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CAREGIVER ROLE AND LIFE PROJECT OF SIBLINGS OF PERSONS WITH DISABILITIES

Julia Córdoba[1], Eugenia Barbosa[2], Andrea Gonella[2], Lucía Barreto[1], Agostina Mirandetti[2], & Yohnattan Mignot[2]
[1]*Facultad de Psicología, Universidad de la República (Uruguay)*
[2]*Facultad de Artes, Universidad de la República (Uruguay)*

Abstract

In Uruguay, the last decade has seen a deepening of care issues; this is reflected in public policies and in the academic interest in addressing, teaching and researching these topics. According to Uruguay's National Integrated Care System (SNIC), there are three populations requiring care: children, people dependent due to disability and/or old age. A fourth population becomes relevant: caregivers, both formal and informal. This project focuses on an intrafamily caregiving figure, the siblings of people with disabilities. Although there are studies at the international level, work with these figures has not been systematized or promoted at the local level. They have remained invisible, but they are the ones who assume care when parents are unable to do so. This study aims to characterize the profile of siblings in relation to the burden of care, as well as their perception of family health and social support. Results related to the intersection of these three dimensions are presented, as well as the presence of double burden of care and whether the participant lives with his/her sibling with a disability.

Keywords: *Siblings, disability, caregiving, family, social support.*

1. Introduction

This study seeks to characterize intrafamilial caregivers, particularly siblings of people with disabilities (Meltzer, 2021). Along with the demand, both from state and international agencies, social organizations and academia, to produce scientific information on how people with disabilities live (Massé & Rodriguez, 2015), there is also the need to characterize caregivers (Araujo Guimarães & Hirata, 2020).

After the COVID 19 pandemic, families with members with disabilities have suffered the impact of state retraction, making it evident that these nuclei precariously meet the care needs (PAHO, 2020). According to relevant studies, little is what they expect but much is what they need (Abellán Lopez et al., 2021).

When the main caregivers, who are generally mothers (Echegoyemberry, 2016), cannot sustain these tasks, those who assume this place, when the family structure allows it, are the siblings (Nuri et al., 2020). How this place is assumed may vary depending on, for example, whether the disability is congenital or acquired, the gender of the sibling, family practices, the burdens of stigma and prejudice associated with the type of disability, communication of the diagnosis, among others (Caldin & Cinotti, 2016; Sommantico et al., 2020). Added to this is the assessment made by siblings of people with disabilities in relation to how they care compared to how their parents do it (Avieli, 2020). Some studies show that, compared to their parents, care by siblings promotes autonomy, spaces for participation and inclusion and has lower levels of overprotection (Nuri et al., 2020).

In America Latina, data show that it is the most impoverished women who assume caregiving tasks at younger ages (Batthyány, 2018; Gailán et al., 2023). Particularly, in Uruguay, according to the National Survey of Adolescence and Youth (INJU, 2020) 38.0% of young people between 18 and 24 years of age care for at least some dependent population (children, people with disabilities and/or older adults). It also shows that the burden of care increases with age: 48.2% are caregivers between 25 and 29 years old and 64.1% between 30 and 35 years old.

These data illustrate how care-related tasks begin before adulthood and may be conditioning decision making in relation to personal and collective projects (Burke et al., 2015). This trend is a worldwide phenomenon that must be addressed as it has great impacts, for example, on the economic, health and labor aspects; both in the individual and collective spheres (Echegoyemberry, 2016). Recent studies (Sommantico et al., 2020, Zúñiga et al., 2023) suggest that there are differences between siblings of people with and without disabilities when analyzing results in relation to, for example, social skills, academic achievement, empathy and closeness between siblings. This variability also appears when comparing these results between siblings of people with different types of disability or health conditions.

Recent studies (Burke et al., 2017; Casale et al., 2021) show two fundamental dimensions: i) involving siblings, with and without disabilities, in decision-making and family planning is fundamental to obtain what is called anticipatory or future care and ii) those who access this planning show a reduction in the burden of care, an improvement in the self-determination of siblings and a lower risk of family crisis.

The analysis of family functioning is relevant, since the family structure and the dynamics of family functioning is an effective predictor of the degree of life satisfaction of its individual members. For this reason, when there is a member with a disability in the family, it is of interest to evaluate both the family's ability to adapt to this situation and the cohesion among its members, including siblings, at different stages of the life cycle (Serrano et al., 2023).

Added to this is the emergence of a phenomenon of separation between cohorts of grandparents, children and grandchildren (Alburez-Gutierrez et al., 2021). This generates the so-called dual or composite care: one generation cares for fathers, mothers and children (Williamson & Perkins, 2014). In some cases, care for siblings with disabilities is added.

Considering the above, the present study aims to characterize the profile of siblings in relation to the burden of care, as well as their perception of family health and social support.

2. Method

A mixed, exploratory study is presented, which aims to be a precedent in the study of the psychosocial dimensions of siblings of people with disabilities. The device implemented were biweekly workshops where aspects related to care and the role of the caregiver were worked on. The meeting brought together siblings of participants from different Uruguayan social organizations working with people with disabilities.

Before starting the first meeting, participants were presented with a self-administered questionnaire where different dimensions of interest were surveyed. The following section presents the results obtained from the application of this battery of instruments to 38 participants. Each participant signed an informed consent form guaranteeing the anonymity and confidentiality of the data and that, if they did not wish to continue participating in the workshop, they could withdraw at any time.

First of all, sociodemographic variables were collected about the participant, such as sex, age, highest level of education attained, whether he/she is working, whether he/she has a therapeutic space, whether he/she lives with a sibling with a disability and whether he/she has other dependents such as, for example, children or elderly people. At the same time, aspects related to the sibling with a disability were surveyed, such as, for example, age and whether he/she has a diagnosis.

Secondly, three standardized instruments were applied. The first was the APGAR scale which is a five-question questionnaire that seeks to assess the functional status of the family (Serrano et al., 2023). The second instrument was the MOS questionnaire that measures perceived social support (Martín-Carbonell et al., 2019). Finally, the Zarit Scale was proposed to measure caregiving overload (Albarracín Rodríguez et al., 2016).

Due to the sample size, statistical tests were not applied; instead, what is presented are frequency analyses between the different variables of interest.

3. Results

The sociodemographic characteristics of the participants are presented below (Table 1), followed by a description of the results obtained from the different crosstabs of these variables and the instruments applied. It is necessary to clarify that when we speak of participants, we are referring to the siblings of persons with disabilities.

71.1% of the participants are women and those with the highest level of education. Although both sexes are concentrated in the younger age groups, in the case of men more than 80% are under 45 years of age. Most of the participants are working, and more than 90% of the women are working.

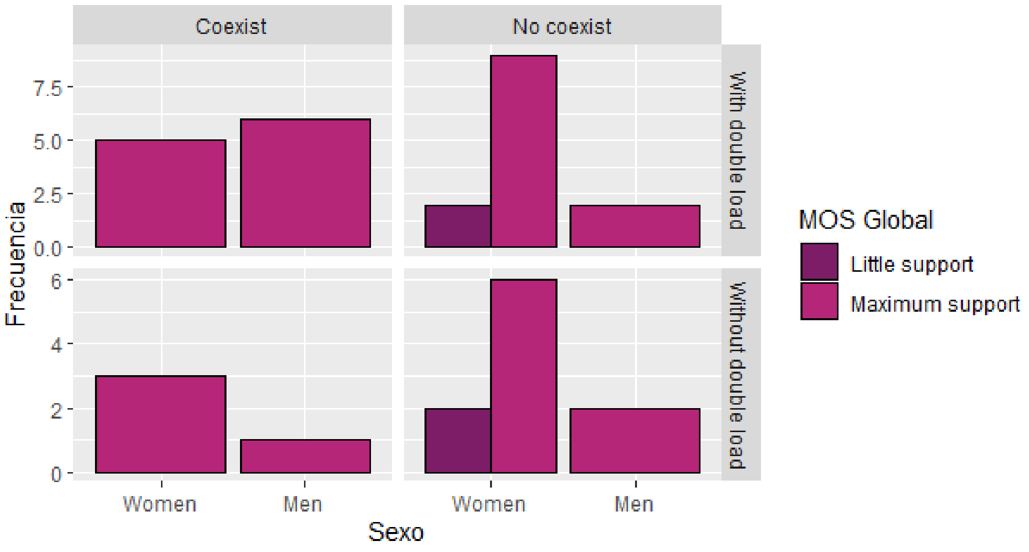
Based on the data on the nuclear family, more than twice as many men as women live with their sibling with a disability. In relation to the variable of double burden of care, most of the participants present it, with men being the ones who most frequently declare that they have a double burden of care.

Table 1. Sociodemographic characteristics of the participants.

	Women (%)[1]	Men (%)[2]	Total (%)[3]
Age			
17 -30	44,4	54,5	47,4
31-45	25,9	27,3	26,3
46-59	14,8	7,4	15,8
60 and more	14,8	0	10,5
Highest level of education achieved			
Basic Secondary	14,8	9,1	44,7
Secondary school	40,7	54,5	13,2
University	33,3	36,4	31,6
Postgraduate	11,1	0	7,9
Working	92,6	72,7	86,8
Siblings living together	29,6	63,6	39,5
Presence of double burden of care	59,3	72,7	63,2
It has a therapeutic space	33,3	27,3	29,0
It has a space for the exchange of information about siblings	26,0	18,2	23,7

[1] This value is based on the total number of women in the sample; [2] This value is based on the total number of men in the sample; [3] This value is based on the total number in the sample.

Figure 1. Global MOS results by sex, presence of double burden of double burden of care and cohabitant.



With respect to the intersection between perceived social support, caregiving overload, living with a sibling with a disability and sex (Figure 1), it can be said that:

(i) the total number of participants who cohabit with their siblings declares to perceive maximum social support. ii) participants who obtain, in global terms, little social support and intense overload are women, from the youngest and oldest groups of the sample, who do not live with their sibling.

With respect to the intersection between perceived overload, living with a sibling with a disability and gender (Figure 2), it can be said that:

(i) the majority of men who live with their sibling with a disability, regardless of whether they have a double burden of care or not, have an absence of overload. When considering the double burden of care, the perception of overload goes from absence to slight. In contrast to women, most of the women who live together and have a double burden of care have a heavy overburden.

ii) some of the non-cohabiting women who do not have a double burden of care obtain light overload; when considering the presence of double burden, the third category of the scale appears, with women declaring absence, but also intense and light overload.

Finally, we present the results obtained from the intersection between family functioning, caregiving overload, living with a sibling with a disability and sex (Figure 3): (i) almost all the cohabiting women, regardless of whether there is a double burden of caregiving or not, reported some level of family dysfunction. ii) most participants, both men and women who do not live with a sibling with a disability, report some level of family dysfunction.

Figure 2. Global Zarit results by sex, presence of double burden of double burden of care and cohabitant.

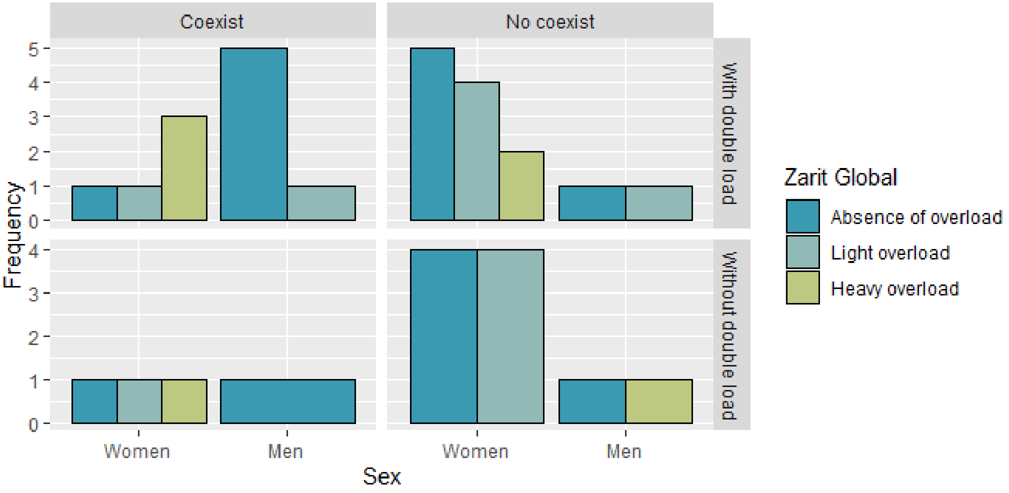
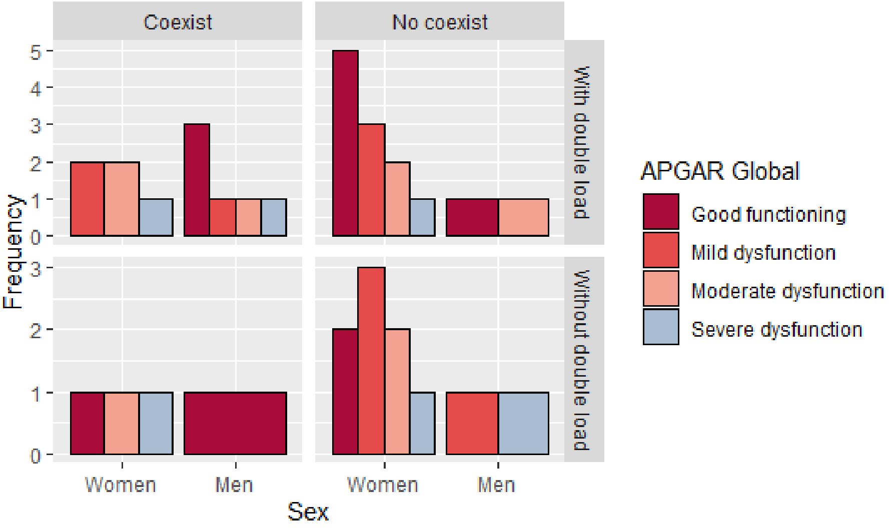


Figure 3. Global APGAR score according to sex, presence of double burden of double burden of care and cohabitant.



With respect to the MOS subscales, the total of women who obtained low perceived social support, at the global level, present maximum support in the emotional subscale but low support in the affective subscale. These women, in turn, report low and lack of support in the material subscale and low support in the subscale of support for leisure and distraction.

All participants who fall into the category of low support in the emotional subscale are male and obtained maximum support in the overall result; the opposite is true for women.

At the intersection between intense caregiving overload and perception of low support are the most prevalent diagnoses within the nosological groups: schizophrenia, Down syndrome and autism spectrum disorder.

4. Discussion

The present study reports on gender-related differences in the perception of caregiving burden, family functioning and social support among siblings of persons with disabilities.

In this sense, one of the findings is the difference between men and women in the perception of caregiving overload. While the majority of men who live with their sibling with a disability report an absence of overload or, in cases of a double burden of care, a light overload, women in the same situation tend to experience an intense overload. In addition, the majority of participants, both male and female non-cohabitating caregivers, report some level of family dysfunction. This suggests that physical distance does not necessarily preclude the family tensions associated with caring for a sibling with a disability.

Although the results of the present study are not generalizable due to the size of the sample, they allow an approach to the characteristics present in the experiences of siblings of people with disabilities, to be taken into account in interventions and policies aimed at this population.

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