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NEUROPSYCHIATRIC SYMPTOMS OF ELDERLY INDIVIDUALS WITH DEMENTIA: REPERCUSSIONS FOR FAMILY CAREGIVERS

Iara Lessa Costa da Silva[1], Gabriella Santos Lima[2], Luana Baldin Storti[3], Paola Aniceto[4], Paulo Fernandes Formighieri[5], Sueli Marques[6]

[1] RN, *Escola de Enfermagem de Ribeirão Preto* (EERP) *Universidade de São Paulo* (USP). Ribeirão Preto, São Paulo, Brazil. E-mail: iaralessa8@gmail.com
[2] M.Sc. student, Fundamental Nursing Program at EERP/USP. Ribeirão Preto, São Paulo, Brazil. E-mail: gabriellasl@usp.br
[3] M.Sc. in Sciences, EERP/USP. Ribeirão Preto, São Paulo, Brazil. E-mail: luanabaldinstorti@gmail.com
[4] Undergraduate student, Nursing Program, EERP/USP. Ribeirão Preto, São Paulo, Brazil. E-mail: paolaniceto@gmail.com
[5] Ph.D. in General Medical Clinic and Geriatrics, *Faculdade de Medicina de Ribeirão Preto* USP. Ribeirão Preto, São Paulo, Brasil. E-mail: pfformig@gmail.com
[6] Ph.D. in Nursing. Professor, EERP/USP. Ribeirão Preto, São Paulo, Brazil. E-mail: smarques@eerp.usp.br

ABSTRACT

Objective: to identify the presence, frequency and severity of neuropsychiatric symptoms among elderly individuals with dementia, identify family caregiver distress, and analyze factors related to caregiver distress.

Method: cross-sectional, descriptive, exploratory and correlational study conducted with 54 family caregivers of elderly individuals with dementia, receiving care in a geriatric outpatient clinic for highly dependent individuals in a tertiary general hospital. The instruments used included a questionnaire to characterize the caregivers, the Neuropsychiatric Inventory and Neuropsychiatric Inventory Caregiver Distress Scale.

Results: most (85.2%) family caregivers were women aged 51.2 years old, on average, who lived with the elderly individuals (74.1%). There was an average of 4.5 neuropsychiatric symptoms; the most prevalent was apathy/indifference (74.1%), followed by disphoria/depression (46.3%). The most frequent was aberrant motor activity (75.1%), followed by agitation/agression (52.9%). Severity of symptoms was most frequently moderate. A strong positive correlation was found between the questionnaires' total scores (r=0.82, p=<0.001) and the total score of the Neuropsychiatric Inventory Caregiver Distress Scale and the number of neuropsychiatric symptoms presented by the elderly individuals with dementia (r=0.83, p=<0.001); weak correlation between the total score of the Inventory Caregiver Distress Scale and number of days dedicated to providing care in a week (r=0.28, p=0.042) and between the caregivers' health problems and the Inventory Caregiver Distress Scale total score (r=0.29, p=0.034); all of these have statistical significance.

Conclusion: the results show a need to invest in the assistance provided to the elderly individual/caregiver pair in order to improve neuropsychiatric symptoms and decrease caregiver distress.

DESCRIPTORS: Aging. Aged. Caregivers. Dementia. Behavioral Symptoms.

SINTOMAS NEUROPSIQUIÁTRICOS DE IDOSOS COM DEMÊNCIA: REPERCUSSÕES PARA O CUIDADOR FAMILIAR

RESUMO

Objetivo: identificar a presença, frequência e gravidade dos sintomas neuropsiquiátricos em idosos com demência, identificar o desgaste do cuidador familiar e analisar os fatores relacionados ao desgaste do cuidador.

Método: estudo transversal, descritivo, exploratório e correlacional, realizado com 54 cuidadores familiares de idosos com demência, atendidos em um ambulatório de geriatria de alta dependência de um Hospital Geral Terciário. Utilizaram-se questionário de caracterização dos cuidadores, o Inventário Neuropsiquiátrico e o Inventário Neuropsiquiátrico Desgaste.

Resultados: a maioria (85,2%) dos cuidadores familiares era de mulheres, média de idade de 51,2 anos e residia com o idoso (74,1%). A média de sintomas neuropsiquiátricos foi 4,5; o mais presente foi apatia/indiferença (74,1%), seguido de disforia/depressão (46,3%); o mais frequente foi o comportamento motor aberrante (75,1%), seguido de agitação/agressividade (52,9%). Quanto à gravidade dos sintomas, a moderada foi a mais prevalente. Observou-se correlação forte positiva entre o escore total dos questionários aplicados (r=0,82, p=<0,001) e entre o escore total do Inventário Neuropsiquiátrico-Desgaste e o número de sintomas neuropsiquiátricos, apresentados pelos idosos com demência (r=0,83, p=<0,001); correlação fraca positiva entre o escore total do Inventário Neuropsiquiátrico-Desgaste e o número de dias na semana dedicado ao cuidado (r=0,28, p=0,042) e entre problemas de saúde do cuidador e o escore total do Inventário neuropsiquiátrico Desgaste (r=0,29, p=0,034), com significância estatística.

Conclusão: os resultados encontrados mostram a necessidade de investimentos na assistência ao binômio idoso/cuidador com vistas ao melhor manejo dos sintomas neuropsiquiátricos e à redução do desgaste do cuidador.

DESCRITORES: Envelhecimento. Idoso. Cuidadores. Demência. Sintomas comportamentais.

SÍNTOMAS NEUROPSIQUIÁTRICOS DE ANCIANOS CON DEMENCIA: REPERCUSIONES PARA EL CUIDADOR FAMILIAR

RESUMEN

Objetivo: identificar la presencia, frecuencia y gravedad de los síntomas neuropsiquiátricos en ancianos con demencia, identificar el desgaste del cuidador familiar y analizar los factores relacionados con el desgaste del cuidador.

Método: estudio transversal, descriptivo, exploratorio y correlacional realizado con 54 cuidadores familiares de ancianos con demencia atendidos en un ambulatorio de geriatría de alta dependencia de un Hospital General Terciario. Se utilizó el cuestionario de caracterización de los cuidadores, el Inventario Neuropsiquiátrico y el Inventario Neuropsiquiátrico de Desgaste.

Resultados: la mayoría (85,2%) de los cuidadores familiares eran mujeres de media edad, 51,2 años, y residía con el anciano (74,1%). La media de síntomas neuropsiquiátricos fue de 4,5. El más presente fue apatía/indiferencia (74,1%), seguido de disforia/depresión (46,3%) y el más frecuente fue el comportamiento motor aberrante (75,1%), seguido de agitación/agresividad (52,9%). En relación a la gravedad de los síntomas, el que más prevaleció fue el moderado. Se observó una correlación fuerte y positiva entre el resultado total de los cuestionarios aplicados (r=0,82, p=<0,001), el resultado total del Inventario Neuropsiquiátrico de Desgaste y el número de síntomas neuropsiquiátricos presentados por los ancianos con demencia (r=0,83, p=<0,001). Hubo una correlación débil y positiva entre el resultado total del Inventario Neuropsiquiátrico de Desgaste y el número de días de la semana dedicados al cuidado (r=0,28, p=0,042), y entre problemas de salud del cuidador y el resultado total del Inventario Neuropsiquiátrico de Desgaste (r=0,29, p=0,034) con la significancia estadística.

Conclusión: los resultados encontrados señalan la necesidad de mayores inversiones en la asistencia para el binomio anciano/cuidador con vistas a un mejor manejo de los síntomas neuropsiquiátricos y para la reducción del desgaste del cuidador.

DESCRIPTORES: Envejecimiento. Anciano. Cuidadores. Demencia. Síntomas comportamentales.

INTRODUCTION

Population aging is a globally acknowledged fact. According to the Brazilian Institute of Geography and Statistics, there were, in 2010, approximately 21 million people in Brazil aged 60 years old or older and it is estimated that in 2050 this population will total 58.4 million people, which will represent 26.7% of the total Brazilian population.[1]

An important characteristic of this process is the prevalence of non-transmissible chronic diseases, which account for an increase in the number of deaths, hospitalizations, and institutionalizations of elderly individuals, as well as decreases in their functional and cognitive capacities.[2] Such diseases include forms of dementia, which have become a public health problem. In 2015, there were approximately 47 million people worldwide with dementia and this number is expected to reach 131 million in 2050; Alzheimer's disease (AD) is the most common, followed by Vascular Dementia (VD).[3-4]

AD is a progressive neurological and degenerative disease that compromises processes of memory and behavior, leading to decreases in memory function, visual-spatial abilities and a loss of independence and autonomy.[5] VD is characterized by a clinical condition resulting from a cerebrovascular disease and cognitive impairment; its onset and progression varies, but its onset is usually more abrupt than AD.[6] The coexistence of a clinical condition of AD and VD characterizes Mixed Dementia, which results from vascular and degenerative lesions capable of determining a clinical-demential condition.[7]

A common condition in dementia is the presence of behavioral and psychological symptoms. The terminology "Behavioral and Psychological Symptoms of Dementia" encompasses a set of signs and symptoms associated with disorders of perception, content, thinking, mood, or behavior that are frequent in dementia, namely: delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behavior, nighttime behavior changes, appetite and eating changes.[8] These signs and symptoms lead to patient distress and caregiver stress.[9]

As dementia progresses, cognitive and physical functions are increasingly impaired, leading elderly individuals to develop greater dependence and require more extensive care, requiring caregivers to devote themselves full time to the task of caring, which often triggers stress and, consequently, worsens the quality of life of caregivers.[10] A caregiver is an individual who provides direct and continuous care to an elderly individual, who may or may not be a family member, because the delivery of care is not necessarily performed by a professional from the health field, as caregivers do not always have a specific technical background.[11]

Caregivers of elderly individuals with dementia face situations like changes in lifestyle and decreased personal time, which may compromise their physical and mental health, resulting in distress and burden.[12]

Neuropsychiatric symptoms are a frequent problem among people with dementia and are as-

sociated with worsened quality of life for patients and caregiver stress. In addition to increasing the costs from healthcare, neuropsychiatric symptoms are among the main factors of institutionalization of patients with dementia.[13]

One study[14] analyzing the self-perception of health among family caregivers according to type of dementia reports that 45.0% of the caregivers assessed their physical health as regular or poor, evidencing the importance of paying attention to the health of family caregivers as part of multiprofessional follow-up. One study[15] addressed female family caregivers of elderly women with dementia aiming to compare the psychological wellbeing of a group of caregivers of elderly women without dementia with that of a group of caregivers of elderly women with dementia, and reports that the latter experienced greater burden, greater difficulty dealing with criticism, improved emotional self-control, and greater perception of support needs and community services when compared to the group of caregivers of elderly women without the disease.

Given the preceding discussion, identifying neuropsychiatric symptoms among elderly individuals with a diagnosis of dementia is essential for health workers to consider them in a individualized care planning as well as assist caregivers so they can provide continuity to the care provided at home.

Therefore, this study's objectives included identifying the presence, frequency, and severity of neuropsychiatric symptoms among elderly individuals with dementia, identifying family caregiver distress, and analyzing the factors related to caregiver burden.

METHOD

This quantitative, cross-sectional study with a descriptive, exploratory and correlational approach was conducted in a geriatric outpatient clinic for highly dependent patients of a general tertiary hospital in the interior of São Paulo.

The study population was composed of family caregivers of elderly individuals with a medical diagnosis of dementia, cared for in the aforementioned clinic from February to May 2016, with the following criteria: a) inclusion: being a male or female family caregiver of an elderly individual with dementia who requires care at home and being 18 years old or older and b) exclusion: caregivers assisting institutionalized elderly patients. A convenience sample was developed. A total of 161 elderly individuals with dementia, accompanied by their caregivers, attended the clinic in the study period. Of these, four were excluded for being formal caregivers, five refused to participate, and 98 were losses, so that a total of 54 participants remained. A formal caregiver is an individual hired to provide care, that is, has a job contract, regardless of having professional qualification in a caregiver function.

Data were collected from February to May 2016, using a structured interview by one of the researchers and an undergraduate student attending the Nursing Program at the University of São Paulo at Ribeirão Preto, College of Nursing (EERP/USP), who was properly trained to apply the instrument. The following instruments were used: Questionnaire to Characterize Caregivers,[16] which addresses the sociodemographic and health information of caregivers, as well as aspects of care delivery; the Neuropsychiatric Inventory (NPI),[17] which was adapted for the Brazilian culture,[18] and assesses the presence, frequency and severity of behavioral and psychological symptoms presented by patients with dementia. It contains 12 domains: delusions, hallucionations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behavior, nighttime behavioral changes and appetite/eating changes. Scores representing severity of behavior range from 1 to 3, where 1 represents mild behavior (present but not distressing to the patient); 2 - moderate (stressful and upsetting but caregiver is able to deal with it); and 3 - severe (behavior is very stressful and upsetting and caregiver cannot deal with it) and scores representing the frequency with which symptoms occur range from 1 to 4: 1 – rarely (less than once a week); 2 – sometimes (about once a week); 3 – often (several times a week but less than everyday); and 4 – very often (once a day or more). The NPI's total score ranges from 0 to 144 points and is obtained by multiplying the frequency score by the severity score of each domain. The third instrument used was the NPI Caregiver Distress Scale (NPI-D),[19] which was validated and adapted for the Brazilian culture,[18] and assesses the emotional and psychological distress of caregivers as consequence of the symptoms previously mentioned. The NPI-D is attached to the NPI so that, after caregivers are asked about the presence, severity and frequency of symptoms in each domain, they classify their own distress on a scale with scores ranging from 0 (none) to 5 (almost unbearable). Its total score ranges from 0 to 60 points.

The interviews were conducted on Mondays from 1pm to 5pm. The interviewers, based on a list of the day's appointments, consulted the medical files and identified those elderly patients with a medical diagnosis of dementia. After identifying potential participants, they approached the family caregiver, before or after the medical consultation, asking them to participate in the study. At this point, they introduced themselves and explained the study and clarified potential doubts. Those who consented signed free and informed consent forms. The interviews were conducted in the waiting room or in another room available in the clinic. Note that an undergraduate student from the EERP/USP assisted the elderly patients while the caregivers were interviewed to avoid biasing their answers. The interviews lasted 27.3 minutes on average.

For data processing, a data sheet was prepared in Microsoft Excel containing a codebook and two spreadsheets in which data were double-entered in order to check for internal consistency. After validation, data were exported to the Statistical Package for the Social Sciences (SPSS), version 22.0, to obtain the distribution of absolute and relative frequencies of all the instrument's variables and measures of central tendency and dispersion for numerical variables. Spearman's coefficient of correlation, denoted by r, was used to verify correlation between the NPI and NPI-D total scores, number of neuropsychiatric symptoms, number of days dedicated by the caregivers in a week, and caregiver's health problems. The maximum value r can assume is 1, and its minimum value is -1, therefore $-1 \leq r \leq 1$. The r-values adopted in this study were: r=-1.0 (Perfect negative correlation); r=-0.8 (Strong negative correlation); r=-0.5 (Moderate negative correlation); r=-0.2 (Weak negative correlation); r=0.0 (No correlation); r=+0.2 (Weak positive correlation); r=+0.5 (Moderate positive correlation); r=+0.8 (Strong positive correlation); and r=+1.0 (Positive perfect correlation).[20] The level of significance adopted for all the statistical tests was 5% ($p<0.05$).

The study project was approved by the Institutioanl Review Board at EERP/USP, protocol No. 51003215.4.0000.5393.

RESULTS

In regard to the sociodemographic characteristics of the family caregivers, most (46; 85.2%) were women; aged 51.2 years old on average and a standard deviation of 12.1; (29; 53.7%) were married and/or lived with a partner; had 8.6 years of education on average with a standard deviation of 4.0; (38; 70.4%) reported no paid job; and (25; 65.8%) quit their jobs to provide care to the elderly individuals. The caregivers' family income/per month ranged from R$650.00 to R$8.000.00; R$2,736.00 on average with a standard deviation of R$1,946.00.

In regard to the caregivers' health, (31; 57.4%) reported some health problem; the most prevalent were hypertension (10; 32.3%) and depression/bipolar affective disorder/stress/panic syndrome (8; 25.8%). The average number of health problems per caregiver was 1.3, with a standard deviation of 1.4.

In regard to the aspects of the care provided by the caregivers, (43; 79.6%) reported they were the primary caregivers; (39; 72.2%) lived with the elderly individual and (40; 74.1%) cared for their father/mother. Duration of time they were caring for the elderly individuals ranged from 12 to 360 months, 73.3 on average, with a standard deviation of 62.6. The number of hours dedicated to care delivery per day ranged from 2 to 24 hours, with 17.31 hours on average and a standard deviation of 7.8. The number of days dedicated to care delivery in a week ranged from 1 to 7 days; 6 days on average and a standard deviation of 1.6.

In term of having support from someone to provide care to the elderly individual, (46; 85.2%) reported they had support, while most (25; 51.0%) received the support of one person. The results show that (25; 46.3%) of the caregivers considered themselves to be "well-informed" about how to provide care to the elderly individual, and (44; 45.4%) reported a health worker was their main source of information.

The distribution of the presence and frequency of neuropsychiatric symptoms presented by the elderly individuals with dementia, as identified by the NPI, is presented in figure 1.

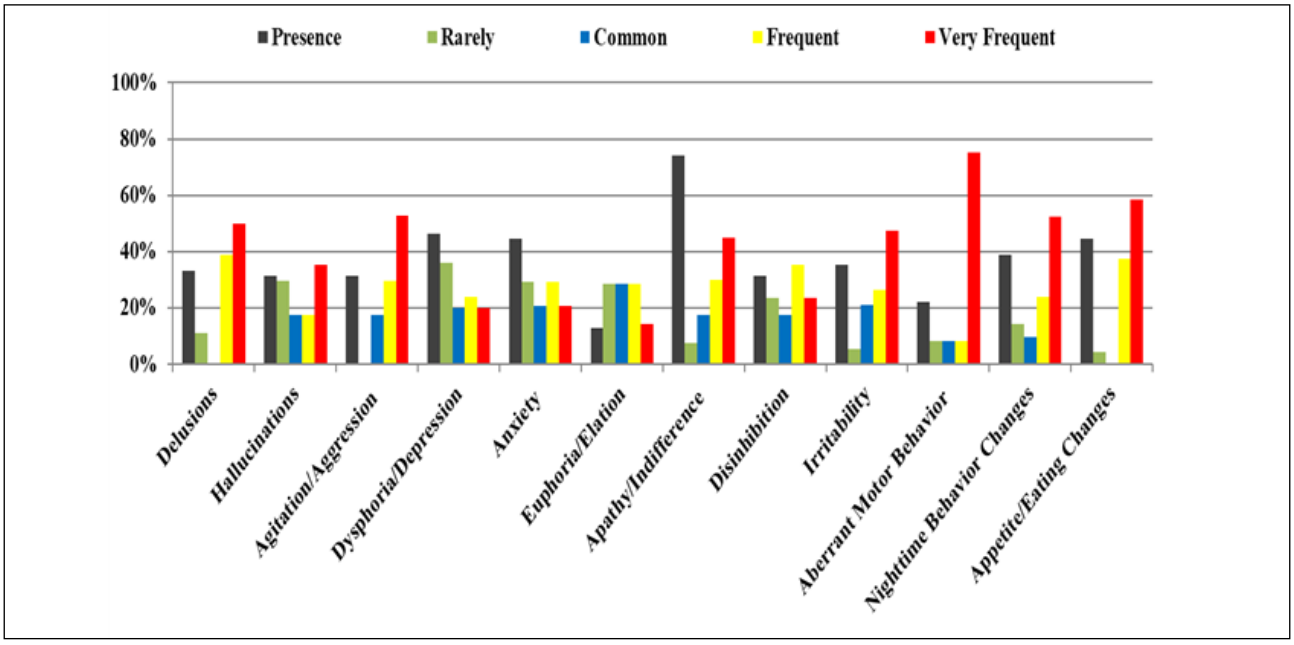

Figure 1 – Distribution of neuropsychiatric symptoms of elderly individuals with dementia according to the presence and frequency. Ribeirão Preto, SP, Brazil, 2016

According to the family caregivers, the most prevalent neuropsychiatric symptoms among the elderly individuals included apathy/indifference (40; 74.1%) and dysphoria/depression (25; 46.3%). The number of neuropsychiatric symptoms per elderly individual with dementia ranged from 1 to 11, with 4.5 symptoms on average and a standard deviation of 3.0. In regard to the frequency of these symptoms, the following were reported to be very frequent (once a day or more): aberrant motor behavior (9; 75.1%); appetite/eating changes (14; 58.3%); agitation/aggression (9; 52.9%); nighttime behavior changes (11; 52.4%); and delusions (9; 50.0%).

Figure 2 shows the distribution of the severity of the neuropsychiatric symptoms presentd by the elderly individuals with dementia from the perspective of family caregivers assessed by the NPI.

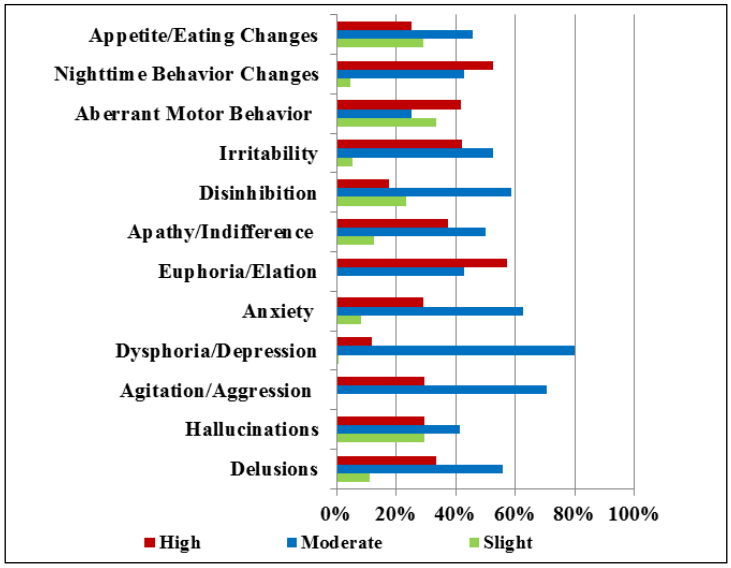

Figure 2 – Distribution of neuropsychological symptoms of elderly individuals with dementia according to the severity. Ribeirão Preto, SP, Brazil, 2016

In regard to the severity of symptoms, moderate (stressful and upsetting but caregivers can deal with them) symptoms were the most prevalent, followed by severe symptoms (very stressful and upsetting and caregivers cannot control them).

The distribution of family caregivers' distress in response to the neuropsychiatric symptoms presented by the elderly individuals with dementia is presented in figure 3.

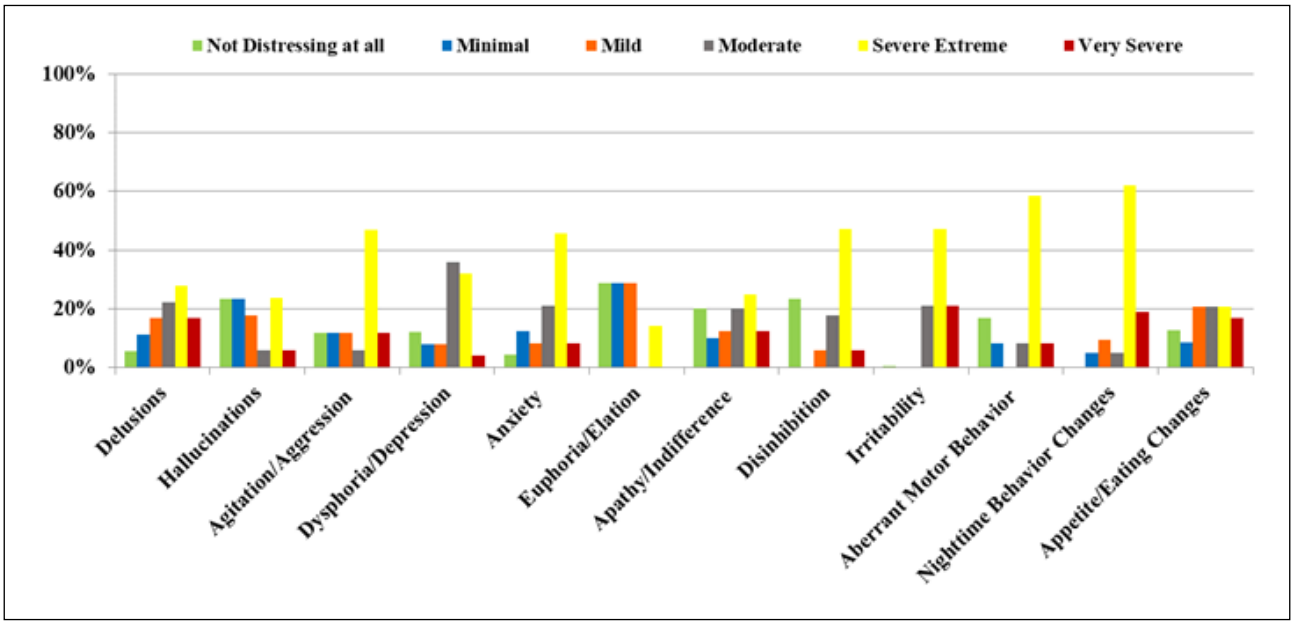

Figure 3 – Distribution of neuropsychiatric symptoms of elderly individuals with dementia according to the caregivers' distress. Ribeirão Preto, SP, Brazil, 2016

Concerning the caregivers' distress caused by the presence of neuropsychiatric symptoms among the elderly individuals, the caregivers considered the following to be very distressing: nighttime behavior (13; 61.9%); aberrant motor behavior (7; 58.4%); irritabiity (9; 47.3%); disinhibition (8; 47.1%); agitation/aggression (8; 47.0%); and anxiety (11; 45.8%).

The NPI total score ranges from 0 to 144 points and in this study, it ranged from 0 to 107 points, with 29.15 on average and a standard deviation of 27.5 points. The NPI-D total score ranges from 0 to 60 points and in this study it ranged from 0 to 43 points, 12.80 points on average and a standard deviation of 12.0.

A strong correlation ($r=0.82$, $p<0.001$) was found between the NPI total score and the NPI-D total score (the higher the frequency and the more severe the neuropsychiatric symptoms presented by the elderly individuals, the greater the level of the family caregivers' distress); strong correlation ($r=0.83$, $p<0.001$) between the NPI-D total score and the number of neuropsychiatric symptoms presented by the elderly individuals with dementia (the greater the caregivers' distress, the higher the number of symptoms presented by the elderly individuals with dementia). Weak correlation ($r=0.28$, $p=0.042$) was found between the NPI-D total score and the number of days dedicated by caregivers in a week (the greater the caregivers' distress, the greater the number of days caregivers dedicate to provide care to the elderly individual with dementia); weak correlation ($r=0.29$, $p=0.034$) was found between caregivers' health problems and the NPI-D total score (the greater the number of caregivers' health problems, the greater the caregivers' distress).

DISCUSSION

Most family caregivers addressed in this study were women.[21-22] It is known that women are traditionally responsible for providing care; that is, society expects women to play the role of caregiver.[10] One study[23] verified that female caregivers of elderly individuals with dementia were more exhausted emotionally than male caregivers. There is a direct relationship between caregiver burden and being a woman, because women play

multiple social roles, such as that of mother, wife, and professional, among others.[21]

The average age of family caregivers of elderly individuals with dementia in this study is similar to that reported by other studies, showing caregivers are often older than 50 years old.[10,21] Most caregivers were married or lived with a partner. One study[24] conducted with family caregivers of elderly individiuals with AD reports that 50% of the caregivers were married, which corroborates this study's findings. This can be a facilitator and positive factor when the spouse/partner provides support or a negative factor when being married or having a partner means an accumulation of tasks.[25]

The educational level of caregivers is an important factor because a low level of education may compromise the quality of care delivery, as it may restrict the communication of the caregiver with the health staff and/or access to sources of information regarding care that is provided to elderly individuals.[26]

In regard to having a work activity outside the home, the literature shows that most caregivers provide care to elderly individuals on a full-time basis, so they are no longer able to keep a formal job, take part in leisure activities or even maintain personal care, a situation that often leads to isolation and depression.[27-28] There is also increased expenditure accruing from care activities, such as the acquisition of medications, that burden the family budget and can generate stress among caregivers.[29]

Most caregivers in this study reported a health problem and the most prevalent were hypertension and depression/bipolar affective disorder/stress/panic syndrome and mental disorders. The literature shows that hypertension is one of the diseases most frequently self-reported by family caregivers of elderly individuals with dementia.[30] The tasks involved in care delivery, associated with health problems, are stressful to caregivers.[31]

A study that assessed burden among family caregivers of elderly individuals with AD reports that most were the primary caregivers and that these caregivers experience more overload than secondary caregivers.[32] This finding is explained by the fact that primary caregivers are responsible for most of the care provided to the elderly individual and they dedicate most of their time to direct care tasks, while secondary caregivers are responsible for tasks that complement the care provided.[33]

The degree of kinship predominantly reported in the literature between the caregiver and the elderly individual is of filiation. Children become primarily responsible for providing care to their parents when spouses are not able to provide care due to advanced age or an inadequate physical condition. Therefore, the children assume a culturally established responsibility, called filial obligation.[34] Most caregivers lived with the elderly individual and spent 17.31 hours a day on average in care delivery. When caregivers live with the elderly individual with dementia, care is fully integrated into their routines, often requiring caregivers to redefine their plans of life and relationship with the social sphere, which may worsen their quality of life.[28,31]

This study shows most caregivers received support. Studies recommend family members provide support to the primary caregiver so that elderly individuals may remain with their families, which contributes to their wellbeing; however, support from health workers is essential to avoiding or alleviating caregiver stress.[27-28]

In regard to the caregivers' knowledge of how to care for elderly individuals, most considered themselves to be well-informed, which may be related to the participants' average number of years of schooling (8.6). One study conducted with caregivers of elderly individuals with AD, intended to understand the knowledge and practices of caregivers, verified they sought information through medical orientation, from TV, and on the internet.[35]

When assessing the neuropsychiatric symptoms presented by the elderly individuals with dementia, apathy/indifference was the symptom most frequently reported by the family caregivers. A study conducted with the family caregivers of elderly individuals with dementia also reports that the most prevalent symptom among elderly individuals was apathy.[36] Apathy might be overlooked by caregivers and underestimated by family members because patients become indifferent due to a lack of motivation and decreased motor activity, but most caregivers were able to identify it.[37] Apathic behavior is one of the neuropsychiatric symptoms that causes distress for those who care for an elderly individual with dementia due to the greater impairment it imposes on patients, leading caregivers to experience frustration.[36-38]

The average number of neuropsychiatric symptoms presented by the elderly individuals with dementia, as reported by the caregivers, was 4.5 symptoms. Aproximately 90% of the patients develop at least one clinically significant neuropsychiatric manifestation throughout the course of the disease.[36]

In terms of frequency of neuropsychiatric symptoms, aberrant motor behavior was the symp-

tom reported by family caregivers as the most frequent, that is, occurring once a day or more than once a day, which is in agreement with the findings of another study.[16] This symptom is characterized by repetitive behavior, which is usually behavior without a purpose.[39] Lack of knowledge concerning these neuropsychiatric symptoms may lead caregivers to interpret it as purposeful behavior, increasing the level of distress.[36]

In regard to the severity of symptoms, moderate severity predominated; that is, there was the presence of symptoms that caused distress for patients, but which caregivers could deal with. Symptoms such as euphoria/elation, nighttime behavior changes, and aberrant motor beahvior were considered to be severe because they cause distress to patients and caregivers are not able to resolve it. These findings indicate that caregivers identify symptoms as factors that interfere in the elderly individual's life, while some behaviors are better dealt with than others.

Among the neuropsychiatric symptoms presented by the elderly individuals and that cause distress among the family caregivers, nighttime beahvior was reported as the most distressing symptom, followed by aberrant motor behavior, irritability, disinhibition, agitation/aggression, and anxiety. One study assessing correlation between neuropsychiatric symptoms and caregiver burden in a community sample in São Paulo reports that symptoms such as delusions, hallucinations, disinhibition and aberrant motor behavior, were those that correlated with the highest scores in the Zarit Inventory.[40] The constant work of caregivers providing care to elderly individuals with dementia who present characteristic neuropsychiatric symptoms may impose higher levels of stress on caregivers, especially symptoms such as aggressiveness and delusions.[23]

Note that there was a correlation between the NPI-D total score (caregiver distress) and the frequency and severity of neuropsychiatric symptoms, number of symptoms, number of days dedicated to care delivery, and the caregivers' health. This result suggests that the greater the intensity of factors such as frequency and severity of neuropsychiatric symptoms, numbers of days in a week caregivers dedicate to providing care to elderly individuals, and the caregiver's health problems, the greater is the distress related to the task of providing care to the elderly individual with dementia.

The concomitant presence of more than one neuropsychiatric symptom is frequent. Note that the presence of these symptoms is related to greater cognitive impairment and advancement of the disease, which worsens the life condition of elderly individuals and the stress of caregivers,[16] considering that this situation reveals the intensity of the elderly individuals' functional impairment, which in turn characterizes greater dependency in the performance of routine activities and, consequently, greater dedication to care is required, in addition to constant supervision.

In this sense, when family caregivers dedicate themselves full time to the care of an elderly individual with AD, they may feel both physically and mentally overwhelmed, which tends to worsen if there is no support available.[41] Note the importance of interpersonal relationships and of formal and informal social support, because seeking and receiving support is essential to coping with adverse situations.

The diseases caregivers most frequently present are non-transmissible chronic diaseses that may be directly or indirectly related to the role they play, as these diseases are associated with multiple factors. Therefore, tasks associated with diseases that are performed by caregivers for long periods of time constitute important stressors. [41-42]

Caregiver stress negatively affects quality of life in the biopsychosocial sphere.[43] Therefore, appropriately treating and managing neuropsychiatric symptoms in patients with dementia may positively influence the patients' quality of life and that of caregivers.[40]

In regard to this study's limitations, the results portray the reality of a local context, so caution should be taken when making generalizations. Additionally, the cross-sectional design employed in this study does not allow causal relationships to be established.

CONCLUSION

This study enabled identifying the presence, frequency, and severity of neuropsychiatric symptoms among elderly individuals with dementia, as well as factors related to family caregiver distress. The NPI-D total score was correlated with the frequency and severity of neuropsychiatric symptoms, number of symptoms presented by the elderly individuals, number of days dedicated in a week to care delivery, and the caregivers' health problems. The conclusion is that the greater the intensity of factors like the presence, frequency and severity of neuropsychiatric symptoms, number of days in a week dedicated to care delivery and the more health problems presented by the family caregivers, the

greater the distress related to the task of providing care for an elderly individual with dementia.

Identifying neuropsychiatric symptoms in elderly individuals with dementia and the distress such symptoms cause in family caregivers is essential to supporting the planning of the care delivered to the elderly individual/caregiver pair with a multidisciplinary focus. Additionally, note the importance of qualifying workers in the health field to manage the neuropsychiatric symptoms presented by these individuals in order to decrease caregiver distress and improve the quality of life of both.

There is also a need for studies focusing on the identification of neuropsychiatric symptoms among elderly individuals with dementia, given its high prevalence among elderly individuals, so that the results of such studies can guide investiment in programs intended to protect elderly individuals with dementia and provide proper guidance and appropriate support to meet the needs of elderly patients and their families.

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Correspondência: Sueli Marques
Avenida Bandeirantes, 3.900
14040-902 - Ribeirão Preto, SP, Brasil
E-mail: smarques@eerp.usp.br

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