



Patient-Centered Innovation

Gender impact of caring on the health of caregivers of persons with dementia



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ABSTRACT

Background: Dementia is a brain syndrome that affects a growing number of persons worldwide and generates a strong and progressive demand for care from a family caregiver, usually females.

Objective: We aimed to describe the care provided by family caregivers of persons with dementia as well as the impact on their health and its interrelation with gender.

Patient involvement: This study was carried out in collaboration with the 13 associations of family caregivers of persons with dementia that are part of a Regional Federation. This partnership worked towards bettering patient care and proposing improvements to the public health system.

Methods: A multi-institutional cross-sectional study. A total of 462 primary family caregivers of persons with dementia from north-west Spain were included. Data were collected between January and April 2019 with an anonymous self-administered validated questionnaire (ICUB-97) based on Virginia Henderson's nursing care model.

Results: The most affected needs in family caregivers are those related to “recreational activities”, “communication” and “rest and sleep”. Statistically significant differences between male and female participants' pattern of care and health-related impacts were found, especially in issues related to work and family reconciliation.

Discussion: Care plans should be developed taking gender perspective into account. From a nurse model point of view, more research is necessary to reduce health disparities. This study provides an assessment of gender differences in care and the impact on caregivers' health.

Practical value: Regarding the specific health conditions of female caregivers and from a holistic point of view, these findings could provide novel and interesting data that might help to implement gender perspective in nursing care plans, generally invisible in routine clinical practice.

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1. Introduction

Dementia is an umbrella term for a set of neurodegenerative diseases that show progressive cognitive decline [1]. In this context, family caregiving plays a critical role, since most persons with dementia (PWD) live in the community, leading to a

worldwide socioeconomic burden. The number of cases has increased in recent decades and it is expected to continue growing due to social and demographic trends, with a significant number of persons that remain undiagnosed [2–4].

According to the characteristics defining the informal nature of care, a “family caregiver”, if it exists, is the person responsible for making decisions and covering the needs of the dependents. In most cases, it is a female family member who assumes the role of primary caregiver due to women's tendency to fulfil the caregiving role in Southern Europe and owing to feeble support from the welfare system [5,6]. However, this care function has continuously evolved over time, since the role of females in society has changed

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in the last decades [2,7–9]. Although evidence exists that female caregivers suffer more burden and this has direct consequences on their health, there is little research that focuses on studying these differences and gender is a neglected dimension in public policies and strategies [9–11].

It is known that family caregivers of PWD experience numerous health-related problems such as anxiety or depression, social difficulties derived from not having time for themselves and work-related complications [3–5]. Among the factors that make the caregivers more likely to suffer from burden are sociodemographic, care and clinical variables (i.e. family connection, age or mental health), having greater burden than caregivers of other dependents [12,13]. All these factors could have an impact on caregivers' health and the quality of care provided.

As a southern European country, Spanish culture, where older persons have a high degree of social support, views people taking care of their counterparts at home very positively [14,15], since it is provided at great personal cost. Currently, the holistic-humanistic model of the American nurse Virginia Henderson remains one of the theories on which nursing care is based in those countries, where care plans pay special attention to health and independence by meeting the basic needs of biological, psychological, social and spiritual areas of their lives [16]. In addition, both in the Academy and in Clinical Practice (hospital, primary and social care) this model is widely used in our country to establish nursing care plans and to improve professional practice and promote personal independence [17–20].

According to the well-known fourteen human needs of the Virginia Henderson nursing model of care and the usefulness of questionnaires based on a nursing perspective in the clinical setting, we aimed to cover the research gap from its own model and language.

Therefore, the objectives were to describe: (1) the care provided by family caregivers of PWD and the impact on their health, (2) the interrelationship between care and health, as well as (3) associations of both with the caregiver gender.

2. Methods

2.1. Study design

Multi-institutional cross-sectional study. Data were collected between January and April 2019 with an anonymous self-administered questionnaire. The study protocol was approved by the regional Research Ethics Committee (Reference 2019/069).

This study was carried out in 13 associations of family caregivers of PWD that are part of a Regional Federation and

distributed in different rural or urban councils or districts of Galicia (north-west Spain).

2.2. Questionnaire and variables

To achieve the objectives of the study, the validated questionnaire ICUB97 was administered [16]. It is composed of two dimensions to describe (a) the care provided to dependents (48 items/dispensed care) and (b) the impact on caregiver's health (46 items/health problems). Sociodemographic data of the caregiver and the relative with dementia were also collected. It was developed according to Virginia Henderson's 14 Needs nursing model based on basic human needs [17].

2.3. Sample and data collection

Participants were primary family caregivers of PWD in the north-west of Spain. Caregivers were recruited through the social work department of each association. All the member families were invited to participate. Eligible participants were caregivers who comply with (a) being > 18 years old and (b) being part of one of the associations. Those who had been caring for less than 5 months were excluded.

2.4. Data analysis

Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) 20.0 for Mac (IBM 3nc.). A descriptive analysis was made of all variables to describe the sample. Reliability tests of the questionnaire were obtained, using the Cronbach alpha index. Non-parametric statistics were applied for analysis because data were not normally distributed. Spearman's correlation coefficients were used to numerically quantify the association between care provided to dependents and perceived health problems. To analyse the existence of gender differences in total scores of two dimensions, the Mann-Whitney *U* test was used; using the Chi-square to make comparisons between items answered affirmatively too. *P* value <0.05 was considered as the nominal threshold for statistical significance.

3. Results

A total of 462 caregivers were enrolled in the study, with the final sample being 431. The questionnaires were excluded due to errors in filling or missing data.

Table 1
Sociodemographic characteristics of family caregivers.

		Frequency (n)	(%)
Gender	Female	317	73.5
	Male	114	26.5
Education level	No studies	26	6
	Primary education or equivalent	123	28.5
	Secondary education or equivalent	68	15.8
	Medium vocational education or equivalent	51	11.8
	Superior vocational education or equivalent	63	14.6
	University studies	100	23.2
Employment situation	Employed	181	42.0
	Unemployed	65	15.1
	Retired	177	41.2
	Study and work	8	1.8
Kinship	Daughter/son	248	57.5
	Partner	131	30.4
	Daughter in law/son in law	14	3.2
	Sister/brother	8	1.9
	Other family members	30	6.9

Table 2
Care provided and impact of caring on the caregiver, sorted by the ten highest frequencies.

Item number	Care provided to dependents	n	%	Item number	Impact on caregiver health	n	%
5	Cooking food	375	87.0	43	Have less free time	331	76.8
4	Buying food	365	84.7	44	Have modified leisure activities	276	64.0
13	Accompanying the patient to healthcare services	355	82.4	32	Have fewer social relationships	269	62.4
36	Keeping the patient company	350	81.2	17	Sleep/rest less	253	58.7
24	Supervising the patient's personal and household hygiene	349	81.0	16	Feel more tired	250	58.0
42	Making decisions for the patient	348	80.7	12	Practice less physical activity	239	55.5
21	Adapting the home conditions	347	80.5	18	Wake up often	226	52.4
35	Being the intermediary between the patient and the healthcare workers	345	80.0	41	Family life has been altered	225	52.2
43	Taking the patient for a walk	324	75.2	25	Feel nervous	218	50.6
34	Administering medication	307	71.2	14	Have back pain	209	48.5

The caregivers' profile was a 59-year-old (59.64 years; 95% CI 58.38–60.77) married woman with primary education. There were a similar number of employed (42%) and retired (41.2%) caregivers who lived in an urban environment (56.6%). They were usually daughters or sons (57.5%) who lived with their parent with dementia (87.0%). Sociodemographic characteristics of the family caregivers are shown in Table 1. The mean age of dependents was 80.86 years (95% CI 80.07–81.65) and 70.3% were females.

The reliability analysis of the two dimensions of ICUB97 showed a Cronbach alpha index of 0.912, indicating excellent internal consistency.

According to the Virginia Henderson nursing model, the most frequently performed care tasks corresponded to the needs of nutrition (items 4 and 5), movement (item 13), communication (item 36), hygiene and skin protection (item 24) and work and feel fulfilled (item 42) (see related items in Table 2).

Regarding the impact that care produces on family caregivers' health (Table 2), the highest frequency corresponds to recreation needs (items 43 and 44), communication (item 32), rest and sleep (items 16–18), movement (items 12 and 14), work and be fulfilled (item 41) and need to avoid dangers (item 25).

Care was provided in a mean of 23.67, SD = 8.27 items (of a total of 48). The impact on caregiver's health was recorded in a mean of 13.63, SD = 7.56 items (of a total of 46). A significant correlation was

found between total scores of care provided and health problems ($p = 0.000$).

The Mann-Whitney *U* test showed significant differences in relation to gender and the score of health problems reported by participants (impact on caregiver's health). The caregiver's profile showing more care-related health problems was a woman ($p = 0.001$) caring for a man ($p = 0.015$). There were no significant gender differences in the total scores of the first dimension of the questionnaire (care provided to dependents).

The item analysis revealed significant differences in some items given to gender (Table 3). In general, females reported the fulfilment of more care-tasks to dependents as well as more health problems related with not performing self-care. No care-task was performed more by males than by females or had more impact on male caregivers' health.

4. Discussion and conclusion

4.1. Discussion

Among the different types of caregivers, family members are the most common [21] and they are usually middle-aged females, even old females. They belong to the nuclear family of the dependent and are frequently daughters [7,13,22]. In contrast with

Table 3
Significant gender differences on the care provided and the caregiver's health items of the ICUB97 questionnaire.

Item number	Care provided to dependents	Female N (%)	Male N (%)	χ^2 Pearson	Statistical analyses
29	Preventing injuries on the skin	141 (44.4)	34 (29.8)	7.46	$p = 0.006$
28	Performing all the patient's hygiene	156 (49.2)	40 (35.0)	6.74	$p = 0.009$
6	Preparing a special diet	86 (27.1)	19 (16.6)	4.98	$p = 0.026$
17	Administering sleep medication	174 (54.8)	49 (42.9)	4.76	$p = 0.029$
25	Performing the patient's hair and/or foot hygiene	183 (57.7)	53(46.4)	4.27	$p = 0.039$
4	Buying food	275 (86.7)	90 (78.9)	3.93	$p = 0.047$
Item number	Impact on caregiver's health	Female N (%)	Male N (%)	χ^2 Pearson	Statistical analyses
22	Spend less time on your personal care	136 (42.9)	21 (18.4)	21.70	$p = 0.000$
9	Bowel habits have been altered	106 (33.4)	19(16.6)	11.45	$p = 0.001$
26	Feel helpless	165 (52.0)	38 (33.3)	11.78	$p = 0.001$
40	Have left your job	44 (13.8)	3 (2.6)	10.92	$p = 0.001$
1	Have a feeling of breathlessness	121 (38.1)	25(21.9)	9.87	$p = 0.002$
27	Feel anxious	150 (47.3)	35(30.7)	9.45	$p = 0.002$
14	Have back pain	167 (52.6)	42 (36.8)	8.42	$p = 0.004$
10	Menstrual cycle has been altered	20 (6.3)	0 (0.0)	7.54	$p = 0.006$
6	Have poor digestion	76 (23.9)	14 (12.2)	6.94	$p = 0.008$
15	Take pain killers	112(35.3)	25 (21.9)	6.94	$p = 0.008$
37	Have difficulties promoting at work	65 (20.5)	11 (9.6)	6.80	$p = 0.009$
7	Have lost/gained weight	145 (45.7)	37 (32.45)	6.06	$p = 0.014$
41	Family life has been altered	176 (55.5)	49 (42.9)	5.28	$p = 0.022$
24	Feel irritated	147 (46.3)	39 (34.2)	5.05	$p = 0.025$
18	Wake up often	176 (55.5)	50 (43.8)	4.57	$p = 0.033$
19	Take sleep medication	64 (20.1)	13 (11.4)	4.41	$p = 0.036$
28	Are depressed	82 (25.8)	19 (16.6)	3.95	$p = 0.047$

the trend towards equal gender distribution of care in Northern European countries [23,24], the predominance of the profile of the married female caregiver between 50 and 60 years with primary education is still valid in Spanish population [13,15,22], as also shown in our study. In this context, the gender study is relevant, since the role of caregiver is mostly carried out by female relatives who live in a weak welfare model with a high dependency on informal and family care, like in other Mediterranean countries where women follow the traditional care tendence [6,25,26].

Participants in this study showed patterns of care and impacts on their own health similar to caregivers of other conditions such as neurodegenerative diseases or cancer [13,27,28]. The caregivers' health status greatly influences the care provided to the dependent. A good quality of life of the caregiver will positively impact not only on her/himself but also on the care provided and, therefore, on the well-being of both parts. Numerous studies show that this activity generates a physical and emotional overload along with a deterioration of social and working life [21,22]. Within a multidisciplinary healthcare team, nurses provide care and it stands out above all support, health education and skills preparation [29]. Supporting the health and wellness of caregivers is beneficial to both carers and dependent persons, as well as the healthcare system [30].

This study showed how gender influences differences in the impact that caregiving has on health. Specifically, females performed more care tasks related with hygiene and skin protection (items 25, 28 and 29) of PWD, while neglecting their own. Also, in relation to the need of rest and sleep, they are more responsible for giving medication to satisfy this requirement (item 17), and they suffer from greater alterations compared to males, even requiring specific treatment. In relation to nutritional needs, female caregivers show health-related issues such as bowel habit alterations, poor digestion and weight loss/gain (see Table 3).

Other studies affirm that caregiving frequently leads to harmful effects on lifestyle, organization of time, physical and emotional health [27], and even deterioration in their working life and economic problems [4,27]. Our study shows differences in the needs to work and being fulfilled and avoiding dangers, as females manifest more problems related to mental health and family/job reconciliation difficulties. This could be related to the degree of involvement in the care given by women, as well as to less support received compared to men [7,31]. Being a caregiver imposes limitations on entering the job market and getting promotions; when they are daughters who work outside the home, they tend to do part-time jobs [7].

Specifically, in relation with gender, similar results are shown, finding gender differences in dementia caregivers in subscales of time dependence, developmental, physical and social burdens. The study showed females had more problems than males [31]. Differences between the gender variable and the burden were highlighted in different investigations, many carried out years ago, indicating the need for more recent research [8,11,32]. One empirical study and a scoping review suggest that females (daughters and wives) are the most vulnerable group and confirm the importance of the particular caregiver's characteristics on their own well-being, rather than those of the PWD [10,32].

4.2. Conclusion

As can be observed in the associations between the care provided and the impact on caregivers' health dimensions, the pattern of care provided by family caregivers of PWD is associated with specific consequences on their own health. According to Virginia Henderson's Model, female caregivers have distinct unmet needs and usually meet particular challenges, showing less time dedicated on their own personal care, more health and

gastrointestinal problems and less job advancement. These findings show that nursing care plans should be designed considering the gender perspective to effectively reduce health disparities.

4.3. Practice implications

The significance of gender in health and employment policies continues to be marginalized towards a gender-neutral perspective [11]. Therefore, this research provides useful and necessary data for healthcare providers, researchers and policy-makers. What is more, it raises awareness of needs based on gender. Few studies contribute with data about the nursing models and terminology used in the implementation of nursing care [19,20]. Our study adds a piece to the complex puzzle of the impact of gender on the well-being from a practical nursing perspective. Making the needs of a specific group visible can help to improve awareness about them, which may be necessary within our welfare system to transform healthcare delivery. Finally, it is necessary to develop and evaluate evidence-based care plans that improve the holistic health of female family caregivers. Likewise, this research could be useful to design specific health education interventions to promote and support self-care of this vulnerable group in different levels of care.

5. Study limitations

Since the study has been carried out in a single region of Spain, more studies are needed in different geographical areas to draw conclusions that can be extrapolated to a much broader context. Secondly, all participants are members of associations, but it is also necessary to identify the situation of those who, for different reasons, do not have this support and for whom the situation is perhaps more complicated. Finally, we did not ask if there was a coexistence prior to the diagnosis of dementia or if this was due to the progression of the disease.

Author statement

Alba-Elena Martínez-Santos: design of the work, acquisition, analysis and interpretation of the data, drafting the work and final approval of the version to be published.

David Facal: design of the work, analysis of the data, drafting the work and final approval of the version to be published.

Noelia Vicho de la Fuente: design of the work, acquisition of the data, revising it critically for important intellectual content and final approval of the version to be published.

Lucía Vilanova-Trillo: design of the work, acquisition of the data, revising it critically for important intellectual content and final approval of the version to be published.

Manuel Gandoy-Crego: design of the work, revising it critically for important intellectual content and final approval of the version to be published.

Raquel Rodríguez-González: project administration, design of the work, acquisition of the data, drafting the work and final approval of the version to be published.

Ethical approval

The study protocol was approved by a Research Ethics Committee (Ethics Committee of Pontevedra-Vigo-Ourense, reference 2019/069).

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Declaration of Competing Interest

All authors declare no current or potential conflicts of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work.

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Appendix A. Supplementary data

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