**Título completo do manuscrito:** Mental Health of Caregivers of Elderly Patients: The Impact of Psychotropic Drugs on Quality of Life, Anxiety, Depression, and Stress

**Título resumido do manuscrito:** Mental Health of Caregivers of Elderly

Patients

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#### **Abstract**

Caregiver burden is a common impairment resulting from coping with the physical dependence and mental incapacity of the care subject. This study aimed to assess the self-perception of formal and informal caregivers of elderly patients regarding burden, quality of life, anxiety and depression, stress, and the impact of psychotropic drugs. The questionnaire was disseminated in nursing homes and caregivers' associations. Statistical analysis was carried out using SPSS V.28, with a significance level of  $\alpha$  = 0.05. The questionnaires used were the Sociodemographic Questionnaire, the Depression, Anxiety and Stress Scales, the Zarit Scale, the Satisfaction with Medication Treatment Questionnaire and Quality of Life. The sample consisted mainly of female individuals, with an average age of 52 years, residing in the northern region of the country and mostly married.

Around half of the respondents admitted taking some psychotropic drug, namely selective serotonin reuptake inhibitor(s) or benzodiazepines. Caregivers who use medication report being moderately satisfied with it, and global satisfaction was correlated with the convenience and effectiveness of the medication. Caregivers also demonstrate that being a caregiver has a high impact on their quality of life, and

informal caregivers are those who report a more severe state of depression, anxiety, and stress. The current study highlights the need to assess mental health status and the impact of pharmacotherapy on the quality of life of caregivers of elderly patients.

Keywords: caregivers, elderly, mental health, quality of life, medication

#### Introdution

Mental health is an integral and vital part of everyone's life. It affects the way of thinking, feelling and behave. It underpins the ability to make decisions, to relate and to help shape the world in which we live. Mental health is also a basic human right. And it is essential for personal, community and socio-economic development. It is a part of us all the time, even when we are not thinking about it (Mental Health Report, 2022).

Good mental health is essential for people to lead healthy and productive lives. Living with a mental health problem can have a significant impact on people's lives, contributing to poorer educational outcomes, higher rates of unemployment and poorer physical health (OECD & European Union, 2022).

A wide range of mental health conditions can disrupt an individual's thoughts and feelings, alter behaviour, affect physical health and disrupt relationships, education or livelihood. According to MSD-5, mental disorders (psychiatric or psychological) include changes in thinking, feeling and behaviour. Minor changes that cause significant distress to the person and interfere with their daily life. These disorders include anxiety, depression, schizophrenia, obsessive-compulsive disorder, eating disorders, bipolar disorder and post-traumatic stress disorder (MSD-5, 2023).

The prevalence of mental disorders varies according to many factors, including age, gender and social environment. For example, before the pandemic, around 970 million people worldwide lived with a mental disorder, although this figure may now be higher. According to gender and age, anxiety and depressive disorders are the two most common mental disorders in both men and women. Anxiety disorders are more common at an earlier age than depressive disorders, which are rare before the age of ten (Mental health report, 2022).

In 2015, depression affected more than 300 million people worldwide, or 4.4% of the world's population, and anxiety disorders affected almost the same number of people (Chyczij et al., 2020). In Portugal, in 2017, the Directorate General of Health (DGH) indicated that 21% of the Portuguese population had an anxiety disorder and 17% suffered from depression (de Carvalho et al., 2017). Anxiety disorders are now the most common type of mental illness (Kalra et al., 2008; Penninx et al., 2021).

Figures already showed a significant increase in the prevalence of these disorders, but the pandemic exacerbated many risk factors associated with poor mental health and weakened many protective factors, leading to an unprecedented deterioration in mental health in the first two years. Moreover, in the first half of 2022, the mental health and well-being of many adults in European Union (EU) countries continued to be affected by the ongoing impact and uncertainty of the pandemic, to which new issues such as the rising cost of living and the war between Russia and Ukraine were added (OECD & European Union, 2022).

The right to mental health is a fundamental human right for all. Having a mental health condition should never be a reason to disenfranchise a person or exclude them from making decisions about their own health (Mental Health Report, 2022).

As mentioned above, these two disorders can affect any person of any age, gender, ethnicity, etc. However, studies have shown that one of the roles with a higher risk of manifesting psychological problems is that of caregiver, regardless of the health status of the dependent person (Denche-Zamorano et al., 2023). For the same reason, there is growing concern about the well-being and mental health of health professionals who earn their living by caring for users in institutions, as well as individuals who care for family members (Moriarty et al., 2015).

This caring activity is often associated with a decline in the mental health of caregivers, particularly those who have a higher than expected workload. However, despite the various negative aspects that have been highlighted about this activity, it also appears to benefit the individuals who perform it, increasing their personal strength, resilience and longer life expectancy (Moriarty et al., 2015).

Therefore, it has been suggested that the presence of poor mental health in caregivers may reduce the quality of services provided to meet the needs of their loved ones. This is because caregivers have less capacity and ability to understand the problems and

needs of patients (Clipp & George, 1990).

That said, the main aim of this study is to assess the self-perceptions of formal and informal caregivers of older users with regard to burden, quality of life, anxiety, depression, and stress, as well as psychopharmaceutical drug use. The specific aims are:

- i. To assess the self-perception of formal and informal caregivers of older people with regard to anxiety, depression, stress, quality of life and caregiver burden.
- ii. To determine the use of psychopharmaceutical drugs, with a focus on antidepressants and anxiolytics, by formal and informal caregivers.
- iii. To assess the self-perceived effectiveness of antidepressants and anxiolytics used by formal and informal caregivers.

#### Methods

Type of study

This is an observational, descriptive, and cross-sectional study, as the questionnaire is administered only once and there is no intervention by the researchers.

## Sample and participants

The target population for this study was defined as all persons providing care to the elderly, including formal caregivers (employees of Lar O Pinhal, Lar dos Santos Passos, Centro Social de Calendário) and informal caregivers (A associação de cuidadores Dinamicamente, Por Mim, Por Ti, Por Nós), aged 18 years or older, who agreed to participate voluntarily. The sample selected was non-probabilistic and consisted of all caregivers who agreed to participate in the study.

### Data collection procedures

After agreeing to the scope of the study, they completed the questionnaire, with anonymity and confidentiality guaranteed. The questionnaires were collected between March and May 2023. In the case of formal caregivers, the questionnaires were distributed on paper in collaboration with the technical management of the care homes. In the case of informal caregivers, the questionnaire was made available online and distributed by the association itself to its members using the means at its disposal, namely social networks.

### *Instrument of the study*

The questionnaire was a combination of five independent questionnaires: Sociodemographic questionnaire: The sociodemographic questionnaire consists of fifteen questions and was used to characterize the caregiver and the pharmacotherapy used; Depression, Anxiety and Stress Scale (Dass-21); Treatment Satisfaction Questionnaire for Medication (TSQM); Zarit Scale: The Zarit Burden Interview (ZBI), the most widely used tool for measuring caregiver burden and Quality of Life (EQ-5D).

### Data processing procedures and statistical analisys

The data were compiled in Excel®, validated and then entered on SPSS® V.28 for statistical analysis, using a significance level of a = 0.05 for all tests. In SPSS®, the independent samples t-test was used to compare the mean between two samples when the variable follows a normal distribution. And the Spearman's correlation was used to compare numerical variables.

#### **Ethics Committee**

The study was submitted to the Ethics Committee of the School of Health of the Polytechnic Institute of Porto. The study was submitted on December 12<sup>th</sup> of 2022 and received formal authorization on January 17<sup>th</sup> of 2023.

#### Results

### Sample characterisation

Formal caregivers were recruited from care homes, while informal caregivers were recruited through national caregivers' associations. During the study period, 77 caregivers responded to the above questionnaire. Of these, 36 (46.8%) were formal caregivers and 41 (53,2%) were informal caregivers.

The samples was mostly composed by female subjects 68(88.3%), aged between 18 and 68 years. There was found a significant difference in the average age between the two groups, since the formal caregivers were younger, with an average age of 40,83 years, while the informal caregivers had an average age of 54,93 years (p<0,001).

Most of the participants (68.8%) were living in the north region of the country, more precisely in the districts of Braga and Oporto, since this was the area of collaborating

institutions were most formal caregivers worked. Regarding the personal life of all the participants, 53%, or 41 of the 77, were married; 23% were divorced; 16% are single and the remaining 8% are widowed.

Mental Health and Well-being of formal and informal caregivers

Self-perception of anxiety, depression and stress among formal and informal caregivers.

The data were collected using subscales DAAS-21 questionnaire, and the results provide insights into the emotional well-being of individuals providing care in different caregiving roles. To assess depression levels, we employed the Depression subscale of the DASS-21. Formal caregivers reported a mean depression score of 4,72 (SD = 5,37), while informal caregivers reported a notably higher mean depression score of 12,59 (SD = 9,04). This discrepancy was statistically significant, underscoring that informal caregiver experienced significantly higher levels of depression compared to formal caregivers (t = -4,70, p < 0.001). The Anxiety subscale of the DASS-21 was used to assess anxiety levels, with higher scores indicating greater anxiety. Formal caregivers reported a mean anxiety score of 5.56 (SD = 7.33), which, surprisingly, was significantly lower than the mean anxiety score of 11,61 (SD = 11,48) reported by informal caregivers (t = -2,790, p = 0,007). Stress levels were evaluated using the Stress subscale of the DASS-21. Formal caregivers reported a mean stress score of 8,28 (SD = 6,90), while informal caregivers reported a considerably higher mean stress score of 15,47 (SD = 8,78). This disparity in stress levels was statistically significant, affirming that informal caregivers faced significantly higher levels of stress than formal caregivers (t = 3,955, p < 0.001).

## Caregiver burden assessment among formal and informal caregivers

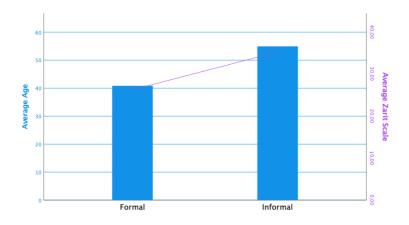
In this section, we present the results of the caregiver burden assessment conducted among both formal and informal caregivers using the Zarit Caregiver Burden Scale. The scale provides valuable insights into the perceived burden experienced by caregivers. The Zarit Caregiver Burden Scale scores were utilized to quantify the level of caregiver burden, with higher scores indicating a greater perceived burden. Formal caregivers reported a mean Zarit score of 26,28 (SD = 16.67), while informal caregivers reported a notably higher mean Zarit score of 34,90 (SD = 16,82).

This difference was statistically significant, highlighting that informal caregivers reported significantly worse caregiver burden compared to formal caregivers (t=-2,253, p=0,027). We explore a potential factor that may help explain the differences in caregiver burden observed between formal and informal caregivers (figure 1).

We conducted a Spearman correlation analysis to investigate the relationship between age and caregiver burden scores, as measured by the Zarit Caregiver Burden Scale. The results indicate that age may be a contributing factor to the variations in perceived burden among caregivers.

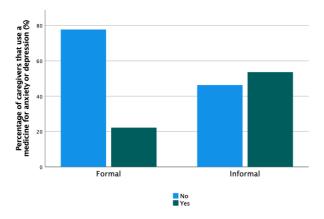
The Spearman correlation analysis revealed a statistically significant positive correlation between age and caregiver burden scores among both formal and informal caregivers (Spearman's  $\rho$  = 2.78, p = 0.015). This significant correlation suggests that as caregivers grow older, they tend to perceive a higher burden associated with caregiving responsibilities.

**Figure 1.**Results for the different groups of caregivers (formal vs. informal), with the age and Zarit Scale



Medication Usage Patterns Among Caregivers

**Figure 2.**Percentage of caregivers that use a medicine for anxiety or depression.



As can be seen from the figure 2, the use of psychotropic drugs differed between the groups of formal and informal caregivers. Only five classes of drugs were named, and surprising benzodiazepine class was the most prominent. Within this class, alprazolam was the most identified of all classes and substances. The next most identified class was the selective serotonin reuptake inhibitors (SSRIs), and fluoxetine was the most commonly used SSRI, identified by five participants, followed by escitalopram and sertraline with three responses each, and finally paroxetine with two users mentioning it. It should be noted (Table 1) that prescribing varies between groups and that for formal caregivers, benzodiazepines were prescribed only as an adjunct to another class such as SSRIs.

**Table 1**Differences in prescription classes between formal and informal caregivers

	Formal Caregiver (n=36)	Informal Caregiver (n=41)
SSRIs	3 (6.8%)	10 (22.7%)
SNRIs	3 (6.8%)	4 (9,1%)
BZD	2 (4.5%)	15 (34.1%)
Antipsychotic	1 (2.3%)	0 (0%)
Tricyclic antidepressants	0 (0%)	5 (11.4%)
Antiepileptics and anticonvulsants	0 (0%)	1 (2.3%)
Total	9 (20.4%)	35 (79.6%)

*Note:* n = number of participants

Evaluating the Perceived Effectiveness of Antidepressants and Anxiolytics in Caregivers for Older Adults

Self-perceived effectiveness of Antidepressants and Anxiolytics medications among formal and informal caregivers

Regarding the results of the Treatment Satisfaction Questionnaire for Medication (TSQM) administered to caregivers who are utilizing psychotropic medications, including antidepressants and anxiolytics. For this analysis only patient who stated they used an antidepressant or anxiolytic was selected. Effectiveness: Globally, an average 59,94 (SD: 12,47) was determined, meaning that patients reported moderate satisfaction with the effectiveness of the medication. Side Effects: this dimension evaluates the presence and severity of any side effects or adverse reactions associated with the medication. The average score in this dimension was 88.95 (SD: 16.63). Convenience: this dimension gauges aspects related to the convenience of taking the medication, including dosing frequency, ease of administration, and any other factors that impact convenience. On average, patients reported a satisfaction score of 75.92 (SD: 20.49) in this dimension. Global Satisfaction: when considering overall satisfaction with the medication, the global score averaged 65.23 (SD: 21.03). These results provide an overview of patient satisfaction across different dimensions of the TSQM survey, with higher scores indicating greater satisfaction and lower scores indicating lower satisfaction in each respective dimension.

## Factors influencing perceived global satisfation of medication

Among caregivers who were using antidepressants and anxiolytics, Spearman correlation analysis revealed that global satisfaction with the medication was positively correlated with Effectiveness ( $\rho$  = 0,497, p=0,005) and Convenience ( $\rho$  = 0,655, p<0,001). However, no significant correlation was found between global satisfaction and the presence or severity of side effects ( $\rho$  = -0,025, p=0,895), or the self-perception of depression ( $\rho$  = -0,352, p=0,102), anxiety ( $\rho$  = -0,219, p=0,246), stress ( $\rho$  = -0,046, p=0,811) or the Zarit Scale ( $\rho$  = 0,060, p=0,752).

#### Discussion

Psychological Well-being of Caregivers for Older Adults

Anxiety, Depression, and Stress

Our research revealed that both formal and informal caregivers experience significant levels of anxiety, depression, and stress. The results from the DASS-21 assessments indicate a noteworthy distinction in self-reported psychological distress between formal and informal caregivers. Informal caregivers, contrary to our initial expectations, reported more elevated levels of anxiety, depression, and stress than their formal caregiver counterparts.

These findings shed light on the unique challenges faced by informal caregivers, often family members or friends, who may lack the formal training and support systems available to formal caregivers. The increased psychological distress experienced by informal caregivers underscores the importance of recognizing and addressing their specific needs, including access to mental health resources, and emotional support. Furthermore, informal caregivers report worst anxiety scores than depression. This higher prevalence of anxiety disorders is in line with the Portuguese DGH guidelines, as 21% of the population suffer from anxiety and only 17% are diagnosed with depression (de Carvalho et al., 2017).

The fact that formal caregivers have fewer or less severe cases of anxiety, depression and stress disorders may not only be due to the fact that they are better prepared for reality because of the of their daily work. However, as it is known that age can be an additional reason for presenting with these disorders, this may be confounded in these studies, as the group of formal caregivers is significantly younger, which may also be a reason for the lower scores (Loo et al., 2022).

Loo et al. also mentioned that the fact of spending more hours with the care recipient and the fact of living with the dependent can be a factor in the development of both anxiety and depression, one more reason why the group of formal caregivers present more cases of these disorders as some of them probably spend a large part of their lives in the presence of the care recipient (Loo et al., 2022).

#### Caregiver Burden

The results derived from the Zarit Caregiver Burden Scale assessments offer important insights into the caregiver burden experienced by formal and informal caregivers. Notably, informal caregivers reported considerably higher levels of perceived burden than their formal caregiver counterparts.

This finding underscores the challenges faced by informal caregivers who often provide care out of love and a sense of duty but may lack the formal training, support, and resources available to formal caregivers. The increased caregiver burden reported by informal caregivers calls attention to the need for tailored interventions and support mechanisms aimed at alleviating the strain they experience. This is in line with what has already been reported in the literature and makes us rethink the approach and attention given to this type of caregiver, who can often feel helpless (Kalra et al., 2008).

Another reason that may explain this is age. Informal caregivers are older than formal caregivers.

The findings from the Spearman correlation analysis, with a correlation coefficient of 2.78 and a p-value of 0.015, emphasize this potential role of age in explaining the differences in caregiver burden reported by formal and informal caregivers. Specifically, as caregivers advance in age, they tend to experience an increased perception of burden associated with their caregiving responsibilities.

## Medication Usage Patterns Among Caregivers

With regard to the results obtained on the issue of medication for anxiety and depression disorders, the scenario is rather curious, as it does not exactly correspond to the guidelines already mentioned (Gautam et al., 2017; Katzman et al., 2014; Park & Zarate, 2019). In fact, the pharmacotherapeutic class with the highest representation was benzodiazepines, a class that is notoriously one of the options that should be considered more carefully because of the negative aspects mentioned (Grace et al., 2016; Penninx et al., 2021).

An important difference was noted in that it was often referred to as a single therapy. We found that a notable proportion of both formal and informal caregivers used antidepressants.

This suggests that caregivers recognize the need for mental health support, and these medications are one avenue they explore. For the treatment of anxiety, it is also important to note that in the positive responses about taking medication for anxiety and depression, both formal and informal caregivers are reported. Anxiolytic usage was also prevalent among caregivers, particularly informal caregivers. This indicates a need for anxiety management strategies within the caregiving context. The latter include participants who are no longer working, so some of them may have worked as formal caregivers.

Evaluating the Perceived Global Satisfation of Medication in formal and informal Caregivers

In our study, we evaluated the self-perceived satisfaction of antidepressant and anxiolytic medications among formal and informal caregivers using the Treatment Satisfaction Questionnaire for Medication (TSQM). One of the crucial dimensions examined was effectiveness, which pertains to how well the medication is perceived to work in terms of symptom relief and overall treatment efficacy (Volpicelli Leonard et al., 2020).

Our findings indicated that, globally, caregivers expressed moderate satisfaction with the effectiveness of the medication. We also explored the dimension of side effects, which evaluates the presence and severity of side effects or adverse reactions associated with the medication.

On average, caregivers score reflects high satisfaction with the safety profile of these medications, with most respondents reporting relatively low levels of side effects or finding them manageable. When assessing overall satisfaction with the medication across all dimensions, the global satisfaction score averaged 65.23 (SD: 21.03).

This global score provides a comprehensive measure of caregiver satisfaction with the medication, indicating a moderate level of overall satisfaction.

#### Conclusion

In conclusion, this study has characterised elderly care in Portugal, namely the self-perception of formal and informal caregivers in relation to their mental health and the impact of psychofarmaceutical medication, particularly antidepressants and anxiolytics. Around half of the respondents admitted taking some psychotropic drug, namely selective serotonin reuptake inhibitor(s) or benzodiazepines.

Caregivers who use medication report being moderately satisfied with it, and global satisfaction was correlated with the convenience and effectiveness of the medication. Caregivers also demonstrate that being a caregiver has a high impact on their quality of life, and informal caregivers are those who report a more severe state of depression, anxiety, and stress. The results presented here provide valuable information on the impact of caregiving on mental health and psychofarmaceutical medication.

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"The authors declare that there are no conflicts of interest."