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Daily life of informal caregivers: perspectives from occupational therapy

Cotidiano de cuidadoras informales: perspectivas desde la terapia ocupacional

Cotidiano de cuidadoras informais: perspectivas da terapia ocupacional

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Abstract

Introduction: This article proposes to understand the daily life of informal caregivers through their narratives from the perspective of Occupational Therapy under the implications in occupational areas. **Objective:** Analyze from the occupation areas of self-care, productivity and leisure, the narratives of women who exercise the role of informal caregiver. **Method:** Qualitative research, with a narrative approach to obtain the experience of the caregivers since they assumed this role, through a semi-structured interview that was carried out with five informal caregivers belonging to the Valdivia commune, Los Ríos Region (Chile). **Results:** Repercussions were identified in the self-care area, expressed in overload, multiplicity of roles, mood and sleep disorders. In terms of productivity, these women manage to reconcile their daily lives with their work, the support of third parties being a protective factor. Finally, in leisure time, the space for themselves is drastically reduced by both the work and the health situation, making it impossible to balance their routines. **Conclusions:** Exercising the role of caregiver implies a change in occupational areas, which directly and indirectly affects daily life, since there is an abrupt break in the routine, enhanced by the lack of social support and / or the normalization of the performance of this role by women. In addition, the confinement measures due to COVID-19 increased the impact of the role of caregiver in the daily life of these women, expressed in a greater workload and a significant decrease in self-care.

Keywords: Occupational Therapy, Activities of Daily Living, Caregivers.

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Resumen

Introducción: El presente artículo propone comprender el cotidiano de mujeres cuidadoras informales a través de sus narrativas desde la perspectiva de la Terapia Ocupacional bajo las implicancias en las áreas ocupacionales. **Objetivo:** Analizar desde las áreas de ocupación de autocuidado, productividad y ocio, las narrativas de mujeres quienes ejercen el rol de cuidadora informal. **Método:** Investigación cualitativa, con abordaje narrativo para obtener la experiencia de las cuidadoras desde que asumieron este rol, a través de una entrevista semiestructurada que fue realizada a cinco cuidadoras informales pertenecientes a la comuna de Valdivia, Región de Los Ríos (Chile). **Resultados:** Se identificaron repercusiones en el área de autocuidado, expresada en sobrecarga, multiplicidad de roles, trastornos del ánimo y sueño. En productividad, estas mujeres logran compatibilizar su cotidiano con la labor, siendo un factor protector el apoyo de terceros. Por último, en ocio los espacios para sí mismas se ven reducidos drásticamente tanto por la labor, como por la situación sanitaria, imposibilitando un equilibrio en sus rutinas. **Conclusiones:** Ejercer el rol de cuidadora implica un cambio en las áreas ocupacionales, que directa e indirectamente afectan su cotidiano, puesto que hay una ruptura abrupta en su rutina, siendo potenciada por la falta de apoyo social y/o por la normalización del desempeño de este rol por mujeres. Además, las medidas de confinamiento por COVID-19 aumentaron el impacto del rol de cuidadora en el cotidiano de estas mujeres, expresada en una mayor carga de trabajo y una disminución significativa del autocuidado.

Palabras clave: Terapia Ocupacional, Actividades Cotidianas, Cuidadores.

Resumo

Introdução: Este artigo se propõe a abordar e compreender o cotidiano de cuidadoras informais e analisar suas narrativas na perspectiva da terapia ocupacional, sob as implicações nas áreas ocupacionais. **Objetivo:** Analisar a partir das áreas de autocuidado, produtividade e lazer, as narrativas de mulheres que exercem a função de cuidadora informal. **Método:** Pesquisa qualitativa, com abordagem narrativa para obter a história e a experiência das cuidadoras desde que assumiram esse papel, por meio de uma entrevista semiestruturada realizada com cinco cuidadoras informais pertencentes à comuna de Valdivia, Região de Los Ríos (Chile). **Resultados:** Foram identificadas repercussões na área de autocuidado, expressas em sobrecarga, multiplicidade de papéis, distúrbios de humor e sono. Em termos de produtividade, essas mulheres conseguiram conciliar o seu cotidiano com o trabalho, sendo o apoio de terceiros um fator de proteção. Por último, no lazer, os espaços próprios são drasticamente reduzidos tanto pelo trabalho como pela situação de saúde, impossibilitando o equilíbrio em suas rotinas. **Conclusão:** O exercício do papel de cuidadora implica uma mudança nas áreas ocupacionais, o que afeta direta e indiretamente o seu cotidiano, visto que ocorre uma ruptura abrupta em sua rotina, sendo potencializada pela falta de apoio social e/ou pela normalização do desempenho desse papel por mulheres. Além disso, as medidas de confinamento devido à COVID-19 aumentaram o impacto do papel de cuidadora no cotidiano dessas mulheres, expresso em maior carga de trabalho e diminuição significativa do autocuidado.

Palavras-chave: Terapia Ocupacional, Atividades Cotidianas, Cuidadores.

Introduction

This article proposes to understand the daily life of female informal caregivers in the Valdivia commune, through the analysis of the narratives from Agnes Heller's Theory of Everyday Life, specifically in the areas of self-care, productivity and leisure.

In this way, from the Occupational Therapy perspective, the use of a qualitative framework was pertinent, through which the experience of the caregiver role of Valdivian women is broken down, since the subject has a holistic view, where the occupation is the main axis of everyday life, a concept that is part of the human beings nature, and that directly influences people's health and well-being (World Federation of Occupational Therapists, 2012).

To contextualize, in Chile according to the data obtained from the II National Study on Disability 2015, it is estimated that around 2,836,818 people are in a situation of disability (Chile, 2015), a concept that for the purposes of this research will be understood as functional diversity[1]. Based on the above, it should be noted that this group of people may require the support or assistance of a third party to carry out their daily life activities, both basic and instrumental, an aspect that directly influences the dimension of the actions to be developed by informal caregivers (Chile, 2016).

According to international studies, an informal caregiver is considered as a family member, friends or someone from a close social environment who performs constant care work for people with functional diversity, usually without receiving financial remuneration (Campione & Zebrak, 2020; Martínez, 2020; Serfontein et al., 2020).

A predominance of gender is reflected, with the majority being women who take this role (Dzul-Gala et al., 2018; Navarro et al., 2019). This phenomenon has occurred historically, since it has been normalized in society that it is the woman who must take care of the health and well-being of her family (Pezo Silva et al., 2004). It is important to emphasize that they are mainly heads of household, with a low educational level and little purchasing power (Félix Alemán et al., 2012), who develop multiple roles, either as mothers, wives, daughters, or others (García-Calvente et al., 2004).

With regard to Chile, it has recently been considered to incorporate a regulatory framework to make the informal caregiver visible through the modification of Law No. 20,422, where the National Congress of Chile defines a non-formal caregiver as "a person who does not receive remuneration for the work performed, such as family, friends or relatives of the person in a situation of disability and/or dependency" (Chile, 2018, p. 6).

However, exercising the role of informal caregiver brings with it a series of repercussions in their daily life, which are reflected in changes in their areas of occupation, such as self-care, productivity and leisure. Well, within their routine they must carry out their activities of daily living, in addition to those that are related to the work of caring, which implies an organization of their routine according to the needs of the person with functional diversity.

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[1] It is a relatively new term, since it arose in 2005 by the Independent Life group in Spain (Negri Cortes & Leiva Olivencia, 2017) who state that this group of people, despite having some type of issues, be it physical, cognitive, sensory, psychological, among others, is capable of dealing and developing in its environment (Aristizábal Gómez et al., 2020) through certain adaptations and/or supports (structural, family, social, etc.) to incorporate a method of functionality based on its particularities.

Therefore, the area of productivity is affected when considering that care requires an overload, especially for women, in addition to suffering provisional or definitive exclusion from the labor market (Casado Mejía & García-Carpintero Muñoz, 2018; Danko et al., 2018; Moral-Fernández et al., 2018).

While in the area of self-care, exercising the role of caregiver leaves women exposed to longer working hours, this makes it difficult to care for themselves, which is often intensified by the lack of family support in care (Okido et al., 2016; Mora-Castañeda et al., 2020).

In turn, given the caregivers' daily life, leisure may be affected, as these spaces are diminished, which leads to a limitation of their social relationships and in parallel could generate family or couple conflicts (Cortés et al., 2020; Grandón Valenzuela, 2021; Hurtado-Vega, 2021).

Following this logic, it is important to highlight the health situation, given that in March 2020 the first case of COVID-19 was confirmed in Chile, which led to a series of preventive public health measures characterized mainly by social isolation, quarantines, and curfews, among others, which, in turn, generated changes in occupations, activities, and everyday life (Morrison & Silva, 2020).

Although the aforementioned has impacted the daily work of most people, in the case of caregivers it has caused an increase in daily care work, a greater overload, fewer spaces for self-care and leisure; added to the concern about the possibility of contagion and prevention measures, such as confinement in homes, the cancellation of social events and workshops, among others.

In this way, the general objective is aimed at analyzing from the areas of self-care occupation, productivity and leisure, the narratives of women residents of the Valdivia commune, Los Ríos Region (Chile) who play the role of informal caregiver.

Method

The present study was approached from a cross-sectional qualitative approach, with a descriptive-exploratory strategy. From these characteristics it is implied that this study allows interpretation, that is, the generation of concepts, propositions and hypotheses from the data.

Regarding the selection of participants, the target population was considered to be women who currently play the role of caregivers in the commune of Valdivia, over 18 years of age, who master literacy for the understanding of the research and the subsequent signing of the informed consent, and that they will have time availability to answer the interview (which lasted approximately 45 minutes).

The collection of general data was considered as a characterization of the caregiver and the care receiver, such as; age, presence of chronic diseases, number of people in the home, relationship and health condition, visualizing in this way the data obtained in the Table 1. Meanwhile, with regard to data collection, a semi-structured interview was conducted online (due to the health situation), in which important aspects of daily life related to occupational areas were emphasized.

The interview consisted of 6 questions aimed at obtaining socio-demographic background (age, presence of chronic diseases, number of people in the home, among others) and general ones, 18 questions directed to the categories proposed by the American Occupational Therapy Association (2020) (for example: what implications has had playing the role of informal caregiver on self-care and the productive area? How has that role of caregiver affected their free time?). It should be noted that the interview was ordered based on these 3 items: self-care, productivity and leisure, all of which were addressed transversally in the health crisis. Finally, they were given a copy and they were given the space to decide whether or not to participate in this study.

After the interview and in order to guarantee the confidentiality of the participants, each of the caregivers was identified with the letter "P" (for participant), followed by a number that corresponds to the order in which they were applied. Each interview was recorded with prior authorization, through the application of informed consent and later transcribed for analysis.

It is worth mentioning that the study was governed by the Declaration of Helsinki (Asociación Médica Mundial, 2013), and the International Ethical Guidelines for Research Related to Health with Human Beings (Consejo de Organizaciones Internacionales de las Ciencias Médicas, 2016). In this way, an informed consent was presented to the potential participants, in which the objectives and general characteristics of the study are detailed, in order to safeguard autonomy and free choice of participation.

Subsequently, the narratives of the informal caregivers were analyzed, being understood as the life history, which includes: educational development, labor competence, forms and styles to execute their routines and activities, family adjustments and religious work, therefore various aspects of a person's life, where biographical, ideological data, special interests, predominant character traits, level of global functioning, among other aspects, stand out (Rueda Castro, 2012).

The analysis contemplates the selection of three baseline categories from the conceptual framework of the American Occupational Therapy Association (2020), self-care, productivity and leisure. However, due to the health and sociohistorical context in which the study was carried out, the impact of the pandemic is incorporated as an emerging category, since it had a direct influence on the three areas mentioned above.

Below is the Figure 1 with the categories of self-care, productivity and leisure, its breakdown into subcategories and a cross-sectional analysis of the impact of the pandemic.

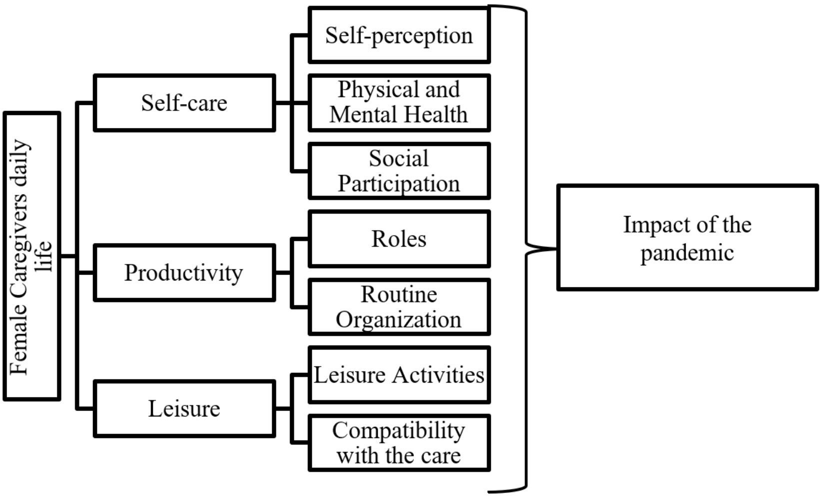

Figure 1. Categories and subcategories of the daily life of female caregivers.

To facilitate the understanding of the qualitative analysis, the daily life of the female caregivers was collected and analyzed in three categories: self-care, productivity and leisure. Subsequently, these items were subdivided into different units of analysis according to the area of performance.

Thus, it can be visualized in self-care; self-perception, physical and mental health and social participation; then in the second unit of analysis, roles and organization of the routine are distinguished; and finally in leisure; where the activities of enjoyment and compatibility with care emerge. In addition, each of the units mentioned is transversally influenced by the impact of the pandemic.

For the purposes of this research, the concept of daily life understood according to Agnes Heller's Theory of the Everyday Life was used, which states that "man is born already inserted in his everyday life" (Heller, 2008, p. 33), that is, people develop, learn how to act and behave within an environment that imposes certain aspects such as customs, language, instruments, cultural practices, among others (Márquez Pulido, 2021), but at the same time they also have a space to choose their own way of life within their possibilities.

Therefore, according to Heller (2008) the everyday life is understood as a set of activities that the individual carries out daily. This is divided into twelve elements, of which three were selected for this research: heterogeneity, hierarchy and provisional judgments, to then analyze the caregivers' narratives from the exercise of this role.

Heller (2008, p. 32) states that "everyday life is largely heterogeneous, and this from different points of view, above all from the content and significance or importance of our types of activity" being this an important part when having a diversification of activities during the day (Heller, 2008).

To continue, it is important to point out that "the meaning of everyday life, like its content, is not simply heterogeneous, but also hierarchical" (Heller, 2008, p. 32). This point refers to the fact that daily activities are carried out according to the level of relevance they have for the person.

Thus, it was also analyzed under the element of provisional judgments, which are empirical thoughts that are based on the daily and social experience of people and it is practice that confirms them as truths (Heller, 2008).

Results and Discussion

Table 1. Socio-demographic data and general background of the informal caregivers, and of the care receiver.

Caregiver	Age	Presence of chronic diseases	Number of people in the home	Relationship with the care receiver	Health condition of the person who they are caring
P1	56	Diabetes Type II	5	Husband	Senile Dementia
P2	53	Insuline resistance	4	Brother	Pulmonary frobrosis
P3	57	Hypothyroidism	5	Husband	Alzheimer disease
P4	31	None	3	Son	Autism Spectrum Disorder/Condition (ASD/ASC)
P5	36	Arterial Hypertension and Rosacea	3	Daughter	Autism Spectrum Disorder/Condition (ASD/ASC)

Self care

Consequences on the caregivers' self-perception

First of all, self-perception and the consequences that it may entail for the participants to have a positive or negative appreciation of themselves within their daily life are identified, as P.1 details in the following excerpt:

> *Before, I used to paint my fingernails a lot and now I haven't painted my nails for a year* [...] *suddenly I sit down and see my little hands there, all damaged, because I've been working more* (P.1).

Regarding 'self-perception', the narrative indicates that the participant has put aside personal care activities that she considered important, due to the increase in work related to caring for her family member, which in some cases can affect significantly the self-esteem. Although in another sense P.3 states:

> [...] *my self-care at the beginning, completely neglected* [...] *therapy helped me to realize that as a caregiver I don't have to neglect myself, but it was hard for me, yes, one tends to forget* (P.3).

Based on the narratives presented in relation to other studies, it can be affirmed that the element of *hierarchy* (Heller, 2008) is present, since it is common for caregivers to perform this role 24 hours a day (Cortés et al., 2020), since they organize their lives and/or routines based on the requirements and needs of their family member (Jofré & Mendoza, 2005).

In summary, the role of caregiver most of the times leads to less space for those activities that favor self-care and positive self-perception of themselves.

The impact of caring on physiological and psychological health

Due to the work overload and duties resulting from their role as caregivers, it can be linked to an impact on the physical and mental health of the participants, as detailed in P.1 and P.5:

> *yeah... suddenly the stress just, oh no', I pay the price, you know. Yes, but... apart from that, I just have to adapt because she is my mother* (P.1).
>
> [...] *caring is so difficult and one forgets that you get so tired and stressed that there comes a point where you can't take it anymore* [...] *routine things that anyone can think they are so easy to do, but not for us, so you keep all these things and accumulate them to the point where you burst and at that moment it is already super late* (P.5).

It can be pointed out that *'overload' entails* the presence of psychological discomfort, expressed in continuous stress and extreme fatigue during the day, where instead of being prevented, the person adapts to function under this state.

In accordance with what has been stated by some authors, it must be affirmed that there is a great impact on the physical and mental health of these women, since performing this role along with other domestic tasks entails an overload of activities

(Domínguez-Mejías & López-Espuela, 2017; Flores Villavicencio et al., 2017; Grandón Valenzuela, 2021). This is related to *provisional judgments* (Heller, 2008), given that there is a moral commitment associated with care, by taking care of a close relative (mother, husband, brother, child).

In the same way, few *'moments of self-care'* stand out, as it can be seen in the story of P.3:

> *Look... the first thing the neurologist did when I took my husband, was to send me to therapy,* [...] *when we don't know anything, we try to replace everything we are failing to do... to forget about my things, I knit, I paint, I like to sing, I used to go out a lot with my friends...* [...] *I stopped doing all of that because I got stuck and forgot about myself* (P.3).

In relation to the aforementioned, it is evident that moments of self-care (such as crafts, social activities, among others) were made invisible within the routine when assuming the role of main caregiver for her relative. Similarly P.5 narrates:

> *Yes, because... I have stopped doing things* [...] *for example I can't stop going to the doctor, because I don't know… my daughter needs therapy, or because she doesn't want to go out and I don't want to leave her alone. So I stop going to the doctor, and... my illnesses, I have several* [she reinforces], *they end up being put aside* (P.5).

In this case, the moments of self-care (such as attending to health problems or illness) were postponed because of being the main caregiver and giving priority to the care of the family member before herself.

In the same way, there are certain factors such as stress, concerns about the health of their family member, personal pressure, among other factors (Cortés et al., 2020) which lead these women to prioritize their work, neglect their own health and generate a greater risk of getting sick (Lüdecke et al., 2018; Hurtado-Vega, 2021). This is directly related to the element of Heller (2008) corresponding to *provisional judgments*, since carrying out the care of a relative generates in most cases an overdemand, this both due to the moral commitment associated with care, as well as the expectations linked to the role, leaving aside their own health.

In short, as pointed out by the participants, performing a caregiver role has had a significant impact on their health, since at the same time few moments of caring for themselves have been lost due to the high demand of those who receive care.

Social participation and its restrictions for care

Undoubtedly, the caregivers present a delimitation in their social relationships as a result of performing a role of caregiver, as mentioned by P.1:

> *Yes, yes... I was pretty much an 'outgoer', now I had to stay* [...] *I have not been able to go out and leave her alone, and if I go out for a little while she is already desperate" that I have not arrived, and it also desperate who is taking care of her, my son in this case* (P.1).

In this way, in some cases there is a break in social participation by refraining from activities outside the home, this is due to the fact that there is a certain dependency on behalf of the care receiver, which is why it is difficult for them to delegate care to another member of the family nucleus. Then, P.3 tells that:

> [...] *I had a tendency not to want to go out because getting together with people was like asking you questions and asking questions and I didn't want to talk about it. At first I isolated myself, I was also exhausted-very tired, besides, people started telling you stories and I didn't want to listen, and they said that- "he's going to get terrible, violent, you're going to have to put diapers on him, pure tragedy"- and instead of being a pleasant moment, it was very unpleasant* (P.3).

From this perspective, it is possible to demonstrate that the instances of social participation that she had at the time of being a caregiver did not contribute positively to her own care, because in her environment she presents a stigma associated with the condition of care receiver, giving an increased wear for the caregiver.

Therefore, as noted in the narratives and based on what Heller has stated, the elements of *hierarchy and heterogeneity* are appreciated (Heller, 2008), since the low social participation is linked to the fact that these women must be attentive to the needs of their relative, which directly and indirectly makes it impossible to disconnect from their role (Grandón Valenzuela, 2021; Hurtado-Vega, 2021). Likewise, some caregivers choose to give up certain social activities (Cortés et al., 2020) due to the stigmatization towards the person with functional diversity (Danko et al., 2018; Palacios-Espinosa, 2021), which influences their having less support and understanding from their close environment (Bosh et al., 2017).

By way of reflection, it was possible to appreciate that performing the role of caregiver has a significant impact on the social participation of these women. Even this restriction may have a social cause, since there is a stigma towards the health condition of the care receiver.

The family as support in care

Depending on the circumstances, family support (partners, children, among others) is a fundamental pillar for caregivers to have moments for self-care, as indicated by P.2 and P.3:

> *Yeah. There is always someone who can cooperate with me. So I can, I say what I'm going to do, I go out, the same, my sister-in-law stays* [...] *I can't say -I'm alone* (P.2).

> [...] *the psychologist summoned my children, to therapy, and she summoned them and told them - Either they get their act together or they get their act together, because they have to solve this as a family, if not their mother is going to burst. So the truth is that we got our act together,* [...] *they began to investigate, search, what can I do here, what we can do there, how we can help our mother with this, and... I've had a lot of help. And at that time, we took turns* [...] *So, that helped me* (P.3).

Based on the narratives, the idea that a stable family network provides necessary support to the participants is complemented, since it enables these women to have moments of rest and self-care. Even when the members of the family nucleus play an active role in assistance and care, in a certain way the stereotype that only women are the ones who provide care is broken.

Likewise, the family constitutes the main support network for caregivers, being classified as secondary caregivers (Delicado Useros et al., 2010; Kepic et al., 2019), who can fulfill the role of rotating care to provide moments of rest (Delicado Useros et al., 2010), which translates into a decrease in the burden for the caregiver (Mora-Castañeda et al., 2020).

In parallel, the element of *provisional judgments and heterogeneity* is evident (Heller, 2008), since the presence or not of family support in tasks associated with care depends on the morale of the members, which varies according to several factors, such as the traditions, culture and beliefs of the geographical area where they live.

In short, the family is vital in accompanying this work, although many times the support of a professional is required to raise awareness, structure family dynamics and balance the tasks associated with care.

Productivity

Diversity of roles in everyday life

There is no doubt that all people, as occupational beings, play different roles, but society sometimes assumes that women should only focus and dispose of their time to provide care for another.

This assumption is contradicted by the story of the caregivers P.3 and P.5, who refer to the large number of roles in their daily lives:

> *I still participate, I am a volunteer in "Teleton*[2]*" and ANTP*[3]*, it is something I do,* [...] *I also participate in the "I care*[4]*" association, we are new here in Valdivia and we do everything through Zoom meetings or things like that, so I can be together and my daughter can be sitting next to me listening to music, but yes, I participate, I have meetings with I don't know, with mayors, with representatives, with different entities* (P.5).

The interviewees mention that they maintain a *'multiplicity of roles'*, that is, that in addition to exercising the work of caregiver, they are also mothers, wives, professionals and workers. Despite the fact that all these tasks are aimed at meeting different

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[2] Non-profit institution in Chile, dedicated to the comprehensive rehabilitation of children and young people with motor disabilities, in improving their quality of life and developing their abilities to achieve their social inclusion (Teletón, 2021).

[3] (Now we have to participate) Ahora Nos Toca Participar (ANTP) is a team made up of young professionals gathered during the social outbreak in Chile (2020) to create a training and citizen participation project; that commits the strengthening of democracy and with it the promotion of the right to participation from a diverse and inclusive perspective, which has the need to share knowledge, experiences and emotions to keep the political interest and participation of citizens active (Ahora Nos Toca Participar, 2021).

[4] It is a private non-profit association of a national nature, whose mission is to contribute to improving the quality of life of informal and main caregivers of people in situations of disability, dependency, serious illness, rare disease and/or different condition. All of the above, without considering the age or socioeconomic level of the care receiver [I Care Association - Asociación Yo Cuido (2021)].

objectives, they must perform effectively in each one of them, which produces great exhaustion.

In this way, research shows that caregivers perform multiple roles, responsibilities and fulfill tasks according to the expectations of their close environment, therefore, this has an impact on the other roles of their daily lives (Gérain & Zech, 2019; Kepic et al., 2019). While, from the theory it is directly linked to *heterogeneity* (Heller, 2008), which points to this diversity of roles and tasks performed by caregivers in daily life.

They also point out that since they took care of their relative there are other factors that have affected the productive area, such as the *'limitation in productive activities due to care'*, which is reflected in the narrative of P.1:

> *I stopped working in February 2020, so since I was working I had a schedule, but later I decided that I would dedicate that schedule to my mother* (P.1).

According to what was mentioned, in this case the participant, before assuming her role as caregiver, was carrying out a paid productive activity incorporated into her routine, which was left in a second place to prioritize the care of her family member. On the other hand, P.2 mentions in the fragment that:

> [...] *there are times when it feels so bad that we really need someone else, and if I see that it is too much I have to go to the emergency room, that is why I look for my jobs like this with few hours, not so long shifts, to be able to return home* (P.2).
>
> *Last year I graduated, now I have been trying to find a job, but it is difficult for me because I cannot leave him alone, if I have to look for a job it must be part-time and it is still somewhat difficult to find that type of job* (P.4).

In this sense, as expressed in the excerpts, in everyday life these women prioritize tasks associated with care, therefore, the area of productivity is modified since they must restrict their choices and occupational opportunities, mainly those linked to the workplace.

What has been expressed in the previous narratives can be linked to the perspectives of some authors, since performing this role means that most caregivers must dedicate themselves to it full-time (Cortés et al., 2020), which causes them to leave their paid jobs, and in turn generates some economic consequences such as: economic dependence (from their family or from the state), repercussions on their professional development, suspension of health insurance payments, exclusion from pension funds, among others (Grandón Valenzuela, 2021; Mayo Corbacho, 2019).

Thus, based on what was mentioned in the narratives, the element of *hierarchy* can be distinguished (Heller, 2008), because before assuming this role of informal caregiver, some of the participants carried out the work of worker or other paid productive activity, which was restricted or limited, because when they faced with this situation they decided to prioritize this new occupation over others.

In the same way, the *'perception of the role'* of being a caregiver is addressed, in the narratives of the participants P.2 and P.5 two different positions are seen from the environment:

> [...] *everyone tells me - Uhh, you really deserve a statue for everything you do at home with your brother, no! and everything you've done, they tell me back that I took care of my mommy, they admire me* (P.2).

In this case, it can be pointed out that the participant has a positive perception of the exercise of this role, since she constantly receives validation from her environment, and this recognition generates the person to perceive herself as competent and altruistic. In contrast, P.5 states that:

> [...] *it is so predetermined that the woman has to take care of her children and what the children bring... it's like it's normal, like oh... I tell him: -listen to me, dad, oh I'm tired', and he answers me: -Well, you brought your daughter into the world, so it is your responsibility, or he tells me: -Your mother was going through the same thing* (P.5).

As expressed in the narrative, there is this perception of obligation attributed to gender, instead of exercising this role by choice, which at the same time is often promoted by the family and the environment that frames the woman as a care provider.

When analyzing this point, it should be considered that culturally we develop in a conservative, patriarchal and heteronormative society, with predetermined roles for each gender, where women are described and visualized as a reproductive and maternal figure, in charge of assuming care from others (Casaña-Granell et al., 2018; Grandón Valenzuela, 2021).

That is linked to the element of *provisional judgments* (Heller, 2008), since these comments come from the morality of the people, which has been reaffirmed over time by the close context, who transmit their perceptions of caregivers.

In short, external opinions can have totally opposite perspectives, and it is important to consider this factor, since people are validated from the opinion of their environment, therefore, if they minimize their work, it can have an impact on the caregiver's motivation to exercise the role.

Organization of the routine based on care

Naturally, each person organizes and plans his/her routine based on the roles he/she plays in daily life. This is how caregivers must structure their day to day based on this role and the needs required by the care receiver and also maintain their productive role. As described in the following excerpts from P.1 and P.2:

> *I took care of children, I was in charge of a house, I was a home advisor* [...] *I still take care of them, because suddenly they come to leave them with me* (P.1).

> *Yes, well, yes, it is flexible. Yes, because I set my entry and exit times, then it's like the right thing to do, I work, I finish and I come. I set my own schedules* (P.2).

According to what was expressed by the participants, they have managed to preserve their paid productive activity, since they have learned to *'organize their time efficiently'*, since conditions of flexible hours have been agreed between the worker-employer.

On the other hand, within their daily organization, they indicate the time they dedicate to caring for their family member, as reported by P.3, P.4 and P.5:

> *Almost all day, because he gets up and tells me to get up, that he's hungry, and I get up and do his things* (P.4).
>
> [...] *if I go out he drives the boys crazy, where is his mother? Where is she? just like children* (P.3).
>
> *Almost all day and part of the night, I mean, I don't care anymore! and before I used to stay up all night with her, but now I can't anymore! and I stay up until three in the morning and then I fall asleep because I really can't* (P.5).

As evidenced, most of the participants affirm that the "*time dedicated to care*" is extensive, since they must be aware of the needs and requirements of their family member, where the care is carried out both during the day and at night, which at the same time will vary according to the level of *dependency on the care receiver*'.

The results obtained from the research are consistent with previous studies, which state that caregivers perform strenuous shifts, performing their role even 24 hours a day, since all tasks are performed in the same space, which is commonly their home (Peña et al., 2016; Sacco et al., 2018; Zamarripa Esparza et al., 2017).

The data obtained is related to the element of *heterogeneity* (Heller, 2008), since they organize their everyday life from their particularity, and structure their routine according to their reality and context, which leads to their self-perception as more or less effective. At the same time, there is a *hierarchy* (Heller, 2008), since assuming this role has led them to organize their day-to-day life based on the requirements and/or needs of their family member, this can be detrimental when organizing their time and sometimes it can decrease the feeling of efficacy in the different tasks that they carry out in their daily lives.

In summary, although being a caregiver requires dedicating a large part of the day to these activities, it is possible to maintain or perform other productive roles, whether paid or unpaid, as long as the routine is adequately organized and there are flexible work opportunities.

Leisure

Enjoyment activities in the background

It is common that within the daily activities a space is allocated for leisure, where enjoyment activities that give meaning to daily living are usually carried out. However, on some occasions these can be affected by the limits of space, time and different roles. Which is mentioned in the narratives of P.2 and P.3:

> [...] *I do more knitting, crocheting, I have fun myself, it relaxes me a lot, so the day goes fast, I was just in my sewing room with my sticks* (P.2).

> *Yes, I am weaving like a spider, I love cooking, I cook what someone asks for* [...] *I also recovered that, I make kuchen, cake, all those things, I stopped doing all that and I do it with pleasure* (P.3).

In this way, in the stories presented, the participants comment that they carry out activities within the home related to manual tasks (weaving, embroidery, painting, among others), which can be associated with the fact that these are more accessible, allowing them to regulate their times dedicated to these spaces and despite the fact that they are in the environment where they perform the role of caregivers, they manage to disassociate themselves from it to be part of these significant and valuable activities. On the contrary, P.1 narrates that:

> *In the neighborhood council, I participated there, because we did a lot of things, gardening... in these times we would be already doing the gardens of the squares, there was coexistence, a lot of crafts, a lot of things, they work with sewing machines, with clay* [...] *now they still do things, but I don't participate, so not to bring the virus to my mom* (P.1).

As can be seen in the extract, there is also the position in which they stop carrying out leisure activities to care for their family member, this is directly related to values and the preconceived idea of how their role should be assumed, thus displacing this type of activities to prioritize the development of this work, which in turn was intensified as a result of the existing health protocols due to the COVID-19 pandemic, in which the free movement of the population was restricted, which particularly affected the individuality of these women, since it implied greater limitations by prioritizing the protection of their family member.

In this sense, theorists point out that being a caregiver can limit occupational choices, the use of time for oneself or the performance of activities not related to the role (Rodríguez et al., 2000), which leads to less time for interaction with their peers and leisure experiences with other people (Villanueva & García, 2018). On the other hand, the incorporation of spaces for enjoyment and adaptation of the routine can be seen as a source of well-being and improvement for health (Oñate & Calvete, 2017).

This is associated with the element of *hierarchy* (Heller, 2008) since these women, when organizing their daily lives, have as a central priority taking care of their family member, reducing their activities in space, time, and quantity. In the same way, the element of *provisional judgments* is present (Heller, 2008) when considering that caregivers restrict leisure because from their personal and moral perspective, ensuring the care of their family member is more relevant than participating in leisure activities.

Summarizing what has been stated, the way in which caregivers carry out their leisure activities depends on different factors, among which the organization of their routines stands out and whether or not they achieve a balance between care and enjoyment activities. However, there are environmental limitations such as the availability of time, space, materials, support from third parties and even their own morality that influence their participation.

Compatibility of activities with care

The times dedicated to leisure activities vary, and on some occasions both the organization of the routine and the performance of the various roles can facilitate the development of this recreational time. However, this does not occur in all cases. As P.2 relates in the following excerpt:

> *I don't feel well being like this* [without carrying out activities], *I have to be doing something, keep myself busy* [...] [has she been able to make the role of caregiver compatible with other activities] *No, I don't organize anything, I say I'm going to do this and If I see that my brother is not feeling well, I go there and help him and that is how I move forward with my things* (P.2).

As expressed, there is a feeling of global discomfort when feeling inactive, therefore, when spaces for recreation or leisure appear, she decides to explore them in productive activities, but always prioritizing the requirements of her family member. On the other hand, P.5 points out that:

> *I have succeeded, not to the maximum, but I have managed to match those spaces in which my daughter is calm and we are not doing anything, then I also take advantage of it. So she doesn't bother me and I don't bother her, so it's like each one's space, there aren't many, but there are some* (P.5).

Meanwhile, an adaptation is observed in the participant, who to give herself these instances of rest prefers to share time with her daughter and thus reconcile her role of caregiver, while she enjoys leisure spaces.

In this regard, being a caregiver can limit the occupational choices of activities not related to the role (Rodríguez et al., 2000). On the other hand, the incorporation of spaces for enjoyment and adaptation of the routine can be seen as a source of well-being and improvement for health (Oñate & Calvete, 2017), and therefore a protective factor against the possible presence of overload, anxiety and depression.

Thus, in contrast to the theory, it is evident that the element of *hierarchy* is present (Heller, 2008) because when these women assumed the role of caregiver there was a greater priority for their role and little attention to leisure activities, but with the passage of time, they managed to match their times, and in some cases prioritize their individuality. Also, in this process, it is seen that the participants incorporated greater *heterogeneity* (Heller, 2008), since they went from caring full-time to integrating some recreation and rest spaces into the routine.

Regarding leisure, it was possible to show that, initially, when the role of caregiver is assumed, the exercise of recreational spaces is quite restricted, since they prefer to watch over the needs of their family member. However, as this work is internalized, they can make leisure activities compatible and provide a space as long as they have the support of the environment; while in other cases they are restricted by the load of the role, motivation and lack of organization in daily life.

Conclusion

Based on the results presented, it can be affirmed that informal caregivers present difficulties in their daily lives, which directly affects their occupational areas. In this way, in the area of self-care, the participants prioritize the tasks associated with the care of another, over their own needs, which added to the presence of overload causes the postponement of activities that benefit their health, well-being and self-perception in a positive way.

In this sense, assuming the role of informal caregiver also had an impact on the area of productivity, since it generated a decrease in the participation of paid productive activities, since in most cases it was decided to position informal care as the main activity, which consequently generates a negative impact on the economic context and on access to job opportunities.

Regarding leisure, it can be seen that, globally, when assuming this role, spaces for enjoyment are reduced, or they are completely lost, given the high demand involved in caring for a person with functional diversity. However, when the caregivers manage to adapt their routine, it is possible to resume free time activities, but this participation will be conditioned by personal and environmental factors such as the support of third parties, availability of space, among others.

On the other hand, a factor to consider is the current health situation due to COVID-19, where most of the participants have chosen to reduce their social instances or isolate themselves in their homes to prevent contagion and protect their family environment, which has influenced both activities related to self-care, as well as the areas of productivity and leisure.

However, some participants highlight as a positive aspect of this situation the possibility of interacting socially through video calls, making use of online platforms to maintain links with third parties and carry out a multiplicity of roles in their day-to-day life as a way of adaptation.

In this sense, it can be noted that on some occasions the participants, despite having spaces for self-care, productivity and leisure, are not considered a priority in their daily lives, due to a generalized internalization of the role as a result of various factors; when perceived as a moral obligation because they are the closest person, this added to the social validation of the environment, praising the work done, and above all the imposition of the socio-historical role of women within society.

It is important to mention that given the demands that the role of caregiver implies and also the development of other tasks (whether as head of household, mothers, workers, among others), these women find themselves in need of receiving psychosocial support from an interdisciplinary team that safeguards their physical and mental well-being. In addition to this, the importance of delegating these responsibilities in the family environment should be mentioned, so that this is a task shared by all.

Therefore, for Occupational Therapy as a discipline, it is a necessary field of study to raise awareness, empower and stop normalizing this situation, being a guide in the process of recognition, changes and adaptations at a political, social and cultural level, so that both the close environment and the community are places of protection where these women can develop their occupations without feeling judged.

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