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Care transitions among Medicare beneficiaries at the end of life

By Susan E. Lowey, PhD, RN, CHPN

Mrs. K, age 72, is a widow who lives alone in a two-story home. She's recently been discharged after a 3-day hospitalization for worsening heart failure (HF). She's receiving home healthcare services for ongoing assessment of cardiopulmonary and functional status, for education about her medication and diet regimen, and for an evaluation of her home environment. This is her third hospitalization in the past 6 months and her second admission to home care.

During the home care admission visit, Mrs. K reports increasing fatigue and weakness over the past few weeks. She also says that she has to use her oxygen most of the time, not just when walking as in the past. Her son reports that she can no longer walk up the stairs and has been sleeping in the recliner since being discharged home. Mrs. K told the nurse that she no longer wants to go back and forth to the hospital and just wishes she could get "fixed up at home" instead.

In this case, the nurse is in an ideal position to further assess and implement a feasible and appropriate plan of care for this patient. Although each patient's situation differs, the nurse can use some key pieces of information to help minimize unnecessary care transitions for patients who may be nearing the end of life. This could improve the quality of patient care while helping to reduce costs.

This article incorporates findings from a national study that explored the care transitions of 110,218 Medicare beneficiaries during their last year of life.¹ Using a retrospective cohort design, Medicare administrative data were used to examine and compare health service use in the last year of life among older adults with HF, chronic obstructive pulmonary disease (COPD), and lung cancer.² Using a fictitious patient, Mrs. K, this

article explores pertinent issues faced by older adults living with end-stage diseases and their many care transitions as they near the end of life. It highlights the nurse's vital role of improving these patients' transitions by incorporating evidence-based findings into practice, by using a framework to help clarify patients' goals of care, and by advocating for needed policy changes for this population.

End-stage illnesses and transitions in care

Nearly 80% of older adults in the United States live with one or more chronic diseases, such as HF or COPD.² These patients have the highest rates of hospital readmissions and comprise a larger percentage of home care admissions than any other age group.³ As these illnesses become more advanced or end-stage, patients often live in a cycle of frequent transitions between care settings, particularly between the hospital and home healthcare. Repeated transitions between care settings can be costly, both in terms of finances and overall quality of life. Go and colleagues reported that HF alone contributed to 1.8 million healthcare provider office visits, 668,000 ED visits, and 293,000 outpatient department visits over the course of 1 year.⁴ The total cost of HF was estimated to be nearly \$30 billion and is projected to increase to \$70 billion by 2030.⁵

One contributing factor associated with the high cost of HF is the growing rate of rehospitalization among patients, particularly within 30 days of discharge. The Medicare Payment Advisory Commission reported a 17.6% readmission rate among Medicare beneficiaries, which cost taxpayers approximately \$12 billion. Based on its report, this commission recommended that Congress require mandatory reporting of risk-adjusted readmission rates among U.S. hospitals.⁶ This report also suggested that many readmissions could have been prevented.

Another study determined that the number of prior hospitalizations and worsening dyspnea levels were the strongest patient-related factors associated with 30-day readmissions among patients with HF.⁷ Improvements in both health and cost-related outcomes for vulnerable populations, such as older adults, have been identified as a national priority by the Institute of Medicine.⁸

A closer look at transitional care

Transitional care, also known as transitions in care, has been defined as a broad range of services aimed at providing continuity of care and preventing poor outcomes among high-risk patients during the transfer from one level or setting of care to another.⁹ Transitional care is a broad context of care under which individual components, such as dis-

charge planning and care coordination, are housed. Although similar to discharge planning and care coordination, the main focus of transitional care is facilitation of key strategies to prevent adverse patient outcomes, including avoidable rehospitalizations.⁹

Many patients with HF and COPD frequently transition between the hospital and home due to the chronic-exacerbating trajectory of their illness. Because these patients often require care from multiple clinicians across various care settings, they're more vulnerable to receiving fragmented care.⁹ Patients who live with an advanced disease associated with this type of trajectory should be evaluated for home care services, particularly if they live alone.

Despite an increased use of health services, many patients continue to live with unmet needs, including distress from inadequately managed symptoms.¹⁰ Because worsening dyspnea commonly associated with these end-stage illnesses is a strong predictor of rehospitalization, healthcare programs and services must focus on interventions that address the multiple needs of patients, including inadequately managed symptoms. Like Mrs. K, some patients with end-stage diseases may not want to experience repeated transitions in care.

In a study that examined the perspectives of patients who delayed seeking care for worsening symptoms, patients viewed the hospital as a symbol of getting worse; most reported that they'd do anything to avoid another hospitalization.¹¹ To better understand how to help improve care for these patients, nurses need a better understanding of the care transitions this population goes through.

Insights from the study

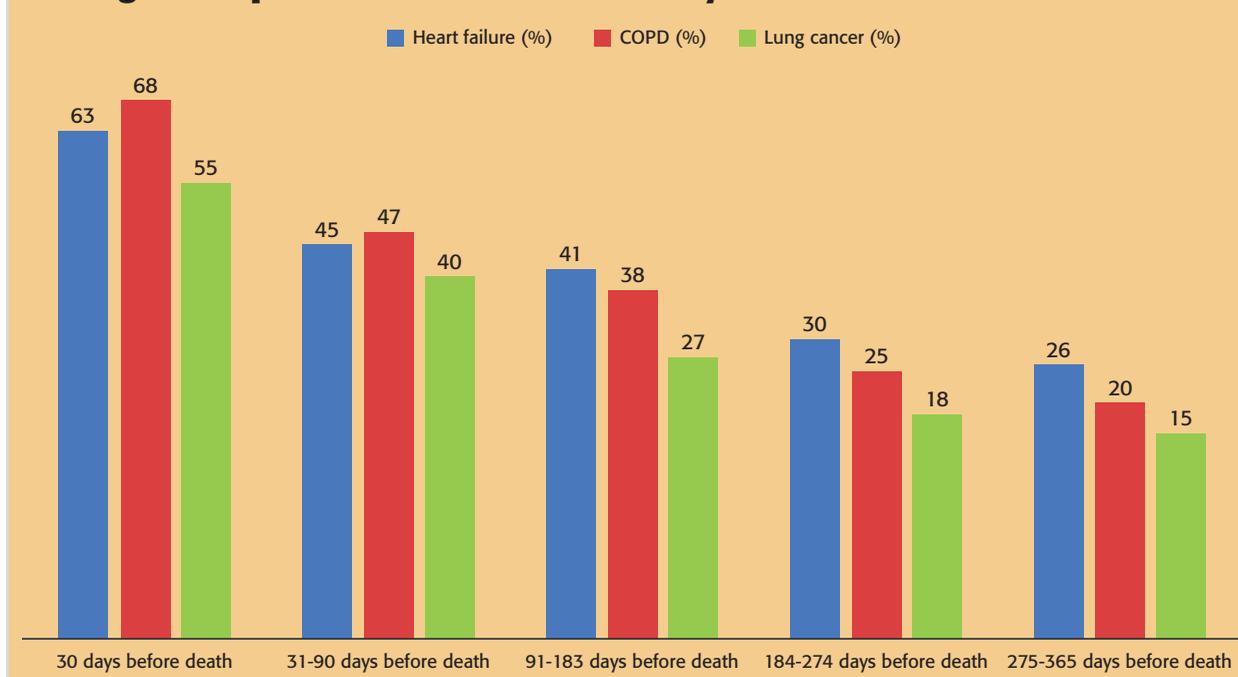
In a national study, the author and colleagues examined care transitions in the last year of life.¹ Institutional

Beneficiary demographics

	Diagnosis			Total
	HF	COPD	Lung cancer	
				110,218
Mean age at death	84 ± 9	79 ± 9	76 ± 8	80 ± 9
Male gender (%)	40.8	50.6	51.6	47.6
Ethnicity (%)				
Caucasian	86.6	89.5	87.4	87.8
African American	9.4	7.0	8.5	8.3
Other	3.9	3.5	4.1	3.8

Abbreviations: HF = heart failure, COPD = chronic obstructive pulmonary disease.

Timing of hospital transitions in the last year of life



review board approval was granted from the author's academic institution before the start of the study.

Research design. We conducted a secondary data analysis using a retrospective cross-sectional design with a cohort of Medicare decedents who died between January 1, 2009, and December 31, 2009, using data from the Centers for Medicare and Medicaid Services Chronic Conditions Data Warehouse (CCW). This approach was selected to examine care transitions with a nationally representative sample of patients during their last year of life. The care transitions of three cohorts of patients with HF, COPD, and lung cancer were examined. Beneficiaries with lung cancer were selected as the comparison group due to the similar symptom burden related to dyspnea and fatigue. Additionally, we examined three different types of transitions: from home to hospital, from hospital to home, and from home or hospital to hospice.

Study sample. Data files obtained from the CCW are organized by

predefined diagnostic cohorts of patients meeting specific chronic disease categories. We aimed to obtain data from three disease categories (HF, COPD, and lung cancer) and requested a 25% random sample be drawn from each diagnosis cohort. The CCW dataset created for our predefined cohort included a 1-year period preceding date of death from the beneficiary summary, hospice claims, and Medicare Part D files. Patients were eligible to be included in the study cohort if they met these eligibility criteria:

- age 65 or older
- a Medicare beneficiary with a date of death in 2009 obtained from the beneficiary annual summary (BAS) file
- enrollment in Medicare for 1 year or more
- main diagnosis flagged for COPD, HF, or lung cancer.

Variables and measures. The beneficiary summary and BAS files were used to obtain patient demographic information, including age, gender, ethnicity, date of death, and diagnosis. Hospital claims data were

derived from the Medicare Provider and Analysis Review (MedPAR) file that contains claims related to an inpatient hospital stay and includes diagnoses, procedures, dates of service, length of stay, and reimbursement amounts. Hospice claims data were derived from the hospice Standard Analytic File, which includes all hospice-related claims, including dates of service, level of hospice care, terminal diagnosis, and reimbursement amounts. Data management and analysis were performed using SPSS 20.0. Descriptive analyses were performed to describe beneficiary demographics and number of care transitions between various settings of care.

Results. The study population included 110,218 Medicare beneficiaries with HF, COPD, or lung cancer who died between January 1, 2009, and December 31, 2009. The mean age at death was 80 ± 9 , with nearly half (47%) of the sample over age 80 at entry (1 year before death) and over one-quarter (27%) of the sample over age 85 at entry. (See *Beneficiary demographics*.) The sample

was almost equally represented by females (52%) and males (48%) and was largely Caucasian (87.8%), followed by African American (8.3%), and other (3.8%).

Total transitions in care. During the last year of life, beneficiaries in this sample had a mean of 4.09 total transitions in care. Beneficiaries with HF had the most total transitions (mean = 4.39), followed by those with COPD (mean = 4.20), and lung cancer (mean = 3.69). Most beneficiaries had a range of 2 to 6 total transitions in care. These include the transition from home to the hospital, from the hospital back to home, and from home or hospital to hospice care.

Transitions to and from the hospital. The mean number of transitions between the home and hospital were similar among the three diagnosis groups, with an average of 1.79 transitions per beneficiary. Beneficiaries with COPD had slightly more home-to-hospital transitions than patients from the other two diagnostic cohorts (mean = 1.89, range,

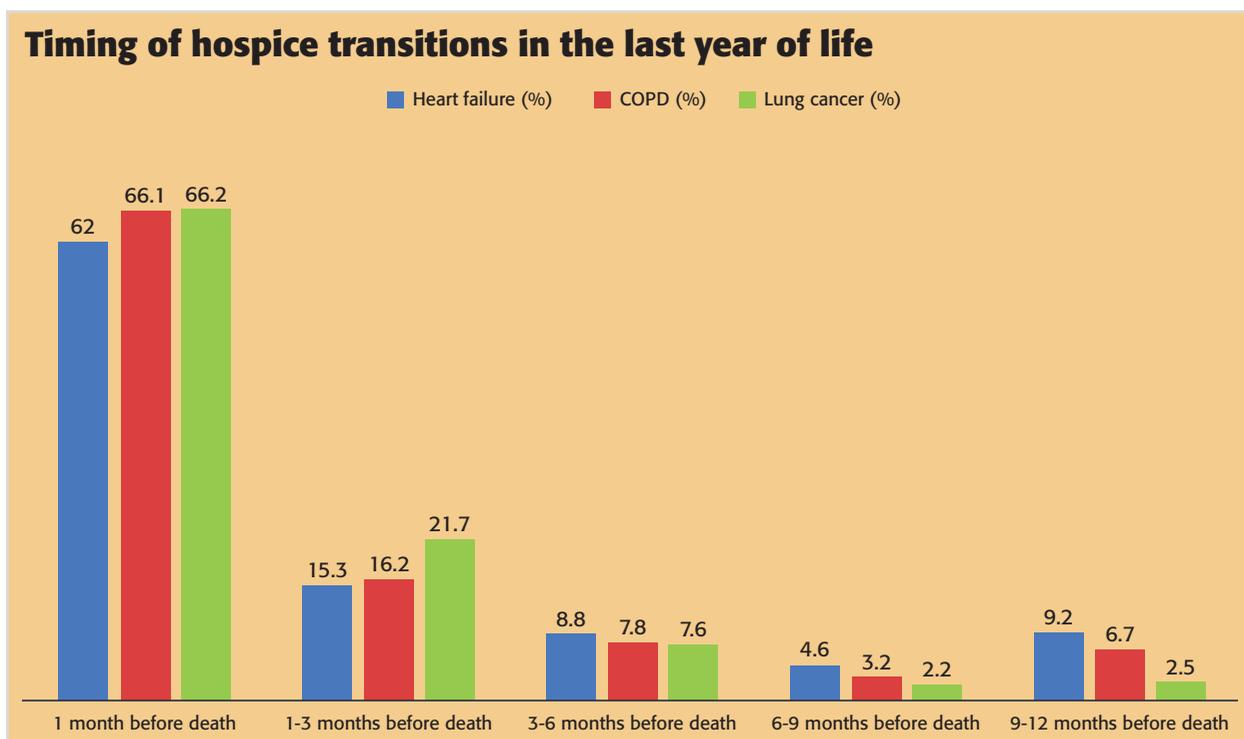
1-21). Similar findings occurred with the number of transitions from hospital to home. Among all beneficiaries who transitioned from home to the hospital, most also had an associated ED claim (mean = 1.33), 56% had an associated ICU claim, and 20% had an associated cardiac care unit (CCU) claim. Not surprisingly, over a quarter (28%) of beneficiaries with HF also had an associated CCU claim. The highest volume of transitions occurred in the 30 days before death, with a mean length of stay of 4.83 days. (See *Timing of hospital transitions in the last year of life.*) During the last month of life, 68% of beneficiaries with COPD had at least one transition from home to hospital, as did 63% of those with HF and 55% of those with lung cancer.

Transitions to hospice. Among all three diagnosis groups, about 41% transitioned to hospice care from either the hospital or home. Hospice was used by 42.0% of beneficiaries with HF, 40.8% of those with COPD, and 67.7% of those with lung cancer. Beneficiaries with

HF stayed on hospice care the longest, with a mean of 67 days, followed by those with COPD (54.8 days), and lung cancer (41.3 days). The transition to hospice from home or the hospital also occurred most frequently during the last month of life. (See *Timing of hospice transitions in the last year of life.*)

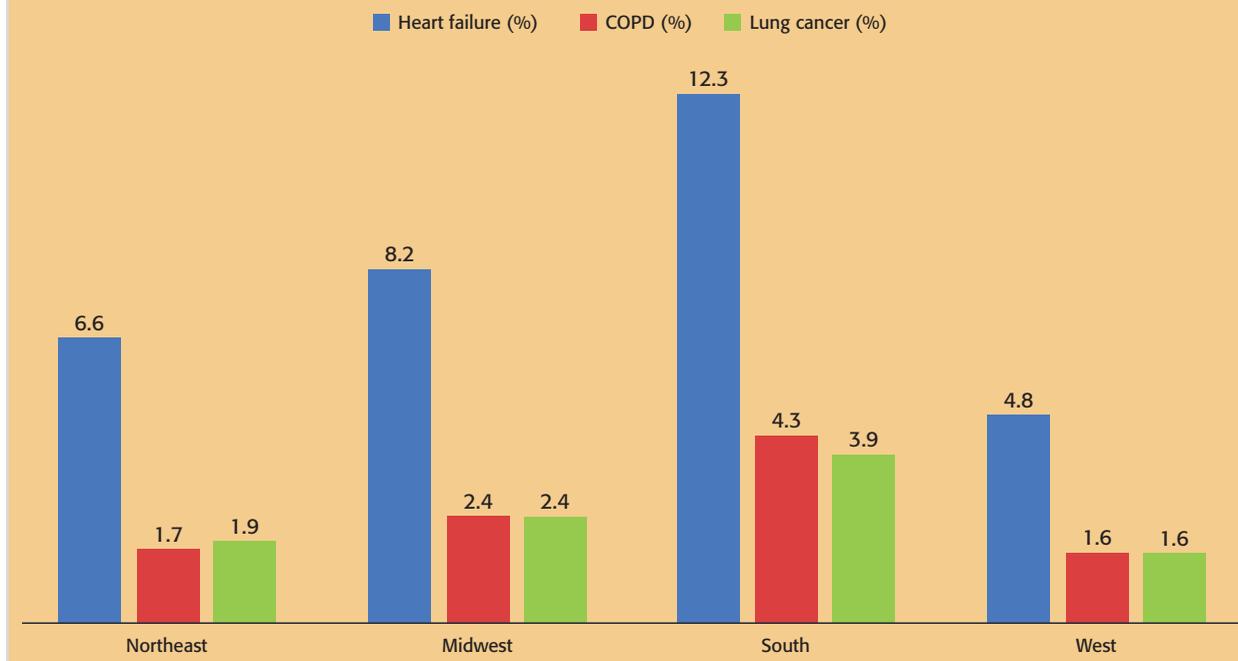
Regional differences in transitions. We examined the number of care transitions within four regions of the United States (Northeast, Midwest, South, and West). Across all three diagnosis groups, the most care transitions occurred in the South followed by the Midwest, Northeast, and West. (See *Geographic differences in care transitions.*) Among patients with HF, about 12.3% of care transitions occurred in the South, followed by patients with COPD (4.3%) and patients with lung cancer (3.9%).

Discussion. The findings from this study provide a nationally representative description of the care transitions that occur in the last year of life among older adults diagnosed with HF, COPD, or lung cancer. In



Geographic differences in care transitions

This figure represents the percentages of Medicare patients with HF, COPD, and lung cancer who had transitions between care settings over the course of 1 year.



the overall study sample, beneficiaries had an average of two to six total transitions between care settings during the last year of life. Previous research has suggested that some of these transitions could have been prevented, especially among patients whose transitions resulted from symptoms that were not well managed.⁷

Mrs. K seems to fall into the average frequency of care transitions among HF patients in this research study. Further assessment of her symptoms and current interventions are critical before developing the plan of care. What's precipitating her transition to the hospital and what can home healthcare professionals do to help minimize these readmissions? The nurse should obtain a thorough assessment of each symptom the patient reports, including both objective and subjective data, current interventions being used and their effectiveness, the patient's usual symptom level, and the goal the patient has for each symptom. The nurse can use this

information to develop a feasible plan of care for this patient.

After the assessment, if the nurse determines the patient has multiple complex symptoms that aren't being well managed, it may be appropriate to begin a conversation about introducing palliative care. An abundance of research over the past decade has demonstrated the efficacy of palliative care for patients with end-stage diseases.¹²

Palliative care is a broad philosophy of care defined by the World Health Organization as an approach that improves the quality of life of patients with life-limiting illnesses and their families through the prevention and relief of physical, psychosocial, and spiritual suffering.¹³ Palliative care programs have increased steadily over the past decade in U.S. hospitals and home healthcare agencies.¹⁴ Usually composed of physicians, nurse practitioners or physician assistants, nurses, and social workers, palliative care consultation teams evaluate patients

who have some type of need, such as symptom management, or assistance with decision making in light of a serious diagnosis. For patients whose symptoms are poorly managed, palliative care may improve their overall quality of life and enable them to remain at home.

Although most home healthcare agencies have a palliative care team, few patients with end-stage non-cancer illnesses are referred to palliative care.¹⁵ The reasons for this aren't well understood. This is an area where nurses can use their skills to help improve the care for patients with end-stage diseases.

Implications for nursing practice and policy

Nurses are in an ideal position to further assess and implement feasible and appropriate care plans for their patients. This can often be achieved through something as simple as using active listening skills when assessing a patient. In our case study,

Mrs. K told the nurse that she no longer wanted to go back to the hospital and would rather stay at home to have her heart failure managed. Once the nurse hears this important care preference from the patient, he or she should clarify what was said by restating the patient's response.

The nurse repeats to Mrs. K, "I understand that you'd prefer to stay at home to get fixed up rather than go back to the hospital for a stay. Did I understand you correctly?" Mrs. K responds to the nurse, "Yes, I'm tired of going back to the hospital. I'd prefer to have any care that I might need for the time I have left here at home." The nurse responds by telling Mrs. K about the palliative home care team. "We have a palliative home care team that helps manage patients' symptoms at home. The nurses are specialized in handling the complex needs of some patients with advanced diseases, such as your heart failure. They can help you to clarify your goals and wishes for care and implement a plan that meets your needs." Mrs. K says that palliative care sounds exactly like what she wants and she's happy that the nurse told her about this. Although each patient's situation will differ, the nurse can elicit the patient's goals for care and use that information to help minimize care



Nurses can help minimize unnecessary care transitions for patients nearing the end of life.

transitions and benefit both the quality of patient care and decrease costs.

During the hospital discharge process, home care or discharge

coordinators are the gatekeepers responsible for facilitating the home care referral process, including referrals to palliative home care. The standard of care that determines which home care team is chosen for a patient largely depends on the provider's diagnosis and referral.¹⁵ After understanding the patient's goals of care, the nurse can inform the patient's provider so that the patient can be placed on the appropriate home healthcare team.

Although it's part of the nurse's professional role to advocate for patients, some nurses may not be entirely comfortable talking to patients about end-of-life issues. Ask, listen, respond, and advocate (ALRA) is a framework that nurses might find helpful to remember because its individual components are well known by practicing nurses. (See *Nursing use of ALRA*.) Nurses commonly ask, listen, and respond as part of their assessment. Nurses must begin to better advocate for this population of patients because many aren't informed about palliative options for care and instead are caught up in the cycle of frequent transitions between care settings.

Health policy is defined as "a set course of action to obtain a desired health outcome for an individual, family, group, community, or society."¹⁶ Sometimes changes to existing health policy or the development of a brand-new health policy are needed to improve the quality of care for patients.

In the case of Mrs. K, the frequent transitions in care were not only financially costly but costly for her overall well-being. Once she said that she no longer wanted to go back and forth to the hospital, the nurse could use that information to develop an individualized plan of care for Mrs. K.

Difficulty occurs when the patient doesn't verbalize his or her wishes or concerns, or isn't asked about them during the admission or intake

Nursing use of ALRA

Ask

- about the goals patients want to achieve about their current health.
- whether patients would prefer to receive care that's comfort-oriented rather than curative.
- if patients would like more information about palliative care.

Listen

- to patients' needs and concerns.
- for words that may indicate a desire for improving comfort and quality of life.
- for words that may indicate a desire to decrease transitions between care settings.

Respond

- by clarifying what patients said.
- by asking for further information to understand the patients' goals of care.
- by telling patients that you're going to help facilitate their goals of care.

Advocate

- for patients whose symptoms aren't adequately managed with the current regimen.
- by talking to patients about their preferences for and goals of care.
- through interdisciplinary communication and individualized care planning.

process. With the increased use of standardized assessment questions with electronic medical records, some less experienced nurses may not go beyond asking about things that are in the documentation protocol.

Nurses are in an ideal position to advocate for improvements in healthcare for their patients. This includes understanding the importance of using current evidence for practice, individualizing the assessment for each patient to encompass his or her unique health scenario, and speaking up and advocating for changes needed within and outside of their organization. ■

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