ARIC Manuscript Proposal #2478

PC Reviewed: 12/9/14   **Status: <u>A</u>**   **Priority: <u>2</u>**
SC Reviewed: _____   **Status: _____**   **Priority: ____**

1.a.   Full Title: Do patterns of care preceding hospice predict length of hospice episode?

  b.   Abbreviated Title (Length 26 characters): Care trends prior to hospice

2.   Writing Group:
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I, the first author, confirm that all the coauthors have given their approval for this manuscript proposal. __BK__ **[please confirm with your initials electronically or in writing]**

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3.   Timeline: Completed September 2015

4. Rationale:

Hospice care has been associated with improved quality of life at the end of life.[1-5] Utilization of hospice services has increased over the last decade, and in 2011 almost half (44.6 percent) of all deaths among Medicare beneficiaries in the United States were under the care of hospice.[6] However, about one third of those beneficiaries do not enroll in hospice until the final week of life.[6,7] Up to 42 percent of families perceive the timing of hospice enrollment as late or too late, a perception that was more likely among the families of patients with a length of care of less than 4 weeks.[8] Hospice patients with a diagnosis of congestive heart failure, coronary artery disease, hypertension, or diabetes are more likely to have shorter hospice stays compared to those with other terminal diagnoses.[9-12] Delayed hospice use is associated with more unmet needs, higher reported concerns, and lower satisfaction.[13] To address his gap in the quality of end of life care, it is critical to examine factors associated with short hospice episodes.

The care setting both directly preceding and during hospice use has been associated with the length of hospice stay. Hospice patients with a hospital or emergency room as the preadmission setting were 50 percent more likely to experience a hospice stay of less than one week compared to those in outpatient or long term care settings.[14] Of hospice admissions occurring in the last three days of life, 40 percent were preceded by hospitalization with intensive care use.[7] Care settings preceding hospice use have also been associated with diagnosis, for example patients with heart failure were more frequently referred to hospice from hospitals and nursing facilities, compared with patients with advanced cancer.[10]

While this research suggests that utilization of specific health services preceding hospice use is associated with the length of hospice episode, no study has evaluated trends in the intensity of care leading up to the initial hospice episode. This study will identify patterns of care preceding hospice entry and examine the relationships with key patient characteristics (e.g., diagnosis) and subsequent hospice episode length. The ARIC data set is uniquely suited to this study given that cardiovascular disease is a risk factor for short hospice stays. The long-term goal of this research is to contribute evidence to inform policies and interventions that will prevent delays in appropriate hospice use and improve the quality of end of life care.

5. Main Hypothesis/Study Questions:

The conceptual model (Figure 1) illustrates the role of hospice in end of life care. Gaps in current knowledge that will be addressed by this study are indicated by the red arrows to and from patterns of care. Specifically, this study will evaluate the relationships between patterns of care, patient characteristics, and length of hospice episode

Figure 1: Hospice and Quality of Life Conceptual Model
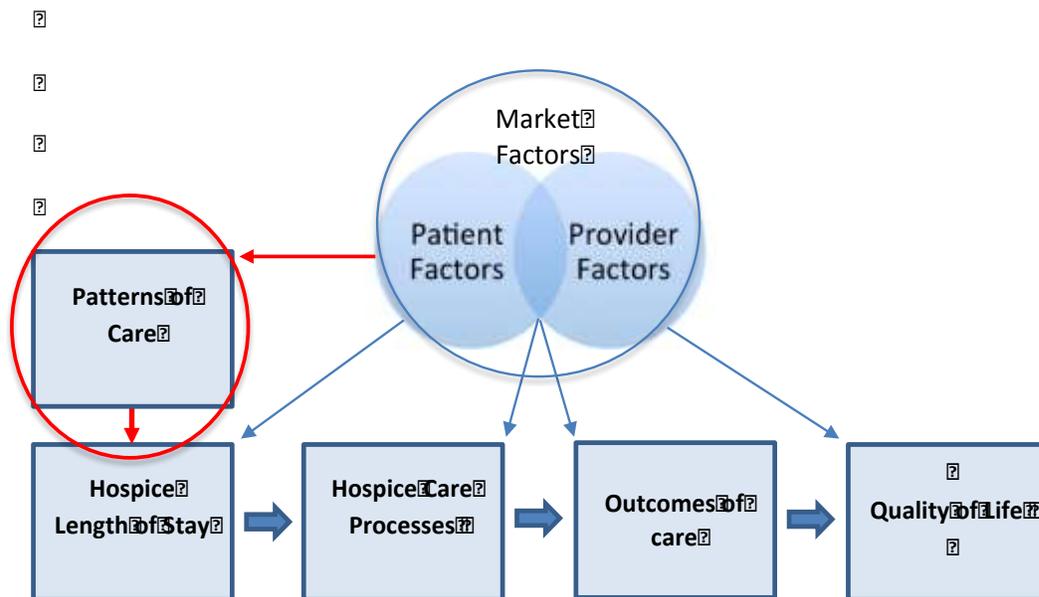
Aim 1: Identify patterns of care intensity over the180 days preceding hospice use. Tentatively, patient-level trends in weekly health service use preceding hospice episode will be described as increasing, declining, stable or variable intensity of care.

Aim 2: Explore associations between patient characteristics and patterns of care. We hypothesize that, controlling for other observed characteristics, patterns will differ by primary hospice diagnosis (e.g., cancer, dementia, heart failure, or other conditions), onset of this primary diagnosis, age, and geographic location.

Aim 3: Explore associations between patterns of care and length of episode. We hypothesize that, controlling for other observed characteristics, length of hospice episode (short versus long) will differ by patterns of care prior to hospice initiation.

6. Design and analysis (study design, inclusion/exclusion, outcome and other variables of interest with specific reference to the time of their collection, summary of data analysis, and any anticipated methodologic limitations or challenges if present).

The analysis will use ARIC cohort hospitalization surveillance, Annual Follow Up telephone interviews, and Medicare claims data. The study population includes all ARIC cohort participants that have utilized the Medicare hospice benefit between 2006 and 2012 (N=1,252). The period for assessing patterns of care consists of the 180 days prior to hospice utilization for each Medicare beneficiary in the ARIC cohort study who has used the hospice benefit at least one time. Patterns of hospital use can be constructed for all ARIC cohort members since ARIC tracks hospitalizations for all enrollees. Analysis of non-hospital services will be limited to FFS beneficiaries.

The primary outcome measure will be the length of hospice episode. As in prior hospice literature, short hospice episode is defined as <7 days prior to death. Long hospice episode is defined as >180 days. We will also assess rates of live discharge. Terminal diagnoses will be grouped into dementia, heart disease, cancer, and other diagnoses. Patient-level control factors include marital status, nursing home status, age, gender, race, and ARIC site.

Aim 1: Descriptive analysis of patterns of care over the 180 days prior to hospice use and the distribution of these patterns in the cohort sample. Tentatively, four patterns of care will be defined in this study: (1) Increasing intensity; (2) declining intensity; (3) stable intensity; or (4) variable and unpredictable intensity of care over time. Measures of intensity will include frequency and timing of events, including site of care (e.g., home, nursing home, hospital days), hospital admissions, intensive care unit days, skilled nursing days, observation stays, emergency room visits, specialist visit, primary care visits, and new diagnosis. We will define patterns of care based on the weekly trends in the intensity of health services use leading up to the hospice admission.

Aim 2: Regression analysis will be used to explore relationships between key patient characteristics and the four patterns of care defined in Aim 1 controlling for observed patient factors. Key independent variables include patient diagnosis, ARIC site, and age at hospice use.

$Pr\,(Y=j|x) = \text{ß}0 + \text{ß}1\;Diagnosis + \text{ß}2\;Onset + \text{ß}3\;Age + \text{ß}4\;Site + \text{ß}4\;Patient + \varepsilon$

Aim 3: Regression analysis will be used to explore associations between patterns of care and length of hospice episode, controlling for observed patient factors. The key independent variables are the four care patterns identified in Aim 1 and interactions with diagnosis groups.

$Pr\,(Y=j|x) = \text{ß}0 + \text{ß}1\;Care\;Patterns + \text{ß}2\;Care\;Patterns*Cancer + \text{ß}3\;Individual + \text{ß}4\;Site + \varepsilon$

This study builds on current knowledge about factors influencing the timing of hospice enrollment in the trajectory of care by examining patterns of care leading up to hospice use. If successful, this research will support the development of policies to maximize the benefits of hospice care and improve quality of life at the end of life.

7.a. Will the data be used for non-CVD analysis in this manuscript?   ____ Yes __x__ No

   b. If Yes, is the author aware that the file ICTDER03 must be used to exclude persons with a value RES_OTH = "CVD Research" for non-DNA analysis, and for DNA analysis RES_DNA = "CVD Research" would be used?   ____ Yes   ____ No
   (This file ICTDER has been distributed to ARIC PIs, and contains
   the responses to consent updates related to stored sample use for research.)

8.a. Will the DNA data be used in this manuscript?
      ____ Yes   __x__ No

8.b. If yes, is the author aware that either DNA data distributed by the Coordinating Center must be used, or the file ICTDER03 must be used to exclude those with value RES_DNA = "No use/storage DNA"?
      ____ Yes   ____ No

9. The lead author of this manuscript proposal has reviewed the list of existing ARIC Study manuscript proposals and has found no overlap between this proposal and previously approved manuscript proposals either published or still in active status. ARIC Investigators have access to the publications lists under the Study Members Area of the web site at: http://www.cscc.unc.edu/ARIC/search.php

      __x__ Yes   _____ No

10. What are the most related manuscript proposals in ARIC (authors are encouraged to contact lead authors of these proposals for comments on the new proposal or collaboration)?

11.a. Is this manuscript proposal associated with any ARIC ancillary studies or use any ancillary study data?   ____ Yes   __x__ No

11.b. If yes, is the proposal
      ___   **A. primarily the result of an ancillary study (list number* _____)**
      ___   **B. primarily based on ARIC data with ancillary data playing a minor role (usually control variables; list number(s)* _____ _____ _____)**

*ancillary studies are listed by number at http://www.cscc.unc.edu/aric/forms/

12a. Manuscript preparation is expected to be completed in one to three years. If a manuscript is not submitted for ARIC review at the end of the 3-years from the date of the approval, the manuscript proposal will expire.

12b. The NIH instituted a Public Access Policy in April, 2008 which ensures that the public has access to the published results of NIH funded research. It is **your responsibility to upload manuscripts to PUBMED Central** whenever the journal does not and be in compliance with this policy. Four files about the public access policy from http://publicaccess.nih.gov/ are posted in http://www.cscc.unc.edu/aric/index.php, under Publications, Policies & Forms. http://publicaccess.nih.gov/submit_process_journals.htm shows you which journals automatically upload articles to Pubmed central.

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