## Original Article

# Assessing the Quality of Death and Dying in an Integrated Health Care System in Rural Pennsylvania

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## Abstract

**Context.** With growing emphasis on improving the value of health care, there is increased scrutiny of quality outcomes and high health expenditures during the final months of life.

**Objectives.** The purpose of this project is to answer 1) how do next of kin (NOK) perceive the quality of their loved ones' dying and death; 2) are there patient and NOK characteristics that predict lower quality; and 3) are there structural aspects of care associated with lower quality?

**Methods.** A mailed survey was administered to a stratified random sample of NOK of Geisinger Health System patients who had died in the past year. The Quality of Death and Dying, the General Anxiety Disorder seven-item scale, the Patient Health Questionnaire eight-item depression scale, and selected questions from the Toolkit of Instruments to Measure End of Life Care were used.

**Results.** There were 672 respondents. Significant predictors of Quality of Death and Dying score were number of doctors involved in care ($P = 0.0415$), location of death ($P < 0.0001$), frequency of receiving confusing or contradictory information ($P < 0.0001$), illness progression ($P = 0.0343$), Patient Health Questionnaire-2 score ($P = 0.0148$), and General Anxiety Disorder seven-item scale score ($P < 0.0070$).

**Conclusion.** Several findings suggest that factors such as NOK depression and anxiety, prolonged illness, dying in the hospital, receipt of conflicting information, and confusion around the doctor in charge are associated with lower quality of the dying and death experience for NOK. Further investigation is warranted to facilitate high-quality measurement and the use of measurement results to improve care.   J Pain Symptom Manage 2015;50:343−349. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

*Key Words*
End-of-life care, quality of dying and death, next of kin, conflicting information

## Introduction

With the growing emphasis on improving value in health care delivery, there is increased scrutiny of both the quality of health outcomes and the high health expenditures during the last few months of life.[1] As noted by Provonost and Angus,[2] traditional models of value measurement, for example, "increases in quality adjusted life years divided by costs," are nonsensical when applied to the deceased. Developing accurate methods to measure the quality of the dying process is a necessary step toward delivering greater health value to dying patients and their families.

Deficits in understanding the experiences of patients and families,[3,4] failures in communication and care coordination,[3] and an often misguided emphasis on high-intensity treatment despite poor prognoses[3,5] are prominent well-documented barriers to advancing the quality of care for patients at the end of life. There has been little attention paid to the dying process as a

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performance measure for health care systems or health plans.

The purpose of this project is to answer three questions about end-of-life outcomes in the Geisinger Health System (GHS) located in rural Pennsylvania: 1) how do next of kin (NOK) perceive the quality of dying and death experienced by their loved ones; 2) are there patient and NOK characteristics that predict lower quality; and 3) what structural aspects of care delivery, such as frequency of receiving confusing or contradictory information, clarity of which doctor was in charge, and number of doctors involved in care, are associated with lower quality? It is known that patients with such chronic conditions as end-stage renal disease (ESRD), congestive heart failure (CHF), and chronic obstructive pulmonary disease (COPD) are at greater risk for dying experiences of poor quality;[3,6–11] thus, these populations were oversampled for analysis and future initiatives.

## Methods

GHS is an integrated health system providing care to more than 2.6 million residents throughout 44 counties in central and northeastern Pennsylvania. The population is generally older than the average for the U.S., with a heavier burden of chronic disease.

A random sample of deceased patients was drawn from the electronic health record. Patients were eligible for selection if they were older than 65 years at the date of death. Additionally, they had to have had at least one outpatient visit within the two years before death and died between three and 15 months before the administration of the survey. Patients with ESRD, CHF, and COPD on their electronic health record problem list were oversampled; any patient with one of these three diseases was included in the sample. Of the remaining patients who did not have ESRD, CHF, or COPD, a random sample was included.

A survey was mailed to the listed NOK of the selected sample of deceased patients. To obtain the mailing addresses of NOK, we used the emergency contact field in the deceased patient's chart. A modified Dillman method[12] was used for mailing the survey. The mailing packet included spiritual care information, a notification letter explaining the initiative, and instructions for opting out of the project. The initial survey was sent to the full sample. After three weeks, NOK who had not asked to be removed from the project were called by a member of the project team to confirm receipt of the questionnaire and inquire about interest in participation. Those interested in participating were sent a follow-up letter explaining the project in more detail and a copy of the survey to complete and return by mail.

Geisinger's institutional review board reviewed and declared this initiative to be a quality assurance project and thus exempt under the federal regulations governing human subjects research.

### Questionnaire

The survey questionnaire comprised the Quality of Death and Dying instrument (QODD), the General Anxiety Disorder seven-item scale (GAD-7), the Patient Health Questionnaire eight-item depression scale (PHQ-8), selected questions from the Toolkit of Instruments to Measure End of Life Care, and questions created by the project team.

The QODD is a 25-item measure of the quality of death and dying as perceived by NOK.[13] The GAD-7 and PHQ-8 were used to assess NOK for symptoms of anxiety and depression. The brief two-question version of the PHQ (PHQ-2) also was considered for analysis purposes. A series of questions related to coordination and continuity of care and location of death were added from the Toolkit of Instruments to Measure End of Life Care.[14] Finally, the research team added a question regarding illness progression at the end of life.

### Statistical Analysis

Scoring instructions of each survey instrument were followed. An overall QODD score was calculated if the respondent answered at least one of the 22 questions used for scoring. Possible overall scores ranged from 0 to 100 (low quality to high quality).[15] An overall PHQ score was calculated if the NOK responded to all eight questions. Possible overall scores ranged from 0 to 24 (no symptoms of depression to severe depressive symptoms).[16] Similarly, an overall GAD score was calculated only if the NOK responded to all seven questions, with a range from 0 to 21 (no symptoms of anxiety to severe anxiety symptoms).[17]

Characteristics of deceased patients, NOK, the quality of the dying process, and coordination of care and conflicting information are summarized using the mean and SD or, for skewed distributions, the median and interquartile range (IQR) for continuous variables; categorical variables are presented using frequency counts and percentages. Comparisons between respondents and nonrespondents were tested using the Wilcoxon rank sum test, Pearson's Chi-squared test, or Fisher's exact test, as appropriate. To identify patient or NOK characteristics and structural aspects of care delivery associated with lower quality of the dying process, a series of linear regression models were fit. Models were constructed using both the PHQ-8 and PHQ-2 scores. Because both models produced similar results, the PHQ-2 was used in the