BURDEN ON THE FAMILY CAREGIVER OF THE PERSON WITH DEMENTIA IN THE COVID-19 PANDEMIC

Sobrecarga do cuidador familiar da pessoa com demência na pandemia por covid-19

Sobrecarga del cuidador familiar de la persona con demencia en la pandemia del covid-19

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ABSTRACT

Background: the person with dementia experiences an increasing number of problems, which may lead to family caregiver burden. Follow-up of these caregivers is crucial for early detection of changes. **Objectives**: to assess the family caregiver burden of persons with dementia enrolled in a Family Health Unit in Portugal and to identify the interventions that family nurses adopt in the management of this burden. **Methodology**: quantitative, cross-sectional, and descriptive study carried out with 45 family caregivers, using a survey completed by telephone interview, including the physical, emotional and social impact assessment of the family caregiver role during the COVID-19 pandemic. **Results**: the majority of family caregivers are female, more than 65 years old, with a low level of education and with care time of more than five years. The domains with the greatest impact were financial burden, implications for personal life and emotional burden. Support from the family nurse was scarce; the most mentioned type of support was telephone guidance and instrumental activities. **Conclusions**: family care of the person with dementia during the COVID-19 pandemic generated a physical, emotional, and social burden on the caregivers.

Keywords: dementia; caregiver burden; covid-19; family nursing

RESUMO

Enquadramento: as Pessoas com Demência experienciam um número crescente de cuidados, podendo conduzir a sobrecarga do Cuidador Familiar. O acompanhamento destes cuidadores é crucial para a deteção precoce de alterações. **Objetivos**: avaliar a sobrecarga dos Cuidadores Familiares da Pessoa com Demência inscritos numa Unidade de Saúde Familiar de Portugal e identificar as intervenções que os enfermeiros de família adotam na gestão desta sobrecarga. **Metodologia**: estudo quantitativo, transversal e descritivo, realizado com 45 Cuidadores Familiares, recorrendo-se ao preenchimento de um formulário por entrevista telefónica, incluindo a Avaliação do Impacto Físico, Emocional e Social do Papel de Cuidador Informal (QASCI). **Resultados**: a maioria dos cuidadores familiares estudados são do sexo feminino, com idades superiores a 65 anos, com baixo nível de escolaridade e com um tempo de cuidado superior a 5 anos. Os domínios com maior impacto foram a sobrecarga financeira, as implicações na vida pessoal e a sobrecarga emocional. A frequência de apoio do enfermeiro de família foi escassa e o tipo de apoio mais referido foi orientação por telefone e atividades instrumentais. **Conclusões**: o cuidado familiar da Pessoa com Demência, durante a pandemia por COVID-19, gerou uma sobrecarga física, emocional e social destes cuidadores.

Palvras-chave: demência; sobrecarga do cuidador; covid-19; enfermagem familiar

RESUMEN

Marco contextual: las personas con Demencia experimentan un número creciente de procedimientos de cuidado, lo que puede llevar a la sobrecarga del Cuidador Familiar. El seguimiento de estos cuidadores es crucial para la detección temprana de cambios. **Objetivos**: evaluar la sobrecarga de los Cuidadores Familiares de Personas con Demencia inscritas en una Unidad de Salud de la Familia en Portugal e identificar las intervenciones que los enfermeros familiares adoptan en el manejo de esta sobrecarga. **Metodología**: estudio cuantitativo, transversal y descriptivo, realizado con 45 Cuidadores Familiares, mediante el llenado de un formulario por entrevista telefónica, incluyendo la Evaluación del Impacto Físico, Emocional y Social del Rol del Cuidador Informal (QASCI). **Resultados**: la mayoría de los cuidadores familiares estudiados son del sexo femenino, mayores de 65 años, con bajo nivel educativo y con tiempo de cuidado superior a 5 años. Los dominios con mayor impacto son carga financiera, implicaciones para la vida personal y carga emocional. La frecuencia de apoyo de la enfermera de familia fue escasa y el tipo de apoyo más mencionado fue la orientación telefónica y las actividades instrumentales. **Conclusiones**: el cuidado familiar de la Persona con Demencia, durante la pandemia de la COVID-19, generó sobrecarga física, emocional y social de estos cuidadores.

Palabras clave: demencia; carga del cuidador; covid-19; enfermería de la familia

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Como referenciar:
Perucci, A., Tavares, J., & Simões, J., (2024). Bruden of family caregiver of the person with dementia in the COVID-19 pandemic. *Revista de Investigação & Inovação em Saúde,* 7(2), 1-14
https://doi.org/10.37914/riis.v7i2.341

Recebido: 20/04/2023
Aceite: 08/05/2024

INTRODUCTION

With population aging, associated with a higher rate of longevity, there is an increased number of people with dementia. According to the World Health Organization (WHO, 2018), it is estimated that approximately 50 million people are currently diagnosed with dementia, this figure projected to triple to 152 million by 2050.

Dementia implies permanent care and attention resulting from changes in different domains of cognition, mood, personality, behaviour and functionality, and, in moderate or advanced stages, it causes dependence (Sequeira, 2018). In most situations, this care is assumed by family caregivers.

As a result of caring for people with dementia, the family caregiver role interferes with aspects of their personal, family, work, economic and social life, resulting in overload (Rodrigues et al., 2023). Due to their proximity to family caregivers, health professionals, namely family nurses in primary health care, have a central role in training these caregivers (e.g. training, counselling, psychoeducation, communication training); they can also promote the articulation of existing resources in the community, which contributes to reducing overload (Wang et al., 2018).

Bearing in mind the impact of overload on the quality of life and physical, psychological and social wellbeing of family caregivers, especially during the COVID-19 pandemic, and the importance of family nurses in primary health care implementing prevention and/or mitigation interventions, this study aimed to evaluate the overload of family caregivers of people with dementia enrolled in a Family Health Unit in the central region of Portugal and to identify, in the opinion of the family caregivers, the interventions that the family nurses of this Family Health Unit adopt in managing family caregivers' overload.

BACKGROUND

People with dementia experience an increasing amount of care that is conditioned by the type and severity of dementia, functional dependence, multimorbidity and psychobehavioural symptoms (WHO, 2018). Recently, a systematic review study with meta-analysis (n = 1,011 people with dementia and 1,188 family caregivers) identified 24 areas of care needs for people with dementia living in the community, reported by them and their caregivers, with emphasis on those relating to memory, nutrition, domestic activities and financial management (Curnow et al., 2021). Therefore, most of the care for people with dementia living in the community is provided by family caregivers.

The Caring for Informal Caregivers Movement study with 1,133 family caregivers concluded that dementia, especially Alzheimer's, is the main disease leading to the need for informal care (32.6%). Data from this report also show that more than half of family caregivers (51.4%) take care of their parents; 86.6 per cent are female; 48.3 per cent are aged 55 or over; 51.4 per cent have an education level ranging from 1 to 12 years; and 54 per cent have an active work situation (Movimento Cuidar dos Cuidadores Informais, 2018). In another study, Leocadie et al. (2020) concluded that family caregivers are spouses (51%) and children (49%); 71 per cent live with the person and carers have an average age of 66 years. In this sense, it appears that people with dementia are cared for mainly by close relatives (Allen et al., 2020; Leocadie et al., 2020), most of the care being provided in the community (Sequeira, 2018).

Among the main challenges and difficulties associated with the role of family caregiver are emotional/psychological support (64.6%), need for other human resources (64.6%), social and work support (59.1%), financial support (51.8%), and caregiver training/training (51.8%) (Movimento Cuidar dos Cuidadores Informais, 2018). Family caregivers present frequent manifestations of fatigue, frustration and risk of deterioration of their mental health, such as anxiety, depression and overload (Cheng & Zhang, 2020). Burden is defined as the "wear and tear perceived by the caregiver when caring for a family member and/or loved one over time" (Liu et al., 2020, p. 438). This is the result of the requirement to provide care, influenced by personal factors, health, the context of care provision, and social support, among others (Sequeira, 2018). As a result of this overload, negative events occur in physical and psychological health, reducing care provision and reducing quality of life (Cheng, 2017; Cheng & Zhang, 2020). Among the risk factors for caregiver overload are advanced age (Unnikrishnan et al., 2019), little preparation and knowledge to provide adequate care (Zubaidi et al., 2020), and frequency of care and prolonged time in the role of family caregiver (Ducharme et al., 2011). In relation to the person being cared for, especially those with dementia, the following risk factors stand out: the level of dependence and/or cognitive impairment, and presence of multimorbidity and psychobehavioural symptoms (Cheng, 2017; Wulff et al., 2020). Caregivers of people with dementia have higher levels of burden compared to caregivers of people without dementia, (66.3% and 45.5%, respectively) (Sequeira, 2018). Additionally, these caregivers dedicate more time to care compared to caregivers of more motor-dependent people (Kerpershoek et al., 2018). Recent data on the impact of the COVID-19 pandemic on the role of family caregiver report a worsening of overload, the most significant, on a scale of 0 to 10, being emotional overload (7.9), impact on quality of life and wellbeing (7.63), mental health (7.6), physical overload (6.94), increase in hours of care (6.96) and loneliness (6.87) (Movimento Cuidar dos Cuidadores Informais, 2018).

Monitoring informal caregivers of people with dementia by health professionals is crucial to promote timely detection of the emergence of changes in physical health and emotional wellbeing, allowing early intervention and specialized referral (Kerpershoek et al., 2018) . Therefore, special attention must be paid to family caregivers due to the implications that this care process may have for their wellbeing and quality of life (Frias et al., 2020; Kerpershoek et al., 2018). Appropriate and personalized interventions that support these caregivers can allow people with dementia to remain at home for longer (Kerpershoek et al., 2018), avoiding institutionalization and/or hospitalization. The study by Parra and colleagues (2019) demonstrated that a "caring for the caregiver" programme implemented by nurses had a positive impact on reducing burden.

Nurses in primary health care have been highlighted as a crucial resource to support family caregivers, particularly through these professionals' education, proactivity, technology and cultural awareness so that they can lead interdisciplinary teams and provide access to quality care for family caregivers and/or people with dementia (Palumbo & Rambur, 2020). Furthermore, the intervention of the family nurse allows a broad assessment of the needs of caregivers of people with dementia, allowing the development and implementation of responses that can provide these caregivers with support tailored to their needs and those of the people with dementia (Zwingmann et al., 2019). Therefore, the family nurse plays a fundamental role in promoting the quality of life of the family caregiver and/or person with dementia, helping to minimize physical and psychological overload (Broekema et al., 2021).

METHODS

The descriptive and cross-sectional study with a mixed quantitative and qualitative approach was carried out in a Family Health Unit in the central region of Portugal. Data collection took place between January and February 2021 (during the third wave of the COVID-19 pandemic) via telephone (due to travel and contact restrictions).

The study population was made up of family caregivers of people with dementia who were accompanied by a family nurse in this informal care. The study included caregivers identified by the family nurses of the aforementioned Health Unit who were over 18 years of age, who spoke Portuguese and who cared for an elderly person (aged 65 years or over) with dementia at least once a day, even if they were not cohabiting with this person. Caregivers with diagnosed cognitive changes that interfered with understanding the questions were excluded. The sample was obtained by convenience and was composed of 45 family caregivers of people with dementia, users of the aforementioned Health Unit.

In this study, the sociodemographic and clinical variables of the person with dementia were studied (sex [male, female]; age [years]; marital status [single, married, widowed]; cohabiting member [husband, child, sister-in-law, daughter-in-law/son-in-law]; length of diagnosis of dementia; schizophrenia; self-care [through the Barthel Index]) and the sociodemographic variables of the family caregiver (sex [male, female]; age [years]; marital status [single, married, cohabitant, separated, divorced]; educational qualifications [can read and write, fourth grade/first cycle, preparatory education/second cycle; 12th year/secondary education; daily care; living with the patient with dementia [yes, no]; sharing care with other people [yes, no]). The study also targeted the physical, emotional and social impact of the role of family caregiver and the opinion of informal caregivers on the interventions that family nurses promoted to alleviate the burden of daily informal care provided at home.

The data collection instrument used consisted of four parts: the first included questions for the sociodemographic and clinical characterization of the person with dementia; the second part contained questions to characterize the family caregiver and the care provided; the third part assessed the impact of the physical, emotional and social role of informal caregiver (Informal Caregiver Burden Assessment Questionnaire [QASCI]) (Martins et al., 2013); and the fourth part consisted of two semi-structured questions with the purpose of ascertaining caregivers' opinion on the interventions that family nurses promoted to alleviate the burden of daily informal care provided at home. The time since diagnosis of dementia was obtained by consulting the clinical file of the person with dementia.

The QASCI is entirely made up of 32 items evaluated on an ordinal frequency scale that ranges from 1 to 5. It includes seven dimensions: implications for the caregiver's personal life (11 items); satisfaction with role and family (5 items); reactions to demands (5 items); emotional overload related to the family member (4 items); family support (2 items); financial burden (2 items) and perception of effectiveness and control mechanisms (3 items). Items 23 to 32 are inverted so that higher values correspond to greater burden. In general, analysis of the metric properties showed satisfactory results, indicating the suitability of the instrument to assess family caregiver burden (Martins et al., 2013).

This form was subject to an assessment of its content by two experts in the field of family health nursing. These experts both had at least ten years' experience in the field and had experience in providing care to families with people with dementia.

Subsequently, a pre-test was carried out on three family caregivers to collect information about its application. After carrying out the pre-test, no need to make changes to the questions asked was identified, considering that they were understood by the participants. The results of this pre-test were not included in the study results.

Regarding data collection, people with dementia were identified based on the medical diagnosis of dementia carried out by the medical team and registered in the Health Unit's information system. After this initial identification, family caregivers were contacted by telephone, informing them of the nature and objectives of the study, the estimated duration of the interview, and the guarantee of confidentiality and anonymity. After consent to record the call, free and informed consent was initially obtained from each participant orally and a telephone interview was scheduled to collect data. Each interview lasted an average of 25 minutes.

Regarding ethical procedures, prior to the implementation of the study, a favourable opinion was obtained from the Ethics Committee of the Regional Health Administration of the Centre (Opinion no. 58/2020) and authorization from the Board of Directors responsible for the aforementioned Health Unit. Free and informed consent was also obtained orally via telephone from all participants. This consent was recorded with the knowledge and authorization of the participants; the recordings were destroyed after the end of the study. The secrecy and confidentiality of the data collected were always guaranteed, using passwords to access files or folders and numerical coding to organize the completed forms.

This study was based on descriptive statistical analysis carried out with the support of the computer software Statistical Package for the Social Sciences (SPSS) version 23. Categorical variables were analysed using relative and absolute frequencies, and quantitative variables using means and standard deviations. The content analysis of the responses to the semi-structured questions was based on Van Manen's (2017) proposal with the aim of isolating phenomenological thematic aspects, or structures of meaning, that point to the meaning of experiences. Thus, this process resulted in conceptual categories that constitute the true essence of the lived experience of those family caregivers who participated in the study.

RESULTS

The sample of the present study consisted mainly of female family caregivers (60.0%) aged between 75 and 94 years (88.9%), with an average age of 84.5 years (Table 1). Regarding marital status, the participants with the greatest representation were those who were married (48.9%), the majority living with their husband or child, representing 46.7 per cent of participants in both cases.

Regarding clinical characterization, it was found that most elderly people had been diagnosed with dementia between four and six years ago (57.8%). Other diseases associated with dementia stood out: stroke (44.4%) and heart disease (42.2%). It is important to highlight that, according to an assessment of the basic activities of daily living (BADLs) carried out using the Barthel Index, most individuals (97.7%) were completely dependent.

Table 1

Sociodemographic and clinical characterization of elderly people with dementia. Central region, Portugal, 2021 (n = 45)

Sociodemographic variables	**n**	**%**	**Clinical variables**	**n**	**%**
Sex			**Time since dementia diagnosis**		
Male	18	40.0	1–3 years	1	2.2
Female	27	60.0	4–6 years	26	57.,8
			7–9 years	12	26.7
			10–12 years	5	11.1
			>12 years	1	2.2
Age			**Associated diseases**		
65–74 years	1	2.2	Schizophrenia	4	8.8
75–84 years	21	46.7	Stroke	20	44.4
85–94 years	19	42.2	Diabetes mellitus	17	37.7
≥95 years	4	8.9	Heart disease	19	42.2
			Hypertension	18	40.0
			Cancer	14	31.1
			High triglycerides	18	40.0
Marital status			**Barthel index**		
Single	3	6.7	Total dependence (0–20 points)	44	97.8
Married	22	48.9	Other degrees of dependence	1	2.2
Widowed	20	44.4			
Cohabiting member					
Husband/wife	21	46.7			
Son/daughter	21	46.7			
Brother/sister	1	2.2			
Brother-in-law/sister-in-law	1	2.2			
Son-in-law/daughter-in-law	1	2.3			

Source: Own preparation

Regarding family caregivers who took part in the study, it was found that the majority were female (64.4%) and aged over 65 years (82.2%) (see Table 2). Regarding marital status, the majority were married (64.4%). Furthermore, the majority had a low level of education.

Regarding the family care provided, it was found that most participants had been family caregivers for more than five years (91.1%). In most cases the family caregiver lived with the person with dementia (97.8%) and took care of them 24 hours a day, alone (53.3%). Caregivers who shared care with someone else (46.7%) mostly did so with their child (33.3%).

Table 2

Sociodemographic characterization and care provided by family caregivers. Central region, Portugal, 2021 (n = 45)

Sociodemographic variables	n	%	Care variables	n	%
Sex			**Lives with the person with dementia**		
Male	16	35.6	Yes	44	97.8
Female	29	64.4	No	1	2.2
Age			**Time as family caregiver**		
45–54 years	2	4.4	1–5 years	4	8.9
55–64 years	6	13.3	6–10 years	14	31.1
65–74 years	19	42.2	11–15 years	13	28.9
75–84 years	12	26.7	16–20 years	5	11.1
≥85 years	6	13.3	21–25 years	7	15.6
			>25 years	2	4.4
Marital status			**Time dedicated to care**		
Single	13	28.9	12 hours/day	1	2.2
Married	29	64.4	24 hours/day	44	97.8
De facto union	2	4.4			
Separated/divorced	1	2.2			
Educational qualifications			**Sharing informal care**		
Knows how to read and write	1	2.2	Yes	21	46.7
Fourth class/first cycle	27	60.0	No	24	53.3
Preparatory education/second cycle	3	6.7			
Ninth year/third cycle	6	13.3			
Twelfth year/secondary education	6	13.3			
Higher education	2	4.4			

Source: Own preparation

Regarding assessment of the physical, emotional and social impact of the role of family caregiver (Table 3), it was found that the factors in which caregivers obtain higher scores, and that therefore present overload, are financial overload (average (M)=4.27 ± 1.42), followed by implications for personal life (M=3.99 ± 1.27), emotional overload (M=3.68 ± 1.58) and family support (M=3.44 ± 1.66). With regard to factors with lower scores, suggesting that caregivers are not overloaded, the highlights are satisfaction with the role and family (M=1.30 ± 0.84), reactions to demands (M=2.46 ± 1.34) and efficacy and control mechanism (M=2.51 ± 1.13).

Table 3

Assessment of the physical, emotional and social impact of family caregivers. Central region, Portugal, 2021 (n = 45)

Variables	Mean ± standard deviation	Mode
Emotional overload	**3.68 ± 1.58**	**5**
1. Do you feel like running away from the situation you find yourself in?	1.62 ± 1.09	1
2. Do you consider taking care of your family member psychologically difficult?	4.78 ± 0.74	5

Variables	Mean ± standard deviation	Mode
3. Do you feel tired and exhausted from caring for your family member?	4.78 ± 0.74	5
4. Do you conflict with yourself because you are taking care of your family member?	3.56 ± 1.03	4
Implications in personal life	**3.99 ± 1.27**	**5**
5. Do you think your health condition has worsened because you are caring for your family member?	3.67 ± 1.13	4
6. Has taking care of your family member required a lot of physical effort?	4.58 ± 1.03	5
7. Do you feel like you have lost control of your life since your family member became ill?	3.27 ± 1.14	3
8. Have the plans you had made for this stage of life been changed due to taking care of your family member?	4.16 ± 1.19	5
9. Do you think you dedicate too much time to caring for your family member and that there is not enough time for you?	2.93 ± 1.19	3
10. Do you feel like life has played a trick on you?	4.16 ± 1.26	5
11. Is it difficult to plan for the future, given that your family member's needs cannot be predicted (they are unpredictable)?	4.71 ± 0.84	5
12. Does taking care of your family member make you feel trapped?	4.51 ± 1,18	5
13. Do you avoid inviting friends to your house because of your family member's problems?	3.82 ± 1.25	4
14. Has your social life (e.g. holidays, spending time with family and friends) been affected by caring for your family member?	4.13 ± 1.22	5
15. Do you feel alone and isolated because you are caring for your family member?	4.00 ± 1.38	5
Financial burden	**4.27 ± 1.42**	**5**
16. Have you experienced economic difficulties because of taking care of your family member?	4.29 ± 1.42	5
17. Do you feel that your economic future is uncertain, as you are caring for your family member?	4.24 ± 1.43	5
Reactions to demands	**2.46 ± 1.34**	**1**
18. Have you ever felt offended and angry with your family member’s behaviour?	3.00 ± 1.04	3
19. Have you ever felt embarrassed by your family member's behaviour?	3.16 ± 1.31	3
20. Do you feel that your family member asks you too much for unnecessary situations?	1.71 ± 1.04	1
21. Do you feel manipulated by your family member?	1.44 ± 0.87	1
22. Do you feel like you don't have as much privacy as you would like because you are caring for your family member?	3.00 ± 1.31	3
Effectiveness and control mechanism	**2.51 ± 1.13**	**2**
23. Can you do most of the things you need to do, despite the time you spend taking care of your family member?	2.60 ± 0.96	3
24. Do you feel capable of continuing to take care of your family member for much longer?	2.02 ± 1.10	2
25. Do you think you have the knowledge and experience to care for your family member?	2.91 ± 1.16	4
Family support	**3.44 ± 1.66**	**5**
26. Does the family (who don't live with you) recognize the work you do in taking care of their family member?	3.49 ± 1.65	5
27. Do you feel supported by your family members?	3.40 ± 1.70	5
Satisfaction with role and family	**1.30 ± 0.84**	**1**
28. Do you feel good about taking care of your family member?	1.20 ± 0.46	1
29. Does your family member show gratitude for what you are doing for them?	2.09 ± 1.44	1
30. Are you satisfied when your family member shows appreciation for small things (like treats)?	1.07 ± 0.33	1
31. Do you feel closer to your family member because you are taking care of them?	1.02 ± 0.15	1
32. Has taking care of your family member increased your self-esteem, making you feel like a special person, with more value?	1.11 ± 0.61	1

Source: Own preparation

Regarding the characterization of family nurse interventions in managing family caregivers’ burden, it was found that 95.6 per cent of caregivers received regular support from the family nurse, 71.1 per cent of these participants receiving this support once a month at the Family Health Unit (66.7%) or at home (31.1%). Regarding the support received, most participants referred to telephone guidance (62.2%). Regarding the support they would have liked to receive but did not receive, 55.6 per cent highlight psychological support and 28.9 per cent financial help.

Table 4

Characterization of family nurse interventions in managing family caregivers' burden. Central region, Portugal, 2021 (n = 45)

Variables	n	%
Family nurse support		
Yes	43	95.6
No	2	4.4
Frequency of support (per month)		
0	3	6.7
1	32	71.1
>2	10	22.2
Support location		
Residence	14	31.1
Family Health Unit	30	66.7
Other	1	2.2
Type of support		
Telephone guidance	28	62.2
Wound care	7	15.6
Vaccines	5	11.1
Medicines	1	2.2
Hygiene care	2	4.4
Bladder catheterization	2	4.4

Source: Own preparation

DISCUSSION

This study analysed the burden on family caregivers of people with dementia during the COVID-19 pandemic. The results show that these caregivers were mostly female, of advanced age, mostly married and/or widowed, and with low education, reinforcing the profile of the family caregiver reported in other studies (Leocadie et al., 2020; Movimento Cuidar dos Cuidadores Informais, 2018; Sequeira, 2018). These data highlight the feminization of the role of caregiver, in line with Sequeira (2018), who identified that 64.4 per cent of family caregivers are female, the role being based on belief, moral responsibility, guilt, duty and gratitude. The phenomenon of elderly people caring for elderly people is clear, essentially resulting from the dyad established between the couple (spouse caregiver). This result is particularly relevant because it represents a risk factor for overload. Furthermore, due to advanced age, these caregivers present an increase in their own care needs, which means that they may need more support from professionals. They may also present more physical, cognitive and functional problems, as well as having less preparation and knowledge to provide adequate care (Zubaidi et al., 2020). This makes them more vulnerable to adverse health events, particularly greater overload, generating a need for care that transforms them from caregivers into targets of care.

Equally relevant is the time spent as a caregiver—91.1 per cent had spent six or more years in the role—resulting from the natural progression of dementia, which in most situations is at an advanced stage (97.7 per cent were totally dependent for BADLs), factors that contribute to the burden among these caregivers (Cheng, 2017). Additionally, these caregivers deal not only with the care inherent in dementia, but with other associated pathologies, namely stroke, heart disease, diabetes and hypertension. It is important to highlight that these pathologies are risk factors for dementia, especially cardiovascular situations (associated with Alzheimer's, vascular and mixed dementia) and diabetes, also evidenced in the study by Santos et al. (2017). Multimorbidity implies a greater demand for care, increasing the complexity and demands of the caregiver role. These data, associated with dependence and a full-time care role (97.8%), which in many cases implies the impossibility of caregivers carrying out their own routines and roles in society, are associated with physical and emotional exhaustion and the need for services and support (Cheng, 2017; Curnow et al., 2021; Soltys & Tyburski, 2020; Wang et al., 2018). It was found that most people with dementia lived with close relatives and that the family was the main provider of care, among those who have support (Allen et al., 2020; Leocadie et al., 2020; Sequeira, 2018). These data suggest the family hierarchy that characterizes family caregivers, with spouses, especially wives, in the first line, followed by children if the spouse is not available (Alzheimer’s Disease International, 2018).

Regarding the assessment of the physical, emotional and social impact of the informal caregiver role, it was found that financial overload, implications for personal life, emotional overload and family support are the areas most affected, in line with other studies (Cheng, 2017; Movimento Cuidar dos Cuidadores Informais, 2018; Sequeira, 2018). The profile of family caregivers (women, fewer academic qualifications, living with the person with dementia, socially isolated and with more care time) (Alzheimer's Disease International, 2018; Unnikrishnan et al., 2019) and of the person with dementia (total dependence, multimorbidity) are factors for higher levels of burden (Cheng, 2017; Sequeira, 2018; Wulff et al., 2020). The emotional dimension is reported in the literature as normally being the most affected (Cheng & Zhang, 2020). However, in the present study, most participants had experienced financial difficulties and uncertainties and implications for their personal lives (both physical and social). Possibly, uncertainty, the need for support, isolation and the worsening of anxiety and depression symptoms during the COVID-19 pandemic may have contributed to the worsening of overload, which may be reflected in the results found, in particular regarding the financial dimension, implications for personal life, and emotional overload. Family caregivers during the pandemic reported that the care help that would make a difference would be assistance in providing care (relief from physical burden) (46.9%), financial support (39.6%) and psychological support (13.5%) (Movimento Cuidar dos Cuidadores Informais, 2018). It is important to note that in Portugal, economic support for caregivers, in addition to Social Security pensions, is non-existent despite being provided for in the Caregiver Statute, the majority reporting that they do not have sufficient services and support: only 3.3 per cent have financial help (Movimento Cuidar dos Cuidadores Informais, 2018). The fact that in this study almost all people with dementia present high dependence and more than half of family caregivers do not share informal care may imply a high physical burden and suggest dedication to a career as a full-time caregiver, which may contribute to the results found for implications for personal life. These caregivers report a lack of time to care for themselves, physical tiredness, and lack of effectiveness mechanisms (knowledge and experience), aspects that are considered to contribute to social overload (Ferreira, 2013). This overload, often associated with reduced family and social support networks and greater social isolation, may have been aggravated by epidemiological control measures (isolation, restriction of contacts) and conditioned the type of support offered by informal and formal support networks of care. Furthermore, more than half of the family caregivers in this study do not share the task, which may further contribute to the result of overload in the family support dimension.

Lower levels of overload were found in the efficacy and control mechanisms and reactions to demands dimensions. A possible explanation for these results may be related to the fact that most of these caregivers already have a long career as a caregiver, so they have acquired knowledge and experience to manage care. However, the changes resulting from the dementia process and the needs associated with dependence, especially in elderly caregivers, imply continuous training and support, which is not always available, contributing to feelings of less efficacy and control. In demand reactions, it appears that the behaviours of the person with dementia have a higher average value. This may be due to the trajectory of dementia, which in many cases is associated with disruptive behaviours such as aggressiveness, anxiety or agitation, and confusion, which represent challenges for caregivers of the person with dementia (WHO, 2018) and contribute to higher levels of burden compared to caregivers of people without dementia (Sequeira, 2018). It is important to highlight that the lowest level of overload is related to satisfaction with the role and family. This dimension is often associated with the positive experiences felt by family caregivers, expressed with feelings of gratification, satisfaction, fulfilment, and wellbeing for caring for their family member (Cheng, 2017). Furthermore, almost all the family caregivers in this study consider that they have increased their self-esteem, making them feel like a special person, with more value. Much of this stems from feeling that their family member can maintain their dignity, seeing the person well cared for and happy, and the opportunity to express love and affection. Therefore, this dimension must be valued by professional caregivers, which is often more focused on overload, overshadowing the positive impacts that can emerge.

Regarding family nurse interventions in managing family caregivers' burden, most caregivers have received support from these professionals, but the frequency is low and most contact is not face-to-face. These data may have been influenced by the restrictions imposed by the COVID-19 pandemic and the reduced availability of nurses, since many of them were allocated to epidemiological surveillance or vaccination, which means less time to meet the needs of family caregivers. Furthermore, care essentially focuses on instrumental/technical activities (e.g. treatments, vaccinations, among others). However, the areas with the greatest care needs are related to psychological/emotional support, help with caring for

https://doi.org/10.37914/riis.v7i2.341

the person, financial support, and training (Movimento Cuidar dos Cuidadores Informais, 2018). Therefore, the nurse's role with family caregivers of dependent elderly people must consider the difficulties the caregivers feel, as well as their needs, to alleviate their burden, at the same time providing them with techniques and knowledge to provide better care, which will ultimately promote the wellbeing and quality of life of the person with dementia. Therefore, structured interventions aimed at empowering caregivers and a majority response in articulation with existing resources in the community must be implemented by primary health care nurses, their impact on alleviating overload having been demonstrated (Broekema et al., 2021; Parra et al., 2019; Wang et al., 2018).

This study has some limitations. The first is related to the limited number of participants and the study being carried out in a single Family Health Unit as a result of the research team's limited contact with the care delivery context, limiting the generalization of the results to other caregivers and family members from different areas covered by these types of unit. Secondly, it is important to highlight the confinement and contact restriction measures that made data collection difficult, especially in-person application of the questionnaire. Finally, data collection was carried out via telephone interviews, and this may have conditioned the availability and responses of these family caregivers, especially because the majority of family caregivers are advanced in age, have low education, and may be less accustomed to this type of care data collection strategy.

This study constitutes a contribution to the area of nursing by highlighting the characteristics of family caregivers and people cared for, making it possible to evaluate the physical, emotional, social and financial impact on family caregivers in a Portuguese Family Health Unit and thus alert family nurses to understand the importance of monitoring these caregivers, as well as identifying risk factors for family caregivers and/or people with dementia that are associated with higher levels of burden. We therefore think that family nurses' interventions with these family caregivers are essential to maintain the person with dementia in their family environment, reduce institutionalization and consequently keep them integrated in a more protective context from both an epidemiological and social point of view. This can only be achieved with family caregivers who are qualified to provide care and are resilient in managing the burden associated with informal care. As recommendations, we suggest the development of a study based on follow-up in which it is possible to understand whether the difficulties of family caregivers change over time after being accompanied by a nurse. It also seems important to us to carry out a qualitative study to analyse the significant experiences of these family caregivers.

CONCLUSIONS

The results of this study showed that most cared for people with dementia are female, aged 75 or over, married, living with their spouse or child, were diagnosed with dementia between four and six years ago, and present high levels of dependence and multimorbidity. Family caregivers are mainly female, aged 65 or over, married and with low educational qualifications, highlighting the feminization of the caregiving task and the phenomenon of elderly people caring for older people. Higher levels of overload were identified in the financial dimension, along with implications for personal life (physical and social overload), emotional overload and family support. On the other hand, lower values were reported in the dimensions of satisfaction with the role of caregiver and with the family member. Almost all caregivers receive support from family nurses, but the frequency of this support is low (once a month for 71.1%). Finally, the type of support is essentially telephone guidance and support in instrumental activities. It is demonstrated that greater investment in a structured nursing intervention to manage the burden on family caregivers is necessary and urgent, particularly investment in providing emotional support and in supervision of the mobilization of family resources to support the person with dementia and family caregivers.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

FUNDING SOURCES

This study was supported in part by National Funds through the Fundação para a Ciência e a Tecnologia, I.P. (FCT) - Ministério da Ciência, Tecnologia e Ensino Superior, Portugal, within the scope of the Financing of the Research and Development Unit (CINTESIS) (reference UIDB/ 4255/2020 and UIDP/4255/2020).

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