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‘Don’t touch/push me!’ From disruption to intimacy in relations with one’s wheelchair.

An analysis of relational modalities between persons and objects.

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Abstract

In this article, I re-examine the question of the relationships between humans and non-humans, between subjects and objects. I analyse how relationships shape and define these – both them and their assemblage. While I concur with work in STS that has shown the ongoing process through which the embodied self is performed, I shift my attention from this ongoing process to the nature of the entities resulting from this process. I shift my attention from adjustment to entanglements and analyze the different ways of ‘being entangled’. Some of these produce intimacy, other don’t. This analysis is based on ethnographic fieldwork on the use of wheelchairs. I identify five relational modalities between the person and their wheelchair: intrusional, instrumental, functional, internalized and bound. Each defines the particular status of the wheelchair and of the person, and the way they live together. This analysis allows me to discuss the way different relationships lead to different descriptions and perceptions of the wheelchair and of the person. This analysis has implications for both the analysis of ‘prosthesis’ and of ‘disability’.

Keywords

Prosthesis, embodiment, relationships, wheelchair, disability, materiality, attachment

Introduction

The concept of prosthesis has been used by several authors to describe relationships between humans and technology (Jain, 1999; Smith and Morra, 2006; Van Der Ploeg, 2001). In particular, it has been used to call attention to a change in the status of technical objects that we all use on a daily basis. Increasingly ubiquitous, these are considered an extension of the human body that augments the human subject’s capabilities. For example, drawing both on publications –such as (Sobchack, 2010; Nancy, 2010, etc.)– and her own research on heart transplants, Shildrick (2008, 2013) shows that life with a prosthesis – internal or external, mechanical or organic – constitutes a process of bodily and subjective transformation of the person, which she describes as a process of hybridization. She uses the concept of assemblage for designating the ‘incorporated self’. This is always the temporary and conditional result of a set of connections and relationships among different elements (technical, human, animal,

material or cultural, etc.). Whether or not we are disabled, from the outset we are all made up of multiple relationships, of heterogeneous entities, technical objects, animals, data, etc. In other words, 'We are all always already prosthetic'. At stake in this expression is its emphasis on heterogeneous assemblages that define each person. It is used to emphasize the incompleteness of every human body and the necessary recourse to various other entities that, by transforming it, enable it to act or to acquire certain qualities. It is also used to emphasize that the body, far from being a distinct entity –circumscribed in particular by skin – is considered to be a process, unfinished from the start and always in a state of becoming.

Shildrick's work reflects the present use of a broad notion of prosthesis as designating any entity joined to the body and transforming its dis/abilities. However, as Dalibert (2014) has noted, this broad use of the concept of prosthesis prevents an understanding of the concrete realities of relationships that exist and take shape between humans and non-humans. It focuses analysis on the relationship between the individual, their body and the object, with the presupposition that this relationship always transforms the embodied self. It thus avoids questioning the status of the non-human entity attached to the body, and more precisely, questioning the different statuses that this entity can acquire in the relationship: as a part of me, as not a part of me, as a part of the world. In other words, by using the term prosthesis, researchers fail to analyze the way in which the object and the person are relationally defined – that is, are defined by how they attach and detach from each other, what Latimer refers to with the key concept of 'relational extension'¹ (Latimer, 2013; Latimer and Munro, 2009).

In this article, I re-examine the question of the correlative status of the entity and the person, defined by and in their relationships, which are at the same time relationships of attachment and detachment. The manners of attachment and detachment define relational modalities. In the first place, they define the nature of the entities, human or non-human, that make up each assemblage. They define their status: as part of me, as not part of me or as part of the world. In this sense, these relationships produce differences between the entities of an assemblage. Secondly, these relationships define the nature of assemblages and differentiate among them. I use the term 'entanglement' to refer to these relational modalities. The qualifier 'intimacy' allows a rethinking of the question of the incorporation of the object – in ways other than that of 'material incorporation' – into a whole that is the embodied self. It enables thinking about the different ways – material, emotional intellectual, etc. – in which an object transforms – or does not transform – who a person is. 'Intimacy', understood as an effect of relationships (Latimer and Lopez, 2019, p. 3) thus denotes the way in which a person

lets themselves be affected – or not – in and by their relationship to the wheelchair. In this analysis of relational modalities, I draw on an ethnographic study of the use of the wheelchair. From the outset, this is an ambivalent object, since it is in contact with the body while remaining detachable. This initial ambivalence renders visible the variation in relational modalities between the person and their chair. Finally, this analysis is based on a theoretical approach, drawn from Science and Technology Studies, which I develop in the following section.

From adjustment to entanglements

In order to explore the nature of relationships that are formed between persons and objects, and which define their status, I draw on a body of work from the field of Science and Technology Studies. This work has re-examined theories of action and, in relation to these theories, the correlative nature of objects and subjects (Callon & Law, 1995; Latour, 1991; Law, 2006). As concerns action, it has been shown that it emerges through heterogeneous networks composed of humans and non-humans, hence the notion of Actor-Network-Theory, as well as that of attachment (Gomart & Hennion, 1999; Hennion, 2017; Latour, 1999). The concept of attachment refers to the notion that agency materializes through an interweaving of relationships and interactions that all contribute to agency, which all ‘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, their status, but also their qualities, are produced by these attachments, which are constantly being performed.

Some authors (Akrich & Pasveer, 2004; Berg & Akrich, 2004; Mol, 2002; Mol & Law, 2004; Moreira, 2004), following this approach, have re-examined the notion of body. Drawing on ethnographic studies, they suspend any a priori definition of the subject (as an autonomous or dependent subject, as a capable/incapable subject) and of the body (as an organism, a set of perceptions, etc.). They study how different embodied selves are constituted in practice, through specific and heterogeneous arrangements made up of actions, knowledge, techniques, places and experiences. In this work, embodiment is considered as a series of trials enabling (or not) the emergence of an embodied self that brings together different bodies. The concept of embodiment (and similar concepts such as those of performance or enactment) ‘can be seen to point at the ongoing nature of the process: these are entities that have to be continually performed and maintained for them to persist’ (Berg &

Akrich, 2004, p.4). This work thus highlights the processes of learning, of being affected (Latour, 2004), of adjustment (Winance, 2006) or even of bricolage (Mol, Moser & Pols, 2010) that underlie relationships between humans and non-humans, between things and bodies, and that define what they are. What the embodied self is – its qualities, its in/abilities (Law & Moser, 1999; Moser, 1999; Moser, 2009), its in/ter/dependency and autonomy (López & Domènech, 2008; López, 2015) – is defined, performed or enacted through this continuous process.

While I concur with this body of work², in this article I shift my attention to examine not just the processes of adjustment that underlie relationships, but to look as well at those relationships as they take form at a certain moment and through which the status and qualities of the involved entities are defined. This will lead me to analyze the tension between two dimensions of the embodied self: simultaneously becoming and defined, unfinished and constituted, incomplete and complete. In other words, while the challenge is to pay attention to the temporal dynamic, emphasis is no longer on ‘the becoming dimension’ of this dynamic, but rather on ‘what is defined through it’. I will then analyze the nature of the relationships formed between humans and non-humans entities that generate differences that are not only specificities, but which create distinctions between entities and between embodied selves. These distinctions are discernable in the ways people describe their wheelchair and describe themselves. After presenting my methodology, I focus on the various relational modalities that underlie the use of a wheelchair. In conclusion, I discuss the way this study transforms the analysis of the status of technical objects as prostheses.

Methodology

This article is based on an ethnographic study carried out between 2007 and 2009 among manual wheelchair users aged between 6 and 96 years old who had used a wheelchair at different points in their life and for various reasons (disease, accident, disability at birth, the aging process, etc.). The study consisted of observations of people trying out wheelchairs and of interviews with wheelchair users. The observations (15) were made at a wheelchair testing centre. The centre did not sell wheelchairs, but informed people about those available for sale, let them try out several wheelchairs and counselled them on their choice. The interviews (23 females and 32 males) were carried out with people met through the testing centre, through mutual acquaintances, and through retirement homes for elderly persons³. Among people we

met, some had used a wheelchair for only a short time (less than 1 year), others for a very long time (up to 45 years). Place of residence was varied (city or country, private home or institution).

Content analysis was carried out using the body of observations and interviews in order to identify significant differences in the way wheelchairs were used and related to, but also differences in ways of talking about and perceiving the wheelchair. Above all, it was the contrast between two types of data – observations versus interviews – that made it possible to shift from an approach in terms of adjustment to an approach in terms of relational modalities. These two types of data offered two contrasting entry points into relationships between the person and the wheelchair: their temporality and their spatial dimension. While the testing provided a ‘snapshot’, the interview described ‘a life with’.

Indeed, testing of wheelchairs appeared to be a critical moment. The wheelchair became the focal point bringing together the person using it, a professional who directed the trial, and at times a relative of the person or a professional who cared for them on a daily basis. During the trial, these actors examined the relationships between the person and the wheelchair and how these relationships defined the body and the environment of the person. They attempted to redefine these relationships. This collective work was based both on perceptions of the person (exploration of the way they perceived themselves and their ‘body-in-this-wheelchair’) as well as on a process of bricolage (of mutual transformation of the person, the wheelchair and their environment). This process, during which the two dimensions of embodiment were articulated – ‘having a body’ and ‘being one’s body’ – allowed the person to feel at home in their wheelchair and to act in and with their wheelchair. Testing of the wheelchair thus rendered highly visible the process of adjustment between the person, their body, the wheelchair and their environment – a process that defines each one of them.

While the observed testing appeared to be a critical moment for questioning the relationship between the person and their wheelchair, the interview with wheelchair users appeared to be a moment of reflection during which people recounted their experiences (on the role of interviews in making attachments perceptible, see Callen and López, this volume). They explained how in daily life they managed to do this or that. These interviews were no longer about the process of adjustment between the person and their wheelchair, but more broadly about a process of organization through which the person sets up a mode of action by marshalling a series of resources that are of different types – objects, persons, knowledge, etc.

– and by arranging them in a way that makes action possible. This arrangement still assumes there to be a process of complementary adaptation of the person and their surroundings. But primarily, the interviews brought to light another dimension of attachment, not the indeterminate process but rather the nature and intensity of attachment that is created over time. This is because, while the trial is an instant, a moment in the life of a person, the interview reveals a long temporality, a duration. Consequently, the continual process of adjustment through which entanglements are defined no longer appears, but rather the entanglements themselves. Differences between users make it possible to identify modalities of ‘being entangled’, which may or may not lead to a form of intimacy, and which *define* different subjective configurations– some of whose characteristics are fixed – as well as different worlds. I have identified 5 relational modalities, which I describe below. For clarity of discussion, I chose to describe each modality from a typical example, even if several cases shared similarities.

The variable status of both the wheelchair and the person

An intruder that makes me feel ‘non-human’

Madame Berger is quadriplegic following a road accident. She lives alone in her house, which was retrofitted after her accident. Her bedroom is on the ground floor in the former dining room. To get around in the house she uses an electric wheelchair that she controls with a highly sensitive joystick. For trips outside she is always accompanied and uses a manual wheelchair pushed by the accompanying person. This is how she described to me her experience of the wheelchair:

What strikes me most is the global and technological aspect ... that is that it is very ... well, the more technology advances, the more it increases the disability because I have the impression of being in a ... you know, in a quad, in an immense thing ... while I would have preferred a little manual, if it wasn't necessary to propel oneself ... a little thing ... when I see that, it's absolutely ... it's not human ... (interview, January 2008, Madame Berger, aged 50 years, road accident in 2005).

In this quotation, Madame Berger evoked the massive aspect of her electric wheelchair. One could interpret this remark as being related to the aesthetic dimension of the wheelchair. However, the end of the quotation suggests a different analysis. Indeed, the way Madame Berger described her wheelchair and her situation – ‘it's not human’ – is paradoxical, since

her wheelchair is an object, a technology, and thus is indeed ‘non-human’, as defined by STS. But what Madame Berger pointed out is the way in which an object, in certain situations and at particular moments, is felt to be non-human and transforms the person, what they are, their qualities. The wheelchair is no longer an object but something non-human. It is viewed as an intruder, making one feel a stranger to oneself. This feeling of intrusion caused by the relationship with another entity – and which remains another entity – is explained by Nancy when he describes his heart transplant: ‘Once the [intruder/stranger] is there, if it remains a stranger, as long as it stays that way instead of simply “naturalizing itself”, its visit never ceases. It continues to draw closer and it never stops being an intrusion in a way; that is, without rights and unfamiliar, without becoming intimate, and on the contrary being an inconvenience, a disruption of private life’ (our translation) (Nancy, 2010, pp.11-12).

This description of the wheelchair as ‘non-human’ is not an a priori definition, but results from experience and a temporal process. Madame Berger uses an electric wheelchair that she hastily chose during her stay in rehabilitation soon after the accident. This is her first wheelchair. But after using it, she realized it did not suit her. She finds it massive, and above all, she no longer feels safe since she has slipped out of the seat several times without noticing it until ‘ending up with my legs on the floor’ (interview, January 2008). In her case, there was no adjustment process that might have led to ‘an intimacy, a familiarity’. On the contrary, a reverse process of distancing is taking place that, again quoting Nancy, ‘disrupts privacy’ and makes one feel and define oneself as disabled (‘it increases the disability’). Paradoxically, the proximity of the wheelchair, which is in contact with the person, becomes a distance that denotes the difference in nature between the person and the object and defines the status of the person as ‘disabled’. This process can also be observed among some family members of wheelchair users. For example, in reference to specially made pushchairs and manual wheelchairs suggested for her 8 year old boy with cerebral palsy, a mother told me ‘these were things...really ugly...if they had put a sign over it: “warning, disabilities”...it would have been the same...I find that...I don’t know why they make such ugly things’ (observation, January 2008). The status of the wheelchair as ‘non-human’ affects the human status of the person, who becomes ‘disabled’.

A tool that makes places accessible

Madame Debra has always had difficulty walking. She was born with undiagnosed hip dysplasia and not immediately treated, which gave rise to significant sequelae. Madame Debra walks over short distances using crutches. For the past 10 years, she has participated in monthly touristic outings organized by an association of disabled persons. She rapidly found these trips to be tiring and acquired a wheelchair, which she only uses during these outings. During an interview, she told how she had chosen her wheelchair:

When I entered the pharmacy and said I wanted a wheelchair, the pharmacist told me 'ok, let's go into the other room'. It turned out that that wheelchair, which was for demonstration purposes, it suited me, as if by magic. So I decided not to look any further ... and besides, I think it was the simplest one since it was not expensive; I didn't want a sophisticated wheelchair. I wanted one with solid tires and a reclining seat back. I didn't try to find out what colour it was; for me, what was important was that it had solid tires and a reclining seat back. And of course I wasn't going to take a wheelchair with a head rest or ... it's just to help me out in case I'm tired when we go out. [...] Because that chair there, it's called a wheelchair but it's like putting even just a chair for me, as long as I have something under my bottom, it doesn't matter what it's called. Except I'm not going to take my wicker chair, because I couldn't do anything because it doesn't have wheels. It's clear that I need a wheelchair with wheels.
(interview, September 2008, Madame Debra, 57 years old, hip dysplasia not treated at birth).

In Madame Debra's case, the relationship with the wheelchair is based on instrumental logic. The wheelchair is an instrument that allows her to participate in touristic outings without tiring since it facilitates her moving about thanks to 'its wheels'. The wheelchair is not 'a prosthesis attached to the person', but a tool for accessibility to the extent that it gives Madame Debra access to places that are not normally accessible to her way of getting about (her way of walking). In other words, use of the wheelchair depends on the place she visits and the manner of the visit (group visit, which assumes moving at the same pace as the others).

In line with this logic, the choice of the wheelchair was not problematic for Madame Debra. Moreover, there was not really a choice made since she bought the wheelchair that was on demonstration at the pharmacy, 'which suited her, as if by magic'. This logic was also seen in some of the wheelchair trials, often very short, during which the person wished to acquire the least expensive wheelchair possible, just to move about occasionally. For example,

Madame Thin, aged 65 years, has polyarthritis. Like Madame Debra, she still walks and is looking for a wheelchair to facilitate outings with her husband. The trial led to the choice of a basic wheelchair with a reclining seat back, the only criterion enabling the occupational therapist overseeing the trial to select that wheelchair rather than another. Furthermore, after the trial, the occupational therapist explained to me that she could have suggested a whole series of standard wheelchairs to the lady without there being any single criterion to distinguish them.

When the wheelchair is described as a tool for accessibility, the adjustment process is minimal, almost non-existent. Whether it was at the pharmacy for Madame Debra or during the trial for Madame Thin, there was little or no collective work needed to adapt the person to the wheelchair, and vice versa. On the other hand, the interview with Madame Debra revealed a process of adjustment (Winance, Marcellini & Léséleuc, 2015). Indeed, Madame Debra decided to remove the foot rests, which she found to be too high, leading to an uncomfortable position for her legs. Without the foot rests, either she places her feet on the ground and uses them to push the wheelchair, or she holds her legs straight out in front when she is being pushed. In this way, she minimally adapted the wheelchair for her particular use.

This process of minimal adjustment and of adaptation does not lead to a feeling of ownership for the wheelchair. The wheelchair is defined as a tool that remains outside and different from the person. When not using it, Madame Debra leaves her wheelchair in the garage situated in the courtyard of her building. The wheelchair never enters her apartment. No intimate entanglement is created. The wheelchair is kept at a distance, as a separate entity and different from the person, unable to transform his or her qualities. This is what Madame Debra expressed by using the term in French 'situation de handicap' (literally 'disabling situation') and by identifying herself as a 'falsely disabled person'.

When I propel myself, I raise my feet a little and I put my legs in front; that surely makes people who see me laugh. They must wonder what...especially sometimes when they see me stand up. It even embarrasses me in relation to them because they must be thinking 'is that a falsely disabled person, or what?' In a way, I am a falsely disabled person, I'm a person 'in a disabling situation', but I'm not going to cup my hands and shout to them 'watch out, I'm going to stand up' (September 2008, Madame Debra).

Thus, in this case, the wheelchair is a tool that the person uses. It facilitates some activities and extends their area of mobility. It becomes familiar to a certain extent, but in the end it is

conceived of as an object that is part of their world, useful and separate, easily replaceable and replaced. The person does not let themselves be changed or affected by it.

The means for a functional transformation

Madame Chini, 60 years old, is hemiplegic following the rupture of an aneurysm. When I met her, she was in a period of recovery and had regular rehabilitation sessions. She could walk short distances on flat surfaces using a tripod cane, or by leaning on someone. Inside, she used an old manual wheelchair, especially convenient for sitting at the table. For outside trips, she used a manual wheelchair. When I asked her what the wheelchair meant to her, she answered:

I'd say it was useful. A useful tool. It's indispensable for my progress to the extent that I can go out where I can see more things, so I think it is somehow necessary for recovery. I don't take it as a restriction, but on the contrary as a springboard. It's a springboard for my more... To go further. But having as a goal one day to do without it.[...] The wheelchair allows me to have a window on the world. To see other things. That's how I take it. (interview April 2008, Madame Chini, 60 years old, hemiplegic following the rupture of an aneurysm at age 60).

Following functional logic, the wheelchair is also considered as a tool, but its role is no longer solely one of providing access to a space, it is one of modifying bodily functions, the person's functional inabilities and abilities. As noted by Madame Chini, the wheelchair is an instrument useful for her progress, for gaining abilities. In other words, it is assimilated into a person's present and future transformation, in body and in identity.

This logic manifests itself in wheelchair testing. During Madame Chini's session, the occupational therapist's attention was focused more on Madame Chini's mobility than on her comfort. The therapist focused on the way the wheelchair would or would not make Madame Chini mobile, thanks to its features (a system of double handrims on the left, her non-paralyzed side) and on its settings (especially lowering of the seat so she could touch the ground and thus use foot propulsion in addition to manual propulsion). A process of adjustment, exploration and bricolage takes place, which leads to a different body and brings about a transformation in the person. Dealing with a wheelchair thus makes it possible for them to think about another potential body since it brings to light a new dynamic articulating 'being one's body' and 'having a body'.

In this dynamic, the wheelchair remains external to the person, an object of the world, while being a means for regaining ownership of one's evolving body. By using their wheelchair, the person gains a new awareness of their different body and discovers its new dis/abilities. The wheelchair thus brings about a double transformation for the person: on the one hand, in the way they perceive their body and use it to act, and on the other, the way they perceive the world through their body. Thus, Madame Chini described how the sitting position has changed what she sees when, for example, she does her shopping (she doesn't see the same objects on the shelves) or has changed her relationships with children who are now on the same level as she. As she says: 'use of the wheelchair turns out to be a window on the world, a possibility to go towards...the outside'. In this functional logic the wheelchair, as external object, is what helps the person reconstruct themselves, re-establish ownership of their changed body, and redefine its qualities and abilities. It's the mediator of a bodily transformation.

In Madame Chini's case, this functional dynamic is part of a dynamic of progress but the former can also be found in a dynamic of regression. This is the case with some elderly persons. Madame Moulin, 86 years old, talked about her wheelchair as follows:

Sociologist: What does this wheelchair represent for you?

Madame Moulin: What does it represent? I'll tell you that it represents what? My life now. No, that's not it... I don't know. I can't tell you what it represents. I'm OK in it, now that I've gotten used to it. But to tell you what it represents, I'll tell you, it represents the end of my life. I can't do anything anymore, since I'm taken out of the wheelchair to go to the toilet; it's taken over, it's put in front and the wheels are blocked then someone grabs me under the arms. I stand and someone lowers my panties and then puts me on the toilet. And in the evening, then I come here, they take you up with the elevator, I come here, I take off my top and put on my nightgown. And then I go there and brush my teeth and wash my face. And then I wait. [...] [A]nd then they put me to bed. There, that's my day! (interview, August 2009, Madame Moulin, 86 years old, in a retirement home).

For her, the wheelchair is part of a dynamic of loss of ability, a functional regression. This dynamic produces a 'loss of ownership' and 'alienation' in relation to her body. The person dissociates themselves from their body, which becomes a manipulated and passive body, and is experienced as such by the person.

Internalized as a way of being and doing

Monsieur Dos, 47 years old, has paraplegia following a motorbike accident when he was 17. He has been using a wheelchair for 30 years. He participates in lots of disabled sports, especially tennis. He belonged to the national team when he was younger, and is still very involved in a club of adapted tennis. He owns 5 manual wheelchairs: a light town wheelchair that he uses when he travels outside and that stays in his car when he is home; 2 older manual wheelchairs that he uses at home and that he leaves outside in front of his home to facilitate transferring from wheelchair to car; 1 older wheelchair converted into a handbike; 1 manual sports wheelchair. In addition, he uses an electric wheelchair for verticalization and to tinker or work in his garden. When I asked him what the wheelchair represented for him, he answered:

It's my legs. We can say that...it's legs and then, it's like you, when you walk you take a good pair of shoes. Well me, to feel good I take a good wheelchair, it's the same thing. You have to sit in it all your life. You have to sit comfortably, to avoid having painful hips, or to hurt anywhere else. (interview July 2008, Monsieur Dos, 47 years old, paraplegia following a motorbike accident at age 17).

In this excerpt, we can see ambivalence concerning the status of the wheelchair, described by Monsieur Dos as both 'legs' and 'shoes'; on the one hand part of the body, on the other, an article of clothing, that is, an external object, different from the body. This ambivalence points to a process of adoption of the wheelchair; over time, it was assimilated by the person through a double process of adjustment and arrangement. Not only was there a process of correlative adaptation between Monsieur Dos, his body and the wheelchair, but a process of practical organization as well. That is, Monsieur Dos has set up ways of acting in a wheelchair by drawing on networks of heterogeneous entities. His in/abilities are made up of and emerge from these practical arrangements. But in Monsieur Dos' case, what is adopted is not so much the wheelchair, the object as such, as it is a certain savoir-faire and knowledge resulting from the handling of his wheelchair.

By operating his wheelchair, by adjusting to it, Monsieur Dos has acquired savoir-faire. Monsieur Dos uses several wheelchairs, depending on his different activities. Each wheelchair is adapted to Monsieur Dos, and especially to each one of his activities. This is the practical dimension of the wheelchair. This practical dimension reflects the ability of the

person to act on a daily basis and to manage in various places, their ability to adapt when they are not in their usual environment. For example, Monsieur Dos often travels in groups, with other people in wheelchairs. Yet hotels rarely have more than two or three accessible rooms, so he is obliged to accept a standard room.

Monsieur Dos: We get by with nothing.

Sociologist: a room that is not necessarily accessible?

Monsieur Dos: That's it. If we need to climb onto a chair to get to the bathroom, we put a chair in it, we put our wheelchair inside, we climb on a chair. These are things we do for a week, when we are on vacation. (July 2008, Monsieur Dos).

Thanks to this *savoir-faire*, Monsieur Dos can manage and act by marshalling the resources available in the environment. He has also acquired knowledge, that is, an understanding of the wheelchair, or more precisely, the wheelchair that suits him in terms of characteristics, settings, etc. Over the course of changing wheelchairs – but also at sporting events in which he has participated and which bring together large numbers of wheelchair users who compare their wheelchairs – he has formed an idea of what he needs. When he needs to change wheelchairs, he knows in advance exactly what wheelchair will be suitable for him: 'A salesman can never know how you are sitting. Everything depends as well on the size of your body' (interview, July 2008). While Monsieur Dos does not go to a testing centre when he changes wheelchairs, some users who fit this profile continue to do so. The trial is then very technical and essentially revolves around an examination of technical characteristics that distinguish wheelchairs (for example, the method of folding or nuances in the settings) and identify the one best adapted to the person and to which the person will best adapt.

This logic brings about a bodily transformation, but above all, an adoption of the wheelchair, an 'incorporation'. At the same time, what is incorporated is not the object itself, but the wheelchair as a form or mode of moving about and a way of acting. Monsieur Dos' case reveals a paradox. While there exists a strong attachment to the wheelchair as a way of being and acting, there's no attachment to a specific wheelchair, to a particular object. On the contrary, the *savoir-faire* and knowledge he has acquired enable him to easily change wheelchairs, to easily detach himself from any specific wheelchair. Indeed, these changes are very frequent in his case (every 2 years) as he makes rough use of his wheelchair and wears it out until it breaks down. The ambivalence in the status of the wheelchair, noted at the beginning of this section, is a result of this tension; the wheelchair is internalized and incorporated as a mode of being and of action, while remaining an object external to the

person. This is the origin of an intimate entanglement: the wheelchair, in its form, constitutes the bodily and subjective wholeness of the person, even though the object as such remains detachable. This is found in what Monsieur Dos said. When he talked about himself, he talked about ‘his disability’ as well as about ‘his wheelchair’ and asserted the fact of ‘being autonomous’. His disability and his wheelchair are two of his characteristics that define his way of being, that define his intimacy, so much so that he can’t stand for his wheelchair to be washed or to be pushed by someone.

Even my wife sometimes takes up the cleaning cloth. I tell her to leave the dirt on it.

You can’t clean a wheelchair. I hate that. [...]

Sociologist: Does someone sometimes push you?

Monsieur Dos: I hate that. Oh my! Sometimes my grandchildren come to the house, for fun, because they love to push me. But I hate that. For them it’s a game to push me in my wheelchair, but I hate that. The day I can no longer get by alone, I’ll stay at home. I could never stand that. The day when I arrived in a wheelchair I wanted to be independent; even though my mother and my relatives, they were there but I told them ‘I don’t need you, I’ll manage, if I can’t manage my life will soon be over’. Since I was stubborn I was able to do what I do today, be independent, leave when I want to, come back when I want to, do what I want to. (July 2008, Monsieur Dos).

Bound to my wheelchair, like to a part of my body

Monsieur Jon, 55 years old, had a leg amputated following a motorbike accident when he was 35. He has a leg prosthesis. He can walk, either with his prosthesis, or with crutches. When he was working he moved about primarily using his prosthesis, but since his retirement, he mainly uses his wheelchair. Indeed, he has difficulty putting up with his prosthesis, which ended up giving him a stump wound when he wore it all day. Here is the way he talked about his wheelchair:

‘You get used to it, the wheelchair is part of you, I couldn’t get by without it anymore’.

And likewise, he explained to me he has become incapable of sitting in another chair:

‘I already tried to sit in it [a living room armchair].... Before my accident it was always my armchair for watching television. Now, I can’t stand it anymore. I can’t stay in it, I find it uncomfortable. I prefer to stay in this [in his wheelchair] when I watch TV with my wife; I sit to the side, and I prefer staying in it, I am a lot more comfortable in it than

in an armchair like that.’ (interview March 2008, Monsieur Jon, 55 years old, left leg amputated following a motorbike accident at age 35).

In Monsieur Jon’s case, there is not the ambivalence noted in quotes from Monsieur Dos. For Monsieur Jon, ‘the wheelchair is part of him’. A process of adoption has taken place concerning not only the acquisition of savoir-faire and knowledge, but especially the wheelchair itself, that is, that particular wheelchair. Thus, Monsieur Jon doesn’t often change wheelchairs (he has had 3 since his accident); he tries to make them last and takes care of them.

From time to time, once a month, I take it apart and clean it. [...] I take off the wheels and put a little oil or grease on so that it stays in good shape. We take care of it. It’s vital for us. (March 2008, Monsieur Jon).

Following this logic, the adjustment process produces an incorporation of the wheelchair that is no longer an external object, but becomes a part of the person. It produces a material attachment to the wheelchair, incorporated as such. For this type of user, this often leads to the difficulty or even the impossibility of changing a wheelchair when it’s worn out, and even more so when it’s worn out since this wear is the result of a very advanced process of adjustment. In a sense, they have been bound together through this process. This may lead as well to a feeling of mutilation when the person, for one reason or another, is deprived of their wheelchair. For example, Mademoiselle Babet, who has paraplegia because of spina bifida, told me:

If, for example, I can’t move about and I don’t have a wheelchair, if it’s broken, I’m disgusting. I have a very aggressive attitude. If I can’t get about and I have to stay sitting on a chair, even for an hour, I am not easy to get along with. Half my body has been taken away. (interview January 2008, Mademoiselle Babet, 44 years old, paraplegia following spina bifida).

The wheelchair –as that particular wheelchair– becomes a constituent part of a person’s bodily integrity, to the point that being deprived of it is experienced as an attack on bodily wholeness.

Conclusion

In this article, I have re-examined the question of the relationships between persons and technical objects. To this end, I have attempted to articulate an analysis in terms of adjustment with an analysis in terms of entanglement. Beyond the diversity of the hybrid assemblages that define every person, I identified relational modalities – ways of connecting and disconnecting oneself to the wheelchair – that correlatively define the status of the wheelchair and of the person. Describing these forms of entanglement, some of which define and redefine the ‘intimacy’ of the person, enables an understanding of the process of embodiment by emphasizing not only its processual dimension – as some STS approaches have done – but also what is produced through this, as described by the people involved. These approaches have deconstructed the autonomous subject and shown that their qualities and skills, their autonomy, are the result of the relationships of which they are constituted; they are emergent qualities of a hybrid assemblage. The concept of hybrid assemblage enables emphasizing the relational and heterogeneous nature of each embodied self. However, these approaches do not analyze how the nature of the entities is defined in these assemblages, producing differences not only between entities, but also between assemblages. As I have suggested in this article, the analysis of relational modalities between the person and their wheelchair allows us to do this and shows that the process of embodiment is not a process of hybridization that is infinitely adaptable. It is also a process of definition.

Certainly, we are all abled and disabled, and ‘prosthetic’, but what varies, or what distinguishes assemblages is the ways entities attach to and detach from each other. This dynamic defines relational modalities. I have described 5, perhaps there are others. These relational modalities do not correspond to types of users. Over time, a person can move from one to the other without following a predetermined order. These modalities are not either distributed over a continuum that goes from intrusion to being bound. But they do characterize ‘ways of being together’ that define what the wheelchair and the person are, and what ‘the person in/with/far away from/etc. their chair’ is⁴. They correspond to identifications/differentiations, more or less stable depending on people (on their history, on their other characteristics as age, type of impairments, etc.). They make it possible to account not only for the specificity of each ‘hybrid assemblage’, but also, and especially, for their differences, which are erased by the affirmation ‘we are all dis/abled and prosthetic’.

Indeed, the relational modalities that I described differ in several aspects. Their intensity varies and produces a greater or lesser distance between the person and their wheelchair as object. While the proximity between the person and the wheelchair can produce

a form of intimacy from day to day, it can also, conversely, be perceived as an intrusion, distancing the person not only from the object that is the wheelchair, but also from themselves. These forms of entanglement offer various possibilities and impossibilities for action, and produce different forms of knowledge, both perceptions and reflective knowledge. They also provide different ways and opportunities for becoming attached and of disengaging oneself. Above all, these relational modalities enable defining the status of the wheelchair on the one hand and the particular qualities of the person on the other.

Firstly, while the wheelchair always transforms the dis/abilities of the person, this does not initially make it a prosthesis. Its status varies: it can be seen as part of me, as not part of me, or as part of the world. These statuses are not always exclusive of each other. Moreover, the separation between what is me, what is not me and what is part of the world does not correspond to a clear boundary between the entities, but rather to a set of attachments and detachments. The notion of intimate entanglement enables assigning these relational modalities to an entity, which in one form becomes me, while remaining both distinct and of a different nature. It enables modifying the process of incorporation of an object, which can connote an embodiment of the modes of acting and being or an incorporation of the material object as such.

Secondly, these forms of entanglement are linked to certain qualities. Relational modalities don't all have the same normalizing or 'ab/normalizing' potential. On this point, the contrast between Madame Berger and Monsieur Dos is of interest because they are, in a way, at the two extremes of a continuum. In the interview, Madame Berger said she 'feels disabled', while Monsieur Dos says 'he is athletic and self-sufficient'. Taking these self-perceptions and self-portraits seriously enables linking the analysis in terms of process with the analysis in terms of entanglement, and understanding how relative qualities can become what defines the person at a particular moment in their history and over a certain time.

Finally, this study opens interesting avenues of research for re-examining the question of time. This subject was approached by the STS in terms of dynamics, becoming, and process, focusing on the body as embodiment. However, time is not just a continuous flow, a sequence that produces a past, a present and a future. These dimensions are reworked by people in their narratives to define, to redefine, their bodily and social subjectivity. The relational modalities I have identified suggest that the way in which abilities and disabilities are fixed or modified results from a dynamic incarnation that associates a body as it has become with im/possibilities of transformation. This analysis invites us to reinstate the

question of the narrative construction of the self as a constituent element of the reality of the person; in other words, that of the articulation between practice and discourse, between what the person does and what they say they are, between forms of entanglement and the definition of an identity.

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Notes

1. Drawing on the work of Strathern, Latimer proposes this notion of 'relational extension as another way to think through being with non-humans that does not reduce human/non-human animal assemblages to hybrids.' (Latimer, 2013, p.98). It allows thinking about how, in the relationship between diverse entities, connection and unity are produced that preserve some form of division and alterity. Latimer also describes these relationships with the term 'being alongside', which enriches the term 'being with'.
2. My work on the political and scientific history of disability has however led me to underline the limits of these approaches and to suggest new directions of analysis (Winance, 2016), which I wanted to study further by again examining past research on the use of the wheelchair.
3. I wish to thank M. Pierret for conducting 16 interviews with elderly persons. I conducted the other ones.
4. At this stage in my thinking, the nature of these relational modalities partly remains a question. I thank one of the referees for having brought to my attention both the uncertainty of my text on this point and on possible options, as well as their risks. However, my work on Disability Studies has convinced me that one should not be satisfied with an idea that dilutes 'disability' in 'specificities', 'being' in 'continual becoming'. It's necessary to understand what assumes a pattern and defines any one person over time, without falling back into an essentialist and deterministic position. In

other words, not all relationships between diverse entities are equivalent, but they produce ‘*relative differences which are essential*’.

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Author biography

Myriam Winance is a sociologist at INSERM (National Institute of Health and Medical Research). She is based at CERMES3 (Research Center, Medicine, Sciences, Health, Mental Health, Society). In her research, she is interested in how the concept of disability is defined in our society through institutional policies and systems on the one hand, and through the practices and experience of people on the other hand. Her work is built at the intersection of a political socio-history of disability, the sociology of health and the sociology of science and technology. It questions notions of care, of the person, of the body, of disability. In previous work, she became interested in the interaction between the person and the wheelchair. Her attention subsequently focused on the evolution of disability policies, particularly in France, and conceptual models of disability. Currently, her research focuses on the evolution of care practices and how these practices are organized for people with rare disabilities or multiple disabilities. She explores the notion of resistance in relation to that of fragility. She is one of three co-editors-in-chief of the journal *Alter, European Journal of Disability Research*.