



Contents lists available at ScienceDirect

Geriatric Nursing

journal homepage: www.gnjournal.com

Feature Article

Nursing home care trajectories for older adults following in-hospital palliative care consultation

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ARTICLE INFO

Article history:

Received 5 January 2017
 Received in revised form
 22 March 2017
 Accepted 23 March 2017
 Available online xxx

Keywords:

Palliative care
 Hospitalization
 Nursing homes
 Skilled nursing facilities
 Patient care planning
 Patient discharge

ABSTRACT

Palliative care consultation (PCC) during hospitalization is increasingly common for older adults with life-limiting illness discharged to nursing homes. The objective of this qualitative descriptive study was to describe the care trajectories and experiences of older adults admitted to a nursing home following a PCC during hospitalization. Twelve English-speaking adults, mean age 80 years, who received a hospital PCC and discharge to a nursing home without hospice. Data were collected from medical records at five time points from hospital discharge to 100 days after nursing home admission and care trajectories were mapped. Interviews ($n = 15$) with participants and surrogates were combined with each participant's medical record data. Content analysis was employed on the combined dataset. All PCC referrals were for goals of care conversations during which the PCC team discussed poor prognosis. All participants were admitted to a nursing home under the Medicare skilled nursing facility benefit. Seven were rehospitalized; six of the 12 died within 6 weeks of initial nursing home admission. The two care trajectories were *Focus on Rehabilitative Care* and *Comfort Care Continuity*. There was a heavy emphasis on recovering functional status through rehabilitation and skilled nursing care, despite considerable symptom burden and poor prognosis. Regardless of PCC with recommendations for palliative interventions, frail older adults with limited life expectancy and their family caregivers often perceive that rehabilitation will improve physical function. This perception may contribute to inappropriate, ineffective care. More emphasis is needed to coordinate care between PCC recommendations and post-acute care.

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Introduction

National attention to palliative care program development and research has focused primarily on hospital-based programs.^{1–4} However, many patients seen by hospital palliative care consultation (PCC) teams who survive to discharge will undergo a transition to another care setting—and in many cases, a nursing home.^{5–8} It is unclear whether hospital-initiated PCC recommendations are implemented after discharge because palliative care is not widely available in the nursing home setting.⁹

Challenges to delivering palliative care in nursing homes include frequent and burdensome care-setting transitions; inadequate staff

training accompanied by high turnover; and a work environment that focuses on task completion rather than individualized, resident-centered care.^{10–12} Consequences of these barriers include emphasis on aggressive rehabilitation through use of the Medicare skilled nursing facility (SNF) benefit and missed opportunities for symptom management.^{13–15}

Earlier research has identified common use of SNF care at the end of life (EOL); many nursing home residents are not appropriate candidates for rehabilitation due to their poor medical prognosis.¹⁶ Aragon et al found that almost one-third of Medicare decedents used the SNF benefit in the last six months of life, and that over 9% of these older adults died while on the benefit.¹⁷ Miller et al examined the use of the SNF benefit in the last three months of life among older adults with advanced terminal dementia and found that residents were less likely to receive hospice and more likely to die in the hospital—both are indicators of poor EOL care.¹⁸ Together, these studies offer a global picture of nursing home SNF benefit use

Conflict of Interest Declaration: No author has any declared conflict of interest.

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at the EOL, but do not describe the day-to-day care perceptions and experiences for older adults with serious illness and their families.

Few researchers have examined post-acute care following PCC; those that have examined nursing homes along with other healthcare settings.¹⁹ Yet palliative care organizations and the Institute of Medicine emphasize the need to promote palliative care coordination between settings.^{20,21} Closer, in-depth examination of transitions after PCC is needed to understand and guide the care for seriously ill older adults in nursing homes.

The purpose of this study was to describe the care trajectories, including indicators of quality care (e.g. advance-care planning, symptom management, psychosocial support, spiritual care, nursing, rehabilitation, and medical care), experiences, and care perceptions for patients discharged to a nursing home after receiving an inpatient PCC.

Methods

Setting and sample

Two settings in the mid-Atlantic United States were involved in the study: one hospital with a PCC team and one nursing home where most patients requiring post-acute or long-term care were referred. Most data were collected in the nursing home after hospital discharge.

Patients were eligible to participate if they were 60 years or older with a life expectancy more than seven days, spoke English, and received a PCC while hospitalized. If the potential participant lacked decision-making capacity (as determined by the PCC team) or could not participate in a 20-min interview, a designated surrogate was contacted for participation. Participants were recruited as soon as possible after receiving a PCC and a discharge plan that included the participating nursing home. To identify potential participants, the palliative care team census was reviewed daily for eligible participants. A research team member met with potential participants/surrogates after they expressed interest in the study to the PCC team, presented details about the study, and obtained signed informed consent. A university institutional review board approved this study as did the research review committees at the participating facilities.

Procedures

Study participants were enrolled and data were collected from January 2014 through December 2014. Semi-structured interviews took place in a private location using an interview guide that had been pilot tested (Table 1). The interviews were conducted with participants, their surrogates, or both (if the participant requested) one week and one month after nursing home admission. Interviews, which lasted 10–50 min, were audio recorded and professionally transcribed. Transcribed interviews were then compared to the audio recording to verify accuracy and note additional emotions that may not have been captured in the transcript (e.g., vocal strain and pitch associated with sadness, crying, or laughing).

A medical record audit tool was used to collect data at the hospital and nursing home at five time points: hospital discharge; nursing home admission; and seven, 30, and 100 days after nursing home admission. In the hospital medical record, participant demographics, medical diagnoses, medications, advance care planning discussions and documentation, and details of the hospital palliative plan of care were collected. The nursing home's medical records were then reviewed to determine pain and symptom assessment and ongoing management, interventions, and outcomes; and psychosocial and spiritual support. Other data collected from the nursing home record included information about advance

Table 1

Semi-structured interview guide.

Describe the type of care that you need to feel comfortable.
Can you give an example of a time when you received this kind of care here?
Is this the same care as in the hospital?
Can you talk more about this type of care?
Tell me about how the staff has talked to you about this type of care.
Tell me about what is most important to you.
How do you want to spend your time in the coming days?
How is this the same or different from now?
Can you talk about how you decided that?
Tell me about [insert symptoms noted in hospital palliative care consult and chart review].
So how is it going with those symptoms?
Are they better or worse than in the hospital [or last interview]?
How does the staff talk to you about [insert symptoms]?
What does the staff do for your [insert symptoms]?
How do you want the staff here to support your feelings [insert feelings of depression, anxiety, sadness referenced in the palliative care consult or chart] you have while you are here?
Can you give an example of a time when you felt supported in that way here?
Is there a time these things got in the way of having a good day?
Tell me about meetings or talks you have had with the staff here.
What did you tell them?
What did they ask you?
Is there anything else I have not asked that you think I should know?

care planning (including goals of care conversations, family meetings, and general care planning discussions), and the nursing, medical, and rehabilitation care delivered (including hospitalization and emergency department visits).

Analysis

All data were entered and managed in NVivo v9 (QSR International, Burlington, MA). Using analytic approaches described by Saldana, In Vivo and Descriptive First Cycle coding were applied to the interview transcripts and medical record data.²² During this foundational approach, the first author assigned data direct and simple codes. During Second Cycle coding Pattern Coding was employed to examine commonalities, explain similarly coded data, and to guide the development of themes through use of matrices.²³ Integrating both interview and medical record data, detailed care trajectory matrices were constructed using graphical representations of the care that participants received from days 1–100, including symptom assessment and management, primary care provider visits, emergency department visits, hospitalization, and discharge. Coded interview responses were also entered into a data summary table to examine participant and/or surrogate perceptions of symptom management, adherence to goals of care, and psychosocial support. This organization of data allowed for further examination of data subsets and the development of care trajectories.

Several strategies were used to reduce bias, enhance credibility, reliability, and transferability. Interview and medical record data provided methodological triangulation.²⁴ A study diary comprised of memos, field notes, reflections, and detailed descriptions of analytic and coding decisions was maintained during data collection and analysis.²⁵ A codebook was developed identifying codes, definitions, and examples to establish interrater reliability and consistency.²⁶ Interrater reliability was established by the second author independently coding data using the coding scheme. The two coders reached 95% consensus after discussing and resolving coding differences.

Results

Thirty-seven eligible participants were approached to participate in the study; of those, 23 declined. Two were ineligible due to

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