Published in final edited form as:

J Hosp Palliat Nurs. 2018 April ; 20(2): 153–159. doi:10.1097/NJH.0000000000000420.

Care in Nursing Facilities after Palliative Consult

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Abstract

Despite hospital palliative care consultations during which goals of care are discussed in the context of poor prognoses, older adults are admitted to nursing homes for post-acute care where the focus is on rehabilitation. The purpose of this qualitative descriptive study was to describe factors that influence discontinuity between a palliative care consult and nursing home care and explore the potential consequences of this discontinuity. Twelve adults (mean age of 80 years) were enrolled from one community hospital and nursing home in the mid-Atlantic United States. Semi-structured interviews and medical record reviews were used to elicit information about clinical course, care processes, and patient/family preferences at hospital discharge and up to four times after nursing home admission. Data were analyzed using inductive content analysis techniques. Analysis revealed two themes: *Inadequate Communication* characterized by the lack of information about the palliative care consult after hospital discharge and *Prognosis Incongruence* evidenced by data demonstrating a discrepancy between hospital prognosis and nursing home care. Ongoing communication between settings to re-address goals of care, prognosis, and symptoms—the central tenets of palliative care—is lacking. Efforts to improve access to comprehensive palliative care delivery after hospitalization and during nursing home transitions are greatly needed.

Keywords

hospitalization; palliative care; nursing homes; continuity of patient care; postacute care

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Disclosures

No competing financial interests exist.

Introduction

Specialty palliative care teams are increasingly common in US hospitals. Two thirds of hospitals with greater than 50 beds have a palliative care program.¹ In contrast, palliative care delivery models are not as well developed in community settings, including nursing homes (NHs).^{2–4} NH programs are hindered by regulatory and reimbursement barriers and challenges with staff palliative care training, support, and education.⁴ Still, many palliative care patients with serious illness are discharged to NHs after hospitalization.⁵ The scarcity of palliative care in NHs suggests a potential disruption in high quality care after a hospital palliative care consult (PCC).⁶

The need for comprehensive palliative care throughout advanced illness and accompanying transitions is widely endorsed.^{7,8} Both researchers and clinicians emphasize that care continuity across settings is an essential element of palliative care.⁶ During transitional periods, seriously ill older adults and their caregivers need supportive care planning and symptom management that is consistent with their stated goals and preferences.^{8,9} Moreover, effective care transitions can reduce hospitalizations and acute care use for older adults.¹⁰

There is limited research on how hospital PCC teams are managing transitions and care continuity for patients discharged to NHs; findings are embedded in larger studies and do not reflect the unique NH patient needs and palliative care delivery challenges in NHs.¹¹ NH patients are typically frail with multiple chronic medical co-morbidities, cognitive impairment, and functional limitations.¹² The majority of patients are older and receive both short and long-term NH services by nurse-led teams who manage and coordinate the overall care as well as assume facility leadership positions.¹³ Short term care is typically provided under the Medicare Skilled Nursing Facility (SNF) benefit and focuses on rehabilitation and skilled or complex therapies for unstable conditions. Many older patients who are discharged from the hospital to the NH are not appropriate candidates for SNF care or rehabilitation due to their poor medical prognosis.^{14,15}

Our previous work showed that, regardless of hospital PCC recommendations for supportive care, most frail older adults and their family caregivers focused on rehabilitative and curative SNF care after NH admission.¹⁵ Our goal in this analysis was twofold; first we sought to describe factors that influenced discontinuity between a hospital PCC and NH admission for continued care. Second, we explored the potential consequences of this discontinuity.

Methods

Setting

We collected data between January and December 2014 at one community hospital and one NH (each with 250–300 beds) located in the mid-Atlantic United States. We obtained study approval from a university institutional review board and study protocol approval from research review committees at the hospital and NH.

Sample

We used purposive criterion sampling to identify patients who received an inpatient PCC with a discharge plan to the participating NH. Adults were eligible if they (a) were English speakers, (b) were 60 years and older, and (c) had a life expectancy of at least 7 days. If an eligible participant was not decisional or could not participate in an interview, the surrogate decision maker (a legally authorized representative) was contacted to provide written consent and be interviewed. We excluded patients enrolled in hospice at hospital discharge because of existing evidence that better palliative care outcomes in NHs are achieved with hospice care.¹⁶

Participants were recruited as soon as possible after receiving a PCC and a discharge plan that included admission to the participating NH. The first author reviewed the PCC team census daily to identify eligible patients. A PCC team member or the first author approached the patient or the surrogate decision maker in person or via telephone to inform them about the study. Written informed consent was obtained from either the patient or the surrogate up to 48 hours after hospital discharge. In total, we approached 37 eligible participants to explain the study and enrolled 12 participants (Figure 1). We stopped enrollment when data within and across participant cases were abundant in describing what factors influenced discontinuity between a hospital PCC and NH admission and the potential consequences of this discontinuity.^{17,18}

Data Collection and Procedures

We collected data from medical records up to five times (at hospital discharge and after NH admission; 24–48 hours; 7 days; 21–30 days; and 100 days) per participant using an audit tool that was developed and revised based on expert opinion. The audit tool was informed by current palliative care clinical practice guidelines.⁷

Text about clinical course and care processes was copied, de-identified, and stored on an encrypted computer. The medical record review included information about: (a) pain and symptom assessment, management, and outcomes; (b) psychosocial and spiritual support; (c) advance care planning (e.g. goals-of-care discussions, family meetings, and care-planning discussions and outcomes; (d) nursing, medical, and rehabilitation care; and (e) health care utilization, including rehospitalization, and discharge disposition. Most of the medical record data for this analysis were found in the PCC note and hospital discharge summary, care goals as documented on NH admission note (e.g., objectives, goals, plan of care), and any subsequent advance care planning discussions. This data collection yielded a median of 4 medical record audits (range 2 to 5) for each participant; incomplete data were attributable to death or discharge.

The first author also conducted two interviews with each participant or the surrogate at 7 and 21–30 days after hospital discharge to determine which of the hospital PCC recommendations were implemented in the NH. Interview guides were developed and revised after pilot testing. Questions in the interview guides were designed to elicit patient and/or family perceptions of pain and symptom management, adherence to goals of care

(e.g., preferences for treatment), and psychosocial support in nursing homes after hospital discharge with a palliative care consult.

Interviews lasted 10 to 50 minutes and were digitally recorded and professionally transcribed. Accuracy of transcribed interviews was verified through comparison to audio recordings. The first author wrote field notes throughout the data collection process to describe the setting, actions, and behaviors and reflect on thoughts and ideas during and immediately following interviews.¹⁹

Data Analysis

We uploaded, organized, and managed textual data from medical record audits and interviews by participant case in NVivo v10[®] (QSR international Pty Ltd., Victoria, Australia) qualitative data analysis software. We then constructed care trajectory matrices listing time and corresponding events using the medical record audit data to gain a comprehensive account of each participant's care from hospital discharge to 100 days after NH admission. Next, we coded the interview and medical record text with First cycle coding methods (e.g. initial descriptive data coding) guided by inductive content analysis techniques.^{20,21} During coding, we embedded reflective analytic notes and linked coded text in the care trajectory matrices to expand and add detail to the matrices.²² We then used Second cycle coding (e.g. reorganizing and condensing coded data) to compare similarities and differences among coded data and each case longitudinally and to identify overarching categories.²¹ We examined the categories and defined the properties of each by characteristics of the corresponding data codes. Categories were then grouped by their properties to develop themes. The authors met weekly during analysis to discuss codes, categories, and initial themes. The first author maintained a comprehensive audit trail, including methodological, analytic, and theoretical memos throughout the project.¹⁹

Results

Sample

Twelve older adults were enrolled (Table 1). All participants were seriously ill with a poor prognosis and limited life expectancy at the time of study enrollment; one participant wanted a higher level of rehabilitative care and was discharged to a different NH three days after admission; six died within six weeks of NH admission (two of the six were transferred to a hospice inpatient unit after rehospitalization). Of the seven participants who were not decisional, four were completely nonverbal and thus their surrogate was interviewed on their behalf.

Qualitative Themes

Analysis of abstracted medical records and interview transcripts revealed two overarching themes that appeared to influence discontinuity: *Inadequate Communication* and *Prognosis Incongruence*. We defined *Inadequate Communication* as the factors that contributed to lack of information conveyed between the hospital and NH. We defined *Prognosis Incongruence* as discrepancies in documented prognosis between the hospital PCC team and the NH admission notes or differing views about the patient's prognosis among the patient/

surrogate, PCC team, and NH staff. *Inadequate Communication* and *Prognosis Incongruence* contributed to mismatches between staff and family caregiver expectations; inappropriate use of the Skilled Nursing Facility (SNF) benefit; and a focus on rehabilitation and the perception that an illness was going to improve.

Inadequate Communication was characterized by the lack of information that was shared about the PCC recommendations and care preferences upon NH admission. Of three opportunities to capture information (PCC note, hospital discharge summary, and NH admission note) there was little information about the PCC found in the medical record. First, the written PCC notes were in only three of the 12 medical records that accompanied the patient to the NH. Second, nine of the hospital discharge summaries mentioned that palliative care had been consulted during the hospitalization but none elaborated on the content or outcomes of the PCC. Instead the summaries included cursory statements such as “palliative care was consulted,” “hospice and palliative care were offered,” “Consultation: Palliative Care,” and “palliative care has discussed goals of care.” Specific details such as care-planning discussions; values or goals to inform plans for future care; recommendations for symptom management; and hospice referral were not included. Third, only three admission notes from the NH medical staff indicated that palliative care was involved during hospitalization. Of these three patients; two were admitted on “comfort measures only” with “do not hospitalize” medical orders and the surrogates expected them to die at the NH. The third patient’s NH medical record stated, “He is now on palliative care...decreased appetite, will eat what he can tolerate now that he is more comfort care.” However during the interview with this patient’s surrogate, the surrogate clarified that while the patient did have a Do Not Resuscitate (DNR) order placed after the hospital PCC, he was not on “comfort care” and his care preferences included the use of intravenous fluids, antibiotics, and hospitalization “Because when I—I filled out the form. And I know when I signed for it, I did sign for my father to be treated. DNR does not mean Do Not Treat.”

Data from interviews highlighted and expanded on the lack of information that was communicated among the PCC team, other hospital clinicians, and the NH. When asked about follow up meetings after NH readmission to discuss goals of care and treatment preferences, the surrogate of a participant who also was a long-term resident of the NH replied, “We haven’t met, except for one time. There’s been no meeting over here about care plan or nothin’.” Another surrogate of a patient with recurrent aspiration pneumonia replied, “Not really, no. I’m just sort of making those decisions, you know, based on the little—I – I know she doesn’t want to be a vegetable.”

Prognosis Incongruence was a discrepancy in documented prognosis between the PCC team and the NH admission notes or differing views about the patient’s prognosis among the patient/surrogate, PCC team, and NH staff. The PCC team documented a poor prognosis for 11 patients, whereas the NH admission notes documented a poor prognosis for only one patient. In contrast, the NH staff recorded a fair or good prognosis and rehabilitation potential for eight patients.

Patients and families reported a more positive outlook on prognosis than what was reflected in the PCC notes. During interviews, patients and families talked about their goals for NH

care which included “to get better,” “to get more independent,” and “to get out, to get home.” When asked about what her father with end-stage cardiac disease needed to feel comfortable in the NH, a daughter responded, “He wants his independence back. That’s what he’s striving for, is to regain his strength so that he can be more independent.” He died in the hospital less than two weeks later. One participant was a long term care patient readmitted to the NH with newly diagnosed advanced metastatic cancer and dependent in all activities of daily living. When asked how she wanted to spend her time in the coming days, she responded, “Feeling, uh, that I—that I am able to do for myself.” Within ten days she was rehospitalized with uncontrolled symptoms and transferred to an inpatient hospice unit where she died.

While experiences varied for participants, all 12 were admitted under the Medicare SNF benefit, which included physical, occupational, and/or speech therapy; care for a feeding tube placed in the hospital; wound care; and intravenous antibiotics. The focus on rehabilitation was not congruent with the overall poor medical prognosis.

Case Illustrations

Two particular cases illustrate how Inadequate Communication and Prognosis Incongruence affected the care of participants. We present these exemplars below.

Case 1—Mr. X. was a 62 year old nonverbal long-term care NH resident with a history of multiple cerebrovascular accidents, multi-morbidity, and dependent for all activities of daily living. He received nutrition and medications via a percutaneous endoscopic gastrostomy tube. Mr. X was admitted to the hospital for aspiration pneumonitis and encephalopathy and stayed one week. He was referred to the PCC team, who discussed his poor prognosis, which was complicated by recurrent tube feeding aspiration and a non-healing wound, with his wife and children. The team recommended palliative interventions to reduce aspiration risk (e.g., hold/reduce tube feeding, dietary consult). The hospital discharge summary noted that the palliative care team met with the family and the family chose to continue all life sustaining treatments except cardiopulmonary resuscitation. Admitted under the Medicare SNF, Mr. X was given a “fair” prognosis and “fair” rehabilitation potential. There was no mention of the PCC in the NH admission note and the PCC note was not in the NH medical record. Occupational therapy was ordered five times/week. Within one week of the admission to the NH, Mr. X was re-hospitalized for aspiration pneumonia. During the rehospitalization, the clinical team discussed inpatient hospice care; however, the family declined these services stating, “It’s a bit too soon to be thinkin’ about that”. He was again readmitted to the NH under the SNF benefit. Mr. X’s surrogate reported her understanding of his condition, “They [hospital clinicians] want to give him more of his feed because he has a bad wound on his bottom. And they said he needs nutrition to heal. But if they pump it up, he’s gonna aspirate it, so it’s like— where do you go?” Two weeks later he was rehospitalized a third time when nursing staff had noted several days duration of “grimacing”, “moaning”, “emesis”, and “coughing tube feeding”. He was subsequently transferred in an inpatient hospice unit where he died.

Case 2—Ms. Y was an alert and oriented 72 year old woman with morbid obesity and degenerative joint disease hospitalized with an elevated white blood count and several months duration of vaginal bleeding. She was diagnosed with advanced uterine cancer and pulmonary metastasis during her six-day hospitalization. Ms. Y was a resident of the NH for two years prior to hospitalization and had been fairly independent in activities of daily living needing only assistance occasionally. During hospitalization, her hospitalist consulted the palliative care team for symptom management and a goals of care discussion. During her evaluation, the team documented she was “not having pain, shortness of breath, dysuria, or other uncontrolled symptoms” and she was not using any medications for pain, nausea, or other symptoms. She expressed a desire to pursue more diagnostic testing and a preference for all life sustaining treatments except intubation. After being told by the medical oncologist “there was wasn’t much they could do” for the malignancy, she stated she would follow up with the gynecologic oncologist and would “do whatever she could.” She received two follow-up visits from the team social worker and pastoral care for support and illness coping. The hospital discharge summary and the NH admission notes did not include any information about the PCC. The initial PCC note was located on the NH chart on admission. The NH staff documented a “poor” prognosis and “poor” rehabilitation potential however Ms. Y was admitted under the SNF benefit with physical and occupational therapy ordered five times a week. Within a few days of NH readmission, she was unable to take part in therapy and was experiencing “discomfort, poor intake, nausea with emesis”, and was “unable to stand.” Ms. Y said, “Breathing’s been a little harder” and “I just felt very bad with the throwing up.” After being transferred to the emergency department for evaluation, Ms. Y was admitted to a hospice inpatient unit where she died four days later.

Discussion

The purpose of this study was to describe factors that influenced discontinuity between a hospital PCC and NH care and explore the potential consequences of this discontinuity. Our findings suggest that poor communication and discrepancy in documented prognosis between the PCC team and the NH admission notes as well as differing views about prognosis between care settings, providers, and patient/surrogates contribute to mismatches between staff and family caregiver expectations; inappropriate use of the SNF benefit; and a focus on rehabilitation and the perception that an illness would improve.

There are many areas of breakdown in communication in this study that can be attributed to the clinicians in both settings, and patient or surrogate misunderstanding or reluctance to accept a poor prognosis. Regardless, study findings are consistent with the widely recognized problems associated with “handoffs” across healthcare settings, including transfers between hospitals and NHs.³² Missing, inaccurate, and conflicting information from hospital discharge records can lead to serious delays in patient care, including pain management and rehospitalization.³³

Many participants in our study were rehospitalized or were transferred to the emergency department. Consistent with previous research, our study showed that burdensome transitions are common in the SNF population and cognitively impaired nursing home patients at the end of life.^{23,24} Hospitalizations expose frail older adults to several risks

including burdensome treatments, pressure ulcers, higher mortality, and poorer end-of-life outcomes.^{24,25}

Our findings are similar to those of Miller et al, who reported that the absence of substantive documentation regarding the PCC in the hospital discharge summary is concerning.²⁶ Without proper goals of care information (e.g., a progress note reflecting who is making decisions, patient/surrogate illness understanding, topics discussed) at NH admission, the staff may be left to speculate about values and preferences that inform goals, treatment plans, and portable medical orders for life sustaining treatment (e.g. POLST). Poor communication about care preferences may also lead to miscommunication with families and possible errors.

Despite more widespread adoption of the POLST paradigm in recent years, these forms are limited in scope. While all study participants had a POLST form completed according to state law, the POLST orders only focused on CPR, intubation, and invasive/non-invasive ventilation (table 1) Researchers corroborate our findings and report that when transferring from the hospital to a NH, the POLST orders often document only code status.²⁷ Additionally, POLST forms do not include a provision for the detailed discussion that is essential during goals of care conversations.

Clear explanations about prognosis and assessment of the patient's and family's understanding of the illness trajectory is critical to delivering high quality, person- and family-centered end-of-life care. Previous research demonstrates that patients with advanced disease regularly report expectations for survival that are quite different from their healthcare providers.²⁸ Prognosis incongruence may lead to mixed messages and result in confusion and discontinuity regarding goals and treatment preferences.

In this study, the SNF benefit supported some patients' goals to improve an overall condition, despite a poor medical prognosis. Hope for functional improvement is supported by interventions that are delivered along with the SNF benefit. Words and phrases used by participants and surrogates when discussing goals, including "stronger," "better," and "more independent," support this notion. Concern arises in these situations because functional improvement is often not realistic due to continued progression of an underlying serious illness. In these situations and at times of uncertainty, "time-limited trials" (e.g. the use of certain treatments or therapies over a specified time and decisions to continue are based on progress) would encourage revisiting goals frequently with plans to pursue less aggressive care when indicated.²⁹

Our findings suggest several areas for future work. Most pressing is the need to conduct research focused on the best way to identify goals of care and achieve symptom management for older adults with serious illness after admission to a SNF. Future research should focus on developing and testing palliative care delivery models for traditional Medicare SNF beneficiaries. Understanding the long-term outcomes of PCC for those who do not elect or qualify for hospice care is needed. Additional work should investigate how well PCC teams and nursing facilities are readdressing care preferences throughout patients' illness trajectory to ensure concordance between preferences and delivery of care. Our

results also highlight the need for initial and ongoing communication and care coordination between PCC teams and NH clinicians to enable access to appropriate services at the EOL. Future studies should examine effective communication processes to coordinate and maintain continuity of care between the PCC team, NH/SNF team.

Study Limitations

Our findings should be interpreted with an understanding of the study limitations. First, the sample was small and described care at only one community hospital and one NH. However, the purpose of this study was to conduct an in-depth analysis rather than a broad survey approach to the issue. Also, the nursing staff was not interviewed or observed during this study, and thus it is unknown how much verbal communication occurred during nursing report from the hospital to NH (e.g., informal conversations between nursing staff and patients/patients or surrogates). Relying on medical records leaves many questions related to absent documentation. For example, was everything done for the patient actually recorded in the medical record? Future research should gather information from staff members to offset these limitations and observe actual conversations between staff, family, and patients.

Clinical Implications

Our analysis highlights the need for better continuity of palliative care between hospitals and NHs and an increased provision of palliative care services in NHs. First, discussion and documentation of goals, values, and care preferences needs to occur in each setting and more importantly be communicated across settings. Second, patients in nursing facilities and their family members need ongoing disease and prognostic information to better make health care decisions. Third, careful examination of why patients with a poor prognosis and their families choose to focus on rehabilitation under the Medicare SNF benefit is critical to explore their illness understanding and determine goals for care. For older adults with serious illness, special attention must be paid to providing high-quality palliative care and advancing palliative care in NHs.

Acknowledgments

Dr. Carpenter was a 2011–2013 Archbold Scholar supported by the John A. Hartford Foundation's National Hartford Centers of Gerontological Nursing Excellence Award Program. This work was supported by National Institute of Nursing Research of the National Institutes of Health under Award Numbers T32NR013456 and F31NR014608.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The funding organization had no role in the design and conduct of the study or in the preparation, review, or approval of the manuscript.

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Figure 1.
Enrollment Schema

Table 1

Patient Characteristics

Age, years (range 62–95)	80.9
Gender	
Male (<i>n</i> = 3)	25%
Female (<i>n</i> = 9)	75%
Race	
African American (<i>n</i> = 3)	25%
White (<i>n</i> = 9)	75%
Decisional status	
Makes own decisions (<i>n</i> = 5)	41.7%
SURROGATE* makes decisions (<i>n</i> = 7)	58.3%
Spouse (<i>n</i> = 2)	28.6%
Adult child (<i>n</i> = 3)	42.8%
Extended family member (<i>n</i> = 2)	28.6%
Treatments	
Tube feeding (<i>n</i> = 4)	33.3%
Dialysis (<i>n</i> = 1)	–
Treatment preferences (#MOLST form)	
Attempt CPR (<i>n</i> = 4)	33.3%
No CPR, prevent arrest with intubation (<i>n</i> = 1)	–
No CPR, prevent arrest only with non-invasive ventilation (<i>n</i> = 1)	–
No CPR, palliative and supportive care (<i>n</i> = 6)	50%
Diagnoses	
Advanced cancer (<i>n</i> = 4)	33.3%
End stage cardiac, pulmonary, and/or renal disease (<i>n</i> = 4)	33.3%
Neurological disease with dysphagia (<i>n</i> = 4)	33.3%

* SURROGATE: legally authorized representative;

MOLST (Medical Orders for Life Sustaining Treatments); MOLST = POLST in specific states such as New York and Maryland

Table 2

Recommendations for Clinical Practice.

Problem	Actionable Solution
Palliative care team not direct enough communicating consultation recommendations to patient, family, and/or primary team.	Reduce ambiguity by using strong, clear language in written and verbal communication.
Hospital palliative care notes not transferring	Increase NH staff access to hospital electronic medical record; provide a verbal handoff between clinicians.
Discharge summaries lacking PCC information	Emphasize content of palliative care consult and goals of care in a discharge summary for a patient being discharged to a nursing home.
Inconsistent messaging regarding poor prognosis	Ensure primary team and patient and surrogate understand prognosis during/after consultation.
NH focus on rehabilitation at the end of life	Explain limited benefit of intense physical rehabilitation at the end of life; discuss burdens of treatments in light of limited benefit; provide follow-up palliative care in NH after care setting transition (e.g. via phone or in person).