

“To become independent and remain independent”

Living with mobility impairments in rural Peru

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**Centre for International Health
Faculty of Medicine and Dentistry
University of Bergen, Norway 2017**

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ABSTRACT

Background: The UN emphasizes the need for understanding the living conditions of persons with disabilities (PWD) and enhancing their inclusion into society. Peru has endorsed the Convention on the Rights of PWD through legislative approaches, but inequalities persist. The aim of this qualitative study was to explore the situation of persons with mobility impairments in a rural part of San Martín Region in northeastern Peru, and the experiences of other stakeholders in the field of disability. To ensure a critical approach on disability and rehabilitation, anthropological perspectives on the body were used, as well as concepts from the International Classification of Functioning, Disability and Health (ICF) and Community-based Rehabilitation (CBR), such as activity, participation and empowerment.

Population and sampling: Nine individuals with a mobility impairment, six caregivers and/or spouses to PWD, and four other stakeholders working with PWD were recruited using purposive and snowball sampling techniques.

Methods of data collection: The data collection was carried out from September to mid-November in 2015, including nine in-depth interviews, three natural group discussions, and participatory observation in a local hospital and in a school for children with special needs.

Data analysis: The data was analyzed using thematic content and narrative analyses.

Findings: The findings confirm that persons living with mobility impairments in a remote area do not receive adequate assistance to cover their needs, or that services are completely lacking, such as rehabilitation or assistive device services. Although some informants did not feel disabled at all, many informants emphasized the importance of better social support and more understanding of their limitations by people in their community. This includes supporting caregivers of PWD as well. Spiritual strength and faith in God was found to be a guiding force in the lives of the informants, and lack of trust in the authorities appeared to be a common perception among the informants.

Conclusions: The study indicates a strong need for improving health and social service provision for PWD living in rural and distant communities. As well, there is a need for raising awareness and helping communities to become more inclusive in line with the intentions and legislative steps taken by the Peruvian government when endorsing the rights of PWD.

Implications: The needs of PWD must be addressed in order to improve their capabilities and social inclusion in Peruvian communities and society. More research in rural areas is needed.

Key words: persons with disabilities; mobility impairment; assistive devices; rural Peru

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ACRONYMS AND ABBREVIATIONS

AT	Assistive Technology
CONADIS	National Council for the Integration of Persons with Disabilities
CBR	Community-based rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
ICF	International Classification of Functioning, Disability and Health
MINSA	Ministry of Health of Peru
OMAPED	Municipal Office of Attention to Persons with Disabilities
PWD	Person(s) with disabilities
SDGs	Sustainable Development Goals
SIS	Health Insurance Scheme
UN	United Nations
WHO	World Health Organization
WRD	World Report on Disability

1. INTRODUCTION

“The society kind of disables the disabled, making it difficult to be disabled.”

— Simo Vehmas, Professor of Disability Studies, Finland (2014)

The World Health Organization (WHO) (2016b) estimates that around 15 percent of the world population, over a billion people, have a disability of some degree, and 2 to 4 percent of those who are 15 years and older are estimated to have considerably impaired functioning. The most vulnerable people affected by disability are women, older people and the poorest, and in line with today’s aging populations and the amount of chronic and mental conditions, the number of persons with disabilities (PWD) is expected to increase (WHO and The World Bank, 2011, pp. 29, 262, Helman, 2007, p. 10). There is thus a steady rise of years lived with disability (YDL), and this requires a response from the health systems worldwide (Vos et al., 2012).

The United Nations General Assembly (2013) has reported that approximately 80 percent of PWD live in developing countries. Lack of services are among the many additional barriers that restrict the lives of PWD in under-resourced settings (WHO and The World Bank, 2011, p. 24). In addition, inequalities and violations of rights, and the poverty-disability cycle that many PWD, especially in lower-income countries, fall into, prevent PWD to have a dignified and autonomous life (WHO, 2015b, p. 1, CBM Australia, 2016).

Many PWD have impairments in body functions or structures resulting in mobility deficiencies, e.g. neurological disorders such as cerebral palsy, poliomyelitis or multiple sclerosis. A spinal cord injury can be caused by a sudden trauma or an injury and result in paralysis of the limbs. Older people tend to have gradual weakness and increasing impairments along with injuries, functional disorders and activity problems. Aging also brings along chronic diseases, such as diabetes and osteoarthritis that can lower functioning and mobility.

Mobility can be defined as the “ability to move from one position to another independently and safely” (O’Sullivan and Schmitz, 2010, p. 6). It is crucial for an individual to get around in the environment (Field-Fote, 2009, p. 136), and mobility enables an individual to pursue activities of daily living (ADL), recreations, and to participate in the community (Rousseau-Harrison et al., 2012). Hence, mobility is an important factor for independence, and limitations in mobility may further impact the quality of life (Carver et al.,

2015). Difficulties in mobility predict the progression of disability and often lead to declining of physical functioning (de Vries et al., 2012).

Many PWD need assistive solutions due to impaired mobility. Assistive Technology (AT) can be an aid or a piece of equipment that either improves, increases or maintains decreased functioning (United States Congress, 2004, Cowan et al., 2012). Common and usually very visible examples of AT are mobility devices, such as canes, crutches, rollators, wheelchairs, orthoses and prostheses (WHO and USAID, 2011, p. 7) that enable persons with mobility impairments to change and maintain body position, and walk and move around, thus ensuring them to enhance and maintain a level of activity and participation (WHO, 2001, p. 150). Lack of mobility devices can result in a greater dependence on others, diminishing people's personal decision-making about performing activities (WHO and The World Bank, 2011, p. 10). Yet, having a mobility device is not enough; accessible and supportive environment is a prerequisite for its use (WHO and USAID, 2011, p. 23).

The United Nation's (UN) *Convention on the Rights of Persons with Disabilities* (CRPD) declares to protect the human rights of PWD at international level requiring states to take care of the juridical and moral responsibility to guarantee these rights (UN, 2006). The Article 1 of the Convention states that:

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

Under guidance of the CRPD, *the 2030 Agenda for Sustainable Development* aims to improve the inclusion of the marginalized group of PWD (International Disability Alliance, 2016). Of the *17 Sustainable Development Goals* (SDGs), disability is referenced in five goals, and in seven of the 169 targets, particularly in topics of inequality, accessibility of human settlements, education, growth and employment, data collection and goal monitoring (UN, 2016c). Moreover, the UN (2006) emphasizes the need for understanding the living conditions of PWD and enhancing their inclusion into the society, as agreed upon through the CRPD. Personal mobility of PWD with the greatest possible independence is addressed, and the States have the responsibility to promote and secure the availability and access to AT (UN, 2006).

This growing recognition of PWD being a “marginalized and disenfranchised constituency” (Tremain, 2015, p. 247/9815) has triggered political initiatives in Peru as well. In 1999, Peru enacted a General Law on Disability (*La Ley General de la Persona con Discapacidad - Ley N° 17050*) attempting to pursue social integration and promote the rights of PWD (Reynaga Soto, 2013, p. 7). This law, however, had loopholes and was more of a declarative than an effective instrument, and it treated PWD in a traditional paternalistic way (ibid.). Finally in 2012, after Peru had signed the CRPD in 2007 and ratified it as the first Latin American country in 2008 (UN, 2016b), the government signed a new disability law, Law 29973 - the General Act on Persons with Disabilities (*La Ley General de la Persona con Discapacidad - Ley N° 29973*), including the principles of the CRPD (Reynaga Soto, 2013, p. 8). This law has been seen as an inclusive revolution, recognizing the full rights and opportunities of PWD, and establishing a legal framework for the promotion, protection and realization of equality and rights of PWD (ibid.).

Through these anti-discriminatory legislative approaches and reforms by the congress, government agencies, and civil society, Peru has made improvements in recognizing the rights and needs of PWD (Ronceros, 2014, UN, 2012, Mann, 2013, Human Rights Watch, 2012, p. 4). Despite of these efforts, however, inequalities persist between rural and urban areas, and the Committee on the Rights of Persons with Disabilities (CRPD) has addressed several concerns in its concluding observations report (UN, 2012). It gives recommendations for Peru to fulfill the requirements declared in the CRPD, e.g. to ensure access of PWD to rehabilitation, as well as access to health services, personal assistance, public facilities and transportation. In addition, the report underlines the lack of resources and services which would improve the inclusion and independency of PWD, especially in rural areas, as well as the situation of indigenous and minority persons with disabilities, such as children and women living in rural areas.

A limited number of disability studies have been done in rural Peru, and there is a particular lack of qualitative evidence on the lives of persons with mobility impairments throughout the country. This supports the need for research on this topic. Disability estimates based on the first Specialized National Disability Survey in Peru (INEI, 2014) give a lower number of disabilities compared to the global estimates, 5 percent and 15 percent, respectively. However, this may not necessarily give the accurate picture of the extent of disability. Moreover, the real picture of the living circumstances of PWD is not available. Therefore, it is

important to examine the interaction of individuals in their environment to better understand the inequalities that may exist in the lives of PWD.

Most studies on mobility impairments and AT are done in higher income countries, and because the existing data yields for further research, e.g. on the effects of mobility devices on the activity and participation of mobility-impaired people (Salminen et al., 2009), this type of research is needed in lower income countries as well. In Peru, such information could contribute to show the needs within specific socio-cultural environments, and help to solve problems that are particular to the country and its regions (Bernabe-Ortiz et al., 2016b).

Lastly, the UN's new agenda on accessibility and disability inclusion focuses on the urban environment (UN, 2016a) due to growing urbanization worldwide and expected rise in the number of PWD in cities. Therefore, it is even more crucial to pay attention to those staying in the rural areas so that PWD are not left behind more than they may already be in all contexts, rural as urban.

This study was conducted in "Villa Hermosa"¹, a rural jungle town in northeastern part of Peru. As a physiotherapist with working experience from Finland and Norway, and volunteering experience from Peru and the USA, I was from the onset particularly interested in the situation of persons with mobility impairments. Moreover, given existing family relations and previously having visited the study location, as well as fair Spanish language knowledge, studying disability in a Peruvian context seemed an obviously relevant choice of topic.

According to the local health authorities² in Villa Hermosa, there is a need for research concerning the situation and needs of PWD, especially of those in need of AT, due to limited resources in the health care sector and lack of related services for PWD. This study is a unique inquiry using a qualitative approach³ in a particular, unexplored setting. At the same time, Villa Hermosa is an example of a rural town in the jungle area, where there is no public transportation system, and where the nearest functioning airport is several hours drive away. The study's findings may therefore be comparatively interesting and to some degree representative for similar rural living environments in the Amazonian jungle.

¹ "Villa Hermosa" is a fictive name chosen to anonymize the fieldwork site.

² Personal communication with a local health directorate 9 March 2015

³ Personal communication with a local health directorate 10 April 2015

The overall goal of this study is to explore the experiences of stakeholders in the field of disability living in rural Peru, and produce knowledge about the living conditions of persons with mobility impairments. Moreover, the study aims to understand how well the demands of the CRPD for insuring personal mobility are met, and document the need for appropriate services in a rural town of northeastern Peru.

The specific objectives of this study are:

- 1) To understand the experiences and perceptions of individuals with mobility impairments living in Villa Hermosa, the challenges they meet as well as the needs they express regarding their disability.
- 2) To explore the experiences and opinions of other stakeholders in the field of disability, such as social services providers, health- and rehabilitation workers and local authorities.

This thesis consists of five main chapters: first, I will provide information about and describe the Peruvian research context. I will then present the theoretical frameworks and methodology used in the study. The findings and discussion are presented in conjunction, ending with final thoughts and methodological reflections. The last part of the thesis includes conclusions and recommendations.

2. THE RESEARCH CONTEXT

This study was carried out in the rural part of the Peruvian jungle, where not only the geographical and natural conditions pose a variety of challenges to guarantee adequate services and living standards to the population, but in addition the social, economic and political environment may be different compared to the rest of the country. I will next provide relevant information about Peru to better situate the study context.

2.1 Peru: The national context

Peru is an upper middle income country (The World Bank, 2016d) located in the central and western area of South America with an estimated population of 31 million (INEI, 2016b). It is a multicultural, multilingual and multi-ethnic country; in fact, 45 percent of the population are indigenous people (CIA, 2016). The country is divided into three geographical areas: the coast (*La Costa*) which covers almost 12 percent of the surface, the highlands (*La Sierra*), 28 percent, and the jungle/Amazon (*La Selva*) covering the majority, 60 percent, of its territory (INEI, 2016a). Amazingly, Peru's ecological area is incredibly diverse with 84 of the 104 known living ecological regions in the world and with 28 different climates (Escobal and Torero, 2000, p. 7). Peru consists of 25 administrative regions, except for the capital of Lima being a province, and the regions are further divided into provinces and districts (CIA, 2016). Almost 80 percent of Peruvians live in urban areas (The World Bank, 2016a).

According to the International Monetary Fund (IMF) (2015), Latin America has been rated one the most unequal region in the world in terms of income distribution. This results in higher poverty rates that normally would be expected with similar average incomes in other countries. Nevertheless, due to efforts to reduce poverty, inequality has been in decline in almost all countries (ibid.), including Peru, which in fact has one of the fastest growing economies in the region (The World Bank, 2016c). Notwithstanding, in 2015, almost 22 percent of the total population in Peru was estimated to live in poverty and 4.1 percent in extreme poverty (ibid.). These rates have dramatically decreased since 2005, with rates of 55.6 percent and 15.8 percent, respectively (ibid.). In rural areas, 46 percent of the population was estimated to be poor in 2014, and 14.6 percent extremely poor compared to poverty rates of 15.3 percent and 1 percent in urban settings, respectively (INEI, 2016c).

2.2 Health care and rehabilitation in Peru

In Peru, there is a public and a private health care sector. The public sector is decentralized through the Ministry of Health (*Ministerio de Salud* - MINSa) that mandates the Health Insurance Scheme (*Seguro Integral de Salud* - SIS), a free or a low-cost health insurance prioritizing the most vulnerable groups living in extreme poverty, as well as the Social Security Health Insurance Institution (*El Seguro Social de Salud del Perú* - EsSalud) that covers patients through employment (Vermeersch et al., 2014, pp. 2-5). Other coverage programs are provided by the police, army, air force, and navy health funds, and the private health sector consists of private providers and insurance companies, private health care professionals, and non-profit entities (ibid. pp. 2-3). In addition, traditional or indigenous medicine is widespread (ibid. p. 3).

In 2013, around 35 percent of the total population received health care through SIS, and about 25 percent through EsSalud (Vermeersch et al., 2014, p. 3). Less than five percent received their health services through the other insurance types, leaving almost 35 percent of Peruvians without health insurance (ibid.). For them especially out-of-pocket spending, which is almost 35 percent of total health expenditures, can impose barriers to seek care (Carpio and Santiago Bench, 2015, p. 21).

As the health care coverage system is fragmented, medical rehabilitation is provided through both the public and private sector. There are, however, disparities within the country in the quality of rehabilitation services available, and especially without health insurance, many PWD may not have access to it. For instance, the National Institute for Rehabilitation (*Instituto Nacional de Rehabilitación* - INR) is a specialized rehabilitation center in Lima, where only the highly complex cases are referred to by health providers around the country and many of the patients have to travel across the country to receive rehabilitation (MINSa, 2015).

2.3 Disability in Peru

The first Specialized National Disability Survey in Peru was conducted in 2012 (INEI, 2014). According to the results, almost 1.6 million people are estimated to live with a disability, which affects 5.2 percent of the total population in the country. Over 50 percent of those disabled are over 65 years of age, and many PWD suffer from chronic conditions as well.

Motor disability affects almost 60 percent, and of those, 92 percent have difficulties to move outside home. The majority, 88 percent, of PWD receives no treatment or rehabilitation. Four out of ten depend on another person to perform daily activities. Almost 30 percent of PWD have difficulties to access health facilities, and almost one out of five have difficulties to physically enter and/or move in rehabilitation services, something that results in increased dependence. Almost 44 percent of those with mobility impairments live without an aid.

Other studies focusing on disability in Peru show similar results in low access to services and greater health risks among PWD compared to non-disabled people. For instance, a door-to-door survey conducted in the rural highlands of Peru by Rohrer et al. (2010) reported self-assessed disability to be a risk factor for poor self-rated health. Persons with poor health were more likely to report general disability and even more likely to report joint pain. In addition, less than 30 percent of respondents reported excellent, very good, or good self-rated overall health. Similarly, another survey in the same region (Merry et al., 2012) found disparities between PWD and non-disabled people in access to medical care, disability indicating a strong additional predictor of decreased clinic utilization.

Furthermore, frailty has been found associated with comorbidity, and together these factors predict disability among elderly people in rural areas in Latin America (Curcio et al., 2014). A population-based cross-sectional study (Guerra et al., 2009) carried out among elderly people in Peru, Mexico and Venezuela found consistent association between physical impairments and depression.

In a secondary and ecological analysis, Gutiérrez et al. (2014) reported disability in locomotion and visual impairment to be the most common forms of disability due to traffic accidents in Peru. Peru has reported high records of traffic accidents, most of them happening in the urban areas.

Qualitative methods were used in a Master's thesis study (Hunt, 2011) that made a situation analysis of disability resources and needs of persons with mobility-related disabilities in shantytowns near Lima. Poverty appeared to be strongly linked to disability, and environmental barriers together with perceptions of others were mentioned as reasons for social exclusion of PWD.

2.4 The general disability law and responses to the CRPD

As mentioned in the introduction, the new General Act on Persons with Disabilities is a legal treaty to protect the rights of PWD in Peru, and to provide a regulatory structure for developing disability policies (GIZ and BMZ, 2015, p. 3). In 2012, when the law was enacted, disability was also included in the State budget programs, but the financial funds directed at disability inclusion have not been sufficient (ibid.).

The National Council for the Integration of Persons with Disabilities (*El Consejo Nacional para la Integración de la Persona con Discapacidad* - CONADIS) is a public decentralized executing agency specializing in legal disability issues (CONADIS, 2016a). For instance, CONADIS implements projects in the country (GIZ and BMZ, 2015, p. 10), such as an educational program *Alcides Salomón Zorrilla* that was established in Lima in 2009 (Hernandez, 2016). It has provided free entrepreneurship training for PWD, e.g. in computing, textile clothing, carpentry, massage, and gardening, and more than 3000 PWD have attended the program. In addition, a pilot program *Tumbes Accesible* (Accessible Tumbes) is an example of a multisector intervention between levels of government to treat structural and systemic disability focusing on the issues of accessibility, education, employment and health of PWD (MIMP, 2013).

In 2015, Peru initiated a Non Contributing Pension program for severely disabled people living in poverty in Tumbes and Ayacucho regions (CONADIS, 2016b). The pension is PEN 150 (US\$ 45) per month, and five hundred people were estimated to be covered by the end of the year. With a continuing aim to identify more eligible persons for the pension in the two regions, in 2016 the program was planned to reach three poor regions in Peru: Amazonas, Cajamarca and Huancavelica. Almost 4500 beneficiaries were estimated to be reached.

2.5 The study setting

Villa Hermosa is a rural town in the San Martín Region in northeastern Peru, which is mainly located in the rainforests of the Amazon (see Figure 1). In 2015, Villa Hermosa had a population of around 25,000 inhabitants according to the local authorities⁴.

⁴ Personal communication with a local health directorate officer 9 March 2015



Figure 1. San Martín Region and the geographical areas of Peru (Google Earth, 2017)

Based on the Specialized National Disability Survey (INEI, 2014, pp. 301, 398), the disability prevalence rates in the provinces in the San Martín Region are similar to the national average, except for Moyobamba, Lamas, and San Martín where disability are estimated to be 20.1, 22.6 and 19.5 percent, respectively. Poverty could be one explanation to this high prevalence and difference, as, for instance in Lamas, which has the highest disability rate, the poverty estimates are the highest in the whole region, between 48.0 and 57.2 percent (INEI, 2015, p. 134). Moyobamba has poverty rates between 24.8 and 30.2 percent, but San Martín, on the other hand, has lower rates, between 21.6 and 27.0 percent (*ibid.* pp. 85, 133, 135). The poverty estimation in the whole San Martín Region is 40.2 percent (INEI, 2016c). However, another province like El Dorado has similar poverty rates as Lamas, but lower disability rates to the national average (INEI, 2014, p. 301, INEI, 2015, p. 134). Therefore, it is not easy to explain the differences in disability prevalence, because it is difficult to measure disability with single socioeconomic indicators, as suggested by Bernabe-Ortiz et al. (2016b). In their study, the authors reported conflicting findings with disability prevalence in Peru: the disability rates were lower in rural areas than in the urban settings, contradicting the general picture of having more poor people in the rural areas and poor people reporting higher disability prevalence. They also found lower rates among people who have a high education level, but those with better socioeconomic position reported higher disability rates. The authors concluded this to be a result of survival bias and access-to-care bias, following from

reductions in childhood and communicable diseases, and with higher levels of injuries and non-communicable diseases in urban areas.

In the field of public assistance to PWD, CONADIS has regional and municipal offices throughout the country. The Municipal Office of Attention to Persons with Disabilities (*Oficina Municipal de Atención a la Persona con Discapacidad* - OMAPED) aims to assist PWD in applying for a national disability ID (*el carnet de discapacidad*) to be requested from CONADIS in Lima. A disabled person needs to have a statement from the hospital about her/his disability, which is then sent to Lima together with needed paperwork, and it normally takes two to three months up to a year to obtain a resolution about the disability and the ID⁵. However, according to the national statistics, 92 percent of PWD do not have the official disability ID (INEI, 2014, p. 16). Villa Hermosa has such an OMAPED office.

I will now move on to the theoretical perspectives of the study.

⁵ Fieldwork notes

3. THEORETICAL APPROACHES

To situate the study in the body of knowledge on disability, I will present the various theoretical approaches and concepts touched upon and used in this thesis. Indeed, disability being a subject both in medical and health disciplines and in social sciences, a pragmatic mix of theoretical concepts are used (Green and Thorogood, 2014, Diccio-Bloom and Crabtree, 2006). This includes concepts from the International Classification of Functioning, Disability and Health (ICF) and Community-based Rehabilitation (CBR) as suggested by the WHO as “activity” and “participation”, as well as anthropological concepts of the body.

In this chapter, I will start with defining the concepts of disability and rehabilitation, and I will present the use of these concepts in disability studies. Then I will present an anthropological approach of the body, including a critical approach in disability studies and rehabilitation.

3.1 Definitions

3.1.1 Disability

Practically all cultures hold a division between the “able” and the “disabled” body, although there are variations in definitions and meanings depending on the social, cultural, economic and historical contexts (Helman, 2007, pp. 35, 38). To define disability is challenging due to its complexity, dynamics and multidimensionality (WHO and The World Bank, 2011, p. 4). On the one hand, the CRPD (UN, 2006) defines PWD as:

“...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (Article 1)

On the other hand, Leonardi et al (2006) propose another definition for disability, suggesting it to be:

“...a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors.” (p. 1220)

Disability is easily equated with incapacity (WHO and The World Bank, 2011, p. 6), which attributes unnecessary limitations to the disabled person. Many PWD do not actually consider themselves as disabled neither do they let impairments define their identity (Watson, 2002). Hence, disability can be seen as “an oppressed social condition” where the interaction between bodies and the environment causes the disability to become a problem (Charlton, 1998, p. 56/197). It has been shown that the inaccessible environment restricts the lives of disabled people rather than the disabilities themselves, thus preventing PWD integrating into society (Eide and Jele, 2011, p. 12). For Oliver and Barnes (2012, p. 5/240), both material and cultural aspects determine impairment, as social restrictions can occur in many ways, e.g. through inaccessibility of built environments, inability to use sign language by non-disabled people, or unsympathetic attitudes towards non-visible conditions and impairments.

According to the *World Report on Disability* (WRD) (WHO and The World Bank, 2011, p. 10), disability increases the risk of economic and social disadvantages, including for the families of PWD. In addition, PWD are faced with higher risks in health events compared to people without disabilities, such as psychological distress and less social-emotional support (Healthy People, 2015). This is true for all age groups, where children might be impeded attending school and receiving an education, whereas adults may be impeded in earning a living and care for themselves and their families. Moreover, PWD are vulnerable to oppression based on class, race and gender (Charlton, 1998, p. 9/197), making these other social categories interconnect with disability to form a person’s identity (Liasidou, 2013).

3.1.2 The WHO framework of disability: The ICF model

Within medical and health sciences, the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001) offers another definition of disability. The ICF is a universally agreed framework and conceptual basis for measuring human functioning, disability and health, which can be applied at an individual, institutional or social level. It approaches disability and health from a holistic perspective, emphasizing on the importance of activities and participations, as well as the environment of an individual to better

understand functioning (ibid.). Moreover, the model attempts to synthesize a biopsychological model by bridging the medical and social models together (ibid.).

In terms of mobility impairments, in the ICF model (Figure 2), mobility falls under both activities and participation, including further classification into changing and maintaining body position, carrying, moving and handling objects, and walking and moving (WHO, 2001). Activity can be seen as the act of an individual to accomplish a task, such as taking a shower. Participation combines activities with the social and economic aspect, like going to school. Activities and participation can be constrained more or only by the environment instead of the actual impairment of the body (Mont, 2007, pp. 3-4). Measures of rehabilitation target all the factors presented in the diagram (WHO and The World Bank, 2011, p. 95).

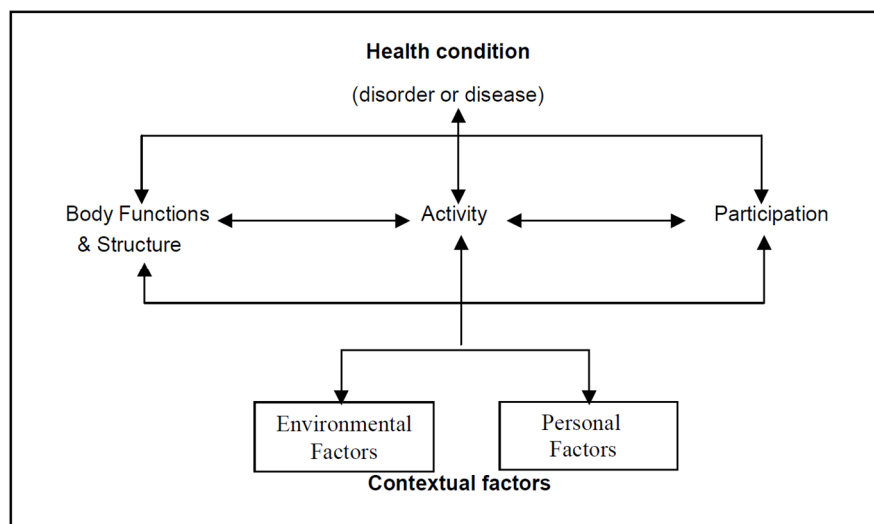


Figure 2. The ICF Diagram (WHO, 2011)

The ICF provides a strong guideline to understand the functional status of a disabled person in multiple dimensions at all levels of life (Kostanjsek, 2011). At the same time, the ICF framework has been criticized for the risk of ignoring the cultural perspectives of impairment and disability (Goodley, 2011, p. 20/217).

3.2 Rehabilitation

Some PWD need rehabilitation, which includes interventions to improve body function to achieve and maintain optimal functioning in interaction with the environment, as well as measures to promote inclusion, e.g. in education and employment (WHO and The World

Bank, 2011, pp. 95, 97). Rehabilitative measures directly relating to health include rehabilitation medicine, therapy, and assistive technologies (ibid. p. 97).

According to guidelines of the CRPD (UN, 2006), rehabilitation should start as early as possible, based on the individual's needs and strengths and through multidisciplinary assessment. In addition, rehabilitation services should be available as close as possible to PWD (ibid.). Importantly, rehabilitation is voluntary, and it should always aim to empower PWD and their families (WHO and The World Bank, 2011, p. 95). In addition, availability, knowledge and use of assistive devices and technologies for PWD should be promoted (UN, 2006).

To implement interventions which can improve or restore function and ability holistically, contextually adaptable frameworks for rehabilitation have been developed since the 1980's, as the Community-based rehabilitation approach.

3.2.1 The Community-based rehabilitation model

The conceptual framework of *community-based rehabilitation* (CBR) is a method meant to work closely with all necessary stakeholders concerning the needs of PWD in a community, such as PWD themselves together with their families, organizations and other relevant entities (WHO, 2010a, WHO and The World Bank, 2011, p. 83). Particularly in less-resourced settings, a CBR program can facilitate access to services, e.g. physical rehabilitation, and reduce poverty by equalizing opportunities and improving the social inclusion of PWD (WHO 2010). The CBR matrix (see Figure 3) follows the principles of the CRPD and has five main components. These are the development sectors of health, education, livelihood and social life, and the additional principle of empowerment which relates to the four other components (WHO, 2010a, pp. 24-25).

In Peru, some CBR programs have been implemented, which are focusing on children and adults with visual and hearing impairments, and multiple disabilities in particular (CBM, 2016, Sense International, 2016).

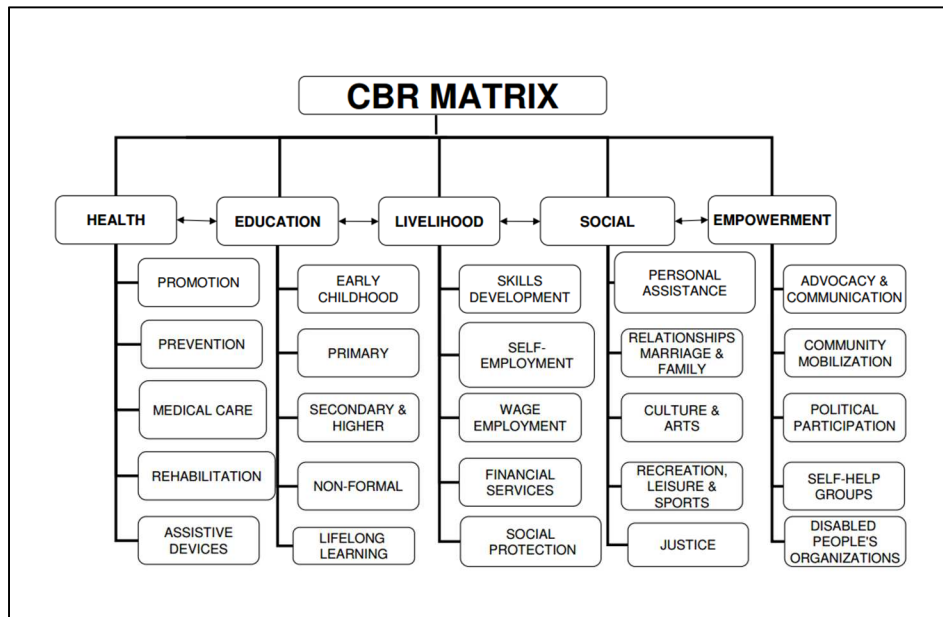


Figure 3. CBR Framework (WHO, 2016a)

3.3 Anthropological concepts of the body

As disability is understood as socially constructed around specific physical impairments, an anthropological, theoretical and epistemological approach is well suited. Scheper-Hughes and Lock (1987) introduced an analytical framework to analyze the meaning of the body in social life, taking into consideration different perspectives. In this thesis, I will attempt to apply this approach on the “disabled body” in a particular place, Villa Hermosa, and at a particular moment in time. Scheper-Hughes and Lock’s framework deconstructs the body/mind into three interconnected perspectives: The Individual Body, the Social Body and the Body Politic.

The first aspect, the “Individual Body”, is the self-evident, phenomenological sense of the individual (Scheper-Hughes and Lock, 1987, p. 7), which can explain how an individual receives and experiences disability. The “Social Body”, on the other hand, looks at the body in relation to nature, society, and culture as a structuralized and symbolized phenomenon (ibid.). This approach may help to understand how “disability” is culturally created and experienced in society. Individuals represent their culture, e.g. through perceptions and feelings, and how they relate to others and others to them (Helman, 2007, p. 24), and these should be viewed in the context of everyday interaction among people, as suggested by Ingstad and Whyte (1995, p. 4).

The last perspective, the so-called post-structural “Body Politic”, refers to the social and political control of disability, as well as to power, in the individual and collective sense (Scheper-Hughes and Lock, 1987, p. 8). To pay particular attention to the last two perspectives, I will present the approaches of critical disability studies and critical approaches on rehabilitation.

3.3.1 Critical disability studies

Critical disability studies question the distinction of disability and ability (Goodley, 2011, p. 160/217), and aim to understand both the experienced reality of disabled people, and the social and political aspects of disability (Reaume, 2014). According to Meekosha et al. (2013), PWD have been victims of adverse effects by social and public policy, altered by political, social and economic processes. An impairment does not define disability, but it is rather the social relationship between social status, power, culture and political citizenship that are central to inclusion and exclusion (Meekosha, 2005).

Thus, disability is a social creation; a person with an impairment is disabled by an “unjust and uncaring” society, as described by Oliver and Barnes (2012, p. 5/240). The authors further use the term “disablement” referring to impairment and disability created by economic and social processes, and influenced by the politics of disability (p. 6). Therefore, the “moral, social, political, cultural, and discursive mediators of disablement” are the focus of critical disability studies (Gibson, 2016, p. 11).

3.3.2 Critical rehabilitation perspectives

Disability has produced a number of professionals, as well as academic fields, that represent a community of “special needs”, including “healing professions” such as rehabilitation workers (Mitchell and Snyder, 1997, p. 1). A dominant biomedical focus in rehabilitation aims to fix the “problems” of individual deficits, and the rehabilitation specialists have the power to set the goals and determine the scale of outcomes of rehabilitation, as well as to produce the way disability is understood (Gibson, 2016, pp. 9, 12).

A central focus in rehabilitation is movement, whether seen as physical movements of body parts, or as a broader concept such as participation (Gibson, 2016, p. 2). Yet, the primary focus of today’s rehabilitation remains in the mechanical part, keeping rehabilitation

at the biomechanical level (ibid.). Consequently, disability remains as a “problem” that ought to be fixed, in spite of acknowledging the biopsychosocial models of care (ibid. p. 11). The practice of normalization in rehabilitation, i.e. aiming for normal function, normal activities, etc., may provide positive outcomes, but it may also allow negative attitudes toward PWD to persist (ibid. p. 27).

Applying critical disability studies in rehabilitation allows integrating both bio-scientific and sociopolitical approaches in the field of disability, as suggested by Gibson (2016, p. 12). Even though the environmental factors, as included in the ICF model, are acknowledged in rehabilitation, Gibson points out how the bigger sociopolitical aspects are generally not considered (ibid. p. 27).

In respect of disability and rehabilitation in a Latin American country, it needs to be addressed that disability experience, particularly in terms of human rights, in the global “South”, compared to the global “North”, is very complex, according to Meekosha and Soldatic (2011). Often times, the voices of PWD living in the South have not been heard by Northern researchers, for instance when planning programs in rehabilitation or traditionally relying on giving aid. The authors thus call for acknowledging the structural poverty and isolation in these Southern countries, and critically assess the contextual politics of impairment.

I will next present the methodology of the study.

4. METHODOLOGY

This study enquires about the situation of persons living with mobility impairments in a rural Peruvian community, and the interaction between attitudinal and environmental barriers together with the impairments. Indeed, as stated by Meekosha (2005, p. 4), although a universal phenomenon, impairment is “culturally defined in disability”. Therefore, perceptions and barriers were studied contextually, in their local environment, while being sensitive to local values, norms and policies.

In this chapter, I will present the research strategy and methodological design, as well as situate myself as a researcher. I will further describe the fieldwork preparations, the research assistants, as well the study participants, and the methods of data collection used during fieldwork. Finally, I will go through the data analysis process and consider the ethics of the study.

4.1 Research design

To understand disability in a social context and according to a human rights perspective, and to capture personal meanings of disability, a descriptive qualitative approach is useful (O'Day and Killeen, 2002). The design of the study can be described as a case study, with the aim of providing a thick description using several methods and understanding of a phenomenon within a context (Green and Thorogood, 2014, pp. 47-48).

The methodology of this qualitative study is based on phenomenological and hermeneutical elements that focus on the lived experiences and subjectivity of individuals, as well as on the understanding and interpretation of unique meanings (Green and Thorogood, 2014, pp. 14, 16, Rolfe, 2015) In addition, this study has a naturalistic orientation towards an inquiry that happens in real-life settings and natural environments as in anthropological approaches (Walsh and Wiggins, 2003, p. 23). Moreover, there is an awareness that the research setting itself impacts on the behavior of the participants, something requiring reflexivity from the participant researcher and observer (Green and Thorogood, 2014, p. 23).

In the following, I will present my role as a researcher.

4.2 The researcher: Studying living conditions in a less privileged setting

My own impressions and values have been part of the study process, which in qualitative traditions is even more recognized (Green and Thorogood, 2014, p. 23). Previous visits to Peru, and having Peruvian friends, as well as engaging with a Peruvian family for almost a decade, had given me some sense of the local culture and pre-understanding of the way of life in Peru. Seeing less-resourced settings within the country during my previous trips, and remembering my first visit in Villa Hermosa in 2010, a jungle town with dirt roads and poorly constructed houses, made me sensitive about of the possible limitations that the local people would have compared to the more comfortable living conditions that I was used to in Europe.

My personal values of equal rights and believing in the responsibility of the state to look after its citizens are based on growing up in a society with a strong social security system that provides public benefits to PWD, such as adequate rehabilitation, assistive technology (AT) and home adjustments. Knowing that this may not be the case in Peru, I tried to see the world from the perspective of the local people who may not take such benefits and rights for granted. However, being a so-called “able-bodied” person limits my ability to truly see the world through the eyes of disabled people, even though I have dealt with issues of different impairments when working or volunteering as a physiotherapist in Finland, Norway, the USA and Peru. I have also worked as a personal assistant to a person with a brain injury and to another person with spinal cord injury in Finland. Those experiences have probably taught me a lot more about the daily lives of people with disabilities than if only working as a health care professional in clinical settings.

4.3 Accessing the study site and preparing for fieldwork

Through personal contacts that I had from Villa Hermosa, I was able to get access to the local health authorities to propose the study in the first place. After the proposal process, I traveled to Peru in September 2015, first stopping in the capital city of Lima for a few days, and from there I took a two-hour flight to Tarapoto, which has one of the biggest airports in San Martín Region. In order to get to my destination, I had to take a taxi drive, which took several hours. Since my first visit in Villa Hermosa, five years earlier, the road from Tarapoto was now almost completely asphalted, making the ride much faster and more comfortable.

In Villa Hermosa, I had a host family I stayed with during my fieldwork, a family I had known since my first trip. We were thirteen people in total, and occasionally there were other relatives visiting. The house was big with several bedrooms, as the grandmother who was the head of the house had a big family. In fact, from the beginning, my host, a daughter of the grandmother, was my key contact in Villa Hermosa when I approached the authorities with my research proposal, and she helped me to arrange the required documents and preparations, as well as assisted me with the planning of the trip and organizing transportation and accommodation.

Within the first days after my arrival, I visited the director of a near-by hospital that covers patients through the Health Insurance Scheme (SIS) under the Ministry of Health (*Ministerio de Salud*), commonly referred to as MINSa by local people. We discussed about my research in Villa Hermosa and getting the research permit. In addition, we planned how I could be of help in the hospital and work as a physiotherapist during my stay.

4.4 Research assistants

To carry out data collection, and due to needed fluency in Spanish and for understanding slang words and local expressions, a local research assistant was recruited and trained. Upon my arrival in Villa Hermosa, the director of MINSa recommended me to contact a local English teacher, a woman close to my age, to help me conducting the interviews. I invited her to my house and after the first meeting she got my research proposal to get familiar with the topic. We would meet again a couple of times to discuss about the research, my background, to get to know each other better, and to train for interviewing. The research assistant was born in Villa Hermosa and it was expected that she might know some of the informants beforehand. Therefore, it was crucial that I addressed the confidentiality of the accounts of the interviewees.

However, three of the interviews were done with the help of two other people. The first interview was proposed to me already during the first week, and my host suggested me to ask her relative to assist me. The man had an academic background and previous experience with interviews, and he knew Villa Hermosa very well so I felt comfortable to collaborate with him with such a short notice. He also advised me on the language used in the information sheet and informed consent (see Appendices 1-5) and made corrections to make the text more suitable for the local people.

Two other interviews were conducted together with my host, a woman born and raised in Villa Hermosa. She had relevant working experience from international projects and she was comfortable with interviews. I relied on her assistance after I had scheduled a meeting with my main assistant to visit a potential informant, but she was late and I was not able to reach her through phone. I returned home and on the way my host suggested us to visit a person that was living close to our house. The second time I was accompanied by my host was when my assistant had fallen sick, and instead of canceling the interview, which had already been postponed because I had been sick, she assisted me for carrying it out.

4.5 Research participants

A person with any kind of mobility impairment and able to take part in an interview was eligible to be included in the study as well as stakeholders being caregivers to a person with a mobility impairment, or other individuals working within the field of disability. Interviewing different types of stakeholders increases the heterogeneity of participants in the case study, thus producing multifaceted knowledge (Green and Thorogood, 2014, p. 123).

Purposive and snowball sampling techniques were used to include enough individuals to provide rich data to address the research questions (Green and Thorogood, 2014, pp. 121-122). Adequate sample size was estimated to be between ten and thirty interviewees or until saturation of information was reached, with a possible combination of individual and group interviews.

The recruitment and enrollment of the research participants was done through local people. My host family knew potential interviewees, my assistant introduced me to one of her friends with a mobility impairment, one informant first came to see me for physiotherapy in the hospital, and I also approached a couple of persons whom I saw with a mobility impairment in public areas. In addition, I walked into the municipal disability office (OMAPED), the Catholic Church parish, and the school for children with special education needs to propose to do an interview. Through the school, I met some of the mothers of the disabled children and at the end of my stay I asked four of them to take part in a group interview, of whom three eventually accepted.

Nineteen individuals participated in the study; nine of them were having a mobility impairment, six were caregivers and/or spouses to a person with a mobility impairment, and four other stakeholders were working with PWD. The age range among the informants varied

from early twenties to seventies. Five of the individuals with mobility impairments were men, and five persons had a disability ID from CONADIS. Diagnoses, impairments and disabilities varied: the persons could be having an ankle trauma, Parkinson's disease, polio, scoliosis, a spinal cord disorder, a spinal cord injury, stroke, or visual impairment (two persons). In addition, two children had cerebral palsy (CP) and one had a chromosomal condition.

4.6 Data collection methods

Fieldwork with data collection was carried out from September to mid-November in 2015. Interviews were chosen as a main method to access the worldview of the individuals by talking to them in depth and thus allowing them to form their own stories instead of relying solely on my own views as a researcher (Green and Thorogood, 2014, p. 22). Other methods of data collection during fieldwork included notes on a selection of ethnographic observations during volunteer work. Indeed, from the beginning, I found it a moral obligation to volunteer as a physiotherapist in the community because of the lack of physiotherapy services at MINSA. This was something I had considered as an option beforehand, when I discussed about my study with the director of MINSA. Therefore, it was even more important to keep a reflective journal in order to deepen the learning from experience and reflect on my participation as an investigator in the study (Jasper, 2005).

4.6.1 Participant observation and observing participation

Observations in this study were done from the beginning, through my interaction in the community, and through my volunteer work in the hospital of MINSA and at the school for children with special educational needs (*Centro de Educación Básica Especial – ENE*). This was a way to see, know and understand how the local health care and educational systems function, and to perceive the natural and cultural environments. In addition, I got to see more PWD than I otherwise would have in Villa Hermosa.

After I started my volunteer work in the hospital and had my own small office it took a couple of weeks to finally have a constant flow of patients. My office was in the back of the hospital, and only after some time I realized the need to put a poster outside of the building to inform about the physiotherapy services I was providing. One time when I visited the nurses that were working with children, they were surprised to know that I was working in the

hospital. The information had not reached them, even though I was introduced to the hospital staff before I started my work. After this episode, I got several children referred to me. In addition, a local TV channel interviewed me about my volunteer work. I believe my appearance on TV gave some people a better understanding of my presence in the community, and one time a man approached me on the street asking me to help his daughter with therapy. In fact, the interviewer suggested I could give educational lectures on TV later on but as I became fully occupied with my research and volunteer work, I did not have the time for it.

At first, I dedicated four hours in the morning from Monday to Friday at MINSa. In my office, I only had an examination table, and I would bring my own massaging oils, muscle creams and kinesiotape. On one day, I was encouraged to accompany a general practitioner to meet his patients and assess their health issues. After the first month of my stay I was approached by the teachers of ENE to share my time with the pupils. ENE is a center for children with special educational needs close to the center of Villa Hermosa. There are approximately 25 pupils with a variety of disabilities, and six teachers. The school has three classes, and the children are divided into groups based on their skills.

I decided to change my schedule at MINSa to three times a week in order to attend the school on Tuesdays and Thursdays. In addition, I took part in the festivities of the school on the International Day for Persons with Disabilities when we marched in the city center to raise awareness about disability and afterwards gathered for a ceremony. I also went to a mass in the Catholic Church parish that dedicated an evening for the children with disabilities.

I occasionally did home visits to people who had difficulties to come either to the hospital or to the house where I was staying. A few times a person would walk into the house and ask for my consultation. After some time, however, I noticed how I had to prioritize my time and even though having the desire to respond to every request for therapy I did not have the means to manage all of it. In fact, at some point I started to feel overwhelmed.

In addition to the observations I made through my volunteer work during fieldwork, I felt fortunate to be part of a local family that allowed me to participate in local traditions and everyday activities, such as a high school reunion, birthdays and a wedding. I was also invited to have lunch together with other local families (see Figure 4) and the teachers from ENE.

To record my observations, I kept a notebook and an electronic reflective journal on my computer, as well as documents of my volunteer work in the hospital. In addition, I took several pictures during my fieldwork.



Figure 4. Lunchtime with a local family

4.6.2 In-depth interviews and group discussions

Nine face-to-face in-depth interviews were conducted using a semi-structured interview guide with open-ended questions (Appendices 3-5). According to Green and Thorogood (2014, p. 96), a semi-structured interview includes predetermined topics done by the interviewer, but the nature of responses are dependent on the interviewee's choice of importance and relevance to the questions. In an in-depth interview, the interviewee has enough time to share her/his account (ibid.). In this study, there were no time restrictions for the interviews, letting the informants to respond with their own pace. In fact, one of the interviews was close to a narrative interview, a way to let the interviewees tell their story (ibid.), as one of the informants told quite an extensive story of becoming disabled.

The questions were translated from English to Spanish and back translated to English to test the accuracy. The interviews varied from 20 minutes to two hours in length, the average time being approximately 70 minutes. The interviews were scheduled with each participant and appropriate location was chosen according to the wishes and convenience of the participants. It was found most comfortable and convenient to visit the informants in their homes. Only the first interview was done in the house where I stayed because it was more spacious and peaceful compared to the informant's home.

All the other participants with mobility impairment were visited in their homes, and the community workers in their work places. In a few occasions, there was a lot of

background noise because of traffic from the streets or loud music from the neighbors that caused some inconvenience for me personally, but my assistant and the informants seemed to be used to it and did not complain. On two occasions, the recordings of the interviews were disrupted by other family members entering the setting.

Some of the questions were reformulated once we gained more experience in conducting the interviews. For instance, a Spanish word *dispositivo* for a device was not always well understood and often needed further explanation, hence we would rather use a term *ayuda para la movilidad* (mobility aid).

During this study, three natural group discussions were conducted. A natural group discussion includes interviewees who know each other beforehand, to see how and what kind of social knowledge is generated (Green and Thorogood, 2014, p. 131). A couple where both had mobility impairments were interviewed together. Another group discussion included two representatives of disability authorities. Finally, it was easier to invite some of the mothers that I met at ENE for a formal natural group discussion. The discussion was arranged in the school facilities. One of the teachers asked to come and observe the discussion, but in order to guarantee privacy and for the mothers feeling free to say what they wanted to say; I politely explained that only the mothers and the interviewers could be present.

Even though I trusted that my assistants were able to carry out the interviews, as they all knew the place and local customs very well, I sometimes interrupted the interviewers and asked questions on my own. This happened when I felt that my assistant had not touched upon a certain topic or I wanted to engage myself more in the conversation and show the informants that I was genuinely interested in their lives.

4.7 Data analysis

I used a thematic content analysis to capture the key elements, and important issues in relation to the research questions, of the accounts of the interviewees (Green and Thorogood, 2014, pp. 209-210). In the analysis, I aimed to find out any associations between perceptions, attitudes and experiences of the informants (ibid. p. 206). As Green and Thorogood (2014, p. 204) recommend, a “good analysis draws widely on more general social science knowledge, and locates the particular findings of one study within a broader context, and not purely focus on the data collected when doing analysis”. Hence, having several frameworks on the background guided me in the analysis rather than pre-determining the themes before

commencing the analysis (ibid. p. 206). This mix of deductive (pre-existing concepts) and inductive (data-derived) analysis is inevitable as the theory and my previous reading influenced the way I read the data (ibid. p. 205).

In fact, the data analysis began already during the data collection phase, helping to generate an emerging understanding about the research topic while affecting the sampling and interview questions as the data collection process developed, as described in qualitative method literature (Dicicco-Bloom and Crabtree, 2006). I started to see similarities between the accounts of the informants quite early during data collection, which guided me to try to have a more diverse sample of informants as well as trying to probe the informants to respond to questions such as “why do you think so?”

In addition, a narrative analysis was used in three interviews to include richness to the findings by presenting life stories of some of the informants. A narrative method of analysis links a theory between the stories told in the interviews and the wider social structure (Green and Thorogood, 2014, p. 246).

4.7.1 Getting familiar with the data

Except for the first one, which I did myself, my assistant transcribed all the interviews. The man who assisted me with the first interview went through my transcription afterwards to correct the words I had missed or misheard. The transcriptions were all done in Villa Hermosa, and my assistant explained all the unfamiliar words and expressions to me. After all the interviews being transcribed verbatim in Spanish, they were further translated to English. In my proposal, I had planned to get the translations done professionally in Lima, but because of the time constraints, the amount of data, and noticing how well I understood the written interviews, I decided to do the translations on my own. These were done both in Villa Hermosa and after returning home. In this process, I was able to add nuances to the conversations while re-listening the audits.

The English translations were included in the analysis, however, the Spanish transcriptions were kept attached because it was sometimes easier to understand the true meaning of the expressions when read in the original language. I first familiarized with data by going through the interviews through listening and re-reading the transcriptions, translations and notes. I also formed short summaries of the interviews.

4.7.2 Generating codes

I began the initial coding by using descriptive and in vivo codes for relevant excerpts. I did this manually on the printed interviews. For instance, an excerpt “*I drove a moto normally, lived my life like anyone else*” I coded as “from normal life to disability”. The interview questions often already separated the answers into different topics, guiding me to start forming categories and themes with conceptually similar codes. After pre-coding I re-coded some excerpts such as “*they give you prison time in your own home*” from “prisoner at home” to “burden of disability”. I then started to look for commonalities and differences between the accounts.

4.7.3 Forming categories

Through coding I could organize the data into categories that showed a pattern (Saldaña, 2009, p. 8). I organized the codes both by manually writing, as well as by using a Word file due to the amount of codes. I came up with categories such as “in/dependence” and “faith”, and with sub-categories such as “shame and pity” (under “feelings, perceptions, experiences of disability”) and “having a disabled child” (under “effects on stakeholders”).

4.7.4 Defining and re-defining themes

In thematic content analysis, themes are derived from the data to collect conceptually similar things and put them together (Green and Thorogood, 2014, pp. 210, 213). Initially, the interview questions (Appendices 3-5) guided how the generated categories were separated. This meant categorizing the findings according to topics such as the use of mobility devices, history in rehabilitation and need for it, the experiences in the health care services, etc. In fact, I first came up with five themes and several categories (see Figure 5) that covered all relevant findings suited for the frameworks of ICF (WHO, 2001) and CBR (WHO, 2010a).

However, in order to have a more comprehensive understanding of the findings, and “link it into theory” (Green and Thorogood, 2014, p. 217), I reconstructed the themes according to the anthropological framework (Scheper-Hughes and Lock, 1987). Within this framework, I separated the categories into three themes representing the “individual body”, the “social body”, and the “body politics”, in order to include the socio-political aspects of

disability, and without forgetting the importance of subjective experiences as well. I then re-named the categories and sub-categories, as well as added new ones, to fit under each theme. This process turned out to be a longer process, and I returned to the transcripts, my notes, and categorizations during this phase. The defining of the categories would evolve while writing up the findings.

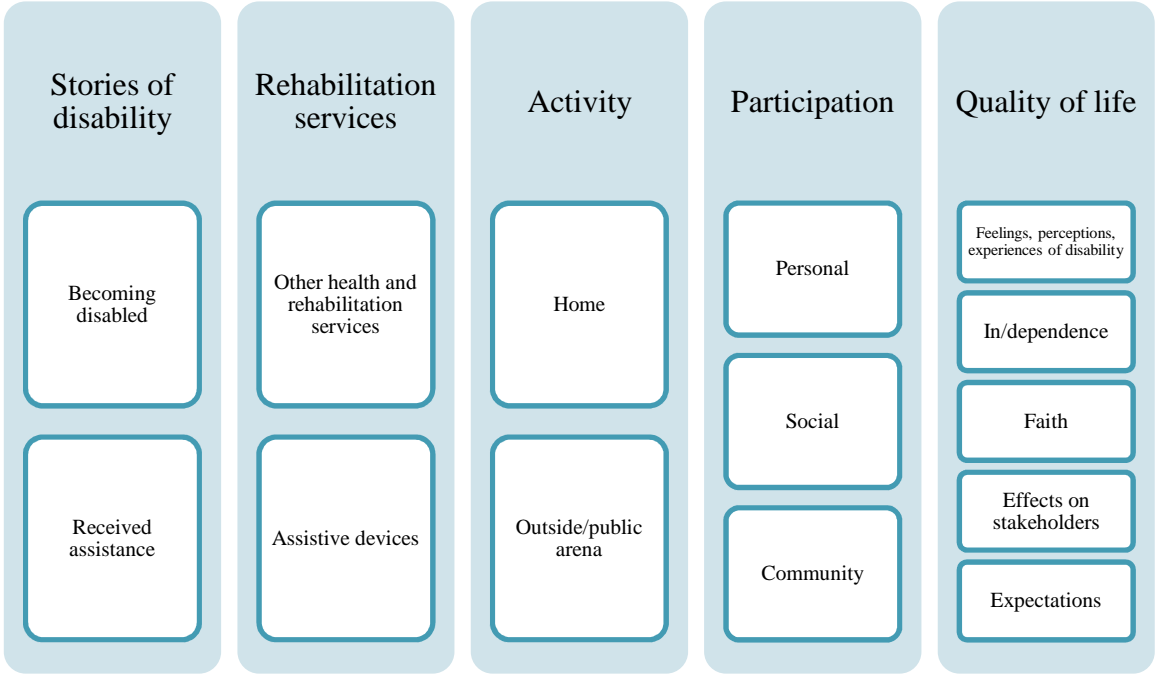


Figure 5. Initial formation of themes and categories.

4.7.5 Narrative analysis

In narrative analysis, the story itself is the focus of the analysis, that can help to make better sense of the data (Green and Thorogood, 2014, pp. 241-242). Personal memoirs reflect the developments of the surrounding culture (ibid. p. 241), such as how one becomes impaired and receives needed support and services throughout the course of life, reflecting the prevailing social context. A narrative stores an experience, organizes it and makes it relevant (Bamberg and Demuth, 2016). Even though all the interviews conducted were semi-structured in-depth interviews or group discussions, three of the informants spoke in a narrative way, telling their life stories of dealing with their mobility impairments. I used a thematic content analysis in those more “narrative” interviews as well, but the depth of their accounts produced richer findings, and allowed to make better sense of the “experience of disability”.

4.8 Ethical considerations

Ethical clearance was gained from the Regional Committees for Medical and Health Research Ethics (*Regionale Komiteer for Medisinsk og Helsefaglig Forskningsetikk* - REK) (Appendix 6) in Norway before my departure to the study site. However, REK did not permit the use of secondary data such as hospital registries, and this was therefore taken away from the data collection process. Thus, I relied on the information received in the interviews and when working as a volunteer. In Villa Hermosa, the local research authorization was approved by the Provincial Health Directorate (Appendices 7 and 8).

The informed consent (Appendices 1 and 2) was read to all the informants by the assistant and the interview process and the voluntary participation in the study was explained and confirmed well understood. Sixteen informants were asked to sign an informed consent. Three participants: two spouses and a mother to an adult son did not sign the consent, as their presence in the interview was not planned. However, because they answered some of the questions during the interviews spontaneously and gave their input to the results, they have been counted as participants in the study with the same ethical considerations applying to them. These participants consented to the interview orally. Two persons with visual impairments who were interviewed were at first reluctant to sign the informed consent because of the principle of not signing any papers, something I agreed with. However, they changed their mind and signed the document voluntarily, trusting that the document did not include anything that would be harmful to them. In addition, the informants consented to be tape-recorded and photographed.

All data collected; tape recorder, informed consents, and my computer were kept in a locked room, and the pictures and transcriptions are in password-protected online storage. Tape-recorded data was destroyed after the analysis was complete. The written data will be safely stored for five years after the end of the research project.

Asking questions about personal experiences, such as the psychological and physical difficulties in life when living with a disability, may place the informants in vulnerable emotional states and make them feel less powerful (Green and Thorogood, 2014, pp. 74-75). I decided from early on that the informants would be allowed to talk freely about the issues they felt comfortable with. The safety and wellbeing, confidentiality and privacy of all participants in the study was respected and protected, according to the Declaration of Helsinki (WMA, 2013). The anonymity of the informants was guaranteed by labeling their accounts

with numbers, which list was stored safely, and in the findings, I used fictitious names. As I have given detailed descriptions of the informants, the names of the study setting, of the special school and of the charity association are also fictitious to impede identification.

In the following, I will present the findings and discussion.

5. FINDINGS AND DISCUSSION

To answer the research questions, the findings of this study are presented according to themes (Figure 6), categories and sub-categories addressing the main issues raised by the informants and during fieldwork, and according to the three perspectives suggested by Scheper-Hughes and Lock (1987). I will start by presenting the individual level.

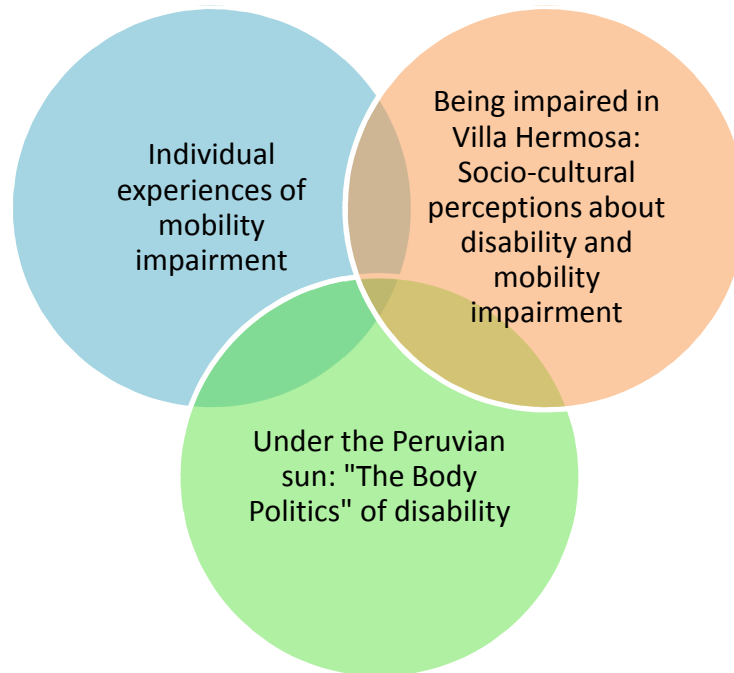


Figure 6. Main themes

5.1 Individual experiences of mobility impairment

This section presents a first set of findings, which are related to the lived experiences of individuals with mobility impairments, as well as of caregivers of PWD, in line with the “individual-self” theoretical approach according to Scheper-Hughes and Lock (1987).

Looking at mobility impairment and its manifestations at an individual level, I wanted to understand how an impairment and disability is received, and expressed by the informants. I will commence with selected individual life stories about living with a mobility impairment in Villa Hermosa and elaborate on findings that rose during the interviews and fieldwork. The main categories are presented in Figure 7.



Figure 7. Analytical categories under the “Individual Body” theme

5.1.1 Personal stories of dealing with an impairment

In the following paragraphs, three informants tell their story of becoming impaired and their narratives shed light on their lived experiences, their way of making sense of these and of giving them a meaning (Helman, 2007, p. 140). The narratives illustrate how impairment is not necessarily perceived as a tragedy, but rather point at aspirations to live with dignity, despite unfortunate events in life.

“Peter”: A painful body with lasting hope

Peter is a retired man in his fifties with scoliosis, a deformity of the thorax, since his youth. He started to have pain and discomfort when he was an adolescent, with no indications of what was wrong with his body. After several incidents of pain in the following years, and without experiencing any relief from the help he got from local doctors, or from natural remedies his parents would give him, Peter was referred to another city, and eventually to Lima. There, in the capital city, he went through medical exams to determine his condition, which was defined as a congenital malformation of the spine. This was a tough time for a growing young man, and Peter described how being in the hospital in Lima and going through uncomfortable exams was a real suffering for him, as well as how he struggled to give meaning to all this pain:

*“I said: ‘God, pick me up, I am here. I have such pain here, and pain there.’
Later began the difficulties. This is no longer a life and I did not have the
spiritual growth to understand God, I was immature in everything.*

Physically... Spiritually... What was the purpose [of all this suffering]? What were God's plans?"

Over a period of nearly thirty years, Peter had gone through four operations in his back, all done in Lima. This had required several trips to the capital, and he said he would still have to go for controls every three months. The medical exams and operations of the back had left him memories of suffering, always requiring time to recover and rehabilitate. Still, after the third operation, less than ten years ago, the pain became persistent:

"I started to feel worse, feeling increasingly restless, uncomfortable in everything... I frequently had sleepless nights and I could not sleep... I asked for sleep, I wanted to rest, but I could not because of the pain, the discomfort and...I came to understand...how unbearable it is to suffer."

The last operation was done a year after, and since then Peter has been using a walking frame instead of a cane because his balance became too poor. He lives alone in a house that has enough space for him to move around. He needs to take a motocar, a motorbike carrying 2-3 passengers, which is a common way of transportation in Villa Hermosa, to get to the center of the town. To move around in public facilities, he would always ask someone to help him to climb up or come down stairs. Sometimes he would feel tired after standing long periods and at such moments, he would have liked to have a wheelchair. Peter reflected on his loss of function:

"Your activities are no longer the same as before. I used to run, I could jump or carry something. I had to learn to accept my reality and get used to what I had left [of capacity] after the [first] operation."

Peter relies on other people to assist him with household duties, such as cleaning up. He has siblings and friends in Villa Hermosa, he participates in any event he is invited to, and he visits church regularly. After all his experiences of coping with pain and medical interventions, Peter tries to stay active and socialize, and he appears to have a positive look at life. If he had lived in Lima, the medical services would be closer, but he chose to stay in his beloved Villa Hermosa, among others because of the diversity of the nature and climate:

"Honestly, I tell you, I have so much love for this city of Villa Hermosa. I stayed here... I have had opportunities to leave and not to remain here, but..."

It didn't go like that, I stayed in Villa Hermosa. The jungle is beautiful; it is stimulating, nice...because in the jungle you see the different climates. There is sun, there is rain, there is a little bit of rain, there are dry winds."

Thus, in spite of the suffering his impaired body had given him, Peter knew to enjoy life, willingly living in his rural, peripheral hometown, which was situated far from specialized health care facilities. When asked about his expectations for the future, he replied: "*Hope. They say hope is the last thing you lose.*"

The next narrative also illustrates how lived impairment may imply long time suffering, physically, emotionally and socially. Yet in the case of Esperanza, it also illustrates how historical and political events are related to, and used to give meaning and explain lasting experiences of suffering.

"Esperanza": From suffering the dark period of terrorism to losing her children

Esperanza got an impairing injury decades ago, and when walking, she has needed and used a wooden crutch ever since. I met her in the main square of Villa Hermosa, where I asked her whether she would agree to be part of my study. Esperanza is approaching her fifties, and she is a mother of twelve children. She lives with her husband, her youngest daughter and a grandchild. She speaks both Spanish and Quechua, the latter being her mother tongue as she represents the indigenous Quechua population. Esperanza became impaired three decades ago when experiencing a severe trauma. In the 80's and 90's Peru went through a period of internal terrorism⁶. During an incident while running away from an armed man and carrying three of her children to hide in the woods, Esperanza was hit by a bullet. She injured her ankle when falling on an armadillo (a mammal with an armor shell). She spent weeks in the local hospital, but nothing was done to the ankle. The ankle in fact required an operation, but in those times, it was impossible for Esperanza to travel all the way to Lima:

⁶ During these times, the members of terrorist affiliations of the Shining Path and *Movimiento Revolucionario Tupac Amaru* (MRTA), and the Peruvian military and police forces patrolled everywhere, also in the San Martín Region. Indeed, and related to this, the region was part of coca production for the illegal cocaine industry. POOLE, D. & RÉNIQUE, G. 1992. *Peru: time of fear*, London, New York, NY, Latin American Bureau; Distribution in North America by Monthly Review Press.

“I did not have any operation; I did not have the possibility to go to San Juan de Dios [hospital in Lima] to be operated... They told me they would do an operation over there, that there were better doctors there. That is what they told me, but as I had no financial resources.”

Esperanza lives in a neighborhood from where it takes her 15 minutes to walk to the center of town. Even though it is physically strenuous to walk with a crutch, she still manages to do those trips weekly. However, she says she feels exhausted after she returns home, and sometimes she falls sick because of the pain in her body. Because of this, Esperanza expressed her need for a wheelchair.

“I have headache, pain in the lungs, in the spine, in the knees and the soles of the feet... [I also have pain] in the arm but mostly in the feet.”

As both Esperanza and my assistant explained during and after the interview, the unfortunate history of Peru is not a topic people easily talk about. In fact, I did not get to know about the story behind Esperanza's disability until we sat in her home and she, after being asked explicitly, started to tell about her ankle. She burst into tears while telling her story and taking us back to the 80's, which she described as terrible times for innocent people in Peru:

“At that time the army tortured, and violated everybody, [also] innocent people... We were all scared. The Shining Path came and we were scared, and then the army came... Finally, we were encouraged to leave [our farm] to go to live in Villa Hermosa, which was safer... Even though you saw killings you still lived in a somewhat less dangerous setting, but there were always deaths. Sometimes they would kill us in the center of the city. (...) Entire families disappeared, only a few were left, the older ones... While they slept the children heard nothing [of the killings], but when the morning came they stood up in the silence: their mothers, fathers, uncles, grandparents, everybody, the whole family had disappeared... [And] the river was the cemetery where they were thrown away; the dead bodies were going down the river daily, with torn necks, all. (...) Life was horrible! Because of this I have lost my children.”

Indeed, Esperanza had lost six of her twelve children, and the extremely traumatizing experiences of the war seemed to have left indelible mental scars, which seemingly explained

to her the continuing tragedies, which had affected her life after the war. Before the accident, she had four children, and two of them died during the war. After the accident, she gave birth to eight more children, but four of them died for reasons that were not mentioned in the interview. Esperanza explained how she was bedridden for almost one year after the accident, and how she was depressed for months after it. Eventually, with the support of her husband, she had learned how to manage life with her impaired ankle and she continued raising her family.

Esperanza has not received any kind of rehabilitation or social services for her condition. An aspect, which raised her concerns, was the economic situation of her family, and she was quite honest about going through moments of poverty:

“There have been shortcomings, yes... A day when I didn’t have anything to eat, we didn’t eat and we spent the day like that. When you suffer, you have to deal with it... My children don’t eat either sometimes.”

Esperanza had lost her job in the market allegedly due to discrimination by a particular person, and her husband was left as the only provider for the family. However, she told he worked in unjust conditions where he was not being paid as he should. Because of this, the family was planning to move to a farm to raise their own animals.

Esperanza appeared to carry a very sensitive past on her shoulders. In the end, however, she expressed to do well in her daily life with her family. Learning to manage her life with an impaired ankle and with all the invisible scars on her soul after the war was the only option she had had, and from our first encounter, she stayed gracious and kind.

The last personal story gives a description of an independent and self-employed man with a mobility impairment, who apparently first envisions ability rather than disability.

“Jose”: “I have no limitations at all” - Proudly independent, and promoting empowerment

Jose is a lively and good-spirited man in his mid-thirties living in the center of town. He runs his own business at home, where he repairs shoes. When Jose was three years old, he was diagnosed with vaccine-derived polio. He walks around with crutches that need yearly maintenance. What struck me while talking with Jose was his positive attitude towards life. He spoke passionately about treating other people with love and respect. Jose found it

challenging to talk about disability because he did not see himself as disabled, as he had managed to become independent “by his own will”. He expressed:

“I learned how to wash clothes, I learned how to cook, I learned how to deal by myself, I learned what is to pay a house-rent. (...) I have never felt disabled, never in my life.”

In addition, Jose had never looked out for help from doctors because he did not expect to benefit from it. As he put it: *“They give you a diagnosis, but they don't give you a solution.”* With a solution, Jose refers to the comprehensive enabling support that is needed after one becomes disabled. There is need for treatment and therapy, yet there is not least the need to learn to cope with life as disabled, as Jose expressed. Having a name for the disease does not carry long in life, if no other support is given and he claimed:

“This [condition, disability] is an abyss they tell you [the doctors]. ‘If you fall you die.’ But they are also pushing you [down] because they give you a diagnosis in which you feel more depressed, you feel less. Why? Because what we need is psychological training [counselling, coaching], somebody to tell you: ‘You know what? You can do many things; I know you can. But we will support you in therapy, we will support you in education, we will teach you how to use the internet, we will teach you how to turn on a computer, we will teach you this and that...’ This is what a person needs, he or she does not need flattering... Or things like a diagnosis and pity, we don’t need that. I tell you, I personally don’t need that.”

Jose puts further emphasis on the personal responsibility for own life. He strongly opposes to ask help from others, in fact he said he never had reached for help. He left home when he was thirteen so that he could learn to live on his own, learn how to feel and be independent. Jose was an example of a man, who would not see his impairment as a limitation, nor would he let other barriers stop him from pursuing a flourishing life:

“I left home, I did not ask for a permission, I left because I wanted to manage by myself... My parents gave me a very good education and... That was the supporting wall that has always led me forward. I have gone through several things... I know what hunger is, I know what it is to feel cold, I know what it is

to feel lonely. (...) That has been a part of the stem of my life, that has been a part of my roots... Where the land had to be broken so that the roots have the power to resist storms, water, rain... It made me strong, I became the person I am now... I have that strength that many who have fortune don't have."

Jose seemed very proud to be autonomous and he expected others to educate themselves in order to do the same, emphasizing how the most important thing in life is education. He was concerned about common attitudes in Peru, and he explained why he was not affiliated with other PWD:

"I have never liked to include myself in that social circle [of the disabled]... We fight for the crumbs of the government and it shouldn't be like that, it should be a right as a person, right? It's like going to the bank to deposit money or take out money; there are people who get it and you are not given this right. [You should get it], not because you look nice to the cashier or are disabled, [but because] simply it is your right to go, to be the person with preferential attention, but no... We have lost many [of the good] human values, we no longer give importance to the elderly when they cross the street, you know what I mean? We drive the motorcycles like crazy, not realizing that from one night to a morning we can make someone disabled. We have lost the sense of humanity we had before. I include myself because I am also human and we are prone to failure, but we should be more humanitarian to the people around us, we should be better people."

According to Jose, to help would mean to give an education to a person who needs it, and he emphasized the importance of promoting continuous self-development. For this purpose, he would also give away his old crutches to people who needed them. To care for himself, he would occasionally do trips to Tarapoto, the biggest city in the region, to receive therapy at a spa, with a preventive purpose and for his wellbeing. With the self-acquired power and control over his own life, Jose considered himself to be fortunate, in particular because he was living in the center of town, with access to needed services.

"Well, my quality of life is perfect... I have learned to cope with things, I have no limitations at all... I think the sky is the only limit."

Jose presented himself rather as a man with abilities than with disabilities. For instance, he would acknowledge the fact that he was not able to go for a run, even if he wanted to, but that would not determine his potential as a person. Instead, he would focus on doing things that he was capable of doing. Living alone, learning a profession and taking care of his responsibilities had allowed him to become independent.

The narratives presented above give three different stories and approaches to life by persons with a mobility impairment, based on different experiences, and different ways of coping. I will now present some recurring challenges encountered by individuals with a mobility impairment and caregivers of disabled people.

5.1.2 The challenges of disability: Some experiences and interpretations

According to Scheper-Hughes and Lock (1987, pp. 28-29), emotions affect the experience of impairment and disability. This section describes different emotional experiences associated with an impairment and disability, and the effects on caregivers when caring for a disabled person.

Grieving for the loss of function: Distress, depression and despair

Limited functioning in mobility can impose a great emotional burden on a person, and accepting the impairment, especially when losing the ability to walk after a trauma or a disease, had been difficult for many of the informants. Lisa, for example, a woman in her thirties with a spinal cord disorder, used to have an active life until she was 25 years old, when she was suddenly diagnosed with a gradually progressing disabling condition. Because of the weakening of the muscles in her lower extremities, she had to start to use a wheelchair. Lisa described how her condition made her feel:

“Sometimes depression takes a hold on me. I don’t want to talk to anyone, I don’t want to have a conversation. The only thing that calms me down is to lie down on my bed and close my eyes and spend hours like that... It is very hard.”

Having a progressive disease, while knowing that the functioning might get even more limited, may cause much distress. For instance, Manuel, a man with Parkinson's disease in his seventies, felt his disease was progressing which resulted in increased trembling and pain in his whole body. This would affect his sleep, he would often feel tired, get annoyed easily, and have little appetite. The medication he had been prescribed did not relieve his symptoms efficiently anymore, something he explained because he had been on the same prescription for eight years already. As he expressed: *"Sometimes I feel drained, everything feels bad... Sometimes someone makes me angry with whatever issues [and] I have to swear."*

Another example is Ricardo, a man in his early twenties, who was injured when he was 16 years old resulting in a spinal cord injury paralyzing his arms and legs. Losing his ability to get up and go, play football with his friends and spend time in the farm, had taken him time to adjust to. He would sometimes fall into despair when worrying about his condition and whether he would be able to walk again. He would like to get up and stand, but not succeeding made him feel sad again, until he calmed down and reminded himself to stay patient.

During fieldwork, I also met a married couple with visual impairments. Visually impaired persons need to adapt themselves to the physical environment, thus experiencing a mobility impairment as well. The couple worked as masseurs close to the center of town. Both of them had had high myopia since childhood, and Amalia, in her fifties, had lost her vision completely ten years ago. The husband Carlos, in his mid-forties, had lost his sight when he was thirty years old, and in the beginning, it was difficult to learn to use the white cane because he thought other people might be staring at him. He expressed:

"I grabbed the cane and 'praa' I threw it out there and I did not want to learn anything... I had to beat myself, because I felt I needed to go and do something, as I was used to work and do my things."

Sensory loss creates many challenges. As Amalia said: *"When you have become blind it is like starting all over."* Amalia and Carlos had attended a special school for the blind in Lima, where they had learned to manage daily activities, such as cooking and using the white cane. They had also received professional training in the school. However, even after training how to live independently with a visual impairment, limitations in enjoying some basic activities would remain, especially when living in the jungle. For instance, Amalia expressed how she

missed being able to read a book, or having somebody to read a book for her, and she emphasized her frustration explaining that she was not even able to cross the street alone.

Adjusting to life after a loss of function and accepting oneself with an impairment can be a long emotional process. Especially if disability comes unexpectedly and suddenly, such as Lisa and Ricardo had experienced, the emotional process is likely to be more stressful than for those who grow up with an impairment, or who have slower transitions when becoming impaired (Helman, 2007, p. 291). For instance, Jose, the shoe repairer, was diagnosed with polio as a child, and as he explained, his parents raised him as any other child. This may have helped him to adjust to his condition from early on, and to gradually strengthen his self-esteem. According to Li and Moore (1998), emotional support and self-esteem are important factors to adjust to disability. Moreover, the experience of an impairment, or disability, is not a static position, but it seems to change over time and through the whole course of a lifetime (Priestley, 2000). This seemed to be true in the case of Peter, who would have moments in his life when he would feel better, but then he had to go through another back operation and rehabilitation, which was again a challenging experience with lots of sufferance.

Longitudinal data shows that physical disability is a risk factor for depression, even more among women (Noh et al., 2016). It is further shown that extreme situations resulting in post-traumatic stress disorders can add an additional burden to disability. This might explain Esperanza's persisting additional suffering after her traumatic experiences from the war. In such, she is probably not unique, as the Peruvian political violence and civil unrest period have been reported to affect the Quechua population with long-term consequences on mental health in the country (Tremblay et al., 2009).

A next group that is affected when somebody becomes impaired are the caregivers. I will now present some experiences of those caring for children or adults with a mobility impairment.

Caring for a child or adult with an impairment: Emotional and physical demands

In addition to what the informants with mobility impairments expressed about themselves, the caregivers of disabled children or adults also experienced stress and concern. Taking care of a person with a mobility impairment can be both mentally and physically strenuous. Lifting a child or even more an adult with impairment was straining. For example, the mother of Ricardo would help him moving from one surface to another, helping him bathing, pushing his wheelchair, carrying him in the arms etc., which all requires physical strength. When I was

volunteering as a physiotherapist in the special school, I met mothers bringing their children to receive services. I interviewed three of them during a natural group discussion, and all experienced physical strain due to carrying and lifting their children. One of the mothers, Sofia, who had a boy with cerebral palsy (CP), complained about back pain when carrying her son. Her son was in fact able to walk with a walking frame, but he needed continuous guidance also during the physiotherapy sessions. Similarly, Evelyn, the mother of an adolescent daughter with CP, expressed to suffer back pain. She explained about the heaviness of care work:

“I can't even lift her because my back hurts a lot. At home, I have to support my back to be able to lift my daughter, but it beats me down, until I drop her on the floor. I have dropped her three times already... It is because she weighs more now.”

A third mother, Mary, whose daughter was not able to walk due to a chromosomal condition, would always carry her. However, she was concerned about her daughter getting bigger and heavier, not only because she was growing:

“While my husband is working, I give her breakfast and everything... And he tells me not to give her too much because she already is heavy...but how can I stop doing that? [But] there are days when it hurts in all my bones and I say my God, how am I going to be able to lift her.”

Moreover, caring for a disabled child would put an emotional burden on the mothers. Evelyn explained how suffering was part of both her and her daughter's lives:

“I want the best for my daughter, but I am not able to. Besides, her father has left us, he lives happily and I suffer here with my daughter. I know my sons support me, but I struggle with her and I don't want that. (...) My daughter suffers because...the two of us live together [and] I share everything with her. Sometimes my daughter sees me crying, and she feels bad... ‘Everything is fine my daughter’, I say. ‘You have to fight in life.’ [But] she only shakes her head my daughter.”

Mary, on the other hand, talked about parental worries and struggling:

“I tell my husband, if they tell me to go to a place where they will help our daughter, I will go...it doesn't matter where, I give my life, I give everything I have for my daughter to become normal [crying]... That's why I sometimes don't... I am very sensitive and sometimes I don't want to take part in such interviews because it hurts me a lot, it is an enormous suffering... Us mothers who have these children we are depressed.”

In fact, Mary expressed to be severely depressed to the point of requiring psychiatric help. Still, she would force herself to take care of her daughter but there were days that this would take a toll on her.

Interviewing Sofia, Evelyn and Mary together was an emotionally strong experience for us interviewers, because we sensed the pain of the mothers when they shared their stories with us. Moreover, it was not only the everyday challenges that would stress the mothers; there was also a concern for the future of their children. For instance, Evelyn was worried about what would happen to her daughter when she grows older: *“One day I will die, who will look after her? In what situation are children with disabilities left? Helpless, worse if they are girls.”*

Assisting someone who is severely disabled day and night can tire the caregiver. Several studies report negative consequences on parents of disabled children, e.g. depression, various forms of pain, and economic pressure. Mothers could feel overwhelmed by their caregiving role, such as was demonstrated among Zimbabwean mothers of children with CP (Dambi et al., 2015). High levels of parent-related stress among parents of adolescents with intellectual disability in Australia have been shown as well (Patton et al., 2016), and general stress and guilt negatively affect happiness among mothers to children with developmental disabilities in Israel (Findler et al., 2016). Hunt (2011, p. 26) reported financial stress among caregivers living in shantytowns in Lima. In addition, according to Traustadottir (1991), mothers are more pressured to stay at home to take care of their disabled children given that fathers are easily seen as the traditional providers for the family. Therefore, she claims the gender role division of mothers and fathers should be considered in order to balance care work.

As well, according to the World Report on Disability (WRD), the increased life expectancy of many children with disabilities may actually make it impossible for parents to continue providing care unless there is formal support service available (WHO and The World Bank, 2011, pp. 141-142). Indeed, in the case of the children and the mothers interviewed in

Villa Hermosa, the prospects for their future seemed to be limited. The children would need full-time assistance for the rest of their lives, and this might become a serious problem for instance for Evelyn, as she was alone to care for her daughter. Moreover, the opportunities for, especially, severely disabled girls, as the daughters of Evelyn and Mary were, can pose additional difficulties in the long run, as women with disabilities face gender discrimination (ibid. p. 262).

At the same time, the positive aspects of care must be acknowledged, and mothers of disabled children tend to have strong feelings of love and commitment of caring (Traustadottir, 1991). A literature review (Ryan and Runswick-Cole, 2008) found mothers of disabled children to develop multiple skills when dealing with their children. Barlindhaug et al. (2016) studied families with disabled children in Malawi and reported that families invest time and effort in providing for their disabled children, creating meaning and hope in their lives. This was something that I also observed in the mothers I interviewed, and which they expressed while talking about their children; because of the love they felt for their children, they tried to make their life best possible for them.

Caring for a disabled adult appeared to be challenging as well, not the least in case of severe disability, such as living with quadriplegia. Ricardo's mother was affected by the condition of her son. Ricardo was just beginning to study a profession and become independent, but as a quadriplegic, the opportunities for self-development were limited, as he needed continuous assistance. Another example of the difficulties of caregiving was given by the husband of Victoria, a woman in her fifties living with a stroke. Her husband told how the family had learned to be more patient ever since his wife had the stroke eight years ago, which resulted in half of her body being paralyzed. He expressed that he did not want the same thing to happen to anyone, because of the difficulties and complexity it had brought to their lives. First finding his wife unable to speak and move in bed in the middle of the night, then waiting for her to wake up from a coma in the hospital in Lima where she had to be taken, and where she went through an operation. Later on, after returning home he would see his companion depressed and crying, and failing to stand and falling.

This experience had been hard for the whole family. Certainly, Victoria may have had to deal with her own emotions of low self-esteem and depression, which is usual among stroke patients (Vickery et al., 2008). These certainly add to the reported burden of family-members and non-professional caregivers of stroke patients (Jaracz et al., 2014). Nevertheless, just like for disabled children, for adult relatives with disabilities as well, family

caregivers provide support and care in a number of ways, and they share the different experiences of impairments and disability (Grossman and Webb, 2016).

I will next move to the second theme that discusses the socio-cultural environment of the informants living in Villa Hermosa and how disability appears to be perceived in the community.

5.2 Being impaired in Villa Hermosa: Socio-cultural perceptions about disability and mobility impairment

In this part I will address the relationship between individuals and the cultural context of Villa Hermosa, where the informants and their relatives live, and I will examine how disability and mobility impairments in particular are culturally produced, in line with Scheper-Hughes and Lock (1987) suggestions. Social attitudes are part of the environmental factors as viewed within the ICF framework (WHO, 2002), and these affect the experience of disability, both in a challenging way but also in a rewarding way. This theme is divided into two categories as presented below in Figure 8.

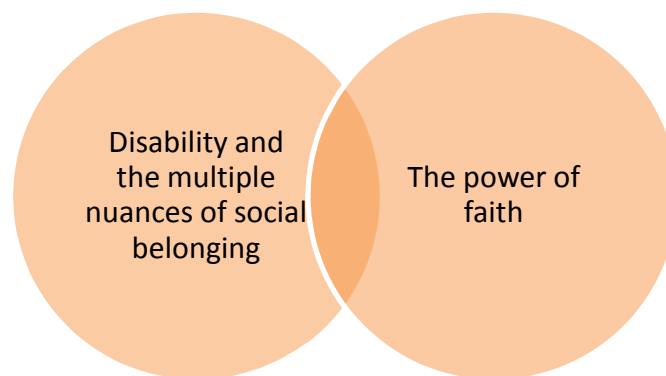


Figure 8. The socio-cultural context and the “Social Body” of disability

5.2.1 Disability and the multiple nuances of social belonging

In this section, I will present the issue of social discrimination that many of the informants expressed, especially in the case of children with disabilities and how they represent a marginalized group.

Shame, guilt and superstition as social limitations

Being a child in Villa Hermosa was one main cause of difference in the challenges accompanying disability, and consequently of the possibility of obtaining one's rights, such as rehabilitation services. The three mothers of children with disabilities, a teacher of the local school for children with special educational needs (ENE), and a Catholic Church priest whom I interviewed all reminded me how much more vulnerable the children with disabilities are. Evelyn expressed the following:

“There are many children who need that [specialized care], I have seen it...these children need that, but some of the children are abandoned by their parents. They [the parents] are also poor and we [all] need that [assistance].”

Similarly, Mary explained how she had been shocked to find out the number of children with disabilities in Villa Hermosa after moving thereto:

“The first day I came [to Villa Hermosa] I did not know there were so many children here with disabilities, with different disabilities. It broke me, it hurt me. My daughter is not the only child, there are many children in need.”

At the same time, local authority persons such as teachers were aware about the needs, which were to be covered in the community. For example, the teacher of ENE emphasized the importance of social inclusion of children with disabilities, and the responsibility of the teachers to help recognize the existence of those children in the community:

“Fundamentally the idiosyncrasy of our people is that these children are very...excluded from our society, and this is one of our jobs, community awareness. (...) [Therefore], any cultural action to be taken within society is appropriate, for us to show that these children do exist, these children have a life, these children feel, these children want, they are capable of loving like others.”

One reason for the exclusion of disabled children appeared to be the existing prejudices and ignorance among parents, according to the teacher. For instance, he mentioned how a person with Down syndrome may still be considered as a punishment from God, or how some people would believe that a child was disabled because the mother involved herself with an animal

during pregnancy, and therefore gave birth to a child that is slow in features, like a sloth. The teacher continued explaining how some parents would actually keep their disabled children indoors their whole lives because of shame:

“A lot depends on their [the children’s] homes, on parents. Sometimes the fathers are ashamed of their children when they are born with disabilities. For example, we have children with Down syndrome, there are many of them here... Because of the shame about their children, they take them neither out nor to the sidewalk, and there are several boys who are now forty, fifty years old and have never been to the sidewalk of their house.”

Besides the shame related to having children with disabilities as mentioned by the teacher, Mary and Evelyn told about how they faced disdain and vulgar language aimed at their children by other people. Evelyn expressed the following:

“I have been told: ‘Why don't you let her die? That [the child] no longer serves! (...) Why do you suffer with her, throw it away, [and] detain her [somewhere].’ But no, I want more for my daughter than for myself, because I want her to live more than I...but I can’t.”

Language is indeed a powerful tool to diminish the value of persons. In addition to what the mothers had heard, my assistant told me how some devaluating words like *minusválido* (invalid) and *cojo* (crippled) may still be used to describe disabled people in Peru. Though these words clearly possess a negative tone and many may avoid using them, I heard the word “cojo” being used in conversations, whether by joke or not.

These accounts show how some people would consider a disabled child as without a value, or as an unnecessary burden. Moreover, as shown by the example of people with Down syndrome, the superstition surrounding them reflected a moral position that sees disability as a sin (Goodley, 2011, p. 5/217). However, as put by Helman (2007, p. 36), the degree of stigma that lingers in a society can be explained in many ways; what type of impairment a person has, the socio-economic position of the person or her/his family, and the level of technology, access to services and social organization of the society. Moreover, the society and culture define the standards of behavior and the norms of people, and based on those values, which are learned as a child, people judge each other (Hendry, 2008, p. 172).

As was shown during fieldwork in the case of children with disabilities in particular, stigma affects the opportunities of disabled people to participate in society (Eide and Ingstad, 2011, p. 6). According to Meekosha (2005), these kinds of judgments are rooted in pre-existing perceptions of privilege, hierarchy and unfair treatment. In addition, disability, just like gender, class and race, is a social construction of exclusion, especially when used in a discriminatory manner to classify an individual in the full potential of a citizen (ibid.). Green et al. (2005) studied how such interacting processes of social discrimination affect the social experiences of PWD and their families in the US. The seriousness of the negative consequences varied among the components of stigma. Social awkwardness such as stereotyping with pity and labeling was found to be easier to manage, as well as losing status or discrimination in work and social lives. However, hostility, violence, and social shunning were reported to have profound effects on the persons involved and their families, something which probably affected some of my informants as well as those persons with disabilities whom I did not meet in Villa Hermosa.

The term “disablism” denotes the social burden of restrictions on the psycho-emotional wellbeing, aspirations and activities of persons with impairments (Thomas, 2007, p. 73). As Reeve (2012) explains, disablism can be categorized into structural disablism and psycho-emotional disablism: structural disablism consisting of barriers on the public level, such as inaccessible buildings and information limiting the things that PWD can do, and psycho-emotional disablism referring to the private aspects, such as stigma and internalized oppression that restrict who PWD can be. Somehow, one could add “socio-cultural” disablism referring to the socio-cultural exclusion mechanisms occurring at community level as described above. Yet, on the other hand, socio-cultural inclusion mechanisms were also present.

Next paragraph includes perceptions and attitudes fighting disablism by promoting local inclusive education for children with disabilities, yet it also shows how lack of awareness and disabling attitudes are present at the local authority level.

Inclusive education and –community support in Villa Hermosa

Indeed, raising awareness at ENE was something that was considered an effective way of changing existing attitudes in the community. Many of the pupils of ENE had mainly developmental and intellectual impairments, yet teachers there emphasized awareness raising

for all types of impairments affecting children. The teacher interviewed stressed the responsibility of the profession and of the state to provide schooling for children with disabilities. According to him, the school's aim was to support the children with disabilities in developing skills in order to carry on later in life:

“One of the primary purposes of education...and of the state policy is that the child is entitled to health and education...without distinction of any kind, in this case a disability... The educational part is to give them basic tools, the necessary tools so that these children, if not severely disabled, can learn something and develop a skill, which they can have and bring to the society and serve it. (...) [So] that they can have a moment of independence, albeit not complete but at least partial, because you know parents, siblings, aunts and uncles, no one is eternal in the world... Suddenly a close relative dies, but they keep on living and therefore they have to have something to be able to move forward.”

The teachers would do home visits to enroll more disabled children in the school and help the families to have their children included, as well as the school participated during public awareness arrangements.

On the International Day for Persons with Disabilities, I joined the teachers, most of the pupils and their parents, as well as other PWD in the main square of Villa Hermosa to walk together. We hold placards that had written messages such as “You and I have the same rights” (*Tu y yo tenemos los mismos derechos*) and “Look at me: I am human like you, I have feelings, abilities, concerns and hope” (*Mírame: soy humano como tú, tengo sentimientos, aptitudes, inquietudes y esperanza*). Afterwards we gathered for a big meal and entertainment in one of the public buildings (see Figure 9), and we listened to speeches given by both the President of OMAPED, the local public disability office, and the President of Angel Azul, a local charity association. This kind of community initiative brings visibility to PWD. A study in Lima by O’Shea et al. (2012) suggested that educational campaigns were a useful tool to “raise popular consciousness about intellectual disability, together with the issue of poverty in order to influence policy making and intervention planning” (p. 8). This appeared to be exactly what the school, as well as OMAPED and Angel Azul, were aiming at with the event.



Figure 9. A social gathering on the International Day for Persons with Disabilities

However, in spite of such efforts by the teachers and local authorities, some of the parents still kept their children at home. One reason was widespread poverty, and the other lack of trust in the education system. This will be addressed when the structural conditions of disability are discussed in the last part of the analysis.

However, the issue of poverty and of disability create socio-cultural values and moral norms about how to cope with these problems when public assistance is poor, and in Villa Hermosa, moral views on how to support the poor had resulted in various initiatives based on religious values. The President of Angel Azul expressed the following about involving local people to volunteer with charity work:

“There are people who get involved, who serve... There are still some people in Villa Hermosa with a good heart who help you to do something for the people in the greatest need.”

Angel Azul and the Catholic Church directed their charity work for the poor. For instance, Angel Azul aims to help PWD in poor economic situations by distributing food supplies. It has also done some wheelchair donations to PWD. The priest explained how the Catholic Church, especially on the coast of Peru, has colleges, universities, hospitals and nursing homes, thus contributing to general development in the country. Hence, he considered that the church had power to respond to other needs of people, not only spiritually: *“As the church*

grows everything grows. First comes the evangelization, but it is always accompanied with charity.”

However, not all would give priority to supporting PWD. The priest of the Catholic Church continued explaining how it was more difficult to help those who are both poor and disabled, because the resources of the church were limited. Indeed, there were no means to help those with a chronic disability in the long run, who were in constant need of support. As the priest put it: *“It is one thing to give medicine to someone or help with an operation but another thing with a person with a chronic disability.”* This implies that the charity work the church was doing was restricted because of the limited resources at hand, which would force them to prioritize, in this case leaving poor people with chronic conditions in a more vulnerable situation.

Notwithstanding, the role of the church, as expressed through the role of religion and faith, came out to be one of the strongest powers the informants had in dealing with disability, both personally and as a community.

5.2.2 The power of faith

I came to the field with a secular mind-set, and even though I was born and raised in an Evangelist-Lutheran culture, I had no concrete church and religious affiliation in my adult life. Therefore, I had to reorient myself once I arrived in an environment with a strong spiritual life and where religion had an important moral part to play. In fact, 77 percent of Peruvians are Roman Catholics, and 10 percent Evangelicals (Corporación Latinobarómetro, 2014, p. 6).

Many informants seemed to have God as a guiding force in their lives, a strength that apparently carried them through thick and thin. For example, in the early stages of becoming disabled and having to accept the situation, some of the informants would turn to God with questions of why this had happened to them. Peter explained the following:

“I am Evangelist Christian and I remember when one time I said to God: ‘Why all this suffering for me?’ This life is already not good, and all the pain is so frightening. To be in the hospital, going through these tests and everything that happens to me is anything but nice. It is very emotional for me.”

Evelyn, on the other hand, would turn to God to talk about the fate of her daughter saying that: *"My God, if my daughter had been a normal child, how would she be like... God only knows why."* Grippingly, both Evelyn and Mary hoped to have their daughters being born "normal", implying the widely spread representation of disability as an "abnormal" condition. Similarly, Jose described himself being born as a normal child until he got polio after vaccination. As Helman (2007, pp. 35, 38) writes, practically all cultures hold a division between the "able" and the "disabled" body. This division is further linked to the assumption that an able body is the norm, and culture determines the criteria for what is "normal" and "abnormal" (Barnes and Mercer, 2010, p. 186). In fact, Tremain (2015, p. 1904/9815) states that a person cannot be labeled "impaired" without comparing to a statistically created "normal case". Kumari Campbell (Tremain, 2015, p. 2349/9815), on the other hand, writes that "disability discrimination is an outcome of the practices of ableism, not their cause." The issues of stigma and shame discussed previously are connected to these perceptions, and seeing one's children or persons with disabilities as "abnormal" reflects the cultural perceptions of the society in which people live and perceptions of ability and disability.

However, God was said to be important to help some informants to accept the fact that they were disabled, as Jose expressed:

"I believe in a God, maybe it's not the God that all preach, but I believe in a God in the way that if something happened to me I have to accept it, because maybe without my disability I wouldn't be who I am... It made me to be a responsible person."

Faith seemed also to give hope for improvement of one's condition, as it did for Lisa:

"I have hope...that...my quality of life will improve, because I have put my faith in God and I know that He will help me in any way."

In this small Peruvian jungle town, religion and faith is apparently a source of mental and spiritual strength that gives many people, with and without disabilities, comfort and a meaning in life. For instance, Carlos believed that faith in God would ultimately make one stronger, and give protection and guidance: *"We have a lot of faith, we believe in God and feel that God protects us and is with us, truly taking care of us."* Mary said that she would leave everything in the hands of God in the case of her daughter. She further expressed her gratefulness for the persons who would give a helping hand on the street:

“I'm always thinking about God who is the creator, to give me strength, to give me patience to move forward... I thank Him for giving [us] people with a good heart who...provide their selfless support because these children really need it.”

Obviously, the priest of the Catholic Church whom I interviewed emphasized the strengths faith provided to people. By attending the religious services, it would make people feel valued and welcomed, because God loved them and saw them equal to others. In fact, I attended a mass one time in the central parish together with the pupils from ENE, their families and the teachers. This was a special occasion dedicated to the children with disabilities on the International Day for Persons with Disabilities. The parish was full, and I could observe quite a few adults with Down syndrome attending the service. The priest explained during the interview that many children and adults with Down syndrome and with psychiatric illnesses were in fact very active in attending church activities.

As shown by the examples, spiritual strength and faith can help a person who has been affected by an unfortunate event, for instance losing the ability to walk after an accident, to adjust to a new life situation (Hendry, 2008, p. 144). Moreover, attending the church and sharing the same faith with others becomes a collective force that gives people a sense of belonging. A systematic literature review (Rizvi and Hossain, 2016) found positive association between religion and happiness. Feelings of unity and security, as well as feeling blessed and being cared mutually was reported to explain religion's contribution to happiness. These same feelings can explain why many of the informants saw their faith as a positive aspect in their lives.

Boswell et al. (2001) who studied spirituality among women with disabilities in the US, propose that rehabilitation should take spirituality into consideration when addressing disabled people's needs, and provide opportunities and resources for clients to share their stories about spirituality and disability. In addition, for family caregivers, spirituality can provide comfort, reflection and shared moments of faith (Grossman and Webb, 2016).

To sum up, in disability and poverty, the support from family and friends seems to be very important, and all my informants had family members and relatives helping them out in one way or another, thus illustrating the socio-cultural importance of family ties and kinship. As well, social norms of inclusion and solidarity in the community, as well as religious values of charity were other important socio-cultural aspects relating to disability. I turn now to the last

thematic section of this study, which addresses the “body politics” of disability as perceived in Villa Hermosa and in the Peruvian society, and I discuss how the exclusion of PWD is intensified through poverty, barriers in communication, physical restrictions and lack of services (Pisani and Grech, 2015).

5.3 Under the Peruvian sun: The “Body Politics” of disability

In this final part of the findings and discussion I will present material which deals with the social and political control of ability in Peruvian society that directly or indirectly affects the lives of PWD, as suggested by Scheper-Hughes and Lock (1987). Aspects of power and control of activities and participation of PWD are related to the environmental factors of the ICF model (WHO, 2001), and socio-economic and political structures defining disability. Understanding of social and political control of the body in health, education, livelihood, social life and empowerment is important to analyze dis/ability holistically, as pursued according to all the principles of the CBR framework (WHO, 2010a), as well as to critical thinking in disability studies and rehabilitation.

Applying a “body politics” analysis of the control of ability made me ask following questions: What are the educational, health care and welfare services for PWD, and how are these regulated? Does poverty concur with disability, and how do governmental policies affect the living conditions of disabled citizens? How are the requirements of the UN’s Convention on the Rights of Persons with Disabilities (CRPD) met in the context of a Peruvian town in the jungle? The main categories resulting from the data analysis are illustrated in Figure 10.

With poverty and infrastructural barriers, decent livelihood and access to services such as education, health care and welfare support becomes limited. In the following section, I will discuss poverty, education and health services, and availability of human resources, as one of the main complaints that the informants expressed was the lack of re/habilitation “specialists” in education and health care.

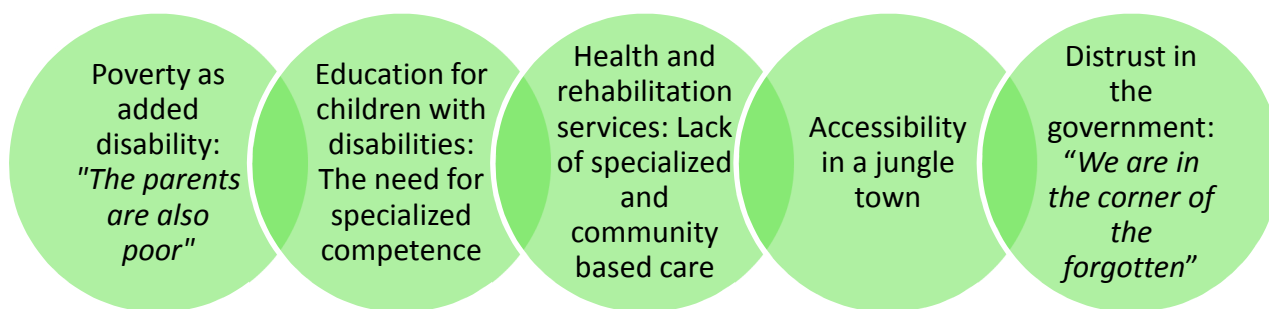


Figure 10. “Body Politic” categories of ability in a Peruvian town

5.3.1 Poverty as added disability: “*The parents are also poor*”

The topic of poverty was raised among some of my informants, either by direct confessions about not having enough money to meet the ends, or when explaining the financial barriers to receive needed services. The situation of Evelyn and her daughter illustrates how caring for a disabled child not only prevents a single mother to have access to labor, but how the burden of limited financial means adds up to the emotional stress of being a caregiver:

“If I have to suffer with my daughter, I will suffer... But I will go forward for my sons so that they will become something and thank God for their completing of their secondary [education], and for the small careers they have. They help me with a living, they have rented a house for me, they send me their money to share with my daughter, because I am not able to work, she will not let me work, because she has convulsions. When she convulses she gets very...she cries all day or all night... And for example, if she convulses in the night I don’t sleep. I go out on the street with her, because she does not sleep, crying... I have to stay on the street with her, risking my life for her, because she gets worse inside and weeps, she is in despair, she shouts and again convulses and for her not to convulse I have to go out on the street (...) to distract her.”

The burden of poverty affected many of the informants, and as the example above illustrates, it is mainly relatives who provide help to survive and cope, while public welfare support seemed often to be absent, or at least too insignificant to be mentioned.

Esperanza and her large family had financial struggles as well, as described earlier. She had lost her job, and her husband was not being paid fairly. Lisa, the single mother using a wheelchair, told how her family would not always have enough food to eat, because her mother was the only one working. OMAPED would in fact provide her family food supplies, but she found it not steady and sufficient. She expressed.

“I am a single mother since my daughter was born and my daughter is thirteen years old and all this time I’ve been alone. Now I’m with my mom and my daughter and we are doing fine, sometimes like in every home there are some problems, but normally we manage, and yes there are days when there are wants at home, there is sometimes need for food and if there is none there is none. That’s how we live. My mom is the one who brings the bread and butter, she’s already old at sixty-five years... Sometimes when she makes a sale there is [something] to eat and when she doesn’t... That’s how we live.”

For Lisa, not having enough money was also a barrier to seek rehabilitation. When she had received specialized therapy in Lima, she had paid PEN 100 (US\$ 30) daily. In total four months of rehabilitation had cost her PEN 12,000 (US\$ 3,800), excluding relevant tests and other costs. Lisa stayed mainly at home because of the difficulties to move by herself, but also because of the economical limitations her family had. Staying at home further limits a person’s participation in social life. This seems to be true especially for girls, yet there are differences between disabled girls, depending on whether they are better off economically or not (Eide and Ingstad, 2011, p. 7).

However, similar situations could be found among disabled men as well. For instance, Ricardo could not continue the therapy he had received after the accident. He had received three sessions free of cost, but as he would have been charged PEN 18 (US\$ 6) per session, he could not afford to pay for it. Moreover, Peter had been retired for years already, and as he expressed, his pension would only cover his basic expenses:

“What I get is not a lot, just to help me cover my expenses, but for other greater things it’s not enough, it doesn’t cover me, in one word it is [just enough] to survive.”

In fact, the teacher of the special school once said that I would be surprised to see the extent of extreme poverty in Villa Hermosa if I joined him for his home visits:

“Ninety-five percent of the homes of our pupils are in extreme poverty... I can confirm that this is evidently true, because I am with them constantly in their homes.”

This widespread poverty and absence of public support of the poor seemed to mobilize voluntary private, and some public support initiatives in the community, as indicated in the earlier section on socio-cultural values of solidarity. The difficult situation of some families made some individual teachers but also the school as a public institution try to promote school attendance by supporting the families. For instance, in order to get poor children with disabilities to school, the teachers would provide free transport for them, picking them up with a motorcycle or a motocar in the mornings and taking them home after school. A taxi ride would normally cost PEN 2-3 (US\$ 0,6-1) one way. In addition, the school provided free meals for the pupils. Thus, in this Peruvian community, there seemed to be both private and public initiatives trying to promote education among children with disabilities. Given that disability, as well as poverty, may result in reduced education levels, these kind of incentives can help to get disabled children into school (Moodley and Graham, 2015).

However, the need for more systematic economic support of the poor and the need for fulfilling of public welfare rights seemed obvious in Villa Hermosa, something which still seems to be true other places in Peru as well. In 2014, the International Centre for Evidence in Disability (ICED) conducted a qualitative study on inclusive social protection for PWD in northwest of Peru (GIZ and ICED, 2015, p. 33). The study investigated the experiences of households living with PWD enrolled in the *Juntos* program, a support program for the poorest, as well in the *Pensión 65* program, which provides a pension to people over 65 years of age living in extreme poverty. Both of the programs were found unable to cover the costs resulting from traveling to other cities for specialist consultations and other costs that PWD faced. In addition, a need for complementary services and benefits for both PWD and their households were reported. Another study, a population based-survey with a nested case-

control study in a northern semi-urban district with high poverty in Peru, concluded PWD to have greater needs for social protection, however they were not more likely to be enrolled in social protection programs (Bernabe-Ortiz et al., 2016a). The authors call for better inclusion of PWD into cash transfer programs as well as to implement specific interventions for PWD.

In the next paragraph, I will address the body politics of disability in education specifically, and the challenges experienced and voiced by parents of children with disabilities.

5.3.2 Education for children with disabilities: The need for specialized competence

When I met the three mothers I would eventually interview, they were all concerned that the teachers in the school were not trained to deal with children with so many different conditions. Because of this, Sofia and Mary did not bring their children to the school. Sofia explained her mistrust, pointing at the lack of special education competence among teachers:

“The UGEL [Local Educational Management Unit] has no support to provide, there are no specialized teachers, you see the children how they are... There are teachers here but they are not specialists in [working with] these children...and that is what we want... And sometimes, the same person from the UGEL would ask: ‘But what do these children need to learn?’”

Thus, even local educational authorities could not be aware of the special needs and capacities of the children at stake.

These findings are consistent with other studies. Hunt (2011, p. 30) reported that a community worker in the shantytowns of Lima did not trust the special education school due to the inadequate understanding of disabilities by the teachers and the lack of proper equipment. The same issue was raised in another qualitative study done in Lima by O’Shea et al. (2012). The study reported that the teachers did not have special training to offer substantial education for the pupils with intellectual disabilities.

Yet, the perceptions of the teachers and of the parents in Villa Hermosa could vary, and teachers showed lots of professional commitment. Indeed, I sometimes met the teachers outside the school and they often reflected on their work, for instance on how to deal with children with autism. The teachers seemed deeply dedicated and proud to give their part in the special education. One of the teachers knew sign language as well. Furthermore, during

fieldwork, authorities from the Ministry of Education visited the school for class observation, showing that the government had placed surveillance on the quality of educational work. In spite of the efforts by the teachers, some of the parents remained unsatisfied with the quality of education and decided to keep their children at home.

Unsatisfactory inclusive education structures and resulting parental attitudes might partially explain why children with disabilities are attending school less than children without disabilities according to national figures, in addition to poverty and lack of access. The primary school attendance among Peruvian children is approximately 97 percent, both in urban and rural areas (UNICEF, 2015). However, according to a report by Plan International (2013, pp. 250-251, 253), there are lower levels of school attendance of Peruvian children with disabilities compared to their non-disabled peers; both boys and girls with disabilities were found to be over ten times less likely to be in school. In addition, they were more likely to have a severe illness in the past 12 months. Globally, children with disabilities are less likely to start and stay in school, as well as to get promoted and continue with further education than children without disabilities (WHO and The World Bank, 2011, p. 263).

In fact, the issue of special education was controversial, in light of the right to inclusive education in mainstream schools. In Villa Hermosa, the President of Angel Azul, a local charity association, questioned the need to separate children with disabilities in a special school. In his opinion, the children with disabilities should be able to attend any school in the community, and not put them into a special institute, such as ENE. This is also stated in the general disability law, saying that public schools cannot deny any child admission on the basis of a disability (Congreso de la República, 2013). The practice of segregating children with special needs from general education can further their categorization and labeling them, as well as denying them opportunities to succeed in conventional class rooms (Hodkinson, 2015, p. 77). However, as I could observe, ENE was in reality often the only competent place to send the disabled children to in Villa Hermosa. A case study done in Lima (Noto, 2005) on a private special education center for children with significant disabilities found the education model successful through the school's emphasis on integrating parents, developing relationships within families and community, developing skills of committed teachers, and giving opportunities for the children to become active in the community. These appeared to be the goals of ENE as well.

In the next section, specific health and rehabilitation issues as raised by informants in Villa Hermosa are addressed.

5.3.3 Health and rehabilitation services: Lack of specialized and community based care

Access to necessary support services and devices is a prerequisite for a reasonable life quality (Charlton, 1998, p. 102/197), and maintaining the functioning of the citizens is one of the most important aspects in health and social services (Ojala, 2003, p. 18). Obviously, there seems to be a lack of specialized health care workers in Villa Hermosa. Given my voluntary work as a physiotherapist during fieldwork, I did times and again got to hear how poor service delivery was for PWD in town. All the informants expressed the urgent need for better service provision in the region, having access to specialists and more professional help locally instead of being dependent on the services offered mainly in the capital and requiring financial means and long travels. I will now look at the experiences of receiving health care in Villa Hermosa.

Absence of specialists and lack of proper equipment

The director of MINSA, as well as other acquaintances I had in Villa Hermosa, and especially the mothers I interviewed addressed the need for a pediatrician at MINSA. In fact, the hospital had a priority in maternal health and I could only imagine the pressure in delivering adequate care. Evelyn complained about the poor health service delivery in Villa Hermosa:

“Sometimes you have to take at least an X-ray... [But] they don’t have it [here], everything is in Tarapoto, sometimes we don’t have the means to go, because it costs, you have to have money to go...and if you don’t have [the money] our children die. Here you go to the hospital, you have to queue to have them attend you and they are not good at all. How can you go at three or four o’clock in the morning to be early in the queue? It is not possible. I say my God if someone could help us to have a permanent rehabilitation center for these children, wouldn’t it be nice? To support us with the care, and us moms we would devote ourselves to come. Even if it was to do something, [a rehabilitation center] for these children to stay in the morning, these children to eat, I don’t know. In my case, if there was a rehabilitation center here I would not mind if I did not get payed, I would come.”

Here, Evelyn seemed to express the need for a rehabilitation center, where the mothers themselves could contribute when bringing their children. All three mothers expressed their

concern about the need for such center for the children with disabilities. In addition, the teacher of ENE suggested the need for more professional care in the school, such as physiotherapy. In fact, he spoke about the teachers themselves doing stretching to some of the children to try to imitate therapy. Other teachers in the school addressed the need for a psychologist as well.

Among the adult informants, similar topics regarding the need for specialists in Villa Hermosa were brought up during the interviews. Six of the nine persons with mobility impairments had received rehabilitation in Lima: Peter, Lisa, Ricardo, Victoria, Amalia and Carlos. Yet the therapies were usually given at the moment of the diagnosis and during the first months after getting an impairment, and because rehabilitation in Lima is expensive, as well as transport, the therapy had not continued. Traveling to Lima from Villa Hermosa is demanding, as Manuel illustrated, the man with Parkinson's disease, who had to consult with a neurologist in Lima eight years ago. It took a three-hour-drive by car to the nearest airport and two hours by plane to reach the capital. At the same time, he could only get his prescriptions from there. Thus, having a chronic disease combined with living far from where services are provided added to the financial burden of paying for necessary drugs and appliances, as it also implied additional costs for traveling to these service centers. Similarly, Lisa could only get specialized therapy in Lima, but due to the costs of traveling, staying in Lima and paying for the rehabilitation sessions, she had no means to meet the needs that her condition required. In fact, I was the first one to give her therapy in Villa Hermosa.

Because the more specialized care is centralized in Lima, this creates barriers for all people living in provinces far away from the capital. Social protection programs, such as *Juntos* and *Pensión 65*, were found unable to cover the costs of persons to travel to other cities for specialized health care, as well as other disability-related costs (GIZ and ICED, 2015, p. 33). A study by Palma et al. (2013) about the use of the Ponseti method to treat clubfoot among children in Lima concluded that the Peruvian health care system is inefficient, as SIS does not cover the costs of congenital diseases resulting in disability. In addition, the doctors were allegedly forced to do the casting procedures on their free time, because MINSA did not permit extra scheduled appointment time to apply casts, and the patients needed to purchase the materials themselves. Other barriers were the lack of communication between specialists in Lima and the general hospitals in other provinces, lack of knowledge among parents especially from other provinces than Lima, as well as physical distance and transport to treatment centers in Lima that impose financial barriers to the families. These sort of

inequalities call for improvements in health care systems throughout the country, according to the authors, as Peru covers a large and diverse geographical area, and travelling may not only take a lot of time, but the costs can become too high, especially for poor families. The same seems to apply for most other disabilities requiring rehabilitation services.

Another issue in Villa Hermosa was the lack of appropriate equipment in the hospital, which made it difficult to respond to the health needs of patients. Peter had received physiotherapy many years ago, but he thought it had not benefited him because of the lack of proper therapeutic equipment. Ricardo expressed the same; he had received short-term therapy in Villa Hermosa earlier, but the therapy had only consisted of application of heat pads instead of stretching and exercises, which he had hoped to receive. Victoria, who had a stroke eight years ago, had received physiotherapy through MINSa after her stroke, but as her husband explained, the hospital did not have the proper equipment to help his wife:

“The inconveniences in the hospital is that it is not equipped to give a more consistent treatment... They don’t have those and I don’t know if they know what the reason for that is. (...) Only those who administer know it. (...) Sometimes those who are more professional can’t do as much as they want because there are no necessary ways of treatments. And so they have to limit themselves. When it [the hospital] is very well equipped, it will maximize the development in everything.”

From my point of a view as a professional volunteer at MINSa, proper facilities for rehabilitation could indeed give better opportunities for the staff to provide more adequate and sufficient forms of therapy. Peter summarized the situation in Villa Hermosa:

“Villa Hermosa is a small town that has many needs, in so many fields... There are authorities that can provide services, let’s say rehabilitation, physiotherapists [in Peru]... [There are] good places with services implemented [in Peru], where people with all kinds of conditions or even with small problems can go. In San Martín this is what we don’t have, in San Martín it doesn’t exist.”

A pediatrician and a neurologist, as well as a physiotherapist were the most required specialists in their town according to the informants. As previously mentioned, there used to

be a physiotherapist at MINSA but it was months since that person had left and during my stay, there were no signs of employing a new therapist.

The findings show how limited or non-existent access to proper treatment or rehabilitation was in this peripheral Peruvian town settlement. This supports the statistics from the first Specialized National Disability Survey, which show that 88 percent of PWD do not receive treatment or rehabilitation services (INEI, 2014, p. 13). Based on an evaluation in the same survey for rural areas (Bernabe-Ortiz et al., 2016b), lower rates of access to rehabilitation services were reported compared to PWD in urban areas. The authors explain that this could be due to inaccessibility to health care services, not having health insurance, and lack of specialized health care in rural areas. Geographical barriers might also create difficulties in transportation to health facilities. However, this phenomenon does not appear to be limited to rural areas, as barriers to rehabilitation of PWD living in shantytowns in Lima have also been reported (Hunt, 2011, pp. 36-37). As the general access to health services in Peru is low and inequitable, this is even a greater problem for PWD.

Improvements in the quality of health care are top priorities that the government of Peru has pointed at in order to have equal economic growth for the poor, and the government has an extensive inclusion agenda for the rural areas to improve accessibility to basic services (The World Bank, 2016c). In fact, between 2009 and 2011, Peru made an increase from 50 percent to 89 percent of health care professionals working in rural and urban marginal areas through a special SERUMS program (Carpio and Santiago Bench, 2015, p. 78). However, challenges in health care provision remain, as Peru has a critical shortage of health care workforce with 2.3 health workers per 1,000 inhabitants, and the unequal distribution of health care in the regions persists (Vermeersch et al., 2014, p. 24). On top of that, almost 45 percent of all health-personnel in Peru are draining out of the country (Carpio and Santiago Bench, 2015, p. xix).

This puts further pressure in the rural areas where there is already a shortage of workforce in the health sector, to keep the workers in place and/or attract new professionals. A study done in Ayacucho, a poor region in Peru, concluded that medical doctors were five times more likely to favor working in urban settings than in rural areas (Miranda et al., 2012). On the other hand, a similar study done in the same region among nurses and midwives found that substantial raise in salary, access to a permanent job and a scholarship for specialization were found attractive enough for the informants to consider working in rural areas (Huicho et al., 2012). Few years later, university students from medical, nursing and midwifery fields in

Ica and Ayacucho were interviewed to determine factors for future job preferences (Huicho et al., 2015). Here too, medical students preferred jobs in urban hospitals because of higher salaries and higher welfare expectations. Multiple incentives, such as adequate health facility equipment, family welfare, opportunities for professional development, access to information and communications technology, better road infrastructure and possibility for a permanent job were shown more effective among nursing and midwifery students.

Therefore, financial incentives combined with non-financial incentives could work as a strategy to persuade health care personnel, especially doctors and rehabilitation workers, to work in rural areas. Applied in Villa Hermosa, this could be effective, especially for MINSA, as salaries among professionals working for EsSalud are higher compared to the salaries at MINSA (Pardo et al., 2011).

Still, the particular situation regarding rehabilitation professionals should be considered, as these human resources are even scarcer in a global perspective. Both national and global information and evidence on human resources for rehabilitation is usually inadequate and fragmented, as there are no common definitions and classifications of health care workers (WHO, 2009). Gupta et al. (2011) assessed the global needs for human resources in rehabilitation and found lower supplies among low- and middle-income countries. WHO (2015a) estimated the density of “other health professionals”, including professionals such as physiotherapists, in Peru to be 0.72 persons per 1000 population in 2012.

In the light of the Sustainable Development Goals (SDGs), recommendations on how to deal with the shortage of human resources in health care are being addressed (WHO, 2016c, p. 6). Yet, it is estimated that there will be a shortage of more than 14.5 million health care workers globally by 2030 (ibid. p. 6). Therefore, implementing a CBR program where laypeople in local communities are trained to provide personal support, basic rehabilitation and referral of PWD in areas with deficiencies in health care workforce may be an effective alternative (WHO and The World Bank, 2011, p. 144). However, a successful implementation of the CBR guidelines may be demanding (Mannan et al., 2012).

Another topic considering health care delivery was the informants’ perceptions on the competence of local professionals and the negative experiences some of them had had.

Dissatisfaction with services: Experiencing impotence and abuse

During the accounts of the mothers, it often appeared that the problem was not only the lack of specialists or special equipment, but that there was an overall disappointment with the local health care professionals. For instance, Sofia, whose boy had CP, blamed the neglect of local general doctors for not taking care of her son when he was born. He had had jaundice, and Sofia was sent home from the hospital until her son got worse, so that she had to take him to the nearest big city. After that, he was diagnosed with CP. A similar incident had happened to Evelyn. Her daughter was reportedly born healthy, but after falling sick Evelyn took her to a nurse who allegedly treated her badly:

“Because of one nurse [my daughter ended up with CP]. I took my daughter for her to cure her because she had high fever and, as you know how the nurses are in the countryside... [Earlier] I had brought her to get her vaccinated, but I could not find her [the nurse]. Two, three, four days later, I went again and I still did not find her. All her three vaccines were delayed and on that day [when she was sick] when I took her for treatment, the nurse refused, saying: ‘You have neglected her vaccines.’ I said: ‘We could not find you and you stayed in your house and you didn’t attend us, you only do so when you feel like it.’ The nurse told me: ‘No, I will now give her vaccines.’ I told her no: ‘But she is with fever, how are you going to give the shots?’ ‘I am the nurse, I am the one who is educated, you don’t know [anything].’ And I let her put them, and that made her convulse. Because of that, she remained like that until today, since that day my daughter stayed like she had just been born... I could not do anything for my daughter... You know how it is in the countryside; there are no transport facilities to go to Lima.”

The other mothers also addressed the lack of adequate neurological care to their daughters. Mary expressed how she felt about not receiving the necessary care for her daughter: “[We are] *desperate about the impotence, the abuse that the doctors sometimes show us, it is horrible...*”

The informants further emphasized the importance of the quality of care in available facilities. Even in such centers in Lima, Evelyn and Mary had bad experiences, and they

found them often not good and safe enough for their daughters. Evelyn expressed the following:

“I would hospitalize my daughter in a place where they take care of her, where they treat her better because every mother feels for her child, you want all the best for your child and this is what I need and I want to be helped with. (...) God, I already lived my life, I know how it’s like. If I could donate my organs, I know I would do it so that my daughter would be better, in a place where my daughter could recover, so that my daughter could live. She needs to live [her life].”

These experiences suggest that even the health care facilities in the capital offer no guarantee for satisfactory services, according to the mothers, and despite the fact that there are more resources in Lima. In fact, Mary still takes her daughter to Lima for occasional medical check-ups and therapy. Nevertheless, because of the lack of certain advanced tests in Peru, she claimed that her daughter’s diagnosis was not necessarily correct. She shared her experience in Lima:

“She goes to Lima, I take her to therapy, but since she has been put under ‘Quality of Life’ [a program], they say to take her there only twice a year, and it is not enough... That’s what I don’t understand. I told the doctor: ‘I don’t understand this work plan you have in the institute, because my daughter is in this state and not only she, but many children who are in the same condition like my daughter or perhaps even worse, they need constant therapy. Why do you put them on [this] program?’ ‘It is only to improve, nothing else.’ [The doctor says]”

It seemed therefore that communication with health personnel about optimal care for the children was not always good, neither at home nor in the capital.

Other informants also criticized the quality of health services. For instance, the President of OMAPED explained how PWD in Villa Hermosa felt discriminated at MINSA:

“When some disabled people go there, they don’t take care of them. I go there many times to explain [to the staff]: ‘Look, the law says that a disabled person is entitled to a preferential treatment.’ But they don’t want to [attend them].”

Esperanza also expressed how she would not always receive immediate care at MINSA:

“Sometimes you go with fever, with aches, but they don’t attend you... You have to wait till tomorrow or if not till after tomorrow, that’s what the doctors or nurses tell you.”

Esperanza explained how there was a need for health care workers and better attention at MINSA. She criticized the local nurses employed in the hospital and told about a health care professional, who had come to Villa Hermosa to work, but who had eventually been fired allegedly because of the local staff. She continued:

“These people, these nurses in Villa Hermosa, whether they have a title or not, they say they have studied all of them but they haven’t. If they have a title, if they have a curriculum it is from here, from Villa Hermosa... But they mistreat you, they push you... And when others [professionals] come from another place, from Lima or Tarapoto or elsewhere they hate them. (...) When you are working there [in the hospital], you have to be very careful, because people here from Villa Hermosa, they throw you out by politics... That’s how it is... When one doesn’t know these [local] people one can say they are good people, [but] the colleagues [the new workers] must be very careful in front of the hypocrites at work. So, at work here in Villa Hermosa, there are envious people, and when one doesn’t know them... (...) People coming from outside are coming with good titles, they are well-prepared people, but these local practitioners, these ladies are the ones that are hypocrites.”

Low quality of care and inappropriate treatment by the health care providers appeared to lower the satisfaction among some of the informants. In fact, data from the Human Development Report (UNDP, 2015, p. 267) show that only 37 percent of Peruvians are satisfied with health care quality.

From the perspective of health care professionals, one could assume that they are under a lot of pressure to deliver adequate care with limited resources. In addition, lack of confidence in own skills to address the variety of conditions among PWD, as well as lack of awareness about disability may affect the attitudes of health personnel (Ong et al., 2016). As Gibson (2016, p. 27) suggests, the aim for (unreachable) normalization in rehabilitation, i.e. returning the functioning of a patient back to normal, may allow these types of negative

attitudes toward PWD to persist. Thus, the inability of the local health care professionals to provide “traditional rehabilitation” and them feeling unable to help may result in neglect of PWD.

In the next paragraph, I will discuss the provision of assistive devices as an important part of health services for persons with mobility impairments, and what kind of barriers they faced in accessing and utilizing them.

Assistive devices: The troubles of access and maintenance

Difficulties in mobility predict the progression of disability and often lead to declining of physical functioning (de Vries et al., 2012). A mobility device can enhance or maintain mobility and further allow one to feel free and independent (Hansen and Philo, 2007). The mobility devices used by my informants were wheelchairs, crutches, walking frames, orthoses, and canes. Wheelchairs were donated either by CONADIS, OMAPED, ENE, or by relatives. Other devices were often purchased by own means. As an example, Jose, the shoe repairer, would buy his crutches in other cities, and Esperanza had her crutch made by a local carpenter. Amalia and Carlos had acquired their white canes in Lima. Carlos emphasized how having a white cane had been the first step to become independent, even though at first it was challenging for him to use it. This is what made Amalia wonder about how some persons with a visual impairment would not use a cane but rather rely on another person: *“That makes me sad because the blind should not be so reliant on...another human being. You must have independence.”*

There were also other devices that were very much needed, even though less apparent for outsiders, such as diapers. This was needed both by one informant with a spinal cord affection as well as by Evelyn and Mary’s daughters with severe disabilities. Diapers are an important everyday requisite, and, for those using them, buying diapers could be costly, and to change them required assistance. Evelyn’s daughter was already an adolescent, and she sometimes had to change her diapers four times a day, such as during menstruation. Evelyn found it frustrating because her daughter would not always signal the need to change the diaper, whether she was menstruating or she had defecated. She used disposable diapers but I also observed her sometimes having a piece of cloth in her pants during therapy, which is recyclable after laundry. In fact, Evelyn expressed that the diapers were the costliest expense

for her daughter, and she was hoping to receive financial support from the state to buy them, yet she had not applied for any assistance.

Another aspect, mentioned by Amalia and Carlos, the couple with visual impairments, was communication technology allowing access to information, such as through internet with speech. Amalia was keen on learning and both she and her husband were hoping to have a computer. Amalia expressed:

“I like to read and I can’t do it, but I don’t have a computer because I don’t have the necessary resources [financial means] to have it...and I feel a bit frustrated. Because I like knowledge, I like to learn. To watch TV, I don’t like wasting time doing it, and I think my quality of life has gone down a few points. Not because I didn’t want to, but because it is still not available to me all that, all modernity. My sisters from Lima sometimes call me on the phone and they read me anything I want on the internet.”

In Peru, the provision of assistive technology (AT) is left mainly on the hands of the private sector. Bernabe-Ortiz et al. (2016a) report very low access to AT among PWD in northern Peru, and national figures show that almost 44 percent of those with mobility impairments live without an aid (INEI, 2014, p. 84). Even if all except one of the persons with mobility impairments in this study had at least one mobility device, there is neither public nor private regular provision and maintenance of AT in Villa Hermosa, only occasional donations channeled by the community workers. This illustrates how access to AT services is difficult in rural places.

The Ministry of Health (MINSA) and the local governments in Peru are obliged to guarantee the provision and access to adequate medicine, assistive technology, and support, assistance, habilitation and rehabilitation taking into consideration the socio-economic status of the disabled person (Congreso de la República, 2013, pp. 10, 28). During fieldwork, no attempts to implement the law could be observed nor did people talk about such AT service provision coming soon. Lack of support for mobility may significantly impact the household income and impede access to services (GIZ and ICED, 2015, p. 33), meaning that PWD needing AT may not be able to access work.

Another reported challenge with AT was access to appropriate aids. The three mothers I interviewed complained about the inadequacy of the wheelchairs in terms of not giving

enough support to their children, or being already too old and falling apart. Evelyn had been advised in Lima to acquire a special chair for her daughter with CP but she had neither information where to buy it nor the means to pay for it:

“[Appropriate wheelchairs] are in other countries that are more advanced; they have [wheel]chairs that are of superior quality... In the same chair there is a table that folds nicely and goes normally, you eat in it, and the arm rests. I think it has hinges, like...it extends and serves as a table, serves to sleep, that chair has some haulers to rest, to sleep peacefully and you go...but I don't know, those chairs are in other countries...but not here in Peru.”

Similarly, Mary had been advised in Lima to buy a special relaxation wheelchair for her daughter, who not only had a low vision but who was not able to stand or walk on her own due to her chromosomal condition that had caused her muscles to be weak (with decreased muscle tone). However, Mary did not have the information about where to buy such chair and in fact; both she and her husband asked me to look for information about which countries could deliver an appropriate wheelchair for their daughter. In the case of Ricardo, he dreamt about having an electric wheelchair to allow him to move around by himself, and not being dependent on his mother always pushing him.

Sometimes, however, the lack of services made people become creative and produce the needed devices locally. For instance, once I visited Mary and her daughter, I could observe that she had a standing device built by a friend for her daughter, which she used every morning (see Figure 11). Furthermore, on one occasion I observed a man on the street who had a wheelchair made of a plastic chair put on top of wheels. The lack of services made indeed local people to take action by themselves, and with carpenters and other handy people, they were able to build such devices. This seemed to be an opportunity for developing service provision in the community, as promoted in community-based rehabilitation as well. However, in order to have appropriate devices of some quality, skilled professionals and trained personnel is needed (WHO and USAID, 2011, p. 24). Moreover, as the WHO and the USAID (2011, p. 22) advise, there should be adequate funding and improvement of affordability for AT, based on local needs. The essential AT should also be available free of charge for those who cannot afford to purchase them (ibid.).



Figure 11. Self-made standing device for a child using a wheelchair

If public resources are limited, other stakeholders such as private providers and international entities can help to fill the gap in the provision of AT (WHO and USAID, 2011, p. 9). Charities have a role in distributing aids, and for instance, according to the President of OMAPED, a contract with China would help import wheelchairs to be given to PWD in the region. These wheelchairs would be of standard sizes, which means that they are not individually tailored for use. Inadequate devices in size and functioning may have negative consequences for physical functioning, occupation and life quality (Hunt et al., 2004, Scherer and Glueckauf, 2005). A wheelchair intervention implemented in India and Peru (Mukherjee and Samanta 2005) showed the need for proper assessment of the individual abilities and the environment to determine the efficacy of charity wheelchair use for a disabled person, as charity wheelchairs were sometimes reported to be unsuitable for independent mobility outdoors because of geography and poor architecture. However, a study conducted in the same settings (Shore, 2008) found contradicting evidence, showing positive impact on health and quality of life by the use of donated wheelchairs for PWD. Significant improvements were found for instance in mobility, and in domestic and social life. Nevertheless, donations through charity may dominate the supply chain, and may potentially be hindering locally produced devices.

Thus, assistive technology (AT) is important, yet during fieldwork, wheelchairs were a typical example of how access and maintenance could be a challenge. As there was no professional provision of assistive devices in Villa Hermosa, the maintenance of the wheelchairs and other devices was up to the individuals, who would take the devices to a local person who had the tools to fix them. Usually the assistive devices needed maintenance once a year.

Another challenge met was the lack of professional service provision and follow-up for persons needing assistive devices. For example, Victoria had had a stroke eight years earlier. She owned three different orthoses (hand splint, shoulder and ankle-foot orthoses) that her daughter had bought in Lima, but she told that she did not use them regularly. In fact, I asked her to show them to me but she said she needed to find them first, clearly indicating these had not been used for a while. Her spouse also said that after her stroke, she was recommended during a home-visit by a physiotherapist to use those orthoses but it had been challenging to put them on. Apparently, because of the spasticity of her arm, it was difficult to tie them up properly unless better professional adaptation.

To sum up, and considering all the challenges in AT provision, programs such as community-based rehabilitation (CBR) can improve services. With a range of stakeholders involved, CBR can result in AT service provision in areas that are more difficult to reach, such as in the jungle, and where there is a shortage of workforce (WHO and USAID, 2011, pp. 23, 25). A literature review (Velema et al., 2008) of the outcomes of rehabilitation-in-the-community programs in Asia, Africa and Central America found increased independence, mobility and communication skills of PWD. Still, if indeed a program such as CBR could respond to the need of AT and other rehabilitation service provision in the rural areas, professional follow-up may be a problem in the long run.

Given that to allow social activities and participation, accessibility is fundamental, I will next address the issue of accessible home environments and public infrastructure, and how these facilitate or impede activity and participation for PWD.

5.3.4 Accessibility in a jungle town

In order to understand the reality of being disabled, it is fundamental to look at how an impaired person carries out her/his daily duties and how much the impairment affects the activities (Hansen and Philo, 2007), as well as how accessible the surrounding physical

environment is. According to the WRD (WHO and The World Bank, 2011, pp. 262-263), environmental factors add disabling barriers to PWD, and as it became evident in this study, these environmental factors include the home environment, infrastructure and transportation. These types of barriers are also defined as structural disablism, because they limit what PWD can do (Reeve, 2012).

Living environments at home and outdoors: “It feels like jail time at home”

Several informants experienced that being able to move around and coping with daily life activities at home and outdoors was problematic, and poorly constructed houses, uneven roads, and intense traffic were easy to observe everywhere. Firstly, a home environment that is not properly adapted to the needs of a disabled person restricts her/him to freely move around. For instance, a wheelchair requires enough space, and it has to function well to provide a proper support for the person. Lisa for example, a wheelchair user with a spinal cord disorder, was mainly able to move between her bed and the living room area, which would cover no more than four square meters. Her bathroom was located beyond the kitchen area, which was not accessible with a wheelchair. In order to satisfy her needs, she would have to use a basin, but when she was alone in the house, while her daughter was in school and her mother was working, she could not empty the basin until someone else would do it. She expressed the following feelings about performing activities at home:

“I feel like...when they give you jail time in your own house... A prisoner. And the space in prison is also tiny. That is how I feel. The only thing I can do is, to take my head out and then enter it, like a turtle [laughing]... That is how I live.”

I could observe that the doorstep of the entrance door to her house was at least ten centimeters higher than the floor (see Figure 12). This would require always having someone else to help her getting out. Spending her days inside with limited activities would also make her feeling bored, and four other informants expressed the same challenges in mobility and participation at home. Ricardo, another wheelchair user, described how he would transfer himself with his wheelchair to get out of his house:

“I only stay here [at home]... Sometimes I try to move the [wheel]chair to go outside... I sit here on the right and I get up, I put my hands here...in this corner, I lean over here and I give it a push over there... Bit by bit I get outside.”

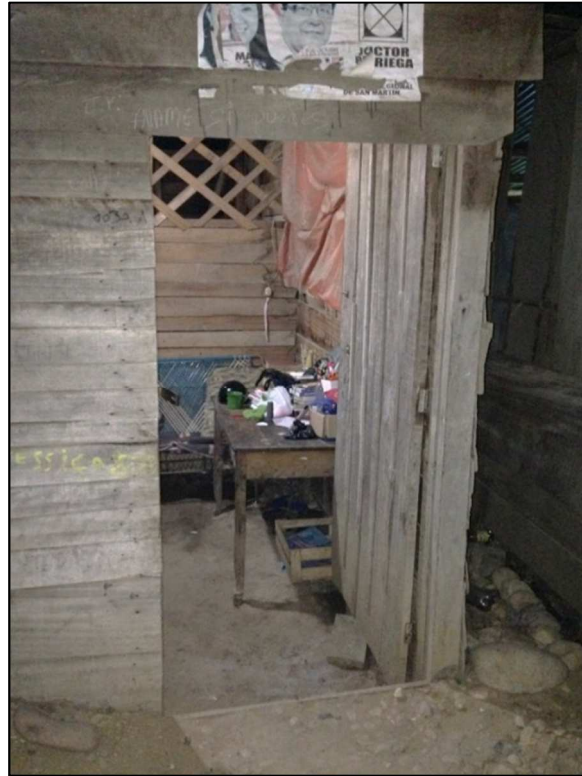


Figure 12. The entrance to the house of a wheelchair user

An adjusted home is a prerequisite for the proper use of a mobility device. In fact, I did not see or hear about any specific adjustments that had been done in the informants' homes, and this seemed to be totally left to private initiatives. Peter and Jose had apartments that were spacious enough for them to walk around with their mobility devices. Having clear pathways was one way to allow more space but many of the houses in Villa Hermosa had floors made of cement or dirt that were not even. For instance, I visited Evelyn and her daughter a couple of times and they lived in a tiny house with dirt floor with just enough space to move the daughter's wheelchair around. Evelyn had a mattress on the floor in the bedroom and she would have to lift her daughter to move her there. The entrance to her house had a higher step, similar to Lisa's apartment.

As it was discussed under the previous theme, some parents may keep their disabled children at home because of socio-cultural factors such as shame, but sometimes PWD had

simply no possibilities to go out due to lack of structural support, such as appropriate assistive devices, personal assistance or clear pathways. Persons missing a necessary mobility device may have to stay in one spot for periods. For example, the Catholic Church priest told about his experiences when visiting people's homes and discovering persons immobilized and isolated by the lack of wheelchair:

“It is very sad, you enter a house and get to the room and it's all dark and you have to turn on a light and you find... for example, there is one here [in a district of Villa Hermosa], a man who can't walk and you walk in and there he is on a bed lying.”

Charlton (1998, p. 2127/4361) writes how families may give a place in the house to a disabled person to stay throughout the day, as the house is not accessible, thus impeding a physically disabled person to participate in the housing duties while severely restricting personal mobility.

Moreover, climatic and geographical factors, such as weather conditions including heat and rain can cause more unpredictable situations for persons with mobility impairment, especially for the ones that have no other means to move except a wheelchair. During my fieldwork, which was under El Niño and the hotter period of the year, there were temperatures of 36 degrees Celsius, high humidity and no proper rain for almost two months. As Ricardo expressed, his house could become unbearably hot during the day, especially because of the metal roof, which would heat up the house even more. In fact, he would sometimes lie on the floor because of the heat. Another concern was the natural heavy summer rain in the jungle area, which could reach the point to cause floods in the buildings. This was a big concern for Lisa, because her house was not stable enough to support high pressure:

“When it rains sometimes this whole part floods, the water comes into the house, and begins to fill all around and we can't move and I can't climb on the top [of the furniture]. And my house is almost falling, because all that water is eating the wood, so if something heavy would fall and if I was here alone, I could not move myself anywhere. The situation I live in is not good...such living conditions are not suitable for a disabled person.”

According to the disability law in Peru, the Article 18 states that PWD have the right to access programs for accessible housing (Congreso de la República, 2013, p. 22). The CRPD

promotes PWD to live independently, which applies to housing as well (UN, 2006). Studies show that an accessible home environment correlates with better health and wellbeing, as well as with increased scores for Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) among people with functional limitations (Cho et al., 2016).

This study shows that there was no support given to the informants to adjust their living spaces, which means that only those with the required financial means could make proper adjustments to their houses. This shows a gap between the rights which are endorsed by Peru, and their application, especially in rural areas such as Villa Hermosa. However, it appeared that the informants were not aware of being entitled any legislative rights as persons with disabilities. Getting appropriate housing seemed, therefore, to be a luxury. In fact, after visiting Lisa, I had written following notes in my journal about the living conditions of my interviewee:

“These kind of moments like I had today really reminded me of the privilege we in the Nordic countries have, or whoever who has a better economic status. To be able to have enough space at home, and to have public services that provide assistance according to our needs and our rights.”

The only informant who apparently had been offered a housing was Esperanza, and this was due to being a victim of the war. Although she had been waiting for it for years already, her rights as a disabled person had at least been recognized. This illustrates though that the cause of disability makes a difference when it comes to access to rights, and disability because of war injuries has been shown to result in a better fulfillment of one’s rights than other causes of disability. For instance, in Zimbabwe in the 80’s, disabled war veterans received higher benefits compared to other disabled people (Kawewe, 1994). In the US, military veterans are entitled to different disability benefits, such as economic compensation and adapted housing (U.S. Department of Veteran Affairs, 2016). These kind of policies create a hierarchy in disability, giving some causes of impairments a better “approval” thus controlling the abilities of disabled people politically.

In the next section, I will discuss the challenges some of the informants addressed about being able to move around in Villa Hermosa.

Difficulties in transport and infrastructure: “Sometimes, those taxi drivers are not charitable people”

One of the challenges for outdoor mobility for persons with a mobility impairment in Villa Hermosa is transportation. Indeed, there is no public transportation system in Villa Hermosa. Therefore, in order to travel to other towns, a taxi or a combi (bigger car) is often used. Some busses exist as well, while locally, the motocars and motorbikes are the most common way for transport.

The roads in Villa Hermosa are only partly paved (see Figure 13) and in particular, Lisa and Ricardo expressed that going around with a wheelchair was difficult, even impossible. Dirt roads that during the rainy season become muddy and unequal, as well as the many hills in the neighborhoods, made it physically challenging for persons with physical limitations to move around. In addition, the motocars were often too small to carry a wheelchair, and the drivers were not always willing to take neither passenger with a wheelchair nor someone with a visual impairment, something both Lisa and Amalia expressed. Lisa said:

“Sometimes it rains and the wheelchair is adapted only for hard floor, it is not for clay, for dirt, so I can't get out. I only go to certain places with my [wheel]chair and from there I grab a moto... But sometimes those taxi drivers are not charitable people.”

The motocars also created a lot of dust on the dirt roads, many of the drivers had a high speed, and the traffic was noisy. Because of this, Amalia and Carlos, the couple with visual impairments, found it very unpleasant to go out and walk on the streets, and Amalia said she would only use a motocar driven by family members, or with someone she knew. Victoria, with hemiparesis due to a stroke, needed assistance to enter and get out of a motocar and she usually relied on a relative to drive it. Intense traffic, not trusting unfamiliar drivers or having difficulties to get a ride, and the need for assistance may be additional reasons why so many of the informants mainly stayed at home. Just to move on the street by foot or with a wheelchair can be challenging enough, as Lisa described. Amalia also paid attention to the condition on the pedestrian side of the streets:

“To start with the sidewalks, the sidewalks are full of motorcycles, of motorcars or if not, there are dogs. (...) [There are] horses...chairs, people

unconsciously take their chairs out and leave them there... Here you can't walk... [There are] some terrible uneven [sidewalks]. In Lima I walk a lot and stay slim, here I am gaining weight. (...) Why is it like this? Because people do not have knowledge, the authorities do not place order. In Lima we move better, but here, well...you have to accept the reality."



Figure 13. An urban dirt road

Similarly, Jose mentioned how some non-disabled people would neglect the needs of PWD to access public areas, and he suggested PWD to speak up and make reclamations in order to make a change to such careless attitudes:

"If you don't know how to talk here no one respects you... You go to the main square here and where there is space for a wheelchair to go, there is going to be a car parked, unfortunately... And if you don't go and complain, nobody will help you. You have to inform him as disabled because he is going against your rights as a person, because they have made it [a ramp] for you [person with a disability], not for a person to park the car, or for a healthy person, because you can't walk and need that ramp to pass, right? And that person is

blocking you. It's like [somebody] coming to knock on your door and you close it, it's the same... We are in Peru...unfortunately.”

Access to services and buildings was another issue. Lisa talked about how public facilities would not be accessible for persons with mobility impairments:

“For you to get into a public institution, no places are adapted for a disabled person. Sometimes there are steps, sometimes they can help you, sometimes not, and in the ENE, you only remain in here [a district in town]. You may need to call for assistance, and sometimes they attend you, and sometimes not, and that is the difficulty.”

In addition, Peter expressed that he would need to ask assistance from others to help him to climb up the stairs or come down whenever he would visit the city center. In Villa Hermosa, I could indeed not always see ramps to get into buildings. The hospital of MINSA had a wheelchair ramp outside. Yet, usually, to access the stores and other facilities from the road, there would be a step up to a pavement.

To sum up, in terms of infrastructural accessibility for PWD in Villa Hermosa, in particular for wheelchair users, unpaved roads and lack of ramps in buildings imposed difficulties. Yet, even if all the streets would have been paved in the area, because of the natural environment being a jungle, it is challenging to make a motocar accessible for people with wheelchairs. This was a reason why the pupils of ENE would usually have two wheelchairs, one at home and one in the school. However, the daughter of Evelyn had only one wheelchair and the school would occasionally help in transportation. Most of the time Evelyn pushed her daughter to school, which would take her at least half an hour, as the neighborhood they lived in did not have a paved road. Sofia pointed at the responsibility of the Local Educational Management Unit (UGEL) to take care of the transportation for the pupils at ENE.

According to Ojala (2003, p. 15), who writes about accessibility in high-income countries but which seems to be true everywhere, the functioning and capacity of a person depends on the stage of the development of the society where s/he lives, as well as on the personal and economic resources at hand. Participation depends on the built environment and on attitudes, how accessible the environment is for a disabled person and how PWD are seen (ibid. p. 26). If the needs of PWD are not considered, such as making buildings accessible and

providing transport, the threshold to get out and be a participant in the community becomes a lot higher. Often times, physical barriers are aggravated in urban slums (WHO and USAID, 2011, p. 18). This seemed to apply to Lisa and Evelyn too, who both lived further away from the city center where the roads were not paved, and the house of Lisa was located up in the hills. In an economic analysis of Peru, Escobal and Torero (2000, p. 48) found that the more hostile geographic areas are, the more limited is access to public infrastructure. The WHO and the World Bank (2011, p. 263) remind that regardless of the laws on disability, obedience to provide access to public buildings is often low. This could be observed in Villa Hermosa as well.

The need to speed up the improvement of accessibility in public facilities and transportation in urban and rural areas in Peru has been addressed by the Committee on the Rights of Persons with Disabilities (UN, 2012). Furthermore, the WRD recommends universal design, which is accessible environment for all, as well as building a “culture of accessibility” by removing basic environmental barriers (WHO and The World Bank, 2011, p. 169). Making improvements in accessibility incrementally, such as improving buildings bit by bit is also more achievable (ibid.).

I will now move on to focus on the apparent role of the Peruvian government. Inequalities in the provision of services and support suggest that there is a lack of political action to make concrete changes in order to guarantee equal rights to disabled people.

5.3.5 Distrust in the government: “*We are in the corner of the forgotten*”

Peru has ratified the CRPD (UN, 2016b), and enacted a general disability law (Congreso de la República, 2013) based on the principles of the CRPD. Hence, Peru is obliged to ensure the rights of PWD according to these legislative commitments. However, as it became evident during fieldwork, many of the informants addressed the impotence of the state, or they accused the government for not considering PWD, and making promises it would not keep. This seemingly created an attitude among the people that there is nothing to be expected from the government, neither at national nor regional nor local level.

Particularly in the case of children with disabilities, the need for better public support was a concern for many, not only for the mothers I interviewed. The teacher of ENE and the

Catholic Church priest both emphasized the need for giving priority to children with disabilities. Mary expressed the following:

“What we need here is...there are many children and...even adults who need support...moral, economic, psychological help and we don't have this because the government does not consider it easily, neither local nor regional government...they are not interested...they are not interested in these children.”

Sofia also referred to the inefficiency of the authorities when the mothers discussed about having adequately trained teachers in the school, stating that the authorities in practice did nothing, even though “*everything*” depended on them. Furthermore, the mothers and the teacher brought up entitlement for financial support. The teacher explained about the “Non Contributing Pension” program, which had been implemented the same year by CONADIS in three other regions in Peru for severely disabled people, and he was hopeful to see it extended to other regions, as also planned by the government (CONADIS, 2016b). Evelyn apparently mentioned the same benefit:

“The President has offered us a small salary for them [the children], but so far nothing, not even to help with diapers for our children or to mobilize them...we get nothing... In other places, they are giving [more support].”

Sofia shared her experience when trying to apply for economic support for her son:

“I know that our children should have financial support but I don't know if there will be any. They say they are preparing the documents... However, it has been a few years now... He [her son] has his disability license and I have been told that with that he can get economic support but we have to wait for that.”

At the same time as informants were waiting for this promised support, the teacher actually questioned the effects of financial benefits to PWD. He meant that too much welfare (*asistencialismo*) would not be a good thing, except in the case of children with disabilities living in poverty, for whom he saw the disability pension as a positive initiative. Interestingly, Eide and Ingstad (2011, p. 5) also discuss the negative effects of such disability grants or pensions, especially in developing countries, as this in fact may keep PWD in poverty, as the

benefits would not help them to get an employment. The income of PWD would still stay relatively low despite of such types of grants. Similarly, Moodley and Graham (2015) discuss how social grants for women with disabilities only seem to lift them up to a minimum daily standard of living but do not solve the additional costs they may face, e.g. health and transport costs.

The right to financial benefits, such as the examples mentioned above, or even the preferential benefits to disabled war veterans as discussed previously, ultimately leads to the underlying problem of poverty, and its ramifications to persons with disabilities and vice versa. Despite the reductions in poverty that Peru has made over the years (The World Bank, 2016c), people living in the rural areas are more likely to face poverty, even extreme poverty (INEI, 2016c). The poverty-disability cycle (CBM Australia, 2016) places a person in a vicious situation, and the role of the state in providing security is obvious. Poverty and disability affect in both ways; a poor person may suffer from malnutrition, lack of clean water and sanitation, not being able to attend school nor having a safe work environment (ibid.). Disability, on the other hand, may lead to poverty because of the costs of disability, lack of education or exclusion from the labor market, or low wages (The World Bank, 2016b). Persons with disabilities face greater barriers to health and rehabilitation, as well as to education, which cause deeper and long-lasting poverty (Pisani and Grech, 2015). Thus, disability is a cause and a consequence of poverty. Children with disabilities are even more at risk to these negative ramifications with their dependency on others, and once in that situation, it lays the foundation for their future ahead. Hence, with functioning social protection programs, as suggested by Bernabe-Ortiz et al. (2016a), that help to remove barriers to access health care, education, and labor, can assist disabled individuals and families with disabled members to overcome and/or defeat poverty, and to become in fact more “abled” in the society.

Overall, the informants in fact could perceive being pushed down by the state, in addition to reporting lack of support and services. The husband of Victoria, for instance, expressed how the authorities would make investments in areas that were not the biggest concern:

“In the community we need practically everything... Sometimes our leaders spend people's money on things that are superficial... Like building more discotheques and such.”

When asking Lisa what other services were needed in Villa Hermosa apart from medical assistance, she replied:

“Here we, people with disabilities, are forgotten. We have no support from the authorities while we need social support, medical support...to improve our quality of life and to become independent and remain independent. (...) The truth is, we are in the corner of the forgotten, we don't exist for the government, we don't have the support that other countries offer to children with disabilities.”

Jose judged the government for not meeting the needs of neither PWD nor the rest of the Peruvians:

“They have not gotten into everyone's shoes. They have a minister who is only on the screen and does not represent anyone, only represents his family because his family wants a position here and there...[laughing] They never think about others and that is what the government is doing, that is why this government is the ugliest government that Peru has had, more horrible. It has done nothing, it is doing nothing...it has done nothing for the country, to dedicate itself for doing something good for the disabled people. They don't give any importance to them. Unfortunately, it is so, it is our Peru. Peru should be a powerful country because it has different types of water, beautiful vegetation, it has its coast, its mountains, its jungle. It must be a powerful country. Other countries should come to work here and not us to go elsewhere. Why do you think there is emigration of the Peruvians? Because the state is not giving you what you need. For example, you go from here to the other side [of the frontier] and they pay you well. Why? Because they give you the value of what you are doing, they have another type of culture, they have another type of education. (...) The state should not give you a punishment; the state should give you a job. (...) They are the fathers of the country; they should know what their children need.”

The general disability law in Peru clearly declares the rights of PWD to health, rehabilitation, assistive technology, and to work (Congreso de la República, 2013, pp. 25-28, 32). As mentioned earlier by the President of OMAPED, this shows that the laws are not well

implemented in the health care system. As the President of Angel Azul put it: *“We live in a country where the laws are not fulfilled.”*

Political and economic structures and systems influence the way PWD have opportunities and access in society, and these can cause their oppression (Charlton, 1998, p. 48/197). Considering the history of Peru, in particular the recent period of terrorism in the 80’ and 90’s, this kind of violent experience may traumatize the whole society. As it was discussed with my assistant and Esperanza, up to today, Peru’s sad history is not easily talked about in public because of the fear that still lingers in the country. This kind of insecurity, including the human rights violations done by the military during those times may have contributed to continuing distrust in the government and to a doubt about the government’s ability to actually keep its promises.

In addition, as the presidents of OMAPED and Angel Azul expressed, who were both well aware of the legal rights of PWD, they did not see the laws in practice. Thus, it seems, it is understandable that Peruvian people may see the authorities as unreliable. Such attitudes about the incapacity of the Peruvian state may be even stronger in distant areas far from the capital. In fact, as few as 24 percent of Peruvians are estimated to have trust in national government (UNDP, 2015, p. 267). Rénique (2009) put forward similar thoughts, addressing the illegitimacy of the invisible political system in Peru that works behind the public’s eyes.

Seemingly widespread corruption in the country may also play a big role on the lack of trust among the citizens, and this seemed to be true both for NGOs and for governmental offices. For instance, Amalia shared a story about how a foreign organization for the blind had donated Braille speakers to a Peruvian NGO for distribution:

“[That] has happened in Peru, they have given this support for the blind, but the leaders of the [organization for the] blind have taken these accessories. (...) They have sold those devices. Almost always when the NGOs and the world give them such benefits, they do not help the others, only take them for themselves.”

In Peru, corruption is reported to be pervasive in all branches of government, especially in the judicial system (US Department of State, 2015, p. 14). Despite of criminal penalties for corruption, the government was found inefficient implementing the law (ibid.). Interestingly, the Ministry of Health (MINSA) (2016) has acknowledged the problem of corruption within the health care sector, something that may direct the current system towards concrete

reforms. However, as corruption appears to be deeply rooted in the political system, it may be challenging to promptly improve the trust of the Peruvian citizens to their political leaders and other authorities.

In turn, corruption, weak rule of law, and inadequate public services may lead to other institutions, such as religious ones, to try to act as substitutes of governance in rural areas, something which has been reported from Central Asia (UNDP, 2015, p. 116). In the Peruvian context of Villa Hermosa, the Catholic Church may in fact be an institution that enjoys the trust of the public more than the governmental institutions.

In the next section, I will address the organization of PWD and working on their self-empowerment.

Calling for own rights and empowerment: The role of public and private actors

The fifth component in the CBR framework is empowerment, and it is about ways to improve the inclusion of PWD in the community (WHO, 2010b). As the guidelines underline, the “change must start with people with disabilities shifting their mindset from being passive receivers to active contributors” (ibid. p. 4). The focus of disabled people’s organizations is indeed in the promotion and protection of disabled people’s rights and interests (ibid. p. 7).

The national disability registry kept by CONADIS and the disability ID is helping to keep record of the number of PWD in the country, but it was also seen as helping PWD meet the rights they are entitled to. That is how the teacher of ENE saw it:

“Look, the disability ID from CONADIS is to let ourselves be recognized nationally, right? That’s the case for all the regions and in whole Peru, to become aware of the disabled people.”

In fact, according to the President of OMAPED, more people were contacting them to obtain a disability ID. For instance, since early 2015 the number of disability ID holders had increased from 295 to 374 in the province at the moment of this study, meaning that awareness was increasing. OMAPED provides mainly wheelchairs that are distributed throughout the province and they give food supplies to disabled people living in poverty. The President of OMAPED emphasized the purpose of their work to help PWD with their lives, to make them feel like everyone else, and not to feel limited.

Still, in Villa Hermosa, Amalia and Carlos criticized OMAPED for doing nothing, in spite of them delivering a disability ID to facilitate access to work and studies. The couple saw that self-development and studying for PWD was not efficiently promoted. Instead, PWD would rather “*reach out their hands*” for money or alimentation, referring to the negative side effects of welfare as discussed previously. As Carlos further expressed:

“We would like, for example, to have more contact with the leaders of persons with disabilities, to exchange knowledge and to help each other, right? Because it is difficult in certain things... The picture here in Villa Hermosa with people with disabilities is that they are hidden, they do not go out... That's a problem. They are marginalized, and if you go out, the people collide with them and they tell you: ‘Why do you go out?’ So where are we? We need more support among us to grow, directional assistance to help people with disabilities. OMAPED needs to progress, the groups with disabilities are asleep.”

Despite the good will of the President of OMAPED, it appears that some PWD were not satisfied with the work mandated by CONADIS. The gap between OMAPED and the local people may result from poor communication between them, as illustrated by Ricardo’s mother who complained about the difficulties in receiving information from OMAPED. It may also be that OMAPED lacks enough resources, as the President, who appeared to be the leading spirit of the office, carried a major workload. The President of Angel Azul on his side complained about how his association did not have proper facilities to hold meetings, and how these would normally take place in front of his own house.

Hence, by ensuring that OMAPED, and Angel Azul, receive sufficient support and improve communication, awareness-raising, self-advocacy and participation may be improved and more PWD get empowered, also politically. In fact, The Human Rights Watch (2012, p. 16) has addressed the need of ministries and governmental agencies in Peru to include disabled persons’ organizations (DPOs) and PWD in the political decision-making. At the local level, other channels to make PWD more visible and/or share information could be for instance airtime on a local TV channel, the same way I was interviewed about my volunteer work at MINSa during fieldwork.

Next, I will discuss about topics that need summarizing and about future prospects for the study context.

5.4 Health, dis/ability and rehabilitation in Peru: The way forward

If one looks at the website of CONADIS or MINSA by 2017, or reads the news in the Peruvian media, there is indeed a growing attention paid to PWD. Initiatives to address social protection, poverty, better health care services and providing insurance to PWD are being addressed. CONADIS has several regional and municipal offices around the country, and new research regarding disability issues in Peru has been published after this study was conducted. However, as it became evident during this study, there appears to be challenges especially in marginal, less-resourced settings, where simply geographical conditions may pose difficulties to create a fully inclusive society with all adequate services available. In the case of Villa Hermosa, there may be difficulties to retain and attract health care professionals, particularly specialists, to work there. Obviously, the provision of AT needs to develop in the area as it is non-existent.

The different health insurance schemes in Peru create a division within the population, where those with better economic status turn to, for instance EsSalud. In 2013, the coverage by SIS in San Martín Region was around 66 percent (INEI, 2016c). Solari (2014) criticizes the current fragmented provision of health care service in Peru:

“In an era in which the approach to health is that of human rights, and human rights are respected for all citizens without distinction, having different types of services for different ‘types’ of Peruvians seems a contradiction.” (p. 623)

Solari further proposes to unify the health system, and indeed, in 2009 Peru passed the Universal Health Insurance Law, which means that universal health coverage is expected to be reached by 2021 (Oxford Business Group, 2016). However, according to Kuper et al. (2016), if persons with disabilities are not explicitly included, achieving universal health care coverage becomes difficult. The provision of rehabilitation services and assistive devices should be added as a priority, as these services are needed and important for PWD to participate in social and economic development (ibid.).

Regardless of getting increased health coverage, all the informants of this study, as well as the health directorate of MINSA with whom I planned the study, addressed the need

for more specialist doctors and rehabilitation workers in the area. Concerning medical rehabilitation, an obvious need in the community, my voluntary work experiences in the hospital also confirmed the lack of equipment or adequate facilities, leaving activities to be mainly informative.

The Ministry of Health of Peru (MINSA) has recently reported to reorganize its health care system by improving human resources by increasing the pay scale of health professionals, investing in infrastructure and equipment, and improving primary care attention (MINSA, 2016). In addition, as 600,000 PWD do not have any form of health insurance, SIS now covers provision of care and rehabilitation to people with moderate or severe disability at the National Institute for Rehabilitation (INR) in Lima (MINSA, 2015).

One of the key findings in this study is the social exclusion of PWD in Villa Hermosa that takes place in the forms of negative attitudes, ignorance, exclusion from education, health care, as well as work. A recent qualitative study conducted in South Africa (Neille and Penn, 2015) presents similar findings, as the experience of PWD residing in a rural area was found associated with social exclusion, discrimination and isolation. In addition, experiences of corruption and lack of transparency in governmental activities (ibid.) are comparable to those found in this study.

In terms of meeting the requirements of the CRPD, Borea Rieckhof (2015) suggests how the prevailing barriers of PWD both at a public and private level are the result of the medical model of disability that still exists in Peruvian society. She further writes that as there are no more legal justifications to constrain the rights of PWD, there should be a more effective recognition of the Convention in Peru. Moreover, if the focus is kept on disability, and hence on the deficiencies of PWD, their abilities are underestimated, and PWD are treated with a paternalistic and charitable attitude making them have less value than the rest (Toboso, 2011). Oliver and Barnes (2012, p. 6/240) draw a similar conclusion from a more general perspective; they see that little change has been made in the past two decades to alleviate the oppression of PWD mainly because in most societies disability is still seen as an individual medical problem. They further state that if disability is plainly seen as a tragedy, PWD are continued to be seen as victims of unfortunate circumstances, both in normal life activities as well as in social policies (p. 14/240). Instead, when seeing disability as a social oppression, PWD are “collective victims of an uncaring and unknowing society” and the focus can be moved on to social policies in order to alleviate oppression and not compensate PWD themselves (ibid.).

Moreover, according to the critical disability scholars, PWD appear be inactive to address these issues as well. Many of them, especially those in the lowest social classes, often have no other choice except to adopt a conventional disability identity, thinking that they are not “normal” (Oliver and Barnes, 2012, p. 111/240). Furthermore, feeling inferior as disabled may prohibit PWD to confront power and contest their powerlessness (Charlton, 1998, p. 1470/4361). The systematic exclusion from economic and social activity make PWD feel alienated and this kind of false consciousness and sense of isolation disguise the actual reasons for their oppression (Oliver and Barnes, 2012, p. 111/240). According to Mitchell and Snyder (1997, p. 11), the real reason for the social invisibility of PWD comes from neglecting PWD. According to Peruvian researchers of disability, there are solutions to increase their inclusion, such as social protection systems. These can help to reduce the environmental and social barriers and promoting social inclusion of PWD (Bernabe-Ortiz et al., 2016a).

Changing policies is not, however, easy. If the values of the CRPD are against entrenched policies, to operationalize them easily gets opposition (Oddný Mjöll and Quinn, 2009, p. 216). According to these authors, to see the CRPD in its full glory, it first needs to reshape the conventional politics into something that sees the rights of PWD as a natural reflex and a matter of justice, instead of as an after-thought and plainly part of welfare (ibid. p. 218). Moreover, the CRPD should be viewed as an authoritative tool to change the way PWD are seen from an annoying distraction to holders of justice and rights (ibid, p. 256). This can be done by persuading and socializing the political process through civil society, international society, and in particular through governments and national institutions (ibid.), Importantly, PWD need to be included in the decision-making about their lives (ibid.).

I will now reflect critically on the methodology applied in this study.

5.5 Methodological reflections

This study was a unique inquiry in a chosen location, and it was the first qualitative study done in the field of disability according to the local authorities. Thus, it was both exciting and frightening to try to conceptualize the situation of PWD in the study setting. The qualitative approach was found to be a valuable method to address the issue of disability. Using triangulation through in-depth interviews, group discussions, and participatory observation allowed to get a broader picture of the situation and answer the research questions (Malterud,

2001). The aim to develop an overall interpretation of the findings (Mays and Pope, 2000) seems fulfilled.

As this is a Master thesis study with certain time constraints and limited financing, a longer in-depth study was not possible to conduct. Moreover, the study was limited to persons with mobility impairments, even though disability affects people with other kinds of impairments. However, interviewing other stakeholders who engage with people with all kinds of disabilities through their work enlightened me with reflections that can be applied more widely. The sample of study participants was very relevant to answer the research questions. Because of convenience and snowball sampling techniques, the recruited participants were fairly easy to get involved.

More individuals could have been selected by approaching more people on the streets and include those who were in an even less advantaged situation, especially the ones living further from the center of town. For instance, occasionally when I went to the market in town I would see a few disabled people working as street vendors. My host and some other friends told me about a particular poor family in which almost all members were physically impaired. Later on, I recognized some of the family members in the center of town. I first exchanged a few words with one of the daughters on the International Day for Persons with Disabilities when I marched in the central square together with the pupils from ENE, their parents and the teachers. I saw her the second time when she asked me to give her a few coins for a motorcar ride. Afterwards I thought that I should have tried to include her in my study, but the two encounters I had with her had left me with a feeling of a gap between us, as if she looked at me as someone who was “too” privileged. Unfortunately, I never saw her again to allow me to approach her, ultimately. This was something I looked back on after my fieldwork, as it was obvious that some of these disabled people in Villa Hermosa lived in visible poverty, which I did not document. Moreover, interviewing local health professionals could have given different kinds of insights on the questions. In fact, I had scheduled an interview with one health care professional, but she fell seriously ill and by that time, I already had sufficient amount of data.

The limited sample size is a limitation of the study, as it makes generalization difficult to all PWD. Moreover, if transferred to another context, findings might differ because of the contextual nature and environment in the study. However, based on other studies as well, the experiences of my informants correspond to what has been found in similar contexts, such as about the need for better understanding of the situation of PWD, better social support and

inclusion, and better access to services in less-resourced settings. Therefore, the findings of this study have some general relevance, beyond the fact that the local culture, language and historical context influence this study's informants' perceptions and worldviews in a particular way.

An important part of my stay was inevitably my involvement with my host family. This gave me the advantage of getting more easily integrated, I argue, because I had a strong social support, and I was being helped at any moment I needed it. The family members were well known in town, hence I could easily introduce myself as a member of the family, and in fact, many of my informants would know the family. Moreover, I took part in social gatherings with friends I had made in the community. This helped me to understand the social environment that was particular to that place even more.

Carrying out fieldwork was, however, at times emotionally strenuous. As I approached people to talk about their impairments and views on disability, and to make them trust me and open up to me and my assistants, some issues may have been more sensitive to talk about, such as talking about personal hygiene or mental health. I was empathizing with the informants when they discussed about penetrating issues, and I sometimes cried when I felt overwhelmed by my informants' life situations and the experiences I had while volunteering.

I acknowledge the vital role of language in qualitative research and how important it is to understand and interpret correctly the accounts of interviewees. The cultural and linguistic barriers that I confronted from time to time during the interviews may have weakened the quality of the data. With a complete fluency in Spanish, I as an investigator could have engaged myself more in the conversations and develop a stronger rapport with the interviewees. In addition, even though I was confident enough to translate and understand the transcriptions, some misunderstandings may have occurred.

My standpoint as a researcher, and as a health care professional, has influenced the way I have read and interpreted the data. I believe I was seen more as a therapist than as a student and this may have influenced the way some of the informants emphasized the need for rehabilitation, especially for physiotherapy, in the community. It was my intention to have a wider approach to the study participants giving them the freedom to express themselves about issues they found most important in their personal lives, and in their cultural and social context. During my fieldwork, I became friends with some of the informants. The three mothers I interviewed in the end of my stay had already gotten to know me while I volunteered in the school. This may have made it easier for them to open up to me and

emphasize the needs of their children, for instance for therapy. Developing personal relationships with the informants was therefore inevitable, and I acknowledge the potential impact this may have had on the findings (Sanjari et al., 2014). However, I suggest that my involvement did not make me exaggerate some findings, such as the need for rehabilitation services and better access to adequate AT. Rather, it allowed me to go in depth into some vital aspects of rehabilitation.

In one occasion, an informant asked if my study would only benefit my career and myself, because I was a Westerner from somewhere far away. This is something I thought about during the whole study. I knew that I was seen as a white person from a rich country, and that people would have great expectations from me, especially as a health professional. Some may have thought that I only came to get something that would only benefit my own interests. Notwithstanding, in the end, people behaved towards me with great warmth and interest. Many of the informants were grateful for my initiative, I was even described as sent by God (!), and my proposal for doing research was taken very positively by many.

6. CONCLUSIONS

Through my study I wanted to show a “true-life verification that disability provides a specific and distinct perspective of its own”, as expressed by Mitchell and Snyder (1997, p. 10). Indeed, this study has given a voice to some of the individuals living in Villa Hermosa, a rural jungle town in Peru, who either manage their lives with a mobility impairment, take care of an impaired person, or work among persons with disabilities. This study shows how impairment and personal mobility limitations affect not only activity and, in many cases, identity, but participation in social life as well, due to a number of social, cultural, political and economic barriers encountered in the Peruvian society. The findings indicate a strong need for improvements, in various fields and at various levels, to be guided by the principles of the CRPD, in order to insure equal opportunities for disabled people.

From an individual perspective, persons with mobility impairments go through a number of emotional difficulties due to their loss of function. On the other hand, the narratives presented describe life stories of individuals who, through obstacles of becoming or being impaired, learned to carry on in life with a positive attitude and without losing hope. Some individuals managed to cope well with their impairments without receiving any public help.

The role of caregivers to persons with disabilities appeared important and family members, who are often their main supporters, may deal with caregiving-related distress, and they may experience hopelessness when lacking public support.

From a socio-cultural perspective, attitudinal barriers such as shame and ignorance may block opportunities for people, and, for instance, impede disabled children to attend school. In order to fight these oppressive attitudes, the local school for disabled children was active in raising awareness in the community.

On the other hand, many, or in fact most people draw a lot of strength and motivation from religious faith and spirituality, which seemingly guided many to reach for a better life, or to be satisfied with their current life situation.

When attempting to analyze the body politics of disability in this peripheral Amazonian context, it was found that disability and poverty mutually exacerbate the burden of social exclusion. For instance, mobility impairments limit access to work and school, and lack of funds impedes access to necessary rehabilitation services. Beyond inequality in health and social development, insufficient human resources and school facilities made some

caregivers perceive educational opportunities for their children to be inadequate, thus making them rather keep the children at home.

Local access to specialized care and rehabilitation services seemed to be almost completely lacking, with pressure on people to seek assistance from distant cities, which poses a number of limitations. Acquiring assistive devices resulted as well as being the responsibility of the individuals themselves, yet local charity institutions had tried to respond to the immediate needs of the most vulnerable people living in poverty.

Many of the persons interviewed had faced neglect from health care workers not attending them, or local people not considering the obstacles of persons with mobility impairments encounter when needing accessible pathways and assistance. Indeed, poor infrastructure in public buildings and spaces, as well as in housing makes it difficult for individuals, especially those using mobility devices, to access buildings and move freely, at home as well as in the city (Figure 14). Lack of public transport, and inadequate means of transportation, further decrease the chance of people with mobility impairments to leave their houses.



Figure 14. A neighborhood with long steps

Finally, the impotence of authorities to deliver adequate services for the disabled was widely agreed on among the informants. There seemed to be resistance among the local people against the Peruvian government and the authorities at any level, which aggravated the relationship between the citizens and the authorities. Due to this, some individuals found it

crucial to pay attention to existing barriers for disabled people, and they addressed the need for better communication and opportunities for self-development. This included strengthening the work of the local disability authorities and of charity workers.

The findings from this study can provide valuable evidence for planning and evaluating relevant national and local community initiatives to improve the inclusion of PWD and raise awareness about a society for all.

There were several other topics of relevance for disability studies as discovered during this study, as for instance persons with cognitive and sensory impairments, or aspects of sexuality within the lives of PWD, and more. Yet this must be for other projects.

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APPENDICES

Appendix 1. Informed Consent Form in English

Informed Consent Form

Information Sheet

I am Maija Rankinen, a master student of International Health in the University of Bergen, Norway. I am doing research on the situation of persons with mobility impairments in Villa Hermosa, Peru. I want to understand the experiences and perceptions of persons with mobility impairments, as well as the challenges and needs they express. I also want to explore the experiences and opinions of other stakeholders in the field of disability.

This research will involve your participation in a face-to-face interview together with a research assistant and me. The interview will take up to 60 minutes of your time, and notes will be taken about what you say. If you accept, a tape recorder will be used and photographs will be taken.

You are being invited to take part in this research because I feel that your experience can contribute much to my understanding and knowledge of the research topic. There will be no direct benefit to you, but your participation is likely to help me find out more about the research topic, and the results of this research can provide useful information to the local community.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not.

The information recorded is confidential, and no one else except the interviewers will access to the information documented during your interview. You will not be identified by name on the tape. The tape will be kept stored in a locked place. The information recorded is confidential, and no one else except the interviewers will have access to the tapes. The tapes will be destroyed after the data has been analysed for the master thesis by June 2016.

We will not be sharing information about you to anyone. The information that I collect from this research project will be kept secure. Any information about you will have a number on it instead of your name. Only the research assistant and I will know what your number is and we will keep that information in a secure place. It will not be shared with or given to anyone.

The knowledge that I get from this research will be published at the University of Bergen.

If you have any questions, you can ask them now or later by contacting me.

Certificate of Consent

I have been invited to participate in a research on the situation of persons with mobility impairments in Villa Hermosa, Peru.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction.

I consent voluntarily to participate in the interview. Yes No

I consent voluntarily to be tape-recorded. Yes No

I consent voluntarily to be photographed. Yes No

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the Researcher

I have accurately read out the information sheet to the potential participant and I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of Researcher _____

Signature of Researcher _____

Date _____

Day/month/year

Print Name of Research Assistant _____

Signature of Research Assistant _____

Date _____

Day/month/year

Appendix 2. Informed Consent Form in Spanish

Documento de Consentimiento Informado

Información

Mi nombre es Maija Rankinen, estudiante de Maestría de Salud Internacional de la Universidad de Bergen, Noruega. Estoy haciendo una investigación sobre la situación de las personas con movilidad limitada en Villa Hermosa, Dpto. de San Martín, Perú. Quiero conocer las experiencias y percepciones de las personas con limitaciones en la movilidad, así como los retos y necesidades que manifiestan. También quiero explorar las experiencias y opiniones de otros interesados en el ámbito de la discapacidad.

Esta investigación incluirá su participación en una entrevista cara a cara junto conmigo y con una asistente de investigación. La entrevista tendrá una duración máxima de 60 minutos de su tiempo, y se tomarán notas acerca de lo que dice. Si usted acepta, se utilizará una grabadora y se tomarán fotografías.

Se le invita a participar en esta investigación porque siento que su experiencia puede aportar mucho a mi entendimiento y conocimiento del tema de investigación. Puede que no haya beneficio para usted, pero con su participación, es probable que me ayude a encontrar más información sobre el tema de investigación, y los resultados de ésta pueden proporcionar información útil para la comunidad local.

Su participación en esta investigación es totalmente voluntaria. Es su decisión si desea participar o no.

La información registrada es confidencial, y nadie más, excepto los entrevistadores tendrán acceso a la información documentada durante la entrevista. Usted no será identificado por su nombre en la grabación. La cinta se mantendrá almacenado en un lugar seguro con llave. La información registrada es confidencial, y nadie más, excepto los entrevistadores tendrán acceso a las cintas. Estas serán destruidas después de que los datos hayan sido analizados para la tesis de Maestría, en junio de 2016.

No compartiremos información sobre usted con nadie. La información que recoja para este proyecto de investigación se mantendrá confidencial. Cualquier información acerca de usted tendrá un número en vez de su nombre. Sólo el asistente de investigación y yo sabremos cuál es su número y se mantendrá la información guardada en un lugar seguro. No será compartida ni entregada a nadie.

El conocimiento que adquiera de esta investigación será publicada en la Universidad de Bergen, Noruega.

Si tiene cualquier pregunta puede hacerla ahora o más tarde poniéndose en contacto conmigo.

Formulario de Consentimiento

He sido invitado a participar en la investigación de la situación de las personas con la movilidad reducida en Villa Hermosa, Perú.

He leído la información proporcionada o me ha sido leída. He tenido la oportunidad de preguntar sobre ella y se me ha contestado satisfactoriamente las preguntas que he realizado.

Doy mi consentimiento voluntariamente a participar en la entrevista. Sí No

Doy mi consentimiento voluntariamente para ser grabada. Sí No

Doy mi consentimiento voluntariamente para ser fotografiado. Sí No

Nombre del Participante _____

Firma del Participante _____

Fecha _____
Día/mes/año

Declaración del Investigador

He leído con exactitud o he sido testigo de la lectura exacta del documento de consentimiento informado para el potencial participante y el individuo ha tenido la oportunidad de hacer preguntas. Confirmando que el individuo ha dado consentimiento libremente.

Ha sido proporcionada al participante una copia de este documento de consentimiento informado.

Nombre del Investigador _____

Firma del Investigador _____

Fecha _____
Día/mes/año

Nombre del Asistente de Investigación _____

Firma del Asistente de Investigación _____

Fecha _____
Día/mes/año

Appendix 3. Interview guide for PWD in English

Semi-structured interview guide for persons with mobility impairments

1. Characteristics (age, sex, marital status, level of education, occupation)
2. Tell me about your disability, limitation(s) and health condition(s).
3. What type of assistive device(s) for mobility do you use in your daily life? Do you use other devices or receive assistance?
4. Do they work properly? How do you maintain your assistive device(s)?
5. What type of assistive device(s) and/or assistance do you need? Where can you get them?
6. Tell me about your experiences in the use of health and social services and/or rehabilitation.
7. How do you manage your activities at home? And outside of your home?
8. How would you describe your participation,
 - a. in your personal life (marriage/family)
 - b. in your social life (school/ work/leisure)
 - c. in the community?
9. How would you describe your life with mobility limitation(s) and quality of life?
10. What do you know about assistive devices and other services for persons with disabilities?
11. What kind of services and resources are needed in the community?
12. What kind of expectations and hopes do you have for the future?
13. Do you have anything more you want to say?

Appendix 4. Interview guide for PWD in Spanish

Guía de entrevista semi-estructurada para personas con movilidad reducida

1. Características (sexo, edad, estado civil, nivel de educación, ocupación)
2. Dime acerca de tu discapacidad, limitación(es) y condición(es) médica(s).
3. ¿Qué tipo de dispositivo(s) de ayuda para la movilidad utilizas en tu vida diaria?
¿Utilizas otros dispositivos o recibes asistencia?
4. ¿Funcionan correctamente? ¿Cómo mantienes tu(s) dispositivo(s) de ayuda?
5. ¿Qué tipo de dispositivo(s) de ayuda y/o asistencia necesitas? ¿Dónde se puede obtener?
6. Dime acerca de tus experiencias en el uso de los servicios sanitarios y sociales y/o rehabilitación.
7. ¿Cómo controlas tus actividades en casa? ¿Y fuera de tu casa?
8. ¿Cómo describirías tu participación,
 - a. en tu vida personal (matrimonio/familia)?
 - b. en tu vida social (escuela/ trabajo/ocio)?
 - c. en la comunidad?
9. ¿Cómo describirías tu vida con limitación(es) de movilidad y la calidad de vida?
10. ¿Qué sabes acerca de los dispositivos de ayuda y otros servicios para personas con discapacidad?
11. ¿Qué tipo de servicios y recursos se necesitan en la comunidad?
12. ¿Qué tipo de expectativas y esperanzas tienes para el futuro?
13. ¿Tienes algo más que quisieras decir?

Appendix 5. Interview guide for other stakeholders

Semi-structured interview guide for other stakeholders

1. Tell me about your work in the community.
2. What kind of experiences do you have with persons with disabilities, especially with persons with mobility impairments?
3. How would you describe the situation for them in Villa Hermosa?
4. What type of services there are for persons with disabilities?
5. How could the services be improved?
6. What types of services are needed?
7. How is the situation in other parts of the province and in the region?
8. Do you have anything more you want to say?

Translation to Spanish

Guía de entrevista semi-estructurada para otros interesados

1. Dime acerca de tu trabajo en la comunidad.
2. ¿Qué tipo de experiencias tienes con las personas con discapacidad, especialmente con las personas con limitaciones de movilidad?
3. ¿Cómo describirías la situación para ellos en Villa Hermosa?
4. ¿Qué tipo de servicios existen para las personas con discapacidad?
5. ¿Cómo se podría mejorar los servicios?
6. ¿Qué tipos de servicios se necesitan?
7. ¿Cómo es la situación en otras partes de la provincia y en la región?
8. ¿Tienes algo más que quisieras decir?

Appendix 6. Ethical clearance from REK



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Arne Salbu	55978498	09.09.2015	2015/1160/REK vest
			Deres dato:	Deres referanse:
			16.06.2015	

Vår referanse må oppgis ved alle henvendelser

Graziella Van den Bergh
Høgskolen i Bergen
Møllendalsveien 6
BERGEN

2015/1160 Bevegelseshemming og hjelpemidler - En casestudie i [redacted] Peru

Forskningsansvarlig: University of Bergen
Prosjektleder: Graziella Van den Bergh

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 20.08.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale

This case study aims to study the experiences and needs of persons with mobility impairments in [redacted] while providing a situation analysis of the opportunities and Challenges they meet. The study is located in a Peruvian community in San Martin Region, using a qualitative research design, with triangulation of methods. Study methods include ethnographic observations, document reviews, reflective field notes and interviews of individuals with mobility impairments as well as other stakeholders in the field of disability. Experiences with accessibility, availability, distribution and use of mobility devices, as well as satisfaction with how these facilitate integration for persons with physical disabilities will be examined. The project will include 10-30 participants, depending on the number of persons with mobility impairment in [redacted] accessible and willing to participate.

Vurdering

We understand this study as a qualitative study. However, we have noticed that there are suggested several sources for the data collection, including personal health data from hospitals, regional health data etc.

We believe that this study can not be carried out in a proper way within the frame of master degree, if all the suggested sources of information should be collected. Methodically we also see lots of problems and challenges if one should use all the suggested sources of data. Therefore, we believe that one must limit the data collection, i.e. that all register data are excluded. We also believe that from a legal point of view, it might be difficult to gain access to all this information. We therefore suggest that this study will be carried out, purely as a qualitative study.

Research project end date: 30.06.2016.

Besøksadresse:
Armauer Hansens Hus (AHH),
Tverrfloy Nord, 2 etasje, Rom
281, Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

Vedtak

REK vest approve the project. The condition is that it is the study is carried out purely as a qualitative study without the use of register data.

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 31.12.2016, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.


Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komitéleder

Arne Salbu
rådgiver

Kopi til:bcntc.mocn@uib.no.

Appendix 7. Local ethical clearance in English



DIRECCIÓN REGIONAL DE SALUD

"Año de la Diversificación Productiva y del Fortalecimiento de la Educación"

AUTHORIZATION OF INVESTIGATION

[REDACTED] September 15th 2015

According to the authorization of la Red de Salud [REDACTED] signed by the Director [REDACTED] (MD) on the [REDACTED] and since the ethical committee of the hospital is in the process of finalizing the execution of their duties, [REDACTED] as Director of the public management and Director of the [REDACTED] assumes the responsibility, professionally and morally, that this study will be performed according to the universal ethical norms.

AUTHORIZING

MAIJA HELENA RANKINEN, researcher of the University of Bergen, Norway to carry out the research study **"Exploring the experiences and needs of individuals with mobility impairments: A case study in [REDACTED] Peru"** with the purpose of analyzing the opportunities of the situation and the challenges they meet. The study is located in [REDACTED] a Peruvian community of San Martín Region, using a qualitative research design, with triangulation of methods. Study methods include ethnographic observations, reflective field notes and interviews of individuals with mobility impairments as well as other stakeholders in the field of disability. Experiences with accessibility, availability, distribution and use of mobility devices and how these facilitate integration for persons with physical disabilities, as well as, their satisfaction will be examined. The project will include 10-30 participants, with a possibility of increasing the number of participants according to the number of persons with physical disabilities in [REDACTED] accessible and willing to participate in the study.

Research project begins on the 16th of September 2015 and ends on the 30th of June 2016.

Therefore:


La Dirección del Hospital [REDACTED] **APPROVES** the project to be carried out in [REDACTED]

Sincerely,

[REDACTED]

Cc
Arch
EMD/LLGT

Appendix 8. Local ethical clearance in Spanish

 **DIRECCIÓN REGIONAL DE SALUD**

"Año de la Diversificación Productiva y del Fortalecimiento de la Educación"

AUTORIZACION DE ESTUDIO DE INVESTIGACION

[REDACTED]

[REDACTED] 15 de setiembre del 2015

De acuerdo a la Autorización de la Red de Salud [REDACTED] firmado por el Medico Cirujano [REDACTED] **Director**, con fecha [REDACTED] y en cuanto el Comité de ética del Hospital se encuentra en vías de consolidar la Resolución de ejecución de sus funciones; la Obstetra [REDACTED] Magister en Gestión Pública - Directora del [REDACTED] asume profesionalmente y moralmente que el estudio se realizara según las normas éticas universales:

AUTORIZANDO

A la Srta. **MAIJA HELENA RANKINEN** investigadora de la Universidad de Bergen, Noruega a realizar Estudios de investigación titulada **"Explorar las experiencias y necesidades de individuos con impedimentos de movilidad: Estudio de casos en [REDACTED] Perú"** cuyo propósito es realizar el análisis de las oportunidades de la situación y los desafíos que ellos experimentan. El estudio se desarrollara en la ciudad [REDACTED] comunidad peruana en la región de San Martin, usando un diseño cualitativo, con métodos de triangulación.

Los métodos del estudio incluye observaciones etnográficos, notas de campo reflexivas y entrevistas a individuos con impedimento de movilidad, así como también a personas profesionales que trabajan en este campo de la discapacidad. Experiencias con accesibilidad, disponibilidad, distribución y uso de equipos para asistencia a la movilidad de los pacientes y como estos facilitarían la integración de las personas que tengan incapacidad física, tanto como su satisfacción serán evaluados. El proyecto incluye un promedio de 10 a 30 participantes con la posibilidad de incrementarse el número de participantes según la magnitud del número de personas con incapacidad física en la localidad y que estén dispuestos a participar en el estudio.

El inicio del Proyecto de investigación se iniciará el 16 de Setiembre del 2015 y finalizará el 30 de Junio del 2016.

Por tanto:

La Dirección del Hospital [REDACTED] **APRUEBA** la realización del Proyecto en la localidad de [REDACTED]

[REDACTED] Atentamente,

Cc
Arch
EMD/LLGT

[REDACTED]