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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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Abstract

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.

Keywords

quality of life; caregiving; sleep disturbance; pain; dementia

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 2050.¹ Among the consequences is a projected rapid rise in the costs of care for the ongoing support and treatment that persons with dementia require.² Because the disease

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is not curable. the primary objective of care is the maintenance and promotion of quality of life (QoL).³ 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.^{4,5} 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.⁶ Two prevalent and potentially modifiable factors influencing QoL ratings in older adults are undertreated pain and sleep disturbances.^{7,8} The perception of pain has been identified as an important contributory factor to QoL in several recent studies of community dwelling persons with dementia.^{9,10} Similarly, the presence of sleep disturbances may impact QoL ratings for patients with dementia.¹¹ 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.¹² 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 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 DEMQoL - 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 2010.¹¹ 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 ≥ 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 ≥ 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 minutes 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.¹¹ 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 (DEMqoL-Proxy).¹² This 31-item DEMqoL-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 DEMqoL-Proxy have shown it to be both reliable and valid for measuring QoL for people with dementia by proxy-report.¹³ 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)¹⁴ with the Faces Pain Scale, originally developed for children¹⁵ and validated with older adults¹⁶. 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)¹⁷, 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 sociodemographic 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 ± 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 ± 8.0 (range = 56–97). Caregivers had an average age of 65.8 ± 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 ± 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 1 sleep problems which occurred once a week. Table 2 provides the frequency of occurrence for levels of pain and for each sleep symptom.

Relationship of Pain and Sleep Disturbance to QoL and Subscales

In multivariate regression analysis, pain, sleep disruption and mental status scores were associated with overall total score on the DEMQoL ($p = .04$, $p = .02$; $p = .04$, respectively), such that greater pain, more sleep disruption symptoms, and lower cognitive status predicted lower reports of QoL by caregivers.

The presence of pain and sleep disruptions had different associations with the specific DEMQoL domains. Both types of symptoms were significantly associated with the specific DEMQoL domain of “Feelings” ($p = .01$, $p = .04$, respectively). Additionally, pain, sleep

disruption, mental status score, and number of health conditions were associated with the DEMQoL domain of “Everyday life” ($p=.009$, $p=.01$, $p=.02$, $p=.0003$, respectively). However, pain alone was associated with the DEMQoL domain of “Memory” ($p=.02$). Sleep quality was not significantly associated with the DEMQoL domain of “Memory” (Table 3). These results indicated that while pain and disturbed sleep had an effect on overall QoL, there were differential effects of these symptoms on various dimensions of QoL.

Discussion

The results presented in this study confirm those of previous studies concerning the prevalence of pain and sleep disruption and their respective influence on QoL. References? Our study also extends previous findings by demonstrating the unique influence of pain and sleep on three QoL domains while controlling for demographic and disease severity factors. References? Pain and sleep disruption were common in this sample of community dwelling persons with dementia and were associated with their caregiver’s perception of their lower QoL.

The interrelationships of pain and sleep disturbance on the various domains of QoL in dementia patients need to be carefully considered in geriatric nursing research and practice. The relationship between these variables is most likely complex and beyond a mere cause and effect relationship. While this study provides evidence that pain, quality of sleep, and quality of life are interrelated, no causality can be inferred from these findings. These results did not demonstrate whether quality of sleep (or pain) affected quality of life, or vice versa. Research has shown that the pain-sleep relationship is bidirectional.¹⁸ That is, the experience of pain can cause sleeplessness and, in turn, poor-quality sleep can exacerbate pain. Sorting out which symptom is the primary causal factor or contributor to poor quality of life for this clinical population remains a question for future research.

The question arises as to why sleep and pain had differential effects on each domain of QoL. Pain and sleep disruption both negatively impacted the “feeling” domain of QoL. This finding is in line with other studies demonstrating that pain and sleep increase risk for affective disorders such as depression in older adults.^{19–20} From this we can infer that poor sleep and increased pain may impact unfavorable emotions and psychosocial functioning in older persons with dementia.

Pain may also worsen memory. Pain’s influence on the “memory” domain of QoL may be explained by the cognitive impairment noted in persons with chronic pain. In that pain may disrupt the ability to hold, process and retain information for storage in longer-term memory.²¹ Although sleep disruption has been shown to affect memory in studies of older adults without cognitive impairment,²² it was not significantly associated with the “memory” domain in our sample of individuals with mild to moderate stage dementia.

Finally, the effects of sleep disturbance and pain on the “every life” domain of QoL may be explained from studies demonstrating how both of these types of symptoms restrict a person’s ability to perform physical activities.²³ Disrupted sleep interferes with a person’s ability to participate daily activities that require sustained attention. The presence of painful

conditions decreases physical activity that may then lead to a decline in muscle strength and the development of mobility and functional limitations

The possible causes of pain and sleep disturbance in persons with dementia include fatigue, functional limitations, inflammatory processes, sleep disorders, and dyspnea. Research is need to examine whether the presence of certain morbid conditions associated with pain and sleep disruption, such as inflammatory diseases or sleep disorders such as restless leg syndrome and sleep apnea are associated with poor QoL This line of inquiry could shed light on the mechanisms underlying the relationship between sleep disruption, pain and QoL in order to determine effective interventions to impact QoL in this population

Limitations

In light of several study limitations, these results warrant caution in generalizing the findings. Limitations include the small sample size and cross sectional design. Longitudinal studies are needed to determine whether lower quality of life persists after the treatment for pain or sleep problems. Another limitation was the method used to measure pain; neither the duration of pain nor pain intensity could be determined. Also, proxy report was used for the assessment of the person's sleep-quality. The presence of sleep disturbances are measured most accurately with use of polysomnography.²⁴ Polysomnography readings could possibly detect organic causes of the effect of sleep on QoL, although are quite challenging to measure in a community sample of persons with dementia. Other methods of measurement, including actigraphy or a sleep diary, may be more reliable than caregiver report. However, we used a sleep quality measure that has been validated and compared with polysomnography, and the use of this measure represents an improvement over other studies in QoL of persons with dementia. Other variables that we did not study, such as anxiety and depression, may be associated with symptoms of pain and depression and may also explain QoL ratings and should be considered in future research.

Meanwhile, considering the known relationship between sleep disturbances, pain and quality of life in dementia patients, it is imperative that nurses not underestimate these important issues and routinely assess quality of sleep and pain. As we show in this research, poor ratings of QoL may signal underlying contributory factors that can be addressed. Nurses caring for older persons with dementia must appreciate the often multifactorial effect of sleep disruptions and pain on QoL in order to achieve a better and more efficacious plan of care. Comprehensive and accurate assessment using available valid and reliable instruments, such as those used in this study, is essential to identifying and implementing appropriate nursing interventions. Routine treatment of these symptoms using nonpharmacologic (e.g., implementing healthy sleep routines or meaningful activity; distraction and integrative therapies) or pharmacologic (e.g., pain medication) strategies may enhance life quality. Furthermore, sleep disturbances and unrelieved pain have been linked to behavioral disturbances and increased caregiver distress, emphasizing the need for on-going monitoring and intervention in this area.

Conclusions

This study suggests that both pain and sleep disruption of persons with dementia contribute to caregiver ratings of poor QoL in community-dwelling persons with dementia and thus indicates the need for geriatric nursing intervention. Given the prevalence of undertreated sleep disruption and pain symptoms in this population, better guidelines for intervening are needed to routinely assess and treat concomitant sleep and pain disturbances in patients with dementia. Because of the side effects and risks associated with the use of analgesics and sedative–hypnotic medications in older adults, geriatric nurses need accurate information about both pharmacologic and nonpharmacologic management of pain and sleep disruption in dementia patients to treat them properly.

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Table 1

Characteristics of study sample (N=88)

Characteristics	Frequency/Mean
Caregiver and care recipient relationship, n (%)	
Spouse	49 (55.68)
Non-spouse	39 (44.32)
Care recipient	
Age, mean (SD)	81.67 (8.02)
Race, n (%)	
Caucasian	67 (76.14)
African American	20 (22.73)
Other	1 (1.14)
Marital status, n (%)	
Not married	35 (39.77)
Married	53 (60.23)
Health condition, n (%)	
Poor	6 (6.82)
Fair	26 (29.55)
Good	31 (35.23)
Very good	14 (15.91)
Excellent	11 (12.50)
MMSE, mean (SD)	17.70 (4.57)
Antidepressant medication, n (%)	39 (44.32)
Behavior medication, n (%)	25 (28.41)
Memory medication, n (%)	64 (72.73)
Pain medication, n (%)	15 (17.05)
Sleep medication, n (%)	11 (12.50)
Caregiver	
Age, mean (SD)	65.80 (12.19)
Gender, n (%)	
Male	10 (11.36)
Female	78 (88.64)
Race, n (%)	
Caucasian	68 (77.27)
African American	18 (20.45)
Other	2 (2.27)
Education, n (%)	
HS	2 (2.27)
> HS	86 (97.73)
Employment, n (%)	
Employed	33 (37.50)
Unemployed	55 (62.50)

Characteristics	Frequency/Mean
Marital status, n (%)	
Not married	12 (13.64)
Married	76 (86.36)
Living situation, n (%)	
Alone	2 (2.27)
With others	86 (97.73)
Paying for basics, n (%)	
Not difficult at all	36 (40.91)
Not very difficult	21 (23.86)
Somewhat difficult	28 (31.82)
Very difficult	3 (3.41)

Table 2

Prevalence of Pain (VAS) and Sleep Disturbance (PSQI) Symptoms

Symptom	N (%)
No pain	50 (57.47 %)
Some pain	31 (32.19 %)
Extreme Pain	9 (10.34%)
Snoring	39 (45.88%)
Apnea	17 (20%)
Leg twitching during sleep	22 (25.58%)
Disorientation during sleep	38 (44.19 %)
Restless sleep	32 (33.72%)

Table 3

Association between DEMQoL-Proxy Domains, Pain and Sleep Quality

Outcome	Parameter	Estimate	Standard error	t Value	Pr > t
DemQoL-Proxy Total	Age	-0.12	0.18	-0.67	0.5068
	MMSE	-0.62	0.31	-2.01	0.0475
	Number of health conditions	-1.09	0.47	-2.31	0.0237
	Pain (VAS)	-2.33	0.67	-3.46	0.0009
	Sleep quality (PSQI)	-5.38	0.18	-2.47	0.0156
DEMQoL-Proxy Feelings	Age	-0.14	0.09	-1.45	0.1518
	MMSE	-0.15	0.16	-0.94	0.3495
	Number of health conditions	-0.34	0.24	-1.42	0.1597
	Pain (VAS)	-0.87	0.35	-2.50	0.0146
	Sleep quality (PSQI)	-2.28	1.12	-2.03	0.0458
DEMQoL-Proxy Memory	Age	-0.04	0.09	-0.41	0.6794
	MMSE	-0.20	0.16	-1.28	0.2052
	Number of health conditions	-0.06	0.24	-0.23	0.8166
	Pain (VAS)	-0.77	0.34	-2.27	0.0261
	Sleep quality (PSQI)	-1.10	1.09	-1.01	0.3150
DEMQoL-Proxy Everyday Life	Age	0.05	0.07	0.74	0.4640
	MMSE	-0.27	0.12	-2.31	0.0235
	Number of health conditions	-0.68	0.18	-3.79	0.0003
	Pain (VAS)	-0.69	0.26	-2.67	0.0094
	Sleep quality (PSQI)	-2.00	0.84	-2.39	0.0193