

**Original Article** 

# "I was raped inside, being in a place where I was supposed to be taken care of": Experiences of oppression and violence in health contexts towards women with disabilities and approaches from feminist occupational therapy<sup>1</sup>

"Yo fui violentada adentro, estando en un lugar que me tenían que cuidar": Experiencias de opresión y violencias en contextos de salud hacia mujeres con discapacidad y abordajes desde la terapia ocupacional feminista

"Eu fui violentada por dentro, estando em um lugar deveria ser cuidada": Experiências de opressão e violência em contextos de saúde em relação a mulheres com deficiências e abordagens da terapia ocupacional feminista

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#### **Abstract**

**Introduction:** The practices of violence in health contexts constitute one of the multiple manifestations of violence against women with disabilities. In Chile, as in the rest of the world, the development of studies on this violence is still incipient. **Objectives:** To characterize practices of violence against women with disabilities in

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health contexts, and to characterize experiences of vindication of human rights of this group of women in Chile, from the voices of activists and professional occupational therapists. Method: A secondary analysis of qualitative data from a study executed between 2015 and 2020 was conducted. From a qualitative approach and collective case study, a secondary thematic analysis of the data obtained from 8 interviewees was performed. Results: From the perspective of the informants, women with disabilities experience structural violence in a systematic and transversal way, which crosses other various forms of violence: physical, psychological, sexual, obstetric, and symbolic-institutional. The experiences of this group in claiming their human rights reflect processes of emancipation, resistance, and construction of practices that transform these violations. Conclusion: The practices of violence in health contexts toward women with disabilities in Chile is a situation visualized as manifestations of domination and oppression against them, which perpetuate their social exclusion and inequalities in health. Faced with this situation of social injustice, women activists and professional occupational therapists propose the need to implement strategies for the vindication of human rights, together with practices of collective resistance.

**Keywords:** Violence Against Women, Women's Health, Women's Rights, Occupational Therapy.

## Resumen

Introducción: Las prácticas de violencia en contextos de salud constituyen una de las múltiples manifestaciones de la violencia contra las mujeres con discapacidad. En Chile, como en el resto del mundo, el desarrollo de estudios sobre estas violencias aun es incipiente. Objetivos: Caracterizar prácticas de violencia hacia mujeres con discapacidad en contextos de salud, y caracterizar experiencias de reivindicación de derechos humanos de este colectivo de mujeres en Chile, desde las voces de activistas y profesionales terapeutas ocupacionales. Método: Se realizó un análisis secundario de datos cualitativos de un estudio ejecutado entre los años 2015 y 2020. Desde un enfoque cualitativo y estudio colectivo de casos, se realizó un análisis temático secundario de los datos obtenidos de 8 entrevistadas. Resultados: Desde la perspectiva de las informantes, las mujeres con discapacidad experimentan violencia estructural de forma sistemática y transversal, la que atraviesa otras diversas formas de violencia: física, psicológica, sexual, obstétrica y simbólica-institucional. Las experiencias de reivindicación de derechos humanos de este colectivo reflejan procesos de emancipación, resistencia y construcción de prácticas transformadoras de estas vulneraciones. Conclusión: Las prácticas de violencia en contextos de salud hacia mujeres con discapacidad en Chile es una situación visualizada como manifestaciones de dominación y opresión contra ellas, que perpetúan su exclusión social y desigualdades en salud. Frente a esta situación de injusticia social, mujeres activistas y profesionales terapeutas ocupacionales plantean la necesidad de implementar estrategias de reivindicación de derechos humanos, junto a prácticas de resistencia colectiva.

**Palabras clave:** Violencia Contra la Mujer, Salud de la Mujer, Derechos de la Mujer, Terapia Ocupacional.

## Resumo

Introdução: As práticas de violência em contextos de saúde constituem uma das múltiplas manifestações de violência contra as mulheres com deficiências. No Chile, como no resto do mundo, o desenvolvimento de estudos sobre esta violência ainda é incipiente. Objetivos: Caracterizar práticas de violência contra mulheres com deficiências em contextos de saúde e caracterizar experiências de reivindicações de direitos humanos deste grupo de mulheres no Chile, a partir das vozes de ativistas e terapeutas ocupacionais profissionais. Método: Foi realizada uma análise secundária dos dados qualitativos de um estudo realizado entre 2015 e 2020. A partir de uma abordagem qualitativa e de um estudo de caso coletivo, foi realizada uma análise temática secundária dos dados obtidos de oito entrevistadas. Resultados: Da perspectiva das informantes, as mulheres com deficiência experimentam a violência estrutural de forma sistemática e transversal, que atravessa outras formas de violência: física, psicológica, sexual, obstétrica e simbólica-institucional. As experiências deste grupo na reivindicação de seus direitos humanos refletem processos de emancipação, resistência e a construção de práticas que transformam estas violações. Conclusão: As práticas de violência em contextos de saúde em relação às mulheres com deficiências no Chile é uma situação visualizada como manifestações de dominação e opressão contra elas, que perpetuam sua exclusão social e desigualdades na saúde. Diante desta situação de injustiça social, as mulheres ativistas e terapeutas ocupacionais profissionais propõem a necessidade de implementar estratégias para a reivindicação dos direitos humanos, juntamente com práticas de resistência coletiva.

**Palavras-chave:** Violência Contra a Mulher, Saúde da Mulher, Direitos da Mulher, Terapia Ocupacional.

## Introduction

Violence against women with disabilities<sup>2</sup> is one of the most widespread human rights violations worldwide (United Nations, 2012, 2017). Various studies have deepened into this situation; however, during the last decade, its low visibility in the scientific literature has been emphatically denounced (Gomiz Pascual, 2016; Iniesta Martínez & Muñoz Sánchez, 2017; Pino-Morán & Rodriguez-Garrido, 2019; Serrato et al., 2018; United Nations, 2017).

Currently, violence against women is a violation of human rights, a social and health problem of epidemic proportions (Ferrer-Perez, 2017; Heise & Kotsadam, 2015; United Nations Women, 2020). One of its most accepted definitions is the one proposed by the United Nations through the Declaration on the Elimination of Violence against Women:

Any act of violence based on belonging to the female that has or may result in physical, sexual, psychological harm or suffering for women, as well as threats

<sup>&</sup>lt;sup>2</sup>In this manuscript, the term "woman, girl or young person with disabilities" is used as proposed by the United Nations (United Nations General Assembly, 2007). This decision lies in its preferential use by Chilean social organizations for disability, the authors' country of origin.

of such acts, coercion or arbitrary deprivation of liberty, both whether they occur in public life or private life (Organización de Naciones Unidas, 1994, s/p).

In 2011, the World Report on Disability (Organización Mundial de la Salud, 2011) declared that disability affected more than a billion people in the world, it was more prevalent in women, and that almost the fifth part of the global female population had a disability. Since then, the existence of a greater risk of violence in girls, young people, and women with disabilities was already recognized, as they are exposed to a greater number of oppressions (Moscoso, 2007; Serrato et al., 2018).

At the international level, the existence of specific barriers for women and girls with disabilities to report and confront violence has been recognized, such as those related to information, communication, credibility, or mobility, among others (Uruguay, 2013). Despite the greater risk of these women facing violence, there is currently underreporting of a large part of it (Iudici et al., 2019), because even if the information was sufficiently accessible, the mechanisms of power, stigma and existing discourses around women with disabilities act as mechanisms that make it impossible to report.

In particular, violence through abusive practices, inhuman treatment, and torture exercised against women with disabilities in health contexts, is another of its many manifestations (Millett, 1991; Morris, 1996; United Nations, 2012, 2017; Valls-Llobet, 2017; Yupanqui Concha & Ferrer Pérez, 2019). These practices of violence are related to a persistence of the medical-rehabilitative model of disability, enhanced by a predominant patriarchal model, which as a whole places women with disabilities in a diminished position in the social and gender order, for which their oppressions are usually made invisible (Serrato et al., 2018). Contrary to the guidelines provided by the Convention on Persons with Disabilities (United Nations General Assembly, 2007), in the world "[...] serious abuses continue to be committed in health environments, which often override the decisions of people with disabilities, based on their alleged best interest [...] or good intentions of health professionals" (Center for Human Rights & Humanitarian Law, 2013, p. xvii). Also, the exposure of people with disabilities to "[...] rape and sexual abuse, chaining to dirty beds [...] non-consensual medical treatment, unmodified use of electroconvulsive therapy and sanitation, and manifestly inadequate nutrition" (Center for Human Rights & Humanitarian Law, 2013, p. xvii). interventions that meet the criteria of torture.

A few years ago, the United Nations denounced the performance of forced medical interventions worldwide, that is, without the free and informed consent of girls, women, and young people with disabilities, such as forced contraception, abortion, and sterilization (United Nations, 2017), practices that also cover up other violence directed at this group, such as sexual violence (Yupanqui-Concha et al., 2021a, 2021b; Yupanqui Concha & Ferrer Pérez, 2019).

Scientific evidence has shown that much of this violence continues to exist in health contexts in Chile, such as electroconvulsive treatments (Cea Madrid & Castillo Parada, 2020), psychosurgery, prolonged isolation in cells without heating or basic services, physical restraints (Comité sobre los Derechos de las Personas con Discapacidad, 2016), violations of motherhood (Dehays et al., 2012, 2016), and various treatments administered without the full, and informed consent form of the woman (United

Nations, 2017), such as forced sterilization (Yupanqui-Concha et al., 2021b). In Chile, as in the rest of the world, the development of studies on this violence is still incipient (Yupanqui Concha & Ferrer Pérez, 2019).

We should highlight that in 2015, the Chilean State carried out the II National Study on Disability, which observed a clear predominance of disability in women over 18 years old, with 24.9% to 14.8% in men with disabilities (Instituto Nacional de Estadísticas, 2015). Despite having these statistical data on the number of women with disabilities in Chile, their needs in public policies and gender are still invisible (Pino-Morán & Rodriguez-Garrido, 2019). Another aggravating element of its low visibility in the country has been the adoption of Law 20,584 since its article 28 states that "[...] no person with mental or intellectual disabilities, who cannot express their will, may participate in scientific research" (Chile, 2012). This element, controversial to the National Research Ethics Committees (Oyarzún et al., 2014), has restricted the possibilities of generating scientific knowledge related to the health of an important part of this group.

For the occupational therapy profession, the unrestricted defense of human rights is the central axis of the paradigm that governs today. This was ratified by the World Federation of Occupational Therapists, declaring that people have the right to choose, not to be pressured, forced, or coerced, not to participate in occupations that may threaten safety, survival, or health and those occupations that are dehumanizing, degrading or illegal (World Federation of Occupational Therapists, 2019). In this context, the perspective of feminist Occupational Therapy has emerged to denature practices of injustice and eradicate practices of violence and oppression experienced by women and marginal groups in the world and, in turn, to generate resistance practices (Morrison & Araya, 2018; Lima, 2021). In Chile, our profession has had to face its political and social responsibility to rebuild a more just, inclusive, and caring country, in the face of the consequences that persist today inherited by our histories, such as discrimination, racism, and social inequities, evidenced especially in access to decent health for women with disabilities (Dehays et al., 2016). For all of the above, today our role and responsibility are clear in situations where people's rights may be violated, and the challenges we face today are related to the professional responsibility of identifying and addressing occupational injustices, as well as limiting the impact of such injustices experienced by people (World Federation of Occupational Therapists, 2019).

With the need to generate scientific knowledge on these issues in the country, together with the responsibility of the occupational therapy discipline in its approach, this study set out the objectives of characterizing practices of violence against women with disabilities in health contexts and characterizing experiences of claiming human rights of this group of women in Chile, from the voices of women activists representing groups of people with disabilities and professional women occupational therapists. Its central purpose has been to reflect on the need to promote occupational therapy practices of resistance and modification of this reality.

## Method

# Design

This research responds to secondary data analysis (Scribano & De Sena, 2009), which considers the reuse of qualitative data obtained in the research called "Violence

against women and girls with disabilities through forced sterilization: a human rights situation", corresponding to the doctoral research of the main author, carried out between 2015 and 2020. Following the approach of Corti (2000), on the use of secondary data, 'new questions for old data' are proposed by approaching them in a systematic way, different from the original address. Secondary data analysis has become widespread due to the challenges of conducting empirical research, including emerging global health crises such as COVID-19, which pose a barrier to recruiting participants. As O'Connor (2020, p. 280) argues, "[...] one of the problems that some scientists face [...] is the recruitment of populations [...] that are difficult to reach due to a myriad of social, cultural and cultural, economic and political reasons". Therefore, leveraging existing data to address new research questions can be beneficial to the advancement of science.

The original study (Yupanqui-Concha et al., 2021b) used a qualitative methodology, with a descriptive-relational scope of the discourses, together with the qualitative perspective of the collective case study (Stake, 1999).

Based on a phenomenological design, we sought to describe the experiences of women involved in the practices of violence studied to discover the common elements of shared experiences (Hernández et al., 2014, p. 493). It was also based on a feminist desing due to the need to develop an epistemology and research that started from the point of view of women (Harding, 1998), and as Jenny Morris (1993) points out, that would give a voice to women who have been absent of research and creation of knowledge, and at the same time, "[...] they have been reified and alienated as an object of research" (Cobeñas, 2018, p. 139).

This study corresponds to a secondary thematic analysis of qualitative data, obtained from an original study. It is intended to answer two new research questions for the original data: What characteristics do the practices of violence against women with disabilities have in contexts of health? What are the characteristics of the collective human rights claiming experiences? The themes and comprehensive approach of the original project are appropriate to the new research question.

## **Participants**

In this secondary data analysis, the following inclusion criteria were considered. For group 1: women over 18 years old, activist representative of groups of people with disabilities (with deficiencies in their physical, mental, intellectual, sensory, or multiple health conditions), with experience linked to practices of violence in care contexts in health in Chile. For group 2: women by profession occupational therapists, with at least one year of experience, linked to the claim of human rights of women with disabilities. For this study, 8 interviews with participants in the original study were analyzed. All of them met the inclusion criteria of the new study.

## Data collection method

The original study opted for the semi-structured in-depth interview instrument of the episodic type (Flick, 2004) because through it, it was possible to combine a thematic script and narrative elements. The interviews in their entirety were conducted by the main researcher, qualified, with 11 years of experience in qualitative research methods. They were carried out through videoconferences, in private contexts for the informants, the audios were recorded and later transcribed. The data was collected between March 2017 and February 2018. The main researcher was responsible for the custody of the audios and protected the confidentiality of the information throughout the process.

## Analysis of data

This secondary analysis of qualitative data was made from the transcripts and audios of the original study of the interviews included in the new one, which was used by the main researcher to avoid errors or omissions from the initial transcripts.

For the new question, we used the inductive thematic data analysis strategy, following the six phases proposed by Braun & Clarke (2006): (i) The authors became familiar with the transcripts of the data collected through successive readings and commented on the impressions that emerged. Then, in the (ii) initial code generation phase, the most relevant concepts recovered for each code were identified and classified. At this phase, the information collected was processed and coded with the Atlas.ti software version 8.4.0 (Friese, 2019). Once the entire text had been coded, the research team discussed and reached a consensus on the name of each unit of meaning. The third phase was the (iii) search for themes. At this phase, relevant codes and data were collected for each potential topic. Next, (iv) the review of topics, where all the fragments selected for each category were read, and the consistency of the categories was checked. It was also checked whether the codes were associated with the category to which they had been assigned. In the fifth phase (v), the definition and assignment of names to themes were carried out, a continuous analysis was made to perfect the details of each theme and the general history, which was aligned with the objective of the study, generating clear definitions and names for each theme. Finally, in the sixth phase (vi) preparation of the report, the categories of analysis were described, along with examples of extracts, in a narrative of the results related to the research question.

## Methodological rigor criteria

Regarding the rigorous criteria used in this secondary analysis, the authors had the advice of an academic committee, in which a theoretical reflection was carried out on the theoretical and methodological relevance of the original study to answer the new question of research. The authors developed a reflexive critical analysis from their feminist perspective and theoretical perspectives from the health and social sciences, literature review, note writing, and consensus meetings of the research team. All of the above allowed deepening the analysis of the experiences of violence of this group of women. Throughout the research process and the writing of the new report, we adopted the COREQ Consolidated Criteria for Qualitative Research Reports (Tong et al., 2007).

## **Ethical considerations**

The procedures carried out by this study respected the principles of the Declaration of Helsinki (World Medical Association, 2013). The original and larger study project

was approved by the Research Ethics Committee of the Universitat de Les Illes Balears (Number 1541/2017). The participants received information about the project, its objectives, and guarantees of respect for autonomy, anonymity, and confidentiality from the main researcher. Each person signed the informed consent form before their participation.

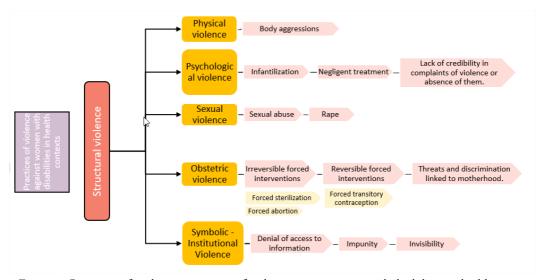
#### Results

In this secondary analysis, we analyzed 5 interviews with activists and 3 with professional occupational therapists. The average age of the participants was 41 years (between 27 and 56), their place of residence represents 4 regions of the country, contemplating the north (1), center (2), south (1), and austral (4). of Chile, and their years of experience linked to women with disabilities is 13 years on average. Among the main activities in which the study participants develop is activism, representing a civil society organization linked to disability, human rights advocacy, teaching, and community intervention.

The analyzes carried out will be presented based on the two main areas studied: (I) Practices of violence against women with disabilities in health contexts and (II) Experiences of occupational therapists who have collaborated with the claim of human rights in Chile.

## (I) Practices of violence against women with disabilities in health contexts

The categories were raised based on the information obtained on the experiences related to violence in health contexts by the informants. In this analysis, the main categories emerged: (1) structural violence, (2) physical violence, (3) psychological and/or emotional violence, (4) sexual violence, (5) obstetric violence, (6) symbolic-institutional violence (Figure 1). We will describe each one of them.



**Figure 1.** Categories of analysis on practices of violence against women with disabilities in health contexts. Source: Our elaboration.

## Structural Violence

This first category arises from all the informants and is defined as the violence that is produced through the deprivation of basic human needs (well-being, survival, freedom, among others), related to the health care received by this group of women, those that manifest in different ways depending on the particular characteristics of each of them, as can be seen in the following statements.

If a woman with a disability has not been forcibly sterilized and manages to get pregnant, and then achieves delivery, there are also protocols within the public health system that must be activated to alert the family courts so that the newly born child, be protected from her mother, that is, be taken away from her so that the State takes care of the baby because the State considers that a mother with a disability is a danger to her child (Interviewee 4, activist).

An example is seen in how the experiences of structural violence deprive this human group of basic needs and are revealed through inequality in the distribution, access, and use of resources, due to operative asymmetries of power between social groups that operate in this context. This category appears transversally and is at the base of the rest of violence: physical, psychological and/or emotional, sexual, obstetric, symbolic-institutional violence.

# **Physical Violence**

This category arises only from activist voices. It refers to experiences related to practices characterized by the use of force to achieve an end, especially to dominate or contain women, or to impose something causing pain. At this level, the bodily aggression subcategory emerges.

## **Body aggression**

They are defined as the use of excessive force to subdue a woman with a disability, emanating from health personnel, particularly in psychiatric settings.

The practices that they call therapeutic were abusive, abusive in forced restraints, in isolation, in solitary confinement, in physical and chemical restraints [...]. Recently there was a discussion of women with psychosocial disabilities on violence against women with disabilities by mental health services (Interviewee 1, activist).

They cannot have these containment protocols that are generalized, because they are used everywhere, and [name] denounced that, and nobody believed her in the Presidential Commission, and she said 'there are containment protocols that are naturalized in the institutions, especially in psychiatric hospitals', and people told her that they are no longer allowed, and she said 'it's done, here's the proof, it's also practiced! (Interviewee 5, activist).

These speeches denounce different types of aggression, emphasizing restraints and forced hospitalizations.

# Psychological and/or Emotional Violence

The second category is defined as psychological or emotional damage caused by one or more people or health institutions. Its subcategories are infantilization, negligent treatment, lack of credibility in the face of complaints of violence, or absence of complaints.

## Infantilization

This subcategory emerges from the discourses of activists and professionals. It is defined as the manifestation of violence reflected in the childish treatment of an adult woman in health contexts.

Little delivery of information by health professionals, nullifying this woman's ability to make her decisions about her health, even at some point a social science professional suggested that the baby of this disabled mother should be given in adoption at birth so that this mother would not notice (Interviewee 6, professional).

When I was hospitalized, I called him uncle, from the sweeper to the doctor, they were all uncles. The system infantilizes you, it does not give you power, and empowerment is also emancipation, of understanding that I am the owner of the construction and reconstruction of something (Interviewee 2, activist).

The diminution of power and undervaluation of the capacities of a woman with a disability through these practices is emphasized, along with the possibility of reversing it with access to feminist education.

# Negligent treatment

Subcategory that also appears from activist and professional voices. It is described as a breach of care protocols, causing medical negligence in health care contexts.

From forced sterilizations, which is the most critical, to anaphylactic shock, because the pregnant mental health patient is medicated and begins to suffer during childbirth, and they think she is making up that she feels bad and the partner ended up in anaphylactic shock. So, their children are born with hypotension, because they do cesarean sections and the mother is medicated, so the children are born blue and lose attachment. There is also no communication towards the mother because they understand that the mother is not in a position to do anything for her child. That does not happen to a mother who is sane or normal (Interviewee 2, activist).

# Lack of credibility in the face of complaints of violence or absence of complaints

This subcategory is recognized only from the speeches of activists. It is defined as the scant validation and acceptance of complaints of violence made by women with disabilities.

I have had to represent rape victims, women with severe cognitive disabilities, and with a social impossibility of rehabilitation in criminal courts and, therefore, communication for them is practically impossible. And also, the lack of credibility that her story has regarding the court is fierce (Interviewee 2, activist).

It is also conceptualized as the lack of complaints of violence by women with disabilities, due to fear caused by intimidation and pressure from the media or their aggressor.

From the social point of view, of course, there is the fear that later they will not be treated in the office, that they will be mistreated, that they will be marginalized even more than they are already marginalized [...]. So, it is super difficult to get these people to file a complaint, it is very, very difficult (Interviewee 4, activist).

In general, deficiencies in access to quality health that put their dignity at risk are reiterated.

## Sexual Violence

The third category appears only in the speeches of activists. It is defined as sexual abuse and rape by people who exercise care, or unknown. Its subcategories are sexual abuse and rape.

#### Sexual abuse

It is described as sexual activity or contact without consent, with emphasis on the asymmetry of power.

While in mental health, I was violated inside, being in a place that had to take care of me (Interviewee 2, activist).

## Rape

Sexual intercourse without consent, through threats or domination.

I was sterilized at the age of 30, after three children, because the last two were for rape by my ex-husband. In my case, my guardian was my ex-husband, the rapist. He didn't even care to sign... for the second time the medical board went and told him that her husband raped her and continues to rape her, and the next time she has a pregnancy she is going to kill herself (Interviewee 2, activist).

The expression of violent experiences of sexual connotation stands out, whose silence and impunity mark the life trajectories of these women.

#### Obstetric Violence

This category is distinguished by activists and professionals. It is described as the form of violence exercised by health personnel towards women, which can occur at different stages of their life cycle, in the context of sexual and reproductive health benefits and care, carried out without reasonable adjustments<sup>3</sup>. This category is subdivided into irreversible and reversible forced interventions, threats, and discrimination linked to motherhood.

#### Forced interventions of an irreversible nature

These are those medical procedures carried out in a forced manner, that is, carried out in the absence of the complete, informed consent of a person, or carried out despite express rejection. They are of a permanent and definitive nature and are exercised by health professionals, omitting the woman with a disability in the delivery of information. It is subdivided into forced sterilization and forced abortion.

#### Forced sterilization

Permanent and definitive contraceptive medical procedure applied without the consent of the woman.

For women with Down syndrome, all of them are offered when they go to clinics, and not only clinics but also in private consultations. Now I think that the most vulnerable one is the one who is in an institution, that woman is the most vulnerable because they sterilize her... but this is done daily in the clinics because it is like a covert State policy because I cannot believe that the President or the Minister of Health does not know, or that the Director of the Hospital does not know, how can he not know what is happening in his hospital, that is, it is something that the doctors agree should be done, and that the doctor who is doing it must be protected (Interviewee 5, activist).

This starts with the doctor, but there is also influence from the other moms who have already done the matter and the doctor has already done the procedure. Generally, they pass on the information about who did the procedure and they all go to that doctor [...] And that happens, it is happening. Not only with Down syndrome, but with any other disability it is the same. People disassociate from the problem by applying radical solutions, and they do not say so, and they enter the children for appendicitis and they come out sterilized (Interviewee 3, activist).

<sup>&</sup>lt;sup>3</sup>Concept coined by the Convention on the Rights of Persons with Disabilities that refers to the necessary and appropriate modifications and adaptations that do not impose a disproportionate or undue burden, when required in a particular case, to guarantee persons with disabilities the enjoyment or exercise, on equal terms with others, of all human rights and fundamental freedoms (United Nations General Assembly, 2007, p.5).

Another professional suggested sterilizing her during childbirth, without even asking or informing her. The same professional asked until when she was going to help her, that if she couldn't do it on her own, she couldn't be a mother and that her daughter was at risk (Interviewee 7, professional).

Over the years I have also witnessed stories of families that carry out forced sterilization processes, often suggested by the medical team, supposedly to prevent abuse; however, we know that this is far from being true. Adult women who think they are going to undergo polycystic ovary surgery or similar, however, it is a sterilization process that they are unaware of (Interviewee 7, professional).

These experiences, both of women activists and professionals, reflect that this practice is part of a network of violence that deepens oppression and inequalities in health for the collective. These experiences demonstrate how the hegemonic biomedical model acts with these women.

#### Forced abortion

Procedure for the premature termination of a pregnancy, carried out without the consent of the woman.

On one occasion a colleague had already lost a baby who went to the [health facility] and the doctor came to the emergency room. She was 4 months pregnant, and she told the doctor. Since she had a psychiatric history, the doctor asked if she medicated, she said 'yes, but when I found out that I was pregnant, I stopped taking medication'. And well, the problem was that they did the touch, according to the protocol it was done only from certain weeks, they did it the same because she was more than 4 months old, and that night at dawn she lost the baby. But, since she was a mental health patient, it is impossible to sue the system like that, because they made her appear as an interdict (Interviewee 2, activist).

## Reversible forced interventions

These are forced medical procedures, of a transitory or temporary nature, carried out without informed or accessible consent, carried out by health professionals, omitting the woman with a disability in providing the information.

## Forced transitory contraception

Use of a method or device for birth control applied without the woman's consent.

Relatives took their daughters to clinics and without a sign language interpreter, they told the girl to put her arm in and they introduced a pellet for contraception. But the girl did not know what the doctor was saying to her mother, or what the mother was saying to the doctor, all her will was impossible for her to intervene and without a sign language interpreter, she could give her consent (Interviewee 1, activist).

I met a 20-year-old woman who had become pregnant as a result of a love relationship of several years. Inquiring into her history, she had not received a clear education from the [health center] regarding the intake of her contraceptives, taking one or two pills a week, thinking that if they ran out, they would not give her more from the health center (Interviewee 6, professional).

## Threats and discrimination linked to motherhood

Subcategory that arises from activists and professionals. It is presented as the lack of recognition and contempt for the marital capacities of women with disabilities to exercise care for their daughters and sons, exercised by professional health teams, putting up resistance, and even threatening women with disabilities about who is/are suitable for the care of their sons and daughters.

I had to intervene with another woman with a hearing disability. She went with her family to the hospital when she went into labor, she was having contractions for several hours, without information, since she had no sign language interpreter. His partner, also deaf, was in the same situation. They did not allow her to carry her son, or her family, her hearing mother-in-law did not understand anything, she began to investigate and was told that they could not give her son to the couple, since they had informed the child protection office that the child was at risk, since being both deaf, they could not take care of the child (Interviewee 7, professional).

I had to intervene for the first time with a young mother with an intellectual disability, who faced a series of questions resulting from prejudices in society about her abilities to play a role as a mother, especially the teams of health professionals, at that time, they questioned her abilities day by day, blaming her, diminishing her abilities, invalidating her, and frightening her by taking her daughter away from them for not being "normal" (Interviewee 7, professional).

Complaints by professional teams to remove sons and daughters of mothers with disabilities, without objective evaluations and without incorporating reasonable adjustments in the processes. Women who have experienced the loss of their unborn babies, without providing clear information and with little support from the health institution (Interviewee 6, professional).

These findings identify systematic and hegemonic practices by health teams, where substitution predominates in decision-making and/or coercion towards these women.

# Symbolic-Institutional Violence

Category defined by activists and professionals. It is seen as the systematic imposition of power and violence, based on the prejudice of superiority and inferiority of certain institutions on social groups concerning health care. It is made up of the subcategories of denial of access to information, impunity, and invisibility.

#### Denial of access to information

Subcategory raised by activists and professionals. It refers to the manifestation of violence that consists of limiting access to information in some area of the daily life of a woman with a disability, or if it is delivered, it is carried out without reasonable adjustments based on national and international legislative standards, causing control of information by health professionals, which limits autonomous and informed decision-making.

I was a witness to that when the young woman spoke that possibly, perhaps, she could have children because she felt that she was qualified to do so, and her mother called me aside and told me that she does not know that she does know she cannot have children. In other words, they do not even know as adults that they are sterilized, they are not informed of that either (Interviewee 5, activist).

Most of the women belonging to labor workshops, who did not receive comprehensive sexual education and therefore, when they were taken to a gynecological procedure, they were not informed or explained what procedures they were going to undergo (Interviewee 8, professional).

# **Impunity**

Subcategory recognized by activists only. It refers to the non-existence of sanction or punishment in the event of an offense or crime in health contexts, or when health teams, witnessing practices of violence, do not make the respective complaints.

There are few convictions for doctors who perform these complicated procedures [forced sterilizations], and few are successful because of the affiliations that the doctors have, which is not with a political party or religion, but with the environment in which they operate. with other doctors, with a line of protection, of lawyers, in the shadows, she is the one who makes the decisions of everything. It is older than ourselves (Interviewee 3, activist).

It turned out that in less than a week when I had to see her again, she tells me Mrs. [name], I have to apologize. I didn't know what she was talking about, and it was because they had taken out the page, who was she? nor did she know. They took the information that I had been abused inside the institution and that was for a summary. My guardian should have sued the health service of the regional hospital, they would have compensated him. But that had to be covered. And she let those papers disappear. And that can happen with many of us (Interviewee 2, activist).

So, what criteria does the medical board use and what criteria does the doctor use of not denouncing the rapist, putting him in jail, putting the records in a prosecutor's office, but they prefer the lesser evil, which was me (Interviewee 2, activist).

## Invisibility

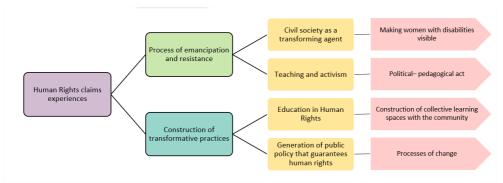
It is a subcategory viewed only by professionals. It is defined as the manifestation of violence exercised by the State regarding not protecting the rights and not meeting the needs of women with disabilities.

The invisibility of women with disabilities by the State in its public policies also constitutes a violation of their human rights and often in the structural violence they must face in their daily lives (Interviewee 7, professional).

The stories describe health care that lacks a human rights approach. Therefore, they do not guarantee access to a basic right for this population.

# (II) Experiences of claiming the human rights of women with disabilities in Chile

This analysis is based on the discourses of the informants, emerging the following main categories: (1) processes of emancipation and resistance, and (2) construction of transformative practices (Figure 2), described below.



**Figure 2.** Categories of analysis on experiences of claiming the human rights of women with disabilities in Chile. Source: Our elaboration.

# Processes of Emancipation and Resistance

They are the actions of change, organizational, mobilizing, and collective at the community level, identified by the participants, mostly professional women occupational therapists.

# Civil society as a transforming agent

Subcategory viewed by activists and professionals. It is described as the set of transformative actions of inclusion, participation, and empowerment of women with disabilities in various contexts of their daily lives, exercised by civil society.

During the years of exercise I have been able to visualize and learn about various initiatives and proposals for the vindication of human rights of women with disabilities in Chile, most of them come from civil society, from the activism of

women with disabilities, their families and/or professionals who have managed to visualize the problem and who have been interested in addressing it (Interviewee 7, professional).

On the other hand, support the leadership training of empowered women with disabilities as active agents of social change, in addition to providing tools for the prevention of violence against women in the various contexts in which they operate (Interviewee 6, professional).

Mental health belongs to the people, I believe that as long as we do not learn to work with each other horizontally and not vertically, mental health will continue with this same paradigm (Interviewee 2, activist).

They state that the resistance processes are led and supported by the community, in which organizations of and for people with disabilities have played a relevant role.

## Teaching and activism

Subcategory raised by the professionals. It is conceived as the political-pedagogical act, a space that promotes critical thinking, articulating processes of understanding and transformation of reality and resistance in which multiple knowledge and diverse knowledge are intertwined towards the defense of the rights of the collective.

We have developed various activities from teaching through the incorporation of this theme in various undergraduate subjects, installing these themes as relevant in professional work, in addition to carrying out urban interventions from 2014 to date, every November 25 making visible the International Day for the Elimination of Violence against Women, emphasizing the barriers and violence experienced by women with disabilities, such as forced sterilizations, discrimination, violation of rights regarding motherhood, among others. On the other hand, interweaving activism through the voices of women with disabilities in teaching settings enriches the delivery of knowledge (Interviewee 6, professional).

Install the issue of disability and gender violence from school education and at the university, regardless of the profession. It is extremely important to understand that people, especially, women with disabilities have rights just like other people, regardless of their condition. In this context, it is essential to incorporate this area of education and training (Interviewee 8, professional).

From training specifically in the area of occupational therapy, it is suggested that training, tools, strategies, etc. be provided from the first year concerning the theme, and how one can be an agent of change when they encounter situations of violation of the rights of women with disabilities (Interviewee 8, professional).

The speeches focus mainly on the university training of occupational therapists and other professions, to promote their ethical-professional commitment and activism in their work.

## Construction of Transformative Practices

They are seen as actions of change with a territorial approach located in the local realities of girls and women with disabilities. This category appears in the speeches of professionals.

# Human rights education

It is defined as the construction of collective learning spaces with the community, from horizontality and participatory strategies, involving various actors, from and towards women with disabilities, families, professionals, university students, authorities, and organizations of the State.

Transversal education in human rights is the starting point to continue raising awareness of various types of violence experienced by women with disabilities, especially to families and professional teams from various areas: health, education, justice, etc., and to raise awareness among professionals about the rights of people with disabilities, people who run State institutions, both locally and nationally, Seremis, regional directors of various services, mayors, governors, even from a more macro perspective, professional teams of the various ministries or legislators. All this to create public policy according to the needs of women with disabilities (Interviewee 6, professional).

These exchanges of knowledge take place with an emphasis on making the needs of women with disabilities visible.

## Generation of public policy that guarantees human rights

It is described as the generation of instances of problematization about the needs of women with disabilities concerning the programmatic offer offered by state institutions in central areas of their daily lives.

It is frustrating to see how the years have gone by and this issue remains the same, professional teams, including civil society organizations, having to apply for competitive funds to work on issues as relevant as gender violence (Interviewee 6, professional).

It is the responsibility of the State to address this issue, in the first place, generating these public policies, allocating resources so that the programs that exist are accessible and reach all people, including women with disabilities, and support the work carried out by organizations of civil society, groups of women with disabilities, families and/or professionals (Interviewee 7, professional).

In summary, the informants show the experiences related to practices of violence in multiple forms and systematically in health contexts towards women with disabilities in Chile, which are viewed as manifestations of domination and oppression against them, which perpetuate their social exclusion and inequalities in health. Faced with this situation of social injustice, women activists and professional occupational therapists

raise the need to implement strategies to claim human rights, together with practices of collective resistance.

#### Discussion

This study aimed to characterize practices of violence against women with disabilities in health contexts, along with experiences of claiming human rights of this group of women in Chile, from the voices of women activists representing groups of people with disabilities and women professional occupational therapists. The purpose has been to reflect on the need to promote occupational therapy practices of resistance and modification of this reality.

The participants revealed that the practices of violence towards women with disabilities in health contexts are recurrent. Their speeches show that, in the environments where they operate, women with disabilities experience structural violence in a systematic and transversal way, which crosses other various forms of violence: physical, psychological, sexual, obstetric, and symbolic-institutional, evidenced in health policies of control, coercion, and torture towards these women in health contexts.

They report that the visualized practices are characterized by the abuse of power relations and by strategies of domination over them, which replicate dominant patriarchal models of inequality and discrimination, as well as capitalist, patriarchal, and colonial models, which endorse, justify, and make invisible the various types of violence against these women.

The experiences of claiming human rights of this group that emerge from the discourses analyzed reflect processes of emancipation, resistance, and construction of transforming practices of these violations, where the focus has been civil society as a transforming agent, teaching and activism, education in human rights and the generation of public policy that guarantees human rights.

These findings are related to the approach of various authors regarding the abusive experiences that women with disabilities have experienced when facing health care (Cruz Pérez, 2015; González, 2010; Mogollón, 2002; Peláez Narváez et al., 2009). They highlight the presence of components that violate the basic and fundamental rights of this social group since when gender, disability, and other multiple identity characteristics intersect, they are exposed to a greater number of oppressions and social exclusion. These results are in line with international studies on abusive experiences of women in health care, which indicate that "[...] 63% had experienced violations of ethical principles by staff at some point, and many of them perceived these acts as abusive and illicit" (Brüggemann et al., 2012, p. 750). Along the same lines, Brüggemann & Swahnberg (2013), assert that experiences of abuse of women in health care were preceded by lost power struggles, mainly due to the use of domination techniques by health personnel.

From a feminist theory, the perspectives of intersectionality and decolonialism make it possible to make the theoretical and conceptual opening to understand how the systems of domination and the axes of exclusion are articulated in the contexts studied, allowing the elimination of universalist generalizations and the classic essentialization of the notions 'disability' and 'woman', since this only favor the reproduction of social exclusion dynamics by isolating gender or disability from other axes of inequality to

which they are exposed (Cubillos, 2017) and that are visualized in this study. In this way, it is possible not to privilege some inequalities over others, but rather to understand them in a close relationship, and finally, the real complexity of the impact of intersectional discrimination and violence to which these women are subjected. With these references, it is appealed to put a value on those subalternate subjectivities that have been historically excluded and silenced in the constitution of social reality, in the generation of knowledge about their health and about the violence they experience.

The exposed findings show the importance of visualizing the harmful effects of the homogenized, stereotyped, and biased vision of women with disabilities in health contexts because it places them on the path of infantilization, undervaluation, and disempowerment, on many occasions denying basic information, without the reasonable adjustments necessary to make decisions independently regarding their health, and with unmet needs in this area. For this reason, it is more urgent to value the real incorporation of inclusion and intersectionality in public social and health policies, as a basic element of social justice, which allows them to address in a unified way the issues of violence, sexual and reproductive health, gender and disability, in a society of growing health inequalities (Couto et al., 2019).

Critical literature on the explanation of violence ensures that one of its limitations is that it tends to create the false impression that women (with disabilities) have limited to being victims, or that they have never successfully protested, that they cannot be effective social agents in favor of themselves or others (Quintero & Fonseca, 2008, p. 8). However, this must be modified with the approach to the problem, because by denouncing, analyzing and reflecting on these practices of violence, it becomes possible to critically visualize these realities present in the national context, and even allow the assessment of activism of people with disabilities, those who, through social mobilizations, permanently demand vindicating and remedial actions, such as *Movimiento en Defensa de Nuestra Salud Mental*,

[...] el Círculo Emancipador de Mujeres y Niñas con Discapacidad de Chile (CIMUNIDIS), el Colectivo Palos de Ciegos, el Colectivo Locos por Nuestros Derechos, el Observatorio de Derechos Sexuales y Reproductivos de Personas con Discapacidad (ODISEX), el Colectivo Autogestión Libre-Mente, among others, are some of the genuine community expressions (Pino-Morán & Rodríguez-Garrido, 2017, p. 191).

From a disciplinary context, the invitation is to position from a critical and feminist occupational therapy, which exercises its political and social role of promoting the claim and collective struggle for the defense of the human rights of this social group and all those marginalized groups and oppressed, giving space to the appreciation and promotion of the activism of these social groups as part of the daily practices and resistance of the occupational task. Frank & Muriithi (2015) propose the concept of occupational reconstruction, to emphasize a non-traditional way of studying, designing, and evaluating community interventions that promote decolonization, participation and inclusion, empowerment, activism political practices, equal rights, and social justice. Therefore, the strength that falls on the collective and cooperative participation of civil society, as a transforming agent of social struggles, is essential in situations of

violation of fundamental rights. In this sense, maintaining a close relationship between activism and the academy is vital to favor respect for human rights in the global approach to teaching in the profession, where multiple knowledge and diverse knowledge are intertwined, with emphasis on the visibility of the needs of women with disabilities as full subjects of rights, valuing their self-determination, autonomy, and independent life, from ethical-political actions that guarantee full social inclusion.

Complementing the above, it is relevant to highlight the occupational awareness raised by Ramugondo (2015), a term that is defined as the "[...] continuous awareness of the dynamics of hegemony and recognizes that the dominant practices are sustained through what people do daily with implications for personal and collective health" (Ramugondo, 2015; Sonday et al., 2019). In this way, valuable and key guidelines are provided that relate understanding to processes of recognition of practices of domination, abuse of power, and inequality, present in the hegemonic biomedical model, which is usually normalized by health personnel. Faced with the realities exposed in this study, the possibility of generating transformative awareness of health systems or practices, through which violence is exercised, is transcendental. As the author states, occupational awareness is a tool that can be adopted, as a transgressive act, to interrupt the cycles of oppression. For this reason, occupational awareness is probably the most powerful mechanism for the resistance and promotion of the empowerment of these women.

We also highlight the importance of activist and feminist research from our profession, as a powerful way of denouncing and fighting against highly discriminatory, exploitative, and unjust situations. From this place, it is also possible to generate actions that challenge the structures and systems of power.

This study also has its limitations. The qualitative approach used limits the possibilities of generalization, and the low number of participants in a context and topic full of difficulties to access the participants.

The practical implications are related to the identification and prevention of colonial practices of racism, abuse of power, and other violence against women with disabilities that prevail in the health systems where the occupational therapist can work, together with stressing the institutions that systematically perpetuate these multiple forms of violence. From this perspective, it is transcendental to think of a feminist Occupational Therapy that works in coordination with social movements and activism, a strategy that would allow a more committed perspective on social transformations and daily professional practice.

## Conclusion

The practices of violence in health contexts toward women with disabilities in Chile are situations viewed as manifestations of domination and oppression against them, which perpetuate their social exclusion and health inequalities. Faced with this situation of social injustice, women activists and professional occupational therapists raise the need to implement strategies to claim human rights together with practices of collective resistance.

This work contributes to raising awareness of the responsibility of occupational therapists in the prevention and interruption of cycles of oppression, the propagation of

transformative consciousness, systems and practices of resistance through feminist occupational therapy, activist research, and the promotion of social justice.

Finally, as Pino-Morán & Tiseyra (2019, p. 512) put it, we agree with the idea of opening the invitation to "[...] highlight the acts of resistance that take place in the 'south' from a place of recognition and careful listening of knowledge and praxis". Our call is to value and unite these transformative efforts.

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## **Author's Contributions**

The main author was responsible for the design and data collection of the study. All the authors contributed to its conception, data analysis, theoretical discussion of results, and production of the document. All authors approved the final version of the text.

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