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Prevalence of sleep disturbances in people with dementia living in the community: A systematic review and meta-analysis

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Abstract

This study aimed to systematically review and meta-analyse the prevalence of sleep disturbances in people with dementia and examine demographic predictors and whether overall prevalence has changed over time. We searched Embase, MEDLINE and PsycINFO for studies reporting the prevalence of sleep disturbances in people with dementia living at home. We meta-analysed the data and calculated the pooled prevalence of sleep disturbances in people with dementia overall and in dementia subtypes. We used meta-regressions to investigate the effects of study characteristics, publication dates and participant demographics. Eleven studies fulfilled the inclusion criteria. The pooled prevalence of any symptoms of sleep disturbance was 26% (95% confidence intervals, CI: 23 to 30%; n= 2719) and of clinically significant sleep disturbance 19% (13 to 25%; n= 2753). The pooled prevalence of sleep disturbance symptoms was significantly lower among

people with Alzheimer's disease (24%; 16 to 33%, n=310) than Lewy body dementia (49%; 37 to 61%, n=65). Meta-regression analysis did not find that publication year, participant's age, sex and study quality predicted prevalence. Sleep disturbances are common among people with dementia living in the community, especially in Lewy body dementia. There was no change in prevalence according to publication dates, suggesting treatment has not improved over time.

Keywords: dementia; sleep disturbance; insomnia; systematic review; meta-analysis

1. Introduction

Dementia affects around 50 million people globally, and this is expected to triple by 2050 (World Health Organization, 2020). Cognitive decline is the core symptom of dementia but, neuropsychiatric symptoms (NPS) are common, particularly agitation, apathy, depression, irritability, sleep disturbances and psychotic symptoms (Ryu et al., 2005; Siafarikas et al., 2018).

Sleep disturbances are defined as any disturbance to the sleep process and encompass difficulties in falling or staying asleep, short sleep duration, getting up during the night, early morning wakening and excessive daytime sleepiness (Boeve et al., 2002; McCleery & Sharpley, 2020). In people with dementia, the suprachiasmatic nucleus of the hypothalamus, sometimes referred to as the body's "internal clock" often undergoes extensive neurodegeneration (Vitiello & Borson, 2001). This can disrupt the circadian rhythm of sleep and wakefulness, resulting in disturbed sleep (Cipriani et al., 2015). Other contributors to sleep disturbances in people with dementia include light and noise

exposure, lack of stimulation and exercise during the day, medical and psychiatric morbidity, and medications (Vitiello & Borson, 2001).

Poor sleep may contribute to agitation, aggression and irritability (Cipriani et al., 2015; Webster et al., 2020), decreased social engagement (Ooms & Ju, 2016), and reduced attention and motivation, which can impact cognitive performance (Cole & Richards, 2005). Poor sleep is also associated with greater risk of depression, cardiovascular disease, diabetes, and falls in older adults (Bonanni et al., 2010; Jaussent et al., 2011; Philipps & Mannino, 2007; Stone et al., 2014). In addition, disturbed sleep may contribute to amyloid deposition, increased Tau and inflammation leading to neurodegeneration, and so cause or worsen cognitive impairment (Livingston et al., 2020).

Disrupted sleep is problematic for those who live with and care for someone with dementia. Caregivers' sleep may be impacted by having to attend to the care recipients' needs and behaviours and provide comfort at night (Peng et al., 2018; Webster et al., 2020) and by worry and anxiety about the care recipient (Gibson et al.,2014; Peng et al., 2018). Consequently, the caregiver's physical and mental health may be impacted (Cipriani et al. 2015), and it is more common that those relatives become unable to continue caring, and the care recipient has to move into a care home (Reinhard et al., 2008).

Disturbed sleep is one of the most reported symptoms in people with dementia (Zhao et al., 2016), but estimates of its prevalence vary significantly, ranging between 5% (Koopmans et al., 2009) and 86% (Hsieh et al., 2009). Differences in the measures used to identify sleep problems, dementia subtypes, and dementia severity of people in the sample being studied,

might all contribute to this variability in estimates. The prevalence of sleep disturbance may also vary depending on the setting in which the persons with dementia live. Home setting and long-term residential setting are two very different contexts; for example, they differ in privacy and noise levels.

A systematic review and meta-analysis of fifty-five studies of people with dementia living in care homes reported the pooled prevalence of clinically significant sleep disturbances to be 20% measured via validated questionnaires and 70% when sleep problems were measured using actigraphy (Webster et al., 2020a), which is not validated in older people with dementia. It is important to consider sleep disturbances in people with dementia living in their own homes separately to those living in a care home setting, as around 84% of people with dementia across the world live in the community (Wimo et al., 2018), and sleep disturbances are a predictor of people with dementia living in the community moving into care homes (Gaugler et al., 2000; Hope et al., 1998).

To our knowledge, there is currently no systematic review and meta-analysis of the prevalence of sleep disturbances in people living with dementia in their own homes. In this review, we aim to address this gap and establish the overall prevalence of sleep disturbances in home-dwelling people with dementia, the prevalence in dementia subtypes and explore in meta-regression study characteristics that predict prevalence rates.

2. Methods

We registered our review protocol with the Prospero International Prospective Register of Systematic Reviews (CRD42021244411). We searched Embase, MEDLINE and PsycINFO,

from database inception to April 30, 2021. We used the following terms, developed from those used in a systematic review on the prevalence of sleep disturbances in people with dementia living in care homes (Webster et al., 2020a): (dementia OR demented OR Alzheimer*) AND (sleep* OR insomnia OR circadian OR night* OR neuropsychiatric) AND (prevalence OR epidemiolog* OR frequency), without any restrictions on language. We further restricted the search to "humans". The search strategy is presented in the Appendix A. We hand-searched the reference lists of included studies for further relevant studies. We translated twenty-four non-English articles to determine their eligibility.

2.1 Inclusion and exclusion criteria

We included quantitative studies reporting:

- a) the prevalence of sleep disturbances in a complete or representative sample of people with dementia living in their own homes;
- b) sleep disturbances in individuals with a clinical dementia diagnosis or one using standardised diagnostic criteria;
- c) sleep disturbances measured via validated questionnaires for sleep disturbance in dementia populations or actigraphy;
- results for people with dementia living in their own homes separately from those living in care homes;
- e) cross-sectional or longitudinal data (if longitudinal, we included baseline data only).
 We excluded studies if:
 - a) the study did not specify where people with dementia lived;
 - b) sleep disturbances were inclusion criteria;

- c) the study reported prevalence of primary sleep disorders (e.g. REM sleep behaviour disorder) rather than sleep disturbances;
- d) the study was a randomised controlled trial, pilot, or feasibility study.

2.2 Screening and data extraction

Two researchers (TK and EF) independently screened the first twenty search results to assess exclusion procedure reliability. There was an agreement on all papers. TK screened all papers and EF independently screened a random 25% of titles and abstracts and full texts. Disagreements were resolved by a discussion with two other researchers (GL and PR). TK extracted and entered data from the papers into the pre-piloted form. Data extracted included: first author, year, country, study design, mean age, percentage of males, dementia diagnosis criteria, dementia type, dementia severity, recruitment method, measure of sleep disturbances, sample size assessed for sleep disturbances and number of cases. EF crosschecked 25% of data extraction. We contacted the authors of five studies (Guerra Hernandez et al., 2011; Manini et al., 2021; Menegardo et al, 2019; Storti et al., 2016; Teipel et al., 2015), where the data required was not reported, but did not receive additional data, and so the studies were excluded.

2.3 Methodological quality

Two researchers (TK and EF) independently examined the quality of included studies using the Mixed Methods Appraisal Tool (MMAT) – Version 2011, criteria for the quantitative descriptive studies (Pluye et al., 2011). This assesses the quality of different studies on four elements:

1. Is the sampling strategy relevant to address the quantitative research question?

- 2. Is the sample representative of the population understudy?
- 3. Are measurements appropriate (valid or standardised instrument)?
- 4. Is there an acceptable response rate (60% or above)?

Each study is given a point for each criteria met, with potential scores ranging from 0-4, where a higher score indicates a higher quality study.

2.4 Data analysis

Given the prevalence of sleep disturbance varies notably depending on what is measured (Webster et al., 2020a), we separated the prevalence data into two categories of measurement: (1) sleep disturbance symptoms and (2) clinically significant cases of sleep disturbances. Sleep disturbance symptoms are defined as any sleep disturbance irrespective of severity or frequency (Webster et al., 2020a). Clinically significant cases of sleep disturbance are defined as a score of 4 or higher on The Neuropsychiatric Inventory (NPI) (Cummings, 1994) sleep item, obtained by multiplying frequency and severity scores (Cummings, 2020).

We then used STATA version 16.0 to conduct separate meta-analyses for symptoms and clinically significant cases. We computed the study-specific prevalence estimates and standard errors, along with 95% confidence intervals (CI) using the "*metaprop*" command (Nyaga, 2014). We also employed the "*metaprop*" command, which uses inverse-variance weights, to conduct the logistic-normal random-effects model of overall pooled prevalence and associated 95% CI. We computed the 95% CI using the exact method recommended for binomial data (Newcombe, 1998). We used the I^2 statistic to assess heterogeneity where I^2 equal to or greater than 50% indicated a high heterogeneity (Higgins & Thompson, 2002).

We conducted a sub-group meta-analysis on the prevalence of symptoms of sleep disturbance by dementia subtypes. To investigate if participant demographics or study characteristics could account for the high heterogeneity in prevalence estimates, we conducted a random-effects meta-regression using the *"metareg"* command (Higgins & Thompson, 2002). In six separate meta-regressions, we combined the data from the metaanalyses and examined the study covariates of publication year, age of participants, percentage of males in the sample, method of measurement, sampling strategy and study quality. In the meta-regressions, we added the category of measurement as a first covariate as it is a significant moderator of prevalence (Webster et al., 2020a).

We assessed the non-reporting bias using funnel plots generated by "*metafunnel*" command in the studies meta-analysed. We completed sensitivity analyses including only high-quality studies. As some studies did not have an acceptable response rate (as defined by MMAT) or did not report the response rate, we regarded those studies as lower quality studies.

3. Results

We screened 6432 studies (see Figure 1, PRISMA diagram) of which 11 studies, comprising 14 reports on the prevalence of sleep disturbances, fulfilled the inclusion criteria (see Table 1). Six studies were conducted in low-to-middle income countries (Acosta-Castillo et al. 2012; Baiyewu et al., 2003; Baiyewu et al., 2012; Haibo et al., 2013; Paddick et al., 2014; Yoro-Zohoun et al., 2019) and five in high-income countries (Aalten et al., 2003; Caputo et al., 2008; Férnandez-Martinez et al., 2008; Honda et al., 2013; Lyketsos et al., 2002). The majority of studies (Acosta-Castillo et al., 2012; Baiyewu et al., 2003; Baiyewu et al., 2012; Baiyewu et al., 2003; Caputo et al., 2008; Férnandez-Martinez et al., 2012; Baiyewu et al., 2003; Baiyewu et al., 2012; Caputo et al., 2008; Férnandez-Martinez et al., 2008; Honda et al., 2013; Lyketsos et al., 2002). The

Haibo et al., 2013; Paddick et al., 2014; Yoro-Zohoun et al., 2019, Férnandez-Martinez et al., 2008) were population-based, employing a door-to-door approach to recruitment. In three studies (Aalten et al. 2003; Caputo et al., 2008; Honda et al., 2013), participants were selected from a consecutive series of patients presenting to memory clinics. In one study, the cohort was identified through national health insurance lists (Lyketsos et al., 2002). Most studies (Acosta-Castillo et al., 2012; Baiyewu et al., 2003; Baiyewu et al., 2012; Férnandez-Martinez et al., 2008; Honda et al., 2013; Paddick et al., 2014; Yoro-Zohoun et al., 2019) reported the prevalence of sleep disturbance symptoms. One study (Caputo et al., 2008), reported the prevalence of clinically significant cases of sleep disturbance, and three studies (Aalten et al., 2013; Haibo et al., 2013; Lyketsos et al., 2002) reported the prevalence estimates of both symptoms and clinically significant cases of sleep disturbance. These three studies were therefore included in both meta-analyses.

Most studies used the NPI sleep disturbance item to measure sleep disturbance. The NPI is an informant-based interview covering 12 NPS domains completed by a clinician (Cummings, 2020). Sleep is assessed via the sleep and night-time behaviour disturbance item of the NPI, measuring sleep disturbances during night-time, early morning awakening and excessive daytime sleepiness. Three studies employed the Neuropsychiatric Inventory-Questionnaire (NPI-Q) sleep item to measure sleep disturbance, which is a brief questionnaire form of the NPI, completed by an informant and is validated for use in dementia populations (Kaufer et al., 2000). The screening question for sleep disturbance is derived from the NPI, but the NPI-Q does not contain sub-questions and only considers the severity of NPS.

3.1 Study quality

The overall scores on the MMAT were three or four (Table 1). Five studies were of high quality, scoring 4 points and six scored 3 points. Five studies did not report how many people responded, and in one study, less than 60% of potential participants participated.

3.2 Prevalence of sleep disturbance symptoms

Ten studies, including a total of 2719 participants, provided the prevalence of sleep disturbance symptoms in people with dementia living at home. The prevalence estimates ranged from 17% to 37%, and the pooled prevalence was 26% (95% CI: 23 to 30%) (see Figure 2). The heterogeneity was high (l^2 = 72.8%). We also conducted a sensitivity analysis by removing five lower quality studies, as assessed by the MMAT (Baiyewu et al., 2003; Paddick et al., 2014; Aalten et al., 2003; Férnandez-Martinez et al., 2008; Honda et al., 2013). The prevalence estimates ranged from 22% to 37%, and the pooled prevalence was similar, although slightly higher (28%; 95% CI: 22 to 33%). Again, the heterogeneity was high (l^2 = 80.9%).

3.3 Prevalence of clinically significant cases of sleep disturbances

Four studies with a total of 2753 participants reported clinically significant cases of sleep disturbance in people with dementia living in their own homes. The prevalence across individual studies ranged from 13% to 26% (see Figure 3). The pooled prevalence was 19% (95% CI: 13 to 25%), with significant heterogeneity present (I^2 = 92.8%). We also conducted a sensitivity analysis by removing two lower quality studies (Aalten et al., 2003; Caputo et al., 2008). The pooled estimate prevalence slightly decreased from 19% to 16% (95% CI: 15 to 18%).

3.4 Prevalence of sleep disturbances by dementia subtype

In terms of dementia subtypes, three studies reported the prevalence of sleep disturbances for Alzheimer's disease and vascular dementia (Paddick et al., 2014; Férnandez-Martinez et al., 2008; Honda et al., 2013), and two studies (Férnandez-Martinez et al., 2008; Honda et al., 2013) provided data for Lewy body dementia and frontotemporal dementia. The pooled prevalence of sleep disturbance symptoms varied by dementia subtype (see Figure 4). The pooled prevalence of sleep disturbance symptoms was 24% (95% CI: 16 to 33%) for Alzheimer's disease, 32% (95% CI: 11 to 52%) for frontotemporal dementia, 35% (95% CI: 22 to 47%) for vascular dementia and 49% (95% CI: 37 to 61%) for Lewy body dementia, with non-overlapping confidence intervals between Alzheimer's disease and Lewy body dementia. There were no other significant differences in the prevalence of sleep disturbances.

3.5 Meta-regressions

Meta-regressions did not find that any covariates significantly moderated the estimates of prevalence (all p > 0.10). We investigated reporting bias using funnel plots. The funnel plot for meta-analysis of symptoms appeared to be symmetrical (see Figure 5). The funnel plot for meta-analysis of clinically significant cases appeared to be asymmetrical (see Figure 6).

4. Discussion

This study is the first systematic review and meta-analysis to synthesise the evidence on the prevalence of sleep disturbances in people with dementia living at home. The pooled prevalence of symptoms of sleep disturbance in people with dementia living at home was

26%, and of clinically significant cases, 19%. Prevalence was significantly higher in people with Lewy body dementia than in those with Alzheimer's disease (49% vs. 24%). There was no change in prevalence rates over time according to publication dates.

Compared to the community-dwelling elderly, where the prevalence of sleep disturbances was found to be 30.5% (Bao et al., 2017), it seems people with dementia have comparable, although slightly less sleep disturbance.

We found the pooled prevalence of having any symptom of sleep disturbance to be 26% (95% CI: 23 to 30%). The prevalence in the community was, thus, lower than the pooled prevalence in care homes reported previously (38%; 95% CI: 33 to 44%) (Webster et al., 2020a). Given that people with dementia and sleep disturbances are more likely to move into care homes than those without sleep disturbances (Porter et al., 2016), this would be expected unless care homes were able to improve sleep or if sleep disturbances resolved over time.

People living in their own homes may sleep better than those living in care homes because environmental factors that contribute to sleep disturbances in dementia may be exacerbated by living in a care home. For example, insufficient daytime light and noise in a care home can contribute to sleep disturbance (Ancoli-Israel & Vitiello, 2006), and individuals may be disturbed by other residents or night-time care procedures (Neikrug & Ancoli-Israel, 2010). Additionally, in care homes, residents often go to bed early due to the care home culture (Luff et al., 2011). Staff shift changes and lower night-staffing levels especially influence residents' bedtimes, as staff may want to get residents ready before the

nightshift begins (Luff et al., 2011). Many residents thus spend several more hours in bed than needed for sufficient sleep, which can fragment and disturb sleep (Reynold et al., 2014). Furthermore, people living in care homes tend to be less active during the day than people living in their own homes (Douma et al., 2017), which may also contribute to sleep disturbance. However, there may be under-reporting in care homes as the persons' sleep difficulties may be less recognised by the care home staff than by someone who shares a bed with them.

Moreover, people with dementia living in care homes are generally at a more severe stage of dementia. Studies in our meta-analysis included participants across the severity range of dementia, with the majority being in moderate stages. As some studies find that sleep disturbances increase as the severity of dementia increases (Caputo et al., 2008; Huang et al., 2017), a lower pooled prevalence in the current study might be expected. However, others reported no evidence of an association between dementia severity and frequency of sleep disturbance in care homes (Webster et al., 2020a; Castineiras et al., 2012; Suzuki et al., 2017).

Interestingly, we did not find a lower prevalence of clinically significant sleep disturbance in the community than in care homes. We found the pooled prevalence of clinically significant sleep disturbance of people with dementia living at home to be 19% (95% CI: 13 to 25%). This was similar to the care home study, which found a pooled estimate of clinically significant cases to be 20% (95% CI: 16 to 25%) (Webster et al., 2020a).

We found the pooled prevalence of sleep disturbances varied by dementia subtype, possibly due to different underlying neuropathological processes associated with the disease (Rongve et al., 2010). Symptoms of sleep disturbances were less common in those with Alzheimer's disease than Lewy body dementia. This is in line with a smaller previous study of 431 patients that found sleep disturbances were less prevalent in Alzheimer's disease (48%) compared to Lewy body dementia (66.7%) (Guarnieri et al., 2012) and with specific sleep disturbance (REM behaviour sleep disorder) being one of the features which contributes to a diagnosis of Lewy body dementia.

Meta-regression analysis revealed that prevalence estimates of sleep disturbances were not affected by the year of publication, which ranged between 2002 and 2018. This indicates that any possible advances in sleep disturbance treatment have not been reflected in improvements for individuals with dementia. The average age of the participants did not affect the prevalence estimates of sleep disturbance, which is in line with a previous study (Webster et al., 2020a). Our study also found no association between the percentage of males and the prevalence, suggesting sex does not affect the likelihood of experiencing sleep disturbances in people with dementia living in the community.

Another factor that varied across studies was the measure of sleep disturbances. Even though the NPI and NPI-Q have been cross-validated, the prevalence of symptoms reported on them can differ by as much as 15% (Boada et al., 2002; Camozzato et al., 2014). This could be because the NPI-Q sleep screening question is broader than that of the NPI. The measures are also administered in a different format, which could introduce bias, however,

in this instance the meta-regression analyses revealed that the method of measurement did not significantly affect the prevalence estimates of sleep disturbances.

The majority of studies in our meta-analysis employed population-based sampling. But in three studies, participants were selected from a consecutive series of patients presenting to memory clinics. Because NPS are an important feature of why individuals with dementia present to clinics (Peters et al., 2006), this may have increased the prevalence estimates of sleep disturbances. However, our analysis showed that the sampling method did not affect the results of individual studies.

4.1 Strengths and weaknesses of the review

We searched three databases with no restrictions on language and included studies conducted across four continents, increasing the generalizability of the findings. Overall, 48% of the included participants were from low-to-middle income countries (LMICs). Given that around 60% of people with dementia live in LMICs (Prince et al., 2015), this was a better representation of people living in those countries than in most dementia research (Sexton et al., 2021). Conducting a sub-group analysis and meta-regressions to identify sources of heterogeneity between the studies was also a strength.

Quality assessment by two reviewers independently using the MMAT indicated low risk of sampling and selection bias in primary studies. Information bias might be present as NPI and NPI-Q, are observer-rated instruments and they do not directly evaluate sleep disturbances but rely on information gathered from the informants. However, they are validated and reliable measures, and meta-regression did not find a difference between the prevalence

rates depending on which method of measurement was used. Although we included any instrument, most studies had used the NPI to assess sleep. There was a presence of nonresponse bias in several studies, which was accounted for by conducting sensitivity analyses of only studies with an acceptable response rate. Funnel plot asymmetry for studies reporting the prevalence of clinically significant cases of sleep disturbances indicated the presence of non-reporting bias. As prevalence estimates are unlikely to be affected by publication bias, other sources such as poor methodological quality, true heterogeneity, artefactual and chance could account for the funnel plot asymmetry (Sedgwick, 2013; Page et al., 2021). There was no indication of reporting bias for studies reporting the prevalence of sleep disturbance symptoms.

Only three included studies assessed sleep disturbances in dementia subtypes, so we were unpowered to show differences between all the subtypes. There are also relatively few studies, so there are fewer people in the rare dementia groups and there may be more differences between the subtypes that we were unable to detect. Moreover, we were unable to explore other potential sources of heterogeneity because relevant information such as dementia severity was not routinely reported. Secondly, most people living with dementia have other illnesses, for example depression, physical disability and pain, that may in itself cause sleep disturbances (Browne et al., 2017; Gulia & Kumar, 2018). However, as the included studies did not report such data, we were not able to comment on whether these problems caused sleep disturbances, either independently or together with dementia. While it is a strength that studies were quite diverse in terms of geographic region, as most studies in dementia come from higher income countries this may have contributed to differences in prevalence of sleep disorders by dementia subtypes.

There is high but acceptable heterogeneity. Over 75% is used as a cut-off to indicate considerable heterogeneity and lack of generalisability (Deeks et al., 2019).

4.2 Implications of the findings

This study shows that sleep disturbances are common in people with dementia living at home. There are, however, currently no treatments with conclusive effectiveness for sleep disturbances in dementia (Forbes et al., 2014; Gibson et al., 2016; Kinnunen et al., 2017; McCleery et al., 2014; Tewary et al., 2016). This is reflected in our study as the prevalence of sleep disturbances did not change over the years, indicating that current treatments are not making an impact.

Reducing the prevalence of sleep disturbances in dementia thus remains an important challenge, especially due to the relatively high prevalence of sleep disturbances reported across studies, combined with the detrimental effects sleep disturbances have on both people with dementia and their family caregivers (Cipriani et al., 2015; Cole & Richards et al., 2005; Gibson et al., 2014; Jaussent et al., 2011; Ooms et al., 2016; Peng et al., 2018; Webster et al., 2020). Differential prevalence levels for differential subtypes indicates the importance for clinicians to be aware of the increased risks for different groups.

Further longitudinal studies may inform us whether sleep disturbances in people with dementia living in the community resolve on their own. This, however, seems unlikely given that a recent study of people with dementia living in care homes found that sleep disturbance symptoms resolved for only just over a quarter of people (Webster, 2020).

Given the high prevalence of sleep disturbances, a future research priority should be to understand the other effects that sleep disturbances have on people with dementia. The potential for interventions to increase the time that people with dementia can live well at home and delay transition to a care home should also be explored. Additionally, future research should explore the effects that sleep disturbances have on cognition. There is evidence that insomnia may increase the risk of dementia (de Almondes et al., 2016; Shi et al., 2018), and it is thus worth investigating how sleep may impact cognition in people with dementia, and further, if improved sleep could potentially help stabilise or even slow cognitive decline in people with dementia.

In conclusion, we have demonstrated that sleep disturbances are prevalent in people with dementia living in the community in many different countries, occurring more frequently in people with Lewy body dementia than Alzheimer's disease. We have also found no change in prevalence rates over twenty years of studies, suggesting that there has been no improvement in treatment received.

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Declaration of Interest

Declarations of interest: none.

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Reference List:

Aalten, P., de Vugt, M.E., Lousberg, R., Korten, E., Jaspers, N., Senden, B., Jolles, J., Verhey,
 F.R.J., 2003. Behavioral problems indementia: A factor analysis of the
 neuropsychiatric inventory. *Dement Geriatr Cogn Disord.* 15(2), 99-105.
 https://doi.org/10.1159/000067972

Acosta-Castillo, G.I., Sosa, A.L., Orozco, R., Borges, G., 2012. Neuropsychiatric symptoms in older adults with dementia and their relationship to disease severity. *Re Invest Clin.* 64(4), 354-363. https://www.medigraphic.com/pdfs/revinvcli/nn-2012/nn124f.pdf.

- Adebiyi, A.O., Fagbola, M.A., Olakehinde, O., Ogunniyi, A., 2016. Enacted and implied stigma for dementia in a community in south-west Nigeria. *Psychogeriatrics.* 16(4), 268-273. https://doi.org/10.1111/psyg.12156
- Ancoli-Israel, S., Vitiello, M.V., 2006. Sleep in Dementia. *Am J Geriatr Psychiatry*. 14(2), 91-94. https://doi.org/10.1097/01.JGP.0000200973.93494.aa
- Anor, C.J., O'Connor, S., Saund, A., Tang-Wai, D.F., Keren, R., Tartaglia, M. C., 2017.
 Neuropsychiatric Symptoms in Alzheimer's Disease, Vascular Dementia, and Mixed
 Dementia. *Neurodegener Dis.* 17, 127-134. https://doi.org/10.1159/000455127
- Baiyewu, O., Smith-Gamble, V., Akinbiyi, A., Lane, K.A., Hall, K.S., Ogunniyi, A., Gureje, O., Hendrie, H.C., 2003. Behavioural and Caregiver Reaction of Dementia as Measured by the Neuropsychiatric Inventory in Nigerian Community Residents. *Int Psychogeriatr.* 15(4), 399-409. https://doi.org/10.1017/S1041610203009645
- Baiyewu, O., Unverzagt, F.W., Ogunniyi, A., Smith-Gamble, V., Gureje, O., Lane, K.A., Gao, S.,
 Hall, K.S., Hendrie, H.C., 2012. Behavioural symptoms in community-dwelling elderly
 Nigerians with dementia, mild cognitive impairment, and normal cognition. *Int J Geriatr Psychiatry*. 27, 931-939. https://doi.org/10.1002/gps.2804
- Bao, Y., Han, Y., Ma, Y., Wang, R., Shi, L., Wang, T., He, J., Yue, J., Shi, J., Tang, X., Lu, L., 2017.
 Cooccurence and bidirectional prediction of sleep disturbances and depression in older adults: Meta-analysis and systematic review. *Neurosci Biobehav Rev.* 75, 257-273. https://doi.org/10.1016/j.neubiorev.2017.01.032
- Boada, M., Cejudo, J.C., Tàraga, L., López, O.L., Kaufer, D., 2002. Neuropsychiatric Inventory Questionnaire (NPI-Q): Spanish validation of an abridged form of the Neuropsychiatric Inventory (NPI). *Neurologia*. 17(6), 317-323.
- Boeve, B.F., Silber, M.H., Ferman, T.J., 2002. Current Management of Sleep Disturbances in Dementia. *Curr Neurol Neurosci Rep.* 2(2), 169-177. https://doi.org/10.1007/s11910-002-0027-0
- Bonanni, E., Tognoni, G., Maestri, M., Salvati, N., Fabbrini, M., Borghetti, D., Di Coscio, E.,
 Choub, A., Sposito, R., Pagni, C., Iudice, A., Murri, L., 2010. Sleep disturbances in
 elderly subjects: an epidemiological survey in an Italian district. Acta Neurol Scand.
 122,389-397. https://doi.org/10.1111/j.1600-0404.2010.01324.x
- Browne, J., Edwards, D.A., Rhodes, K.M., Brimicombe, D.J., Payne, R.A., 2017. Association of comorbidity and health service usage among patients with dementia in the UK: a

population-based study. *BMJ Open.* 7(3),1-8. http://dx.doi.org/10.1136/bmjopen-2016-012546

- Camozzato, A.L., Godinho, C., Kochhann, R., Massochini, G., Chaves, M.L., 2014. Validity of the Brazilian version of the Neuropsychiatric Inventory Questionnaire (NPI-Q). *Arq Neuropsiquiatr*. 73(1),41-45. https://doi.org/10.1590/0004-282X20140177
- Caputo, M., Monastero, R., Mariani, E., Santucci, A., Mangialasche, F., Camarda, R., Senin,
 U., Mecocci, P., 2008. Neuropsychiatric symptoms in 921 elderly subjects with
 dementia: a comparison between vascular and neurodegenerative types. *Acta Psychiatr Scand*. 117(6), 455-464. https://doi.org/10.1111/j.1600-0447.2008.01175.x
- Castineiras, A.R., Diaz Gravalos, G.J., Hermida, S.R., Gonzalez, A.L., Gil, C.V., Caballero, A.A., 2012. Prevalencia de síntomas neuropsiquiátricos en pacientes institucionalizados con diagnóstico de demencia y factores asociados: estudio transversal multicéntrico. *Rev Esp Geriatr Gerontol.* 47, 96-101. https://doi.org/ 10.1016/j.regg.2012.02.002
- Cipriani, G., Lucetti, C., Danti, S., Nuti, A., 2015. Sleep disturbances and dementia. *Psychogeriatrics.* 15(1), 65-74. https://doi.org/10.1111/psyg.12069
- Cole, C., Richards, K., 2005. Sleep and cognition in Alzheimer's disease. *Issues Ment Health Nurs.* 26(7), 687-698. https://doi.org/10.1080/01612840591008258
- Creese, J., Bédard, M., Brazil, K., Chambers, L., 2008. Sleep disturbances in spousal caregivers of individuals with Alzheimer's disease. *Int Psychogeriatr.* 20(1), 149-161. https://doi.org/10.1017/S1041610207005339
- Cummings, J.L., 1994. The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. *Neurology*. 48(Suppl. 6), 10-16.
- Cummings, J.L., 2020. The Neuropsychiatric Inventory: Development and Applications. *J Geriatr Psychiatry*. 33(2):74-84. https://doi.org/10.1177/0891988719882102
- de Almondes, K.M., Costa, M.V., Malloy-Diniz, L.F., Diniz, B.S., 2016. Insomnia and risk of dementia in older adults: Systematic review and meta-analysis. *J Psychiatr Res.* 77, 109-115. http://dx.doi.org/10.1016/j.jpsychires.2016.02.021
- Deeks, J.J., Higgins, J.P.T., Altman, D.G. 2019. Analysing data and undertaking meta-analyses.
 In Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., Welch,
 V.A. (Eds.) Cochrane Handbook for Systematic Reviews of Interventions.
 https://doi.org/10.1002/9781119536604.ch10

- Douma, J.G., Volkers, K.M., Engels, G., Sonneveld, M.H., Goossens, R.H.M., Scherder, E.J.A.,
 2017. Setting-related influences on physical inactivity of older adults in residential
 care settings: a review. *BMC Geriatr.* 17,97-107. https://doi.org/10.1186/s12877-017-0487-3
- Férnandez-Martinez, M., Castro Flores, J., Pérez de las Heras, S., Mandaluniz Lekumberri, A.,
 Gordejuela Menocal, M., Zarranz Imirizaldu, J.J., 2008. Prevalence of
 Neuropsychiatric Symptoms in Elderly Patients with Dementia in Mungialde County
 (Basque Country, Spain). *Dementia Geriatr Cogn Disord*. 25,103-108.
 https://doi.org/10.1159/000112215
- Ferri, C.P., Ames, D., 2014. Behavioural and Psychological Symptoms of Dementia in developing countries. Int Psychogeriatr.16(4), 441-459. https://doi.org/10.1017/S1041610204000833
- Forbes, D., Blake, C., Thiessen, E., Peacock, S., Hawranik, P., 2014. Light therapy for improving cognition, activities of daily living, sleep, challenging behaviour, and psychiatric disturbances in dementia. *Cochrane Database Syst Rev.* https://doi.org/10.1002/14651858.CD003946.pub4
- Fuh, J.L., Wang, S.J., Cummings, J.L., 2005. Neuropsychiatric profiles in patients with Alzheimer's disease and vascular dementia. J Neurol Neurosurg Psychiatry. 76, 1337-1341. https://doi.org/10.1136/jnnp.2004.056408
- Gaugler, J.E., Edwards, A.B., Femia, E.E., Zarit, Z.H., Parris Stephens, M., Townsend, A.,
 Greene, R., 2000. Predictors of Institutionalization of Cognitively Impaired Elders:
 Family Help and the Timing of Placement. *J Gerontol.* 55(4), 247-255.
 https://doi.org/10.1093/geronb/55.4.P247
- Gibson, R.H., Gander, P.H., Dowell, A.C., Jones, L.M., 2016. Nonpharmacological interventions for managing dementia-related sleep problems within community dwelling pairs: a mixed-method approach. *Dementia*.16(8), 967-984. https://doi.org/10.1177/1471301215625821.
- Gibson, R.H., Gander, P.H., Jones, L.M., 2014. Understanding the sleep problems of people with dementia and their family caregivers. *Dementia*. 13(3),350-265. https://doi.org/10.1177/1471301212473884
- Guarnieri, B., Adorni, F., Musicco, M., Appollonia, I., Bonnani, E., Caffarra, P., Caltagirone, C., Cerroni, G., Concari, L., Consentino, F.I.I., Ferarra, S., Fermi, S., Ferri, R., Gelosa, G.,

Lombardi, G., Mazzei, D., Mearelli, S., Morrone, E., Murri, L., Nobili, F.M., Passero, S., Perri, R., Rocchi, R., Sucapane, P., Tognoni, G., Zabberoni, S., Sorbi, S., 2012. Prevalence of Sleep Disturbances in Mild Cognitive Impairment and Dementing Disorders: A Multicenter Italian Clinical Cross-Sectional Study on 431 patients. *Dement Geriatr Cogn Disord*. 33,50-58. https://doi.org/10.1159/000335363

- Guerra Hernandez, M.A., Guerra, J.J.L., Arjona, L.G., 2011. Síntomas psicológicos y conductuales en adultos mayores con diagnóstico de demencia. *Pan Cuba Salud.* 6(2-3), 20-25.
- Gulia, K.K., Kumar, V.M., 2018. Sleep disorders in the elderly: a growing challenge. *Psychogeriatrics.* 18, 155-165. https://doi.org/10.1111/psyg.12319
- Haibo, X., Shifu, X., Pin, N., Chao, C., Guorong, M., Xuejue, L., Shiming, B., Wenli, F., Jun, L., Mingyuan, Z., McCabe, M.P., 2013. Prevalence and severity of behavioral and psychological symptoms of dementia (BPSD) in community dwelling Chinese: findings from the Shanghai three districts study. *Aging Ment Health*. 17(6), 748-752. http://dx.doi.org/10.1080/13607863.2013.781116
- Higgins, J.P.T., Thompson, S.G., 2002. Quantifying heterogeneity in meta-analysis. *Stat Med.* 21(11), 1539-1558. https://doi.org/10.1002/sim.1186.
- Honda, K., Hashimoto, M., Yatabe, Y., Kaneda, K., Yuki, S., Ogawa, Y., Matsuzaki, S.,
 Tsuyuguchi, A., Tanaka, H., Kashigawi, H., Hasegawa, N., Ishikawa, T., Ikeda, M.,
 2013. The usefulness of monitoring sleep talking for the diagnosis of dementia with
 Lewy bodies. *Int Psychogeriatr.* 25(5), 851-858.
 https://doi.org/10.1017/S1041610213000185
- Hope, T., Keene, J., Gedling, K., Fairburn, C.G., Jacoby, R., 1998. Predictors of Institutionalization for People with Dementia Living at Home with a Carer. Int J Geriatr Psychiatry. 13, 682-690. https://doi.org/10.1002/(sici)1099-1166(1998100)13:10<682::aid-gps847>3.0.co;2-y
- Hsieh, C., Chang, C., Lin, C., 2009. Neuropsychiatric profiles of patients with Alzheimer's disease and Vascular Dementia in Taiwan. *Int J Geriatr Psychiatry*. 24(6), 570-577. https://doi.org/10.1002/gps.2156
- Huang, S., Wang, W., Liao, Y., 2017. Severity and prevalence of behavioural and psychological symptoms among patients of different dementia stages in Taiwan.
 Arch Clin Psychiatry. 44(4), 89-93. https://doi.org/10.1590/0101-6083000000127

- Jaussent, I., Bouyer, J., Ancelin, M., 2011. Insomnia and Daytime Sleepiness Are Risk Factors for Depressive Symptoms in the Elderly. *Sleep.* 34(8), 1103-1110. https://doi.org/10.5665/SLEEP.1170
- Kaufer, D.I., Cummings, J.L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O.L., DeKosky, S.T., 2000. Validation of the NPI-Q, a Brief Clinical Form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci.* 12(2), 233-239. https://doi.org/10.1176/jnp.12.2.233
- Kinnunen, K.M., Vikhanova, A., Livingston, G., 2017. The management of sleep disorders in dementia: an update. *Curr Opin Psychiatry*. 30, 491-497. https://doi.org/10.1097/YCO.00000000000370
- Koopmans, R.T.C.M., van der Molen, M., Raats, M., Ettema, T.P., 2009. Neuropsychiatric symptoms and quality of life in patients in the final phase of dementia. *Int J Geriatr Psychiatry*. 24(1), 25-32. https://doi.org/10.1002/gps.2040
- Livingston, G, Huntley, J., Sommerland, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales, H.C., Kivimäki, M., Larson, E.B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sampson, E.L., Samus, Q., Schneider, L.S., Selbæk, G., Teri, L., Mukamad, N. 2020. Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission. *The Lancet Commision*. 396(10248). 413-446. https://doi.org/10.1016/S0140-6736(20)30367-6
- Luff, R., Ellmers, T., Eyers, I., Young, E., Arber, S., 2011. Time spent in bed at night by carehome residents: choice or compromise? *Ageing Soc.* 33(7), 1229-1250. https://doi.org/10.1017/S0144686X10001285
- Lyketsos, C.G., Lopez, O., Jones, B., Fitzpatrick, A.L., Breitner, J., DeKosky, S., 2002. Prevalence of Neuropsychiatric Symptoms in Dementia and Mild Cognitive Impairment. *JAMA*. 288(12), 1475-1483. https://doi.org/10.1001/jama.288.12.1475
- Lyketsos, C.G., Steinberg, M., Tschanz, J.T., Norton, M.C., Steffens, D.C., Breitner, J.C.S., 2000
 Mental and Behavioural Disturbances in Dementia: Findings From the Cache County
 Study on Memory and Aging. *Am J Psychiatry*. 157, 708-714.
 https://doi.org/10.1176/appi.ajp.157.5.708

Manini, A., Brambilla, M., Maggiore, L., Pomati, S., Pantoni, L., 2021. The impact of lockdown during SARS-CoV-2 outbreak on behavioral and psychological symptoms of dementia. *Neurol Sci.* 42(3), 825-833. https://doi.org/10.1007/s10072-020-05035-8

- McCleery, J., Cohen, D., Sharpley, A., 2014. Pharmacotherapies for sleep disturbances in Alzheimer's disease. *Cochrane Database Syst Rev.* Issue 3. https://doi.org/10.1002/14651858.CD009178.pub2
- McCleery, J., Sharpley, A.L., 2020. Pharmacotherapies for sleep disturbances in dementia (Review). *Cochrane Database Syst Rev.* Issue 11, 1-71. https://doi.org/10.1002/14651858.CD009178.pub4
- 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 Med Rev.* 11(2), 143-153. https://doi.org/10.1016/j.smrv.2006.09.002
- Menegardo, C.S., Friggi, F.A., Scardini, J.B., Rossi, T.S., dos Santos Vieira, T., Tieppo, A.,
 Morelato, R.L., 2019. Sundown syndrome in patients with Alzheimer's disease
 dementia. *Dement Neuropsychichol.* 13(4), 469-474.
 http://dx.doi.org/10.1590/1980-57642018dn13-040015
- Neikrug, A.B., Ancoli-Israel, S., 2010. Sleep Disturbances in Nursing Home. *J Nutr Health Aging.* 14(3), 207-211. https://doi.org/10.1016/B978-0-12-378610-4.00519-2
- Newcombe, R.G., 1998. Improved confidence intervals for the difference between binomial proportions based on paired data. *Stat Med.* 17, 2635-2650. https://doi.org/10.1002/(SICI)1097-0258(19981130)17:22<2635::AID-SIM954>3.0.CO;2-C.
- Nyaga, V.N., Arbyn, M., Aerts, M., 2014. Metaprop: a Stata command to perform metaanalysis of binomial data. *Arch Public Health.* 71(1), 39-49. https://doi.org/10.1186/2049-3258-72-39.
- Ooms, S., Ju, Y., 2016. Treatment of sleep disorders in dementia. *Curr Treat Options Neurol.* 18(9), 40. https://doi.org/10.1007/s11940-016-0424-3
- Paddick, S.M., Kisoli, A., Longdon, A., Dotchin, C., Gray, W.K., Chaote, P., Teodorczuk, A.,
 Walker, R., 2014. The prevalence and burden of behavioural and psychological symptoms of dementia in rural Tanzania. *Geriatr Psychiatry.* 30(8), 815-823.
 https://doi.org/10.1002/gps.4218

- Page, M.J., Higgins, J.P.T., Sterne, J.A.C., 2021. Chapter 13: Assessing risk of bias due to missing results in a synthesis. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane Handbook for Systematic Reviews of Interventions*. Cochrane: Available from: www.training.cochrane.org/handbook.
- Peng, H., Lorenz, R.A., Chang, Y., 2018. Factors associated with sleep in family caregivers of individuals with dementia. *Perspect Psychiatr Care.* 55, 95-102. https://doi.org/10.1111/ppc.12307
- Peters, K.R., Rockwood, K., Black, S.E., Bouchard, R., Gauthier, S., Hogan, D., Kertesz, A., Loy-English, I., Beattie, B.L., Sadovnick, A.D., Feldman, H.H., 2006. Characterizing neuropsychiatric symptoms in subjects referred to dementia clinics. *Neurology*. 66(4), 523-528. https://doi.org/10.1212/01.wnl.0000198255.84842.06
- Philipps, B., Mannino, D.M., 2007. Do Insomnia Complaints Cause Hypertension or Cardiovascular Disease? J Clin Sleep Med. 3(5), 489-494. https://doi.org/10.5664/jcsm.26913
- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., Rousseau, M.C., 2011. Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.

http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/M MAT_2018_criteria-manual_2018-08-01_ENG.pdf

- Porter, C.N., Miller, M.C., Lane, M., Cornman, C., Sarsour, K., Kahle-Wrobleski, K., 2016. The influence of caregivers and behavioural and psychological symptoms on nursing home placement of persons with Alzheimer's disease: A matched case-control study. *SAGE Open Mede.* 4, 1-9. https://doi.org/10.1177/2050312116661877
- Prince, M., Guerchet, M., Prina, M., 2015. The Epidemiology and Impact of Dementia Current State and Future Trends. WHO Thematic Briefing. World Health Organization. https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_ epidemiology.pdf.
- Reinhard, S.C., Given, B., Huhtala Petlick, N., Bemis, A., 2008. Supporting Family Caregivers in Providing Care. In: Hughes RG, ed. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville (MD). https://www.ncbi.nlm.nih.gov/books/NBK2651/

- Reynold, A.M., Bowles, E.R., Saxena, A., Fayad, R., Youngstedt, S.D., 2014. Negative Effects of Time in Bed Extension: A Pilot Study. *J Sleep Med Disord*. 1(1), 1002.
- Rongve, A., Boeve, B.F., Aarsland, D., 2010. Frequency and correlates of caregiver-reported sleep disturbances in a sample of persons with early dementia. *J Am Geriatr Soc.* 58(3), 480-486. https://doi.org/10.1111/j.1532-5415.2010.02733.x
- Ryu, S., Katona, C., Rive, B., Livingston, G., 2005. Persistence of and changes in neuropsychiatric symptoms in Alzheimer's disease over 6 months: the LASER-AD study. *Am J Geriatr Psychiatry.* 13(11), 976-983. https://doi.org/10.1176/appi.ajgp.13.11.976.
- Schneider, L.S., Tariot, P.N., Lyketsos, C.G., Dagerman, K.S., Davis, K.L., Davis, S., Hsiao, J.K., Jeste, D.V., Katz, I.R., Olin, J.T., Pollock, B.G., Rabins, P.V., Rosenheck, R.A., Small, G.W., Lebowitz, B., Lieberman, J.A. 2001. National Institute of Mental Health Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE): Alzheimer Disease Trial Methodology. *Am J Geriatr Psychiatry*. 9(4), 346-360. https://doi.org/10.1097/00019442-200111000-00004
- Sedgwick, P. 2013. Meta-analyses: how to read a funnelplot. *BMJ.* 346:f1342. doi: https://doi.org/10.1136/bmj.f1342
- Sexton, C., Snyder, H.M., Chandrasekaran, L., Worley, S., Carrillo, M.C. 2021. Expanding Representation of Low and Middle Income Countries in Global Dementia Research: Commentary From the Alzheimer's Association. *Perspective.* 12, 633-777. https://doi.org/10.3389/fneur.2021.633777
- Shi, L., Chen, S., Ma, M., Bao, Y., Han, Y., Wang, Y., Shi, J., Vitiello, M.V., Lu, L. 2018. Sleep disturbances increase the risk of dementia: A systematic review and meta-analysis. *Sleep Med Rev.* 40, 4-16. https://doi.org/10.1016/j.smrv.2017.06.010
- Siafarikas, N., Selbaek, G., Fladby, T., Šaltytė Benth, J., Auning, E., & Aarsland, D. 2018. Frequency and subgroups of neuropsychiatric symptoms in mild cognitive impairment and different stages of dementia in Alzheimer's disease. *International Psychogeriatrics*, 30(1), 103-113. https://doi.org/10.1017/S10416102170018793
- Stone, K.L., Blackwell, T.L., Ancoli-Israel, S., Cauley, J.A., Redline, S., Marshall, L.M., Ensrud,
 K.E. 2014. Sleep Disturbances and Risk of Falls in Older Community-dwelling Men:
 The Outcome of Sleep Disorders in Older Men (MrOS Sleep) Study. *J Am Geriatr Soc.*62(2), 299-305. https://doi.org/10.1111/jgs.12649

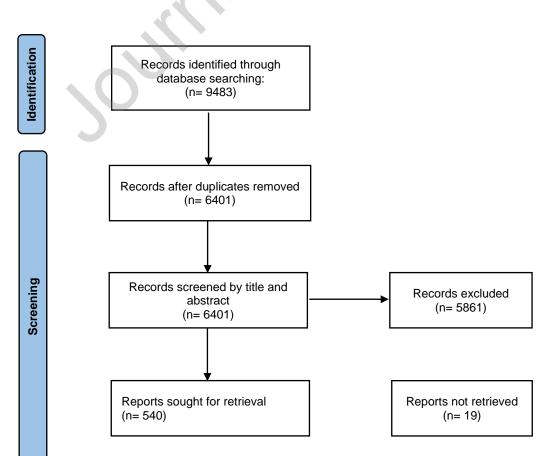
Storti, L.B., Quintino, D.T., Silva, N.M., Kusumota, L., Marques, S. 2016. Neuropsychiatric symptoms of the elderly with Alzheimer's disease and the family caregivers' distress.
 Rev Lat-Am Enfermagem. 24, 2751. https://doi.org/10.1590/1518-8345.0580.2751.

- Suzuki, M., Hattori, H., Fukuda, K., Ooshiro, H., Saruhara, T., Furuta, Y., Abe, K., Kanamori, M.
 2017. The effects of quality of life on behavioral and psychological symptoms in
 elderly people with dementia residing at long-term care facilities. *Nihon Ronen Igakkai Zasshi*. 54, 392-402. https://doi.org/10.3143/geriatrics.54.392
- Teipel, S.J., Thyrian, J.R., Hertel, J., Eichler, T., Wucherer, D., Michalowsky, B., Killmann, I., Hoffmann, W. 2015. Neuropsychiatric symptoms in people screened positive for dementia in primary care. *Int Psychogeriatr.* 27(1), 39-48. https://doi.org/10.1017/S1041610214001987
- Tewary, S., Cook, N., Pandya, N., McCurry, S.M. 2016. Pilot test of a six-week group delivery caregiver training program to reduce sleep disturbances among older adults with dementia-innovative practice. *Dementia*. 17(2), 234-243. https://doi.org/10.1177/1471301216643191
- United Nations Department of Economic and Social Affairs. 2019. *Population Facts: Living arrangements of older persons around the world*. https://www.un.org/en/development/desa/population/publications/pdf/popfacts/P opFacts_2019-2.pdf.
- Vitiello, M.V., Borson, S. 2001. Sleep Disturbances in Patients with Alzheimer's Disease. CNS Drugs. 15(10), 777-796. https://doi.org/10.2165/00023210-200115100-00004
- Webster, L., Costafreda, S.G., Stringer, A., Lineham, A., Budgett, J., Kyle, S., Barber, J.,
 Livingston, G. 2020. Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis. *Sleep.* 43(4), 1-14. https://doi.org/10.1093/sleep/zsz251
- Webster, L., Powell, K., Costafreda, S.G., Livingston, G. 2020. The impact of sleep disturbances on care home residents with dementia: the SIESTA qualitative study. *Int Psychogeriatr.* 32(7), 839-847. https://doi.org/10.1017/S1041610220000642
- Webster, L. 2020. Sleep Disturbance in people with dementia living in care homes:
 measurement, prevalence, manifestation, causes, impact and persistence. PhD
 Thesis. University College London.

https://discovery.ucl.ac.uk/id/eprint/10119727/7/Webster_10119727_thesis_redact ed.pdf

- Wimo, A., Gauthier, S., Prince, M. 2021. *Global estimates of inromal care*. Alzheimer's Disease International and Karolinska Instituet. https://www.alzint.org/u/global-estimates-of-informal-care.pdf.
- World Health Organization. 2020. *Dementia*. https://www.who.int/en/news-room/fact-sheets/detail/dementia.
- Yoro-Zohoun, I., Nubukpo, P., Houinato, D., Mbelesso, P., Ndamba-Bandzouzi, B., Clément,
 J., Dartiguers, J., Preux, P., Guerchet, M. 2019. Neuropsychiatric symptoms among
 older adults living in two countries in Central Africa (EPIDEMICA Study). *Int J Geriatr Psychiatry*. 24(1), 169-178. https://doi.org/10.1002/gps.5006
- Zhao, Q., Tan, L., Wang, H., Jiang, T., Tan, M., Tan, L., Xu, W., Li, J., Wang, Y., Lai, T., Yu, Y.
 2016. The prevalence of neuropsychiatric symptoms in Alzheimer's disease:
 Systematic Review and meta-analysis. *J Affect Disord*. 190, 264-271.
 https://doi.org/10.1016/j.jad.2015.09.069

Figure Captions



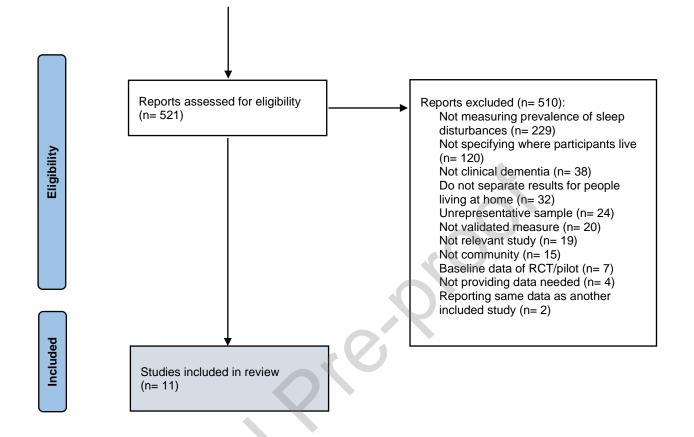


Figure 1: PRISMA flow diagram of references identified and included in the review.

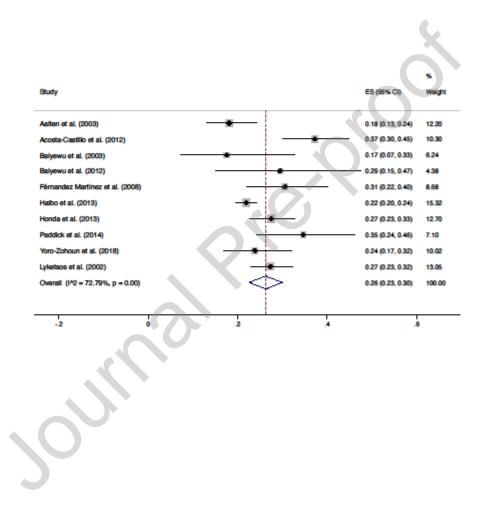


Figure 2: Forest plot of the prevalence symptoms of sleep disturbances.

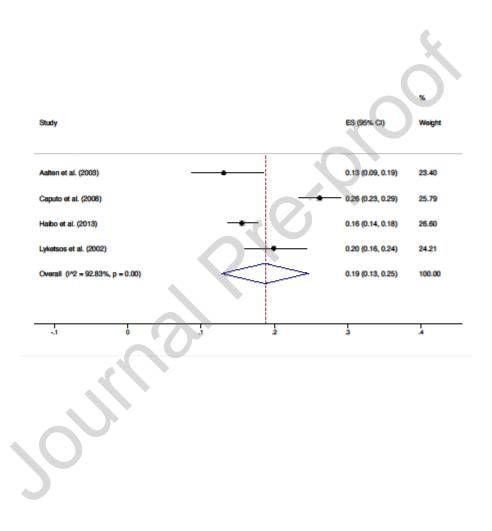


Figure 3: Forest plot of the prevalence of clinically significant cases of sleep disturbances.

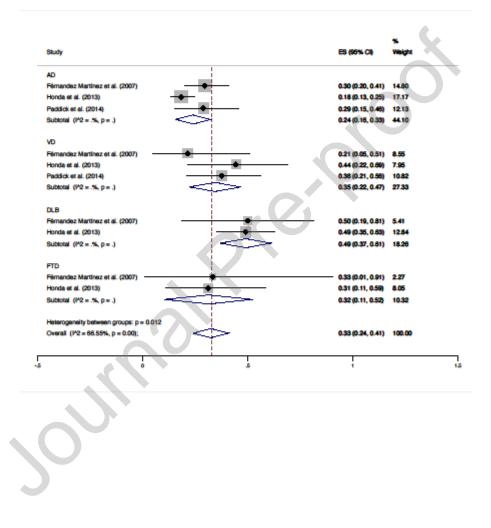


Figure 4: Forest plot of the prevalence of symptoms of sleep disturbances by dementia subtypes.

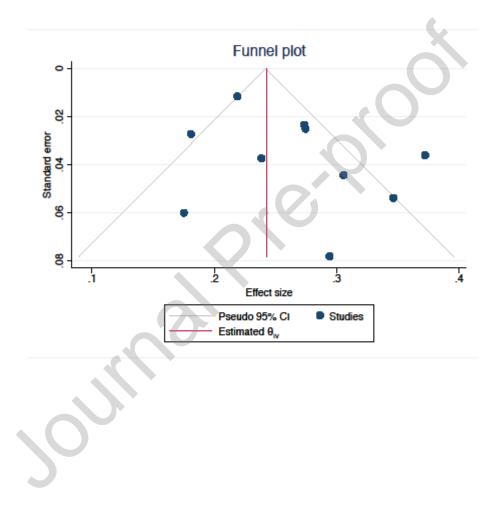


Figure 5: Funnel plot for studies reporting the prevalence of symptoms of sleep disturbances.

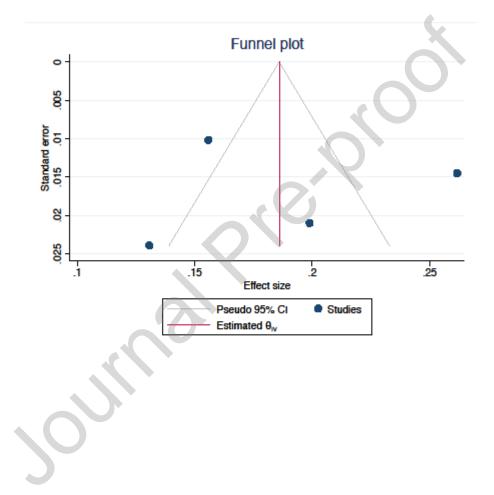


Figure 6: Funnel plot for studies reporting the prevalence of clinically significant cases of sleep disturbances.

Appendix A

Embase, MEDLINE and PsycINFO were searched simultaneously using the Ovid interface on

30/04/2021.

1 (dementia or demented or Alzheimer*).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, nm, ox, px, rx, an, ui, sy, tc, id, tm]

2 (sleep* or insomnia or circadian or night* or neuropsychiatric).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, nm, ox, px, rx, an, ui, sy, tc, id, tm]

3 (prevalence or epidemiolog* or frequency).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, nm, ox, px, rx, an, ui, sy, tc, id, tm]

4 limit 3 to humans [Limit not valid in APA PsycInfo; records were retained]

5 1 and 2 and 3 and 4

Table 1: Study characteristics of studies included in the review

				05		Study qualit y		
Study	Country	Sampl e size (N)	Age (mea n± SD)	Male s (%)	Dementia type 146 AD; 32	Dementi a severity	Measur e used	1 2 3 4 Total
Aalten et al. 2003 ^{Error!} Reference source not found.	Netherland s	199	76.4 (8.0)	42.7	VD; 2 LBD; 3 FTD; 6 mixed; 5 PDD; 4 PPA; 1 alcohol related dementia	Mean MMSE score 18.09	NPI	√ √ √ ? 3
Acosta- Castillo et al. 2012 ⁰	Mexico	180	/	31.1	/	87.8% mild, 12.2% moderate to severe	NPI-Q	$ \sqrt[]{} \sqrt[]$
Baiyewu et al. 2003 ⁰	Nigeria	40	84.7 (10.3)	12.5	39 AD; 1 unspecified	Mean MMSE score 12.4	NPI	$\sqrt{}$ $\sqrt{\times}$ 3
Baiyewu et al. 2012 ⁰	Nigeria	34	83.3 (9.2)	17.6	29 AD; 5 unspecified	Mean MMSE score 12.8	NPI	√ √ √ ? 3

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Caputo et al. 2008 ⁰	Italy	921	77.4	33.8	690 AD; 131 VD; 100 LBD	20.1% mild, 54.6% moderate, 25.3% severe	NPI	√ √ √ ? 3
Férnande z Martínez et al. 2008 ⁰	Spain	108	81.3 (8.4)	29.6	81 AD; 14 VD; 10 LBD; 3 FTD	Mean MMSE score 11.6	NPI	$\sqrt{\sqrt{4}}$
Haibo et al. 2013 ⁰	China	1271	80.9 (6.3)	33.7	/	Mean MMSE score 16.5	NPI	$\sqrt{}$ $\sqrt{}$ 4
Honda et al. 2013 ⁰	Japan	317	75.0	47.6	191 AD; 18 VD; 55 LBD; 16 FTD; 37 unspecified	Mean MMSE score 18.4	NPI	√ √ √ ? 3
Paddick et al. 2014 ⁰	Tanzania	78	85.0	28.2	38 AD; 32 VD; 3 PDD; 5 other	1	NPI-Q	√ √ √ ? 3
Yoro- Zohoun et al. 2018 ⁰	CF and DRC	130	75.0	1	98 AD; 15 VD	57.7% mild, 21.5% moderate, 10.8% severe	NPI-Q	$\sqrt[]{} \sqrt[]{} \sqrt[]{$
Lyketsos et al. 2002 ⁰	US	362	77.0 (5)	37	258 AD; 86 VD; 6 PDD; 12 other	/	NPI	$\begin{array}{c} \checkmark \checkmark \\ \checkmark \checkmark \\ 4 \end{array}$

SD – standard deviation; AD – Alzheimer's disease; VD – vascular dementia; LBD – Lewy body dementia; FTD – frontotemporal dementia; PDD – Parkinson's disease dementia; PPA – primary progressive aphasia; MMSE – Mini-Mental State Examination; sig. – significant; / - not reported; CF – Central African Republic; DRC – Republic of Congo; NPI – Neuropsychiatric Inventory; NPI-Q – Neuropsychiatric Inventory-Questionnaire

Highlights

- Sleep disturbances are common among people with dementia living in the community
- Sleep disturbances are especially common in people with Lewy body dementia
- There has been no improvement in treatment for sleep disturbances over time

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