

Original Article

# The personal is political: a feminist analysis of the daily experience of informal female caregivers of adult people in dependence situation, in Santiago de Chile

Lo personal es político: un análisis feminista de la experiencia cotidiana de cuidadoras informales de personas adultas en situación de dependencia, en Santiago de Chile<sup>1</sup>

# O pessoal é político: uma análise feminista da experiência cotidiana de cuidadoras informais de pessoas adultas em situação da dependência, em Santiago de Chile

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# <u>Abstract</u>

**Introduction:** The article raises, from a feminist perspective, how the growing crisis of care, accentuated in neoliberal states, generates an absorption of this problem by women, especially when it comes to dependent adults. **Objective:** To describe the daily life of informal caregivers of dependent adults, in addition to the effects that this work has had on their lives. **Method:** Qualitative research, framed as critical and feminist, which has included the semi-structured interview and participant observation of the daily life of 7 informal caregivers in Santiago de Chile, between 2018 and 2019. **Results:** A complex web of activities was identified that make up the daily life of care work, which produces a great level of overload on caregivers. In addition, multiple effects were evidenced in their daily lives, which include those of a personal, family, and economic nature. **Conclusions:** The sexist social organization of care produces gendered occupations as its effect, evidencing the socio-historical character that generates precarious daily lives for women who undertake care work for dependent adults in an informal way as a political and not personal problem.

**Keywords:** Gender-Based Division of Labor, Activities of Daily Living, Disabled Persons, Gender Perspective, Feminism, Occupational Therapy.

# <u>Resumen</u>

**Introducción:** El artículo plantea, desde una perspectiva feminista, cómo la creciente crisis del cuidado, acentuada en Estados neoliberales, genera una absorción de esta problemática por las mujeres, especialmente cuando se trata de personas adultas en situación de dependencia. **Objetivo:** Describir la cotidianidad de cuidadoras informales de personas adultas en situación de dependencia, además de los efectos que este trabajo ha tenido en sus vidas. **Método:** Investigación cualitativa, enmarcada como crítica y feminista, que ha incluido la entrevista semiestructurada y observación participante de la cotidianidad de 7 cuidadoras informales en Santiago de Chile, entre 2018 y 2019. **Resultados:** Se

<sup>1</sup> This article is a synthesis of the research entitled "The personal is political: experiences of women caregivers of dependent adults in Santiago de Chile", developed between 2018 and 2019 in Chile, to obtain the Master's degree in Gender and Culture Studies, from the University of Chile.

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identificó una compleja trama de actividades que componen la cotidianidad del trabajo de cuidados, que producen gran nivel de sobrecarga en las cuidadoras. Además, se evidenciaron efectos múltiples en sus cotidianidades, que incluyen los de tipo personal, familiar y económico. **Conclusiones:** La sexista organización social del cuidado produce ocupaciones generizadas como efecto, evidenciando el carácter sociohistórico que genera cotidianidades precarizadas para las mujeres que asumen el trabajo de cuidado de personas adultas en situación de dependencia de modo informal, como problema político y no personal.

**Palabras-clave:** División del Trabajo Basado en el Género, Actividades Cotidianas, Personas con Discapacidad, Perspectiva de Género, Feminismo, Terapia Ocupacional

# <u>Resumo</u>

**Introdução:** O artigo propõe, a partir de uma perspectiva feminista, como a crescente crise de cuidado, acentuada nos estados neoliberais, gera uma absorção desse problema pelas mulheres, principalmente quando se trata de adultos em situação de dependência. **Objetivo:** Descrever o cotidiano de cuidadoras informais de adultos dependentes, além das repercussões deste trabalho em suas vidas. **Método:** Pesquisa qualitativa, classificada como crítica e feminista, que realizou entrevistas semiestruturadas e observação participante do cotidiano de 7 cuidadoras informais em Santiago do Chile, entre 2018 e 2019. **Resultados:** Foi identificada uma complexa teia de atividades que compõe o cotidiano do trabalho de cuidado, que produz alto nível de sobrecarga para as cuidadoras. Além disso, foram evidenciados múltiplos efeitos em seu cotidiano, que incluem os de ordem pessoal, familiar e econômica. **Conclusões:** A sexista organização social do cuidado produz como efeito ocupações generizadas, evidenciando o caráter histórico-social que gera cotidianidades precárias para mulheres que realizam informalmente trabalhos de cuidado de adultos em situação de dependência, como um problema político e não pessoal.

**Palavras-chave:** Divisão do Trabalho Baseado no Gênero, Atividades Cotidianas, Pessoas com Deficiência, Perspectiva de Gênero, Feminismo, Terapia Ocupacional

# Introduction: care as a political problem

We witness worldwide, a growing social crisis regarding care based on what the theorists of feminist economics have called the capital-life conflict, that is, the incompatibility between the sustainability of life, with the neoliberal capitalism socioeconomic model in force (Pérez, 2014). Issues such as the progressive dismantling of welfare states at the global level, the active participation of women in paid labor markets, the privatization and the commodification of the care offer, the increase in population aging, and the prevalence of disability situations have created hostile scenarios for the development of care activities, and most of them continue to be assumed by women, reproducing a sexist social care organization (Gonzálvez, 2018).

According to the National Time Use Surveys (*ENUT*) developed in different Latin American countries by the Economic Commission for Latin America and the Caribbean (ECLAC), there is a pattern that shows that despite the increase in paid female labor participation, male participation in domestic and care work has not increased (Instituto Nacional de Estadísticas de Chile, 2016). According to ECLAC "the conciliation between work and family life based on the redistribution of care tasks between the State, the market and families continue to be the blind spot of public policies in Latin America and the Caribbean" (Comisión Económica para América Latina y el Caribe, 2011, p. 29), a matter of little encouraging prognosis, since it is also expected that:

In the coming decades, the aging process of the population of the region will worsen and, therefore, the care for older adults, the chronically ill people, and people with disabilities will increase, and the costs of health care and pension systems will rise (Comisión Económica para América Latina y el Caribe, 2017, p. 19).

In Chile, this crisis has been intensifying because in addition to contemporary demographic changes characterized by the decrease in birth rates and the increase in life expectancy, a rigid sexual division of labor persists in the households that assume the care gaps that the State does not guarantee

(Durán, 2011; Batthyány, 2015; Fraser, 2016). Chilean public policies underwent a radical change of focus after the civic-military dictatorship starting in 1973, dismantling the various advances that had been made towards a Welfare State, in pursuit of the installation of a profound neoliberal model after privatizing a series of basic social rights (Arriagada, 2004; Arriagada & Todaro, 2012). The inclusion of public policies aimed at caring for adults who are in dependency situations - which is the focus of this research - is extremely recent and with a very little scope at the national level. In 2016, Chile Cuida was created. It is the country's support and care system included in the social protection system (Chile Cuida, 2020) that offers a support program for the care of people in a situation of dependency, especially for adults and the elderly people, people with disabilities, and their caregivers. However, this program has a series of access barriers: (1) it is only developed in 21 communes<sup>2</sup> of the country, which means 6.06% of the national total (346 communes); (2) it is only aimed at the 60% of the most vulnerable households in the country that have one member in a situation of dependency (according to the Social Registry of Households); and (3) the program does not provide daily care services but only offers "relief for the caregiver", which implies that to become effective there must already be the main caregiver, to whom the program gives some relief in a few hours during the week.

We observe a series of problems here, ranging from structural determinants that keep the right to health municipalized, providing differentiated services to the inhabitants of the various communes of the country; and also the care for people in a situation of dependency is conceived as an issue related to poverty that continues to highlight the problem as a private issue, which must be resolved by each family - and especially - by the women from each family. According to the National Study of Dependency in Older People carried out by the Servicio Nacional de Adultos Mayores (2010), 85.6% of caregivers of older people with dependency are women. In the case of disability, according to the data provided by the Second National Disability Study (*ENDISC*) carried out by the Servicio Nacional de Discapacidad (2015), 73.9% of the caregiver of people with disabilities are women of which 77.1% are family members and/or relatives who live in the same home as the person with a disability without getting paid for this care (only 6.4% state that they receive some remuneration).

We should consider that many daily activities<sup>3</sup> characterize the work of caring for people in situations of dependency, from carrying out activities that guarantee subsistence such as eating or going to the bathroom, to activities that allow maintaining social ties such as those linked to social participation. In particular, the fact that care work involves the performance of basic, repetitive, and daily activities implies that women who undertake this work must dedicate exclusively to them, having a little possibility of articulating these activities with paid work, given the inflexible found (Carrasquer et al., 1998). In this sense, the high demand for this type of work is highlighted by its daily type and rigidity, requiring exclusivity and intensifying gender inequalities for the women who assume it (Rogero, 2010).

In Chile, there are non-state citizen initiatives dedicated to making care work visible as a political issue. These initiatives are mostly organized and promoted by women caregivers of people living in dependency situations. Among them, we can find "I take care for caregivers" and "Mom Therapist". In 2018, these organizations conducted an online survey of informal caregivers, entitled "First Survey Report on informal caregivers" (Fundación Mamá Terapeuta & Asociación Yo Cuido, 2018), which indicates that 97.7% of the people who care informally are women, considering a total of 906 surveys. Of this total, 77% declared having had to stop a paid working for assuming the role of informal caregiver, which immediately shows the impoverishment and job insecurity. That is why this research aimed to know the daily life of care work, and the effects generated in informal caregivers of old adults in situations of dependency, from a feminist reading.

# Theoretical Approaches to Care Work: A Feminist Perspective

Trying to draw conceptual boundaries for care work is extremely complex, precisely because one of its characteristics is having fuzzy limits, which overwhelm it as a solely bodily or mechanical act,

<sup>&</sup>lt;sup>2</sup> In Chile, a commune is the most basic territorial unit of the country's administrative-territorial division, which is administered by a Municipality or Municipality, whose leaders are elected through popular suffrage of its inhabitants every 4 years.

<sup>&</sup>lt;sup>3</sup> As an epistemic decision, I have chosen to call "daily activities" to that group of activities that from the Anglo-Saxon tradition have been called "Activities of daily life", in their "basic" and "instrumental" drifts. This, to accompany the criticisms of authors such as Galheigo (2003, 2012, 2020), Medeiros (2008) and Palacios (2016), who denounce the fragmentation and depoliticization that Anglo currents have impressed on the profession, taking for granted as a matter neutral and ahistorical the relationship that human activities have with daily life, in which a network of power relations operate that in turn produce human activities as their effect

in which we can observe concrete and determining actions that can be quantified (Morini, 2014). On the contrary, care work is *untranslatable* to this logic and can be understood as emotional work since rather than producing an object as a result, it produces life and well-being (Morini, 2014). According to Gonzálvez (2018, p. 200), care work is "any activity –direct or indirect– that enables the multidimensional well-being of people, facilitating the development and maintenance of daily life", which can be characterized from three subtypes of differentiated activities that compose it. For the feminist economist Pérez (2014) it would be (1) direct care activities, which imply a direct relationship between bodies and emotions; (2) activities that provide material preconditions for care (such as housework); and (3) mental management activities, associated with the control, evaluation, planning or supervision of the care process.

We need to emphasize that, from the feminist economy, care is a basic and transversal need to live, coming from our vulnerable human condition that requires a series of continuous actions to maintain life (Arendt, 2003; Nussbaum, 2006; Carrasco, 2017). Thus, care is not linked exclusively to people who require some type of support due to their age, health condition, or who experience disability, but it is an irrefutable need as part of the human condition. This consideration is fundamental since it allows to displace that claim of autonomy and self-valence that economic and social relationships assume from a stereotypical subject projected as universal (Nussbaum, 2006). Thus, rather than thinking in a binary way that there is only dependence, as a pathological state outside of a certain functional norm, and autonomy, as a state associated with normality, we need to consider that "people are not autonomous or dependent, but that we are placed in different positions in a continuum of interdependence" (Pérez, 2006, p.14).

As human beings of needs, we must inevitably articulate permanently, both with other individuals and with nature to be able to provide social responses that are linked to our fundamental needs (Pampliega De Quiroga & Pichon-Rivière, 1985). How each society is articulated to respond to these care needs, through several agents and mechanisms, corresponds to the *social organization of care*, which includes actors such as families, communities, the State, and the market (Gonzálvez, 2018). In neoliberalist societies, where States increasingly subtract from their responsibility to respond to care needs, through systematic structural adjustment policies, a gendered institutional architecture has been generated (Comas-D'Argemir, 2017; Gonzálvez, 2018), where women absorb the tensions and crises from a neoliberal model that does not guarantee conditions for care (Fraser, 2016).

This gendered architecture permanently produces gender relationships as its effect, *requiring* them as part of the economic and socio-sexual organization that sustains a certain daily life (Grandón, 2018). Therefore, it is interesting to link care work with everyday life since it can be understood as a *mirror of history* (Heller, 1987), in which we develop and appropriate the skills we require to operate effectively in the daily life corresponding to our historical moment, appropriating at the same time social, economic and political structures, a question that allows us to reproduce a given socioeconomic order (Pampliega De Quiroga & Pichon-Rivière, 1985). Thus, in everyday life we manifest the social relationships that regulate our life in our time (Pampliega De Quiroga & Pichon-Rivière, 1985), gender relationships being a fundamental link to sustain and reproduce a phallus/capital centric economic model that establishes a socio-economic organization. that permanent usufruct of the invisible work of women (Cameron & Gibson-Graham, 2003; Federici, 2018). Thus, everyday life can be understood as an embodiment of the network or structure of relationships that we sustain through our life practices, where we must recognize that:

Patriarchy and capitalism are not separate objects from their producers, their objective reality is sustained by human beings in their life practice, and they last as long as the life practice of human beings who embody that structure of relationships (Izquierdo, 1998, p 219).

However, everyday life should not be understood as something since we passively introject since it has a dynamic and paradoxical character, while those activities we carry out to shape the world, in turn, shape us as individuals (Heller, 1987). This *formative* aspect of everyday life shows how it constitutes the scenario in which we develop human occupations and/or activities that, at the same time, create the world, which in epistemological terms allows us to displace the understanding of social reality as an objective and natural reality, and, rather, evidences the paradoxical nature of human occupations since they are the producers of the world that, at the same time, produces them (Rubio & Sanabria, 2011). Thus, "the world in which we were born would not exist without the human activity that produced it" (Arendt, 2003, p. 37). By positioning everyday life as an incarnation and a stage for the reproduction of social structures and relationships, we need to understand it together with the idea of common sense, because through this, social structures and relationships make sense and are assumed as natural issues. The examination of common sense that organizes daily life is a critical and political act insofar as "what was previously taken for granted, what was supposed to be common sense knowledge, normality" (Izquierdo, 1998, p. 16). That is why the critical examination of daily life can denature what has been claimed as essential to turn it into a *contingency*, that is, something that can be intervened (Izquierdo, 1998).

From this point of view, we can observe that the feminization of care work - understood as a *gendered occupation* (Grandón, 2018), is not given by essence or natural attribute of femininity, but rather responds to a contingent historical construction, crystallizing the gender relationships that produce and reproduce an economic order founded on inequality, based on a rigid sexual division of labor, in which men are associated with the productive/commercial/public and women with the reproductive/domestic/private (Pérez, 2006). The tasks of reproduction and care have been imposed since its biologist naturalization, as stated by Federici (2013, p. 39) when pointing out that "once domestic work is naturalized and sexualized, once it has passed to be a feminine attribute, all of us as women are characterized by it". In this sense, domestic and care work becomes an archetypal construction of being a woman, which is reproduced by social structures, through a series of devices of socialization (Palacios, 2016) that produce care occupations as feminized labor (Vidal et al., 2017). This causes that, by assuming unpaid work as a *naturally* feminine attribute, it is not considered as work, but as a mandate or a feminine duty-to-be crossed by moral responsibility for others.

Therefore, the daily life of women is part and sustains an economic-sexual structure, which, by freely enjoying care work, is reproduced without having to guarantee the reproduction of life or its sustainability in its mechanisms of capital accumulation.

# Methodology

The research is a qualitative production since we emphasized in the exploration of the daily experience of care work, where "we observe settings and people from a holistic perspective, that is, people, settings or groups they are not reduced to variables, but considered as a whole" (Taylor & Bogdan, 1987, p. 7). Also, it is framed as a critical and feminist investigation, recognizing that as a researcher, I have read and interpreted my situation in the world, so that in no case will my appraisals be neutral (Guba & Lincoln, 1994; Haraway, 1995), again reinforcing the choice for qualitative methods, as they:

Take the researcher's communication with the field and its members as an explicit part of knowledge production, rather than excluding it as much as possible as a partially responsible variable. The subjectivities of the researcher and those who are studied are part of the research process (Flick, 2004, p. 20).

Regarding ethical safeguards, the research considered the voluntary participation of 7 women, who signed an informed consent form after knowing the objectives and theoretical references of the research. Their identities appear under fictitious names that they chose, except in the case of one who preferred to appear with her real name, as a political visibility product of her activism for the expansion of the right to care in Chile.

As information production techniques, we carried out semi-structured interviews and participant observations in the daily contexts of each of the participants, between October 2018 and April 2019. We selected the first technique for its flexible conversational character, which goes beyond the question-answer logic, and allows us to delve into emerging themes, despite having a previous script in which its order varies according to the conversation with each interviewee (Hammer & Wildavsky, 1990). As a secondary information production technique, we observed the daily life of the participating caregivers to "witness the social behaviors of individuals or groups in the places of their activities or residences, without modifying their ordinary routine" (Peretz, 2000, p. 20). This enabled to observe the care work contextually, being part of the daily lives and social interactions of the participating women, in actions such as having breakfast, lunch, or dinner; walk together through their neighborhoods; accompany them in their care work and also support them in carrying out the

domestic work associated with caring. At the end of each observation day, estimated to last between 2 to 3 hours, we made a written record in a research log.

We carried out the sampling in an intentional, non-probabilistic way, mainly through the chain sampling strategy or "snowball", in which we identify "cases of interest from someone who knows someone who may be is a good candidate to participate" (Martínez-Salgado, 2012, p. 616). In this sense, from professional networks and networks among the same interviewees, we generated the chain sample, which concluded in the eighth interview, based on the saturation criterion, that is, the "moment in which the information results in what is known, and therefore the object has been exhausted in its descriptors" (Canales, 2006, p. 24). The inclusion criteria of the participants were the following:

- a) Woman (as gender identity)
- b) Being the main caregiver of a dependent older adult in the city of Santiago de Chile, and being her main activity.
- c) Caring informally, that is, being part of a close network of the person taking care (family member, neighbor, etc.) without receiving remuneration.

While the research sought to know the daily life of care work and its effects on the lives of the caregivers, it was not relevant to make a sample differentiation according to the health condition of the person cared for or the bonding type since the inclusion criteria based on the experience of the caregivers prevailed. In any case, we included these elements in the following Table 1 to show the diversity of situations of the participants, which include characteristics such as their age, profession or occupation, bonding with the person they take care of, time taking care, health condition of the older adult and socioeconomic status, and their fictitious names:

Name	Age	Profession or Occupation	Person taking care	Health condition	Time caring (in years)	Socioeconomic level
Aurora	65	Accountant	Husband (69)	Spastic Parkinson's	5	Medium-high
Mariana	49	Technician in Early Childhood Education	Mother (73)	Alzheimer's, organic damage caused by cerebrovascular accident (CVA), and dementia.	4	Low
Carolina	55	Senior assistant technician	Father (91)	Dementia	3	Medium-low
Fanny	54	Home advisor; chocolate shop saleswoman	Daughter (25)	Cerebral palsy	25	Low
Victoria	52	Computer engineer	Son (19)	Autism Spectrum Disorder (ASD) and refractory epilepsy	19	Medium
Ofelia	58	Housewife; saleswoman at fairs; seamstress.	Son (38)	Williams syndrome (intellectual disability)	38	Low
Matea	50	Engineer	Daughter (27)	Intellectual disability	1	Medium

Table 1. Characterization of women who participated in the investigation.

We recorded and transcribed the interviews to later perform content analysis, understanding this technique as a way of treating the existing content in the messages and interpreting them (Bardin, 1996). Thus, we determine coding units to manage the contents, whether thematic or meanings, always observing the contexts that produce them, considering not only the obvious but also those latent or "hidden" contents in the communication processes (Bardin, 1996). To facilitate the application of this analysis technique was used the qualitative data analysis program Atlas.ti 2.0 ©, analyzing the information in the following 2 categories:

#### 1. Daily care work

2. Effects of the assuming care work on the lives of the caregivers

# Results

#### The daily care work

From the reports of the interviewees, we could identify various activities and tasks of the daily work of caring for dependent adults, which only exceed direct care tasks such as feeding, dressing, or bathing. As indicated above, according to Pérez (2014) these activities can be classified into three: a) Direct care activities; b) Activities that provide material preconditions for care; and c) Mental management activities. Based on this conceptualization<sup>4</sup>, and on what we observed, we decided to expand this last group of activities since the research showed that in the case of caring for people in a situation of dependency, there is a series of management actions that not only they are associated with the "mental", but also with the medical and also with the institutional.

Regarding the first group of activities related to direct care - or *corporeal care* as I have preferred to call it -, are those aimed at satisfying the vital and basic organic needs of the people who are being cared, and involve a bodily, face-to-face and direct relationship between the caregiver and the person cared for. When thinking about this group of activities from the keys of Arendt (2003), we can understand them as work activities, that is, activities that respond to the cyclical and endless organic needs of bodies, in which the survival and life depend on resolution and response, as expressed by one interviewee when pointing out that: "I do not live through her, but she does live through me because if I do not feed her, I do not change her, I do not bathe her if I do not raise her If I don't care if she's breathing, she doesn't live" (Fanny).

As shown by the quote, in situations of severe dependency, even the confirmation of whether the person cared for is breathing is part of this group of body care activities, and other activities identified from the interviews and observations, such as feeding, bathing, changing, cleaning and grooming, brushing teeth, combing, shaving, dressing/undressing, administering medication, lying down/lifting, transferring, mobilizing, supporting posture transitions - such as passing from a supine position (lying down) towards sitting and biped, or transfers between the bed and other surfaces such as wheelchairs or toilet. The satisfaction of vital needs constitutes a central and fundamental axis in the work of caring for old adults in a situation of dependency, and given its cyclicality and repetition, the daily life of the women taking care of the person is organized from the resolution of these needs, which in many cases also entail technical specialization due to the requirements of caring for people with complex health situations. The execution of these tasks, which implies relationships between bodies in a direct way, makes it necessary to highlight the place of the caregivers' body in care work. Unlike many paid jobs where the use of the body represents light or moderate effort, such as those dedicated to administrative work, care work depends directly on the bodily capacities of the person who cares. For example, having to bend down to be able to clean the cared person or the great weight load that must be carried out to transfer people from one place to another, implies the use and direct effort of the body, an issue that, when dealing with adults, it involves a great load of weight and a high effort.

The indirect care activities are associated with domestic work such as cooking, organizing, and cleaning, and are those that provide the material preconditions for care work. All the participants recognized performing these tasks as an important part of their daily life, many times in a juxtaposed way to the care work, which allows observing that they carry out two unpaid jobs in the same space: care work and domestic work. As I have stated, it is complex to try to separate the two jobs since the actions of domestic work allow creating the material preconditions for the body care activities to develop. For example, the activity of cooking allows the person to be cared for to be fed, as well as washing and organizing the clothes that allow them to dress. Therefore, we observed that both body care activities and indirect domestic activities are closely related, an issue that becomes evident in the daily routines of women.

<sup>&</sup>lt;sup>4</sup>. It is important to note that this research does not intend to install a new way of organizing or fragmenting daily activities as the Anglo-Saxon traditions of the profession have done, but rather seeks to make visible the complexity of those actions that, otherwise, would be hidden and naturalized under the univocal and androcentric conception of work, which considers it solely as a paid activity.

A relevant aspect to highlight is that in several cases, we observed that indirect care activities are not only intended to create the optimal conditions for the care of the dependent person, but they are also usually carried out for nuclei complete family members, which considerably increases the workload and time of women. Thus, in the home space, we assumed that women caregivers must also cope with the domestic work of the entire household, making the parallel execution of two highly demanding jobs invisible, which produces densification of women's time, that is, an experience of time that is characterized by the permanent superposition of a series of unpaid jobs that are carried out in the same time-space (Durán, 2010). In the juxtaposition of the bodily care and indirect care activities, it tended to generate a work overload in the participants, who recognized a vicious cycle of overload production, given that in their continuous performance of care activities, they developed greater skills and abilities to do so, what the families naturalized as their sole responsibility. This also generated the caregivers assuming that they were the most suitable and capable people to carry out the different activities (such as preparing special meals, adjusting clinical cots and technical aids, organizing medication, etc.), feeling essential and irreplaceable in the care scene. This vicious circle was reinforced by the modernization of the caregiving role of women, who have had to incorporate a series of specific techniques and maneuvers, some highly complex, made them *experts by experience*.

On the other hand, from the experience of the participants, we observed that there are mental management, medical management, and institutional management activities as part of the daily care work. Mental management can be understood as a way of *being-in-the-world* associated with permanent alertness, based on the need for caregivers to be constantly ready for any need or urgency of the person cared for. Mental management could be seen as a series of mental operations associated with the permanent connection with the people cared for and their schedules and/or routines, as it involves control, evaluation, planning, and supervision actions of the care process (Pérez, 2014). We observed that this type of management is carried out permanently by the caregivers, who despite not being directly assuming the responsibility of care for being in another space carrying out another activity such as a procedure or a social outing, recognized that they were permanently connected with the daily routines of care, which kept them restless, preventing their disconnection from care work. This restlessness or inability to disconnect led many participants to abandon their social activities or even vacation projects, assuming that they would be constantly attentive to care work and could not effectively enjoy those spaces, as one participant pointed out:

Sometimes I say, I would like to go to the beach for a weekend, alone, and then I say Oh and I will be there and Estela Did she take the snake? Did they give him lunch? Has she eaten well? Have they moved her? Is she ok? Has the bedding been changed? Then no. No, why am I going out? (Fanny).

Closely linked to this way of being in the world are the activities that I have called medical management, a category that refers to those activities specifically aimed at controlling, supervising, and accompanying health-disease and rehabilitation processes. This was expressed in specific highly specialized tasks such as requesting appointments and medical examinations, strategic scheduling of recurrent and specialty medical controls, dosage and compliance with medication-taking schedules, monitoring of examinations and receiving of their results, learning, and execution of rehabilitation exercises such as kinesiology, speech-language therapy or occupational therapy, etc. To carry out this type of management, the participants indicated using various strategies, such as setting daily alarms on their cell phones to remind them of medication schedules, scheduling medical interventions on visible blackboards in common spaces, using agendas or notebooks, and familiarizing with medical nomenclatures. As an example that intersects both mental management and medical management, we observed:

Sometimes you wear it, his dad stays with him. He "already," tells me, "go out, don't worry, I'll stay here with him." And of course, I go out, but one is the same: that at this time the remedies, I call him for [...] don't forget, at this time the remedies, you know? (Victoria).

Many of the interviewees, especially those associated with medium and low socioeconomic levels, described a third type of management in their daily lives, which I have called institutional management. This is all the actions carried out to promote the effective exercise of the social rights of the people cared for, such as the right to health, housing, or social protection. Some interviewees recognized that to effectively conquer these rights, they had to go to a different state and/or municipal

administration entities such as clinics, municipalities, and hospitals in a sustained and repeated manner, in a relationship of tension with them to have clinical supplies or money bonds. Several interviewees knew that these devices tend to proceed in a bureaucratic way and mistreatment, in which they made complaints, demanding their rights and those of the people they care for, either by calling by phone, sending letters, believing in diagnoses, and having economic expenses to receive grants and benefits, as recognized in the following story:

If I tell you that I, sometimes I did not have diapers for my daughter, even diapers. It doesn't matter, I said. And they all told me oh! Go to the municipality, tells about your case, and in your case, you came out devastated, because the assistant humiliated you, and why you did not take care, madam, and why did you have so many children (Fanny).

As evidenced in the quote, in addition to the action of begging for social rights, the caregiver was subjected to a sexual moralization of her life, based on a hierarchy of institutional power. This type of management was observed especially in those caregivers belonging to lower socioeconomic strata who, as they were unable to access certain services privately, depended exclusively on state and municipal provision. Considering Chile's neoliberal deepening, and the absence of public policies that transcend the needs approach to operating from rights and gender perspective, institutional management can be thought based on the intersectionality concept, which accentuates how the network of social relationships - such as those of class, race or functional diversity, is consubstantial and coextensive with gender relationships, intensifying their oppressions and effects of domination, as these relationships are reciprocally constructed (Viveros, 2016). Thus, institutional management is expressed as a body of activities necessary to be assumed by female caregivers whose social class does not allow them to access basic services in an extra-state (private) way. This is a paradoxical issue since, even though they are basic social rights such as health or housing, they must be actively managed by them, becoming a daily part of their care activities.

Finally, we need to point out how all these daily activities of care work are related to a certain temporality that subjects them. The organization of the lifetime of the caregiver women is always traversed by care activities, but also by *potential* care demands -which may or may not materialize-, an issue that hinders their free disposition and use of time. In this sense, they are "usually short of time, because they are donors of time" (Carrasco, 2006, p. 54), which means that they must constantly be carrying out a series of steps mediated by third parties to organize their everyday time. In the interviewees' reports, we identified how their temporal routines were structured based on the organic time of the person cared for, a phenomenon that contributes to an indistinction of work time and lifetime (Durán, 2010; Morini, 2014) since as organic the needs do not cease, the care work has no beginning or end limits, but rather constitutes a temporal continuity.

#### Effects of care work on the daily lives of caregiver women

As we observed, care work for dependent older adults is extremely demanding and has limited flexibility margins, as its temporality associated with the organic needs of the person cared for gives it a cyclical and repetitive nature. It also has the characteristic of being territorialized to the care space –the home-, which restricts the possibilities of splitting the care scene by women. All of the above has generated a series of multiple effects in the participants, which include effects on their physical and mental health, on their social relationships and spaces for participation, and the economic effects that have impoverished them and made them economically dependent on others.

Regarding the personal effects, we identified that most of the women experienced injuries and/or physical ailments as a result of the overload of care work, expressed in lumbar hernias, muscle and/or joint pain, and irritable bowel syndrome. As they did not have care relief, the participants reported the difficulty of being able to heal these injuries, either due to the difficulty in attending health centers, the impossibility of giving their muscles and joints rest or due to economic problems to perform medical treatments. In addition to injuries and physical ailments, we observed that a large part of the women interviewed experienced mental health problems, associated with exhaustion, stress, anguish, or fear. The participants reported not being able to get sick, a product of being essential in the care scene, as evidenced by the following reports:

Apart from stress, frustration, yay! Disappointment, grrrrr! Anguish!! (cries) Sadness sometimes (cries) and all that leads to depression, and I can't get depressed either (Matea).

I demand a lot of myself and I get anxious and my chest gets tight, and I act, and suddenly I act, and when I act I don't do things right, I had a period in which I forgot, I have been forgetting everything, and I said no, I have Alzheimer's, I have dementia, I have something, because everything, I left the kettle on, I forgot the dates of the controls, the medications, I was like in a nebula, just like I was walking like this, like this (Carolina).

We observed that these effects on the health of the caregivers were associated with overload and the postponement of self-care due to the *impossibility of caring for oneself*. All the interviewees recognized the difficulty to carry out self-care activities for their health in the middle of the execution of care work, which, as I have indicated, keeps them territorialized or circumscribed to the space of reproduction of life - the house, with few possibilities of support and relief in the role of caregiver.

Poor sleep and a shortage of rest times were other very common daily effects among the participants. In some cases, poor sleep was a product of the complexities of the health conditions of the people cared for, such as apneas, sleep disorders, or others; while, in other cases, poor sleep was associated with a permanent state of alertness that prevented them from having a full rest. Only in some cases, we observed that women who had greater support networks were able to manage times and spaces for rest, although they were mostly carried out within the same space where the person cared for was, an issue that hinders for them to disconnect total respect of caregiving routines and responsibilities. There is an interesting phenomenon here that even to be able to rest, women had to carry out arrangements and coordination with their nearby networks, which made their possibilities of rest subject to the availability of a third person to make it effective.

Given the coexistence with the person cared for, the participants declared having a loss of privacy in some basic daily activities, such as going to the bathroom to perform their needs or in the development of their sexual life. For several participants, the possibility of sustaining a sex-affective relationship while caring for a dependent person was complex to conceive, given the limitations of space and time, as evidenced in the following reports:

> For example, now, if I wanted to have a pololo<sup>5</sup>, how do I bring him here, and if my daddy has an emergency and made something wrong, I don't know, I tell you, where, how, I can't, I'm like... well basic (Carolina).

> I give you the example that one day my boyfriend told me I want to go out with you, or I want us to go to such a place, with whom did I leave my son? My daughters already have her life, she has her daughter and her partner, she goes out with her partner and I couldn't bother (Ofelia).

For many caregivers, the possibility of projecting a couple of relationships was nil, and they assumed it as something out of mind. On the other hand, within the main effects at the family level, we observed that when deciding who would undertake care work, families were reorganized following a rigid sexual division of reproductive work, with women being the caregivers in all cases. In this sexist decision, the bond that women had with the person who presented dependency prevailed ---such as a wife, daughter, or mother-, an issue that, as it occurred between families composed only of women, was reconsidered based on income level. Thus, women who received lower wages or who had unstable working conditions were the ones who preferably assumed care work. Furthermore, in many cases, women performed a series of other unpaid care work, especially when there were grandchildren or granddaughters in the households. We also recognized that the experience of care has great differences according to the type of bond that women have with the person cared for, since in the case of caregivers-mothers, the care work began at the same time that their children were born, in which the care returned to her only occupational projection, even for several decades. Also, in these cases, the essentialisms of motherhood decided that they were the caregivers even more automatic, leaving at an early age deprived of access to higher levels of education, paid jobs, leisure and free time, and several occupational choices and social rights.

Also, we observed a series of economic damage for the participants who after taking on care work, had to abandon their paid jobs, except for those who worked as "housewives", for whom the overall workload was notably intensified. This implied, without exception, a strong precariousness expressed in the absence of payment, irregularity or suspension of payments of health insurance and retirement

<sup>&</sup>lt;sup>5</sup>In Chile means "boyfriend" or "partner."

pension funds, the existence of labor "gaps" in the curricula of caregivers with professional careers, and economic dependence on third parties and/or entities, becoming economically dependent on their families or state benefits such as bonds or pensions. The fact that all the participants had to abandon paid work to dedicate themselves to care, highlights the existing care gap in social life (Fraser, 2016), where the social organization of care falls completely in the women. Thus, to be able to care, the women "are giving up studying, working in the market, are losing years of contributions for their future retirement and possibilities for personal development and fulfillment" (D'Alessandro, 2018, p. 161).

On the other hand, in all cases, we evidenced that care in situations of dependency represents a high economic expense, a paradoxical issue with the fact that this work is not paid, despite its high specialization and demand. As a consequence, women have had to develop work self-management strategies, both to cover their subsistence and to be able to partially improve their living conditions, which are seen to be precarious. Therefore, in addition to the care and the series of unpaid jobs in their daily lives, women have also had to endure work self-management initiatives that can be made compatible with care work, highlighting activities such as a chocolate shop, sewing, or online jobs (IT).

Finally, women who informally care for people in a situation of dependency become full-time caregivers, shifting their occupational identities towards the identity of caregivers, as a matter that organizes their daily lives and that, for some participants, is transformed into a political identity. Half of the total number of participants declared that they actively participate in caregiver organization networks, as part of a political struggle for the recognition of this invisible work by the State and civil society, based on the recognition of care as a social right. In practically non-existent times, women managed to articulate and organize themselves politically to replace the ravages of the neoliberal deepening in public policies and the precariousness of human ties, mainly through social networks such as Facebook, Instagram, and WhatsApp.

# Discussions

Based on the research, we could recognize how the daily lives of women who informally care for dependent adults constitute a mirror of history (Heller, 1987), which expresses the voracity and usufruct that the current socioeconomic system carries out on unpaid work undertaken by women. As it is a job that takes place in the same time/space in which they spend their daily lives, ----unlike most paid jobs that are carried out outside the home, with a defined start and end day-, this characteristic of coexistence of caregivers with the person cared for tended to territorialize women more strongly towards domestic spaces. In addition to the great overload of the multiple actions that make up care work, it had multidimensional effects on their daily lives, such as the abandonment of their paid jobs, an issue that made them economically dependent; limitation to participate in social spaces and meaningful activities; negative impacts on their physical and mental health, almost complete reduction of rest and leisure times, and incompatibility of care work with the development of a satisfactory or stable sex-affective life. With this, we can affirm that the research participants have been precarious, not only as an economic issue, but as part of a daily life experience, because by being economically dependent on others, they have lost possibilities of exercising their autonomy, both in the free use and disposition of their time and in the determination of their activities and finances.

Despite contemporary changes, where more and more women participate in paid labor markets, the sexual division of labor remains a rigid remnant of the "family theater of gender relationships" (Segato, 2014, p. 92), a form of socialization that has produced the subject-woman as an essential caregiver subject, so that in some health condition that generates dependency, all women appear as potential caregivers, insofar as it is a condition of femininity. In addition to this component of socialization and subjectivation, the reproduction of gender relationships encounters material and objective conditions that facilitate its re-registration in daily life, since as long as there are gaps in care as a result of the sexist social organization of care, there is a decrease in state investment in welfare policies and wage gaps that discourage the permanence of women in paid labor markets, the phenomenon of who takes care in a situation of dependency, will continue to be a feminized issue. This analysis allows us to sustain how human occupations and activities constitute a social and cultural expression -more than an intrinsic and individual impulse-, built in a complex network of intersecting power relationships. Thus, we can understand care work as a gendered occupation whose reproduction finds a place in the structures and apparatuses of the State, in the organization of the

economy, in the processes of socialization, in cultural representations, in the common senses, that is, in the complex texture of everyday life (Galheigo, 2020).

Given this, the political organization of the women who care for people constituted a very important political finding, as it challenges univocal ways of thinking about alternatives and solutions to care crises, so not only the State is the only way to appeal, while the women and their agency capacity reveal the possibility of practicing resistance right there where power operates (Foucault, 1980). Thus, this finding shows how women move away from the representation of a subject-victim, abandoning the "spectacle of subordination" (Segato, 2014, p. 99) to affirm their capacity for self-determination in their collective resistance, and at the same time, they construct a collective political identity, which can also be read based on the concept of *collective occupations* (Ramugondo & Kronenberg, 2015; Palacios, 2017). They arise intentionally as a critical organization proposal in the face of a common malaise, which for this case derives from an inequitable and sexist social organization of care.

#### Conclusions

Faced with the withdrawal of neoliberal states from social welfare issues, the growing commercialization of care, and the reorganization of family structures, the women are who absorb the tensions of a socioeconomic model that does not consider care as a basic condition of social organization, especially with older adults in situations of dependency. Although this research is specific in delving into the relationship between gender, care, and dependency from a feminist perspective, we need future research to deepen and make the analysis more complex, intending other relationships to those already exposed to think about this problem intersectionally, with variables such as social class; health condition of the person cared for; bond type between caregiver and person cared for; migration and global care chains, and political organization of caregivers.

Finally, as feminist researchers, we need to feminize social research, illuminating those problems that have been considered as "second-order" or as "women's problems", showing that the personal is political and that human occupations and activities occur in a complex web of power relationships. The possibility of illuminating and investigating those territories that we have historically occupied as female individuals constitutes a need and a debt that women have with ourselves to demonstrate the political architecture that has sustained those feminized occupations usufruct by the capital.

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