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Sowmya Vasudevan Date

Palliative Care: Improving research through standardized informatics

By

Sowmya Vasudevan

Degree to be awarded:
MPH
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Executive Master of Public Health

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Abstract

Palliative Care: Improving research through standardized informatics

By

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment for the degree of
Master of Public Health in Applied Public Health Informatics in the
Executive MPH program 2018

Abstract

Palliative Care: Improving research through standardized informatics

By

Sowmya Vasudevan

Purpose: The goal of the thesis is to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology. The overarching goal of palliative care clinical research is to improve patient enrollment and outcomes.

Methods: Based upon the collection of requirements from an expert panel, a solutions architecture for the palliative care research registry was developed. The solution uses standardized methodology to obtain data from the data warehouse and applies a preliminary algorithm to identify cancer patients in need of palliative care treatment. Criteria were developed and validated with subject matter experts to ensure that it met the requirements for selection from the data warehouse. Standardized queries were developed in the hospital data warehouse system to extract relevant palliative care patient information for cancer patients. A prototype research database was developed to store the de-identified palliative care patient information. Queries were developed in the research database to combine data and present information for research studies. Also, visual analytics templates were developed using Tableau.

Results: A registry prototype was built which could be used as a model for a palliative care research registry. Preliminary criteria were identified in the database to select cancer patients eligible for palliative care. Preliminary visual analytics was performed to understand the palliative care utilization. Data from the registry prototype was analyzed and used in palliative care research papers.

Conclusions: The study provided an opportunity to explore palliative care research data needs. A standardized methodology was selected to build a registry along with validated criteria for identifying cancer patients in need of palliative care. The resulting data architecture provided a useful illustration of how a standardized palliative care registry could support and improve palliative care enrollment.

THESIS

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Chapter 1: Introduction

Introduction and Background

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification, and assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2013). Palliative care is provided to patients with curable, chronic, or life-threatening illnesses; and can be incorporated at any stage of the illness. Hospice is a type of palliative care and is provided when curative treatment is no longer beneficial or desired, and when life-expectancy is measured in months or less (McAteer, Wellbery 2013).

Palliative care is an important component of delivering holistic treatment which is intended to alleviate symptoms and manage pain at any stage of a chronic or a terminal disease. This is often confused with hospice which is an end-of-life care for individuals no longer receiving aggressive treatment and who are expected to die within 6 months.

Palliative care began as a philosophy aimed at improving care for patients at the end of life during the 1960s; and has slowly evolved into a professional specialty that provides comprehensive care for patients with life-limiting illnesses, throughout the disease trajectory (Hui et al. 2016). Over the past decade, a growing body of literature has emerged supporting the role of palliative care in improving patient and caregiver outcomes (Zimmermann et al. 2008). This evidence supports the integration of palliative care and oncology. Five areas of integrating palliative care and cancer treatment have been identified: clinical structure, clinical processes, education, research, and administration. The goal of the thesis is to explore three research questions in order to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology.

In summary, palliative care does not cure or treat diseases like cancer. Instead, palliative care relieves physical, emotional, and psychosocial symptoms. It begins when a patient is diagnosed with serious illness and continues through all phases of treatment and follow-up to the survival or end of life. Implementation of informatics solution supporting cancer and palliative care may improve overall patient outcomes and quality of life.

Problem Statement

There is a need to improve enrollment in palliative care for patients diagnosed with cancer. The current electronic health record system in the hospital does not provide sufficient prompts or informational indicators for oncologists and nurses to recommend patients to palliative care. Currently, there is no standardized informatics process to enroll cancer patients in palliative care. Hence, palliative care is an under-utilized treatment option that might improve the quality of care not only for the patients but also for caregivers. To address this situation, data must be collected in a systematic manner to support palliative care research. Additional informatics research is needed to define a standardized methodology to create a palliative care registry and systematically populate the registry with data from the electronic health records system and identify cancer patients in need of palliative care.

Purpose Statement

There is a need to improve enrollment in palliative care for patients diagnosed with cancer. The goal of the thesis is to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology. To support this effort, three research questions are specifically explored.

Method

The methodology followed to create the prototype of the registry was based on the Agency for Healthcare Research and Quality (AHRQ) publication "Registries for Evaluating Patient Outcomes: A User's Guide, 3rd edition" (Gliklich et al. 2014). In this publication, Chapter 2, which deals with planning a registry, is applied to the methodology section of the registry.

An expert panel of palliative care research team, headed by the director of palliative care research, provided the general requirements and palliative care needs to help inform the research questions. Weekly team meetings were held to gather and refine data architecture requirements. Using these requirements, clinical data sources were identified.

A prototype "palliative care registry" for research purposes was developed using de-identified patient data and standardized templates. This methodology was used to create a solution architecture for developing a palliative care registry that automatically identifies cancer patients eligible for palliative care enrollment using an algorithm.

This expert-informed exploration of palliative care data will help the palliative care team to easily identify cancer patients in need of this specialized care. The preliminary algorithm used to identify future palliative care patients can be refined in subsequent iterations to make the search more efficient.

Significance

There is a need to improve enrollment in palliative care for patients diagnosed with cancer. Oncologists today face challenges in providing comprehensive care to patients in an era where medical advancements have increased the survival rate. For patients with metastatic cancer, current treatment will allow nearly half to continue living for a period of years after their current diagnosis (Rangachari, Smith 2013). The next focus of treatment should be to provide personalized, compassionate, and cost-effective care that translates into better outcomes and quality of care for patients. Palliative care is a distinct medical specialty that encompasses all the above elements of patient care.

The goal of palliative care is to improve quality of life for both patient and caregivers. This is different from the end of life or hospice care which is defined by Medicare as "care of patients with physician-estimated life expectancy of 6 months or less." Palliative care is part of best practice in oncology, as endorsed by the American Society of Clinical Oncology (ASCO), European Society for Medical Oncology, the National Comprehensive Cancer Network (NCCN), and the Society for Surgical Oncology (Rangachari, Smith 2013). Although oncologists agree that integrating palliative care at the time of cancer diagnosis enhances patient care and complements their practice, recent studies suggest that the integration needs significant improvement.

A palliative care database, with focus on oncology, could provide the information needed to study outcomes of cancer patients. There needs to be systematic approach to collecting data to conduct research studies and to identify patients in need of palliative care. The proposed solution will help to build a registry that can be used for palliative care research to improve enrollment and for studying patient outcomes.

Research Questions

The research questions this study intends to answer are:

1. What data currently exist in medical records that could inform providers around the need for palliative care enrollment?
2. What information architecture is required to establish a palliative care registry to research and explore improvements in palliative care effectiveness?
3. What kind of preliminary algorithm be developed to identify cancer patients in need of palliative care?

Chapter 2: Review of Literature

Introduction

There is a need to improve enrollment in palliative care for patients diagnosed with cancer. The goal of the thesis is to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology. To support this study, a systematic literature review was conducted.

Literature Review Strategy

Palliative care enrollment needs to be improved. The literature around palliative care and palliative care enrollment appears to be largely uncharacterized. Specifically, there appears to be no clear understanding in the literature about palliative care research and data needs. The literature review strategy supporting this study consisted of searching keywords within PubMed and governmental reports from the past five years using generic terms related to palliative care such as palliative care informatics; referral by physicians; outpatient palliative care utilization; and electronic alerts for palliative care. These terms were further refined to make the search more relevant to palliative care for cancer patients and the informatics associated with palliative care enrollment.

Literature Results Overview

The literature review produced about 78 results about palliative care in oncology. Relative to this study, these articles were classified into the following discussion categories:

1. Palliative Care Referral by Physicians
2. Outpatient Palliative Care Utilization among Cancer Patients

3. Electronic Alerts for Palliative Care
4. Automatic Referral for Palliative Care
5. Palliative Care Trigger Algorithm

Out of these articles, 9 articles were selected for further review and inclusion as the foundation for this research. The criteria for selection is described in each of search categories below.

Palliative Care Referral by Physicians

The search details used in Pubmed for this are as follows:

(palliative[Title] AND care[Title]) AND primary[Title] AND (("referral and consultation"[MeSH Terms] OR ("referral"[All Fields] AND "consultation"[All Fields]) OR "referral and consultation"[All Fields] OR "referral"[All Fields]) AND ("physicians"[MeSH Terms] OR "physicians"[All Fields])) AND ("2013/10/22"[PDat] : "2018/10/20"[PDat])

This search produced 3 results out of which one study relevant to the search was selected for analysis. The definition of palliative care, according to the Center of Advance Palliative Care, is "focused on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis or prognosis. The goal is to improve quality of life for both the patient and the family." According to the American Society of Oncology Provisional Clinical Opinion, palliative care is "focused on relief of suffering, in all of its dimensions." (Ghosh et al. 2015). Palliative care focuses on symptom assessment and control while maintaining open communication with families and develops strategies for appropriate goals of care, especially in patients with advanced illness

Palliative care referral and enrollment begins when a serious illness is diagnosed, and continues throughout treatment, during follow-up, and at the end of life. The goal of palliative care is to help patients with serious illnesses feel better. It prevents or treats symptoms and side effects that patients experience due to disease and treatment. Palliative care also treats emotional, social, practical, and spiritual problems that arise due to illnesses. When the person feels better in these areas, they experience a better quality of life. Palliative care can be administered at the same time as treatments to cure or treat the disease. Thus, palliative care, as shown in Figure 1, is a continuum of care that can begin at the point of diagnosis with serious illness to death. Hospice is the Medicare defined benefit that provides palliative care for patients who have life expectancy of less than six months. The focus of hospice shifts from curative care to care that is focused on providing solace to the patient.

Figure 1

Outpatient Palliative Care Utilization among Cancer Patients

The search results produced 60 articles out of which two studies were selected for the purpose of this thesis based on relevance to the research questions. The search details in Pubmed for this are: (("outpatients"[MeSH Terms] OR "outpatients"[All Fields] OR "outpatient"[All Fields]) AND ("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND ("neoplasms"[MeSH Terms] OR "neoplasms"[All Fields] OR "cancer"[All Fields]) AND ("patients"[MeSH Terms] OR "patients"[All Fields])) AND ("2013/10/22"[PDat] : "2018/10/20"[PDat] AND cancer[sb])

Cancer is the second leading cause of death in the USA and accounts for one in four patient deaths annually. People with incurable malignancies usually experience a variable period of stability followed by a 3-6 month period of declining functional status and increasing symptom burden prior to death (Blackhall, Read et al. 2016). Lung cancer is the leading cause of cancer-related death in the U.S. and is associated with a high symptom burden and poor quality of life (King JD, Eickhoff J, et al. 2016). In this study, all outpatients with advanced cancer from 2007 to 2011 were identified. Overall survival, hospice enrollment and length of stay, and chemotherapy utilization were calculated for patients treated with early palliative care (EPC) and compared to standard oncology care. EPC in advanced lung cancer was associated with a nearly two-month survival advantage compared to standard oncologic care. This finding provided supportive evidence to previously published reports of survival benefit with EPC intervention.

Another study that was considered for the purpose of this thesis is CARE – the Comprehensive Assessment with Rapid Evaluation and Treatment. This program is a phased intervention integrating outpatient palliative care into cancer care at the University of Virginia Emily Couric Cancer Center (Blackhall, Read et al. 2016). The program provides outpatient consultation including symptom management and end-of-life planning with multidisciplinary care coordination. The Palliative Care Center at the University of Virginia includes inpatient consultation, a palliative care unit, and home hospice components. All of these care settings are staffed by the same physicians and nurse practitioners ensuring continuity of care across settings. Patients were enrolled in the CARE Track Year 1 program on referral to palliative care clinic if they met entry criteria (stage IV solid tumor or other advanced cancer as incurable by the referring oncologist or surgeon). The control group consisted of patients with similar diagnoses undergoing treatment at the same location but not enrolled in the palliative care clinic. The data for this study was provided by the Clinical Data Repository (CDR), a data warehouse that contains information about patients by the University of Virginia Health System. The data showed the benefit of concurrent outpatient palliative care. The patients enrolled in the Year 1 CARE Track intervention who were referred to outpatient palliative care services at the discretion of their oncologists had decreased hospitalization at the end of life, increased hospice utilization, and hospice length of stay. The differences between the control and CARE Track care patients in terms of hospitalizations were due to earlier and more frequent referral to hospice services by those in the CARE Track group. Patients and the family members in the control group, who were unprepared for the natural course of the disease, sought urgent care for their problems wherever it was available. Sometimes, this meant frequent visits to the hospital. Early referral to palliative care facilitated educating patients and families of the illness trajectory, which resulted in better hospice utilization and fewer hospitalizations at end of life in the CARE Track group.

Electronic Alerts for Palliative Care

The thesis investigates the use of electronic alerts for palliative care to improve palliative care enrollment by cancer patients. This literature search yielded 10 results of which one paper were considered in this thesis based on the relevance of the paper to the research questions. The search details in Pubmed are as follows:

(("electronics"[MeSH Terms] OR "electronics"[All Fields] OR "electronic"[All Fields]) AND Alerts[All Fields] AND ("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields])) AND ("2013/10/22"[PDat] : "2018/10/20"[PDat] AND cancer[sb]).

The study shows how palliative care enrollment can be increased by integrating brief and validated patient-reported outcome assessment into electronic health record (EHR) and clinical workflow (Wagner LI, Schink J, et al. 2015). Cancer patients commonly experience disease and treatment related pain and fatigue symptoms. These are best assessed using direct patient reported questionnaire. While decreased symptom manifestations usually indicate positive response to treatment, increased symptom burden can indicate disease progression. Symptom burden due to treatment often helps guide decision-making with regard to dose adjustments. Discrepancies have been noticed between clinical and patient reports of symptom severity. Patient-reported outcomes (PROs) measures are considered to be the gold standard for quantifying patient’s experience of a particular symptom. PROMIS (Patient-Reported Outcomes Measurement Information System) is a National Institutes of Health Common Fund Initiative to measure patient-reported symptoms and health-related quality of life across various conditions and disease populations (Wagner LI, Schink J, et al. 2015). The measurements used in PROMIS CATs (Computer Adaptive Tests) included pain interference, fatigue, physical function, depression and anxiety. In addition to the PROMIS CATs, additional assessment items to include psychosocial and nutritional concerns were administered for triage to supportive oncology services. The psychosocial assessment was adapted from the National Comprehensive Cancer Network Distress Thermometer and Problem List for Patients (NCCN, 2018). Nutritional assessment included new items and items adapted from Patient Generated Subjective Global Assessment (PG-SGA) (ACCC, 2018). Advances in health informatics have facilitated the development of systems for electronic administration and scoring of PROs (ePROs) (Wagner LI, Schink J, et al. 2015). This was the first program to accomplish the clinical integration of PROMIS CAT administration, scoring, and reporting within an EHR system. Outcomes measurements were not done and the authors identified it as a next step to evaluate the implementation.

Referral Criteria for Palliative care

This search would help in identifying criteria for cancer patients to be enrolled in palliative care. These criteria could be built into the new system to identify cancer patients eligible for palliative care.

The search details for this are:

Referral criteria[Title] AND ("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]) AND ("2013/10/22"[PDat] : "2018/10/20"[PDat] AND cancer[sb])

This search yielded 2 results both of which were considered for further analysis. The first study discusses the referral criteria for outpatient specialty palliative cancer care based on international consensus. A Delphi study was conducted to develop consensus on a list of criteria for referral of patients with advanced cancer at a secondary or tertiary care hospitals to outpatient palliative care (Hui, Mori, et al. 2016). 60 international experts (26 from North America, 19 from Asia and Australia, and 11 from Europe) on palliative cancer care rated 39 needs-based criteria and 22 time-based criteria in three iterative rounds. At the end of the third round, the panelists reached consensus on 11 major criteria for referral: severe physical symptoms, severe emotional symptoms, request for hastened death, spiritual or existential crisis, assistance with decision making or care planning, patient planning, patient request for referral, delirium, spinal cord compression, brain or leptomeningeal metastases, time-based criteria of advanced cancer diagnosis with median survival of 1 year or less, and advanced cancer with progressive disease despite second-line therapy. In addition to these, 36 minor criteria were also recommended; however, these need to be validated in clinical settings. The paper concludes that these criteria should be tailored to each institution, and could help increase referrals, streamline and standardize clinical practice, research, and resources related to palliative-care access for cancer patients.

The second study discusses automatic referral to standardize palliative care access in an international Delphi survey (Hui et al. 2018). The Delphi panel reached a consensus that automatic referral may improve the volume and timing of palliative care referral. The panelists favored the combination of automatic referral and clinician-based referral, instead of either referral model alone. Clinical-based referral is the popular mode of access to palliative care in most clinical centers. The process is based on 1) Recognition of care needs; 2) Judging whether this warrants a referral; and 3) Initiating a palliative care consultation. Typically, all three steps are performed by the oncology team, giving rise to wide variations in referral because of differences in judgement, time, education, experience, interest, and understanding of palliative care (Hui et al. 2018). In another study conducted prior to this study, the team led by Hui et al. reported the use of the Edmonton Symptom Assessment Scale for routine symptom distress screening in a general oncology outpatient clinic. Patients who reported three or more symptoms with intensity>=7/10 were assessed by a social worker for triaging. The proportion of highly distressed patients who were referred to palliative care, before and after program implementation, increased from 12% to 28%, but this was not statistically significant (Hui et al., 2017). More studies are needed to examine the outcomes associated with automatic referral. The study discussing the automatic referral to palliative care concluded that a combination of the two approaches, namely the clinical-based referral and automatic referral conducted in a parallel mode would be ideal for better palliative intake and outcomes.

Palliative Care Trigger Algorithm

The search for Palliative Care Trigger identifies the algorithms to be applied to medical records to identify prospective palliative care patients. The algorithm used identified patients with a serious illness in combination with high hospital utilization, limited functional status, or at least one palliative care uncontrolled symptom. This was helpful in building the architecture for the proposed system. The search details for PubMed are:

("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]) AND ("precipitating factors"[MeSH Terms] OR ("precipitating"[All Fields] AND "factors"[All Fields]) OR "precipitating factors"[All Fields] OR "trigger"[All Fields]) AND ("algorithms"[MeSH Terms] OR "algorithms"[All Fields] OR "algorithm"[All Fields])

This search produced 3 results out of which one study was analyzed. This study uses algorithms against patient data in the electronic health records system to improve identification of patients who would benefit from palliative care. (Gruhler et al. 2018). This study used a mixed–methods randomized retrospective study design. Three iterations of 30 days of clinical data were analyzed for patients who received palliative care consults, as well as patients identified by the electronic algorithm. During the second and third 30-day iterations, palliative care clinicians conducted chart reviews on a weekly basis to determine whether the identified patients were appropriate for a palliative care consult. After the third iteration, the positive predictive value (PPV) was found to be

80.1%. Based on the PPV, the projected palliative care penetration rate may be as high as 26.4% of the total inpatient population.

Chapter 3: Methodology

Introduction

There is a need to improve enrollment in palliative care for patients diagnosed with cancer. The goal of the thesis is to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology. The purpose of this chapter is to describe the methodology used to develop the information systems architecture including the requirements around the standardization of the process of identifying oncology patients in need of palliative care at a major Atlanta area hospital.

In order to accomplish this goal, the research group at the palliative care center of the hospital wanted to create a dedicated database system to support palliative care research. A prototype was developed using de-identified clinical data of palliative care patients undergoing cancer treatment at this center. The purpose of this thesis is to develop an architecture to enhance this prototype database system to create a registry to include clinical data that would identify cancer patients in need of palliative care. This would improve enrollment in palliative care.

Research Questions

1. What data currently exist in medical records that could inform providers around the need for palliative care enrollment?
2. What information architecture is required to establish a palliative care registry to research and explore improvements in palliative care effectiveness?

3. What kind of preliminary algorithm be developed to identify cancer patients in need of palliative care?

Method

The methodology followed to create the prototype of the registry was based on the Agency for Healthcare Research and Quality (AHRQ) publication “Registries for Evaluating Patient Outcomes: A User’s Guide, 3rd edition” (Gliklich, et al. 2014). The following figure shows the process used to create the prototype registry based on this methodology.

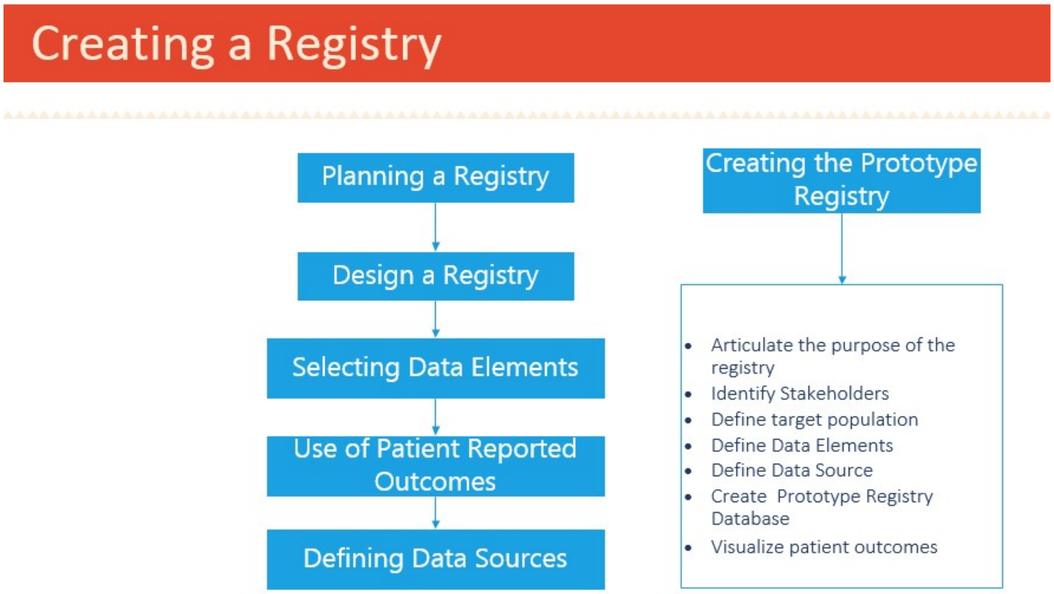


Figure 2

An expert panel of palliative care research team, headed by the director of palliative care research, provided the general requirements and palliative care needs to help inform the research questions. The project was performed during the fall of 2016. Weekly team meetings were held to gather requirements. Using these requirements, potential data sources were identified. A reliable data source for this purpose is the data warehouse which has a daily feed from the EHR system. Analysis of the requirements led to identification of data elements, and queries were developed in the data warehouse to extract data relevant to palliative care patients between the years 2012 and 2017. Initially, the queries had a broader filter for all the years and took a very long time to run. Then, a parametrized filter was created to select patients for each year. This reduced the time for data extraction significantly.

Standardized parameterized query templates were developed using this filter to retrieve de-identified data pertaining to demographics, patient-hospital encounters, insurance, re-admissions, medications, and comorbidities of the desired patient population. In this case, the parameters were customized to select palliative care patients seen at the clinic during the years between 2012 and 2017. Further data mining identified data elements that could be used to identify cancer patients in need of palliative care. The data mining techniques were used to develop an architecture for the palliative care registry, consistent with the research questions.

The purpose of the AHRQ publication is to provide guidelines for developing a registry to study outcomes. This thesis uses the guide as a reference to define the purpose of the registry, identify stakeholders, data sources and elements for the registry, perform some preliminary analytics on the sample database to evaluate outcomes, and develop a preliminary algorithm to identify cancer patients in need of palliative care. Each of the steps used to creating the palliative care registry prototype are discussed in detail below.

A Plan for the Palliative Care Registry

Purpose of the Registry

The primary purpose of the registry was to 1) study patient outcomes among palliative care patients to help palliative care researchers produce research papers to fund palliative care research projects, and 2) study the current infrastructure to identify a solution to improve enrollment in palliative care for patients diagnosed with cancer. The registry prototype would store information about cancer patients enrolled in palliative care. The registry would be used to identify trends in palliative care utilization among various subgroups of population. This registry prototype was used as a model for finding palliative care identification criteria definitions that could be applied and studied for analysis (Gruhler et al. 2018). A preliminary algorithm was developed for identifying cancer patients in need of palliative care. Palliative care experts could then verify the accuracy of the results of this algorithm by conducting chart reviews and reporting their findings. This preliminary algorithm could be refined in subsequent iterations to develop a process for identifying cancer patients in need of palliative care.

Registry Prototype

For the current system, the palliative care research director identified the criteria to extract patient data from the clinical data warehouse. Patients enrolled in palliative care in the hospital population were identified using a flag in the “Powernote Template” field in the data warehouse. The patient data was completely de-identified. Data pertaining to cancer patients in this population was extracted using the ICD-9 codes as defined by the palliative research team. The ICD-9 code filter included codes for neoplasm, radiology, and chemotherapy. Data from this registry prototype was then analyzed using Tableau.

A registry prototype was developed to include de-identified patient data from the clinical data warehouse. The main patient population in the clinical data warehouse was filtered using the “Powernote Template” flag for Palliative Care Consults and “Admit Year” between 2012 and 2017. Standardized queries were written in the clinical data warehouse to extract de-identified patient information pertaining to:

1. Demographics (race, gender, ethnic group),
2. Encounters (number of visits)
3. Insurance (Insurance type such as Medicare, Medicaid etc.)
4. Re-admissions (number of readmissions)
5. Medications (prescribed medication)
6. Comorbidities (ICD-9 diagnosis codes)

Then filters were used in the queries to extract the population of interest (i.e. palliative care patients) who were admitted during the years 2012-2017. This information was stored in a prototype database using Microsoft Access. Queries were written in this database to extract information pertaining to cancer patients for research papers. A prototype registry was created to store this sample population. Information from this registry was used to analyze palliative care utilization trends among cancer patients at this center.

Solutions Architecture for the Proposed Palliative Care Registry

The standardized queries in the data warehouse system that were developed in the prototype could be expanded to include all cancer patients enrolled at the palliative care center (see Figure 3 for Cancer Patient Registry – Palliative Care Enrollment Process). A filter could be created in the registry to identify patients with active PC (palliative care) consult. This filter could be used to create PC consult group in the database. For the remaining patients, the control group with demographics and health conditions similar to the PC group could be created. Analysis to identify differences in outcomes could be performed using these two groups.

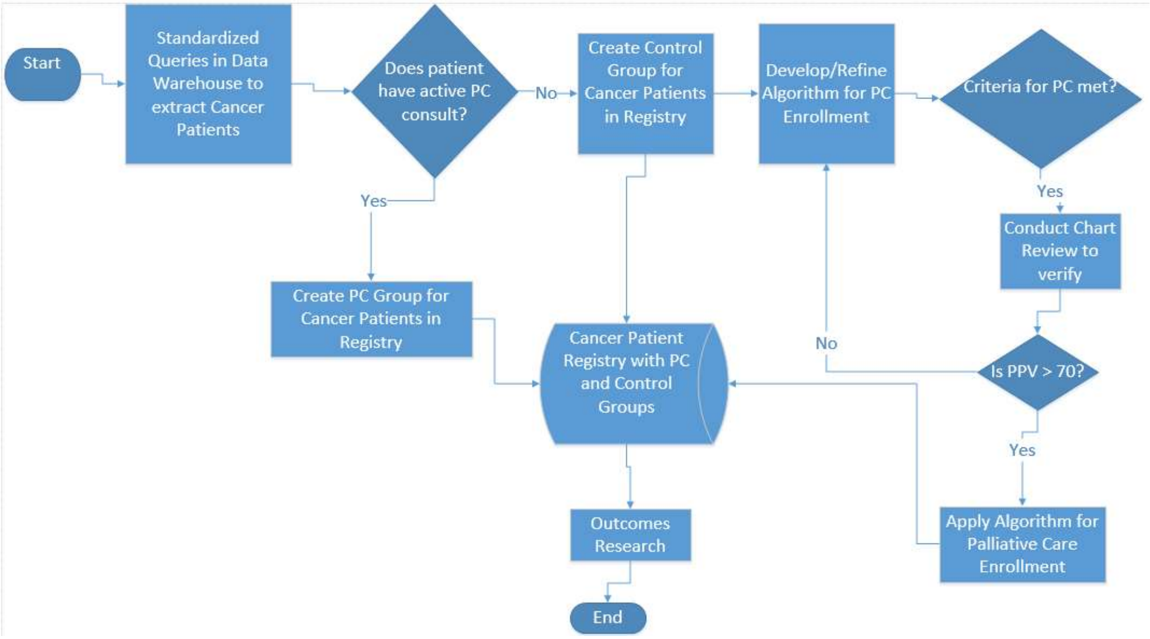


Figure 3 - Cancer Patient Registry – Palliative Care (PC) Enrollment Process

Then, a palliative care identification algorithm could be applied to the cancer patient group (see Table 1 for Palliative Care Identification Algorithm Criteria definition). Combined filter for ICD-9 diagnosis of "cancer" and high utilization, as defined in table 1, could be created to extract cancer patients with recurrent readmissions from the hospital data warehouse. Symptoms for functional status and uncontrolled symptoms could be extracted from the data warehouse if it exists or could be derived from the electronic health record system.

Criteria	**Definition**
Serious illness	A qualifying ICD-9 diagnosis from the principal diagnosis or problem list in the EHR that was clinically identified as a serious or life-threatening illness The following is the broad representation of the actual code for Cancer as the principal diagnosis. Cancer • Recurrent • Metastatic
High utilization	• Two or more inpatient admission within 30 days • Three or more inpatient admissions within 180 days • Two or more emergency admissions within 180 days
Limited functional status	Any of the following indicators documented in the EHR: • history of falls • being at risk for falls • ambulation • gait weakness

	• having an existing or new gastrointestinal or endotracheal tube
Palliative care uncontrolled symptoms	Any of the following symptoms documented in the EHR: • confusion or disorientation • nausea • weakness • anorexia • shortness of breath • drooling • constipation • diarrhea • incontinence • uncontrolled pain scores

Table 1: Palliative Care Identification Algorithm Criteria Definitions

The algorithm for palliative care recruitment is shown in Figure 4. Based on the palliative care identification criteria shown in Table 1, cancer patients could be evaluated for PC enrollment based on whether they have some form of metastatic or recurrent cancer, high hospital utilization, limited functional status, or any of the palliative care uncontrolled symptoms. These could be obtained either from the data warehouse or from the electronic health record system. Chart reviews confirm the validity of the preliminary algorithm which can be refined in subsequent versions of the algorithm.

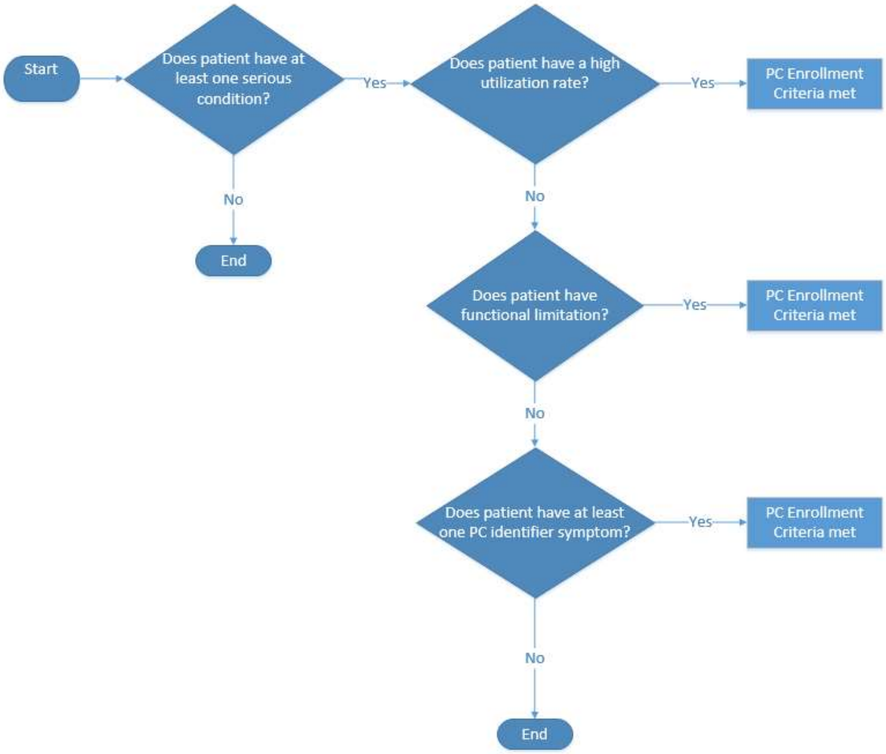


Figure 4

Palliative Care Identification Algorithm

Chapter 4: Results

Introduction

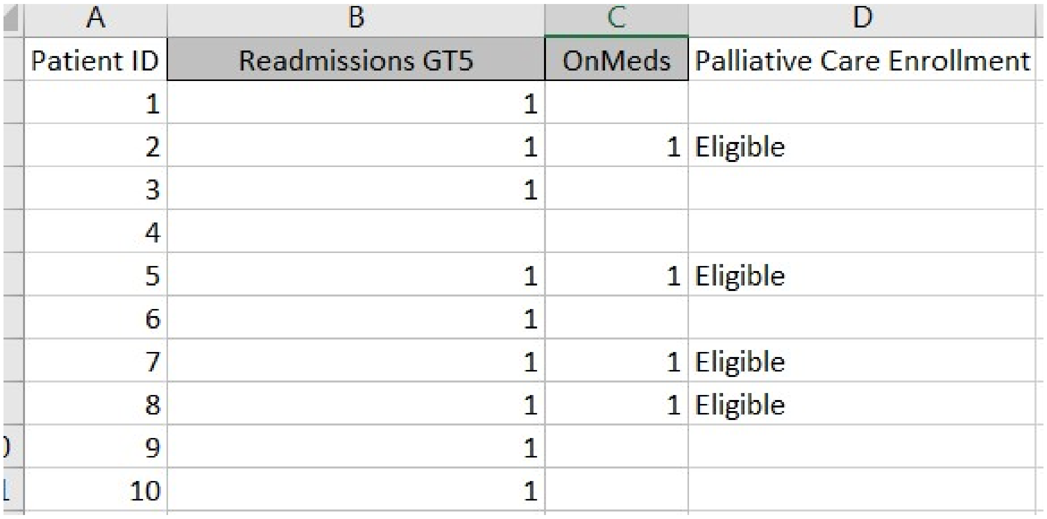
The goal of the thesis was to develop an information systems architecture for supporting palliative care clinical research using a standardized methodology. As discussed below, three research questions were specifically explored. This chapter discusses the answers to the research questions and presents some of the exploratory visual analytics developed using Tableau.

Findings

The thesis was written to address the following research questions:

1. **What data currently exist in medical records that could inform providers around the need for palliative care enrollment?**

During the discussion, the hospital data warehouse and the electronic health record system were found to be good data sources for building the registry for palliative care research purposes. The registry can be periodically populated from the data warehouse and can serve as a good research database for palliative care to study outcomes and improve enrollment in PC. The prototype registry has two outcome variables which can be used for palliative care enrollment – a flag to indicate if re-admissions is greater than 5 with a period of 6 months, and a flag to indicate if a patient is on a very high dose of pain medication, as shown in the figure below. If both the criteria are met, then the patient is eligible for palliative care enrollment.



A	B	C	D
Patient ID	Readmissions GT5	OnMeds	Palliative Care Enrollment
1	1		
2	1	1	Eligible
3	1		
4			
5	1	1	Eligible
6	1		
7	1	1	Eligible
8	1	1	Eligible
9	1		
10	1		

Figure 5: Table with hospital readmissions and pain medication data to determine palliative care enrollment

The above data can be used by palliative care specialists to compile a list of cancer patients eligible for palliative care. This list could be sent periodically to oncologists for review. The oncologists can then analyze the patients' records from the electronic health record system and determine if the recommended patients can be enrolled in palliative care. This combination of automated referral and clinical-based referral, as discussed in the literature review, would be ideal for better palliative intake and outcomes.

2. **What information architecture is required to establish a palliative care registry to research and explore improvements in palliative care enrollment?**

As discussed in Chapter 3, a registry prototype database was established, and some preliminary analytics were performed to study palliative care outcomes. The proposed architecture provides a solution to enhance the database to a full-fledged registry with preliminary criteria for identifying cancer patients who could be enrolled for palliative care. The basic requirement of this project was to develop a prototype database to meet the research needs of the palliative care team. The purpose of the database was to simply provide data for research papers that would generate funding for research projects. But the long-term goal of the team was to improve enrollment in palliative care. The purpose of this thesis was to research and explore improvements in the existing system to meet this long-term goal. A solutions architecture model was developed based on the data-warehouse as the primary data source. The suggested model is flexible and can accommodate additional data sources, such as patient survey data, and hospital administration data that could be added to meet future needs. Here are some visual analytics developed using Tableau to explore improvements in palliative care enrollment.

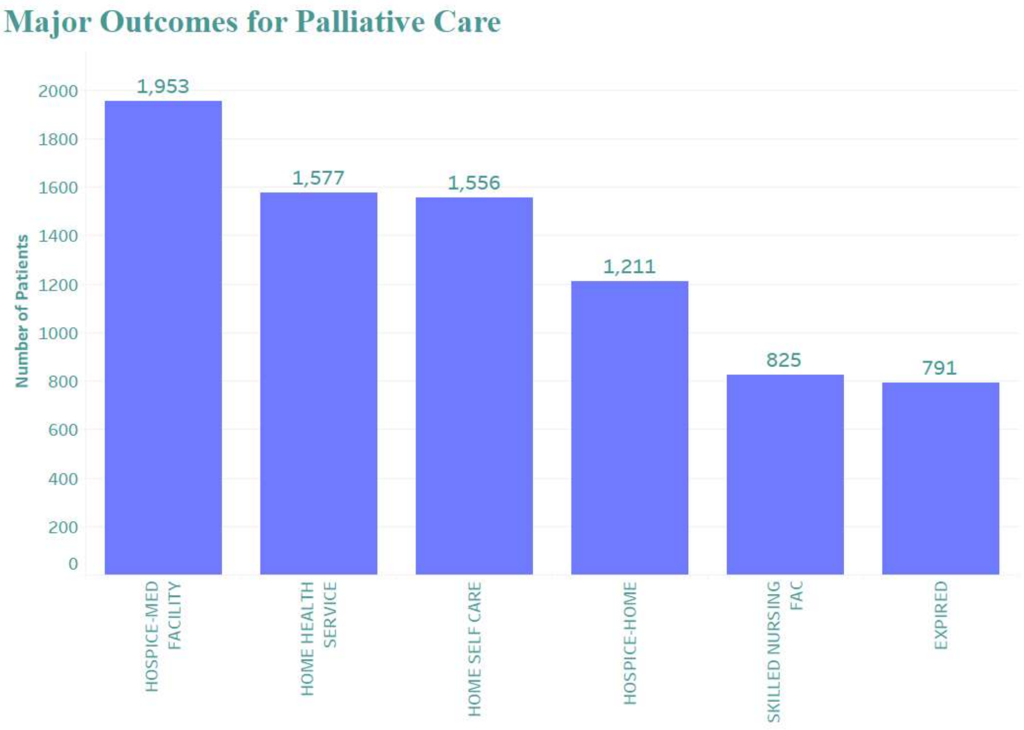


Figure 6: Major Outcomes include Hospice, Home Health Service, Home Self-Care, Hospice-Home care, Skilled Nursing Facility, and Expired

Figure 6 shows the major outcomes of cancer patients enrolled in palliative care. Most of them were discharged to hospice-med facility, followed by home health service and home self-care, hospice-home care, skilled nursing facility, and death. This kind of outcome analysis could be used to identify trends in outcomes over time and provides an insight into the quality of the palliative care service.

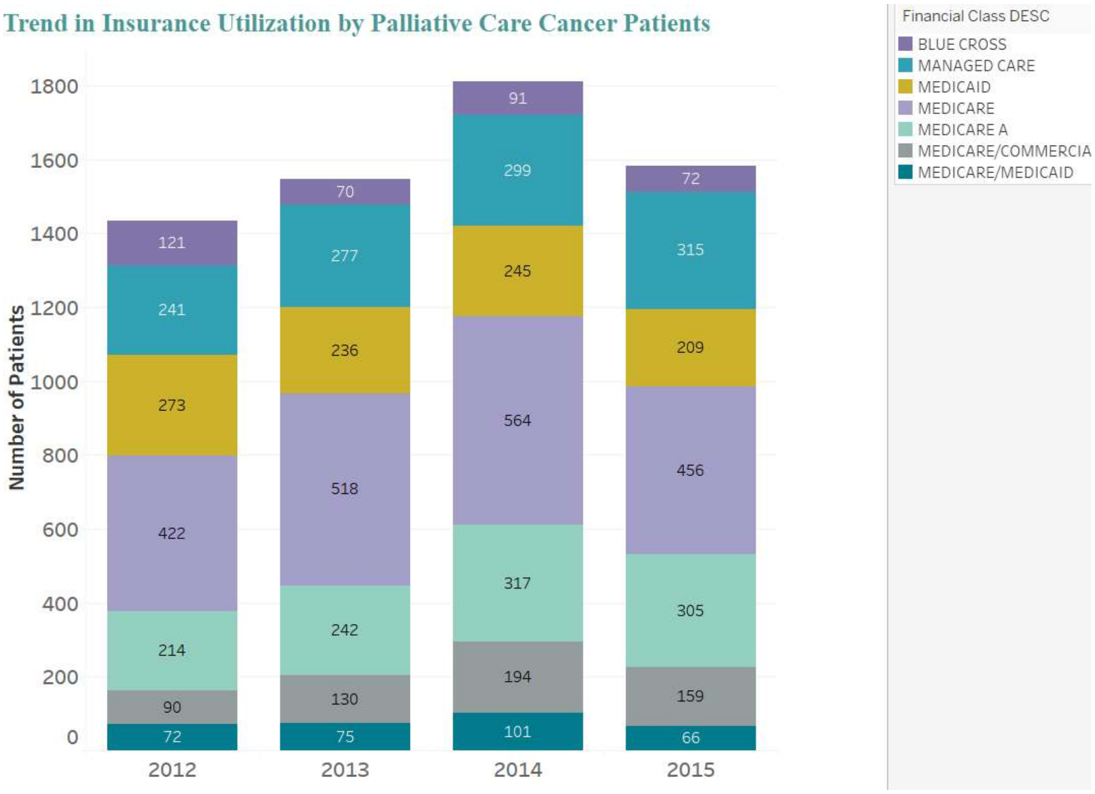


Figure 7: Insurance Utilization

Figure 7 shows the trend in insurance utilization by palliative care cancer patients. Most of them used Medicare, Managed Care, Medicare A, and Medicare/Commercial for paying their hospital bills. Among the commercial insurance, Blue-Cross was widely used. Analysis of insurance utilization shows how insurance coverage affects palliative care enrollment. This kind of analysis enables palliative care specialists and hospital administration navigate health programs to enroll more cancer patients in palliative care.

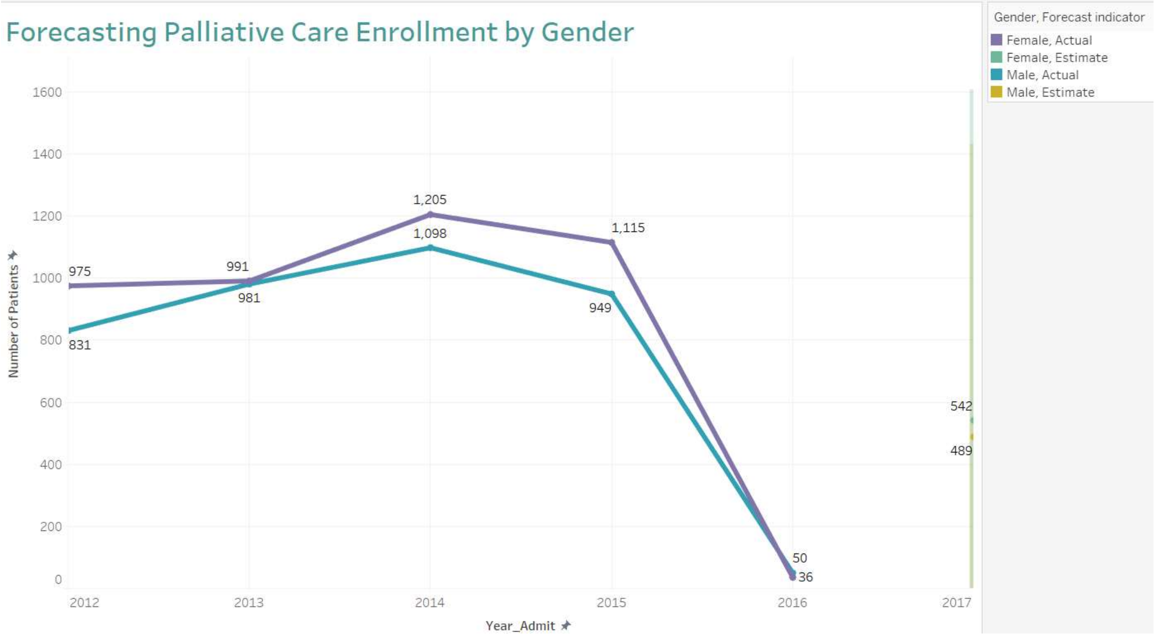


Figure 8: Forecasting Palliative Care Enrollment for Cancer Patients

The above figure shows the trend in palliative care enrollment by gender for cancer patients. We see a decreasing trend in 2016 and forecast values of 542 for female patients and 489 for male patients in 2017. This visual graph can be used by the palliative care department and hospital administrators to analyze the reasons for decreasing enrollment, and to take adequate measures to improve palliative care enrollment.

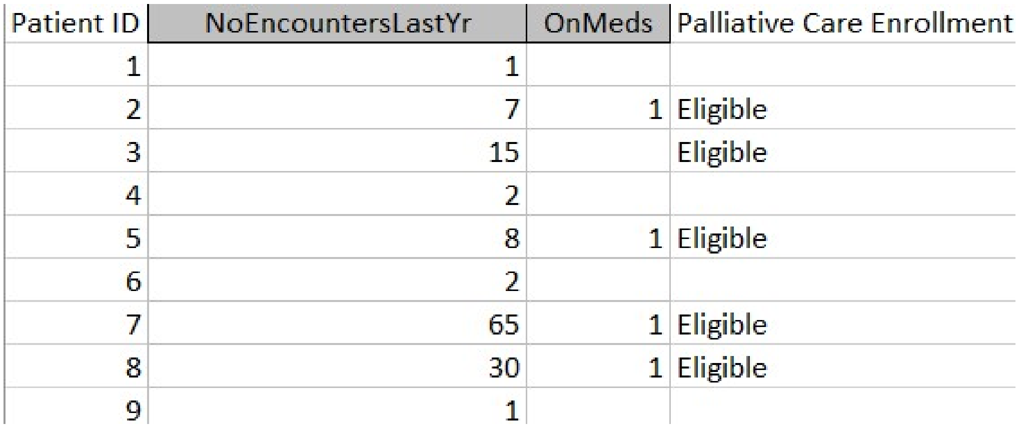
3. **What kind of preliminary algorithm be developed to identify cancer patients in need of palliative care?**

As discussed in Chapter 3, the preliminary algorithm in Table 1 included:

a. Combination of ICD-9 code for cancer and high-utilization rate

b. Combination of ICD-9 code for cancer and limited functional status

c. Combination of ICD-9 code for cancer and any of the PC uncontrolled symptoms



Patient ID	NoEncountersLastYr	OnMeds	Palliative Care Enrollment
1	1		
2	7	1	Eligible
3	15		Eligible
4	2		
5	8	1	Eligible
6	2		
7	65	1	Eligible
8	30	1	Eligible
9	1		

Figure 9: Pain medication and hospital encounter data, considered individually for palliative care enrollment

Figure 9 shows two fields – a flag for high dose of pain medication and the number of patient-hospital encounters. The number of hospital encounters with the ICD-9 code for cancer can be used to identify patients in need of palliative care. Similarly, the flag for high dose of pain medication indicates uncontrolled pain symptom. These two flags, along with the ICD code for cancer care, can be used independently to determine eligibility for palliative care enrollment.

Conclusion

Based on the registry prototype that was developed for simple research purposes, a solutions architecture was developed to build a full-fledged registry with standardized methodology to improve palliative care research and enrollment. Also, preliminary criteria for selecting cancer patients for palliative care were developed. Using these criteria, cancer patients who are eligible for palliative care were flagged. This list of prospective palliative care patients could be sent to oncologists for patient review and enrollment in palliative care. Once the criteria and process for selecting palliative care patients have been validated, the criteria for selection can be used to create an automatic trigger in the patients' electronic heath record. Cancer patients can be then be automatically identified for palliative care enrollment based on validated algorithms that can incorporated in the research registry and the patient electronic health record system. Thus, the registry prototype can be expanded to a full-fledged palliative care registry based on the architectural design suggested in this thesis.

This registry can have more than one data source – currently, the primary data source is the data warehouse. In addition to this, patient surveys can be incorporated in the registry and can become a reliable source of patient-reported outcomes. The palliative care outcomes data can be used to improve the quality of palliative care services and hence increase palliative care enrollment. The registry prototype has already become a major source of clinical data for palliative care research papers.

Limitations and Delimitations

This project had limitations and delimitations.

Limitations

1. This was only a registry prototype done with palliative care patients at the center between 2012 and 2017 (N=8381).

2. Only preliminary exploratory analyses were done on this population.

3. The only data source considered was the university's data warehouse.

Delimitations

1. The proposed architecture is viable because the data fields exist in the data warehouse and extracts from this data source can be done periodically to keep the registry updated.

2. The exploratory analyses demonstrated that it is possible to establish standardized templates in Tableau to perform in-depth analyses

3. Additional data sources could be added in the future, one of which is periodic data export from the electronic health records system. Other data sources that would improve the quality of research data include patient survey data collected using validated survey instruments for palliative care; and hospital administration data. This would provide a more accurate view of the quality and level of service provided at the palliative care center.

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