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## Feature Article

## Caregiver's distress related to the patient's neuropsychiatric symptoms as a function of the care-setting



Laura Lorenzo-López, PhD<sup>a</sup>, Carmen de Labra, PhD<sup>b</sup>, Ana Maseda, PhD<sup>a</sup>,  
Trinidad Lorenzo, PhD<sup>b</sup>, Helena Agrafojo, PhD<sup>a</sup>, José Luis Rodríguez-Villamil, PhD<sup>a</sup>,  
Isabel González-Abraldes, PhD<sup>a</sup>, José C. Millán-Calenti, PhD<sup>a,\*</sup>

<sup>a</sup> Gerontology Research Group, Instituto de Investigación Biomédica de A Coruña (INIBIC), Complejo Hospitalario Universitario de A Coruña (CHUAC), SERGAS, Universidade da Coruña, 15006 A Coruña, Spain

<sup>b</sup> Research, Development and Innovation Department, Gerontological Complex La Milagrosa, Provincial Association of Pensioners and Retired People (UDP) from A Coruña, A Coruña, Spain

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## ABSTRACT

Prevalence of neuropsychiatric symptoms (NPS) and correlation between its intensity and caregiver distress were evaluated as a function of the care-setting in a cross-sectional study including 72 patient-caregiver dyads. The Neuropsychiatric Inventory and the Caregiver Distress Scale were administered. The most prevalent symptoms were: in the formal care-setting, agitation/aggression and depression/dysphoria (42.4%), and in the informal care-setting, aberrant motor behavior (59.0%). While changes in appetite and eating behaviors, depression/dysphoria and irritability/lability were more prevalent in the formal care-setting ( $p < .0001$ ,  $p = .011$ ,  $p = .021$ ), aberrant motor behavior was more prevalent in the informal care-setting ( $p = .007$ ). NPS were positively correlated with caregiver distress. High patients' scores in hallucinations, sleep and night-time disturbances, anxiety, and aberrant motor behavior were the best predictors of professional caregiver's distress. Agitation/aggression, delusions, disinhibition, apathy/indifference, depression/dysphoria, and elation/euphoria were the best predictors of informal caregiver's distress. Findings may have important clinical implications.

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## Introduction

The elderly population and the aging process itself are chief concerns in developed and developing countries. The 2015 Ageing Report<sup>1</sup> showed that, from the beginning of the century, improvements in general living conditions have dramatically increased life expectancy. The prevalence of different pathologies and age-related syndromes increases throughout the aging process. Dementia is a common and serious syndrome characterized by a global cognitive and functional decline, as well as by the presence, in the majority of cases, of neuropsychiatric symptoms (NPS) such

as delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, sleep and night-time behavior disturbances, and changes in appetite and eating behaviors.<sup>2,3</sup> NPS have important implications for patients and their families, as they generate significant stress, not only in the patients but also in their caregivers, as their physical, psychological, and emotional distress increase.<sup>4–6</sup> In fact, a high prevalence of NPS in patients negatively impact quality of life of caregivers.<sup>7</sup> With these associated problems, informal caregivers may find necessary to take the patient into a day-care center (semi-institutionalization) or even decide on potentially premature institutionalization.<sup>8</sup> Day care assistance is effective in reducing NPS in dementia patients and in alleviating caregivers' burden.<sup>9</sup> These possibilities demonstrate two distinct types of scenarios: the support group of "informal caregivers," including family members, friends, and other people who are close to the patient, sometimes paired with formal care services when the option is a day-care center; and a "formal care system" provided by nursing staff when the patient has been institutionalized. One essential characteristic of informal caregiving

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Conflicts of interest: none.

Permission for use the Spanish translation of the NPI was obtained from Jeffrey L. Cummings at <http://npitest.net>.

\* Corresponding author. Gerontology Research Group, Department of Medicine, Faculty of Health Sciences, Universidade da Coruña, Campus de Oza, E-15071 A Coruña, Spain. Fax: +34 981 167 120.

E-mail address: [jcmillan@udc.es](mailto:jcmillan@udc.es) (J.C. Millán-Calenti).

is the decrease in economic and social costs because the patient is living with his/her family, whilst, on the contrary, formal caregiving by specialists results in a more expensive cost. Despite the particularities of each type of care-setting, and despite the clear difference existing between these two types of support, it is widely accepted that both, informal and formal caregiving, imply a high degree of distress.<sup>4–6,10</sup>

Given the relatively high incidence of NPS in each care-setting and the modest efficacy of current strategies, correct identification and evaluation of NPS are a relevant and meaningful clinical target for intervention in dementia care. The present study has the ability to increase our understanding of how to improve non-pharmacological caregiver interventions and reduce the adverse outcomes associated with NPS in both formal and informal care-settings. This is relevant because the association between NPS and caregiver distress may be different as a function of the care context. It is important to note that most of previous studies used the NPI total score as the sum of individual neuropsychiatric symptoms scores. Because this approach does not provide information on specific dimensions, which may have different etiologies, symptoms and prognosis (and interventions/treatments response), and which may differently impact on caregiver distress and wellbeing, we have analyzed single NPS scores in the present study. It has been demonstrated that some individual symptoms may result in more caregiver distress than others.<sup>11</sup> Further studying individual symptoms is a relevant point, since there is no consistent evidence in the literature about specific or symptom-targeted strategies for individual NPS. By knowing which individual symptoms generate distress and their association with the provision of help (formal vs. informal care context), it could allow developing effective interventions to improve the caregivers' wellbeing.

Bearing all of this in mind, the primary aim of this article was to explore the phenomenon of caregiving distress in a population of formal (professional) and informal caregivers by assessing their likely predictors of distress related to individual patients' NPS, and to test the hypothesis that individual NPS will be different in both care contexts as predictors of caregivers' distress.

## Material and methods

### Participants

Patients and caregivers were recruited from a Gerontological Complex sited in A Coruña, Spain. The complex has the capacity for 70 semi-institutionalized people in a day care-setting and 64 institutionalized people in a nursing home. We used a purposive/judgmental nonprobability sampling method, being the specific inclusion criteria for the patients: (1) aged 65 or above, (2) having shown at least one of any of the 12 neuropsychiatric assessed symptoms in the previous 4 weeks, and (3) willingness to sign the informed consent form directly or through their legal representative. The inclusion criteria for formal caregivers (paid institutional care at nursing-home) were being the professional providers of assistance to the patients with activities of daily living for at least the previous 6 months, and signing informed written consent for study participation. For family caregivers, the inclusion criteria were being the primary informal caregiver (unpaid care) for at least the previous 6 months (having a significant personal relationship and providing a broad range of assistance to the patient), irrespective of whether the caregiver lives with or separately from the patient, and signing informed written consent. 107 patient-caregiver dyads were enrolled. Of these 107 patients, 67.3% ( $n = 72$ ) had shown at least one of any of the 12 neuropsychiatric symptoms in the previous 4 weeks. Thus, 72 patient-caregiver

dyads (formal care-setting  $n = 33$ ; informal care-setting  $n = 39$ ) were finally included in the study.

### Procedure

The study protocol was approved by the Ethics Committee of the University of A Coruña and the research was conducted in accordance with the ethical standards of the Declaration of Helsinki. Before data collection, all patients (or their legal representatives) and caregivers were informed about the study and provided their informed consent to participate.

### Variables and instruments

A structured sociodemographic questionnaire was designed to record self-reported information on patient's age, gender, and educational level, classified into three categories: (a) less than 9 years of school attendance, (b) from 9 to 17 years of school attendance and (c) more than 17 years of school attendance. Self-reported information on the caregiver's gender and type of relationship with the care recipient was also obtained. The global cognitive status of the patients was assessed using the Spanish version<sup>12</sup> of the Mini-Mental State Examination (MMSE).<sup>13</sup> The MMSE is composed of 11 items that generate a score ranging from 0 to 30, with lower scores indicating a higher degree of cognitive impairment. Scores were adjusted for age and level of education and the cut-off score in our study was 24/25 (a score below 24 indicates dementia).<sup>12</sup>

The Spanish validated version<sup>14</sup> of the Neuropsychiatric Inventory (NPI)<sup>2,3</sup> was administered by a geriatrician to assess neuropsychiatric symptoms during a structured interview. This instrument is one of the most extensively used methods to assess NPS and it has been validated in several languages.<sup>15</sup> In the formal care-setting, the NPI was administered to the professional caregiver (nursing assistant) while in the informal care-setting it was administered to the primary informal caregiver or the family member involved in the daily care of the patient. The caregivers rated the frequency of the symptoms using scores from 1 (occasionally, less than once per week) to 4 (very frequently, once or more per day or continuously), and their severity using scores from 1 (mild) to 3 (severe). A symptom intensity score was calculated for each neuropsychiatric symptom by multiplying its frequency (range 0–4) and severity (range 0–3). The total NPI score was computed by adding all composite scores of each domain (range between 0 and 144, with higher values indicating more behavioral and psychological alterations).

When the caregivers had rated the frequency and severity of each individual behavior, the Neuropsychiatric Inventory Caregiver Distress (NPI-D),<sup>16,17</sup> was used to evaluate their own distress. They were asked to rate their emotional or psychological distress in relation to the patients individual NPS, on a scale from 0 (not at all distressing) to 5 (very severely or extremely distressing). The NPI-D provides a reliable and valid measure of subjective caregiver distress in relation to NPS measured by the NPI, and it has been shown to be useful in both clinical and research settings for assessing the contribution of NPS to caregiver distress in dementia patients.<sup>16</sup> The NPI-D total score is the sum of individual symptom scores and ranges from 0 to 60.

### Statistical analysis

The software package IBM SPSS Statistics v.23.0 was used for data analysis. Descriptive statistics (means, standard deviations, and percentages) were used to characterize the sample. In addition to this analysis, patient and caregiver's sociodemographic characteristics, as

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