

Experiences and perceptions on disability and social participation in community rehabilitation centers in Chile

Experiencias y percepciones sobre discapacidad y participación social en centros de rehabilitación comunitaria de Chile¹

Jame Rebolledo-Sanhueza^a

 <https://orcid.org/0000-0003-3245-1431>

Email: jame.rebolledo@uchile.cl

Álvaro Besoain-Saldaña^a

 <https://orcid.org/0000-0001-8174-6303>

Email: abesoain@uchile.cl

Mónica Manríquez-Hizaut^a

 <https://orcid.org/0000-0002-5325-1749>

Email: mmanriquezh@uchile.cl

Gabriela Huepe-Ortega^b

 <https://orcid.org/0000-0002-8755-5097>

Email: gabrielahuepe@uchile.cl

Verónica Aliaga-Castillo^a

 <https://orcid.org/0000-0001-6704-7493>

Email: valiaga@uchile.cl

^aUniversity of Chile Faculty of Medicine. Department of Physical Therapy. Independencia, Metropolitan Region, Chile.

^bUniversity of Chile Faculty of Medicine. Department of Bioethics and Medical Humanities. Independencia, Santiago, Metropolitan Region, Chile.

Abstract

This study seeks to describe experiences and perceptions about disability and social participation of people with disabilities and professionals who are part of community rehabilitation centers in the Metropolitan Region of Chile. A qualitative study was carried out with a theoretical sampling of key actors from 4 community rehabilitation centers. 16 focus groups were conducted and a semantic content analysis was applied. The experiences of people with disabilities are diverse, there are common elements such as dependency made equivalent to disability and recognition of social barriers. Perceptions of disability represent individual and social models. The latter appears when injustices and discrimination are experienced. Social participation linked to the center is intense and affective. However, other participation spaces are scarce. The concepts of disability and levels of social participation show the need for more guidelines, training and resources for an effective implementation of community rehabilitation.

Keywords: Disabled Persons; Social Participation; Disability Studies; Rehabilitation.

Correspondence

Verónica Aliaga-Castillo

Av. Independencia, 1.027. Independencia, Santiago, Chile. Zip

Code: 8380453.

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Resumen

Este estudio busca describir experiencias y percepciones sobre discapacidad y participación social de personas con discapacidad y profesionales sanitarios de centros de rehabilitación comunitaria de la Región Metropolitana de Chile. Se realizó un estudio cualitativo con muestreo teórico de actores claves en cuatro centros. Se realizaron 16 grupos focales y análisis de contenido semántico. Las experiencias de personas con discapacidad son diversas, existen elementos comunes como la homologación de la dependencia con la discapacidad y el reconocimiento de barreras sociales. Las percepciones sobre discapacidad representan los modelos individual y social, esto último se evidencia en las injusticias y discriminaciones. La participación social es intensa y afectiva en el centro de salud, sin embargo, otros espacios de participación son escasos. Las concepciones sobre discapacidad y niveles de participación señalan la necesidad de más lineamientos, capacitación y recursos para la efectiva implementación de la rehabilitación comunitaria.

Palabras clave: Personas con Discapacidad; Participación Social; Estudios de la Discapacidad; Rehabilitación.

Introduction

Community-based rehabilitation (CBR) has been implemented worldwide since the 1980s. The World Health Organization (WHO) defines it as “a multisectoral, top-down strategy [...] to satisfy the basic needs of people with disabilities and allow access to health, education, subsistence and social opportunities, all these activities meet the goals of the Convention” (WHO, 2012, p. 24).

CBR is part of the Convention on the Rights of Persons with Disabilities (UN, 2006, p. 4), which says that

persons with disabilities include 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.

This definition reflects the social model of disability, a social construction that reproduces practices and subjects (Rosato et al., 2009) and that originates from binary categories that take on special relevance in people with disabilities: normal/pathological, health/disease, valid/invalid (Oliver, 1998). Its fundamental assumptions include the recognition of predominantly social causes, as well as the limitations of society itself as the source of the disability problem, downplaying individual limitations (Palacios, 2008).

The origin of the social model comes from reflections and critiques of the individual model and from the need to separate the conceptualization of disability as a disease, since its joint understanding affects both the subjectivities of people and the practices to address it (González López, 2007). However, disability is addressed in public policies as a problem derived from health conditions, and bodily deficiencies are interpreted as personal tragedy or social deviation (Oliver, 1998). In that sense, they are the object of medical, pedagogical and psychological studies (Rosato et al., 2009).

From a social point of view, the non-fulfillment of the expected roles within the neoliberal ideology, such as competition, productive work and individual responsibility, put people with disabilities in

the place of incompetence and, therefore, of less social value (Oliver, 1998; Rosato et al., 2009). Thus, the individual model of disability assumes a “normality” to be achieved (Palacios, 2008), in which the stigmatization of disability has the effect of excluding deficient and socially discriminated bodies (Goffman, 2006).

The introduction of the social model in the understanding of disability has permeated health policies and systems. On the one hand, the current International Classification of Functioning, Disability and Health (ICF) incorporated the understanding of this matter considering the encounter between both models (WHO, 2001). On the other hand, CBR, from a rights perspective, considers the social model to promote the understanding of disability, recognizing the barriers to inclusive development with the purpose of being “a link between people with disabilities and development initiatives.” (WHO, 2012, p. 24).

Assuming the social model implies implementing practices beyond the approach to pathologies. However, the studies available in Chile show heterogeneity of practices framed in the different models of care, such as the biomedical scientist, who focuses on pathology through individual care; the biopsychosocial model, whose focus is the articulation of local and intersectoral networks; and the community model, that includes the community as a subject and whose central axis is the role of local actors and participatory management (Guajardo et al., 2015). The community model is more consistent with the social model of understanding disability, given its approach, which is systemic and not exclusively focused on the pathology, and therefore including intersection,;for example, the coordination with other services or institutions for labor intermediation.

It is relevant to know the perspectives of the people who are part of CBR, which is possible to learn through qualitative research, given the depth and richness of the information it provides. The objective of this study is to describe the experiences and perceptions about disability and social participation of people with disabilities and health professionals who are part of community rehabilitation centers in the Metropolitan Region of Chile.

Methodology

A qualitative and interpretive study was carried out using the methodological principles of grounded theory, mainly the constant comparison and theoretical sampling, which allows to reveal the symbolic and intersubjective dimensions associated with the research objectives considering an inductive analysis, also based on the notion of constructivist grounded theory proposed by Charmaz (apud Soneira, 2006). This idea rejects the “objectivist” vision and proposes that people create and maintain worlds that give meaning to their realities by acting on them.

A theoretical sampling was carried out, which helped us find those categories of people or events that we want to deeper explore (Ruiz Olabuenaga, 2003)—in this case it helped us select men and women with physical disabilities over 18 years old and health professionals with at least 6 months of experience in the community field. Both groups were part of 4 community rehabilitation centers located in the Metropolitan Region that implement CBR. The final number of participants and interviews was established according to the theoretical saturation criterion for the main analytical categories of the study (Mendizábal, 2006; Minayo, 2007).

The data production lasted 7 months and 16 semi-structured group interviews were carried out aiming to raise the group discourse and reflect about the experience on disability and social participation. Four interviews were carried out with women with disabilities, 4 with men with disabilities (Table 1) and 4 with health professionals (Table 2).

The interviews took place in each center and were moderated by members of the research team with training and experience in qualitative techniques; they lasted approximately 90 minutes and were recorded and later transcribed verbatim. A semantic content analysis was performed using open and selective coding, as well as constant comparison. Emerging categories were identified, respecting the flexibility and rigor of the grounded theory method (Guber, 2011; Soneira, 2006). The main categories of analysis in the field of disability were: perceptions on disability, experiences of discrimination, conceptualization from the individual model

and from the social model. In the field of social participation, the main categories of analysis were: experiences of participation in the rehabilitation

center, in the community and in other contexts. For data management, we used the qualitative data analysis software Atlas.ti.

Table 1 - Description of the sample of people with physical disabilities

Participants/subjects	Age	Participation in community rehabilitation centers
28 women	Average age: 70 years (minimum age: 28 years, maximum age: 86 years)	Users of individual sessions and workshops. 50% also participated in some organized group in the community rehabilitation center.
21 men	Average age: 61.7 years (minimum age: 46 years, maximum age: 79 years)	Individual session users. One of the participants was a leader of an organization of people with disabilities.

Table 2 - Description of the sample of health professionals

Participants/subjects	CBR experience	Careers
14 people (9 women and 5 men)	More than 6 months	5 physical therapists 4 occupational therapists 3 speech therapists 1 psychologist 1 physical education teacher

The criteria of credibility, transferability and consistency of the information produced and analyzed through the following rigorous strategies were especially protected (Shenton, 2004): (1) Triangulation of relevant actors; (2) Triangulation of researchers; (3) Detailed description of the investigative process; (4) Intense and prolonged data collection until the established and emerging categories are saturated.

An activity was carried out to give a feedback with the results to the participants, that included people with disabilities and health professionals, thus validating the results and increasing their transferability and consistency. In this activity, the main results of the study were presented in figures and quotes, which were analyzed and validated in discussion workshops held with health professionals and people with disabilities from each participating community rehabilitation center.

An informed consent process was carried out with each participant, safeguarding their anonymity and

also the rehabilitation centers. A coding was used for the confidentiality of the data. This research was approved by the Ethics Committee for Research with Human Beings of the Faculty of Medicine of the University of Chile in December 2015 (code 169-2015).

Results

Experiences and perceptions on disability

The experiences of people with disabilities are diverse and are related to their health condition, the amount of time they have lived with a disability, and the degree of dependency and assistance required. However, common elements were recognized in the process of living with disability, for example, the loss of functional independence as the main problem and the recognition of social barriers. Although both models of disability coexist, the recognition of injustices and discriminatory treatment reflects the presence of the social model (Table 3).

Table 3 - Models of disability present in the perceptions of people with disabilities

Scopes	Social Model	Individual model
	<p>Physical barriers: inaccessible streets and public transport do not facilitate independent movement.</p> <p><i>If this chair does not go down the ramp, because it is too heavy, how will it go up? That is why I don't like going out, because of all the effort I have to make. (Woman, 63 years old)</i></p>	<p>Disability associated with the body: it generates difficulties in participation and in daily activities.</p> <p><i>I feel so disabled because I have no legs, so what can I do if I can't do anything? If I can't walk. (Woman, 79 years old)</i></p>
Place or origin of disability	<p>Attitudinal barriers: insufficiency and misuse of physical facilitators such as elevators, preferential lines, preferential seats.</p> <p><i>[...] The question is [that] people need to respect that, you shouldn't use the elevator of the disabled just because you're tired; because it has to be for someone who is in a wheelchair, on crutches, then it is part of people's education and it will take centuries for them to change. (Man, 56 years old)</i></p>	<p>Disability is made equivalent to functionality: absolute dysfunction as synonymous of disability.</p> <p><i>I feel frustrated because, without being able to do anything because of the disability I have... I can't move, just by myself... now... before at least I could dress myself when this thing just started, now I can't even get dressed. (Man, 62 years old)</i></p>
Vision on health services	<p>Physical barriers: present in access to rehabilitation and health care.</p> <p><i>Fernanda told her "we are women, it has been so long that I cannot do a Pap smear [Papanicolaou test] because there are no stretchers for the disabled" [...] they got confused and just looked at her... there is nothing for disabled people, nothing. (Man, 57 years old)</i></p>	<p>Validation of expert knowledge: rehabilitation seeks to improve people's bodies to achieve their well-being.</p> <p><i>And the exercises have done me very well, that's why I tell the lady that I'll only leave when they kick me out because they made me much better. (Woman, 68 years old)</i></p>
Experiences of discrimination and stigmatization	<p>Discrimination due to lack of education: ignorance regarding disability.</p> <p><i>Among many discrimination there is... the other day I had a very bitter experience, in a banking service, the cashier told me "We don't deal with drunk people!" and I took out my [medical] papers, I always carry my papers, and showed them to him. (Man, 58 years old)</i></p>	<p>Self-stigma: people with disabilities are seen as a burden or problem for others.</p> <p><i>I worked my whole life, after I got like this, [...], because I know that I am a burden, that they have to take me to the bathroom and all that. (Woman, 68 years old)</i></p>

Both men and women describe negative experiences in the situation of disability. The experience of men shows a traumatic event associated with a health problem, mostly sudden, with a consequent decrease in their functional capacity, impacting on their

self-efficacy. For them, the loss of functionality is a central element of their experiences.

I am currently disabled because I cannot move my hands, they fall off, see? So I can't do anything with

this hand, I could do things, but with this other I can't. (Man, 79 years old)

It is super traumatic, and it is very fast too, [...], it is very violent [...] that is, today you are fine and the next day you are about to die and, after a week, you wake up and you are there in the middle, only half of you is working. (Man, 68 years old)

Women, whose health conditions are chronic and progressive, acknowledge loss of autonomy, decrease of authority in the family and representation of the caregiver role in the family group. The loss of position and role is at the heart of their disability experiences.

I feel disabled, [...] I can't walk well and that's when I get angry because I was self-reliant, I was a person who used to get up at 5 in the morning, left everything done at home, and went to work. On the other hand, now I depend on others, on my son, to put my socks on in the morning. (Woman, 59 years old)

Regardless of gender, perceptions of disability reflect personal tragedy by visualizing a non-normal and non-functional body, affecting the way of relating to the family and the exercise of roles. Focusing on functional dependency and the need for personal effort accounts for the presence of the individual model of disability, that is, the greater the dependency, the greater the disability.

Disabled is a person who is already prostrate, who cannot do anything. As long as we can move, I think we no longer have to fight for something. (Man, 54 years old)

In this sense, rehabilitation processes reflect an experience of disability that emphasizes personal effort as a solution to the problem of functionality.

I ended up with my right side completely damaged and thanks to the therapies and also to my effort, because you have to do your part, I am standing as I am. (Man, 54 years old)

From the perspective of health professionals, and following the individual model, disability

is experienced as a personal tragedy that limits people's lives, therefore, rehabilitation seeks to contribute to redefine this experience:

To give them a sense that they can continue to live in a dignified way, that they can continue to participate in society in different ways; however very few people achieve that, as they all feel like their life is over. (Psychologist)

The social model is mainly manifested in experiences in which discrimination is perceived, for example, in the lack of accessibility in the city, in public transportation and in health centers. They also face stigmatization as a barrier, noticing negative attitudes from the rest of society.

You can't walk, get on the micros [buses], in the subway, people just kick you out, I have to stand on the stairs so I don't fall, because young people of all ages pass by suddenly like that, or with bags. (Woman, 50 years old)

The experiences of people with disabilities shift over time towards an understanding of social disadvantage over physical or bodily limitations. Those people linked to community organizations, whose purpose is to achieve social demands and better living conditions, express the demand for cultural changes, better public services and compliance with the legislation on universal accessibility. For those who are not part of community organizations, this recognition is more like an expectation than a demand for their rights.

For all participants, disability also affects the family, especially their partner in the case of men. Consequently, health professionals support the family in this process, including self-care activities for caregivers. However, all groups recognize that this is insufficient, so systematic specialized psychological support is required.

Although health professionals recognize the relationship between disability and physical dependence, they incorporate complex social contexts into their understanding, as an aspect that deepens social exclusion due to disability:

“dependence is exhaustion, it is a change of roles, it is grief, there are many conflicts from before that are now exacerbated, it is lack of resources, lack of participation, lack of work” (Occupational therapist).

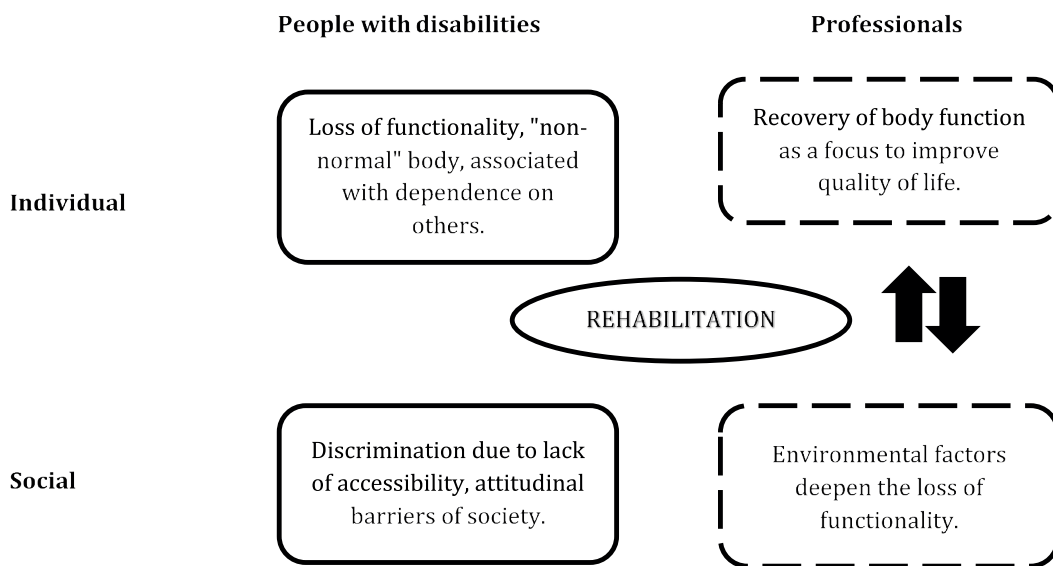
The coexistence of the two conceptual models (Figure 1) is more evident for health professionals when they account for the relationship between the functional limitations of people and the contextual factors that deepen the deficit; therefore, the success of the rehabilitation would

be conditioned by various social factors, such as lack of opportunities for inclusion.

More than anything else, the work here [...] I see that it is trapped by social limitations, because there are educational barriers present... (Occupational Therapist)

However, the practices and accompaniment carried out by health professionals do not consider the confrontation of these social barriers.

Figure 1 - Models that coexist in rehabilitation



Experiences and perceptions on social participation

The bond that people achieve in the rehabilitation center is intense and affective. They describe their relationship with healthcare professionals and other users as “a second family”, valuing this space as a place of trust where they are heard and understood.

They go to your house to look after you, they check if you have movement restriction [...] it really is a family, you feel good. (Man, 53 years old)

They recognize that most of the social and recreational activities carry out in their daily lives are

linked to the rehabilitation center. They do not usually go to other places, reporting lack of accessibility in the streets and in public transport, which limits their visit to places outside the rehabilitation center. For men, the inability to work becomes their greatest difficulty, so they look for other ways of obtaining income (informal, sporadic and independent jobs). Women do not have concerns about incorporation into the workplace, but they report greater participation in other community groups, such as club for older people or other health programs.

I studied, and now I teach at home, as a monitor [...] last year I took the course to become a monitor at

the home for older people. I taught various people, I had about 20 students, and I worked with them throughout the year. (Woman, 67 years old)

Health professionals also recognize rehabilitation centers as places where there is coexistence and affection, considering this experience as a first step for people with disabilities to be able to coexist socially again. However, and coinciding with their medical vision on disability, health professionals understand the favorable changes in the physical and psychological condition of users as a requirement to increase participation within community contexts. In this sense, links with organizations of people with disabilities and intersectoral coordination have little presence in the rehabilitation process.

Discussion

The conceptions that the participants have about disability are reflected in the beliefs and experiences that they live in their daily lives. When analyzing these experiences from the social and individual models of disability, the coexistence of both models stands out, as well as the tensions of their application in the rehabilitation process.

Perceptions about disability describe what some critical studies call “personal tragedy theory”, which they define as a cultural representation of disability resulting from the abnormality described in the first critical studies on disability (Shakespeare, 1997), which is similar to the belief of people with disabilities in our results who feel like the greater the dependency, the greater the disability. Considering these ideas, recent studies, from feminist theories, have explained that the hegemony of male values in our cultures does not accommodate the diversity of women and men with disabilities (Gómez Bernal, 2014), our results coincide with this perspective in particular when revealing the feeling of loss of the productive role that people have when the situation of disability occurs, especially for men.

According to Oliver (2008), the theory of personal tragedy, linked to the individual model

of disability, seems typical of the helper-helpee relationship, which occurs between health professionals and people with disabilities within the biomedical model of health care in Chile, and which is reflected in the professionals’ vision of the need for standardization as a means for social participation, even when they recognize the barriers of the physical and social environment. At the social and public policy level, the previous relationship is reproduced, conditioning the position that people with disabilities live in society as a result of a disease condition in which they are recognized. Based on Bourdieu’s theory of domination, the person with a disability naturalizes symbolic violence, recognizing themselves as the bearer of a “deficiency” that marginalizes them from general social life (Ferrante; Dukuen, 2017). Our results confirm this embodiment of the concept of disability, which is expressed especially when it is difficult for people with disabilities to analyze the situation in a systemic way and they are restricted to feeling their own body and their loss of functionality.

Considering that the context of the study is CBR, the scant paradigm shift in disability models is surprising. Although the participants recognize the role of society in limiting social participation, this does not transcend a critical view of the rehabilitation process. This could be explained by the care emphasis of the implementation of CBR in Chile, the predominance of the medical model and the understanding of “the community” restricted to a territorial space (Calle Carrasco et al., 2019; Guajardo; Recabarren; Parraguez, 2014 ; Ossandón, 2014) rather than as a resource for people with disabilities to defend their rights. However, the bond they achieve in the community rehabilitation center is intense and affective, and represents one of the few spaces for participation, mainly in recreational activities.

As limitations of this study, it is recognized that the results are limited to urban areas of the Metropolitan Region of Chile, therefore, they do not account for the experiences lived in rural areas and in other regions of the country. In addition, a finding of this study was the homogeneity of experiences in social participation, with few

experiences of active political participation in disability issues.

In this work, some gender differences are recognized in the conception of disability. Future studies with a gender focus could delve into these differences, as well as explore experiences and perceptions of disability and social participation in various sociocultural contexts.

Final considerations

For CBR participants in the Metropolitan Region of Chile, the understanding of disability is associated with health practices from a biomedical model and expresses, mainly, the individual model of disability by appealing to the need for personal effort to overcome this situation, focusing on functional dependence, which is considered a negative experience for both men and women.

Although physical rehabilitation is necessary for people with disabilities and, therefore, activities focused on the recovery of functionality are highly valued, professionals and people with disabilities also recognize social and environmental elements that restrict participation, such as the negative attitudes of society and the lack of accessibility in the city, in public transport and in health centers, thus reflecting the presence of the social model of disability.

These results challenge public rehabilitation policies, in terms of the need for further development of guidelines, training of health professionals and availability of resources for the effective implementation of CBR, which contributes to the empowerment of people with disabilities and the community and intersectoral work to achieve the recognition and elimination of social barriers that limit the full exercise and universality of the rights of this population.

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Authors' Contribution

Rebolledo-Sanhueza contributed to the design, data production, data analysis, interpretation of results, writing of the first draft and corrected versions of this manuscript.

Besoain-Saldaña contributed to the design, data production, data analysis, interpretation and revision of the corrected versions of this manuscript.

Manríquez-Hizaut contributed to the design, data production, data analysis, interpretation of results and revision of the corrected versions of this manuscript.

Huepe-Ortega contributed to the data analysis, interpretation of results, writing of the first draft and corrected versions of this manuscript.

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