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Research Article

# The Impact of Social Anxiety and Social Phobia on Difficulties in Providing Care for Family Caregivers to People with Dementia

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## Abstract

**Objective:** The main objective of this study was to examine whether social anxiety and social phobia can predict the difficulties faced by family caregivers in providing care to elderly people with dementia. The study also investigated whether these predictive effects remain consistent when larger samples are obtained through data simulation.

**Methods** The study involved a sample of 100 family caregivers, primarily women, who had been providing care to people with dementia for an average of 5 years. The instruments used in the study were a sociodemographic questionnaire, the Carers Assessment of Difficulties Index, Social Phobia Scale and Anxiety Scale in Social Interaction Situations.

**Results:** The findings of the study indicated that both social phobia and social anxiety significantly predicted the difficulties experienced by caregivers in providing care to individuals with dementia. These predictive effects were observed in both the original sample and the simulated samples obtained through data simulation.

**Conclusion:** The presence of anxiety disorders, specifically social phobia, and social anxiety, can serve as important predictors of the challenges faced by family caregivers in providing care to elderly people with dementia. The researchers suggested that specialized interventions targeting these anxiety disorders could help prevent a deterioration in the quality of care provided to dependent people with dementia.

**Keywords:** Dementia; Caregivers; Social Anxiety; Social Phobia; Difficulties in Caregiving

## Introduction

The World Health Organization [1] indicates that the number of people with dementia has been increasing. It is estimated that the number indicated in 2015, 50 million people in the world, could triple by the year 2050. Aging, genetic component or lifestyle (e.g., prolonged exposure to toxic environments), are risk factors for this clinical condition that is characterized by cognitive, behavioral, and functional changes that deteriorate over time [2]. The progression of dementia makes subjects more debilitated, fragile, and dependent to carry out their instrumental activities (e.g., using the phone or shopping) and basic activities of daily living (e.g., bathing or eating) [2,3]. The care provided by family members is based on an affective relationship between the caregiver and the patient and implies great dedication, effort, time, or assistance on the part of the caregiver. The care provided is unpaid and its level of demand can lead to difficulties for caregivers. The aggressiveness, agitation and irritability of the patient, communication problems between caregiver and patient, the greater need for supervision of the patient to avoid accidents or health problems [2,4] are

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factors that influence the care provided to people with dementia. The study by Bookman and Harrington [5] indicated that when family caregivers do not have specialized training for care, receive little support or must manage many tasks, including medical care, difficulties in care increase. There are also situations such as managing finances, controlling behaviors, or providing emotional support to the patient, which caregivers consider difficult tasks to perform [6]. In a study carried out with 62 caregivers of people with dementia, it was found that several instrumental activities of daily living require maximum assistance from caregivers [7]. When caregivers are younger and less experienced, caregiving tasks may be considered more difficult. Managing physical health issues, behaviors or taking on household chores may have a greater negative impact on caregivers' mental health. Involvement in caring for others may also compromise the caregiver's financial capacity, time for social activities or general health [8]. Difficulties in care tasks cause emotional distress in caregivers [9]. When caregivers suffer from psychological problems, the difficulties experienced in caring seem to increase [10]. The presence of depression may indicate a worse functional status of caregivers, greater difficulty in providing care or more time devoted to tasks [11]. Likewise, the presence of anxiety may indicate concern, fear, or discomfort on the part of the caregiver and may become persistent over time [12]. Anxiety is characterized as a disorder that manifests itself when anticipating a threat that may happen [13], it can also be related to feelings of despair that lead people to make distorted evaluations of themselves or to feel failure, which makes daily situations more difficult to bear [14]. When caregivers experience social anxiety, fear negative evaluations about themselves [13], tend to avoid or run away from social situations, compromising their friendships, and increasing the difficulty in building new relationships [15]. Social anxiety causes sweating, nausea, or tremors that the subjects cannot control and that compromise their performance [16]. Studies indicate that anxiety levels also tend to be higher as the time spent on care increases [17,18]. The constant fear of social situations or the small criticism that people may receive are taken as something devastating or highly destructive when subjects experience social phobia [19]. Social phobia is the fear of being exposed to others. Subjects tend to avoid other people in the most diverse contexts, such as at work [13]. Caregivers with social phobia are afraid of being rejected or humiliated [20]. Barlow's model [21] argues that although people deal poorly with disapproval or criticism received by others, social phobia only tends to manifest itself if the person is anxious due to their fragile biopsychological characteristics. This biopsychological vulnerability can also be justified by the fact that parents who were diagnosed with social phobia have children with a greater tendency to reveal social phobia, not forgetting that family dynamics factors, such as overprotection or rejection, are also considered risk factors [22]. However, social anxiety and social phobia still need to be studied. Although it is known that these characteristics may appear with comorbidities, such as depression [23], it is not clear what the predictive value of social anxiety and social phobia is in terms of difficulties in caring for people with dementia. The literature has pointed out that the difficulty in care may be associated with the type of tasks [24], medical care for the patient [5], depression [11] or burnout [7], but little is known about the impact of social anxiety and social phobia on difficulties in caring for people with dementia and whether it differs significantly if the number of caregivers increases. The main objective of this study is to verify whether social anxiety and social phobia are predictors of difficulties in providing care to people with dementia and whether this predictive value can significantly change if a larger sample of family caregivers of people with dementia is simulated.

## Methods

### Participants

In this study, 100 main family caregivers of people with dementia were considered. 76% of caregivers are female and 24% are male. Caregivers provide care for an average duration of 4.89 years (±4.84) and spent an average of 10.96 hours per day (±8.52) in caregiving activities. The marital status of the caregivers included 45% married, 5% widowed, 32% single, and 18% divorced. Regarding education, 1% had no formal education, 8% completed the 1st cycle of studies (4 years), 7% completed the 2nd cycle (6 years), 11% completed the 3rd cycle (9 years), 34% completed secondary studies (12 years) and 39% had higher education. Only 7% of respondents reported receiving formal training to provide care, while the majority (93%) did not receive any training. In terms of subjective well-being, 75% of caregivers considered themselves happy in their caregiving role, while 25% expressed dissatisfaction. As inclusion criteria, the study focused on primary family caregivers aged 18 years and above who provided care for elderly people with dementia.

## Measures

In this study, a sociodemographic questionnaire was employed to collect participants' information. The Social Phobia Scale and the Anxiety Scale in Social Interaction Situations were utilized to assess social phobia and social anxiety, respectively [25] (Portuguese version by Pinto-Gouveia and Salvador [26]). Both scales are rated on a Likert-type scale ranging from 0 (Not at all characteristics of my way of being) to 4 (Extremely characteristic of my way of being). The Social Phobia Scale comprises 20 items, while the Social Anxiety Scale consists of 19 items. A higher score indicates greater severity of symptoms in the subjects. Both instruments demonstrate good psychometric properties, including good discriminant validity and excellent internal consistency (both with α = .90). To assess the difficulties identified in caregiving, the Careres Assessment of Difficulties Index [27] (Portuguese version by Brito [28]) was employed. This instrument encompasses six dimensions (e.g., relational problems, social constraints, caregiving demands, caregiver reactions, lack of family support, and lack of professional support). The items are rated on a Likert-type scale ranging from 1 (Does not occur in my case) to 4 (Occurs and greatly disturbs me). Higher levels indicate a greater level of difficulty reported by the caregiver in providing care. The instrument demonstrates good psychometric properties, with a Cronbach's alpha coefficient of .94.

## Procedure

The collaboration of caregiver support institutions was necessary for this study. After the initial contact was established, a meeting was scheduled with the directors of the institutions to present the study objectives and clarify all necessary research procedures. The institution representatives granted permission for telephone or email contact with family caregivers. All caregivers who expressed interest in participating in the study were asked to sign an informed consent form. Caregivers were informed of all ethical and professional obligations related to the research, and their participation was entirely voluntary. Multiple meetings were scheduled to allow caregivers to complete the study protocol in person or online. For in-person assessments, a room with good lighting and minimal noise was provided by the institutions, while online assessments were conducted using the Google Forms tool. All ethical and professional obligations inherent to the research were fulfilled.

## Data analysis

The Statistical Package for the Social Sciences, version 29 for Windows (IBM, SPSS Statistics 29), was utilized for statistical analysis. Descriptive statistics, including means and standard deviations for quantitative variables, as well as frequencies and percentages for nominal or ordinal variables, were calculated. Normality assumptions were tested, and the Pearson correlation coefficient was used to calculate the correlations between variables. Furthermore, assumptions for multiple linear regression were evaluated to estimate the magnitude and direction of the impact of explanatory variables on the difficulty in providing care. The model incorporated variables that exhibited significant correlations. Additionally, a data estimation study was conducted using the available sample. Randomly generated data obtained through simulation were employed for samples of 1000 and 10000 subjects, respectively, in order to gain a better understanding of the most effective explanation for the study's response variable. The chosen level of significance for the statistical tests was a p-value < .05.

## Results

### Correlation between difficulties in caregiving and social phobia and social anxiety among caregivers

Difficulties in caregiving demonstrate a positive, moderate, and significant relationship with social phobia (r = .412, p ≈ .001) and social anxiety (r = .428, p ≈ .001). Regarding the dimensions of caregiving difficulties, it is observed that problems in the relationship exhibit a positive, weak, and significant relationship with social phobia (r = .249, p = .012) and social anxiety (r = .238, p = .017). The restrictions in caregivers' social life exhibited a positive, weak, and significant relationship with social phobia (*r* = .392, *p* ≈ .001), and a positive, moderate, and significant relationship with social anxiety (*r* = .417, *p* ≈ .001). The demands of caregiving demonstrated a positive, moderate, and significant relationship with social phobia (r = .406, p ≈ .001) and social anxiety (r = .441, p ≈ .001). The caregiver's reaction to the care provided displayed a positive, moderate, and significant relationship with social phobia (r = .444, p ≈ .001) and social anxiety (r = .439, p ≈ .001). The lack of family support for the caregiver demonstrated a positive, weak, and significant relationship with social phobia (r = .350, p ≈ .001) and social anxiety (r = .336, p ≈ .001). However, the lack of professional support did not show a correlation with social phobia (r = .041, p = .689) or social anxiety (r = .085, p = .400). By conducting simulation calculations, it is possible to identify the correlations that persisted in a sample of 1000 subjects (Table 1) and a sample of 10000 subjects (Table 2). The data indicate that significant correlations remain consistent between the original sample of 100 participants and the simulated samples of 1000 and 10000 participants. However, in the specific case of the lack of professional support, it was only found to be uncorrelated with social phobia in the simulated samples of 1000 and 10000 subjects.

| | **Social Phobia** | | **Social Anxiety** | |
|---|---|---|---|---|
| | **r** | **p** | **r** | **p** |
| Difficulty in providing general care | .421 | ≈ .001* | .407 | ≈ .001* |
| Problems in the relationship | .249 | ≈ .001* | .231 | ≈ .001* |
| Restrictions in caregivers' social life | .454 | ≈ .001* | .434 | ≈ .001* |
| Demands of caregiving | .451 | ≈ .001* | .452 | ≈ .001* |
| Caregiver's reaction | .462 | ≈ .001* | .463 | ≈ .001* |
| Lack of family support | .401 | ≈ .001* | .374 | ≈ .001* |
| Lack of professional support | .007 | = .837 | .092 | =.003* |

**Table 1:** Simulation of correlations between difficulties in caregiving, its dimensions, and social phobia and social anxiety for 1000 subjects.

Note. *Significant correlation for p-value = .01; r = Pearson's correlation; p = p-value.

| | **Social Phobia** | | **Social Anxiety** | |
|---|---|---|---|---|
| | **r** | **p** | **r** | **p** |
| Difficulty in providing general care | .379 | ≈ .001* | .377 | ≈ .001* |
| Problems in the relationship | .231 | ≈ .001* | .258 | ≈ .001* |
| Restrictions in caregivers' social life | .304 | ≈ .001* | .383 | ≈ .001* |
| Demands of caregiving | .369 | ≈ .001* | .367 | ≈ .001* |
| Caregiver's reaction | .440 | ≈ .001* | .397 | ≈ .001* |
| Lack of family support | .322 | ≈ .001* | .312 | ≈ .001* |
| Lack of professional support | -.002 | =.805 | .033 | ≈ .001* |

**Table 2:** Simulation of correlations between difficulties in caregiving, its dimensions, and social phobia and social anxiety for 10000 subjects.

Note. *Significant correlation for p-value = .01; r = Pearson's correlation; p = p-value.

### Prediction of difficulties in caregiving

The explanatory variables significantly correlated with difficulties in caregiving were included in the regression model (Table 3). The results of the multiple linear regression model are presented for the original sample (step 1), the simulation of 1000 subjects (step 2), and the simulation of 10000 subjects (step 3).

## Discussion

The main objective of this study was to verify whether social phobia and social anxiety are significant predictors of difficulties in caring for people with dementia and whether these results were significantly different when simulating larger samples.

| **Regression Models** | **B** | **SE** | **P** |
|---|---|---|---|
| 100 Subjects | | | |
| Model 1 ($R^2$ = 27.3%) | | | |
| Caregiver's age | .237 | .117 | .045* |
| Daily caregiving hours | .493 | .196 | .014* |
| Social Phobia | .453 | .097 | ≈ .001* |
| Model 2 ($R^2$ = 27.8%) | | | |
| Caregiver's age | .263 | .117 | .027* |
| Daily caregiving hours | .418 | .197 | .037* |
| Social Anxiety | .559 | .117 | ≈ .001* |
| 1000 Subjects | | | |
| Model 1 ($R^2$ = 27.4%) | | | |
| Caregiver's age | .240 | .037 | ≈ .001* |
| Daily caregiving hours | .613 | .078 | ≈ .001* |
| Social Phobia | .451 | .29 | ≈ .001* |
| Model 2 ($R^2$ = 24.8%) | | | |
| Caregiver's age | .222 | .038 | ≈ .001* |
| Daily caregiving hours | .569 | .080 | ≈ .001* |
| Social Anxiety | .496 | .035 | ≈ .001* |
| 10000 Subjects | | | |
| Model 1 ($R^2$ = 23.9%) | | | |
| Caregiver's age | .236 | .012 | ≈ .001* |
| Daily caregiving hours | .586 | .025 | ≈ .001* |
| Social Phobia | .436 | .010 | ≈ .001* |
| Model 2 ($R^2$ = 23.2%) | | | |
| Caregiver's age | .257 | .012 | ≈ .001* |
| Daily caregiving hours | .504 | .025 | ≈ .001* |
| Social Anxiety | .525 | .012 | ≈ .001* |

**Table 3:** Regression models for the original sample, for 1000 subjects, and for 10000 subjects.

Note. B = unstandardized Beta Coefficients; SE = standard error (unstandardized Coefficients); P = p-value (*.05).

The results showed that both social phobia and social anxiety were correlated with difficulties in caring for people with dementia and their dimensions, except for the lack of professional support in the original sample. By simulation, the same correlations were also verified, except for the lack of professional support, which showed no correlation with social phobia. Regarding the regression model, it appears that both for the original sample and for the simulated samples, social phobia and social anxiety are factors that can predict difficulties in providing care to people with dementia. It is also verified that the proportion of variability in the explained variable is similar in all samples, with only a slight increase being noted in the original sample when social anxiety is considered as a predictor.

In the literature, although there are situations where care difficulties may not be perceived as very severe, the study by Bakas and Burgener [9] was able to identify that the psychological state of the caregiver is a significant predictor of the worst care provided to the dependent person. Specifically, Bakas and Burgener [9], verified through the regression model in 104 family caregivers, that the predictor variables of worse care, explained 45% of the variability of the model, standing out as important variables high task difficulty, high threat appraisal, emotional distress and low benefit appraisal. In this same study, 48% of the model variability explained emotional distress based on predictors such as high task difficulty, high threat appraisal, and low caregiver self-esteem. Finally, in a sample of 98 family caregivers, what predicts their worst health status was high threat appraisal, were not living with the patient, and low household income, explaining 25% of the model variability. Carrillo-Cervantes., *et al*. [29] indicate that informal caregivers tend to present clinical problems such as anxiety. The presence of anxiety in caregivers leads to a greater probability of suffering from other mental illnesses [30]. In the particular case of social anxiety, it can have different levels of severity, ranging from the person not being able to eat with other people, to completely avoiding social contact [31]. This situation of observing relational problems and restriction of social life can lead to caregivers not seeking help from other people when they have trouble in the care provided to patients with dementia. One of the caregivers' reactions when experiencing social anxiety is to avoid having assistance for their own needs [16], this can make them feel a greater deficit of both family and professional support if they have a profession in addition to the care they provide to the person with dementia. From a functional point of view, subjects with social anxiety tend to have more problems and seek less medical help compared to people with other types of psychiatric disorders or people considered healthy [32]. Subjects with social anxiety also tend to consume substances [32], which can lead them to have reactions that compromise their functionality in care [23]. The presence of social phobia compromises the actions that must be performed in front of other people or that are the target of attention [23], which also causes suffering to caregivers. As it is known that the presence of social phobia is associated with comorbidities such as depression [23], the study by Chung., *et al*. [11] showed that caregivers with depression spend more time on care, are less functional and experience more difficulties in carrying it out than people without this symptomatology. In the study by Amato., *et al*. [7] it was found that the difficulties that caregivers experience in tasks is lower than the level of assistance required in caring for people with dementia. More instrumental types of tasks, such as housekeeping, driving, going to appointments, can increase difficulties in the caregiver's daily life. In our study, we also found that the hours caregivers dedicate to care predict their difficulties. Likewise, Bakas., *et al*. [6] found that there are tasks that require more time to perform (e.g., managing finances, transport, etc.) that are more difficult and promote negative changes in caregivers' mood. The caregivers' age also has an impact on the difficulty experienced in providing care, as we saw in the analysis model. When caregivers are younger, they experience great difficulties in dealing with behavioral changes, household chores or financial management [8]. It is also in adolescence that social phobia tends to appear, a condition that makes the subject, when faced with more challenging moments, show greater vulnerability or difficulty [23], as can happen in the provision of care to dependent people. These are situations that help to understand why caregivers feel that their mental health or their life in general worsens when they start to exercise the functions of caregivers [8] even if it is known that the presence of self-esteem in caregivers can help reduce emotional distress [9]. This study can help create specialized intervention programs in social phobia and social anxiety for family caregivers of people with dementia, as these clinical conditions in caregivers, if not treated, can persist over the years, and increase difficulties in care. The creation of information guides for family members can help to reduce the negative impact that anxiety disorders have on the functionality and quality of daily life of caregivers. On the other hand, this study has some limitations. The original study sample could have been larger. In the simulated samples, although the data were not very different, the simulation of data for 1000 or 10000 only indicates an estimation of the theoretical value of the result variable to describe a reality. The present study also does not allow inferring any type of causality, which would be important for future studies to be able to understand, over time, how anxiety disorders, beliefs or perceptions of caregivers can affect the difficulties in the care provided to the person with dementia.

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