Subverting medical vulneration: Dissident bodily itineraries of disability in Chile

Subvertir la vulneración médica: itinerarios corporales disidentes de la discapacidad en Chile

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ABSTRACT Acknowledging dissident bodies of persons with disabilities is an act of continuous resistance, and as such our objective in this article is to analyze the vulnerability and bodily violation of disability activists in Chile. In order to do so, between September 2018 and February 2019 we conducted 11 in-depth interviews using the technique of bodily itineraries, as well as 6 discussion groups. Through qualitative thematic analysis, several categories emerged: the central category of "Bodily change or difference: experiences of medicalized fragility;" and three subcategories, "Bodily diagnosis: the institutional management of differences;" "Medical treatment: correcting bodily and social abnormality;" and "Rehabilitation: to function once again as a normative body." Activists' itineraries reveal the coaptation and bodily violation that they are subjected to by the biomedical apparatus, where they are systematically denied their human rights; however, despite attempts to discipline and control them, they create subversive strategies to validate their corporealities.
KEY WORDS Political Activism; Human Body; Disabled Persons; Social Vulnerability; Chile.

RESUMEN El reconocimiento de los cuerpos disidentes de la discapacidad ofrece una situación de continua resistencia, por lo que nuestro objetivo fue analizar la vulnerabilidad y vulneración corporal de las personas activistas de la discapacidad en Chile. Para eso, entre septiembre de 2017 y febrero de 2018, se realizaron once entrevistas en profundidad utilizando la técnica de los itinerarios corporales y seis conversatorios. A través del análisis temático cualitativo, surgió la categoría central "el cambio o diferencia corporal: experiencias de fragilidad medicalizada", y tres subcategorías: "diagnóstico corporal: la gestión institucional de las diferencias"; "tratamiento médico: corregir la anormalidad corporal y social"; y "rehabilitación: volver a funcionar como un cuerpo normativo". Los itinerarios de las personas activistas develan la coaptación y vulneración corporal a la que son sometidas al ingresar a los dispositivos biomédicos que niegan sistemáticamente sus derechos humanos. Sin embargo, a pesar de intentar disciplinar y controlar sus cuerpos, crean estrategias para subvertir y validar sus subjetividades.
PALABRAS CLAVES Activismo Político; Cuerpo Humano; Personas con Discapacidad; Vulnerabilidad Social; Chile.

INTRODUCTION

The present study develops the results of the first research aim of the project "*Cuerpo(s) en luchas: itinerarios disidentes de la discapacidad en Chile*" [Body(ies) in struggle(s): dissident itineraries of disability in Chile]. In recent years, the body has been the object of innumerable tensions and interventions produced under the mandates of contemporary neoliberal globalization.[1] Today, any subject that escapes the esthetic, functional, rational or economic order is seriously threatened to form part of the mass of people deemed expendable, disposable or delegitimized; therefore, it is increasingly common for situations of disability to be recognized as a part of everyday life. In this sense, the institutional order, and particularly the International Convention on the Rights of Persons with Disabilities, understands disability as

> an evolving concept… that… results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[2]

From this perspective, the social struggles of the activism and associationsim[3] of people with disabilities become relevant, as they put emphasis on the social determinants of their disability,[4] including the systematic impact of the medical institutions in their trajectories. Nevertheless, this analysis does not contemplate corporeality[5] as a material depositary of subjective malaise.[6] In recent years, sociology of the body[7] and feminist disability studies[8] have brought attention to the acknowledgement of bodily vulnerability, overcoming a reductionist and essentialist understanding of the body that disability activism itself has attempted to subvert over the last decades, represented by collectives such as *Movimiento de Vida Independiente latinoamericano*[9] [Latin American Movement for Independent Living], the Latin American anti-sanism movements,[10] and, more recently,

the mad feminism movements in Chile.[11] Nevertheless, this epistemological issue persists in body and disability studies.

This study sought to explore this still unfinished relationship following the bodily itineraries[12] of those with diversities outside of the diagnostic-clinical classifications proposed by the hegemonic medical model and/or the most recent version of the International Classification of Functioning, Disability and Health (ICF),[13] and to analyze how these people move through different social positions from their first disease diagnosis until their understanding of themselves as people with disabilities, with the series of markers, prejudices and labels that shape their identities in this medical and social becoming.

In this way, we will review how entering into the medical apparatus[14] implies subjugation over the course of years or, in some cases, over one's entire lifetime, a particular form of bodily vulnerability that gives meaning to their transformation into activists.[15]

Vulnerability precedes the person; nevertheless, this premise is understood historically in certain bodies. For this reason, dominant representations of people in situations of disability involve bodily vulnerability, a situation that at the same time implies tutelage through paternalist and assitentialist policies that systematically deny their human rights. Far from denying the vulnerability of this collective, we understand the vulnerable body not as a particular essence of a specific group or body – as cisheteropatriarchal ableist binarism posits – but rather as a relational, affective, corporal matter belonging to all of us. As Butler[15] holds, vulnerability is considered to be resistance, a principal of equality, justice, freedom and interdependence, highlighted as the willingness to expose and put ourselves before one another.

The vulnerable body: agent of the dissidence of disability

Within disability studies,[16,17,18,19,20,21] the social exclusion that people with disability have faced in the social structure is widely

acknowledged. However, we have preferred to highlight the idea that they have been vulnerated, not just that they are vulnerable. In this sense, we believe a binary analysis centered primarily on the idea of inclusion/exclusion to be limited for understanding the current situationality presented by these bodies. For this reason, we see vulnerability as a common place from which to together think about their itineraries and political struggles.

We understand vulnerable bodies from a Butlerian feminist epistemological lens, which refers to vulnerability in dialogue with embodied agencies beyond the traditional victim view of disability. To the contrary, the itineraries of the activists are in constant play with the agencies of resistance in favor of a possible and desirable life, in which their bodies have spaces to materialize justice and recognition. This proposal is interesting, as it articulates a fundamental political relationship among vulnerability, agencies and discourses, weaving a corporal dialogue of exposition, performativity and language,[22] in which projects towards a dignified life are inscribed. From this perspective, an ethical and political dimension exists in the work toward collective action that the dissident disability activists carry out, "motion that is at once movement in that double sense, bodily and political."[15]

The body vulnerated by the hegemonic biomedical model

Vulnerated bodies arise in the close relationship among precarious living conditions, suffering and bodily vulnerability. This framework challenges us to think beyond the autonomy of the patriarchal liberal subject, that is, as a relation of continuity and care among bodies with and without disability.[23] However, this situation faces tensions in its framework in that conceptions exist that position dissident people as exclusively sick and passive bodies.[14]

Indeed, the hegemonic biomedical model establishes dissident bodies as incapable, as subjects with no knowledge of their condition and, additionally, as unilaterally responsible for their situation. According to Menéndez,[24,25] biomedical indoctrination towards subjects was problematized primarily in the 1970s as the result of a group of social actors, actresses and sectors who questioned the clinical characteristics that allopathic medicine was developing with respect to individuals. This criticism was reflected, especially, in the constitution of people as objects of illness, dispossessed of autonomy through the medicalization of their lives. The primary effect was the precarization of the subjective conditions of existence through obligatory tutelage, invisibilizing people's knowledge and life practices and generating normalization and control through the dominant social forces of capital.

We can therefore speak of the existence of an institutional biomedical culture that is sustained upon the construction of authorized knowledge based on hierarchical logics of power reflected in the valid knowledge of the biomedical body.[26] This corpus additionally implies a fragmentation of body and mind, considering the body as a machine that can be transformed and to which external apparatuses can be taken on and off without affecting the subjectivity of the individual.[27]

Medical treatment (as both manner and therapeutic action) represents systematic forms of how the rationality of the biomedical apparatus is enacted for any abnormal body.[28] Articulation into a network is the founding principal of biomedicine and for this reason if a diagnosis exists, at the same time a particular type of treatment or therapy is proposed in the sense of cause and effect. In agreement with this explanation, a series of arguments regarding medical causality are developed to justify the diagnoses and treat the dissident bodies.

Taking into account the ideas developed above and with the aim of visibilizing this situation, the objective of this study was to analyze the situation of bodily vulnerability and vulneration of dissident disability activists who live in Chile.

METODOLOGY

Study design

The methodological design that oriented this research was qualitative, given that it implies "situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world."[29]

This framework allowed us to use as a research technique the bodily itineraries proposed by the feminist anthropologist Mari Luz Esteban, which "serve above all to show lives, bodies in movement, as dynamic, open and constantly changing processes and therefore singular, contradictory and unfinished."[12] From this perspective, we sought to examine and systematize life trajectories to show inflections, positions, disputes and contradictions that these activists incarnate in their bodies and in their lives, as "experience hasn't yet taught anyone what a body can do purely through the laws of physics."[30]

Study context

The study was carried out in Chile, which is located in the most southwestern point of South America, and is divided into sixteen regions from north to south. Of the activists interviewed, eight lived in the central area (Metropolitan Region in the city of Santiago, and the Valparaiso region in the city of Valparaiso) and three in the south of the country (Bio-Bio Region in the city of Concepción).

It should be highlighted that the political and economic centralization of Chile into its capital and nearby cities, associated with the geographic and urbanistic difficulties presented in the regions far from the central area, considerably impede the collective organizing of people in the situation of disability. This state of affairs generates not only complexities in the organization, logistics and communication of collectives but also hinders the subjective processes of agency that a person in these conditions might undergo.

For this reason, people who identify as dissident disability activists and live in regions with geographic, political and economic adversities reveal the importance of developing an agency-producing trajectory and of organizing collectively despite these setbacks.

Selection and characteristics of the activists

The first contact was initially made through invitations to participate via e-mail and via the social networks of referential activists in the world of disability. Later, in a second opportunity, snowball sampling was used to identify other activists who, although not as well known, carry out extensive work in defense of the human rights of people in situations of disability.

The activists included were those that accepted the invitation to participate. Their individual characteristics involve: having an experience or identifying with the world of disability, regardless of whether the disability derived from a congenital condition or was acquired, and making no distinctions in terms of health diagnoses; having an active presence in activist or critical disability collectives in Chile; and having lived in the country from 2010 until the time of the interview. Another relevant characteristic is that the interviewed activists, irrespective of their condition, were able to recover the historical meaning of their experience situated in the struggles of social difference.

Once they had been contacted, the aim of the research was explained to them and they were asked to sign an informed consent form in order to take part in the study. The informed consent form expressed the objective and purpose of the research, as well as the voluntary nature of participation, the guarantee of anonymity regarding the information obtained and the confidentiality of their identities. Given that the research was not based at an institution, once informed consent was obtained the person's participation was considered to be formalized.

Table 1. Profile of the activists. Chile, September 2017 to February 2018.

False name	Sex	Age	Relationship to the world of disability	Collective
Julio	M	50	Survivor of psychiatry	Autogestión Libre-Mente
Guillermo	M	33	Low vision	Colectivo Palos de Ciegos
Esteban	M	58	Low vision	Colectivo Palos de Ciegos
José	M	50	Survivor of psychiatry	Corporación voces
Ricardo	M	40	Survivor of psychiatry	AESAM
Hugo	M	45	Survivor of thalidomide	Colectivo Talidomida
Erika	F	40	Blindness/deafness (partial)	ODISEX
Karina	F	55	Survivor of psychiatry	COMUNIDIS
Elisabeth	F	34	Generalized dystonia	Corporación Distonía
Beatriz	F	55	Multiple amputee	Corporación Bio-Bio
Francisca	F	36	Neurodiversity	Mil Capacidades

Source: Own elaboration.

Information collection techniques

The encounter with the activists was carried out using two techniques. First, 11 in-depth interviews with activists who identified with the world of disability and lived in the central (Santiago and Valparaiso) and southern (Concepción) areas of the country were carried out. This technique was chosen as it was the best way to access and learn about the bodily itineraries. Two to four sessions per participant were carried out, respecting their situation and needs at all times. The places the interviews were held were also decided with the activists according to their availability and time. To preserve their identities, the 11 interviews use false names (Table 1).

Second, we participated in six talks lead by dissident disability activists and carried out in the aforementioned cities. The discussions covered topics related to the struggles and resistance of people with disability, the visibility of their work and future intervention strategies as a collective. Both the interviews and the discussions were carried out between September 2017 and February 2018 (Table 2).

Criteria for methodological rigor

Flexibility and relevance were used as criteria for research quality, in so much as the understandings compiled from the narratives of the activists justify and respond to the study

Table 2. Activist talks. Chile, September 2017 to February 2018.

Name of talk	City	Region
Psychosocial mental health	Viña del Mar	Fifth
Anti Stigma	Concepción	Eighth
Different childhoods and neoliberal education	Santiago	Metropolitan
Activism and social movements	Santiago	Metropolitan
Logic of the insane asylum	Santiago	Metropolitan
Beyond the chemical madhouse	Santiago	Metropolitan

Source: Own elaboration.

objective, as well as allow for new findings that help strengthen the theoretical, conceptual and methodological analysis undertaken.[31]

In addition, the criteria of universal accessibility and design for all[32] were adopted as they respond to the versatility of people with physical, sensory and cognitive diversities, making it possible to dialogue more fluidly with the different bodily dispositions of the activists at the time of the interview and talks.

Information analysis

The interviews were transcribed verbatim and analyzed as they were carried out, so as to identify aspects that should be taken into account in following interviews. Similarly, the talks were transcribed literally for later analysis.

To analyze the transcriptions of the interviews and the talks the program Atlas ti 8.2.3 in Spanish was utilized. The analysis technique used was the qualitative thematic analysis proposed by Braun and Clark, as it can "interrogate patterns within personal or social meaning around a topic," identifying behaviors "within and across data in relation to participants' lived experience."[33] In addition, an intertextual strategy of a subjective nature was employed, as each enunciation was interpreted in relation to the characteristics of the subject who produced the discourse.[34]

In this way, a central category of analysis emerged, "bodily change or difference: experiences of medicalized fragility," as well as three subcategories: "bodily diagnosis: the institutional management of differences," "medical treatment: correcting body and social abnormality," and "rehabilitation: to function once again as a normative body."

RESULTS AND DISCUSSION

When the paths of dissident disability activists are analyzed, different trajectories and meanings can be identified that shape the becoming of bodies and struggles. In this way, the vulnerable body[15] offers a particular positionality with which to interpret bodily itineraries.[12] This underlying condition situates people on a route that begins with a bodily change or difference.

We use bodily changes to refer to times when the corporeality of a person is modified throughout the course of their lifetime or as a result of an unexpected situation, presenting new social functioning. We understand bodily difference as a nonstandard corporal condition expressed at birth. Both situations can lead to a situation of disability for dominant heterosexual thought.[35]

Bodily change or difference: experiences of medicalized fragility

In all of the trajectories of the dissident disability activists, corporeality[7] was transformed into an embodied experience of precarious life[36] that, at the same time, expresses an augmented position of vulnerability. This situation is aggravated by the social conditions that patriarchal neoliberalism installs in our common sense, in our body-territory[23,37] and in the geopolitical spaces of Latin American otherness.[38]

One activist – a survivor of psychiatry – tells how she went from a situation of apparent everyday "normalcy" to an unplanned bodily experience:

> The truth is I had stable work. But something was going on with that, I didn't realize, I was working long hours, I didn't have space for the things that I later saw were fundamental to life and the reality is that I started to have a nervous problem and the possibility of having a problem […] I somehow thought there were things that were really there, that weren't so difficult to face. Until I started having panic attacks. From one day to the next I started having panic attacks, I even went to the emergency room … one day, after being at home a ten PM drinking tea, I felt like I was

going to die. As simple as that. It was something I had never felt, and suddenly I had the sensation that something was happening to me, if you ask me what, I don't know, but I felt like I was going to die, I couldn't calm down, I was in my pajamas so I got dressed, took a taxi … I was dying. (17:7)

This narrative allows us to clearly identify how the social determinants in which the activist carries out her life end up effecting a bodily suffering of unthinkable magnitude. When the social determinants of present-day work are interpreted in the framework of a neoliberal organization that seeks increased productivity, workers are required to keep long hours, and occupational imbalances are gradually installed.[39] Such imbalances are an expression of the disproportion of work in relation to people's everyday activities, leisure and recreation. We can also see the reproduction of hegemonic mandates associated with the female gender – the production of "healthy" people, the conformation of a heterosexual family and grueling work that represents neoliberal success – which come to be the fundamental pillars of a cishetero-patriarchal ableist regimen.[40]

When we think about vulnerable bodies, we also problematize vulnerability as a product or result of the social and cultural determinants that produce greater accidentability and crises. This is the comment of an activist who lost a lower and upper extremity in a traffic accident in her childhood:

My sisters and I were home alone because my mother had gone to a mother's center for the church [...]. So my sister says to me, "you know what, mama's going to come home and there's no bread." And that means leaving the neighborhood, crossing the tracks [of the train] and going to Prat [another sector] to buy bread. And the prison of Concepción is located at 70 Chacabuco. And my sister says, "ugh, I don't want to go," my older brother didn't want to go alone, and she says "Toñi [false name]

will go, Toñi can go with you," and I don't know if it was a sixth sense that warns you of things but I said no, for the first time in my life I resisted, I said, "you know what, I'm not going, I don't want to go, I don't want to go," so that my older brother doesn't have to go alone, I was about nine years old. So my sister says to me, "you have to go, I'm your older sister, I'm in charge of you and you both have to go." I said "please, don't make me because I'm not going to go." […] *The public jail used to have these areas where people could cross over and we kids always used those spaces to run, to play, because there were no spaces where kids could play… Well, and so there I was and I ran into some neighbor girls and so when I was crossing there were some things that I stepped on and a girl says "who stepped on this stuff?" and the girl says to me "you did it!" and my brother, worried, says to me, "let's get out of here." Home, without the bread, without anything. So I was worried about where my brother had gone because we got separated, I was crying with fear because the girl was going to get me and hit me, I will always remember, and I looked back and I didn't see anything; and there was a train, just the machine car, it was stopped, so people started walking, crossing the tracks. Ahead of me a woman was crossing with two children on one side and three on another, and I was right behind her. And suddenly the conductor went into reverse and I couldn't get out of the way because the woman pushed her kids forward and that's when the train got me. I remember absolutely everything, how the wheel of the train first went over one leg and then then one arm, there were even girls who saw me and were standing there, shocked, and I tried to stand up, I said "please," I tried to stand up, I thought I was dreaming, I fell, and I said to them "hey, go to my house and tell my big sister that she needs to come see*

what happened to me." And the train kept going. (7:4)

This graphic description reflects how social and family dynamics interconnect with conditions of class and urban organization within cities. Making explicit the inequalities and inequities in spatial relationships is a perspective that has been extensively elaborated by David Harvey[41] over decades, when he considers the geography of difference, as well as the *Movimiento de Vida Independiente,*[42] who fight for universal and intercultural accessibility to different territories.

The urban area described by the activist is still problematic in the city of Concepción, in which problems of vehicle traffic and accidents associated with the dangerous train tracks repeat themselves, in contraposition to an urbanism attentive to the necessities of difference and its causes. It is an area bordering a working class neighborhood with little social protection, security and urban infrastructure, which impedes – as both the activist and feminist geography describe[43] – inhabiting a healthy space for the leisure and recreation of the people, families, and children of the neighborhood. The traumatic accident and consequent bodily change involved losing two extremities. Without a doubt, this challenge meant learning to function and move in her body and in her city in a radically different way.

Bodily diagnoses: the institutional management of differences

Bodily change and difference are connected to an entry into a particular way of explaining bodies. The "diagnosis" becomes an institutional tool of corporal evaluation that establishes a social mechanism to order, analyze, and interpret the bodily trajectories of the activists that were interviewed. In order to do this, a separation between the normal and the pathological[44] establishes a dividing line that explains the introduction of a disciplining clinical reason[26] to observe, prioritize and treat corporal difference.

With the introduction of a clinical-scientific explanation of bodily change appears a medical apparatus[45] that directs people's bodily itineraries. According to this medical apparatus, people will first go through diagnoses, treatments, rehabilitations, and next, or in parallel, a situation of disability. This series of disciplining mechanisms establishes a network of relationships among different heterogeneous elements: disciplines, institutions, professionals, scientific knowledge, referrals, technologies, through which the lives and personal and collective identifications of the activists will pass.

To diagnose, it is necessary to specify a condition's causality directly and independently. In this mechanism the signs and symptoms that lead to diagnoses-diseases operate; however, this situation is even more complex when the formula is applied to so-called "behavioral alterations" or the "subjective differences" of the population.[6] This activist explains how her personal story unfolds upon entering into the world of psychiatry, detailing her "diagnostic" transformations and the bodily repercussions that she suffered:

> *Well, at 19, 20 years of age I started having adolescent problems and fell into psychiatry. And psychiatry quickly diagnosed and medicated me. And I entered into an underworld, where I lived 25 years psychiatriatized… with the diagnosis of severe Asperger's, not Asperger's, borderline personality, and all types of depression, endogenous depression, deep depression and all those things they do. Finally I came to borderline personality, then I was given… neurovegetive disorder, I was the only case in Chile, with one of the best psychiatrists in the country, Dr. [XXX]. Then the diagnosis, during more than 15 years, was bipolar II and the last bit of time was bipolar with schizophrenia… and well, one feels an emptiness, a sadness, an inexplicable sadness. In your body, physical fatigue, lack of energy, excessive thinking, confusion, sleep disorders,*

difficulty focusing your mind, wanting to cry, wanting to talk; that is angst. (4:14)

This puts into evidence how the rationality of psychiatric power[46] delimits social and subjective problems and transforms them into individual diseases. The entry into the underworld is a lifetime of subjection – in this experience, 25 years – in which the body incorporates and upholds a very difficult regimen from which to devise and develop a healthy life project in all its dimensions, to the point that it becomes impossible.

The emotional, cognitive and social deterioration that bodies show in psychiatric trajectories makes these experiences difficult to endure. In this narrative, we see how the diagnosis is never "objective," "single" and "unchanging," but rather is transformed into a series of new categories and labels that the body itself must incorporate and reproduce. The activist also narrates how the medical apparatus subjectivates her understanding of reality when "illness insight" introjects. The medical resource of insight has been widely elaborated upon, especially in spaces of mental health to generate adherence to the clinical apparatus, with the effect of confirming the prevailing hypothesis that the psychiatric diagnosis is an individual tragedy of the neurobiological order.

This explanatory model has been widely criticized by a current of thought related to antipsychiatry starting in the 1960s,[47,48,49,50,51] as well as not-psychiatry,[52] who posit the impossibility of a lineal relationship between neuroscientific causes and human behavior. Therefore, they question the supposed scientificity of psychiatric knowledge. One male activist reflects:

> At that time I thought and would say, "what a terrible illness I have..." It's an illness that keeps getting worse and keeps mutating because, of course, the manifestations over time kept changing and the diagnosis also kept changing. It's not like someone says to you, "listen, you have such-and-such a disease and will spend twenty, thirty years

> treating that disease," no, my disease kept changing in its manifestations, symptoms, the medications and drugs changed, it changed in the diagnosis, the labels, they kept changing them. So I was left pretty confused and I would say, "how do I face this, if every time I start understanding something, something new appears." The truth is that psychiatry would impose itself with, "no, your issue is complex, it's difficult, it's hard to diagnose." Of course I bought that line, I bought it, of course, that the real problem was me. (4:15)

Confusion is a complex emotion that generates an immobilization to question the explanatory justifications of the dominant psychiatric model, at the same time that it generates despair in the person's life project. This mechanism ends up making the person individually responsible for all subjective malaise, creating a sensation of a mantle of wasted lives.[1] In this point a clear convergence is produced between the psychiatric diagnoses and the neoliberal individualist model of responsibility.

In other situations, we see how the diagnostic process deadens future hopes and possibilities and is communicated in this way in the first stages. This type of interaction is a way in which medical knowledge-power positions itself in relation to the other person. One example was narrated by a blind activist regarding his experience when he was given the information about his situation and "diagnosis":

> I had bad myopia that had been aggravated by injuries inflicted during torture. I started studying at that age, 50 years. By then I was very myopic. And there was a time, when I was in the second year of my social work degree, that the ophthalmologist said, "look, there's nothing left to do, there's no operation, no treatment, there's nothing" ... the thing is that that was a huge shock, I got depressed, my life's dream was facing a barrier there. I remember that one young

woman – all of my peers were in their twenties, I was the old man at the university – and this girl said to me, "ok, you found your limit, there's your limit." And in that situation I tried to find a psychologist that could help me with that, in that situation of depression, of angst, of seeing the future literally black. (1:151)

The diagnostic experience is internalized corporally through the dominant representations of what a disease implies and is accentuated when the disease involves the senses primordial for carrying out every day life. The prioritized knowledge-power in the medical institution establishes the mandate that "there is nothing left to do," limiting all future life projections. This translates into a premature death and a mourning that has to be quickly assimilated, with depression, discouragement and despondency constituting a logical response. This situation is aggravated when the social context naturalizes corporal differences of functioning as deficient and limiting. This naturalization translates into a matter of individual responsibility, without questioning the disabling structures of the society.

Medical treatment: correcting bodily and social abnormality

Medical treatment (as both manner and therapeutic action) represents systemic forms of how the rationality of the medical apparatus operates. As we mentioned previously, articulation into a network is a foundational principal, acting in the sense of cause and effect. In this way, arguments regarding medical causality are developed to justify diagnoses and treat dissident bodies based in the paradigm of ableist normalcy.

Through the production of the dichotomies of healthy/sick, man/woman, white/black, abled/disabled, identities are designed in which the second category of each binomial is constituted as inferior, pathological and threatening to the social order, and therefore open to the intervention of an institutional apparatus.[53]

In the majority of the trajectories of those interviewed, psychopharmacological intervention – as treatment – was central to acting upon different corporealities, evidencing the existing tensions between the clinical-medical approaches and the psychosocial interventions that become secondary and peripheral.

In the following experience, an activist – a survivor of psychiatry – comments on his interpretation of the medical treatment he received:

I didn't receive anything close to the help I expected, although these were the people that supposedly could tell me, explain to me what was happening to me and help me with that process. I kept getting what most people get, a diagnosis or several diagnoses, in my case, almost exclusively a pharmacological treatment for several years, of several different drugs, in different doses. And as time passed, I began to realize that although I had developed what is called "illness insight and treatment adherence," that is, I believed myself to be mentally ill, with a chemical imbalance in my brain, and that I needed to take psychiatric drugs for the rest of my life – and that's what I did for seven years – I was not getting the results I supposedly should be getting, in the first place. And, in the second place, I was having serious problems that were not allowing me to have a quality of life, if that concept even exists, that was more or less reasonable: I was overweight, with serious memory issues, sexual and relational dysfunction, a little bit of everything, what happens to the majority of people who follow the biomedical model, the psychiatric model, to the letter. (16:24)

This experience highlights a paradox in the meaning of a medical treatment that, supposedly, is done for the good of the person being treated, even though its effects appear to indicate the contrary. The primary treatment is anchored in the administration of psychiatric drugs that are managed in varying doses

following the criteria of "illness insight," in such a way that they are adjusted according to the following triad: illness insight, pharmacological treatment and submission of the body.

The bodily experience associated with pharmacological treatment and its consequences in weight, sexuality, and social relations are disabling effects of the poorly named "side effects."[54] These effects have little relevance from a clinical standpoint, especially when the emphasis is placed on a special region of the body: the brain and its neurochemical functioning. Another activist offers the corporal consequences that he experienced when submitting himself to psychiatric medical treatment:

> I remember the side effects, you can imagine, I had memory issues, concentration issues, I was very overweight, I had a tremor in my hands, my body, I was physically fatigued. And I associated it all with a lot of loneliness, a lot of discrimination. I was always lying down, what I most remember is lying down, and I had no incidence in what happened and no incidence in the solution. All I had to do was take the pill. (4:52)

The bodily effects of the euphemistically named "side effects" of the psychopharmaceuticals institute a corporal regime founded in psychiatric knowledge-power that establishes a hierarchy among "able" and "disabled" bodies. A regime of truth is established that naturalizes the moral superiority of the decisions of psychiatry over the lives of people. It is therefore important to resignify these consequences as primary, and not secondary or "side" effects, as medicine would like to convey. In this way, tremors, fatigue, lying down for long periods of time, only demonstrates the disabling effects of this type of corporal reproduction.

The justification of the moral superiority of psychiatric knowledge-power requires installing the moral incapacity for decision-making of the people who are diagnosed. This situation can be seen in different research studies that manifest the loss of legal capacity and the loss of rights that people with psychiatric diagnoses face.[55,56]

This situation occurs more frequently among women with psychosocial diversity, who receive worse treatment and are more subjugated within the medical sphere,[40,57] indicating the gender bias of psychiatric knowledge-power[58] expressed in the mental health apparatuses. This bias is ratified in the experience of a female activist who voluntarily entered a health apparatus:

> First of all, I was never told ... look, I went myself, voluntarily, it wasn't like ... you're not going to find in Chilean psychiatry people who voluntarily go and allow themselves to be hospitalized and say, "ok, I'm staying here." Secondly, I was never told what my diagnosis was, what my life expectancy was, what the possibilities were of me resolving my problems, as a professional, as a human person, after getting a diagnosis. I was never told the consequences of what it means to live with the diagnosis of a person with psychosocial disability: never. No one told me, in those forty days, what my diagnosis was, no one. No one told me what it meant to be a person with psychosocial disability. No one. (6:86)

This series of events is an example of how sexist medical treatment is established with "psychiatrized" women. For this reason the Chilean feminist collective has coined the phrase "it's not the same to be a crazy man as a crazy woman" to make visible how gender oppressions play a fundamental role in the psychiatrization of people.[59]

Rehabilitation: to function once again as a normative body

Rehabilitation and habilitation are central topics within the collective of dissident disabled people and one of the final occasions in which the medical apparatus operates directly upon the vulnerable body. This makes

it so that both rehabilitation and habilitation can be thought as a particular extension of medical treatment regarding bodily difference.

It is in this space where the predominant model of the situationality of the trajectories of the activists – widely described in the bibliography of disability studies – is shaped and explained; as is upheld by the rehabilitationist medical model,[14,17,19] if a medical-scientific problem exists, it does not necessarily need to be cured, but must obligatorily be repaired or rehabilitated. In synthesis: one must normalize, applying a corporal rule and norm.

The majority of critiques of the rehabilitationist model put forth by disability activism do not seek to dismiss specific and transitory needs for rehabilitation that certain bodily experiences might require, but rather to question the dominant understanding that the problems of people with disabilities have a single explanation and solution through the medical/health/rehabilitating sphere, overlooking and invisibilizing social, cultural, economic and political problems that structure the roots of the conflicts and situations. One activist offers her experience of the different stages of rehabilitation and their tension with normalization:

> I didn't imagine it. That is, I dreamt of course, and when they said there were protheses, I imagined them like a normal leg for you. I mean, geez, I would like to have a leg. And I said to myself, "ok, I have to just keep moving forward," but then the doctor says, "you know what, little one, I'm going to give you a pilón." A pilón was a wooden stick with plaster. Ok. "But you know what, sweetheart, I am doing your spinal column a great favor and you'll start preparing yourself for when it's time for the prothesis." And I had that for part of elementary school, part of middle school, until the first and second years of middle school. But there was a problem, as time went on and with all that walking, because I tried to have a normal life, the plaster would break

> down really quickly on the top, and there I'd be, stuck, wherever I was. And I had to ask for help, go home, and then the next day back to the doctor. (7:11)

The experience of this activist shows the precarity of the rehabilitation that existed in Chile in the 1980s and 1990s. The hopes people with disabilities had for their future and the lack of public policies for this collective generated the need to fight for the right to rehabilitation, which was and continues to be one of the main demands of activists.

The passing of Act 20.422 in 2010, which establishes "Norms for the equality of opportunities and social inclusion for people with disabilities,"[60] includes among its principles those of participation and social dialogue; nevertheless, the collective recognizes the lack of a practical legal framework that can materialize what is laid out in the law. This situation reflects the lack of interest on the part of the State and its institutions in generating a democratic and conversation-producing process with all its citizens.

Rehabilitation in Chile has a long history of precarity dating back to its origins, which served to justify the social construction of a culture of charity and beneficence associated with rehabilitation outside of any understanding of rights guaranteed by the State. Through public-private alliances, the collective has had to manage conflicting models and approaches. This tension makes it difficult to dismantle one of the most well-known organizations in the country related to rehabilitation, that emerged in the context of the civil-military dictatorship, known as "Teletón."

This organization works primarily with children and adolescents and collects funds through a very popular television campaign carried out once a year. It has a very perverse media impact in the cultural construction of the able body, as one female activist comments:

> When I was a girl [...] I remember that when we would go out with the other kids in wheelchairs: "Look, there's a

teletón, there's a teletón." So they didn't see you as a person, but as a teletón. And we would laugh. I even remember there was an old lady on the street who wanted to give us money and we had to tell her no. (7:56)

Within the critical proposals of disability activism is the demand that the different physical environments be adapted to the diverse characteristics of people or that balances be established. These proposals are often controversial, depending on whether or not the bodily change was acquired in the life course or if the bodies are diverse due to a congenital condition. In the latter case, activists make reference to the need for acknowledgement so as to participate based on their difference without the need for rehabilitation. On the other hand, a blind female activist says the following:

> *What we need, I think, is a good rehabilitation system because this allows for a very important bridge towards inclusion. If you aren't rehabilitated you can't be included, even if people want to. If from one day to the next I lose my hearing, I lose my sight, I break my back, my foot is cut off, how am I going to go out the next day, as someone who is included? It doesn't work like that, you have to rehabilitate yourself first, you have to take on the mechanism to live in a different way, because that's how it is.* (9:46)

In accordance with what we mentioned previously, in this narrative speaks to a position that represents a large group of activists who demand universal coverage for rehabilitation in order to reach the goal of "inclusion." This situation is posited as inevitable for obtaining full social participation, even as it is recognized that in the end a new life must be made.

The becomings that people with corporal difference embody are part of the medicalization of their lives that "impose a technology of self-management and management of the body"[61] and that therefore affects their intimate and public lives. The dissident activists' questionings of medical knowledge in all of its authoritarian processes in favor of a life with dignity, as Menéndez suggests,[24,25] is breaking down the historic asymmetry between "professionals" and "patients."

CONCLUSION

The bodily itineraries of dissident disability activists living in Chile allowed us to analyze the situations of vulnerability and corporal vulneration through which their lives pass in the apparatuses of the biomedical model. In this sense, the itineraries should be acknowledged as an ontological position of diversity. However, this matter is not unique to people labeled as "disabled" but rather is a position common to all people, as we are only temporarily "valid" and are continually exposed to the fragility of vulnerability.

Despite this, health apparatuses tend to fix vulnerability as an attribute of certain collectives through the construction of the medical diagnosis. In addition, we understand that this vulnerability is experienced differently in relation to gender, with medical conduct toward and treatment of dissident disabled women exacerbated due to their inhabiting a gendered corporal condition.

Similarly, we identified that the reality of the Chilean context and its connection to people in the situation of disability is constructed through precarized logics of a collective still invisibilized in the heterogeneity of its demands and struggles. This situation is reflected in the lack of public policies with a perspective of human rights that recognizes dissident disabled people as political agents of their condition and as co-definers of those policies, especially in relation to the identification of their needs and the ways to meet those needs. Despite these circumstances and contexts, the activists subvert these situations, freeing themselves from the biopolitical disciplining of the present-day neoliberal society and resisting the vulnerations of the system.

ACKNOWLEDGEMENTS

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