


## RESEARCH ARTICLE

# Care home residents with dementia: Prevalence, incidence, and associations with sleep disturbance in an English cohort study

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## Abstract

**Introduction:** People living with dementia in care homes often have sleep disturbances, but little is known about incidence and importance.

**Methods:** We interviewed 1483 participants in 97 care homes and report prevalence, 1-year incidence, and baseline associations of clinically significant sleep disturbance in people with dementia.

**Results:** Baseline prevalence of clinically significant sleep disturbance was 13.7% (200/1460); 31.3% (457/1462) had them at least once over 16 months. One-year incidence was 25.2%. At baseline, residents with sleep disturbance had lower quality of life (mean difference  $-4.84$ ; 95% confidence interval [CI]  $-6.53$  to  $-3.16$ ) and were more frequently prescribed sleep medications (odds ratio 1.75; CI 1.17 to 2.61) than other residents.

**Discussion:** Approximately one-third of care home residents with dementia have or develop sleep disturbances over 1 year. These are associated with lower quality of life and prescription of sedatives, which may have negative outcomes; therefore, it is important to develop effective treatments.

## KEYWORDS

associates, care homes, dementia, incidence, prevalence, sleep disturbances

## 1 | INTRODUCTION

Sleep disturbances in people living with dementia are defined as difficulty falling asleep, reduced duration of sleep, waking or getting up during the night, and excessive daytime sleepiness.<sup>1</sup> They are common among people with dementia, with a meta-analysis finding that 39% of people with Alzheimer's disease experience symptoms of sleep disturbances on questionnaires (ranging from 14% to 69% across individual studies).<sup>2</sup> These disturbances may be distressing for the person with dementia and their family carer and make it more likely that a person with dementia moves into a care home.<sup>3,4</sup> Our systematic review

found that on questionnaires 38% of care home residents with dementia experience some degree of sleep disturbance and that 20% of residents with dementia experience clinically significant symptoms severe enough that health professionals judge they require treatment.<sup>5</sup> Furthermore, we also found that 70% of residents with dementia had sleep disturbances on actigraphy,<sup>5</sup> in which sleep is inferred from a lack of movement via a watch worn on the wrist; however, actigraphy is less used with this population due to its limitations.<sup>6</sup>

In previous cross-sectional studies, the most common manifestations of sleep disturbances in care home residents with dementia were awakening in the night and getting up during the night.<sup>7,8</sup> To our

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knowledge, no study has considered whether people with dementia have different symptoms of sleep disturbances over time. A few studies have reported the incidence of sleep disturbances in this population, but all have had small sample sizes; long and differing times between follow-ups; and do not describe the 1-year incidence, which is the commonly used definition.<sup>9</sup> One small study of care home residents in Norway<sup>10</sup> and two in the Netherlands<sup>11,12</sup> found an incidence of clinically significant sleep disturbances over 16 months of 21% and for symptoms over 2 years 18% and 29%, respectively. A larger study found an incidence of 20% of clinically significant sleep disturbances over 53 months.<sup>13</sup>

There is consistent quantitative evidence cross-sectionally that sleep disturbance in people living with dementia is associated with staff distress, resident agitation, and prescription of psychotropic medications as well as being more common in care homes with a higher percentage of males.<sup>5,14</sup> Qualitatively, sleep disturbances in care home residents are described as being associated with agitation, lower quality of life, falls, and staff distress, and as being more common when nights are lighter.<sup>15</sup>

Using data from the MARQUE (Managing Agitation and Raising Quality of Life) longitudinal cohort study, we aimed to first describe the point and cumulative prevalence of sleep disturbances in care homes residents with dementia over 16 months, as well as the prevalence of different manifestations of sleep disturbance. Second, we aimed to describe the 1-year incidence of sleep disturbances in this population. Finally, we aimed to investigate the cross-sectional relationships of sleep disturbance to residents' quality of life, prescription of medications, sociodemographic characteristics, dementia symptoms, and time of year.

## 2 | METHOD

### 2.1 | MARQUE cohort study

The study was a secondary analysis using data from the MARQUE cohort study,<sup>16</sup> which recruited residents with dementia between 2014 and 2015 from 97 English care homes. The study was approved by the London-Harrow Research Ethics Committee 14/LO/0034. Researchers approached residents that were judged to have capacity to consent, assessed this, and if they had it, asked them for informed consent. For all other residents, the resident's family carer was approached as a personal consultee as specified in the Mental Capacity Act.<sup>17</sup> If the care home could not find a personal consultee, we used a professional consultee.

Researchers collected data about residents up to five times, every 4 months from baseline until 16 months. Further details about recruitment, sampling, and procedures are published elsewhere,<sup>16,18</sup> including the sample size calculation of a target of 1466 people living with dementia across 97 care homes for the primary aim of the cohort study, which was achieved.

The MARQUE study recruited residents with a recorded diagnosis of dementia and used the Noticeable Problems Checklist (NPC,<sup>19</sup> a val-

### HIGHLIGHTS

- One-third of care home residents with dementia have a sleep disturbance over 16 months.
- One-quarter of residents with dementia will develop a new sleep disturbance over a year.
- These disturbances are associated with poorer quality of life and prescription of sleep medications.

### RESEARCH IN CONTEXT

1. Systematic review: Our published systematic review reviewed the literature on the prevalence and associates of sleep disturbances in people with dementia living in care homes. However, there remains no research on the yearly incidence rate of sleep disturbances in this population, and little research on the cross-sectional associations with sleep disturbances in large cohort studies so it is unclear whether sleep disturbance affects residents' well-being.
2. Interpretation: Our current study shows that one-quarter of residents with dementia will develop a new sleep disturbance over a year. These disturbances are associated with poorer quality of life, and residents are more likely to be prescribed sleep medications, even though these medications have side effects and poor efficacy.
3. Future directions: Effective non-pharmacological treatments need to be developed, as there is a negative impact of both sleep disturbances and sleep medications. Future research also needs to investigate the persistence of sleep disturbances in residents, which would indicate how often they resolve without active treatment.

idated screen for possible dementia) to identify others, as many people with dementia living in care homes will not have been diagnosed.<sup>20</sup> There was no other inclusion criteria beyond having a diagnosis or possible dementia on the NPC, and residents did not have to have sleep disturbances to participate.

### 2.2 | Resident measures

Resident demographics were collected at baseline and included date of birth, sex, marital status, and ethnicity. All other measures were collected at each follow-up timepoint from a care home member of staff who knew the resident well:

- Neuropsychiatric symptoms including sleep disturbances: The Neuropsychiatric Inventory Nursing Home Version (NPI-NH)<sup>21,22</sup> is a measure of the presence, severity, and frequency of 12 neuropsychiatric symptoms, including sleep disturbance, delusions, hallucinations, agitation, depression, and anxiety. The score for each of the 12 symptoms is zero if the symptom is absent. If present then the frequency times severity is rated, with possible scores ranging from 1 to 12. Higher scores indicate worse symptoms. If the individual symptom score is  $\geq 4$ , symptoms are considered clinically significant,<sup>23</sup> and we used this to classify clinically significant sleep disturbance on the sleep disturbance item. If the participant had sleep disturbance, as in “yes” to the sleep item, we classified this as a symptom of sleep disturbance, regardless of score. For the sleep disturbance item, eight sub-questions can be ticked to highlight how the sleep disturbance manifests, none of which contributes to the sleep item score. These are in regard to the resident having difficulty falling asleep; getting up during the night; wandering, pacing, or getting involved in inappropriate activities at night; awakening you (others) at night; being awake during the night; dressing and planning to go out; awakening too early in the morning; sleeping excessively during the day; and any other nighttime behaviors.
- Quality of life: The Dementia Quality of Life Instrument (DEMQL) proxy<sup>24</sup> is a measure of health-related quality of life for people with dementia completed by someone who knows them well. Higher scores indicate better quality of life.
- Dementia severity: The Clinical Dementia Rating (CDR)<sup>25</sup> is a measure of the severity of dementia impairment in six domains, the global score of which can be used to classify severity into mild, moderate, or severe dementia.
- Agitation: The Cohen-Mansfield Agitation Inventory (CMAI)<sup>26</sup> is a measure of agitation covering 29 different agitated behaviors and how often each has happened in the last 2 weeks. Higher scores indicate higher levels of agitation.
- Medication: Data were also collected on resident medication prescribed regularly for the past 4 weeks, and prescribed pro re nata (PRN; when necessary) for the past 2 weeks. We classified sleep medications as non-benzodiazepine hypnotics, benzodiazepines, and melatonin.
- Time of year/minutes of daylight: We used minutes of daylight on the date that the NPI data was collected as a variable reflecting the time of year, including information on the length of daylight in hours and minutes with London set as the location, as this was a central location for half of the homes.<sup>27</sup>

### 2.3 | Analysis

We used STATA (version 16) for all analyses. We described the resident's baseline characteristics using appropriate summary statistics. We report the point and cumulative prevalence of clinically significant sleep disturbances (the NPI sleep item score  $\geq 4$  score), symptoms of any severity, and each type of sleep disturbance.

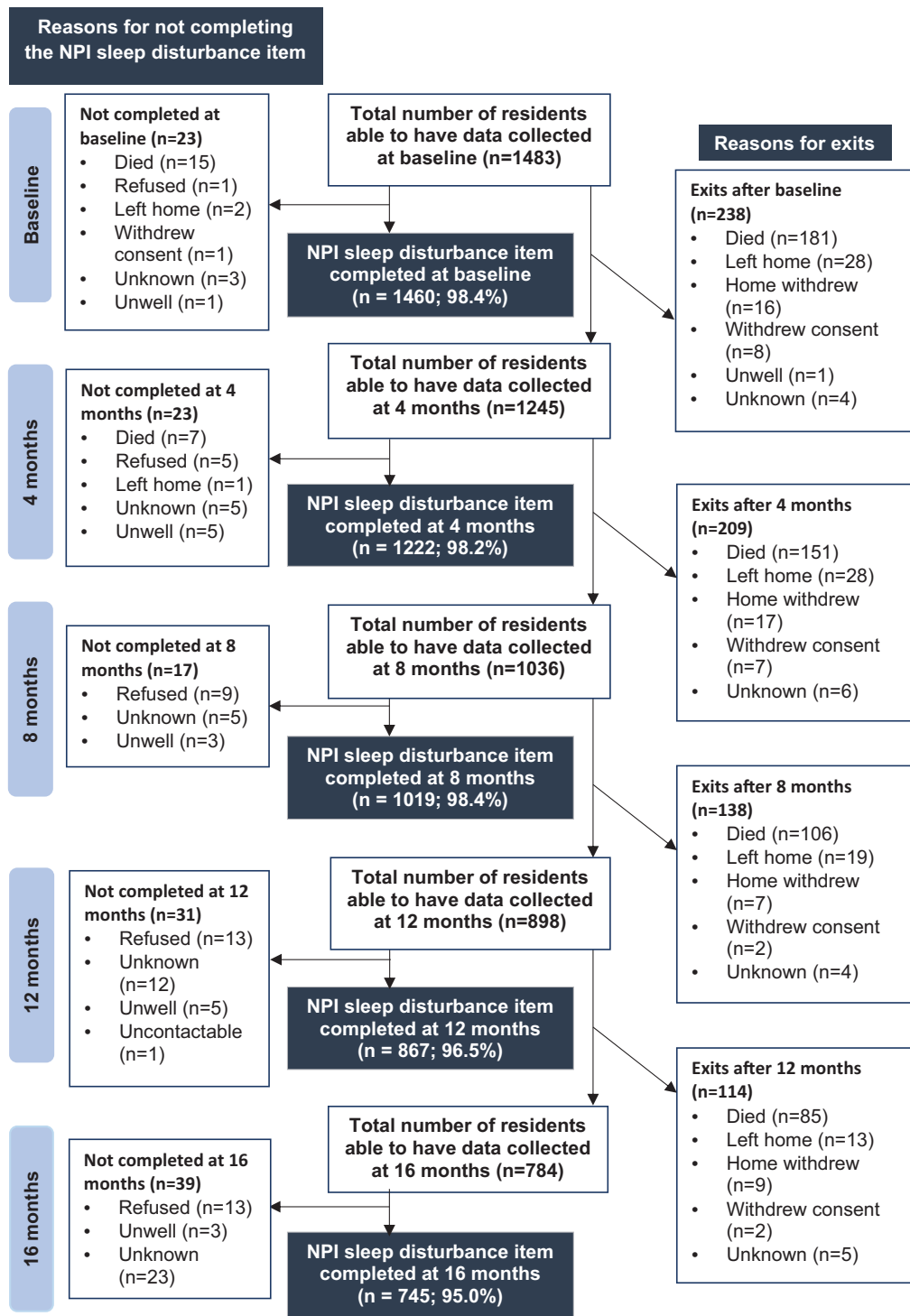
We report the incidence rate of both symptoms of any severity and clinically significant sleep disturbances. The numerator was those who developed symptoms or became a clinically significant sleep disturbance over 16 months after baseline, respectively, with the denominator being person-years at risk.<sup>9</sup> Calculations excluded those who had symptoms or clinically significant sleep disturbance at baseline, respectively. The number of years at risk comprised the time when residents were in the study without sleep disturbance. It excludes the time after they developed symptoms of sleep disturbance or exited the study from death or withdrawal after which data were censored. When data were missing about the date that a resident died or exited the study, we used the halfway point between when the proxy questionnaires were completed for them at the previous timepoint and when they would have been completed 4 months later at the next follow-up. If fewer than 50% of the items of the DEMQL proxy or CMAI were missing then we used the mean of the resident's item scores for missing items to calculate total scores.

We used baseline data only for investigations of cross-sectional associations of sleep disturbances to resident's sociodemographic characteristics (sex, age, dementia severity), dementia symptoms (agitation, depression, anxiety, delusions, hallucinations), time of year (minutes of daylight), quality of life, and prescription of medications (sleep medications, antipsychotics, and antidepressants). All models described below were three-level models fitted to account for clustering due to residents living in the same care homes and the same staff members acting as a proxy for multiple residents.

We used a multi-level logistic regression model to investigate the relationship between baseline clinically significant cases of sleep disturbance with the residents' variables: sex, age, dementia severity (CDR global score categorized as mild, moderate, or severe dementia), agitation score, depression score, anxiety score, delusions score, hallucinations score, and minutes of daylight, using clinically significant sleep disturbance as the binary dependent variable in the model. In a sensitivity analysis, we also investigated the relationship of any symptoms of sleep disturbance as a binary dependent variable, with the same resident variables, also as a three-level, multi-level, logistic regression model.

We used a multi-level linear regression model to investigate the association between clinically significant sleep disturbance and quality of life, using the DEMQL proxy score as a continuous dependent variable, and sleep disturbance as a binary independent variable.

We then used three separate multi-level logistic regression models to investigate the association between clinically significant sleep disturbance and prescription of psychotropic medications, with either regular or PRN sleep medications, regular or PRN antipsychotics, and antidepressants as the dependent variable. All models were adjusted for resident age, sex, and dementia severity (CDR global score categorized as mild, moderate, or severe dementia). For sensitivity analyses, we also conducted multi-level regression models to investigate if having symptoms of sleep disturbances, of any severity, as a binary variable was associated with the same four resident variables at baseline.



**FIGURE 1** STROBE diagram of completion of the Neuropsychiatric Inventory (NPI) and subject follow-up. STROBE, Strengthening the Reporting of Observational Studies in Epidemiology

### 3 | RESULTS

Of the 2825 residents with dementia who were approached for participation, 1489 residents from 97 care homes consented, and data were collected on 1483 of those residents. The flow diagram (Fig-

ure 1) shows how many residents had their data collected on the NPI sleep disturbance item at each timepoint and study exits and deaths. Of the 1483 residents, 1462 (98.6%) had data collected on the NPI sleep disturbance item on at least one timepoint in the study.

**TABLE 1** Baseline characteristics of the 1483 residents who participated in the MARQUE study

Resident characteristics [n of residents data collected about]	Frequency (unless stated otherwise)	Percentage (unless stated otherwise)
Sex [1482]		
Female	1025	69.2
Male	457	30.8
Age [1437]	86.1 years (median)	40–105 years (range)
Marital status [1424]		
Widowed	792	56.0
Married	345	24.0
Single, separated, divorced	287	20.0
Dementia diagnosis [1483]		
Recorded clinical diagnosis	1281	86.4
Met NPC criteria for possible dementia	202	13.6
Ethnicity [1451]		
White British	1280	88.2
White Irish	43	3.0
White other	50	3.4
Black British, Caribbean, African	33	2.3
Asian or Asian British, Indian, Pakistani, Bangladeshi	13	0.9
Mixed: White and Black Caribbean	1	0.1
Chinese	2	0.1
Other	29	2.0
Dementia severity (CDR) [1457]		
Mild	426	29.2
Moderate	482	33.1
Severe	549	37.7

Abbreviations: CDR, Clinical Dementia Rating global score; MARQUE, Managing Agitation and Raising Quality of Life study; NPC, Noticeable Problems Checklist.

### 3.1 | Demographics

The characteristics of the 1483 residents who participated in the study are presented in Table 1. At baseline, the median age of residents was 86 years, and most residents were widowed. One thousand two hundred eighty-one of the participants (86.4%) had a recorded clinical diagnosis of dementia with the remainder being diagnosed based on NPC score.<sup>19</sup> The median length of time that residents had lived in the care home at baseline was 717 days (range 3–6824 days).

### 3.2 | Prevalence of sleep disturbance

#### 3.2.1 | Clinically significant sleep disturbance

The point prevalence of clinically significant sleep disturbances was 13.7% (n = 200) at baseline and remained similar across the five timepoints up to 16 months (range: 12.9% to 16.0%; Table 2). Almost one-third of residents (31.3%) had a clinically significant sleep disturbance on at least one timepoint.

#### 3.2.2 | Symptoms of sleep disturbance

The point prevalence of experiencing any symptom of sleep disturbance was 24.7% (n = 360) at baseline and remained stable across the five timepoints (range: 24.3 to 26.6; Table 2). Half of the residents (n = 696; 47.6%) had symptoms of sleep disturbances of any severity on at least one of the timepoints.

The most prevalent individual symptom of sleep disturbance across all timepoints was sleeping excessively during the daytime (n = 350; 24.0%) followed by getting up during the nighttime (n = 312; 21.3%; Table 2).

### 3.3 | Incidence of sleep disturbance

#### 3.3.1 | Clinically significant sleep disturbance

Of the 1260 residents that did not have clinically significant sleep disturbances at baseline, 257 residents developed clinically significant sleep disturbance over the following 16 months. These 1260 residents

**TABLE 2** Point prevalence and cumulative prevalence of sleep disturbances

Sleep disturbances	Baseline frequency (%) (n = 1460)	4 months frequency (%) (n = 1222)	8 months frequency (%) (n = 1019)	12 months frequency (%) (n = 867)	16 months frequency (%) (n = 745)	Cumulative prevalence <sup>a</sup> frequency (%) (n = 1462)
Clinically significant cases of sleep disturbance	200 (13.7)	103 (13.6)	69 (13.5)	59 (16.0)	26 (12.9)	457 (31.3)
Symptoms of sleep disturbances of any severity	360 (24.7)	163 (25.5)	85 (25.3)	52 (26.6)	36 (24.3)	696 (47.6)
Sleep excessively during the day	153 (10.5)	76 (9.1)	47 (7.6)	49 (10.7)	25 (7.5)	350 (24.0)
Getting up during the night	149 (10.2)	70 (8.7)	40 (7.3)	25 (7.8)	28 (8.5)	312 (21.3)
Difficulty falling asleep	131 (9.0)	59 (7.4)	35 (5.6)	29 (5.9)	21 (5.5)	275 (18.8)
Wander, pace, or inappropriate activities at night	110 (7.5)	56 (7.4)	27 (6.0)	21 (6.1)	12 (5.4)	226 (15.5)
Awaken you during the night	90 (6.2)	47 (5.6)	34 (5.3)	27 (4.8)	11 (3.1)	209 (14.3)
Awaken too early in the morning	92 (6.3)	34 (3.8)	16 (2.7)	16 (2.5)	8 (2.6)	166 (11.4)
Awaken during the night, dress, and plan to go out	50 (3.4)	24 (2.6)	16 (2.4)	13 (2.2)	10 (2.4)	113 (7.7)
Other night-time behavior	47 (3.2)	46 (4.1)	27 (3.5)	18 (3.6)	9 (2.1)	147 (10.1)

<sup>a</sup>Cumulative prevalence is defined as the proportion of residents having any or one of the symptoms or clinically significant case on at least one timepoint over the 16 months.

contributed 1019.7 person-years at risk of developing clinically significant sleep disturbance. Therefore, the incidence rate of clinically significant sleep disturbances was 252.0 cases per 1000 person-years, equating to 25.2% of residents developing a clinically significant sleep disturbance over a year.

### 3.3.2 | Symptoms of sleep disturbance

Of the 1100 residents who did not have symptoms of sleep disturbance at baseline, 336 residents developed symptoms over the 16-month follow-up. These 1100 residents contributed 819.1 person-years at risk of developing symptoms of any severity during the 16 months, giving an incidence rate of 410.2 cases per 1000 person-years, or 41.0% of residents developing any symptom of sleep disturbance over a year.

## 3.4 | Associated factors with sleep disturbance at baseline

### 3.4.1 | Clinically significant sleep disturbance

Residents with clinically significant sleep disturbances at baseline had a significantly lower quality of life score on average compared to those without clinically significant sleep disturbance at baseline. They also had higher odds of being prescribed both regular and PRN sleep medications, and antipsychotics at baseline. There was no evidence of a difference in the prescription of antidepressants (Table 3).

**TABLE 3** Association between clinically significant sleep disturbances and quality of life, sleep medications, antipsychotics, and antidepressants at baseline

Factor [n]	Adjusted difference in means or odds ratio comparing clinically significant sleep disturbance (yes vs. no)	95% confidence interval
Quality of life score (DEMQOL) [1445]	-4.84 <sup>a</sup>	[-6.53 to -3.16]
Regular and PRN sleep medications [1413]	1.75 <sup>b</sup>	[1.17 to 2.61]
Regular and PRN antipsychotics [1413]	1.95 <sup>b</sup>	[1.28 to 2.95]
Antidepressants [1413]	1.06 <sup>b</sup>	[0.76 to 1.47]

<sup>a</sup>Difference in means, linear model.

<sup>b</sup>Odds ratio, logistic model; Models are multi-level regression models adjusted for sex, age, dementia severity, and symptoms and with random effect for care home and proxy staff member; CMAI, Cohen-Cohen-Cohen-Mansfield Agitation Inventory; values in bold are statistically significant at 5% significance level.

Abbreviations: DEMQOL, Dementia Quality of Life Instrument; PRN, pro re nata.

Agitation and depression were significantly associated with clinically significant sleep disturbance at baseline, and male residents were more likely to have a clinically significant sleep disturbance than females (Table 4). There was no evidence that clinically significant sleep disturbances at baseline were associated with anxiety, delusions, hallucinations, dementia severity, age, or minutes of daylight.

**TABLE 4** Multilevel logistic regression model of factors associated with clinically significant cases of sleep disturbances at baseline

Factor [n = 1331]	Odds ratio	95% confidence interval
Sex		
Female	0.66	[0.46 to 0.96]
Male	1	
Age	1.01	[0.99 to 1.03]
Dementia severity (CDR)		
Mild	1	
Moderate	0.91	[0.58 to 1.92]
Severe	0.88	[0.86 to 1.97]
Agitation score (CMAI)	1.03	[1.02 to 1.04]
Anxiety score (NPI)	1.07	[0.99 to 1.14]
Depression score (NPI)	1.16	[1.08 to 1.24]
Delusions score (NPI)	1.02	[0.95 to 1.10]
Hallucinations score (NPI)	0.99	[0.89 to 1.09]
Minutes of daylight (time of year)	1.00	[0.99 to 1.00]

Notes: Models are multi-level regression models adjusted for sex, age, dementia severity, and symptoms and with random effect for care home and proxy staff member; based on a 5% significance level, significant values are in bold.

Abbreviations: CDR, Clinical Dementia Rating global score; CMAI, Cohen-Mansfield Agitation Inventory; NPI, Neuropsychiatric Inventory item.

### 3.4.2 | Symptoms of sleep disturbance

Similar results were obtained in sensitivity analyses considering those with symptoms of sleep disturbances of any severity (Appendix; Tables A1 and A2).

## 4 | DISCUSSION

In this large cohort study, we found that sleep disturbance was common in care home residents, as the point prevalence of clinically significant sleep disturbances ranged from 13% to 16%, across the five timepoints of the study. Nearly one-third of residents (31%) experienced clinically significant sleep disturbance at one timepoint of the 16-month study. One-quarter (25%) of residents without a clinically significant sleep disturbance at baseline, developed one over 1 year. This is in the range but higher than that reported in two previous studies using the same measure (21% and 20%, respectively), though these studies measured incidence over 16 and 53 months, respectively.<sup>10,13</sup> The point prevalence of symptoms of clinically significant sleep disturbances in this study was lower than in our meta-analyses, with the majority of the included studies using the NPI sleep item (20%, 95% confidence interval 16–24).<sup>5</sup> However, many of the individual studies in our meta-analyses reported a similar point prevalence of clinically significant sleep disturbances to the MARQUE cohort study also using the NPI sleep item.<sup>10,28,29</sup>

Those with significant sleep disturbances had a lower quality of life. Residents with clinically significant sleep disturbances at baseline were more likely to be prescribed sleep medications, and antipsychotics, but not antidepressants, than those without sleep disturbance. It is plausible that being sleepy during the day and unable to participate in many activities may cause lower quality of life even in those who do not remember it, and this is in line with results from a recent randomized controlled trial in the community.<sup>30</sup> In addition, sleep disturbances may also impact residents' quality of life because residents are more likely to be prescribed psychotropic medications.<sup>31</sup> Sleep medications, including both benzodiazepines and Z drugs, increase the risk of falls in nursing home residents with and without dementia,<sup>32–34</sup> and antipsychotics cause increased mortality and lower cognition.<sup>35</sup>

We think this is the first study to investigate the relationship of minutes of daylight based on time of year with sleep in care homes. Previous studies have found a mix of evidence about variations in sleep disturbances by the time of year in general populations.<sup>36,37</sup> In our sample, daylight minutes was not associated with sleep disturbances. This could be because the measure of time of year does not reflect exposure to light in our sample, and in care homes, residents with dementia often have less exposure to light than residents without dementia.<sup>38</sup>

Neither age nor dementia severity was significantly associated with residents having clinically significant sleep disturbances. Previous studies have found no association between age and sleep disturbances<sup>8,39,40</sup> and mixed results for dementia severity<sup>39,40</sup> on both the NPI sleep item and the extended version of this, the Sleep Disorders Inventory (SDI).<sup>41</sup>

The two most prevalent types of sleep disturbances across all five timepoints were excessive daytime sleepiness, which ranged from 8% to 11%, and getting up during the night, which ranged from 7% to 10%. Nearly one-quarter of residents (24%) had excessive daytime sleepiness at one of the timepoints, and one-fifth (21%) got up during the night at one timepoint. A similar cross-sectional study<sup>7</sup> reported the most common manifestation as awakening at night, then sleeping excessively during the daytime and getting up during the night, which also mirrored the results of our qualitative study.<sup>15</sup> However, a second cross-sectional quantitative study<sup>8</sup> found that the most common sleep disturbances were getting up during the night and difficulty falling asleep. In contrast to MARQUE, sleeping excessively in the daytime was the least reported sleep disturbance in the previous study, which used the SDI.<sup>8</sup> In people with dementia living in the community, the most common sleep disturbances are getting up during the night and awakening the family carer at night, followed by difficulty falling asleep and sleeping excessively in the day.<sup>42</sup>

Depression and agitation were the only two neuropsychiatric symptoms strongly associated with sleep disturbances at baseline. This is in line with multiple studies in residents with dementia measuring sleep disturbances on the NPI sleep item.<sup>14,43,44</sup> In our qualitative study,<sup>15</sup> staff described resident agitation as both a cause and consequence of sleep disturbances, as agitation may be why residents sleep badly but they may be agitated for other reasons, such as pain,<sup>45</sup> which could also contribute to poor sleep.<sup>46</sup> Agitation and quality of life are highly correlated in the MARQUE cohort study<sup>16</sup> and a previous study in Japanese

care home residents found sleep disturbances on the NPI sleep item associated with lower quality of life.<sup>40</sup>

Additionally, male residents were more likely to have clinically significant sleep disturbances than women. However, a previous meta-analysis found no sex differences in the prevalence of sleep disturbances on the NPI sleep item in people with dementia living in the community.<sup>2</sup> When admitted to European care homes, men tend to be younger than women<sup>47</sup> and as they are younger they may be more mobile and able to get up during the night, so staff may be more aware of them being awake.

#### 4.1 | Strengths and weaknesses

The MARQUE cohort study included 1483 residents with dementia from 97 care homes around England, and is, to our knowledge, the largest prospective study of care home residents in the UK, as well as one of the most detailed longitudinal cohort studies of care home residents worldwide, with four sampling times over 16 months. This design and the large numbers enabled us to investigate important research questions in detail.

We also conducted sensitivity analyses, using different measures of sleep disturbances, which helped to determine any associations between sleep disturbances and other variables. The sensitivity analyses on any symptoms of sleep disturbance mirrored the main analyses, providing robustness to our findings. The care homes were diverse in terms of types of care provided and ownership (private or charity) and were geographically spread around England, increasing representativeness. Most of the homes that were approached (75%) agreed to participate. Care homes that are of better quality or that have more resources may be more likely to participate in research, which may introduce selection bias at the care home level. However, as there were no eligibility criteria other than a diagnosis of dementia or meeting the criteria for possible dementia on the NPC, this meant a diverse group of care home residents with dementia were recruited without selection bias. Most of the residents participating were female and mainly White British, which is reflective of both the older adult population<sup>48</sup> and the specific care home population in the UK.<sup>49</sup> The study was based in English care homes which limits generalizability; however, the sample demographics were similar to those living in care homes across Europe.<sup>47</sup>

We used the NPI sleep disturbance item,<sup>21</sup> the most widely used questionnaire on sleep disturbances in this population.<sup>5</sup> The sub-questions of the sleep disturbance item have also been developed into the SDI,<sup>41</sup> which has been validated in the care home population with dementia.<sup>7</sup> As the SDI was not used in MARQUE, but the NPI sleep item, we had data on the types of sleep disturbances from the sleep items sub-questions, and to our knowledge, we are the first longitudinal study with these details. Most of the data about residents' sleep disturbance were collected from staff, some of whom did not work night shifts, and may not have always known how the residents sleep, though this information should be passed on during hand-overs, and therefore sleep disturbances may have been underestimated.<sup>7,50</sup> As this was

a secondary analysis of already collected data, we did not have data on other outcomes of interest, such as staff distress<sup>5</sup> and resident's pain,<sup>20,46</sup> and additionally other measures of sleep disturbance, such as actigraphy or polysomnography. However, both measures have limitations with use in people living with dementia.<sup>6</sup>

Furthermore, as the data about residents was collected from staff members, this could introduce an element of measurement bias by the proxy rater,<sup>51</sup> although there is no reason to think that it was a systematic bias that had more effect on one group than another. Additionally, all measurements used are validated instruments for use with people with dementia.

In our analyses, we used multi-level models to account for clustering for residents living in the same care homes and staff answering questionnaires for multiple residents, which meant we were able to account for variance introduced by unobserved variables so that the findings should be more generalizable to the wider care home population.<sup>52</sup>

## 5 | CONCLUSION

Overall, in this study, we found that, over 1 year, one-quarter of residents with dementia without a clinically significant sleep disturbance will develop one. Despite 24-hour staffing, the problems of sleep disturbance remain important in care homes as we found evidence of negative outcomes, including lower quality of life and prescription of antipsychotics and sleep medications. It is therefore important that effective treatments are investigated in this population. We found that sleep disturbances most commonly manifest as getting up during the night and excessive daytime sleepiness. This indicates that these could be the focus of future research developing treatments. Further research is needed to investigate the course of sleep disturbances in residents and delineate in whom they persist, fluctuate, or resolve over time, which would also indicate if these sleep disturbances need active treatment or management, or if they resolve without it. Additionally, longitudinal studies may further inform us about the direction of causation of between sleep disturbance, depression, and agitation, as well as quality of life and medication.

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### CONFLICTS OF INTEREST

LW reports that the analyses in this paper were undertaken as part of their ESRC-funded PhD studentship. SGC reports receiving research funding from Alzheimer's Research UK Grant, European Research



Council and Dunhill Medical Trust. JAB reports voluntary work on data safety monitoring boards and receiving research funding from NIHR and MRC. SDK reports no-cost access to a digital sleep intervention (Sleepio, Big Health Ltd.) in clinical trial research. GL reports participating on the Lancet Healthy Longevity Board and receiving research funding from Alzheimer's Society, Wellcome trust, and NIHR.

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## REFERENCES

- McCleery J, Cohen DA, Sharpley AL. Pharmacotherapies for sleep disturbances in dementia. *Cochrane Database Syst Rev.* 2016;11:CD009178. <https://doi.org/10.1002/14651858.CD009178.pub3>
- Zhao Q-F, Tan L, Wang H-F, et al. The prevalence of neuropsychiatric symptoms in Alzheimer's disease: systematic review and meta-analysis. *J Affect Disord.* 2016;190:264-271. <https://doi.org/10.1016/j.jad.2015.09.069>
- Porter CN, Miller MC, Lane M, et al. The influence of caregivers and behavioral and psychological symptoms on nursing home placement of persons with Alzheimer's disease: a matched case-control study. *SAGE Open Med.* 2016;4:2050312116661877. <https://doi.org/10.1177/2050312116661877>
- Risco E, Cabrera E, Jolley D, et al. The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: a prospective observational cohort study. *Int J Nurs Stud.* 2015;52(5):980-987. <https://doi.org/10.1016/j.ijnurstu.2015.02.013>
- Webster L, Gonzalez SC, Stringer A, et al. Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis. *Sleep.* 2020;43(4):zsz251. <https://doi.org/10.1093/sleep/zsz251>
- Camargos EF, Louzada FM, Nobrega OT. Wrist actigraphy for measuring sleep in intervention studies with Alzheimer's disease patients: application, usefulness, and challenges. *Sleep Med Rev.* 2013;17(6):475-488. <https://doi.org/10.1016/j.smrv.2013.01.006>
- Hjetland GJ, Nordhus IH, Pallesen S, et al. An actigraphy-based validation study of the sleep disorder inventory in the nursing home. *Front Psychiatry.* 2020;11:173. <https://doi.org/10.3389/fpsy.2020.00173>
- Wilfling D, Dichter MN, Trutschel D, Köpke S. Prevalence of sleep disturbances in German nursing home residents with dementia: a Multicenter Cross-Sectional Study. *Alzheimers Dis.* 2019;69(1):227-236. <https://doi.org/10.3233/JAD-180784>
- Spronk I, Korevaar JC, Poos R, et al. Calculating incidence rates and prevalence proportions: not as simple as it seems. *BMC Public Health.* 2019;19(1):512. <https://doi.org/10.1186/s12889-019-6820-3>
- Bergh S, Engedal K, Røen I, Selbæk G. The course of neuropsychiatric symptoms in patients with dementia in Norwegian nursing homes. *Int Psychogeriatr.* 2011;23(8):1231-1239. <https://doi.org/10.1017/S1041610211001177>
- Bauhuis R, Mulders AJ, Koopmans RT. The course of neuropsychiatric symptoms in institutionalized patients with young onset dementia. *Aging Ment Health.* 2018;24(3):439-444. <https://doi.org/10.1080/13607863.2018.1531379>
- Wetzels RB, Zuidema SU, de Jonghe JFM, Verhey FRJ, Koopmans R. Course of neuropsychiatric symptoms in residents with dementia in nursing homes over 2-year period. *Am J Geriatr Psychiatry.* 2010;18(12):1054-1065. <https://doi.org/10.1097/JGP.0b013e3181f60fa1>
- Selbaek G, Engedal K, Benth JS, Bergh S. The course of neuropsychiatric symptoms in nursing-home patients with dementia over a 53-month follow-up period. *Int Psychogeriatr.* 2014;26(1):81-91. <https://doi.org/10.1017/S1041610213001609>
- Blytt KM, Flo-Groeneboom E, Erdal A, Bjorvatn B, Husebo BS. Sleep and its association with pain and depression in nursing home patients with advanced dementia—a Cross-Sectional Study. *Front Psychol.* 2021;12:1330.
- Webster L, Powell K, Costafreda SG, Livingston G. The impact of sleep disturbances on care home residents with dementia: the SIESTA qualitative study. *Int Psychogeriatr.* 2020;32(7):839-847. <https://doi.org/10.1017/S1041610220000642>
- Livingston G, Barber J, Marston L, et al. Prevalence of and associations with agitation in residents with dementia living in care homes: mARQUE cross-sectional study. *BJPsych Open.* 2017;3(4):171-178. <https://doi.org/10.1192/bjpo.bp.117.005181>
- Mental Capacity Act, Mental Capacity Act.* The Stationery Office; 2005.
- Laybourne A, Livingston G, Cousins S, et al. Carer coping and resident agitation as predictors of quality of life in care home residents living with dementia: managing Agitation and Raising Quality of Life (MARQUE) English national care home prospective cohort study. *Int J Geriatr Psychiatry.* 2018;34(1):106-113. <https://doi.org/10.1002/gps.4994>
- Levin E, Gorbach P, Sinclair I. *Families, Services, and Confusion in Old Age.* Avebury; 1989.
- National Institute of Health Dissemination Centre. *Advancing Care: Research with Care Homes.* National Institute of Health Dissemination Centre; 2017.
- Cummings JL. The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. *Neurology.* 1997;48(5 Suppl 6):S10-S16. [https://doi.org/10.1212/wnl.48.5\\_suppl.6.10s](https://doi.org/10.1212/wnl.48.5_suppl.6.10s)
- Wood S, Cummings JL, Hsu MA, et al. The use of the neuropsychiatric inventory in nursing home residents - Characterization and measurement. *Am J Geriatr Psychiatry.* 2000;8(1):75-83. <https://doi.org/10.1097/00019442-200002000-00010>
- Margallo-Lana M, Swann A, O'Brien J, et al. Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *Int J Geriatr Psychiatry.* 2001;16(1):39-44. [https://doi.org/10.1002/1099-1166\(200101\)16:1<39::AID-GPS269>3.0.CO;2-F](https://doi.org/10.1002/1099-1166(200101)16:1<39::AID-GPS269>3.0.CO;2-F)
- Smith SC, Lamping DL, Banerjee S, et al. Development of a new measure of health-related quality of life for people with dementia: dEMQOL. *Psychol Med.* 2007;37(5):737-746. <https://doi.org/10.1017/S0033291706009469>
- Morris JC. Clinical dementia rating: a reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *Int Psychogeriatr.* 1997;9(Suppl 1 S1):173-176. discussion 177-8.
- Cohen-Mansfield J, Billig N. Agitated behaviors in the elderly. I. A conceptual review. *Am Geriatr Soc.* 1986;34(10):711-721. <https://doi.org/10.1111/j.1532-5415.1986.tb04302.x>
- Time and date. *Time and Date - Sunrise, Sunset and Day Length.* Time and Date; 2019 [Last accessed: Last accessed 30/04/2019]; <https://www.timeanddate.com/sun/uk/london>
- Appelhof B, Bakker C, de Vugt ME, et al. Effects of a multidisciplinary intervention on the presence of neuropsychiatric symptoms and psychotropic drug use in nursing home residents with young-onset dementia: behavior and Evolution of Young Onset Dementia part 2 (BEYOND-II) study. *Am J Geriatr Psychiatry.* 2019;27(6):581-589. <https://doi.org/10.1016/j.jagp.2018.12.032>
- Mulders AJ, Fick IWF, Bor H, et al. Prevalence and correlates of neuropsychiatric symptoms in nursing home patients with young-onset dementia: the BEYOND Study. *J Am Med Dir Assoc.* 2016;17(6):495-500. <https://doi.org/10.1016/j.jamda.2016.01.002>
- Livingston G, Barber JA, Kinnunen KM, et al. DREAMS-START (Dementia RElAted Manual for Sleep; STRAtegies for RelaTives) for people with dementia and sleep disturbances: a single-blind feasibility and acceptability randomized controlled trial. *Int Psychogeriatr.* 2019;31(2):251-265. <https://doi.org/10.1017/S1041610218000753>

31. Ito E, Berge LI, Husebo BS, Nouchi R, Sandvik R. The negative impact of psychotropic drug use on quality of life in nursing home patients at different stages of dementia: cross-sectional analyses from the COSMOS trial. *J Am Med Dir Assoc*. 2020;21(11):1623-1628. <https://doi.org/10.1016/j.jamda.2020.03.028>
32. Berry SD, Placide SG, Mostofsky E, et al. Antipsychotic and benzodiazepine drug changes affect acute falls risk differently in the nursing home. *J Gerontol A Biol Sci Med Sci*. 2016;71(2):273-278. <https://doi.org/10.1093/gerona/glv091>
33. Westerlind B, Östgren CJ, Mölstad S, Midlöv P, Hägg S. Use of non-benzodiazepine hypnotics is associated with falls in nursing home residents: a longitudinal cohort study. *Aging Clin Exp Res*. 2019;31(8):1087-1095. <https://doi.org/10.1007/s40520-018-1056-0>
34. Lippert T, Maas M, Fromm MF, et al. Impact of sedating drugs on falls resulting injuries among people with dementia in a nursing home setting. *Gesundheitswesen*. 2020;82(1):14-22. <https://doi.org/10.1055/a-1071-7911>
35. Banerjee S. The use of antipsychotic medication for people with dementia: time for action. 2009.
36. Hashizaki M, Nakajima H, Shiga T, Tsutsumi M, Kume K. A longitudinal large-scale objective sleep data analysis revealed a seasonal sleep variation in the Japanese population. *Chronobiol Int*. 2018;35(7):933-945. <https://doi.org/10.1080/07420528.2018.1443118>
37. Sivertsen B, Overland S, Krokstad S, Mykletun A. Seasonal variations in sleep problems at latitude 63-65 in Norway: the Nord-Trøndelag Health Study, 1995-1997. *Am J Epidemiol*. 2011;174(2):147-153. <https://doi.org/10.1093/aje/kwr052>
38. Ancoli-Israel S, Klauber MR, Jones DW, et al. Variations in circadian rhythms of activity, sleep, and light exposure related to dementia in nursing-home patients. *Sleep*. 1997;20(1):18-23. <https://doi.org/10.1093/sleep/20.1.18>
39. Castineiras AR, Díaz Grávalos GJ, Hermida SR, et al. Prevalencia de síntomas neuropsiquiátricos en pacientes institucionalizados con diagnóstico de demencia y factores asociados: estudio transversal multicéntrico. *Rev Esp Geriatr Gerontol*. 2012;47(3):96-101. <https://doi.org/10.1016/j.regg.2012.02.002>
40. Suzuki M, Hattori H, Fukuda K, et al. 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*. 2017;54(3):392-402. <https://doi.org/10.3143/geriatrics.54.392>
41. Tractenberg RE, Singer CM, Cummings JL, Thal LJ. The Sleep Disorders Inventory: an instrument for studies of sleep disturbance in persons with Alzheimer's disease. *J Sleep Res*. 2003;12(4):331-337. <https://doi.org/10.1046/j.0962-1105.2003.00374.x>
42. Webster L, Martin A, Livingston G. The minimum clinically important difference on the sleep disorders inventory for people with dementia. *Int J Geriatr Psychiatry*. 2020;35(11):1418-1423. <https://doi.org/10.1002/gps.5384>
43. Palm R, Sorg CGG, Ströbel A, Gerritsen DL, Holle B. Severe agitation in dementia: an explorative secondary data analysis on the prevalence and associated factors in nursing home residents. *Alzheimers Dis*. 2018;66(4):1463-1470. <https://doi.org/10.3233/JAD-180647>
44. Prado-Jean A, Couratier P, Druet-Cabanac M, et al. Specific psychological and behavioral symptoms of depression in patients with dementia. *Int J Geriatr Psychiatry*. 2010;25(10):1065-1072. <https://doi.org/10.1002/gps.2468>
45. Veldwijk-Rouwenhorst AE, Zuidema SU, Smalbrugge M, et al. Very frequent physical aggression and vocalizations in nursing home residents with dementia. *Aging Ment Health*. 2020;25(8):1442-1451. <https://doi.org/10.1080/13607863.2020.1786799>
46. Flo E, Bjorvatn B, Corbett A, Pallesen S, Husebo BS. Joint occurrence of pain and sleep disturbances in people with dementia. A systematic review. *Curr Alzheimer Res*. 2017;14(5):538-545. <https://doi.org/10.2174/1567205013666160602234932>
47. Achterberg WP, Everink IH, van der Steen JT, Gordon AL. We're all different and we're the same: the story of the European nursing home resident. *Age Ageing*. 2019;49:3-4. <https://doi.org/10.1093/ageing/afz145>
48. Office for National Statistics. Overview of the UK Population. Office for National Statistics; 2019 [Last accessed:12/02/2020]; <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/august2019>
49. Office for National Statistics. Changes in the Older Resident Care Home Population between 2001 and 2011. Office for National Statistics; 2014 [Last accessed:19/08/2018]; <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathandmarriages/ageing/articles/changesintheolderresidentcarehomepopulationbetween2001and2011/2014-08-01>
50. Blytt KM, Bjorvatn B, Husebo B, Flo E. Clinically significant discrepancies between sleep problems assessed by standard clinical tools and actigraphy. *BMC Geriatr*. 2017;17(1):253. <https://doi.org/10.1186/s12877-017-0653-7>
51. Arons AM, Krabbe PFM, Schölzel-Dorenbos CJM, van der Wilt GJ, Olde Rikkert MGM. Quality of life in dementia: a study on proxy bias. *BMC Med Res Methodol*. 2013;13(1):1-8. <https://doi.org/10.1186/1471-2288-13-110>
52. Holodinsky JK, Austin PC, Williamson TS. An introduction to clustered data and multilevel analyses. *Fam Pract*. 2020;37(5):719-722. <https://doi.org/10.1093/fampra/cmaa017>

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## APPENDIX A

### Additional regression analyses

**TABLE A1** Individual multilevel regression models of the association of symptoms of sleep disturbances of any severity with other resident outcomes with quality of life, sleep medications, antipsychotics, and antidepressants at baseline

Factor [n]	Regression coefficient or odds ratio	95% confidence interval
Quality of life score (DEMQOL) [1445]	-4.93 <sup>a</sup>	[-6.28 to -3.59]
Regular and PRN sleep medications [1413]	1.77 <sup>b</sup>	[1.27 to 2.45]
Regular and PRN antipsychotics [1413]	1.70 <sup>b</sup>	[1.20 to 2.41]
Antidepressants [1413]	1.07 <sup>b</sup>	[0.82 to 1.40]

<sup>a</sup>Regression coefficient, linear model.

<sup>b</sup>Odds ratio, logistic model; CMAI, Cohen-Mansfield Agitation Inventory; significant values are in bold.

Abbreviations: DEMQOL, Dementia Quality of Life Instrument; PRN, pro re nata.

**TABLE A2** Multilevel logistic regression model of factors associated with symptoms of sleep disturbances of any severity

Factor [n = 1331]	Odds ratio	95% confidence interval
Sex		
Female	0.77	[0.56 to 1.05]
Male	1	
Age	1.00	[0.98 to 1.02]
Dementia severity (CDR)		
Mild	1	
Moderate	1.02	[0.70 to 1.50]
Severe	1.11	[0.80 to 1.56]
Agitation score (CMAI)	1.03	[1.02 to 1.04]
Anxiety score (NPI)	1.05	[0.99 to 1.12]
Depression score (NPI)	1.17	[1.10 to 1.25]
Delusions score (NPI)	1.02	[0.96 to 1.09]
Hallucinations score (NPI)	0.99	[0.90 to 1.08]
Minutes of daylight/time of year	0.99	[0.99 to 1.00]

Abbreviations: CDR, Clinical Dementia Rating global score; CMAI, Cohen Mansfield Agitation Inventory; NPI, Neuropsychiatric Inventory item; significant values are in bold.