



## Care tasks and impact of caring in primary family caregivers: A cross-sectional study from a nursing perspective

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### ABSTRACT

**Background:** Family caregivers of persons with dementia often experience a negative impact on their health. More studies based on nursing theories are needed to improve the provision of care.

**Aims:** To describe the care provided by family caregivers of persons with dementia and the impact on their health, as well as to analyse how personal variables of caregivers are related to care tasks and their health impact.

**Methods:** Multi-centric cross-sectional prospective study conducted on a sample of 423 primary family caregivers of persons with dementia from Spain. Data were collected through ICUB97-R questionnaire (January–April 2019), based on the fourteen needs of Virginia Henderson's Nursing Model. Data was analysed through one-way analysis of variance and Student's *t*-test.

**Results:** The caregiver profile was a middle-aged married woman without higher education living with the cared person, predominantly her mother. The most frequently provided care corresponded to “nutrition” and “movement” needs. Lack of free time, modifications on leisure activities, reduced sleep or rest and disruption of family life emerged as the greatest repercussions on the caregiver's health. The age of the caregiver and time caring showed differences on impact of care and care tasks, respectively.

**Conclusion:** The identification of the types of care provided, the health impact of caring and the variables affecting the family caregiver's vulnerability is essential to develop effective individualised nursing care plans, including health education interventions to improve the quality of life of both caregivers and persons cared for.

### 1. Background

Global life expectancy is on the rise as 9.1% of the world's population is 65 or older. Spain is expected to become the second oldest country in the world by 2050. Currently, 19.6% of the population is over 64 years old. Galicia, located in the north-west of the country, is the third region where more elderly people are living (Abellán García et al., 2019; United Nations, 2019).

As the population gets older, dependency levels grow due to the increase of chronic and degenerative diseases. The old-age dependency ratio worldwide stands at 15.9 and is more than twice that in Spain (ratio of 32.2). Dementias are one of the main causes of disability and

dependency through the aging process. Although not inherent to aging, the probability of suffering from a degenerative dementia increases with age (United Nations, 2019; World Health Organization, 2017).

It is estimated that around 50 million persons suffer from dementia, being Alzheimer's disease the most common among the elderly. This circumstance brings a high socio-economic burden, causing 28.8 million of disability-adjusted life years (Alzheimer's Disease International, 2019). Consequently, the World Health Organization launched a Global Action Plan in 2017 to improve the lives of individuals with dementia and their families, being a priority issue in public health (World Health Organization, 2017).

Dementia syndromes are progressive brain diseases that progress

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variably to a point of intense care. These are characterized by impairment in multiple cognitive functions with behavioural and psychological symptoms, among other manifestations. The deterioration of dementias is widespread, affecting physical, functional, affective, and social areas, and the level of dependency and the demand for care are aggravated by the progress of the disease (Gallagher-Thompson et al., 2020; World Health Organization, 2017).

Given the ever-increasing relevance of support in daily activities, the figure of the caregiver becomes essential. In our context, care is mainly provided by family caregivers, who are relatives or close persons responsible for making decisions and satisfying needs. This type of care is defined by the absence of a written contract of employment and, in many cases, the absence of institutional support or specific training. The most common family caregiver profile described is usually a middle-aged or even elderly female who is part of the nuclear family, has elementary studies and is of a medium or low socio-economic level (Martínez-Santos et al., 2021).

The circumstances surrounding caregivers influence the care and condition of individuals with dementia, who, in turn, influence the health of caregivers. Frequently, caring has negative effects on the caregiver's physical and mental health, becoming a burden along with a deterioration of social and working life, especially in females (Martínez-Santos et al., 2021). This becomes particularly important when the behavioural and psychological symptoms of dementia are present, while Alzheimer's disease one of the pathologies which would most likely lead to burnout (Rodríguez-González & Rodríguez-Míguez, 2020; Schumann, Alexopoulos, & Perneczky, 2019).

Dementias have a high negative impact on multiple socio-economic areas, including country budgets and the family economy. In informal care, costs are borne by the individual's family environment but remain poorly visible to society. The family economy is impacted by both the expenses that come with satisfying the dependent's needs, as well as by job-related complications of the primary caregiver (such as doing part-time jobs or giving up work). Therefore, the economy as well as psychosocial aspects of the caregiver's life are affected, leading to a scarcity of primary health care support to the family in most contexts (Michalowsky et al., 2016; World Health Organization, 2017). In our context, Alzheimer's associations have helped to compensate for the lack of social and health resources through health education programmes, psychological counselling and social support groups. This could become relevant in cases where certain characteristics, such as age, economic level or degree of education could make caregivers more vulnerable.

The nursing-based theoretical model that supports this research considers persons as an integral being with fourteen basic needs to be satisfied. Although caregiving consequences is a well-studied topic, this holistic perspective provides information of great importance for nursing research and practice. Thus, the use of nursing theories and concepts make it easier to develop interventions to improve people's quality of life and the provision of evidence-based nursing care (Potter, Perry, Stockert, & Hall, 2017). This is especially useful in Spain and other countries where the Henderson model is used to help persons to recover or maintain their independence by the meeting of their needs (Fuentelsaz Gallego et al., 2001).

Based on the fourteen human needs of Virginia Henderson's nursing model of care, the aim of this research is to describe the care provided by family caregivers and the impact on their health. Furthermore, we aim to analyse how age, time caring and education level of the caregivers might be related to care tasks and their health impact.

## 2. Research methods

### 2.1. Design and setting

This multi-centric cross-sectional prospective study was undertaken between January and April 2019. Participants were recruited using convenience sampling from 13 associations of family caregivers of

persons with dementia (PwD) that are part of the Regional Federation of Alzheimer's and other dementias in Galicia, NW Spain. Inclusion criteria included: (1) to be 18 or more years old, (2) to be the primary family caregiver of a PwD, (3) to be part of one association pertaining to the Regional Federation, and (4) to have been caring for a minimum of five months. Caregivers receiving remuneration for care and those displaying difficulties in understanding the nature of the study or the questionnaire were excluded. A total of 423 questionnaires were considered valid after exclusion for being incomplete ( $n = 28$ ) or for not meeting inclusion criteria ( $n = 3$ ).

### 2.2. Data collection

Data collection was carried out through a structured, voluntary, anonymous, and self-administered questionnaire (ICUB97-R).

The ICUB97-R questionnaire was chosen to assess the intensity of care provided and the repercussions on family caregivers (Chirveches-Pérez et al., 2014). This reduced version of the instrument is based on the fourteen needs of the well-known Virginia Henderson's Nursing Model, validated for Spanish population (Fuentelsaz Gallego et al., 2001). This questionnaire obtains information regarding the level of both care given and repercussions of that care, focusing on the caregivers' voice from a nursing perspective. Such approach aims to evaluate holistic health support priorities of different types of caregivers from a community-based clinical practice point of view.

### 2.3. Instrument

ICUB97-R is composed of two parts. The first one explores the nature of the care tasks provided by the caregiver to a dependent relative, whereas the second evaluates the impact of caring on the family caregiver, both essential aspects for primary health care interventions as well as for prevention approaches. Both parts are in turn divided into three dimensions: physical, environmental, and psychosocial care provided (part 1, scoring range 0–35) and psychophysical, socio-economic, and emotional repercussions (part 2, scoring range 0–30). The questionnaire comprises 65 closed questions (yes/no) and respondents must mark the answers they feel identified with. In both cases a higher score indicates more items from each scale are present. All items assess human needs according to Virginia Henderson's Need Theory.

Sociodemographic data designed *ad hoc* were requested to investigate details of the caregivers, including gender, age, cohabitation, family relationship and level of education, among others.

### 2.4. Ethical considerations

The study protocol was approved by the regional Clinical Research Ethics Committee (Reference 2019/069) and by the Regional Federation of Alzheimer's and other dementias. Participants were informed about the purpose of the study, participation was voluntary, explicit consent was obtained, and all data were processed anonymously according to the current national and European regulations on data protection.

### 2.5. Data analysis

Data were analysed using Statistical Package for the Social Sciences (SPSS) 25.0 for Mac (IBM Inc.). The frequencies of each item were recorded, and then the means of each dimension were calculated, scoring 1 if the answer was positive and 0 if negative. Subsequently, differences between groups were calculated by comparing these means. One-way analysis of variance (ANOVA) was conducted to evaluate differences in the two abbreviated ICUB97-R subscales for the age and time-care groups. Also, Student's *t*-test was carried out to examine differences in the two groups of education level. *p* values < 0.05 were considered significant.

### 3. Results

#### 3.1. Patient characteristics

The sample consisted of 423 primary family caregivers of a dependent PwD with an average age of 59.94 years (SD: 12.77) and mostly female (73.3%). The person being cared for was also mostly female (70.4%). The profile of the caregivers is shown in Table 1.

#### 3.2. Care tasks and impact of caring

The mean number of care tasks provided by family caregivers was 26.06 ± 6.13 (minimum = 2, maximum = 32, scoring range 0–35). Table 2 shows the frequency distribution of item responses related to care tasks provided by the primary family caregiver (first part of the questionnaire). Most frequently provided care were those related to cooking and buying food, as well as accompanying the patient to health services, therefore corresponding to nutrition and movement needs, respectively.

Regarding the repercussions of caring on the well-being and health of the caregiver, the mean number of items was 9.21 ± 5.17 (minimum = 0, maximum = 25, scoring range 0–30). Table 3 shows the frequency distribution of responses related to the impact of caring (second part of the questionnaire). Most frequently affected needs were *play or participate in recreation* and *sleeps or rests less*. Psychophysical and socio-economic dimensions are strongly affected, with a reduction in resting time, fatigue, and anxiety-related symptoms as well as reporting a negative impact on the amount of free time, leisure activities and disruption of family life.

In addition, below we show the differences on care tasks and impact of care based on sociodemographic characteristics.

**Table 1**  
Sociodemographic characteristics of primary family caregivers (N = 423).

	N (%)
Gender	
Female	310 (73.3)
Male	113 (26.7)
Age range (years)	
≤45	49 (11.6)
46–64	218 (51.5)
≥65	156 (36.9)
Civil status	
Married or living as a couple	319 (75.4)
Lone (single, divorced, widow/widower)	104 (24.6)
Higher education	
Yes	158 (37.3)
No	265 (62.7)
Employment situation	
Working	181 (42.8)
Retired	177 (41.8)
Unemployed	65 (15.4)
Place of residence	
Urban	239 (56.5)
Semiurban	108 (25.5)
Rural	76 (18)
Kinship relationship with the cared person	
Daughter/son (including in-law)	256 (60.5)
Partner	130 (30.8)
Other (sibling, granddaughter/grandson, others)	37 (8.7)
Living with the cared person	
Yes	369 (87.2)
No	54 (12.8)
Time caring	
5 months–1 year	33 (7.8)
1–3 years	111 (26.3)
3–5 years	103 (24.3)
5–10 years	116 (27.4)
>10 years	60 (14.2)

**Table 2**

Frequency distribution of item responses corresponding to the first part of the questionnaire (N = 423). It is composed of three dimensions reflecting areas of care provided, each including specific needs according to Virginia Henderson's Need Theory.

DIMENSION	Item	N (%)	
Type of care provided and needs			
PHYSICAL	Accompanies the patient to health services	348 (82.3)	
	Supervises the hygiene of the patient and the house	341 (80.6)	
	Helps the patient to choose suitable clothing and footwear	280 (66.2)	
	Cuts the patient's toenails	252 (59.5)	
	Accompanies the patient to the bathroom	235 (55.5)	
	Performs hair and/or foot hygiene	231 (54.6)	
	Helps the patient to dress and undress	219 (51.7)	
	Changes nappies	205 (48.4)	
	Performs all the hygiene	194 (45.8)	
	Dresses and undresses the patient	175 (41.3)	
	Prevents skin injuries	170 (40.2)	
	Helps the patient to roam around the house or from bed to the couch	163 (38.5)	
	Performs mouth hygiene	147 (34.7)	
	Heals skin injuries	142 (33.5)	
	Gives medication or enemas to regulate bowel movements	93 (22)	
	Performs postural changes	61 (14.4)	
	Places the bedpan	25 (5.9)	
	Cooks food	368 (87)	
	ENVIRONMENTAL	Buy food	357 (84.4)
		Adjusts the temperature of the house	342 (80.8)
Adequates home conditions		272 (64.3)	
Gives medication		229 (54.1)	
Monitors body temperature		122 (28.8)	
PSYCHOSOCIAL	Feeds the patient	118 (27.9)	
	Prepares a special diet	103 (24.3)	
	Gives medication to regulate temperature	33 (7.8)	
	Helps or practices respiratory rehabilitation	11 (2.6)	
	Feeds the patient by nasogastric tube	1 (0.2)	
ENVIRONMENTAL	Accompanies the patient for a walk	320 (75.6)	
	Provides entertainment	298 (70.4)	
	Makes it easier for the patient to live by his/her beliefs and values	279 (65.9)	
	Provides resources to learn	207 (48.9)	
	Makes it easier for the patient to do his/her hobbies	187 (44.2)	
	Teaches the patient how to improve health and well-being	183 (43.2)	
	Teaches the patient the management of his/her disease	82 (19.4)	
	Learn, discover, or satisfy curiosity	279 (65.9)	
	Worship according to one's faith	298 (70.4)	
	Play or participate in recreation	279 (65.9)	

**Table 3**

Frequency distribution of item responses corresponding to the second part of the questionnaire (N = 423). It is composed of three dimensions reflecting areas of repercussions of caring in caregivers, each including specific needs according to Virginia Henderson's Need Theory.

DIMENSION	Item	N (%)	
<b>Type of repercussion and needs</b>			
PSYCHOPHYSICAL	Sleeps or rests less	247 (58.4)	
	Avoid dangers	245 (57.9)	
	Breathe normally	221 (52.2)	
	Sleep and rest	213 (50.4)	
	Feels powerless	196 (46.3)	
	Feels irritated	181 (42.8)	
	Feels anxious	181 (42.8)	
	Has a feeling of shortness of breath	142 (33.6)	
	Takes medication	102 (24.1)	
	Is depressed	99 (23.4)	
	Takes medication to sleep	77 (18.2)	
	Feels disinterested in his/her environment	73 (17.3)	
	Smokes more	43 (10.2)	
	Takes self-protection measures	30 (7.1)	
	Has started smoking	10 (2.4)	
	SOCIO-ECONOMIC	Has less free time	325 (76.8)
		Play or participate in recreation	271 (64.1)
Keep the body clean and well-groomed and protect the integument		221 (52.2)	
Dress and undress		192 (45.4)	
Work with a sense of accomplishment		152 (35.9)	
Has difficulty distributing her/his time		145 (34.3)	
Spends less time on personal care		84 (19.9)	
Her/his economy has weakened		71 (16.8)	
Has adapted her/his work outside the home to take care of		60 (14.2)	
Has difficulties in promoting herself/himself in the workplace		49 (11.6)	
EMOTIONAL	Works less time away from home	47 (11.1)	
	Has alterations in the intestinal rhythm	123 (29.1)	
	Eliminate body wastes	54 (12.8)	
	Worship according to one's faith	23 (5.4)	
	Takes laxatives	19 (4.5)	
	Has changes in her menstrual rhythm	19 (4.5)	

**3.3. Effects of age, time caring and educational differences on care tasks and impact of care**

Differences in age group were only found in two dimensions of the second part of the scale measuring impact of care (see Table 4). Post-hoc comparison showed differences between the youngest group and the two

**Table 4**

Distribution of the care tasks and impact of care dimensions depending on the age group of the caregivers.

Part	Dimension	≤45 years (n = 49)	46–64 years (n = 218)	≥65 years (n = 156)	Total (n = 423)	F <sup>a</sup>
Care tasks	Physical	7.02 (4.11)	7.88 (4.08)	7.82 (4.24)	7.76 (4.14)	0.88
	Environmental	4.45 (1.96)	4.67 (1.89)	4.61 (1.64)	4.62 (1.81)	0.32
	Psychosocial	4.02 (1.97)	3.61 (1.81)	3.67 (1.96)	3.68 (1.88)	0.87
	Total	15.49 (6.20)	16.16 (6.23)	16.10 (6.01)	16.06 (6.14)	0.241
	Impact of care	5.28 (3.16)	4.61 (3.05)	5.11 (2.87)	4.87 (3.00)	1.82
Impact of care	Socio-economic	0–12 (2.69)	0–13 (2.36)	0–12 (2.02)	0–13 (2.31)	5.62*
	Emotional	0–3 (0.96)	0–4 (0.79)	0–3 (0.69)	0–4 (0.79)	6.74*
	Total	10.65 (6.12)	9.12 (5.34)	8.88 (4.54)	9.21 (5.18)	2.260

Note: Results are shown as mean, standard deviation (in brackets), and range. Scoring ranges are 0–35 for care tasks and 0–30 for impact of care.

<sup>a</sup> F (2,420).  
\* p < 0.01.

other groups.

Differences depending on the time spent caring were found for physical care and environmental care tasks (see Table 5). Post-hoc comparisons showed that the group which spent from five months to one year caring does fewer physical care tasks than those who spent a minimum of three years. Groups caring from five months to one year and from one to three years do fewer environmental care tasks than the rest. Analysing this part as a whole, the groups that spent from five months to one year and from one to three years do fewer care tasks than those who spent three to five and five to ten years. Nevertheless, no differences among groups were found regarding the impact of care.

No significant differences were found between education level and the ICUB97-R dimensions (Table 6).

**4. Discussion**

The study revealed that the profile of the family caregiver is that of a middle-aged daughter living with the person she cares for. This portrait agreed with data found in other studies previously conducted in the other regions in Spain (Ruisoto et al., 2020) and the general profile in Europe (European Union, 2018). Nevertheless, in areas of northern Europe the sociodemographic characteristics differ slightly in proportion and the female predominance is less marked (Bleijlevens et al., 2015; Hajek & König, 2018).

In this study, the most provided cares are aimed at supplementing instrumental activities of daily life (activities that take place every day to take care of yourself and your home), since they are the first affected with the onset of dementia. In the dimension “psychophysical care”, accompanying the dependent to health services and supervising hygiene were the most common tasks. Given the characteristics of the studied population, a high frequency of these activities was expected. The need for both cares seems associated to cognitive limitations of PwD rather than physical needs and are also frequently provided by family caregivers in other contexts such as palliative diseases (Fuentelsaz Gallego

**Table 5**  
Distribution of the care tasks and impact of care dimensions depending on the time spent caring.

Part	Dimension	5 months to 1 year	1 to 3 years	3 to 5 years	5 to 10 years	>10 years	F <sup>a</sup>
Care tasks	Physical	5.56 (3.53)	6.42 (3.90)	8.32 (3.83)	8.92 (4.24)	8.20 (4.19)	8.71*
	Environmental	3.91 (1.67)	4.08 (1.64)	4.93 (1.76)	4.91 (2.07)	4.93 (2.07)	6.01*
	Psychosocial	3.72 (1.89)	3.67 (1.83)	3.89 (1.88)	3.47 (1.95)	3.70 (2.04)	0.68
	Total	13.21 (6.05)	14.17 (5.51)	17.15 (5.68)	17.31 (6.22)	16.83 (6.49)	7.04*
Impact of care	Psychophysical	4.27 (2.99)	4.64 (3.00)	4.70 (2.94)	5.37 (3.05)	4.93 (2.99)	1.38
	Socio-economic	3.67 (2.41)	3.76 (2.12)	4.07 (2.47)	3.89 (2.25)	3.47 (2.41)	0.72
	Emotional	0.33 (0.65)	0.50 (0.76)	0.46 (0.78)	0.53 (0.75)	0.72 (0.98)	1.58
	Total	8.27 (5.46)	8.92 (4.93)	9.22 (5.23)	9.79 (5.10)	9.12 (5.17)	0.57

Note: Results are shown as mean and standard deviation (in brackets).

Scoring ranges are 0–35 for care tasks and 0–30 for impact of care.

<sup>a</sup> F (4,418).

\* p < 0.01.

**Table 6**  
Distribution of the care tasks and impact of care dimensions depending on the educational level of the caregivers.

Part	Dimension	Higher education	No higher education	t <sup>a</sup>
Care tasks	Physical	7.54 (4.09) 0–17	7.88 (4.17) 0–17	0.81
	Environmental	4.58 (1.87) 0–9	4.64 (1.76) 1–10	0.37
	Psychosocial	3.80 (1.88) 0–7	3.61 (1.89) 0–7	–1.01
	Total	6.29 (0.50) 2–32	6.06 (0.37) 2–31	0.35
Impact of care	Psychophysical	4.84 (2.93) 0–12	4.88 (3.05) 0–13	0.12
	Socio-economic	4.03 (2.31) 0–10	3.70 (2.30) 0–10	–1.44
	Emotional	0.51 (0.80) 0–3	0.52 (0.78) 0–4	0.23
	Total	5.20 (0.41) 0–25	5.16 (0.32) 0–24	–0.54

Note: Results are shown as mean, standard deviation (in brackets), and range.

Scoring ranges are 0–35 for care tasks and 0–30 for impact of care.

<sup>a</sup> t(421).

et al., 2001; Velasco Ramírez, Grijalva, & González Pedraza Avilés, 2015). Therefore, these are not difficulties exclusive to our sample, but rather one of the first areas that requires care after the appearance of a dependency. The most accomplished environmental cares were cooking, buying food, and adjusting the temperature of the home, as reported in other studies using ICUB97-R questionnaire (Chirveches-Pérez et al., 2014; Velasco Ramírez, Grijalva, & González Pedraza Avilés, 2015). As for the psychosocial dimension, accompanying walking and providing entertainment were the most performed activities by the family caregivers in our study, being less common in caregivers of other dependent patients (Bonacasa, Rosa, Camps, & Martínez-Rubio, 2019). In general, since needs of PwD and the care provided are related, the tasks less provided by family caregivers were more specific and those carried out in advanced stages of the disease or when complications occur, like feeding the patients by nasogastric tube or practicing respiratory rehabilitation with them.

Previous studies underlined the most provided care by family caregivers in our study as predisposing factors to suffering burnout syndrome, such as performing practical tasks to supplement instrumental activities of daily living or supervising the PwD (Schumann, Alexopoulos, & Pernecky, 2019). Therefore, our results stress the need to provide assistance, counselling and health education to caregivers.

Regarding repercussions, those of the psychological sphere were the most prevalent, being “sleeping and resting less” and “being more tired” the most common items expressed by our participants. Both the quality and quantity of sleep are largely affected in family caregivers of PwD, as reported by recent studies (Gao, Chapagain, & Scullin, 2019). In

addition, the physical and mental overload of caring could result in altered physical and mental health, contributing to the appearance of diseases such as depression and anxiety (Avargues-Navarro et al., 2020; Gao, Chapagain, & Scullin, 2019) and increasing the chances of deteriorating the quality of care (Gao, Chapagain, & Scullin, 2019), making the situation more complex. In the socio-economic sphere, caregivers stated having less free time as well as having modified their leisure activities. In general, these are among the most affected areas in family caregivers, both of PwD and of another dependent populations, greatly contributing to the increase of the feeling of overload (Pudelewicz, Talarska, & Bączyk, 2019; Velasco Ramírez, Grijalva, & González Pedraza Avilés, 2015). The more care the caregivers of PwD carry out, the more impact they suffer. As evidenced in interventions performed in this population, family caregivers experience a reduction in overload and distress when they receive help (Kales et al., 2018). Therefore, the impact of this activity being such, it is evident that intervening in care would reduce the impact on health, which would result in benefits for the family system.

In terms of socio-economic and emotional spheres, the impact of caring on family caregivers in our sample decreases with age. Emotionally, suffering the fewest repercussions may be associated with resilience. As previous studies point out, this quality is greater with age and is a protective factor against the appearance of burnout syndrome (Ransmayr et al., 2018; Ruisoto et al., 2020). This relationship could be due to the moral obligation they feel because the dependent is a member of the family or a close friend (Avargues-Navarro et al., 2020). The social conception could also play an important role in this result, since older people may consider care as an obligation or a task for which they are intended, as opposed to younger caregivers who usually will not assume that role. It is also possible that this is influenced by the fact that the youngest caregivers have other types of life cycle obligations, such as childcare or job promotion, although women still remain the main caregivers in Europe (Avargues-Navarro et al., 2020; European Union, 2018). The differences found in the proportion of time spent caring for caregivers and the impact of care were not statistically significant, but there is a trend towards the increase of impact on caregivers' lives the more time they dedicate to care, especially in the emotional sphere.

Our findings are in line with previous studies analysing the impact of caring on caregivers of PwD (Reed et al., 2020), whose increase would be in line with the care provided. Despite this, in the psychophysical and socio-economic sphere, a slight decrease in the repercussions is observed after ten years of care, which could be due to the fact that only the people who best cope with care persist in such tasks (Cheng, 2017).

#### 4.1. Strengths & limitations

The main strengths of this investigation include the large sample size, considering the characteristics of the population and the difficulty in accessing it, and the analysis of family care from the nursing point of view provided by the ICUB97-R questionnaire, enabling the

development of evidence-based interventions led by nurses. This research also has some limitations that need to be addressed. It was carried out in a single region of Spain, therefore similar studies in other areas of the country are needed to extend our conclusions. Secondly, all participants are members of associations, and ideally the situation of those who do not have the support of those associations should be also investigated. Finally, limitations from a non-probabilistic sampling and the exploratory nature of the data collected using this instrument should be considered.

## 5. Conclusions

We present evidence about the profile of the caregivers of PwD in a particularly aging region of Spain, providing key information to develop evidence-based nursing care. The integrity of families undergoes considerable alterations with the onset of dependency, and nurses play a key role in reducing such an impact by instructing in care and self-care, as well as by supervising and assisting when necessary. The population analysed in this study belongs to the group of caregivers of PwD, but the literature has shown that their needs are largely similar regardless of the nature of the patient's dependency.

The individualised analysis of families with dependents will allow for the identification of specific needs and training opportunities related to care tasks with room for counselling and health education interventions. This would increase the quality of care provided and reduce overload, benefiting both the caregiver and the person cared for. Negative repercussions on the psychological sphere were reported as the most prevalent by family caregivers, particularly those related to poor sleeping and greater tiredness. Since sustained physical and mental overload might contribute to the development of diseases, early identification and development of preventive interventions in these areas are priority objectives of nursing assistance.

Nursing approaches aimed at supporting family caregivers should identify their specific contexts from a holistic perspective to design individualised and effective care plans that satisfy their needs. The need to design nurse-led prevention and intervention programs for family caregivers is evident. Future research should be focused on identifying the profile of caregivers in different contexts, as well as on analysing the effectiveness of interventions aimed at improving their quality of life and, therefore, also that of patients. This might provide evidence to develop practice guidelines that promote the delivery of high quality, evidence-based health care.

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## CRediT authorship contribution statement

**Alba-Elena Martínez-Santos:** Conceptualization, Investigation, Formal analysis, Writing – original draft, Validation. **Noelia Vicho de la Fuente:** Conceptualization, Investigation, Formal analysis, Writing – original draft, Validation. **David Facal:** Investigation, Formal analysis, Supervision, Writing – review & editing, Validation. **Lucía Vilanova-Trillo:** Investigation, Formal analysis, Supervision, Writing – review & editing, Validation. **Manuel Gandoy-Crego:** Investigation, Formal analysis, Supervision, Writing – review & editing, Validation. **Raquel Rodríguez-González:** Conceptualization, Investigation, Formal analysis, Supervision, Writing – review & editing, Validation.

## Declaration of competing interest

No conflict of interest has been declared by the authors.

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