



## NGNA Section

# The influence of sleep disruption and pain perception on indicators of quality of life in individuals living with dementia at home



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## A B S T R A C T

**Keywords:**  
Quality of life  
Caregiving  
Sleep disturbance  
Pain  
Dementia

This cross-sectional study evaluated the influence of sleep quality and pain perceptions on different dimensions of quality of life in community-dwelling persons with dementia. Evaluations of pain were collected using Visual Analog Scale (VAS), sleep disruption using Pittsburgh Sleep Quality Index (PSQI) items, and quality of life indicators using the DemQOL-Proxy in 88 persons with dementia and their family caregivers. Lower overall quality of life was associated with the presence of pain and symptoms of sleep disruption when controlling for mental status, age, and number of health conditions. Pain and sleep symptoms were differentially associated with different aspects of QoL. As symptoms negatively impact quality of life but are modifiable, better clinical procedures are needed to prevent and also identify and treat symptoms of pain and sleep disturbance in community-dwelling persons with dementia.

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## Introduction

According to the 2013 World Alzheimer Report, there are currently 36 million people with dementia worldwide. This number is projected to exceed 60 million by 2032, and 115 million by 2050.<sup>1</sup> Among the consequences is a projected rapid rise in the costs of care for the ongoing support and treatment that persons with dementia require.<sup>2</sup> Because the disease is not curable. The primary objective of care is the maintenance and promotion of quality of life (QoL).<sup>3</sup> Therefore, QoL has become a primary target for and outcome of intervention studies as well as an indicator for the quality of care in this population.<sup>4,5</sup> It is important for nurses who care for older persons with dementia to understand factors that impact QoL and be positioned to impact this outcome.

Many studies have shown the QoL of dementia patients to be lower than that in the general older adult population.<sup>6</sup> Two prevalent and potentially modifiable factors influencing QoL ratings in older adults are undertreated pain and sleep disturbances.<sup>7,8</sup> The

perception of pain has been identified as an important contributory factor to QoL in several recent studies of community dwelling persons with dementia.<sup>9,10</sup> Similarly, the presence of sleep disturbances may impact QoL ratings for patients with dementia.<sup>11</sup> Despite the prevalence of undertreated pain and sleep disruption, there are no studies that examine the unique influence of both pain and sleep quality and on different indicators of QoL in community residing persons with dementia. Moreover, it is difficult to separate the effects of disturbed sleep from those of comorbid conditions and pain. Thus, the purpose of this study was twofold: to determine the prevalence of common sleep disturbances and pain and evaluate the unique contributions of both sleep disturbance and pain on overall QoL and three subscales in community dwelling persons with dementia controlling for factors such as number of health conditions and cognitive status.

QoL is a complex construct that encompasses different aspects of everyday life. The DEMQoL is a validated and widely used measure specific to dementia that captures three important components of daily life.<sup>12</sup> These include daily activities (daily life), self concept (feelings), and cognitive functioning (memory). Our hypothesis stated that both symptoms of pain and sleep disturbance would be significant predictors of poor overall QoL in persons with dementia

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as rated by caregivers, when controlling for demographic and illness severity factors. We did not have specific hypotheses as to the relationship of these predictors to the three subscales of the DEM-QoL – everyday life domain, memory domain and feeling domain.

## Materials and methods

### Subjects and setting

A total of 88 dyads (persons with dementia and family caregivers) were enrolled in this study between January 2009 and October 2010.<sup>11</sup> Participants with dementia were eligible if they lived in their own homes or with a family caregiver and spoke English. Also, participants with dementia were included if they had a Mini Mental Status Examination score of  $\geq 10$  since we sought participants with mild to moderate disease stage who had the potential to respond to questions concerning pain. Participants who were bed-bound and unresponsive to their environment were excluded. Caregivers were eligible based on the following criteria: 21 years of age or older; lived with or in close proximity to patients; spoke English; provided care for  $\geq 6$  months; and self-identified as the primary person involved in day-to-day coordination or hands-on care. Both persons with dementia and their family caregivers had to meet study criteria for enrollment.

Family caregivers were contacted and recruited through three primary sources: mailings, media advertisements, and outreach involving distribution of study flyers to aging and faith-based organizations. Caregivers contacting the research office were administered a brief telephone screen to determine initial eligibility. If eligible and willing to participate, a telephone battery was administered to the caregiver and a follow-up home visit of approximately 90 min was scheduled. At the first home visit, after signing an approved Institutional Review Board consent form and obtaining assent for participation from patients, assessors (occupational therapists) administered the MMSE to confirm study eligibility.<sup>11</sup> Following consent, background characteristics including a combination of caregiver reports and objective assessments were collected. Background characteristics were obtained for patients (age, race, sex, marital status) and caregivers (age, race, sex, depression, marital status, education level, relationship to patient [spouse/non-spouse], years caregiving, and financial difficulty level ranging from 1 = not difficult at all to 4 = very difficult). For patients' health conditions, caregivers indicated presence (yes/no) of 26 common conditions (e.g., diabetes, high blood pressure, arthritis, vision impairments). A total number of health conditions was derived.

### Instruments

To assess QoL, we used the Dementia Quality of Life Caregiver version (DEM-QoL-Proxy).<sup>12</sup> This 31-item DEM-QoL-Proxy is a structured interview in which 3 subscales of quality of life are administered to the caregiver. The 31 items and one global QoL item were developed from a conceptual framework that includes cognitive functioning (memory domain e.g., “forgetting names”), daily activities (everyday life domain e.g., “keeping him/herself clean”) and self concept (feeling domain e.g., “felt worried”). The psychometric properties of the DEM-QoL-Proxy have shown it to be both reliable and valid for measuring QoL for people with dementia by proxy report.<sup>13</sup> Caregivers are asked to assess items on a four-point Likert scale ranging from 0 (not at all) to 3 (a lot) with higher scores indicating better quality of life. The cognitive functioning subscale contains 9 items; the daily activities subscale has 11 items; and the self concept subscale has 11 items.

Mean subjective pain was assessed using the Visual Analog Scale (VAS<sup>14</sup>) with the Faces Pain Scale, originally developed for children<sup>15</sup> and validated with older adults.<sup>16</sup> A horizontal row of faces that range from smiling to crying with corresponding numbers, 0 to 10, are presented to the person with dementia. A numerical rating is obtained on a scale of 0 (no pain) to 10 (worst possible pain).

Sleep quality was assessed using the Pittsburgh Sleep Quality Index (PSQI),<sup>17</sup> in which caregivers (bed partners) report patients' frequency of disturbed sleep symptoms on 5 items (loud snoring, long pauses between breaths, legs twitching, episodes of disorientation during sleep, restless sleep) using a four-point Likert scale ranging from 0 (not during the past month) to 3 (three or more times a week). Scores were calculated to produce a global score (range of 0–15); a score of greater than five is suggestive of sleep disturbance. We also examined the number of patients who experienced one or more items more than once a week (score of “2” or “3”).

### Statistical analysis

Descriptive data for patient and caregiver included socio-demographic characteristics and proposed correlates of QoL. Summary statistics were presented as mean (SD), range for the continuous variables, and as frequencies for the categorical data. Correlation analysis with Pearson and Spearman coefficients was used to assess relationships among the demographic, pain, QoL, and sleep variables as appropriate. Statistical significance was based on a value of  $p < 0.05$  with a 95% confidence interval. Stepwise hierarchical multiple regression analyses were conducted to evaluate the independent effects of pain and sleep disruption on overall proxy reports of QoL and on each of the QoL domains of memory, feelings and everyday life. The models were constructed to remove variance accounted for by demographic variables and disease severity found significant in univariate analysis. Variables in the final equation were (1) demographic and disease variables (age, mental status, and number of health conditions); (2) pain and sleep quality.

## Results

### Sample characteristics

Of 113 dyads screened, 111 (98%) met initial study criteria and received the telephone battery. Of these, 101 (91%) received an initial home visit for which 91 were eligible with 10 (9%) dyads ineligible based on patient MMSE ( $< 10$ ). Of 91 eligible and enrolled dyads, 88 (97%) completed two home assessments and were included in the analyses.

Patients had mild to moderate cognitive impairment (Mean MMSE =  $17.7 \pm 4.6$ , range = 10–28), were primarily female (52.3%,  $n = 46$ ) and white (76.1%,  $n = 67$ ), and had an average age of  $82 \pm 8.0$  (range = 56–97). Caregivers had an average age of  $65.8 \pm 12.2$  (range = 38–89), were primarily female (88.6%,  $n = 78$ ), white (77.3%,  $n = 68$ ) and spouses (55.7%,  $n = 49$ ), with 100% having a high school or higher education. Caregivers provided care for an average of  $5.1 \pm 3.3$  (range 0.5–22) years. Most reported little to no difficulty (64.8%) paying for basics such as food, housing or medical care. Characteristics of the study sample are provided in [Table 1](#).

### Prevalence of pain and sleep disturbance

Most patients (55%) reported pain ranging from some to extreme pain, and 49% had  $\geq 1$  sleep problems which occurred  $\geq$  once a week. [Table 2](#) provides the frequency of occurrence for levels of pain and for each sleep symptom.

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