Feature Article

A Pilot Study of Nonpharmacological Interventions for Hospice Patients With Behavioral and Psychological Symptoms in Dementia

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Agitation is a common, treatable symptom that profoundly impacts quality of life and exacerbates caregiver fatigue in the hospice setting for patients with dementia. The objective of this study was to analyze the efficacy of tailored nonpharmacological interventions for mitigation of unwanted behaviors in the population of patients with behavioral and psychological symptoms in dementia while receiving hospice care. The 4-domain Pittsburgh Agitation Scale (PAS; Motor, Verbal, Aggressive, Resistance to Care) was used for multiple baseline and posttest measurements of agitation. Effectiveness of nonpharmacological interventions was evaluated using analysis of variance for repeated measures for the total PAS score. Motor agitation was the presenting problem with highest-rated severity compared with Verbal, Aggression, and Resistance to Care domains. Analysis of variance demonstrated no difference between baseline referral and pretest total PAS measures ($P = .8$), but a significant drop in total PAS agitation after intervention ($P < .001$). The best outcomes, however, were with patients receiving both nonpharmacological and standard pharmacological interventions as opposed to nonpharmacological interventions alone ($P = .034$). For patients with dementia presenting with behavioral and psychological symptoms, selected nonpharmacological interventions provide significant mitigation of agitation.

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An aging population has changed the epidemiological profile of patients and diseases in later life, and this trend is likely to continue. The Alzheimer's Association anticipates 13.8 million people in the United States will be living with dementia by the year 2050.[1] Patients with various subtypes of dementia comprise a growing percentage of patients enrolled in hospice services.[2] Behavioral and psychological symptoms of dementia such as agitation, anxiety, irritability, and other neuropsychiatric manifestations occur in as many as 90% of patients with dementia.[3] The manifestations of these symptoms are the leading factor in families' decisions to place patients in nursing homes[4] and contribute significantly to poor quality of life for patients while increasing hospitalizations, costs, and caregiver fatigue.[3,4]

Agitation is a significant component of behavioral and psychological symptoms of dementias and can manifest as disruptive and loud talking, increased and erratic movement, aggression, and either verbal threats or pushing or striking caregivers, among other behaviors. Agitation places a tremendous burden on caregivers and subsequently can reduce the likelihood of positive interactions with affected patients and their caregivers.[5] The most common interventions for agitation are pharmacological; complementary modalities have also been shown to be helpful[6] but are not well studied.[7] Complementary treatments for agitation have encompassed numerous modalities, such as music, art, play, and aromatherapies, as well as treatment with durable medical equipment such as weighted blankets, dolls, lights, and modesty garments.[6] Interventions for agitation have shown widely varied efficacy.[6]

At a foundational level, hospices look to serve their patients by providing symptom management, while also allowing patients and families to maintain and strengthen their relationships. To achieve such broad and holistic goals, hospices utilize both pharmacological and nonpharmacological interventions. This use of complementary therapies

provided the opportunity to closely examine their impact based on Pittsburgh Agitation Scale (PAS) scores.

The intersection of a growing population of patients with dementia and the impact of agitation on a patient's quality of life provides adequate justification to examine the diverse list of viable treatment options for agitation. The goal of this study was to examine the benefit of reasonable and actionable nonpharmacological interventions for the effective management of agitation in hospice patients with dementia.

METHODS

Study Design

This study utilized a sample population of patients referred to the Agitation Committee by clinical nursing staff. In the event clinical nursing staff had difficulty with management of agitation, they were able to refer the patient to the Agitation Committee. The Agitation Committee, a specialist interdisciplinary team, convened weekly and reviewed and discussed the case and then made recommendations to tailor interventions to the patient's identity in order to ameliorate patient behaviors that were disruptive or unsafe. The Agitation Committee routinely consisted of a provider, a registered nurse, a medical social worker, a licensed nursing assistant, a chaplain, a music therapist, and a volunteer manager. Referring staff were instructed to provide a baseline PAS on referral, as well as a description of the circumstances of the agitation (eg, during showers). Referring staff was also asked to provide a description of the patient on a "Getting to Know You" form utilized by Casa de la Luz, a regional Tucson hospice. The latter form described likes and dislikes, past career, hobbies, interests, usual activities, accomplishments, and relationships.

This pilot study used a baseline, pretest intervention, and posttest study design. Because patients were referred to the Agitation Committee because of agitated behaviors, all referring staff were necessarily given recommendations for intervention; thus, there was no control or comparison group. In such a study, the presence of both baseline and pretest provides some control for the alternative hypotheses that any change was due simply to regression to the mean or progression or remission of disease with the passage of time from pretest to posttest.[8-12] No consent was necessary because this study did not impact medical decision making for any patient. Data obtained were initially used to assess whether the intervention worked on an individual level because the scoring system provided high interrater reliability.

The Pittsburg Agitation Scale is a direct observational measure, designed to be easily used by clinical staff, of patient agitation in 4 domains of behavior: Verbal, Motor, Aggressive, and Resistance to Care.[13] Each domain provides a subscale score of 0 to 4 (0 = symptom not present to 4 = severely disruptive/unsafe behavior). Concrete descriptors of behaviors accompany each potential score (e.g., "threatening gestures; no attempt to strike" defines a rating of 2 for aggressiveness) with lower ratings for behaviors that are easily redirected.[13] The PAS can be completed in 1 minute, whereas a drawback of many agitation/neurocognitive measures is their length and laboriousness for raters.[14]

The PAS has been used in acute and chronic care facilities,[13] for patients with primary degenerative dementia,[13] and to assess agitation in Alzheimer disease patients with dementia.[15]

Participants

The participants were male and female patients with dementia referred to the Agitation Committee between May 1, 2018 until October 1, 2019 for agitated behavior. Referrals came from participating adult care, assisted living, skilled nursing, and personal homes, as well as inpatient facilities served by Casa de la Luz.

Although 62 patients were referred, this pilot study concentrates on the 29 patients with complete data for baseline, pretest, and posttest scores and intervention description. The 33 excluded had incomplete PAS data or no tracked intervention because of recency of referral, early death (eg, 1 patient died within 1 day of contact), discharge to new facilities, or incomplete data provided by facility staff (eg, new or untrained staff). The Results section reports on the differences between those with complete data and those without.

After referral, hospice field staff implemented the Agitation Committee's recommended intervention and documented pretest and posttest PAS scores.

Interventions

Nonpharmacological

Twelve nonpharmacological interventions were tested: aromatherapy, art expression, contact comfort, light therapy, music therapy, personal visit, pet therapy, play therapy, shower poncho with personal care kit, volunteer visit, walk therapy, and a weighted blanket or shawl. Patients received a comforting object, such as a stuffed animal, in contact comfort. Music therapy was performed by a certified music therapist either live with music or later, with recordings of the patient's favored music. The shower poncho is a light terry-cloth garment designed primarily to preserve the patient's modesty while showering and, through its weight and feel, to be calming. Ponchos were typically accompanied with care kits including instructions, bubbles, and lollipops for distraction. Trained volunteers sat quietly with patients or interacted with patients, as seemed appropriate in volunteer visits. In walk therapy, the patient was accompanied on walks in protected

venues by staff or a trained caregiver. Weighted blankets were used to induce a calming effect through touch pressure.

Pharmacological

Pharmacological intervention consisted of modifying the dosage or schedule of medications designed to address symptoms or causes of agitation. The provider who participated in the Agitation Committee reviewed the patient's medications, disease history, and symptomatology and consulted with the attending provider. This was done in accordance with current standard-of-care practice.

Outcome Measure

In the current analyses, individual domain/subscale scores from the PAS describe the severity of the different problems presented by participants at baseline. However, given the small sample size for the current study and the need to retain power by using a measure with more scale points and higher reliability, total scores, added across domains and thus potentially ranging from 0 to 16, were used for outcome measurement. Because a few patients were referred back to the Agitation Committee for new interventions for continuing or new problems, the average scores for baseline PAS, pretest or posttest were used in those instances.

Analysis

Descriptive statistics are calculated for patient demographics. Comparisons of means across groups use one-way analysis of variance techniques. When within-subject repeated-measures comparisons are made, the Wilks λ F is reported.[16,17] Predicted differences between means use pre-hoc orthogonal comparisons. Post-hoc comparisons use the conservative Bonferroni correction to establish significance for multiple comparisons.[18] Diagnostic categories with sufficient sample size are compared using the χ^2 statistic.

RESULTS

Patient Characteristics

As the Table 1 indicates, the 29 patients in this pilot study did not differ from those with incomplete data in sex, age, diagnosis, or days until death for the subset of patients who had died. They were, however, rated as significantly less agitated on the total PAS ($F_{1,56}$ = 6.40) and its verbal ($F_{1,56}$ = 9.86) and resisting care ($F_{1,56}$ = 3.94) subscales.

The 29 patients of this pilot study averaged 83 years of age and were 41.38% male (n = 12) and 58.62% female (n = 17). The most common primary diagnoses were senile dementia and Alzheimer disease, together accounting for 68.96% (n = 20) of diagnoses. The patients' presenting behaviors were generally slight to mild (ratings near 1 or 2), although each subscale had ratings of 0 to 4 across the patient sample. There were significant differences in the ratings among the 4 subscales for the patients ($F_{3,26}$ =4.58, P = .011). Post-hoc tests of difference for repeated measures and multiple comparisons revealed motor agitation to be a significantly higher-ranking presenting problem compared with Aggression (P = .013) and Verbal subscales (P = .026).

Interventions

The patients in this sample received an average of 2.52 (SD, 1.33) visits, ranging from 1 to 6 visits. Thirteen patients (44.83%) received only nonpharmacological interventions, whereas 15 (51.72%) received combined nonpharmacological/pharmacological interventions, and 1 individual received a pharmacological-only intervention (3.45%).

Nonpharmacological

Most patients received more than 1 nonpharmacological intervention session, 2.86 on average (SD, 2.05), sometimes addressing more than 1 agitation issue and using more than 1 nonpharmacological intervention modality in a single visit by the clinician providing direct regular care to the patient, usually the patient's assigned registered nurse case manager. The nonpharmacological interventions included, in order of frequency, music therapy (24.10% of 83 total interventions), contact comfort with a stuffed animal or other comforting object (16.87%), a weighted blanket or shawl (15.66%), play therapy (13.25%), a visit from a hospice volunteer (8.43%), a shower poncho (6.02%), light therapy (6.02%), a personal visit (3.61%) encouraged by staff, accompanied walk therapy (2.41%), pet therapy (1.20%), aromatherapy (1.20%), or art expression (1.20%). On average, patients received 2.03 (SD, 1.21) different types of nonpharmacological interventions.

Pharmacological

More than half (55.17%) of the patients had their medications adjusted, nearly all only once, and in 1 case twice. The changes to medications were suggested by the Agitation Committee provider to the attending provider who would decide to act on the suggestions or not. After changes to medication profiles were made, the Agitation Committee subsequently discussed efficacy and offered further suggestion or monitored as needed.

Outcome

Figure indicates a significant drop in total rated agitation from baseline and pretest to posttest ($F_{2,27}$ = 16.00, P < .001, for repeated-measures analysis of variance, $M_{baseline}$ = 5.26 [SD, 3.99]; $M_{pretest}$ = 5.13 [SD, 3.92]; Mposttest = 1.52 [SD, 1.88]). Planned orthogonal contrasts reveal no difference between baseline and pretest measures (P = .8), but significant difference between those two measures and posttest ($F_{1,28}$ = 32.31, P < .001), making the hypothesis that agitation decreased because of the passage of time or disease change less likely.

TABLE Demographic and Baseline Characteristics of Total Patients, Patients With Complete Data, and Patients With Incomplete Data

	Total Sample (n = 62)		Patients With Complete Data (n = 29)		Patients With Incomplete Data (n = 33)		
	n	%	n	%	n	%	*P*
Sex							n.s.
Male	23	(37.10)	12	(41.38)	11	(33.33)	
Female	39	(62.90)	17	(58.62)	22	(66.67)	
	Mean	SD	Mean	SD	Mean	SD	
Age, y	84.15	(8.36)	83.03	(8.42)	85.12	(8.31)	n.s.
	N	%	N	%	N	%	
Diagnosis							
Senile dementia	22	(35.48)	11	(37.93)	11	(33.33)	n.s.
Alzheimer disease	18	(29.03)	9	(31.03)	9	(27.27)	n.s.
Heart disease	5	(8.06)	1	(3.45)	4	(12.12)	
Lewy body dementia	4	(6.45)	3	(10.34)	1	(3.03)	
Cancer	4	(6.45)	2	(6.90)	2	(6.06)	
Cerebrovascular disease	3	(4.84)	2	(6.90)	1	(3.03)	
Parkinson disease	2	(3.23)	1	(3.45)	1	(3.03)	
Other	4	(6.45)	0	(0.00)	4	(12.12)	
	Mean	SD	Mean	SD	Mean	SD	
Days to death from first visit[a]	74.50	(84.00)	103.60	(105.07)	53.71	(59.42)	n.s.
Range	(1–410)		(5–410)		(1–258)		
Baseline PAS scores[b]							
Total	6.61	(4.26)	5.26	(3.99)	7.96	(4.15)	.014
Verbal	1.74	(1.39)	1.21	(1.26)	2.28	(1.33)	.003
Motor	1.93	(1.19	1.86	(1.29)	2.00	(1.10)	n.s.
Aggression	1.34	(1.71)	1.00	(1.58)	1.69	(1.79)	n.s.
Resists care	1.59	(1.59)	1.19	(1.55)	2.00	(1.56)	.052

Abbreviation: n.s., not statistically significant; PAS, Pittsburgh Agitation Scale.
[a]*Thirty-six patients had died, 15 of whom had complete data and 21 with partial data.*
[b]*Because only 29 of the 33 patients without complete data had complete baselines, total n = 58.*

The Effect of Nonpharmacological Interventions

The fact that 13 individuals had only nonpharmacological interventions allowed a test of the hypothesis that all effects were likely due to changes in prescribed medications. Analysis of variance, using posttest scores as the dependent measure, and initial baseline scores as a covariate to control for initial severity of agitation revealed that those with only nonpharmacological interventions did only

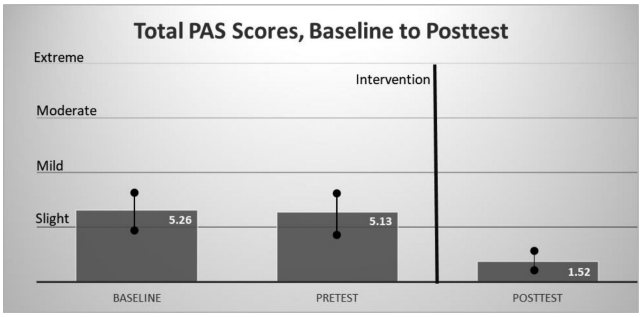

FIGURE. $M_{baseline}$ = 5.26 (95% confidence interval, 3.74-6.78). $M_{pretest}$ = 5.13 (95% confidence interval, 3.64-6.62). $M_{posttest}$ = 1.88 (95% confidence interval, 0.81-2.24).

slightly less well than those dually treated. Given that there was only 1 person in the sample receiving only changes in drug therapy, that person was assigned to the combined pharmacological/nonpharmacological intervention group. The posttest mean for those receiving nonpharmacological intervention only was 1.89 (SD, 2.44) on the total PAS, whereas it was 1.22 (SD, 1.31), with less variability, for those receiving combined treatment ($F_{2,26}$ = 3.87, P = .034) (Figure).

DISCUSSION

The results of our pilot study provided repeatable and significant support to the value of nonpharmacological interventions for hospice patients with agitation in dementia. While numerous previous studies have had difficulty drawing conclusions on the effectiveness of caregiver-level interventions,[19] several findings not only indicate the value of nonpharmacological intervention in this population, but also highlight the need for further study.

While this pilot study, at this stage, is unable to specify individual interventions that provide mitigation of agitation symptoms, the study does demonstrate that nonpharmacological interventions are reasonable to consider for a hospice team. The mechanism used in this study to select for interventions was a specialized interdisciplinary team.

A hospice interdisciplinary group (IDG) traditionally consists of a physician, nurse, social worker, and chaplain, as well as several other care modalities depending on the organization and patient needs.[20] The utilization of a team model for care in hospice not only brings diverse perspectives for interventions, but also allows the team to view the needs of patients and families from multiple perspectives.[20] The IDG is an accepted tool Medicare requirement for hospice. The utilization of a specialized IDG, including specialists not typically included in a traditional hospice IDG, for the management of agitation should improve patient quality of life and satisfaction with care and may also reduce caregiver fatigue. It is also possible that management of agitation improves rates of medication compliance and reduces the risk of patient and caregiver injury. Another potential utilization for IDG management of agitation is in the inpatient setting, where it may additionally serve to stabilize and improve the therapeutic milieu.

Limitations

Because of the nature of the population studied, the sample size was inherently limited. By analyzing multiple modalities of treatment, as well as utilization of the PAS, we were able to demonstrate statistical significance across a spectrum of classical presentations of agitation in patients with dementia. The sample available for study also presented the complication of advancing disease and decreasing functional status that could obfuscate presentation of agitation. This was mediated utilizing the PAS at 3 standardized intervals, at the initiation of involvement, prior to intervention, and after an intervention. By spacing measurements and assuming advancing disease state was independent of Agitation Committee involvement, the complications presented by examining a patient population at the end of life are as mitigated as possible.

Our findings indicate that recommended nonpharmacological interventions show improvement in agitated behaviors. Given a larger sample size and more time, enhanced specificity pertaining to individual interventions will be possible. Our ongoing intent is to continue to gather data and enhance the specificity of our findings, both regarding specific treatment efficacy and the subsequent effect on various presentations of agitation.

CONCLUSION

This study looked to analyze the value of nonpharmacological intervention for the management of agitation in hospice patients with dementia. Agitation is a frequently encountered symptom for hospice patients, which can profoundly impact patient quality of life and caregiver fatigue. This study found that repeatable, cost-effective, and measurable interventions showed value. Prescribed attentive care utilizing pharmacology, reflecting standards of care, along with nonpharmacological interventions may lead to the best possible patient outcomes for the treatment of agitation in dementia.

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