INSOMNIA IN FEMALE FAMILY CAREGIVERS OF TOTALLY DEPENDENT PATIENTS WITH DEMENTIA: AN EXPLORATORY STUDY

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Abstract

The aim of this study was to estimate the prevalence of primary insomnia in female family caregivers of totally dependent patients with dementia, and to examine the relation between this sleep disorder and a number of characteristics of the caregivers, care recipients, and caregiving situations. The participants were 134 female caregivers, who answered a diagnostic interview according to DSM-IV-TR diagnostic criteria. The functional status of the dependent person was assessed through the Barthel Index, and sociodemographic and related caring variables were collected through an ad hoc questionnaire. The prevalence of primary insomnia was 41.0%. Caregivers over 55, with more than eight years providing care and more than 12 daily hours of care, had a higher risk of developing insomnia. Multivariate analysis through binary logistic regression analysis showed that the factors more strongly associated with this diagnosis were the years of care duration (Wald= 4.02, *p*= .045, adjusted OR= 2.12, 95% CI= 1.02-4.42) and the daily hours of care (Wald= 4.07, *p*= .044, adjusted OR= 5.01, 95% CI= 1.05-23.92). Health care professionals should carefully check sleep complaints in female caregivers.
KEY WORDS: *primary insomnia, prevalence, caregivers, caregivers burden, demented patients*.

Resumen

El objetivo de este estudio fue estimar la prevalencia de insomnio primario en cuidadoras familiares de pacientes con demencia totalmente dependientes y examinar la relación entre este trastorno y diversas características de las cuidadoras, los destinatarios de la atención y la situación de cuidado. Participaron 134 cuidadoras quienes contestaron a una entrevista diagnóstica según el DSM-IV-TR. El estado funcional de la persona dependiente se evaluó mediante el Índice de Barthel. La prevalencia de insomnio primario fue 41,0%. Las cuidadoras mayores de 55 años, con más de ocho años proporcionando cuidados y más de 12 horas diarias de dedicación a esta tarea presentaron un mayor riesgo de desarrollar insomnio. El análisis multivariado mediante regresión logística binaria mostró que los factores más asociados con este diagnóstico fueron los años de duración del

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cuidado (Wald= 4,02; *p*= 0,045; OR ajustado= 2,12; IC 95%= 1,02-4,42) y las horas diarias de atención (Wald= 4,07; *p*= 0,044; OR ajustado= 5,01; IC 95%= 1,05-23,92). A tenor de estos resultados, los profesionales de la salud deben controlar cuidadosamente las quejas de sueño en las cuidadoras.

Palabras clave: *insomnio primario, prevalencia, cuidadores, sobrecarga, demencia*.

Introduction

In the European Union, the prevalence of dementia among the population over 65 years ranges between 5% to 10% (Berr, Wancata, & Ritchie, 2005; Qiu, De Ronchi, & Fratiglioni, 2007), and it is estimated that there are around 5 million people affected (Andlin-Sobocki, Jönsson, Wittchen, & Olesend, 2005), approximately 600,000 in Spain, with the Alzheimer's disease as the predominant aetiology (65-70% of cases) followed by the vascular dementia (De Pedro-Cuesta et al., 2009). Although dementia is the main reason for admission to a nursing home, most patients with dementia live at home under the care of a family member (Rosa et al., 2010).

Providing care to persons with dementia is a very challenging and stressfull task that demands dedication and continuous effort, particularly if they are patients with a high degree of dependency and disability. Research carried out in this domain suggests that the burden associated with caregiving has a very important negative impact on the physical and emotional well-being of the caregiver and, consequently, causes a decrease in the quality of life. More concretely, family caregivers of subjects with dementia have shown high levels of depression (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014; Smagula et al., 2017), anxiety (Schulz & Martire, 2004), increased risk for cardiovascular diseases (Mills et al., 2009), and impaired immune functioning (Segerstrom, Schipper, & Greenberg, 2008). Also, these family caregivers visit healthcare professionals more frequently than other people of their age and they use more medication (Brodaty & Donkin, 2009). Many of these negative effects on health are significantly higher in caregivers of people with dementia compared with other family caregivers groups and with non-caregivers controls (Peng & Chang, 2013).

Poor sleep quality is a very common complaint among family caregivers of persons with dementia and, in fact, these caregivers report greater problems to obtain adequate rest during the night compared with age - and gender - matched controls (Peng, Lorenz, & Chang, 2016). Also, it is estimated that two-thirds of them experience some form of sleep disturbance during the course of their caregiving career (McCurry, Logsdon, Teri, & Vitiello, 2007). This sleep impairment has a negative impact on the well-being and health of the caregiver, including depression onset (Creese, Bèdard, Brazil, & Chambers, 2008), thus it could significantly affect to the quality of care provided. Moreover, it is often a main reason for the institutionalization of the care recipient (Castro et al., 2009). However, despite its clinical relevance, caregivers' sleep disturbances, particularly primary insomnia, are an under-recognized and poorly treated problem.

Many different factors can contribute to the development and maintenance of insomnia disorder in family caregivers of dementia patients. Some of these factors can be directly related to the caregiving situation, but others may be partially or completely independent of it. Variables such as age and gender of caregivers are important predisposing factors that may explain changes in sleep and a higher prevalence of insomnia (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2009). This fact is very important, because the majority of family caregivers are women, sometimes middle- or advanced-aged. Also, variables related to the care recipients may have some influence on the occurrence of insomnia in caregivers. Changes in the nighttime routines of people with dementia and the presence of nocturnal disruptive behaviors result in frequent nocturnal awakenings in family caregivers, decreasing the total sleep time due to sleep fragmentation and, consequently, may be a precipitating factor of insomnia in predisposed or vulnerable caregivers (McKibbin et al., 2005; Tractenberg, Singer, Cummings, & Thal, 2003).

In the domain of the care of dementia patients, few studies have focused specifically on the insomnia as the main focus of interest (Peng & Chang, 2013) and, to the present, epidemiological studies on this disorder in female family caregivers of totally dependent patients have not been conducted. For this reason, the purpose of this exploratory study was to estimate the prevalence of primary insomnia in female family caregivers of totally dependent patients with dementia, as well as to examine the relation between this sleep disorder and a number of characteristics of the caregivers, care recipients, and caregiving situation.

Method

Participants

A cross-sectional study with family caregivers was carried out. Participants were randomly recruited from among 6.717 female caregivers of totally dependent patients with dementia, listed in the official register prepared by the Dependency Technical Coordination Unit of the Ministry of Labor and Welfare of the Autonomous Community of Galicia (Spain). Galicia is a 29,434 km^2 region in the northwest of Spain with 2,732,347 inhabitants. This register was created on the basis of the Spanish Law 39/2006 of December 14, of Promotion of Personal Autonomy and Care for People in Situations of Dependency Act (Ley 39/2006, 2006). Subjects were included in the study on the basis of fulfilling the following criteria: a) female gender, b) to be a primary caregiver for a family member (spouse/partner, father/mother, other family member) in a state of dependence, i.e., the person on who rests the responsability of caring, c) the care recipient must be a patient with dementia in a situation of complete dependency recognized by the official organization, d) the caregiver must live at home with the person cared. The exclusion criteria were: a) do not give informed consent, b) having another mental disorder that could explain insomnia (e.g, major depressive disorder, substance use disorder), drug use, or medical illness, c) any difficulty in communication (e.g., severe auditive loss) or any condition that makes the evaluation impossible (e.g., cognitive impairment).

The sample size calculation was estimated on the basis of the prevalence of insomnia diagnosis (6%) found in the general population (Ohayon, 2002) and a loss of subjects of approximately 20%. Thus, a sample of 133 participants was required in order to achieve accuracy of ±4 and α= .05. However, we initially contacted 166 subjects to counteract subject loss.

The randomly selected female family caregivers were personally contacted by mail and telephone, and invited to participate in the study after being informed of its nature, objectives, risk and benefits. The response rate was 94,5%. Nine female caregivers (6.3%) declined to participate. Twenty-three (13,9%) participants were excluded due to having one mental disorder, drug use or medical condition which caused insomnia, leaving a final sample of 134 subjects with a mean age of 54,84 years (SD= 10,79) (see Figure 1). The study protocol was conducted in accordance with the Declaration of Helsinki and was approved by the ethics committee of the University of Santiago de Compostela. Participation was voluntary and no incentives were offered to the participants. All caregivers gave written informed consent.

Figure 1
Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) flow diagram
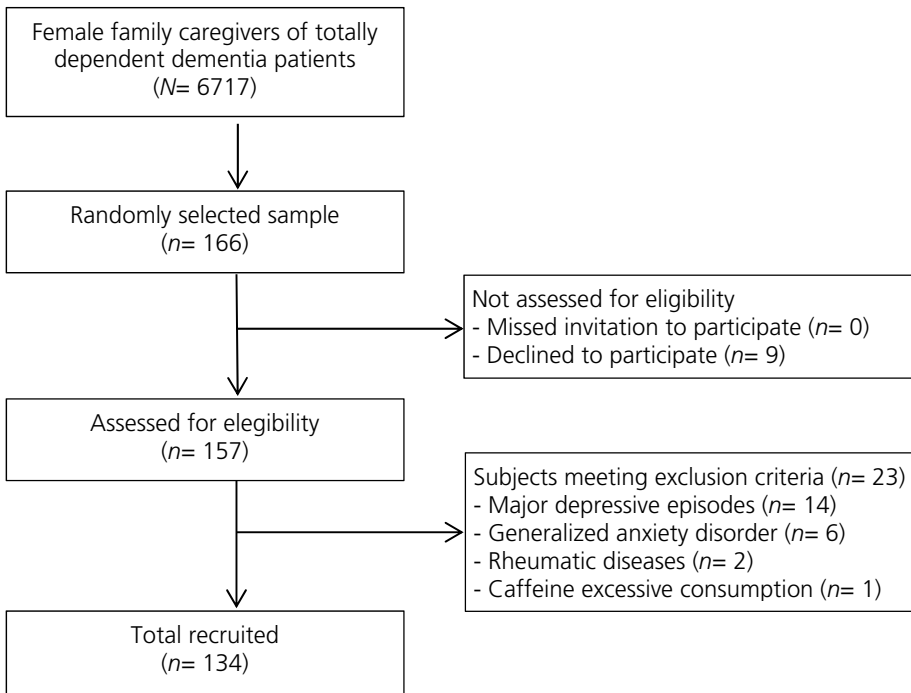
Instruments

a) *Ad hoc Socio-demographic Questionnaire*. This questionnaire was employed to collect data on several sociodemographic characteristics of the female caregivers (age, marital status, educational level, area of residence, employment status and monthly incomes), of the care recipients (age and gender) and of the caregiving situation (relationship between care recipients and caregivers, years of care duration and daily hours of care).

b) *The Barthel Index* (BI) (Mahoney & Barthel, 1965). Spanish version of the BI (Baztán et al*.,* 1993) was used to assess the degree of dependence of the care recipients. This standardized scale is widely used by clinicians and researchers, and has been recommended for routine use in the assessment of disability in older people (Quinn, Langhorne, & Stott, 2011; Sainsbury, Seebass, Bansal, & Young, 2005).The total score of the test ranging from 0 to 100, with the higher scores signifying better degrees of function, and scores between 0-20 indicating total dependence. The Spanish version of the BI has a good internal consistency (.86-.92) (Cid-Ruzafa & Damián-Moreno, 1997).

c) *The Diagnostic Interview in Mental Health* (Vázquez & Muñoz, 2002) was used to assist in the determination of clinical diagnosis of primary insomnia in the female caregivers. This instrument follow the criteria of the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR) (American Psychiatric Association, 2000). The outcome measure was the presence/ausence of primary insomnia diagnosis. Specifically, for the clinical diagnosis of primary insomnia had to be fulfilled: 1) The caregiver shows one or more of the following: difficulty initiating sleep (sleep onset latency more than 30 minutes), difficulty maintaining sleep (nighttime awakenings of a duration greater than 30 minutes), waking up earlier than desired (termination of sleep at least 30 minutes before the desired time and a concomitant reduced total sleep time), or nonrestorative sleep and resistance to going to bed on appropriate schedule, for at least 1 month. 2) Caregiver exhibits one or more of the following related to the nighttime sleep difficulty: fatigue/malaise, attention, concentration, or memory impairment, impaired social, family or occupational performance, mood disturbance/irritability, daytime sleepiness, behavioural problems, reduced motivation/energy/iniciative, proneness for errors/accidents, concerns about or dissatisfaction with sleep. 3) The sleep/wake difficulty is not better explained by another sleep disorder, particularly narcolepsy, circadian rhythm sleep-wake disorders, breathing-related sleep disorders or a parasomnia. 4) The disturbance does not occur exclusively during the course of another mental disorder (e.g., major depressive disorder, generalized anxiety disorder, a delirium). 5) The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition. To exclude other mental disorders, the Spanish version of the Structured Clinical Interview for DSM-IV Axis I – Clinician Version (SCID-CV) (First, Spitzer, Gibbon, & Williams, 1997/1999) was used. The SCID-CV is a semi-structured interview designed to provide information on the most common DSM-IV Axis I disorders. It comprises six modules (mood episodes, psychotic symptoms, psychotic

disorders, mood disorders, substance use disorders, and anxiety and other disorders) and needs to be administered by a clinician. This diagnostic instrument is widely used and has good test-retest reliability for psychiatric patients (k= .61) (Rush, First, & Blacker, 2008).

Procedure

Previous to the study, a research protocol was drawn up detailing the study objectives, design and setting, participants (target population, accessible population, inclusion/exclusion criteria, sampling, and recruitment), measures (outcome and predictor variables), bias (non-response, recall bias, and selection bias), data analysis strategy, quality control, data management, schedule, and ethical issues.

Then, a pilot study was conducted to evaluate the feasibility of the study and the competence of the interviewers. The pilot study involved 20 randomly selected caregivers. Those caregivers were assessed by four clinical psychologists with 4 to 15 years of experience in the assessment and treatment of mental disorders. Additionally, these psychologists received one full week specific training to assess the participants in this study by two expert clinicians (a clinical psychologist and a psychiatrist) with an average of 20 years of experience in the assessment, diagnosis and treatment of mental disorders. This training consisted in theoretical and practical seminars that included an approximation to the caregiver population assessment, DSM-IV-TR primary insomnia diagnostic criteria, the SCID-CV standard training components and role-playing interviews. The average length of the interviews was approximately 40 minutes and all these interviews were recorded to assess the evaluators' performance and to provide them with feedback.

Next, the caregivers were personally contacted and invited to participate in the cross-sectional study. All female family caregivers were assessed by the four clinical psychologists mentioned above. Each caregiver was interviewed individually face-to-face at a location near their home provided by social community services. First, subjects answered questions about the sociodemographic characteristics of caregivers, care recipients and the caregiving situation described above. Later, the functional status of the dependent person was assessed through the BI. Finally, the presence of primary insomnia was identified with the aid of the Diagnostic Interview in Mental Health and other mental disorders were excluded with the aid of the SCID-CV. The duration of this assessment session was approximately 40-45 minutes. Along the study, a random sample of 10% of interviews were recorded and supervised, and the job of the interviewers was also weekly supervised by one of the clinical experts.

To minimize subject dropout, data collection strategies for this type of study were followed, such as planning a systematic series of repeated contact tests, reminders of the interview date, avoiding invasive or annoying procedures for information collection, and presenting the study to the participants in an appealing fashion (Hulley, Cummings, & Newman, 2013).

Data analysis

The statistical analyses were performed using IBM SPSS Statistics 20.0 (IBM, 2011). In the initial descriptive analysis, data are expressed as frequencies and percentages for the categorical variables or as means and standard deviations for the continuous variables. Ninety-five percent confidence interval (95% CI) was calculated for the estimation of prevalence of primary insomnia. In the bivariate analysis we used Chi-square test to analyze associations among insomnia and the variables included in the study. For statistical or clinical reasons, some of these variables were redefined as follows: based on the distribution of data, the age of female caregivers was classified as ≤ 55 years or > 55 years, the age of the care recipient as ≤ 88 years or > 88 years, and the years of care duration as ≤ 8 years or > 8 years; to distinguish care during daytime hours from care exceeding those hours, the daily hours of care variable was classified as ≤ 12 hours or > 12 hours. Subsequently, the significant variables in bivariate analysis were then introduced into a multivariate analysis by means binary logistic regression analysis to identify the main variables associated with primary insomnia in the studied sample. The results are reported providing the Wald test value and the adjusted odds ratio (OR) with 95% confidence interval (CI).

Results

As summarized in Table 1, the mean age of the sample studied was 54.84 ± 10.79 years, ranging from 21 to 82 years. The majority of the female family caregivers were married or lived with a partner (80.6%) and more than a half had completed at least primary education (58.2%) and lived in a rural area (52.2%). Moreover, most female caregivers did not work outside the home (84.3%) and reported that their monthly incomes were between 1000 and 2000 Euros (56.0%).

The mean age of the care recipients was 88.20 ± 6.44 years, ranging between 72 and 104. They were predominantly females (89.6%) and had a mean BI score of 3.43 ± 6.08, ranging from 0 to 20, which was indicative of total dependency.

The female caregivers provided care mostly to their parents (57.5%), devoting a mean of 16.74 ± 3.53 hours per day to this task. The mean of care duration was 9.18 ± 4.85 years.

A total of 55 female caregivers received a primary insomnia diagnosis according to the compliance of the DSM-IV-TR diagnostic criteria, resulting in a prevalence of 41.0% (95% CI= 32.1-49.3).

Table 2 presents prevalence of primary insomnia as a function of the selected variables. On the bivariate analysis, the factors significantly associated with the insomnia diagnosis were the age of female caregivers (χ^2= 5.89, *p*= .015), the years of care duration (χ^2= 4.25, *p*= .039) and the daily hours of care (χ^2= 6.12, *p*= .013). The caregivers older than 55 years old (OR= 2.38, 95% CI= 1.17-4.81), with more than 8 years providing care (OR= 2.09, 95% CI= 1.03-4.23) and more than 12 daily hours of care (OR= 5.71, 95% CI= 1.24-26.23) were exposed to a higher risk of developing insomnia. In fact, the prevalence of this sleep disorder was significantly higher in these three subgroups of female caregivers (51.5%, 49.3% and 44.9%,

respectively). By contrast, marital status, education level, area of residence, employment status, monthly incomes, age of the care recipient, gender of the care recipient, and relationship between care recipient and caregiver, were not associated with primary insomnia.

Table 1
Characteristics of the female caregivers, of the care recipients, and of the caregiving situation (*n*= 134)

Characteristics	*M*	*SD*	Range	*n*	%
Age (years)	54.84	10.79	21-82		
Marital status					
Without partner				26	19.4
With partner				108	80.6
Educational level					
Without education				34	25.4
Primary education				78	58.2
Secondary or higher education				22	16.4
Area of residence					
Rural				70	52.2
Urban				64	47.8
Employment status					
Employed				21	15.7
Unemployed				113	84.3
Monthly incomes (Euros)					
< 1000				32	23.9
1000-2000				75	56.0
> 2000				27	20.1
Age of the care recipient	88.20	6.44	72-104		
Gender of the care recipient					
Female				120	89.6
Male				14	10.4
Degree of dependence of the care recipient (BI)	3.43	6.08	0-20		
Relationship between care recipients and caregivers					
The care recipient is spouse/partner				4	3.0
The care recipient is father/mother				77	57.5
The care recipient is other family member				53	39.5
Care duration (years)	9.18	4.85	1-30		
Daily hours of care	16.74	3.53	2-24		

Finally, the multivariate analysis through binary logistic regression analysis showed that the factors most associated with primary insomnia diagnosis were the years of care duration (Wald= 4.02, *p*= .045, adjusted OR= 2.12, 95% CI= 1.02-4.42) and the daily hours of care (Wald= 4.07, *p*= .044, adjusted OR= 5.01, 95% CI= 1.05-23.92).

Table 2
Prevalence of primary insomnia as a function of the selected variables

Variable	N	n (%)	χ^2 (df)	p	OR	95% CI
Age (years)						
≤55	68	21 (30.9)	5.89 (1)	.015	2.38	1.17-4.81
>55	66	34 (51.5)				
Marital status						
Without partner	26	9 (34.6)	0.55 (1)	.458		
With partner	108	46 (42.6)				
Educational level						
Without education	34	18 (52.9)	2.98 (2)	.226		
Primary education	78	30 (38.5)				
Secondary or higher education	22	7 (31.8)				
Area of residence						
Rural	70	26 (37.1)	0.92 (1)	.337		
Urban	64	29 (45.3)				
Employment status						
Employed	21	5 (23.8)	3.06 (1)	.080		
Unemployed	113	50 (44.2)				
Monthly incomes (Euros)						
< 1000	32	12 (37.5)	0.76 (2)	.683		
1000-2000	75	30 (40.0)				
> 2000	27	13 (48.1)				
Age of the care recipient						
≤ 88	67	28 (41.8)	0.03 (1)	.861		
> 88	67	27 (40.3)				
Gender of the care recipient						
Female	120	51 (42.5)	1.01 (1)	.316		
Male	14	4 (28.6)				
Relationship between care recipients and caregivers						
The care recipient is spouse/partner	4	2 (50.0)	0.48 (2)	.788		
The care recipient is father/mother	77	33 (42.9)				
The care recipient is other family member	53	20 (37.7)				
Care duration (years)						
≤ 8	63	20 (31.7)	4.25 (1)	.039	2.09	1.03-4.23
> 8	71	35 (49.3)				
Daily hours of care						
≤ 12	16	2 (12.5)	6.12 (1)	.013	5.71	1.24-26.23
> 12	118	53 (44.9)				

Note: Goodness of fit of full model: χ^2= 1.134, *df*= 4, *p*= .889.

Discussion

To date, this is the first study carried out with the purpose to estimate the prevalence of primary insomnia in female family caregivers of totally dependent patients with dementia. Besides, we have examined the relation between this sleep disorder and several characteristics of the female caregivers, the care recipients, and the caregiving situation.

The results obtained showed that insomnia is highly prevalent (41.0%) among female family caregivers of totally dependent patients with dementia. This prevalence is lower than the two-thirds of sleep disturbances found in caregivers during their caregiving career by McCurry et al. (2007), although it should be noted that our results are confined to females and, moreover, refers specifically to a particular sleep disorder, i.e., with a current insomnia diagnosis instead of complaints and dissatisfaction with sleep quality. The prevalence of primary insomnia in the present study is sevenfold higher than the estimated 6,0% insomnia prevalence in the general population (Ohayon 2002), in line with previous findings of more sleep problems reported in caregivers compared to noncaregivers (McKibbin et al., 2005).

We found a significant relation between this sleep disorder and some of the studied variables. Age of female caregivers, years of care duration and daily hours of care, were factors significantly associated with the insomnia diagnosis. In fact, the prevalence of this sleep disorder was significantly higher in older caregivers, with more years and more daily hours providing care (51.5%, 49.3% and 44.9%, respectively). In the analized sample, caregivers older than 55 years old had approximately a twofold higher risk of having insomnia. This result is consistent with those of previous studies that found that older age is a predisposing factor for insomnia both in cagerivers (McCurry et al., 2009) and general population (Gooneratne & Vitiello, 2014), and it is in line with changes in the sleep related with age (Pandi-Perumal et al., 2002). Caregivers with more than 8 years providing care and with more than 12 daily hours of care had respectively twofold and fivefold higher risk of developing insomnia. A possible explanation is that caregivers caring through more years and daily hours could have relatives with more advanced dementia and probably more nighttime disruptive behaviors, which have found related with the presence of sleep disfunctions in caregivers (Peng & Chang, 2013). In addition, we can conclude that the factors most associated with primary insomnia diagnosis are the years of care duration and the daily hours of care. This result is consistent with recent studies that suggest that caring in dementia patients may amplify caregiver burden significantly, especially for the female caregivers who spend more time in care (D'Onofrio et al., 2015).

This study has some limitations. First, a cross-sectional study was carried out and only correlates could be assessed. Second, the sample size was small and did not include a group of non-caregiving women matched by age. Third, information about the sleep quality and other significant measures commonly utilized in the insomnia research was not included. Therefore, it would be interesting to use specific instruments and scales, such as the Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) or the Insomnia Severity Index (Bastien,

Vallières, & Morin, 2001), to assess several critical elements of the sleep in the female family caregivers.

The data provided in this study, if confirmed in future research, could allow insomnia prevention efforts to be focused on those subgroups of female family caregivers who appear to be exposed to a higher level of risk of this sleep disorder. Health care professionals, particularly in primary care, should carefully check difficulties and sleep complaints in the female caregivers that may represent a health risk (older than 55 years old, caring a relative for more than 8 years and 12 hours a day). Providing psychological support to these family caregivers and, when necessary, brief cognitive-behavioural treatment, will impact positively both the caregivers' health and, supposedly, the care recipients, improving the quality of care provided to the dementia patients (Van Mierlo, Meiland, van der Roest, & Dröes, 2012). Increasing our knowledge about sleep disorders in female family caregivers, particularly on insomnia, and developing procedures for its prevention and effective treatment, is the goal of future research in this field by our research group.

References

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders, fourth edition, text revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association.

Andlin-Sobocki, P., Jönsson, B., Wittchen, H. U., & Olesend, J. (2005). Cost of disorders of the brain in Europe. *European Journal of Neurology, 12*, 1-27.

Bastien, C. H., Vallières, A., & Morin, C. M. (2001). Validation of the Insomnia Severity Index as an outcome measure for insomnia research. *Sleep Medicine, 2*, 297-307.

Baztán, J. J., Pérez del Molino, J., Alarcón, T., San Cristobal, E., Izquierdo, G., & Manzarbeitia, J. (1993). Índice de Barthel: Instrumento válido para la valoración funcional de pacientes con enfermedad cerebrovascular [The Barthel Index: A valid instrument for the functional assessment of patients with cerebrovascular disease]. *Revista Española de Geriatría y Gerontología*, *28*, 32-40.

Berr, C., Wancata, J., & Ritchie, K. (2005). Prevalence of dementia in the elderly in Europe. *European Neuropsychopharmacology, 15*, 463-471.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*, 217-228.

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Research, 28*, 193-213.

Castro, C. M., Lee, K. A., Bliwise, D. L., Urizar, G. G., Woodward, S. H., & King, A. C. (2009). Sleep patterns and sleep-related factors between caregiving and non-caregiving women. *Behavioral Sleep Medicine, 7*, 164-179.

Cid-Ruzafa, J., & Damián-Moreno, J. (1997). Valoración de la discapacidad física: El Índice de Barthel [Assessment of physical disability: The Barthel Index]. *Revista Española de Salud Pública, 71*, 127-137.

Creese, J., Bèdard, M., Brazil, K., & Chambers, L. (2008). Sleep disturbances in spousal caregivers of individuals with Alzheimer's disease. *International Psychogeriatrics*, *20*, 149-161.

De Pedro-Cuesta, J., Virués-Ortega, J., Vega, S., Seijo-Martínez, M., Saz, P., Rodríguez, F., Rodríguez-Laso, A., Reñé, R., de las Heras, S. P., Mateos, R., Martínez-Martín, P., Manubens, J. M., Mahillo-Fernández, I., López-Pousa, S., Lobo, A., Reglà, J. L., Gascón, J., García, F. J., Fernández-Martínez, M., Boix, R., Bermejo-Pareja, F., Bergareche, A., Benito-León, J. de Arce, A., & del Barrio, J. L. (2009). Prevalence of dementia and major dementia subtypes in Spanish populations: A reanalysis of dementia prevalence surveys, 1990-2008. *BMC Neurology*, *9*, 55.

D'Onofrio, G., Sancarlo, D., Addante, F., Ciccone, F., Cascavilla, L., Paris, F., Picoco, M., Nuzzaci, C., Elia, A. C., Greco, A., Chiarini, R., Panza, F., & Pilotto, A. (2015). Caregiver burden characterization in patients with Alzheimer's disease or vascular dementia. *International Journal of Geriatric Psychiatry, 30*, 891-899.

First, M. B., Spitzer, R. L., Gibbon, M., & Williams, J. B. W. (1999). *Entrevista clínica estructurada para los trastornos del eje I del DSM-IV – versión clínica (SCID-CV)* [Structured Clinical Interview for DSM-IV Axis I Disorders, Clinician Version (SCID-CV)]. Barcelona: Masson. (Orig. 1997).

Givens, J. L., Mezzacappa, C., Heeren, T., Yaffe, K., & Fredman, L. (2014). Depressive symptoms among dementia caregivers: The role of mediating factors. *The American Journal of Geriatric Psychiatry, 22*, 481-488.

Gooneratne, N. S., & Vitiello, M. V. (2014). Sleep in older adults: Normative changes, sleep disorders, and treatment options. *Clinics in Geriatric Medicine, 30*, 591-627.

Hulley, S. B., Cummings, S. R., & Newman, T. B. (2013). Designing cross-sectional and cohort studies. In S. B. Hulley, S. R. Cummings, W. S. Browner, D. G. Grady, & T. B. Newman (Eds.), *Designing clinical research* (4th ed.) (pp. 85-96). Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins.

IBM (2011). IBM SPSS Statistics for Windows, Version 20.0 [Computer software]. Armonk, NY: IBM Corp.

Ley 39/2006, 2006, 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia [Law 39/2006. The Promotion of Personal Autonomy and Care for People in Situations of Dependency Act]. Boletín Oficial del Estado, 299, December 15, 2006.

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: the Barthel Index. *Maryland State Medical Journal, 14*, 56-61.

McCurry, S. M., Gibbons, L. E., Logsdon, R. G., Vitiello, M. V., & Teri, L. (2009). Insomnia in caregivers of persons with dementia: who is at risk and what can be done about it? *Sleep Medicine Clinics, 4*, 519-526.

McCurry, S. M., Logsdon, R. G., Teri, L., & Vitiello, M. V. (2007). Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment implications. *Sleep Medicine Reviews, 11*, 143-153.

McKibbin, C. L., Ancoli-Israel, S., Dimsdale, J. E., Archuleta, C., von Kanel, R., Mills, P., Patterson, T. L., & Grant, I. (2005). Sleep in spousal caregivers of people with Alzheimer's disease. *Sleep*, *28*, 1245-1250.

Mills, P. J., Ancoli-Israel, S., von Känel, R., Mausbach, B. T., Aschbacher, K., Patterson, T. L., Ziegler, M. G., Dimsdale, J. E., & Grant, I. (2009). Effects of gender and dementia severity on Alzheimer's disease caregivers' sleep and biomarkers of coagulation and inflammation. *Brain, Behavior, and Immunity, 23*, 605-610.

Ohayon, M. M. (2002). Epidemiology of insomnia: What we know and what we still need to learn. *Sleep Medicine Reviews, 6*, 97-111.

Pandi-Perumal, S. R., Seils, L. K., Kayumov, L., Ralph, M. R., Lowe, A., Moller, H., & Swaab, D. F. (2002). Senescence, sleep, and circadian rhythms. *Ageing Research Reviews, 1*, 559-604.

Peng, H. L., & Chang, Y. P. (2013). Sleep disturbance in family caregivers of individuals with dementia: A review of the literature. *Perspectives in Psychiatric Care, 49*, 135-146.

Peng, H. L., Lorenz, R. A., & Chang, Y. P. (2016). Sleep quality in family caregivers of individuals with dementia: a concept analysis. *Clinical Nursing Research, 25*, 448-464.

Qiu, C., De Ronchi, D., & Fratiglioni, L. (2007). The epidemiology of the dementias: An update. *Current Opinion in Psychiatry, 20,* 380-385.

Quinn, T. J., Langhorne, P., & Stott, D. J. (2011). Barthel Index for stroke trials. Development, properties, and application. *Stroke, 42*, 1146-1151.

Rosa, E., Lussignoli, G., Sabbatini, F., Chiappa, A., Di Cesare, S., Lamanna, L., & Zanetti, O. (2010). Needs of caregivers of the patients with dementia. *Archives of Gerontology and Geriatrics, 51*, 54-58.

Rush, A. J., First, M. B., & Blacker, D. (Eds.) (2008). *Handbook of psychiatric measures* (2nd ed.). Washington, DC: American Psychiatric Publishing.

Sainsbury, A., Seebass, G., Bansal, A., & Young, J. B. (2005). Reliability of the Barthel Index when used with older people. *Age and Ageing, 34*, 228-232.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry, 12*, 240-249.

Segerstrom, S. C., Schipper, L. J., & Greenberg, R. N. (2008). Caregiving, repetitive thought, and immune response to vaccination in older adults. *Brain, Behavior, and Immunity, 22*, 744-752.

Smagula, S. F., Krafty, R. T., Taylor, B. J., Martire, L. M., Schulz, R., & Hall, M. H. (2017). Rest-activity rhythm and sleep characteristics associated with depression symptom severity in strained dementia caregivers. *Journal of Sleep Research*, *26*, 718-725.

Tractenberg, R. E., Singer, C. M., Cummings, J. L., & Thal, L. J. (2003). The Sleep Disorders Inventory: An instrument for studies of sleep disturbance in persons with Alzheimer's disease. *Journal of Sleep Research, 12*, 331-337.

Van Mierlo, L. D., Meiland, F. J., van der Roest, H. G., & Dröes, R. M. (2012). Personalised caregiver support: Effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry, 27*, 1-14.

Vázquez, C., & Muñoz, M. (2002). *Entrevista diagnóstica en salud mental* [Diagnostic Interview in Mental Health]. Madrid: Síntesis.