

Grant Final Report

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CHOICE: Coalition of Hospices Organized to Investigate Comparative Effectiveness

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Abstract

Purpose: To develop and test a system for extracting quality indicators from hospice Electronic Medical Records (EMRs).

Scope: 12 pilot hospices in the CHOICE network (Coalition of Hospices Organized to Investigate Comparative Effectiveness) CHOICE is a research-focused collaborative of which have agreed to share their data for research purposes. Participating hospices range in size from 400-1700 patients/day and are located in New Mexico, California, Florida, Pennsylvania, Wisconsin, Michigan, Ohio, Texas (3 hospices), Kentucky, and Kansas/Missouri. All are not-for-profit.

Methods: Patient data were extracted from the electronic medical records of 12 hospices in the CHOICE network. Warehouse data reside on a secure server that is managed by Suncoast Solutions. Extracted data were then stripped of identifiers in order to create a HIPAA-compliant limited dataset that was transferred as an encrypted file to the University of Pennsylvania for analysis. Key data elements included demographic data, indicators of illness severity (e.g. functional status, staff visit frequency), outcomes (e.g. survival, site of death), as well as selected indicators of quality (Family Evaluation of Hospice Care survey scores and adequacy of pain management).

Results: During the course of this project, we have established that EMR data extraction from hospice is feasible on a large scale. Specific results (described below), include tracking of outcomes related to preferences (e.g. regarding site of death) and comparison of underrepresented hospice subpopulations (e.g. children, older adults in assisted living) and the development of an acuity index that can be used in subsequent studies of the impact of visit frequency on outcomes..

Key Words: hospice; electronic health record; quality; palliative care; cancer

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Final Report

Purpose

The overarching goal of the proposed project to investigate the feasibility and validity of EHR-derived hospice data, and to establish the value of the CHOICE network in answering key hospice-focused CER questions that fall under the heading of in PA-08-269 question #3: Health IT to improve health care decision-making. To achieve this goal, the project was designed to accomplish the following 3 Aims:

Specific Aim 1: To evaluate the feasibility and validity of using quality measures abstracted from hospice electronic records.

Research Question 1. For what proportion of patients can key palliative care quality indicators be extracted from EHRs?

Research Question 2. How reliable are EHR-based quality indicators compared to quality indicators that are abstracted by trained nurses?

Specific Aim 2: To define associations between quality indicators and families' perceptions of care (Family Evaluation of Hospice Care survey results).

Research Question 3. Which EHR-based quality indicators have the strongest association with families' perceptions of care?

Specific Aim 3: To identify high-priority targets for improvement.

Research Question 4. Which EHR-based quality indicators do hospice stakeholders believe should be high-priority targets for performance improvement activities and pragmatic clinical trials?

By establishing the feasibility and validity of CHOICE's data collection, and by defining stakeholders' priorities for performance improvement and research, this project was designed to lay the foundation for a line of comparative effectiveness research that can drive meaningful improvements in the quality of hospice care.

Scope

Background

In the US today, more than 5,000 hospices provide care for more than 1.5 million patients every year. These patients receive care in their own homes, in nursing homes, in hospitals, and in

dedicated hospice units. In order to provide high quality care that is competent, patient- and family-centered, coordinated, and compassionate, hospices need an evidence base of comparative effectiveness research (CER).

Context

However, it is unlikely that CER data will come primarily from randomized controlled trials. These trials are very difficult in the hospice setting because the majority of hospice patients are unable to participate. Moreover, patients enroll in hospice very late in the course of illness. Half of hospice patients enroll in the last 3 weeks of life, one third enroll in the last week, and 10% enroll in the last 24 hours, making clinical trials and most primary data collection studies very difficult.

Settings

In order to advance the science of CER for hospice care in other ways, the research team has developed an innovative CER hospice network. This growing network (CHOICE: Coalition of Hospices Organized to Investigate Comparative Effectiveness) has 12 hospice members that care for more than 40,000 patients every year, and is currently expanding to include a total of 50 hospices.

Participants

EMR data were extracted from the records of 12 hospices, including a total of 164,293 patients. All patients were enrolled in one of the 12 participating hospices, and were receiving hospice care in a private home, nursing home (including assisted living), hospital, or inpatient hospice unit.

Methods

Study design

As described above, this project used data extracted from the EMRs of the 12 CHOICE hospices. Analysis used either cross-sectional design (i.e. for assessment of extraction reliability) or a prospective cohort design (e.g. for most published studies that resulted from this work).

Data sources

All data were collected from the EMRs of participating hospices. These hospices all use Suncoast Solutions software, and store data in a cloud-based warehouse that Suncoast Solutions maintains. A subcontract from the University of Pennsylvania with Suncoast Solutions for this project supported the extraction of data elements for validation and analysis.

Measures

Key data elements included demographic data, indicators of illness severity (e.g. functional status, staff visit frequency), outcomes (e.g. survival, site of death), as well as selected indicators of quality (Family Evaluation of Hospice Care survey scores and adequacy of pain management). Additional measures included the ability to extract test quality measures (e.g. the National Quality Forum #0209 measure) and accuracy of data extraction vs. review by trained nurses.

Limitations

These methods have two main limitations. First, these data come from only 12 hospices, therefore the findings reported here may not be widely generalizable. Second, all hospices in this sample were not-for-profit. In the US, hospices are increasingly for-profit, and many are part of large chains. This further limits the generalizability of the findings reported here.

However, it is important to note that this project was designed as a preliminary test of feasibility and validity. The use of this EMR extraction technique should be generalizable to other hospices, regardless of profit status. Indeed, as the CHOICE network expands, 3 for-profit hospices have agreed to join. One of these, Bristol Hospice, is a multisite for-profit chain with a daily patient census of approximately 1,000 patients. Therefore, although the initial test of feasibility was conducted in a limited sample, we are confident that future growth of the CHOICE network will include a mix of hospices that is diverse with respect to profit status, geography, and patient characteristics.

Results

Principal findings

During the course of this project, we have established that EMR data extraction from hospice is feasible on a large scale. This process has involved the following steps, which together reflect the creation of the CHOICE infrastructure that will continue after the conclusion of this grant, in the form of an electronic QI/benchmarking network.

- A. Creation of Data Use Agreements with all participants in the CHOICE network
- B. Development of a CHOICE steering committee with representation (primary and alternate) from each
- C. Creation of a multi-site database
- D. Development of techniques for reliable data extraction and transfer

Specific results are listed below.

Outcomes

Below the main outcomes are summarized by study Aims and Research Questions

Aim #1: To evaluate the feasibility and validity of using quality measures abstracted from hospice electronic records.

Research Question 1. For what proportion of patients can key palliative care quality indicators be extracted from EHRs?

Overall, across all 12 hospices in the CHOICE network, the main quality indicator used to test feasibility (NQF #0209), data could be extracted for 96.5% of records reviewed. However, we also found significant variation among hospices (88.3%-98.4%).

Research Question 2. How reliable are EHR-based quality indicators compared to quality indicators that are abstracted by trained nurses?

For the #0209 score, overall accuracy compared to a hand review in a sample of 100 charts was 97%. The remaining 3 charts were adjudicated and could have been classified as either correct or incorrect, based on limited data.

Aim #2: To define associations between quality indicators and families' perceptions of care (Family Evaluation of Hospice Care survey results).

Research Question 3. Which EHR-based quality indicators have the strongest association with families' perceptions of care?

We have examined several quality measures, linked with FEHC data from 4 hospices (Lancaster, Largo, Bluegrass, and Marin). Quality measures tested have included the NQF #0209 score, as well as all mandated CMS Hospice Item Set scores (e.g. pain screen, dyspnea screen, spiritual assessment, documentation of preferences). None of these measure showed a significant association with the FEHC overall rating of hospice quality.

However, significant associations were found between overall quality ratings and the presence of a hospice staff visit on the last day of life. This measure was developed based on participation and feedback from CHOICE members, and particularly the nursing representation on the CHOICE steering committee. This measure is being included among the core measures that will be used for reporting and benchmarking in the next iteration of the CHOICE network. (See #3, below).

Aim #3: To identify high-priority targets for improvement.

Research Question 4. Which EHR-based quality indicators do hospice stakeholders believe should be high-priority targets for performance improvement activities and pragmatic clinical trials?

As noted above, a key step in creation of the CHOICE network was the establishment of a CHOICE steering committee. This committee meets approximately quarterly, and also provided input into a series of focus groups to establish priorities for CHOICE network data collection and benchmarking.

After extensive discussion, the steering committee identified the following high-priority targets for future data collection and benchmarking as the CHOICE network expands to 50 hospices:

1. Pain screening on admission (CMS Hospice Item Set variable).
2. Dyspnea screening on admission (CMS Hospice Item Set variable).
3. Opioid accompanied by a bowel regimen (CMS Hospice Item Set variable).
4. Preferences assessed regarding CPR/resuscitation (CMS Hospice Item Set variable).
5. Preferences assessed regarding hospitalization (CMS Hospice Item Set variable).
6. Visits done on the patient's last day of life.

Discussion

By establishing the feasibility and validity of CHOICE's data collection, and by defining stakeholders' priorities for performance improvement and research, this project was designed to lay the foundation for a line of comparative effectiveness research that can drive meaningful improvements in the quality of hospice care.

Conclusions

Extraction of clinical, operational and quality data from hospice AMRs is feasible on a large scale. It is possible to create a national research network of hospices, which is focused on answering key questions related to hospice quality and outcomes.

Implications

The results of this project provide an initial proof of concept for the creation of a national QI/benchmarking network, which can be used to answer hospice CER questions.

List of Publications and Products

Publications

Dougherty M, Harris P, Teno J, Corcoran A, Douglas C, Nelson J, Way D, Harrold J, Casarett D. Hospice care in assisted living facilities versus at home: Results of a multi-site cohort study. *Journal of the American Geriatrics Society* (in-press).

Dingfield L, Bender L, Harris P, Newport K, Hoover-Reagan M, Feudtner C, Clifford S, Casarett D. Comparison of pediatric and adult hospice patients using

electronic medical record data from 9 hospices in the United States, 2008–2012. *Journal of Palliative Medicine* (in-press).

Hurley S, Colling C, Harris P, Harrold J, Teno J, Ache K, Casarett D. Increasing inpatient hospice use vs. patient preferences: Are patients able to die in the setting of their choice? *British Medical Journal: Supportive Care* (in-press).

Casarett D, Harris P, Bender L, Harrold J, Teno J. Is continuous home hospice care associated with better outcomes? *Journal of Palliative Medicine* (under review).

Casarett D, Bender L, Ouslander J, Barg F, Casarett D. Best practices for hospice in long term care (in preparation).