1 DIFFICULTIES FULLFILLING SELF-CARE NEEDS AMONG FAMILY

- 2 CAREGIVERS: AN OBSERVATIONAL STUDY
- 3 Key words: Family Caregivers; Informal Caregivers; Self-Care; Occupational
- 4 Satisfaction; Occupational Performance; Quality of Life, COPM; Whoqol-Bref.
- 5 **Importance**: Assuming the care of a family member with a disability and/or chronic illness
- 6 constitutes a health risk factor, related to different symptoms and diseases, together with
- 7 neglected self-care among caregivers.
- 8 **Objective:** The purpose of this study was to analyze the self-care activities affected in
- 9 caregivers of a family member with disability and/or chronic illness, and the impact on their
- 10 satisfaction and quality of life.
- 11 **Design:** A descriptive, cross-sectional, analytic study.
- 12 **Setting:** Community.
- 13 **Participants:** Five hundred caregivers of family members with disabilities and/or chronic
- 14 illness in the city of Zaragoza (Spain).
- 15 Outcomes and Measures: The sociodemographic variables of the caregivers were gathered,
- 16 and their occupational performance and satisfaction were assessed using the Canadian
- 17 Occupational Performance Measure (COPM). Quality of life was assessed using the World
- 18 Health Organization Quality of Life (WHOQOL-Bref).
- 19 **Results:** In total, 32.8% of family caregivers had difficulty in all activities related to self-care
- 20 and 46.6% of caregivers had difficulty sleeping and resting, followed by receiving health
- 21 related treatments (31.6%) and the performance of physical exercise (31.2%). Women and
- 22 younger caregivers show greater impairment in self-care. Performance, satisfaction, and
- quality of life worsen as the number of affected activities increases.

Conclusions and Relevance: Caring for a dependent family member has a negative impact on the self-care activities of caregivers, especially among female caregivers and those of younger age, and is associated with lower occupational satisfaction and quality of life. What This Article Adds: This study provides information to help occupational therapists prevent a decline in self-care activities among family caregivers and improve their quality of INTRODUCTION Caring constitutes an occupation that involves two types of activities: caring for others and parenting, which involve providing care and supervisory activities (AOTA, 2020). Caring occupations are determined by culture, especially among Familism states or Latin-Mediterranean cultures, in which women have historically been assigned the social function of providing care in the private sphere. This model is characterized by high family involvement in care and scarce formal care (Cetré Castilblanco, 2023, Bagatell et al., 2023; Letrondo et al., 2023; Santana et al., 2023). Caregivers of a family member with a disability and/or chronic disease typically assume this role for an indefinite period and the onset usually appears suddenly, involuntarily and without any preparation whatsoever. Caregiving is highly stressful, impacts the family organization and has a negative effect on health, especially regarding the main caregiver (Agulló Cantos et al., 2019; Castellanos, 2022). Consequently, caregivers accumulate a series of symptoms such as emotional exhaustion,

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stress, depression, tiredness and physical fatigue, which are all part of caregiver syndrome

and which other authors associate with diseases such as hypertension, diabetes mellitus, dyslipidemia, depression, circulatory disorders, thyroid disorders and even cognitive impairment (Buenfil Díaz et al., 2016; Orta et al., 2016) Some studies include the abandonment of self-care by family caregivers as a consequence of the high level of demand of the caregiving activity, however they do not analyze the affected activities and their relationship with health (Agulló Cantos et al., 2019; Guato-Torres & Mendoza Parra, 2022).

Self-care constitutes one of the main areas of human occupation along with productivity and leisure. It comprises all those activities and tasks of daily living related to self-care (Forn de Zita, 2009). Difficulty in carrying out these activities and participating in daily life situations can affect health and wellbeing (AOTA, 2020). Knowing which self-care activities (SCAs) are affected among family caregivers can contribute to the creation of more effective intervention programs.

Study Purpose:

63	In this article, we analyze the SCAs that are affected in caregivers of a family member
64	with disability and/or chronic illness based on three objectives:
65	Objective 1: To describe the sociodemographic and caregiving profile of family
66	caregivers.
67	Objective 2: To analyze the affected SCA and their relationship with performance,
68	occupational satisfaction, and quality of life (QoL).
69	Objective 3: To analyze whether there are differences in the alterations of SCA related
70	to the sex and age of the caregivers.
71	METHOD
72	A descriptive, cross-sectional, and analytical study was conducted among family caregivers
73	from 20 social-healthcare entities in the city of Zaragoza (Spain) that care for people with
74	physical, mental/cognitive, sensory, intellectual, and developmental disabilities throughout
75	2018.
76	The following inclusion criteria were established for the sample selection:
77	- Family caregivers aged 18 years of age or older, who do not suffer from mental illness or
78	cognitive impairment and who do not receive specific remuneration for the care provided.
79	- Being the primary caregiver, sharing care with other caregivers or collaborating in care
80	on an ad hoc basis for at least one year.
81	- The family member receiving care suffers from some functional limitation, either
82	physical, mental, intellectual and/or sensory, derived from age and/or chronic illness, and
83	may be dependent or only require supervision and/or support in activities of daily living
84	on a long-term basis.

The sample size was defined as 377 persons with a maximum margin of error of 5% for a confidence level of 95% and under the assumption of maximum variance (p = q = 0.5). Finally, a sample of 500 persons was obtained and, therefore, the margin of error was 4.3% for a confidence level of 95%. Assessment instruments The sociodemographic variables of the caregivers and their family members were collected using an ad hoc questionnaire and the following assessment instruments were administered: - The Canadian Occupational Performance Measure (COPM) was used to assess occupational performance and satisfaction. The respondents identify the activities where they have problems with their performance and assign them a value from 1 to 10 to rate their satisfaction and performance when carrying them out (Gatta et al., 2022; Law et al., 2014). - The WHOQOL-Bref (World Health Organization - Quality of life, 1998) was used to measure QoL. It consists of 26 questions and is scored from 1 to 5, where 1 represents the worst condition and 5 the highest rating. It provides a profile of QOL perceived by the person through four areas: physical health, psychological health, social relationships, and environment (WHO, 2002; Salinas-Rodríguez et al., 2022). The questionnaires were delivered, collected, and analyzed personally by the principal investigator, safeguarding the identity of the participants at all times. Data Analysis Qualitative variables were described using absolute (n) and relative (%) frequencies and the mean and standard deviation (SD) for quantitative variables. Comparison between groups was performed using the Chi-square test (qualitative variables), once the assumptions of normality (Kolmogorov-Smirnov test) and homogeneity of variances (Levene test) had been verified. Two-by-two comparisons were made, using the Bonferroni correction in cases

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where there were more than two groups and where the statistical test was statistically significant. To determine the possible relationship between quantitative variables, the Pearson's correlation coefficient was calculated. A statistical analysis was performed using the SPSS 23.0 program for Windows. Statistically significant differences were considered to be those with a p<0.05. The study was approved by the Research Ethics Committee of the Autonomous Community of Aragón and was carried out in accordance with the ethical considerations of the World Medical Association in the Declaration of Helsinki. All participants signed the informed consent form and both their privacy, and the confidentiality of their personal information were protected. All the collaborating entities in the study signed a written agreement and gave their authorization for the study.

RESULTS

The sample consisted of 500 caregivers. Table 1 shows the sociodemographic information and caregiver profile of participants. Notably, a larger proportion of primary caregivers were women, with an average age of 60.3 years; more than half of them had university education or higher and 61.6% did not have a paid job. The total number of family members cared for was 500, mostly women (55.8%), with mixed disability in 69.8% of the cases and with high dependency. They had assumed the role of caregivers for an average of 13.2 years, for 15 hours a day, with four hours off each day. More than a third of them had illnesses that hampered their caregiving duties and 75.5% were living with the family member they cared for (n=377); (Table 1).

Regarding the affected activities, a greater affectation was found in activities related to self-care, followed by those concerning community management and mobility. One third of caregivers considered that they had difficulty in fulfilling all the activities related to self-care that they would like to perform. Getting enough rest and sleep was found to be the most affected activity (46.6%), followed by receiving treatments to improve health (31.6%) and physical exercise (31.2%) (Figure 1).

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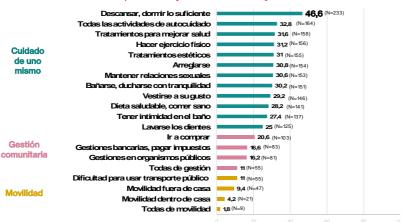


Figure 1. Prevalence of affected self-care activities.

The caregivers showed performance scores of 3.77(2.18), satisfaction values of 5.02(2.69) and QOL scores as follows: physical health 56.39(19.49), psychological health 54.75(18.52), social relations 50.1(20.84) and environment 54.31(15.51). After analyzing the occupational profile variables and their relationship with performance, satisfaction and QOL, it was observed that as the number of affected activities increased, performance, satisfaction and QOL decreased, with the exception of self-care activities, which were not correlated with satisfaction (Table 2).

After relating the affected SCAs and sex of participants, the Chi-square test revealed that female caregivers have greater difficulty than male caregivers in certain aspects related to self-care, such as taking a shower in peace, personal grooming, dressing according to their preferences, as well as receiving medical and beauty treatments. In addition, women have greater difficulty than men for moving around outside the home and for using public transport. No significant differences were found between the sexes in relation to community management tasks. Significant differences were observed when age was related to self-care difficulties. Younger caregivers perceived more difficulties fulfilling all self-care activities, with the exception of sleeping, resting and brushing teeth, where no significant differences were observed in relation to the age of the caregiver. In contrast, older caregivers presented greater difficulty with their mobility both indoors and outdoors (Table 3). DISCUSSION This is the first study to analyze the affected SCAs while relating them to performance, occupational satisfaction and QoL in a population of family caregivers, providing a perspective on sex and occupational performance. Our results show how SCAs are impaired in family caregivers, and their relationship with lower satisfaction and QoL, especially among women, in line with other authors (Guato-Torres & Mendoza Parra, 2022; Van Roij et al., 2021). Caregiving has a negative impact on the health of caregivers, who are unable to get sufficient rest, making it difficult for them to receive medical treatment or engage in healthy activities, such as physical exercise. In fact, one third of the caregivers had illnesses that hampered their ability to care for their family member. A lack of self-care is evident, which would justify a decrease in adherence to medical

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treatments and unhealthy lifestyles, such as substance abuse (tobacco, alcohol, drugs etc....),

together with inadequate nutrition and a higher incidence of diseases. This pattern of behavior could be related to caregiver syndrome (Park, 2021; Buenfil Díaz et al., 2016; Orta et al., 2016; Turtós Carbonell et al., 2016), associated with a lower subjective well-being and physical health (Castellanos, 2022; Guato-Torres & Mendoza Parra, 2022; King et al., 2021). According to our results, the reality of caregivers does not correspond to a lack of awareness as considered by other authors (Yip, 2021). Rather, it is more likely that they are unable to perform their own self-care activities, or do so with much difficulty, prioritizing time spent caring for their family member, which negatively affects their health due to their inability to carry out meaningful activities and participate in life situations, as recognized by the WHO (AOTA, 2020). Our findings are in agreement with authors such as De Wit J et al. (2019) in their study on caregivers with a family member suffering from amyotrophic lateral sclerosis. These authors state that mobility difficulties limit caregivers' participation in social activities and that a great amount of the caregivers' time is dedicated to bureaucratic procedures, which, added to the need to accompany their family member to medical visits, reduces their own self-care time and affects their working life and can generate stress (Bagatell et al., 2023; De Wit et al., 2019). Our data show that difficulties involving rest and sleep affect more than half of the caregivers. These results coincide with those published by other authors (Lauritzen et al., 2015) who highlighted insomnia and fatigue as the main repercussions of caregiving affecting the health of caregivers, with a negative impact on their physical, psychological, and social health (Garro-Gil, 2011). In contrast, a study by Hijuelos García et al. (2018), reported that lack of sleep and the need for rest did not appear to be an issue affecting the performance of caregivers. These conflicting findings could be because their caregivers presented higher levels of performance and their relatives presented lower levels of dependency than those in our study. Moreover, the cited study presents certain limitations

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such as the small sample (18 caregivers) and the reduced number of variables, with a homogeneous population of caregivers of relatives with physical disabilities.

Caregivers aged 18-40 years displayed the most difficulty in all the self-care activities assessed, with the exception of sleeping and resting. Thus, a trend is observed, in which, as the caregiver ages, the person reports less difficulty in self-care activities, in line with other studies (Roca Roger, 2000). Some authors interpret this as an acceptance of their condition as caregivers, which leads them to adjust their values and interests (Agulló Cantos et al., 2019). Gender and occupational analyses are fundamental in research related to caregiving. However, we have not found any study that includes both analyses: occupation and gender, as is our case. Our results could help to explain these differences, since the female caregivers in our study reported greater difficulties in aspects related to self-care such as personal grooming, receiving beauty treatments and medical treatments, and dressing according to their preferences. In addition, they had greater difficulty than men regarding mobility outdoor, which may help to understand why men perform more caregiving tasks outside the home (e.g., shopping and errands), which are protective activities in terms of perceived health decline (García Calvente et al., 2011). In addition, the greater self-care involvement of female caregivers could explain their worse QoL, compared to male caregivers. García Calvente et al. (2004) showed that female caregivers who had no health problems prior to caregiving were those who perceived their health status as poor or very poor, in contrast to female caregivers who already had some kind of health problem before caregiving. Both studies show the impact on health and QoL of female caregivers; our findings complement this by also assessing male caregivers, providing evidence of a greater impairment of QoL in female caregivers compared to male caregivers. Moreover, if we consider the greater involvement of women in caregiving, this constitutes a key element for understanding the impact of gender roles on health inequalities (García Calvente et al., 2011). The obligation to care clashes with

the concept of occupational justice, which ensures that people have the opportunity for full participation in occupations that define and complement them as persons (Bailliard et al., 2020). Similarly, the WHO and the philosophies advocated in the Ottawa Charter for Health Promotion recognize that health can be affected by the inability to carry out activities and participate in life situations, thus highlighting occupational performance and participation as factors that benefit people's health and well-being (AOTA, 2020). Consequently, programs directed towards family caregivers should consider affected QoL and seek appropriate treatments along these lines.

Limitations

Although our sample size was sufficient, the population was limited to a single region in Spain, which limits the extrapolation of the results to other contexts.

Conclusions

Caregivers of family members with disabilities and/or chronic disease, and to a greater extent young people and women, experience a decline in self-care activities, especially in terms of difficulty resting and sleeping. This situation is directly related to lower performance, satisfaction and QoL.

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Con formato: Izquierda

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Table 1: Sociodemographic information and characteristics of caregivers and their family members

Characteristic	Mean (SD). range	n(%)
Participants		
Age. yr	60.3 (13.64). 18-96	
Sex		
Female		364 (72.8)
Male		136(27.2)
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Marital status		
Married/Couple		380(76)
Single/Widowed/Separated		120(24)
Relationship		
Son/daughter		168(33.6)
Spouse/partner		144(28.8)
Parent		153(30.6)
Other		35(7)
Educational level		
University Studies		158(32.2)
Secondary Education		153(31.2)
Primary Education		146(29.8)
No education		33(6.7)
Employment status		
Active employment		192(38.4)
Inactive		166(33.2)
Retired		142(28.4)
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Years of care/supervision/support	13.22(12.05). 1-59	
Type of caregiver		
Primary Caregiver		365(73)
Co-responsible caregiver (equal sharing of		112(22.4)
care with another family member)		112(22.4)
Collaborative caregiver (occasional help		23(4.6)
with care)		23(4.0)
Number of family members cared for		
Cares for one dependent family member		357(71.4)
Care for more family members		143(28.6)
Care for more family members		143(20.0)
Care provided		
Monitoring/control		443(88.6)
Emotional support		398(79.6)
Instrumental activities of daily living		361(72.2)

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Basic activities of daily living		280(56)
Frequency of care Every day of the week, 24 hours a day Every day except the hours that the family member is at the center and/or after work Occasional supervision		99(19.8) 259(51.8) 144(28.8)
No. of hours of care on a normal day	14.48(8.54). 0.5-24	
No. of real hours off on a normal day	3.97(4.65). 0-24	
Illnesses that hinder care No Yes		172(61.4) 108(38.6)
Family members receiving care		
Age	61(28.2). 2-99	
Disability Intellectual and developmental disability Mental/cognitive disability Sensory disability Physical disability		335(67) 279(55.8) 256(51.2) 253(50.6)
Dependency Grade I (moderate) Grade II (severe) Grade III (high dependency)		29(5.7) 123(24.6) 348(69.7)

Grade III (high dependency)

29(5.7) 123(24.6) 348(69.7)

Table 2. Correlation between the number of self-care activities affected and performance, together with satisfaction scores and quality of life (physical, psychological health, social relationships, and environment).

	Performance	Satisfaction	Physical	Psychological	Social	Environment
VARIABLES			Health	Health	Relationships	
				(r)		
Self-care	-0.154**	-0.074	-0.312**	-0.277**	-0.312**	-0.289**
Mobility	-0.175**	-0.117*	-0.224**	-0.117**	-0.089*	-0.191**
Community	-0.197**	-0.154**	-0.260**	-0.188**	-0.216**	-0.309**
management						

r= Pearson's correlation coefficient *p<0.05; **p<0.01.

Table 3. Self-care activities in which the caregiver has difficulty and their relation to sex and age.

\$7:-1-1	Sex		χ2	Age. n (%)				
Variables	Men	Women	p	18-40	41-60	61-80	> 80	p
Self-care								
Bathroom intimacy			0.1					0.01*
No	103 (78)	249 (70.5)	-	16a (59.3)	148b (67.6)	156b (77.6)	30b (85.7)	
Yes	29 (22)	104 (29.5)		11a (40.7)	71b (32.4)	45b (22.4)	5b (14.3)	
Showering in peace			0.03*					0.05*
No	102 (77.3)	236 (66.9)		14a (51.9)	145b (66.2)	150b (74.6)	26b (74.3)	
Yes	30 (22.7)	117 (33.1)		13a (48.1)	74b (33.8)	51b (25.4)	9b (25.7)	
Brushing teeth			0.25					0.06
No	104 (78.8)	260 (73.7)		17 (63)	155 (70.8)	160 (79.6)	29 (82.9)	
Yes	28 (21.2)	93 (26.3)		10 (37)	64 (29.2)	41 (20.4)	6 (17.1)	
Personal grooming			0.02*					0.04*
No	102 (77.3)	234 (66.3)		16a (59.3)	140b (63.9)	149b (74.1)	28b (80)	
Yes	30 (22.7)	119 (33.7)		11a (40.7)	7b (36.1)	52b (25.9)	7b (20)	
Dressing to your liking			0.02*					0.04*
No	104 (78.8)	239 (67.7)		16a (59.3)	145b (66.2)	151b (75.1)	29b (82.9)	
Yes	28 (21.2)	114 (32.3)		11a (40.7)	74b (33.8)	50b (24.9)	6b (17.1)	
Beauty treatments			0.01**					0.00**
No	104 (78.8)	231 (65.4)		13a (48.1)	139a.b (63.5)	151b (75.1)	29b.c (82.9)	
Yes	28 (21.2)	122 (34.6)		14a (51.9)	80a.b (36.5)	50b (24.9)	6b.c (17.1)	
Sexual activity			0.37					0.02*
No	96 (72.7)	242 (68.6)		15a (55.6)	140b (63.9)	151b (75.1)	27b (77.1)	
Yes	36 (27.3)	111 (31.4)		12a (44.4)	79b (36.1)	50b (24.9)	8b (22.9)	
Medical treatment	. ,	• /	0.03*	. ,	•	, ,	• •	0.01*
No	100 (75.8)	231 (65.4)		14a (51.9)	141b (64.4)	147b (73.1)	29b (82.9)	
Yes	32 (24.2)	122 (34.6)		13a (48.1)	78b (35.6)	54b (26.9)	6b (17.1)	
Rest and sleep	, ,	• /	0.07	. ,	•	, ,	• •	0.22

Comentado [u2]: Generalmente el valor de p se pone a la derecha de los valores que se comparan. Al ponerlo en la fila superior lo veo raro

No	80 (60.6)	181 (51.3)		16 (59.3)	107 (48.9)	110 (54.7)	23 (65.7)	
Yes	52 (39.4)	172 (48.7)		11 (40.7)	112 (51.1)	91 (45.3)	12 (34.3)	
Eating a healthy diet			0.03*					0.00**
No	101 (76.5)	247 (70)		15a.b (55.6)	143a.c (65.3)	157b.d(78.1)	30c.d (85.7)	
Yes	31 (23.5)	106 (30)		12a.b (44.4)	76a.c (34.7)	44b.d (21.9)	5c.d (14.3)	
Physical exercise			0.34					0.02*
No	95 (72)	238 (67.4)		14a (51.9)	140b (63.9)	149b (74.1)	27b (77.1)	
Yes	37 (28)	115 (32.6)		13a (48.1)	79b (36.1)	52b (25.9)	8b (22.9)	
Difficulty in all			0.10					0.01*
No	96 (72.7)	229 (64.9)		14 (51.9)	134 (61.2)	147 (73.1)	27 (77.1)	
Yes	36 (27.3)	124 (35.1)		13 (48.1)	85 (38.8)	54 (26.9)	8 (22.9)	
Mobility								
Indoors			0.39					0.00**
No	128 (97)	336 (95.2)		26a.b (96.3)	212a (96.8)	196a (97.5)	29b (82.9)	
Yes	4 (3)	17 (4.8)		1a.b (3.7)	7a (3.2)	5a (2.5)	6b (17.1)	
Outdoors	, ,	, ,	0.02*		, ,	, ,	, , ,	<.001***
No	126 (95.5)	312 (88.4)		21a.c (77.8)	204b (93.2)	187a.b (93)	26c (74.3)	
Yes	6 (4.5)	41 (11.6)		6a.c (22.2)	15b (6.8)	14a.b (7)	9c (25.7)	
Public transportation,	` ,	` /	0.06	, ,	` ′	` '	, ,	0.1
adapted taxi			0.06					0.1
No	123 (93.2)	307 (87)		22 (81.5)	192 (87.7)	188 (93.5)	31 (88.6)	
Yes	9 (6.8)	46 (13)		5 (18.5)	27 (12.3)	13 (6.5)	4 (11.4)	
Difficulty in all	, ,	, ,	0.73	, ,	, ,	, ,	, ,	0.57
No	130 (98.5)	346 (98)		27 (100)	216 (98.6)	196 (97.5)	35 (100)	
Yes	2 (1.5)	7 (2)		` ,	3 (1.4)	5 (2.5)	` ,	
	` '	. ,			` '	` '		
Community Management								
Going shopping			0.23					0.42
No	109 (82.6)	274 (77.6)		19 (70.4)	169 (77.2)	165 (82.1)	28 (80)	<u>-</u>
	()	, . ()		- ()	(/	(/	- ()	

Yes	23 (17.4)	79 (22.4)		8 (29.6)	50 (22.8)	36 (17.9)	7 (20)	
Administrative procedures		0.21					0.63	
No	114 (86.4)	288 (81.6)		21 (77.8)	187 (85.4)	165 (82.1)	28 (80)	
Yes	18 (13.6)	65 (18.4)		6 (22.2)	32 (14.6)	36 (17.9)	7 (20)	
Public entities			0.27					0.46
No	114 (86.4)	290 (82.2)		20 (74.1)	185 (84.5)	171 (85.1)	28 (80)	
Yes	18 (13.6)	63 (17.8)		7 (25.9)	34 (15.5)	30 (14.9)	7 (20)	
Difficulty in all			0.51					0.87
No	115 (87.1)	315 (89.2)		23 (85.2)	194 (88.6)	180 (89.6)	32 (91.4)	
Yes	17 (12.9)	38 (10.8)		4 (14.8)	25 (11.4)	21 (10.4)	3 (8.6)	

^{*}p<0.05; **p<0.01; ***p<0.001.