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Alexandria Nasr

Wright State University - Main Campus, nasr.5@wright.edu

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Palliative performance scale as a prognostic tool for patients with dementia in hospice

Alexandria Nasr

Dr. Larry Lawhorne, Professor Emeritus, Department of Geriatrics

Clinical Science

Scholarship in Medicine Final Report

**By checking this box, I indicate that my mentor has read and reviewed my draft proposal prior to submission**

**Abstract**

*Objective:* Palliative and hospice care have been shown to benefit people with dementia and their families. However, for patients with dementia who are nearing the end of life, hospice referral can be challenging because of the difficulty in predicting prognosis. The objective of this retrospective, exploratory study is two-fold: (1) to describe trajectories by analyzing trends in Palliative Performance Scale (PPS) scores for patients admitted to hospice with a neurocognitive disorder from time of enrollment to time of disenrollment and (2) to determine the relationship between PPS and length of stay (LOS) in hospice care.

*Methods:* The setting for the study is a geriatrics clinic in west central Ohio. Data collection utilized the Athena™ EMR to identify patients with a neurocognitive disorder who were enrolled in a home-based hospice program between January 1, 2015 and December 31, 2018. PPS scores for 55 patients were recorded from periodic hospice documents submitted to the attending physicians in the geriatrics clinic and from progress notes entered by the geriatricians, as they co-managed the patients alongside hospice.

*Results:* Fifty-five patients received care across five hospices during the study period. Of those included, 22 had a primary diagnosis of Alzheimer's dementia, and 33 had vascular dementia. The median length of stay in hospice care was 93 days, with death being the reason for discharge in all but one patient. Median length of stay decreased incrementally with each decrease in initial PPS score. With regard to PPS changes over time, there was wide variability in individual trajectories, which demonstrates the highly variable and unpredictable nature of dementia. Almost three quarters of the study population died prior to the 6-month mark in hospice care, suggesting that patients with dementia may be receiving hospice care later than they qualify.

Key Words: palliative; performance; scale; hospice; dementia; Alzheimer; prognosis

## **Introduction/Literature Review**

### **Dementia**

Dementia is a diagnosis that encompasses numerous etiologies and shows variable expression among patients. It is becoming more prevalent every year. In 2017, the World Health Organization estimated that about 50 million people worldwide have some form of dementia, with approximately 10 million new cases each year.<sup>1</sup> It is a progressive and incurable disease. Despite the increasing number of cases and severity of symptoms, patients with advanced forms of dementia are underrepresented in palliative care compared to those with other diagnoses.<sup>2</sup> There are several reasons why this may be the case, including ambiguities in eligibility criteria and difficulties in classifying disease stages.

When it comes to terminal illnesses like end-stage dementia, palliative care is crucial for maintaining comfort and quality of life throughout the dying process. Surveys completed by relatives of deceased patients with dementia reported increased quality of care, fewer unmet

needs, and greater emotional support while in hospice care compared to non-hospice care.<sup>3</sup> In 2018, Harrop et al. created a program to provide social workers and peer groups to patients and families receiving palliative care. Outcomes included self-reported improvements for patients and caregivers alike, including fewer cases of isolation and an improved sense of feeling “at home” among patients.<sup>4</sup> Despite the apparent benefits of hospice, gaining access to palliative care for patients with dementia can be complex, especially in the early stages of disease.

### **Hospice Eligibility and Prognosis**

The majority of deaths in older patients with dementia occur in the setting of a nursing facility.<sup>2</sup> However, it has been shown that patients with advanced dementia in nursing facilities who receive hospice care have lower risks of dying in the hospital.<sup>5</sup> The spectrum of patients served by hospice is evolving, and every disease has a unique progression. This variability makes it difficult to establish specific criteria for hospice enrollment. Hospice eligibility has been a dynamic and sometimes controversial issue. As such, there have been studies that analyze hospice eligibility requirements and their role in patient care.

Current hospice eligibility for people with dementia is based on etiology and FAST (functional assessment screening tool) scores. Shown in Table 1, FAST is a scale from 1 to 7 derived from a standardized instrument, with one being “normal” aging, and seven being advanced dementia. Most guidelines today require that a patient is FAST stage 7a or greater, which implies severe dementia. These patients are mainly non-ambulatory or have limited ability to speak. Recent studies have shown that this assessment alone is not sufficient to indicate prognosis in patients with dementia.<sup>6</sup>

Stage	Characteristic
1 - Normal Aging	No subjective or objective difficulty
2 - Possible MCI*	Subjective functional deficit
3 - MCI	Objective functional deficit, interferes with complex tasks
4 - Mild Dementia	Deficits in IADLs
5 - Moderate Dementia	Needs help selecting proper attire
6a - Moderately Severe Dementia	Needs help dressing
6b - Moderately Severe Dementia	Needs help bathing
6c - Moderately Severe Dementia	Needs help toileting
6d - Moderately Severe Dementia	Urinary incontinence
6e - Moderately Severe Dementia	Fecal incontinence
7a - Severe Dementia	Ability to speak limited (1 to 5 words a day)
7b - Severe Dementia	All intelligible vocabulary lost
7c - Severe Dementia	Unable to ambulate without assistance
7d - Severe Dementia	Unable to sit up without assistance
7e - Severe Dementia	Unable to smile
7f - Severe Dementia	Unable to hold head up

**Table 1: FAST Scale**

\*MCI = Mild Cognitive Impairment

Prognosis is determined by numerous factors, including marital status, dementia-driven symptoms such as anorexia, and comorbidities like hypertension, stroke, and diabetes mellitus.<sup>7</sup> The Advanced Dementia Prognostic Tool (ADEPT) has been an alternative way to estimate prognosis. In 2010, Mitchell et al. aimed to determine reliability of this tool in the nursing home setting. The conclusion was that ADEPT was modestly better at predicting a 6-month survival time than hospice eligibility guidelines.<sup>8</sup> The results of this study, combined with results of studies on FAST, show that current eligibility guidelines are lacking when it comes to prognosis for patients with dementia. In terms of LOS in hospice care, a longitudinal study in 2017 found

that the mean length of stay in hospice for those without a primary diagnosis of dementia versus those whose primary diagnosis was dementia was 74 days and 112 days, respectively.<sup>9</sup>

### **Palliative Performance Scale**

The palliative performance scale (PPS) was created in 1994 by Anderson, et al. as a modification of the Karnofsky Performance Scale. It was established due to an increasing need to assess functional capacity and decline in patients receiving palliative care.<sup>10</sup> The scale works on a percentage basis and declines by increments of ten. One hundred percent represents a person whose medical condition does not affect overall functioning, while zero represents death. Table 2 shows PPS descriptors, as adapted from The Victoria Hospice Society. Today, the scale functions on two levels. Not only does it act as a reference for the assessment of a patient's status and prognosis, but it is also used to assess hospice eligibility across a spectrum of relevant diseases.

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Level of Consciousness
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or Reduced	Full
70%	Reduced	Unable to do normal work Significant disease	Full	Normal or Reduced	Full

60%	Reduced	Unable to do hobby/housework Significant disease	Occasional assistance necessary	Normal or Reduced	Full or Confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or Reduced	Full or Confusion
40%	Mainly in bed	Unable to do most activities Extensive disease	Mainly assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Totally bed bound	Unable to do any activity Extensive disease	Total Care	Normal or Reduced	Full or Drowsy +/- Confusion
20%	Totally bed bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally bed bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

**Table 2: PPS descriptors**

Due to the emergence of literature, the PPS has become an addition to assessments used for hospice eligibility. Myers et al. concluded that specific PPS stages in patients with advanced cancer can be used for conducting key care discussions among patients and clinicians.<sup>11</sup> These discussions help direct medical decisions to provide the highest quality care. Palliative performance scale, unlike ADEPT, is not specifically for dementia; it can be used to assess patient functioning at the end of life due to any cause. In a study by Jansen et al., initial PPS score was compared between those with dementia and those with other diagnoses. It was found that although most patients in both groups died within three months, PPS score at time of enrollment for patients with dementia varied by as much as 60%.<sup>12</sup> In a separate study, Lo et al.

concluded that patients with a diagnosis of advanced dementia had lower PPS scores on average than patients with other diagnoses. Despite this, there appeared to be no difference in LOS between the two groups.<sup>13</sup> Studies like these endorse the idea that prognosis for people with dementia is particularly difficult to predict when compared to other diseases.

Although the PPS has been increasingly studied in recent years, there are gaps in the literature regarding its utilization in clinical practice. For patients with dementia, there is literature regarding PPS status at time of hospice admission, but little exists for how these scores change throughout the length of care. By analyzing PPS status throughout a patient's entire time with hospice, trends may become apparent in functional decline. In this way, the PPS may be used as an additional tool for prognosis prediction in complex disease processes like dementia to ensure that patients are getting quality end-of-life care in a timely manner.

## **Conclusion**

The goal of this study is to track PPS scores in patients with dementia from time of hospice enrollment until the end of care. Final PPS scores will also be compared to specific outcomes of care and length of stay with hospice. By analyzing trends in functional decline, insight may be gained into prognosis for dementia. As such, the utilization of PPS scores may alter important care decisions, including appropriate timing for hospice enrollment.

## **Specific Aims:**

1. Determine PPS at time of hospice enrollment for Wright State Physicians Geriatrics clinic patients with major neurocognitive disorder.
2. Describe PPS trajectories from enrollment to time of discharge from hospice because of death, extended prognosis, or family decision to dis-enroll.



3. Determine the relationship between PPS and length of stay (LOS) in hospice care.

## **Methods**

### *Context/Protocol*

The setting for this study is a geriatrics clinic in a faculty practice affiliated with a community-based medical school. The 55 subjects included in the study are patients from the Wright State Physicians Geriatrics clinic whose information is extracted from Athena EMR. Patients with a diagnosis of dementia who were enrolled in a home-based hospice program between January 1, 2015 and December 31, 2018 were included. The diagnosis of dementia includes Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease, and vascular dementia. Patients without a primary diagnosis of any of the above were excluded from the data group.

### *Data Collection*

Following IRB approval, data was gathered on the number of patients from the geriatrics practice admitted to hospice, their PPS at admission, and discharge information. PPS was determined by chart review from initial hospice evaluation and intermittent and final hospice reports. These assessments of patient function are based on information from patients themselves, a knowledgeable informant, and a healthcare professional skilled in the diagnosis of dementia. Additionally, formal neuropsychological testing or the MOCA (Montreal Cognitive Assessment) had provided objective support for a major neurocognitive disorder. The observed cognitive deficits have been determined to interfere initially with performance in all IADLs, followed by increasing dependence in ADLs. Finally, the impact of comorbidities on overall

functional status was taken into account. While compiling this data, there was no direct interaction with patients, and confidentiality was maintained by use of a number system.

### *Data Analysis*

Univariate procedures included means, medians, and counts. PPS scores were compiled for each patient over time, and each individual's trajectory was plotted on one graph. All patients were compiled together in one figure to visually display trends. Group trends were displayed using LOESS smoothing to account for the visually nonlinear form of the trajectories. A test for trend with PPS scores and LOS was conducted using a general linear model with PPS score group entered as a continuous variable and LOS as the outcome variable (normality of the data distribution was assumed for this test). Data analysis was completed with Dr. Peterson, a geriatric researcher, using SAS version 9.4.

### **Results**

The study population of 55 subjects included 35 women and 20 men, with an average age of 85 years old. Twenty-two had a primary diagnosis of Alzheimer's dementia, while 33 had vascular dementia. The median length of enrollment in hospice across all patients was 93 days, or about three months. For the population with Alzheimer's and vascular dementia, average LOS was 114 and 120, respectively. In terms of comorbidities, 35 patients had concurrent hypertension, 15 had a history of stroke, and 24 had coronary artery disease. Diabetes was present in 8 patients, and 11 had atrial fibrillation. Ten patients had concurrent Parkinson-like symptoms, which may be related to side effects of antipsychotic medications or to Parkinson's disease. Regarding outcomes, one patient was discharged due to extended prognosis, while all

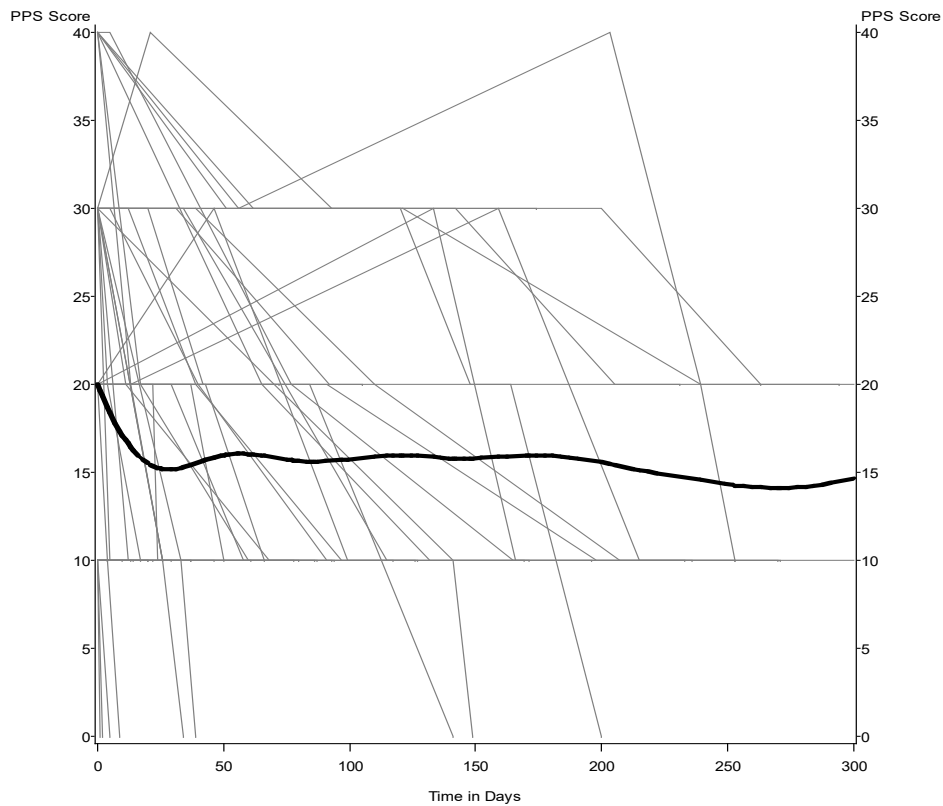
others were disenrolled due to death. Two patients included in data analysis are still currently enrolled in hospice care, and do not have discharge information to include.

For PPS, admitting scores ranged from 40 to 10, with an average of 22. At discharge, values ranged from 30 to 0, with an average of 9.6. Table 3 shows the initial PPS scores and their corresponding mean and median LOS in hospice care. There was a significant linear trend ( $P < 0.0001$ ) associated with lower initial PPS and shorter LOS. For the 10 patients with Parkinson's disease, average LOS was below the mean at 83 days.

Initial PPS	n	Mean/median LOS
10	20	31.65/18.5
20	11	130.6/106
30	17	164.7/148
40	6	226.7/251

**Table 3: Initial PPS and corresponding LOS**

Figure 1 illustrates PPS trajectories for each individual patient. The bolded line gives a trajectory for the group as a whole. From this figure, it is evident that there is an initial drop in PPS within the first month of care, while values level off thereafter.



**Figure 1: PPS trajectories**

Table 4 provides details about the 6 patients (3 men and 3 women) who had a PPS of 40 at the time of enrollment. Patient A had a length of stay of 73 days while the length of stay for each of the remaining 5 patients was over 200 days. Caregiver stress was a prominent feature among 5 of the 6 patients with a PPS of 40 at the time of enrollment, with patient sleep disturbance being a key contributor to caregiver stress.

Patient	Age	Gender	Diagnosis	Comment
A	91	M	Vascular	Sleep disturbance due to OSA and inability to use CPAP; CHF; repetitive vocalizations; caregiver stress (younger spouse)
B	90	F	Vascular	Recurrent episodes of pancreatitis; CHF; intermittent dysphagia; slowly decreasing albumin level; sleep disturbance; caregiver stress (daughter)
C	74	F	AD	Slow weight loss; frequent falls; frightening delusions/hallucinations; sleep disturbance (no caregiver stress as spouse, 2 daughters, and 1 granddaughter shared caregiving)
D	96	F	Vascular	PVD with recurrent arterial ulcers; painful peripheral neuropathy; sleep disturbance; caregiver stress (3 daughters with different goals and expectations)
E	91	M	Vascular	Recurrent vertebral fractures; frequent falls; pacing; resistive to care; distressing delusions; caregiver stress (daughter)
F	62	M	AD	Aggressive behavior; delusions; hallucinations; wandering; caregiver stress (spouse undergoing cancer treatment)

**Table 4: Patient characteristics with admitting PPS of 40**

## Discussion

This study takes an exploratory approach through the journey of hospice care for patients with dementia. Numerous studies demonstrate that hospice care improves overall outcomes in this patient population.<sup>3,4</sup> However, the issue of hospice eligibility criteria has made it difficult for patients to enroll. The Palliative Performance Scale is an objective tool that used to assess patient functionality at the end of life and may be useful in assessments for hospice eligibility.

The first aim of this study was to determine PPS scores at the time of hospice enrollment. As has been shown in previous studies, PPS for those with dementia showed wide variability at time of enrollment.<sup>12</sup> This supports the prior notion that dementia is a highly variable disease that can

be difficult to predict. Additionally, the maximum initial PPS was 40, indicating that all patients were mainly bedridden, and required almost total assistance in providing self-care at the time of enrollment.

In attempts to correlate PPS with prognosis, it is also important to discuss length of hospice care. The median LOS for the 53 patients in the study who disenrolled from care was 85 days, or just under three months. This is similar to previous studies that have explored LOS in hospice for patients with dementia.<sup>9</sup> However, the LOS values had a wide range, from 1 day to just over a year at 381 days. Once again, this highlights the variability in prognosis for patients with dementia. To make a hospice referral, a physician must affirm that the patient has a life expectancy of 6 months or less to meet criteria for enrollment. Our data shows that almost 75% of the study population died prior to the 6-month mark.

In describing the trends of PPS as a population overall, it is evident that PPS remained generally constant after an initial 5-point drop in the first 30 days of enrollment. Finally, in comparing comorbidities and their effects on outcomes, it is interesting to note that for patients with concurrent Parkinsonism, the average LOS in hospice care was over one month shorter than average LOS for all other patients.

## **Conclusion**

Findings in this study show a significant linear correlation between initial PPS and LOS in hospice for patients with dementia. Small sample size is the main limitation. The final sample size was 55, with two of those patients still currently enrolled in hospice care. Additionally, demographics were not a main focus of the study, including comparisons in outcomes between genders and various ethnic groups. It is important to consider that only two etiologies of

dementia were studied here. There are several other causes of dementia, and that information would be important to explore in future studies. Finally, the logistics of assessing a patient's PPS score may be another limitation. Although PPS is an objective measure of functional decline, it is important to note that two different providers performing these assessments may not give identical scores to the same patient. Furthermore, PPS assessments are not always conducted at regular intervals, which can make it difficult to assess the data accurately.

Future directions for research of this type may include closer investigations into etiology of dementia and patient comorbidities to assess their specific effects on prognosis. It may also be valuable to conduct a prospective study to trend PPS over time at regularly spaced intervals for cleaner analysis. There is still much to be learned when it comes to prognosis for patients with dementia. As hospice eligibility continues to evolve, finding ways to provide the best possible care for these vulnerable populations at the end of life should be a priority.

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