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Preliminary Data from an Advanced Dementia Consult Service: Integrating Research, Education, and Clinical Expertise

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Abstract

Hospitalized patients with advanced dementia often receive care that is of limited clinical benefit and inconsistent with preferences. We designed an Advanced Dementia Consult Service and conducted a pre and post pilot study to evaluate it in a Boston hospital. Consults were conducted by geriatricians and palliative care nurse practitioner. They consisted of structured consultation, counseling and provision of an information booklet to the family, and post-discharge follow-up with the family and primary care providers. Patients > 65 admitted with advanced dementia were identified and consults were solicited using pop-ups programmed into the computerized provider order entry (POE) system. In the initial 3-month period, patients received usual care (N=24). In the subsequent 3-month period, consults were provided to patients for whom it was requested (N=5). Data were obtained from the electronic medical record and proxies interviews (admission, 1-month post-discharge). The patients' mean age in the combined sample (N=29) was 85.4, 58.6% were from nursing homes, and 86.2% of their proxies stated comfort was the goal of care. Nonetheless, their hospitalizations were characterized by high rates of intravenous antibiotics (86.2%), > 5 venipunctures (44.8%), and radiological exams (96.6%). Acknowledging the small sample size, there were trends towards better outcomes in the intervention group including: higher proxy knowledge of the disease, greater communication between proxies and providers, more advance care planning, lower re-hospitalization rates, and fewer feeding tube insertions after discharge. Targeted consultation for advanced dementia is feasible and may promote greater engagement of proxies and goal-directed care for patients after discharge.

INTRODUCTION

Patients with advanced dementia are commonly admitted to the hospital where they often receive burdensome and costly care that is of limited clinical benefit and inconsistent with preferences.¹⁻⁵ Whether targeted in-hospital consultation can improve the quality of their care is unknown.

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Research suggests that palliative care consultation improves the care of patients with other life-limiting illnesses.⁶⁻⁹ However, advanced dementia patients have unique palliative care needs that require a disease-specific approach to understanding dementia as a terminal illness, counseling families about the clinical course, decision-making for common complications (e.g., eating problems), and managing symptoms.¹⁰ The objective of this report is to present our experience designing and implementing an Advanced Dementia Consult Service (ADCS) at the Beth Israel Deaconess Medical Center (BIDMC), a 631-bed teaching hospital in Boston. We also present preliminary data collected before and after implementation of the service, although this effort was not powered to detect differences in outcomes.

METHODS

The Institutional Review Board at Beth Israel Deaconess Medical Center approved this study.

Development of the ADCS

Guided by prior work,^{1-9,11-13} the ADCS included the following: 1. In-patient consultation, 2. Printed decision support for proxies, and 3. Post-discharge telephone support to proxies and feedback to primary care providers. The consult team included geriatricians and a palliative care nurse practitioner. A consult form was designed to include key palliative care issues and administrative metrics. An in-person or telephone meeting between the proxy and the ADCS team was held within 24 hours of admission and covered the following: proxy understanding of the clinical situation and advanced dementia; goals of care; aligning the goals of care with decision-making; palliative care and hospice; and proxy's needs.

A pocket-sized booklet was developed and given to all proxies to provide standardized information (On-line appendix; copies available from Dr. Susan L. Mitchell). The chapters (2-3 pages each) included: 1. What is Advanced Dementia 2. Determining the Primary Goal of Care, 3. Basic Approach to Decision-Making, 4. Approach to Eating Problems, 5. Approach to Decisions about Hospitalization, 6. Approach to Treatment Decisions for Infections, 7. How Advanced Dementia Affects the Family, and 8. What is Hospice and Palliative Care. The booklet was written by a palliative care nurse practitioner and four geriatricians then edited based on feedback from an independent practitioner panel (palliative care physician, chaplain, geriatrician, bioethicist, geriatric nurse practitioner) and three proxies of patients with advanced dementia.

At discharge, the ADCS team sent the patient's primary care providers a 1-page report summarizing the consultation focusing on recommendations for symptom control, goals of care, and advance care planning. Two weeks post-discharge, the proxy was telephoned to review the patient's health status, advance care planning, decision making, and proxy needs.

Identification of patients and solicitation of consults—The BIDMC maintains a state-of-the-art clinical computing system that includes out-patient and in-patient electronic medical records (EMR), physician order entry (POE), and administrative data. Our team worked with the Division of Clinical Informatics to develop and program a series of pop-ups for the POE system to identify patients admitted with advanced dementia and solicit consults. The first pop-up appeared upon admission for all patients > 65 years with a diagnosis of dementia (any type) based on existing data in the EMR (i.e., out-patient problem lists, prior discharge diagnoses) which read, "This patient has a diagnosis of dementia. At baseline, patients with advanced dementia are: 1. functionally mute (e.g. cannot verbalize meaningfully), 2. non-ambulatory (e.g. bedbound), and 3. incontinent of bowel and bladder. To the best of your knowledge, does this patient meet at least two of

these three criteria?" These features were based on the Global Deterioration Stage (GDS) stage 7.¹⁴ An automated email alerted the research team when a newly admitted patient met these criteria. A team member then confirmed that the patient had a diagnosis of advanced dementia by chart review and discussions with the patient's hospital nurse, primary care physician, or nursing home staff.

During the intervention period, a second pop-up appeared for patients meeting two of the three aforementioned criteria on the first pop-up, which read: "Patients with advanced dementia are extremely vulnerable when hospitalized. To help you optimize their care we are offering an Advanced Dementia Consult Service. Do you wish to have your patient receive this consult? Yes or No?" If "yes", an automated email was sent to the ADCS team.

Pilot Testing—Preliminary data was ascertained in the 3-months prior (control) and 3-months after (intervention) initiating the ADCS to better describe our implementation experience and assess the feasibility of collecting data for evaluation. This effort was not designed to have adequate power to detect differences between outcomes in the control and intervention groups. Patient eligibility criteria included: 1. age > 65, 2. admitted to any clinical service for < 48 hours, 3. advanced dementia based on GDS 7 criteria,¹⁴ and 4. English-speaking proxy was available. In the 3-month control period (November 2011–January 2012), eligible patients were identified using the first POE pop-up. The second POE pop-up offering a consult did not appear. They received usual care. In the 3-month intervention period (February 2012 – April 2012) eligible patients were identified as those possibly having advanced dementia by the first POE pop-up and had a consult requested using the second pop-up. Patients with multiple admissions were only eligible during their first admission.

Data were obtained from the EMR and proxy telephone interviews at baseline and 1-month post-discharge. Baseline EMR data included: demographic information, admitting service, and comorbid conditions. Proxies quantified the patients' baseline functional status using the Bedford Alzheimer's Nursing Severity-Subscale (range, 7 to 28; higher scores indicate greater impairment).¹⁵ EMR data describing the admission included: length of stay, discharge diagnosis, use of burdensome interventions (intravenous therapy, venipunctures, artificial ventilation, restraints, and feeding tubes), radiological examinations, advance directives, and goals of care discussions between proxy and providers. Patient death was ascertained from the EMR and follow-up proxy interview. Information about the post-discharge course from the follow-up interview, included: tube-feeding, re-hospitalizations, emergency room (ER) visits, hospice referral, and comfort using the Symptom Management at the End-of-Life in Dementia scale (range, 0–45; higher scores indicate greater comfort).¹⁶

Baseline proxy data included: demographic information, whether they lived with the resident, hours spent providing direct patient care each week, and the primary goal of care. At the follow-up interview, proxies were asked about knowledge of advanced dementia (range, 0–12; higher score indicates better knowledge), knowledge, preparedness about advanced dementia, and goals of care. Preparedness was assessed by asking whether the proxy felt they understood the complications expected in advanced dementia and whether they felt the patient had < 6 months to live. They were also asked to rate the quality of communication with hospital providers (Quality of Communication scale, range, 0–130; higher scores indicating better communication)¹⁷ and satisfaction with hospital care (Satisfaction with Care at the End-of-Life in Dementia scale; range, 10–40; higher scores indicating better satisfaction).¹⁶

Analysis

Descriptive statistics were calculated using frequencies for categorical variables and means for continuous variables. Comparative analyses were not performed as the pilot evaluation was not designed to detect differences in outcomes between the intervention and control groups.

Results

Patient identification

In the control period, 419 admissions generated the first POE pop-up identifying patients > 65 years with dementia. A total of 26.7% (N=112/419) of these admissions were identified as having two of three advanced dementia criteria, among whom the diagnosis was confirmed for 31.3% (N=35/112). Eleven admissions were excluded from further data collection for the following reasons: already recruited during a prior admission (N=5), unavailable proxy (N=3), proxy could not speak English (N=3). The remaining 24 patients were recruited into the control period.

During the intervention period, 394 admissions generated the first POE pop-up, identifying patients > 65 years with dementia. The admitting physician indicated that 19.8% (N=78/394) of these admissions had two of the three advanced dementia criteria and requested a consult for 30.8% (N=24/78). Advanced dementia was confirmed for 45.8% (N=11/24) of referrals. Three of these patients were already in the study, 2 proxies refused enrollment and 1 patient died prior to enrollment. The remaining 5 patients were recruited into the intervention period.

Baseline characteristics—The mean age of patients in the pre and post periods was 85.4 + 6.9 (SD) years, the majority were white, female, and resided in nursing homes (Table 1). A mean BANS-S score of 20.1 + 1.7 (SD) indicated severe functional disability.¹⁶ The distribution of most baseline subject characteristics was similar pre and post periods.

Hospital course—The mean length of stay was 3.6 days (Table 1). Infections were the most frequent discharge diagnosis. Most patients had intravenous antibiotics (86.2%) and underwent some type of radiological examination (96.6%). Only 13.8% of patients were discharged on hospice. Features of the hospitalization were similarly distributed in the control and intervention groups.

Follow-up—At 1-month post-discharge, 24.1% of patients had died, 27.6% were referred to hospice, 27.6% had at least one ER visit, and 24.1% were re-hospitalized (Table 2). Hospice referral was more common whereas ER visits and re-hospitalizations were less frequent in the intervention groups. Four patients had feeding tube inserted (control, N=3; intervention, N=1). Only 2 proxies felt the patient had had < 6 months to live, both from the intervention period. The vast majority of proxies in both groups felt comfort was the goal of care. Proxies in the intervention group more commonly reported they understood what to expect in advanced dementia. Quality of communication and satisfaction with care scores were slightly higher in the intervention group.

DISCUSSION

In this report we demonstrate the feasibility of developing, implementing, and collecting data to evaluate an ADCS in a teaching hospital. Devising a practical way to identify patients admitted to the hospital with advanced dementia was the most challenging aspect of this effort. The method we employed using the hospital's EMR and POE systems, while

innovative, was overly inclusive and required considerable additional screening efforts. We also only captured patients with an existing diagnosis of dementia in the hospital's database. Nonetheless, once identified, the characteristics of our sample were comparable to other advanced dementia cohorts.^{1,3,4,5}

Our study corroborates research suggesting that many hospitalizations for patients with advanced dementia are potentially avoidable.^{1,2,18,19} The most common admitting diagnoses (e.g., infections) may have been adequately managed in the outpatient or nursing home settings.^{18,19} Moreover, 86% of proxies stated the primary goal of care was comfort. Hospitalized patients with advanced dementia endure unfamiliar surroundings and providers and are at risk for burdensome interventions that may be of limited benefit.¹⁻⁵ Thus, hospitalization is seldom consistent with a goal of comfort, with possible rare exceptions such as hip fractures

There are several logical points at which to target an intervention to promote more goal-directed care in advanced dementia. Given our growing knowledge of the clinical course of this disease,¹ ideally primary care providers should counsel and solicit preferences from proxies before acute illnesses. Unfortunately, advance care planning does not consistently occur. To the extent that hospitalization of these patients stem from lack of counseling, their proxies may particularly benefit from in-patient consultation. While it may be challenging to influence care during a short admission, our results suggest that improved communication with proxies during the hospitalization may translate into more goal-directed care after discharge.

This study has several limitations. The ADCS was piloted at a single hospital. Its implementation may not be generalizable to other settings. The pilot study was also not powered to compare outcomes between the control and intervention groups. We also did not assess the experience of the hospital providers with the ADCS. Finally, we did not evaluate costs associated with developing or implementing the service. The effort of the involved clinicians and informatics specialists was incorporated into their usual responsibilities.

Currently, there is tremendous effort focused on reducing unnecessary and costly acute care.²⁰ Advanced dementia patients are obvious targets for such initiatives. Rigorous trials of complex interventions, such as the ADCS, are challenging, expensive, and lengthy to conduct. The compelling impetus to improve their care precludes the need to wait for such evidence. While refinement of case-finding is needed, our experience suggests that standardized consultation to address the distinct concerns of these patients is feasible and worth pursuing.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Characteristics of hospitalized patients with advanced dementia and their proxies.

Characteristic	Total (N=29)	Control (N=24)	Intervention (N=5)
Patient			
Age – mean years (SD)	85.4 (6.9)	84.4	90 (2.8)
Female – no. (%)	18 (62.1)	15 (62.5)	3 (60.0)
White – no. (%)	21 (72.4)	17 (70.8)	4 (80.0)
Residence – no. (%)			
Nursing home	17 (58.6)	13 (54.2)	4 (80.0)
Private home	10 (34.5)	9 (37.5)	1 (20.0)
Assisted living facility	2 (6.9)	2 (8.3)	0
Bedford Alzheimer's Nursing Severity Score ^a – mean (SD)	20.1 (1.7)	20.2	19.6 (1.7)
Comorbid conditions – no. (%)			
Congestive heart failure	13 (44.8)	8 (33.3)	5 (100.0)
Stroke	12 (41.4)	10 (41.7)	2 (40.0)
Diabetes	11 (37.9)	9 (37.5)	2 (40.0)
Chronic renal failure	9 (31.0)	6 (25.0)	3 (60.0)
Length of stay – mean days (SD)	4.6 (3.8)	4.1 (3.6)	6.6 (4.7)
Admitting Service – no. (%)			
General medicine/ Hospitalist	22 (75.9)	17 (70.8)	5 (100.0)
Geriatric medicine	5 (17.2)	5 (20.9)	0
Other	2 (6.9)	2 (8.3)	0
Primary discharge diagnosis – no. (%)			
Infection	14 (48.2)	11 (45.7)	3 (60.0)
Transient mental status change	4 (13.8)	4 (16.7)	0
Metabolic disturbance/dehydration	4 (13.8)	4 (16.7)	0
Cardio-pulmonary	4 (13.8)	3 (12.5)	1 (20.0)
Hip fracture	2 (6.9)	1 (4.2)	1 (20.0)
Gastrointestinal bleed	1 (3.5)	1 (4.2)	0
Intravenous antibiotics – no. (%)	25 (86.2)	20 (83.3)	5 (100)
>5 venipuncture – no. (%)	13 (44.8)	10 (41.7)	3 (60.0)
Intubated– no. (%)	3 (10.3)	3 (12.5)	0
Limb restraints – no. (%)	4 (13.8)	2 (8.3)	2 (40.0)
Feeding tube placed– no. (%)	0	0	0
Radiological exam – no. (%)	28 (96.6)	23 (95.8)	5 (100.0)
Chest X-ray	25 (86.2)	20 (83.3)	5 (100.0)
Computed tomography	12 (41.4)	10 (41.7)	2 (40.0)
Goals of care discussion documented –no. (%)	22 (75.9)	17 (70.8)	5 (100)
Do not resuscitate	22 (75.9)	18 (75.0)	4 (80.0)

Characteristic	Total (N=29)	Control (N=24)	Intervention (N=5)
No tube feeding	2 (6.9)	1 (4.2)	1 (20.0)
Discharged on hospice – no. (%)	4 (13.8)	3 (12.5)	1 (20.0)
Proxy			
Female – no. (%)	23 (79.3)	19 (79.2)	4 (80.0)
White – no. (%)	19 (65.5)	16 (66.7)	3 (60.0)
English primary language – no. (%)	22 (75.9)	19 (79.2)	3 (60.0)
At least some college education – no. (%)	22 (75.9)	18 (75.0)	4 (80.0)
Married – no. (%)	22 (75.9)	18 (75.0)	4 (80.0)
Working part or full time – no. (%)	19 (65.5)	16 (66.7)	3 (60.0)
Relationship to patient – no. (%)			
Child	20 (69.0)	17 (70.9)	3 (60.0)
Other family or friend	5 (17.2)	5 (20.8)	0
Spouse	2 (6.9)	2 (8.3)	0
Legal guardian	2 (6.9)	0	2 (40.0)
Lives with patient – no. (%)	4 (13.8)	3 (12.5)	1 (20.0)
Hours providing direct care to patient per week – no. (%)			
>7 hours	16 (55.2)	14 (58.3)	2 (40.0)
1-7 hours	11 (37.9)	10 (41.7)	1 (20.0)
None	2 (6.9)	0	2 (40.0)
Comfort is primary goal of care – no. (%)	25 (86.2)	22 (91.7)	3 (60.0)

^b The Knowledge of Advanced Dementia Score ranges from 0-12 with higher score indicating greater knowledge

^a Bedford Alzheimer's Nursing Score, possible score 7-28, higher scores indicate greater functional disability.

Table 2

Characteristics of patients with advanced dementia and their proxies one-month post-discharge

Characteristic	Total (N=29)	Control (N=24)	Intervention (N=5)
Patient			
Deceased – no. (%)	7 (24.1)	6 (25.0)	1 (20.0)
Referred to hospice – no. (%)	8 (27.6)	6 (25.0)	2 (40.0)
At least one emergency room visit – no. (%)	8 (27.6)	8 (33.3)	0
Re-hospitalized at least once – no. (%)	7 (24.1)	7 (29.2)	0
Feeding tube inserted– no. (%)	3 (10.3)	3 (12.5)	0
Symptom Management at the End of Life in Dementia ^a – mean (SD)	28.5 (9.5)	28.5 (9.7)	28.4 (9.5)
Proxy			
Knowledge of Advanced Dementia Score ^b – mean (SD)	9.2 (1.7)	9.1 (1.6)	9.6 (2.3)
Understand health problems in advanced dementia – no. (%)	17 (58.6)	13 (54.2)	4 (80.0)
Feels patient has < 6 months to live ^c – no. (%)	2 (9.1)	0	2 (50.0)
Comfort is primary goal of care ^c – no. (%)	20 (90.9)	16 (88.9)	4 (100.0)
Quality of Communication Score ^d – mean (SD)	85.0 (25.3)	84.3 (26.5)	88.6 (20.3)
Satisfaction with Care at the End of Life in Dementia ^e – mean (SD)	30.1 (4.8)	29.9 (4.5)	30.8 (7.0)

SD = Standard deviation

^aSymptom Management at the End of Life in Dementia ranges from 0-45 with higher score indicating greater comfort.¹⁶^bThe Knowledge of Advanced Dementia Score ranges from 0-12 with higher score indicating greater knowledge.^cThe denominator of these variables excludes deceased patients.^dQuality of Communication Score ranges from 0-130 with higher scores indicating better communication skills.¹⁷^eSatisfaction with Care at the End of Life in Dementia ranges from 10-40 with higher score indicating greater satisfaction.¹⁶