

UNIVERSIDADE FEDERAL DO RIO DE JANEIRO

LAURA MARIA MORALES NAVARRO

ENACTING CYBORG COLLECTIFS:  
PATIENTS, PROSTHESES AND REHABILITATION PRACTICES

RIO DE JANEIRO

2014

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Thesis submitted to the Graduate Program in History of Science and Technics and Epistemology at the Federal University of Rio de Janeiro in partial fulfillment of the requirements for the degree of Doctor in History of Science and Technics and Epistemology.

Supervisor: Ivan da Costa Marques

RIO DE JANEIRO

2014

N322e Navarro, Laura Maria Morales.

Enacting cyborg collectifs: Patients, prostheses and rehabilitation practices / Laura Maria Morales Navarro. – 2014.

236 f.: il., ---, 30 cm.

Thesis (Doctorate in History of Science and Technics and Epistemology) – Federal University of Rio de Janeiro, Graduate Program in History of Science and Technics and Epistemology, 2014.

Supervisor: Prof. Dr. Ivan da Costa Marques.

1. Rehabilitation (Medicine) – Theses. 2. Prostheses – Theses. I. Marques, Ivan da Costa (Supervisor). II Federal University of Rio de Janeiro, Graduate Program in History of Science and Technics and Epistemology. III. Title.

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## ACKNOWLEDGEMENTS

A PhD is a very long, exciting and sometimes even painful enterprise; by no means, it is an individual achievement, rather, it is the product of collective hard work. This thesis materializes such collective work; as such, I want to thank the many people who have contributed, in some way or another, to its completion, I am very grateful to all of them:

To begin with, I want to thank Ivan da Costa Marques for his huge academic support, his trust in my work and his friendship. I also profoundly thank John Law and Vicky Singleton for their caring academic guidance and strong commitment to my research for several years at Lancaster. Celia Roberts and Adrian Mackenzie contributed with their critical reading. Annemarie Mol, Ingunn Moser and Lucy Suchman provided me with their critical comments at different stages of this thesis. I am also very grateful to Regina Maria Macedo Costa Dantas, Márcia Barros da Silva, Daniela Alves de Alves, Henrique Luiz Cukierman and Eduardo Nazareth Paiva, members of my thesis examination board, for their critical review and enriching suggestions to my work. I also thank Antonio Augusto Passos Videira and his research group for their feedback to my work. I have been very fortunate to have such an outstanding academic support.

Additionally, I want to thank all the patients who allowed me to witness their journey, they opened their hearts to me and shared their pain, their hopes and their stories; without them this thesis wouldn't have been written. Patients' carers shared their experiences with me too; I do hope they could find a sympathetic listener in me. The team of rehabilitation specialists was another crucial element for my research; they were always willing to be observed and followed everywhere they went and always made time for me and for my thousands of

questions. Despite the distance, Mariah Martins was always available to help me with paperwork. I thank all of them for making possible this thesis.

Throughout these years Antonio Arellano brightened up my PhD journey with his loving care and support. With their unconditional friendship, Simon Western and Ziad Asfour tenderly sustained me and helped me to keep going. I am profoundly grateful to my family for their everlasting and unconditional love; without their permanent support, trust and care, nothing would I ever accomplish. My caring Friends at LQMH were always there for me, holding me with their light and affection.

Finally, I want to thank all my friends at Lancaster and Rio de Janeiro for bringing joy, support and exciting discussions during my stay at both places, including Angeliki Laoutari, Basak Tanulku, Julian Müller, Sung-Yueh Perng, Daniele dos Santos, Isabel Cafezeiro, Marcelo Bueno, Arthur Ferreira, Fabio Marinho and José Marcos Gonçalves, just to mention a few of them for the list is long, my gratitude to all of them.

## ABSTRACT

MORALES NAVARRO, Laura Maria. **Enacting Cyborg Collectifs: Patients, Prostheses and Rehabilitation Practices**. Rio de Janeiro, 2014. Thesis. (Doutorado em História das Ciências e das Técnicas e Epistemologia) Universidade Federal do Rio de Janeiro. Rio de Janeiro, 2014.

Disability is an issue of crucial importance in contemporary society. It unavoidably brings forward a wide variety of questions related to its medical and social management, clinical treatment, rehabilitation strategies, social difference, inclusion and equity, just to mention a few. All of them, topics that touch not only the medical and social spheres, but also, a highly political realm. In this thesis I explore disability and rehabilitation from an empirical perspective. The work I present here is the result of an ethnography I conducted in a Mexican rehabilitation centre where, for over a year, I followed the rehabilitation process of patients who were prescribed either orthotic or prosthetic devices as part of their treatment. My intention has been to reflect on, and theorise about, the multiplicity of materially heterogeneous relations that get enacted during the rehabilitation process of patients with prostheses. In addition, I have tried to destabilise the categories of normality, disability and rehabilitation, this, by looking at how such categories are performed and enacted in practices and by problematising the ontological politics behind them. In my work, I have mainly drawn on a material semiotic perspective informed by the feminist technoscience tradition. I have also explored the contributions of disability studies and its critic to the way in which disability is currently approached.

My ethnographic fieldwork followed the whole process of incorporation of a prosthesis into the patient's body and life, from its very prescription, going through its design and fitting to its everyday use. To do this, I closely observed the rehabilitation practices conducted by rehab specialists, patients and carers, at three different areas of the centre, namely, the Gait and Movement Laboratory, the Orthotics and Prosthetics Laboratory and the Occupational Therapy Area, which are the sites directly related to rehabilitation treatment by means of an orthotic or prosthetic device.

Through my research I have analysed the complex and materially heterogeneous relations that are configured between body, prosthesis and person at every stage of the rehabilitation process. Through ethnographic extracts, my thesis tries to make sense of the multiplicity of ontological reconfigurations and dis/articulations that take place during rehabilitation, pressing on the importance of attending to the situatedness and the specificities of categories. Disability and rehabilitation, I argue, need to be analysed and reconceptualised through alternative methodologies capable of showing what living with a disability actually means in everyday practices, as well as of incorporating more flexible and politically inclusive understandings of disability and rehabilitation.

Keywords: Rehabilitation. Prostheses. Body.

## RESUMO

MORALES NAVARRO, Laura Maria. **Enacting Cyborg Collectifs: Patients, Prostheses and Rehabilitation Practices**. Rio de Janeiro, 2014. Tese. (Doutorado em História das Ciências e das Técnicas e Epistemologia) Universidade Federal do Rio de Janeiro. Rio de Janeiro, 2014.

A deficiência é uma questão de importância crucial na sociedade contemporânea. Ela inevitavelmente traz uma grande variedade de questões relacionadas com a sua gestão médica e social, tratamento clínico, estratégias de reabilitação, a diferença social, inclusão e equidade, apenas para mencionar alguns. Todos eles, temas que tocam não só as esferas médica e social, mas também, um reino altamente político. Nesta tese exploro deficiência e reabilitação de uma perspectiva empírica. O trabalho que apresento aqui é o resultado de uma etnografia que realizei em um centro de reabilitação mexicana, onde, por mais de um ano, eu segui o processo de reabilitação dos pacientes que foram prescritos tanto aparelhos ortopédicos ou próteses, como parte de seu tratamento. A minha intenção foi a de refletir e teorizar sobre, a multiplicidade de relações materialmente heterogêneas que se promulgada durante o processo de reabilitação de pacientes com próteses. Além disso, eu tenho tentado desestabilizar as categorias de normalidade, deficiência e reabilitação, este, olhando como tais categorias são realizadas e promulgadas em práticas e problematizando a política ontológica atrás deles. No meu trabalho, tenho tirado principalmente em uma perspectiva semiótica de material informado pela tradição tecnociência feminista. Eu também explorei as contribuições dos estudos sobre deficiência e sua crítica à forma em que a deficiência é atualmente abordada.

Meu trabalho de campo etnográfico seguido todo o processo de incorporação de uma prótese para o corpo e a vida do paciente, desde a sua prescrição, passando por seu design e adequado para o seu uso diário. Para fazer isso, observei de perto as práticas de reabilitação realizados por especialistas em reabilitação, pacientes e cuidadores, em três diferentes áreas do centro, ou seja, um Laboratório de Marcha e Movimento, um Laboratório de Órteses e Próteses e uma Área de Terapia Ocupacional, que são os locais diretamente relacionados com o tratamento de reabilitação por meio de um dispositivo ortopédico ou protético.

Através de a minha pesquisa eu ter analisado as relações complexas e materialmente heterogêneas que são configuradas entre corpo, prótese, e pessoa em todas as fases do processo de reabilitação. Através de extratos etnográficos, minha tese tenta fazer sentido da multiplicidade de reconfigurações ontológicas e dis/articulações que acontecem durante a reabilitação, pressionando sobre a importância de atender a contextualização e as especificidades das categorias. Deficiência e Reabilitação, defendo, precisam ser analisadas e repensadas através de metodologias alternativas capazes de mostrar o que é viver com uma deficiência significa, na verdade, em práticas cotidianas, bem como de incorporar entendimentos mais flexíveis e politicamente, inclusive de deficiência e reabilitação.

Palavras-chave: Reabilitação. Prótese. Corpo.



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# **INTRODUCTION:**

## **SITUATING REHABILITATION PRACTICES**

### **Tales on Ethnographic Research**

Orthotic and prosthetic devices are at the core of the clinical rehabilitation management of patients with neuromusculoskeletal disorders and amputees. ‘*Orthotics*’, on the one hand, are orthopaedic appliances designed to assist the function of the patient’s body and/or to affect its morphological structure. These devices are widely used in the treatment of patients with neuromusculoskeletal disorders in conjunction with other therapeutic interventions, including the surgical and the pharmacological ones. ‘*Prosthetics*’, on the other, are artificial devices designed to replace or augment a missing part of the body. These are used for therapeutic, functional and/or cosmetic purposes in patients with congenital limb absence or acquired limb loss.

Drawing on empirical material from an ethnography I conducted in a Mexican rehabilitation centre<sup>1</sup>, in this thesis I present an exploration of the clinical rehabilitation management practices around those patients, in order to show the multiplicity of relations that are developed between patients and prostheses

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<sup>1</sup> Although the ethnography I present here was developed mainly in this rehabilitation centre, in this thesis I have also included some fieldwork excerpts from ethnographic work conducted in another rehabilitation institute in Mexico.

throughout such process as well as their mutual transformations and reconfigurations. The ethnographic stories I present come from three different areas within the rehabilitation centre, namely: the Gait and Movement Laboratory (GMLab), the Orthotics and Prosthetics Laboratory (OPLab), and the Occupational Therapy Area (OTA). In my research I follow the daily practices of a rehabilitation medicine doctor, a biomedical engineer and a dozen of prosthetists and occupational therapists working with patients in their rehabilitation process.

On the basis of a material semiotics intellectual tradition and by following the patients' rehabilitation process, in my research I show how patients and prostheses *come into being* 'in relation' and mutually transform and reconfigure one another throughout the rehabilitation process, this as opposed to the assumption of 'patient' and 'prosthesis' as entities that precede the rehabilitation process. In addition, I investigate the variety of embodied, material and subjective relations that emerge between patients and prostheses during such process. Finally, my research problematises the notions of 'rehabilitation' and 'disability' by showing how they are done within clinical rehabilitation management practices involving orthotic and prosthetic devices, as opposed to them as categories independent of the rehabilitation process.

Two particular origins and personal histories are behind this research; the first one goes back several years, to the time when I was working as a psychologist at a therapy unit for children and adolescents diagnosed with different sorts of medical conditions that result in physical and/or mental impairments. During my time there, I worked with children with a wide variety of diagnoses, from mild Down syndrome and cerebral palsies to severe neuromotor and neurobehavioural development

disorders. My work included several activities, which I carried out in coordination with a group of trained speech, physical and occupational therapists. Besides working with the children, I conducted periodic meetings with their families, in order to provide advice and guidance related to living with the particular condition and managing the difficulties that it brings.

At the Therapy unit, the discourse that prevailed was one in which references to categories such as *abnormality*, *disability* and *rehabilitation* were present on an everyday basis. Furthermore, these categories were permanently reinforced through the therapists' common objectives of providing every child with the abilities to live a life as 'normal' and 'independent' as possible, as well as of creating a 'more inclusive' family and social environments for him or her.

I felt, however, that the idea of creating a more inclusive environment for the children on the basis of labelling them as disabled and in need of normalisation was not actually very inclusive. On the one hand, there was always a tension between the therapists' reference to the children as disabled or with a disability, and what 'being disabled'/'having a disability' really meant for those children in their everyday life, in their daily practices and routines. On the other hand, evaluating children's capacities and abilities with reference to a 'normal', standard subject and working towards achieving those standards meant, paradoxically, that the children at the Therapy unit would always be in a position of disadvantage and of difference.

What did it really make those children disabled?, was it being diagnosed with a particular condition?, was it wearing an orthotic device?, was it a missing limb?... Looking closely, one could not affirm that these situations *per se* made those children disabled; rather, disability always manifested in relation to things that they could do

or could not do, to activities, to practices. But then, what did this mean for them and, in general, for people who are considered to be disabled?, what were the politics of it?, how to make sense of it? These and other questions made me focus, in this research, on an issue related to disability and rehabilitation.

The second personal history behind this work has to do with my academic background in psychology, some medical training and my contact with the sociological literature. For a long time, I have been deeply interested in the intersections between these disciplinary fields as well as in their joint analytical and explicative possibilities<sup>2</sup>.

A wide diversity of issues cross and interrelate the medical, the psychological and the sociological, making more and more visible their entanglements, the multiple interferences that resonate between them and a myriad questions that such entanglements and interferences make. In clinical settings, one such issue has to do with the series of relationships that develop between patients, their bodies and the artefacts they relate to, as well as with the way in which these relations are being continually redone and reconfigured.

With those histories in background, in this thesis I move between and within the issues of the social, material and subjective relations that unfold in clinical rehabilitation settings between patients and prostheses, on the one hand, and the issues of disability and rehabilitation, on the other. In my study I look closely into the clinical practices carried out by a biomedical engineer, a rehabilitation doctor, and a

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<sup>2</sup> Using some modernist categories, they could be said to attend to the physical, the mental and the social spheres, respectively, or, put in another way (but equally modernist), to the body, the individual and the society.

dozen of orthotists/prosthetists and occupational therapists involved in the rehabilitation process of patients who have been prescribed an orthotic or prosthetic device. My purpose is to explore and reflect on the different ways in which patients and prostheses, as well as disability and rehabilitation are *enacted* in everyday clinical rehabilitation practices and how particular ontologies of them get configured.

Focusing on the field of rehabilitation medicine around orthotic and prosthetic devices constitutes an excellent case study because orthotics and prosthetics are powerful material-semiotic devices that allow us to destabilise many of the modernist distinctions between categories such as body/person, human/machine, natural/artificial, self/other. In addition, orthotics and prosthetics mobilise a variety of material, social and subjective practices and discourses around disability and rehabilitation which allow us to look deeply into the politics of these notions and their involvement into the patient's rehabilitation process.

In my thesis I do not attempt to conceptualise clinical rehabilitation management practices as a whole because, as Berg and Mol (1998) have argued in relation to other sorts of clinical practices, rehabilitation medicine is not a homogeneous entity. Neither do I want to talk about them by making reference to a 'Mexican context', or even worse, to a 'Mexican reality' (as if there was one!). Following what technoscience scholars have persistently shown us, I take it that there is not such a thing as singular and homogeneous practices –contexts, realities or whatever– which can be generalised and said to happen exactly in the same way everywhere. Rather, practices, –all sorts of them, including those related to clinical rehabilitation management– are both, 'situated' and the result of specific arrangements of particular heterogeneous materials (see e.g. Callon, 1986; Law, 1994;

Haraway, 1991b; Mol, 2002). By adopting this framework for studying rehabilitation practices around orthotic and prosthetic devices, instead of asking what a body *is*, or trying to conceptualise what ‘the natural’ and ‘the artificial’ are, and to provide clear-cut distinctions between them, my work pays attention to the relations between natural-artificial, subject-object, body-artefact, and other epistemological dichotomies that *emerge in* and *within* clinical rehabilitation management practices, how they come into being, and the way they are performed in everyday ordinary life.

### **How the ethnography unfolded**

The early stages of this research involved an exploration of possible sites of study where I could carry out my ethnography. I was interested in finding a site where I could observe a more or less complete picture involving prostheses, patients and their relations, from the design and manufacture of the devices to the patient’s day-to-day experience of living with a prosthesis. With this in mind, I made some investigations of research institutes, health centres, and universities in Mexico working on areas relevant to Orthotics and Prosthetics. This resulted in a period of ‘*preliminary ethnographic fieldwork*’ which included several visits to those places and interviews to the people involved, with the purpose of exploring the practices, subjects, spaces, artefacts, etc. that could be relevant for my study, the variety of research possibilities that every site could offer me and, very importantly, the ethical, political, institutional and other concerns that could arise from my ethnography.

During the preliminary fieldwork I visited five possible study-sites which included three university research departments of mechatronic and electric engineering and two medical centres of rehabilitation; while visiting those places I conducted interviews and made *in-situ* observations. After a couple of months of

looking at, talking, manipulating, inclusions, exclusions and decision-making, I focused my empirical analysis on one of the rehabilitation centres. Throughout another two further periods of fieldwork, I focused my ethnography on three different areas within the centre: the Gait and Movement Laboratory, the Orthotics and Prosthetics Laboratory, and the Occupational Therapy Area.

During my ethnography I did *in-situ* observations of the instrumental practices of both, rehabilitation specialists and patients. I also conducted several formal and informal interviews with patients, patient's relatives, orthotists, occupational therapists a rehabilitation doctor and a biomedical engineer. The formal interviews were non-structured, one-to-one, and programmed for a maximum of an hour; for them, I followed a general guide of the issues I was interested in addressing. At the beginning of my interviews I stated the aims of my work and explained the interviewees the topics that we would be exploring during our conversation, how I would use the information provided and who would have access to it. The health professionals I was working with were more familiar with my research, since they have been involved from the beginning of my ethnographic fieldwork and we have had several conversations about it; this wasn't the case, however, for parents or patients themselves, because of this I put special attention while explaining the purpose of my research and the use the information provided.

For the informal interviews, rather than following a specific written guide, I took the practices being done by my 'objects of observation' as a background for the conversation. All the interviews were conducted in Spanish and latter translated into English. Throughout them I also took some written notes registering my observations in relation to the general situation of interaction, the context, the non-verbal



communication, as well as with respect to my own position as ‘the’ interviewer and my role as a researcher-ethnographer. In addition to in-situ observations and interviews, I followed specific *stories* of ‘people’ (patients and rehabilitation specialists) and ‘artefacts’ (mainly orthotics and prosthetics) ‘*in-the-making*’, and analysed a diverse range of written documents, including medical formats, prescriptions, orthotics and prosthetics catalogues and related webpages. My ethnographic records took the form of written field-notes, digital photographs and digital audio-records.

During my ethnography, I had a very active involvement in the practices I was observing, even having my own gait study done, helping to ‘prepare’ the patients for undergoing a gait analysis, casting plaster moulds for the manufacture of prostheses and ‘taking’ plaster casts of some patients’ body parts, practices that I describe and analyse throughout this thesis.

### **Exploring the Rehabilitation Centre and its Laboratories**

January 17<sup>3</sup>. It’s 7:15am and I have just arrived at the Centre... I walk all the way down the long corridor towards the coffee machine, holding on my right hand my ‘ethnographer’s handbag’, as I call it, which contains all my ethnographic equipment: notebook, pen, voice-recorder, camera and identity card. The colourful scenario of the Centre contrasts with the usually omnipresent white of medical institutions. The building and furniture are all full of colours in bright shades; blue, green, yellow, red, orange, purple and

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<sup>3</sup> All of the field note excerpts included in this thesis were originally written in both, Spanish and English. I have tried to keep their full translations into English as close to their original meaning as possible.

pink cover the walls, the floor, the chairs and the desks; even members of staff's coats are colourful: yellow for administrative staff, blue for occupational and physical therapists, beige for orthotists, purple for students. Somehow all those colours transform the atmosphere and seem to fill it with energy, optimism and hope.

Above, there is an excerpt of my field notes; I conducted my ethnography here, in this colourful institution, a child rehabilitation centre in Mexico which offers specialised medical treatment and rehabilitation to children suffering from different neuro-musculoskeletal disorders, from birth to 18 years of age. Neuro-musculoskeletal disorders refer to a variety of conditions which affect the nerves that control the body's voluntary muscles, when those nerves become unhealthy, communication between the nervous system and the voluntary muscles breaks down, resulting in the damage and atrophy or wasting away of the muscles as well as bones, cartilage and joints of the body; in consequence, this can lead to aches, pains, cramps, twitching, joint and movement problems, these disorders might also affect the person's heart function and ability to breathe (MedLinePlus, 2009). Examples of neuro-musculoskeletal disorders include multiple sclerosis, muscular dystrophy, Duchenne's syndrome, etc. Although, the majority of these disorders have a genetic origin, they may also have other origins (e.g. as a result of an immune system disorder); since most of them have no cure, treatment is oriented towards the improvement of symptoms (MedLinePlus, 2009).

The centre is located in the State of Mexico, the region with the largest concentration of children with neuro-musculoskeletal diseases in the country (CRIT, 2007); it offers specialised medical services at low cost, to children from deprived

areas, providing attention to more than ten thousand children annually. In addition, the centre is also involved in academic teaching and research activities offering, in conjunction with the state university, degree programs in Occupational and Physical Therapy, as well as conducting epidemiological research on neuro-musculoskeletal diseases.

Fully equipped with state-of-the-art technology, the centre offers a variety of services, among them, *diagnosis* and *treatment* are two essential components<sup>4</sup>, and they involve the participation and coordination of different diagnostic laboratories and therapy areas of the centre. The work of diagnosis requires the collaboration of several laboratories and it involves different sorts of medical examinations, including clinical tests, imaging, electro-neural exams, gait and audiometry tests, etc. The treatment or therapy areas at the centre are four, namely: early stimulation and neural therapy, language therapy, physical therapy and occupational therapy<sup>5</sup>. In addition,

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<sup>4</sup> Other services available include: preventive medicine (offering assessment in relation to genetic testing, familiar planning, etc.), school for parents (addressing the role of the family in the child's rehabilitation process, carrying out periodical group information sessions, organising seminars and providing counselling to parents), and social integration activities (working towards "the incorporation of a person with a disability to society" (CRIT, 2007), offering counselling on family, school and labour integration).

<sup>5</sup> The area of *Early stimulation and neural-therapy* is focused on stimulating the development of children at high-risk of developing any kind of brain injury, for the improvement of their intellectual and physical development). *Language therapy* works towards the development and improvement of the child's abilities of verbal and non-verbal communication). *Physical therapy* focuses on the improvement of the child's movement and balance in order to achieve the better performance of his/her physical and functional activities (this area is sub-divided in: electrotherapy, mechanotherapy, hydrotherapy, cryotherapy, and fluidotherapy). *Occupational therapy* is focused

there is also an area specialised on the design, manufacture and fitting of orthotic and prosthetic devices for patients who require them as part of their rehabilitation process (CRIT, 2007).

Medical attention is structured around six different specialised ‘clinics’ which are organised according to a disease classification<sup>6</sup>; each of these clinics is coordinated by a rehabilitation specialist. Supporting the work of the clinics there is an area of “*interconsulting doctors*”, as they are called at the centre (the original term in Spanish is “*médicos interconsultantes*”), specialists from various medical backgrounds apart of that of rehabilitation medicine who also take part in the child’s rehabilitation process. Among the team of interconsulting doctors there are paediatricians, orthopaedists, urologists, geneticists, ophthalmologists, psychiatrists, dental surgeons, nutritionists, anaesthetists and clinical psychologists. Finally, but equally important to the functioning of this rehabilitation institution, a ‘computerised administration system of clinical information’, which stores every single patient’s medical records and follow-ups reports, is also a vital element in the rehabilitation process; the data from this system is also used for epidemiological research.

The centre refers to its rehabilitation approach as one based on a ‘medical model of integrated rehabilitation’ in which not only patients but also their families receive

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on improving the child’s functional independence for carrying out his/her ‘activities of daily living’ (e.g. dressing, bathing, eating, moving around, etc.), through the use of functional adaptations and/or orthotic devices (CRIT, 2007).

<sup>6</sup> The ‘clinics’ are: 1-Infantile Cerebral Palsy and Cerebral Injury, 2-Spina Bifida & Spinal Cord Injury, 3-Neuromuscular Diseases, 4-Amputees & Osteoarthropathies, 5-Congenital and Genetic Diseases, and 6-Early Stimulation & Neurotherapy.

rehabilitation treatment, for this reason, the rehabilitation process involves working with the patient's family as much as with the patient his/herself (CRIT, 2007). Following this integrative approach, the child's rehabilitation process is supported by an interdisciplinary medical team that works with the aim of achieving the patient's reinsertion into the family, the school, the work-place and the society, as the institute states it (CRIT, 2007).

### **The patient's rehabilitation trajectory**

As in every medical institution, here too, standardised management mechanisms of medical attention are in place and, at the centre, all patients must follow a determined trajectory in the rehabilitation process; in order to describe it briefly, in what follows I assume for a while the idea of a linear, tidy and organised patient's rehabilitation trajectory.

Such trajectory starts with the first visit to the centre. Many patients –their relatives, to be more precise– have previously arranged an appointment by telephone; for those who have not, an appointment is scheduled for the same or next day. Usually, patients who come here have already been diagnosed with a certain neuro-musculoskeletal disorder, either as newborns or in early childhood, and they have been referred at the centre in order to receive treatment. Patients who have been diagnosed with a disease that falls outside of the neuro-musculoskeletal category are provided with information about the different institutions where they can be treated.

In order to receive medical treatment, the patient has to go through an entry process that includes a series of medical, psychological and socio-economical examinations. All the data provided is then stored in the computerised database as a part of the patient's personal records. Throughout the rehabilitation process, this file

will become a crucial tool for everyone involved in it (patients, doctors, therapists, etc.) since it will be used as a 'follow-up tool', containing detailed data related to appointments (including dates, times and therapy areas), patient's medical records, diagnoses, treatments, therapies, etc.; the data collected will be also used for epidemiological research purposes.

Following this entry process, the patient is located in one of the six specialised *clinics* (which I have already mentioned) and assigned a '*medical companion*', a rehabilitation specialist who will follow his/her rehabilitation treatment from beginning to end. At each particular clinic, the medical staff will carry out diverse tests and other examinations in order to detect the different issues to be dealt with. In addition, several appointments with the team of 'interconsulting doctors' will be also scheduled.

The rehabilitation sessions start by designing a rehabilitation program that is specific for each therapy area and defined by the therapists in charge of the patient, these therapists will set different 'practical' objectives to be achieved in a certain period of time. In the same way, the medical companion will establish a general prognosis of social integration and elaborate a rehabilitation plan. When different treatment alternatives are available, these will be discussed with the patient and/or the patient's relatives in order to decide, with the support of the medical companion and the therapists, the most convenient of them. In deciding a treatment, different aspects, in addition to medical considerations, are taken into account, for example, issues related to the context in which the patient is immersed, family environment, schooling, mobility, etc.

With a full rehabilitation program designed the treatment starts. Throughout the process, the medical companion will hold periodic meetings with the rest of the medical team in charge of the patient, in order to assess the patient's progress. Also during these meetings the objectives of the therapies will be reviewed and, when necessary, reset. Later on, when the rehabilitation program is nearly concluded, the therapists will decide to discharge the patient or to continue with the rehabilitation according to the results of his/her progress assessment, which is materialised in the form of a series of reports included in the patient's medical records. When the general program has been completed and the patient's improvement assessed, s/he is finally discharged from the centre.

As I said before, this linear, tidy version of events is how the treatment process is 'officially' organised at the centre; however, as I show throughout this thesis, *in practice*, the enactment of such a process is performed in a very different way, becoming messy and many times very frustrating. As we might expect, if we look at them a bit closer all these apparently stabilised and completely defined stages become less clear, overlapping one another, and asking from the collectives involved to 'break' with such a linearity, breakings that sometimes are acknowledged with a bit of shame –by using for example the phrase: “something went wrong” –, and that some other times are just hidden away along with a sense of guilt and failure.

For this research, I focused my ethnographic work on three different areas of the rehabilitation centre: the Gait and Movement Laboratory, the Orthotics and Prosthetics Laboratory and the Occupational Therapy Area. For most of the patients, after they have been located in one of the specialised clinics, in order to structure the rehabilitation program, their medical companion will request a gait assessment which

will be carried out at the Gait and Movement Laboratory (GMLab). The GMLab is a diagnostic and evaluation area for the assessment of the patient's gait. Gait assessments involve the performing of a series of clinical examinations and gait analyses, at the centre, these are carried out by a specialist in Rehabilitation Medicine (RMD) and a Biomedical Engineer (BE). The gait assessment starts with an exploration of the patient's lower limbs, measuring them, palpating them, observing them, this is done by the RMD. After the clinical examination both, the RMD and the BE carry out the gait analysis. These kinds of assessments are used for identifying anomalies in the patient's gait that might put at risk the function of one or more body organs (Fish and Nielsen, 1993). The results of the clinical examination and the gait analysis are then used for determining the most convenient treatment for the patient. Rehabilitation management options include surgical procedures, pharmacological therapy and/or the prescription of an orthotic/prosthetic device or any other kind of rehabilitation aid.

When an orthotic/prosthetic device has been prescribed, the patient will be sent to the Orthotics and Prosthetics Laboratory (OPLab), which is where the design and manufacture of the devices take place. Ten orthotists/prosthetists work at the OPLab; week after week, each of them is assigned a certain number of patients whom they take plaster casts which are then used for the manufacture of the orthotic or prosthetic device. Every Monday, more than a hundred casts are taken from the patients' limbs. Then, on Fridays, patients attend a fitting session in which they –and their relatives– will learn how to put on the device, how to use it, and other technicalities. Patients will be asked to come back from time to time for assessment, this in order to make some adjustments to the device or to change it for a new one.



But for the patients, this is not the end of the story. Incorporating an orthotic or prosthetic device into one's everyday life is not an easy task; it requires practice, sometimes, a lot of it; this is where the Occupational Therapy Area (OTA) comes into the picture. At OTA, patients learn how to use their prosthesis on their daily living. Through one-to-one therapies, patients and occupational therapists work together on developing the former's skills and abilities for interacting with their everyday material environment and, in turn, improving their social integration into their family and their community. Here, patients practice over and over again all sorts of *activities of daily living*, as they are called among rehabilitation specialists, activities that include dressing and undressing, eating, bathing, etc. Throughout the day, patients are seen moving around the room while wearing their prostheses, practicing their gait on different floor textures, different inclinations, etc. In addition, occupational therapists will dedicate some time to provide advice on viable physical adaptations to the patient's quotidian spaces (e.g. the patient's house, furniture, etc.), in order to make his/her interactions with the material environment easier and smoother and to provide him/her with as much independence as possible in everyday life. Finally, other activities carried out by the occupational therapists at OTA include the design and manufacture of upper-limb orthotics, as well as the design of special equipment for improving the patient's posture and preventing the development or worsening of injuries and other related problems (e.g. special wheelchair-seats).

During my ethnographic research I closely followed the patient's trajectory throughout these three places. By choosing those particular areas, my intention was to be able to follow the whole '*prosthetic experience*' process –as I call it–, from the very first patient-prosthesis contact to the day-to-day 'living-with-a-prosthesis' situation. In this way, at the GMLab, I followed the diagnostic and evaluation work

that results in the prescription of an orthotic/prosthetic device. Then, at the OPLab, I followed the manufacturing and fitting of the device and, finally, at OTA, I followed the rehabilitation practices around everyday-living with prostheses.

## 1. HOW TO TALK ABOUT PATIENTS, PROSTHESES AND REHABILITATION PRACTICES?

During my fieldwork at the rehabilitation centre, I observed a wide variety of practices and witnessed a multiplicity of encounters between doctors, orthotists, occupational therapists, patients and all sorts of machines. For each of the labs I explored, I had to learn a whole new language around disability and rehabilitation management, including the names –and nicknames– of endless medical conditions, technical equipment and clinical protocols. I learnt that a mother might mistake the first symptoms of her son’s Duchenne’s syndrome for him being careless while running around and falling down; that during a gait assessment some children become frightened when they have to be connected to the telemetric unit; I learnt that, among orthotists, one of the most appreciated tools at the workshop is a “*magnum*”, which is how they call the transarticular screws used in long orthoses; and that wearing a prosthetic device can become something *cool* if the prosthesis is creatively designed.

While doing my ethnography, I followed dozens of patients at different stages in their rehabilitation program and looked into the diverse examinations they underwent. I also watched the medical team in charge of those patients both, while working with them or when discussing particular cases among themselves. And, some other times it was an orthotic or prosthetic device what I was coming after. During my fieldwork, the stories that were unfolding before my eyes were not exclusively about people, but also about objects, they were not only about the patients’ journey throughout the

rehabilitation process, but also, about that of the prostheses. What to make of what I was witnessing during the long days at the centre?, how to think and talk about what was happening there?, what theoretical resources would help me to make sense of such practices?. In order to make sense of it, for my ethnography I turned to some of the contributions made from a variety of intellectual traditions including Disability Studies, Science and Technology Studies and Feminist Technoscience Studies<sup>7</sup>.

### *Disability Studies*<sup>8</sup>

The emergence of the Disability Rights movement, during the latter half of the twentieth century, was what detonated the discussions about the issue of Disability which have continued until today. This movement brought into focus simultaneously the medical, social, moral, economic and political dimensions of disability,

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<sup>7</sup> The way we tell our stories and account for the world, does contribute to the way we make such world and reality. This reasoning also applies to how we approach the phenomena we attempt to account for, as well as to the way we produce and inscribe knowledge about such phenomena. Writing about the world, especially in science, is not an innocent activity at all; how we present our ‘data’ requires a great deal of reflection and awareness about the fact that our account is only one way, from among many other possibilities, of approaching to, and talking about, the world we are actively involved in knowing. For the case of this thesis, my intention while writing the present chapter has not been that of reproducing the modernist divide between theory and practice —the chapters that follow are an attempt to make both simultaneously—; rather than that, after much reflection, I considered it necessary to provide the reader with an exploration of the theoretical perspectives and approaches that have informed my work, so that s/he can have a general framework of reference about the past and current discussions and debates underlying this work.

<sup>8</sup> An extended analysis about Disability Studies was presented in my MA dissertation (see: Morales-Navarro, 2005).

questioning the way in which, up until then, disability and disabled people were socially portrayed and dealt with.

Nowadays, Disability has become a central topic of debate and controversy among a wide range of sectors, including disabled people's groups, health-care professionals, policy-makers, politicians and activists. The inclusion of disabled people into the community, the management of their health-care and the design of disability-related policies are among the issues that have been addressed, incorporating the participation of an extensive variety of groups.

Due to the huge impact that this issue has had in all spheres of contemporary society throughout the years, it has also attracted increasing attention from social science scholars, particularly in countries such as USA, Canada, Great Britain, Australia and New Zealand. Within the medical and social sciences issues related to disability have been extensively analysed from a broad range of individual disciplines, such as medicine, philosophy, sociology, psychology and history (Oliver, 1996). However, the study of Disability as an academic subject is of relatively recent origin. In the last two decades there has been a rise of cross-disciplinary contributions to the analysis an understanding of Disability, conforming a vast literature on the subject and giving shape to a body of work known as *Disability Studies*.

Scholars from the field of Disability Studies focus their efforts on the development of a critical inquiry about Disability considering not only its medical aspects, but also the social, political and environmental factors related to it. They are concerned about the understanding of disability, its implications and management, and work towards a more inclusive society and against marginalisation, segregation and social oppression of disabled people. Disability Studies academics have often

approached to diverse controversial issues such as the meaning of disability, the right to live or die (Swain, *et al*, 2003), or questions such as who disabled people are and who should speak for them (Bjarnason, 2004). In addition to addressing these sorts of inquiries, the debates about Disability have led other scholars to put into question the very notion of disability, by problematising both, what we think of as a person, as well as the distinctions between ‘normality/abnormality’ and ability/disability.

The literature about disability makes reference to two main models that have dominated the understanding of disability, these are: the ‘Individual or Medical Model of Disability’ and the ‘Social Model of Disability’. These models are associated with different periods of social, political and economic transformations, each of them are linked with a specific organisation, management of, and practices around disability and disabled people; it is important to note that these models are not particular ‘theories of disability’ (Oliver, 2004), rather, they are better thought of as two different perspectives or paradigms of it.

#### Individual or Medical Model of Disability

The historical legacy of the representation of disability as a personal tragedy has contributed to the maintenance of a dominant paradigm which addresses disability in terms of disease, illness or abnormality. From such perspective, disability is treated as a medical condition located exclusively in an individual’s body or mind (Johnstone, 1998; Swain, *et al*, 2003; ODI, 2003). This individual or medical model relies primarily on a bio-physiological definition of ‘normality’, and focuses exclusively on a person’s impairments and the way in which they cause some degree of functional limitation or incapacity (Swain, *et al*, 2003), this is, it looks at bodily ‘abnormality’, disorder or deficiency (Barnes, *et al*, 1999; Bjarnason, 2004).

Within such a framework, disabilities are evaluated in quantitative terms according to a certain set of parameters<sup>9</sup>; this is done through the measurement of the individual's functional restrictions against a 'normal' standard, in this way, the individual's assumed 'abnormality' is then translated into a determined level of incapacity or impairment. The quantitative measurement of an individual's degree of incapacity is a highly complex process, since "it involves body structures and functions as well as a person's activities and the environment [...] in which the individual's functioning is being assessed" (Catterji, *et al*, 1999:397). In addition, there is no consensus in relation to the kind of variables that should be considered in the measurement of disability; because of this, each approach uses particular tools and instruments that take into account different variables<sup>10</sup>. According to the World Health Organization, a person shall be considered to be disabled only if he or she has a 'severe' and 'prolonged' mental or physical disability (Joslyn, 1999; ODI, 2003).

The individual/medical model equates disability with illness and emphasises the status of the disabled person as a patient. This model is grounded in the principle of 'normalisation', focusing its attention on returning the patient to a bodily 'wholeness' (Johnstone, 1998), and seeking to provide curative and rehabilitative strategies for

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<sup>9</sup> These parameters include the type of impairment, the level of severity, the number of an individual's impairments, the extent of an individual's limitations for performing *Basic Activities of Daily Living* (BADL) and, the duration of such limitations. *Basic Activities of Daily Living* refer to the abilities of perceiving, thinking and remembering, feeding and dressing oneself, hearing and speaking so as to understand and to be understood in a quiet setting by another person, seeing and walking, and eliminating (bowel or bladder functions).

<sup>10</sup> These variables include: symptomatology, Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), cognitive functioning, well-being and quality of life (Catterji, *et al*, 1999).

disabled people with the involvement of an increasing number of health-care professionals (Barnes, *et al*, 1999); such rehabilitation schemes are designed in an effort to ‘change the individual to fit in society’. In this context, an individual with impairments becomes a ‘passive-object’ of professional attention, and it is the ‘experts’ who define his needs and the way in which they should be satisfied.

It is precisely the focus on an individual’s functional incapacity what constitutes the basis of an understanding of disability as a personal tragedy which, in consequence, results in the person’s portrayal as a victim in need of care and dependent on others (Barnes, *et al*, 1999).

Although widely extended, the assumptions of the individual/medical approach to disability present a series of problems. In addition to the complexity of the measurement process of the individual’s degree of incapacity as well as the lack of consensus about the variables that should be considered (both of which have been already mentioned above), this approach does not take into account the influence of social and environmental factors in its understanding of disability. Instead, from this perspective the environment is seen as fixed and neutral (Barnes, *et al*, 1999), while disability is understood as a health condition produced entirely as a consequence of a person’s impairment and, in this sense, located exclusively in a particular individual, who is, in turn, defined as defective and abnormal (ODI, 2003); in other words, disability is explained as an effect, rather than as a process.

In addition, this model “projects a dualism which tends to categorise the able-bodied as somehow better or superior to people with disabilities” (Johnstone, 1998:15), a dualism which portrays disabled people as functioning at a lower rate than an able-bodied person. According to Johnstone (1998), an able-bodied is considered



to fulfil certain criteria that make it ‘able’, it is said to be ‘normal, good, fit, and independent’; a disabled-bodied, in contrast, is considered as ‘abnormal, defective, unfit and dependant’. Such assumptions are then used to justify the politics of doing something ‘to’ disabled people rather than doing something ‘with’ them (Johnstone, 1998).

Other problems that the medical model presents have to do with its reductionist approach to disability, considering this as uniform and homogenous<sup>11</sup>; with the question of how to distinguish a set of ‘daily activities’ that can be defined as normal while evaluating the individual’s degree of incapacity (Burchardt, 2004) and, what is more, how to trace a boundary between ‘normality’ and ‘abnormality’ (Barnes, *et al*, 1999; Morales-Navarro, 2005).

A final critique worth to be made here relates to the issue of rehabilitation and assistive devices. As mentioned before, the medical model of disability focuses its efforts on the person’s rehabilitation; this is, on his return to a ‘normal’ standard. Rehabilitation strategies might include the incorporation of assistive devices and other technical aids used as substitutes of missing organs and/or functions of a particular body, in order to ‘compensate’, to a certain degree, the lost or diminished abilities for the performance of the natural functions of a ‘normal, competent’ body; those artefacts or ‘prostheses’ are supposed to bring disabled people closer to ‘normality’ (Moser, 2000).

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<sup>11</sup> Such an assumption results in the exclusion of disabled people whose daily activities and experiences do not match with the pre-established and standardised parameters considered by the medical tools of disability’s evaluation (for example, the ‘Activities of Daily Living’ (ADL) format, a questionnaire commonly used in the evaluation and classification of disabilities) (Joslyn, 1999).

However, as Moser points out, such practices of rehabilitation or ‘enabling practices’, paradoxically implicate simultaneous ‘disabling practices’, in the sense that, if ability refers to ‘independence and autonomy’, a disabled subject who has incorporated enabling material artefacts, becomes once again ‘dependent’, but now in relation to such technologies and, therefore, once again disabled, in Moser’s words: “[t]he dependence has simply been relocated” (Moser, 2000:205). In the same context, following the medical model, disabled people are constituted as dependent to assistive technological devices in their interaction with the able-bodies’ world. Another paradox can be identified, however, in the sense that such a dependency is simultaneously produced in the opposite way; this is, abled-bodies become dependent to the very same technologies in order to interact with a disabled world (Moser, 2000).

In conclusion, the individual or medical model results very reductionist in its understanding of disability, considering this as a pathology located in an individual’s body which, in consequence, results in the necessity for disabled people to be normalised, in order to get as close as possible to being autonomous, independent, ‘able’ subjects (see: Morales-Navarro, 2005).

### Social Model of Disability

The decades of 1960s and 1970s witnessed the emergence of several movements around the world related to human rights, including the black movement, the women’s movement, the peace movement and the disabled people’s movement. It was this last movement, along with the publication of *Fundamental Principles of Disability* (UPIAS, 1976), and Mike Oliver’s academic contributions to the study of disability and society, that formed the basis of a ‘social model of disability’, a

response and an alternative to the individual/medical model, which would highlight the importance of taking into account non-medical criteria in the analysis of disability.

In 1976, the *Union of the Physically Impaired Against Segregation* (UPIAS), the first political coalition of disabled people in the United Kingdom, published *Fundamental Principles of Disability*, a monograph in which, based on their personal experiences, they exposed their own definitions of disability (Barnes, *et al*, 1999; Finkelstein, 2004). UPIAS claimed that people with impairments become disabled when they are excluded from society and prevented from a full participation in the life of the community and that, rather than a medical condition, disability is a product of social oppression.

UPIAS argued against a medical definition of disability pointing out that, although the notion of ‘impairment’ is more related to an individual-medical condition, ‘disability’ must be explained in relation to the disadvantages and restrictions caused by a society which excludes people with impairments from mainstream activities (UPIAS, 1976). In this sense, whereas ‘impairment’ might be seen as an individual’s attribute, ‘disability’ is “the outcome of an oppressive relationship between people with [...] impairments and the rest of society” (Finkelstein, 1980:47).

During those years the World Health Organisation (WHO) proposed the definitions of the concepts of impairment, disability and handicap that are still used today. According to WHO’s *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) —the first major classification system to focus specifically on disability—, ‘Impairment’ is defined as “any loss or abnormality of psychological, physiological or anatomical structure or function” (WHO, 1980:27). ‘Disability’ is

understood as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980:28). Finally, ‘Handicap’ is defined as “a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal for that individual” (WHO, 1980:29).

According to the ICIDH’s classification, disability would be the result of a linear process that begins with impairment, while handicap would be the product of disability in an individual’s social day-to-day setting. In other words, it is the interaction between a person’s impairment and the social and physical environment what might produce a profile of disadvantage (or advantage) for different individuals and, in consequence, this might result in a disability (Burchardt, 2004). Critics of the ICIDH’s classification, however, argued that this has been established by non-disabled people speaking about disabled people and that disability shouldn’t be equated with illness, simply, because it is possible to be both healthy and disabled (Joslyn, 1999).

As a response to the definitions proposed by WHO, *Disabled People’s International* (DPI), a British disabled people’s organisation, proposed its own definitions of impairment and disability, referring to ‘impairment’ as a functional limitation within the individual, and to ‘disability’ as the loss or limitation of opportunities to take part in the life of the community in the same way than other people do due to physical or social barriers imposed by society (DPI, 1982; in: Johnstone, 1998). Following this line of argumentation, disability is not a condition that a person ‘has’, but something that society ‘does’ to the person.

The assumptions that disability is a social construct created by ability-oriented environments and that the disadvantages experienced by people with impairments are related to activities associated with social roles rather than to medically tested limitations (ODI, 2003; Barnes and Mercer, 2004) would be at the core of the social model of disability<sup>12</sup>.

From this perspective, even though impairment has an objective reality attached to an individual's body or mind, 'disability' is strongly related to society's failure to understand and fulfil the particular needs of the so called disabled people (Barnes and Mercer, 2004; Bjarnason, 2004). Rather than focusing exclusively on the medical aspects, this model seeks to provide a way of conceptualising disability which emphasises the social, economic, physical and environmental barriers that people with impairments are faced with on a daily basis (Burchardt, 2004; Joslyn, 1999)<sup>13</sup>; to say it another way, the social approach is interested in the 'collective experience of disablement', rather than in the 'personal experience of impairment' (Oliver, 1990, 2004).

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<sup>12</sup> This model formally coined its name in 1983, with the publication of Oliver's book *Social Work with Disabled People* (see: Oliver, 1983).

<sup>13</sup> It is mainly focused on three kinds of factors: personal factors (e.g., age, gender, cultural identity, life history, etc.), environmental factors (the social context in which the person lives, e.g., region, integration policies, programs, family circumstances, income, education, employment, housing, transport, built environment, etc.) and life habits (the person's daily activities) (Barnes, *et al*, 1999; Barnes and Mercer, 2004). In addition, it is also highly concerned about the individual's inherent dignity as a human being, stating that equality does not mean treating all individuals in the same way; rather, it means recognizing and accommodating to their differences (ODI, 2003).

From this perspective, making a distinction between the notions of ‘impairment’ and ‘disability’ is crucial. ‘Impairment’ is understood as a particular condition of an person’s body or mind; while ‘disability’ is explained in terms of the person’s loss or limitation of opportunities to actively participate in the life of the community in the same way than the rest of the people who conform such a community (Barnes, *et al*, 1999; Thomas, 2004).

In contrast to the individual/medical model of disability, which suggests that disabled people should be normalised in order to fit society, the social model considers that it is society the one who should make efforts to adapt and accommodate its structure to people with disabilities. Rejecting a linear cause-and-effect explanation of disability, it claims that the condition of disability depends on the environment in which a person lives and performs his daily activities (which means that in an environment adapted to the person, the disability condition might change) (ODI, 2003; Thomas, 2004).

The assumption that society is the direct cause of disability results in the total rejection of the idea of disability as a personal tragedy, since the barriers that a disabled individual has to face are not considered to be intrinsic to him (the product of his impairment), but rather, socially constructed (Oliver, 1990; Oliver and Barnes, 1998), in Bury’s words:

“Disability is the product of definitions and practices that seek to exclude individuals who might be seen to deviate from the socially constructed norms of the ‘able-bodied’. In short, ‘disability’ is what a ‘disablist’ society decides so to call... it is not the inherent nature of disability that matters, but the labelling process, which categorises people by virtue of their position in relation to the dominant structures and values of the society” (Bury, 1996:25).

In the last two decades, there has been strong pressure from disabled people's groups urging for the development and application of new disability policies capable to address their necessities and to protect them against discrimination. This is considered an issue of human rights and equality, therefore, society's failure to cover the necessities of people with impairments is perceived as discrimination, since it involves a preference to cover the necessities of those without impairments (Burchardt, 2004). These groups have also called for the creation of organisations run by, rather than on behalf of, disabled people, arguing that, since they experience disability day after day, they are the ones who know best about their necessities and the implications of living with disabilities, therefore, they should have the right to participate actively in the decision-making around disability matters<sup>14</sup>.

Nowadays, thanks to the contributions of scholars and activists working from a social model of disability, there have been attempts to move from a medical explanation of disability to a more expanded bio-psycho-social model, which considers human functioning at the bodily, personal and social levels (Catterji, et al, 1999).

In conclusion, as it has been exposed, the individual/medical model understands 'disability' in terms of loss or diminution in bodily organs and/or functions. This model assumes the existence of an essential 'state of normality' constituted by a standardised 'natural human body' with a particular and well defined set of organs and functions. A standardised able-bodied is considered to be 'normal, independent,

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<sup>14</sup> The propositions developed from this social approach to disability have slowly started to materialise in the formulation of new policies about disability and, more important, in a change of attitude from society towards disabled people.

autonomous and competent'. In this sense, in order to qualify as an 'able' person, an individual may demonstrate that he/she counts with such a standardised set of organs and functions; otherwise he/she will be constituted as deviant, deficient and unable to qualify as 'competent and independent'; consequently, he/she will be automatically excluded of the 'normal/able-bodied' sector and considered 'disabled' (Morales-Navarro, 2005).

The main problem with the principle of normalisation is that it "locates agency, mobility and a centred subjectivity in a naturalised and given human body" (Moser, 2000); taking into account these parameters, 'disability' is explained as 'abnormality, dependency, and incompetence'. As a result, the disability discourse generated from the medical perspective has been shaped on the bases of an ideology of 'rehabilitation', one that would provide the patient as closer a return to 'normality' as possible, a normality which has been previously defined and legitimised by a combination of medical, statistical, social and moral criteria.

In comparison with the medical model's focus on normalising disabled people through rehabilitation practices, the social model of disability focuses on normalising disabled/disabled societies, this is, on making social and material arrangements and adjustments within society to create the most adequate conditions for the active incorporation of people with impairments in the social life of the community that they belong to.

The main critique to both approximations on disability, however, is precisely the idea of 'normalisation' as a way of inclusion (Moser, 2000), in the sense that, paradoxically, such an idea has been originated from a first movement of exclusion. On the one hand, from the very consideration of disabled people as a sector apart, as



‘different’, as Other with whom something has to be done. On the other, from the process of labelling the individual as ‘disabled’ based on a measurement against a preconceived ‘normality’. In Moser’s words, “normalisation is an attempt to include by means of an exclusive manoeuvre” (Moser, 2000: 210). Then, in a second movement, the efforts get focused on the disabled people’s rehabilitation in an attempt to (re-)include ‘them’ into the ‘normal’ world.

As it has been shown above, in the attempts to elaborate a clear definition of disability the notion of ‘normality’ –and its counterpart the one of ‘abnormality’–, has been always present at the core of the discussion. At the same time, it is latent the idea of a return to a state of normality to be achieved by disabled people. However, such an assumption is controversial since it brings forward the question of what constitutes a state of normality and what might be considered ‘normal’.

### **Science and Technology Studies**

Frequently called by its short name simply as *STS*, this relatively new intellectual field started to take shape during the second half of the twentieth century - although its intellectual bases are much older, dating back to the beginning of it<sup>15</sup>-- building on the work of scholars from a variety of fields of knowledge including the history, philosophy, sociology and anthropology of science and technology<sup>16</sup>. As its

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<sup>15</sup> Ludwig Fleck’s work ‘*Genesis and Development of a Scientific Fact*’, published in 1935, is an example of this; in this monograph Fleck already raises some of the issues that would later become the focus of STS scholars.

<sup>16</sup> One of those scholars, worth to be mentioned here, is Thomas Kuhn, coming from the history and philosophy of science, whose book ‘*The Structure of Scientific Revolutions*’ (1962) was of an enormous importance for posterior studies of science. In his work, Kuhn criticised the idea that the

name indicates, Science and Technology Studies academics are concerned with the way science and technology are produced and shaped, understanding technoscientific activity as a social enterprise.

Different intellectual approaches and research programs have been developed within STS which have contributed to its rapid development, including the sociology of scientific knowledge (SSK) the social construction of technology (SCOT) and the social shaping of technology (SST)<sup>17</sup>. From within Science and Technology Studies, for this research I focused on a body of work known as the Actor-Network approach, a material-semiotic perspective whose antecedents are found within several anthropological, philosophical and sociological traditions, drawing on Serres' philosophical accounts, Greimas' semiotics, Garfinkel's ethnomethodological propositions, Bloor's principles for the study of science, Foucaultian poststructuralism and Blumer's symbolic interactionism, among others<sup>18</sup>.

The foundations of Actor-Network can be traced back 30 years, during the late seventies and early eighties, to Michel Callon's studies on the electric vehicle (1986) and the scallops of St Brieuc Bay (1986), to Bruno Latour and Steve Woolgar's work on the construction of scientific facts in a neuroendocrinology lab (1979), to Latour's

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progress of science was achieved through the linear accumulation of knowledge arguing that, science undergoes periodic 'shifts in intellectual paradigms' which radically transform scientific inquiry.

<sup>17</sup> For introductions to these approaches, see: Bloor, 1976; Bijker, Hughes and Pinch, 1987; Mackenzie and Wajcman, 1985.

<sup>18</sup> For some of the antecedents to this approach, see: Serres, 1974; Greimas, 1976; 1979; Garfinkel, 1967; Bloor, 1976; Foucault, 1971; 1991; 2003; Blumer, 1986 and Law, 1994.

studies on Louis Pasteur (1983;1988) and, finally, to John Law's works on navigation technologies and the Portuguese expansion (1986a; 1987) and on the power strategies deployed within a scientific laboratory (1986b). Together, these and other studies gave shape to the approach that would later become known as Actor-Network Theory, or ANT, also referred as 'sociology of translation' in its early years (see e.g. Law, 1992).

By the middle of the twentieth century, the assumption from scientific practice of 'Nature' (with a capital N) as an external reality separated from 'Society' (with a capital S) was widespread. Following this idea, the task of scientists was assumed to be the neutral and careful observation, apprehension and description of such external reality, as scientists their role was merely one of witnesses of Nature and natural facts. The work developed by scholars within an emerging field of Science and Technology Studies would problematise such an assumption.

STS scholars argued that, instead of being part of an external reality, scientific facts and artefacts were socially constructed. For them, knowledges and technologies were outcomes of controversies and social negotiations. Shapin and Shaffer's famous historical account on 'Hobbes, Boyle and the Air-Pump' is a great example of the socio-technical arrangements that were put in place during the seventeenth century in order to produce what would be considered as reliable scientific 'facts' (see: Shapin and Schaffer, 1989<sup>19</sup>). Although, the argument of scientific facts as being socially

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<sup>19</sup> Two other wonderful examples of these sort of social and material arrangements in scientific practice are: Latour's historical account on Pasteur's laboratory, this time during the nineteenth century (see: Latour, 1983; 1988) and, from more recent times, Latour and Woolgar's ethnography of a neuroendocrinology lab during the late seventies (see: Latour and Woolgar, 1979).

shaped represented a considerable change in the way techno-scientific activity had been conceived until then, an even more radical shift would take place with the development of the actor-network approach.

Early actor-network theorists offered an alternative response to the propositions about the social construction of science and technology and the nature/society dualism. Such response would involve precisely putting into question the very distinction between the natural and the social (Callon and Latour, 1992)<sup>20</sup>. Investigating empirically techno-scientific practices, these scholars argued that ‘nature’ was “[...] neither given outside society, nor socially constructed. Rather, [nature] is co-produced with the social [...]” (Moser, 2003:26). With respect to ‘society’, they suggested that what we call ‘the social’ was not simply social, but that the social was actually entangled to and supported by an enormous array of *heterogeneous* materials, other than just people (Law, 1992). In other words, for these authors, neither nature was only about a given, external reality, nor was society only about people. Rather than that, they said, society, nature, people, machines, knowledge, science, technology, etc. “are all *effects* generated in patterned networks of diverse (not simply human) materials” (Law, 1992:380).

Following such argument and arguing against the ‘human-centredness’ of some sociologies, these authors suggested that there was no reason to make an *a priori* distinction between humans and non-humans, proposing to treat both of them in the same analytical terms: as *network effects*, rather than causes. As it is the case with machines, they said, people too are products of networks of heterogeneous materials. Such proposition of analytical symmetry towards humans and non-humans, has

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<sup>20</sup> For some empirical examples, see: Callon, 1986a; 1986b; Latour, 1988; Law, 1986a; 1986b.

constantly been the object of serious misunderstandings from scholars who argue against the possibility of treating those entities in the same terms; however, as ANT scholars have endlessly pointed out, this is “...an analytical stance, not an ethical position.” (Law, 1992:383).

In addition to destabilising the dualisms society/nature and human/nonhuman, ANT assumptions also destabilised and eroded the modernist ontological distinctions between agency/structure, objectivity/subjectivity, materiality/sociality, micro/macro, etc., making visible the complexities and the tensions between them<sup>21</sup>. The argument from ANT was not that there are not such divisions, but that they are relational effects, rather than inherent attributes of entities.

Drawing on the argument from semiotics that meaning is a product of relations, the actor-network approach extends this proposition to all sorts of materials –not only to signs and meanings, but also to artefacts–, proposing a ‘material semiotics’ that treats entities as relational effects. In other words, scholars working from this process-oriented methodological perspective assume that entities –as well as their attributes– are produced in interaction with other entities, they are shaped and performed in and through those relations, in Law’s words, “...entities take their form and acquire their attributes as a result of their relations with other entities” (Law, 1999b:3), they are ‘*made to be*’ what they are ‘*in relations*’.

For that reason, the academic concern for actor-network theorists does not lie in establishing clear definitions and boundaries of/between entities such as society and

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<sup>21</sup> For a discussion on what Bruno Latour has referred to as the ‘modern’ constitution, see: Latour, 1993.

nature or subject and object, but on investigating their simultaneous co-production, to say it another way, on the ‘network-building’ activities that generate particular entities, realities and practices (Callon and Latour, 1992); in this sense, ANT authors are opposed to social reductionism, they do not look for social causes or explanations; instead, their interest focuses on the exploration of the character of relations and how –not why– they get configured.

Since entities and their attributes are performed in relations, from an ANT perspective, ‘agency’ too became a network effect, rather than an essentialist quality of people; in other words, agency is not seen as a purely human attribute anymore; this assumption, in consequence, brought to life the possibility of nonhuman agency, one of the main propositions ANT has been known for. ANT academics argue that, rather than belonging to humans, the capacity to act emerges ‘*in relation*’ and is distributed among a network of heterogeneous materials. As with the notion of agency, the actor-network approach puts into question other attributes considered to be purely human, such as those of subjectivity, identity, intentionality and morality, which are too understood as situated relational effects (see: Law, 1999a), adding to the contemporary discussions on issues such what it means to be human, what a subject is, etc.

In their studies, ANT scholars avoid making a priori assumptions with respect to the entities that might be granted agency; because of this, they frequently refer to both humans and nonhumans as ‘actants’, since they both have the capacity to act<sup>22</sup>. The argument about ‘non-human agency’ was developed by Callon and Latour in their early work on the scallops and Pasteur’s laboratory, respectively (see: Callon, 1986

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<sup>22</sup> For more on the notion of ‘actant/actor’, see: Akrich and Latour, 1992.

and Latour, 1988). Such argument has been misinterpreted by some scholars as literally granting agency and intentionality to objects, becoming thus an issue of heated debate and criticism. ANT theorists, however, have responded to this criticism by making clear that the approach they propose, grants agency & intentionality neither to non-humans nor to humans, but instead, it treats both attributes as relational effects rather than exclusively human qualities<sup>23</sup>.

In addition, from an actor-network perspective, entities are simultaneously both, effects of networks, and also networks in themselves; people, machines, discourses, etc., they are all networks of heterogeneous materials, objects which are simultaneously ‘more than one and less than many’ (Law, 1999). On those bases, actor-network theorists are not concerned with defining primary entities, but with exploring their circulation and translation –using Latour’s terminology (see: Latour, 1999a, 1999b)–, with investigating the way in which heterogeneous materials generate themselves within networks and become particular entities, on how those entities are relationally performed. ANT insists ‘on the performative character of relations and the objects constituted in those relations. [Insisting] on the possibility [...] that they might be otherwise’ (Law, 1999b). In addition, rather than simplification and clarity, their work tries to show the tensions and complexities of the process of achieving more or less stable and durable relations.

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<sup>23</sup> These and other issues were famously discussed in what became known as the ‘epistemological chicken’ debate in which an article by Harry Collins and Steven Yearley criticising ANT propositions was followed by a reply from Michel Callon and Bruno Latour (see: Callon and Latour, 1992; Collins and Yearley, 1992).

Although, it is frequently referred to as Actor-Network Theory, this approach, rather than a theory, is better described as a set of material-semiotic tools, methods, diasporic practices and interferences (Law, 1999b; 2007). In Latour's words, "... ANT is [...] like ethnomethodology, simply a way for the social scientists to access sites, a method and not a theory, a way to travel from one spot to the next, from one field site to the next..." (Latour, 1999a:20).

In the same way than the objects of its concern, the actor-network approach cannot be characterised as a singular object. Instead, ANT is itself an object which is 'more than one and less than many', in Law's terms, it is a "fractional object" (Law, 1999b:12), an intellectual space of theoretical and empirical intersections, as well as generative partial connections (see: Law, 2007). ANT material semiotics has been shaped by a body of works which share an interest in exploring processes, which are based on empirical case-studies and which treat entities as relational effects. Throughout the decades, the actor-network insights have been translated into many different ways and mobilised within a wide variety of research fields (see: Law, 1997). New concerns have arisen, new areas of inquiry have been explored, new intellectual tools developed, new metaphors proposed, new versions of politics articulated and new insights offered.

The work developed during the last decade drawing on an actor-network perspective has been shaped by a reconfiguration of the materially heterogeneous networks of early ANT into a material semiotics characterised by the propositions of the enactment of realities, the multiplicity of them and their co-existence, fluidity and malleability, as well as by an explicit awareness of the politics of its own studies and



the part they play in enacting particular realities, particular epistemologies and particular normative stands in relation to themselves and their objects of research.

Drawing on an ANT perspective, my research explores the clinical processes and practices through which patients and prostheses come into being in the context of rehabilitation, and it does this, by following the variety of heterogeneous relations that emerge and get shaped between them. My ethnography also problematises the clinical notions of Rehabilitation and Disability by tracing different ways in which they get configured throughout the patient's rehabilitation program.

### **Feminist Technoscience Studies**

Feminist scholars have too become involved in the study of technoscientific activity; their work stands out from other intellectual traditions, however, because it is greatly concerned with the politics of technoscience and how it contributes to shape and reinforce particular dominant and oppressive agendas in detriment of vulnerable groups.

Early Feminist debates about technoscientific activity, during the seventies and eighties of the past century, took the shape of strong critiques to science and social science. These debates highlighted how Western science had become the hegemonic mode of knowing and exposed some of the implications of this, not only in the production of knowledge and our understanding of the world, but also, in empowering certain sectors of society and disempowering others. Examples of this were brought forward by critiques focused on a variety of areas, including those about research

carried out in the fields of biology and medicine, which suggested that this was focused on men, naturalised gender differences and alienated women<sup>24</sup>.

Feminists argued that, from its birth, modern Western science had been characterised by its androcentrism and its patriarchal assumptions about gender, for example, regarding women as less cultured or less capable for science<sup>25</sup>, which resulted in their exclusion from scientific work. As with science, research in social science was too the target of Feminist criticisms, which denounced what was seen as the ‘maleness’ of its methods and theories, referring to mainstream science and social science as ‘malestream’ and pointing out that scientific research was mainly produced by men, for men and about male issues, often ignoring women.

Since science was an almost exclusively male activity, it was not objective but partial, feminists argued, advocating for the inclusion of women into it, which would contribute, they said, to achieve the objectivity required of scientific work, as well as a more inclusive and democratic science. Mapping out feminist critiques to scientific activity and knowledge production, Sandra Harding (1986a; 1986b; 1991) identified this kind of epistemology as ‘Feminist empiricism’.

For feminist empiricists the world, as the object of knowledge, was completely independent of the subject of knowledge; they agreed that there were ‘facts’ of nature and social life out there to be revealed; however, for them, an androcentric science offered biased claims about the world, “[...] science distorted by masculine bias in

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<sup>24</sup> Relevant works on this matter include: Fausto-Sterling, 1985; 2000 and Ruth Hubbard, 1990; 1995.

<sup>25</sup> As opposed to men, women were often seen as ‘emotional’, which, in consequence, could undermine the objectivity required in scientific practice.

problematics, theories, concepts, methods of inquiry, observations, and interpretations of results of research” (Harding, 1986b:399), this prevented scientists from seeing the reality as it really was; for this reason, including more women in science as well as more women's issues as objects of inquiry would eliminate this gender bias and provide objective scientific accounts of reality (Harding, 1986a; 1986b; 1991). In Harding's words, from this perspective “[f]eminist inquiry represents not a substitution of one gender loyalty for the other - one subjectivism for another - but the transcendence of gender which thereby increases objectivity” (Harding, 1986b:648).

In addition, feminist empiricism took for granted both, scientific objectivity and gender dimorphism. On the one hand, it accepted the assumption of [the possibility of] an impartial, objective science which, paradoxically, both reaffirmed and undermined the Enlightenment project. It reaffirmed it precisely by seeking to grant more objectivity to science; while, simultaneously, it undermined it in the sense that, according to the Enlightenment project, science should be neutral and completely detached from social influences, this idea would, in turn, put into question the way in which including more women in scientific work would make science less biased and more objective, when the production of knowledge was, supposedly, value free. On the other hand, feminist empiricism also accepted a dual gender division of man *vs.* woman as valid and unproblematic, without questioning further these categories; there were only two opposed genders to deal with, and creating a balance between them within the scientific community was the key to an unbiased and objective science.

Some feminists were not so enthusiastic about Feminist empiricism propositions claiming that, both, natural sciences and social sciences were themselves grounded on patriarchal assumptions and part of a patriarchal ideology. Science, they argued,

assumes that there is a separation between the knower and the known and that it is possible to achieve a transcendental standpoint from which to witness and describe the world as it ‘really’ is (Harding, 1986b). According to these authors, the mere incorporation of women into that same patriarchal institution did not mean producing true and impartial knowledge. Following this line of argumentation, for some feminists the way forward seemed to be the complete abandonment of science and the creation of alternative modes of knowing that reflected female experience and understanding of the world and the reality.

Other scholars involved in the feminist debates about knowledge production and the possibility of objectivity, who also shared the critiques to male-produced science as being patriarchal, partial and distorted, suggested that truth was only visible to the unprivileged groups, to those members of the community who were in an unprivileged position, in this case, to women. Thus, from this perspective, the only objective scientific knowledge was that produced by women. This kind of feminist approach to science became known as ‘Standpoint epistemology’ (Harding, 1986).

One of the main proponents of such a feminist epistemology was Sandra Harding<sup>26</sup>. For her, the question feminists were being confronted with was not about women in science anymore; instead, it had become one about science in feminism (Harding, 1986a, 1991). She claimed that those who were in an unprivileged position within their knowledge community possessed an epistemic advantage in relation to the knowledge they generated about the world since they produced less partial and less distorted perspectives. In addition, Harding argued that, instead of abandoning the idea of objectivity, as some scholars suggested, feminists should reformulate the

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<sup>26</sup> For a great discussion on Harding’s Standpoint epistemology and its paradoxes, see: Rolin, 2006.

notion of objectivity itself and ask for stronger standards of it (Harding, 1986a, 1991). According to her, a 'strong objectivity', as she called it, required from the researcher "a commitment to acknowledge the historical character of every belief or set of beliefs – a commitment to cultural, sociological, historical relativism" (Harding, 1991:156), an acute and constant sense of self-awareness and critical reflexivity with respect to her own position as the subject of knowledge as well as that of the scientific community she belongs to.

Harding rejected the assumption that there is a neutral, impartial "view from nowhere" (Harding 1991:311), and claimed instead that all knowledge and its production were socially and historically situated (Harding, 1986a, 1991). Following these claims she suggested that, in the same way that the researcher asks questions about her object of study, she should also question herself about the way in which her own beliefs and experiences –and those of her scientific community– shape both, her object of study as well as her research itself; in other words, she should be able to account not only for the results of her research, but also, for the socio-cultural context of knowledge production.

Harding's idea of scientific activity and objectivity was not about a rational cognoscent subject, completely separated from her object of study, applying specific scientific methods in order to provide a neutral description of reality. She is rather careful when referring to the ultimate goal of science, by saying that this should move "away from falsity rather than toward truth" (Harding, 1991:185). For her instead, science was about a socially and historically situated subject of knowledge whose particular experiences and reality played an important part in shaping every stage of

the scientific inquiry, a part which had to be recognised and accounted for rather than denied.

Although, a Feminist standpoint epistemology greatly contributed to the debate about the relations of inequality between women and men, and it made even more visible women's unprivileged and oppressed position in society, such an approach, however, treated 'Women' as a unity, assuming that there was such a thing as a 'women's perspective', assumptions that would later be challenged by the emergence of the women of colour and the lesbian movements, as Moser (2003) has explained in the following way:

“Women of colour and lesbian women questioned the neutrality and universality of Woman and a feminist identity politics based on Woman as an unproblematised category. The Woman in feminism, it was argued, is a western, often US-American, white, middle class, heterosexual position. But what woman means in practice, is not obvious: there are only different women, not one woman. And academic feminism, feminist theory included, is also blind to its own positioning and so contributes to the denial of difference.” (Moser, 2003).

The feminist debate on science was left, in consequence, facing a new reconfiguration of the category of Woman, in which this was no more a singular unity whose interests and concerns could be represented by a single feminist voice; neither could Woman be understood simply as the counterpart of the rational male subject anymore. 'Woman' instead, became a multiplicity of women from different social backgrounds, cultures, races, and sexualities, a multiplicity of experiences and realities, a multiplicity of standpoints towards knowledge production and objectivity.

With no homogeneous women's experience of the world and no single vision and understanding of reality, the problematisation of the notion of Woman would pose

new questions to an standpoint epistemology, for example, if there were different standpoints, then, whose standpoint was the true one?, could it be the case that all of these standpoints were equally valid?, but then, if this was the case, could Standpoint feminists be heading towards a hopeless relativism?.

The rejection of both, a ‘grand narrative’ and an idea of ‘universal knowledge’, as well as the feminist confrontation with difference and multiple ‘local’ knowledges would, in turn, give way to a ‘postmodern’ feminist epistemological approach to knowledge production, of which Donna Haraway became its central figure.

The feminist debates about science and objectivity taking place during the decade of the 1980s had strongly highlighted the urgency to reformulate the very notion of ‘objectivity’ itself, in an attempt to confront what was seen as the mainstream, male-shaped version of objectivity with which science operated. For Haraway, such a masculine version of scientific objectivity, positioned [male] scientists as disembodied entities, capable of “seeing everything from nowhere” (Haraway, 1999:176). According to her, this androcentric science exercised a perverse capacity “to distance the knowing subject from everybody and everything” (Haraway, 1999:176) —what she referred to as the “god-trick” (Haraway, 1999:176)—, based on the modernist proposition of a ‘nature vs. culture’ binary and the series of dichotomic formulae linked to it, including that of ‘subject/object’.

By mobilising the metaphor of *vision*, Haraway (1999) argued that such a modernist science assumed the possibility of direct and unrestricted vision of the world and reality, while taking for granted the multiple, historically specific ‘mediation technologies’ through which scientists (and everybody else) see the world. She emphasised the role of these technologies in the generation and shaping of the

scientists' objects of knowledge and how they see and make sense of them. Rather than purely representing an independent reality, mediation technologies (theoretical frameworks included) contribute to make those very realities; to say it another way, rather than just described and interpreted by the researcher, realities are produced<sup>27</sup>.

Instead of predicating transcendence of the knower, an ubiquitous gaze from nowhere and an unmediated access to the world, Haraway insisted on the necessity to "learn in our bodies" (Haraway, 1999:177), to acknowledge ourselves as embodied knowing subjects, proposing a reformulation of scientific objectivity framed in terms of specific locations, particular embodiments, and accountable knowledges; in her own words: "feminist objectivity means quite simply *situated knowledges*" (Haraway, 1999:176).

Although, Haraway's proposition of situated knowledges coincided with that of Harding, unlike the latter, she strongly opposed to a standpoint epistemology and its suggestion that the perspectives of the unprivileged were less partial and less distorted than those of other people. Seeing from below, she said, is neither unproblematic nor unmediated<sup>28</sup>; subjugated standpoints are not any more innocent than those of the powerful, for this reason they too should be accounted for and subjected to critical examination (Haraway, 1999).

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<sup>27</sup> A consequence of this assumption is that, following a conventional definition of scientific objectivity, then, there is no such a thing as an objective reality.

<sup>28</sup> Haraway refers to the partiality of subjugated standpoints accounts as follows: "Instruments of vision mediate standpoints; there is no immediate vision from the standpoints of the subjugated. Identity, including self-identity, does not produce science; critical positioning does, that is, objectivity." (Haraway, 1999:180).



According to this scholar, since all knowledges are situated, they are, therefore, *partial* and so, contestable. However, rather than a failure, such partiality was for Haraway a fundamental element for knowledge production in both, analytical and political terms, since “only partial perspective promises objective vision” (Haraway, 1999:177). Following this proposition, not only does Haraway argue against universal claims about the world and totalizing perspectives, but also, she warns us against relativist positionings, which claim ‘to be everywhere equally while being nowhere’ —what she sees as another form of god-trick— (Haraway, 1999:178) and which suggest that there is equality among all standpoints and knowledge claims. A non-innocent account of objectivity, on the contrary, recognizes that there is no equality of positioning, but rather, there are different power-differentiated communities. In Haraway’s view, both totalization and relativism share a doctrine of impartial, disembodied and, thus, unaccountable objectivity; feminist objectivity is, instead, about partial, located and embodied accounts of the world, as Haraway puts it: “[t]he science question in feminism is about objectivity as positioned rationality” (Haraway, 1999:182).

In addition, Haraway’s account of feminist objectivity challenges the modernist assumption of the object of knowledge simply as a fixed thing, a screen, or a resource (Haraway, 1999:183). For her, the world is neither a passive nor a static entity, which sits still while its mysteries are unraveled by the cognoscent subject<sup>29</sup>. Instead, she conceptualizes the objects of knowledge as “material-semiotic actors”; this is, as

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<sup>29</sup> Haraway explains it as follows: “The world neither speaks itself nor disappears in favour of a master decoder. The codes of the world are not still, waiting only to be read. [...] the world encountered in knowledge projects [sciences] is an active entity” (Haraway, 1999:184).

active, meaning-generating agents in the production of knowledge. Objects do not preexist as such; rather, they are “boundary projects” whose boundaries are socially produced (Haraway, 1999:185). Rather than being just about accounting for the subject’s location and positions or identities —as it was the case for a standpoint epistemology—, a feminist objectivity then, puts great emphasis on how the cognoscent subject relates to the [active] object of knowledge in the research process.

Haraway suggests an understanding of knowledge production in terms of ‘situated shared conversations’. Knowledge production, she says, is about generating webs of partial connections between different accounts of the world, developing in this way, a collective subject position which is able “to see together without claiming to be another” (Haraway, 1999:179); for her, objective knowledge emerges from within those connections.

In Haraway’s view, feminist objectivity has to do with all the multiplicities, complexities, contradictions, tensions, resistances and non-coherences which are an essential part of both knowledge production and reality; it is not afraid of them, rather, it is fascinated about them, it looks for them, it makes them visible. Finally, feminist objectivity is for Haraway, about intervening with reality, about making changes; it is about an epistemology and politics that ‘interferes’ with the world we live in.

Since post-modern feminist epistemologists reject the idea that it is possible to make reference to a ‘women’s experience’, it has been criticized for being politically paralyzing, under the argument that it subverts the very possibility of a feminist identity and a feminist collective.

## **2. CYBORG COLLECTIFS: PATIENTS, PROSTHESES AND THE REHABILITATION PROCESS**

April 10. It's quarter to seven in the morning and the waiting area of the centre is already full of patients accompanied by their relatives. At the reception desks, the secretaries make sure that all of the 7.00am patients are here; they do this by reading aloud a list of their names. Behind the reception area several doctors can be seen greeting each other outside the consulting rooms and getting ready for one more day of work...

...It's almost 2.00pm, lunch time. I am in the cafeteria of the centre waiting on the queue to be served, hearing the whispering voices of patients and doctors mixed with the faint sounds of the cutlery and the coffee machine. From time to time the cry of a child will be interrupted by a loud laugh from a doctors' table...

Throughout the year, thousands of patients, like those I refer to in these excerpts from my field-notes, are treated at the rehabilitation centre. While doing my fieldwork I saw dozens of them. Patients from different ages and genders, with different conditions and prognoses. Silent patients and talkative ones; patients in pain, anxious or calm; patients full of hope or frustration. Patients holding different histories, living different realities, shaping different futures for themselves...

The stories I tell in this thesis refer to all those patients, to their rehabilitation process at the centre, to the orthotic and prosthetic devices that they incorporate (or not) into their lives and bodies along the way, to the rehabilitation specialists in charge of their treatment, to the patients' relatives, who also become involved in the process. My stories<sup>30</sup> try to portray those patients, travelling from one lab to another, undergoing multiple examinations, getting attached to all sorts of technical devices and being inscribed in, and translated through, a wide array of protocols, medical prescriptions and clinical procedures.

In clinical settings patients come and go; patients are examined, diagnosed, treated, rehabilitated, etc.; their bodies are manipulated and intervened in many different ways: they are looked at, palpated, heard, measured, cut, moved... Patients are at the centre of clinical practice because they are the very source of medical knowledge. Without the figure of the patient there would not be a '*clinic*', and modern (Western) medicine, as we know it, would not exist. Put in this way, multiple questions in relation to such a crucial entity of clinical practice start to emerge: How is it that people get transformed into patients?, how are patients articulated?, what does being a patient entails?, these are just some examples.

In the context of rehabilitation medicine, particularly, some of the questions that arise include: how is the 'rehabilitation patient' configured?, what are its characteristics?, what elements participate in its configuration?, what transformations this particular patient goes through during the rehabilitation process?. Since patients

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<sup>30</sup> I refer to them as stories because rather than considering them as faithful accounts of what 'really' happens at the rehabilitation centre, I try to acknowledge that these stories have been shaped by my own account of the world (see the previous chapter).

are the main component of the rehabilitation process, it is sensible to ask how it was that all those people who were admitted to the centre for undergoing rehabilitation treatment came to be patients in the first place. This is precisely the question that I explore in this chapter.

### ***The Diseased Body and the Ill Subject***

In *The Birth of the Clinic: An Archaeology of Medical Perception* (2005), Foucault explores the semiotic, social and material mechanisms that made possible the development of modern, Western medicine. According to him, modern medicine and clinical practice were the result of a radical reorganization of knowledge, which took place at the end of the 18<sup>th</sup> century. For Foucault, the articulation of ‘*the clinic*’ arose on the bases of a transition from one particular ‘discursive formation’ or *episteme* —as he calls them—, to another one (from a ‘taxonomic’ organization of knowledge to an ‘organic’ one) which made possible a new material-semiotic configuration of medical discourse (and practice) around disease and the body (Foucault, 2005). This new episteme has been radically transforming medical theory and practice, as well as the way in which health and sickness are currently conceptualised and dealt with, the contemporary distinction between disease and illness is a clear example of this.

Within the social sciences, the majority of studies around health, sickness and the body have commonly taken aboard the distinction between disease and illness. Some of the roots of this distinction date back to the Cartesian separation between body and mind. The treatment of the patient on the basis of this binary distinction also comes from an anthropological tradition and is central to medical anthropology and medical sociology (Helman, 2001).

For medical anthropologists and medical sociologists, the term *disease* refers to a physical or mental condition of an individual's body. In contrast, *illness* denotes a person's experience and interpretation of *having a disease*, of *being ill*. Whereas, as a clinical condition, disease can be diagnosed in humans, animals and plants, illness can only be experienced by humans (Lupton, 2003).

The dualist assumption of a body that has a disease and a person who is ill became visible in the middle of the twentieth century. Sixty years ago, for instance, Talcott Parsons, one of the founders of medical sociology<sup>31</sup>, referred to illness as “a state of disturbance in the “normal” functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments. It is thus partly biologically and partly socially defined” (Parsons, 1951:431). These biological and social aspects Parsons talked about would, later on, be referred to as disease and illness, respectively. Following such a distinction, while the object of concern for physicians is the ‘biological’ part (disease), medical anthropologists and medical sociologists focus their attention on the ‘social’ part, on how such diseases are experienced by people (on illness).

Although, widely accepted among medical anthropologists and medical sociologists, the disease vs. illness distinction poses several problems:

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<sup>31</sup> In addition to Parsons, medical sociologists also recognize the work of Lawrence J. Henderson (1935) as forming the foundations of their discipline. Other key authors who have contributed to the development of Medical Sociology include Carl May (see e.g. May, 1992a; 1992b; 2006; 2007), Peter Conrad and Joseph W. Schneider (see e.g. Conrad and Schneider, 1992), and Thomas Szasz (see e.g. Szasz, 1961; 1970; 1984; 1996).

Firstly, it is based on the modernist separation between *nature* and *culture*, from which ‘disease’, on the one hand, would belong to the realm of the ‘facts’, studied by specialists in laboratories or hospitals and supported by objective scientific analyses. Illness, on the other hand, would be associated with a subjective realm, based on the laypeople’s feelings and interpretations.

Secondly, it distinguishes between the patient as a person –who is ill– and as a body –which has a disease–, separation that, in practice, can hardly be sustained, as we will see later in this work.

Thirdly, it over-emphasises the individual subject (the person and his/her body), which results in an understanding of disease as located exclusively in a person’s body and as an exclusively individual experience of the particular person who suffers the disease.

Fourthly, it takes for granted the category of ‘disease’, which remains largely unproblematised and untheorised within the social sciences, while focusing only on the study of illness. In this respect, Mol has pointed out that there is a political danger of “leaving “disease” in the hands of physicians alone. [...] For [...] as long as “disease” is accepted as a natural category and left unanalysed those who talk in its name will always have the last word” (Mol, 2002:22).

Fifthly, it does not take into account the material bases of illness, considering that this is not experienced in the abstract, but rather, when experiencing a certain illness, patients will refer to the discomfort or/and the pain that a certain condition causes to them, they will express what they experience through their bodies, this is, they will talk of the materiality of illness (explained in these terms, illness becomes

simultaneously a particular mode of embodiment as well as a particular mode of subjectivity).

By problematising the category of ‘patient’ through an empirical example, in what follows I explore an alternative view to the disease/illness divide, a view that understands the patient as being relational and materially heterogeneous, rather than as a fractured, *a priori* entity.

### **Becoming a Patient**

April 10. Today, as usual, the Occupational Therapy area is full of patients... Wearing their blue coats, the OTs [Occupational Therapists] come and go from one side of the room to the other, from one working area to the next. A patient has arrived for her session, she was born with some fingers missing and doctors have been discussing the possibility of a surgery...

OT: *“Hi, how are you?, how are your hands today?”* [the patient smiles, the OT looks attentively at her hands]; *“does she ride the bicycle?”*

Mother: *“no, she is afraid of doing it”*

OT: *“why don’t you ride your bike?, is it too big?, ask your mother to buy you a smaller one”* [the child smiles]... *“Let’s see...”*

The OT and the girl start working. During the session, she is asked to perform different tasks while the OT observes: She unbuttons her sweater and buttons it up again, she unties her shoelaces and ties them up again, she takes a pencil and writes down some sentences on a piece of



paper, she colours a small drawing from a colouring book, she takes the scissors and cuts out some figures...

OT: *"we are doing a functional assessment" [to me and to the girl's mother, then he makes a pause] "the doctors would take a toe and attach it to her hand as a thumb, as an opposition finger... but the thing is that she is very skilful with her hands... and the other question is that you are told that you should improve the person's corporal scheme, but she is complete in this way... you see?, without the fingers she is completely functional, she doesn't have any limitation at all to do anything... so, we are going to tell the doctor this"*

Mother: *"my question is whether the surgery is going to be worth it, whether the thumb is going to be functional"*

OT: *"as I said, I don't see any functional problem at all. If she wants to be an engineer, a musician, a teacher, she wouldn't have any problems, maybe if she wants to be a tennis player, but even in that case there are adaptations" [the patient's mother nods]. With the question of the surgery, what doctors would do is that, in her left hand the thumb is there but it's just a flap, so, they would take a piece of bone from her ankle, to give it [the thumb] firmness so that she is able to use it as an opposition finger. In the case of her right hand, the doctors' idea is to take the second toe from her foot and attach it as a thumb, it would not have any flexion but it would be used as an opposition finger too. But I repeat, functionality problems, which is what the doctors are concerned about, I don't see any"*

Mother: *“the surgery worries me... I’ve been told that if they remove a toe she would get tired easily and have difficulties walking... and also I want to be sure that later on she won’t have other problems [as a consequence of the surgery]”*

OT: *“no, it’s not like that... this kind of surgical intervention has been performed in many other patients, if they [doctors] were not sure about its benefits they would not do it. So, you can tell her doctor that I don’t see functionality problems. However, there is also the aesthetic question so, a surgery could be performed for this reason but, if so, you have to bear in mind that there would not be any significant differences in terms of functionality because, I repeat, she has almost complete functionality, she is complete as she is right now, she is not missing anything and she can do everything”*

Mother: *“yeah, I understand”*

OT: *“but this is only my professional opinion as an occupational therapist... with my opinion, that of her doctor and yours, we will make a final decision [on the matter]”*

My field-note above talks about a little girl who is a patient at the centre for disabled children and whose rehabilitation program includes periodic occupational therapy sessions. But this excerpt tells about much more than just an everyday therapy session in OT. It also makes reference to the fragile line that separates two different identity possibilities for a little girl: that of being a normal, complete child, who can do all the things that any other child of her age does, and that of a child who

was born physically incomplete and might become a candidate for a surgery which, somehow, promises to return her missing wholeness to her.

What is at stake in this story is a series of tensions between elements that don't quite fit together, and yet, that are simultaneously present in a girl's life. These are tensions between a sense of normality and wholeness, and that of difference and incompleteness; between recognition of belonging, and being perceived as *Other*; between competence and disability; between autonomy and dependency.

When does a little girl, able to do everything that children with eight fingers and two thumbs do, become someone different from them?, when does she stop belonging to the highly appreciated 'us' and begin being part of the so feared 'them'?, where is the boundary between normality and disability?, is it ever possible to move beyond this binary?. An exploration of these sorts of questions requires of an approach capable to account for the tensions and contradictions of everyday life, for the things that don't fit and the boundaries that get blurred, for the identities that collide and yet, coexist, for the multiple realities that are configured in practice. Since this is the case, a Material Semiotics approach becomes very useful to this analysis.

Within the sociological sciences considerable contributions have been produced from a Material Semiotics framework, the work of Michel Foucault is an outstanding example of this perspective. Through his processual approach to the study of social institutions such as the clinic, the prison, sexuality and madness, Foucault developed a historical examination of the semiotic, social and material mechanisms that made possible their radical reconfiguration.

In "*Discipline and Punish, the Birth of the Prison*" (1991), for instance, Foucault tells us about a process of 'redistribution of the economy of punishment' and

configuration of a new penal system, which took place at the end of the eighteenth and beginning of the nineteenth centuries. In his study, he traces historically the transformation of the judicial apparatus, from one rooted on 'the spectacle of public torture', to another one (that still operates in modern Western society) in which 'the ritual of punishment' takes a whole new meaning. "Monarchical punishment", the former one, exerted control over the population through the exhibition of prisoners and the public display of torture and execution. The power to judge and punish laid on the sovereign, while the act of punishing was visible, centred on the convict's body, and carried out for the sake of revenge<sup>32</sup> and the regulation of actions that were not allowed by the law (Foucault, 1991). In contrast, "disciplinary punishment", the latter one, aims to correct deviant behaviour, to reform. The power to punish is distributed among a group of 'professionals'<sup>33</sup>, while the act of punishing becomes invisible, hidden from the public. Punishment is now based on the idea of normalisation and exerted through the imposition of disciplinary constraints, the individual's privation of liberty and imprisonment (Foucault, 1991).

Foucault characterises those apparatuses of justice as two different types of "*technologies of punishment*", technologies which are historically contingent and constituted by particular social, semiotic, and material arrangements. The transition from one technology to the other one involved a series of deep changes that included the reformulation of the 'punishment-body relation' as well as the rise of a new

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<sup>32</sup> According to Foucault (1991), in a monarchical structure the law represented an extension of the sovereign's body; therefore, punishment of an infringement of the law would, in turn, 1) take the form of a physical punishment to the convict's body and 2) embody the sovereign's revenge.

<sup>33</sup> Those professionals include doctors, psychologists, criminologists, etc.

‘treatment’ of the body, which became “an instrument or intermediary”, rather than “a recipient of torture” (Foucault, 1991). In this transition, a new body-politics was put in place, a politics of individualised, disciplined and docile bodies. The new technology of disciplinary power would, in turn, permeate and reshape not only the penal system, but also other socio-material organisations, including the military, the clinical, the industrial and the educational ones, resulting in the configuration of a large scale ‘disciplinary’ system embodied in modern Western society.

As it is the case of Foucault’s work, Actor-Network Theory, from which I talked about in the previous chapter, is also a material semiotic approach, which authors like John Law have referred to as an empirical, scaled-down version of Foucaultian post-structuralism, comparing Foucault’s discourses or epistemes with ANT’s ‘actor-networks’ (Law, 1994; Law, 2007:6).

Through its empirical studies, the actor-network tradition has managed to erode the strongest binaries dictated by the modern constitution, including those of society/nature, human/nonhuman, agency/structure, objectivity/subjectivity, etc. It has done so, precisely by showing the way in which such distinctions are generated in everyday practices. According to ANT authors, each of these apparently binary elements both, co-produce and are entangled to, one another. What is more, for them, all entities are relational effects, products of networks of heterogeneous materials (Law, 1992; Callon and Latour, 1992). In other words, entities do not exist *per se*, rather, they become so ‘in relation’, and they take its particular form and shape in interaction with other entities. And the same applies to their boundaries and any other of their attributes, which also get configured in relation rather than being inherent to those entities.

One of the fundamental starting points that distinguishes this approximation is what has been called the ‘symmetry principle’, which argues that, while studying a certain phenomenon, all entities should be approached in the same analytical terms. Subjects and objects, humans and non-humans, nature and culture, in practice, none of them is more important than the other in the configuration and reformulation of heterogeneous relationalities; subjectivities are not more relevant than materialities in the constitution of material-semiotics relations and vice versa (Law, 1997)<sup>34</sup>.

The actor-network approach is well known for its human-decentredness, which comes from the symmetrical treatment of all entities. Since entities and their attributes do not pre-exist their relations, ANT says, humanness and the attributes attached to being a person —such as agency and subjectivity— should be explained as relational effects rather than causes; this is, as both, produced in interaction with, and distributed among, a network of heterogeneous materials.

Actor-network studies suggest that entities and realities are sets of material-semiotic practices and discourses, performed and re-produced ‘in and through relations’ that are materially heterogeneous. ANT also assumes no initial causes; everything is an ‘effect’, a ‘product’ of relations. In this way, the focus of ANT’s material-semiotics lies on uncovering the relations and practices that produce and sustain the entities it analyses and how these entities circulate in and are performed by the network to which they belong.

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<sup>34</sup> For a background about the ‘symmetry’ argument and some empirical examples, see: Bloor, 1976; Callon, 1986a; 1986b; 1987 and Law, 1991.

So, what about the figure of the 'patient' then?, what can a material-semiotic approach such as actor-network tells us about this entity?...

Following the illness/disease paradigm from classical medical anthropology, the patient is approached by means of a distinction between body and mind. In addition, the patient is seen as a static entity with inherent attributes, constituted *a priori* to any particular clinical practice. Also, this is a 'fractured' patient, whose materiality results completely separated from its subjectivity, resulting in its dualist configuration as both, a body and a person. Focusing on my ethnographic story about the little girl with missing fingers presented above, the distinction between body and subject is expressed as a tension between an incomplete body vs. a completely functional person.

In this sense, a classical medical anthropological perspective would tell us about the girl's experiences of living with a non-standard body within a particular social and material environment. Although, such an analysis might bring us closer to her individual interpretations of a physical disorder, it stops right there, leaving unproblematised the girl's status as a patient and letting her disease to be explained exclusively by medical professionals.

When analysed from a material-semiotic perspective, however, the story takes a completely different shape. Material-semiotics opens up a whole new space of enquiry. By following this approach we cannot take any entity for granted. Attending to this principle, my starting point is then that patients, are not patients per se, but rather, they become so, they get configured as such. Furthermore, this reconfiguration of persons into patients is a precondition to the rehabilitation process and to the multiple medical interventions people are subjected to throughout this process.

So, rather than assuming the 'patient' as an a priori entity with particular and well defined attributes, we must ask questions about such a figure itself. From a material-semiotic perspective the patient becomes simultaneously a relational effect as well as an entity in-the-making. In the same way, 'disease' is also problematised and, like the patient, it too becomes an effect and in-the-making. This can be clearly appreciated in my field-note excerpt in the following way:

Looking at our case story with material semiotic glasses makes different questions arise, including how it is that the girl was reconfigured into a patient in the first place, what happened that resulted in her being granted the status of a patient, how it is that the girl's 'disorder' was constituted as such.

As I mentioned in the previous chapter, the rehabilitation centre I studied is exclusively for disabled people, so, for a child to be treated there, having a disability/being disabled is a 'must'. In order to be considered as a patient of the centre, a child has to qualify as one first. How?, well, this is done in several ways. To start with, prospective patients have to be dealing with ('suffering from') a particular disease or condition that enters in the spectrum of a neuro-musculoskeletal disorder, which are those exclusively treated at the centre, a condition that is disabling enough that moves them away from normality, so that they can be, in turn, suitable candidates for rehabilitation.

When they arrive at the centre, most of the people have already been diagnosed with a neuro-musculoskeletal disorder in another health institution which has then channelled them there for rehabilitation. Upon arrival, a person seeking for rehabilitation has already been through an initial reconfiguration process from being a person into becoming a patient; however, this does not simplify things because in



order to receive rehabilitation treatment, his/her identity as a patient has to be confirmed and sustained. S/he has to demonstrate that s/he qualifies as a rehabilitation patient (this is, that s/he has a disease that can be treated there and that s/he is in need of rehabilitation). Sustaining the person's identity as a patient is done by means of different materials and practices, including referral letters from other medical institutions or individual specialists, reports of previous medical examinations and diagnoses, personal health histories, new examinations, etc.

In the little girl's case, her medical records indicate that she presents a condition called Aplasia which, in colloquial language, basically refers to an incomplete or defective development of the foetus. This disorder affected the girl's hands and resulted in the absence of thumbs. Following the centre's patient acceptance criteria, the girl appears to fulfil all the requirements: she suffers from a Neuro-musculoskeletal disorder that medical discourse relates with both, abnormality and disability; then, being labelled as disabled makes her, in turn, a good rehabilitation candidate. Having arrived with her diagnosis does not mean that the girl's identity as patients is now stable and well defined, as my field-note shows:

During her Occupational Therapy session, the girl undergoes a functional assessment with the aim of evaluating her capacity to do everyday tasks involving the use of the hands. A decision about performing a surgery or not is to be made soon and the result of this assessment will be part of the elements that, together, the rehabilitation team, the medical companion, parents and patient will take into account when making such a decision.

During the assessment, the OT points out that the girl "*is very skilful with her hands*" and makes clear that he does not "*see any functional problem at all*". In his view,

*“without the fingers she is completely functional, she doesn’t have any limitation at all to do anything”*. She might not have thumbs, but this is not disabling in any way for her, her aplasia does not stop her from doing anything.

The functional assessment can be seen as a specific piece, among several others, of a negotiation process related to a surgical procedure. With this and other elements (the results of other sorts of clinical tests and examinations, rehabilitation experts experience and knowledge on similar cases, parents opinions, social and material considerations of the girl’s surroundings, etc.) the participants will decide between going ahead with a surgery on the little girl’s hands or avoiding such a physically and emotionally invasive intervention and just leaving her hands the way they already are.

But there is something else: I want to suggest that this process is also one of identity negotiation and configuration. Having a closer look to what is happening during the functional assessment we see that it is not only a decision about a surgical intervention that rehabilitation experts, parents and child are dealing with; simultaneously, it is also the girl’s identity either as a normal, healthy child or as a patient in need of a correction —as someone lacking of something, abnormal, deviant— that is on the negotiation table.

Because of the nature and specificities of the girl’s medical condition, this case results particularly interesting for our exploration of the process of configuration and assemblage of patients. The kind of aplasia she has can be referred to as a ‘boundary’ condition in the sense that it is located precisely within the boundaries between normality and abnormality, between health and illness. In order to perform a surgery on her, the girl has to be configured as a patient first. This collective work of patient configuration is crucial to allow any kind of medical intervention, including the

surgical one. Being granted the status of 'patient' legitimises the doctors' work on the person's body, which would otherwise be considered as a violation of the self. In the girl's case, the configuration of her as a patient becomes problematic because her condition destabilises contemporary Western concepts of normality and health.

In a society of docile bodies disciplined by medicine (see Foucault, 1991; 2003), medical discourses on normality and disability play a crucial role in setting the standards of what should or should not be accepted as a normal, healthy, able body. In clinical practice, such medical discourses get supported by a series of tests and examinations that, I suggest, are used as material 'proofs' of a person's deviance, defectiveness or/and abnormality, as well as of his/her subsequent need of normalisation. This is also the case when the outcome of those multiple tests gets configured in the opposite way; this is, when the person's identity is negotiated as being within the standards of normality and health. In the girl's case, the OT's functional assessment report will be one of such material proofs. This and other examinations will play a crucial role in the process of reconfiguring the child's identity either as a patient, status that would then allow for a corrective surgical intervention, or as a normal child, which would mean that surgery is not the path to follow.

The little girl of my story does not have all the fingers that the majority of people have, she does not look totally like them, she does not fit into a standard corporal scheme, and this is so by only two thumbs. Two thumbs are what seems to separate her from an 'us', from a 'normal'; two thumbs make her enter into the group of the 'deviated from the norm', the 'different', the 'others'. She seems to be missing her 'wholeness', and yet, she is complete like that, as the occupational therapist tells.

Although, from certain medical disciplines, non-standard bodies are assumed to be incomplete or defective and, therefore, disabling, in practice, this does not always result either in impairment or in disability, something that occupational therapy work very often shows.

As strange for the standard-bodied as it might appear, despite her aplasia, this girl can do just everything they do, even having a body that they consider incomplete or not fully developed. The functional assessment destabilises the girl's identity as a patient, as someone in need of normalisation, in this case, by means of a corrective surgery. It does so, by making visible the difficulties of tracing clear boundaries between normality/abnormality and ability/disability in clinical practices of rehabilitation.

However, this is not the end of the story: For the standard-bodied functionality might not be enough for someone to be accepted as one of them. The girl might be capable of doing everything we do, they would say, but she still does not look like us. Belonging to 'them', to 'the normal', takes more than doing the tasks they do, sometimes it might also require reshaping one's body into a standardized corporal scheme that makes oneself look like them. In the girl's case, a corrective surgery might be the means to achieve this complete fullness, not a functional fullness, but a corporal and an aesthetic one.

In clinical practices of rehabilitation, medical discourses around corporal scheme, aesthetic appearance and functionality do not always fit together, as the occupational therapist clearly points out: *"[...] the thing is that she is very skilful with her hands... and the other question is that you are told that you should improve the person's corporal scheme, but she is complete in this way... you see? [...]"*. There is a fine line that

divides normal, able people from the abnormal and disabled, a fine line that makes some bodies to be labeled as deviated and in need of a return to normality, a process which is called rehabilitation.

For any clinical intervention to take place, I suggest, a person has to be transformed into a patient first, s/he has to be configured as such. The configuration of a person into an object of medical knowledge does not precede clinical practice, in other words, patients are not pre-given entities that are somehow brought into a particular set of clinical practices. Rather than that, patients come-into-being *within* clinical practices and *in relation* to a wide variety of heterogeneous materials, including medical examinations, diagnostic tests, doctors, prescriptions, prognostic sheets, medical protocols and classifications, technical equipment, clinical discourses, health policies, etc. Patients are assembled through different practices, and it is throughout, not before, the rehabilitation process that they acquire all their attributes.

In order for a person to become a patient, I want to argue, a coherent narrative of a disorder or disease that will support his/her identity as such has to be produced. This ‘disorder/ disease narrative’ will, in turn, allow for and legitimise any clinical intervention on the patient’s body. However, the process of becoming a patient is neither straightforward nor automatic, there are a series of ‘*translations*’ —borrowing Latour’s term (see: Latour, 1987; 1991; 1999a; 1999b)— that have to take place, as we have seen (entering into a medical institution, for instance, does not automatically transform people into patients). This process is not linear either, on the contrary, throughout the rehabilitation process the person’s identity as a patient will be continuously re-negotiated, as I will show all along the chapters of this thesis. The work of patient-assemblage is neither straightforward, nor smooth; sometimes the

status of patient is destabilised and becomes difficult to sustain. Paradoxically, the very medical practices and discourses that turn a person into a patient can simultaneously question and put into tension such an identity.

My suggestion is that, becoming a patient is also a process of ‘identity legitimization’, both processes get materialised in a diversity of clinical practices carried out within diverse medical settings. These processes also take material shape as textual ‘inscriptions’ that circulate in different ways (in the form of prescriptions, diagnostic sheets, examination reports, test results, etc.). Together all these elements interweave a material, subjective, social and instrumental relationship between person, body, patient and disease.

### *Patients as Hybrid Collectifs*

In order to better understand the always-in-the-making, relational character of the figure of the ‘patient’, the notion of the ‘*hybrid collectif*’ can be very useful. This metaphor was proposed by Michel Callon and John Law in the mid-nineties, partly as a methodological alternative to their earlier material-semiotic notion of the ‘*network*’, which had been criticised for its —apparently— centering tendencies, as well as for what was seen as a managerialist and masculinist language of its empirical studies (see e.g. Star, 1991<sup>35</sup>).

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<sup>35</sup> In addition to these criticisms to the Actor-Network perspective there were other, including its use of metaphors associated with the military, the focus of its studies on the powerful, its role as a technology of Othering and the unawareness of its own politics (see: Star, 1991; Lee and Brown, 1994; Haraway, 1997). Throughout the years, Callon, Latour and Law, the founders of the ANT approach, have all responded to these criticisms in several ways, for some of these responses, see: Law, 1994; 1997; 1999; 2007; Latour, 1999b; 2005; Callon, 1999).

Rather than its English translation, these authors used the French term '*collectif*' in an attempt to avoid an erroneous understanding of the concept as purely made up by social or human elements. Instead, engaged with symmetry and human-decentredness, both characteristic of the actor-network tradition, they wanted to highlight the materially heterogeneous (not exclusively human) configuration of realities, even those commonly called 'social'.

Callon and Law's *hybrid collectif* denotes sets of specific and ordered arrangements of materially heterogeneous relations (Callon and Law, 1995; 1997). And these relations are said to be 'materially heterogeneous' because they are neither purely 'social' nor purely 'natural', but include, simultaneously, human and non-human materials: they might include people, artefacts, institutions, narratives, inscriptions, practices, subjectivities, embodiments, all at the same time. Put in relation, the heterogeneous materials that constitute these arrangements mutually help to shape one another and also sustain the *collectif*. In addition, it is through this mutual inter-shaping that they acquire all their attributes which, in turn, means that attributes considered to be purely human, such as agency and intentionality, are, in fact, relational effects, this is, they are collective products rather than intrinsic human qualities.

Unlike the early ANT metaphor of the networks, the '*hybrid collectif*' accounts for more than the functional relations and exchanges between human and non-human materials (see: Moser, 2003). As a tool of sociological reflection and analysis, this notion is less about the 'materials' themselves, and more about the [inter-]relations that configure such materials as individual entities with particular attributes, as well as about the always situated socio-material realities that such relations enable.

This metaphor results useful for the analysis of the figure of the patient because it allows us to explore the process of configuration and assemblage of entities as well as their fluidity (see: Law and Singleton, 2000) and mutability. Explained in these terms, ‘patients’ can be understood as *hybrid collectifs*, as ordered and situated arrangements or assemblages of materially heterogeneous relations.

In their work on surgery and surgical practices, Michel Callon and Vololona Rabeharisoa (1999) have mobilised the metaphor of the ‘hybrid collectif’ by making reference to what they call the ‘*patient collective*’. These authors explore the reconfiguration of bodies and persons within surgery<sup>36</sup>. They tell us that these reconfigurations take place not only during the surgical procedure itself, but that

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<sup>36</sup> In their paper on labour sociology applied to surgery (see: Callon and Rabeharisoa, 1999), Callon and Rabeharisoa critically comment on Peneff’s exploration of the surgeon’s work (see: Peneff, 1997) and on his argumentation that surgery can be seen as ordinary labour. According to Peneff (1997), during an operation the surgeon plays the role of an orchestra host, of a coordinator of small teams, which are divided by their background, their place in the hospital and their knowledge hierarchy; the surgeon’s work, says Peneff, is the harmonious assemblage of the tasks of all these teams. Drawing on Hirschauer’s work on the ontological reconfigurations of patients and bodies in surgery, and on surgical operations as encounters of disciplined bodies (see: Hirschauer, 1991; 1994), the authors argue that, although Peneff’s exploration gives us a good insight into the organisational work carried out by heart surgeons, his analysis of surgical work pays no attention to the body of the patient who undergoes the surgery (Callon and Rabeharisoa, 1999). For them, Hirschauer’s exploration of surgery within the operating room complements, in a way, Peneff’s analysis, since it takes into account the surgical bodies of both, patient and surgeon, as well as paying attention to surgical skills, techniques and artefacts. However, unlike Peneff and Hirschauer’s analyses, Callon and Rabeharisoa (1999) suggest that, the study of surgery and surgical practices should also look at the work preceding and following the surgical procedure itself.



surgical reconfigurations start well before the operation and continue after this has been carried out. Their suggestion is that, in order to understand surgery, it is necessary to pay attention to what happens before and after the surgical procedure itself, this is, to look at other places and events in addition to the operating room and the surgical intervention.

The series of reconfigurations of bodies and persons Callon and Rabeharisoa talk about refer to the multiple transformations that the ‘patient collective’ goes through before, during and after surgery and they also tell about the collective’s fluidity and mutability. Callon and Rabeharisoa’s ‘patient collective’ is an arrangement of bodies and persons, artefacts, techniques and skills, subjectivities and modes of embodiment, shifting boundaries, mutable identities and distributed agencies. Patient collectives, as any other hybrid collectif, are fluid entities, they transform themselves and the heterogeneous materials within them; they take particular shapes but they can always be otherwise, and this is because different relations and exchanges between their materials produce different outcomes, different configurations of/within hybrid collectifs enable different realities.

Unlike the metaphor of the ‘networks’, the *hybrid collectif*,

“makes it possible to grant bodies their full significance at the heart of the political articulations of the collective; to deal with boundaries, within and between collectives, as more than quantitative, technical considerations; to deal with the identities, individual and collective, that these collectives and boundaries shape; and to deal with the diversity of settings and forms of relations that make collectives” (Moser, 2003:45).

Regarding to patient collectives in particular, Callon and Rabeharisoa argue that their reconfiguration takes place through what they call ‘trials’, which refer to

particular moments or events in which the heterogeneous relations within the collective as well as the entities that they make possible become tested and get redefined, e.g. taking new shapes, expressing new attributes, distributing agencies and boundaries differently, performing new subjectivities and modes of embodiment, etc. (Moser, 2003). According to these authors, such trials and their outcomes help to trace particular trajectories of bodies and persons in surgery. In his work on surgical trajectories and following Callon and Rabeharisoa's argument, Moreira also makes reference to such trials, which he understands as "occasion[s] in which the specificity of the forces, the relations, the elements, involved in the collective become determined, available, and (re)constituted" (Moreira, 2001:33, in: Moser, 2003:45).

Referring to the same concept, however, Moser (2003) argues that identifying trials and the subsequent alternative trajectories that these might trace, shapes one's narrative and enactment of reality in a way that is based on an assumption of singular, exclusive and closed paths, which are created by homogenising differences and concealing complexities (2003:46). For this reason, in her study of road traffic accidents, she proposes to take instead a slightly different approach, asking us to pay attention to the differences, the shifts and the multiplicities. For Moser, "it is more fruitful to speak of a continual process of decomposition and recomposition, in which hybrid collectives are shifted and reconfigured, than to try to identify a set of more important trials that shape a singular and exclusive future trajectory of the collective" (Moser, 2003:46).

It is by looking at this process of *ontological reconfiguration*<sup>37</sup> of hybrid collectifs —which Moser calls of decomposition and recomposition (see: Moser 2003)— that, in the next chapters, I explore the multiplicity of interrelations between patients and prosthetic devices that emerge throughout the rehabilitation process. The notion of the *hybrid collectif* is crucial to this exploration precisely because it allows us to understand the complexity, heterogeneity and fluidity of entities and of their relations. In this context, in my analysis I mobilise an understanding of bodies, persons, patients and prostheses as hybrid collectifs that elaborate and re-elaborate themselves and one another within clinical practices of rehabilitation; my interest is to follow the ontological reconfiguration of these entities all along the rehabilitation process, which itself can be conceptualised as a hybrid collectif in its own right.

Introducing the metaphor of the hybrid collectif into my exploration of the figure of the patient, which I have been developing in this chapter, and specifically, into the analysis of the empirical case presented above, what we can make of the occupational therapy session and the girl's functionality assessment is that it becomes a process of configuration and assemblage of a new medicalised hybrid collectif, of a patient-in-the-making. In addition, the assessment can also be understood as a crafting tool for assembling 'patients'.

However, during the occupational therapy session, the functionality assessment has also turned into a forum of contestation and destabilisation of the very same collectif that rehabilitation professionals attempt to produce. And this is because, at

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<sup>37</sup> In his work on surgical practices, Hirschauer mobilises the notion of 'ontological reconfiguration' which he understands as a process of recomposition of the attributes and abilities of bodies and persons (see: Hirschauer, 1991; 1994).

the same time, another hybrid collectif, one that embodies the figure of a normal and healthy child, is also being enacted and redefined by the human and non-human participants involved in the assessment. We could say then, that the session has become one of [dis]configuration and [dis]assemblage of hybrid collectifs, in which both, the work of configuring patients and the one of disconfiguring them are simultaneously displayed.

As we can appreciate from my field-note excerpt, the sort of hybrid collectif that is being reconfigured during the occupational therapy session is shaped by many different heterogeneous materials: a little girl with a non-standard body; the prospect of a corrective surgery; a mother with expectations and concerns, an occupational therapist weighing up discourses on functionality and corporal aesthetic appearance; medical narratives on normality and disability; functionality assessment methods and techniques; diverse embodiments of what it means to be complete and healthy; identities that don't fit together and yet, co-exist; boundaries that get blurred, a sense of belonging, difference and bodily wholeness; a series of mundane artefacts and daily activities; different possible futures for negotiation, and even myself, as the ethnographer producing this very situated, partial, subjective and non-neutral account of the situation described. Together, all of these elements give shape to this hybrid collectif called 'patient', or more precisely, the '*rehabilitation patient*'—since 'patient' cannot be taken to be a singular entity; the 'rehabilitation patient', for example, is different from the 'surgical patient', although they might share many of each other's attributes—. This new *rehabilitation patient* hybrid collectif is full of alternative outcomes, full of tensions, full of imprecisions, full of objects, meanings and boundaries in-the-making.

As we have seen, the notion of the *hybrid collectif* helps us to shape a kind of ‘patient’ that is considerably different to that from classical medical anthropology. Within this discipline, the figure of the ‘patient’ is conceived as an already given entity, immutable, singular and with well-defined attributes and properties; and it is precisely because of this assumption that it is taken for granted and left unproblematised. In addition, the patient is understood in terms of a distinction between the patient as a body and as a person, separation that can hardly be sustained empirically. Understood in terms of hybrid collectifs, on the contrary, patients become entities in-the-making, multiple and materially heterogeneous assemblages. As relational entities performed in clinical practices, patient hybrid collectifs transgress the modernist divide between body and person; rather, from this stance patients are better understood as ‘embodied subjects’.

The little girl of my field-note, for example, cannot be reduced to a body with missing and defective parts which, in turn, make her an object of medical knowledge. Neither can she be reduced to the purely subjective experience of what Western medicine has constituted as a disorder. During the functional assessment, multiple corporealities and subjectivities get simultaneously enacted by the participants: A sick body that is an object of medical knowledge, a body in interaction with mundane artefacts, a body worn within a specific socio-material context, a body judged according to particular functional and aesthetic criteria. An abnormal child and a child just like any other, an incomplete person and a complete one, etc. Throughout the assessment, these different embodiments co-exist with each other, enacting at once, a girl and a patient.

In the session, occupational therapist, girl and mother, artefacts and clinical examinations, daily activities and narratives of the quotidian reality, all of these and other elements help to shape different corporealities and subjective experiences. In practices, at least in those related to clinical rehabilitation, body and person do not exist in separate realms, rather, they are fully intertwined elements of the same hybrid collectif called patient.

### *Enacting and Multiplying Hybrid Collectifs*

Inside the different laboratories and areas of my ethnographic site multiple ‘*rehabilitation collectifs*’ are made emerge all along the patient’s rehabilitation process. Undertaking an exploration of the heterogeneous materials and practices that shape these sort of hybrid collectifs can help us to better understand how bodies, prostheses and persons, as well as the very notion of rehabilitation, get done and re-done during the process.

Studies that draw on the material semiotics intellectual tradition —unlike the more conventional sociological and philosophical studies—, orbitate around the question ‘how’, rather than that of ‘why’, which directs the latter ones. Material semiotic studies preoccupations and reflections move from epistemology to ontology. Instead of analysing finished objects of knowledge and elaborating absolute definitions and principles, these studies focus their attention on processes and practices, which allows them to explore their objects ‘in-the-making’. And this is so because material semiotic scholars do not take their objects for granted, rather, they question their very nature and, in turn, generate knowledge about them precisely by looking at the practices in which such objects emerge, and assuming that such

practices are always situated within particular sets of materially heterogeneous arrangements.

In her study on atherosclerosis, for example, Annemarie Mol (2002) undertakes an exploration of the situated practices *in* and *through* which such a disease gets materialized. Different research methods and strategies tell us different things about our objects of knowledge. Although, atherosclerosis has been widely discussed in thousands of medical textbooks, scientific papers and clinical reports, instead of immersing herself in endless pages that describe with rigorous detail *what* atherosclerosis *is*, Mol decides to take an ethnography-based research approach that she calls ‘empirical philosophy’ and asks *how* atherosclerosis is *done in practice*.

Engaged with the exploration and theorising of philosophical questions, her empirical philosophy does not attempt to explore atherosclerosis in the abstract, but instead it grounds its explorations in empirical cases of analysis<sup>38</sup>. In addition, Mol’s empirical philosophy takes as a starting point the idea of the ‘situatedness’ of the issues studied; in consequence, its formulations are not intended to be universalistic in kind, but circumscribed to the particular case(s) of study. In this context, throughout her ethnography, this author follows patients, clinicians, pathologists, sick vessel walls, cell samples, severe leg pain, medical records, clinical reports and other human and non-human participants around the wards and laboratories of a Dutch university hospital. By analysing the situated practices carried out around the diagnosis and treatment of atherosclerosis, Mol is able to look at the way in which each of the

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<sup>38</sup> Furthermore, it does not intend to find a single ‘right’ answer, but it may well arrive to several different answers, some of them even contradicting each other.

participants ‘*does*’ atherosclerosis in and through a variety of medical practices; to say it another way, she looks at how participants ‘*enact*’ atherosclerosis.

At this point it is necessary to be especially cautious with two concepts in particular that might come to mind; these are the one of ‘*representation*’ and that of ‘*production*’. The concept of representation implies that the object of knowledge is independent from the cognoscent subject, a completely separated, passive entity which is part of an outside ‘real’ reality, one that is out there waiting to be discovered by the viewer. As I have already explained in the previous chapter, many STS and feminist science studies scholars have strongly argued against such idea since this vision of the world and reality can hardly be sustained empirically. With respect to the concept of production, the issue is that it implies the existence of a rational, conscious and intentional human producer who is capable to, somehow, produce an [non-human] entity which, again, is seen as passive and separated from the subject. In this sense, agency is exclusively located in the human actor, while non-humans are stripped away of all character as active agents in the production of reality. From a material semiotics approach, on the contrary, agency is not an inherent human quality, but an attribute acquired in relation. In addition, there is no rational, intentional human constructor of a passive reality at all, but endless arrangements of materially heterogeneous relations in which subjects, objects and even reality emerge. No entity pre-exists its relations, rather, entities are done in practice; the notion of enactment derives from this assumption.

Mol’s notion of enactment constitutes a material semiotic alternative to those concepts. In her analysis, atherosclerosis is neither represented nor produced; it does not exist *per se*, prior to its relations, rather, it is *relationally enacted in and through*



*practices*. Positioning oneself within this framework generates what Mol refers to as a “multiplying effect”, in her words:

“Attending to enactment rather than knowledge has an important effect: what we think of a single object may appear to be more than one. [...] a plaque cut out of an atherosclerotic artery is not the same entity as the problem a patient with atherosclerosis talks about in the consulting room, even though they are both called by the same name.”  
(Mol, 2002:vii).

In this sense, enactments of atherosclerosis are multiple, co-existing with each other. Sometimes different atherosclerosis may coincide, some others they may contradict one another. Such a multiplicity of enactments makes Mol suggest that atherosclerosis is not a single object, but a multiple one. In practices, she argues, each of the participants enacts a different atherosclerosis. Although, they both call it ‘atherosclerosis’, clinicians and pathologists refer to a different object. Although, patients too talk of atherosclerosis, this is a very different one to those of the clinicians and the pathologists. In practices, atherosclerosis becomes a multiple object, one that is, at once, ‘more than one and less than many’.

Drawing on Mol’s notion of enactment, this research deals with a variety of rehabilitation management practices conducted at the rehabilitation centre by a biomedical engineer, a rehabilitation medicine specialist, and a dozen of orthotists/prosthetists and occupational therapists. It is not my aim to analyse the ways in which rehabilitation-oriented medical fields (Biomedical Engineering, Rehabilitation Medicine, Orthotics & Prosthetics and Occupational Therapy, for the case of this study) ‘know’ their objects of concern; neither, I want to state what those objects are or should be, nor to try to provide any universal definition of them. Instead, following a material-semiotic perspective, in this study my interest is focused

on the clinical practices that make emerge particular ‘rehabilitation’ entities, on how those entities ‘*come into being*’ and get shaped and reconfigured throughout the rehabilitation process.

My purpose, in other words, is to explore and reflect on the different ways in which such rehabilitation objects are ‘*enacted*’ in everyday clinical rehabilitation practices, on how they are *performed*<sup>39</sup> and their ontologies [re]configured. In this sense, the character of my research resonates with Mol’s empirical philosophy program since, among other things, it seeks to reflect on an ‘*ontological politics*’ of rehabilitation practices around orthotic & prosthetic devices. This focus on ontological politics and enactment radically contrasts with the epistemological interest in the nature of knowledge as well as the methods, limits and validity of the different ways of knowing reality. From a relational ontology approach instead, entities as well as realities do not pre-exist their relations but are constituted in practice, as I have already pointed out above.

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<sup>39</sup> As in the case of ‘enactment’, there are other notions that have also been mobilized to make reference to the idea that ‘realities are constituted in and through practices’; one of them is the concept of ‘performativity’, term that has been used by authors like Erving Goffman (1959), Judith Butler (1990, 1993, 1997, 2004), Karen Barad (2003), Andrew Pickering (1995) and Michel Callon (1998, 2007). As a notion, ‘performativity’ has been used differently by different authors, each of them giving it particular meanings and attributes. Some other authors, however, have preferred to avoid the term pointing out that it gives a sense of a theatre-like event taking place when referring to specific practices (see e.g. Moser, 2003). In addition to this, and in contrast to ‘performativity’, the notion of ‘enactment’ considers entities as material-semiotic effects that are the product of heterogeneous relations between humans and non-humans.

In the following three chapters I explore empirically how clinical practices of rehabilitation around orthotic and prosthetic devices make emerge multiple ‘rehabilitation collectifs’. Here, I mobilize an understanding of patients, prostheses and rehabilitation as hybrid collectifs *in-the-making*, and of the rehabilitation process as one of configuration and assemblage of a hybrid entity in which patient and prosthesis are put in relation and become intertwined into a new and complex collectif of material semiotic relations. To do this I follow the series of transformations and reconfigurations that patients and prostheses go through during the rehabilitation process at the three different laboratories of the centre described in the first chapter of this thesis, namely, the Gait and Movement Laboratory, the Orthotics and Prosthetics laboratory and the Occupational Therapy Area.

In my thesis, I approach each of these laboratories as collectifs-in-the-making themselves which, simultaneously, make emerge other rehabilitation collectifs within them. I want to suggest that, throughout the rehabilitation process, patient and prosthesis get constituted as a new hybrid entity which I call the ‘rehabilitation patient’ and that will move and be reconfigured from one laboratory to the other; this new hybrid, rather than singular will be shaped as a multiple entity, since different materially heterogeneous practices will enact specific kinds of rehabilitation patients. In addition, I argue that, during the rehabilitation process, particular enactments of bodies, prostheses and persons, as well as of rehabilitation, [ab]normality and [dis]ability come into being and coexist with each other. Also, I show how different collectif assemblages produce different realities, different patients, different prostheses and different ‘rehabilitations’.

### **3. ENACTING REHABILITATION COLLECTIFS AT THE GMLAB I**

At the beginning of this thesis I presented a general overview of the rehabilitation centre where I carried out my ethnography. I told about its overall distribution and its administrative and medical organisation. I also introduced briefly the three areas within the centre in which my field research was focused: the Gait and Movement Laboratory (GMLab), the Orthotics and Prosthetics Laboratory (OPLab) and the Occupational Therapy Area (OTA). In addition, I described the standardised rehabilitation treatment trajectory at the centre—including the way in which it is established and negotiated together by the medical team of interconsulting doctors, the patient and his or her relatives—as well as how such a trajectory usually unfolds<sup>40</sup>.

As I explained, the centre specialises in the rehabilitation treatment of patients with neuromusculoskeletal disorders and amputees. Such treatments, I said, very often involve the use of an orthotics or a prosthetics. Although, they are at the core of the clinical management of many such patients, these devices have drawn practically

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<sup>40</sup> Here I am using the conventional meaning of the term ‘trajectory’. For a discussion on what ‘trajectory’ means particularly for the case of surgical practices, see: Moreira, 2001.

no attention as an object of study neither from a sociological, nor from a STS-informed perspective<sup>41</sup>, which is precisely one of my aims in this thesis.

A basic starting point of this work is the idea that within the different areas, departments and laboratories of the centre, multiple *rehabilitation collectifs* get enacted. In this research, I have focused on those collectifs specifically related to the incorporation and use of prostheses into the patient's rehabilitation treatment. Here, I am mobilising the term '*prosthesis*' to make reference to either prosthetic or orthotic devices, in the understanding that both of them act, simultaneously, as extensions and as parts of a person's body.

In the case of the Gait and Movement Laboratory, which is the focus of the present chapter, human and non-human agents interact together establishing particular relations between them, this, in order to shape a very particular *gait collectif* that will, in turn, allow for specific practices —crucial to the patient's rehabilitation process— to take place. By tracing the emergence of such *gait collectif*, in this chapter I analyse and reflect on the clinical practices of rehabilitation around orthotic and prosthetic devices carried out at the GMLab.

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<sup>41</sup> From the sociological and STS approaches the studies related to assistive devices have focused on other kinds of artefacts, such as wheelchairs (e.g. Winance, 2006 and Moser, 2003) and blood glucose monitoring systems (e.g. Mol and Law, 2004). Studies around prosthetic devices can be found within the fields of psychology and medicine, as well as related sub-disciplines such as Occupational therapy and Rehabilitation medicine (see e.g. Dillingham, et al, 2001; Wetterhahn, 2002; Haber, 2006). It results particularly interesting to note that, from the psychological field, there is a considerable amount of studies related to amputee patients and the experience of amputation which focus on what is known as the 'phantom limb' (see e.g. Jensen, et al, 1983; Katz and Melzack, 1990; Nikolajsen and Jensen, 2001).

### *Story 1:*

December 07<sup>th</sup>. Full of small toys lining up and waiting to be discovered by a child's gaze, the bright blue shelves on the left side of the room stand out from the white walls of this lab... Next to the shelves, there is an examination couch where physical evaluations are performed to all patients before the gait assessment takes place.

At the back of the room, on the right corner, there are three computer monitors on a desk, this is the place where all the data collected during the gait assessment is processed and also where the clinical reports are written. Next to this 'central control', also at the back of the room, there is a viewing light box that is used to read the X-rays of patients whose medical team has required them to be looked at by the specialists at the GMLab.

A ten meter brown & black walkway extends all along the room. Its surface is full of receptors that capture diverse data related to the patient's gait pattern, data that is then employed to both, evaluate any pathological aspects of his/her locomotion, and to provide information about how it might have been affected by the patient's diagnosed disorder.

After the patient has been admitted for treatment at the rehabilitation centre, s/he is assigned what is called a 'medical companion', a specialist who will be following her rehabilitation process from the beginning to the end. Among other tasks, the patient's medical companion will be the main communication channel between the interconsulting team, the patient and her relatives, task that will take special relevance particularly in decision-making situations.

The first stage of the rehabilitation process involves a thorough assessment and the performance of multiple tests which are conducted in order to: firstly, evaluate the patient's initial clinical state; secondly, decide among the different treatments available; and thirdly, structure the most optimal rehabilitation program for him or her. Among the whole battery of tests, the medical companion will frequently request an analysis of the patient's gait pattern, an evaluation that is performed at the GMLab. A gait analysis is defined as "the systematic measurement, description and assessment of those quantities thought to characterize human locomotion" (Davis, et. al., 1991:575), it provides quantitative data that allows clinicians to evaluate the extent to which an already diagnosed disorder has affected the patient's gait<sup>42</sup> (Brand and Crowninshield, 1981).

Inside the GMLab everyday clinical practices are organised around what is called the '*Gait Assessment*'. Different sets of clinical protocols and technical equipment are used for the assessment of a patient's gait, one of them –which is the one used at the GMLab– is the '*gait analysis laboratory*'. This 'laboratory' was developed as an instrument for "quantified assessments of human locomotion which assist in the orthopaedic management of various paediatric gait pathologies" (Davis, et. al., 1991:575). The GMLab's lab consists of a stereophotogrammetric video-based data collection motion-measurement system and a dynamometric platform, which include a ten meter walkway with two force plates, a motion capture and analysis software, an optoelectronic system of eight infra-red cameras, and a set of twenty-

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<sup>42</sup> Brand and Crowninshield (1981) highlight the use of the gait analysis as an evaluation tool, rather than a diagnostic one.

three retroreflective markers<sup>43</sup>. In addition, the material infrastructure of the laboratory is complemented by a telemetric electromyography (EMG) system — equipped with several pairs of electromyographic transducers—, as well as by different equipment and tools used for physical examinations, including goniometer<sup>44</sup>, pelvimeter<sup>45</sup>, small orange headed reflex hammer<sup>46</sup> and measuring tape.

At the GMLab, the gait analysis laboratory is shaped by multiple elements; its material infrastructure is only one part of it. These elements not only include things, but also instrumental and social practices which, arranged as a complex set of heterogeneous materials, together they constitute one of the multiple material-

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<sup>43</sup> There are several commercially available systems for motion data collection which are used in clinical gait analysis, these include the English *Vicon* (by Oxford Metrics, Limited) and the American *ExpertVision* (by Motion Analysis, Incorporated). Similar optical tracking systems have been developed in a variety of medical institutions, such as the one at the Newington Children's Hospital in the USA developed in 1980 by United Technologies Corporation (Davis, et. al., 1991).

<sup>44</sup> A goniometer is a tool used in medical and clinical practice to measure the degree of movement of a patient's joints.

<sup>45</sup> A pelvimeter is a tool used in medical and clinical practice to measure the dimensions of a person's pelvis.

<sup>46</sup> This is a medical instrument used to test deep tendon reflexes as a part of a neurological physical examination, this, in order to detect abnormalities in the central and peripheral nervous systems. Reflex hammers started to appear at the end of the nineteenth century; nowadays there are several models and designs, the one used at the GMLab is known as the Taylor or tomahawk hammer which consists of a metallic handle with a thermoplastic rubber triangular head. The Taylor hammer was designed by John Madison Taylor in 1888, is significantly lighter in weight than the European ones, and it can also be used for the percussion of chest and abdomen.



semiotic apparatuses<sup>47</sup> involved in what I call the ‘gait-collectif’, as I will show in this chapter. This material-semiotic apparatus will be vital for the production of meaningful data during the gait analysis and, therefore, for the sort of medical intervention that will result from the gait assessment.

The specificities of the laboratory’s material setting, along with determined clinical methods, techniques and procedures, help to shape particular testing protocols for gait assessment<sup>48</sup>. Different protocols have been developed around the world by the joint work of clinicians, rehabilitation specialists, biomedical engineers and other experts from the medical field. In this context, the gait protocol used at the centre’s GMLab is known as the Davis protocol, named after the clinician who proposed it (see: Davis, et. al., 1991).

Following the Davis protocol, at the GMLab the gait assessment involves two different evaluations, first of all, patients undergo a *physical examination* and, afterwards, they undergo a *gait analysis*, also known as a *motion test*. Although, this

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<sup>47</sup> Here I am drawing on the Foucaultian ‘*dispositif*’ (see: Foucault, 1991; 2003).

<sup>48</sup> By following the construction and use of an oncology protocol and the Cardio-Pulmonary Resuscitation protocol (CPR), Timmermans and Berg (1997) have studied the practices of standardization through medical protocols. For these authors a protocol can be understood as a “technoscientific script which crystallizes multiple trajectories” (Timmermans and Berg, 1997:275). In their work, they argue that universality is always local, and that the process of achieving such *local universality* involves the protocols being changed and partially re-appropriated. According to them, “[L]ocal universality emphasizes that universality always rests on real-time work, and emerges from localized processes of negotiations and pre-existing institutional, infrastructural and material relations” (Timmermans and Berg, 1997:275). Universality, therefore, becomes a distributed activity which actually emerges in and through locality.

is the usual order in which gait assessments are performed, in some laboratories the physical examination is carried out after the motion test. For the clinicians at the GMLab, conducting the physical examination first allows patients to become familiarised with them and, it also gives them some time to relax and prepare themselves for the gait analysis they are about to perform. For some patients, the gait assessment will include an *electromyographic study*, this will depend on the sort of evaluation prescribed by his or her medical companion<sup>49</sup>. At the GMLab all the assessments are always jointly conducted by two specialists of the centre, Dr Valle, a doctor specialised in Rehabilitation Medicine, and Dr Campos, who is a biomedical engineer<sup>50</sup>. From time to time, a graduate student –or, indeed, an ethnographer– will attend the sessions too.

In clinical practice, gait assessments can be performed for four different purposes:

“1) [for the] *Diagnosis* between disease entities, 2) [for the] *Assessment* of the severity, extent or nature of a disease or [an] injury, 3) [for] *Monitoring* [the patient’s] progress in the presence or absence of intervention, [and] 4) [for the] *Prediction* of the outcome of intervention (or the absence of intervention)” (Baker, 2006:2)<sup>51</sup>.

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<sup>49</sup> In addition to gait assessments, there are other sorts of practices which also take place at the GMLab, for example, the work of ‘trying on, fitting and adjusting’ several kinds of assistive devices and rehabilitation aids (e.g. wheelchairs, gait trainers, etc.). However fascinating these practices are for sociological exploration, they are out of the scope of this research.

<sup>50</sup> All names mentioned in this thesis are not the real ones; this is to conceal the identity of the people I have worked with during my ethnography.

<sup>51</sup> Richard Baker (2006) has proposed these four reasons for performing a clinical gait analysis as a modified version of Richard Brand’s four reasons for performing *clinical* tests (Brand, 1981; 1987),

At the GMLab, the gait assessment is used more often as an evaluation tool, rather than a diagnostic one, this is because when patients arrive here they have already being diagnosed<sup>52</sup>. On the one side, patients with neuromusculoskeletal (NMS) diseases will be referred to the GMLab in order to determine whether or not they are suitable candidates for orthotics and, if so, the sort of device that would be optimum for them. On the other, certain lower-limb amputee patients will be referred here too, in this case, as potential candidates of a prosthetic device.

In what follows I analyse in detail the gait assessment process as a series of material semiotic practices aimed at assembling –and enabling– a particular gait collectif<sup>53</sup> in and through which different relations between patient and prosthesis are made possible and, in turn, get enacted and multiplied, resulting in the intertwining of both into a new multiple entity.

### **Enacting the GMLab's rehabilitation collectif**

As I mentioned in the previous chapters, the patient's rehabilitation process can be analysed, for methodological purposes, as a series of different stages<sup>54</sup> or sets of practices through which the patient moves all along his or her rehabilitation treatment

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which are: “1) to distinguish Diagnosis between disease entities (diagnosis), 2) to determine severity of disease or injury (i.e. assessment or evaluation), 3) to select among treatment options, and 4) to predict prognosis” (Baker, 2006:2).

<sup>52</sup> Nevertheless, such a diagnosis is confirmed before the beginning of the patient's treatment program, this, in order to avoid misdiagnosis.

<sup>53</sup> Here I am drawing on Callon and Law's notion of the *hybrid collectif*, as I explained in the previous chapter (see: Callon and Law, 1995).

<sup>54</sup> Using Callon and Rabeharisoa's terms, these stages could be referred to as 'trials' (Moreira, 2001).

program. Inside each of the labs several phases can also be identified while exploring the emergence and assemblage of rehabilitation collectifs. In this sense, looking at these different sets of activity is the strategy that I follow in this and the next two chapters, this in order to develop my analysis of such rehabilitation collectifs.

### **Configuring the Gait Collectif**

For a gait assessment to be performed, it is necessary to set the required conditions in order to configure a particular gait collectif that enables such an assessment to be conducted, this is, that allows for the interweaving of specific and [more or less] coherent and durable relations between patient and prosthesis. This configuration entails a series of different coordinated and distributed actions<sup>55</sup> between the many heterogeneous participants involved in the gait assessment — including patients, medical specialists, administrative staff, patients’ relatives, request forms, prescriptions, rehabilitation protocols, gait analysis systems, diagnostic techniques, etc.—, which themselves constitute part of the material infrastructure that sustains the rehabilitation process. The preparations are diverse and complex, and get unfolded more or less as follows:

#### **Paperwork preparations**

*Story 2:*

December 19<sup>th</sup>. The 9.00am assessment has finished and the patient has left. Now we wait for the next case to arrive. In the meantime, I look through my field-notes and write down some of my thoughts, while Dr

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<sup>55</sup> On ‘*coordination*’ and ‘*distribution*’, see: Law, 1994 and Mol, 2002.

Campos —the biomedical engineer— looks through the next patient's medical records and through the assessment request form sent by his medical companion. According to what it says on the computer monitor, the patient is a young toddler who has been diagnosed with PDR, "*Psychomotor Development Retardation*", Dr Campos tells me. This will be the child's first gait assessment; his medical companion and team of interconsulting [doctors] are trying to decide whether a treatment program with orthotics could be a good option, and if so, the kind of devices that would be appropriate for him; for this reason, they have asked for a complete evaluation. The patient's assessment request form asks for an EMG to be performed, so this time we will also need to use the TET-Unit, which we have already prepared for the analysis. Dr Campos tells me that, since the patient is a toddler, the markers might be very close to each other when attached to his body, this could cause difficulties in the data collection because the infrared cameras could get confused and process the information "*in an odd way*" —they might miss some of the markers or, on the contrary, they might perceive markers that do not exist—; this would make the data collected very difficult to 'clean up' from all that 'noise'<sup>56</sup>... Therefore, he says, we will have to pay close attention to all those issues when conducting the assessment.

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<sup>56</sup> When performing a gait analysis, different kinds of 'interferences' might present, such as those mentioned in the field-note excerpt, these interferences are commonly referred to as 'noise', and they can be caused by a diversity of variables (e.g., by insufficient distance between markers when placed in specific anatomic landmarks, as indicated in the field-note). In consequence, when processing the data, the specialist must 'clean' all that noise before he can interpret the 'real' data.

*Story 3:*

April 12<sup>th</sup>. It's quarter to eight in the morning. Dr Valle —the rehabilitation specialist— and I look through the data from an assessment conducted days ago while waiting for the 8.00am patient, a nine year-old girl with mild CP (Cerebral Palsy). On another computer screen we have a physical examination format ready to be filled with information gathered during the patient's assessment.

Time passes slowly and the girl has not yet arrived...

Now, a conversation between Dr Valle and Dr Campos unfolds about some mistakes apparently made in several of the examinations conducted in the past few days. They do not know the cause of these mistakes yet, but decide that they will check the equipment and recalibrate the laboratory later in the day. From time to time this conversation is interrupted by one of them leaving the room to see whether the patient is here.

8:30am and still no news from the patient. There were three patients scheduled for today, at 7, 8 and 9 o'clock, respectively. The 7am patient did not arrived, and the 8am one is still not here. I wonder what is happening... Yesterday it was the same, none of the patients arrived, and it seems that today it is going to happen again.

8:40am. The patient is here. It turns out that she was here but there was some confusion among the administrative staff which did not call her name and ask her to come to the lab (it also seems that yesterday they sent

the gait patients to physical therapy instead). Now there is another problem with the patient: Her mother argues that they were not told either about the kind of clothes her daughter had to wear for the assessment or that she had to bring her new orthoses (the purpose of this assessment was precisely to evaluate the extent to which the kafos<sup>57</sup> help to improve her gait)... In the end, Dr Valle and Dr Campos decide to reschedule the assessment for next week.

#### *Story 4:*

February 23<sup>th</sup>. Our next case has just arrived: A little boy who can hardly articulate some words... sounds that result almost incomprehensible for everyone there but his mother. The child<sup>58</sup> uses a specially designed padded walker which allows him to lean on two cushioned steel bars that give support to his arms while walking, and which also includes a small seat so that he can sit down whenever he gets tired or when the pain is so unbearable that makes it impossible for him to keep walking.

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<sup>57</sup> Among orthotists and rehabilitation specialists, the word 'kafo' is used as a shortened version of 'Knee-Ankle-Foot Orthosis' which, as its name indicates, is an orthotic device that goes from the patient's knee to his foot.

<sup>58</sup> For confidentiality reasons, throughout this thesis I avoid referring to patients by their names; instead, in field-note excerpts as well as text, I have substituted their names for the words: *the child*, *the patient*, *he*, or *she*.

It is very visible how badly his gait has been affected by the numerous disorders he has been dealing with throughout all his life. It is too difficult and painful for him to give even a couple of steps. [...] In the case of this patient, the gait assessment will help doctors to determine the kind of treatment path to follow (which can involve either surgical, pharmacological or orthotic management or a combination of them). Dr Campos looks at the request form sent by the child's orthopaedist on the computer screen and the following conversation takes place:

Dr Campos: [...] So, his doctor is requesting kinetic and kinematic analyses, with no electromyography... Did she explain to both of you what this evaluation was about? [the child smiles and articulates a sound that we all take to be a yes].

Mother: Yeah, well, she mentioned that he would be asked to walk on a platform several times...

Dr Campos: Yeah, that's right; that is what we are going to do today. First, we are going to take you a picture, and then you are going to walk from here to that wall... But before we start, the doctor is going to examine you and, after that, we are going to attach these little spheres to your body, so that those cameras can see you while you walk [pointing to the infrared cameras]. Could you take off his clothes and leave him only with his underwear? [to the child's mother].

Mother: Oh, by the way, the doctor also asked me to tell you if you could order one of those little cars, for him to move around.



Dr Campos: Little cars?, what kind of little cars?...

Mother: Like those that some children are using outside... I have seen several of them here at the centre.

Dr Campos: Oh yeah, the carts, those are 'hand propelled carts'<sup>59</sup>... Did his orthopaedist say that?, are you sure?...

Mother: Yes, she did... [she said] that maybe he could use one of those instead of his walker.

Dr Campos keeps silent for a moment, takes a deep breath and the conversation continues like this:

Dr Campos: Well, it does not say anything about the cart here... [He is abruptly interrupted by the patient's mother]

Mother: Maybe he could try on one of them today, after the test... in that way, it would be ordered this week, so that he could have it sooner; otherwise he would have to wait until the next appointment with his doctor [the orthopaedist].

Dr Campos: Look, I can't prescribe or make a patient to try on anything that has not been indicated in the request form... Besides, I find it

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<sup>59</sup> A 'hand-propelled cart' is a device that some non-ambulatory children may use as a mobility aid. Different kinds of carts are used according to the user's necessities. Those most commonly used have a padded plastic base and back support; the cart's base is often at ground level and has wheels on each side. As its name indicates, the cart is propelled by pushing its wheels with the upper limbs, while the lower limbs are kept still in a straight position.

quite strange that his orthopaedist considered that he could use a cart, because they are counter-indicated for children with the sort of disorders he presents...

Mother: But if he had a cart like those, it would make it easier for him to move around...

For what she says and how she says it, as well as for Dr Campos' reaction, it becomes clear to me that the child's orthopaedist did not order any cart for him, but rather, it was his mother's idea.

Dr Campos: With the disorders that he presents, if I gave him a cart, yes, it would be easier to move around, but at the same time I would be harming his internal organs and his bones... All the children you have seen with those carts, their [health] problems are different, and they use the cart just for a couple of hours; however, your idea is for the cart to substitute his walker, to spare him from the pain and so on, but that would make him more harm than good... When we prescribe a piece of equipment we have to make sure that it is not going to worsen the patient's condition. It is not only about which equipment provides [the patient] the most comfort and mobility and that's it, no, it is much more complicated than that... it is about finding a piece of equipment that, as I said, will not worsen the child's condition. Believe me, if he could use a cart without it causing him further problems, I would have ordered one for him ages ago. But there is a reason why he was prescribed that kind of walker. What we want is to make him walk, to make him move all of his body as much as possible, and that includes his legs... and [in order] to achieve that, we are trying to

facilitate his gait with the walker he has plus whatever his doctor decides after this analysis, be it an orthotics, or surgery, or whatever the assessment indicates it is best for him. So, next time you see his orthopaedist, just tell her that I did not want to order the cart, ok?.

Mother: Ok... [she nods]

Throughout the patient's treatment program multiple '*rehabilitation collectifs*' will get enacted. Sometimes, they will coexist with one another, more or less as parallel entities; some other times, they will come into being within other collectifs. In order to participate of their assemblage, the ethnographer should be able to keep continuously 'changing of scale', to put it in Latour's terms (see: Latour, 1983; 1987; 1991; 2005); this is, to move from the smaller to the bigger picture and back or, as Singleton and Michael (1993) would say, to become skilled in the business of zooming in and out.

At the centre's Gait and Movement Lab, carrying out a gait assessment implies the configuration of a particular 'gait collectif' constituted by specific agents and material relations that will, in turn, allow for the assessment to be performed. This gait collectif is only one of the multiple rehabilitation collectifs that, day after day, get shaped at the centre. Although, it comes into being inside the GMLab, it coexists in a parallel way with other collectifs outside of it, such as those enacted in the orthotics & prosthetics lab or in the occupational therapy area. Simultaneously to this parallel coexistence, many other heterogeneous collectifs will emerge precisely from within the gait collectif, allowing for—and sometimes resisting—its enactment.

Configuring a gait collectif involves, first of all, what in Foucaultian terms could be referred to as the setting of the required 'conditions of possibility' for its

emergence (see: Foucault, 1991; 2005). Looking at the activities that precede any rehabilitation process involving prostheses can give us new insights about the process itself as well as about the materials and practices that enable and sustain it. Authors like Callon and Rabeharisoa have made a similar suggestion for the case of the study of surgery and its management (see: Callon and Rabeharisoa, 1999). They argue that, in addition to the surgical procedure itself, a sociological analysis of surgery would be enriched by taking into account what happens before and after the actual operation. Their work on surgery comes as a response to Hirschauer's, in which he explores the socio-material interactions established between the body of the patient and what he calls 'the surgical body'. In his paper, Hirschauer's ethnographic observations are circumscribed to the operating room and the surgical procedure itself, ignoring any of the activities related to surgery that take place outside of them (see: Hirschauer, 1991).

For the case of this chapter, it is worth to explore what happens before a gait assessment takes place since, as I show below, those activities will give shape and sustain the gait assessment and its possible outcomes. At the GMLab, the setting of conditions for a gait evaluation is a diverse and complex process which involves a wide variety of agents, materials and practices, including those related to some of the most mundane activities, such as that of paperwork.

The stories above presented tell about three different patients in three different situations. What these stories have in common —apart that they all unfold at the GMLab— is that all of them have to do, in some way or another, with paperwork, be it in the form of a gait assessment request form, a prescription, a medical records electronic file, or even a simple sheet listing the patients of the day.

In order for a patient to have a gait assessment done, this has to be requested by his or her medical companion, who will send an assessment request form to the GMLab. In the form, the medical companion will indicate the parameters of the gait pattern characterisation that require a more detailed exploration and whether an electromyographic analysis should be also included in the assessment. Such characterisations include spatiotemporal, kinetic and kinematic parameters. Spatio-temporal parameters include: cadence, stance, single support normalised stride length and normalised walking speed. Kinetic parameters include: peak of plantarflexion moment and peak of ankle generated power. Finally, kinematic parameters include: range of motion (ROM) at hip, ROM at knee, ROM at ankle, peak of ankle plantarflexion, peak of ankle dorsiflexion in swing and foot progression (Davis, et. al., 1991; Vismara, et. al., 2007). If required, the electromyographic analysis evaluates neuromuscular activation and muscle action potentials within any activity.

When the request is made, a member of the administrative staff will schedule an appointment on one of the gait-assessment days —either on a Tuesday or a Wednesday—. Three other assessments will be scheduled for the same day, starting at seven or eight in the morning and finishing at noon. If everything goes according to plan, each of them will last for up to an hour. The scheduled appointments and assessment request forms are stored in the centre's computerised administration system, which also stores every single patient's medical records and rehabilitation history at the centre. All of this data can be accessed at any time by every one of the specialists involved in the patient's rehabilitation program.

At the GMLab, the first contact between patients and rehabilitation specialists is made through the assessment request form. On the one hand, this form includes

general information about the patient's identity (name, age, gender, medical companion's name, diagnosis, etc.). On the other, it describes the reasons why such an assessment has been requested, the gait parameters that require a detailed analysis, the course of action that is being considered, and any health or other issues to be taken into account when suggesting a treatment<sup>60</sup>, among other aspects. In this way, this simple format reveals crucial information not only about the patient, but also about the treatment program itself and the possible rehabilitation trajectory(ies) that might be followed. In other words, the request form tells about the sort of heterogeneous assemblage specialists at the GMLab will be dealing with during the assessment, the possible futures that might be created for the patient, as well as the kind of rehabilitation collectif that might be expected to be articulated for the next phase of the process.

The assessment request form from *Story 2* told Dr Campos, for example, that the patient was a toddler, that he had been diagnosed with PDR and that this was the first time he would undergo a gait assessment. It also told him that the child's medical team was considering orthotics as the next step in his rehabilitation trajectory and that, given the case, the GMLab would have to recommend a certain kind of orthotic device. In addition, through the request form Dr Campos learnt that they would need to use the TET-Unit during the assessment—for an EMG—, so he could have it ready before the child's arrival. Finally, he was also reminded about the

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<sup>60</sup> For some patients who suffer from osteoporosis, for example, it is not recommended to prescribe certain kind of orthotics and mobility aids, since walking itself could cause their porous bones to break. For some other patients, certain treatments and what they involve might result too expensive to be considered as an option. Therefore, the medical companion must clearly state all this in the form for the gait specialists to take this into account and consider alternative possibilities.

probabilities of technical difficulties while conducting the analysis and processing the data, as well as about the precautions he would have to take, all this given the patient's physical characteristics. In summary, the request form allowed Dr Campos to make sense of the patient and the sort of socio-material interaction they would be dealing with, to plan the gait assessment process in advance and to make all the necessary arrangements for it to develop as smoothly as possible.

Although, at the centre, assessment request forms are perceived more as a part of the burden of paperwork-related activities that clinicians cannot escape, and less as an element of their 'real' clinical practice, these and other apparently 'non-medical, paperwork' materials and activities are actually essential to the rehabilitation process, since they act as linkages between departments, clinicians, relatives, and particular sets of practices, and contribute to the configuration of the gait-collectif, as well as to the enactment of the patient as an object of clinical intervention particularly situated and full of specificities.

Request forms are only one of the many vital agents that mediate the first contact between the patient and the GMLab. As simple as a list of patients' names and areas might be, this is actually a key element for making possible such first contact, as *Story 3* clearly shows: Through the request form they were sent, Dr Valle and Dr Campos were able to know who they were expecting. They learnt that the patient was a nine year-old girl, that she had CP and that she would be wearing orthoses. They were able to prepare, in advance, for the reception of a very specific material-semiotic assemblage. However, the lack of an accurate list of patients and their scheduled appointments prevented the link between her and them from being established.

Assessment request forms are vital for the GMLab's clinical activities. No gait analysis can be performed without a request form backing it up, no patient can undergo any sort of examination without the written indications for it. Request forms tell clinicians what it is to be observed during the evaluation, what to look for, and how to do it (this, in terms of technological means, clinical procedures, etc.). But request forms do not stand by themselves; rather, they are always sustained by the patient's clinical history. Before every assessment, Dr Valle and Dr Campos will always have a look at the patient's medical records. This allows them, among other things, to put in context what they are being asked in the request form; this is, to relate the examinations requested to the individual's rehabilitation process as a whole. With the joint information from those two sources (request form and medical records), they are able to tune themselves in the same 'rehabilitation frequency' as the medical companion and the rest of the medical team, to make better-founded suggestions for intervention and, sometimes, even to pick up certain inconsistencies, as in the case of the patient from *Story 4*.

At the centre, it is part of the administrative procedures that, when a clinician orders any kind of study or analysis, s/he must always write it down in a request form, s/he cannot just tell a colleague what they want, not to mention asking the patient herself to tell the clinicians what she needs!. Following this principle of action, GMLab's specialists do not perform any kind of examination unless it has been clearly stated by the patient's doctor in the request form --exceptions are made when gait specialists consider that they should analyse a certain parameter in more detail or carry out a test that was not previously indicated in the form but that would add important information for the child's treatment and clinical management--. So, when the child's mother from *Story 4* asked Dr Campos, on behalf of the child's



orthopaedist, to order a hand-propelled cart for him, the situation got a bit suspicious, since there was no mention of any cart in the format at all. Our doubts were confirmed by the patient's medical records showing a history of multiple conditions for which a cart like those would result counter-indicated. Knowing this and considering the mother's behaviour, it became evident who was really the one behind the idea of ordering a hand-propelled cart for the child.

In addition to the results of the tests that will be performed to the patient throughout the whole rehabilitation process, medical records will be a crucial defining agent of the type –and structure– of rehabilitation trajectory to which the patient will be subjected. Medical records constitute a very specific historical, social and material representation of the patient, of her body and of the sort of diseases and disorders that have interfered with its normal functioning throughout the patient's life, as it can be observed in the case of the patients from the three stories presented above. The patient from Story 2 had been diagnosed with psychomotor development retardation, condition that had to be taken into account while deciding on the sort of orthotic device that would be prescribed to the child. The girl from Story 3 had a diagnosis of cerebral palsy; even though it was a mild CP, it still affected her gait; specialists, therefore, would have to consider such a condition, as well as the measurable results of the use of *kafos* ('knee-ankle-foot orthotics'), when determining whether the girl should keep using them or they should be changed for another type of orthotics. Finally, a history of multiple diseases prevented the child from Story 4 to use a hand propelled cart, even though it could spare him from the terrible pain of walking and greatly improve his mobility at home and elsewhere.

The three cases presented above tell us something about the role that assessment request forms, together with patients' lists and medical records, play in a gait assessment and, more broadly speaking, in an individual's rehabilitation treatment program. These materials and the initial preparations associated to them are crucial for the assemblage of a particular gait collectif that will, in turn, allow for the gait assessment to be performed. The information provided by them allows the GMLab's specialists to make sense, in advance, of the sort of 'gait situation' they will be dealing with during the assessment (the individual's characteristics, type of diagnosis, technical concerns, possible clinical management, etc.) and, at the same time, it allows them to visualise the kind of gait collectif they expect —and are expected— to enact during the assessment, setting the parameters for it.

A final element that plays a crucial role when conducting a gait assessment is the computerised management system. This system acts as an agent of control, surveillance and coordination of the materials, actors and activities involved in a patient's treatment. It allows the rehabilitation team to coordinate their actions and develop a coherent program of intervention. It keeps track of each and every one of the different interventions performed on the patient's body, allowing specialists access to a detailed step-by-step panorama of her rehabilitation trajectory. It also gathers the subject's complete rehabilitation history in one single place, providing clinicians a full picture of the process and of the outcome of each 'set of activities' developed within it. Furthermore, the computerised management system is an essential element for the configuration of the different collectifs that will be shaped throughout the whole rehabilitation process.

I want to suggest here that the four elements above mentioned —this is, assessment request forms, patients’ lists, medical records and computerised management system— can be seen as different forms of ‘infrastructure’ and, at the same time, they also act as ‘boundary objects’. Here, I am drawing, of course, on Star’s work (see: Star and Griesemer, 1989; Star and Ruhleder, 1996; Star, 2002).

Star defines infrastructure “as something that other things “run on”, things that are substrate to event and movements. [... For her,] Good infrastructure is by definition invisible, part of the background for other kinds of work” (Star, 2002:116). This scholar has highlighted the importance of attending to infrastructure while conducting fieldwork, as she puts it:

“Study a city and neglect its sewers and power supplies (as many have), and you miss essential aspects of distributional justice and planning power (but see Latour and Hermant, 1998)<sup>61</sup>. Study an information system and neglect its standards, wires and settings, and you miss equally essential aspects of aesthetics, justice, and change. Your ethnography will be incomplete.” (Star, 2002:117).

According to Star, many studies focus on certain categories and processes while ignoring the infrastructural settings that support them (see: Star and Ruhleder, 1996; Bowker and Star, 1999). Some researchers, for instance, may find following the trail of paperwork activities and materials too boring or uninteresting. However, even if taken for granted or unnoticed most of the time, these infrastructural elements are actually the pillars that sustain the rehabilitation process, as I have shown above.

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<sup>61</sup> Here, she makes reference to Latour and Hermant’s beautiful book *Paris ville invisible*.

Studying infrastructures is, then, a way to explore socio-technical systems in the making. Here, I am adding the ‘socio-’ prefix that Star tends to take for granted!, in my view, as in that of several STS writers, the technical and the social are never separate issues; instead, they are intertwined with, and sustain, one another<sup>62</sup>.

In the case of my object of empirical study, medical records and computerised management system actively participate in the rehabilitation process as infrastructures of representation, technologies in and through which the patient gets translated and re-presented in a specific, material-semiotic, ‘noise-free’ version, purified of any irrelevant information. They get mobilised as materials for the production, inscription and preservation of knowledge about the patient.

In addition to assessment request forms and patients’ lists, medical records and computerised management system work too as infrastructural communication tools and as linking devices. These diverse technologies help the team of rehabilitation specialists to establish a single infrastructural regime —as Star would say— around rehabilitation and, specifically, around a particular diseased body of clinical concern. A regime common to all and that, therefore, can be used to communicate among each other and to make themselves and their practices understood by the rest of the members of the collectif.

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<sup>62</sup> Beginning the list with the ANT triad (Latour-Callon-Law) and following with the countless works that have derived from that approach, including those originated from the After ANT discussions.

Within the patient's rehabilitation process, paperwork materials work as boundary objects<sup>63</sup>, this is, as infrastructural arrangements "that dwell in more than one community of practice [they provide] a lingua franca for exchanges" (Star, 2002:118; see also: Star and Griesemer, 1989; Star, 1989). Boundary objects allow different groups to collaborate on a common task, they make possible coordination without the condition of consensus (see: Harvey and Chrisman, 1998). Following Star and Ruhleder's claim that infrastructure is a fundamentally relational concept<sup>64</sup> becoming real infrastructure in relation to organized practices (see: Star and Ruhleder, 1996; Jewett and Kling, 1991), I want to argue that not only these boundary objects link the technical apparatus of, in this case, a rehabilitation system; but also, they connect a heterogeneous array of materials that include patients, medical histories, rehabilitation trajectories, prosthetic devices, medical experts, clinical treatments, possible futures, etc.

Throughout the rehab process, those infrastructural arrangements will give a more or less standard meaning and certain logic to the patient, her body and its diseases, on the one side, and, to the sort of collective interventions that will be performed upon them, on the other. The way in which such objects are constructed and handled will indeed have an effect in the patient's rehabilitation.

So, computerised system, request forms, patients' lists and medical records frame and coordinate the interactions between patients, gait specialists, medical

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<sup>63</sup> Susan Leigh Star developed the notion together with James Griesemer while conducting a study of the development of the Museum of Vertebrate Zoology at UC, Berkeley.

<sup>64</sup> According to these authors, "[a]nalytically, infrastructure appears only as a relational property, not as a thing stripped of use" (Star and Ruhleder, 1996:113).

companion and the rest of the rehabilitation team. Together, these agents contribute to enact a particular ‘gait-patient’, this is, a particular object of medical examination within a specific clinical context, a particular body with specific anatomical and physiological characteristics, and a particular person living in specific socio-material conditions. Finally, it is possible to affirm that such actants not only outline the setting of the gait assessment, but also its possible outcomes—which get materialised in a specific clinical management that might involve pharmacological, surgical or/and orthopaedic treatments—and, very importantly, they actively participate in tracing the patient’s trajectory within and beyond his/her rehabilitation program.

### **Preparing Assessable Bodies**

Story 5:

December 13<sup>th</sup>. [...] We have just started the next assessment. Dr Valle has asked the patient to take his clothes off, except for his t-shirt and underwear. The physical examination starts. I observe and write down my notes while simultaneously preparing the markers at the request of Dr Campos to give him a hand with it (at the moment he is getting ready with the computer program for the gait analysis).

Mother: *“we came here a month ago doctor”* [to Dr Valle, he nods]

Dr Valle: *“do you think the somatometry has already been stored?”* [to Dr Campos]

Dr Campos: *“yeah, I’ll search for it”* [to Dr Valle]; *“what’s his name again?”* [to the mother]

By now Dr Valle has finished the physical examination and now Dr Campos has come to the examining couch and carefully attaches the markers to the patient's body.

Dr Campos: *"why could we not do the analysis last time?"* [to the father]

Father: *"because he couldn't cope with it, he didn't finish the test"* [to Dr Campos]

Dr Campos: *"and from that time, has he been doing what I asked him to do?, has he been walking?"* [to the father]

Father: *"he has been trying to walk at home, but he gets tired very fast. He is able to take some steps, but if he is standing for a long time he does get very tired"*

Dr Campos: *"ok, we'll try to do it quickly this time for him not to get exhausted"* [to the father]

Dr Campos finishes placing the markers on the patient's body.

Dr Campos: *"the 'standing' has to be quick, because he gets tired"* [to Dr Valle]

Dr Valle: *"ok"*

With a camera that is connected to the computer, Dr Valle takes the patient a picture (the 'standing') and the trials start (before the gait trials

start, a digital picture is taken from the patient, who will be standing in the middle of the walkway, at the GMLab this is referred to as 'taking the standing')...

The child has very visible difficulties taking every single step. His facial expression denotes pain...

Considering that he gets very tired and that his legs hurt, the patient has been asked to walk only from the beginning of the walkway to the middle of it, where the force plates are located, in other conditions the patient would have to keep walking until the end of the walkway. In addition, after every trial, Dr Valle and the patient's father carry him from the middle of the walkway to the beginning of it, in order to perform the next trial...

Dr Valle: *"let's take another one [step], you can do it [to the child] we are almost there"* [almost reaching the force plates in which the child must step on]

Several trials have been conducted, but all of them have failed so far... the trials continue... For a trial to be valid, the patient has to step on the force plates with the complete sole, if this is not achieved the trial must be repeated. This is very distressing for all of us, I can see the frustration in our faces every time a trial fails, because the more trials are conducted the more tired the patient gets and, in turn, the less possibilities he has to complete the assessment... I worry that they will have to reschedule the analysis again, because next time the patient would come back even more anxious than he is now...



After several failed attempts and huge effort and pain, the patient finally manages to complete the test (and, of course, we all feel relieved that it's done!).

As I have already explained, paperwork preparations are a vital set of activities that support the configuration and maintenance of the GMLab's gait-collectif. In addition to them, there are other crucial sets of activities that must be developed for the collectif to emerge; among them, I want to argue, we find the simultaneous preparation of the patient as a body and as an embodied subject.

For any kind of examination to be carried out at the GMLab, patients have to be 'prepared' beforehand. As objects of clinical assessment, patients must be materially and semiotically shaped in a way that allows them to meet the necessary requirements to become *assessable bodies*. This 'shaping' work is carried out in several forms, at different places and by several actors of the gait-collectif.

When arranging an appointment for a gait assessment, patients are required to wear shorts and a t-shirt. During the test, very young patients will only wear their underwear. Such 'dress requirement' has different purposes: it provides comfort and better mobility to the patient while being assessed, it allows the clinicians better manageability of the body and body parts to be examined, it also minimises the interferences during the assessment, so that external variables, unrelated to the body being assessed, do not affect the results. In gait assessment language, these external interferences are called 'artefacts'. The problem with them is that, in the image produced from the patient, they might appear as "*markers that in fact don't exist*", distorting the 'real' data. Therefore, before processing the data, Dr Campos must 'clean' it by eliminating all those artefacts. Administrative and medical staffs refer to

attire as the only requirement for an assessment to be conducted. In practice, however, other crucial requirements become present and too visible to be ignored, as my field-note above shows.

*Story 5* talks about a child who could not complete the gait analysis in a previous appointment. The analysis requires from the patient to walk along a ten meter walkway, and several trials are needed in order to produce meaningful data. In his case, such a task ended up being too difficult to be done. His body could not cope with the physical effort that the analysis required from him, his legs were in pain and he was not able to walk. As a consequence, the assessment was re-scheduled and the patient was asked to prepare for a new one by practicing his walking skills at home.

After some weeks, the patient came back to the GMLab and performed the test once again. Fortunately, this time he was able to complete it. In order to achieve this, a joint effort between different agents –including the patient, his parents, the clinicians and a pair of weak hurting legs– had to be displayed; an effort which was not only circumscribed to the session and to the lab, but that it extended in time and place before the assessment itself. The patient and his parents had to work together at home on preparing his body to endure the physical demands of a gait analysis. Then, during the test, clinicians had to be quick when taking ‘the standing’ and, afterwards, one of them had to carry the child to the beginning of the walkway after every trial. The child’s body did its part too, cooperating and getting ready during weeks—even if sometimes resisting—for the gait assessment and all the suffering that it entails.

In the case of this patient the analysis was finally performed successfully; however, for some other patients, completing a gait assessment will take more than two appointments and much more effort and frustration. During my fieldwork, for

instance, several assessments had to be cancelled because the patient's body was too stiff that morning or going through a lot of pain, which made even assisted gait impossible. In practice, in addition to particular clothing, a particular physical state of the patient's body is crucial for performing a successful gait analysis and for producing meaningful data. In other words, not just any body can be subjected to the test, patients' bodies need to be transformed before being translated into specific gait parameters and patterns. In order to be manipulated, measured, evaluated and diagnosed, the body must be specifically trained and shaped, so that it can be assembled with the rest of actants of the gait-collectif.

And the list does not stop there; coming to the test with the right emotional preparedness plays a part too: Many patients have considerable difficulties for walking, when this is the case the assessment becomes a very difficult and painful task. Some patients get so anxious when they are told that they will have to walk several times all along the walkway that they become completely paralysed and unable to give one single step. During my fieldwork, more than once I heard patients saying "I can't do it" even before they had started. When situations like this happen, clinicians and relatives take a significant role encouraging the patient to walk and giving him/her confidence. In Story 5, for example, Dr Valle tries to encourage the patient by saying "you can do it" and "we are almost there".

For an analysis to be performed patients have to be able to control their anxiety; they must have confidence on themselves and on their body; they must be able to cope emotionally with pain, to be physically relaxed, to negotiate —and succeed!— with their bodies' material resistances, etc. This means that, even if at first sight,

‘preparing’ for a gait assessment might seem pretty straight forward, this can be as demanding for the patient as the test itself.

‘Preparing’ the patient can be understood as a set of activities that involve making emerge a particular material-semiotic configuration of him/her that will allow for a gait assessment to take place. This configuration entails a series of different coordinated and distributed actions which require the intervention not only from the patient, but also from several other human and non-human actors involved in the gait-collectif, such as patient’s relatives, gait specialists, administrative staff, particular gait protocols and diagnostic techniques, pain-enduring legs, under-control emotions, etc.

What all of that means is that, such ‘preparation’ can be translated as the patient’s active participation in transforming him/herself into an object of clinical assessment, this is, into becoming an ‘assessable body’ able to be subjected to clinical analysis. To say it another way, preparing the patient for a gait assessment means the subject’s active engagement into becoming a passive object. It is worth to note here, though, that this is not only done during the ‘preparation’ stages of the rehabilitation process, but it is something that occurs permanently throughout the process. In addition, this process of what I call the ‘*subject’s active objectivation*’ is always linked to the sort of relations (between patient, clinicians, technical equipment, gait evaluation protocols, diagnostic techniques, etc.) that will emerge during the assessment. In other words, it is about ‘a patient-*in-action*’, a patient who is more than just a body of flesh and bone, and who is part of a heterogeneous network of material-semiotic relations.

Other authors have documented through empirical studies similar cases of active involvement of the patient into becoming a passive object. In her work on reproductive technologies, Cussins, for instance, portrays a woman who has actively contributed to her re-presentation as an experimental site and to her performance of a role of mere 'carrier' of a baby (see: Cussins, 2001; 2007). For Cussins, during an infertility treatment, the objectification of the patient does not necessarily turn her into a victim of medical technologies and practices, as it has been sustained by different scholars, especially from medical sociology and feminist studies. According to this author's research, in the particular setting of an infertility clinic, for a patient to exercise her agency during treatment she must be multiply objectified. What her study shows, in a few words, is that agency and objectification are co-constitutive, as well as oppositional.

The understanding of the patient as an active agent of its own objectification contrasts greatly with the conventional vision of the patient as a disciplined passive object, a helpless victim of the clinic going through the dehumanising procedures that medicine has designed for its subjection. In short, my point is that preparing the patient for a gait assessment involves her active participation into becoming an assessable body which is, simultaneously and alternately, an embodied active subject. All these preparations of the patient will provide the conditions of possibility for the configuration of a gait collectif and the re-presentation of the patient in numerical, algorithmic and visual forms.

The collectif goes through multiple ontological changes throughout the rehab process. A patient is ontologically reconfigured, it is the same person and yet

someone else in every stage of the rehab process, in the end, he is someone different, something has happened to him, to his body and his subjectivity.

### **Preparing the Lab for the assessment**

#### *Story 6:*

[...] I came in to the GMLab and discovered Dr Campos walking all around the room, on the dynamometric platform. He had a long metallic rod on his hand and was swinging it... From time to time, he randomly pressed on the platform with the tip of it... When I asked him what he was doing with that, he explained to me that he was 'calibrating' the lab. He says that this must be done from time to time, to make sure that all the equipment is 'well attuned' and working properly, so that the cameras and the walkway are receiving the right information, free of *noise* [interferences].

#### *Story 7:*

7:15am. Dr Valle, Dr Campos and I are getting ready to start with a day of assessments... Dr Valle prepares his tools for the physical examination: a goniometer, a pelvimeter, a reflex hammer and a measuring tape. As usual, he also prepares a white sheet folded in half and a thin pen that he carries everywhere, always on the left pocket of his coat. During the examination, he will use this sheet to write down the measurements taken to the patient's body. Meanwhile, Dr Campos checks that the [gait analysis] software is ready to be used... Now he starts preparing the TET-Unit and the markers.

Dr Campos: *“this is isopropyl alcohol, it’s not the common one, that’s ethyl alcohol; this one is lighter and we use it for cleaning the markers, because the ethyl one takes the reflective paint out of them, it’s very strong...”* [to me]

Story 8:

10:30am. Our patient is here. He is a very energetic and talkative toddler, and we are having a nice chat while his mother and father prepare him to be examined...

The physical examination starts. Dr Valle could be described as a man of few words. He is usually very silent; when performing an examination he hardly utters a word, he speaks only when necessary. This attitude, however, should not be confused with apathy, antipathy, rudeness or violence, for he speaks with a tender silence, with a serene gaze and a kind touch, always comforting and reassuring for patients, especially for those in need of a firm hand to hold onto...

We are done with the physical examination and ready to continue with the gait analysis; however, one of the retro-reflective markers seems to be missing, without it we won’t be able to proceed. I help Dr Campos search for it under the examination couch, on the computer desk (in case one of us took it there by mistake), on the shelves... nothing. We start to get worried because without one single marker the analysis cannot be performed since it would distort the rest of the data.

Child: *"can I take this with me?..."* [to me]

Ethnographer: *"show me... what is it that you want to take home?. Oh!, it's the marker, Dr Campos, the marker"*

It is not unusual to have children touching and playing with the markers, the small and glowy spheres catch their attention and many of them find it funny when the markers are sticked to their bodies and they can see themselves in the mirror on the far left end of the room. For those children who have come here before, the marker-body attachment part is actually a highlight of the assessment, something that gives at least some enjoyment to an otherwise stressful and painful experience.

Performing a gait assessment, not only requires a particular configuration of patients and their bodies, but also a particular configuration of the rest of the human and non-human participants which are part of the gait-collectif, including the laboratory itself. Configuring the gait laboratory as an instrument for producing reliable clinical knowledge about the patient's body involves carrying out different actions before, during and after the assessment, as well as assembling a very precise technical materiality of the lab.

Every multifactor gait analysis produced through the GMLab's gait laboratory integrates the measurements generated by the stereophotogrammetric system<sup>65</sup> in

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<sup>65</sup> Stereophotogrammetry, involves estimating the three-dimensional coordinates of points on an object.

These are determined by measurements made in two or more photographic images taken from different positions. Common points are identified on each image. A line of sight (or ray) can be



conjunction with the measurements from the dynamometric platform<sup>66</sup>. Whereas the stereophotogrammetric system detects the trajectories followed by a series of retro-reflective markers attached to a body in motion, the dynamometric platform generates information related to spatiotemporal, kinetic and kinematic parameters of a person's gait. The combined data produced by these two technical systems or reference frames is then "transformed into one global absolute time-space reference system" (Rabuffetti, *et al.*, 2001:638). In a gait analysis, specialized software captures and processes the information generated by a person's gait comparing and contrasting it with the parameters previously set by this absolute reference frame.

Although usually invisible, the technical and material complexity of the GMLab's gait laboratory comes to the spotlight when the data produced by the machines is not exactly what should be expected, this considering other sources of information, such as the patient's physical examination, previous gait analyses, clinical knowledge about similar cases, etc., a short field-note excerpt from Story 3 tells briefly about this. Dr Valle and Dr Campos have been checking the data from several examinations carried out recently and they have detected some mistakes; however, they do not know the reason for this. From the excerpt, it can be inferred that they have been careful enough while doing their part of the job, as to consider a human error, as the cause. Hence, it is highly likely that they are facing an issue with their objects. With this assumption in mind, they decide to "check the equipment and recalibrate the laboratory later in the day".

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constructed from the camera location to the point on the object. It is the intersection of these rays (triangulation) that determines the three-dimensional location of the point.

<sup>66</sup> For a detailed description about the technicalities of a multifactor motion analysis, see: Frigo, *et al.*, 1998; Rabuffetti and Baroni, 1999; Riener, *et al.*, 1999; Rabuffetti, *et al.*, 2001.

A gait laboratory requires an accurate calibration. All dynamometric platforms and stereophotogrammetric systems are calibrated by developers and manufacturers before installation. However, the installation itself, as well as its continuous use and age “can cause changes in instruments’ sensitivity over time and undesired cross-talk between measured variables, leading to a general lack of accuracy” (Chockalingam, et al., 2002, in: Cappello, et. al., 2004), and to the systematic generation of errors in the data produced. A tiny mistake made during a gait analysis means that the whole assessment must be repeated, which, in the best scenario, means time, money, technical resources, professional skills and an awful lot of pain and distress wasted. What can be even worse is that decisions about a specific treatment path for a patient’s rehabilitation might have been made on the basis of erroneous information, putting at risk not only the patient’s gait management, but his/her whole rehabilitation process and its expected outcome. In order to prevent an event of this nature from happening, Dr Campos and Dr Valle must routinely recalibrate the lab, to make sure that it works properly, that all its parts –including the dynamometric platform and the stereophotogrammetric system– are well attuned to one another and operating as a singular entity, as the short field-note extract from Story 6 shows. The excerpt describes Dr Campos walking on the dynamometric platform swinging a long metallic pole fitted with a set of optical markers, and pressing randomly on the platform with the tip of it from time to time.

Although, every gait-lab manufacturer has its own calibration guidelines and procedures, numerous post-installation recalibration methods are permanently being developed all over the world, with the objective to obtain more accurate data of normal and pathological gait. For the calibration of the GMLab’s gait laboratory, Dr Campos and Dr Valle use a pole with optical tracking markers fixed to it (see e.g.

Lewis, et al., 2007) and arranged in a three-dimensional configuration. In addition, this instrumented pole has a pointed tip, which allows the gait experts to measure the forces applied in very precise contact spots when the pole is pressed against the platform. This long and thin rod “allows arbitrary directions and magnitudes of force to be manually applied to the force plate in arbitrary locations, using a motion capture system to record kinematics” (Steven, et al., 2009:10).

As for every single activity at the GMLab, a particular procedure must be followed to perform the calibration process. When calibrating the gait lab, there must be an excellent coordination between the force platform and the motion capture system. Diverse parameters are measured, including Ground Reaction Forces (GRF) and Center of Pressure (COP), which are two crucial values for any biomechanics assessment, including gait analyses. By pressing the instrumented pole against random spots of the platform with varying forces and angles, Dr Campos obtains the quantified values of GRF and COP (see e.g. Cappello, et. al., 2004; Steven, et al., 2009), which are contrasted to the external reference values obtained from the motion capture system (see e.g. Rabuffetti, et al., 2001; Holden, et al., 2003), data that is collected by tracking the movement of the luminous sensors fitted on the pole through the optoelectronic system of cameras, which emit an infrared flash that is then reflected by every single marker. The overall values obtained from both systems will also be compared with the reference force and moment vectors originally set by the gait-lab manufacturer. In order to make sure that an accurate calibration has been achieved, several testing trials must be performed and their results compared. “In a movement analysis laboratory, stereophotogrammetric motion capture systems and force platforms must share one absolute reference frame that allows the computation of joint moments and powers. The correct calibration of the platform location

identifies the transformation between force plate and absolute reference systems, which determines the spatial coherence among the equipments” (Rabuffetti, et al., 2001:638).

This brief account of the gait lab’s calibration process captures its material complexity and the precision required for attuning the two systems to one another, for them to behave as a singular unity and generate the right information about a patient’s gait characteristics. But the dynamometric platform and the stereophotogrammetric system are not the only materials that play a crucial role in a gait assessment. Let’s not forget some of the other sets of activities and artefacts involved in it, such as the physical examination and its objects. Story 7 tells something about it.

On a gait assessment day, Dr Valle and Dr Campos will arrive early at the GMLab. Before the first patient arrives, they have to get ready with all the necessary equipment to be used during the tests. At 7 o’clock, Dr Valle will diligently prepare his physical examination toolkit, goniometer, pelvimeter, reflex hammer and measuring tape. Every morning he will take these out of the first drawer of the blue shelf, at the foot of the examination couch. He will also add a piece of paper and the pen that he always carries on the left pocket of his coat. Sometimes, depending on what has been indicated in the request form by the patient’s medical companion, Dr Campos and Dr Valle will also prepare the TET-Unit.

For conducting the gait analysis, in addition to the tools used for the physical examination, the gait experts will take a small plastic box out from another drawer and ‘prepare’ the markers that it contains. The *markers* are small spherical reflective balls –10 mm in diameter–, which are used to track the patient’s movements and to record them on the computer while performing the gait analysis. *Preparing the*

*markers* means sticking adhesive tape on them in order to attach them on specific positions or anatomical landmarks of the patient's body. These luminous sensors, as Dr Campos explains to me in Story 7, need special care, they should always be cleaned with isopropyl alcohol, which is lighter than the more common ethyl alcohol, otherwise the reflective paint would come out. And it is imperative to have the complete set of twenty three sensors, otherwise the test would produce a completely distorted representation of the patient's gait; so, if one of them is missing, then, the gait analysis cannot be performed, as it almost happens in the case described in Story 8 where, attracted by the small gloomy spheres, a little child wanted to take one home.

Above I have described some of the material and infrastructural conditions of possibility necessary to perform a gait assessment; without these basic artefacts it is not possible for the gait experts to produce a numerical and a virtual representation of a patient's gait. During the assessment, the laboratory, with its human and non-human elements, must work literally as a unit. For this to happen, every single artefact of the lab must be 'attuned' to one another, this is, they must display a specific material relationality and a very precise infrastructural coordination, which in turn, will produce a unitary configuration of the gait lab as a singular entity. If one of these materials fails, then the whole laboratory collapses.

### **Preparing the Clinicians**

In action, the GMLab has to do with more than just the 'things' that compose it. It also incorporates a whole set of other materials, crucially, a body-in-motion and a couple of people with the required knowledge and expertise not only to make the lab work, but also, to make sense of what they 'witness' in every assessment. Along with paperwork preparations, assessable bodies and infrastructural equipment,

rehabilitation experts are an essential component of the gait-collectif, and they too have to be ‘prepared’ to play their part within such a collectif.

As it probably happens with any other patient in any other clinical setting, the gait patient at the GMLab does not configure itself as such. Instead, paperwork materials, infrastructural devices and rehabilitation experts contribute greatly to its configuration. To achieve this, however, gait professionals must be skilled enough. Before they were able to carry out an assessment, gait experts must have acquired specific knowledges and abilities; they must have learned not just ‘what’ to look, but ‘how’ to look. Among many other skills, this is what medical training provides. It teaches its practitioner what their objects of concern should be and the ‘right way’ to approach to and to know those objects. At the GMLab, it is not unusual to be joined by a rehabilitation medicine postgrad student in the process of acquiring these sorts of skills —as an ethnographer conducting fieldwork there, I myself had to acquire some of those very skills to be able to talk the same language of my own objects of concern!—. For the clinician, knowing their objects of concern implies developing the capacity to ‘perceive’ them with all of one’s senses: to be able to see them, to touch them, to hear them, to smell them... At the GMLab, ‘perception’ can be conceptualised as both, an acquired ability and an embodied skill that gait professionals develop through rigorous training. They must train all of their senses and, as with the lab’s technical equipment, finely attune themselves and their whole body<sup>67</sup> to what they are about to perceive during a gait assessment. The act of ‘perceiving’ I am referring to involves much more than just receiving, recognising,

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<sup>67</sup> For the case of surgery and the involvement of the whole body on this kind of practice, Hirschauer (1991) offers an outstanding account in which he develops his idea of ‘the surgical body’.

noticing, distinguishing or grasping external signals. Instead, I want to sustain that, for the medical practitioner, learning how to perceive their objects of concern actually means learning ‘how to make their objects *come into being*’.

Gait professionals must be skilled and knowledgeable enough to be able to identify what is considered normal from that which is not, to distinguish with enough precision between healthy and pathological body morphology and between healthy and pathological gait. In order to be able to do that, clinicians had to acquire a wide variety of abilities and knowledge. They had to learn how to perform a physical examination and a gait analysis, how to use particular measuring tools and how to operate a specific motion-capturing system; they also had to become ‘competent readers’ in many different senses. As a rehabilitation medicine specialist working with patients from 0 to 18 years old, Dr. Valle must be skilled in manipulating and handling paediatric bodies; he must know about their standard, clinically accepted, appearance and characteristics: texture, temperature, colour, range of motion and flexibility, etc.; he must be capable of recognising any abnormalities when examining a patient’s body. In turn, as a biomedical engineer working in a rehabilitation centre, Dr. Campos must be very skilled in operating the gait lab and its machines if he is to generate meaningful data; he also must know all about the anatomical landmarks where each of the markers should be located, and what to do when these landmarks do not quite correspond to the normal body standard; he must have knowledge on how to ‘read’ the data collected, on the correlation between the numbers and shapes on the computer screen and specific characteristics of what is considered healthy and pathological gait, this according to Mexican standards. In addition, he must develop a fine intuition to detect when the machines might be producing distorted data. When writing a diagnosis, he must have learnt about the different conditions and disorders

that affect adult and paediatric gait and how they are medically managed, so that he can make the best suggestion of treatment to the medical team or/and prescribe the most adequate technical aid for the patient. Those are only a few examples of concrete practices, knowledges and skills that gait professionals must master.

At the GMLab, Dr. Campos and Dr. Valle become crucial actants for the gait collectif to come into being, since they are the ones who possess the technical and clinical knowledges and skills required firstly, for performing the gait assessment, secondly, for ‘producing’ meaningful data out of it and, thirdly, for translating these data into particular medical conditions as well as diagnoses and treatment options for the patient’s rehabilitation process. In addition, gait experts must develop the skills and knowledge about how to communicate to others what they have observed; how to put it in words pulling the right vocabulary in accordance to the medical writing conventions; how to frame their findings within a particular clinical context; how to relate the data to particular conditions and disorders; etc., all of this, in order to make themselves understood by the rest of the medical team.

In everyday practices, as mentioned in Story 2, before every assessment at the GMLab, Dr Campos and Dr Valle will look through the patients’ medical records in order to familiarise themselves with the type of case they will be assessing: sex, age, diagnosis, treatments that the patient might be undergoing at the time, and even non-medical issues (family, social context, financial situation, environmental conditions, etc.) that might have caught the medical team’s attention due to their potential effects on the rehabilitation process, those are some of the relevant data that they will take into account.



I want to argue that, going through the patient's medical records not only provides the gait experts a first contact with, and a detailed picture of, 'the case'. Rather than that, this practice effectively contributes to enact the person whose gait they will be assessing in a certain way and not in another. There are two ideas here: On the one side, there is the idea that medical records not only describe the clinical history of a person; rather, clinicians and medical records together help to 'do' that person in a particular way. On the other side, there is the idea that, from a multiplicity of possibilities, the actants that conform the gait collectif —gait experts and medical records included— will enact the person in particular ways (in plural!) and not in others. In other words, (1) patients are done differently by different collectifs and, (2) within a collectif, one or more enactments might be performed —even simultaneously— and some others might be left out.

Finally, besides from gathering enough medical knowledge and mastering their clinical skills, 'preparing' themselves for the gait assessment also means for clinicians enacting the person they will be dealing with, both, as a patient and as an object of medical intervention. Drawing on my ethnographic observations, this specific set of activity is crucial for the gait evaluation to take place, since it allows the very possibility of medical intervention.

Above I have talked extensively about the 'preparations' that must take place for the configuration and coming into being of the gait collectif. The different preparations that each of the actants involved goes through are the practices or sets of activity that allow the patient collectif, as a whole, to make the transition to the next phases of the rehabilitation process, at this stage concretely, to the physical examination and then, to the gait analysis.

## 4. ENACTING REHABILITATION COLLECTIFS AT THE GMLAB II

At the beginning of this thesis I presented a general overview of the rehabilitation centre where I carried out my ethnography. I told about its overall distribution and its administrative and medical organisation. I also introduced briefly the three areas within the centre in which my field research was focused: the Gait and Movement Laboratory (GMLab), the Orthotics and Prosthetics Laboratory (OPLab) and the Occupational Therapy Area (OTA). In addition, I described the standardised rehabilitation treatment trajectory at the centre—including the way in which it is established and negotiated together by the medical team of interconsulting doctors, the patient and his or her relatives—as well as how such a trajectory usually unfolds<sup>68</sup>.

### *First Reconfiguration of the Gait collectif: The Physical Examination*

#### Story 1

We have just finished the assessment of a boy with Duchenne's [syndrome] and now we are waiting the arrival of our third patient of the day, a 12 year-old girl named Alma. Dr Campos and Dr Valle spend some time looking over the girl's medical file, learning about the sort of

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<sup>68</sup> Here I am using the conventional meaning of the term 'trajectory'. For a discussion on what 'trajectory' means particularly for the case of surgical practices, see: Moreira, 2001.

examination we are about to perform. According to the electronic file, Alma presents “developmental dysplasia of the hip” or DDH<sup>69</sup> which, in her case, has been classified as severe. Along with DDH, she is dealing with some other associated anatomic issues, particularly in her left leg, something which, I have learnt, is relatively common in these cases.

Someone knocks on the door, Dr Valle stands up from his chair and, seconds later, Alma appears together with her mother, who helps her to walk in. As it happens with many of the patients who are assessed at the GMLab, Alma’s gait has been visibly undermined by the condition... Every time I come across cases like this, I mean, with older children, I wonder why it has taken them so long before seeking medical treatment. Sad and frustrating...

Dr Valle asks Alma to partially undress herself, keeping only her tank top and underwear. I quietly (and discreetly!) observe from the foot of the examination table, beside the blue shelf, looking through my fieldnotes and writing down a few observations. Meanwhile, Dr Campos puts away the TET-Unit, which we have used in the assessment of the previous patient.

Dr Valle: Do not help her (to the girl’s mother), let her do it by herself (he is referring to getting undressed; this is not the first time I realize that, although, apparently doing something else, Dr Campos and Dr Valle keep a close eye on the patient at all times).

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<sup>69</sup> Developmental Dysplasia of the Hip (DDH) is a condition in which a deformation, misalignment or underdevelopment of the hip joint is present. It can be congenital or acquired, bilateral or unilateral. This condition is more frequent in females than in males.

By now, I have witnessed dozens of examinations but still can't fully grasp what it is exactly that Dr Valle observes while conducting the evaluation. He is always very quiet. This time, however, attending to my request, he has agreed to 'talk through his practices'.

Dr Valle: Let's see... Can you sit on the edge of the couch, so I can examine you? (to Alma). Here we don't perform a complete physical examination, our focus is more on the neuromusculoskeletal area, on the parts of the body that have to do with mobility and gait, because that's what this lab is for (to me). Of course, I do have a general look at the child; I can't just concentrate on the lower limbs and ignore the upper half of the body... When I receive a patient, I do check, first of all, that everything is fine with him, that there is nothing suspicious overall. Then, I can concentrate specifically on the neuromusculoskeletal system and the lower body... Each of the [clinical] areas [of the rehabilitation centre] performs their own kind of examinations depending on their specialty. In our case, we are interested in the anatomic structures that allow movement to the body – motor nervous system, bones, muscles, joints and connective tissues (tendons and ligaments)–, particularly in those elements that allow locomotion, because that is the focus of the lab: mobility and gait. So, my job is to carry out a general examination of the whole body, followed by a detailed examination of the lower body, this by taking into account its neurological and orthopaedic components.

Alma, her mother and I listen attentively to his explanation.

Dr Valle: Are you cold?, I will hurry up with this.

Alma: Yeah, I am cold, but just a little bit.

Dr Valle: To begin, you must observe the general state of the patient's body (to me, he is standing in front of Alma). You have to observe the head, the face –eyes, nose, mouth, ears–, the neck, the shoulders, the trunk, the back and the extremities... You have to consider variables such as position, size, shape, symmetry, alignment, etc... Those are the sorts of things you must pay attention to.

Ethnographer: Do you always start from the head down?

Dr Valle: Yeah, I do, always... that's the way it must be done, it's the protocol. You must follow certain order, if you don't, you might get confused [with respect to the parts of the body that have –and have not– been examined] and miss something important.

Ethnographer: Ok...

Dr Valle observes the patient and makes a quick note on his white paper sheet folded in half. To me, everything looks fine with this girl, considering the DDH, but this is the first time I see her and, therefore, I am not familiar with her rehabilitation process at all.

Dr Valle: When examining thorax and back you have to attend to their symmetry and shape... you examine the clavicles, the length of the sternum, the ribs, the scapulas, the spine... many patients present some degree of scoliosis, either as a primary or secondary condition, this affects their posture and gait. It is also important to pay attention to the [patient's] breathing, the intensity of breathing, the length of inspiration and expiration,

the length of the pause between them, the abdominal and intercostal motion during breathing... In her case all these variables look normal, you can see the difference between her and Pedro (the boy with Duchenne's syndrome we previously assessed), it is quite evident, isn't it?.

Ethnographer: Ok... yeah, it is!...

After looking at the patient from both views –anterior and posterior–, Dr Valle takes his orange reflex hammer and gently strikes the patellar ligament of both knees.

Dr Valle: This is the 'patellar reflex', it has to do with posture and balance. When you tap the ligament with the hammer, there is a contraction of the quadriceps femoris muscle, this one here; that is what makes the leg to kick... When you do this, just make sure that you are beside, not in front, of the patient.

Ethnographer: Ok... I will make sure of that, I will even write it down in my field diary, so as not to forget it! (we all laugh).

Dr Valle: Can you put your foot like this? (to Alma)... This is the 'Achilles reflex' (tapping with the hammer on the Achilles tendon, at the back of the ankle), you must check this reflex in dorsiflexion (with the foot flexed upwards, this is, towards the shin)... When you tap the [Achilles] tendon the calf muscles contract and this makes the foot go downwards.

Ethnographer: What does this reflex indicate?

Dr Valle: Well, you are stimulating the sciatic nerve, which is a spinal nerve that runs from the sacral region to the gastrocnemius muscle (in the calf) in which the Achilles tendon is inserted... Basically, it tells you that there is good innervation; a deficient reflex might be a sign, for instance, of a disk herniation at the sacrum level, which is something that will affect the patient's gait and, in severe cases, it can be disabling... I am not hurting you, am I? (to Alma).

Alma: No, it just feels funny...

Dr Valle: If it just feels funny, then, there is no problem; but if it hurts, tell me, ok?...

Alma: Ok.

Dr Valle: Can you lie down on your back with the face up, please? (to Alma). This is called 'supine position', the opposite one is the 'prone' position (to me)... Can you lift a bit your tank top so I can examine your abdomen (to Alma, who lifts her tank top. He starts pressing the patient's abdomen)... Does it hurt? (to Alma).

Alma: No, it doesn't.

He presses from the left side to the centre, and then from the right side to the centre of the abdomen. Now he is tapping on the patient's abdomen. To do this, he places his left hand on the abdomen with the fingers separated from each other and taps on his middle finger with the middle finger of the opposite hand. He does this repeatedly, moving his hand through different abdominal regions.

Dr Valle: I first palpate the abdomen and look for any signs of distension, rigidity or pain... I also locate the internal organs and check size, shape, position and consistency... I make sure that there are not any abnormal masses or hernia... Then, I use this technique called 'percussion' to check if there is any fluid where it should not be (to me).

Ethnographer: Ok...

Dr Valle: Now, I can focus on the lower body, from the waist below... When examining the lower extremities, first you see their size and shape, and check if there is any sort of deformity or anomaly present... Then you inspect the skin, it should not look dehydrated or with signs of desquamation... it must have a good colour –it shouldn't look red, or yellow, or blue; if it looks cyanotic (blue) that would mean that there is a deficient oxygen supply–... when pressing on the skin you look how quickly the normal colour and shape returns... you see?... You also have to check temperature and texture... In addition, you have to see if both legs look similar –and react in a similar way– or if they look different from one another...

Ethnographer: Ok...

Dr Valle: You also must look for any abnormal marks and growths... sometimes there are little eruptions or nodules that should not be there... You have to pay attention to any scars too, including surgery scars like these ones... How many surgeries has she had? (to the mother).

Mother: Eight. Next month she will have another one.



Dr Valle: When was the last one?

Mother: mmm... almost five months ago (at the rehabilitation centre, patients who undergo many surgical interventions are not rare at all; this is why specialists routinely ask about it).

Dr Valle does not comment anything else about the surgeries. He then takes his measuring tape from the blue shelf and starts measuring the patient's legs laterally, from hip to knee, from knee to ankle and from hip to ankle.

Dr Valle: You have to check if both legs have the same length or if one is shorter than the other one. When there is dysplasia present, it may look as if one leg was shorter, and sometimes that is the case, but some other times it is actually the dysplasia that makes it look like that. So, you have to find out which of these cases applies to the patient you are assessing, because the clinical and rehabilitative management will be different.

Dr Valle takes the pelvimeter and measures the patient's pelvic bones, including intercrestal and interspinous diameters (sometimes the pelvic bones present certain abnormalities, some other times certain diseases or medical conditions affect the pelvis; in both cases, this may affect the person's gait). He then writes down those measurements.

Dr Valle: With the pelvimeter you take the measurements of the [patient's] pelvic dimensions, these numbers are then compared against

standardised parameters; obviously, all these measurements will differ from population to population due to racial differences.

Ethnographer: Ok... and the same applies to the case of the parameters of the gait analysis, isn't it?... there are particular standards by population; however, what I was telling Dr Campos is that it is difficult to talk about a Mexican standard, because the regional differences are significant...

Dr Valle: Well, yeah, you are right... however, we have to depart from something, that is why we have those standards... but we complement that data with our own observations of each individual case and we include those observations in the final report.

Dr Valle carefully takes the patient's right leg and lifts it up in a straight position; then, he flexes it and stretches it again several times.

Dr Valle: Does it hurt? (to Alma)... you must check the joints too... look if there is any tenderness or swelling [to me].

Alma: It does hurt here (she points at her left hip)...

Dr Valle puts the patient's right leg down and examines the left leg in the same way. He then examines both knees by pressing the patella and making circular motions with his hand. Afterwards, he takes the goniometer and measures the range of motion of each knee.

Dr Valle: Toes up, that's right... toes down, right... to the left, right... to the right, ok!...

He takes the girl's feet by the soles and examines the movement of her ankles making circular motions with them.

Dr Valle: You have to examine movement, flexibility, muscular control and muscular strength --some of the patients that we assess here present involuntary movements, or paralysis, or tremors... All those kinds of situations affect their gait--... Alignment and symmetry are other important parameters, many of these patients present either genu varum or genu valgum, do you know what that is?<sup>70</sup>.

Ethnographer: Yeah, I do. Actually, I think you explained it to me a while ago... or maybe it was the prosthetists who told me about it.

Dr Valle: Well, then you know what I mean... It is important to observe the consistency of the muscles, to detect if there is muscular waste or hypertrophy, those can be early signs of a serious problem.

Ethnographer: Like in Pedro's case?, there is a pseudohypertrophy of the gastrocnemius, and this is a sign of Duchenne's [syndrome].

Dr Valle: Yeah, that's right. Apparently, what you see is hypertrophy, but what really is happening is the loss of muscular mass.

Ethnographer: Ok...

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<sup>70</sup> The term 'genu varum' designates a condition in which the knees stay wide apart when a person stands with the feet and ankles together, it is colloquially known as "bowlegs". The opposite condition is called 'genu valgum', in which the legs are turned inward, because of this the knees touch, but the ankles do not touch; colloquially, it is referred as "knock knees".

Dr Valle: We are done with this (to Alma)... you can get dressed now, afterwards we will walk a little bit on the platform.

After performing every single physical examination, Dr Valle always goes to the washbasin –on a corner of the room, across the platform– and cleans his hands thoroughly. Afterwards, he sits at the computer desk and fills in a format with the measurements and notes taken during the examination. Meanwhile, Dr Campos prepares the markers that will be attached to the patient's body in order to conduct the gait analysis.

After all the preparations, reconfigurations and reconstitutions undergone by the diversity of actants that give will shape to the gait collectif, the process can go forward to the next step, which is the gait assessment *per se*. As previously said, the first of the two main sets of activities that compose a gait assessment is the physical examination, the second being the gait analysis by using a motion-capture system. At the GMLab, the physical examination is carried out by Dr Valle, who is a specialist in Rehabilitation Medicine. As it is well known among practitioners, the objective of the physical examination is to determine whether or not the patient's body presents any kind of physical problem or signs of disease. It involves four main diagnostic practices which are systematically applied to specific regions of the body and body parts. These practices are: inspection –looking at the body–, palpation –feeling the body–, auscultation –listening to the body– and, percussion –producing sounds with the body–. Together with the patient's medical history and the results of the gait analysis, the physical examination helps the team of interconsulting doctors to make a diagnosis and to trace an integral treatment plan, this is, an individualized map with

detailed information about the clinical procedures, practices and actions that will be followed towards the achievement of the patient's rehabilitation.

When talking about the physical examination and its use as a diagnostic tool, the medical literature commonly makes reference to the activities that the practitioner must undertake and the right techniques to perform it. Interesting things might be said about the many clinical skills that s/he should develop in order to be a good examiner. From the beginning of medical school, students learn that they must train hard and memorise by heart all those endless names of anatomic structures, muscles, bones, ligaments; how each of them look, feel and sound; the way they function; how they relate to each other, etc. Med students also must learn multiple and very complex procedures and techniques, because every single action they make must be done in a very particular way; in clinical practice, they are thought, nothing is left to chance, everything is carefully calculated... at least, that's what doctors say!!

The close observation of dozens of physical examinations being performed while doing my ethnography made me realise that there was much more going on than what is said about this procedure in medical textbooks; particularly, that this is an activity that involves several human and non-human participants, rather than just a single actor who performs the evaluation. Story xxx tells us about a diversity of entities coming into being and interacting with one another during the physical examination. By themselves, patients, bodies, practitioners, goniometer, pelvimeter, measuring tape, examination protocols, body segments, joint, ligaments, skin textures, scars, breaths, reflexes, etc. all these materials mean nothing much. It is what they generate when they come together, by interacting with one another in practices, that

matters, it is the ontological choreography that they perform, using Cussins words (see: 1996), that help us to make sense of the physical examination process.

A physical examination may be focused on a particular area or function of the body, or be as complete to involve the thorough evaluation of every single body part, from head to toe. Since what concerns the GMLab's health experts is gait and everything that has to do with it, the physical examination here is oriented to the evaluation of the musculoskeletal and gait performance of the patient's body as a whole and as body parts. Vital signs (temperature, pulse rate, respiratory rate, blood pressure, weight and height) are not taken at the GMLab since their recording and the required general physical examination is carried out by another clinical area of the rehabilitation centre. These and other relevant values are periodically taken and stored in the patient's computerized medical file.

To begin with the consultation, Dr. Valle makes some general ice-breaking questions to become acquainted with the patient. Although, usually children are a bit shy when they first arrive, there are a few exceptions, some children start the conversation with the examiner and ask many questions about the doctor, the procedure, this and that. Dr Valle's approach to children is always friendly and reassuring. Although some of the patients treated here have certain conditions that entail low levels of comprehension and communication, he always addresses the children directly, acknowledging their presence and involvement in the test.

A variety of physical examination protocols and techniques have been developed around the world, outlining in great detail how this evaluation must be carried out step-by-step, depending on the patient's individual characteristics, the anatomic structure and the function being examined, among other things. This, in

order to get precise information about the patient's body and to prevent any diagnostic mistakes, as Dr Valle tells me when I ask him about the order of the procedure, as my Story 1 narrates.

In practice, however, physical examinations do not really follow a specific and rigid routine. Rather, they are always adapted to the child's characteristics (including age, temperament and medical state) and the very much specific situation that unfolds during the consultation. Sometimes, even relatives get involved, when asked to hold the child, to calm him down when they are afraid or moving too much, etc. Some children are cooperative, some others are not. Some of these children have gone through so many medical procedures that they are really scared of hospitals and doctors, and they cry and cry during they whole assessment; for many of them tests are experienced as uncomfortable and painful. Furthermore, a considerable proportion of children who come to the GMLab to be assessed are not able to speak in a way that allows them to be understood. For this reason, careful observation from the gait experts is an essential evaluation tool.

In addition, the physical examination is not restricted to the moment the patient is on the examining table, it does not start with the exploration of the head, as medical students learn at school. In practice, it starts from the very moment the child enters the room until s/he leaves. When a patient comes into the GMLab, the practitioner is able to observe certain aspects of the patient's health state that, in turn, provide elements for the diagnosis – e.g. degree of consciousness; degree of comprehension of spoken and non-spoken language; expression and communication; cooperation skills; reaction to relatives and doctors; nutrition; physical abnormalities; posture, gait and coordination; degree of activity/prostration due to their current medical condition;

etc.—. In this way, the observation of these aspects is done outside of the more structured and artificial clinical setting established by an examination protocol, which gives the practitioner a glimpse of how the patient's day-to-day life might be experienced. Observing patients carrying out more mundane activities (walking into the room, undressing, getting dressed again, sitting on the examination couch and getting up from it) provides the practitioner with a sense of the patient's everyday experience of the disease or condition, of how it affects their lives and, consequently, of the potential rehabilitative measures and treatment path to follow. Additionally, this adds clinical/diagnostic information to the formal examination itself.

If we want to be more precise, we might say that the physical examination starts, in a way, even before the patient's arrival to the GMLab. The observation of the patient's body starts before the practitioner comes into direct contact with such a body, and this is made through the patient's electronic file and medical history, which gait experts review previous to the patient's arrival to the lab. It is through these materials that Dr Campos and Dr Valle establish a first contact—even if indirect—and a preliminary clinical picture of the patient, the body and the disease. This is how they get to know a detailed history of the particular conditions and diseases that the child has and is currently experiencing. This knowledge, in turn, informs the physical examination and the way it is performed, since it tells the examiner what he is about to look, what to look for and how to look, allowing him to pay special attention to those areas identified as of particular concern.

Counting with a complete and very detailed electronic file is, therefore, crucial for the assessment work carried out at the GMLab—we can assume that this also applies to the rest of the clinical areas at the rehabilitation centre too—, since the



information provided by it will give a certain direction to the physical examination and a clinical background for medical diagnostic reasoning. In other words, the patient's electronic file and medical history delineate a specific trajectory of diagnostic questions and examination practices. It is no surprise then, the amount of time that practitioners spend reviewing and filling in the patient's file at every consultation.

While examining the body, Dr Valle takes notes and writes down several measurements, which are then compared with standard charts used in the diagnosis. At the end of the assessment, follow-up visits are scheduled in order to check the child's progress. In addition to the electronic file and the medical records, another important source of information are the patient's relatives, who participate in the examination answering particular diagnostic questions about the child's medical history and current health issues, as Story 1 narrates. This provides the practitioner with more elements to make sense of what he observes during the examination and useful guides to assemble his clinical report afterwards. So, even though there are particular medical protocols for physical examination, in practice, these are modified when other elements, besides the body being examined, are added to the examination and the consultation. The information obtained from all these means will lead the practitioner to focus his attention on particular anatomical segments and particular body functions.

As we might infer from Story 1, physical examinations involve much more than bodies and body parts. At the GMLab, observation and the act of observing a body

involves all of the senses. Not only sight is put into play, but also hearing, touch<sup>71</sup> and smell. They all, I argue, become part of the bodily instrument of evaluation that the practitioner embodies each time he performs an examination. Understood as an instrument of evaluation himself, the practitioner—in interaction with a multiplicity of entities— contributes to enact the patient and his/her body in a certain way (and not in another!). The examination could be referred to as a practice of ‘making sense through the senses’. While looking, feeling, hearing and smelling the practitioner makes sense of the patient, the body and the disease he has been put in interaction with, this in the context of a gait assessment. Seeing, touching, hearing... all these different vocabularies get intertwined into one another, inform and are informed by one another<sup>72</sup>. Those multisensorial perceptions are mediated by a wide array of professional and tacit knowledges and skills as well as of artefacts.

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<sup>71</sup> In their work on paediatric rheumatology, Rapley, et. al. (2007), present an interesting reflection specifically about the diagnostic practice of touch. They explore the qualities and knowledges that emerge in and through the touch and movement of patients’ bodies. These authors argue that diagnostic touch is often a seen but unnoticed aspect of our contemporary descriptions of the clinical gaze. For them, touch is a central resource through which diagnostic knowledge is produced, mediated and challenged. Touch, they claim, is as important as any other types of technologically mediated diagnostic technologies of medical work.

<sup>72</sup> Rapley, et. al. (2007) refer to this in the following terms: “[...] the ways that practitioners attempt to transform the patient’s body, in such a way, as to make available what might be hidden, to create a tactile, visual and aural phenomenal field so as to see, know and/or feel the problem”. (Rapley, et. al., 2007:13).

Observing is also an act of body surveillance; at the GMLab, nothing must escape the clinical gaze, as Foucault would say<sup>73</sup> (see: Foucault, 2005). As I have suggested, the examination starts before the patient is laying on the examination couch and it ends even after s/he has got up from it. From the time a patient enters the room until s/he leaves, s/he is observed through the eyes of a clinical gaze. Everything s/he does or says, even the most mundane acts or expressions, will be understood in the context of, and through, a clinical gaze.

The amount of writings about the physical examination and what it entails in terms of techniques, procedures, knowledge and skills that every practitioner must learn is very vast. However, nothing much is said about the participation of the patient himself as the subject of examination, neither about his body, his knowledges and his skills. As an STS researcher and ethnographer trained in the material semiotic account of the world, I have learnt that 1) humans and non-humans are much more closely related than we like to acknowledge, since they are not different in kind, that is, ontologically speaking (this last two words should be read in bold, italics and underlined!, to avoid that dreadful misunderstanding of old times), 2) things are not solid materials, rather, they are fluid entities, 3) focusing on processes tells us new stories about the making of realities, different than those, more conventional stories, which are told in terms of products.

Drawing on Hirschauer's notion of the surgical body (see: 1991), I want to make an interference by introducing now the notion of the '*diagnostic body*'. This

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<sup>73</sup> In his *Birth of the Clinic*, Foucault tells about the emergence of a perceptive and inferring glance, "the glance goes beyond what it sees, it is not misled by the immediate forms of the sensible, for it knows how to traverse them" (Foucault, 2005:149-150).

diagnostic body comes into being from the interaction between many different entities. On the one hand, it involves the body of the medical professional or 'examiner'; on the other, the body of the patient or 'examinee'. In addition to bodies, it also involves particular perceptions, particular skills and particular knowledges. These latter ones, I argue, do not always come a priori; rather, they arise at the very moment of interaction between examiner and examinee. The diagnostic body, I claim, is the materially heterogeneous collectif that comes into being during the physical examination process; this, as a result of the situated interaction between a multiplicity of human and non-human entities.

The practitioner must be formally trained to perceive the clinical variables that differentiate a healthy from an ill body. For a lay person with no medical training these variables are almost impossible to discern. Furthermore, what the practitioner perceives about the body of the patient during the physical examination is always 'mediated' by different aspects that include: the formal medical knowledge and skills he has previously acquired; the information obtained through the medical records, the patient and relatives; and, the technical means he uses to examine the body (pelvimeter, goniometer, etc.), among others. With this in mind, it is also possible to suggest that, at some extent at least, there is a kind of knowledge that is configured in, and comes from, the practices of observation and manipulation of the body. To put it differently, there is some clinical/diagnostic knowledge that emerges '*in practices*', during the physical examination process. Consequently, this means that such knowledge comes from an embodied nature and it is made 'in practice' (rather than merely reproduced from textbooks).

The practitioner has professional/clinical knowledge embodied in his senses, his eyes, his hands, his hears... As it is told by Story 1, through his hands the practitioner knows how muscle waste feels, through his eyes he knows how DDH looks. Within the clinical setting of the GMLab the act of observation involves, on the one hand, the interaction of the physical senses. Looking is not done separately from feeling, neither from hearing. On the other hand, it involves the interaction between the physical senses and the professional knowledges from which very specific, situated, ways of perceiving and reality-making derive.

My proposed notion of the *diagnostic body* also entails that there is a collaborative and simultaneous enactment of the body and the disease, as well as of the examination outcome —be it in the form of a diagnosis, a report or a treatment suggestion—; such enactment takes place in the process of examining the patient's body. In other words, body, disease and evaluation outcome are all being performed together as a result of the interplay between patient, practitioner, relatives, other clinicians, electronic file, medical history, scars, skin, muscular characteristics, cognitive and emotional traits, etc. At the GMLab, the patient's body is examined not as an isolated element, but always in relation to some other materials.

Finally, the physical examination is a process of configuration of the gait collectif. It involves the coordination of a vast array of embodied and professional knowledges and skills, in an attempt to make sense of the clinical past, present and future of the patient.

### ***Second Reconfiguration of the Gait collectif: The Gait Analysis***

After taking each measurement, he will walk to the desk next to the couch, where he leaves his pen and the folded white sheet, and register every data on it.

When the physical examination has concluded, Dr Valle —the Rehabilitation Medicine specialist—, will go to one of the computers and write a report of it that will be kept as part of the patient’s medical records.

While Dr Valle performs the physical examination, Dr Campos —the Biomedical Engineer— will ask the patient’s companion some general information about him/her (name, birth date, age, phone number, etc) and fill in a register form on the computer screen. When Dr Valle finishes the examination, he always goes to the small sink on the other side of the room and washes his hands. After the Physical examination, Dr Campos prepares the patient. The practice of ‘*preparing the patient*’ implies the mounting –or sticking in– of the markers into specific ‘anatomical landmarks’ on the patient’s skin surface, specifically: “the two anterior and posterior iliac spines (ASIS, PSIS), great trochanter (GT), lateral epicondyle (LE), head of the fibula (HF), tibial tuberosity (TT), lateral malleolus (LM), the Achille’s tendon insertion on the calcaneus (CA), dorsal margins of the first (FM) and fifth (VM) metatarsal heads. The centre of the femoral head (FH) is reconstructed by a geometrical prediction method based on the location of the four anatomical landmarks of the pelvis [12]. This provides a third point on the femur, which enables reconstruction of a relevant technical frame [2]. The medial epicondyle (ME), medial malleolus (MM) and dorsal margin of the second metatarsal head (SM) are calibrated [6,10]. The centres of the hip, knee and ankle joints are taken respectively as FH, the mid points between LE and ME, and between LM and MM” (Leardini, et.al., 2006).

The attaching of the markers is done with the patient lying on the couch, then sitting, and finally standing on the ‘force plate’, usually starting from the pelvis towards the feet. The correct collocation of the markers is fundamental for the

*generation* of 'valid' results. Thus, it is crucial for the Gait Assessment that they are in the right position and correctly aligned. For this reason, the mounting of the markers can take up to 20 min.

The GMLab is equipped with a Gait Analysis system that consists on a force plate, a motion capture and analysis software, plus eight infra-red cameras located in different points of the lab.

With the markers in place, Dr Campos sits in front of one of the computers and Dr Valle takes the patient towards the centre of the force plate. When they are there, Dr Campos asks the patient to stand straight, looking at the other end of the platform, with his/her arms separated from the body and his/her legs separated from each other. Then, Dr Campos takes a picture of him/her with the infra-red cameras, and looks on the computer screen whether all the markers can be seen appropriately (by the infrared cameras) and whether electromyographic (EMG) data is being collected, in the case of patients who have been required to have the test done.

The infrared cameras will capture the patient's movement –which is actually the movement of the reflective markers– throughout the analysis, and then a software will translate it into quantitative data. Depending on the angle of the cameras and the points of reference, the number of ways in which a person's gait can be quantified is almost unlimited, making possible to examine the geometry of movement as the limbs travel through space (kinematics) as well as the forces involved in such movement (kinetics).

After Dr Campos has taken the picture, he explains the patient that, in order to perform the analysis, he/she will have to walk up and down the laboratory, from one end of the platform to the other one several times, whilst video data is being collected.

The force plate is a five metres long platform that, while performing the gait analysis, collects information, from three different angles, about the ‘moments and powers’ acting in the patient’s lower limbs while walking –information that is called kinetic data– as well as the ‘movement and trajectories’ of the patient’s hips, knees and ankles –information called kinematic data–.

When everyone and everything is in place, Dr Campos will indicate with a ‘ready’ when the patient (with the help of Dr Valle, who holds his/her hand) has to start walking. If the patient uses any walking aid he/she performs the test using it. It is in this way how the ‘walking trials’ begin.

Each five metre walk across the force plate is classed as a ‘trial’. While the patient is walking across the force plate, the infra-red cameras track the position of the markers attached to him/her, allowing the software to reconstruct the patient’s movements in real time on the computer screen.

Throughout the gait analysis, multiple trials are performed at the GMLab, in order for Dr Campos and Dr Valle to make sure that enough data is collected and that such data corresponds with the patient’s ‘real’ gait –who is asked to walk as he/she does ‘normally’–. Usually, at least three trials will be recorded; however, the number of them also depends on the overall patient’s performance, for instance, if he/she is physically unable to walk for a long time or long distances (because of an injury, fatigue, etc) less trials are collected.

If required, an electromyography is also performed, allowing the medical professionals to collect data about muscular activity. To do this, immediately after attaching the reflective markers (before the gait analysis starts), Dr Campos sticks



several pairs of ‘surface electrodes’ over specific points of the patient’s lower limbs, for each ‘active electrode’ he sticks also a ‘reference electrode’.

The electrodes are called ‘surface’ electrodes because, unlike other kind of invasive electrodes, these are attached to the skin surface, they work as conductors through which an electric current is conducted; the ‘active’ electrode is the one placed nearest to the site of the bioelectric activity being recorded, determining the potential in that localized area. The ‘reference’ electrode is the one placed far from the site of the bioelectric activity being recorded, its potential is assumed to be constant.

‘Semimembranosus, semitendinosus, biceps femoris and biceps rectus...’ depending on the muscular region required to be ‘sensed’, during the electromyographic examinations, either Dr Valle or Dr Campos will repeat the same words time and again.

The electrodes are then connected through four pairs of cables to a portable rectangular machine called TET-Unit (Telemetric Electromyography Transmission Unit) that sends the information received to a Wireless Remote Monitor (WRM), a piece of equipment that captures the data related to the patient’s muscles electric activity. When conducting the gait analysis Dr Valle holds the patient’s hand with one hand and with the other one he holds the TET Unit.

Synthesising, while the patient is walking, the infrared cameras translate the location of the markers into coordinates, which are then stored by the computer and transformed into equations that calculate the variables previously selected by Dr Campos; with the data collected by the force plate and sent to the computer, a special software generates a two dimensional image of the patient’s body with the shape of a moving stick-figure, which appears on the screen. Simultaneously, the TET-Unit

sends the captured data to the WRM. In this way, kinematic, kinetic and electromyographic information about the patient's gait are produced.

Once enough trials have been conducted Dr Valle takes the patient to the couch and Dr Campos removes the markers from his/her body. After the gait analysis has concluded what follows is the processing and interpretation of the data. In this sense, the translation of the patient's gait characteristics into quantifiable data allows Dr Campos to answer different questions in relation to how much, how fast, how far, how high, how long and how wide the patient's gait is performed.

Dr Campos will process the data generated. When processing the data from the multiple trials recorded, Dr Campos tells me that he usually takes the data of the last trials as the 'valid or real' ones, because during the first trials the patient is getting used to the laboratory environment and to walking on the plate surface. The processing of the recorded kinetic, kinematic and muscular activity data from the force plate and the telemetric unit generates a series of graphs and charts that show the patient's gait patterns.

Finally, the complete report of the Gait Assessment, with the results of both, the clinical examination and the gait analysis are printed out and sent to the Rehabilitation doctor in charge of the patient.

The Gait assessment is performed with the objective of identifying certain 'anomalies or deviations' in the patient's gait that could put at risk the function of one or more organs of the body. The results of the assessment are used to determine the kind of rehabilitation treatment to be followed, providing an insight on either the kind of surgical procedure, pharmacological treatment or/and orthotic/prosthetic device or any other kind of rehabilitation aid to be used.

This laboratory acts as a whole, it is impossible to separate it in pieces, 'technically' it is conceived as a whole, for the laboratory to work all the pieces have to be in place, calibrated, tuned among one another; and tuned as well with the human bases of it, including the engineer, the rehabilitation doctor and the patient.

## **5. ENACTING REHABILITATION COLLECTIFS AT THE OPLAB**

In this chapter I focus my analysis on the practices carried out at the Orthotics and Prosthetics Laboratory (OPLab).

### *1. Exploring the relation patient-prosthesis: The practices of doing bodies, artefacts and persons*

As it occurs in many other countries, in Mexican health institutions, the mainstream medical practice around amputee patients and prosthetic devices has been traditionally focused on the purely physical and technical factors of the patient-prosthetics management. Medical experts concentrate their attention, for instance, on the prosthetics technical characteristics (type, material, size, weight, etc.), its fitting-and-adjustment and the prevention of related health conditions associated with the use of prosthetic devices (such as infections, muscular and bone disorders and other syndromes).

The work conducted by the rehabilitation medicine doctors is related to the body-prosthetic physical-technical adjustment and directed towards the achievement of the patient's physical rehabilitation, that is, towards the maximum restoration of the patient's bodily skills and functions.

From a medical perspective, the issue becomes one about the attachment of an artificial limb to a body part and its efficient functioning. Put in these terms, the

person, the body and the prosthetics are assumed to be *passive* entities on which medical experts do some work as a means of rehabilitating the patient.

In the last decades, there has been an important turn in medicine, and in particular in the fields of Rehabilitation Medicine and Prosthetics & Orthotics towards the interdisciplinary management of amputee patients. This turn has allowed psychologists to get involved in this area and, in turn, it has contributed to highlight the relevance of considering the psychological and social issues involved in amputation and rehabilitation management, in addition to the physical and technical factors (Desmond and MacLachlan, 2002).

From this perspective, the concerns are oriented to the therapeutic intervention and treatment of related mental conditions that might arise as a consequence of the loss or/and lack of a limb and the use of a prosthetics (such as depression, posttraumatic stress disorder, low self-esteem, maladaptive coping behaviour, body-image adaptation, phantom pain, age concerns, etc).

As it is from the medical one, from the psychological perspective, person, body and prosthetics are also assumed to be *passive* entities with which psychologists, along with medical experts, work towards the patient's psychological rehabilitation and reintegration to society.

So, from both disciplines, the amputee patient's relation with her prosthetics is assembled around the idea of the patient-prosthetics adjustment. While the medical team emphasises the patient's physical adjustment to the prosthetics, the psychological one focuses on the patient's psychological adjustment to the amputation as a crucial element of the rehabilitation process. Put it that way, those discourses

result too reductionists, because they reduce the patient-prosthesis relation to purely physical-technical or psycho-social factors.

Now, if instead of looking at the patient-prosthesis relation from the disciplinary glasses above mentioned, we look from another direction, we might discover new sorts of questions arising that might give us a different understanding of the issue.

In my attempt to look from somewhere else, rather than particular theoretical discourses, I have taken 'practices' as my starting point, in order to explore 'how the patient-prosthesis relation is actually performed in practice'.

From this angle, the questions that arise relate to the doings, processes, actions, performances, etc., we may ask for example, how does the relation between a patient and her prosthetics is worked on in medical settings, are bodies and prosthetic devices as passive as the medical discourse suggests, are there any other elements involved in this process?, what does it involve to wear (or not) a prosthetics, apart of the technical and psychological implications that can be found cited in the rehabilitation medicine books?...

In this way, rather than taking the theory to the field I want to make theory from practice. To do this, I follow a material semiotics methodological approach and an empirical philosophy, drawing on data from a period of ethnographic fieldwork.

By following the patient's rehabilitation trajectory at the centre, in the previous chapter, I focused my analysis on the clinical practices developed at the Gait and Movement Lab (GMLab).

After the patient had been assigned a medical companion, s/he would request a series of tests which, in most cases, included a gait assessment; when this was the

case, the patient would be sent to the GMLab, where s/he would be subjected to a thorough assessment involving a physical examination and a gait analysis.

The results of such assessment would then take shape in the form of a written report addressed to the patient's medical companion. This report would include the gait experts' suggestion of a particular treatment to be followed for the patient's rehabilitation. Possible treatments included the patient's pharmacological management, a surgical procedure and/or the prescription of a prosthesis –whether an orthotic or a prosthetic device–.

When a prosthesis has been suggested as an option for the rehabilitation management of a patient, the gait assessment report will include some comments on the clinical and technical aspects that the prescription of a particular device should take into account, for example, when the results of the assessment have suggested the presence of an abnormal behaviour of the waist that could affect the patient's body structure and function, the gait specialists might suggest the prescription of an orthotic device that reaches the waistline rather than one that only reaches the knees.

Upon receiving the gait assessment report, the patient's medical companion will request an appointment at the Orthotics and Prosthetics Lab (OPLab). In this chapter I follow the patient's rehabilitation trajectory throughout this lab, in order to trace the reconfiguration of the patient and the *coming into being* of the orthotic/prosthetic device. My aim is to analyse the different ways in which patients and prostheses, as well as their assemblage are enacted within this particular rehabilitation setting.

April 10<sup>th</sup>, 2006. Monday morning at the OPLab... I find myself among aerosol bottles, noisy metal tools, long rectangular work tables and

plaster casts of human limbs. The opaque air full of plaster dust makes me sneeze and irritates my eyes.

Electric drills and saws, telephone rings and a romantic song are the background for an orthotist who sings loudly while covering a plaster cast with transparent plastic.

Meanwhile, other orthotists hurry up polishing up or adding the last screws to the prostheses they will be handing over later in the day... "One of the 16-5-7-7 is ready", "ok, just leave it there and finish the other one, they are for the one [patient] at 11 [o'clock]". At the back of the corridor, the first patients of the day take a sit and wait to be called in to one of the examining rooms...

The Orthotics and Prosthetics Lab (OPLab) is a particularly busy area of the Rehabilitation centre. Its noisy atmosphere radically contrasts with the all pervasive silence of the Gait and Movement Lab (GMLab).

At this lab, long working hours and exhausting physical work are a constant. The combination of medical knowledge and physical skills capabilities from the Orthotists/prosthetists combine a great deal of medical knowledge with acute physical skills.

### **Fabricating an orthotic device**

The manufacture of orthotics requires considerable skill and practice from the orthotists. During the appointment, the orthotist will take a plaster impression of the patient's body part the orthotics is being produced for. This is done using humid plaster bandages of different widths according to the body part. After the plaster cast



has hardened, the orthotist carefully removes it from the patient using a cutter, and then he seals it with plaster bandage. The resultant cast is called a 'negative'.

Then the orthotist places the negative plaster cast into a metallic box full of sand, introduces a metallic tube in the middle of the cast and pours liquid plaster into it and leave it for some time to harden. When the plaster mould has hardened, the orthotist peels and discharge the negative cast; the resultant mould is called a 'positive'.

After that, the orthotist takes the positive mould to the conformation and modification room. There he modifies the cast applying the necessary corrections to it following the medical companion's request form; to do this he uses different kinds of tools to cut, measure, shape and smoothen the plaster.

When the orthotist has finished modifying the positive plaster mould as required, he takes it to the workshop tables for its plastification, which is made using plastic sheets that are in accordance with the material requirements stated in the patient's prescription. The orthotist introduces the plastic sheet in an oven and after it has reached the adequate temperature, he takes it out of the oven and covers the positive mould with it. The plastic is then vacuumed in order to adhere it completely to the positive mould. After the plastic has cooled the orthotist removes it from the mould and cuts it to the shape of the orthotic device required. He then polishes the plastic shape and finally assembles the orthotics gluing the necessary pads and adding the screws, bars and braces to the device.

The patient will be given an appointment for the fitting of the orthotics. During the appointment, the orthotist will check that it fits adequately and that it doesn't cause related problems such as skin irritation.

Follow-up appointments will be scheduled for the patients, in order to ensure that the orthotics is achieving its purpose, and to find out if adjustments or changes to the device need to be made.

## **2. Fitting, Adjusting and Wearing Prosthetics: Tales of shot-puts, cities and monkey bars.**

### **Story 1: Fitting a lower-limb prosthetics**

It is midday; we (two orthotists and me) are in the consulting room waiting for a patient. Minutes later, a middle aged woman and her husband come into the room. The orthotists have done some work on her lower[-left-artificial-] limb. Today, she has come to the centre to try it on, to see how well, 'how adequately the prosthetics fits in the residual limb', the orthotists say.

The orthotist responsible for the patient has invited me to attend to the session, in order to observe 'how the prosthetics works' –in his terms–. I have only taken with me my notebook and a pen, since we have discussed that it might not be appropriate to use my digital recorder or my photo-camera.

I stand on one side of the examining couch, next to the orthotists, who are busy putting the last screws to the artificial foot. No one talks; neither do I, we do not want to disturb the orthotists' work...

Orthotist: *ok, it's ready... can you give me the other shoe?* [to the patient, she is wearing one shoe, and the orthotist takes the other one and puts it on the prosthetic foot]. *Can you wear it?*

The patient is given the prosthetic lower limb fully assembled<sup>74</sup>. Used to these examinations and familiarised enough with the fitting sessions as she seems to be, she positions her residual limb inside the socket, and then, stands up from the wheelchair on her 'two feet'.

Orthotist: *how do you feel it?... is it ok?*.

Patient: *mmm...* [She sits down and repositions the stump inside the socket again].

Orthotist: *move it a bit to the right... no, no, not that much, just a bit... ok, how do you feel it?*.

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<sup>74</sup> A prosthetic device for a lower limb amputation usually includes “an artificial foot connected to an upright assembly (pylon, tube or shaft) which is in turn connected to a custom fitted socket assembly [...] If the amputation is an above-the-knee amputation, the upright assembly will commonly include an artificial knee joint. An above-the-knee prosthesis typically requires two interlaying sockets; an inner socket consisting of a flexible, thermoplastic material, and a stronger, less flexible, thermoplastic outer socket which is attached to the upright assembly of the prosthesis. The inner socket is typically designed to interface with and cushion the amputee's residual limb, to protect the amputee's residual limb from the interconnection components which attach the socket assembly to the upright assembly, and to provide an air-tight seal between the residual limb and the outer socket. This type of prosthesis is typically held on the patient by suction formed in the socket. Therefore, the inner socket will typically include a valve system positioned in the distal inner thigh portion of the socket assembly to release air trapped between the wearer's residual limb and the inner socket as the wearer is inserting the residual limb into the socket. After insertion of the residual limb in the socket, the valve system will be closed, thus forming the suction within the socket” (Slemker, 1997).

Patient: *there is something inside... it makes me feel uncomfortable...*

Orthotist: *is it a screw?*

Patient: *no, I don't think so...*

Orthotist: *let me see...* [He takes the prosthetics and looks inside the socket] *... it might be this... wear it!*

Several times she moves the socket forwards and backwards trying to find a position that makes her feel both, comfortable and secure while wearing the prosthetic limb. After several attempts, she stands up, this time everything seems to be ok.

Orthotist: *ah but, what kind of shoes will you be wearing more often?... the trainers, won't you?*

Patient: *yeah, the trainers...*

Orthotist: *so, change them; we have to make sure that you will feel comfortable with them.*

The patient sits down on her wheelchair, takes off the casual shoes and wears the trainers... Minutes later we are all in the corridor, outside the consulting room. The orthotist has asked her to walk from one side of the corridor to the other, for us to observe her gait. We observe as she goes and comes, walking on 'her two feet' after several weeks of patient waiting on a wheelchair.

Orthotist: *how do you feel your leg?*

Patient: *I feel that, in this part, it doesn't fit very well... here...*

Orthotist: *where?... oh, I see... if it doesn't hurt it's better to leave it like that, remember that you have to lose two or three kilos, after that it will fit much better...*

Patient: *yeah... ok.*

We all continue observing her and her gait while she walks along the corridor wearing her prosthetics.

Orthotist 1: *what do you think?* [to his colleague].

Orthotist 2: *I think it is fine as it is... but, will the size of the foot be changed?, or not?... maybe one size bigger would give her more support...*

Orthotist 1: *how do you feel the foot?, is it ok, or do you feel it too small?* [to the patient].

Patient: *mmm... ok?... I am concerned about the resistance of the socket... in general the prosthetics... because I use the left leg as my support leg in the shot-put* [she is an athlete and in the last years she has been competing in shot-put].

Orthotist: *no, no, don't worry about that, you can do the shot-puts with confidence, these prosthetics are very resistant... it supports very well your weight... in that aspect there isn't any problem... but of course you*

*can't do high-speed running with this prosthetics, it wouldn't resist that...  
how do you feel the socket?, is it comfortable?.*

Patient: *yeah... this position is better, because as it was before, I  
was feeling insecure to walk... I felt that my leg could get out of the  
socket... but now it's ok.*

## **2.1 Bodies, prosthetics and their mutual embodiment**

The *story* above is an ethnographic excerpt of a prosthetics-fitting-and-adjusting session in the rehabilitation centre. What are the orthotists and the patient working on during the session?, who are the participants involved in that process?, what kind of materials are being mobilised by doing so?, by whom?, how?.

The session can be translated as a medical procedure in which a left-lower-limb prosthetics is being fitted and adjusted into a patient's residual limb, to say it another way, as a *practice* of attachment of a human-like artefact into a human body-part.

The fitting-and-adjusting session, involves the *[re]making of links between different heterogeneous materials* across different spheres (the physical, the social, the subjective, the discursive, the practical<sup>75</sup>, etc.). It involves links between a stump and

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<sup>75</sup> Note here my use of the preposition 'the'. From a material semiotics, "'the' social, 'the' material, 'the' subjective', etc. are all constituted by a wide range of 'heterogeneous materials', including artefacts, discourses, technologies, language, bodies, and other human and nonhuman agents". In this sense, the social is never purely social, neither it is the material purely material, nor the subjective purely subjective. This is because they are the product or effects of 'materially heterogeneous relations'.

an artificial limb, between a human body and a prosthetic device, links between two legs, an organic one and another that is half-organic-half-artificial, between the legs and their coordination during the gait, which in turn implies links between legs, shoes and floor surfaces, between muscular regions, gait forces and gait speed, links between a patient and a prosthesis, between a person, her prosthetic limb, her daily activities, and her enactment of herself as an athlete.

Throughout the session, orthotists and patient work time and again on the remaking of those links, and they do so, in order to achieve what the orthotists consider to be the most 'adequate' attachment between the body and the prosthetic device. For the orthotists, the aim of the session is to evaluate how well 'the patient's prosthetics fits into her residual limb' and 'how [well] the prosthetics works' –in the orthotist's terms–. According this orthotists's view, it appears to be that such an [body-prosthetics] attachment is more about the artefact and its technicalities and less about the body itself.

However, after the prosthetics has been attached to her stump, the patient has stood up from the wheelchair and now, she is 'walking on her two feet' from one side of the corridor to the other and, at some point she is asked by the orthotist, "How do you feel 'your leg'?". Now, it is no more about an artefact being attached to a body, but about a person; by this moment, the prosthetic device –an artefact which a few hours ago was standing on a table between plaster casts and thermoplastic sheets– has become part of the patient's body and of herself as a person, it has become 'her leg';

not only the prosthetics has been attached to her body, but it has been integrated into it, it has become part of it, incorporated to it, it has become ‘embodied’<sup>76</sup>.

What does this tell us about the fitting-and-adjusting session and about the patient-prosthetics relation?. It tells us that the session is a practice of becoming, of making emerge new material[ly heterogeneous] arrangements, new assemblages, new [re]configurations, new orderings, a new collectif. In this sense, the orthotists and the patient are working on making emerge a new materiality of her, working on her reordering. Later on I will explain what I mean by such terms.

However, during the fitting session these becoming practices do not run smoothly all the time and difficulties of different kinds might arise that interfere with this process. For the orthotists and the patient, there are some medical and technical difficulties that have to be overcome during the adjustment of the prosthetics to the patient’s limb, hence, another purpose of the session is to detect them and, of course, to solve them. It is expected that, at the end of the session, prosthesis and body should be ‘adequately’ attached to each other.

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<sup>76</sup> In her work on the adjustment of wheelchairs, Wynance (2006), in addition to an Actor-Network approach, she draws on a phenomenological account in order to address the question of ‘embodiment’; she particularly makes reference to Merleau-Ponty, 1971; Leder, 1990; Scarry, 1985; Seymour, 1998. “Using the notion of “embodiment” (Merleau-Ponty, 1971) which means that the body is always perceiving (and perceived) and thereby relating to the world or even giving access and meaning to the world, these authors have analyzed pain (Leder, 1990; Scarry, 1985) and disability (Seymour, 1998) as a transformation of embodiment (i.e., of the relation between the body and the world).” (Wynance, 2006).



In practice, ‘expectations’ do not always fit well with ‘reality’, as prosthetics do not always fit well with bodies, literally, as it happens with the patients in the story above, she is trying out her new leg, but this, does not seem to fit very well in some areas of her residual limb. On the one hand, there are some ‘issues’ with the prosthetic device which need attention, for example, some tiny residues inside the socket makes it uncomfortable to wear, so the orthotists have to do something about it. Symmetrically, on the other hand, there are some ‘issues’ with the body that also need attention, in particular from the patient, in order for the prosthetics to fit well, she has to lose some weight, “after that” –the orthotist says–, “it will fit much better”.

The attachment of the prosthetics is not as easy as it seems, it is not smooth by itself, but it has to be made smoothly by performing new material arrangements, by a...ments[?] new agents and/or making new assemblages between the agents involved in the *collectif*.

But there is also something else implicit here, and this is that, while some of those ‘issues’ can be addressed and solved during the session, some others cannot, they necessarily have to be negotiated during a longer period and somewhere else, rather than in the consulting room at that very precise moment, this means that the work of attachment of the prosthetics to the patient’s leg is neither limited to the fitting-and-adjusting session nor to the rehabilitation centre, such work does not finish when the session ends, instead, it *extends in time, space and practice*, beyond the passage of the patient in the consulting room.

During the session, not only the prosthetic device is fitted and adjusted into a body, but it also happens the other way around, since the patient’s body too literally has to undergo a series of adjustments for it to fit into the prosthetics; in this way,

both prosthetics *and* body have to adjust and be adjusted into each other. In this terms, throughout the remaking and reconfiguring practices, literally and metaphorically, both, prosthetics *and* body undergo different sorts of transformations and they are mutually remade, shaping and being shaped by one another, as well as embodying and being embodied by one another.

## **2.2 ‘Subjectivity & Practice’ in the body-prosthesis arrangement**

Now, before I have pointed out that one of the purposes of the session is to see ‘how adequately’ the prosthetics fits into the residual limb and ‘how well’ it works. What does it mean ‘how adequate’ and ‘how well’ for both, the orthotists and the patient?, what are their concerns?, on what bases do they evaluate such an adequacy?, are those criteria the same for orthotists and patient?.

The orthotist and the patient *relate differently* to the body-prosthetics attachment, this is because, although being part of a particular collectif themselves, they also belong to a variety of other collectifs that are not the same for both parts, and therefore, the kind of ‘materials’ that they relate to from those particular grounds varies; for example, each of them relates to particular knowledges and particular experiences of ‘prosthetics attachment’ practices, that are then mobilised during the fitting-and-adjusting session. On the one side, the orthotists relate to certain knowledges and experiences shaped by the medical and technical discourse about prosthetics being attached to residual limbs; on the other side, the patient relates to the experience and knowledge acquired by wearing a prosthetic device, and of being an

athlete<sup>77</sup>. However, it is also necessary to say that, relating differently to the body-prosthetics attachment does not mean that the orthotists and the patient's criteria and concerns are going to evolve in totally different directions, because of the very reason that they share similar goals, at least, the very general one of making the body-prosthetics attachment to work adequately.

Considering this, what is it that orthotists and patient are looking for?, what are their criteria for evaluating the adequacy and good performance of the body-prosthetics collectif that they are working on to put in place?.

The fieldwork excerpt above provides some clues to answer this question. For the orthotists, on the one hand, such criteria have to do with particular medical and 'technical' characteristics of both, the patient's body and gait as well as the prosthetic device. Weight, size, height, gravity centre, speed, forces, etc. are taken into account during the session, all of which, at some extent –although, probably for different reasons than those of the orthotists–, are also important elements for the patient considering her daily activities and her job as an athlete. For the patient, on the other hand, 'how adequate' and 'how well' translate into the very material practice of finding the best position for the socket in-relation-to the residual limb, the position that can provide with the best attachment in terms of resistance, support, comfort, self-confidence and ease of movements while doing certain activities, for example, walking or doing sports. With these criteria in mind during the fitting session, the socket is positioned forwards and backwards with respect to the residual limb, towards the left side and then towards the right one, aligned in the centre, etc. later on,

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<sup>77</sup> Although, with time, many patients acquire as much medical knowledge about prosthetics as the medical experts, but this is not what I want to explore here.

the trainers will replace the casual shoes, then, certain decisions will be made in relation to the feet size, and so on. This set of concerns might also be shared by the orthotists.

Throughout the session, a series of material recompositions<sup>78</sup> take place, different material [re]arrangements that are negotiated between the orthotists, the prosthetics, the patient, her daily activities as an athlete, the trainers, the comfort, etc.

The ‘fitting and adjusting’ work is a practice of [re]ordering and remaking of links between all these materials, in order to achieve the adequate body-prosthetics attachment. Such an attachment not only implies a *body* and a *prosthetic device*, it also has to do with a ‘*person*’ and her daily *activities*, as well as her lifestyle, her job, and all the heterogeneous [human and nonhuman] ‘materials that are part of the collectifs she is *also* a part of’, in other words, it has to do with a ‘*situated*’ person, with ‘*different sets of practices*’ and with a ‘*network [or collectif] of action*’, a network that is *heterogeneous and embodied*, a network *that performs and is performed*.

In this context, the evaluation of the work of attachment constitutes an evaluation of ‘*a\_[situated]\_body/person-prosthesis\_in\_action*’, who is both, 1) *situated within a collectif of heterogeneous materials, –including humans, non-humans, texts, artefacts, technologies, and ‘specific sets of practices’–*, but also, 2) it is itself a collectif.

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<sup>78</sup> Here I am drawing on Moser’s proposition of decomposition & recomposition (see: Moser, 2003).

It is important to highlight that during this attachment process, *body/person* and *prosthesis* are kept flexible enough to be malleable, mouldable, to embody and be embodied, to remake and reshape one another<sup>79</sup>.

The ‘adequate body-prosthesis attachment’, which orthotists and patient are trying to make emerge during the fitting session, is not the result of the ‘combination’ of two different entities (body and prosthetics), this would presuppose a difference ‘in nature’ between them, as well as the maintenance of a clearly defined distinction between both entities even after the attachment process has been carried out achieving certain degree of [temporal!!] stability. Rather than that, during the fitting process what is at stake is precisely the redrawing of such a distinction; it is a work of embodiment in which the condition of body and prosthetics as separated components is renegotiated and retraced among the different agents involved.

The attachment that is being negotiated here is shaped in two contrasting, but yet possible, ways. On the one hand, it does not involve the mere combination of entities or adding up of components, since their boundaries are not kept intact and immutable; instead, the kind of attachment I refer to is one that involves the ‘conflation’, the ‘fusion’ of heterogeneous materials. On the other hand, such a conflation is ‘partial’, in the sense that, although the merged entity *body[/person]-*

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<sup>79</sup> For an account on ‘action’ and the way it is made possible for people suffering from neuromuscular diseases, see: Winance, 2006. When I say ‘collectif’ I am using Callon and Law’s notion of ‘*hybrid collectif*’ (see: Callon and Law, 1995).

*prosthesis* might attain certain unity, it might also keep the quality of a *composite* whose elements are irreducible to one another<sup>80</sup>.

### **2.3 Destabilising the body: What about the body ‘itself’**

Within the medical discipline, and particularly within rehabilitation medicine, the body is portrayed merely as a passive flesh-and-blood object, one that lie down on the couch of the consulting room or operation theatre waiting to be intervened, sectioned, cut in pieces, studied and described. However, bodies are more than corporeal objects or physical organisms and they might be better explained as a *conflation of corporealities, subjectivities and practices*.

For approaching to this matter, I turn to Mol and Law’s work on hypoglycaemia (see: Mol and Law, 2004). It is something given, Mol and Law tell us, that “the living body is both an object and a subject” (Mol and Law, 2004:43); as an object, we ‘*have*’ a public body, one which is known ‘objectively’ (through scientific methods) by pathologists; as a subject, we ‘*are*’ a private body, one which is known ‘subjectively’ (and personally) by ourselves. In their work, these scholars confront such a ‘body-object/body-subject’ proposition by pointing out that “We all *have* and *are* a body. But there is a way out of this dichotomous twosome. As a part of our daily practices, *we also do (our) bodies*. In practice we enact them” (Mol and Law, 2004:45). Coming back to the fitting session, how is this made in practice?, how are the patient’s body and its links with other heterogeneous materials enacted?.

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<sup>80</sup> Here, I am drawing on Haraway’s notion of ‘*cyborg*’, on Strathern’s ‘*partial connections*’ and on Moser and Law’s discussion on ‘*specificities*’ (see: Haraway, 1991; Moser and Law, 1999; Strathern, 1991).

Throughout the session, a play of visibilities/invisibilities-presences/absences takes place; the ‘patient’ is enacted into two [partially different] versions, a ‘patient/body’ –or ‘body/object’– and a ‘patient/person’ –or ‘body/subject’–.

The session enacts a play between both versions; the patient/body is shadowed sometimes by the patient/person, at other times, they are both shadowed by the prosthetic device taking the central focus. In the session, each element is explored as a separate component, and yet simultaneously, all three elements are kept together and made present as a whole. During the fitting-and-adjusting procedure, corporeal body, subjective body –or person– and prosthetics emerge *each at a time and all at once*, they are lightened and darkened, made visible and invisible, present and absent by the agents participating in the process.

In this way, the fitting session constitutes the background of a situation in which the patient’s *multidimensional identity* is opened up. Not only is the patient, as a medical object of knowledge, made present in the session, but also other faces of her identity are made present at some points in the medical situation. Similar to a polyhedron, the ‘*different faces of this one multidimensional identity*’ are made present, for some moments one of the faces is made visible while the rest are made invisible, then, it is another face which is made present, sometimes many of them are made visible... each of this ‘singular multidimensional’ identity’s faces is made present and absent but keeping simultaneously its ‘partial’ integration with the rest of the faces.

The fitting session involves the remaking of entities in terms of the material relations between them as well as the practices in which they are situated. Here, the body that is being reconfigured does not rest only on ‘physicalities’; instead, this is a

body that is simultaneously ‘*corporeal, subjective and situated in specific sets of practices*’. The Body I refer to is not separated either from its *self* or from its *practices*, since *it is also self and practice*, it also performs and is performed by material practices, it is a body that is done in practice, a body that enacts and is enacted.

It is on this basis how the links between a *Body* (with capital B) –that is *corporeal, subjective and situated in practice*– and a *prosthesis* –that is also situated in a set of practices– are enacted, links through which Body and prosthesis *merge*; some of these links will be broken, some others reinforced, new ones will be also created; the result will be a new entity in which the separation between Body and prosthesis has been *partially* faded. During the fitting session, ‘*Body(=body/person[+action]) and prosthesis[+action]*’ are mobilised, remade and transformed into a continuum, generating a new entity<sup>81</sup>.

### **Story 2: Using a lower-limb prosthetics<sup>82</sup>**

May 9<sup>th</sup>, 2006. Morning in the institute. Sitting outside the *Administrative Area*, I am waiting for my appointment with the coordinator of Rehabilitation medicine. Arrived early, I have been here for nearly two

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<sup>81</sup> Related to the idea of an ‘extended’ body, see: Grosz, 1994. Note that here, I am not arguing for a similar understanding of the case I present; I am not suggesting that prostheses should be seen as extensions of the body, instead, I argue that prosthetics and body become a continuous, partially singular, entity.

<sup>82</sup> From this Story, I do not present any dialog. I did not take notes of the conversation while talking to this person, since it was an informal chat, however, having asked whether he would agree, I took notes on the conversation after our chat.



hours, and still have to wait one more... I observe the movement of an ordinary day in the Institute... White-coated people come and go all the time, with the morning-coffee cup in one hand, and the patients' medical records, radiographies and prescriptions in the other. I see medical students rushing on their way to the classrooms and the wards, for the first session of the day.

From time to time, some doctors will stop at the entrance of the Administration, saying hello to their colleagues and having a quick chat about 'the new cases'. Others will meet with their former patients and talk about their current treatment, their relation with current doctors and their quotidian-lives-with-their-[medical]condition.

While waiting, I see all the time amputee patients coming in and out of the lifts, opposite to me. Some of them have upper limb amputations, many of them, amputations of the lower limbs; there is a large number of the latter who have with them their prosthetics; after some time observing them, I repeat to myself again: they '*have* with them' their prosthetics. It is surprising for me to see that most of those patients are 'carrying' their lower-limb prosthetics, rather than 'wearing' them. Coming out of the lift, I see some patients sitting in their wheelchairs with the prosthetics on their lap, and some others using crutches while carrying the artificial limb in one hand...

A man arrives and shifts from his wheelchair to the sofa where I am sitting. We start talking. His wheelchair is next to him and, on it, it is his prosthetics!. We continue chatting; he asks me some questions like what I

am doing here, how long I have been waiting for, what I think about the institute, etc. Then, it's my turn to ask. He is waiting for his doctor to arrive, today, he will examine his leg[+prosthetics]. He has been using the prosthetic device for several years now, he tells me, starting a couple of years after losing his leg, long time ago... In the last weeks, he has been 'feeling' that 'the prosthetics doesn't fit his leg' very well, so it might be time to 'make some adjustments to it' or perhaps to change it.

What does he 'feel' that makes him think that an adjustment is needed?... With not so much physical exercising to keep his muscles' tone, his leg is becoming thinner, so, while walking, he feels that the prosthetics is a bit unstable, he feels that it moves and it is also uncomfortable; in consequence, he is not very confident about using it. He has tried to solve the problem by changing the cover-stocking for a tighter one, but it is not working.

I infer from his explanation that such is the reason why he is not wearing his prosthetics now, but I still want to ask. The reasons I hear, however, do not precisely have to do with the things that he has told me before: Coming to the institute means for him, that he[-and-his-prosthetics] will go from one of the doctors' consulting rooms to another, undertaking a series of different examinations; so, moving in his wheelchair from one place to another is faster and less energy-consuming than moving in his organic-&-metallic legs. Wearing the prosthetics itself also implies a big effort for him, even if he is used to; it is not just a question of attaching it to his leg and that's it, but instead, it has to be carefully positioned and

adjusted, in order to fit well and to avoid discomfort and injuries in the skin while walking. In addition, if he is wearing his prosthetic device in the institute, he will be asked to take it off to examine both him and it, so, it makes it complicated and exhausting to put it on and take it off so many times in a single morning. Putting aside the effort that takes its attachment to the body, the act of 'using' the prosthetics requires of him a certain amount of concentration on and awareness of his own gait and his body in general, because walking with an artificial leg is certainly not the same than walking with two 'organic' legs, it requires training, concentration and perseverance.

Those are just some of the several reasons he has for not using his prosthetic leg and for preferring his wheelchair while being at the institute. Later, he tells me about some of the situations in which he does wear it: When knowing that he will be sitting most of the time rather than walking, for example at work, where he spends the day sitting at his desk. When going to places that are near to his home and he does not have to walk a long distance, for example, when going to the supermarket. When moving in places where he knows there are not so many stairs to walk up and down. Walking for a long time with an artificial leg can be uncomfortable and painful, he says, and rather than improving his mobility it makes it more difficult, that is why it becomes crucial to take into account the places and activities of the day before making his decision about what to take with him.

### **Story 3: Using an upper-limb prosthesis**

Tuesday afternoon. Manuel is making a phone call; I am looking through one of his students' thesis, while waiting to continue the conversation we have just started. His office is full of shelves with Engineering books, journals and metallic artefacts. A white human skeleton, one of those used in Anatomy courses, stands behind me; and on my left his computer and an image of a mechanical prosthetic arm on the screen. He ends his call and continues talking to me, I press again the *Pause* button in order to continue recording our conversation; here are some excerpts:

*"[...] this prosthetics [...] is a boy's one, he's four [years old] [...] he told me: "I give it to you, I don't want even to see it", why?, because it's uncomfortable, it's very heavy [...]"*

*"[...] there are important limitations [with the mechanical prosthetics] [...] with the shoulder they [the users] open and close it [the hand] [...] they are very difficult to operate. However, [a] doctor was telling me that people with [a long] time using it, and patience [...] and she sees it with one of her patients, [who] with two mechanical prosthetics she is able to introduce a thread in a needle, and that's amazing but not all people achieve that level of precision [...] so, mechanical prosthetics are uncomfortable, they are heavy, difficult to operate and expensive [...]"*

*"[...] the other prostheses are the myoelectric ones... they are very expensive [...] in Mexico there are some people who have myoelectric prosthetics, however, they have some problems [...] here, there are no technicians to repair them, to calibrate them, it is necessary to send them to*

*the US to be calibrated [...] A person was telling me, his son, he has a myoelectric prosthetics, a very elegant one, the kid is 7 [...] so, there are some things, first, because he's growing up a change of prosthetics will be necessary, but also, kids are kids, so, they play, and this person was telling me that the boy is looking at his friends hanging on the monkey bars and he says "I want [to do it]", and then, the prosthetics is hanging there [on the bars] and damaged, of course"*

#### **2.4 A Body-prosthesis arrangement**

In practices, body, person and prosthetic device are reconfigured in specific ways and not in others, what are the implications of such arrangements or reconfigurations for the patient-prosthesis collectif?.

By looking at stories 1, 2 and 3, altogether they show us that the resulted configuration of the links established between body, person and prosthetics *enables* some possibilities of 'action' *and* at the same time, *disables* some others<sup>83</sup>.

For the patient of the first story, as an athlete, the disposition of every part of her body becomes crucial during the training and, obviously, during the competition, and with her new socket and foot, she will be able to do the shot-puts using her left leg as her support leg, '*this*' prosthetics is very resistant to being used for that; however, it is not that resistant for high-speed running; so, while wearing '*this*' prosthetics she will have to limit her running speed, if she doesn't want to get into trouble.

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<sup>83</sup> For an account on the performing of ability and dis/ability, see: Moser and Law, 1999; and Moser, 2000.

The situations that patient of the second story tells about, particularly, are excellent examples of the enabling/disabling issue: Cities, generally speaking, have been built for people moving on two legs, but not for people on wheelchairs; streets and buildings might work well for ‘standard’ standing people, but for wheelchair users they can cause lots of difficulty. Considering these difficulties, some of the main reasons for advising and prescribing the use of lower-limb prosthetics to amputee patients are the independence and mobility that they provide to the user, for him to be able to move ‘freely’ as any other [standard] ‘normal’ person does. An artificial leg is assumed to be more enabling for an amputee patient than a wheelchair for performing his daily activities. Ironically, this is not always the case, not for all people, and not for all situations, and this is precisely what the patient of story 2 is referring to. He is clear about the daily-life situations in which wearing his prosthetic limb is, or is not, the best idea, whether it is the most convenient for him. Prosthetics being worn with visits to the rehabilitation institute don’t match very well, neither do they match with having to stand for a long time, nor to walk long distances.

Finally, upper-limb mechanical and myoelectric prosthetics enable amputee users to do things that, in another way, it would be too difficult to achieve without human aids; with these kinds of prosthetic devices some users may even achieve a very high level of precision and do truly amazing things, like introducing a thread in a needle. However, when configured within particular sets of materials the result is not always that satisfactory, for example, when these prosthetics are put in relation with a 7 year old kid in a playground with monkey bars, they simply don’t work.

In addition to the *enabling/disabling* one, there is also another issue going on here, and it is that of the ‘*specificities*’ and the ‘*situatedness*’, which has been

addressed by Moser and Law (see: Moser and Law, 1999). Put in relation, the arrangement between a ‘specific’ prosthetics attached to a ‘specific’ Body results in the capacity –or incapacity– of the patient to do –or not– certain activities, “[...] if the networks are in place, if the prostheses are working, then there is ability. If they are not [...] there is dis/ability [...] Dis/ability is about specific passages between equally specific arrays of heterogeneous materials. It is about the character of the materials which en/able those passages. And it is about the arrays which secure or don’t secure them” (Moser and Law, 1999:201).

The woman of the first story can use ‘that’ particular prosthetics to do the shot-puts, but she cannot do high-speed running with it; the man’s prosthetics from the second story doesn’t go well with many stairs and long distances; and the child’s upper artificial limb doesn’t match with monkey bars. The ‘*ability*’ and the ‘*inability*’ [of a Body-prosthetic collectif] ‘to act’ *are performed together in specific and situated sets of practices*, practices that involve *specific material arrangements*, *specific ‘passages’*, *specific ‘networks of action’*, specific prostheses, specific bodies...

The attachment of a prosthetic device to a body is not just a matter of working on the residual limb and the prosthetics being ‘fitted’; instead, it involves work on the prosthetics, the body, the person, the practices, the specificities and all the links between them. This attachment is only achieved by creating and performing a work of integration of such materially heterogeneous *collectif*. The attachment and the relation between prosthetics and patient rests on the way they *work together in practice*; in this sense, as I have suggested before, the attachment is not located in the fitting session but it *extends* [in time, space and practice] outside the rehabilitation

centre and *is being done in everyday practices*. It is in this way that the emergence of a *Bodily-prosthetic entity* –made and shaped ‘*in relation*’– is made possible.

Now, I have already mentioned that the attachment of a prosthetic device to an amputee patient involves the partial conflation or fusion of body and prosthetics; in medical practice, the work of prosthetics-fitting seeks to produce *stability* in the relation between the patient with her prosthetic device.

The Body-prosthesis can be understood as a unity, however, such a unity is always partial!. As a unity, a Body-prosthesis might possess certain degree of stability, but, since bodily-prosthetic entities exist always in relation to specific sets of heterogeneous materials and practices, sometimes when certain materials that don’t match with the collectif in place are added, such a stability is broken and the partiality of the unity is made visible, this is the case for instance, of a child wearing an upper artificial limb and playing in the monkey bars.

Stability is not a characteristic of the body-prosthesis attachment that is achieved in the medical centre, but something that is permanently being negotiated in *particular set of practices*, it is a matter of *acting bodies-protheses* and the ‘specificities’ of the day to day situations. Such an attachment is neither permanent nor stable. Rather than stability, what we have in everyday practices are *ongoing, uncertain and continuing arrangements within materially heterogeneous networks of action*, a collection of disjointed elements struggling to achieve integration.

Summarizing, in this document I have explored the way in which material relations between amputee patients and their prosthetics are enacted, focusing on the fitting-and-adjusting and the attachment/detachment of prosthetics to and from the patient’s body. I have pointed out that the Body might be better understood as a



*situated-body-and-its-practices*; then I have argued that bodies and prosthetic devices embody and are embodied mutually, in a simultaneous process. I have suggested that neither bodies, nor prosthetic devices should not be understood as mere passive objects but as *materials-in-action*., bodies are ‘acting bodies’ in the same way than prosthetics are ‘acting prosthetics’. For a *Body-prosthesis* to act, it takes the reconfiguring of links and the [re]making of arrangements between ‘materially heterogeneous, situated and specific’ sets of *bodies-prostheses-practices*. A ‘[acting] *Body-prosthesis*’ means *materially heterogeneous, situated and specific arrangements between body, person, prosthetics and practices*.

## 6. ENACTING REHABILITATION COLLECTIFS AT OTA

A basic starting point of this thesis is the idea that within the different areas, departments and laboratories of the centre, multiple *rehabilitation collectifs* get enacted. In this research, I have focused on those collectifs specifically related to the incorporation and use of prostheses into the patient's rehabilitation treatment and everyday life. To do this, I have mobilised the term '*prosthesis*' to make reference to either prosthetic or orthotic devices, in the understanding that both of them act, simultaneously, as extensions and as parts of a person's body.

In the case of the Occupational Therapy Area, which is the focus of the present chapter, human and non-human agents interact together establishing specific relations between them, this, in order to shape a very particular *collectif* that will, in turn, allow for specific practices —crucial to the patient's rehabilitation process— to take place developing itself, more or less, smoothly. By tracing the configuration of such collectif and what it entails, in this chapter I analyse and reflect on the clinical practices of rehabilitation around orthotic and prosthetic devices carried out at the OTA.

In the previous chapters I have analysed some of the clinical practices that take place at the rehabilitation centre where I conducted my ethnography, particularly those practices circumscribed to two of its clinical areas, namely, the Gait and Movement Laboratory and the Orthotics and Prosthetics Laboratory. The aim of my

ethnographic work has been to follow closely what happens during the rehabilitation process of patients whose rehabilitative treatment includes the incorporation of an orthotic or prosthetic device. In order to explore and make sense of this process I have mobilised the figure of the cyborg-collectif, suggesting that the practices that occur in each of the areas involved in the patient's rehabilitation, are directed towards the configuration of materially heterogeneous hybrid collectifs –made up of human and non-human actants— particular to each specific area, that will, in turn, give place and support to the configuration of a more or less stable entity.

In this chapter I focus my attention on the Occupational Therapy Area, which constitutes the third and final stage of the patient's rehabilitation process at the centre. Here I explore how rehabilitation practices at OTA configure a cyborg collectif that is very particular to this place but that, at the same time, gives continuity to the rehabilitation collectif that clinicians, patients and carers have worked all along the process to produce. I assume that the collectif performed at OTA is expressed by the interaction '*patient+prostheses/environment*' and how this formula relates mainly to the idea of independence.

### Story 1

OT: Tomorrow we are having a patient that you must see.

Ethnographer: Are we?!... What kind of patient?

OT: He is a boy who had an amputation of the right lower limb months ago —he had a terrible accident and nothing could be done to save his leg..., he will probably tell you about it— anyway, he has been using a provisional leg and today he will be fitted with the permanent one. He is

going to the Prosthetics Lab first and then he will come here to learn how to use it.

Ethnographer: Ok!, it sounds really interesting for me... I guess after the boy tries it out you and the prosthetists will have to make several adjustments, isn't it?; I mean, depending on how well he walks with the new one...

OT: Yeah, of course, we will make some small adjustments; I mean, you cannot know if it is going to fit well unless the person tries it out, that is why we consider it very important to produce a prosthesis specifically for a particular person, and not factory-style, each person is different, each person has a different body shape, and a different lifestyle, here, we consider those things, so that the prosthetics we design is actually used, not just stored in the garage... With this patient, we worked very closely with the prosthetists in order to make his new leg. It was hard work!, but it was worth the effort, we wanted to give him a good leg, high quality and nice... They got a nice foot for him and used a special kind of thermoplastic, one that is more resistant to the weather conditions. They also decorated the socket with drawings and everything, he chose them [the drawings] himself... he is such a lovely boy, despite what happened to him he has worked very hard to get better; when you perceive that from a patient, it inevitably makes you feel with the responsibility to do the best you can, if they are giving everything to their rehabilitation you must give everything too, you must do everything in your hands to make sure that the patient receives the best attention you can offer.

Ethnographer: Yeah, I agree...

Following the line of Struhkamp et al's article on severely disabled people (see: Struhkamp et al, 2008), my intention now is to reflect on and discuss about, more specifically, the relationship between rehabilitation and functional independence, the latter assumed as the central aim of rehabilitation, as it is defined by international health organizations and guidelines such as those of the World Health Organization (see: WHO, 2002).

With the purpose of determining objectively —or better said, numerically— an individual's level of disability, the World Health Organization proposed, in 1980, the first version of the International Classification of Functioning, Disability and Health (commonly known as ICF). The ICF measures an individual's levels of capacity and performance, this is, “what a person with a health condition can do in a standard environment [...], as well as what they actually do in their usual environment [...]” (WHO, 2002). To do this, the ICF uses two different lists, one that corresponds to bodily functions and structures, and another one related to domains of activity and participation. Additionally, the ICF also incorporates a list of environmental factors that have an influence on an individual's disability and functioning. When evaluating the capacities and performance of any given person, the numerical measurement of the particular interrelations and interactions established between the elements outlined in those three categories, results in a percentage that corresponds to the person's levels of disability and functioning.

One of the most perplexing features of the guidelines proposed by the ICF is that they strongly suggest that there is a tight relation between disability and functioning; in other words, it is assumed, a priori, that the more disabled a person is,

the less functional; correspondingly, the higher the degree of disability, the lower that of functionality.

Furthermore, we can even point out that the above statement shows only half of the equation, considering that, in the same way that disability and functionality always come together, in clinical settings, there is always a third component associated to them, which is that of rehabilitation. The ICF is a very valuable tool for clinicians for measuring disability and functionality; however, such measurement practices would not make any sense if nothing else, besides of numbers, derived from them. Rather than that, those numbers and percentages are then used to calculate the degree—and, in turn, the type— of rehabilitation a person will need. It is at this point that a new set of measurements comes to the scene.

For clinicians working with people with impairments, disability, functioning and rehabilitation are the three main elements they, along with patients and their carers, must ‘tinker’ with, borrowing Mol, Moser and Pol’s metaphor (see: Mol, et.al. 2010). In order to facilitate these tinkering practices, a variety of scales have been formulated which allow them to deal with those three components in an integrated way, rather than as independent components.

Among some of the most widely used scales we find the Functional Independence Measure (better known as FIM), and the Functional Assessment Measure (better known as FAM). The FIM seeks to assess the degree of physical and/or cognitive disability a person presents and its relation to the amount of care and assistance such a person requires to perform activities of daily living, this, in correspondence to his/her level of disability. The FIM scale includes eighteen items, thirteen of them are related to physical domains, and the remaining five related to

cognitive domains. Each item is scored from 1 to 7 based on the person's level of independence; a score of 1 indicates total dependence, while a score of 7 indicates total independence. Following this logic, the higher the score obtained, the more independent the person. In addition to its use as a diagnostic tool, the FIM scale helps the clinician to monitor the patient's progress, as well as to assess the outcomes of rehabilitation.

Although widely used in many countries for the evaluation of functional independence, the FIM and other similar scales have been criticized for focusing greatly on the physical aspects of disability and independence, while overlooking cognitive criteria. As a response to this, a new scale was developed by Dr. Karyl Hall and his team at the Santa Clara Valley Medical Center, in San Jose California. This scale, was called the Functional Assessment Measure, or FAM, and it incorporates twelve new items to those outlined in the FIM scale; these new items are focused on cognitive and psychosocial aspects such as emotional status, community integration, reading & writing skills, employability, etc.

Even though the FAM scale represented a big improvement with respect to the FIM, many rehabilitation experts considered some of its items to be too vague. For this reason, a new scale was developed in the Regional Rehabilitation Unit at Northwick Park Hospital, in Middlesex, UK. This scale is called the UK FIM + FAM and it has sought to improve the consistency of the old American FAM scale items (Turner-Stokes et al, 1999; UK FIM+FAM, 2010).

As it can be inferred from the description above, considerable amount of time and resources is put into the development of more precise instruments for the measurement of functional independence. But, what does all these instruments and

measurements actually mean ‘in practice’, how do they inform everyday clinical activities and rehabilitation?, what do they communicate to clinicians, patients and carers in day-to-day life?. In order to explore these and other questions, I now, present some empirical material.

## Story 2

December 14<sup>th</sup>. Work has started at OTA; it is sunny outside and the sunshine enters directly from the big windows lightening up the room, this makes the colours of the furniture and the mats seem brighter than usual. We are working with a girl, she is seven years-old and she is trying out her new upper-limb orthoses. Years ago she was diagnosed with muscular dystrophy, which is the direct cause of the spasticity<sup>84</sup> she presents and for which she has been prescribed the orthotics —she uses orthotics for her upper as well as for her lower limbs—. Considering the time I have spent at the centre I can say that spasticity is probably the main clinical feature for which most of the orthotic devices are prescribed here. The girl has been using orthotic devices for several years now; she must be fitted with new ones periodically in order to realign her limbs, prevent deformities and treat the muscle contractures she experiences. The girl complains of pain, right now the occupational therapist is adjusting the orthotics and, since they are

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<sup>84</sup> Spasticity, in clinical terms, refers to a feature in which certain muscles are permanently either stretched or flexed. People diagnosed with medical conditions such as cerebral palsy, traumatic brain injury, spinal cord injury, multiple sclerosis and muscular dystrophy frequently present varied degrees of spasticity, from mild muscle stiffness to severe muscle spasms. The medical management of spasticity includes pharmacological, surgical, orthotic and combined treatments.



new ones, it is even more painful, this is because the limbs are literally forced to adopt new positions that counteract the muscle contractures; despite of this, the girl must wear them all day and night, taking them off only while taking a shower. While adjusting the orthotics to the girl's arms and hands, the OT explains to the girl's mother how to do it by herself at home—it is very important that the devices get adjusted in the proper way, so that they fulfil their function, otherwise they might even worsen the condition they are supposed to correct—, the woman listens silently to him and observes the procedure with a painful look.

### Story 3

We are working with a girl who has recently been fitted with a prosthetic arm, she lost her limb in an accident, a car accident, and has been coming here for rehabilitation ever since. According to her med recs, she is attending to several [specialised] clinics at the centre, including Paeds [paediatrics], PT [physical therapy], OP [orthotics and prosthetics], OT [occupational therapy] and Psy [psychology], where she has been doing excellent progress! —need to ask about the family! (are they being treated too, how are they coping...?)—.

Occupational therapist: Very good, you are doing excellent! [to the girl, she is taking some small lego-like pieces and putting them inside of a yellow plastic container], show her how well you do it [referring to me].

Ethnographer: Oh!, you do it very well!!, we are going to tell your mom to bring you here more often for you to help us teach the other kids... look how well you do it!!... [the girl smiles]

Girl: Aren't they able to do it?...

Ethnographer: Not as good as you! [the girl looks happy with that answer of mine].

Occupational therapist: As OTs, we teach children how to take the objects, how to eat, how to go to the bathroom, how to get dressed and undressed..., none of this is a straightforward thing to do with a prosthetic arm, it requires training and practice... sometimes it happens that the patient learns how to do all those things here, but then, they go home and do not practice –sometimes the parents do not fit them with the prosthesis, you know—, so, when they come back to their therapy they find it very hard to do anything at all... we are back to zero and have to re-start the whole process again. That's why you must use your prosthesis all the time, ah! [to the girl], if your mom doesn't put you the prosthesis on, you must remind her of it, you can tell her 'if you don't put me the prosthesis I am going to tell Carlos' [the OT].

We all laugh and continue working.

Occupational therapist: There are children who adapt very quickly to the prosthetic limbs, but a few of them have a difficult time.

Ethnographer: Why do you think is that?

Occupational therapist: The blue one [to the girl], you are missing that blue one [a blue piece], those are difficult [to take], aren't they?...

Girl: Yes, they are a bit, but if I put it like this it gets easier.

Occupational therapist: Oh, very good!, it's good that you try to find your way to do things, very good!!... [to the girl, then, he continues talking to me] For several reasons, starting with the fact that prosthetic limbs, in general, are not very comfortable, it is not the same to have a flesh-and-bone arm than an artificial one, they are difficult to put on —the straps need to be adjusted by someone else—, they tend to be heavy, especially for a child and, as I say, it requires practice to learn how to operate them... It takes time to get used to the prosthetics but, in the long run, it brings a lot of benefits to the user, you can see that in the children we treat here, they gain a lot of functionality and independence and, of course, that gives them confidence, being able to do things by themselves, without having to rely on someone else to do everything for them.

Ethnographer: Yeah, I can imagine that.

Occupational therapist: And the prosthetics also helps them with the question of body image too, they have a sense of wholeness again, and that improves their self-esteem, but you know about that a lot more than I know...

Ethnographer: How long does it take them to get used to the prosthetics?

Occupational therapist: It varies from person to person but, to a large extent, it depends on the kind of prosthetic device they are fitted with, the person's physical characteristics and on the usage —the more you wear it the faster [you get used to it]—... There are patients who adapt to the prosthesis in just a couple of weeks; it obviously takes time to master the

different skills and activities they can do with it but, I mean, in terms of learning how to use their arm or leg, it can take them only a couple of weeks...

Ethnographer: That's really fast!, I thought that it took like a month at least!!...

Occupational therapist: Well, some take even more than that [he laughs], when they do not practice much it takes ages!... [I laugh too and he continues...] In her case, for example [he is referring to the girl we are working with], you can see how quickly she 'gets it' [she finds the way of doing the things she is asked to do]... the difference between how she was doing the activity at the beginning and now, can you see?.

Ethnographer: Yeah, I can... do you notice the difference too? [to the girl, she nods smiling].

Occupational therapist: There are other elements that you need to consider in addition to the technical ones, for instance, the amputation itself. Many of these kids lost their limb in an accident, which is itself very traumatic for them... they must go through the emotional burden of the accident plus the added impact of losing a limb, of not having an arm or a leg anymore and having to deal with it for the rest of their lives, and with what that implies —you know, the looks, the comments, the name calling, the questioning, the shame, etc., etc., etc.—.

Ethnographer: Yeah, I guess so...

Occupational therapist: We talk sometimes about it [among the OTs]... some of us say that the younger the better, because young kids, in general, do not think too much about their appearance, they are children, you know?, they just want to get on with their lives, they want to run, to play football, [to play] with their dolls... and if they are able to do those things with a prosthetics, then, they start using it straightaway... With older kids it gets more difficult because they have already internalised a particular body scheme of themselves and with an amputation that body image changes drastically; also, they are more aware of their surroundings and social environment and they do care about how they look.

Ethnographer: Yeah...

Occupational therapist: So, if you ask me how long a patient takes to adapt?, I would say that, it depends on multiple factors; adapting to the prosthetics goes beyond the technical aspects, beyond learning to operate the limb... that would be my answer.

Ethnographer: Ok... Actually, I absolutely agree with what you say... sometimes I have the impression that most of the traumatologists and orthopaedists do not really get that, I mean, that they do not take into account that attaching a prosthetics is not just about fitting and adjusting, but about the untangible elements that come with it (emotions, subjectivities, identities, etc.).

Occupational therapist: Ha, ha... [he laughs], well, that's the big difference between us and them; we can see the person within the body, they can only see the body...

We both laugh...

Occupational therapist: From my experience working with these kind of patients, what I can tell you is that if the patient does not adapt to the device within the first couple of months after being fitted with it, then, it gets much more difficult for them to accept the device... At the beginning, wearing a prosthesis is not very comfortable at all, in many ways, and because of this there are some people who use it only occasionally which, in terms of rehabilitation, is not the ideal thing to happen, they are supposed to get used to it and wear it most of the time, I mean, why would you prescribe a prosthesis if the patient is not going to use it then!

#### Story 4

This is a seventeen year-old patient. She has been fitted with a new foot for her leg; the foot she was wearing did not provide her with enough stability and, as she tells me, she has been just about to fall several times. According to her prosthetists, she says, maybe the foot was too small for the leg she currently wears; but also, she has been told that she must lose some weight, otherwise, they will also have to change the socket; this, added to the issue of the blisters, a problem she has been dealing with for some time, which is directly related to her weight. She tells me she has been going out with friends a lot, and not exercising much, something that is very important for people with prosthetics, "[...] people think that you just buy the prosthesis, put it on and that's it, but the truth is that you really have to work hard if you want to accomplish anything... [...]. I must watch out my

weight if I want my leg to fit and avoid these things [the blisters]... the leg itself is very comfortable, but I need to give it a hand too...”.

### **Crafting Disability and Independence**

The stories above talk about three different rehabilitation experiences at the Occupational Therapy Area, three different people with three different prostheses. But there is, however, something that links those three stories, and this is the fact that, in all of them, there is a concern about life with a prosthesis.

At Occupational Therapy, one of the main aims of the rehabilitation work carried out there is to provide the patient with as much independence as possible. Occupational therapists apply a variety of techniques and medical knowledge for the patient to develop, recover and maintain the necessary skills for daily living. OTs help people to explore ways and to learn how they can live daily life with their bodily impairments and the medical conditions they experience. Through their work, they seek to develop the patient’s potential for leading as fulfilling a life as possible.

The activities carried out at the Occupational Therapy Area constitute the third stage in the rehabilitation process of people with prostheses, be it either, orthotics or prosthetics. One of the main aims of rehabilitation is for the patient to achieve as much independence as possible. In order to do this there are many different instruments to evaluate the amount of independence a person has.

At OTA there are very well defined rehabilitation guidelines and evaluation instruments. This is a highly modern rehabilitation centre, with cutting-edge technologies and clinical protocols and procedures that adhere to international standards. Every week occupational therapists must spend several hours filling in

individual formats with information about the rehabilitation progress and therapy outcomes for each of their patients. Being a state of the art rehabilitation centre with international standards means that everything that is done inside must follow precise protocols and procedures that include clear and well documented cases capable to hold for themselves, which implies both a clear treatment program and clear outcomes. Because of this, OTA specialists must explain in detail why, from among a variety of options, they have chosen to do what they do in relation to each patient's rehabilitation program.

Occupational Therapy, as a part of the medical field, focuses its work on two elements and how they interrelate with each other, these are, disability and rehabilitation. As I explained above, there are numerous scales for measuring both aspects and which are used to determine in quantitative terms how disabled a person is before, during and after an occupational therapy intervention, this, in order to measure how much independence s/he has acquired after such rehabilitative intervention has taken place.

Rehabilitation experts obtain valuable information from the results of those scales, for example, if a particular rehabilitation program is actually helping the patient to be rehabilitated and if such rehabilitation program is worth its use in a much larger scale. Although we can learn a lot from those scales, it is only by looking at everyday practices of rehabilitation that we truly get a sense of what disability and rehabilitation mean for patients and professionals who deal with these issues on a day to day basis.

One of the aspects that an ethnographic study around prostheses and rehabilitation practices let us appreciate is the different ways in which disability and



normality get enacted. In the context of Occupational Therapy and its rehabilitative interventions, disability is understood, addressed and performed in several ways, including that of independence. When a person with impairments is subjected to rehabilitation and gains at least some degree of independence, in such a framework, s/he becomes less disabled in the sense that she can perform her activities of daily living in a less dependent manner.

The practices at occupational therapy become practices of carefully crafting a body, a person, a prosthesis and an environment —one that includes architectures, carers, social interactions, expectations, etc., just to mention a few— all of them with very particular features, as OTs do know very well, each individual patient is different and what works for someone might not work for someone else. Crafting the patient's daily life, I argue, involves finely attuning each of these elements to one another, in order to be able to interact as smoothly as possible in their ordinary, day-to-day context. These activities are knitted, practiced, adapted and reinforced in the Occupational Therapy setting, at the rehabilitation centre. It is at OTA that this cyborg collectif made up of multiple heterogeneous materials gets finally tuned up, completely assembled and 'ready to go', this is, ready to leave that controlled, laboratory-like environment and to enter 'real life'.

For the case of patients with prostheses, in particular, one of the main concerns of the patient's rehabilitation work can be expressed in terms of 'how to adapt and become adapted to the prosthesis in daily life'. But this is not all, since there is also a fundamental concern that has to do with the question of how to attune the person's impaired body to its surroundings, and vice-versa, how to attune the person's surroundings to his/her impaired body, this, in order to facilitate his/her daily living

activities and her interactions with the physical and social environment s/he is immersed into. In a material semiotics language, this can be translated, I suggest, into the idea that the work of the occupational therapist is that of crafting mutual inter-adaptations between specific and situated sets of heterogeneous materials, which include very particular enactments of bodies, prosthetic devices, rehabilitation processes, ideas of normality and disability, and everyday lives.

In addition to this, occupational therapists in their professional practice do care about the 'social environment' too; for instance, when making adaptations, technical aids and prostheses, or when developing a particular technique to do a certain activity, they often think about how the artefact or the technique will get inserted within the communities in which the individual participates. Similar concerns are brought forward by the patients themselves too.

Although, there are many well defined protocols that occupational therapists are supposed to follow, in practice, rehabilitation does not quite adhere to those protocols and guidelines. There are tensions and disarticulations, and many times decisions have to be made that confront therapists with what they have been told at school. Occupational therapists are [supposed to be] preoccupied mainly with functionality. In practice, however, such a functionality does not come alone, it also brings other kinds of concerns, which have as much to do with health as with social, economic, aesthetic and even environmental issues.

One of the advantages of working together as a team of interconsulting health experts is that specialists meet periodically to discuss about each individual rehabilitation program, during these meetings they have the opportunity to exchange ideas and concerns of all sorts. In the stories I present above, for example, something

that can be easily appreciated are the series of tensions and disarticulations between body shape, functionality, aesthetics and social inclusion. Therapists teach patients how to use their prostheses and get the best of them, but this is not that straightforward, patients are also thought how to adapt themselves to the prosthesis and what that coupling will —and will not— allow them, in the broadest sense of the word.

Frequently, prosthetists, occupational therapists and social workers discuss about the patient's living conditions. The majority of the patients that the centre receives come from a low socio-economic background, they often live far away from the clinic, mostly in rural areas, and are part of families dedicated to farming and agriculture, activities in which every member of the family —including them— gets involved, at least in some degree. When prescribing a prosthesis, these aspects are taken into account. Prosthetists are meticulous in choosing the right type of device and materials for those particular living conditions. Making a prosthesis that meets all the necessary requirements is often tough; devices must be durable for the hard work involved in farming and agriculture, water-resistant considering the rain and the muddy fields, lightweight for the constant physical activity and the long hours of work.

But this is not all. Occupational therapists must ensure that patients learn how to take good care of their prosthesis and that they are able, willing and committed to provide such care to the devices. In addition, there are some times and cases in which prostheses must also look cool, this is especially the case for children. Prosthetists and occupational therapists often incorporate into the device some distinctive characteristics in correspondence to particular personality features of the wearer.

Getting 'the' prosthesis is an achievement that implies more than just the technical specificities of the device plus the particular characteristics of a person's body.

For the occupational therapist of the stories above, in the end, a nice splint can produce a better rehabilitation outcome than a dull one. If the splint looks cool, the child will probably be more willing to wear it; for their part, the child's carers won't feel aversion towards the device and, therefore, there are more probabilities that they will encourage him/her to wear it. After all, in the early stages of their treatment, patients learn that someone who does wear his orthotic or prosthetic device has potentially a better rehabilitation outcome than someone who does not. At occupational therapy, technicalities, clinical requirements, aesthetics, social relations, expectations, bodies, etc. become articulated towards an apparently very simple coupling that involves a [not so fully] human body and a [n equally not so fully] prosthetic device.

Rehabilitation scales are designed to answer questions such as: what is the degree of a person's disability, what is the degree of a person's independent functionality?, how successful a rehabilitation program results for a patient or a group of patients?, etc.; however, while analyzing rehabilitation practices in situ, at least those performed at the Occupational Therapy Area, the questions that arise are somehow different, for example: what does it mean, in practice, to rehabilitate a person with a disability?, after rehabilitation, how is the person's disability reconfigured?, is 'rehabilitation' the same for patients, health experts and carers?, how much do the outcomes of rehabilitation in practice coincide with those thought to health experts at med school?.

### **Temporality**

Assessment scales measure the patient's progress throughout different stages of the rehabilitation process. They assume that the rehabilitation process follows a linear progression. Occupational Therapists, however, know that, in practice, this is not actually the case. The time length of a complete rehabilitation process varies from patient to patient; this depends on the kind of medical condition being dealt with and the sort of treatment put in place<sup>85</sup>. But, being discharged from the clinic does not mean that the 'issue' has been solved, nor that rehabilitation has come to an end. People who live their lives with neuro-musculoskeletal conditions learn that rehabilitation is something they will be engaged in throughout their whole lives. Orthotics frequently must be modified and readjusted, adapted to the bodily changes and the progression of the disease. People with prosthetics learn this too. Residual limbs change, they transform with age and exercise, they get thicker or thinner, they get swollen and sore. For these patients, more than a linear process as assessment scales portray, rehabilitation is better thought of as a recurrent process, with periods of stabilization and latency followed by periods of readjustment, periods of improvement and periods of deterioration. In day-to-day life there is no such a thing as a linear rehabilitation process.

The conclusion that can be drawn from the above is that, although the quantitative measurements provided by disability & rehabilitation assessment scales is useful for certain clinical tasks —diagnostic work for instance—, when developing a

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<sup>85</sup> Age also plays an important role, since attention at this centre is primarily focused on attending under-aged patients; this does not mean that reaching 18 years-old patients are left all by themselves, instead, they are either referred to governmental health/rehabilitation units or still treated here but paying a determined fee, which sometimes prevents patients from receiving medical attention.

patient's rehabilitation scheme it is crucial to take into account factors such as those exposed above that only get visible when analyzing the day-to-day practices of learning to live and living with a disability, particularly for the case that concerns this thesis, of living with an orthotic or a prosthetic device. Furthermore, at OTA, the question rehabilitation experts, patients and carers often face is not so much about the degree of dependency a person has on other people and on their orthotic or prosthetic devices, but about how to better deal with the sets of simultaneous independencies and dependencies that the interaction between prostheses, bodies and socio-material environments enact in everyday life.

### **Rehabilitation and functional independence**

As in the other areas observed, at OTA, the possibilities are multiple and so too the rehabilitation outcomes. As the very word implies, 'rehabilitation' involves the re-habilitation of a person who, for some reason, has lost some of his or her abilities. At OTA therapists are concerned with what in the world of medicine is called functional rehabilitation, which addresses different sorts of skills, including the ability to perform activities of daily living (eating, drinking, dressing and grooming), locomotion, cognition, communication, etc. When either orthotics or prosthetics are involved in the person's rehabilitation s/he will be thought how to live daily life with the device, how to walk with a new leg, how to grab things with a new hand, how to wear their prostheses in a way that does not cause pain or discomfort.

Currently, many different functional rehabilitation scales have been designed to evaluate the progress of patients and the effectiveness of rehabilitation programs<sup>86</sup>. As it happens in the other areas, at OTA, outcomes are evaluated periodically, particularly in relation to functional independence. At OTA several aspects/skills of functional independence are measured at the time of the patient's admission to the Occupational therapy area and then periodically until the patient has completed his/her rehabilitation program there.

The International Classification of Functioning Disability and Health (ICFDH), proposed by the World Health Organization, takes into account bodily functions and structures, its classification system is based on assessing the extent to which a particular health condition (be it a disorder or a disease) prevents the individual to engage in particular activities (see: WHO, 2002). The concept of 'functional independence' has to do with the degree of dependence a person with impairments has on other people or technical devices in order to function in their daily life. Although, functional independence scales are very useful in clinical settings, health experts and policy makers tend to forget that, in practice, their results do not portray how fulfilling and meaningful a person's life is for themselves after rehabilitation, as Struhkamp et al (2008) point out. The ICFDH does evaluate a set of items that relate to the biopsychosocial aspects of an individual's life; however, their results tend to overshadow what really happens in a person's day-to-day activities and experiences.

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<sup>86</sup> The issue of the quantitative evaluation of the effectiveness and efficiency of rehabilitation programs and treatments and its implications for rehabilitation practices and outcomes is out of the scope of this thesis. For a general discussion about this topic and its relation with increasing efforts to make clinical practices evidence-based, see: Struhkamp et al., 2008.

For the case of this thesis the relevance of instruments such as the ICFDH is that it combines in one single object the two basic elements that are the bases to the work with people with prostheses, namely: disability and rehabilitation. In order to measure a patient's rehabilitation progress it is necessary first to measure how 'disabled' s/he is; the latter understood from a clinical framework of everyday functionality.

When the patient is admitted at OTA, therapists will carry out a functional evaluation, which will evaluate how in/dependent the person is. With those results they can then, elaborate an occupational therapy rehabilitation program. In the program, therapists will set the kind of goals that will have to be achieved in order for the patient to be discharged from the centre. They will also include a timeline that will put in relation specific goals with specific therapy sessions, so that the patient's rehabilitation progress can be followed in a very precise way.

Medicine and clinical practices have long been criticised for alienating the patient, making them passive objects of intervention, imposing the health expert's interests and decisions on the patient, etc. However, observing closely how the work of occupational therapists is actually done in practice it gets clear that rehabilitation is, by no means, an 'only-experts' business; rather than that, rehabilitation at OTA is configured as a joint endeavor, one for which the expert's views and knowledge are only a part of the equation and, sometimes, not even the most important and decisive one.

Here, rehabilitation goals are set not only by the occupational therapist alone, but by the joint work of patient, therapist and carers. Together, they decide what the priorities of rehabilitation are, which activities, among a wide array of them, are more



relevant and fulfilling for a patient, so as to focus the training sessions on them and leaving other activities out of target.

Although assessment scales approach rehabilitation in terms of functional independence, understanding the latter mainly in terms of the quantification of the ability to control and govern a person's own body, at OTA, therapists do know that rehabilitation entails much more than that. Independence is not only about 'degree', but also, about 'kind' (Struhkamp et. al., 2008). At OTA, it becomes clear that rehabilitation is about material-semiotic relations. Therapists do not deal with a diseased body; rather, they work towards putting in relation particular bodies with particular objects and socio-material environments.

At this area of the centre, rehabilitation goals are set according to the possibilities and preferences of each individual patient, considering where and how they live, the type of activity they are involved in (profession, job), the people they interact with, the sort of places they inhabit, etc. For a child with an amputated leg living in the city a goal worth to train for is being able to play football again, for an adolescent living in a farm whose family job is agriculture, the goal he has set for himself is being able to work in the fields again, a middle aged housewife with an amputated arm is mainly concerned about learning how to do the household chores with her prosthetic limb, an office worker tries out the performance of her new hand while typing on the computer.

What is it that is produced as a result of a rehabilitation process involving prostheses?. My argument is that prostheses un/make persons, particular kinds of independent, self-governed people. The incorporations of prostheses into a rehabilitation process is full of contradictions. Prostheses are fully technological and

clearly artificial, and yet, they aim to produce whole bodies and persons. In practice, they forge certain material and discursive relations, while denying others.

### **Independence from objects and people**

Independence, as portrayed in a functional scale, differs greatly with the kind of independence enacted in everyday practices. Measurements provided by functional independence scales developed on the bases of the ICFDH, assume that the highest degree of independence is equivalent to a person who is able to operate in everyday life and perform his/her daily activities without any assistance of technological devices or other people. However, in practice, I want to argue, this proposition can hardly be sustained even for the case of those considered completely healthy and abled-bodied.

Is it possible for us, the ‘abled-bodied’ —those who, at least until now, do not have to live our lives with a disability—, imagine, if only for a second, a life of complete independence of people and technological devices?, is it that, for us, that kind of independence can really be achieved?. My claim is that, actually, it is our dependence on other people and artefacts that makes us what we are; in many ways, those relations are precisely what sustains our very existence. A life without such social and technological dependencies simply cannot even being imagined. Deprive people of socio-technologically mediated interrelations/interdependencies and you will be depriving them of their very nature as humans. We are actually dependent on technological devices as well as on people to be able to live our everyday lives independently, and this is always the case for both, abled and disabled bodied people.

From the above conclusion, however, a second set of questions arises: is the recognition of this fact enough to overcome difference?. Recognizing and assuming

our inevitable dependence is a big step, I think. However, if we —abled and disabled bodied people— are all dependent on artefacts and on people, as I suggest, why is it that the distinction between ‘us’ and ‘them’ still persists then?... part of the answer might lie, I argue, in the following:

### **Independence arises from dependence**

I want to argue that people with prostheses (orthotics or prosthetics) become more independent because they actually develop a tightly knitted, and more or less stabilized, dependency on a —more or less organized— heterogeneous collectif that includes, but is not limited to, artefacts and people. In other words, it is my argument that ‘independence always arises from dependence’. What patients and therapists work on at OTA is the mastering of this dependency of patients on their prostheses (rather than, we must say, on human carers). For the case of orthotics and prosthetics —but this also applies to other disability-related aids, e.g. wheelchairs, white and other assistive canes, mobility aids, etc.—, independence is achieved through technological dependence. Consequently, it can be said that there is a displacement from a ‘human/social’ dependence to a ‘technological’ one. Considering this, it can be assumed that, somehow, it is better to depend on machines than on people then. Why might this be?, maybe because human carers have to be persuaded to give such care, they can always change their minds and refuse to help, they have their own lives and schedules, they are not available all the time at the exact moment when the person needs them, they might even need some care and assistance themselves too. ‘Technological carers/assistants’, on their part, can be subjected —even if not a hundred percent— to the user’s wills, needs and schedule at any time she wishes to. How does this inform a characterization of disability then?. It does so, I think, in the

sense that, in our societies, being ‘abled’ means being capable to decide all those what, where, when, and how that we are faced with constantly, all by oneself. In line with this, then, I pose the suggestion that, in practice, disability is produced when a person is unable to take these sorts of decisions, as any other ‘autonomous, competent, abled-bodied’ person.

### **Independence as a joint achievement**

For the measurement of the degree of a person’s disability and consequently the amount and type of rehabilitation s/he needs, the World Health Organisation has defined a set of activities which have become known as Activities of Daily Living, these have mostly to do with daily self-care and are said to provide information about a person’s functional status. Basic Activities of Daily Living include: bathing/showering, dressing, eating/feeding, functional mobility, personal hygiene & grooming and toilet hygiene. In addition to these ‘basic’ activities, other ‘instrumental’ activities such as health management, communication management, community mobility, financial management, home maintenance, meal preparation, child rearing and shopping are also taken into account. According to rehabilitation scales, the higher the score for these activities, the more independent the person. However, in real clinical practice, it is unlikely for occupational therapists and patients to work towards the fulfillment of all these activities. Rather, throughout the process patients realize that it is better to choose those activities that are more necessary and fulfilling for them to achieve, than trying to do everything. For people with certain kind of orthotics or prosthetics, it takes great efforts to do simple things, this is why, it is crucial to carefully tailor the rehabilitation program and master those activities which are most relevant to their lives.

Within rehabilitation settings, it is strongly advised for care-work to be carried out by one or two main carers of the patient, rather than by many different people, the reasons for this are diverse, including that caring for someone might require the carer to undertake specialized training in order to acquire the necessary knowledge and develop the necessary skills to provide such care, in this sense, it is better to have one or two knowledgeable and skilled carers than many untrained people trying, unsuccessfully, to help.

The constitution of independence as a joint achievement, rather than as an individual task, I argue, is a fundamental premise that OTs continuously reinforce in their professional practice, even if they might not put it in those very terms. At OTA, many patients do need human carers to give them a hand (or two!) with daily tasks. At OTA, the relevance of teamwork is highly encouraged. In practice, the daily experiences of living with a disability result quite different to the in/dependence-assistance relation that rehabilitation assessment scales portray.

### **Simultaneous enactment of independence and dependence**

Struhkamp et al. (2008) argue that, when evaluating functional independence, what really matters is looking at the kind of help a person needs, rather than paying attention to how much help s/he needs, as it is measured by conventional rehabilitation scales. The point their argument makes can be observed at OTA where, day after day, occupational therapists, patients and their carers analyse together each tiny aspect of every activity they are training to perform, including the kind of technological and human help patients require to perform it.

Patients are different from one another in many ways, they vary in age and gender, in body shape, weight and height, in the kind of conditions they are dealing

with and, therefore, in the clinical management they are to follow, but they also vary in emotions, beliefs, desires and expectations... Consequently, occupational therapy goals and training must be carefully knitted according to all those factors. What works best for one patient might not work at all for another one. Why?. This is simply because each of us, according to what we have learnt from the material semiotic approach, is situated within a very particular collectif of heterogeneous materials and, therefore, something different will come into being from each particular patient-network, as Struhkamp et al. (2008) brightly put it, “the issue is to experiment with different modes of dependence that produce different types of independence” (Struhkamp et al., 2008:08).

In/dependence, in everyday living, means something quite different than in rehabilitation assessment scales. Dependence on people will produce a different outcome than that on technological devices, which is not necessarily better nor worse, but just different, specific to that material relation. Even more, dependence on certain people produces a different outcome than that on some other people, and the same applies to technological devices, as the extracts below show:

#### Story 5

Patient: My mom does not have any patience at all; I prefer daddy to adjust the leg for me... When she helps me it hurts all day [since the socket has not been adequately adjusted to the residual limb], daddy is always more careful...

#### Story 6

Patient: In the morning, when I wake up, I immediately jump to my wheelchair, I get ready and everything on it... If I am staying at home usually I use the wheelchair, but for work or going out I wear the prostheses...

Ethnographer: why is this?

Patient: Well, because at home, you know, I am more relaxed, you do not have to be all dressed up and that, it takes time and it is quite an effort to put on the legs, so, it's easier for me to use the wheelchair... But leaving home on my wheelchair is just unthinkable, out of the question! [I laugh]. Moving around on a wheelchair in this city is a real nightmare, you know?, streets do not have ramps for people with disabilities, you end up going in the road rather than on the pavement—which is not in the best conditions, by the way—, the roadway is always full of cars whose drivers do not care if they run over you, wherever you go the buildings do not have access ramps, so you have to ask people to carry you and your wheelchair up and down stairs, some people are willing to help but some others just pretend that they do not see you... So, when I am out it's a lot easier for me to walk around on my own legs rather than on the wheelchair; besides, they make me feel better and make people to see me in a different way, I think people too prefer the legs rather than the wheelchair [he laughs]...

The idea I want to press on here is that, in everyday practices, dependence and independence get simultaneously enacted; they are performed differently by the different human and non-human materials that a person comes in relation with. We can also assume, consequently, that dis/ability too gets enacted differently within

different materially heterogeneous networks which, therefore, means that disability might be better understood as a multiple entity, rather than a singular one. To put it differently, in practice, diverse modes of ordering disability get produced and can even coexist. Here I am drawing, as the reader might guess, on Mol and Law's work, respectively (see e.g. Mol, 2002; Law, 1994). In their empirical analysis on the use of speaking aids by people with speech disabilities, Moser and Law make a similar point (see Moser and Law, 2003), technologies allow for some things while restricting some others.

My proposition is that the work at the centre's Occupational Therapy Area is to tinker with the diversity of arrangements and assemblages that a complex network of heterogeneous materials will allow the patient to establish. It is not just about finding the one network that works best, but also about providing the possibility of more practices of 'networked in/dependence' to be performed with the least of materials involved.

What does this tell us about rehabilitation and independence?. It tells us that rehabilitation is a continuous process of arranging and assembling a variety of material-semiotic relations between bodies (patients and carers included), artefacts (orthotics, prosthetics or any other technical aid) and many other materials (desires, emotions, expectations, etc.). Some arrangements will allow for certain possibilities of independence while, at the same time, restricting some others. I want to argue that, in practice, contrary to what rehabilitation assessment scales portray, independence and dependence are qualities that get necessarily performed simultaneously. In practice, I propose, achieving independence depends on, and is an effect of, creating dependence.



As with any other material semiotic collectif, patients too display very specific characteristics which are particular to each of them; therefore, the sort of rehabilitation arrangements established for and practiced by a particular patient at OTA, does not necessarily applies to another patient; although, there can be similarities between them and similar techniques might be applied, no two rehabilitation trajectories will ever be the same, since rehabilitation practices, I sustain, are always situated and multiple.

The problem with rehabilitation assessment scales is that they define dis/ability, in/dependence and the rest of the categories they mobilise *a priori*, before the rehabilitation practice itself. From a relational perspective, however, those categories become matters of negotiation and contestation, entities which are configured and enacted in practices, rather than solid and passive elements. From a relational standpoint, dis/ability and in/dependence are mutable and fluid qualities which, from my point of view, are located neither in the patient's human body, nor in the capabilities that such a body is able to display (regarding any particular health/physical state), but in the spaces where corporality, subjectivity and materiality meet and get intertwined.

## **FINAL CONSIDERATIONS:**

### **PATIENTS, PROSTHESES AND REHABILITATION PRACTICES**

This thesis is the result of an ethnography I conducted in a Mexican rehabilitation centre. For my empirical research, I focused my attention on the rehabilitation process of patients who were prescribed either orthotic or prosthetic devices as part of their treatment. My intention has been to reflect on, and theorise about, the multiplicity of materially heterogeneous relations that get enacted during the rehabilitation process of patients with prostheses. In addition, I have tried to destabilise the categories of normality, disability and rehabilitation, this, by looking at how such categories are performed and enacted in practices and by problematising the ontological politics behind them. In my work, I have mainly drawn on a material semiotic perspective informed by the feminist technoscience tradition. I have also explored the contributions of disability studies and its critic to the way in which disability is currently approached.

My ethnographic fieldwork followed the whole process of incorporation of a prosthesis into the patient's body and life, from its very prescription, going through its design and fitting to its everyday use. To do this, I closely observed the rehabilitation practices conducted by rehab specialists, patients and carers, at three different areas of the centre, namely, the Gait and Movement Laboratory, the Orthotics and Prosthetics Laboratory and the Occupational Therapy Area, which are the sites directly related to rehabilitation treatment by means of an orthotic or prosthetic device.

Through my research I have analysed the complex relations that are configured between body, prosthesis and person, materially heterogeneous relations which are allowed to emerge and transform through every stage of the rehabilitation process. My work has pressed on the idea that all entities are made in relation with one another and, as such, they should be treated as effects of those interactions, rather than as *a priori* entities. This applies to categories such as normality, disability and rehabilitation. Consequently, it has been my intention to explore how such categories are done 'in practice', particularly in the context of clinical rehabilitation.

In addition, I have problematized the category of the 'patient', showing how patients come into being within clinical practices, rather than being well delimited and stable entities. This work also proposes the notion of the cyborg collectif as a way of thinking about the coupling between body and prosthesis that emerges during rehabilitation.

Through ethnographic extracts, my thesis tries to make sense of the multiplicity of ontological reconfigurations and dis/articulations that take place during rehabilitation, pressing on the importance of attending to the situatedness and the specificities of categories. In this sense, I have argued that, when done in practice, disability, normality and rehabilitation take quite different meanings than those suggested by pre-established clinical, medical or social definitions, since they are enacted in ways that cannot be reduced to singular, constant and stable conceptualisations of them.

I have also suggested that each of the laboratories observed is tightly intertwined with a set of transformations, configurations and enactments of bodies, persons and prostheses that is very particular to them. Simultaneously, each of these

sites with its corresponding enactments and specific collectifs enable and sustain one another in a way that is more or less coherent and consistent.

Disability and rehabilitation, I argue, need to be analysed and reconceptualised through alternative methodologies capable of showing what living with a disability actually means in everyday practices as well as of incorporating more flexible and politically inclusive understandings of disability and rehabilitation. Finally, a there is an urgent necessity of renewed reflections around disability if we really are to build a more inclusive and egalitarian society.

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