

## RESEARCH ARTICLE (ORIGINAL)

## Informal caregiver of dependent person in self-care: burden-related factors


*Cuidador informal de pessoa dependente no autocuidado: fatores de sobrecarga*

*Cuidador informal de personas dependientes en el autocuidado: factores de sobrecarga*

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### Abstract

**Introduction:** Societal changes have led to an increasing number of people dependent for self-care, with the need for support from a family member/informal caregiver. The performance of this role can lead to burden and exhaustion.

**Objectives:** To assess the burden of the dependent person's informal caregiver and to identify factors associated with caregiver burden.

**Methodology:** An observational cross-sectional study was conducted with a convenience sample of 164 informal caregivers of people dependent for self-care. The questionnaire included data on the dependent person (sociodemographic and clinical) and the caregiver (sociodemographic, family, professional, experience, information received, and burden using the Zarit Burden Interview).

**Results:** Most caregivers were women (82.9%), living with the dependent person (70.1%), 62.2% of them had help and spent an average of 105.65 ( $\pm$  54) hours/week in caring. More than half of the caregivers were severely burdened (57.7;  $\pm$  13.9), which was associated with the preparation to provide care and the areas and duration of dependence. More information about the illness and how to care for the dependent person were associated with lower levels of burden.

**Conclusion:** The factors associated with the severe burden experienced by informal suggest that nurses should invest in preventive interventions.

**Keywords:** burden; informal caregivers; family; self-care

### Resumo

**Enquadramento:** As alterações sociais conduziram ao crescendo das pessoas dependentes no autocuidado, com necessidade de apoio de um cuidador familiar/informal (CI). O desempenho deste papel pode conduzir à sobrecarga e exaustão.

**Objetivos:** Avaliar a sobrecarga do CI da pessoa dependente e identificar fatores relacionados com essa sobrecarga.

**Metodologia:** Estudo observacional, transversal, numa amostra de conveniência de 164 CI de pessoas dependentes no autocuidado. O questionário incluiu dados da pessoa dependente: sociodemográficos e clínicos; e do cuidador: sociodemográficos, familiares, profissionais, experiência, informação recebida e sobrecarga (Escala de Zarit).

**Resultados:** A maioria dos CI são mulheres (82,9%), vivem com a pessoa cuidada (70,1%), 62,2% têm ajuda para cuidar, gastando em média 105,65h ( $\pm$  54)/semana. Mais de metade apresenta sobrecarga intensa (57,7;  $\pm$  13,9), relacionada com a preparação para o cuidar, áreas e tempo de dependência. Mais informação sobre a doença e como cuidar da pessoa dependente está relacionado com menores níveis de sobrecarga.

**Conclusão:** Os CI evidenciam sobrecarga elevada e os fatores relacionados sugerem o investimento em intervenções preventivas por parte dos enfermeiros.

**Palavras-chave:** sobrecarga; cuidadores informais; família; autocuidado

### Resumen

**Marco contextual:** Los cambios sociales dieron lugar a un aumento de las personas dependientes en el autocuidado y, con ello, de la necesidad de apoyo de un cuidador familiar/informal (CI). El desempeño de esta función puede llevar a la sobrecarga y al agotamiento.

**Objetivos:** Evaluar la sobrecarga del CI de la persona dependiente e identificar los factores relacionados con esta sobrecarga.

**Metodología:** Estudio observacional, transversal, sobre una muestra de conveniencia de 164 CI de personas dependientes en el autocuidado. El cuestionario incluyó datos de la persona dependiente: sociodemográficos y clínicos; y del cuidador: sociodemográficos, familiares, profesionales, experiencia, información recibida y sobrecarga (Escala de Zarit).

**Resultados:** La mayoría de los CI son mujeres (82,9%), viven con la persona cuidada (70,1%), el 62,2% tiene ayuda para cuidados y gasta de media 105,65 h ( $\pm$  54)/semana. Más de la mitad tiene una sobrecarga intensa (57,7;  $\pm$  13,9), relacionada con la preparación para el cuidado, las áreas y el tiempo de dependencia. Más información sobre la enfermedad y cómo cuidar a la persona dependiente está relacionada con niveles más bajos de sobrecarga.

**Conclusión:** Los CI muestran una elevada sobrecarga y los factores relacionados sugieren invertir en intervenciones preventivas por parte de los enfermeros.

**Palabras clave:** sobrecarga; cuidador informal; familia; autocuidado

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## Introduction

The informal caregiver is the individual from the dependent person's social network who cares for him/her in a situation of chronic illness and/or disability, takes primary responsibility for care, experiences a higher degree of involvement than the other family members, has no specific training, and is not paid to provide care (Naiditch, Triantafyllou, Di Santo, Carretero, & Durrett, 2013). In Europe, it is estimated that 32 million informal caregivers care for an older or disabled relative (Anderson, Mikulić, Vermeylen, Lyly-Yrjanainen, & Zigante, 2009).

Several studies found that these caregivers have high levels of emotional burden (Sequeira, 2013; Rodríguez-González et al., 2017). Given this situation and the lack of caregiver support programs (Dixe et al., 2019), there is a need to assess the burden of the dependent person's informal caregiver and identify the factors associated with the burden of the dependent person's informal caregiver with a view to identifying the best strategies to prevent their burden.

## Background

The characteristics and needs of the person who receives care as well as the evolution of his/her condition are associated with the level and nature of caregiving, with the informal caregiver's qualities and motivation for caring depending on their training, information, psychological support, and the relation between work and care, as well as an accessible, adequate, and timely support (Carretero, Stewart, & Centeno, 2015; Bouget, Spasova, & Vanhercke, 2016).

Caring for another person requires a continuous cognitive, emotional, and physical effort, and it may have a negative impact on the informal caregiver's health and well-being (Cabral, Ferreira, Silva, Jerónimo, & Marques, 2013) and on economic costs for families and society, the assumption being that the higher the level of dependence, the higher the number of hours of care provided by informal caregivers (Oliva-Moreno, Aranda-Reneo, Vilaplana-Prieto, González-Domínguez, & Hidalgo-Veja, 2013).

The identification of factors associated with burden is important to establish preventive interventions. The literature has identified several factors associated with the caregivers and factors associated with the dependent person that lead to burden. Some examples of these factors associated with the dependent person are the degree of dependence, psychological health, and sociodemographic characteristics. Some examples of factors associated with the caregiver are his/her sociodemographic characteristics, type of needs, duration of care, degree of kinship, and psychological health (Zhu & Jiang, 2018).

There are several instruments to assess the caregiver's burden, but the Zarit Burden Interview is considered to have the best conditions for application, and is used in several countries and in different populations (Sequeira, 2013; Crespo & Rivas, 2015).

Caregiver's rest, psychoeducational interventions, cognitive-behavioral therapy, caregivers' training, information on how to provide care and information about the patient's status are strategies that improve both self-efficacy and the communication between the dependent person and the informal caregiver, prevent the caregiver's burden and exhaustion (Vandepitte et al., 2016), as well as the

caregiver's aggressive behaviors, abuse, mistreatment, and neglect toward the dependent person (Carretero & Garcés, 2011).

A systematic review (Vandepitte et al., 2016) found that psychoeducational interventions promote positive health outcomes and delay the dependent person's institutionalization; cognitive-behavioral therapy decreases the caregiver's dysfunctional thoughts; and occupational therapy decreases the dependent person's behavioral problems and improves informal caregivers' self-efficacy.

## Research questions/Hypotheses

What are the factors associated with the burden of informal caregivers of people dependent for self-care?

H1: There is a positive significant association between the informal caregiver's burden and his/her age, the dependent person's age, the duration of dependence, the number of hours of care, the information received by the informal caregiver, and the number of areas of dependence.

H2: There are statistically significant differences between the informal caregiver's burden and the fact of living with the dependent person, having help in caring, and the degree of kinship.

## Methodology

This correlational, cross-sectional study was conducted in a hospital center in Central Portugal, from June 2018 to February 2019. Data were collected through a convenience sampling technique from 164 informal caregivers aged 18 years or older.

The inclusion criteria were: being an informal caregiver, regardless of how long they had been caregiving, being responsible for a dependent person in at least one area of self-care and who had been discharged home from an inpatient unit. The nurses from this hospital unit applied the criteria and selected the caregivers. They applied the Barthel Index to assess the degree of dependence.

On the days scheduled for data collection, the nurses from that unit appointed the informal caregivers who met the criteria for inclusion in the study. Data were collected on the day of hospital discharge through a questionnaire, with an average duration of 10 minutes, applied by students of a master's in nursing. The questionnaire was composed of: (a) Socioprofessional and clinical data of the dependent person (reported by the informal caregiver), including age, gender, length of hospital stay in days, degree of dependence prior to hospital admission, number of areas of dependence (minimum of 0 and maximum of 10, according to the areas of dependence in the Barthel Index), and duration of dependence; (b) Socioprofessional and family data of the informal caregiver, experience as caregiver, level of information received by the caregiver, professional who provided the information; (c) Level of information provided to the informal caregiver during the dependent person's hospital stay. This variable was assessed through 11 indicators with four answer options: *enough* (1); *some, but not enough* (2); *none* (3); and *not applicable* (4). Then, the 11 indicators were: Information about the illness, information about bathing, information about dressing and undressing, information about feeding, information about toilet use, information about transfer, information about mobility, information about medication intake, information about

assistive devices, information about economic support, and information about community services. The 11 indicators were built based on the literature, and their content was validated by five nursing professionals holding a doctoral degree, with publications and experience in this area: (a) Professional who provided the information in each of the 11 indicators mentioned above with multiple choice: *physician, nurse, other* (which, please indicate); (b) Caregiver's burden: Zarit Burden Interview (Sequeira, 2013), composed of 22 items divided into four factors: impact of care delivery, interpersonal relationship, expectation regarding care, and perceived self-efficacy. Each item is scored on a Likert-type scale: (1) *never*; (2) *rarely*; (3) *sometimes*; (4) *quite frequently*; and (5) *nearly always*, with the total score ranging from 22 to 110, where higher scores correspond to higher burden, according to the following cutoff scores: no burden (< 46); mild burden (46-56); severe burden (> 56). The project was approved by the National Commission for Data Protection (no. 3289/ 2017) and the Ethics Committee of the hospital where the study was conducted (04 - 2017/05/02).

All participants were informed about the right not to participate and withdraw during the study, anonymity and data confidentiality, and gave their informed consent. An appropriate venue for conducting the interview was also ensured. Data were analyzed using IBM SPSS Statistics, version 24.0 for Windows 10. Descriptive analysis was used for numerical variables and absolute and relative frequencies for qualitative variables.

In the bivariate analysis, and because the variables did not have a normal distribution (assessed through the Kolmogorov-Smirnov test), non-parametric Mann-Whitney tests were performed for dichotomous variables, Kruskal-Wallis tests when the variables had three or more categories, and Spearman's correlation coefficient for analysis of the correlation between independent quantitative variables. For all statistical tests, the *p*-value < 0.05 was set for rejection of the null hypothesis.

## Results

In this study, 82.9% of informal caregivers were women; the majority of them were children (57.9%), followed by the spouse (25%) and another family member (17.1%). The majority (50.6%) of the caregivers did not complete the 9<sup>th</sup> grade, 23.8% had completed the 9<sup>th</sup> grade, 13.4% had completed the 12<sup>th</sup> grade, and 12.2% had a higher education degree.

In relation to employment status, 34.7% of caregivers were retired, 22% were homemakers, 39% were activity employed, and 4.3% were students. Most of them lived with the person whom they cared for (70.1%), and 62.2% had help in caring. On average, these caregivers spent  $105.65 \pm 54$  hours per week caring for the dependent person, that is, 15 hours per day.

Although the dependent person's caregiver was, on average, younger ( $57.7 \pm 13.4$ ) than the dependent person ( $81.2 \pm 9.9$ ), the difference was not statistically significant ( $r_s = 0.095$ ;  $p = 0.227$ ).

No differences were found regarding the dependent person's gender because males and females had the same percentage and number (50%; 82).

Before being admitted to the hospital, all of them were dependent for at least one area of self-care, and the dependent person's mean length of hospital stay was  $3.55 \pm 5$  days. They had been dependent for at least one of the self-care activities, on average, for  $16.85 \pm 30.2$  years. In relation to the areas of dependence at discharge, 79.9% (131) of them were dependent in eight areas (out of a maximum of 10); 19.5% (32) in more than one area; and only one (0.6%) person was dependent in a single area. They took, on average,  $8.4 \pm 3.7$  medications per day. With regard to the information provided to informal caregivers, the study showed that most of the caregivers received information about the illness and medication intake (Table 1).

Table 1

*Distribution of the answers regarding the level of information received by the informal caregiver and the professional who provided it*

Information about:	Enough		Not enough		None		Not applicable	
	no.	%	no.	%	no.	%	no.	%
Illness	110	67.1	54	32.9				
Bathing	51	31.1	5	3.0	103	62.8	5	3.0
Dressing and undressing	49	31.2	3	1.9	101	64.3	4	2.5
Eating	56	37.6	5	3.4	86	57.7	2	1.3
Toilet use	50	34.2	2	1.4	80	54.8	14	9.6
Transfer	47	33.1	2	1.4	79	55.6	14	9.9
Ambulation	48	32.9	3	2.1	81	55.5	14	9.6
Medication intake	117	71.3	29	17.7	16	9.8	2	1.2
Assistive device	36	22.0	13	7.9	70	42.7	45	27.4
Community services	52	31.7	38	23.2	63	38.4	11	6.7
Economic support	31	18.9	25	15.2	91	55.5	17	10.3

Note.\*n is not always the same because the *not applicable* cases were excluded.

With the exception of the information provided to the caregiver about medication intake, the results show that neighbours, friends or other relatives provided that information (Table 2).

Table 2  
*Distribution of the answers regarding the professional who provided the information to the informal caregiver*

Information about:	Physician		Nurse		Physician and Nurse		Other	
	no.	%	no.	%	no.	%	no.	%
Illness	146	89.0	4	2.4	14	8.5		
Bathing			20	35.7			33	64.3
Dressing and undressing			16	30.8			36	69.2
Eating			21	34.4	4	6.6	36	59.0
Toilet use	1	1.9	15	28.8			36	70.3
Transfer			13	26.5			36	73.4
Ambulation	1	2.0	14	27.5			36	70.6
Medication intake	63	43.2	29	19.9	17	11.6	37	25.4
Assistive device	2	4.1	13	26.5			34	69.3
Community services	2	2.2	18	20.0	1	1.1	69	76.6
Economic support	3	5.4	4	7.1			49	87.5

*Note.* \*n is not always the same because the *not applicable* cases were excluded.

The informal caregivers who participated in the study had a mean burden of  $57.7 \pm 13.9$ , with 52.4% (86) of them having severe burden, 28% (46) mild burden, and 19.5% (32) no burden. Out of the 22 indicators, those with the highest burden score were: "Do you feel your relative is dependent on you?" ( $4.51 \pm 0.90$ ) and "Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?" ( $4.06 \pm 1.27$ ). It should also be noted that the scores in 12 of those indicators were lower than the median value.

The results in Table 3 indicate that there are no statistically significant differences between the dependent person's

age, the caregiver's age, the number of hours of care, and the burden levels; however, the caregivers who care for younger people had higher expectation and self-efficacy values ( $p < 0.05$ ). A longer duration of dependence is associated with lower burden.

In relation to the level of information, the caregivers who reported having received all the necessary information regarding care delivery had a lower burden and impact on care. The caregivers who received information about economic support had higher self-efficacy scores, that is, a better opinion about their performance. Caring for dependent persons in fewer self-care areas causes less burden on informal caregivers.

Table 3  
*Spearman's correlation between the informal caregiver's burden and his/her age, the dependent person's age, the duration of dependence, the number of hours of care, the information received by the informal caregiver, and the number of areas of dependence*

	Total burden	Impact <sup>a)</sup>	Interpersonal relationships	Informal caregiver's expectations	Self-efficacy
Dependent person's age	-0.089	-0.054	-0.083	-0.168*	-0.168*
Informal caregiver's age	-0.064	0.113	0.103	0.033	0.033
Duration of dependence	-0.240**	-0.109	-0.204**	-0.155*	-0.155*
No. of hours of care	0.112	0.067	0.153	-0.006	-0.00
No. of areas of dependence	-0.205**	-0.198*	-0.104	-0.120	-0.068
<b>Information about:</b>					
Illness	0.221**	0.281**	0.059	0.123	-0.127
Bathing	0.137	0.252**	-0.174*	-0.024	0.030
Dressing and undressing	0.231**	0.362**	-0.128	0.063	0.014
Eating	0.216**	0.314**	-0.109	0.073	0.054
Toilet use	0.287**	0.411**	-0.117	0.095	0.034
Transfer	0.372**	0.491**	-0.088	0.131	0.098
Mobility	0.323**	0.450**	-0.101	0.092	0.027
Medication intake	0.271**	0.296**	0.084	0.209**	0.022



Assistive device	0.091	0.194*	-0.084	-0.019	-0.104
Economic support	0.047	-0.018	0.045	-0.014	0.287**
Community services	-0.032	-0.060	-0.085	-0.018	0.150

Note. a) = Impact of care delivery.

\*Very significant correlation ( $p < 0.01$ ); \*\*significant correlation ( $p < 0.05$ ).

Being a female caregiver or a female dependent person are not protective factors for burden ( $p > 0.05$ ). The informal caregiver's burden related to the expectations regarding

care was the only factor associated with having help in caring as the informal caregivers who had help in caring had lower burden (Table 4).

Table 4

Results of the Mann-Whitney U test between the informal caregiver's burden and the fact of living with the person being cared for and having help in caring

		Yes			No			U	p
		M	SD	Mean rank	M	SD	Mean rank		
Living with the person	Total burden	57.2	13.3	80.71	58.7	15.2	86.70	2611.500	0.459
	Impact on care delivery	27.2	9.3	79.61	29.1	9.7	89.28	2485.500	0.233
	Interpersonal relationships	10.2	3.3	80.90	10.7	3.6	86.24	2634.000	0.508
	Informal caregiver's expectations	15.3	2.7	86.73	14.3	3.2	72.56	2330.500	0.078
	Self-efficacy	4.4	1.8	81.13	4.6	1.9	85.70	2660.500	0.563
Help in caring	Total burden	56.6	13.2	78.17	59.4	14.8	89.62	2720.500	0.134
	Impact on care delivery	27.1	9.0	79.22	28.9	10.1	87.90	2827.500	0.256
	Interpersonal relationships	10.4	3.3	84.08	10.3	3.6	79.90	3001.000	0.583
	Informal caregiver's expectations	14.7	2.8	76.50	15.5	3.1	92.37	2550.000	0.037
	Self-efficacy	4.3	1.9	79.16	4.7	1.8	88.00	2821.000	0.236

Note. M = Mean; SD = Standard deviation; U = Mann-Whitney U test; p = significance level.

The degree of kinship with the dependent person (spouse, child, other relative) is not associated with burden (Kruskal-Wallis test = 0.656;  $p > 0.05$ ).

## Discussion

Women remain the main caregivers, as observed in other studies (Sequeira, 2013; Pérez-Cruz, Muñoz-Martínez, Parra-Anguaita, & del-Pino-Casado, 2017), married, wives or children and with a low level of education (Dixe et al., 2019; Pérez-Cruz et al., 2017; Rocha & Pacheco, 2013). The majority of caregivers have help in caring and live with the dependent person (Pérez-Cruz et al., 2017; Dixe et al., 2019). They care for older people who have been dependent on average for  $16.85 \pm 30.2$  years, which is a longer period than that found by Mendes, Fortes Figueiredo, Santos, Fernandes, and Fonseca (2019). Informal caregivers spend on average (15 hours per day) more hours per day caring for their relative than those caregivers in other studies (Pérez-Cruz et al., 2017) or more or less the same number of hours as in other studies

(Alves, Teixeira, Azevedo, Duarte, & Paúl, 2015) and are dependent for more years (Pérez-Cruz et al., 2017; Mendes et al., 2019). For this reason, informal caregivers have very little time to care for themselves and increased burden (Mendes et al., 2019). Given the time spent caring, in the 24-hour period, they only have 8 hours left to sleep, leaving them no time to rest. Therefore, more support structures should be created to promote caregiver rest. More than half of informal caregivers have severe burden, which is in line with other studies (Rodríguez-González et al., 2017) and contrary to the results found by Rodríguez-Medina and Landeros-Pérez (2014). The indicators that most contributed to these burden levels were "Are you afraid of what the future holds for your relative?" and "Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?", which were different from those found in other countries (Rodríguez-González et al., 2017). Given that the same instruments were used, this divergence may be due to different types of samples or support strategies used by informal caregivers to promote their health.

Although they are severely burdened, these caregivers are not embarrassed over their relative's behavior and do not feel uncomfortable about having friends over because of their relative, with these indicators ranging from *never* to *rarely*.

With regard to the information provided to informal caregivers on how to care for the dependent person, this study showed that most of them were not enough. Information needs were the most common needs identified by informal caregivers in other studies, in particular in the studies by Dixe et al. (2019) and Plöthner, Schmidt, de Jong, Zeidler, and Damm (2019) in the period of transition from hospital to home care to assist them in caring. There is also an association between the informal caregivers receiving enough information about economic support and lower levels of self-efficacy.

The caregivers received information about the illness and medication intake mainly from the physicians. On the other hand, fewer caregivers received information about the self-care areas of bathing, dressing and undressing. There is a need to understand the variables identified as causes of burden to establish preventive interventions. It is important to receive enough information about the illness and how to care for the dependent person for burden levels, especially in the self-care areas of dressing and undressing, eating, toilet use, transfer, mobility, and medication intake, some of which were also identified by other authors (Zhu & Jiang, 2018).

The number of areas of dependence increases caregiver burden, as in other studies (Rodríguez-Medina & Landeros-Pérez, 2014; Zhu & Jiang, 2018).

The caregiver's gender, the dependent person's gender, living with the dependent person, and having help in caring were not identified as factors promoting the caregiver's health, unlike what was found in other studies (Zhu & Jiang, 2018; Ramón-Arбуés, Martínez-Abadía, & Martín-Gómez, 2017). On the other hand, unlike the results of Zhu and Jiang (2018), the duration of dependence does not increase burden, which may be because these caregivers are already severely burdened.

Given that the objective of this study was to assess the burden of the dependent person's informal caregiver and identify the factors associated with this burden, a limitation was its cross-sectional design, which does not allow establishing causal relations. Therefore, prospective longitudinal studies should be conducted. The collection of data in a restricted geographical area and the use of a non-probability sampling technique do not allow for the generalization of results. Data collection at the dependent person's discharge may also have introduced a bias, leading to higher burden levels.

## Conclusion

One of the main conclusions is that informal caregivers are severely burdened and do not receive enough information to care for their relative at home. The results of this study call the nurses' attention to the need to invest even more in educating/training informal caregivers to care for their family members so as to prevent burden and improve the quality of care.

In addition to this aspect related to information, the preparation of these caregivers throughout the hospital stay to care for the dependent person in self-care is also important, as well as the supervision and monitoring of

their health by primary care nurses. The identification of informal caregivers with high burden levels, as well as the identification of burden-related factors have implications for clinical practice because they will contribute to the development of appropriate interventions. However, further quasi-experimental studies should be conducted on the effectiveness of these interventions.

The importance of preparing these caregivers throughout the hospital stay to care for the dependent person for self-care should be highlighted.

## Author contributions:

Conceptualization: Dixe, M. A., & Querido, A. I

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## References

- Alves, S., Teixeira, L., Azevedo, M. J., Duarte, M., & Paúl, C. (2015). Effectiveness of a psychoeducational programme for informal caregivers of older adults. *Scandinavian Journal of Caring Sciences*, 30(1), 65-73. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/25856726/>
- Anderson, R., Mikulić, B., Vermeylen, G., Lyly-Yrjanainen, M., & Zigante, V. (2009). *Second European Quality of Life Survey-Overview*. Dublin, Ireland: Office for Official Publications of the European Communities. Retrieved from [https://www.eurofound.europa.eu/sites/default/files/ef\\_publication/field\\_ef\\_document/ef0902en\\_7.pdf](https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef0902en_7.pdf)
- Bouget, D., Spasova, S., & Vanhercke, B. (2016). *Work-life balance measures for persons of working age with dependent relatives in Europe: A study of national policies 2016*. Brussels, Belgium: European Commission. Directorate-General for Employment, Social Affairs and Inclusion. European Social Policy Network
- Cabral, M., Ferreira, P., Silva, P., Jerónimo, P., & Marques, T. (2013). *Processos de envelhecimento em Portugal: Usos do tempo, redes sociais e condições de vida*. Lisboa: Fundação Francisco Manuel dos Santos
- Carretero, S., & Garcés, J. (2011). Psychological interventions to fight against the burden of the informal caregivers. *European Psychiatry*, 26, 1173. doi.org/10.1016/S0924-9338(11)72878-4
- Carretero, S., Stewart, J., & Centeno, C. (2015). Information and communication technologies for informal carers and paid assistants: benefits from micro-, meso-, and macro-levels. *European Journal of Ageing*, 12(2), 163-73. doi:10.1007/s10433-015-0333-4
- Crespo, M., & Rivas, T. (2015). La evaluación de la carga del cuidador: Una revisión más allá de la escala de Zarit. *Clínica y Salud*, 26(1), 9-16. doi.org/10.1016/j.clysa.2014.07.002
- Dixe, M. A., Teixeira, L. F., Areosa, T. J., Frontini, R. C., Peralta, T., & Querido A. I. (2019). Needs and skills of informal caregivers to care for a dependent person: A cross-sectional study. *BMC Geriatrics*, 19, 255. doi:10.1186/s12877-019-1274-0
- Mendes, P. N., Fortes Figueiredo, M. L., Santos, A. M., Fernandes, M. A., & Fonseca, R. S. (2019). Sobrecargas física, emocional e social dos cuidadores informais de idosos. *Acta Paulista de Enfermagem*, 32(1), 87-94. doi.org/10.1590/1982-0194201900012
- Naiditch, M., Triantafyllou, J., Di Santo, P., Carretero, S., & Durrett, E.H. (2013). User perspectives in long-term care and the role of informal carers. In K. Leichsenring, J. Billings, H. Nies (Eds). *Long-term care in Europe: Improving policy and practice*. (pp. 45-80). London, England: Palgrave Macmillan
- Oliva-Moreno, J., Aranda-Reneo, I., Vilaplana-Prieto, C., González-Domínguez, A., & Hidalgo-Vega, A. (2013). Economic valuation of informal care in cerebrovascular accident survivors in Spain.

- BMC Health Services Research*, 13(508). doi.org/10.1186/1472-6963-13-508
- Pérez-Cruz, M., Muñoz-Martínez, A., Parra-Anguita, L., & del-Pino-Casado, R. (2017) Afrontamiento y carga subjetiva en cuidadores primarios de adultos mayores dependientes de Andalucía, España. *Atención Primaria*, 49(7), 381-388.
- Plöthner, M., Schmidt, K., de Jong L., Zeidler, J., & Damm, K. (2019). Needs and preferences of informal caregivers regarding outpatient care for the elderly: A systematic literature review. *BMC Geriatrics*, 19, 82-104. doi.org/10.1186/s12877-019-1068-4
- Ramón-Arbués, E., Martínez-Abadía, B., & Martín-Gómez, S. (2017). Factores determinantes de la sobrecarga del cuidador: Estudio de las diferencias de género. *Atención Primaria*, 49(5), 308-313. Retrieved from <https://www.elsevier.es/es-revista-atencion-primaria-27-articulo-factores-determinantes-sobrecarga-del-cuidador--S0212656716302487>
- Rocha, B. M., & Pacheco, J. E. (2013). Elderly persons in a situation of dependence: Informal caregiver stress and coping. *Acta Paulista de Enfermagem*, 26(1), 50-56. doi.org/10.1590/S0103-21002013000100009
- Rodríguez-González, A. M., Rodríguez-Míguez, E., Duarte-Pérez, A., Díaz-Sanisidro, E., Barbosa-Álvarez, A. A., Clavería, A., & Grupo Zarit. (2017). Estudio observacional transversal de la sobrecarga en cuidadoras informales y los determinantes relacionados con la atención a las personas dependientes. *Atención Primaria*, 49(3), 156-165. Retrieved from <https://www.elsevier.es/es-revista-atencion-primaria-27-articulo-estudio-observacional-transversal-sobrecarga-cuidadoras-S0212656716301962>
- Rodríguez-Medina, M., & Landeros-Pérez, M. E. (2014). Sobrecarga del agente de cuidado dependiente y su relación con la dependencia funcional del adulto mayor. *Enfermería Universitaria*, 11(3), 87-93. Retrieved from [http://www.scielo.org.mx/scielo.php?script=sci\\_arttext&pid=S1665-70632014000300003](http://www.scielo.org.mx/scielo.php?script=sci_arttext&pid=S1665-70632014000300003)
- Sequeira, C. (2013). Difficulties, coping strategies, satisfaction and burden in informal Portuguese caregivers. *Journal of Clinical Nursing*, 22(3-4), 491-500. doi: 10.1111/jocn.12108.
- Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K., & Annemans, L. (2016). Effectiveness of supporting informal caregivers of people with dementia: A systematic review of randomized and non-randomized controlled trials. *Journal of Alzheimer's Disease*, 52(3), 929-65. doi: 10.3233/JAD-151011
- Zhu, W., & Jiang, Y. (2018) A meta-analytic study of predictors for informal caregiver burden in patients with stroke. *Journal of Stroke & Cerebrovascular Diseases*, 27(12), 3636-3646. doi.org/10.1016/j.jstrokecerebrovasdis.2018.08.037

