

# Determinants of burden and quality of life of informal caregivers of individuals with dementia

Mário Miguel Rosa (✉ [mrosa@medicina.ulisboa.pt](mailto:mrosa@medicina.ulisboa.pt))

Universidade de Lisboa

Patrícia Lindeza

Instituto de Saúde Ambiental (ISAMB), Universidade de Lisboa

Lara Ferreira

Centre for Health Studies and Research of the University of Coimbra

Manuela Guerreiro

Universidade de Lisboa

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## Research Article

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# Abstract

*Introduction:* Little is known about the impact of dementia in the quality of life (QoL) and overall burden of informal caregivers. The aim of the study is to assess the QoL and burden of informal caregivers of PwD and identify its associated factors.

*Methods:* Descriptive cross-sectional design with a non-probabilistic and purposive sample of 187 caregivers of PwD. Data collection included the EQ-5D-3L and the Informal Caregiver Burden Assessment Questionnaire (QASCI). Multivariate linear models were estimated to identify determinants of informal caregivers QoL and burden.

*Results:* The results show that the QoL of the informal caregivers was low, and overall burden was found to be moderate. Different explanatory factors were identified for QoL and burden, however, in both cases the familiar relationship and PwD pain/discomfort were identified as potential explanatory factors.

*Conclusions:* Our findings highlight that multiple factors of the informal caregiver and the PwD were correlated with QoL and burden suggesting that the informal care occurs in a complex environment determined by dyads characteristics that together can result in high or low impact for caregiver's personal life. It is crucial to include informal caregivers as a priority topic regarding dementia health policies, being essential to promote their wellbeing and prevent serious burden, which might also lead to better care and improved QoL for the PwD as well.

## 1. Introduction

Worldwide, more than 35 million people live with dementia (PwD) and this is predicted to increase to 115 million by 2050, representing 18,8 million of dementia cases in Europe (Alzheimer Europe, 2019; Prince et al., 2013). In the last years, according to World Health Organization (WHO) reports, dementia should be regarded as a global public health priority due to its fast-growing worldwide that will lead to a dramatic increase in its prevalence in the next decades, remaining a major public health faced by health-care and social-care systems worldwide (Banerjee, 2013; Orellana, 2003; Shah et al., 2016; World Health Organization, 2012). Dementia affects not only the individuals with the condition, who gradually lose their abilities and autonomy with serious impact on quality of life (QoL), as well as their relatives, that care for them as their dependency increases, as informal caregivers (Brodaty & Green, 2002; Livingston et al., 2017; Wortmann, 2012).

Informal care is commonly known as unpaid care or family care and constitute a significant share of the total long-term care provision in European countries, predicted as over than 80%, depending on the countries (Hoffmann & Rodrigues, 2010). A large amount of the informal caregivers are often women at retirement age, either providing care to a partner, parents or parents-in-law (Colombo et al., 2011). Typically, caregivers provide assistance to patients in their own home, helping patients in activities of daily living (ADLs) such as walking, toileting, bathing; in instrumental activities of daily living (IADLs) like

managing finance, transportation, shopping, meal preparation, communication and managing medications, but also providing emotional support (OECD, 2017).

Dementia has a considerable negative impact on patients' family members, placing physical, emotional, and financial strains on these non-professional caregivers (World Health Organization, 2012). As a result, informal caregivers of adults with dementia experience high distress and burden leading to prolonged consequences of poor physical, emotional health and burnout (Gérain & Zech, 2019; Srivastava et al., 2016). Helping their relative's dementia with daily activities systematically along time is wearing and overwhelming (Gérain & Zech, 2019). According to the World Alzheimer Report (A. International., 2019), half of the dementia patients' caregivers tend to experience health problems, 49% modify their professional life and 62% have their social life affected because of the caring obligations. Additionally, emotions involved in caregiving (such as guilt, resentment, anticipated loss, sadness and loneliness) are often very difficult to cope with. On the other hand, previous studies demonstrated that despite the negative aspects of informal caregiving, it is emotionally rewarding, bringing up self-esteem and sense of worthiness and life mission (ADI, 2019; Gérain & Zech, 2019; Givens et al., 2012; Lindeza et al., 2020). Despite the positive aspects, being an informal caregivers mean, in many cases, combining the care with labor responsibilities. As a result, some caregivers quit their jobs to be able to respond the patient needs, and this decision may be detrimental in their life as it compromises future employability (OECD, 2011).

The relevance of informal care is likely to become even higher in the future due to demographic change leading to the favoring community care options over institutionalization where possible, with informal care being a substitute for formal care services until once a certain degree of dementia severity is reached. (Riedel, 2012). At some point, health support becomes harder to be provided by the family and institutionalization is commonly considered (Bremer et al., 2017). Informal care is a cost-effective alternative and a well-being alternative for patients who may remain at their homes. So in several countries across Europe, different public supports have been offered to informal care as a form of incentive and support to these families (OECD, 2011).

Since caregiving varies from case to case, some studies discuss how sociodemographic factors, such as gender, the nature of relationships with the care recipient or the age of caregiver affect the caregiving role (Denning et al., 2012; Garand et al., 2005; Lin et al., 2012). Available studies from Portugal or including Portuguese data focus mainly on the perspective of formal caregivers and do not allow a good and fully characterization of the Portuguese context of dementia informal caregiving (Barbosa, A., Cruz, J., Figueiredo, D., Marques, A. & Sousa, 2011; Kerpershoek et al., 2018). A study with Portuguese informal caregivers for relatives with Alzheimer's disease (AD) concluded that they the caregivers suffer important repercussions in their lives, especially physical overload and emotional changes that compromise their well-being as well as that of the patient (Pereira, 2007).

Despite the increasing development in the research of degenerative dementias, there is still a current worldwide mismatch between current knowledge, the lack of awareness and in-depth understanding of dementia, as well as the impact of informal care in caregiver's life.

Due to the lack of studies and knowledge on informal caregivers of PwD in Portugal, the main objective of this study was to assess the QoL and physical, emotional and social burden of informal caregivers of PwD, in a Portuguese sample of informal caregivers. Moreover, we also aimed to explore the relationship between informal caregivers QoL and their relatives' demographics, disease characteristics, functional and cognitive status and daily context (data collected in our previous study: *"Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample"* (manuscript submitted to *Ageing & Society*, June 2021). According to our knowledge, this is one in few studies focusing informal caregivers of PwD QoL associated factors (including PwD characteristics) in Portugal. Results will be extremely useful, as community service for dementia in Portugal to describe the unknown scenario of the impact of dementia in informal caregivers and its associated factors.

## 2. Methods

### 2.1. Design

This study followed a descriptive cross-sectional design using a non-probabilistic and purposive sample of informal caregivers. The participants were invited to a unique semi-structured face-to-face interview of 30–40 minutes with the aim of answer questions about themselves and their relative with dementia (results for PwD are described in *"Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample"*(manuscript submitted to *Ageing & Society*, June 2021). The questionnaire applied to informal caregivers of PwD included data about caregivers QoL and physical, emotional and social burden.

### 2.2. Participants and recruitment process

The recruitment process applied in the present study is the same of *"Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample"*(manuscript submitted to *Ageing & Society*, June 2021). Briefly, a short presentation of the study, written information including the details of the study (goals and procedures) and the informed consent form was given to the invited participants. Informal caregivers were invited to participate from two different settings: upon a neurology appointment at the Hospital de Santa Maria of Centro Hospitalar Universitário Lisboa Norte E.P.E (reference university hospital for dementia) and after a brief presentation of the project on a recognized National Care Institution and Dementia-related Public Institutions and data collection occurred between January and December 2019.

Informal caregivers were considered the closest family member of the PwD (clinical diagnosis of dementia, without the need for specification of the type of dementia), not being defined any minimal hours of care or the need to co-habitation with the PwD. The sample was constructed with the intention of covering a wide range of scenarios (i.e., including, caregivers of relatives in early and in advanced stages of dementia, participants with different ages, different time of diagnosis, different family relationships as spouse or daughter, different formal care resources utilization).

## 2.3. Independent review board approval and consent to participate

### Ethical approval

was obtained from the competent Ethics Committee (Centro Académico de Medicina de Lisboa - CAML) in October 2018. Participants were informed verbally, and the written consent form was signed. The participation was consented and voluntary. The participants knew that they could withdraw at any time without any prejudice. To ensure participant's anonymity, a code number was assigned for each participant. Information having the potential to allow the identification of any participant was withdrawn from the questionnaires. Demographic elements were only used as a context for interpretation the qualitative data and for describing (in an aggregated form) the sample.

## 2.4. Tools

To study informal caregivers HRQoL and burden we used the EQ-5D three level (EQ-5D-3L) and the Informal Caregiver Burden Assessment Questionnaire (QASCI). The other questionnaires applied to informal caregivers were already described and presented in *"Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample"* (manuscript submitted to *Ageing & Society*, June 2021)., namely: sociodemographic data about the dyad, PwD EQ-5D-3L, the Quality of Life in Alzheimer's Disease (QoL-AD), Blessed Dementia Rating Scale (BDRS) and the Mini-Mental State Examination (MMSE) of PwD.

### *Informal Caregivers QoL*

#### EQ-5D-3L

The EQ-5D-3L is a generic HRQoL instrument widely used, in which respondents evaluate their (or proxy) health state "at the moment" and increasingly used in patient with neurological disorders (Jönsson et al., 2006; Naglie et al., 2006). The short descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, with three levels of severity per dimension: "no problems", "some problems" or "extreme problems" (EuroQol Research Foundation, 2018). The respondent is asked to indicate his/her (or proxy) health state by choosing the most appropriate response level of each of the five dimensions. This generates a five-digit number; thus 243 possible health states may be obtained. This health state is transformed through a value set into a single summary index value (index, ranging from - 1 to + 1) that summarizes the individual's health state and can be used in economic evaluations of healthcare interventions (EuroQol Research Foundation, 2018). The second part of the EQ-5D-3L consists of a visual analogue scale (VAS), the EQ-VAS, that records the rated health on a vertical VAS with a range of 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-5D-3L has been developed to describe and value health in different diseases (EuroQol Research Foundation, 2018). Studies such as Bryan et al., 2005, Diaz-Redondo et al., 2014 are examples of proxy

versions available for populations in which self-completion is not possible (EuroQol Research Foundation, 2018); thus we have used the EQ-5D-3L patient-by-proxy assessment.

In this study, we have used the Portuguese version of the EQ-5D-3L (P. L. Ferreira et al., 2013). The EQ-5D-3L index was calculated using the Portuguese tariffs (L. Ferreira et al., 2014).

### *Informal Caregiver Burden Assessment Questionnaire (QASCI)*

The QASCI is an instrument built to assess the physical, emotional and social burden of the informal caregiver which consists of 32 items comprising seven dimensions: Emotional burden (4 items- 4 to 20 points), Implications for personal life (11 items- 11 to 55 points); Financial burden (two items- 2 items- 2 to 10 points); Reactions to demands (five items-5 to 25 points); Perception of efficacy and control mechanisms (three items- 3 to 15 points); Family support (two items- 2 to 10 points); Satisfaction with the role and the family member (five items- 5 to 25 points). Each item is assessed by an ordinal frequency scale ranging from one to five answer categories: “No/Never”, “Rarely”, “Sometimes”, “Almost always”, “Always”. The final score results from the sum of the answers obtained for the 32 items (possible range from 32 to 160) related to each field, divided by the total number of domains or by the mean of items (range from one to five) after reversal of scores in the items of the three positive dimensions. Higher values correspond to situations with higher relevance or higher burden. In order for the final scores of each dimension to present homogeneous and comparable values, all items were added together, and a formula was applied to them to promote a uniform and comparable reading of what each factor (values between 0 and 100). Although there are no established cut-off points (since they are under study), the author of this instrument, Professor Teresa Martins, suggests that the value of 0 indicates no overload; 10 to 25 suggests a slight overload; from 25 to 50 corresponds to a moderate overload; 50 to 75 indicates a severe overload and a value greater than 75 indicates an extremely severe overload). This instrument is validated to the Portuguese population (Martins et al., 2003, 2004) and has already been applied to informal caregivers of older persons with dementia (Pereira, 2007).

## **2.5. Data analysis**

Data analysis was performed using IBM SPSS Statistics 26. The EQ-5D-3L index score and visual analog scale (VAS), were presented according to age groups and caregiver genders to allow a comparison with the Portuguese population norms (L. N. Ferreira et al., 2014). The QASCI score were presented according to its seven dimensions. Descriptive analysis was also carried out using the EQ-5D-3L and QASCI instruments to describe the informal caregivers HRQoL by its personal life and characteristics and PwD related factors. The acceptability of EQ-5D-3L was estimated through score ranges (observed vs possible), closeness of means to medians, floor and ceiling effects (less than 15% of responses accumulated at minimum or maximum values) and skewness (between - 1 and + 1) (Hays et al., 1993).

Correlations between the EQ-5D-3L, QASCI scores, caregivers' personal characteristics and PwD scores obtained in *“Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample”*(manuscript submitted to *Ageing & Society*, June 2021). were evaluated using

Spearman's rank correlation coefficient (for EQ-5D-3L) and Pearson Coefficient (for QASCI). Correlations were classified in three categories: weak ( $p/rh0 < 0.3$ ); moderate ( $0.3 < p/rh0 < 0.5$ ); and strong ( $p/rh0 > 0.5$ ) (Cohen, 1977). P-value  $< 0.05$  was considered statistically significant. We hypothesized that the EQ-5D-3L and QASCI score would correlate at a moderate or high level with and PwD BDRS, EQ-5D-3L, QoL-AD and MMSE (Juniper et al., 1996). Additionally, the correlation with time of care was also analyzed with the hypothesis of being moderately correlated to EQ-5D-3L and QASCI scores and that both instruments correlated with BDRS score or domains.

In addition, differences between age groups were analyzed based on non-parametric tests because the EQ-5D-3L index do not follow a normal distribution. The Mann–Whitney  $U$  (i.e., two groups, such as diagnosis) and Kruskal–Wallis  $H$  (i.e., more than two groups) tests were the most appropriate in this context, followed by Bonferroni correction.

Based on the significant correlations identified between the EQ-5D-3L and QASCI with the sociodemographic variables and the instruments applied to PwD in *“Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample”* (manuscript submitted to *Ageing & Society*, June 2021), multivariate linear regression models were used for identifying the factors that can be potentially associated with informal caregivers HRQoL (model 1) and burden (model 2). The overall fit of the models was assessed, and the existence of multicollinearity and heteroscedasticity was tested.

## 3. Results

### 3.1 Participants

One hundred eighty-seven dyads informal caregivers were part of this study, together with their relative with dementia in included in *“Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample”* (manuscript submitted to *Ageing & Society*, June 2021). All the sociodemographic data of included caregivers and PwD is presented in Table 1 and Table 2, respectively, of *“Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample”* (manuscript submitted to *Ageing & Society*, June 2021).

Briefly, the informal caregivers were family members of a PwD (32 wife's, 29 husbands, 70 daughters, 38 sons, 6 sisters and 12 were other family members) and the mean age was 61 years old. Of the caregivers, 92.5% were living with their relative with dementia and seventy-five caregivers had a professional occupation (36.4% were in working in full-time work and 3.7% in part-time). The PwD were mostly female (74.3%), the mean age was 82 years old, with dementia diagnosis from 6.6 years (ranged from 1 and 20 years). The PwD scores obtained in *“Quality of life and functional ability of older adults living with dementia: outcomes of a Portuguese sample”* (manuscript submitted to *Ageing & Society*, June 2021), were in mean  $-0.005 \pm 0.31$  ( $-0.536$ - $0.766$ ), indicating that PwD had complications in multiple domains of EQ-5D-3L,  $36.9 \pm 1.4$  (varying from 5 to 90) for EQ-VAS,  $19.5 \pm 4.0$  (15.5-23.5) for QoL-AD score,  $15.8 \pm 4.8$  (11.0 to 20.6) to BDRS score and  $16.0 \pm 5.5$  (10.5 to 21.5) for MMSE.

## 3.2 Quality of life

The frequency distributions for the EQ-5D-3L dimensions, as well as the means of EQ-5D-3L/EQ-VAS for the overall sample and by age group are presented in Table 1. Regarding the EQ-5D-3L index, the mean was  $0.375 \pm 0.28$  (-1.11-1.00), indicating that the informal caregivers had complications usually in two or three domains of EQ-5D-3L. According to L. Ferreira et al., 2014, the EQ-5D-3L tariffs for the Portuguese population varied between -0.536 (worst health state) and 1 (best health state). In our study, the minimum obtained for EQ-5D-3L index was the value of -1.112, revealing a lower minimal value (revealing worst states of health) and a lower mean value, in comparison to the Portuguese population norms ( $0.375 \pm 0.28$  vs  $0.758$  (SD not shown), respectively) (L. N. Ferreira et al., 2014). Despite the low QoL of these caregivers, there were some cases (six cases, corresponding to 3.2%) reaching a maximum of 1 (the best health status) in the EQ-5D-3L index (“no problems” in all domains). Thus, one of the main limitations of the EQ-5D-3L regarding the ceiling effect, seen in this sample, in 3.2% of the cases and 2.7% in the EQ-VAS (value of 100). These six caregivers were a wife (85 years old), two daughters (23 and 43 years old), two sons (52 and 55 years old) and a grandchild (42 years old), the EQ-VAS varied from 55 to 90 and the time since PwD diagnosis was mostly less than 4 years, with exception to two cases where it reached 7 and 16 years. The EQ-VAS mean considering all cases was  $60.7 \pm 19.7$  (varying from 10 to 100), indicating that there were cases of very bad QoL related to extreme problems in multiple domains (probably informal caregivers with multiple health conditions, or caring for PwD in advanced stages), and some mild cases (caregivers of PwD in their initial phases, younger caregivers, or caregivers that dedicated less hours in caring tasks). As well as in the EQ-5D-3L, the mean value found for EQ-VAS was lower when comparing to Portuguese population norms ( $60.7 \pm 19.7$  vs  $74.9$  (SD not shown), respectively) (L. N. Ferreira et al., 2014).

In our study, there were statistical differences regarding both EQ-5D-3L and EQ-VAS between age groups. In detail, for the EQ-5D-3L index, there were differences between the group of caregivers aged 70 or more years and the group aged 30-49 years old ( $p=0.002$ ), and between 50-59 years old and 30-49 years old ( $p=0.01$ ), with the EQ-5D-3L mean value being higher caregivers aged 30-49 years old, so, younger caregivers. Additionally, the older group (aged 70 or more years old), differed from 30-49 ( $p=0.001$ ) and 50-59 years old groups ( $p=0.02$ ) for the EQ-VAS score, presenting the lowest value. Also, there were differences by caregivers' gender, with EQ-5D-3L being most of the times better in men's comparatively to woman's (with exception to 18-29 years old group), with this difference being statistically significant for the caregivers aged 50-59 years old ( $p<0.01$ ).

Regarding all the cases (Table 1), the dimensions such as mobility and ability to do self-care tasks reveal mostly “no problems” (96.8% and 93.6%, respectively). In the dimension of usual activities, informal caregivers had mostly “some problems” (41.7%) and “no problems” in 35.3%. The dimensions that gathered a higher number of cases with “extreme problems” were pain/discomfort and anxiety/depression, (42.8% and 59.4% respectively), while 34.8% and 29.4% had “some problems” and 22.5% and 11.2% had “no problems” regarding these dimensions. In detail, it is possible to see in Table 1 that despite the group age, caregiver's mobility was almost not compromised. Some of the caregivers

aged 70 or more years presented some or extreme problems regarding self-care tasks, while the difficulties in usual activities (i.e., work, housework, family activities) started sooner, in the group aged 30-49 and aggravated in older ages. Finally, in the last two domains of EQ-5D-3L (pain/discomfort and anxiety/depression), the younger caregivers (18-29 years old), present almost “no problems”, while the remain groups revealed mostly “extreme problems”, mainly in the groups of 50-69 and more than 70 years old, and in anxiety/depression dimension (Table 1).

The comparisons between the results obtained for QoL in our study and the overall Portuguese population (L. N. Ferreira et al., 2014), showed that, despites the age group and the gender, the informal caregivers had lower QoL than the non-caregivers, at same age: 18-29 years old ( $0.59 \pm 0.36$  vs  $0.86$  (SD not shown)), 30-49 years old ( $0.51 \pm 0.23$  vs  $0.82$  (SD not shown)), 50-69 years old ( $0.35 \pm 0.27$  vs  $0.69$  (SD not shown)), 70 or more years old ( $0.29 \pm 0.29$  vs  $0.60$  (SD not shown)). The same occurred for the EQ-VAS score: 18-29 years old ( $70 \pm 19$  vs  $84.3$  (SD not shown)), 30-49 years old ( $68 \pm 20$  vs  $79.8$  (SD not shown)), 50-69 years old ( $62 \pm 19$  vs  $68.5$  (SD not shown)), 70 or more years old ( $53 \pm 19$  vs  $62.1$  (SD not shown)).

< Insert Table 1 about here >

### ***3.3 Informal caregiver burden***

The QASCI univariate values are presented in Table 2. The overall score in our study ranged between 48 to 155. The mean value was  $99.6 \pm 17.8$ , corresponding to 53 (when the values are normalized to 0-100) meaning moderate burden. Regarding the seven dimensions of QASCI, the domain of financial burden was the one that reached high levels ( $73 \pm 26$ ), revealing an extremely severe overload situation. The followed dimensions with higher scores were the emotional burden ( $66 \pm 21$ ) and implications in personal life ( $62 \pm 21$ ), meaning moderate burden. The remain four dimensions of QASCI presented lower values meaning slight burden regarding the reactions to demands, perception of efficacy and control mechanism, family support and satisfaction with caregiver role and their relative with dementia. In sum, the included caregivers presented high levels of burden regarding financial, emotional and personal life issues.

< Insert Table 2 about here >

### ***3.4 Impact of dementia according to informal caregivers and PwD related factors***

Briefly, the results of the instruments used in this study are presented in Table 3 according to the caregiver's characteristics (familiar relationship with the PwD, professional situation, educational level, parenthood, years of care, hours of care). This table also integrates the characteristics of the PwD (daily occupation and educational level). Regarding the familiar relationship, the wife's were the ones with lower QoL and higher burden ( $0.232 \pm 0.24$  EQ-5D-3L,  $50.9 \pm 18.5$  EQ-VAS,  $57 \pm 15$  QASCI), followed by the

daughters ( $0.359\pm 0.27$  EQ-5D-3L,  $62.2\pm 19.4$  EQ-VAS,  $53\pm 12$  QASCI). The husbands presented slightly high scores regarding QoL than wife's but experienced lower levels of burden. The sons were the ones with high QoL and less burden. Other familiar relationships (grandchild, daughter-in-law...) presented the highest scores of QoL, however, the QASCI score was as high as the wife's, being higher than daughters, husbands, and sons.

Regarding the professional occupation of the caregivers, the ones that were professional active presented better QoL and less overall burden (slight overload) than the ones that were professionally inactive (moderate overload).

The educational level revealed that for the caregivers that attend school for less or during six years there was no big differences regarding the QoL (by EQ-5D-3L) and burden experienced, however, more years of education revealed more QoL (by EQ-VAS). The caregivers that attended school over 9 years revealed highest levels of EQ-5D-3L than the previous ones, but the lower EQ-VAS score ( $53.7\pm 19.7$ ). Finally, caregivers that had 12 or more years of education revealed high scores of EQ-5D-3L and EQ-VAS, meaning higher QoL than caregivers with lower education. Moreover, the caregivers with more years of education presented lower scores in QASCI score, which means lower burden, still, moderate burden, despite the level of education.

The fact that caregivers had or not children did not affect QoL since the obtained values regarding the EQ-5D-3L index, EQ-VAS and QASCI score were very similar in both situations.

The years of care for the PwD indicated that more years of care corresponded to poor QoL and higher overload to the caregiver. When the duration of care was less than 2 years comparing to 3 years of care, the QoL of life increased ( $0.365\pm 0.31$  EQ-5D-3L,  $66.2\pm 19.7$  EQ-VAS comparing to  $0.531\pm 0.24$ ,  $72.6\pm 16.2$ , respectively). However, the QASCI score was very similar in the two situations, revealing slight overload. The period including four to fifteen years showed similar EQ-5D-3L index values and QASCI scores (moderate burden), but the EQ-VAS was high in when caregivers were caring for ten to fifteen years. Finally, when caring included more than fifteen years, only in nine cases, the EQ-5D-3L index decrease a lot comparatively to the remain situations and the QASCI score was the highest level when considering only the years of care ( $59\pm 10$ ). The same occurred with hours of care, where more hours corresponded to less QoL and higher overload. The impact of hours of care in decreasing QoL and increasing caregiver's burden was noticed when caregivers spend more than five hours in caring tasks, being more evident when the hours of care increased to 7 or ten hours a day. So, the caregivers that were caring for their relatives for more than fifteen years and during more than ten hours a day ( $n=5$ ) were extremely affected in both QoL and overall burden ( $0.05\pm 0.21$  EQ-5D-3L,  $50\pm 12.3$  EQ-VAS and  $67\pm 5$  QASCI score).

Considering the PwD characteristics, the resort to day centers during the week resulted in a slight increased QoL for the caregiver, particularly, in the EQ-VAS, however in both situations caregivers revealed moderate burden ( $56\pm 15$  if PwD visited the day center and  $52\pm 13$  if PwD did not attended to day centers). If the PwD educational level is considered, more years of education resulted in better QoL for the caregivers ( $0.350\pm 0.27$  EQ-5D-3L,  $59.4\pm 20.8$  EQ-VAS in caregivers of PwD that attended less than 6 years

of school, comparing to  $0.411 \pm 0.27$  EQ-5D-3L,  $64.0 \pm 17.7$  EQ-VAS when PwD that attended to school for more than 12 years). The burden of the caregiver was nearly the same in all educational levels, being moderate.

< Insert Table 3 about here >

### ***3.5 Correlations between QoL, overall burden and sociodemographic variables of informal caregiver and their relatives with dementia***

The correlations for EQ-5D-3L and QASCI with each other and with sociodemographic variables of the informal caregivers and their relatives with dementia are presented in Table S1 of supplementary material. As expected, the convergent validity of the EQ-5D-3L index with QASCI score was moderate and negative, ( $r=0.476$ ,  $p<0.01$ ), meaning that the increase of the burden led to low QoL. Regarding the QASCI seven dimensions, only two (emotional burden and implications in personal life) correlated in a moderate negative way with EQ-5D-3L, while the financial burden, and perception of efficacy and control mechanisms showed a weak negative correlation, meaning that burden decreased caregivers QoL. The EQ-VAS showed a strong correlation with EQ-5D-3L ( $r=0.610$ ,  $p<0.01$ ).

In what concerns to informal caregivers' characteristics, the majority of the correlations founded were weak, however age ( $r=0.314$ ,  $p<0.05$ ), educational level ( $r=0.334$ ,  $p<0.01$ ) and hours of care ( $r=0.306$ ,  $p<0.05$ ) showed moderated correlations with QoL. The EQ-5D-3L correlated weakly with the majority of sociodemographic variables of the PwD (gender, age, educational level, EQ-5D-3L, mobility, anxiety/depression, EQ-VAS, QoL-AD, BDRS score and one of the BDRS domains) (see Table S1 of supplementary material).

The QASCI score correlated mainly weakly with the informal caregivers' characteristics, but moderated correlations were founded for hours of care ( $p=0.351$ ,  $p<0.01$ ) and some PwD characteristics such as EQ-5D-3L ( $p=0.363$ ,  $p<0.01$ ), and some of its dimensions (mobility, self-care, pain/discomfort and anxiety/depression (weak correlation) and usual activities (moderate correlation). Contrary to EQ-5D-3L, the QASCI score correlated moderately to QoL-AD score ( $p=0.471$ ,  $p<0.01$ ), BDRS score ( $p=0.401$ ,  $p<0.01$ ) and with the three dimensions of BDRS score (changes in everyday life, changes in habits and changes in personality).

No statistically significant correlations were found for both instruments (EQ-5D-3L and QASCI) with the familiar relationship of daughter and husband, years of PwD diagnosis, PwD attend to day centers and MMSE scores.

# ***Factors potentially associated with caregivers' QoL and overall burden***

The data analysis included linear regression models to identify the factors related to informal caregivers QoL and burden (Table S2 (model 1) and Table S3 (model 2) of supplementary material, respectively).

The model for QoL is well adjusted (F test:  $p < 0.001$ ) and explained about 39% of the observed variance in the value of the dependent variable (EQ-5D-3L score). Results showed inexistence of autocorrelation (Durbin Watson= 1.831), and inexistence of heteroscedasticity (Breusch–Pagan test,  $p > 0.05$ ). The model for overall burden is well adjusted (F test:  $p < 0.001$ ) and explained about 57% of the observed variance in the value of the dependent variable (QASCI score). Results showed inexistence of autocorrelation (Durbin Watson= 2.208), and inexistence of heteroscedasticity (Breusch–Pagan test,  $p > 0.05$ ).

In the first model, regarding informal caregivers QoL, the age of caregiver was statistically associated with changes in EQ-5D-3L index, despite its small effect, ( $B = -0.005$ ,  $p < 0.05$ ). The familiar relationship of the caregiver with the PwD presented statistical differences when comparing husbands/wife's, sons/daughters, brothers/sisters with other family members. Being brother or sister of the PwD resulted in better QoL, followed by being nephew, grandchild or son/daughter-in-law. The husband and wives were the ones where the increase on EQ-5D-3L index was smaller, as well as sons/daughters. Regarding the effect of burden in QoL, two of the QASCI domains were included in this model, with only one being statically associated with EQ-5D-3L index: implication in caregivers' personal life ( $B = -0.49$ ,  $p < 0.05$ ), meaning that the impact of dementia in caregivers life decreased its QoL. The characteristics of the PwD that were statically associated with caregivers EQ-5D-3L index included the age ( $B = -0.005$ ,  $p < 0.05$ ) and the pain/discomfort where the increase of PwD problems and age resulted in decreased caregiver QoL. The caregiver gender and PwD mobility were not statistically associated with changes in EQ-5D-3L score, but the presence of these variables increased the model quality.

In what concerns to the informal caregiver overall burden (model 2, Table S3 of supplementary material), the pain/discomfort felt by caregivers, their familiar relationship with the PwD and professional situation were the caregivers-related factors statistically associated to its burden. In detail, the familiar relationship where the burden was more inflected (by increasing the QASCI score) was the nephew, followed by sons/daughters-in-law, grandchild, husband/wife's, brothers/sisters and finally, the sons/daughters. This demonstrates that there were differences regarding the familiar relationship in caregivers perceived burden. For caregivers, being professional occupied in full or part-time resulted in less increased QASCI score, meaning lower overall burden comparatively to domestic or unemployed caregivers. The PwD characteristics statically associated with informal caregivers' burden were the ability to perform self-care tasks ( $B = 0.084$ ,  $p < 0.001$ ), were more difficulties of the PwD resulted in higher burden, and changes in PwD personality (BDRS domain) ( $B = 0.015$ ,  $p < 0.05$ ). The QoL of the PwD (QoL-AD score), was also statically associated with informal caregivers' burden, despite its low effect ( $B = -0.01$ ,  $p < 0.001$ ).

The caregiver ability to perform daily activities, anxiety/depression, hours of care, educational level and the PwD mobility, pain/discomfort were not statistically associated with changes in QASCI score, but the presence of these variables increased the model quality. A briefly analysis of the effect of these variables showed that more hours of care and higher educational levels of the caregivers were associated to higher burden (Table S3 of supplementary material).

## 4. Discussion

The current study sought to assess the HRQoL and physical, emotional and social burden of informal caregivers of PwD in Portugal, while identifying the dyads characteristics that might be influencing the impact of dementia in caregivers HRQoL. The data provide insights involving informal caregivers and PwD characteristics to better describe the current experience of caring for a PwD. It attempts to fill the gap that involves the lack of knowledge about the impact of this disease in informal caregivers and its relation their own and PwD characteristics, particularly in Portugal.

Informal caregiving can have negative impacts on the physical and psychological health of caregivers, especially due to stress that comes with this responsibility, especially when taking care of people affected by any form of dementia. Informal caregivers are of major importance as the severity of dementia increases due to the compromise of patient's autonomy and requirement of continuous care and supervision that is usually done by family members, mostly wife's or daughters, strengthening that informal care is mostly performed by adult woman's, in accordance with our study (Brodaty & Green, 2002; Brodaty & Hadzi-Pavlovic, 2016; Dening et al., 2012; Moore et al., 2001; Prince et al., 2004). In fact, women face higher risks of serving as informal caregivers for AD patients (6.8% vs. 4.0%) comparing to men's, as well as having AD itself (15.5% vs. 13.1%) (Yang & Levey, 2015).

Regarding the QoL of the informal caregivers included in our study, the results of EQ-5D-3L and EQ-VAS were illustrative of a very compromised QoL, where two or three domains of the EQ-5D-3L were affected (mainly the ability to perform usual activities, pain/discomfort, and anxiety/depression). In fact, previous studies reported depression symptoms among dementia informal caregivers (D'Aoust et al., 2015; Karg et al., 2018; Wulff et al., 2020). The domains of ability to perform usual activities and pain/discomfort were also the mostly affected in a recent Spanish study involving informal caregivers of PwD, however the values obtained for the means of EQ-5D-3L and EQ-VAS were extremely higher than the values obtained in our study ( $0.76 \pm 0.22$  mean for the EQ-5D-3L index score and  $66 \pm 13$  mean EQ-VAS, comparing to  $0.37 \pm 0.28$  and  $60.7 \pm 19.7$ , respectively, in our study) (Madruga et al., 2020). In comparison to the Portuguese population norms (L. N. Ferreira et al., 2014), in all age groups and even after the adjustment for caregivers gender, informal caregivers of PwD reported lower QoL than Portuguese non-caregivers. A study performed in Spain including two hundred thirty-seven informal caregivers reported the score of 0.67 (SD not shown) for EQ-5D-3L, far above from the score found in our study (Lopez-Bastida et al., 2006). In the Geras study, that included France, Germany and the UK, the overall mean and standard deviation (SD) of EQ-5D-3L index score of the included AD caregivers was  $0.84 \pm 0.20$  and  $75.1 \pm 17.5$  for the EQ-VAS (Reed et al., 2017), once again greater than the scores obtained in our study. When comparing

our results with caregivers of patients with other health problems than dementia, for example, caregivers of autistic children, the results that we obtained for QoL were also extremely lower ( $0.82 \pm 0.16$  mean for the EQ-5D-3L index score and  $76 \pm 16$  mean EQ-VAS in caregivers of autistic children, comparing to  $0.37 \pm 0.28$  for the EQ-5D-3L index score and  $60.7 \pm 19.7$  for the EQ-VAS, in our study) (Khanna et al., 2013).

About physical, emotional and social burden of the informal caregivers, our results indicated severe burden and the most affected dimensions were the financial burden, implications for personal life and emotional burden. In a study performed also in Portugal, that included a rehabilitation program for informal caregivers of people with musculoskeletal injuries (L. M. P. Rodrigues, 2018), the same QASCI dimensions were founded as the most affected, however, contrary to our study, the domain of perception of efficacy and control mechanisms was the key contributor to the overall burden in these caregivers. Considering the global QASCI score, the informal caregivers of people with musculoskeletal injuries experienced lower burden (moderate overload) than the informal caregivers of PwD included in our study (severe overload), both before and after the intervention program (before the intervention:  $44.1 \pm 5.6$  and after the intervention  $37.7 \pm 4.0$ , compared to  $53 \pm 14$  in our study) (L. M. P. Rodrigues, 2018). Another Portuguese study accessed the physical, emotional and social burden of informal caregivers for their elderly relatives that was found to be moderate ( $31.8 \pm 15.4$ ), with implications for personal life and the perception of efficacy and control mechanisms being the domains with higher impact, while the financial burden was the domain with lower impact for this caregivers (Félix, 2008). In a Portuguese including informal caregivers for AD patients, the implications for personal life was the domain with higher punctuation, followed by emotional burden, while the QASCI score was  $43.7 \pm 18.6$ , suggestive of sight burden (Pereira, 2007). Also, in the referred study, the male caregivers also presented lower burden than female caregivers, and older caregivers experienced higher burden that is in accordance with our study, unfortunately this study did not access informal caregivers QoL for comparison (Pereira, 2007).

Considering the global context, our results indicated that informal caregivers and PwD characteristics influence differently the caregivers QoL and experienced burden. In general, caregivers with lower burden reported significantly better perceived health and higher EQ-5D-3L and EQ-VAS mean score than caregivers with higher burden. However, since caregiving varies from case to case, some studies discuss how sociodemographic factors (such as gender and age of caregivers), as well the nature of relationships with the care recipient, affect the caregiving role (Kwak et al., 2012; Lin et al., 2012). In accordance with previous studies, in our study the included female caregivers reported having lower QoL and elevated burden than male caregivers, in detail, wife's and daughters in comparison to husbands and sons (Lin et al., 2012). Contrarily to Kwak et al., 2012, in our study the sons and daughters did not experience the stress and burden process similarly, since sons were the ones among all the familiar relationships with lower QASCI scores and higher EQ-5D-3L, meaning less physical, emotional and social burden and better QoL. In fact, other familiar relationships such as nephew, grandchild, or sons/daughters-in-law, presented lower QoL scores and higher levels of burden than informal caregivers that were sons of the PwD. This fact is possible related to a more distant familiar relationship in these situations that resulted in a lesser understanding of the obligation to care for that PwD particularly, since it was not their parent or companion, leading to a higher impact in these cases. With that being said, studies including other

familiar relationships besides the parents, sons/daughters and brothers/sisters, must be considered as important as the most directed family members.

Another widely explored theme in the literature was also illustrated in our study: the financial burden that dementia brought to the family and caregivers (Åkerborg et al., 2016; Kronborg Andersen et al., 2003; Moore et al., 2001). The high costs of dementia make this one of the most expensive diseases for families, due to the need of a full-time caregiver that might involve professional changes (reduction of working hours/quit jobs), and consequently, lower financial income. However, despite the severe financial burden present in our study, that is in accordance with previous studies, the professional occupation of the informal caregivers revealed better QoL and lower overall burden suggesting that it worked as a relief, a free time from the care tasks and obviously a higher familiar income (Åkerborg et al., 2016; Kronborg Andersen et al., 2003; Moore et al., 2001). Contrarily to what was found by Karg et al., 2018, where higher levels of QoL occurred in unemployed caregivers suggesting that work played an important role in the development of stress, in our study, having a job seemed to have the exactly opposite effect. Of the included caregivers in our study, 40% were professional active and this is probably related with the retirement age (66.5 years old, in Portugal), the lack of income due to low remunerations in the Portuguese work community and the almost inexistence of financial support for informal caregivers (C. F. Rodrigues & Andrade, 2014; Santana, 2002). Despite the approval of the Informal Caregiver Status in Portugal from almost two years, this support measure was described as a relatively low financial support and not fully inclusive or sufficiently disseminated in the community ([www.deco.proteste.pt](http://www.deco.proteste.pt), published in D&D março/abril 2021). It is estimated that within the EU, between 50 and 100 million people provide care to people with functional limitation (usually unpaid). As a result, these caregivers usually face a higher chance of poverty, an increased risk of unhealthy behaviours and a 20% higher prevalence of mental health problems (Eurocarers, 2017).

The educational levels of caregivers demonstrated that more years of education lead to better QoL and less overall burden, especially when caregivers attend school for more than 12 years. Interestingly, caregivers that attended school for 9 years were the ones with high QASCI scores. The educational levels of the PwD revealed that caregivers for PwD that attended less than 6 years of school reported poor QoL in comparison to the remain caregivers, however, in all cases, the burden experienced was moderate.

Regarding the years of care, caring for PwD less than 2 until 15 years did not change EQ-5D-3L index score, with the differences being more evident in the EQ-VAS, that decreased as years of care increased. About the burden, the increase of years of care resulted in higher burden for the informal caregivers. However, in the group of caregivers that were caring for 2 to 3 years, a different comportment was found, since they were the ones with higher EQ-5D-3L, EQ-VAS and lower QASCI scores. This fact must could possibly be related to some transitional relief of the PwD symptoms or some external factors of the caregiver life, deserving further investigation. The increase of hours of care resulted, as expected, in higher burden and less QoL for the informal caregivers, due to the all the physical and emotional environment involved. The daily occupation of the PwD, by attending day centers during the week did not changed the QoL and burden of informal caregiving.

As well as in previous studies (Karg et al., 2018; Madruga et al., 2020), the QoL and burden of the informal caregiver were founded to be correlated also in our results. In addition, the dimensions of QASCI that were strongly correlated with EQ-5D-3L were emotional burden and implications in personal life, indicating a deeply involvement of personal and emotional issues related to caregiving. Concerning the PwD characteristics, weak/moderate correlations with the caregiver QoL (PwD EQ-5D-3L, PwD EQ-VAS, age, educational level, mobility, anxiety/depression, BDRS score, changes in PwD habits), however a higher number of correlations were founded between PwD characteristics and the informal caregiver burden (QASCI score). Particularly, QASCI score correlated moderately with hours of care, caregivers QoL, caregiver's ability to perform usual activities, pain/discomfort, anxiety/depression, PwD QoL, and, most important, PwD functional ability (BDRS score), indicating that the functional ability of the patient had higher effect on burden than QoL of the caregivers.

In addition, the results of the multiple analysis showed that different explanatory variables were related to informal caregivers QoL and physical, emotional and social burden. The only explanatory variables that were common in the two models were the familiar relationship with the PwD and PwD pain/discomfort. The model for EQ-5D-3L included besides the previous variables, the caregiver age and gender, as well as the emotional burden and implications for personal life (from QASCI). While the model for overall burden included from the caregiver (the ability to perform activities of daily living, pain/discomfort, educational level and professional situation), and from the PwD (the ability to perform self-care tasks, changes in daily habits, changes in personality and QoL). In sum, there was a strong association between higher levels of caregivers QoL in younger caregivers, daughters or sons, with lower implications in personal life, caring for younger PwD with less pain and discomfort; and lower overall burden in daughter/sons with less pain/discomfort problems, professional active, caring for PwD with less problems in performing self-care tasks, less changes in personality (behaviour problems) and with better QoL.

In Portugal, one remarkable positive aspect regarding informal caregiving is the existence of training programs, however, its lack of dissemination in the community is probably compromising their results (Lillo-Crespo et al., 2018). So, to better reach the target these programs should probably address specifically the informal caregiver of PwD in a more easily and direct way.

A follow-up study including an intervention focusing informal caregivers needs (increasing free time to personal life issues, controlling emotional burden and pain/discomfort) and PwD needs (by promoting mobility and decreasing pain/discomfort and control the changes in personality), with timely evaluations of both informal caregivers and PwD QoL, is of major interest to understand the best methods to reduce the physical, emotional and social burden associated to informal care for PwD, while increasing the dyad QoL.

This study highlights that QoL of informal caregivers of PwD in Portugal is lower when compared to other European countries and higher if compared to other diseases. This is an important topic, deserving more attention due its tremendous impact in family members and in PwD himself. The informal caregivers of PwD are still forgotten in research studies and health policies, which result in a deeply unknowledge of

the holistic experience and impact of caring for a relative with dementia; however, we cannot afford to be inactive regarding this topic any longer, especially with the results obtained in our study. It is urgent to address possible interventions intended to mitigate the impact of dementia in informal caregivers QoL and overload, and due to the complexity of factors involved, an integrated community response is necessary involving both PwD/caregivers needs. Additionally, this study high the need of future research focusing informal caregivers QoL and burden, since the choice of being an informal caregiver for a relative with dementia must not be synonym of physical, emotional, and social burden and decreased QoL.

## 5. Strengths And Limitations

The strength of this study is the description of the sociodemographic and clinical data on QoL and physical, emotional and social burden of informal caregivers living in Portugal that was deeply unknown. As far as we are aware, this is the first Portuguese study to collect such information together, while describing data on PwD as well. Another strength is related to the diversity of the sample characteristics, including informal caregivers of PwD at different stages of the disease, different ages and different living situations, as well as diverse familiar relationships, professional status, and education levels. Additionally, the recruitment of participant included not only the hospital environment, but also, other health care facilities and Portuguese Alzheimer's Associations.

The main limitations of this study were: a) the sample was a non-random sample, that focused mainly on single urban area of Portugal; however, as previously mentioned, the sample characteristics allowed to cover different scenarios to be as much representative of the phenomenon as possible. b) lack of dementia differential diagnosis clinical confirmation.

Similar to the majority of other studies in this field, our data are cross-sectional rather than longitudinal, and thus, causal conclusions need to be drawn with caution. Results from longitudinal data would be necessary to establish a more comprehensive picture of the impact of caregiving on informal caregivers QoL and burden. Finally, it must be noted that all data was obtained using self-report instruments, which constitutes a potential source of biases.

## 6. Conclusion

The findings of the present study show that the informal caregivers of PwD had low quality of life, their ability to perform usual activities was compromised, and they suffered from pain/discomfort and anxiety/depression and moderate physical, emotional and social burden (due to financial and emotional burden, allied to the implications of caregiving for their personal life's).

In line with previous literature, the results of the current study showed that caregiving for a PwD is associated with greater objective (i.e., gender, age, educational level, professional situation, PwD QoL and physical impairment) and subjective strain (i.e., familiar relationship, implications for personal life,

emotional issues), combined with greater burden scores and poor QoL. The present study provides valuable insight into the differences between the associated factors with QoL and burden of the informal caregiver, while identifying the source of these factors (informal caregivers, PwD related factors, or both).

## **Declarations**

### **Ethics approval and consent to participate**

All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Participants voluntarily enrolled in the study. Written consent forms were available and each participant provided informed consent. This study was approved by the competent Ethics Committee (Centro Académico de Medicina de Lisboa - CAML) in October 2018.

### **Consent for publication**

Not applicable.

### **Availability of supporting data**

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

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### **Author’s contributions**

PL recruited and invited the participants. PL created the database. PL and LF treated the data. All authors were responsible for the study conception, design, drafting and reviews the manuscript. MMR and MG supervised the study.

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## Tables

Table 1

Frequency distributions by EQ-5D-3L dimensions and means of EQ-5D-3L/EQ-VAS for the overall sample and by age group

	18-28	30-49	50-69	70+	All cases
	(n=3)	(n=37)	(n=90)	(n=57)	(n=187)
<b>Mobility</b>					
No problems	3	37	89	52	181 (96.8)
Some problems	0	0	0	5	5 (2.7)
Extreme problems	0	0	1	0	1 (0.5)
<b>Self-care</b>					
No problems	3	36	87	49	175 (93.6)
Some problems	0	1	3	8	12 (6.4)
Extreme problems	0	0	0	9	0 (0)
<b>Usual activities</b>					
No problems	3	20	33	10	66 (35.3)
Some problems	0	14	37	27	78 (41.7)
Extreme problems	0	3	20	20	43 (23)
<b>Pain/discomfort</b>					
No problems	1	11	18	12	42 (22.5)
Some problems	0	18	27	20	65 (34.8)
Extreme problems	2	8	45	25	80 (42.8)
<b>Anxiety/depression</b>					
No problems	2	7	9	3	21 (11.2)
Some problems	1	13	27	14	55 (29.4)
Extreme problems	0	17	54	40	111 (59.4)
<b>EQ-5D-3L, mean (SD)/**</b>	0.59 (0.36)	<b>0.51 (0.23)</b>	<b>0.35 (0.27)</b>	<b>0.29 (0.29)</b>	0.375 (0.28)
<b>EQ-5D-3L, mean (SD) by gender/***</b>					
Male	0.50	0.54 (0.19)	<b>0.47 (0.27)</b>	0.34 (0.32)	
Female	0.64 (0.49)	0.50 (0.25)	<b>0.29 (0.25)</b>	0.25 (0.26)	
<b>EQ-5D-3L, (min)-(máx)</b>	(0.29)-(1.00)	(0.01)-(1.00)	(-0.08)-(1.00)	(-0.11)-(1.00)	(-1.11)-(1.00)

<b>EQ-VAS, mean (SD)/**</b>	70 (19)	<b>68 (20)</b>	<b>62 (19)</b>	<b>53 (19)</b>	60.7 (19.7)
<b>EQ-VAS, (min)-(máx)</b>	(49)-(85)	(10)-(100)	(20)-(100)	(20)-(90)	(10)-(100)

EQ-5D-3L, EuroQol 5-dimensions 3-level; EQ-VAS, EuroQol Visual Analogue. \*\* $p < 0.05$ , \*\*\* $p < 0.01$  for the EQ-5D-3L index/EQ-VAS. Comparisons of the EQ-5D-3L index and EQ-VAS distributions amongst groups were analyzed with the Kruskal-Wallis  $H$  test followed by Mann-Witney  $U$  test and Bonferroni correction to find the groups where the difference was significant. EQ-5D-3L index by gender was analyzed by Mann-Witney  $U$  test and Bonferroni correction comparing by age groups.

Table. 2

Distribution of responses of the QASCI score by domain, (n=187)

	<b>Min- Max</b>	<b>Mean (SD)</b>	<b>Normalized values (0-1), mean (SD)</b>
Emotional burden, (4 to 20)	5-20	14.6 (3.3)	66 (21)
Implications in personal life, (11 to 55)	14-55	38.3 (9.1)	62 (21)
Financial burden, (2 to 10)	2-10	7.9 (2.1)	73 (26)
Reactions to demands, (5 to 25)	5-23	11.9 (3.6)	35 (30)
Perception of efficacy and control mechanisms, (3 to 15)	4-15	8.5 (1.9)	37 (13)
Family support, (2 to 10)	2-10	5.4 (2.3)	42 (29)
Satisfaction with role and family member, (5 to 25)	5-25	13.1 (3.7)	40 (18)
Caregiver QASCI Score, (32 to 160)	48- 155	99.6 (17.8)	53 (14)

QASCI: Informal Caregiver Burden Assessment Questionnaire. Higher values correspond to situations with higher relevance or higher burden (Martins et al., 2003, 2004). QASCI score range: 32 to 160, converted to 0 to 100 in the normalized values column for easy comparison. The value of 0 correspond to the absence of burden; 1 to 25: slight burden; 25 to 50: moderate burden; 50-75: severe burden and over 75 correspond to extremely severe burden.

Table 3

Distribution of responses of the EQ-5D-3L index score, EQ-VAS and QASCI score according to informal caregivers and PwD related factors, (n=187)

<i>Caregivers' characteristics</i>	EQ-5D-3L index, <i>mean (SD)</i>	EQ-5D-VAS, <i>mean (SD)</i>	QASCI, <i>mean (SD)</i>
<i>Familiar relationship</i>			
Daughter (n=70)	0.359 (0.27)	62.2 (19.4)	53 (12)
Sons (n=38)	0.510 (0.24)	70.0 (16.8)	47 (15)
Wife (n=32)	0.232 (0.24)	50.9 (18.5)	57 (15)
Husband (n=29)	0.359 (0.31)	55.5 (20.1)	52 (10)
Other (n=18)	0.425 (0.31)	61.1 (19.2)	57 (18)
<i>Professional situation</i>			
Professional active (n=75)	0.468 (0.25)	67.8 (19.1)	49 (14)
Professional inactive (n=112)	0.313 (0.28)	55.9 (18.6)	55 (13)
<i>Educational level</i>			
Less than 6-years school (n=41)	0.261 (0.30)	47.5 (18.6)	56 (14)
6-years school (n=15)	0.271 (0.23)	61.4 (15.4)	56 (12)
9-years school (n=23)	0.285 (0.26)	53.7 (19.7)	58 (16)
12-years school (n=33)	0.378 (0.23)	60.0 (14.2)	52 (13)
More than 12 years school (n=75)	0.483 (0.27)	70.3 (18.3)	49 (13)
<i>Parenthood</i>			
Do not have kids (n=35)	0.400 (0.29)	60.2 (17.0)	54 (14)
Have kids (n=151)	0.366 (0.28)	60.8 (20.2)	52 (14)
<i>Years of care</i>			
Less than 2 years (n=39)	0.365 (0.31)	66.2 (19.7)	49 (15)
2 to 3 years (n=30)	0.531 (0.24)	71.6 (16.2)	47 (10)
4 to 5 years (n=40)	0.369 (0.27)	57.3 (21.2)	53 (15)
6 to 9 years (n=47)	0.323 (0.26)	52.1 (17.8)	57 (14)

10 to 15 (n=22)	0.370 (0.27)	63.4 (18.0)	55 (10)
More than 15 years (n=9)	0.182 (0.28)	52.7 (10.6)	59 (10)
<i>Hours of care</i>			
Less than 1 hour (n=48)	0.466 (0.27)	69.2 (18.5)	47 (15)
2 to 4 hours (n=29)	0.463 (0.34)	65.0 (24.6)	50 (13)
5 to 7 hours (n=41)	0.382 (0.23)	61.6 (18.1)	52 (13)
7 to 10 hours (n=22)	0.312 (0.28)	54.0 (17.5)	56 (8)
More than 10 hours (n=47)	0.247 (0.23)	51.6 (14.9)	60 (12)
<i>PwD' characteristics</i>			
<i>Daily occupation</i>			
Visit day center (n=53)	0.395 (0.27)	63.4 (18.7)	56 (15)
Do not visit day center (n=134)	0.366 (0.29)	59.6 (19.9)	52 (13)
<i>Educational level</i>			
Less than 6-years school (n=133)	0.350 (0.27)	59.4 (20.8)	53 (14)
6-years school (n=16)	0.439 (0.32)	63.8 (14.6)	54 (13)
9-years school (n=13)	0.467 (0.35)	63.9 (16.0)	53 (16)
More than 12 years school (n=25)	0.411 (0.27)	64.0 (17.7)	51 (1)
All cases (n=187)	0.375 (0.28)	60.7 (19.7)	53 (14)

EQ-5D-3L, EuroQol 5-dimensions 3-level; EQ-VAS, EuroQol Visual Analogue. QASCI: Informal Caregiver Burden Assessment Questionnaire. Higher values correspond to situations with higher relevance or higher burden (Martins et al., 2003, 2004). QASCI score range: 32 to 160, converted to 0 to 100 in the normalized values column for easy comparison. The value of 0 correspond to the absence of burden; 1 to 25: slight burden; 25 to 50: moderate burden; 50-75: severe burden and over 75 correspond to extremely severe burden.

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