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Burden and quality of life in caregivers of patients with amputated diabetic foot

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Abstract: Informal caregivers of chronically ill patients often report burden and poor quality of life. This study aimed to evaluate the impact of caring on caregivers of amputated patients with type 2 diabetes and diabetic foot. A cross-sectional study included a convenience sample of 110 caregivers who answered: the Burden Assessment Scale, the Depression Anxiety Stress Scales, the Social Support Satisfaction Scale, the Family Assessment Device, and the Short Form Health Survey. Multiple linear hierarchical regressions were performed to identify the variables that contributed to the burden and the physical and mental quality of life. Differences in burden as well as physical and mental quality of life were found, according to several caregivers' sociodemographic characteristics. Lower social support, more *distress*, and caregiver's perception of the impact of caring on the family dynamics contributed to burden. Lower *distress* and not having a chronic illness besides diabetes explained the physical quality of life whereas exercise and lower *distress* explained mental quality of life in caregivers and reduce the burden associated with caregiving, interventions should focus on social support, distress, and the practice of exercise.

Keywords: amputation; burden; caregivers; diabetic foot; quality of life

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Chronic disease is associated with increased emotional and physical burden, which usually falls on a family caregiver (Brier et al., 2018; Rodrigue et al., 2011). Caregiving can influence several aspects of caregivers' lives at physical, psychological, family, and social levels and may include deterioration of physical health and increased stress, anxiety, and depression (Ong et al., 2018; Rodakowski, Skidmore, Rogers, & Schulz, 2012). The International Diabetes Federation (2019) reported that diabetes is a public health problem due to its rapid expansion around the world. The Organization for Economic Cooperation and Development (OECD) Report, for 2017, estimated that in 2015, Portugal had a diabetes prevalence rate of 9.9% in adults (above the OECD average of 7%).

Type 2 diabetes occurs due to a progressive loss of insulin secretion from b cells, often as a backdrop to insulin resistance (American Diabetes Association, 2019). The determinants of this disease are organized in a matrix with genetic variables, epigenetic factors, and lifestyle that interact with each other (Zheng, Ley, & Hu, 2018). Diabetes is often associated with complications that may lead to a lower limb amputation being considered the second leading cause of amputation (Jeffcoate, Barron, Lomas, Valabhji, & Young, 2017; Soomro & Jalal, 2013). Amputated patients, after the surgery, face great physical, emotional, social, and occupational challenges, being functionally compromised and requiring a caregiver (Costa, Machado, & Pereira, 2018).

Informal caregivers experience burden due to emotional involvement and physical efforts in caring, particularly, during the advanced stages of the disease. Caring also affects the caregiver's physical health (Bevans & Sternberg, 2012; Costa & Pereira, 2018) and quality of life (QoL) (Anaforoğlu, Ramazanoğulları, Algün, & Kutanis, 2012; Costa & Pereira, 2018; Valer, Aires, Fengler, & Paskulin, 2015). The burden felt by caregivers is influenced by the duration of care and patient's functionality (Elhameed & Alam, 2016). Thus, the duration of care is associated with greater burden and greater prevalence of depression in caregivers; in addition, less patient functionality is associated with an increase in caregiver's burden (Khan et al., 2016). Caregivers may feel social and emotional isolation, often abdicating pleasure-generating activities (Dauphinot et al., 2016: Podgorski, 2018).

Caregivers in families with greater conflict and less adaptability report more depression; besides, the prevalence of depression in caregivers is higher than that in noncaregivers (Vitaliano, Ustundag, & Borson, 2016). Social support is negatively associated with psychological morbidity, burden, and psychological suffering (Haya, Ichikawa, Wakabayashi, & Takemura, 2019; Pagnini et al., 2010). Help and support that caregivers get from family and society can influence perceived burden and caregivers are at high risk of burden when the social support network is scarce (Blanco et al., 2019).

According to the model of psychosocial adaptation to chronic disease and disability (Livneh, 2001; Livneh, Bishop, & Anctil, 2014), QoL is the result of an adaptation process to the disease that includes three distinct, interacting variables: antecedents or triggering events related to the physical condition (in this study, the amputation level and the presence of chronic disease in the caregivers); followed by the dynamic process of adaptation that includes the reactions to illness and physical symptoms (in this study, psychological morbidity, burden, family functioning, and satisfaction with social support as well as contextual influences such as age, employment status, kinship, and care assistance; disease-related variables such as duration of care); and finally the impact on QoL, assessed in both physical and mental dimensions.

The burden of caregivers in general has been a concern for several authors (e.g., Dew & Garand, 2019; Gilbertson et al., 2019; Singh Solorzano et al., 2019), being considered a public health priority (Shaji & Reddy, 2012) because no society can afford to replace all informal caregivers with paid workers (Shaji & Reddy, 2012). However, there are few studies on the impact of caring on caregivers of type 2 diabetes patients, with a lower limb, amputation. Although Tsoulou, Karamolegou, Kourakos, Vasilopoulos, and Polikandrioti (2019) found that as the patient's anxiety increases, caregivers' anxiety increases as well and vice versa. In another study, the QoL of caregivers of lower limb amputees was explained by the number of hospitalizations and mental health problems (Ganjparvar, Mousavi, Masumi, Soroush & Montazeri, 2016). However, the psychological factors that contribute the most to the burden and QoL have not been fully identified and understood. Therefore, this study aims to fill this gap by focusing on physical and mental QoL in informal caregivers of patients with type 2 diabetes and diabetic foot, undergoing amputation surgery, with the purpose of evaluating the contribution of psychological morbidity, social support, and family functioning regarding burden and QoL. The variables age, employment status, the presence of chronic illness, kinship, and the support received to care were taken into consideration and controlled. It is expected that distress, social support, and family functioning contribute to caregiver's physical and mental QoL as well as burden.

Methods

Sample

The present study consists of a convenience sample of 110 caregivers of patients with type 2 diabetes, with diabetic foot, undergoing amputation surgery. Inclusion criteria were (a) being over 18 years old; (b) a caregiver of a patient with type 2 diabetes, amputated of a lower limb; and (c) the patient's amputation surgery having occurred 1 month before the assessment period.

Data collection was performed in three multidisciplinary diabetic foot clinics of six hospitals in Northern Portugal during 2015, and was approved by the ethical committees of the six institutions: Santa Luzia Hospital Center, Tâmega and Sousa Hospital Center, Hospital Center of Vila Nova de Gaia/Espinho, Hospital Center of Porto, S. João Hospital Center, and Hospital of Braga. The study was conducted according to criteria set by the Declaration of Helsinki, and each participant signed an informed consent. Participation was voluntary. Patient's identification took into consideration the amputation surgery date, and caregivers who fulfilled the inclusion criteria were identified, contacted, and invited to participate in the study, the day and time of the patient' postoperative diabetic foot consultation, 1 month after the amputation. (at that time, the patient and caregiver are in a new postamputation routine; however, not far enough away from the amputation to mitigate its impact.)

Instruments

The Sociodemographic and Clinical Questionnaire was developed for this study. It evaluates sociodemographic variables (age, sex, marital status, education, employment status, kinship) and clinics (choice to became a family caregiver, beginning of care, duration of care (months), hours a day spent with the patient, physical exercise, sleep time per night, diagnosis of chronic illness in the caregiver, help to care, impact of caring in the caregiver's family dynamics, opportunity to take vacations, previous amputations, current amputation level, and amputation pain).

The *Burden Assessment Scale* (BAS; Reinhard, Gubman, Horwitz, & Minsky, 1994; Research version: Cotrim, 2007) evaluates burden through 19 items, answered in a 4-point Likert scale of 1 (*not at all*) to 4 (*a lot*) (e.g., "Because of caring do you find it difficult to concentrate on your own activities?"). Cronbach's α s ranged from .89 to .91 in the original version, and .81 in the Portuguese version. In the present study, only the Global scale, with a Cronbach's α of .85, was used.

The Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995; Portuguese version: Apóstolo, Mendes, & Azeredo, 2006) assesses depression, anxiety, and distress through 21 items answered on a 4-point Likert scale of 1(nothing applied to me) to 4 (applied most of the time). The Depression subscale assesses symptoms such as inertia, anhedonia, dysphoria, lack of interest/involvement, self-depreciation, devaluation of life, and discouragement. The anxiety subscla assesses the autonomic nervous system excitement, musculoskeletal effects, situational anxiety, and subjective experiences of anxiety. Finally, the Stress subscale assesses difficulty in relaxing, nervous excitement, easy disturbance/agitation, irritability/exaggerated reaction, and impatience. Higher results indicate more negative affective states. In this study, only the Global scale was used, with a Cronbach's α of .95; Cronbach's α in the original study was .94, and in the Portuguese version, the α was .86 for anxiety, .90 for depression, .88 for distress, and .95 for the total scale.

The Satisfaction with Social Support Scale (SSSS; Pais-Ribeiro, 1999) evaluates satisfaction with social support through 15 items, answered on a 5-point Likert scale of 1 (totally disagree) to 5 (totally agree) (e.g., "I am satisfied with how many friends I have."). A high result indicates greater satisfaction with social support. In this study, only the Global scale was used, with an α of .83. In the original study, the α was .85 for the Global scale.

The *Family Assessment Device* (FAD; Epstein, Baldwin, & Bishop, 1983; Ryan, Epstein, Keitner, Miller, & Bishop, 2005; Portuguese version of Almeida, Leandro & Pereira, 2020) evaluates family functioning through 60 items. In the present study, only the Global Function subscale, composed of 12 items, was used. Six items reflect healthy family

functioning and six reflect unhealthy functioning (Epstein et al., 1983), and are rated on a 4-point Likert scale of 1 (*strongly agree*) to 4 (*strongly disagree*), with the scale for the negatively worded items reversed. A high result means problematic family functioning. Cronbach's α in the present study was .90; and in the Portuguese version, with Type 1 adolescents was .79.

Short Form Health Survey (SF-36; Ware, Snow, Kosinski, & Gandek, 1993; Portuguese version: Ferreira, 2000). This questionnaire assesses QoL in two dimensions—physical and mental—including 46 items (e.g., "Does your health limit you in these activities?) answered in different ways. In the original version, the authors did not report Cronbach's α ; the Portuguese version reported for the physical dimension, an α of .92, and .91 for the mental dimension; in the present study, Cronbach's α was .74 in the physical dimension, and .83 in the mental dimension.

Data analysis

To test the association between psychosocial and sociodemographic variables, Pearson and bisserial correlation tests (gender, beginning of care, and previous amputations) were used. To evaluate differences in the sociodemographic and clinical variables regarding burden and QoL, a t test for independent samples and the Mann-Whitney U test (with Bonferroni correction) when the corollaries of the parametric statistic were not present for the categorically dichotomized variables (marital status: unmarried and married; employment status: not active and active; hours of sleep per night: up to 6 hr and more than 6; and kinship: spouse, parents, and other family members were used). To evaluate variables that contributed to explaining burden and physical and mental QoL, three multiple linear hierarchical regressions were performed, and sociodemographic and clinical variables of the previous analysis were introduced in the first block and psychological variables in the second. Data were processed using SPSS Version 25 (IBM, New York, NY, USA).

Results

Characterization of the sample

The sample included mostly females (85.5%, M age = 52 years) who were married (80.9%) and not active (unemployed or retired: 84.4%), with a mean of 6.8 years of education. Of these caregivers, 80.9% took care of their partners and parents (an assignment that they did not choose), a situation that in most cases was prior to the

current amputation. Caregivers have performed the caregiver role, on average, for about six years, spending approximately 4 hr a day with the patient. Regarding the characteristics associated with the patient's amputation, 73.6% were caregivers of patients who suffered a minor amputation (Table 1).

Differences in burden and physical and mental QoL considering sociodemographic and clinical variables

The results showed differences in burden, according to employment status, U = .915, p = .015, $\eta^2 = .393$: Active caregivers (employees) presented less burden; finding time to take vacations, U = .598, p = .010, $\eta^2 = .459$: Caregivers without vacations reported more burden; and regarding the perception of the impact that caring had on family dynamics, $\chi^2(3) = 22.629$, p < .001, $\eta^2 = .185$: Caregivers who perceived more impact reported more burden.

Differences in OoL were found, according to gender, U = .511, p = .041, $\eta^2 = .369$: Male caregivers presented better physical OoL: marital status. U = 1.178. p = .003. $n^2 =$.458: Married caregivers showed less physical QoL compared to those living alone; employment status: Nonactive caregivers present lower physical, U = 1.619, p = .034, $\eta^2 = .393$, and mental QoL, U = 1.662, p = .016, $\eta^2 = .392$; kinship: Caregivers of spouses showed less physical, $\chi^2(3) = 2.165$, p < .030; $\eta^2 = .002$, and mental QoL, $\chi^2(3) = 2.165$, p < .030; $\eta^2 = .065$; exercise: Caregivers who practice physical exercise have more physical, t(108) = -2.357, p = .020, d = .528, and mental QoL, t(108) = -3.752, p < .001, d = .829; chronic disease: Caregivers with chronic disease reported lower physical QoL, t(108) = 4.364, p < .001, d = .840; and support in caring: Caregivers with more support presented higher mental QoL, t(108) = -2.553, p = .012, d = .487.

Variables that contributed to burden

Results showed that employment status, taking vacations, and the impact of caring on family dynamics as well as distress, social support, and family functioning explained 36.5% of the variance of burden. The impact of caring on family dynamics, distress, and less social support contributed significantly to burden (Table 2).

Variables that contributed to QoL

The results showed that not having a chronic disease and lower distress were the only variables that contributed

Table 1

Sociodemographic and	Clinical	Characterization	of	Caregivers	/N	=	110))
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Age	$M \pm SD [m - M]$	51.74 ± 15.16 [19-82]
Gender	Female	94 (85.5%)
	Male	16 (14.5%)
Marital status	Not married	21 (19.1%)
	Married	89 (80.9%)
Employment status	Active	34 (15.6%)
	Inactive	184 (84.4%)
Years of education	$M \pm DP [m - M]$	6.75 ± 3.98 [0-15]
Kinship	Husband/wife	51 (46.4%)
	Parents	38 (34.5%)
	Others	21 (19.1%)
Caring by choice	No	67 (60.9%)
	Yes	43 (39.1%)
Beginning of care	Before	66 (60%)
	amputation	
	After	44 (40%)
	amputation	
Care duration	$M \pm DP [m - M]$	69.28 ± 105.96 [1–720]
Hours/day with	$M \pm DP [m - M]$	4.27 ± 1.24 [1–7]
patient		
Practice of exercise	No	80 (72.7%)
	Yes	30 (27.3%)
Sleep per night (hr)	≤6	55 (50.0%)
	>6	55 (50.0%)
Chronic disease	No	51(46.4%)
	Yes	59 (53.6%)
Receiving help to care	No	56 (50.9%)
	Yes	54 (49.1%)
Perception of		
impact of caring	Nothing	16 (14.5%)
on family	A little	31 (28.2%)
dynamics		
1	Quite a lot	35 (31.8%)
	A lot	28 (25.5%)
Taking vacations	No	89 (80.9%)
C C	Yes	21 (19.1%)
Characteristics associated	with patient amputa	tion
No. of previous	None	55 (50.0%)
amputations	≥l	55 (50.0%)
Level of amputation	Minor	81 (73.6%)
	Major	29 (26.4%)
Pain	No	50 (45.5%)
	Yes	60 (54.5%)

significantly to a high perception of physical QoL, explaining 19.9% of physical QoL (Table 3).

The practice of exercise and less distress contributed significantly to better mental QoL, explaining 36.5% of mental QoL (Table 4).

Discussion

The present study evaluated the impact of caring on caregivers of amputated patients due to type 2 diabetes. The sample consisted mainly of female caregivers, with a mean age of 52 years and who were married, not employed, with

Table 2 Hierarchical Multiple Linear Regression of Burden

					Change statistics				
Model	R	R^2	R ² adjusted	SE of the estimate	R^2 change	SE of the estimate	R ² change	SE of the estimate	R ² change
1	.486	.236	.214	10.37103	.236	10.915	3	106	.000
2	.632	.400	.365	9.32425	.164	9.379	3	103	.000
			В	Error	β	t	p		
1	(Constant)	32.454	3.010		10.783	.000		
	Employment status		-4.124	2.226	164	-1.853	.067		
	Care impa	ct	4.400	0.995	.381	4.423	.000		
	Vacations		-4.649	2.653	157	-1.753	.083		
2	(Constant)	44.931	8.675		5.179	.000		
	Employme	ent status	-3.179	2.067	126	-1.538	.127		
	Care impa	ct	3.671	0.936	.318	3.922	.000		
	Vacations		-2.094	2.444	071	-0.857	.394		
	Distress		0.541	0.172	.289	3.142	.002		
	Social sup	port	252	0.104	223	-2.430	.017		
	Family fur	nctioning	-1.151	1.859	051	-0.619	.537		

Note: At bold the significant results in the last model.

Table 3

Hierarchical Multiple Linear Regression of Physical QoL

					Change statistics						
Model	R	R^2	R^2 ajusted	SE of the estimate	R ² change	SE of the estimate	R ² change	SE of the estimate	R ² change		
1	.474	.224	.179	11.32627	.224	4.964	6	103	.000		
2	.516	.266	.192	11.23445	.042	1.423	4	99	.232		
			В	Error	β	t	р				
1	(Constant)		78.642	5.992		13.125	.000				
	Employment	t status	2.548	2.501	.095	1.019	.311				
	Gender		-1.635	3.575	046	457	.648				
	Marital statu	S	-4.225	3.087	133	-1.369	.174				
	Kinship		0.385	1.578	.024	0.244	.807				
	Exercise		3.865	2.776	.138	1.392	.167				
	Chronic dise	ase	-7.866	2.327	315	-3.381	.001				
2	(Constant)		97.280	13.315		7.306	.000				
	Employment	t status	0.849	2.620	.032	0.324	.747				
	Gender		-1.675	3.569	047	-0.469	.640				
	Marital status		-4.434	3.091	140	-1.435	.155				
	Kinship		-0.116	1.584	007	-0.073	.942				
	Exercise		3.890	2.820	.139	1.379	.171				
	Chronic dise	ase	-8.783	2.345	352	-3.746	.000				
	Distress		-0.433	0.221	216	-1.963	.052				
	Social suppo	rt	-0.198	0.131	164	-1.506	.135				
	Family functioning		-1.465	2.237	061	-0.655	.514				
	Burden		0.004	0.110	.004	0.035	.972				

Note: At bold the significant results in the last model.

6.8 years of education, on average. In fact, informal care is often assumed by women (Dionne-Odom et al., 2019), especially by wives and daughters (Washio, Toyoshima, Miyabayashi, & Arai, 2019) who are older (Dionne-Odom et al., 2019; Singh Solorzano et al., 2019) not working (Washio et al., 2019) and with little education, unlike other studies with caregivers with more education (Dionne-Odom et al., 2019; Singh Solorzano et al., 2019; Washio et al., 2019). Regarding employment status, unemployed caregivers presented lower QoL when compared with employed caregivers (Brier et al., 2018; Rodrigue et al., 2011). Since the group of caregivers in this study were not professionally active, may have been more willing to provide care, which put them at risk of greater psychological morbidity and consequently worse QoL.

Most caregivers in this study took care of their partners and parents (a task they did not choose), and this situation preceded the current amputation. Caregivers of spouses present more psychological morbidity when compared to other direct relatives, such as parents, children, and siblings

					Change statistics				
Model	R	R^2	R^2 adjusted	SE of the estimate	R ² change	F change	df1	df2	Significance F change
1	.431	.186	.155	9.84732	.186	5.985	4	105	.000
2	.641	.411	.365	8.53762	.226	9.671	4	101	.000
			В	Error	β	t	р		
1	(Constant)		43.245	2.366		18.281	.000		
	Employmer	nt status	3.378	2.151	.146	1.570	.119		
	Kinship		1.764	1.333	.126	1.323	.189		
	Exercise		6.937	2.155	.290	3.218	.002		
	Help to care	2	2.295	2.113	.108	1.086	.280		
2	(Constant)		46.428	8.766		5.297	.000		
	Employmer	nt status	1.518	1.951	.066	0.778	.438		
	Kinship		1.128	1.178	.081	0.958	.341		
	Exercise		4.591	1.939	.192	2.368	.020		
	Help to care	2	1.129	1.898	.053	0.595	.553		
	Burden		-0.086	0.085	094	-1.010	.315		
	Distress		-0.680	0.167	397	-4.074	.000		
	Social supp	ort	0.128	0.099	.124	1.292	.199		
	Family fund	ctioning	1.042	1.693	.051	0.615	.540		

 Table 4

 Hierarchical Multiple Linear Regression of Mental QoL

Note: At bold the significant results in the last model.

(Valer et al., 2015). Regarding, the situation faced by several caregivers who did not chose to be caregivers, Stork, Martone, Osterman, Savage, and Mukherjee (2018) emphasized the need for society to appreciate the value of caring and to provide resources to allow caregivers, if they are professionally active, to reconcile their work with the caregiving tasks.

In this sample, caregivers performed the task of caring, on average, for about six years, spending approximately 4 hr a day with the patient. According to Khan et al. (2016), length of care is associated with increased burden and depression in caregivers. The majority of the sample did not practice physical exercise, that helps in dealing with stress in caregivers (Puterman et al., 2018); half of the sample slept up to 6 hr per night, and more than half had been diagnosed with a chronic illness, in line with the study of Nielsen, Neergaard, Jensen, Bro, and Guldin (2016). More than half of the sample considered that caring for the patient greatly affected family dynamics, with many difficulties in taking vacations, as Yu et al. (2017) found. In clinical terms, regarding the characteristics associated with the patient's amputation, most of the sample includes caregivers of patients who suffered a minor amputation; more than half of these patients reported pain at the amputation local and this result is in agreement with the literature (Brier et al. 2018, Jeffcoate et al., 2017).

Less social support, high distress, and high impact of caring on family dynamics contributed to more burden. In fact, the support received was associated with less burden, allowing the family to not compromise its functioning with other family members and to adjust better to the disease without it becoming the family's identity. These results agree with the literature in which caregivers of elderly people with functional dependence without care support present lower family functioning (Pereira & Carvalho, 2012).

Lower distress and not having a chronic disease were the variables that contributed the most to physical QoL. The literature has revealed that caregivers with a diagnosis of chronic disease present a lower physical OoL (Anaforoğlu et al., 2012; Costa & Pereira, 2018; Valer et al., 2015) and that chronic diseases such as diabetes are commonly associated with deterioration of QoL, in patients and relatives (Ong et al., 2018; Rodakowski et al., 2012). In turn, doing physical exercise and feeling less distress were the variables that most contributed to mental OoL. According to Lamotte, Shah, Lazarov, and Corcos (2017), physical exercise has a positive effect on the patients' functional independence and on the caregiver burden, thus improving their QoL. Thus, caregivers of amputees, in the first month after amputation, have similar characteristics to the caregivers of elderly individuals with functional dependence regarding the need for care support in the psychological variables evaluated (Pereira & Carvalho, 2012).

Although there were no significant associations between duration of care and QoL, it is necessary to consider that the moment of assessment after amputation may still have little impact on QoL. On one hand, at this stage, there is greater support from health professionals; on the other hand, the average number of days of hospitalization after surgery is high, and caregivers have not yet been confronted with the obstacles and requirements of caring for a patient amputee at home. Other patients were also integrated into units of continuing care for rehabilitation, where the patient is accompanied by a multidisciplinary team that provides health care and psychosocial support aimed at the rehabilitation and social reintegration of the patient. In addition, almost half of the sample received support in caring which can also contribute, especially in the initial postsurgery phase, to dilute the impact of burden. Thus, the burden reported in this sample refers mainly to daily visits to the patient in the hospital and the duration of care that had begun before the current amputation surgery. Future studies should pursue this hypothesis.

Limitations

The size of the sample and the exclusive use of self-report instruments are limitations that require caution in interpreting the results. In addition, the fact that the sample consists mainly of female caregivers requires caution in the interpretation of the results. The number of patients who had major amputations was lower versus those with minor amputations. Future studies should include a larger number of caregivers, including more male caregivers as well as caregivers of different socioeconomic status also caring for patients with major amputations. Longitudinal studies evaluating changes in burden and QoL would also be important, as the duration of care increases.

Clinical implications

The results showed that older female caregivers with chronic disease who were inactive and without care support presented lower QoL and greater burden, emphasizing the need for psychological counseling. Interventions targeted at reducing distress and increasing social support, as well as physical exercise, may help reduce the burden and promote QoL. Health professionals should also consider age, gender, kinship, available family support, occupational status, and the caregiver's physical health. Finally, the authors note the pleasure in seeing the status of the informal caregiver being recognized, in Portugal (Dispatch n°. 5988/2018) since care-givers are also members of the multidisciplinary health teams providing care to patients.

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Disclosure of conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

References

- Almeida, A., Leandro, E., & Pereira, A. (2020, in press). Psychometric proporties of the Portuguese adaptation of general functioning of family assessment device: A comparative study. Family, Systems & Health.
- American Diabetes Association (2019). Classification and diagnosis of diabetes: Standards of medical care in diabetes-2019. *Diabetes Care*, 42(Supplement 1), S13–S28. https://doi.org/10. 2337/dc19-S002
- Anaforoğlu, İ., Ramazanoğulları, İ., Algün, E., & Kutanis, R. (2012). Depression, anxiety and quality of life of family caregivers of patients with type 2 diabetes. *Medical Principles and Practice*, 21(4), 360–365. https://doi.org/10.1159/000334622
- Apóstolo, J. L. A., Mendes, A. C., & Azeredo, Z. A. (2006). Adaptation to Portuguese of the depression, anxiety and stress scales (DASS). *Revista Latino-Americana de Enfermagem*, 14(6), 863–871. https://doi.org/10.1590/S0104-11692006000600006
- Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Journal of the American Medical Association*, 307(4), 398–403. https://doi.org/10.1001/jama.2012.29
- Blanco, V., Guisande, M. A., Sánchez, M. T., Otero, P., López, L., & Vázquez, F. L. (2019). Caregiver burden and associated factors in family caregivers in the Community of Galicia, Spain. *Revista Espanola de Geriatria y Gerontologia*, 54(1), 19–26. https://doi.org/10.1016/j.regg.2018.03.005
- Brier, M. J., Williams, R. M., Turner, A. P., Henderson, A. W., Roepke, A. M., Norvell, D. C., ... Czerniecki, J. M. (2018). Quality of relationships with caregivers, depression, and life satisfaction after dysvascular lower extremity amputation. *Archives of Physical Medicine and Rehabilitation*, 99(3), 452–458. https://doi.org/10.1016/j.apmr.2017.09.110

- Costa, M. S., & Pereira, M. G. (2018). Predictors and moderators of quality of life in caregivers of ampute patients by type 2 diabetes. *Scandinavian Journal of Caring Sciences*, 32(2), 933–942. https://doi.org/10.1111/scs.12528
- Costa, M. S. A., Machado, J. C., & Pereira, M. G. (2018). Burden changes in caregivers of patients with type 2 diabetes: A longitudinal study. *Journal of Advanced Nursing*, 74(10), 2322–2330. https://doi.org/10.1111/jan.13728
- Cotrim, H. (2007). Impact of colorectal cancer on patients and caregivers/ family: Implications for caring (Doctoral dissertation). University of Porto. Retrieved from http://hdl.handle.net/ 10216/7231. (Accessed on 19th March 2019)
- Dauphinot, V., Ravier, A., Novais, T., Delphin-Combe, F., Moutet, C., Xie, J., ... Krolak-Salmon, P. (2016). Relationship between comorbidities in patients with cognitive complaint and caregiver burden: A cross-sectional study. *Journal of the American Medical Directors Association*, 17(3), 232–237. https://doi.org/10.1016/j.jamda.2015.10.011
- Dew, M. A., & Garand, L. (2019). Beyond cross-sectional snapshots: Charting the course of burden in caregivers of family members with mild cognitive impairment. *The American Journal of Geriatric Psychiatry*, 27(11), 1216–1218. https://doi.org/ 10.1016/j.jagp.2019.06.003
- Dionne-Odom, J. N., Ejem, D., Wells, R., Barnato, A. E., Taylor, R. A., Rocque, G. B., ... Martin, M. Y. (2019). How family caregivers of persons with advanced cancer assist with upstream healthcare decision-making: A qualitative study. *PLoS One*, 14(3), e0212967. https://doi.org/10.1371/journal.pone. 0212967
- Elhameed, S. A., & Alam, R. (2016). Burden of caring for chronic diseases and family caregivers health status. *Alexandria Scientific Nursing Journal*, 18(1), 43–60.
- International Diabetes Federation. (2019). Type 2 diabetes. Retrieved from https://idf.org/52-about-diabetes.html. (Accessed on 27th March 2019).
- Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy*, 9(2), 171–180. https://doi.org/10.1111/j.1752-0606.1983.tb01497.x
- Ganjparvar, Z., Mousavi, B., Masumi, M., Soroush, M., & Montazeri, A. (2016). Determinants of quality of life in the caregivers of Iranian war survivors with bilateral lower-limb amputation after more than two decades. *Iranian Journal of Medical Sciences*, 41(4), 257–264.
- Gilbertson, E. L., Krishnasamy, R., Foote, C., Kennard, A. L., Jardine, M. J., & Gray, N. A. (2019). Burden of care and quality of life among caregivers for adults receiving maintenance dialysis: A systematic review. *American Journal of Kidney Diseases*, 73(3), 332–343. https://doi.org/10.1053/j.ajkd.2018.09.006
- Haya, M. A. N., Ichikawa, S., Wakabayashi, H., & Takemura, Y. (2019). Family caregivers' perspectives for the effect of social support on their care burden and quality of life: A mixedmethod study in rural and sub-urban central Japan. *The Tohoku Journal of Experimental Medicine*, 247(3), 197–207. https://doi.org/10.1620/tjem.247.197
- Jeffcoate, W., Barron, E., Lomas, J., Valabhji, J., & Young, B. (2017). Using data to tackle the burden of amputation in diabetes. *The Lancet*, 390(10105), e29–e30. https://doi.org/10.1016/ S0140-6736(17)32401-7

- Khan, Z., Braich, P. S., Rahim, K., Rayat, J. S., Xing, L., Iqbal, M., ... Almeida, D. (2016). Burden and depression among caregivers of visually impaired patients in a Canadian population. *Advances in Medicine*, 2016, 4683427. https://doi. org/10.1155/2016/4683427
- Livneh, H. (2001). Psychosocial adaptation to chronic illness and disability: A conceptual framework. *Rehabilitation Counseling Bulletin*, 44(3), 151–160. https://doi.org/10.1177/ 003435520104400305
- Lamotte, G., Shah, R. C., Lazarov, O., & Corcos, D. M. (2017). Exercise training for persons with Alzheimer's disease and caregivers: A review of dyadic exercise interventions. *Journal* of motor behavior, 49(4), 365–377.
- Livneh, H., Bishop, M., & Anctil, T. M. (2014). Modern models of psychosocial adaptation to chronic illness and disability as viewed through the prism of Lewin's field theory: A comparative review. *Rehabilitation Research, Policy and Education, 28* (3), 126–142. https://doi.org/10.1891/2168-6653.28.3.126
- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the beck depression and anxiety inventories. *Behaviour Research and Therapy*, 33(3), 335–343. https://doi.org/10.1016/0005-7967(94)00075-U
- Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Psychological distress, health, and socioeconomic factors in caregivers of terminally ill patients: A nationwide population-based cohort study. *Supportive Care in Cancer*, 24(7), 3057–3067. https://doi.org/10.1007/s00520-016-3120-7
- Ong, H. L., Vaingankar, J. A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M. E., ... Subramaniam, M. (2018). Resilience and burden in caregivers of older adults: Moderating and mediating effects of perceived social support. *BMC Psychiatry*, *18*(1), 27. https://doi.org/10.1186/s12888-018-1616-z
- Pagnini, F., Rossi, G., Lunetta, C., Banfi, P., Castelnuovo, G., Corbo, M., & Molinari, E. (2010). Burden, depression, and anxiety in caregivers of people with amyotrophic lateral sclerosis. *Psychology, Health & Medicine*, 15(6), 685–693. https://doi.org/10.1080/13548506.2010.507773
- Pais-Ribeiro, J. L. (1999). Escala de satisfação com o suporte social (ESSS) [Social Support Satisfaction Scale (SSSS)]. *Análise Psicológica*, 17(3), 547–558.
- Pereira, M. G., & Carvalho, H. (2012). Qualidade de vida, sobrecarga, suporte social, ajustamento conjugal e morbilidade psicológica em cuidadores de idosos com dependência funcional [Quality of life, burden, social support, marital adjustment and psychological morbidity in caregivers of elderly with functional dependence]. *Trends in Psychology*, 20(2), 369–383. https://doi. org/10.9788/TP2012.2-07
- Podgorski, C. (2018). Research on caregiver stress: Time for integration and application. *International Psychogeriatrics*, 30(8), 1085–1087. https://doi.org/10.1017/S1041610218001035
- Puterman, E., Weiss, J., Lin, J., Schilf, S., Slusher, A. L., Johansen, K. L., & Epel, E. S. (2018). Aerobic exercise lengthens telomeres and reduces stress in family caregivers: A randomized controlled trial - Curt Richter Award Paper 2018. *Psychoneuroendocrinology*, 98, 245–252. https://doi.org/10. 1016/j.psyneuen.2018.08.002
- Reinhard, S., Gubman, G., Horwitz, A., & Minsky, S. (1994). Burden assessment scale for families of the seriously

mentally ill. *Evaluation and Program Planning*, *17*(3), 261–269. https://doi.org/10.1016/0149-7189(94)90004-3

- Rodakowski, J., Skidmore, E. R., Rogers, J. C., & Schulz, R. (2012). Role of social support in predicting caregiver burden. *Archives of Physical Medicine and Rehabilitation*, 93(12), 2229–2236. https://doi.org/10.1016/j.apmr.2012.07.004
- Rodrigue, J. R., Dimitri, N., Reed, A., Antonellis, T., Hanto, D. W., & Curry, M. (2011). Quality of life and psychosocial functioning of spouse/partner caregivers before and after liver transplantation. *Clinical Transplantation*, 25(2), 239–247. https://doi.org/10.1111/j.1399-0012.2010.01224.x
- Ryan, C., Epstein, N., & Keitner, G. I., Miller, W. I., & Bishop, D. (Eds.). (2005). *Evaluating and treating families: The McMaster approach*. New York, NY: Routledge.
- Shaji, K. S., & Reddy, M. S. (2012). Caregiving: A public health priority. *Indian Journal of Psychological Medicine*, 34(4), 303–305. https://doi.org/10.4103/0253-7176.108191
- Singh Solorzano, C., Steptoe, A., Leigh, E., Kidd, T., Jahangiri, M., & Poole, L. (2019). Pre-surgical caregiver burden and anxiety are associated with post-surgery cortisol over the day in caregivers of coronary artery bypass graft surgery patients. *International Journal of Behavioral Medicine.*, 26, 316–322. https://doi.org/10.1007/s12529-019-09775-6
- Soomro, N., & Jalal, S. (2013). Injuries increase the amputee burden at the prosthesis Centre: A 2-year retrospective survey of amputees in a low-income setting. *International Journal of Injury Control and Safety Promotion*, 20(1), 94–98. https://doi. org/10.1080/17457300.2012.686044
- Stork, R., Martone, M., Osterman, P., Savage, T. A., & Mukherjee, D. (2018). The family caregiving dilemma. *Physi*cal Medicine & Rehabilitation, 10(1), 90–96. https://doi.org/10. 1016/j.pmrj.2017.12.001

- Tsoulou, V., Karamolegou, E., Kourakos, M., Vasilopoulos, G., & Polikandrioti, M. (2019). Association of state and trait anxiety between patients who had undergone traumatic amputation and their family caregivers. *The International Journal of Lower Extremity Wounds*, 18(2), 176–185. https://doi.org/10.1177/1534734619848580
- Valer, D. B., Aires, M., Fengler, F. L., & Paskulin, L. M. G. (2015). Adaptation and validation of the caregiver burden inventory for use with caregivers of elderly individuals. *Revista Latino-Americana de Enfermagem*, 23(1), 130–138. https://doi. org/10.1590/0104-1169.3357.2534
- Vitaliano, P. P., Ustundag, O., & Borson, S. (2016). Objective and subjective cognitive problems among caregivers and matched non-caregivers. *The Gerontologist*, 57(4), 637–647. https://doi.org/10.1093/geront/gnv690
- Washio, M., Toyoshima, Y., Miyabayashi, I., & Arai, Y. (2019). Burden among family caregivers of older people who need Care in Japan. In M. Washio & I. Miyabayashi (Eds.), *Health issues and care system for the elderly* (pp. 17–32). Singapore: Springer. https://doi.org/10.1007/978-981-13-1762-0_2
- Ware, J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). SF-36 health survey: Manual and interpretation guide. Boston: MA The Health Institute, New England Medical Center.
- Yu, H., Li, L., Liu, C., Huang, W., Zhou, J., Fu, W., ... Wu, Q. (2017). Factors associated with the quality of life of family caregivers for leukemia patients in China. *Health and Quality of Life Outcomes*, 15(1), 55. https://doi.org/10.1186/s12955-017-0628-6
- Zheng, Y., Ley, S. H., & Hu, F. B. (2018). Global aetiology and epidemiology of type 2 diabetes mellitus and its complications. *Nature Reviews Endocrinology*, 14(2), 88–98. https://doi.org/ 10.1038/nrendo.2017.151