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Prevalence and Treatment of Neuropsychiatric Symptoms in Hospice-Eligible Nursing Home Residents with Advanced Dementia

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Abstract

Neuropsychiatric symptoms (NPS) are common in dementia, although little is known about their prevalence and treatment near the end of life. This study used a retrospective review of the medical records of 123 hospice-eligible nursing home residents with advanced dementia to investigate the prevalence of NPS and NPS-targeted pharmacological and non-pharmacological treatments. The most prevalent NPS were agitation or aggression (50.4%), depression (45.5%), and withdrawal/lethargy (43.1%). Of the 105 (85.4%) residents who exhibited one or more NPS, 90.5% were receiving at least one NPS-targeted treatment, yet 41.9%, received no documented non-pharmacological NPS-targeted care. The majority of documented non-pharmacological care focused on safety and explanations or instructions given to residents. Given the high prevalence of co-morbidities, associated risks for medication interactions or serious side effects, and potential low-risk benefits of psycho-behavioral care, these findings raise concerns about how to best increase the provision and documentation of non-pharmacological care in advanced dementia.

A majority of individuals with dementia have one or more neuropsychiatric symptoms (NPS) (Kverno, Black, Blass, Geiger-Brown, & Rabins, 2008; Lyketsos et al., 2000). NPS, also commonly referred to as behavioral or psychological symptoms of dementia, tend to cluster with the most common NPS clusters reported to be: 1) depression, 2) psychosis, 3) aggression, 4) motor or behavioral dysregulation, and 5) apathy (Lawlor & Bharian, 2001). These clusters have been found throughout the course of the illness, even into advanced dementia (Zuidema, de Jonghe, Verhey, & Koopmans, 2007).

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NPS are care-intensive symptoms, accounting for nearly one third of the variance in caregiver activity in a recent sample of assisted care facilities (Lyketsos, 2007). They impair quality of life (Samus et al., 2005), are distressing to patients and to caregivers, and are commonly a major contributor to the decision to move a family member with dementia into a nursing home (Chan, Kasper, Black & Rabins, 2003; Gaugler, Duval, Anderson, & Kane, 2007; Volicer, Hurley, & Blasi, 2003; Yaffe et al., 2002). The recognition and treatment of NPS in advanced dementia may improve quality of life, reduce patient and caregiver distress, and ultimately reduce caregiver burden (Lyketsos, 2007).

The treatment of NPS in advanced dementia is challenging because these individuals are often frail, suffer from numerous other medical illnesses (Black et al., 2006), and are taking multiple medications (Blass et al., 2007). In addition, at least some NPS, such as agitation/aggression and dysfunctional behavioral symptoms, tend to worsen with increasing severity of dementia (Lyketsos et al., 2000). Individuals with dementia who are taking antipsychotics to treat NPS have been found to have an increased risk of mortality (Schneider, Dagerman, & Insel, 2005) and this has led to the recommendation that they be used only when the distress caused by the symptoms is significant or when alternative therapies have failed (Rabins & Lyketsos, 2007). Finding effective non-pharmacological treatments for NPS of advanced dementia has also been challenging. Recent systematic reviews of the literature suggest that behavioral management approaches, including caregiver modification of antecedents and consequences of problem behaviors, increasing pleasant events, and lowering stress (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Logsdon, McCurry, & Teri, 2007) are efficacious in early and mid-stage dementia, but it remains unclear whether these approaches have efficacy in the later stages of dementia.

The primary aim of this study was to examine the prevalence and treatment of NPS in advanced dementia by reviewing the medical records of a sample of hospice-eligible nursing home residents. The residents were participants in the Care of Nursing Home Residents with Advanced Dementia (CareAD) study, a project examining the needs of nursing home residents with dementia in the final six months of life.

Methods

Participants

A total of 126 residents were enrolled in the CareAD study from three nursing homes in Maryland between December 2000 and August 2003. (See Black et al., 2006, for a complete description of the study, site selection and enrollment process.) Residents with any type of dementia who either were receiving hospice or palliative care, or met existing hospice criteria for dementia with an estimated life expectancy of six months or less, were eligible for study enrollment. Written informed consent was given by surrogate decision-makers for each of the residents. A surrogate decision-maker was defined as the resident’s legally authorized representative based on either legal guardianship, durable power of attorney for health care, or Maryland’s Health Care Decisions Act, in that order of priority.

The study was approved by the Institutional Review Boards of the Johns Hopkins Medical Institutions and the University of Maryland and by the research review committees at the three study sites. Of 126 residents who were originally enrolled in the study, one was withdrawn by the surrogate and two did not meet hospice guidelines and were not receiving hospice or palliative care, leaving a total of 123 residents for inclusion in the final analysis. Previously published reports stemming from the CareAd study indicate that, in addition to advanced dementia, the residents had multiple, severe comorbidities (Black et al., 2006), and were taking a mean number of 14.6 (SD = 7.4) medications (Blass et al., 2008).

Data Collection

Data were collected by the CareAD research team. At the time of enrollment in the study, a baseline surrogate interview and direct assessment of the resident were performed, and medical records were retrospectively reviewed for the prior six months. Information collected from the medical records included: demographic characteristics, medical diagnoses, and the occurrence of neuropsychiatric symptoms. Surrogate decision-makers were interviewed to provide additional information about the resident's demographic characteristics and history of dementia. The participants with dementia were evaluated directly to determine the severity of dementia based on cognitive function. As part of the CareAD study, follow-up medical record data continued to be collected at 3-month intervals for up to a 42-month period, however the follow-up data were not used in the current analysis.

NPS Categorization

The presence of NPS during the six month period prior to enrollment was ascertained from the documented observations of nurses, physicians, and other health care professionals who had treated each resident. A structured medical record review form was used to identify the behavioral and psychological symptoms as being present or absent. Table 1 shows that 12 categories of NPS were identified and are similar to those of the standardized Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), a commonly used tool that relies on the observations of caregivers to evaluate the presence of NPS.

Diagnosis and Severity of Dementia

Review of the medical records determined residents' dementia diagnoses. Cognitive functioning was assessed directly using the Severe Impairment Rating Scale (SIRS) (Rabins & Steele, 1996), an 11-item instrument designed for use with individuals who are likely to score less than 6 on the Mini-Mental State Examination scale (MMSE) (Folstein, Folstein, & McHugh, 1975). Interrater reliability of the SIRS in this study, on the basis of Pearson correlation tests, ranged from $r = 0.993$ ($p = 0.001$) to $r = 1.0$, ($p < 0.001$). Black et al. (2006) previously reported a mean score of 10.3 (SD = 6.7) out of a possible score of 22 in 121 of the residents of this study. This score confirms the presence of advanced dementia in the resident participants.

NPS-Targeted Treatments

Treatments documented in the medical records were classified as either pharmacological or non-pharmacological psycho-behavioral care. Pharmacological treatments were categorized by the target symptom: behavioral dyscontrol, mood, psychosis, sleep disturbance or anxiety. Non-pharmacological treatments relevant to the treatment of NPS that were documented in the medical record were classified into the following categories: 1) safety focused care; 2) resident education; 3) behavior focused treatments; 4) supportive/comfort therapies; 5) activity therapies; and 6) environmental modification.

Data Analysis

Univariate analyses were used to describe the study participants, their characteristics and the prevalence of NPS and NPS-targeted treatments. The proportions of documented pharmacological and non-pharmacological treatments were identified for the group of 105 residents who had documented NPS. Pearson chi square analysis was used to examine the relationship between treatment types. The data were analyzed using SPSS (2006) software, Version 15.

Results

Residents' Demographic and Diagnostic Characteristics

Of the total sample (N = 123), 55% were female, 84% were white, and 16% were African American. Mean age was 81.5 (SD = 7.1) years, and the mean educational level was 11.5 (SD = 3.4) years. Alzheimer disease (AD) was the most prevalent (58%), followed by mixed AD and vascular dementia (12.2%), vascular dementia (11%), and other dementias (5.7%). Fourteen percent of residents had an unspecified dementia diagnosis.

Neuropsychiatric Symptoms

Of the entire sample, 85.4% had one or more documented behavioral or psychiatric symptom. The prevalence was 89% among those diagnosed with AD and 77% among those diagnosed with vascular dementia. Table 2 shows the frequencies of specific NPS among the entire sample of 123 residents. The most frequent neuropsychiatric symptoms were: agitation/aggression (50.4%), depression (45.5%), and withdrawal/lethargy (43.1%).

Pharmacological Treatments

Among the 105 residents who had documented NPS, 78.1% were taking some type of psychotropic medication (Table 3). Medications aimed at reducing mood-related symptoms including depression, anxiety, and withdrawal or apathy were the most frequent, with 47.6% of the residents taking one or more of these medications. Medications aimed at reducing problematic behaviors such as agitation, aggression, aggressively resisting care, and calling out were prescribed for 44.8%, and medications directed at reducing psychotic symptoms were prescribed for 26.7%.

Non-Pharmacological Treatments

Non-pharmacological treatments of NPS were documented for 58.1% of the residents with NPS (Table 3). Overall, the most frequently documented non-pharmacological treatment was safety focused care (26.7%). Of 17 residents who had documented wandering, all were monitored with electronic wander monitoring systems. Only one of the residents with wandering had documentation of movement restrictive therapy (placement in chair with self-releasing belt). The remaining residents who received safety focused care for NPS were restrained in chairs (n=6) for agitation/aggression, inappropriate touching of females, or withdrawal/lethargy, or placed in bed (n=5) for agitation/aggression, psychosis/delusions, refusal/resistance, or withdrawal/lethargy. The second most frequently documented non-pharmacological treatment was resident education (23.8%), which involved explanations given to residents regarding symptoms and treatment. Psycho-behavioral non-pharmacological interventions were documented less frequently and included: behaviorally focused therapies (19.0%), supportive and comforting therapies (14.3%), and activity therapies (11.4%).

Relationship Between Treatment Types

Of the residents with NPS, 90.5% were receiving at least one pharmacological or pharmacological treatment and 45.7% were receiving both kinds of treatments. Smaller proportions were receiving only pharmacological (32.4%) or only non-pharmacological (12.4%) treatments, or had no documented NPS care (9.5%). There was no significant relationship between receiving pharmacological and non-pharmacological treatments ($\chi^2(1, N = 105) = .03, p = .863$).

Discussion

In this retrospective review of the medical records of 123 hospice-eligible residents with advanced dementia from three nursing homes in Maryland, 105 (85.4%) individuals had had at least one documented NPS during the prior six months. This demonstrates that the high rates of NPS reported in patients with mild and moderate dementia do not decrease in very late stage disease.

Of the residents with both advanced dementia and NPS, 41.9% had no documentation of non-pharmacological care, and of those who did, the focus was primarily on physical safety. This raises the question of whether they were receiving needed but undocumented psycho-behavioral care or whether it was simply not provided. A review of the literature failed to find other comparable studies documenting the distribution of treatments in advanced dementia, so it remains unclear whether these data are representative of general trends.

Many authorities agree that, in advanced dementia, treatment goals shift away from prolonging life and toward maximizing quality of life, dignity, and comfort (Rabins, Lyketsos, & Steele, 2006; Volicer & Hurley, 2003). Volicer (2001) identifies four factors important to the management of behavioral symptoms (NPS) in advanced dementia: medical/pharmacological management, non-pharmacological caregiving activities, and adjustments to the physical and social environments. Medical interventions, in the form of psychopharmacotherapies were well documented for this sample of residents, with 78.1% of the residents receiving NPS-targeted medications. As we have previously reported, this sample of residents was taking a mean number of 14.6 medications (± 7.4) from numerous medication classes, increasing the risk of medication side effects and interactions and highlighting the complexity of their medical situations and care needs (recently described by Blass et al., 2008). Due to these complexities, the risk/benefit ratio of using pharmacotherapy to manage NPS must be carefully considered (Lyketsos, 2007; Rabins & Lyketsos, 2007). Non-pharmacological interventions for NPS may augment pharmacotherapy, if not reduce unnecessary use.

Of the non-pharmacological interventions, modifications to the physical environment to allow for monitored ambulation for those at risk of wandering or to reduce safety risks (safety focused care), or to improve functioning (environmental modification) were the most frequently documented. Caregiving interventions including verbal and non-verbal explanations and supportive comfort (explanations to resident, behaviorally focused therapies, and supportive comfort therapies) were documented for 14–24% of the residents. Finally, meaningful structured activities were documented for even fewer of the residents, though these can continue to be therapeutic even in the terminal stages of dementia (Volicer, 2001).

Limitations

Several limitations of the study have implications for its generalizability and temper the interpretation of the findings. First, the NPS data were gathered by retrospective chart review rather than by prospective, scale-based resident examination or caregiver interviews. Second, the Minimum Data Set (MDS) was not available from all sites so MDS data were not included in the analysis. Furthermore, this study only identified psychiatric symptoms and treatments that were documented in the medical record. It could therefore have underreported both symptoms and treatments. Neither the duration nor the severity of symptoms was available. By dichotomizing the treatment variables, we cannot determine the quantity or quality of care a person received. Finally, because of the chart review methodology, the specific etiology of the psychiatric symptoms could not be identified. Despite these limitations, the study provides meaningful information about the prevalence of psychiatric symptoms among nursing home residents with advanced dementia and the kinds of treatments employed to treat these symptoms. If anything, the true prevalence of both symptom and treatments is likely to be higher than we report.

Implications

Maximizing quality of life, dignity, and comfort in advanced dementia presents a challenge to nursing because the majority of affected individuals will live their final months in nursing homes. These data identify multiple symptom targets that have the potential for improvement with treatment. This suggests that treatment in late stage dementia can benefit both the individuals with dementia and those caring for them. Three recent systematic reviews of the literature have identified promising non-pharmacological approaches for improving the identification and care of NPS of dementia (Livingston, et al. 2005; Logsdon et al., 2007; Volicer & Hurley, 2003). All three reviews conclude that specific training of caregivers and residential staff to improve knowledge of dementia, NPS, and behavioral management strategies is effective in improving care. Nursing models of care with considerable research evidence supporting their effectiveness in the treatment of NPS of dementia are the Progressively Lowered Stress Threshold (PLST) model (Smith, Hall Gerdner, & Buckwalter, 2005), the Seattle Protocol (Logsdon et al., 2007), and the Need-Driven Dementia-Compromised Behavior model (NDB; Whall & Kolanowski, 2004). With the exception of the Balancing Arousal Controls Excesses model of Kovach et al. (2004), very few nursing models have been developed specifically for treating NPS in individuals with advanced dementia.

Developing and testing effective nursing care models for treating the NPS of dementia has been identified as a major emphasis area in geropsychiatric nursing (Kolanowski & Piven, 2006. We believe this is especially true for advanced dementia since most research has focused on mild-moderate stages of illness. Potential barriers to providing optimal care and treatment of nursing home residents with advanced dementia include understaffing (Carlson, 2007; Rice, Coleman, Fish, Levy, & Kutner, 2004), lack of staff stability (Castle & Engberg, 2007), and inadequate staff knowledge or training (Carlson, 2007; Rice et al., 2004). Despite the barriers, regular monitoring, using standardized instruments such as the NPI, and documentation of the responses to care will make needed contributions to the limited research in caring for individuals with NPS and advanced dementia.

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Table 1

Neuropsychiatric Symptoms (NPS) and their Descriptors

NPS	Medical Record Descriptors	NPI Comparison Category
Agitation/aggression	Combative, hitting, grabbing	Agitation / aggression
Depression	Mood disorder, suicidal ideation, mood change, depression with psychosis	Depression or dysphoria
Withdrawal/Lethargy	Decreased socialization, fatigue, social isolation, apathy, social deficit, isolating self in room, sedation	Apathy or indifference
Refusal/Resistance	Refusal or resistance	(Aggressive refusal is included in agitation/aggression category)
Psychosis/Delusions	Delusional disorder, psychosis NOS, schizophrenia, catatonia	Psychosis and Delusions are separate categories
Aberrant Motor	Wandering, behavioral disturbance, nose picking, crawling, restlessness, smearing stools, picking at skin	Motor disturbance
Sleep Disorder	Insomnia, sleep apnea, sleep wake cycle disturbance, drowsiness, awake most of night	Nighttime behaviors
Calling out	Moaning in sleep	
Anxiety	Anxiety	Anxiety
Inappropriate Touching	Inappropriate touching	Disinhibition
Hypomania	Hypomania	Elation or euphoria

Note: NPS = neuropsychiatric symptoms. Descriptors found in the medical records were grouped into symptom categories. The descriptors were based upon the objective assessments of caregivers in the nursing homes. The Neuropsychiatric Inventory (NPI; Cummings et al., 1994), a standardized assessment tool that relies on the observations of others, uses similar symptom categories.

Table 2

Frequency of Documented NPS

NPS (*N*=123)	***n***	**%**
Any NPS or sleep symptoms	105	85.4
Agitation/Aggression	62	50.4
Depression	56	45.5
Withdrawal/Lethargy	53	43.1
Refusal/Resistance	47	38.2
Psychosis/Delusions	33	26.8
Aberrant Motor	29	23.6
Sleep Disorder	17	13.8
Calling Out	11	8.9
Anxiety	10	8.1
Inappropriate Touch	3	2.4
Hypomania	1	0.8

Note. NPS = Neuropsychiatric Symptoms

Table 3

Frequency of Residents with NPS Receiving Specific Treatments (N=105)

Treatment Category		***n***	**%**
Pharmacological	**Medication Category**		
Any NPS targeted medication		82	78.1
Mood	Antidepressants, mood-stabilizers	50	47.6
Behavior	Antidepressants, antipsychotics, benzodiazepines, mood-stabilizers, hormones, dopamine agonists	47	44.8
Psychosis	Typical and atypical antipsychotics	28	26.7
Anxiety	Benzodiazepines, antidepressants	14	13.3
Sleep	Antidepressants, benzodiazepines, non-benzodiazepines, sedative/hypnotics	11	10.5
Non-pharmacological	**Treatment Descriptors**		
Any non-pharmacological		61	58.1
Physically-focused care	Bed rest, bed or chair restraints, electronic monitoring	28	26.7
Resident education	Education/explanation of symptoms and treatments	25	23.8
Behavior-focused	Calm, redirect/distract, orient/remind, minimize interpersonal safety risks	20	19.0
Supportive comfort	Support, comfort, encourage	15	14.3
Activity therapies	Ambulation, groups, recreation	12	11.4
Environmental modification	Place call light within reach, adjust the lights	2	1.9

Note. NPS = Neuropsychiatric Symptoms.