Insomnia and daytime sleepiness in people with dementia residing in assisted living: findings from the Maryland Assisted Living Study

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SUMMARY

Objective To estimate the frequency and correlates of insomnia and daytime sleepiness among people with dementia in AL facilities.

Methods Participants were randomly selected from 22 different assisted living facilities in Maryland. A total of 124 dementia participants were included in the analysis. All participants were rated on an 11-item sleep questionnaire regarding insomnia and daytime sleepiness.

Results Sleep disturbance was present in 59.2% of people with dementia. Of the total sample, 21.8% had insomnia only (IN); 21.6% had excessive daytime sleepiness only (DS); and 16.8% had both IN and DS. 40.8% had no sleep disturbance. IN and DS scores were not significantly associated with each other ($r = 0.07, p = 0.43$). Of those in the IN group, the majority had mild and moderate dementia and of those in the DS only group the majority had severe dementia. Those with IN only performed the best and DS only performed the worst on both cognitive measures (the Mini Mental State Examination) ($F = 3.26, p = 0.014$), and on physical measures (the physical subscale of the psychogeriatric dependency rating scale) ($F = 6.09, p < 0.001$). There was no significant difference between the groups on the Cornell scale for depression in dementia.

Conclusion The frequency of insomnia and daytime sleepiness in dementia subjects in AL is similar to that found in nursing homes. Daytime sleepiness is associated with poorer cognitive and day-to-day functioning. Effective management of DS may lead to improved functioning in the AL residents. Insomnia is associated with the best outcomes, even better than those with no sleep disturbance. This finding needs to be replicated. Copyright © 2007 John Wiley & Sons, Ltd.

KEY WORDS — insomnia; daytime sleepiness; dementia; assisted living

INTRODUCTION

Sleep disturbance is common in dementia, with about 50% experiencing sleep problems (Hart et al., 2003). It increases risk of falls, behavior problems and is a common cause of caregiver burden and nursing home placement (Donaldson et al., 1998). Probable causes of sleep disturbances include damage to neuronal pathways that initiate and maintain sleep, degeneration of the suprachiasmatic nucleus, medications, medical problems, psychiatric illness, and environmental factors (McCurry et al., 2000; Skene and Swaab, 2003).

However, it is still unclear why only some patients with dementia develop sleep problems. There is
minimal literature on the risk factors associated with the different types of sleep problems in dementia. There is no literature on the prevalence and correlates of sleep problems in dementia patients living in assisted living (AL) facilities. This is an important area of study, as sleep disturbance is a common cause of institutionalization and AL facilities serve as a transit between community living and institutionalization. Understanding the prevalence and correlates of sleep problems of dementia patients in AL facilities can help with treatment which may reduce institutionalization. It is with this background that this study was initiated. The objective was to estimate the frequency and correlates of insomnia and daytime sleepiness among people with dementia in AL facilities. Based on literature review and the results of our previous study on sleep disturbances in the elderly (Rao et al., 2005), we hypothesized the following:

1. Increased prevalence of insomnia and daytime sleepiness;
2. Medications, medical co-morbidity and depression will be significant correlates of daytime sleepiness and insomnia;
3. Participants with insomnia will do the best and those with daytime sleepiness the worst on measures of cognitive and physical functioning.

The results presented here are a subanalysis of the previous study (Rao et al., 2005).

METHODS AND MEASURES

The Maryland Assisted Living study has been described in detail by Rosenblatt et al. (2004). This is an ongoing study to determine prevalence, correlates and treatment of dementia and other psychiatric disturbances in residents living in Maryland assisted living facilities.

Study overview

Twenty two facilities stratified by size, were selected at random from a list of all licensed or pending license AL facilities in the State of Maryland. Informed consent was obtained from all residents who could do so. A legal representative provided informed consent for participants who were unable to provide. All participants received a comprehensive psychiatric work-up by a geriatric psychiatrist. The research nurse administer additional tests (described below) and obtained collateral history from a family informant, facility staff and reviewed medical records for current medications and medical problems. At an adjudication conference all the history and test results were reviewed by a multi-disciplinary panel of experts. Diagnoses of dementia and psychiatric illness were assigned using DSM-IV criteria (American Psychiatric Association, 1994).

Participants

The original study sample consisted of 198 AL residents who were evaluated between February 2001 and January 2003. Of these a total of 134 participants were diagnosed with dementia. Of these, nine were excluded from the analysis as the sleep questionnaire was incomplete, resulting in a final sample of 125.

Measures

The Structured Clinical Interview for DSM-IV (Spitzer et al., 1995) was used to make psychiatric diagnoses by a geriatric psychiatrist. The nurse rated the resident on the following scales:

- Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) to assess for behavioral disorders in dementia.
- Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1998). This is an observer rated scale to rate depression in patients with dementia.
- Psychogeriatric Dependency Rating Scale (PGDRS). This has three components: Orientation, Behaviour, and Physical Capacity. The physical subscale which assesses activities of daily living was used in this study (Wilkinson and Graham-White, 1980).
- General Medical Health Rating (GMHR), a measure of medical co-morbidity (Lyketsos et al., 1999).
- Mini Mental State Exam (MMSE) to assess cognitive functioning (Fozstein et al., 1975).
- The sleep questionnaire in use in the Johns Hopkins Alzheimer’s Disease Research Center (see below).

The Sleep Questionnaire (SQ)

The Sleep Questionnaire was developed by staff of the Division of Geriatric and Neuropsychiatry at the Johns Hopkins Hospital (see Figure 1). It includes 11 items scored on a three-point Likert scale, with ‘0’ being little or no disturbance present, ‘1’ being mild to moderate, and ‘2’ being chronic and severe disturbance present. This questionnaire assesses symptoms of...
INSTRUCTIONS: If the patient is unable to answer these questions, use an informant who has observed the patient sleeping at least 3 times in the last week.

1. How long does it usually take you to fall asleep at night?
   0 = less than 30 minutes  1 = 30 minutes to 1 hour  2 = more than 1 hour

2. How many times do you usually wake up during the night?
   0 = 0-1  1 = 2-5  2 = 6 or more

3. Do you wake up earlier in the morning than you would like to?
   0 = rarely or never  1 = occasionally  2 = usually or always

4. Do you take medication or alcohol to help you sleep?
   0 = rarely or never  1 = occasionally  2 = usually or always
   type and amount: ______  type and amount: ______

5. How many hours total do you usually sleep at night?
   0 = more than 8 hours  1 = 4-8 hours  2 = less than 4 hours

6. Do you snore or gasp at night?
   0 = rarely or never  1 = occasionally  2 = usually or always

7. In general, do you have difficulty sleeping at night?
   0 = rarely or never  1 = occasionally  2 = usually or always

8. If you have difficulty sleeping at night, when did it begin?
   0 = within the past year  1 = between 1 and 5 years ago  2 = more than 5 years ago

9. Are you excessively sleepy during the day?
   0 = rarely or never  1 = occasionally  2 = usually or always

10. Do you usually nap during the day?
    0 = no  1 = yes, less than 1 hour total  2 = yes, more than 1 hour total

11. Do you have unusual or excessive dreams at night?
    0 = rarely  1 = occasionally  2 = usually or always

Figure 1. Maryland Assisted Living Study: Sleep Questionnaire.

insomnia, excessive daytime sleepiness and unusual and excessive dreams. The questionnaire was designed to assess sleep disturbance, not diagnose sleep disorders. To estimate its concurrent validity, ratings on the questionnaire were compared to those made on the sleep domain of the Neuropsychiatry Inventory (NPI) (Cummings et al., 1994). The correlation between the score (Frequency * Severity) on the NPI Sleep Domain and the total score (the sum of all items) on the Sleep Questionnaire was significant ($n = 188$, $r = 0.44$, $p < 0.001$), supporting concurrent validity.
**Defining sleep disturbance**

The range of possible scores on the sleep questionnaire was from 0–22. The lowest score possible was '0' and the highest was '22'. Insomnia (IN) was calculated by summing questions 1–5, 7, and 8 and daytime sleepiness (DS) was calculated by summing scores from questions 6, 9, and 10. Subjects with low scores on all the domains of the questionnaire were considered to have no sleep problems. Subjects with elevated insomnia (>7) and daytime sleepiness scores (>4) were considered to have both insomnia and daytime sleepiness (Both IN and DS). Subjects with elevated insomnia scores (>7) but normal daytime sleepiness scores (<5) were considered to have insomnia only (IN Only), and those with elevated daytime sleepiness scores (>4) but normal insomnia scores (<8) were considered to have daytime sleepiness only (DS Only).

**Classifying dementia severity**

To determine the usefulness of MMSE in staging dementia, Perneczky et al. (2006) mapped the MMSE scores onto clinical dementia rating (CDR) categories. They found that the MMSE differentiated between CDR stages 0.5, 1, 2, and 3. Based on this, we classified the severity of dementia as: mild = MMSE > 20; moderate = MMSE 11–19; severe MMSE < 10.

**DATA ANALYSIS**

Analysis of variance and chi-square tests were conducted to examine differences across the four groups. In order to examine the effects of dementia status on sleep problems, regression models were estimated for each of the study scales. The following dummy variables were created and entered into the model:

<table>
<thead>
<tr>
<th>Mild Dementia, Moderate Dementia, Severe Dementia, No Sleep Problem, IN Only, DS Only, and Both IN and DS</th>
</tr>
</thead>
</table>

**RESULTS**

Table 1 provides a demographic description of the total sample. The sample was divided into four groups: No sleep problems, Insomnia only (IN Only) Daytime sleepiness only (DS Only) and both daytime sleepiness and insomnia. Sleep disturbance was present in 59.2%; 20.8% had IN Only; 21.6% had DS Only; and 16.8% had Both IN and DS and 40.8% had no sleep disturbance. IN and DS scores were not correlated ($r = 0.07, p = 0.43$). There were no significant differences in age, gender, race, or education among the four groups.

Hypnotic use was more common in participants with Both IN and DS; otherwise, there was no significant difference between the groups on use of other medications. See Tables 2 and 3.

Of participants in all the sleep groups, those with IN Only performed best, and DS Only performed worst.
on the MMSE \((F = 3.26, p = 0.014)\), the GMHR \((F = 3.60, p = 0.008)\), and the physical \((F = 6.09, p < 0.001)\) subscales of the PGDRS. There was no significant difference between the groups on the CSDD. See Table 4.

Mild dementia accounted for 30.7\%, moderate dementia 40.3\% and severe dementia 29\%. Of those in the IN group, the majority had mild and moderate dementia and of those in the DS only group the majority had severe dementia. (see Table 5).

Table 3. Comparison of the different sleep groups on medication use

<table>
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<th>Variable</th>
<th>No Sleep Problem</th>
<th>IN Only</th>
<th>DS Only</th>
<th>Both IN and DS</th>
<th>x2</th>
<th>P</th>
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<td></td>
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<td>18 (35.3%)</td>
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<td>9 (33.3%)</td>
<td>5 (23.8%)</td>
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<td>18 (66.7%)</td>
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<td>4 (19.0%)</td>
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<td>26 (96.3%)</td>
<td>17 (81.0%)</td>
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<td>Anxiolytics</td>
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<td>0.814</td>
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<td>24 (88.9%)</td>
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<tr>
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<td>48 (94.1%)</td>
<td>25 (96.2%)</td>
<td>26 (96.3%)</td>
<td>16 (76.2%)</td>
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<td>26 (96.3%)</td>
<td>18 (85.7%)</td>
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<td>24 (88.9%)</td>
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<td>26 (96.3%)</td>
<td>19 (90.5%)</td>
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<td>Anti-Depressants (Non-Sedating)</td>
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<td>4.45</td>
<td>0.217</td>
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<tr>
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<td>9 (17.6%)</td>
<td>10 (38.5%)</td>
<td>7 (25.9%)</td>
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<td>16 (61.5%)</td>
<td>20 (74.1%)</td>
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<td>Anti-Psychotics</td>
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<td>0.517</td>
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<td>6 (23.1%)</td>
<td>4 (14.8%)</td>
<td>7 (33.3%)</td>
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<td></td>
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<tr>
<td>No</td>
<td>39 (76.5%)</td>
<td>20 (76.9%)</td>
<td>23 (85.2%)</td>
<td>14 (66.7%)</td>
<td></td>
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</table>

Table 4. Comparison of the different sleep groups on clinical, cognitive and physical functioning variables

<table>
<thead>
<tr>
<th>Clinical Variables (Scales Used)</th>
<th>Mean (SD)</th>
<th>F</th>
<th>P</th>
<th>Post Hoc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition (MMSE)</td>
<td></td>
<td>F = 3.26</td>
<td>0.014</td>
<td></td>
</tr>
<tr>
<td>No Sleep Problem</td>
<td>14.61 (8.19)</td>
<td>&lt; IN only</td>
<td>&gt; DS Only</td>
<td></td>
</tr>
<tr>
<td>IN Only</td>
<td>18.27 (5.40)</td>
<td>&gt; No Problem</td>
<td>&gt; DS Only</td>
<td></td>
</tr>
<tr>
<td>DS Only</td>
<td>10.73 (8.72)</td>
<td>&lt; No Problem</td>
<td>&lt; IN only</td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>14.33 (6.61)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (CSDD)</td>
<td></td>
<td>F = 1.84</td>
<td>0.125</td>
<td></td>
</tr>
<tr>
<td>No Sleep Problem</td>
<td>4.37 (4.52)</td>
<td>&lt; IN Only</td>
<td>&gt; DS Only</td>
<td></td>
</tr>
<tr>
<td>IN Only</td>
<td>5.28 (3.35)</td>
<td>&gt; No Problem</td>
<td>&gt; DS Only</td>
<td></td>
</tr>
<tr>
<td>DS Only</td>
<td>5.36 (4.02)</td>
<td>&lt; No Problem</td>
<td>&lt; IN only</td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>7.42 (5.19)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Medical Comorbidity (GMHR)</td>
<td></td>
<td>F = 3.60</td>
<td>0.008</td>
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</tr>
<tr>
<td>No Sleep Problem</td>
<td>2.92 (8.45)</td>
<td>&gt; DS Only</td>
<td>&gt; Both IN and DS</td>
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</tr>
<tr>
<td>IN Only</td>
<td>2.96 (7.20)</td>
<td>&gt; DS Only</td>
<td>&gt; Both IN and DS</td>
<td></td>
</tr>
<tr>
<td>DS Only</td>
<td>2.37 (7.92)</td>
<td>&lt; IN Only</td>
<td>&lt; Both IN and DS</td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>2.48 (6.89)</td>
<td>&lt; No Problem</td>
<td>&lt; IN Only</td>
<td></td>
</tr>
<tr>
<td>Physical Functioning (PDGRS-Physical)</td>
<td></td>
<td>F = 6.09</td>
<td>&lt; 0.001</td>
<td></td>
</tr>
<tr>
<td>No Sleep Problem</td>
<td>12.40 (8.67)</td>
<td>&lt; DS Only</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IN Only</td>
<td>10.48 (6.44)</td>
<td>&lt; DS Only</td>
<td>&lt; Both IN and DS</td>
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<tr>
<td>DS Only</td>
<td>21.04 (8.61)</td>
<td>&gt; No Problem</td>
<td>&gt; IN Only</td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>16.33 (8.05)</td>
<td>&gt; IN Only</td>
<td>&lt; DS Only</td>
<td>&gt; Both IN and DS</td>
</tr>
</tbody>
</table>
Regression analysis revealed IN Only and DS Only groups significantly predicted MMSE; DS Only and Both IN and DS significantly predicted GMHR and mild dementia, severe dementia and DS Only significantly predicted the physical subscale of the PDGRS (see Table 6).

DISCUSSION

Our results reveal a high frequency of sleep problems among dementia participants in the Maryland assisted living facilities, similar to that reported in the nursing homes (Fetveit and Bjorvatn, 2002). Participants with daytime sleepiness were more likely to have severe dementia in our study, which replicates findings by other researchers (McCurry et al., 2003; Ohadinia et al., 2004). Similar to our earlier findings (Rao et al., 2005), subjects with IN Only performed the best on both cognitive and physical functioning measures, even better than those with no sleep disturbance. There are no other studies that found better cognitive or physical functioning in dementia patients with insomnia. There are two possible explanations: (a) there may be over-reporting of sleeplessness by those with mild dementia (b) structured settings like AL facilities may offer some kind of positive stimulation to people who are awake resulting in better cognitive and physical performance. Several animal studies have provided evidence on the potential for delay in cognition in an enriched environment (Jankowsky et al., 2005; Costa et al., 2007). Huang et al. (2006) have shown that mice exposed to enriched environment had significant increase of hippocampal neurogranin which can improve long-term potentiation and behavioral performance. Our finding of improved cognitive and physical performance in patients with dementia needs replication.

Similar to our earlier findings (Rao et al., 2005) and other studies (Ohayon et al., 1997; Happe 2003), dementia participants with daytime sleepiness performed worst on both cognitive and on measures of physical functioning. Bonanni et al. (2005) have also found a significant correlation between daytime sleepiness and poor in cognition, indicating daytime

<table>
<thead>
<tr>
<th>Variable</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Sleep Problem</td>
<td>15 (29.4%, 41.7%)</td>
<td>20 (39.2%, 40.0%)</td>
<td>16 (31.4%, 42.1%)</td>
</tr>
<tr>
<td>Insomnia Only</td>
<td>2 (7.7%, 5.6%)</td>
<td>14 (53.8%, 28%)</td>
<td>10 (38.5%, 26.3%)</td>
</tr>
<tr>
<td>Daytime Sleepiness Only</td>
<td>14 (53.8%, 38.9%)</td>
<td>6 (23.1%, 12.0%)</td>
<td>6 (23.1%, 15.8%)</td>
</tr>
<tr>
<td>Both IN and DS</td>
<td>5 (23.8%, 13.9%)</td>
<td>10 (47.6%, 20.0%)</td>
<td>6 (28.6%, 15.8%)</td>
</tr>
<tr>
<td>Total*</td>
<td>36 (29.0%, 100%)</td>
<td>50 (40.3%, 100%)</td>
<td>38 (30.7%, 100%)</td>
</tr>
</tbody>
</table>

\[ X^2 = 14.22, p = 0.027 \]

*The severity of dementia on one participant is unknown.

Table 6. Regression models

Dependent Variable/Variables in Equation | B | Statistic | P-value | \( R^2 \)
---|---|---|---|---
MMSE* | | | | 
DS Only | -3.80 | \( t = -2.21 \) | 0.029 | 0.082 |
IN Only | 3.74 | \( t = 2.17 \) | 0.032 | 
CSDD | | \( F = 6.29 \) | 0.013 | 0.042 |
Both IN and DS | 2.61 | \( t = 2.51 \) | 0.013 | 
PDGR-Orientation | | | | 
Mild Dementia | 1.78 | \( t = 4.10 \) | 0.001 | 
DS Only | -1.56 | \( t = -3.27 \) | 0.001 | 
Severe Dementia | -1.29 | \( t = -2.72 \) | 0.008 | 
PDGR-Physical | | | | 
Mild Dementia | -6.16 | \( t = -3.90 \) | < 0.001 | 
DS Only | 7.14 | \( t = 4.51 \) | < 0.001 | 
Both IN and DS | 4.16 | \( t = 2.32 \) | 0.022 | 
Severe Dementia | 3.34 | \( t = 2.01 \) | 0.047 | 

Variables entered into model: DS Only, IN Only, Both IN and DS, Mild Dementia, Moderate Dementia, Severe Dementia.
sleepiness is probably due to ‘impairment of the neurophysiological system involved in the maintenance of wakefulness’. This underscores the importance of diagnosing and treating daytime sleepiness. In a study of nursing home residents with dementia, Richards et al. (2005) have shown that providing individualized social activity intervention for 1–2 hours/day is both cost-effective and significantly reduces day/night sleep ratio.

Medications and psychiatric disturbances have found to be commonly associated with sleep problems (Vitiello and Borson, 2001; Cooke and Ancoli-Israel, 2006). However in our study, surprisingly, only hypnotics was significantly associated with Both IN and DS. Regression analysis also did not find other medications to be significant associates of insomnia or daytime sleepiness. The lack of association between sleep disturbance and depression is a surprising finding. However, many of our participants were on anti-depressants and the average CSSD score in the sample was 5.3 (SD = 4.4) indicating a low level of depression in this sample. McCurry et al. (1999) also found no association between depression and the frequency of nighttime awakening in a sample of community-dwelling AD patients.

The major limitation of our study is that the validity of the sleep questionnaire has not been clearly established. However, on comparing it to the sleep subscale of the NPI, moderate correlation was found. In addition, there is also some variation in collection of the sleep data. We have no reliability data to suggest that a surrogate can accurately respond to the sleep questionnaire. This may have resulted in under- or over-estimation of sleep problems. Finally, this sample is a subset of the cohort discussed in our earlier paper (Rao et al., 2005). Therefore biases which might have influenced the previous study might also be operative here and lead to replication of the findings.

Despite these limitation, this is first study to explore sleep disturbances in AL participants with dementia residing in assisted living facilities. While the findings on daytime sleepiness is consistent with what is available in the literature, the findings of better performance cognitively and physically in those with insomnia (better than those without daytime sleepiness) have not been reported so far in the literature.

CONCLUSION

Future work should focus on use of actigraphy and polysomnography to diagnose the different types of sleep problems such as circadian rhythm disturbances, sleep disordered breathing, restless leg syndrome and periodic leg movements. Research should also focus on treatment and outcomes such as quality of life, medical co-morbidity and mortality, in dementia patients with sleep disturbances.

ACKNOWLEDGEMENTS

This study was supported by grant RO1MH60626 from the National Institute of Mental Health. The authors are grateful to Dr Sonia Ancoli-Israel, Professor of Psychiatry at the University of California San Diego School of Medicine and Director of the Sleep Disorders Clinic at the Veterans Affairs San Diego Healthcare system for her valuable comments during the preparation of this manuscript. In addition, they are also thankful to the residents, families, staff, and management of the assisted living facilities that took part in this research study.

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