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## Nursing Home Care Trajectories for Older Adults Following In-Hospital Palliative Care Consultation

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### Abstract

**Objective**—Palliative care consultation (PCC) during hospitalization is increasingly common for older adults with life-limiting illness discharged to nursing homes. The objective of this analysis was to describe the care trajectories and experiences of older adults admitted to a nursing home following a PCC during hospitalization.

**Design**—Qualitative descriptive.

**Setting/Participants**—Twelve English-speaking adults, mean age 80 years, who received a hospital PCC and discharge to a nursing home without hospice.

**Measurements**—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.

**Results**—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.

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**Conclusions**—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.

### Keywords

palliative care; hospitalization; nursing homes; skilled nursing facilities; patient care planning; patient discharge

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## Introduction

National attention to palliative care program development and research has focused primarily on hospital-based programs.<sup>1–4</sup> 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.<sup>5–8</sup> It is unclear whether hospital-initiated PCC recommendations are implemented after discharge because palliative care is not widely available in the nursing home setting.<sup>9</sup>

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.<sup>10–12</sup> 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.<sup>13–15</sup>

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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup> Together, these studies offer a global picture of nursing home SNF benefit use 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.<sup>19</sup> Yet palliative care organizations and the Institute of Medicine emphasize the need to promote palliative care coordination between settings.<sup>20,21</sup> 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-minute 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 to 50 minutes, 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 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.<sup>22</sup> 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.<sup>23</sup> 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.<sup>24</sup> A study diary comprised of memos, field notes, reflections, and detailed descriptions of analytic and coding decisions was maintained during data collection and analysis.<sup>25</sup> A codebook was developed identifying codes, definitions, and examples to establish interrater reliability and consistency.<sup>26</sup> 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 an unexpected change in hospital discharge location. Twelve participants were enrolled (Table 2).

Of the 12 participants, three were interviewed alone. Others were either interviewed with a family member present or were nonverbal and thus, only their surrogate participated in the interview. Medical record audits were completed a median of 4 times (range 2–5) for each patient from hospital discharge through 100 days after nursing home admission. Analysis included data collected from 50 medical record reviews and 15 interviews. All attrition (Table 3) was related to patient death in the nursing home (n = 3), patient death after rehospitalization (n = 3), discharge to a higher level of rehabilitative care (n = 1), or discharge home (n = 3).

Two unique care trajectories were identified: *Focus on Rehabilitative Care* and *Comfort Care Continuity*. Table 4 summarizes the trajectories.

### Focus on Rehabilitative Care

For ten of the 12 participants, the care trajectory focused on aggressive rehabilitation and interventions to improve the patient's overall condition and function, despite a poor medical prognosis during hospitalization. Health care utilization was high; most participants were rehospitalized once, and one was rehospitalized twice. Participants were visited at least once by nursing home medical staff to address symptoms or manage a change in medical status; one was seen nine times. All had medical orders for rehabilitative therapy. Several received

intravenous antibiotics and/or complicated wound care, even though improvement was unlikely per hospital and PCC notes. Four of the 10 participants died within six weeks of the nursing home admission date. At 100 days after admission, two were in long term care, three had been discharged home, and one had been discharged to another rehabilitation facility.

Most patients receiving rehabilitative care expressed that the goal was to improve their physical function and be independent, even though the hospital PCC team indicated all had a poor prognosis. In the end, three of the ten participants were able to assume greater independence for self-care during rehabilitation.

For three participants who did not have decisional capacity, the hospital PCC recommendations and the patients' previously stated goals were not congruent with the surrogate decision makers' goals. Surrogates stated they were unwilling to accept the poor prognosis and make decisions consistent with patient's expressed care preferences. All three of these patients had gastrostomy feeding tubes, a treatment that was incongruent with previously expressed preferences. In one case, a participant stated that his goal was to not have a feeding tube and to go home, "*before I die. I just see my life as gone.*" Although these remarks were made with the surrogate present, the medical orders reflected aggressive care, including CPR and mechanical ventilation.

Symptom burden was high in this group; pain (10 participants), shortness of breath (six participants), nausea and vomiting (seven participants), and complications associated with dysphagia (seven participants) were most common. Some surrogates expressed concern about the nursing homes ability to manage symptoms. One reported, "*They get worse here. That's why he [sic] sent down to the hospital. Um, most of the time, this is where it starts—and then, he gets sent to the hospital. They patch him up a quick fix and send him back here.*" Psychosocial signs and symptoms such as anxiety, depression, and agitated behaviors were treated, but with medications only. Some participants and surrogates did not feel supported by staff noting the task oriented approach to care, "*They'll—they'll come in, do whatever they're supposed to, and run out.*" When the surrogate of a nonverbal participant was asked about how staff handle agitation, she reported, "*I don't think they help him with that. Um, I really don't think they help him with it.*" Although eight participants saw a chaplain in the hospital, there was no documented spiritual support delivered at the nursing home.

For participants receiving care focused on rehabilitation, reevaluation of this goal did not appear to occur in the nursing home. Hospice was only offered once (and declined) at nursing home discharge. The hospital PCC team discussed hospice with seven of the participants or surrogates. One said, "*It's a bit too soon to be thinkin' about that, I'm gonna just wait and see what happens, and then—you know.*" Others did not want to consider hospice at all. In the words of one surrogate: "*Hospice came by once. During hospitalization. I said, 'Please. Do not use that word.'*" Another patient who was offered inpatient hospice by the PCC team for symptom management responded, "*I'm ready to fight*", indicating her goal for aggressive life sustaining care as opposed to her perception of hospice, "*to lie there and die.*"

### Comfort Care Continuity

For two of the 12 participants, their care trajectory reflected a focus on comfort; these patients were admitted to the nursing home under “*comfort measures only*.” Advance-care planning documentation reflected desire for natural death and palliative or supportive care only. Consistency among the PCC, surrogate decision makers, and nursing and medical staff at the nursing home was noted in the interviews and medical records. Goals were discussed for “*being as comfortable as possible*.” “*Do not hospitalize*” orders were documented in the nursing home medical record. Both participants died after the nursing home admission without experiencing rehospitalization or emergency department visits. Hospice care was recommended but not used because both patients received care under the Medicare SNF benefit.

These participants received between one and three nursing home medical staff visits in the nursing home (on admission and for symptom management only). Nursing care focused on pleasure feedings, bowel care, and pain management. No spiritual support was noted in the medical record or reported in interviews.

Despite the focus on comfort, these participants received occupational and speech therapy evaluations. When discussing speech therapy, a surrogate reported, “*They actually tried speech therapy, but to help her swallow is more or less—it really—it wasn’t doing anything so. And that’s when they decided to adjust the diet.*”

### Discussion

This report describes the care trajectories for older adults admitted to a nursing home following in-hospital PCC during which goals of care were discussed in the context of universally poor prognoses. Despite the poor rehabilitation potential, all participants were admitted to a nursing home under the Medicare SNF benefit. The findings are consistent with analyses of large data sets associating SNF benefit use at the EOL.<sup>17, 18</sup> However, these results offer a new and rich in depth description and extend the foundation of research related to the continuity of PCC after hospitalization. Two distinct trajectories were identified that were informed by varying and complex individual experiences: *Focus on Rehabilitative Care* and *Comfort Care Continuity*. Most older adults’ trajectory followed the *Focus on Rehabilitative Care* in which care concentrated on life-prolonging treatments, either not recommended by the PCC team or not aligned with patient’s previously stated goals. High symptom burden and high healthcare use was noted. In only two cases did the post-acute care trajectory follow *Comfort Care Continuity*; these participants’ experienced minimal symptoms and no hospital transfers. The findings highlight the need to improve post-acute care and palliative care coordination following hospitalization.

First, all participants received the SNF benefit regardless of PCC recommendations or patients’ goals of care. Use of the SNF benefit did support some patients’ and families’ goals who wanted to regain physical function and independence and return home. However, this goal was met in the minority of cases. This finding is consistent with previous research that suggests post-acute care for seriously ill older adults may not improve survival or promote

quality end-of-life care.<sup>17</sup> Instead, it may lead to multiple burdensome care setting transitions and inadequate symptom management.

Second, several residents and families appeared reluctant to acknowledge that deteriorating medical status and increased symptom burden indicated the need to prepare for end of life rather than focus on rehabilitative care. Moreover, goals of care generally were not renegotiated or discussed after nursing home admission. This finding supports the need for providing ongoing nursing home-based palliative care services. Recent research corroborate; nursing home PCCs result in less burdensome transitions (e.g. hospitalizations and emergency department visits) at the end of life.<sup>9</sup> Development of evidence-based nursing home palliative care practice guidelines is an additional step toward integrating palliative care principles into the structure and care processes in nursing homes.<sup>27</sup>

Third, some surrogate decision-makers chose care that was incongruent with the patient's stated preferences. Previous research indicates that when caring for seriously ill residents, nursing home staff often feel swayed by family caregivers' care preferences over nursing home residents previously stated preferences or values.<sup>28</sup> Thus, important components of nursing home-based palliative care should include education and support around substituted judgement (e.g. decision making should be consistent with what the resident would want if he/she could speak for himself/herself). Efforts should focus on how to best communicate with surrogates and guide them in their ethical and legal responsibilities to use substituted judgement to act in accordance with the resident's previously expressed care preferences. This recommendation is reinforced by earlier research showing that higher palliative care knowledge and practice among nursing home staff are associated with better outcomes at the end-of-life.<sup>10</sup>

Finally, it is important to note that in the few cases in which the care trajectory focused on comfort, symptoms were minimal or well managed and rehospitalization did not occur. This trajectory reflects consistent follow-through of in-hospital PCC recommendations post discharge and an example of care coordination between settings. It underscores the importance of transitional care. Prior research demonstrates that patients admitted to a nursing home with strong organizational structure (e.g. tools to assess needs, access to community resources) and staff communication skills (e.g. family meetings, medication/treatment teaching) experience better transitional care.<sup>29</sup>

These findings suggest several areas for future work. Most pressing are to change policies that prevent residents who use the SNF benefit to simultaneously use the Medicare hospice benefit. Traditional Medicare is currently structured to promote use of the SNF benefit for postacute care because the facility receives a higher level of reimbursement. The benefit's payment structure favors rehabilitative or restorative care over comfort-focused care. Only in rare cases, when the diagnosis for hospice care is not related to the diagnosis for SNF care, can a resident qualify for both benefits. Few palliative care resources exist for those who do not qualify for or who do not desire hospice care but who need additional EOL services in nursing facilities; there is a great need for community palliative care services.

All-payer models have transformed the payment for hospital services from fee-for-service to overall population-based expenditures.<sup>30</sup> The goal is to improve health care quality and care experience, while reducing costs through improved care coordination and prevention. Collaboration among health care agencies (e.g. hospital, nursing homes) is essential for success. Moving palliative care teams into the community is a creative and innovative way for hospitals to improve transitions, reduce costs through preventing readmissions, provide high-quality EOL care, and improve the care experience for seriously ill older adults. A pragmatic pilot study of PCC team(s) in nursing facilities would be useful to further support the case for expanding resources.

This study is limited in that all data collection occurred at one hospital and one nursing home and thus findings may not be generalizable. However, these findings are consistent with earlier reports that SNF care is common for older adults at the end of life and is associated with multiple care transitions and infrequent hospice use.<sup>17,18</sup> It is also possible that important information regarding ongoing goals of care discussions and comfort-focused interventions were not recorded in the medical record, thereby resulting in an incomplete picture of the care trajectories. Future research should include staff interviews and observation to provide additional data to confirm findings, uncover data missed in medical record review, and describe their level of involvement in discussions and perceptions about residents EOL care.

## Conclusion

The findings of this study provide a foundation for research related to the continuity of palliative care from hospitals to nursing homes. During times of decision incongruence and medical decline, open honest communication about limited life expectancy presents an opportunity for continued palliative care interventions. Additionally, care-setting transitions pose significant barriers in the communication of care goals after PCC. Future research needs to identify the most appropriate ways to improve care coordination between settings and maintain continuity in order to provide that is more consistent with prognosis and individual preferences.

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**Table 1**

## Semi-structured Interview Guide

<p>Describe the type of care that you need to feel comfortable.</p> <p>Can you give an example of a time when you received this kind of care here?</p> <p>Is this the same care as in the hospital?</p> <p>Can you talk more about this type of care?</p> <p>Tell me about how the staff has talked to you about this type of care.</p> <hr/> <p>Tell me about what is most important to you.</p> <p>How do you want to spend your time in the coming days?</p> <p>How is this the same or different from now?</p> <p>Can you talk about how you decided that?</p> <hr/> <p>Tell me about [insert symptoms noted in hospital palliative care consult and chart review].</p> <p>So how is it going with those symptoms?</p> <p>Are they better or worse than in the hospital [or last interview]?</p> <p>How does the staff talk to you about [insert symptoms]?</p> <p>What does the staff do for your [insert symptoms]?</p> <hr/> <p>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?</p> <p>Can you give an example of a time when you felt supported in that way here?</p> <p>Is there a time these things got in the way of having a good day?</p> <hr/> <p>Tell me about meetings or talks you have had with the staff here.</p> <p>What did you tell them?</p> <p>What did they ask you?</p> <hr/> <p>Is there anything else I have not asked that you think I should know?</p>
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**Table 2**

## Sample Characteristics

Age, years (range 62–95) Mean = 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%
Decision 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%

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**Table 3**

Cases Included at Each Data Collection Point

Event	Hospital Discharge	Nursing Facility Admission	7 Days After Nursing Facility Admission	21–30 Days After Nursing Facility Admission	100 Days After Nursing Facility Admission
Medical record review completed (total = 50)	12	12	11 (discharged to another facility $n = 1$ )	8 (death $n = 3$ )	7 (death $n = 1$ )
Interview completed (total = 15)	N/A	N/A	8 (discharged to another facility $n = 1$ , death $n = 1$ , Surrogate* unavailable $n = 2$ )	7 (Surrogate unavailable $n = 2$ )	N/A

\* Surrogate (legally authorized representative).

**Table 4**

Summary of Trajectories

	Goals	Advance Care Plan	Symptom Burden	Rehabilitative & Skilled Care	Medical Care	Outcome
Comfort Care Continuity N=2	Comfort	Natural Death	Low	-Therapy Evaluation -OT	4 provider visits (range 1-3 each) No transfers	Death (N=2)
<b>Exemplar Quote</b>	"Keep her as comfortable as possible—we're trying to avoid sending her back to the hospital because it is—it's hard on her. No need to transport her back and forth to the hospital."					
Focus on Rehabilitative Care N=10	Aggressive interventions to <i>improve or maintain</i> condition	<ul style="list-style-type: none"> <li>• Various</li> <li>• Life Sustaining Treatment</li> <li>• Natural Death</li> <li>• Feeding tube despite advance directives or verbal directions opposing</li> </ul>	High	-PT/OT/ST -Wound care -Intravenous therapy -Feeding Tube	47 provider visits (range 1-9 each) 9 transfers	Death (N=4) Alive (N=3) Alive with feeding tube (N=3)
<b>Exemplar Quotes</b>	<p>"I've been [pause] the hospitalization where you saw my father was his tenth hospitalization since August 20th. Ten times he's been in the hospital."                      "I've had recently a lot of vomiting. I mean I've been throwin' [sic] up and been—vomiting a lot."                      "He needs a lot more therapy than he gets, but he's only entitled to certain amounts."</p>					