End-of-Life Care for Dementia Patients in the Program of All-inclusive Care for the Elderly (PACE) - A Quality of Care Assessment

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Abstract

Background: The majority of Americans want to die at home, but this occurs <40% of the time. This is particularly challenging for patients with dementia and as our population continues to age, this will become increasingly problematic. The mission of PACE is to allow patients to remain at home until death and therefore offer more support at the end of life allowing a greater percentage to die at home. The National Quality Forum (NQF) and the Carolinas Center for Medical Excellence Hospice PEACE (Prepare. Embrace. Attend. Communicate. Empower) project has developed several quality measures to evaluate care at the end-of-life. The goal of this project was to assess these measures during the last 6 months of life for patients with the diagnosis of dementia while enrolled in PACE.

Methods: Retrospective study starting at 6 months prior to death for patients admitted to the Baltimore PACE with the diagnosis of dementia between years of 2010-2014. Quality measures for evaluation were selected from 2 national quality assessment programs and one from the National Hospice and Palliative Care Organization. Using the quality measure definitions, we evaluated conformance with each metric during the last 6 months of life while admitted to the Baltimore PACE program.

Results: 71 charts were reviewed. Average age was 84.42±7.9 (77%F), 78% of patients had advance directives but only 38% of patients had documentation about preferences regarding hospitalization. None had documentation that spiritual, existential, nor bereavement concerns were addressed. Only 8% had documentation that caregiver burden was assessed. Average number of total medications was 8.6. 46% of patients were not screened for pain and in those who were only 14% was a pain tool used or severity of pain documented. Of the patients who had pain, 48% were treated with Tylenol alone and 51% were treated with opiates (with 38% of those on no bowel regiment). 50% were screened for shortness of breath, 34% screened positive, and only 8% of those were on morphine or any additional medication beyond bronchodilators and oxygen. 58% had documentation of agitation and behavior problems with 53% treated with an antipsychotic, 46% treated with antidepressant, and 14% with benzodiazepine. The average length of stay (since enrollment in PACE) was 39 months, with 0.9 admissions in the last 6 months of life along with only 7% of patients dying in the hospital.

Conclusion: This PACE program allowed most patients with dementia to die outside of a hospital (93%). However, there was a significant gap in care delivered to this patient population and there needs to more standardization in quality metrics, similar to those used in hospice, to ensure high quality of life for dementia patients while dying on PACE.

Keywords: End-of-life; Dementia; Program of All-inclusive Care for the Elderly (PACE)

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Introduction

By 2030, it is predicted that those 65 and older will increase to 71 million [1]. The fastest growing populations are those ages 85 and older and the prevalence of patients with disabilities, frailty, and multiple co-morbidities with uncertain prognosis and large usage of healthcare resources also continues to grow [2]. It is predicted that 80% of all deaths that occur in the United States comprise of Medicare beneficiaries and that about 25% of Medicare dollars are spent on patients during the last year of life [3,4]. Studies have also show a trend towards increased aggressive care, increased transitions of care and increased ICU admissions during the last months of life [4-6]. The Medicare hospice benefit states that the prognosis must be 6 months or less, a standard which

is more appropriate for diseases with a rapid downward trajectory, like cancer, and is not as applicable to the dying process that occurs with the majority of older adults with dementia. For older adults who die from dementia, death is preceded by years of progressive decline. Thus, the transition towards end of life is not well demarcated.

Fifty percent of patients reaching 85 years of age will be afflicted by dementia and the Alzheimer's Association estimates the cost of caring for patients with dementia at $180 billion per year [7,8]. Although significant resources are spent on caring for geriatric patients with dementia, we fail to meet the basic needs of this vulnerable population. The medical field needs to determine a way to deal with this increased need as this will greatly affect health care provisions with increasing cost [9]. The nursing home population in particular is supposed to grow to more than three million by 2050 with nearly 40 percent of Medicare beneficiaries having some nursing home stay in their last year of life [10,11]. The highest cost accrued in nursing homes is during the last months of life and studies have shown inadequate management of end-of-life issues in this population [12-16]. When surveyed also the majority of Americans want to die at home but sadly this occurs <40% of the time [17].

One way to deal with this is through the Program of All Inclusive Care for the Elderly (PACE) whose goal is to allow patients to remain community dwelling in their home. PACE is capitated model in which care for older community-dwelling elderly disabled participants ≥55 years of age certified by states as eligible for nursing home level care, in whom most are dually eligible for Medicare and Medicaid benefits, can receive care in an interdisciplinary model. For most participants, the comprehensive service package enables them to remain in the community rather than receive care in a nursing home. Also on the benefits of PACE is that unlike the Medicare hospice benefit, hospice services in PACE are not limited to time nor palliative treatments only [3,18,19]. Pace is an ideal systems since patients receive careful monitoring, care is coordinated through an interdisciplinary team, the majority of patients are able to remain at home, treatment plans can easily be adjust to patient's needs, and the majority of patient's preference have been elicited and translated into advance directives.

PACE programs were not designed to be specialized program for end-of-life care but it is an ideal setting for this to occur. Greener and colleagues showed that 45% of PACE participants were able to die at home and Schamp et al. [18] showed that by increasing health care wishes documentation, they were able to increase the rate of dying at home from 24% to 65% for patients on PACE [19]. Segelman et al. [20] showed that the rates of hospitalization, readmission, and potentially avoidable hospitalization were lower for PACE participants. Thus PACE is a potential way to allow more patients the chance to die well at home with grace and dignity along with decrease health care cost but no study has focused specifically on end-of-life quality metric for dementia patients during the last 6 months of life. An ideal model would include both PACE and Hospice but because of limitations in funding this model can be challenging. CMS has stated that "Since comprehensive care is provided to PACE participants, those participants who need end-of-life care will receive the appropriate medical, pharmaceutical, and psychosocial services through the PACE organization. If the participant specifically wants to elect the hospice benefit from a certified hospice organization, then the participant must voluntarily disenroll from the PACE organization [21]." Thus currently most PACE agencies provide their own hospice care, but the same quality metric as in hospice should also be applied

to PACE programs to ensure quality of care. Measuring the quality of care delivery is integral to ensure that patients are receiving the best medical care possible. It also allows physicians to determine where quality deficits exist so that actions can occurs to improve patient outcomes.

In 2011, Congress passed the National Alzheimer's Project Act (NAPA) to address the challenges facing people with Alzheimer's disease or related dementias. The National Quality Forum (NQF) and the Carolinas Center for Medical Excellence Hospice PEACE (Prepare. Embrace. Attend. Communicate. Empower.) Project has developed multiple quality measures for end-of-life-care in response to this in the areas of pain, dyspnea, depression, and advance care planning (ACP) to improve high-quality care for dementia patients [22-24]. The goal of our project was assess end-of-life quality measures during the last 6 months of life for patients with the diagnosis of dementia while enrolled in PACE.

Methods

The setting of this project was the Program of all inclusive care for the elderly (PACE), which is a community-based managed care model serving a frail, nursing home-eligible population of Medicare beneficiaries. For this study, we analyzed de-identified data collected. The cohort included patients with the diagnosis of dementia receiving care through the Baltimore PACE program who passed away between 1/1/2010 until 12/31/2014. Variables reflected National Quality Forum quality domains and the Carolinas Center for Medical Excellence Hospice PEACE Project for palliative care and hospice, including symptom assessment and psychosocial needs. Other variables included demographic, disease information, cognitive status, medication usage, length of stay, location of death and number of admission in the last 6 months of life. An inclusion criterion was patient's ≥55 years of age, admitted to PACE at Bay view John Hopkins who passed away between years of 2010-2014. Exclusion criteria included Patients not admitted to Elder plus bay view Hopkins PACE site, patients ≤ 55 years of age or patients discharged from PACE prior to death, and patients without the diagnosis of dementia.

Quality measures for evaluation were selected from 2 national quality assessment programs and one from the National Hospice and Palliative Care Organization. Quality metrics selected: 11 from National Quality Forum-endorsed (NQF) Measures, 1 modified NQF Measure, 3from the Carolinas Center for Medical Excellence Hospice PEACE (Prepare. Embrace. Attend. Communicate. Empower) Project, and 1 from the National Hospice and Palliative Care Organization [22-25]. The domains of the quality metrics included one in the NCP domain Structure and Process (Comprehensive Assessment), six in Physical Aspects (Screening for Physical Symptoms, Pain Treatment, and Dyspnea Screening and Management), two in Psychological and Psychiatric Aspects (screening for depression, anxiety and agitation and management), one in Spiritual and Existential Aspects (Discussion of Spiritual/Religious Concerns), three in Ethical and Legal Aspects (Documentation of Surrogate, Treatment Preferences), two in Social Aspects of care (care given burden and driving assessment) and one global measure (post-survey of care).

Using the quality measure definitions, we evaluated conformance with each metric during the last 6 months of life while admitted to the Baltimore PACE program. Descriptive statistics were calculated. The associations between the independent variables and the sites of

Table 1: Population Characteristics, Comorbidities, Cognitive Status, Medication Usage.

CHARACTERISTICS	Mean ± S.D., or N (%)
DEMOGRAPHICS	
Age in years, mean ± sd	84.42 ± 7.9
Female, % (n)	54 (74%)
White, not Hispanic, % (n)	34 (48%)
African American, % (n)	33 (47%)
COMORBIDITIES	
Congestive Heart Failure	19 (27%)
Hypertension	54 (77%)
Diabetes	25(35%)
Hyperlipidemia	36 (51%)
Chronic Lung Disease	14 (20%)
Chronic Renal Disease	30 (42%)
Cancer	14 (20%)
CVA/TIA	18 (26%)
CAD	31(44%)
Depression	29 (41%)
Other Comorbidity	68(97%)
TOTAL COMORBIDIDITY, mean ± sd (count)	9 ± 3.2
1-3 Comorbidities	2 (2%)
4-5 Comorbidities	9 (13%)
6 or more Comorbidities	60 (84%)
COGNITIVE STATUS	
MMSE Score, mean ± sd	11.6 ±6.9
Mild (20-25)	7 (10%)
Moderate (10-19)	40 (57%)
Severe (<10)	23 (33%)
Total amount of medications	
Medications, mean ± sd	8.6 ± 4.0

death-hospital, nursing home, and home-were assessed in a bivariate analysis using the chi-square statistic. All analyses were approved by the Johns Hopkins University institutional review board.

Results

Sample characteristics

A total of 71 patient's charts were reviewed. All patients were ≥65 years of age with the mean age equal to 84.2 ± 7.9 (Table 1). The majority of whom were female (74%). All patients had documented history of dementia and the mean MMSE score was 11.6 ± 6.9. Comorbidities were collected and the majority (84%) had 6 or more comorbidity, which emphasizes the complexity of these patients. Hypertension (77%) and dyslipidemia (51%) were the most common after dementia. The average number of medication usage was 8.6 ± 4.0.

Health services utilization and location of death

Selected measures are presented in Table 2. The average length of stay (since enrollment in PACE) was 39 months ± 35.1, with 0.9 ± 1.2 admissions in the last 6 months of life along with only 7% of patients dying in the hospital. The chance of dying at home increased

Table 2: Length of Stay, Number of Admission, Location of Death.

Characteristics	Mean ± S.D., or N (%)
Length of Stay	
Length of stay,	39± 35.1
Number of Admission in last 6 months of life	
Admissions	0.9± 1.2
Location of Death	
Hospital	5 (7%)
Home	20 (30%)
Assisted living	46 (69%)
Nursing home	17 (25%)
Rehab	4(5%)

significantly with age, from 30% among those younger than 80 to 70% among those aged 80 and older. Women were also significantly more likely to die at home (70%) than men (25%). Also Caucasians were significantly more likely to die at home (55%) compared to African-Americans (35%) and Hispanics (10%). The chance of dying at home increased significant with length of time in the PACE program with those ≥2 years (65%) compared to those less than 2 years but more than 1 year (15%) and those less than a year (20%). Patients with moderate dementia (MMSE 10-19) were more likely to die at home (60%) than those with mild (10%) or severe (30%) dementia. There was no clinically significant difference between patients in those with higher readmission rates in the last 6 months of life.

Quality measures

Conformances with selected measures are presented in Table 3. 78% of patients had advance directives but only 38% of patients had documentation about preferences regarding hospitalization. None had documentation that comprehensive assessment was done on admission, nor that spiritual, existential, or bereavement concerns were addressed. Also there was no documentation of a post-care survey being performed. Only 8% had documentation that caregiver burden was assessed. 54% of patients were screened for pain but for only 14% was a pain tool used or severity of pain documented. Of the patients who had pain, 48% were treated with Tylenol alone and 51% were treated with narcotics (and 62% of those were on a bowel regiment). 54% were screened for constipation and 17% had documented decubitus ulcers. 50% were screened for dyspnea, 34% screened positive, and only 8% of those had a treatment plan that included morphine or any additional medication beyond bronchodilators and oxygen. 52% were screened for depression or anxiety and 58% had documentation of agitation and/or behavior problems with 53% treated with an antipsychotic, 46% treated with antidepressant, 14% with benzodiazepine and only 1% having documentation of behavior interventions performed.

Discussion

This study revealed that participants were more likely to die outside the hospital (93%), which has been shown in other studies on PACE programs, which is significant since compared to Medicare beneficiary in nursing homes who on average 50% die in the hospital [19]. By 2050, one-fifth of the total U.S. population will be elderly and that growth will bring a corresponding surge in the number of elderly people with functional and cognitive impairments [26]. As stated above by 2050 nearly 40 percent of Medicare beneficiaries will need some nursing home stay in their last years of life [10,11,27].

Table 3: Quality Metrics.

Metric	Specific Metric	Descriptive Results
NQF	Was the patient/responsible party asked about preference regarding the use of cardiopulmonary resuscitation (CPR)? Was the patient/responsible party asked about preference regarding hospitalization?	78% of patients had advance directives but only 38% of patients had documentation about preferences regarding hospitalization.
	Was the patient and/or caregiver asked about spiritual/existential concerns? Was bereavement services offered?	None had documentation that spiritual, existential, nor bereavement concerns were addressed.
	Was the patient screened for pain? Was a standardized pain tool used and severity documented?	54% of patients were screened for pain but for only 14% was a pain tool used or severity of pain documented.
	If the patient screened positive for pain, were they are on treatment and what was the pain treatment?	86% who screened positive for pain were on a pain regiment. 48% were treated with Tylenol alone, 51% were treated with narcotics, 9% were also on lidocaine patch, 2% on gabapentin, 2% on Lyrica.
	If the patient was treated with an opioid, were they on a bowel regiment?	62% of those were on a bowel regiment
	Percentage of patients with advanced chronic or serious life-threatening illnesses that were screened for dyspnea; for those who were diagnosed with moderate or severe dyspnea, a documented plan of care to manage dyspnea existed.	50% of patients were screened for dyspnea with 34% screening positive, severity of dyspnea was not recorded on any patient, and only 8% of those had a treatment plan that included morphine or any additional medication beyond bronchodilators and oxygen.
	Was caregiver burden discussed and documented?	Only 8% had documentation that caregiver burden was assessed.
	Did the patient have agitation/behavior problems? What was the treatment? Was behavior interventions documented?	58% had documentation of agitation and behavior problems 53% treated with an antipsychotic, 46% treated with antidepressant, 14% with benzodiazepine, and 1% with behavior interventions.
	Any documentation regarding risk of driving?	None had documentation about driving risk.
	Was the patient screened for depression or anxiety?	52% were screened for depression or anxiety.
	Did the patient have documentation of new or worsening pressure ulcer?	17% had documented decubitus ulcers
PEACE	Was the patient screened for constipation?	54% were screened for constipation.
	Patient's received a comprehensive assessment (physical, psychological, social, spiritual and functional) soon after admission?	0% patients received a full comprehensive assessment that included physical, psychological, social, spiritual and functional assessment after admission.
	Patient's had documentation of the surrogate decisionmaker's name and contact information or absence of a surrogate.	100% had documentation of surrorgate decision maker and contact information.
Expert opinion	Patients or their families were asked about their experience of care using a relevant survey.	None of the patients or their family members were asked to complete a survey about the care received.

Sadly though many nursing home (NH) patients dying with advanced dementia in the United Sates do not receive hospice care [28]. It is estimated that only 11% of NH residents with advanced dementia are referred to hospice [29]. One of the reasons cited for this is the inaccurate estimation of life expectancy in patients with advanced dementia [30,31]. In a national survey, 80% of hospice agencies stated difficulty in estimating prognosis in dementia patients as a major barrier to hospice care [31,32]. Thus as stated above PACE could fit into the national efforts of improving end-of-life- care for elderly patients with underlying dementia since the 6 month eligibility criteria would not be needed and patients could remain in their home. Our study showed though that there were several limitations with having the PACE agency provide end-of-life care for dementia patients. One problem identified was that none of the patients had documentation that spiritual, existential, or bereavement concerns were addressed, which is common practice in patients undergoing hospice care. Ferris et al. described the 8 domains of potential patient and family suffering to include; disease management, physical, psychological, social, spiritual, practice, end of life care, and loss/grief. If all these domains are not assessed and addressed if needed, then patients and families may go through unnecessary suffering. The deep distress caused by spiritual, social and psychological pain can exacerbate the distress caused by physical pain and other symptoms such as dyspnea. They may also have a negative impact on a patients or family member's capacity to live a meaningful and rewarding life. Also bereavement care is an essential component of hospice care that includes anticipating grief reactions and providing ongoing support for the bereaved over a period of 13 months. If these are not addressed or at least a referral placed so that families received the support and care they need after a death of a loved one, this can lead to the development of complicated grief which can have a negative effect on their ability to functional properly [33].

Second problem identified was that in only 14% of patients was a standardized pain assessment tool used and severity of pain documentation and 38% of patients on opiates were not on a bowel regiment. Multiple studies have shown the underuse of pain medications in cognitively impaired residents, especially in those unable to communicate pain verbally [34]. This is why it is so important to use a standardized pain assessment tool in these at risk patient population to make sure pain is properly treated, especially at the end of life. Additional, constipation is a common side effect of opiate therapy and it is essential that patients are on a proper bowel regiment, especially in this elderly population since constipation is already common and can cause serious side effects as delirium, urinary retention, pain, and obstruction [35].

Third problem identified was that only half of the patients were screened for dyspnea and of those who did screen positive, none had severity of dyspnea recorded, and in only 8% of patients was morphine or any additional therapy beyond bronchodilators and oxygen used. Studies have shown that up to 70% of patients with dementia experience dyspnea, thus screening and proper treatment is essential [36]. Opioid, particular morphine is the standard initial therapy for uncontrolled dyspnea at the end of life. The postulated theory is secondarily to the vasodilatory effects on the pulmonary vascular and decreased oxygen consumption that occurs with opioids, thus having only 8% of patients on morphine who had documented dyspnea is problematic [37]. Fourth Problem identified was that only 8% of patients had documentation that caregiver burden was assessed. Multiple studies have shown high rates of caregiver stress,

burnout, depression, impaired quality of life, and overall poor health among caregivers of patients with chronic neurological conditions [38-41]. Caregiver burden does appear higher in those patients with cognitive and behavioral problems [40]. Also it appears greater in those with bladder dysfunction and greater restrictions in activities of daily living [40]. One study showed that anxiety was present in 17% of caregivers compared to 10% in control group [42]. Another landmark study showed that caregiver strain was associated with 63% higher mortality than noncaregiver controls [43]. Additional studies have shown high rates of weight loss, low self-esteem, depression, social isolation, suicide, and financial stress in caregivers [43,44]. Thus it is very important to screen for caregiver stress and burden. There are multiple scales available to screen for caregiver burden including Zarit Burden Interview (ZBI), Caregiver Assessment tool (CAT), Caregiver Reaction Scale (CRS), Caregiver Burden Scale (CBS), Caregiver Stain Index (CSI), and Screen for Caregiver Burden (SCB) as examples, but Zarit Burden Interview is the most widely used scale [45].

Fifth problem was that 58% had documentation of agitation/behavioral problems and 53% were treated with anti-psychiatrics with only 1% had documentation that behavioral interventions were tried or discussed. The use of antipsychotics in patients with dementia should not be taking lightly given studies showing 1.5-1.7 fold increased risk of mortality and 2-3 fold increase in cerebrovascular events [46-49]. This is why they carry a black box warning from the FDA about this risk and why behavioral interventions should be first line in any dementia patients having agitation/behavioral problems.

We felt that ways to overcome these barriers and to improve the quality of care of dementia patients dying on PACE is to have universal training of staff and physicians on hospice related care, to have standard assessment scales and order sets/protocols available for specific symptoms, and to have standardized hospice quality metrics measured in PACE programs. This would ensue that patients are getting hospice like care even while on PACE and that the care they are receiving is the best possible care at the end-of-life.

Limitations

There are several potential limitations in our study. First, we do not have data on patient preferences for the place of death. There have been multiple studies showing that the majority of patient do prefer die at home [17] but since this was a retrospective study, we were not able to collect that data. The retrospective approach allowed for missing and potentially ambiguous baseline data. Because this was a single site study, it lacks external validity. Also the lack of a control group makes it difficult to estimate the influence of extraneous factors.

Conclusion

This PACE program allowed most patients with dementia to die outside of a hospital (93%). However, there were significant gaps in the quality of care delivered to this patient population and there needs to more standardization in quality metrics, similar to those used in hospice, to ensure high quality of life for dementia patients while dying on PACE. A large-scale, multicenter study is needed to confirm these results from this study.

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