

Characteristics & Outcomes of Dementia Patients Who Receive Inpatient Palliative Care Consultation

Running title: Palliative care for dementia patients

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ABSTRACT

Background/Objectives: Acute hospitalization may be an ideal opportunity to introduce palliative care to dementia patients, who may benefit from symptom management and goals of care discussions. We know little about patients who receive inpatient palliative care consultations (IPCC).

Design: Retrospective analysis using electronic medical record.

Setting: Tertiary academic medical center and affiliated community hospital.

Participants: Patients with dementia by ICD diagnosis, ≥ 65 years old hospitalized between July 1, 2015 and December 31, 2015.

Measurements: We used chi-square and t-test/Mann-Whitney U test to compare characteristics (living arrangement, advanced dementia markers, diagnoses of delirium and dementia with behavior disturbance, and admitting diagnosis) and outcomes (change in code status, length of stay, discharge disposition and discharge medications for symptom management) of patients who did and did not receive IPCC. Patients were matched on gender, age, and race.

Results: Among 927 hospitalized patients with dementia, 17% received IPCC (N=157). Patients who received IPCC were more likely to be admitted from a nursing facility (35.7% vs 12.7%, $p < 0.00$), experience delirium (71.3% vs 57.3%, $p = 0.01$), have behavior disturbance (23.6% vs 13.4%, $p = 0.02$), have a pressure ulcer at admission (26.1% vs 11.5%, $p = 0.001$), have hypernatremia (12.7% vs 3.2%, $p = 0.002$), and be bedbound (20.4% vs 3.2%, $p < 0.000$). Patients who received IPCC had a longer length of stay (median 5.9d vs 4.3d, $p = 0.004$) and were more

likely to be discharged to hospice (56% vs 3.1%, $p<0.000$). Patients with IPCC were more likely to have a discharge code status of DNAR (89% vs 46%). There was no significant difference in comfort medications at discharge between groups.

Conclusions: Patients who received IPCC had evidence of more advanced dementia. These patients were more likely to change their code status and enroll in hospice. IPCC may be useful to prioritize patient centered care and discuss what matters most to patients and families.

Key words: dementia, inpatient palliative care

INTRODUCTION

As of 2019, an estimated 5.8 million Americans had been diagnosed with Alzheimer's Disease. By 2050, that number is projected to grow to 13.8 million.¹ Alzheimer's Disease and other types of dementia significantly impair the quality of life of the affected patient and their family and caregivers. Furthermore, the costs related to dementia care are staggering. Data from the Health & Retirement study suggests that in the last five years of life, total costs (including Medicare, Medicaid, private insurance, out-of-pocket spending, and informal care) for patients with dementia exceed those of patients with heart disease or cancer.²

Additionally, patients with dementia are at risk for poor outcomes in the acute care setting. Compared to hospitalized patients without dementia, studies suggest that patients with dementia have longer lengths of stay, worse symptom management, are more likely to die in the hospital, and have higher per capita hospital costs.^{3,4} Palliative care has been shown to play an important role in improving quality of life, reducing caregiver burden, and lowering end-of-life healthcare costs for those with terminal illness.⁵⁻⁸ Inpatient palliative care consultation (IPCC) is associated with better symptom management and communication, lower rates of re-hospitalization, higher rates of hospice enrollment, and lower costs due to less resource-intensive care.⁹

Although dementia is a progressive and ultimately terminal diagnosis, there is little literature examining the role of palliative care in dementia. Two recent reviews assessing palliative care interventions in dementia care suggest insufficient evidence to draw conclusions

about benefits.^{10,11} Specifically, studies of IPCCs in hospitalized patients with dementia have reported mixed results. In a small number of studies, IPCC has been associated with improvements in family members' ratings of the quality of end-of-life care, reduced pharmacy costs, more frequent assessment and treatment of symptoms, greater likelihood of addressing spiritual needs, and increased use of hospice care. In other studies, IPCC for patients with advanced dementia has not significantly impacted the use of life-sustaining treatments, hospital or emergency department visits, or caregiver distress.^{9,12-14} The available studies on IPCC in dementia care have several limitations, including small sample size, heterogeneous interventions and outcomes, and difficulty assessing outcomes (i.e. assessing pain control in patients with advanced dementia). Given the limitations of current research and the potential benefits of inpatient palliative care consultation in improving quality and reducing costs, this study examines the association of IPCC with care outcomes in hospitalized patients with dementia.

METHODS

Data Source and Population

We performed a retrospective electronic medical record (EMR) review of patients \geq age 65 with a diagnosis of dementia based on ICD-9 (290, 290.0, 290.1, 290.20, 290.4, 290.40, 290.42, 291.2, 292.82, 294.1, 294.10, 294.11, 294.20, 294.21, 331.1, 331.19, 331.82) and ICD-10 (F01.50, F01.51, F02.80, F02.81, F03, F03.90, F03.91, F10.27, F10.97, F13.97, F19.97, G31.09, G31.83) codes who were hospitalized at Duke University Hospital or Duke Regional Hospital in Durham, North Carolina, between July 1, 2015 and December 31, 2015. Both

hospitals use a shared EMR. We used the clinical research and quality improvement query tool to identify patients of interest. To create our study sample, we identified the subgroup of dementia patients who received an IPCC. Each of these patients was then matched (1:1 matching) based on race, age (within five years), and gender with a dementia patient who did not receive an IPCC. The chart abstraction was completed for all dementia patients receiving IPCC and the matched non-IPCC cohort. The study team developed a list of common variables and definitions for EMR abstraction which was completed by one team member. Data were recorded in the Research Electronic Data Capture (REDCAP) database, a secure, web-based application that provides audit trails for data tracking and export procedures.¹⁵ The study was approved by the Duke University Health System's Institutional Review Board.

Variables

We extracted the following variables from the EMR on all patients in our sample.

- 1) Demographics: age, gender, race, ethnicity, marital status, and living arrangement prior to admission (home, nursing home, or assisted living facility).
- 2) Clinical Data: Based on author consensus and availability of data in the EMR, we identified four indicators of advanced dementia. These include: sodium level >145 on admission, weight loss >10% in last year, presence of pressure ulcer at admission (from review of nursing notes and wound care team consultation) and baseline ambulatory status (from case management assessments and initial physical therapy evaluation notes). These markers were consistently reported in the EMR and have been associated with advanced dementia.¹⁶⁻¹⁸ We also recorded

data on whether patients had an ICD-9 or ICD-10 code at discharge indicating dementia with behavioral disturbance and whether patients were diagnosed with delirium during hospitalization. Delirium diagnosis was determined upon review of all discharge diagnoses, and included acute delirium, encephalopathy, and altered mental status. We recorded the primary reason for hospital admission, which was determined based on the assessment and plan in the admission history and physical. Finally, for patients that received IPCC, we recorded reason for consultation from the initial consult electronic order.

3) Code Status: We recorded whether patient's code status order in the EMR at admission and discharge was DNAR or Full code. Admission code status was the order placed on the date of admission. Discharge code status was the most recent order prior to live discharge or death.

4) Hospital Outcomes: These included length of stay and discharge disposition which we categorized as hospice, home (with or without home health services), facility (skilled nursing facility, nursing home, or assisted living facility), and death.

5) Discharge Medications for Symptom Management: We recorded whether patients were continued and/or started on medications to control symptoms from the hospital discharge summary (ex: pain, dyspnea, anxiety), including opiates, benzodiazepines, antipsychotics, and acetaminophen.

Statistical Analysis

We used summary statistics (means and medians for continuous variables; counts and percentages for categorical variables), to describe the sample. We compared characteristics of

dementia patients who received IPCC to those who did not receive IPCC using either t-tests (normal distribution) or the Mann-Whitney U-test (non-normal distribution) for continuous variables and chi-squared tests for categorical variables. P-value < 0.05 was considered statistically significant. Analyses were performed using the SAS 9.4 statistical software (SAS Institute Inc., Cary, NC).

RESULTS

Sample Characteristics

During the study period, 927 patients with an ICD diagnosis of dementia were admitted to a hospital included in our EMR review; 17% (N=157) of them received an IPCC. We matched the 157 patients who received an IPCC to 157 patients who did not receive IPCC based on age, race and gender, yielding a total sample size of 314 (Figure 1).

Table one includes sample characteristics. The mean age of all patients was 84 years old, 63% were female, and 69% were white. There were no differences between the two groups in gender, ethnicity, race, or marital status. Of patients who received an IPCC, the most common indications for consult (provider teams requesting IPCC were able to list more than one indication for consult request) were goals of care discussion (N=125) and symptom management (N=48). Patients who received IPCC were more likely to have been admitted from the nursing home (36% vs. 13%, $p < 0.000$), have a diagnosis of dementia with behavior disturbance (24% vs 13%, $p=0.02$), and have a diagnosis of delirium during hospitalization (71% vs 57%, $p < 0.01$). The most common reason for admission for both groups was altered mental status (28%

among patients who did not receive IPCC and 29% among patients who did receive IPCC, $p=0.80$). Other common reasons for admission included urinary tract infection (9.6% among patients with IPCC and 15.9% among patients without IPCC) and fracture (7.6% among patients with IPCC and 8.3% among patients without IPCC).

Markers of Advanced Dementia

Patients who received IPCC had evidence of more advanced disease. Specifically, patients receiving an IPCC were more likely at admission to have: 1) $>10\%$ weight loss in past year (22% vs 16%, $p=0.15$); 2) a pressure wound (26% vs 12%, $p<0.01$); 3) hypernatremia (13% vs 3%, $p<0.01$); and 4) bedbound ambulatory status (20.4% vs 3.2%, $p<0.000$).

Code Status

There was no significant difference in code status between groups at admission, however at discharge, rates were significantly higher for those with IPCC compared to those without IPCC (figure 2). Nearly 50% ($N=78$) of patients in the IPCC group were DNAR on admission compared to 39% ($N=61$) of those who did not receive IPCC ($p=0.053$). At discharge, 89% ($N=139$) of those with IPCC were DNAR compared to 46% ($N=73$) of those in the non-IPCC group ($p<0.000$). Notably, of the 27 patients who died in the hospital, only one patient had full code documented as their discharge code status; this patient did not receive an IPCC.

Hospital Outcomes

Table two outlines outcomes. Patients who received IPCC had a longer median LOS (5.9 vs 4.3 days, $p = 0.004$). Patients who received IPCC had significantly different discharge

dispositions than those who did not receive IPCC ($p < 0.01$). Patients who received IPCC were more likely to die in the hospital (13% vs 4%) or be discharged to hospice (56% vs 3%), and less likely to be discharged to home (9% vs 37%) or a facility (21% vs 54%).

Indicators of Symptoms Management

We examined discharge medications for symptom management amongst patients who did not die in the hospital or enroll in hospice at discharge. For patients discharged to home or a facility, there was no difference between the two groups in discharge medications for comfort, including opiates, benzodiazepines, antipsychotic medications, and acetaminophen. Overall, 69 patients (35.6%) were prescribed opiates, 29 patients (14.9%) were prescribed benzodiazepines, 41 patients (21.1%) were prescribed antipsychotic medications, and 112 patients (57.7%) were prescribed acetaminophen.

DISCUSSION

Despite the terminal nature of dementia and the high rates of healthcare utilization in this disease, a very small proportion of patients with dementia receive palliative care consultation, and palliative care consultation has not been well studied in this population. In this study at an academic and affiliated community hospital, we found that 17% of hospitalized patients with dementia received an IPCC. Notably, a large retrospective cross-sectional study ($N = 57\,753$ decedents) in the Veterans Affairs health system comparing quality of end-of-life care provided for different serious illnesses found 61.4% of patients with dementia (6.4% of their sample) received palliative care consultation within the last 90 days of life. There was no differentiation

between inpatient and outpatient consultation.⁹ As compared to similar patients who did not receive an IPCC, we found that patients who received an IPCC had more signs of advanced dementia and higher rates of delirium during hospitalization, were more likely to die in the hospital or be discharged to hospice, and were more likely to change their code status from full code to DNAR. The increased discharge to hospice and change in code status suggests IPCC resulted in increased goals of care discussions and possibly lower healthcare utilization, and suggests a benefit of IPCC for hospitalized patients with dementia. We noted that patients who received IPCC had longer length of stay compared to those who did not, but this is confounded by the fact that patients who received IPCC had more delirium and advanced dementia, which may have eventually triggered the IPCC.

The most common reason for IPCC was to address goals of care, followed by symptom management. This is consistent with other published literature on IPCC; advance care planning discussion was the most common reason for IPCC across 78 United States hospitals in the Palliative Care Quality Network collaborative.¹⁹ Given the most common reason for IPCC, our results suggest that IPCC offers an opportunity to discuss what matters most to patients. IPCC targets important components of the “Age-Friendly Health System,” specifically advance care planning to ensure patients receive care and symptom management consistent with their preferences.^{20,21} Whether DNAR code status and enrollment in hospice constitute a “benefit” to patients depends on the patient and family values, but we believe the increased frequency of hospice enrollment and changed code status serve as surrogacy markers for improved goals of

care discussions. This is consistent with other literature showing improved discussions about prognosis, goals of care, and decision-making when an IPCC occurs in hospitalized patients with advanced dementia.¹⁴

Though our sample size is small, we found no difference in symptomatic medication prescriptions at discharge between the two groups (excluding those who were discharged on hospice). Based on these results, we do not know how IPCC affects symptom management. Notably, prescribing patterns represent only one element of symptom management, particularly in dementia when pharmaceuticals are typically not considered first line for behavioral or psychological disturbances, and thus this remains an area that requires ongoing study.

Acknowledging that 17% of hospitalized patients with a diagnosis of dementia received an IPCC, we recognize that there may be opportunities to improve access to IPCC for a broader group of patients. A scoping review assessed existing literature to identify potential barriers for dementia patients to access palliative care. Four key types of barriers were recognized: administrative issues (e.g. financial models for end-of-life care, access to palliative care services), education, communication, and provider/staff attitudes towards end-of-life care.²² Particularly during acute admissions, providers may be focused on correcting reversible issues that prompted the hospital admission, and miss opportunities to focus on the bigger picture concerning the patient's diagnosis of dementia and ultimate prognosis. Our study suggests that IPCC provides an opportunity to fill these gaps in dementia patients' care. Furthermore, patients who did receive IPCC were more likely to have advanced dementia. Early use of palliative care

principles, and specifically having goals of care discussions when dementia is less severe, may provide additional benefit to patients and caregivers. Earlier adoption of palliative care in cancer patients has been shown to improve symptom intensity and quality of life in cancer care, and there is growing evidence that earlier palliative care is also advantageous to clinical outcomes and quality of life in patients with heart failure.^{23,24}

This study has several important limitations. This is a retrospective analysis performed at a single academic center and affiliated community hospital. Our data are from 2015, which was the most recent, complete data set available at the time of study initiation; notably, a 2019 systematic review published suggests a beneficial trend for dementia patients with palliative care consultation in several domains including goals of care discussions, symptom management, and prescribing behavior.²⁵ We also acknowledge that utilization of ICD codes to capture dementia diagnoses is imperfect, and patients with clinical diagnoses of dementia hospitalized within our institution may not have been included in this study as a result. Our institution is a tertiary referral center and our study population was predominantly white and non-Hispanic, which limits generalizability of our data. Given the retrospective nature of the study, we were unable to capture patient or caregiver quality of life data or confirm whether the IPCC interventions aligned with the patients' attitudes and values. Additionally, there was no long-term follow up on patient outcomes. We used prescribing patterns as a surrogate for symptom management, and thus incompletely captured the role of IPCC on symptom management. Finally, to identify the sample of non-IPCC patients, we randomly matched IPCC patients with non-IPCC patients

based on age, gender, and race. There is significant variability in dementia diagnoses not captured in ICD codes. Additionally, other variables related to cognitive/functional status and prognosis are not consistently reported in the EMR. Given this, our method may not have accounted for all important differences and similarities in the two groups which could have impacted decisions about IPCC and subsequently other aspects of care (LOS, DNAR orders, hospice). Despite these limitations, our findings are consistent with other studies of IPCC which show increased rates of advance care planning and hospice enrollment following consult.⁹ Additionally, studies indicate that palliative care is often requested for those with evidence of more advanced disease²⁶, as noted in our work.

Given the progressive and ultimately terminal nature of dementia, it makes intuitive sense for early palliative care involvement to help guide targeted symptom management and end-of-life care. This study suggests a benefit for IPCC in admitted patients with dementia, particularly in improving communication and increasing hospice enrollment. In fact, early utilization of palliative care principles may lead to less need for IPCC; improved goals of care conversations between patients, caregivers, and primary care teams, with outpatient palliative care, may lead to decisions to adopt a DNAR code status, avoid hospitalizations, and consider a hospice transition without an inpatient stay. Additional studies are needed to learn how to best identify patients who can benefit from IPCC and to understand whether such interventions align with patient values and improve quality of life. More research is needed across a variety of care settings,

including in-home and facility, to observe how palliative care impacts patient and family centered outcomes and thus understand how to improve the care of dementia patients.

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Conflict of Interest Disclosures

N Sharda: Dr. Sharda reports no conflicts of interest

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M Kutchibhatla: Dr. Kutchibhatla reports no conflicts of interest related to this manuscript, however discloses that she was a consultant to Aniara Diagnostica, LLC in 2019.

K Johnson: Dr. Johnson reports no conflicts of interest.

Author Contributions

N Sharda: Dr. Sharda had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Dr. Sharda contributed to the conception and design of the study, the data analysis, the data interpretation, the manuscript drafting, and the critical revision of the manuscript.

K Zietlow: Dr. Zietlow contributed to the data interpretation, the manuscript drafting, and the critical revision of the manuscript.

S Wong: Dr. Wong contributed to the data interpretation, the manuscript drafting, and the critical revision of the manuscript.

M Kuchibhatla: Dr. Kuchibhatla contributed to the design of the study, the data analysis, the data interpretation, the manuscript drafting, and the critical revision of the manuscript.

K Johnson: Dr. Johnson contributed to the design of the study, the data analysis, the data interpretation, the manuscript drafting, and the critical revision of the manuscript.

Sponsor's Role

Sponsors provided funding for salary support and statistical analysis

Figure 1. Inclusion Criteria Search Results

Figure 2. DNAR Status at Admission and Discharge related to IPCC (N=157 in each group)

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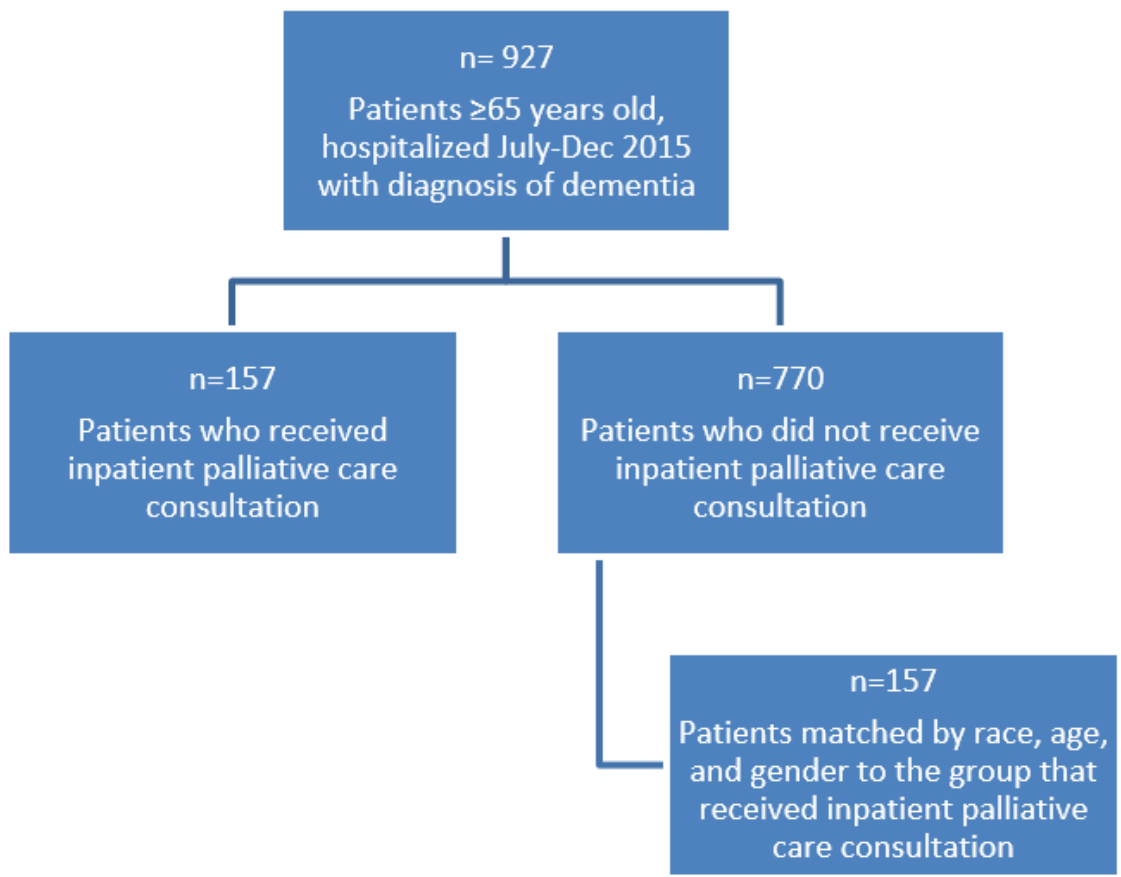
Table 1. Sample Characteristics

	No IPCC (n=157)	IPCC (n=157)	Total (n=314)	p-value
Age – mean (SD)	83.9 (8.0)	84.3 (8.3)	84.1 (8.1)	0.414
Gender (female)	99 (63.1%)	98 (62.4%)	197 (62.7%)	0.907
Race				0.208
White	111 (70.7%)	107 (68.2%)	218 (69.4%)	
Black	41 (26.1%)	45 (28.7%)	86 (27.4%)	
Ethnicity				0.562
Hispanic	2 (1.3%)	1 (0.6%)	3 (1%)	
Non-Hispanic	155 (98.7%)	156 (99.4%)	311 (99%)	
Marital Status				0.952
Single	17 (10.8%)	14 (8.9%)	31 (9.9%)	
Widowed	71 (45.2%)	76 (48.4%)	147 (46.8%)	
Divorced	10 (6.4%)	9 (5.7%)	19 (6.1%)	
Married	56 (35.7%)	54 (34.4%)	110 (35%)	
Prior Living Arrangement				<0.00
Home	109 (69.4%)	84 (53.5%)	193 (61.4%)	
Nursing home/SNF	20 (12.7%)	56 (35.7%)	76 (24.2%)	
Assisted Living Facility	28 (17.8%)	16 (10.2%)	44 (14.0%)	
Dementia with behavior disturbance	21 (13.4%)	37 (23.6%)	58 (18.5%)	0.02
Delirium Diagnosis	90 (57.3%)	112 (71.3%)	202 (64.3%)	0.01
Markers of Advanced Dementia				
Weight loss >10% in 1 year	25 (15.9%)	35 (22.3%)	60 (19.1%)	0.151
Pressure ulcer at admission	18 (11.5%)	41 (26.1%)	59 (18.8%)	0.001

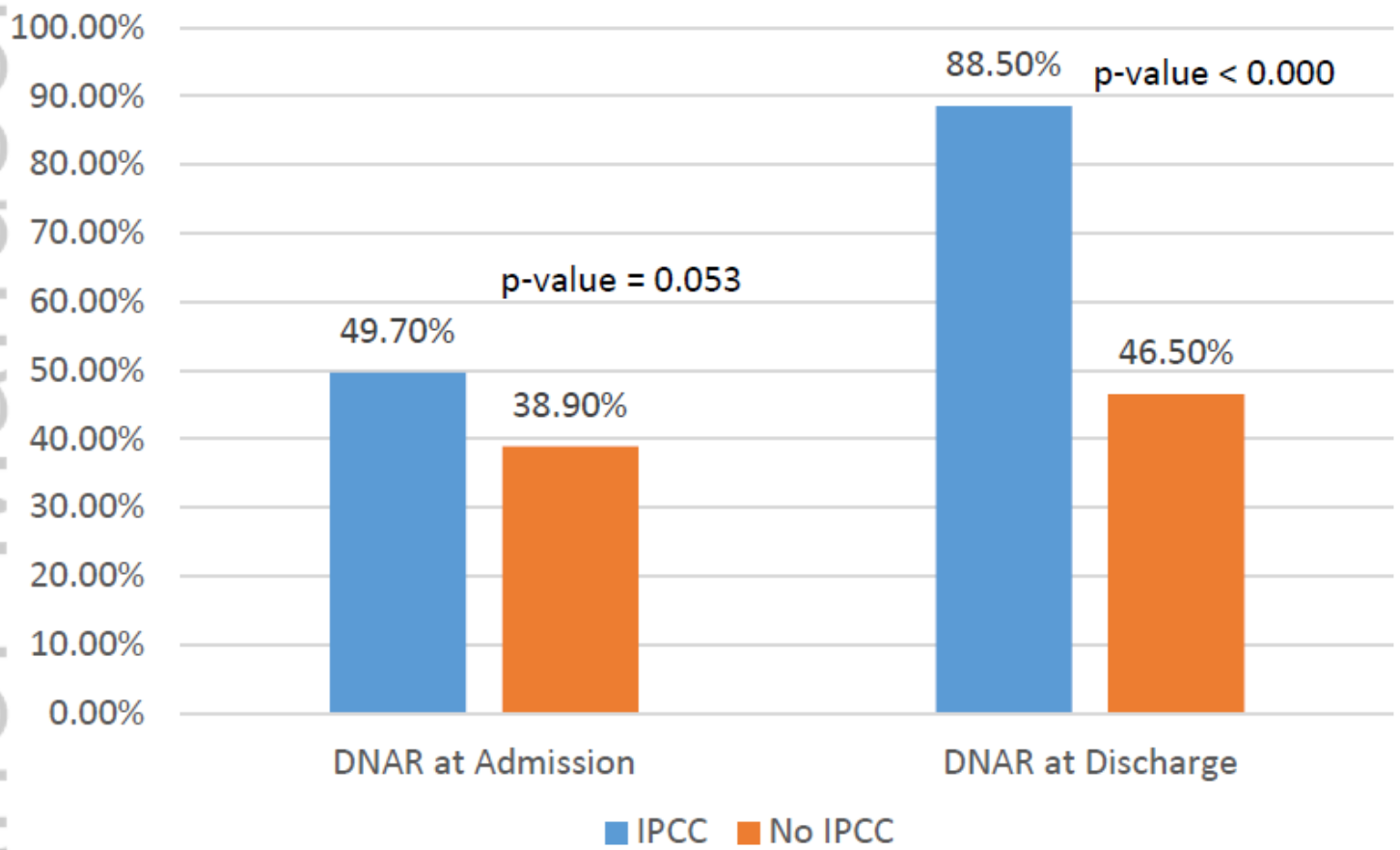
Sodium >145	5 (3.2%)	20 (12.7%)	25 (8.0%)	0.002
Ambulatory without assistive device	36 (22.9%)	21 (13.4%)	57 (18.2%)	0.028
Bedbound	5 (3.2%)	32 (20.4%)	37 (11.8%)	<0.000

Table 2. Outcomes

	No IPCC (n=157)	IPCC (n=157)	Total (n=314)	p-value
Length of Stay, days (median)	4.3	5.9	5.1	0.004
Discharge Disposition				<0.000
Hospital death	6 (3.8%)	21 (13.4%)	27 (8.6%)	
Discharge to hospice	5 (3.1%)	88 (56%)	93 (29.6%)	
Discharge to facility	89 (56.5%)	35 (22.3%)	124 (39.5%)	
Discharge to home	57 (36.3%)	13 (8.3%)	70 (22.3%)	
	No IPCC (n=146)	IPCC (n=48)	Total (n=194)	p-value
Comfort Medications at Discharge				
Opiate	51 (34.9%)	18 (37.5%)	69 (35.6%)	0.747
Benzodiazepine	21 (18.5%)	8 (16.7%)	29 (14.9%)	0.700
Antipsychotic	27 (18.5%)	14 (29.2%)	41 (21.1%)	0.116
Acetaminophen	89 (61.0%)	23 (47.9%)	112 (57.7%)	0.113



JGS_16521_Figure 1.Inclusion Criteria Search Results.IPCC Dementia.Shardaetal.PNG



JGS_16521_Figure 2_IPCC+Dementia_Shardaetal.PNG

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Email Address: neema.sharda@duke.edu

Verify your agreement to pay by signing and dating below. Wiley will send an invoice to the email address you've provided:

Signature: _____ Neema Sharda _____ Date: 4/15/20 _____