to move on loose soil (gravel, sand). Gradually, amputees do learn how to face these situations and find solutions; they also learn how to manage these situations, in ways that were not necessarily anticipated during their rehabilitation in a safe hospital unit.
- 33 Eighteen months after amputation, they find themselves in-between functional potentialities and limitations, in-between habituation, a precarious stability and necessary (re)adjustments. Therefore, in line with the DCP, our research reaffirms the importance of the time variable in analyzing situations of disability. It highlights the need to study daily life with a prosthesis through the lens of a situational and longitudinal approach, especially over the first post-rehabilitation months when the person may suddenly face more or less substantial situations of disability in relation to changing personal factors, environmental factors and life habits which interact and determine the individual’s daily life.

Wearing a device everyday and the (in)visibility of the prosthesis

- 34 Post-amputation life and everyday living with prosthesis must also be analysed through a study of social interactions. This is because beyond its functional benefits, the prosthesis carries social meanings. A body with signs of physical trauma or a body dependent upon a prosthesis often attracts unwanted curiosity, looks, and even comments. Several people interviewed repeatedly described their irritation:

Patrick: “Some chaps say some compassion, but I don’t believe it. Just looking at the way they look at you pff, it can’t be... It’s like when your zip is open, see? It’s like clockwork, you look somewhere else, well here it’s the same.” (I2: 56 years old, vascular, tibial amputation)

Éric: “In the summer, or like I told you when you’re wearing shorts, people saw the prosthesis, or when I was with my crutches, you see, when we went to the beach, it was unbearable, that look, looking at you, ‘oh, poor guy’... and looking at your children, you know, like, ‘oh poor little kids, their dad is...’ And I could feel that my eldest son was... You know, he’s also super sensitive with this kind of... it embarrassed him [...] It was embarrassing for him, but also for me; he was embarrassed, I was embarrassed too [...] it created an ambiguous situation, uneasiness.” (I2: 35 years old, traumatic, femoral amputation)

Évelyne: “What I don’t like is people, sometimes, they see me and say, ‘oh Miss, oh dear!’ I tell them, ‘wait a minute, I’m fine.’ I... I almost want them to get off my back. I don’t want them to feel sorry for me.” (I2: 74 years old vascular, tibial amputation)

- 35 “Like when your zip is open,” “unbearable,” “embarrassed,” “get off my back:” these words reveal a complex emotional experience of wearing prosthesis, echoing the notion of uneasiness (Goffman, 1975). All interviewees emphasize the uncomfortable looks they commonly received, but significantly, they understand, experience, and interpret this in different ways. Crucially, whether these looks are interpreted as suspicious, disparaging, discriminating, a cause for social exclusion, or at other times condescending or overprotective, depends entirely on the individual. These encounters are shaped by social norms and the way each person wishes to be perceived in a social situation (Goffman, 1973). This is best illustrated by examining how interviewees choose various strategies to deal with the able-bodied gaze, specifically whether to make the prosthetic device invisible or visible to others.

Ignore the looks, show the prosthesis: the strategy of visibility

- 36 Several interviewees have chosen not to hide the prosthesis and accept the attention garnered by their prosthetic device:

Patrick: “I show it [...] when I’m told, ‘I’ve never seen,’ I show him. Just like that time with my girlfriend, in shorts, they know I have a prosthesis but it doesn’t embarrass me at all, I’m not embarrassed by this.” (I2: 56 years old, vascular, tibial amputation)

Geneviève: “It didn’t bother me, even just after surgery. It doesn’t now, either, actually. I’m asked fewer questions.” (I2: 89 years old, vascular, femoral amputation)

- 37 Patrick firmly believes the prosthesis is not something that should ever be concealed and expressed no apprehension about showing his artificial limb, nor fear of people’s looks. In similar fashion, the cross-analysis between the two interviews with Robert

reveals a shift in opinion eighteen months following his rehabilitation, from concealing the prosthesis to now leaving it visible for all to see:

Robert:

Interview 1: “I’d rather, if not hide it, at least wear an item of clothing that allows, that prevents seeing the prosthesis. But being with a prosthesis is not something wrong, it’s not shameful, it’s something that you suffer from.” (I1: 90 years old, vascular, femoral amputation)

Interview 2: “It doesn’t affect me, morally, it doesn’t affect me [...] They need to accept me as I am and that’s it. At any rate, I can’t do otherwise.” (I2; 91 years old)

- 38 In the above except, Robert describes the irreversibility of amputation and the unavoidable use of the prosthesis. Eighteen months after amputation, he does not try to conceal the prosthesis anymore. He sees the fact of wearing it, and its visibility, as inevitable. He can see absolutely no point in trying to hide it. Another interviewee demands the right not to conceal the prosthesis in his daily life:

Laurent: “I don’t care about the looks from other people. If they have something to ask me, they should just do it. If they stare at me, I’ll stare at them so, um... In general, they’re the ones who are more embarrassed than me, in the end. They can see that I, well um, I don’t care, in the end. Whether I have the prosthesis or not, or whether I’m wearing it or not, if I want to wear a pair of shorts, I will.” (I2: 20 years old, traumatic, tibial amputation)

- 39 The language used shows the decided stance regarding the strategy adopted in society and the distance taken from possible looks and comments. With a desire of “*becoming public*” (Crawford, 2014) through the visibility of the amputation and the prosthesis, the amputated body fitted with a device may not and must not generate any sorts of negative judgements from other people. Other strategies exist for visibility, not least the opportunities for “*dressing*” the prosthetic device. Several interviewees are critical about the flesh-coloured foam traditionally used to conceal the prosthetic materials and to project an image of an anthropomorphic limb. Thus, during the interview, Etienne talks about his current project to display his prosthesis, using an aesthetic that refuses a simulation of “*natural*” flesh:

Étienne: “It will be in the robotics theme, you know. What I want is a torn aspect, actually, on the calf, and inside, all them cogs... Just like this a bit of robotics, and with also the tattoo aspect that’s also for... um. On one side there’s the leg’s hair and on the other side the rosy aspect... It’s also meant to hide this. That’s why I’ve chosen this.” (I2: 34 years old, traumatic, tibial amputation)

- 40 The flesh-coloured foam covering is designed to be as close as possible to the colour of the remaining leg, but Etienne rejects a natural-based aesthetics. According to him, these attempts are wholly ineffective at concealing the loss of the limb. The natural aesthetic does not suit him, not only because of his preference for other designs, but also because he is convinced it will attract people’s attention and looks. He advances a different presentation of self, a highly individualized one, thanks to different designs and aesthetics, *via* artistic patterns. Étienne’s project tends towards a process of destigmatization (Marcellini, 2007) through a customization and exhibition of the prosthetic-assisted amputated body. However, the strategy is not a rejection of the anthropomorphic shape (Vidal, 2016) of the prosthesis, as it retains a shape resembling the calf, thigh, and human foot. The strategy instead plays with design playing with explicit visual references to robotics and cyborgs,¹¹ while preserving the human body shape of the aesthetic, identical to the curved shape of the calf.

- 41 Going from the visibility of the prosthesis due to the use of shorts to a process of destigmatization by way of the aestheticized visibility and promotion of the prosthesis, the surveyed people from the first category share the desire to show their amputated body fitted with a device, and to do so openly. A rejection of the pressures of ableism, this strategy is materialized by various attitudes which fluctuate – depending on the people – between ignoring the norm, parting with it and/or trying to go beyond it, or even to restructure it.

Adapting to the norm: strategies of invisibilization

- 42 In direct contrast to the visibility strategies, some participants adopt invisibilization strategies to conceal the presence of the prosthetic device. During interviews I1 and I2, two amputees described their strategies in terms of concealment:

Isabelle:

Interview 1: “When I’m in my cart [wheelchair] and that my foot is on the pedal [footrest of the wheelchair], I’ve got very long trousers so the shoe will be visible, well people will see that I’m disabled, that’s for sure.” (I1: 65 years old, vascular, femoral amputation)

Interview 2: “Well, I wear trousers, never mind, I wear trousers. That’s it. I try to choose them a bit dark.” (I2: 66 years old)

Évelyne:

Interview 1: “I’m not ashamed, I don’t want to hide, nothing I can do about it. Well, OK, maybe I shouldn’t have smoked, that’s for sure.” (I1: 73 years old, vascular, tibial amputation)

Interview 2: “That piece of scrap iron [tube and prosthetic foot from the prosthesis], I prefer it not to be visible. I’m careful to wear clothes so that people can’t see it.” (I2: 74 years old)

- 43 A pair of trousers is often the most common strategy used by amputated people to hide the prosthesis. In the case of Isabelle, it is noticeable that, despite the obvious visibility of her disability revealed using a wheelchair, she still pays special attention to present herself as someone who has two limbs (a valid one, a prosthetic one). A dark pair of trousers conceals the prosthesis. In both her first and second interviews, Isabelle insisted that the trousers are not meant to hide disability. Rather, she explained that they communicate a desire to meet the pre-amputation standards of able-bodied people and to convey an illusion of visual symmetry of two legs being at the same length. About whether to hide or uncover her prosthesis, Evelyne changed her mind between the two interviews. In interview I1, Evelyne maintained: “I’m not ashamed, I don’t want to hide, nothing I can do about it.” However, after 18-months since following rehabilitation, she explains that she now tries to conceal the prosthesis with the pair of trousers. Since it is such a common item of clothing, a pair of trousers supplies as an innocuous way with which to conceal the prosthetic and ward off unwanted attention.
- 44 Yet, invisibilization via clothing is not the only strategy opted for. For interviewees, the concealment of the prosthesis is also coupled with a social and functional strategy aimed at walking smoothly, modelled on the walking pattern of an able-bodied person. Well-practiced in the rehabilitation unit, the search for, initiation and desire to reach this normative walking pattern continues beyond rehabilitation. Interviewees stressed that achieving a normal gait is a process that they continue to work on and develop in the weeks and months following the end of the rehabilitation stay:

Aurélien: “Let’s say I try to do as naturally as possible... Even if it’s still a little bit visible.” (I2: 26 years old, tumoral, femoral amputation)

- 45 As mentioned by Aurélien, the strategy used refers to a normalization process (Winance, 2019b)¹² through the search for a smooth walking pattern with the prosthetic device. The desire to try and make the prosthesis undetectable in society in the eyes of uninitiated people is an aim that is claimed for, worked on, adjusted and perfected. As highlighted by Annemarie Mol (2009: 71) for whom “the well-tamed body [...] is characterized by its apparent absence,” the feasibility of concealment, of controlling motor behaviours and of imitation, make it possible to achieve a near invisibility of the prosthesis, and by extension the amputation. The concealment strategy involves a dual approach which couples the invisibility of the prosthesis thanks to the use of trousers with the desire for a smooth, efficient walking pattern based on the able-bodied model. This analysis echoes the theories about the social valuing of amputated people to present themselves as being non-amputated, able-bodied (Kurzman¹³, 2003; Saradjian, Thompson & Datta, 2008; Murray, 2010). This type of strategy generates a redefinition of social boundaries where the amputated person may have an influence on his/her virtual social identity¹⁴ (Goffman, 1975). The shift caused by the concealment of the prosthesis reveals the possibility for amputated people to control the information linked to their social identity. Contrary to the previous category of people interviewed¹⁵ who show their prosthesis, this second category draws attention to individuals who, for various personal and/or social reasons, highlight an unwavering commitment to normalization and a desire to conform to ableism.

Combining strategies depending on the situations: visibility or invisibility

- 46 During the interviews, some amputees describe strategies that were situated half-way, between the visibility and the invisibility of the prosthetic device. Some people highlight that they choose not to show their prosthesis during social interactions but feel no embarrassment if it becomes visible in certain situations:

Olivier: “From the start, I’ve always worn trousers, except for a few times, but, no, that’s it, I will not hide to answer the question.” (I2: 35 years old, traumatic, tibial amputation)

- 47 This interview excerpt suggests an explicit desire to conceal the prosthetic device. Nevertheless, this choice is not a drastic unequivocal measure that the person tries to respect at all costs by rejecting all sorts of exceptions. Interviewees mainly choose to conceal the prosthesis, yet they do not pay any special attention to the way they are looked at. During the interviews, they underline the fact that, in some situations, they may let the prosthesis be seen, voluntarily or involuntarily, without necessarily worrying about people’s looks.
- 48 This half-way strategy is also implemented in more complex situations when dealing with unwanted stares. While waiting for his aesthetics project with a robotics and cyborg-like design, Étienne mentions this type of strategy, which he had to implement during tense situations (Murray, 2009). He thinks that those situations are generated by the fact that the amputation and the prosthetic device are not noticeable in society thanks to his smooth motor behaviours with the prosthesis and to the concealment provided by clothing:

Étienne: “In car parks, yes, often... Well, I have the parking card for people with disabilities. True, they look at you, then the old one tends to tell you, ‘Wait, you’re not disabled.’ You raise your trousers to show them, and then they shut up. [...] I can’t stand anymore people who tell me, ‘Oh, but you’ve been amputated.’ I can’t stand *that* anymore.” (I2: 34 years old, traumatic, tibial amputation)

- 49 Experiencing disparaging looks engenders frustrated and angry responses from some amputated people. Etienne’s will to show the prosthesis voluntarily and temporarily in the car park makes it possible to reveal and have access to the information about the amputated person’s actual social identity¹⁶ (Goffman, 1975), by fully displaying the prosthesis to the eyes of non-amputated people in some specific situations. However, this strategy is not the only one. The choice of making the prosthesis visible temporarily is also used in other situations, but in a strategy of (in)visibility of the prosthetic device. Thanks to the use of clothes, the amputated person may, for example, avoid certain looks:

Bernard: “Indeed, it’s already... actually, it’s true, there are people’s looks, there are... some people who look at you, who look at you, who look at you... who can see that we’re not like them. I concealed it when I took the bus when it wasn’t dressed.” (I2 55 years old, tumoral, tibial amputation)

- 50 The insights from Etienne and Bernard concerning their day-to-day life with the prosthesis shed light on the changing nature of the visibility or invisibility of the prosthesis. Depending on the social environment, the use and the presence of the prosthesis are not implemented once and for all between visibility and invisibility, but they turn out to be strategies appertaining to *passing* (Murray, 2009; Crawford, 2014). Based on a strategy of (in)visibility of the prosthesis, this third and last category ending the study makes the binary visibility/invisibility approach previously analyzed more complex. It provides another outlook and another approach of daily life with a prosthesis and of the social strategies regarding the prosthesis, which should be seen as temporary and dynamic depending on the situations that the amputated person experiences on a daily basis.

Conclusion

- 51 This article has focused on the study of daily life with a prosthesis eighteen months after the end of the rehabilitation stay through an analysis of the perspectives of those who wear and live with the device. Attention was given to this post-rehabilitation period, focusing on the interwoven aspects of situations of disability and social experiences of disability that shape how amputees live and use their prosthetic device. The first year and a half after rehabilitation thus represents a crucial period. It is during this period that a process of adaptation and naturalization with the prosthesis, the technical aids and the daily environment is usually achieved. Although the process begins during the rehabilitation stay, it is when amputees return home that they develop a stronger alliance between the body and the prosthesis. Moreover, this article has also highlighted the various social strategies related to the use of the prosthesis (visibility-invisibility-(in)visibility) and the ability of amputees to adapt, depending on the situations, the interactions, and their level of weariness to glances and stares. The extended analyses shed light on the substantial impacts and social issues that wearing and using a prosthetic device entail, all this conflicting with or trying to conform to ableism. Thus, from the alliance made between the amputated person and his/her/

their prosthetic device to the social meanings inherent to the prosthesis, this study has made it possible to understand the multi-faceted aspect of the life of people with a prosthesis, during which each experience is to be apprehended as a dynamic and situational process based on a range of human and non-human interactions linked to people's daily environment and to social norms.

- 52 Nevertheless, this study is nothing more than a snapshot at a given time over a period in the life path of people with limb difference. It is not meant to provide predictions about the future and personal journeys of these people. Daily life with a prosthesis remains precarious and still depends on the evolution of many biological, psychological and social parameters such as possible complications due to the pathology (especially among people who had a vascular amputation¹⁷), to the ageing process, to the delicate balance of the body-prosthesis alliance, or to the people's personal changes in their relationship with their body (fitted with a device) and in their choices regarding the strategies of (in)visibility of their prosthesis and disability. Wavering in-between feelings of uncertainty and potentiality, the amputated people fitted with a device will continue to think and evolve. In a longitudinal approach, these future life paths open up new perspectives for study: far beyond the eighteen post-rehabilitation months, they spur us to research further the long-term daily life with a prosthesis in order to understand the evolutions, transformations and stabilisations that occur as years go by.

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NOTES

1. The study by Hamill, Carson & Dorahy (2010) deals with the psycho-social adjustments of eight amputated people over the eighteen months following amputation. The results of the study show that, a year and a half after amputation, the survey participants have adapted to the amputation and its consequences thanks to a process of renegotiation with their personal identity based on a wide range of decisional, informational, and social factors.
2. However, when a comparison between what was said by the same amputated person over the two sets of interviews (I1 & I2) proved to be relevant to the study, extracts from I1 interviews were put in perspective with those from I2 and included in the analysis.
3. Over the first few months following the hospital stay, and while waiting for the stump to become stabilised after a period involving putting on and losing weight, this learning process takes place with a so-called “temporary” prosthesis. Once the stump has stabilised and the socket of the prosthesis has been properly fitted, a “final” prosthesis is made by the ortho-prosthetist and worn by the amputated person. The stabilisation of the stump varies depending on each person. It may last from a few months to more than a year in some cases. Eighteen months after the end of their rehabilitation stay, the people surveyed for that study mostly wear a final prosthesis, but some of them still have a temporary one.
4. A limb prosthesis is never worn 24/7. It is impossible for any amputated person to wear the prosthesis all the time, whether s/he is young or old, active or functionally dependent. Indeed, the prosthesis must necessarily be taken off over the night to let the stump in open air and for hygiene purposes. Caregivers advise amputated people to systematically take off their prosthesis at least overnight for hygiene purposes.
5. The first names of interviewees persons have been changed to respect confidentiality.
6. A similar finding has been reported by Hamill, Carson & Dorahy (2010).
7. In the course of this study, the word “ableism” is to be understood with the definition made by Fiona Kumari Campbell (2001), which 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.”
8. Centre for textual and lexical resources: <https://www.cnrtl.fr/>; website visited on May 15th, 2021.
9. Centre for textual and lexical resources: <https://www.cnrtl.fr/>; website visited on May 15th, 2021.
10. As is emphasized by Myriam Winance (2019a: 430), the use of this term refers to the notion of attachment conceptualized by various researchers (Gomart et Hennion, 1999; Latour, 1999; Hennion, 2017): “The concept of attachment refers to the notion that agency materializes through an interweaving of relationships and interactions that all

contribute to agency, which ‘make it happen’ without knowledge of who does what, who acts or who is acted upon. Far from being defined beforehand by any essential nature, the objects and subjects, and their status, but also their qualities, are produced by these attachments, which are constantly being performed.”

11. As is shown by the case of Etienne, this strategy is still minor in France compared to other countries such as the United States, where it is much more developed. Yet, the decision to show one’s prosthesis and to promote new designs is becoming more and more popular in France, particularly among young amputees, and it is advertised in various social media.

12. Myriam Winance (2019b) defines three forms of normalization: 1) conform to the norm by hiding the difference; 2) work on the norm to incorporate the difference; 3) share the norm. In the context of this article, the use of the phrase normalization process refers to the first form.

13. Steven Kurzman (2003) points out the necessity to see the amputated body as an able body, performing able-bodiedness. He specifically insists on the obligation to reconsider and think about amputated people using a device, in line with their own ideas, as “normal” individuals, not disabled, and for whom the use of the term “prosthetic users” would be more appropriate.

14. The phrases “actual social identity” and “virtual social identity” refer to the way Erving Goffman uses them. Here is how he defines them: “the character attributed to the individual, we impute it on him/her potentially in retrospect, which means with an “imaginary” characterization, one that creates a virtual social identity. As to the category and the traits that could be proven to be actually possessed by the individual, they form his/her actual social identity” (1975: 12).

15. Within the group of people interviewed, there is a balance between the men and the women who talk about implementing strategies of invisibilization for their prosthesis. Therefore, there is no visible impact of gender in this qualitative study. However, it would be relevant to make qualitative and/or quantitative studies on the impact of gender with a larger group of people.

16. See footnote 14 for Erving Goffman’s definition of the term “real social identity.”

17. It is important to notice that people who have had a vascular amputation are more likely to face various and more or less serious complications in their stump (delicate skin, vascularization problems, possible risk of amputation higher up on the limb), complications which permanently impact the use of the prosthetic device. Apart from these complications, it is impossible to ignore, at the end of this study, the death risk of patients in the years following their vascular amputation. As a matter of fact, various studies in the scientific literature show that the mortality rate of amputated people suffering from these pathologies is extremely high five years after amputation (Thorud et al., 2016), ranging from 40 to 100 % depending on the various studies and levels of amputation.

ABSTRACTS

This article analyses the everyday experiences of lower limb amputees with prosthesis during the first eighteen months after rehabilitation. It is based on an ethnographic and longitudinal research carried out with fourteen patients whose lower limb(s) has or have been recently amputated. Grounded in semi-directive interviews conducted one year and a half after the end of their rehabilitation ended, this study specifically focuses on the cross-analysis of the amputees' discourses and feedback regarding their daily experiences of, and accommodation to, a prosthesis. In this article, daily life with a prosthesis is analysed from two different points of view. The first one concentrates on the everyday uses of the prosthesis and its repercussions in relation to experiences of disability. The second one deals with the various strategies that amputees use in social interactions, particularly the strategies they use to manage the visibility and/or invisibility of the prosthesis to deal with the pressure of normalcy.

Cet article analyse les vécus quotidiens des personnes amputées des membres inférieurs avec leur prothèse, au cours des dix-huit premiers mois post-rééducation. L'étude se base sur une enquête ethnographique et longitudinale réalisée auprès de quatorze personnes nouvellement amputées d'un ou des deux membres inférieurs. Elle porte spécifiquement sur l'analyse croisée des discours et retours d'expérience des personnes amputées vis-à-vis de leur vécu quotidien et de leur accommodement avec la prothèse, recueillis lors d'entretiens semi-directifs menés un an et demi après la fin de leur séjour de rééducation. Dans cet article, au prisme du handicap, le vécu quotidien avec la prothèse est analysé sous deux angles. Le premier se concentre sur les usages au quotidien de la prothèse et de ses retentissements sur les situations de handicap. Le second porte sur les diverses stratégies sociales mises en place par les personnes amputées lors des interactions sociales vis-à-vis de la visibilité et/ou invisibilité de la prothèse venant réinterroger les normes et les enjeux en lien avec le validisme.

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