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FACTORS IMPACTING SERIOUS ILLNESS CARE IN ALABAMA: AN
ASSESSMENT OF THE CURRENT STATE OF HOSPITAL PALLIATIVE CARE

by

AMY M. BEASLEY

MARIE BAKITAS, COMMITTEE CHAIR
NATALIYA IVANKOVA
DIO KAVALIERATOS
J. NICHOLAS ODOM
RODNEY TUCKER

A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2023

FACTORS IMPACTING SERIOUS ILLNESS CARE IN ALABAMA: AN
ASSESSMENT OF THE CURRENT STATE OF HOSPITAL PALLIATIVE CARE

AMY M. BEASLEY

NURSING

ABSTRACT

BACKGROUND: Palliative care (PC) use has been shown to offer many benefits to patients and families. Hospital PC has expanded in the United States, though growth has been limited within hospital types and geographic locations. According to the Center to Advance Palliative Care (CAPC), Alabama was rated a “D,” indicating that significant improvements in PC are needed. The purpose of this study was to develop a thorough description of access to palliative care in Alabama hospitals.

METHODS: A mixed methods multiple case study was employed with quantitative data embedded into a qualitative case study approach. Four hospitals were selected based upon the existence or nonexistence of PC and additional factors. Quantitative data collection included environmental factors and a descriptive hospital survey. Qualitative data collection included semi-structured interviews and analysis of documents related to serious illness care. Quantitative data were analyzed using descriptive statistics and qualitative data were analyzed using NVivo to generate codes and themes for within cases and through a cross-case analysis.

RESULTS: Hospitals with PC were large, in an urban setting, nonprofit, and served multiple rural counties, while hospitals without palliative care were for-profit and served

a smaller catchment area, with a focus of care on surgical and maternal/child services. The impetus for PC was clinician champions, supportive hospital administration, and mission fit despite limited funding. Serious illness care at hospitals without PC was focused on end-of-life care and goals of care conversations. All hospitals used critical care rounding; however, the disciplines and discussions included in the rounds differed. Hospitals with PC included intensivists, chaplains, and a PC team member, while hospitals without PC completed case management rounding that focused on discharge planning. Serious illness and palliative care training was offered during orientation and through continuing education at hospitals with palliative care. Hospitals without palliative care offered few voluntary training opportunities related to serious illness care.

CONCLUSION: Environmental factors, such as location, and hospital characteristics, such as ownership, support previous literature on the existence of PC. Factors that were present in hospitals with palliative care included palliative care champions, intensivists, multidisciplinary rounding, and focused palliative care training.

Keywords: palliative care, hospital palliative care, Alabama, serious illness

DEDICATION

To my grandparents, Mimi and Granddaddy. The passion for hospice and palliative care would not have been ignited without you.

To each and every hospice patient and family who included me in their journey.

To Randy and my sweet boys, Brayden, Tanner, and Jace. Thank you for the continued love, encouragement, and hugs.

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CHAPTER 1

INTRODUCTION

The Center to Advance Palliative Care (CAPC) defines palliative care as “medical care for people living with a serious illness that focuses on providing relief from the symptoms and stress of the illness with the goal of improving quality of life for both the patient and the family” (2017a, para. 2). Palliative care uses an interdisciplinary team approach that focuses on the management of physical, psychosocial, and spiritual needs (CAPC, 2017a). As the incidence of chronic disease continues to rise with the aging population, palliative care is a useful resource for disease management. Numerous benefits are associated with palliative care, especially with early access to these services. Palliative care has been shown to improve quality of life and reduce symptom burden for patients (Diop et al., 2017; Kavalieratos et al., 2016). Early access to palliative care has also been shown to improve survival for patients with cancer (Bakitas et al., 2009; Bakitas, Tosteson, et al., 2015; Temel et al., 2010). Additional studies have shown that palliative care can reduce pain or symptom burden for individuals living with chronic non-cancer illness (Bakitas et al., 2020; Elsayem et al., 2004; Rabow et al., 2004). In addition to benefits for the patient and caregiver, early palliative care programs reduce healthcare expenditures (May et al., 2018; Morrison, Dietrich, et al., 2011). Despite these known benefits and despite the growth of hospital-based palliative care throughout the

United States, access to these crucial services remains limited in the Southeast United States, including Alabama (CAPC, 2019a).

Problem Statement

Currently, there are 12 million adults in the U.S. living with serious illness (Hayes et al., 2016). A large percentage of these patients may benefit from palliative care. As noted, numerous studies have demonstrated the benefits of palliative care for patients with serious illness as well as their caregivers (Diop et al., 2017; Gaertner et al., 2017; Kavalieratos et al., 2016; Quinn et al., 2020). Access to palliative care has expanded in some hospitals and geographical areas, especially teaching hospitals and hospitals located in urban areas (CAPC, 2019a). Geographic location, hospital ownership, and hospital size have been identified as factors that impact the presence of hospital-based palliative care programs (CAPC, 2019a). It is believed that additional factors that impact the creation and continuation of palliative care programs within hospitals exist but have not been identified in the literature. Understanding which factors or hospital characteristics affect palliative care implementation may provide a roadmap for increasing access to palliative care for persons with serious illness. This is especially true for Alabama (CAPC, 2019a; James et al., 2010), a state with one of the highest rates of chronic illness and one of the lowest rates of hospital-based palliative care (CAPC, 2019a; Newman, 2020).

Background and Significance

Access to hospital-based palliative care in the U.S. has increased over the past decades, in part due to increasing evidence of the multiple benefits to patients, caregivers,

and health systems. However, in the Southeast U.S., especially in Alabama, growth of hospital-based palliative care is still lagging. According to the CAPC State-by-State Report Card (2019a), palliative care programs in U.S. hospitals with 50 or more beds climbed from 67% in 2015 to 72% in 2019. However, nearly a fourth of states, largely those with extensive rural areas, still received a grade of C or D for palliative care availability (A is the best; F is failing) (CAPC, 2019a). Alabama, for example, was rated a D in 2015, and the grade remained a D in 2019 (CAPC, 2015; CAPC, 2019a). The reasons for lower rates of adoption in practice are poorly understood and understudied. Based on literature from other states, some characteristics specific to Alabama that may be responsible include (a) limited palliative care workforce, (b) hospital characteristics, and (c) limited palliative care reimbursement. Despite the fact that a high burden of chronic illness in difficult to reach, under-represented and under-resourced populations remains. Each of these areas of significance is briefly discussed below.

Limited Palliative Care Workforce

A trained palliative care workforce remains limited within the United States. The Joint Commission's standards for the Advanced Certification Program for Palliative Care calls for core staffing that consists of a physician, an advanced practice or registered nurse, a social worker, and a chaplain (Spetz et al., 2016). Approximately 25% of U.S. hospitals with a palliative care program have funded staff members who fulfill this Joint Commission standard of an interdisciplinary team (Spetz et al., 2016). This is particularly concerning because the number of patients eligible for palliative care will continue to rise at a faster rate than the number of palliative care physicians (Kamal et al., 2017). The

lack of growth in the number of physicians is estimated to be similar for other members of the palliative care team; however, the literature is limited in describing the expected lack of growth for these team members (Kamal et al., 2017).

Hospital Characteristics

Hospital characteristics play an important role in understanding access to palliative care. According to the CAPC, hospitals in urban areas that offer a greater number of beds, are associated with a teaching institution, and are nonprofit are more likely to provide palliative care services (Rogers et al., 2020). For example, 94% of U.S. hospitals with more than 300 beds offer palliative care, while only 62% with 50 to 299 beds have a palliative care team. In Alabama, only 17 of Alabama's 90 general hospitals have more than 300 beds, while 48 have 50 to 299 beds and 25 have fewer than 50 beds. Of note, almost all of Alabama's hospitals are located in rural communities (Alabama Hospital Association, 2021). As noted by the CAPC, the access to palliative care is also less available in rural than in urban locations (Rogers et al., 2020). Rural hospitals most often serve a smaller population and have a lower number of hospital beds. The limited number of teaching hospitals could potentially be one factor in lower prevalence of hospital palliative care in Alabama. Alabama offers only two large teaching hospitals, the University of Alabama at Birmingham Hospital and the University of South Alabama Medical Center (Dartmouth Atlas, 2021a). Lastly, 33.3% of hospitals in Alabama operate on a for-profit basis, as compared to only 23.9% nationally (Kaiser Family Foundation, 2021). This may impact the prevalence of palliative care within Alabama, since nonprofit hospitals are more likely to have palliative care.

Limited Palliative Care Reimbursement

Early introduction of palliative care is often associated with lower costs. Morrison et al. (2008) found that seriously ill patients with hospital stays greater than 7 days who received palliative care services incurred significantly lower costs than patients who received usual care. Additionally, a recent meta-analysis found that patients with serious illness who were referred for palliative care consults within 3 days of hospital admission incurred \$3,000 less in hospital costs than patients with serious illness who were not referred to palliative care (May et al., 2018). Despite the evidence for the cost-saving benefits of palliative care, access to palliative care services in Alabama may be impacted by limited payors that offer specific palliative care benefits.

Since 1982, U.S. Medicare has provided payment for hospice services for patients with a terminal illness and a life expectancy of 6 months or less (Centers for Medicare and Medicaid Services, 2016). Additionally, state Medicaid programs and other private insurers cover hospice services. Palliative care visits may be billed on a fee-for-service basis; however, this type of billing does not cover all the services provided by an interdisciplinary palliative care team (CAPC, 2017d). For example, social worker and clergy services are not covered by either the Medicare or Medicaid fee-for-service model. There is a growing awareness among payers and policymakers of the benefits of all palliative care services, but, regrettably, the payment system remains a limitation for the expansion of palliative care. Finally, Blue Cross Blue Shield, the largest commercial insurer in Alabama, does offer a serious illness care coordination program though there are specific triggers and not all insured are eligible (Blue Cross Blue Shield, 2023).

A High Burden of Chronic Illness in Alabama in Difficult to Reach, Under-Represented and Under-Resourced Populations

Serious illnesses that impact patients include chronic kidney disease, chronic obstructive pulmonary disease, cardiovascular disease including heart failure, and cancer. Prevalence of multiple chronic conditions (adults with three or more chronic health conditions) is 9.6% of the U.S. population (United Health Foundation, 2023). According to the Behavioral Risk Factor Surveillance System put in place by the Centers for Disease Control and Prevention (CDC), Alabama is ranked among the worst four states (35.8% of Alabama adults have two or more chronic conditions) in patients suffering from multiple chronic conditions (Newman, 2020). Palliative care benefits those with serious, chronic illness and therefore could have an especially large impact in Alabama.

Study Purpose

The purpose of this mixed methods multiple case study was to develop a thorough description of access to palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. To do this, we identified four hospitals as cases that represent palliative care service availability (two with and two without established palliative care programs), a spectrum of size (greater or less than 150 beds), and geographical location (rural versus urban). Quantitative and qualitative data were collected, analyzed, and integrated for the four selected hospital cases. The goal of the quantitative strand was to examine environmental factors, hospital characteristics, and processes related to serious illness and palliative care by performing an environmental scan of publicly available data to develop individual hospital profiles and by surveying administrators who work at the

four selected Alabama hospitals. The goal of the qualitative strand was to obtain an in-depth understanding of how these same factors, characteristics, and processes influence access to palliative care by interviewing purposefully selected hospital clinicians and administrators in the same Alabama hospitals. Integration of the results from the quantitative and qualitative strands within and across the four hospitals yielded a more thorough description of how these factors may influence palliative care access in Alabama.

The research aims of this study were:

Aim 1 (Quantitative): To explore environmental factors and hospital characteristics and processes related to serious illness and palliative care in four Alabama hospital cases (by using environmental scan and utilizing an adapted National Palliative Care survey). The two research questions for Aim 1 were:

R.Q. 1.1: What hospital and environmental factors (e.g., community demographics, economic stability, education access, and healthcare access) and palliative care resources are associated with the four Alabama hospital cases?

R.Q. 1.2: How do hospital demographics and characteristics such as staffing, education, and resources compare across the four Alabama hospital cases?

Aim 2 (Qualitative): To explore how environmental factors and hospital characteristics and processes influence access to serious illness and palliative care from the perspective of hospital clinicians and senior hospital managers in four Alabama hospitals. The research questions for Aim 2 were:

R.Q. 2: What are the perspectives of hospital clinicians and senior hospital managers about serious illness care and, if available, palliative care within their respective hospital?

R.Q. 2.1: What are the similarities and differences across the hospital administrators' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

R.Q. 2.2: What are the similarities and differences across the clinician leaders' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

R.Q. 2.3: What are the similarities and differences across the frontline clinicians' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

Aim 3 (Mixed Methods): To develop a thorough description of access to palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. The research question for Aim 3 was:

R.Q. 3: In what ways is serious illness or palliative care provided in Alabama based on the integration of the environmental factors and quantitative survey results and qualitative interview and document analysis findings from the four different Alabama hospitals?

Assumptions in this study included that the data obtained through the survey would provide an accurate description of serious illness care within the selected hospitals.

It was also assumed that the information obtained from the participants in this study represented their voice or “truth space” (Onwuegbuzie & Teddlie, 2003, p. 369). We assumed that participants had experience with the phenomenon that we were exploring, palliative care for patients with serious illness, and that they were willing to participate in the study.

Introduction of the Conceptual Framework

The Bainbridge conceptual framework for the evaluation of palliative care integration (Bainbridge et al., 2010) guided this study. Utilizing the structure, process, and outcome constructs that were originally developed in Donabedian’s model (1966), this conceptual framework is a logical fit for the current study. That is, the conceptual model lends itself to collection of quantitative and qualitative data describing the structure and care processes to reveal the existing components of hospital care for patients with serious illness and their families. Additionally, one domain, the structure and process of care, from the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care (4th edition), was incorporated within the framework (National Coalition of Hospice and Palliative Care, 2018). The conceptual framework and the NCP Clinical Practice Guidelines for Quality Palliative Care are presented in detail in Chapter 2.

Introduction of the Design and Methods

This study used a mixed methods case study design. The chosen design embeds mixed methods within a case study, “intersecting the assumptions, intents, logics and

methods to more completely describe and interpret the complexity and theoretical importance of a case or cases” (Plano Clark et al., 2018, p. 20; Plano Clark & Ivankova, 2016; Walton et al., 2019). A mixed methods case study design offers greater insight, compared to a single-method design, into the complexities of assessing healthcare services within a real-life context and allows comparison among cases that do and do not have an established palliative care program in selected Alabama hospitals (Bakitas, Elk, et al., 2015a; Plano Clark et al., 2018; Walshe et al., 2004). A total of four cases were included for this study, allowing for opportunities for comparison and divergence between hospitals that do and do not have an established palliative care program (Stake, 2006). Factors to the adoption or closure of palliative care programs (e.g., geographic location, hospital size) led to for the selection of the four hospitals that were used to study the phenomenon of palliative care access (Stake, 2006).

Definitions

The following definitions are used in this study:

Access: the timely and appropriate availability of palliative care services designed to improve quality of life for the patient and family; this includes gaining access to the location where services are provided and to providers who have been trained to provide the appropriate care (CAPC, 2019a; Institute of Medicine, 1993).

Case Study: a research method that provides a holistic understanding of a phenomenon of interest by using multiple methods of data collection within the context of each case (Stake, 2006).

Center to Advance Palliative Care (CAPC): a national organization focused on increasing availability of palliative care services. CAPC provides resources for healthcare professionals and organizations to support the growth of palliative care (CAPC, 2022).

Comparative Case Study: involves gathering data on numerous cases that are similar in nature and ultimately integrating the results; these cases include multiple sources of data collection, such as interviews, documentation, and observation (Stake, 2006).

Donabedian Model of Structure, Process, and Outcomes: a model that allows inferences to be drawn related to the quality of care through assessing structure, process, and outcome. Structure includes “attributes of the settings in which care occurs.” Process includes “the care that is given and received.” Outcome “denotes the effects of care on the health status of patients and populations” (Donabedian, 1988).

Hospice Care: specialized care that is provided to patients with a terminal illness within their last 6 months of life (National Hospice and Palliative Care Organization, n.d.).

Hospital-based Palliative Care: a form of palliative care that is performed within the acute care setting with a focus on coordinated and efficient care in partnership with other members of the patient’s care team (CAPC, 2015).

Hospital Care Intensity (HCI): a strategy developed by the Dartmouth Atlas of Health Care that uses data to determine the use of acute hospital care in the management of serious illness. The HCI evaluates both the amount of time patients remain in the hospital and the intensity of services provided while in the hospital (Dartmouth Atlas, 2021b).

Hospital Referral Region (HRR): geographic delineations created by the Dartmouth Atlas of Health Care that utilize Medicare data to identify regions with a population of at least 120,000 people and at least one hospital that provides major cardiovascular surgical procedures and neurosurgeries (Dartmouth Atlas, 2021c).

Mixed Methods Case Study Design: embeds mixed methods within a case study, “intersecting the assumptions, intents, logics, and methods to more completely describe and interpret the complexity and theoretical importance of a case or cases” (Plano Clark et al., 2018, p. 20; Plano Clark & Ivankova, 2016; Walton et al., 2019).

Mixed Methods Research: combines approaches used in quantitative and qualitative research to create a triangulated and in-depth understanding of the topic of interest (Creswell & Plano Clark, 2018).

National Consensus Project (NCP) Guidelines: “a blueprint that provides core concepts and structures and processes necessary for comprehensive foundation for gold-standard palliative care (National Coalition for Hospice and Palliative Care, 2018).

National Palliative Care Registry: an optional program that provides profiles of palliative care teams, operations, and service delivery information of enrolled hospital palliative care programs (CAPC, n.d.).

Palliative Care or Non-hospice Palliative Care: “medical care for people living with a serious illness that focuses on providing relief from the symptoms and stress of the illness with the goal being to improve quality of life for both the patient and the family” (CAPC, 2017a, para. 2).

Serious Illness: “carries a high risk of mortality and either negatively impacts a person’s quality of life or excessively strains their caregivers” (CAPC, 2017b, para. 2).

Social Determinants of Health (SDOH): “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (CDC, 2022).

Chapter 1 Summary

Palliative care access remains a challenge in Alabama. The factors that contribute to this access challenge have not been studied but based on available data likely include (a) limited availability of palliative care services, (b) hospital characteristics (e.g., rural, small size), (c) limited palliative care reimbursement and state healthcare policy, and (d) a high burden of chronic illness in difficult to reach, under-represented and under-resourced populations. An adapted Bainbridge Conceptual Framework for the Evaluation of Palliative Care Services at a Hospital Level was used to guide this study’s design. In addition, the design incorporates the NCP Clinical Practice Guidelines for Quality Palliative Care (Bainbridge et al., 2010). This study utilized a mixed methods case study approach to understand the structure and processes of each of four hospitals (cases) that may contribute to palliative care or serious illness care access in Alabama. This chapter introduced the problem, background and significance, purpose, aims and research questions, conceptual framework for the study, and the methods that were utilized. In the next chapter, a comprehensive literature review on the factors that impact palliative care access offers evidence for the need for this study.

CHAPTER 2

INTEGRATIVE LITERATURE REVIEW

The purpose of this chapter is to provide an integrative review of palliative care access including facilitators and barriers of palliative care for patients with serious illness. This chapter includes (a) introduction, (b) epidemiology and concepts of interest, (c) integrative literature search strategy, (d) literature synthesis, (e) theoretical framework, and (f) design and methods.

Introduction

The current palliative care framework was built on the foundation of hospice care, holistic care provided to patients and families that is focused on symptom management and quality of life within the last 6 months of a terminal illness (National Cancer Institute, 2021; National Institute of Aging, 2021). Formal hospice care initially began in the United Kingdom in the 1950s and grew to prominence in the United States during the 1960s and 1970s (Clark, 2014; National Hospice and Palliative Care Organization [NHPCO], 2021). Hospice was developed in response to concerns regarding care for the elderly and dying (Clark, 2014). The benefits of such holistic care did not go unnoticed, and in 1982, Congress passed a Medicare provision for a hospice benefit (NHPCO, 2021), impacting access to care for dying patients and their family members.

A historical shift in hospice began when the World Health Organization (WHO) published a definition of palliative care in 1990. WHO (1990, p. x11 defined palliative care as the “care of patients whose disease is not responsive to curative treatment and that control of pain, of other symptoms and psychological, social and spiritual problems is paramount.” Since this first definition, palliative care has expanded into different models of care used in various patient populations and is provided in combination with curative treatments. What began as a field to care for the dying in the final weeks or months of life has evolved into a subspecialty to care for patients and their families who need holistic support through serious illness. This subspeciality is now known to be beneficial for all patients with serious illness anywhere along the disease trajectory. Palliative care provides a holistic care approach to serious illness that addresses physical, psychological, social, and spiritual domains. Palliative care has been found to provide numerous benefits for the patient and family, especially when initiated relatively early in the disease trajectory (Bakitas et al., 2020; Bakitas, Tosteson, et al., 2015; Dionne-Odom et al., 2015; Temel et al., 2010). Though access to these services has increased over the years, it remains inadequate for some patients (Dumanovsky et al., 2016).

Epidemiological Basis and Concepts of Interest

This section will address the epidemiologic basis and concepts of interest related to hospital-based palliative care. These concepts include (a) an overview of palliative care, (b) palliative care need (epidemiology), and (c) palliative care access.

Palliative Care

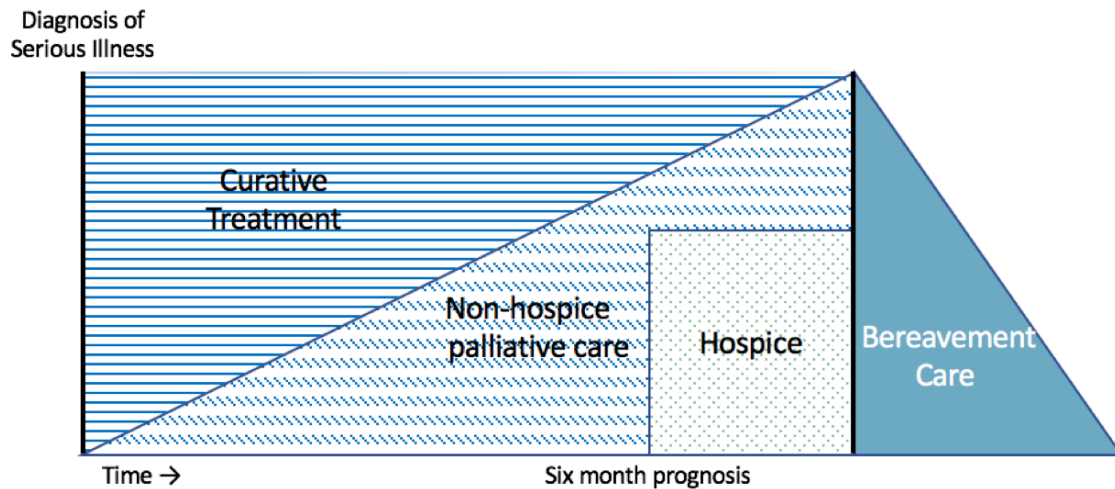
This dissertation used the following definition of non-hospice palliative care to explore access to palliative care in Alabama hospitals:

Palliative care is a patient- and family-centered approach to managing a serious illness. It offers holistic care that is provided by an interdisciplinary team to manage the patient's physical, psychosocial, emotional, and spiritual needs. It is unique in that a patient may seek aggressive and curative disease-specific treatments while a palliative care team assists in managing quality of life and seeking to honor a patient's wishes during treatment. It can be offered at any age and at any stage in the disease. (Beasley et al., 2019, p. 1360)

Beginning at the time of diagnosis of serious illness, a patient may seek curative and palliative care services that provide an extra layer of support. As the disease progresses, a decrease in use of curative services and an increase in use of palliative care is expected. As the serious illness becomes terminal, hospice would be a next appropriate step to provide the patient and the family additional supportive services. Typically, a patient at this stage in the disease trajectory is no longer seeking curative treatments and is approaching end of life. Following the death of the patient, bereavement care is provided to the family. The model of non-hospice palliative care is displayed in Figure 1.

Figure 1

Palliative Care, or Non-Hospice Palliative Care, Diagram



Note. From “Evolution and Conceptual Foundations of Nonhospice Palliative Care,” by A. M. Beasley, M. A. Bakitas, N. Ivankova, and M. R. Shirey, 2019, *Western Journal of Nursing*, 41(10), p. 1362 (<https://doi.org/10.1177/0193945919853162>). Copyright 2019 by Sage Publications, Inc.

Early palliative care, defined as care for patients with serious illness that is initiated early in the disease trajectory and can be provided along with curative treatments, is supported by numerous diverse national and international agencies. In a 2014 report, the WHO and the Worldwide Palliative Care Alliance stated that “palliative care is a human right and should be available for all” (Connor & Bermedo, 2014, p. 71). The American Society of Clinical Oncology recommended providing palliative care for patients with advanced cancer in conjunction with curative treatments (Ferrell et al., 2017). In addition, the American Heart Association/American Stroke Association issued a policy statement that palliative care “should be included in the care for patients with advanced cardiovascular disease early in the disease trajectory” (Braun et al., 2016). The

Pancreatic Cancer Action Network (2019) agreed that introduction of palliative care soon after diagnosis is beneficial for symptom management. The American College of Chest Physicians has updated care recommendations for patients with pulmonary arterial hypertension to include palliative care in conjunction with medical management (Klinger et al., 2019). As additional benefits are shown in other patient populations and access increases it is likely other organizations, including those for chronic (e.g., chronic obstructive pulmonary disease) and neurological (e.g. Parkinson's disease) illnesses, will issue statements supporting the inclusion of palliative care in long-term treatment plans.

Palliative Care Need

In previous studies examining palliative care, researchers have used publicly available mortality data to calculate the extent of need. Research has particularly focused on the need for palliative care services in patients with cancer (Gomez-Batiste & Connor, 2017; Morin et al., 2017; Murtagh et al., 2014). However, this strategy does not capture data for patients living with a serious illness who are not necessarily near death and thus not represented by mortality data, but who may benefit from palliative care services. The WHO and the Worldwide Hospice and Palliative Care Alliance published a report estimating the number of patients in need of non-hospice palliative care services (Connor & Sepulveda, 2014). The most common patient diagnoses were cardiovascular disease (38.47%), cancer (34.01%), and chronic obstructive pulmonary disease (10.36%) (Connor & Bermedo, 2014). According to one method of estimation, approximately 1.33%-7% of elderly (> 65 years old) patients in high-income countries could benefit from palliative care (Gomez-Batiste et al., 2012). Another research team found that

63.03%-69.10% of English patients who died between 2006 and 2008 could have benefited from palliative care (Murtagh et al., 2014). A more recently published study found that using a population-based approach was inadequate for calculating different levels of palliative or hospice care need (Morin et al., 2017). In the U.S. it is estimated that 28.7% of patients with a trajectory of “long term limitations with intermittent serious episodes” would benefit from palliative care (Morin et al., 2017, p. 530).

Morin et al. (2017) assessed existing population-based methods for calculation to estimate the need for palliative care using a sample dataset. This study compared three methods to provide a low estimate and a high estimate among 12 countries, including the United States (Murtagh et al., 2014; Rosenwax et al., 2005). Morin et al. (2017) found that the low estimate of need in the United States was 41% of all deaths and the high estimate was 76% of all deaths. The mortality rate in Alabama in 2020 was 64,779 individuals. Using the mortality rate with the estimate of palliative care need in the United States, it was found that between 26,559 and 49,232 Alabamians may have benefited from some form of palliative care in 2022 (Morin et al., 2017). However, it should be noted that not every patient counted as possibly benefiting from palliative care may have actually benefited (Gomez-Batiste & Connor, 2017). For example, patients most likely to benefit are female, those with “prolonged dwindling,” those with episodes of exacerbations, and the elderly (Morin et al., 2017, p. 530). Additionally, other “denominators” must be considered when estimating the need for palliative care using a public health approach (Kelley & Bollens-Lund, 2018). These denominators include the model of palliative care, types of chronic conditions, and quality measures (Kelley &

Bollens-Lund, 2018). It appears that a population-based approach to calculating palliative care need is appropriate; however, the estimates of need are highly variable.

Palliative Care Access

Palliative care access remains limited in the Southeast United States, especially within Alabama (CAPC, 2019a). According to the CAPC State-by-State Report Card (2019), access in Alabama is 39.3% within hospitals of 50 beds or more. The majority (92.9%, 13/14) of hospitals in Alabama with a palliative care program have more than 300 beds (CAPC, 2019a). Though access still remains limited in Alabama when compared to other states with the U.S., access to palliative care in Alabama was previously 32.0%; again, the majority (58%) of programs were found in hospitals with 300 or more beds (Dumanovsky et al., 2016). Overall growth has been realized since the first CAPC State-by-State Report Card; however, there is still room for additional growth for palliative care access in Alabama hospitals.

In order to understand the problem of access to quality palliative care, it is necessary to assess structure, process, and outcome as presented in the Donabedian (1988) model. These constructs were used within this study with a focus on palliative care. Specifically, the Donabedian model was utilized as the foundation of the adapted Bainbridge Conceptual Framework for the Evaluation of Palliative Care Services at a Hospital Level, which was used for this dissertation.

Structure. Structure is represented by the setting in which care is provided (Donabedian, 1988). It encompasses all resources, organizational structures, environmental factors, and manpower needed to provide care (Donabedian, 1988).

Within this study, structure included the environmental resources, hospital resources, and financial resources that may impact palliative care access for patients living with serious illness.

Process. Process refers to activities that are involved in providing care (Donabedian, 1988). It can include the processes involved in patients seeking care or of providers implementing care (Donabedian, 1988). This dissertation focused on processes related to palliative care access from the perspective of the provider, encompassing activities such as collaboration, communication, and education. Processes related to patients who seek care were not addressed.

Outcome. Outcome is illustrated by the impact of the care on patients' health (Donabedian, 1988). Outcomes can be defined by satisfaction, benefits, knowledge gained, and numerous other indicators (Donabedian, 1988). Though this study did not directly assess outcomes, the assumption was made that if quality structures and processes were in place, quality palliative care access would be the outcome (Bainbridge et al., 2010; Donabedian, 1998).

Conceptual Framework

For this study, an adapted version of the Conceptual Framework for the Evaluation of Integrated Palliative Care Networks was utilized (Bainbridge et al., 2010). This framework was developed using the foundation of the Donabedian (1966) structure, process, and outcome framework, which is shown in Figure 2. The Donabedian framework is commonly used in health services research to assess to quality healthcare and was beneficial in the evaluation of palliative care access within this study (Burns,

1995; Flood, 1994). The Bainbridge et al. (2010) conceptual framework was informed by the concepts of (a) collaborative care, (b) community readiness, and (c) patient-centered care.

Collaborative Care

Collaborative care has multiple definitions; however, collaboration within palliative care is focused on the inclusion of interdisciplinary team members and care coordination to improve patient and family care (Bainbridge et al., 2010; Pfaff & Markaki, 2017). One of the underpinnings of collaborative care involves communication between providers, patients, and families to establish patient-centered goals (Beasley et al., 2019; Pfaff & Markaki, 2017). Collaborative care and the interdisciplinary team will look different depending on factors such as the palliative care model being used, geographic location, patient condition, and program funding (Gaudet et al., 2014; Zimmermann et al., 2014).

Community Readiness

Community readiness, and organizational readiness, is an antecedent to palliative care development and can be described as a community's empowerment and eagerness to develop palliative care services (Bainbridge et al., 2010; Kelley et al., 2011). Variables that should be considered when assessing community readiness include (a) community awareness of palliative care, (b) training and education available for providers, (c) presence of a provider, (d) geographic makeup of the community, (e) hospital types (non-profit versus for-profit), (f) environmental factors (i.e., social determinants of health), and

(g) community momentum to move forward with change (CAPC, 2019a; Crooks et al., 2018).

Patient-Centered Care

Patient-centered care is the core of palliative care and focuses on each patient's values, needs, and preferences (Bainbridge et al., 2010; Meier, 2013). Palliative care includes the entire family unit: the patient, the family, and additional caregivers. Patient-centered care includes development of an individualized plan for each patient that offers informed decisions on treatments, medications, and advance care planning (Akyar et al., 2019).

The conceptual framework for the evaluation of integrated palliative care networks is depicted in Figure 2. Structure is represented by the characteristics of the setting within which the care is provided (Donabedian, 1988). The structure domain includes (a) environmental factors, (b) program characteristics, and (c) economic factors. Process includes the activities involved in providing a palliative care program or service (Donabedian, 1988). The process domain includes (a) provider characteristics, (b) collaboration among providers, (c) information systems, and (d) organization factors. Outcome is the end result and changes based upon the strength or weakness of the structure and process domains (Donabedian, 1988). The outcome domain includes (a) patient and family satisfaction, (b) patient-centered care, and (c) continuity of care.

Figure 2

Conceptual Framework for the Evaluation of Integrated Palliative Care Networks



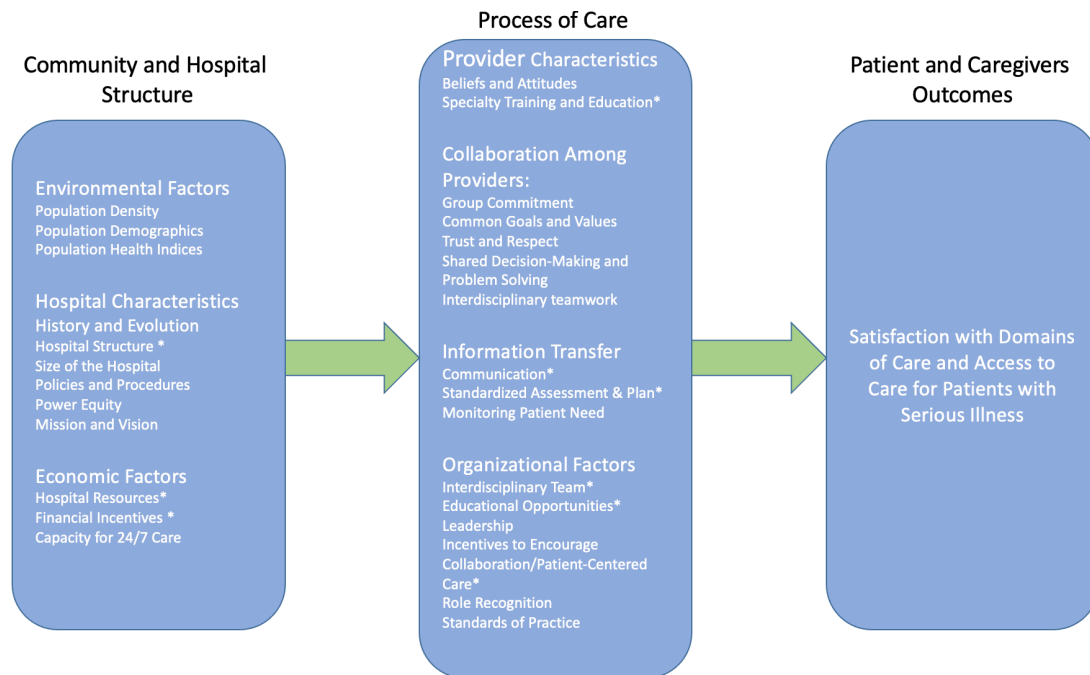
Note. From “A proposed systems approach to the evaluation of integrated palliative care,” by D. Bainbridge, K. Brazil, P. Krueger, J. Ploeg, A. Taniguchi. 2010, *BMC Palliative Care*, 9(8), p. 3 (<https://doi.org/10.1186/1472-684X-9-8>). Copyright 2010 by Springer Nature.

An adapted framework was incorporated into the study because the original conceptual framework was developed for the evaluation of integrated palliative care networks, which are currently found in countries with nationalized healthcare such as Canada, Australia, and the United Kingdom but are not found in the United States (Bainbridge et al., 2010). These networks are often developed by formal policy initiatives

and offer defined networks of healthcare organizations (Bainbridge et al., 2010). The adapted conceptual framework uses the structure, process, and outcome domains and builds on the same concepts of collaborative care, community readiness, and patient-centered care. However, the components of the constructs have been changed to reflect an evaluation of individual community hospitals. The structure domain includes (a) environmental factors, (b) hospital characteristics, and (c) economic factors. The process domain includes (a) provider characteristics, (b) collaboration among providers, (c) information factors, and (d) organizational factors. The outcome domain includes satisfaction with domains of care and access to care for patients with serious illness. The adapted framework is displayed in Figure 3.

Figure 3

Adapted Bainbridge Conceptual Framework for the Evaluation of Palliative Care Services at a Hospital Level



Note. Adapted from “A proposed systems approach to the evaluation of integrated palliative care,” by D. Bainbridge, K. Brazil, P. Krueger, J. Ploeg, A. Taniguchi. 2010, *BMC Palliative Care*, 9(8), p. 3 (<https://doi.org/10.1186/1472-684X-9-8>). Copyright 2010 by Springer Nature.

The National Coalition for Hospice and Palliative Care (NCHPC, 2018, p. v) revised the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines) to “promote access to quality palliative care” and guide organizations and healthcare providers (even non-palliative care specialists) on appropriate palliative care principles that can be integrated into practice. The NCP Guidelines are organized into eight domains that focus on aspects of excellence within palliative care (NCHPC, 2018). The structure and process of care domain was integrated within the adapted Bainbridge Conceptual Framework for the Evaluation of Palliative

Care Services at a Hospital Level. This domain focuses on coordination of care, the interdisciplinary care team, and a comprehensive palliative care assessment and planning (NCHPC, 2018). The guidelines within this domain served as areas of focus within the qualitative interviews and are marked with an asterisk in Figure 3. Table 1 provides a crosswalk between the NCP guidelines and the adapted framework.

Table 1*NCP Guidelines Crosswalk*

Structure and Process Guideline	Relevance to Palliative Care	Adapted Framework Fit
Interdisciplinary Team (IDT)	- Inclusion and importance of all members of the team for palliative care	- Organizational Factors: Interdisciplinary Team
Comprehensive Palliative Care Assessment	- Initial IDT assessment that is individualized and includes appropriate reassessments	- Information Transfer: Standardized Assessment and Plan
Palliative Care Plan	- Care plan developed with IDT that is patient- and family-centered	- Information Transfer: Standardized Assessment and Plan
Continuity of Care	- Processes in place to ensure care transitions and continuity of quality care	- Organizational Factors: Incentives to Encourage Collaboration/Patient-Centered Care
Care Settings	- Care setting	- N/A-all hospital based
Interdisciplinary Team Education	- Education, training, and professional development for IDT	- Provider Characteristics: Specialty Training and Education
		- Organizational Factors: Educational Opportunities
Coordination of Care and Care Transitions	- Patients and families should receive the right care at the right time throughout the disease trajectory	- Information Transfer: Communication
Emotional Support to the Interdisciplinary Team	- Support for IDT within the environment of resilience, self-care, and mutual support	- Organizational Factors: Incentives to Encourage Collaboration/Patient-Centered Care
		- Organizational Factors: Educational Opportunities
Continuous Quality Improvement	- Data-driven process to assess patient- and family-centered outcomes	- N/A-looking at patients and caregiver outcomes
Stability, Sustainability, and Growth	- Area of focus for growth and needs for sustainability	- Hospital Characteristics: Hospital Structure
		- Economic Factors: Hospital Resources & Financial Incentives

This study focused on the structure and process of the framework to assess the outcome of access to palliative care services. When using this framework, the assumption was made that the assessment and quality of the structure and process of a palliative care program would provide quality palliative care outcomes for patients and families (Donabedian, 1966). Additionally, there is a growing body of literature that evaluates palliative care outcomes. Future work will focus on assessment of outcomes in palliative care programs.

Integrative Literature Review

The purpose of this integrative review of literature was to gain a better understanding of current known factors that impact access to palliative care. The findings of this literature review will be organized using the Donabedian Model of structure, process, and outcome.

Search Strategy for the Integrative Review

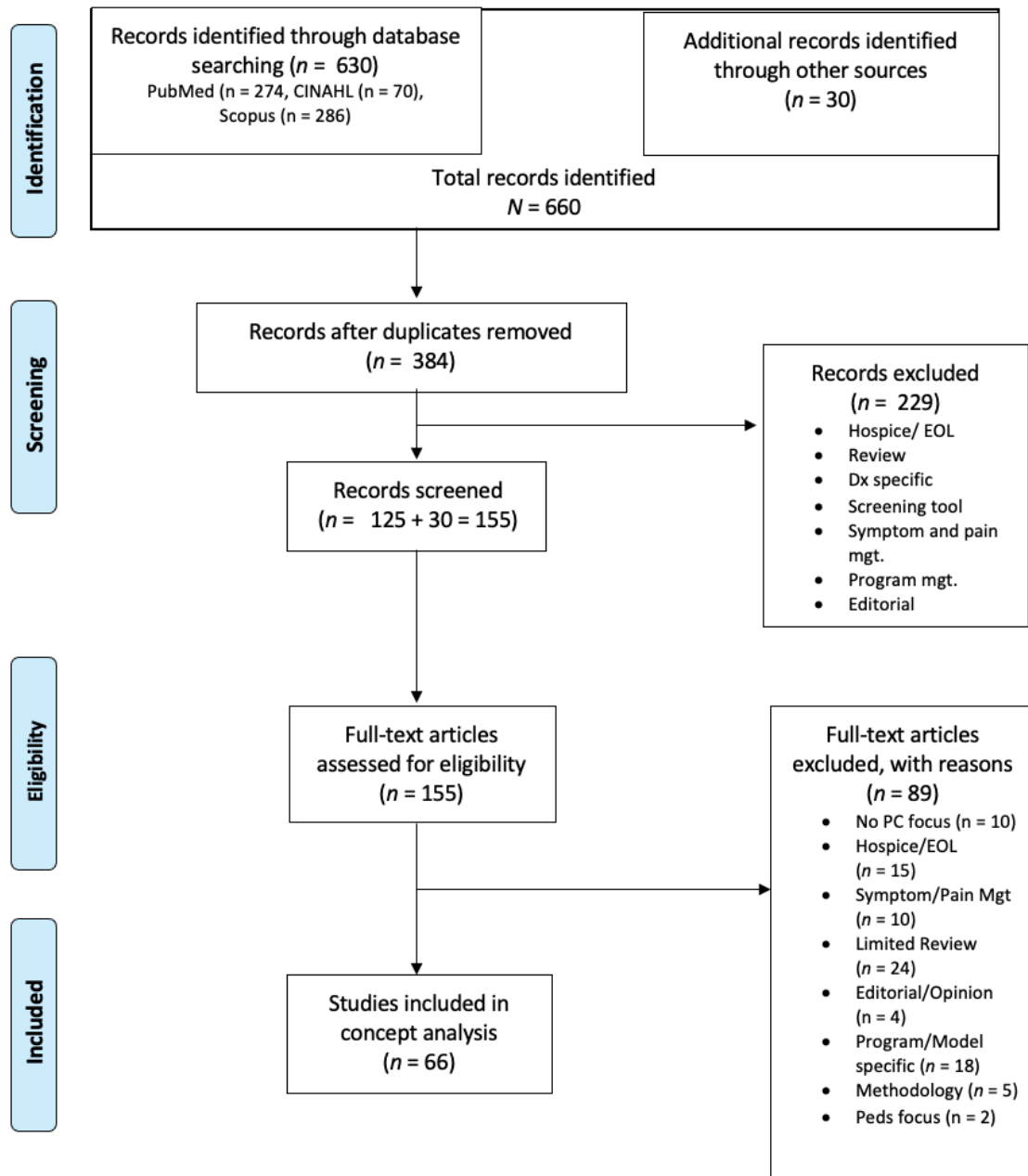
Electronic database searches were conducted using Scopus, PubMed, and CINAHL, which were available from the University of Alabama at Birmingham libraries. Searches were conducted for articles published between 2004 to 2022 with full text availability. The date of 2004 was chosen based upon the first publication of the NCP Guidelines. Additionally, few relevant publications prior to this date often referred to end-of-life or hospice care despite using the term palliative care. The terms utilized within the database searches included “palliative care,” “health services accessibility,” “health care accessibility,” “program development,” “program evaluation,” “needs

assessment,” “structure,” “process,” “hospital care intensity,” “medically underserved area,” “social determinants of health,” and “healthcare disparities.” The inclusion criteria were full-text, peer-reviewed articles written in English that focused on the subjects of palliative care access, palliative care needs assessment, palliative care program evaluation, disparities in access to palliative care, or structure and process of access to palliative care, and hospital palliative care. Non-English articles were excluded. Additional exclusions were (a) study protocols, (b) editorials, (c) program management topics, (d) topics not related to palliative care (i.e., maternity), (e) pain and symptom management, (f) end-of-life or hospice management, (g) pediatric palliative care, and (h) articles that focused on specific disease treatments within palliative care.

As shown in the PRISMA flow diagram in Figure 4, the initial search conducted by publication date yielded 630 (Scopus [$n = 286$]); PubMed [$n = 274$]; CINAHL [$n = 70$]) English language articles. In addition, 30 studies were identified by a manual search of references describing examples of palliative care program evaluation, needs assessment, or program development. After removal of duplicates there were 384 English language articles. An additional 229 articles were excluded after reviewing abstracts to assess for inclusion criteria. The 155 remaining full-text articles were assessed for inclusion. After additional exclusions, the final sample included 66 studies.

Figure 4

PRISMA Flow Diagram



Analysis of the Literature

To better understand the concepts related to palliative care access, the eligible literature was synthesized based upon the similarities and differences addressed in each

study. Of the included studies, 39 (59.2%) were conducted in the United States. Other studies were implemented in Canada ($n = 7$, 10.6%), England ($n = 4$, 6.1%), Australia ($n = 3$, 4.5%), European countries ($n = 2$, 3.0%), Germany ($n = 1$, 1.5%), Middle Eastern ($n = 1$, 1.5%), and global populations ($n = 2$, 3.0%). Additionally, seven (10.6%) review articles were included in the review of literature. A mix of quantitative, qualitative, mixed methods, Delphi study designs, and integrative reviews were included in the review. Of the mix, 29 (43.9%) used a quantitative design, 20 (30.4%) implemented a qualitative design, seven (10.6%) used a mixed methods design, four (6.1%) were from integrative reviews, three (4.5%) used a Delphi design, and three (3.5%) were from gray literature.

The results of the analysis were organized using the framework concepts of structure, process, and outcomes. As previously described, structure encompasses community and hospital attributes. In this review structure included the environmental factors, Hospital Referral Region (HRR), and Hospital Care Intensity (HCI) factors, geographic factors, economic factors, and policy and payment factors contributing to palliative care access. In the review, process included persons and activities related to providing palliative care: clinicians, palliative care education and training, assessment, and communication needs. Outcomes are the end products that result from access to quality palliative care. In this review outcomes encompassed patient/family satisfaction and palliative care benefits for patients, families, and hospitals. A portion of the articles addressed multiple factors related to structure, processes, and outcomes; these articles were presented in more than one concept within the analysis. A literature matrix is provided in Appendix A.

Structure

Environmental Factors. Nine articles that discussed the impact of environmental factors on palliative care access were identified. Environmental factors that were found to be relevant included both population and community characteristics. For example, if the population within the community has limited resources or inadequate access to primary care, it is predicted that palliative care access will also be limited. Furthermore, social determinants of health and health disparities impact palliative care access for patients and their families (Gardner et al., 2019; Nelson et al., 2021).

Referrals and access to palliative care have been associated with socioeconomic class, race and ethnicity, age, culture, and language barriers. Socioeconomic factors were barriers addressed most frequently in the literature. Four studies found that lower socioeconomic status was associated with less palliative care access (Gardner et al., 2019; Hoerger et al., 2019; Nelson et al., 2021; Santos Salas et al., 2019); however, one study in Australia found the opposite (Currow et al., 2012). In addition, palliative care access was more prevalent in less racially diverse populations (Hoerger et al., 2019), although one study found that referral timing was the same between racially diverse populations (but Black and Hispanic patients seemed to suffer from more symptom burden) (Reyes-Gibby et al., 2012). States with a higher percentage of older residents who were more politically liberal had increased access to palliative care (Hoerger et al., 2019). Patients who did not speak the primary language or were not natural citizens of their current country of residence were impacted by decreased (if any) access to palliative care (Brazil et al., 2009; Jansky et al., 2019). Lastly, patient populations with moderate to severe mental illness had less access to palliative care (Butler & O'Brien, 2018).

Hospital Referral Region (HRR) and Hospital Care Intensity (HCI). A total of four articles were identified related to HRRs and HCI. An HRR is a geographic delineation, created by the Dartmouth Atlas of Health Care, that utilizes Medicare data to develop areas encompassing a population of at least 120,000 people and at least one hospital that provides major cardiovascular surgical procedures and neurosurgeries (Dartmouth Atlas, 2021c). As is noted in Chapter 3, HRRs and HCI were used in the selection of hospital cases for this study. HRRs have been utilized in health services research to assess differences among geographic locations (Kilaru et al., 2015). While HRRs cover a large geographic area, it was found that patients are less likely to cross over HRR boundaries to receive inpatient care. Therefore, it is believed that the use of HRRs will encompass the treatment of patients within that particular HRR (Kilaru et al., 2015).

Hospital Care Intensity, also developed by the Dartmouth Atlas of Health Care, uses data to determine the use of acute hospital care to manage serious illness. The index reveals length of hospitalizations and the intensity of services provided while hospitalized (Dartmouth Atlas, 2021b). Patients who live in an area with a higher HCI have an increased likelihood of receiving an intensive procedure within the last 6 months of life (Tschirhart et al., 2014). In contrast, a study comparing hospitals with and without palliative care programs found that the length of stay in intensive care units for patients with serious illness was not significantly different (Horton et al., 2016). However, it should be noted that the study did not compare intensive procedures or usage of physician services (Horton et al., 2016). Similarly, Hua et al. (2018) found patients admitted to intensive care units in hospitals with as opposed to without palliative care programs did

not have significant decrease in length of stay. However, it was found that care coordination and transfer to hospice occurred almost two times more for patients discharged from hospitals with palliative care programs (Hua et al., 2018).

Geographic Implications. Fourteen studies provided evidence that geographic location is a factor in access to palliative care. Urban or metropolitan settings were associated with greater access to hospital palliative care when compared to rural areas (Rogers et al., 2020; Rogers et al., 2021). Rural settings offer a different set of challenges in access to care than urban or suburban settings, and rural communities often have distinct characteristics that must be considered (Gaudet et al., 2014; Johnson et al., 2011). Closure of palliative care programs occurs more often within rural hospitals with fewer than 50 beds (Rogers et al., 2021). Several articles noted that alternative models of care should be considered for rural palliative care programs due to limited resources, travel considerations, and cultural differences (Castleden et al., 2010; Gaudet et al., 2014; Johnson et al., 2011). Telehealth or community-based, and community hospital inpatient palliative care services can provide local, culturally appropriate palliative care without travel (Ceronisky et al., 2013; Keim-Malpass et al., 2015; Kelley et al., 2011). However, as rural hospitals are smaller in size, recruiting and retaining a formally trained specialist or initiating a full-fledged palliative care program can be challenging (Ceronisky et al., 2013; Morrison, Augustin, et al., 2011). Notably, a majority of Alabama counties are

rural (55 out of 67), likely contributing to poor palliative care access in the state (Alabama Rural Health Association, 2017).

Finally, despite inadequate financial resources, many rural communities are developing innovative palliative care programs (Ceronisky et al., 2013). For example, rural programs offer the ability to provide personalized care within the patients' community (Fink et al., 2013). A local palliative care provider who has established relationships with other providers and a link to the community is helpful in establishing a palliative care program (Gaudet et al., 2014; Johnson et al., 2011). Training can be developed and presented locally, or a partnership approach can be implemented with an urban hospital (Crooks et al., 2018; Fink et al., 2013). A rural/urban partnership may offer access to additional resources and well-developed policies and procedures (Fink et al., 2013; Gaudet et al., 2014; Kelley et al., 2011). For example, such a partnership could provide primary palliative care education to all staff and offer specialty services through telehealth with a large community hospital (Kamal et al., 2019). In addition, novel staffing models, such as half-days and cross training, have been utilized to increase availability of services (Smith et al., 2013).

Economic Factors. Sixteen studies addressed the economics of palliative care access. Funding of palliative care remains a barrier for startup and continuation for many programs (Bowman et al., 2019; Brant et al., 2019; Ceronisky et al., 2013; Gaudet, 2014; Kelley et al., 2011). One reason for this ongoing limitation is the lack of policy and full funding mechanisms in the United States (Bowman et al., 2019; Brant et al., 2019; Ceronisky et al., 2013). Funding limitations begin a trickle-down effect, which, in turn,

limits staffing, service availability, and educational opportunities (Bowman et al., 2019). Some programs received grant funding to initiate a palliative care service but were then forced to scramble to find sustainable funding mechanisms (Ceronisky et al., 2013). In addition, the demand for palliative care often exceeds the supply (Bowman et al., 2019; Keim-Malpass et al., 2015; Lancaster et al., 2018).

Several reviewed articles noted that fulfilling referrals for initial palliative care visits/consultations became a challenge due to limited resources and staff (Bowman et al., 2019; Spetz et al., 2016). A movement away from the traditional palliative care interdisciplinary team consisting of a provider, nursing staff, social worker, chaplain, and nursing aide has occurred due to insufficient funding for the full team (Bowman et al., 2019; Spetz et al., 2016). Palliative care providers and nurses were the most commonly funded positions in the palliative care programs reviewed, but chaplain and other support positions (e.g., mental health, therapy services) sometimes lacked funding (Hall et al., 2016). It is important that the interdisciplinary team model remain intact to continue the holistic assessment and care approach while providing benefits to all stakeholders (Spetz et al., 2016). However, it is important to note that funding challenges will vary in the U.S. compared to Canada, Europe, or Australia, which have different systems for funding healthcare. In the U.S., alternate funding mechanisms and institutional support have assisted in closing the funding gap (Ceronisky et al., 2013; Smith et al., 2013). Consideration must be given to foundation support, research funding, and philanthropy (Smith et al., 2013).

Palliative care has demonstrated cost savings for healthcare systems (Greer et al., 2016; May et al., 2017), associated with reduced length of stay, lower treatment

intensities, and fewer ICU stays for patients with serious illness (Goldsmith et al., 2008). The use of palliative care has been shown to reduce readmission rates, which can impact value-based care (Glasgow et al., 2019). Nonetheless, showing the importance of palliative care programs to health system administrations can be challenging because cost savings do not yield increased revenue (Greer et al., 2016; May et al., 2017). The current patterns show that non-profit and public hospitals are more likely to have a palliative care program than for-profit hospitals, while for-profit hospitals are less likely to start or sustain a palliative care program (Dumanovsky et al., 2016).

In addition to using health system resources, the cost of care for serious illness can quickly become financially burdensome for the patient and family (Tasneem et al., 2019). Fortunately, palliative care has been shown to provide cost savings for both patient/family as well as the healthcare system, a benefit associated with positive uptake of services (Goldsmith et al., 2008; Tasneem et al., 2019). Additional cost savings to the patient can result from reduced travel, fewer unwanted or futile treatments, improved depression and anxiety, and other intangible benefits (Tasneem et al., 2019).

Policy and Payment Factors. Five studies addressed the policy and payment factors that impact access such as the limited payment model and funding for education of providers. Despite the growing evidence of the benefits of palliative care, policy changes have been slow to occur in the United States. In contrast, access to palliative care has increased in other high-income countries that have adopted national policies and payment systems (Meier, 2013). Recommendations have been made for the creation of

innovative policies, funding streams, and provider education to increase access to care (Meier, 2011).

In recent years the Centers for Medicare and Medicaid Services (CMS) made funding changes that facilitate palliative care access. These included specific payments for advance care planning discussions and complex chronic care management by approved providers (CAPC, 2019a). Currently, Medicare is piloting an innovative payment model, the Medicare Care Choices Model, which allows a patient who may not be eligible for the Medicare hospice benefit to receive palliative care services from an approved hospice agency while concurrently receiving curative treatment (Centers for Medicare & Medicaid Services [CMS], 2021; Pearce, 2016). Findings for the third year of the pilot study included a 20% decrease in Medicare expenditures and a positive caregiver response (CMS, 2021). A value-based payment system may assist as a payment model for outpatient or home-based palliative care (CAPC, 2019a). The use of such a payment model allows agencies to receive payment for quality services and cost-effective care (CMS, 2020).

The Palliative Care and Hospice Education and Training Act (PCHETA) was previously approved by the U.S. House of Representatives in October 2019 with the intention to move to the Senate for a vote; however, the COVID-19 pandemic has placed this policy on hold (PCHETA, 2019). This act would assist in addressing educational gaps among healthcare providers (Pearce, 2016). Currently, the Patient Quality of Life Coalition (2021) along with multiple hospice and palliative care organizations have written a letter for reintroduction. The bill was reintroduced on May 19, 2022, and if passed could provide necessary education of clinicians to expand palliative care access.

Process

Provider Considerations. Twenty-one selected studies addressed provider considerations as a factor in palliative care access. A full interdisciplinary team encompasses several professionals who address physical, psychosocial, and spiritual needs of the patient and family. The team often includes a provider, nurse, social worker, chaplain, and nurse aide. An extended team could include therapy services, mental health services, and volunteer services (van Riet Paap et al., 2014; Woitha et al., 2014). The interdisciplinary nature of the team is a key component of palliative care; however, as noted above, funding challenges often make it difficult to maintain a full team (Bowman et al., 2019; Hall et al., 2016; Kelley et al., 2011; Spetz et al., 2016; Torke et al., 2010). The chaplain and social worker are commonly the team members “forced out” for financial reasons (Spetz et al., 2016). Likewise, a lack of palliative care providers can negatively impact early referrals by providers, who instead try to manage the care of patients with serious illness despite having limited provider training (Dudley et al., 2019). Nathanson et al. (2016), found states that have populations with a higher burden of illness are associated with less availability of palliative care providers when compared to states with populations with less chronic illness.

Rural communities face additional changes related to access to palliative care providers. Recruitment and retention of trained providers is challenging for palliative care programs in most geographic regions but is especially difficult in rural and underserved areas (Brant et al., 2019; Ceronsky et al., 2013; Kelley et al., 2011), where turnover can interfere with collaboration among providers (Ceronsky et al., 2013; Smith et al., 2013). Constant coverage may not be available in rural areas with fewer providers, reducing

access to palliative care services when they may be most needed (Lancaster et al., 2018; Shipman et al., 2005).

Collaboration and communication among providers is an important aspect of palliative care. Collaboration, communication, and care coordination are crucial in building and growing palliative care programs (Hui et al., 2018; Johnson et al., 2011; Kavalieratos et al., 2014). Increased uptake of palliative care services is important before initiation of the program, thus establishing trust and relationships with referring clinicians is important aspect of buy-in (Gaudet et al., 2014; Johnson et al., 2011; Kelley et al., 2011). Trust between palliative care providers and referring clinicians is essential to ensure timely referrals (Kavalieratos et al., 2014). The importance of collaboration can be seen in successful rural community programs that have been developed with long-term providers (Gaudet et al., 2014). Effective collaboration among the palliative care clinicians should also be linked to a formal communication procedures, which often will improve care coordination for the patient and family (Keim-Malpass et al., 2015; McDarby & Carpenter, 2019).

The use of triggers by providers is important in timely access to palliative care. Standardized and disease-specific triggers for patient referrals are another mechanism to ensure appropriate palliative care uptake including earlier referrals (Heitner et al., 2021; Hui et al., 2018). Some specialties (e.g., cardiology) currently have specific symptoms or classifications to trigger palliative care referral; however, some non-palliative care specialist providers may find the disease trajectory challenging to predict, which, in turn, may delay palliative care referral (Kavalieratos, et al., 2014). It is important to be sure

that education about triggers or the use of palliative care with curative treatment is presented to non-palliative care providers (Hui et al., 2018; Kavalieratos et al., 2014).

Education and Training. Sixteen of the reviewed studies focused on the role of education (for providers, referring clinicians, patients, families, and community members) regarding palliative care in ensuring appropriate access. Though healthcare providers are more familiar with the term “palliative care” now than in the past, the misconception still exists that palliative care is needed only at end of life, and largely for pain and symptom management (Dudley et al., 2019; Fink et al., 2013; Johnson et al., 2011; McDarby & Carpenter, 2019). There is a lack of understanding that advance care planning and care coordination comprise a large part of palliative care (Johnson et al., 2011; McDarby & Carpenter, 2019). These misunderstandings leave the mistaken perception that accepting palliative care is incompatible with curative treatment and is recommended only when the patient is near death (Johnson et al., 2011; Kavalieratos et al., 2014); such misconceptions must be addressed through education.

Several of the reviewed articles emphasized that opportunities for clinician palliative care education are inadequate in terms of number of sessions available, time required to attend, and cost of enrollment (Brant et al., 2019; Cotterell et al., 2007; Fink et al., 2013; Lancaster et al., 2018; McDarby & Carpenter, 2019; Silbermann et al., 2015). However, palliative care clinicians have expressed an interest in additional and more frequent training within palliative care, especially in the format of single-day educational sessions (Fink et al., 2013; Lancaster et al., 2018; Silbermann et al., 2015). More recently, locally developed educational tools and training sessions for clinicians

have shown promise (Crooks et al., 2018). Continued education will, in turn, allow palliative care clinicians to educate other clinicians and the public, resulting in greater access for those in need (Cotterell et al., 2007; Gaudet et al., 2014). Important topics noted in the literature on palliative care education and training include communication techniques, appropriate palliative care referrals, and the understanding of trigger points in palliative care referral (Castleden et al., 2010; Hui et al., 2018; Keim-Malpass et al., 2015).

Communication and Assessment Factors. Four studies addressed the importance of communication and assessment related to palliative care access. To date, palliative care programs have not adequately collected metrics to demonstrate these important factors, and national policy changes are needed to ensure that these measures are obtained (Bowman et al., 2019).

Communication among the care team is an important aspect of providing patient-centered care. It is important for referring clinicians to continue to know the status of the patient; sharing this information would actually help to improve referrals and trust among the whole care team (Dudley et al., 2019).

Communication with patients and family is foundational in offering care to patients with serious illness. Communication may focus on physical goals of care or nonmedical goals, such as spiritual wishes and legacy discussions (Schellinger et al., 2018). Ongoing discussion of the patient's self-defined goals is important as a serious illness progresses, since these goals may change as the disease progresses (Schellinger et al., 2018). Patient and family meetings are an avenue for clinicians to understand goals,

which can at times differ from what is typically expected (Cahill et al., 2020). Cahill et al. (2020) found that allowing the patient to set an agenda for meetings with clinicians allowed empowerment for the patient and enlightened clinicians on areas of importance that they were not aware of during previous conversations with the patient.

As previously noted, larger, urban hospitals are more likely to offer palliative care programs than smaller rural hospitals (Dumanovsky et al., 2016). Partnerships between large, urban hospitals that offer palliative care and smaller community hospitals are a possible route to improve access in rural areas (Dumanovsky et al., 2016; Fink et al., 2013). Additionally, telehealth models of palliative care could increase access in areas where videoconferencing and Wi-Fi are available (Tasneem et al., 2019).

Outcomes

Satisfaction. Seven studies provided information on satisfaction and dissatisfaction with palliative care services, which are directly related to program uptake and expansion. Satisfaction with palliative care was associated with improved quality of life, relief for debilitating symptoms, and patient-centered care. Integration of palliative care services into care for patients with serious illness has created satisfaction for patients, caregivers, and providers (Fink et al., 2013; Hall et al., 2016; Johnson et al., 2011; Silbermann et al., 2015; Tasneem et al., 2019). Palliative care services allow patients to maximize their quality of life while living with serious illness, which includes satisfaction with pain and symptom management (Brant et al., 2019; Johnson et al., 2011). Patient-centered care allows for patients' wishes to be honored, thereby increasing satisfaction with palliative care services (Cotterell et al., 2007). The increase in options

for palliative care, including telehealth, allows the patient to choose the format that is most appropriate for their care (Tasneem et al., 2019).

Benefits of Palliative Care. Seventeen studies provided evidence on the benefits of palliative care as reported by patients and family members. First, improved quality of life and reduced symptom burden were the most common benefits of early palliative care initiation reported in several studies (Bakitas et al., 2009; Fink et al., 2013; Higginson, 2014; Johnson et al., 2011; Temel et al., 2010; Temel et al., 2017; Zimmermann et al., 2014). Mental health, including improved mood and a reduction in depression, was also associated with the early introduction of palliative care (Bakitas et al., 2009; Temel et al., 2010; Temel et al., 2017). Lastly, improved survival rates were reported in patients diagnosed with cancer (Bakitas, Tosteson, et al., 2015; Temel et al., 2010).

Second, caregivers reported benefits from palliative care in the form of decreased stress burden and depression (Dionne-Odom et al., 2015). Caregiver distress may be greater than that of patients at certain times in the disease trajectory (Jeyasingam et al., 2008). Distressed caregivers may need additional support that focuses on factors related to managing patients' symptoms and treatment plans, healthcare decisions for the future, and finding additional services (Dionne-Odom et al., 2019; Dionne-Odom et al., 2021).

Third, patients suffering from serious illness can sometimes “fall through the cracks”; care coordination in early palliative care decreases this risk (Smith et al., 2013). The patient-centered care approach of palliative care allows for communication related to goals of care and documentation of advance care planning (Fink et al., 2013; Gaudet et al., 2014; Temel et al., 2010).

Fourth, as previously mentioned, palliative care results in cost savings and decreased use of unnecessary resources for healthcare systems (Greer et al., 2016; Higginson et al., 2014; May et al., 2017). Early referral to palliative care has been shown to reduce the cost and length of stay of hospital admissions when compared to those of patients who were not referred early or were not referred to palliative care at all (Greer et al., 2016; May et al., 2017).

Summary and Gaps in the Literature

This review provided evidence of factors that impact access to palliative care related to structures, processes, and outcomes. The structure in which palliative care is provided is impacted by environmental factors, hospital care intensity, geographic differences, financial factors, and policies that can increase or limit access. It is known that socioeconomic status, racial differences, and culture can negatively impact use of palliative care. Hospital care intensity and intensive care usage are increased for patients with serious illness. Hospitals with palliative care versus hospitals without palliative care were not shown to significantly impact aggressive care usage, so it is unclear if certain potential environmental factors impact aggressive care or if the population that is served may be associated with more aggressive care. It is well documented that palliative care access is more commonly found in urban areas than in rural hospitals. There are several challenges with access to palliative care within rural communities related to environmental factors and hospital characteristics. Though nontraditional models of rural palliative care have been identified within the literature, further assessment is needed

understand what factors impact the initiation of palliative care in rural communities and the ability to sustain those models of care.

Funding of palliative care remains a challenge. At times this has caused cuts to palliative care staff, required adjusted models of care, and overwhelmed staff because the demand was greater than supply. Palliative care programs have been shown to reduce costs within the health system, but with the current model of healthcare in the United States, many administrators are looking for profit-generating services. Understanding how models of care may be adapted to make initiating and sustaining palliative care to be appealing to hospitals that are looking to maintain a financially viable service. Lastly, current policy and payers limit the growth of palliative care in the United States, especially compared to palliative care in other high-income countries. Understanding current policy and payer changes could potentially impact the growth of palliative care. Countries outside the U.S. that have sustained palliative care programs through national policies or health systems; however, it is challenging to compare factors that impact access in the U.S. to these studies since palliative care is established through national policy.

Palliative care access is impacted by the processes of providing care to seriously ill patients and their families. In this review, the importance of the interdisciplinary team was noted; however, changing models of care and limited budgets often require a decrease in the disciplines represented to provide palliative care. Additionally, the lack of trained specialty care providers leaves a large gap in access to palliative care, especially in rural or underserved areas. To assist with growth in palliative care access, it is vital to identify strategies and models of care for providing palliative care with limited financial

and personnel resources. Evidence has grown related to additional models of care, though further evidence is needed especially within the Southeast U.S. The environmental factors vary depending on the population, hesitancy, and chronic illness when compared to other part of the U.S. Additionally, the use of standardized or disease-specific triggers for patients with serious illness has assisted in the provision of earlier palliative care. It is important to understand how these are used within limited-resource areas or in hospitals without a structured palliative care program.

Misconceptions remain about palliative care, even for clinicians. It is important to identify ways of increasing education for clinicians, as well as for constituents, to impact the growth of palliative care. A gap remains in the number of trained specialty palliative care clinicians; it will be important to understand how best to train all clinicians to increase access to palliative care for all patients with serious illness. Educating all clinicians to provide primary palliative care to patients with serious illness will be important for growth in access in years to come due to the aging population. This will allow specialty palliative care services to be reserved for patients with more complex serious illnesses.

Evidence has been provided on the importance of communication among the care team and with patients and families, including advanced care planning discussions. Though advance care planning is a well-documented aspect of palliative care, it remains limited for certain patient populations. It will be important to further identify gold standards of working with patients and families to create patient-centered goals that honor their wishes once they are faced with serious illness.

Literature on the outcomes of palliative care, such as satisfaction and benefits for patients and families, has grown significantly in the last few years. Evidence has been provided that palliative care, especially access to early palliative care, can improve quality of life and symptom burden for patients. Furthermore, offering caregivers increased support through palliative care has decreased the stress of caring for someone with a serious illness. Lastly, cost savings have been realized by hospitals with the decreased use of resources by patients who are seriously ill.

The literature showing palliative care is beneficial for patients, families, and healthcare systems continues to expand; however, the literature focuses on a limited number of factors related to palliative care access. The literature was more limited on other factors that impact the creation or sustaining of a palliative care program. Despite palliative care being beneficial for many diagnoses, the literature is primarily focused on patients with cancer. An additional limitation of this review is that many of the studies were conducted outside the United States. Healthcare systems in other countries vary greatly when compared to the United States, so access to palliative care will look different depending upon the healthcare system. One strength of this review is the use of manual searching, which revealed a significant number of additional U.S. studies.

Importantly, there were no studies focused on palliative care access in Alabama. The Center to Advance Palliative Care State-by-State Report Card reports limited access in Alabama compared to other states (CAPC, 2019a). Additionally, further research is needed to examine and identify innovative models of palliative care, especially for small and rural hospitals (CAPC, 2019a). Therefore, an assessment of Alabama hospitals will

allow an understanding of the current status of palliative care and serious illness care in the state and offer the potential for future research to increase access to palliative care.

Design and Methods Considerations

For this study, various research designs were considered, including quantitative, qualitative, and mixed methods approaches. The designs that were thoroughly considered included: (a) univariate descriptive, (b) ethnographic, (c) concurrent mixed methods, (d) sequential exploratory mixed methods, and (e) mixed methods case study.

Quantitative Design

Quantitative research uses numerical values to provide new knowledge around a phenomenon of interest (Polit & Beck, 2017). Quantitative research offers generalized information but lacks detail in the results (Plano Clark & Ivankova, 2016). A univariate descriptive design involves numerous variables but is focused on one phenomenon, such as access to hospital palliative care services (Polit & Beck, 2017). The use of a univariate descriptive design would provide evidence on the existence of palliative care in Alabama; however, these would be generalized results and may not apply to a particular community (Plano Clark & Ivankova, 2016).

Qualitative Design

Qualitative research involves obtaining a rich narrative of data through a number of holistic, in-depth methods about a particular phenomenon (Polit & Beck, 2017). The use of a qualitative method would provide in-depth contextual information but may not

be generalizable to other models of palliative care or other communities (Plano Clark & Ivankova, 2016). Ethnography was considered for the design because it would provide the rich results that would include cultural explanations for the existence of palliative care in Alabama communities (Polit & Beck, 2017). However, fieldwork would require an extended period of time due to the need for principal investigator (PI) immersion and acceptance by key informants before research could begin (Munhall, 2012). Additionally, the use of ethnography would reflect the culture of the particular community; however, understanding cultural characteristics may not be reflective of other communities in relation to palliative care access (Munhall, 2012).

Mixed Methods Design

Mixed methods research collects and analyzes both quantitative and qualitative data to offer inferences through triangulation of data from both methods (Creswell & Plano Clark, 2018). The benefit of using a mixed methods design is the opportunity for a more in-depth understanding of access to palliative care services, while also allowing for multiple worldviews.

Consideration was given to a mixed methods sequential QUAN → Qual design for this study (Plano Clark & Ivankova, 2016). This would include utilizing a quantitative survey to collect data on hospitals' palliative care programs and conducting interviews to gain insight into the development of the palliative care program along with factors that limit program development or growth.

While this method would provide a thorough assessment of palliative care programs within Alabama, the quantitative data may be limited due to the small number

of palliative care programs within the state. This method would not fully address the factors for hospitals that do not have a palliative care program in place but provide care for patients with serious illness.

Mixed Methods Case Study Design

As previously stated, mixed methods provide the benefit of an in-depth understanding of the topic of interest, such as palliative care access in Alabama, by triangulating the quantitative and qualitative results (Creswell & Plano Clark, 2018). Case study research is a qualitative method that provides a holistic understanding of a phenomenon of interest by using multiple methods of data collection within the context of each case (Stake, 2006). The chosen design embeds mixed methods within a case study, “intersecting the assumptions, intents, logistics, and methods to more completely describe and interpret interrupt the complexity and theoretical importance of a case or cases” (Plano Clark et al., 2018, p. 20; Plano Clark & Ivankova, 2016; Walton et al., 2019).

The chosen conceptual framework calls for use of multiple methods of data collection. The environmental data (i.e., population demographics, health indices) are historically quantitative in nature, whereas understanding beliefs and the impact of leadership calls for a qualitative approach. The use of multiple cases allows for an in-depth understanding of the provision of serious illness care at each selected hospital. Both mixed methods and case study approaches allow for a comprehensive assessment of palliative care access in Alabama (Plano Clark et al., 2018; Plano Clark & Ivankova,

2016; Walshe et al., 2019). The use of multiple cases allowed for comparison of the provision of serious illness care among Alabama hospitals.

Chapter 2 Summary

Palliative care is focused on increasing the quality of life for patients and their family members by providing holistic assessments and care for patients with serious illness. Numerous attempts at calculating the need for palliative care have been made using a public health approach; however, the estimates are imprecise and vary among researchers. Although the exact number of residents who would benefit from palliative care is unknown, it is evident that palliative care is lagging in Alabama.

This literature review included 66 studies that fit within the framework of structure, process, and outcomes related to palliative care access. Important findings related to structure include the following: (a) environmental factors such as urban and rural classification and socioeconomic status of the population serve affect palliative care access, (b) hospital care intensity is important to understanding where increased serious illness care is being provided, (c) geographic location impacts access, and (d) palliative care provides cost savings, but comprehensive healthcare policy is needed to address adequate funding for palliative care. Important findings related to process include the following: (a) the interdisciplinary team is important to palliative care access, (b) building rapport and trust assists in building palliative care referrals, and (c) collaboration and communication are a key part of palliative care access. Important findings related to outcomes are improved symptom burden and caregiver support impact outcomes for patients who receive early palliative care. The gap that the study will address is to better

understand environmental factors and hospital characteristics and processes related to access to palliative care within Alabama. Understanding this gap will allow for further assessment of how palliative care access may be improved within Alabama.

Alabama lags behind other states in the U.S. in access to palliative care; there is currently no research related specifically to factors in palliative care access in Alabama. This study will fill this gap, allowing for a better understanding of how hospitals with and without palliative care are influenced by environmental factors, hospital characteristics, and administrative and clinical perspectives of serious illness care.

CHAPTER 3

METHODOLOGY

A mixed methods multiple case study design was employed to address the study purpose of exploring access to palliative care within Alabama hospitals. The purpose of this chapter is to describe the methodological characteristics of the study: (a) brief overview of the purpose and specific aims, (b) research design, (c) sampling and recruitment procedures, (d) data collection and analysis procedure, (e) integration strategies, (f) quality assurance, and (g) ethical/human subject issues.

Purpose and Specific Aims

The purpose of this mixed methods multiple case study was to develop a thorough description of access to serious illness or palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. To do this we identified four hospitals as cases that represent a spectrum of size (greater or less than 150 beds), geographical location (rural versus urban), and palliative care service availability (two with and two without established palliative care programs). Quantitative and qualitative data were collected, analyzed, and integrated for the four selected hospital cases. The goal of the quantitative strand was to examine environmental factors, hospital characteristics, and processes related to serious illness and palliative care by performing

an environmental scan of publicly available data to develop individual hospital profiles and by surveying administrators who work at the four selected Alabama hospitals. The goal of the qualitative strand was to obtain an in-depth understanding of how these same factors, characteristics, and processes influence access to palliative care by interviewing purposefully selected hospital clinicians and administrators in the same Alabama hospitals. By integrating the results from the quantitative and qualitative strands within and across the four hospitals, a more thorough description of how these factors influence palliative care access in Alabama was obtained.

The research aims of this study were as follows:

Aim 1 (Quantitative): To explore environmental factors and hospital characteristics and processes related to serious illness and palliative care in four Alabama hospital cases (by using an environmental scan and administering an adapted CAPC National Palliative Care survey). The two research questions for Aim 1 were:

Research Question 1.1: What hospital and environmental factors (e.g., community demographics, economic stability, education access, and healthcare access) and palliative care resources are associated with each of the four Alabama hospital cases?

Research Question 1.2: How do hospital demographics and characteristics such as staffing, education, and resources compare across the four Alabama hospital cases?

Aim 2 (Qualitative): To explore how environmental factors and hospital characteristics and processes influence access to serious illness and palliative care from the perspective

of hospital clinicians and senior hospital managers in four Alabama hospitals. The research questions for Aim 2 were:

Research Question 2: What are the perspectives of hospital clinicians and senior hospital managers about serious illness care and, if available, palliative care, within their respective hospital?

Research Question 2.1: What are the similarities and differences across the hospital administrators' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

Research Question 2.2: What are the similarities and differences across the clinician leaders' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

Research Question 2.3: What are the similarities and differences across the frontline clinicians' perspectives on environmental factors and hospital structures and their impact on serious illness care within their respective hospitals?

Aim 3 (Mixed Methods): To develop a thorough description of access to palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. The research question for Aim 3 was:

Research Question 3: In what ways is serious illness or palliative care provided in Alabama based on the integration of the environmental factors and quantitative

survey results and qualitative interview and document analysis findings from the four different Alabama hospitals?

Assumptions in this study included that the data obtained through the survey were an accurate description of serious illness care within the selected hospitals. We also assumed the information obtained from the participants in this study represented their voice or “truth space” (Onwuegbuzie & Teddlie, 2003, p. 369). We assumed that participants had experience with the phenomenon that we were exploring, palliative care for patients with serious illness, and that they participated willingly.

Research Design

As noted, a mixed methods multiple case study design was employed for this study. Case study research is a qualitative method that provides a holistic understanding of a phenomenon of interest by using multiple methods of data collection within the context of individual cases (Stake, 2006). Mixed methods research combines approaches used in quantitative and qualitative research to create a triangulated and in-depth understanding of the topic of interest (Creswell & Plano Clark, 2018). The chosen design embeds mixed methods within a case study, “intersecting the assumptions, intents, logics and methods to more completely describe and interpret the complexity and theoretical importance of a case or cases” (Plano Clark et al., 2018, p. 20; Plano Clark & Ivankova, 2016; Walton et al., 2019).

Case study methodology was a priority within the study, providing perspectives of hospital senior managers and clinicians while embedding a quantitative survey and collection of environmental characteristics to provide a description of each hospital’s

environmental factors and hospital characteristics and processes. This methodology, although complex, allowed for an in-depth analysis of factors that impact serious illness and palliative care access within Alabama hospitals (Plano Clark & Ivankova, 2016; Stake 2006). Multiple cases (four) were included within this study to provide an opportunity to compare Alabama hospitals with and without palliative care programs (Stake, 2006). The four hospital cases were selected based upon factors that impact the prevalence of hospital palliative care, such as Hospital Care Intensity, hospital size, and rurality. Case (hospital) selection is described in further detail below.

Methodological Approach

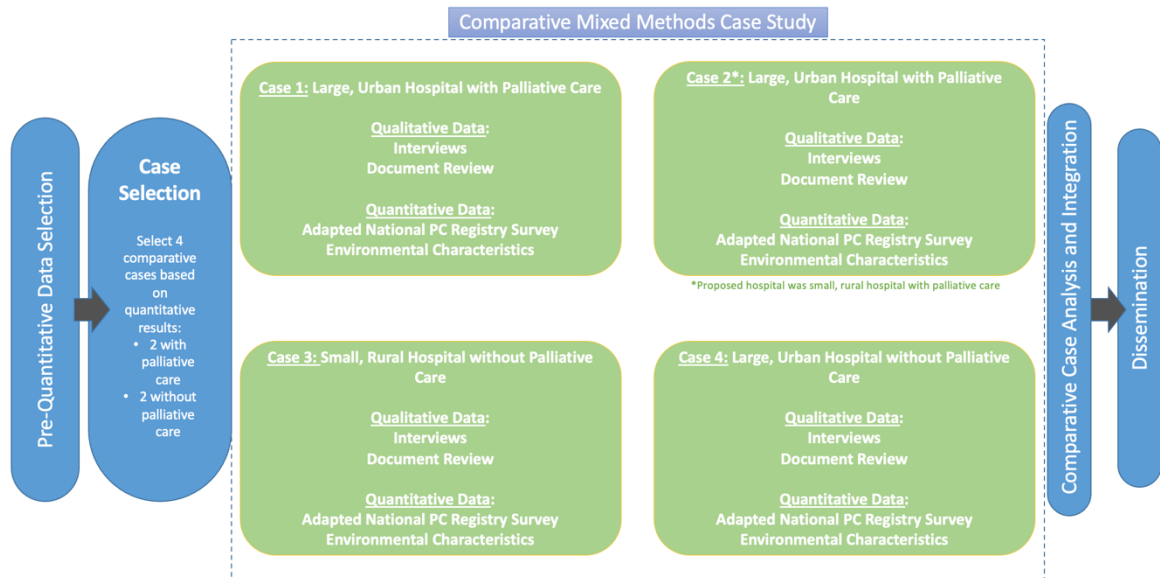
Methodological characteristics of mixed methods studies include (a) the timing of data collection and analysis, (b) the priority strand of the study, and (c) the point of interface. Timing is described by the “relationship” between the two data strands for data collection and analysis and can be concurrent or sequential (Creswell & Poth, 2018; Plano Clark & Ivankova, 2016). This study used concurrent timing, collecting both qualitative and quantitative data independently. Concurrent timing was utilized for this study to “obtain different but complementary data on each hospital” in addition to being an efficient method of data collection for a single researcher with limited time constraints working with hospital personnel with limited availability for extended data collection (Creswell & Plano Clark, 2018, p. 68). Quantitative data included environmental factors and a descriptive hospital survey. Qualitative data included semi-structured interviews with senior hospital managers and clinicians and document reviews.

The priority references the strand that carries more weight in defining the meta inferences (“interpretations drawn from both quantitative and qualitative strands”), which was the qualitative case study (Creswell & Plano Clark, 2018, p. 218). Quantitative data were embedded within the priority stand, to offer a supportive description of each hospital case. The mixed methods multiple case study design allows for in-depth description and practical understanding of the phenomenon of interest, in this case serious illness and palliative care access within Alabama hospitals (Creswell & Poth, 2018; Plano Clark & Ivankova, 2016).

Mixing, or the point of interface, is where the quantitative and qualitative data strands integrate (Creswell & Plano Clark, 2018). The study provided two points of data integration (Creswell & Poth, 2018; Plano Clark & Ivankova, 2016). The first point of integration occurred when combining the qualitative and quantitative data within one case analysis to describe serious illness care at each of the four hospitals. The second point of integration consisted of comparative case analysis, with the integration of the results and creation of meta inferences (Creswell & Poth, 2018). Figure 5 provides a procedural diagram of the study and is fully explained in the following sections.

Figure 5

Procedural Diagram of Study



Rationale for Mixed Methods Case Study

According to Plano Clark et al. (2018, p. 14), “Case study and mixed method research are well suited to address complex research questions.” Integration of the two methods provided an in-depth understanding and meta inferences, interpretations developed based upon the combination of data strands, that can be applied to future studies (Creswell & Plano Clark, 2018). Both methods allowed for multiple philosophical foundations; however, the pragmatic perspective was most compelling in understanding hospital-based palliative care access within Alabama because it allowed focus on multiple worldviews from the perspective of senior hospital managers and clinicians (Walton et al., 2019).

A mixed methods case study design offered greater insight, compared to a single case methodological design, into the complexities of assessing healthcare services within

a real-life context and allowed comparison among cases that do and do not have a palliative care program in selected Alabama hospitals (Bakitas, Elk, et al., 2015; Plano Clark et al., 2018; Walshe et al., 2004). Additionally, the use of a mixed methods case study design yielded more results than would have been provided by a single case study (Newcomer et al., 2015; Yin, 2018). Using this study design along with the chosen conceptual framework allowed assessment of each hospital structure and its processes to provide a holistic understanding of hospital-based palliative care access within the contextual features of each case (Brogan et al., 2019).

Justification for Methodological Approach

This study used a concurrent design typology (Creswell & Plano Clark, 2018; Plano Clark & Ivankova, 2016). The use of Quan + QUAL mixed methods design embedded within a comparative case study design provided an “enhanced description and analysis of multiple cases” (Creswell & Plano Clark, 2018, p. 116; Yin, 2018). Additionally, data from different cases were collected at the same time, thus potentially shortening the data collection time frame (Creswell & Plano Clark, 2018).

Case Selection

Case study research provided an opportunity to include contextual details of a phenomenon of interest, or quintain (Stake, 1995). Cases were purposefully selected and bounded to time and place to understand palliative care access within Alabama (Creswell & Poth, 2018; Stake, 2006). It is important to select an appropriate number of cases when conducting a collective case study to understand areas of concordance and divergence of

the data (Stake, 2006). Recommendations for the number of cases vary within case study research; however, it is important to have enough cases to understand the phenomenon of interest but not so many that they become difficult for the researcher to understand and analyze (Stake, 2006). The number of cases is often defined by the goal of the multiple case study design. For example, a comparative multiple case study would need at least two cases but may require additional cases to better explain the quintain that is being studied (Stake, 2006; Yin, 2018).

Hospital Referral Regions (HRRs) and Hospital Care Intensity (HCI) were utilized to identify the four selected Alabama hospitals (Dartmouth Atlas, 2021b, 2021c). An HRR is a geographic delineation, created by the Dartmouth Atlas of Health Care, that utilizes Medicare data to develop areas encompassing a population of at least 120,000 people and at least one hospital that provides major cardiovascular surgical procedures and neurosurgeries (Dartmouth Atlas, 2021c). HCI, also developed by the Dartmouth Atlas of Health Care, uses data to determine the use of acute hospital care to manage serious illness. The index reveals length of hospitalizations and the intensity of services provided while hospitalized (Dartmouth Atlas, 2021b). HRR was chosen to define cases due to its association with the HCI index, allowing for exploration of increased, possibly unnecessary, acute hospital stays and high numbers of interventions that may not benefit the patient (Dartmouth Atlas, 2008). The higher the HCI, the more likely it is that palliative care is beneficial for the patient, family, and health system (possibly reducing care costs and lengths of stay) (Dartmouth Atlas, 2008; May et al., 2018). There are six HRRs within Alabama: Birmingham, Dothan, Huntsville, Mobile, Montgomery, and Tuscaloosa (Dartmouth Atlas, 2021b). The national average HCI is 68.9%, which is

similar to the median of the HCIs within Alabama. Table 2 provides the HCI rates of all six HRRs.

Table 2

Hospital Care Intensity Rates in Alabama

Hospital Referral Region	Hospital Care Intensity Rate (out of 100%)
Tuscaloosa	83.9%
Huntsville	72.5%
Mobile	71.8%
Birmingham	67.3%
Montgomery	58.8%
Dothan	40.5%

Initial Case Selection

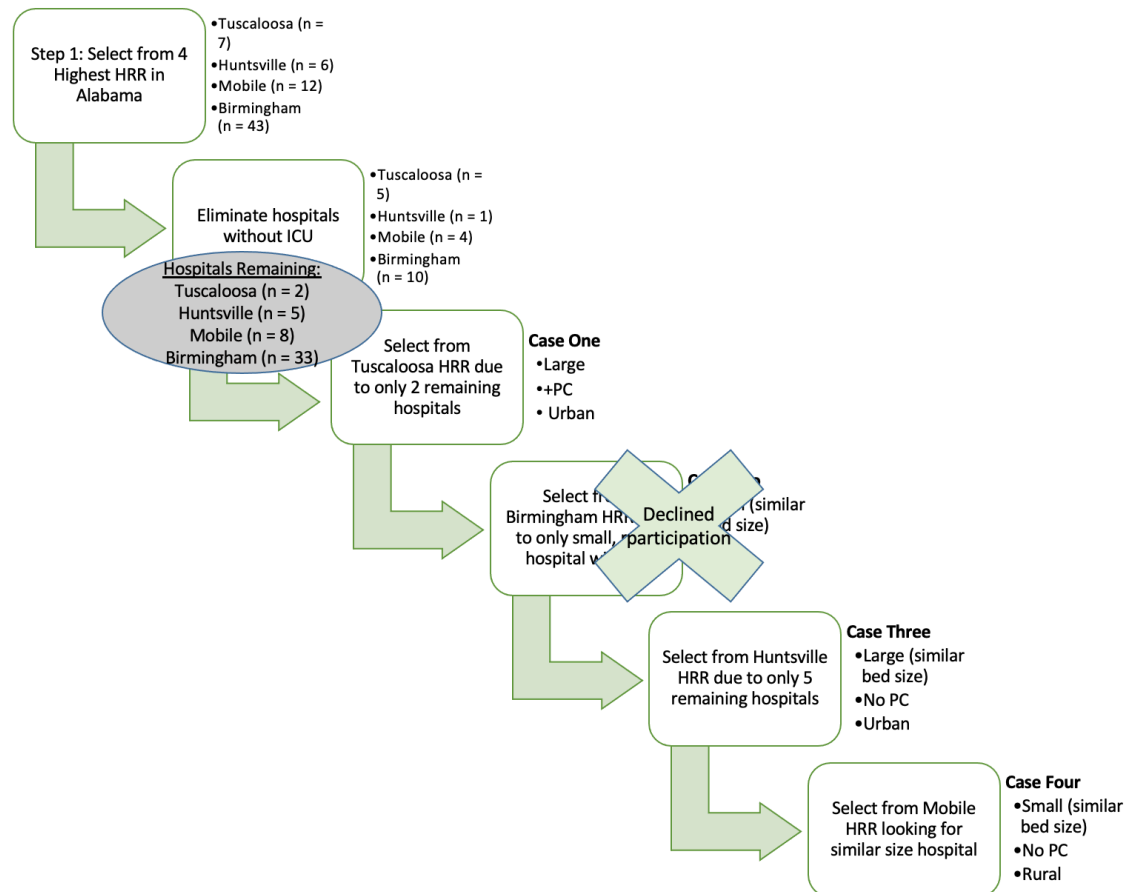
Initially, one hospital was chosen from each of the four HRRs with the highest HCI rates, allowing the PI to compare them based upon the provision of palliative care, hospital size, and geographic location. The case selection criteria were based upon evidence associated with an active hospital palliative care program (CAPC, 2019a; Dartmouth Atlas, 2021b; Rogers et al., 2020). The HRRs included were Birmingham, Huntsville, Mobile, and Tuscaloosa. Two of the selected hospitals had an established palliative care program for seriously ill patients and two hospitals did not. Using a list of hospitals from the Alabama Hospital Association, the PI reviewed each hospital website with a follow-up telephone call to confirm existence or non-existence of a palliative care

program. This information was utilized for the case selection of the hospitals related to the provision of palliative care within the HRRs. A total of 22 community hospitals in Alabama had a palliative care program at the time of this study.

Hospital size was dichotomized into hospitals with fewer than 150 beds and those with greater than 150 beds, based upon the CAPC State-by-State Report Card (CAPC, 2019a). Hospitals with a greater number of beds are associated with a higher likelihood of offering palliative care (CAPC, 2019a). The number of hospital beds was obtained from the Dartmouth Atlas database, which uses data from the American Hospital Association. The geographic location was determined based upon Economic Research Service Rural-Urban Commuting Area Codes (RUCAs); rural is classified as a score from 4 to 10, and urban is classified as a score from 1 to 3 (U.S. Department of Agriculture, Economic Research Service, 2019). To allow for comparable cases, the following hospitals were excluded from the study: pediatric-only hospitals, large, urban teaching hospitals, surgical/outpatient only hospitals, hospitals without intensive care units, and Veterans Affairs hospitals. Figure 6 shows the process of selecting the proposed (hospital) cases.

Figure 6

Proposed (Hospital) Cases Selection Process



Literal replication logic was used to finalize the four hospitals for inclusion in this study (Yin, 2018). Literal logic replication is used in multiple case studies to select two or more cases that are “projected to produce similar findings” (Yin, 2018, p. 287). Selecting two hospitals that had an established palliative care program and two that did not allowed comparisons of serious illness care provided to the patients and families within each hospital. Using literal replication logic allowed for strengthened findings of the two similar cases (with or without palliative care), while allowing the opportunity to

have contrasting cases (with versus without palliative care). Additionally, the selected hospitals were located in varied geographic locations within Alabama.

Final Case Selection

The hospital selection required a substitution after the initial selection due to the limited availability of hospitals with established palliative care programs. The only small, rural hospital with a palliative care program in Alabama chose not to participate in the study at the time of data collection. An alternate hospital was chosen, after reviewing hospitals in Alabama with palliative care programs related to the HRRs and the HCI and networking with palliative care experts. Therefore, hospitals within the study included three among the HRRs with the highest HCI and one within an HRR with the lowest HCI. In turn, this offered a comparison of serious illness care among various geographic areas and HCIs. Figure 7 reflects the updated hospital selection process. The hospitals' HRRs are listed in Table 3.

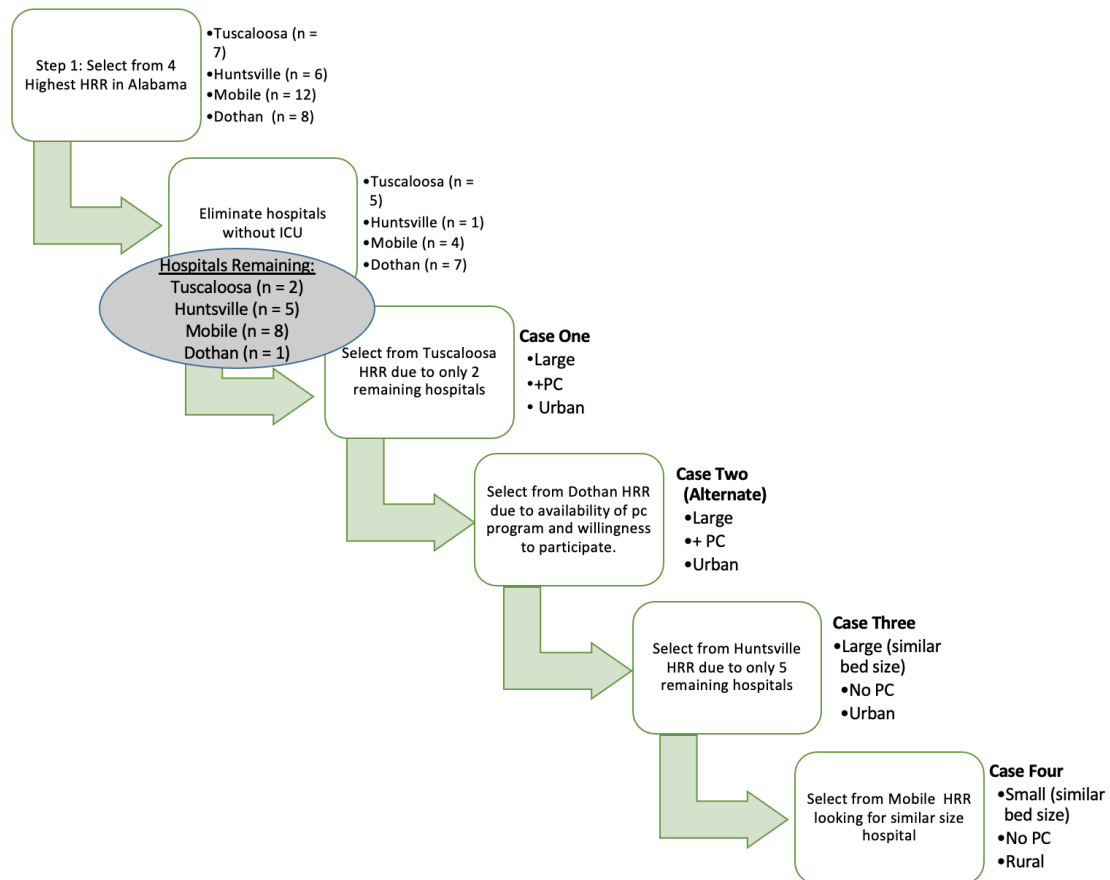
Table 3

Selected Hospital Cases

Large, urban hospital with Palliative Care	Large, urban hospital with Palliative Care	Large, urban hospital without Palliative Care	Small, rural hospital without Palliative Care
Tuscaloosa	Dothan	Huntsville	Mobile

Figure 7

Final (Hospital) Cases Selection Process



Data Collection

Quantitative Data Collection

This section provides an overview of quantitative data collection.

Recruitment and Sampling Procedures for Selected Hospital Cases

The initial telephone contact with each hospital was completed by the PI. The PI received assistance from dissertation committee members and other colleagues for

networking opportunities and introductions at the selected hospitals as necessary. Senior hospital managers, such as the chief executive officer, chief operations officer, chief medical officer, or chief nursing officer, were considered the gatekeepers for hospital entry and recruitment. Gatekeepers/senior hospital managers at the hospitals are listed within Table 4. The hospital gatekeepers were contacted by telephone using a script to discuss the opportunity for participation in the research study. During the call, the PI requested a face-to-face or virtual meeting with the primary contact at the hospital. The initial meeting was used to establish rapport and begin discussions of the overall goal of the current study and the commitment requested of the hospital (e.g., survey, interview participation, publication of results) (Ivankova, 2015; Tashakkori, Johnson, & Teddlie, 2021). Discussion of the study's importance and potential future benefit to patients and the hospital occurred during this time. Support from senior hospital managers has been found to improve recruitment; therefore, recruitment was discussed with senior hospital managers during the initial meeting (Ivankova, 2015). Additionally, the PI discussed completion of the survey and the involvement of other senior hospital managers.

Table 4

Gatekeepers/Senior Hospital Manager at the Proposed Hospitals

Hospital	Hospital A	Hospital B	Hospital C	Hospital D
Senior Hospital Manager Position	Chief Operating Officer	Director of Medical Education, Co-Founder of Palliative Care Services	Chief Nursing Officer	Chief Nursing Officer and Director of Acute Care Services

Quantitative Data

Quantitative data included the use of an adapted Center to Advance Palliative Care National Palliative Care Registry survey and hospital-defined catchment area environmental factors (CAPC, 2019a).

Hospital-Defined Catchment Area Environmental Factors. Environmental factors that describe the hospital-defined catchment areas were collected. These included demographics, economic stability, education access, healthcare access, community healthcare services, and hospital designations. Environmental factors were collected by the PI through publicly available databases (United States Census Bureau Alabama Department of Public Health, University of Wisconsin Population Health Institute, ACGME, and ACS) and websites. These data provided a description of the community comprising the hospital-defined catchment area. The use of the more limited catchment area provides details that are reflective of the community that the hospital services rather than using an HRR. That is, an HRR would yield additional communities that may not be reflective of the hospital-defined catchment area due to the large geographic area that each HRR may cover (Dartmouth Atlas, 2021c). Table 5 provides the hospital-defined catchment areas.

Table 5*Hospital-Defined Catchment Areas*

	Hospital HRR	County
Hospital Cases	Dothan	AL: Coffee, Covington, Dale, Geneva, Henry, Houston, Pike GA: Early, Seminole FL: Holmes, Jackson, Walton
	Huntsville	Jackson, Limestone, Madison, Marshall, Morgan
	Mobile	Baldwin
	Tuscaloosa	Bibb, Fayette, Greene, Hale, Pickens, Tuscaloosa

The environmental data that were obtained for each of the four hospitals included demographic information on the hospital-defined catchment area and information related to social determinants of health (SDOH). SDOH are associated with access to quality healthcare; therefore, understanding these environmental factors allowed for a richer description of access to palliative care in Alabama (Grindrod, 2020; U.S. Department of Health and Human Services, 2021). In addition to SDOH factors that influence access to palliative care, other qualities have been found to be associated with adoption or closure of hospital palliative care programs. These include Centers for Medicare and Medicaid (CMS) Sole Community Provider and Rural Referral Center designation, Accreditation Council for Graduate Medical Education (ACGME) approved residency training

programs, and American College of Surgeons (ACS) cancer center programs. Another factor that could impact patient care at discharge is access to outpatient or home palliative care, hospice, or home health services. An assessment of access to these services within 60 miles of the hospital was included within the environmental assessment. The environmental data that were collected are displayed in Table 6.

Table 6*Environmental Factors Data*

Environmental Data Item	Unit of Measurement	Database
Demographics	Population size	United States Census Bureau
SDOH: Economic stability	Median household income	United States Census Bureau
SDOH: Education access	Poverty level	United States Census Bureau
SDOH: Healthcare access	Educational attainment	United States Census Bureau
	Cancer mortality rate (measure of health)	Alabama Department of Public Health
	Number of primary care providers ratio	University of Wisconsin Population Health Institute
Community healthcare services	Home health agencies	Internet search engine
	Hospice agencies	
	Palliative care agencies	
	Hospitals within catchment area	
Hospital designations	CMS designation	Hospital webpage
	Accreditation Council for Graduate Medical Education (ACGME) approved residency training	ACGME webpage
	American College of Surgeons (ACS) cancer center designation	ACS webpage

Descriptive Hospital Survey. The Center to Advance Palliative Care (CAPC, 2019b) distributes the National Palliative Care Registry survey to hospitals that provide

palliative care services and have 50 or more beds. This survey provides an opportunity for hospitals to describe their overall hospital, the population served, diseases treated, and any palliative care services. The survey is not completed by hospitals without palliative care services; therefore, adaptations were necessary to include questions appropriate for both hospitals with and without a palliative care program (Newcomer et al., 2015). The adapted survey was reviewed by experts in program development and palliative care at the University of Alabama at Birmingham. Additionally, the survey was tested with a healthcare administrator to assess for feasibility in answering the selected questions. The survey for hospitals with palliative care contained 27 questions and the survey for hospitals without palliative care contained 15 questions. The adapted surveys are provided in Appendix B.

Quantitative Data Collection Procedures. Prior to requesting survey completion, the PI met with the primary contact at each hospital to discuss the survey and the goals of completion. The paper and pencil self-reported survey was provided during the initial meeting at the hospital with the primary contact/senior hospital manager. Written instructions were provided on the cover page of the survey with contact information for the PI if needed. The timeline for quantitative survey collection averaged between 2 and 12 weeks per hospital, depending upon hospital personnel workload. After the initial 2-week goal timeline had passed, a follow-up email was sent by the PI. A telephone call and additional email reminder were sent by the PI after each subsequent week until the survey was received. The PI collected the environmental data

independently for each hospital case and recorded the data into an Excel spreadsheet for use within the results of each case.

Qualitative Data Collection

This section provides an overview of qualitative data collection.

Population and Sampling for Qualitative Interviews

The population of interest within each hospital included the senior hospital managers, clinician leaders, and frontline clinicians. Purposeful and snowball sampling was utilized for individual interviews of the hospital staff (Tashakkori, Johnson, & Teddlie, 2021).

The sample depended on saturation and obtaining a thick description of serious illness care, and of the palliative care program, if available, at each hospital. Support for saturation (or in-depth description, in the case of this study) and pragmatic limitations (such as time, number and availability of participants, and research team sizes) served as justification for the number of participants interviewed (Vasileiou et al., 2018). A common minimum size among health research studies can range from 15 to 60 participants if utilizing semi-structured interviews in data collection (Curry & Nunez-Smith, 2015; Saunders & Townsend, 2016). The initial goal was to recruit and interview 5 to 6 participants ($n = 20-24$) at each hospital. The number of interview participants can range from one to 20; however, case studies focused on organizations, such as hospitals, often include a smaller number of interview participants (Curry & Nunez-Smith, 2015).

Based upon considerations of saturation, pragmatic limitations, and current literature, the PI chose to interview one participant within senior hospital management and two clinician leader participants due to the potential of limited availability of these team members due to hospital size and the number of staff in these positions. The goal of interviewing two to three frontline clinicians was intended to include varying members of the interdisciplinary team (e.g., nurse, provider, chaplain, and social worker). Continuous qualitative data analysis was ongoing during qualitative data collection to determine if an adequate description of serious illness care within the hospital was developed (Bazeley, 2018). The final qualitative sample size is provided in Table 7.

Table 7

Hospital Interviews Completed

	Hospital A	Hospital B	Hospital C	Hospital D
Senior Hospital Manager	1	1	1	1
Clinician Leader	4	2	3	3
Frontline Clinician	4	2	2	2

Inclusion and Exclusion Criteria. Inclusion criteria for participants consisted of the targeted job classification (see Table 8), age of over 18 years old, employed at the current hospital for 6 months or more, and classified as full-time staff member; in addition, frontline clinicians must work with patients with serious illness (e.g., intensive care unit, medical-surgical unit, oncology unit). Exclusion criteria for participants

included a non-targeted job classification, under the age of 18 years old, employed at current hospital for fewer than 6 months, part-time or PRN employee, or a frontline clinician not working directly with patients with serious illness on a regular basis (e.g., outpatient surgery).

Recruitment Procedures. The senior hospital manager who served as the initial point of contact and survey coordinator was asked to recommend potential interview participants based on criteria that were discussed during the initial meeting. In addition to recommendations from the senior hospital manager, a snowball sampling technique was utilized, which involves early participants referring others for participation in the study (Polit & Beck, 2017). The PI then contacted these individuals by email or telephone (provided by the senior hospital manager or referring interview participant) to request participation in interviews.

Qualitative Data

Qualitative data included semi-structured qualitative interviews and document reviews.

Semi-Structured Interviews. Qualitative data collection consisted of in-depth, semi-structured interviews and document reviews (Curry & Nunez-Smith, 2015). Twelve interviews were conducted over Zoom, while the rest were conducted in person. Interviews were conducted through Zoom as requested by the hospital and for participant convenience. All were conducted by the PI. Interview guides, specific for senior hospital managers, clinician leaders, and frontline clinicians, were developed to understand

serious illness care from the various perspectives (Curry & Nunez-Smith, 2015). These interview guides were developed using the conceptual framework for this study and feedback from palliative care experts. Once developed, the interview guides were pilot tested with senior hospital managers and clinicians at the UAB Hospital. Interview guides are provided in Appendix D. The interviews were recorded and transcribed verbatim. Table 8 provides a description of senior hospital managers, clinician leaders, and frontline clinicians. Interviews provided a feasible opportunity for data collection while protecting the participants' privacy (Teddlie & Tashakorri, 2009; Yin, 2018). Understanding the contextual features of each hospital and the community assisted in providing a greater understanding of serious illness care within each of the hospitals. Additionally, this information provided an understanding of factors that are related to creating and sustaining a palliative care program. The strengths and weaknesses of each qualitative data source are provided in Appendix E.

Table 8*Interview Participant Description*

Participant Type	Job Titles	Interview Perspective Sought
Senior Hospital Managers	Chief Executive Officer, Chief Operating Officer, Chief Financial Officer, Hospital Administrator, Assistant Hospital Administrator, Vice President of Development, Chief Strategic Officer	This individual has a focus on the overall mission and vision of the hospital. Involvement in strategic planning and program implementation were key.
Clinician Leader	Chief Medical Officer, Chief Nursing Officer, Senior Nursing Leader, Chief Quality Officer, Chief of Staff, Senior Physician Leader, Case Manager	This individual has a focus on the mission and vision of the hospital while having a grasp on the clinical aspects of care. Understanding the process of care and leadership within the hospital were key.
Frontline Clinician	Interdisciplinary Team Members: Physician, Resident, Nurse Practitioner, Physician's Assistant, Registered Nurse, Social Worker, Chaplain	This individual is a care provider for patients and families with serious illness. The goal for this interview was to understand the culture, attitudes, and team dynamics.

Document Reviews

Documentation reviews included verification of documents that entail the hospital's mission, vision, and policies and procedures related to serious illness care. The rationale for completing document reviews was supported by the underpinnings of case study research and the use of multiple sources of evidence to provide an in-depth

description of the phenomenon of interest (Yin, 2018). The documents that were not available publicly were requested by the PI. However, hospital administrators were reluctant to provide all the documents requested, so a form with a list of documents that pertain to serious illness care and the mission and vision of the hospital was provided to administrators. This document was reviewed by the PI and included the information within the analysis. The documents included on the form were (a) annual reports (assessing history and growth of serious illness or palliative care), (b) hospital mission and vision (and program as applicable), (c) any hospital policies and procedures related to management of a patient with serious illness (and program as applicable), and (d) specialty referral or consult documents. Additionally, the PI reviewed the hospital website and other publicly available (published by the hospital) documents to assess the focus on serious illness care. The document list is provided in Appendix F.

Qualitative Data Collection Procedures. Qualitative data collection varied among hospitals. The average timeline for qualitative data collection was between 3 and 12 weeks. Typically, an average of 2 to 3 weeks was included for recruitment and scheduling interviews. Each participant had the option to schedule the interview based upon their timing preference and could choose to complete the interview face-to-face or via Zoom. Interviews were recorded with consent onto a digital recorder and transcribed verbatim by a professional transcription service, Landmark Associates.

Documents lists were reviewed by hospital staff and provided to the PI with responses of “yes,” “no,” or details of the document. The PI reviewed publicly available documents for statements associated with palliative care or serious illness care, for

example, whether the hospital's mission/vision focuses on acute care needs or provides a quality-of-life statement. These data were coded in NVivo 12 for Mac and are presented in aggregate within the themes of the qualitative results in Chapter 4.

Data Analysis

Quantitative Data Analysis

The analysis of these quantitative data provided a descriptive picture for each of the four hospitals and a background for case study reports. The adapted National Palliative Care Registry survey provided a description of hospital characteristics within each hospital and allowed comparison among hospitals with and without a palliative care program (CAPC, 2019b). The PI followed up on all incomplete survey items and unclear responses within the survey. The environmental factors allowed for a description of the hospital-defined catchment area. Descriptive statistics were utilized in this study. For continuous variables, mean, median, and range were calculated. For categorical variables, frequencies and percentages were calculated. Quantitative data between hospitals with and without a palliative care program were compared using hospital structure (e.g., patient population, underlying admitting diagnosis, and discharge dispositions), hospital resources (e.g., relationship with hospice organizations), and financial incentives (e.g., hospital budget sources). Additionally, the two hospitals with a palliative care program were compared using program features (e.g., staffing, initial consults, patient population, and the program budget). A portion of the environmental factor data was not analyzed, but instead served as a description for comparison purposes among hospitals (e.g., community healthcare services).

Qualitative Data Analysis

Continuous thematic analysis was employed throughout data collection to assess for an adequate description of serious illness care within each hospital (Bazeley, 2018; Nowell et al., 2017). NVivo 12 for Mac was utilized for data analysis and organization. Interview discussions were transcribed verbatim by a professional transcription service, Landmark Associates. The PI read the transcriptions for clarity and correctness while listening to the audio recordings. Additionally, this helped the PI become immersed in the data, becoming more familiar with the data while organizing it prior to analysis. Researcher journaling notes were added to the transcripts. Coding, themes, and subthemes were reviewed with a qualitative and mixed methods expert through the analysis process.

Coding of the interview transcripts and document reviews were completed by the PI, using the strategy of segmenting data, reassembling data, and interpreting data (Creswell & Plano Clark, 2018; Ivankova, 2015; Miles et al., 2020). Segmenting data into relevant and meaningful codes allowed for initial coding and comparison and grouping of similar codes (Ivankova, 2015; Miles et al., 2020). Additionally, documents pertaining to serious illness care at each hospital were included in coding. Reassembling data allowed for clustering of codes to form themes and subthemes (Ivankova, 2015; Miles et al., 2020). Data interpretations occurred with the transformation of data into a narrative description of each hospital case (Ivankova, 2015; Miles et al., 2020). The qualitative data representation included a matrix that displays the identified themes, subthemes, and a thick description of quotations (Creswell & Plano Clark, 2018). These themes were combined with the quantitative data to describe palliative care or serious care within each

hospital through a thick narrative description. During the cross-case analysis, the cases or hospitals were compared for similarities or areas of divergent characteristics regarding serious illness care. Table 9 provides the strategy of the qualitative data analysis.

Table 9

Processes and Strategies of Qualitative Data Analysis

Components of Qualitative Analysis (Ivankova, 2019; Miles et al., 2020)	Approaches (Miles et al., 2020)
Segmenting data	Continuous data analysis as interviews are being transcribed Coding of documents A priori codes NVivo coding Code comparison Development of a codebook
Reassembling data	Identification of evolving relationships among categories Clustering of codes to form themes and subthemes
Data interpretations Within-case analysis	Transformation of data into findings Development of narrative description of each case
Comparative case analysis	“Stacking comparable cases” Creation of a meta-matrix to compare similar variables across cases

Points of Integration

The goal of the integration in this mixed methods case study design was to use the analysis of the qualitative data and supportive quantitative data to better understand factors related to palliative care access (Bryman, 2006). The meta inferences, through the triangulation and integration of data, offer rich information for the development of future interventions and offer directions for future research (Creswell & Plano Clark, 2018). As previously stated, there were two points of integration within this study: (a) within-case analysis for each hospital and (b) comparative case analysis among the four cases (Creswell & Poth, 2018; Plano Clark & Ivankova, 2016).

After analysis of the qualitative data, the case themes were triangulated with the results of the quantitative strand to create a within-case analysis (Bazeley, 2018; Yin, 2018). The data from each case were analyzed separately using the explanation building technique (Yin, 2018). The explanation building technique involves “explaining” the case based on causal sequences that have been found in the multiple data sources (Yin, 2018). This information is displayed using joint display matrices and narrative weaving for each case (Bazeley, 2018; Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015). This method also assisted in determining areas of divergence that needed to be explained (Bazeley, 2018).

All cases were analyzed using comparative cross-case synthesis through a strategy known as “stacking comparable cases” (Miles et al., 2020; Yin, 2018). “Stacking comparable cases” involves assessing within-case patterns across all cases and areas of divergence among the multiple cases with the creation of a meta-matrix, a matrix that includes quantitative and qualitative data from multiple cases that is utilized in analysis to

assess for within-case patterns and areas of divergence (Miles et al., 2020; Yin, 2018). The cross-case analysis was approached in three areas: (a) hospitals with palliative care, (b) hospitals without palliative care, and (c) hospitals with and without palliative care. The final cross-case analysis offered the opportunity for literal replication comparison among the cases to understand the areas of similarity and divergence related to palliative care access within Alabama hospitals. The development of a meta-matrix allowed for examination of these patterns (Bush-Mecenas & Marsh, 2018). This was completed by the PI, using notes to color code similarities and areas of divergence.

Study Rigor and Quality Assurance

Quality assessment standards have not been developed for mixed methods case study research; to assess quality, both the case study design and mixed methods design should be evaluated (Bazeley, 2018; Brogan et al., 2019). The rigor of this study was assessed utilizing established strategies in mixed methods research. To measure the overall mixed methods quality, a critical appraisal framework that focuses on the quality of interpretation and inference was applied (Curry & Nunez-Smith, 2015). The domains of mixed methods research quality include: (a) conceptualization and justification of the study as mixed methods, (b) design quality, (c) adherence to respective standards for qualitative and quantitative methods throughout the study, (d) adherence to standards for mixed methods data analysis, (e) quality of analytic integration, and (f) quality of interpretation (Curry & Nunez-Smith, 2015).

Conceptualization and justification for the use of the mixed methods approach was provided within this chapter (Curry & Nunez-Smith, 2015). A mixed methods case

study design offered greater insight, compared to a single case methodological design, into the complexities of assessing healthcare services within a real-life context and allowed comparison among cases that do and do not have a palliative care program in selected Alabama hospitals (Bakitas, Elk, et al., 2015; Plano Clark et al., 2018; Walshe, et al., 2004).

The design quality refers to the alignment of the design with the research aims and respective quantitative and qualitative methods (Curry & Nunez-Smith, 2015). The design typology was described within this chapter; a Quan + QUAL design was utilized. In the mixed methods literature, this is referred to as a concurrent design (Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015), as the collection of quantitative data was independent from the qualitative data for each case. The purpose of the concurrent design was to collect data independently and integrate the results of both strands to better explain the qualitative results; in this study, the concurrent design allowed for the use of qualitative data from semi-structured interviews and document review about serious illness care to explain descriptive quantitative data captured by the survey (Creswell & Plano Clark, 2018).

A standard for assessing mixed methods case studies has not been established; therefore, the multiple case study component of this design will be assessed for trustworthiness utilizing Lincoln and Guba's qualitative criteria. The four criteria for trustworthiness are credibility, dependability, confirmability, and transferability (Brogan et al., 2019; Guba & Lincoln, 1994; Lincoln & Guba, 1985; Polit & Beck, 2017). A detailed presentation of trustworthiness is provided below.

Adherence to standards for mixed methods data analysis includes both addressing divergent findings and assessing concordant findings (Curry & Nunez-Smith, 2015). This was completed during within-case and comparative cross-case analysis for this study.

Quality of analytic integration refers to the detailed description of the type of integration completed within a study (Curry & Nunez-Smith, 2015). The integration within this study was presented previously and focused on within-case and comparative case analysis.

The quality of interpretation was assessed by the transparency of the results from the quantitative and qualitative data in addition to the degree to which the data were utilized to develop meta inferences (Curry & Nunez-Smith, 2015). This was completed during the qualitative data analysis, within-case analysis, and comparative case analysis.

Trustworthiness

Rigor and trustworthiness of the qualitative strand were established by the following measures: (a) prolonged engagement, (b) peer review and debriefing, (c) member checking, (d) audit trail, (e) reflective journaling, (f) data triangulation and thick descriptions, and (g) mentoring, expert consultations, and dissertation committee audits. Table 10 provides a brief overview of the strategies that were utilized to ensure trustworthiness assessment.

Table 10*Trustworthiness of the Study*

Approach	Definition	Strategy
Credibility	Credibility refers to the believability and truth of the findings (Lincoln & Guba, 1985).	Prolonged engagement at each hospital Triangulation Peer debriefing Member checking/summary Mentoring, expert consultations, and dissertation committee audits
Dependability	Dependability refers to the stability of the data (Houghton et al., 2013).	Audit trail Reflective journaling
Confirmability	Confirmability refers to the accuracy of data (Houghton et al., 2013).	Audit trail Intercoder agreement/codebook Mentoring, expert consultations, and dissertation committee audits
Transferability	Transferability refers to the ability to transfer the methodological characteristics to another study within a similar context (Houghton et al., 2013).	Thick descriptions

Engagement at each site was prolonged, with fieldwork (interviews and document review) lasting approximately 8 to 16 weeks at each hospital.

Peer review and debriefing of a selected set of qualitative data assisted in establishing credibility of the study (Houghton et al., 2013; Polit & Beck, 2017). The PI shared multiple transcribed and coded interviews for review along with a codebook with the dissertation committee chair and dissertation committee methodologist. The PI incorporated critiques from the dissertation committee regarding the emerging themes and interpretations of the qualitative data.

Member checking with the interview participants was utilized to build additional credibility of the data (Polit & Beck, 2017). Verbal summaries by the PI were provided to each participant at the conclusion of the interview to confirm the overall description of serious illness or palliative care provision. Additionally, brief review summaries that encompassed interview findings from all three participant categories were created by the PI. These review summaries were distributed through email to senior hospital managers and clinicians to obtain written or verbal feedback on environmental factors and hospital structures and processes that impact palliative care access. Follow up by telephone was completed by the PI as needed. Positive feedback on the description of how serious illness and palliative care was provided was received from at least one individual from each participant group at all four hospitals. However, to better support the rigor of the study, it would have been beneficial to receive feedback from a greater number of participants.

An audit trail outlining decisions made during the study supports the dependability of the methodological and analytic decisions that were made (Houghton et al., 2013; Polit & Beck, 2017). Additionally, a reflective journal was maintained by the PI to provide history and theoretical perspective on the decisions that impacted the results

of the study (Houghton et al., 2013). Multiple data sources and triangulation of the data from cases provided credibility of the data (Polit & Beck, 2017; Yin, 2018). A rich description is provided related to each hospital, location, and participants of the cases (Creswell & Plano Clark, 2018).

Mentoring of the PI by the committee chair, who is well versed in palliative research and the use of multiple methodologies, continued throughout this study through regular meetings and electronic interactions. Additionally, the PI met with other committee members for consultation throughout the study. The committee members have experience in mixed methods research methodology, qualitative research, palliative care research, and health services research. Dissertation committee members also participated in auditing the design process and data collection and analysis.

Ethical and Human Subjects Issues

Issues that were considered included (a) obtaining needed ethical approvals from the University of Alabama at Birmingham, (b) informed and process consent among the participants, (c) weighing of risks and benefits for participation in the study, (d) providing privacy and confidentiality, and (e) additional ethical considerations related to mixed methods research (Polit & Beck, 2017; Pratt et al., 2017; Shamoo & Resnik, 2015).

Ethical Approval

The Institutional Review Board (IRB) at the University of Alabama at Birmingham (UAB) approved this study on 11/22/22 (IRB Protocol 300007594-007). In

addition, a written letter of participation for the study was obtained from the participating hospitals (Curry & Nunez-Smith, 2015; Tashakkori, Johnson, & Teddlie, 2021).

Informed and Process Consent

Informed consent was needed for the quantitative and qualitative strands. The hospital administration provided consent for the hospital; however, individual consent was also obtained, including offering the ability to opt out of participation (Anderson et al., 2015). Written informed consent for the quantitative survey was completed by the senior hospital manager, who assisted with survey completion. Individual verbal consent was obtained prior to interview initiation (Meert et al., 2008).

Risks and Benefits

Consideration of risks and benefits was provided for multiple stakeholders in the study. Collective risks included exposing the hospital to negative repercussions, such as: (a) costs to the healthcare system related to time for participation in the research, (b) risk to the reputation of or financial harm to the hospital due to the publication of the results, and (c) possible lack of sustainability for a future palliative care intervention at the hospital (Hyder et al., 2014; World Health Organization, 2013). To minimize these collective risks, the PI (a) asked that participants attempt to complete interviews after hours as needed and (b) ensured that publications do not include hospital names or identifiers.

Individual risks that were considered included negative effect on relationships among the hospital staff, lack of privacy, and cost of time to the participants (Macklin, 2014). To minimize these risks, the gatekeepers' full support was encouraged, and the PI

discussed the potential benefits of the study with the participants. However, to avoid the risk of coercion or undue influence, consent by participants was only completed by the PI (Resnik, 2016). Documents and discussion for recruitment clearly indicated that participation or nonparticipation would have no impact on employment or benefits status (Resnik, 2016). Time away from work required for the interviews was minimized by scheduling them prior to or after participants' shifts or during shifts if allowed by hospital administration. Providing this flexibility for data collection likely assisted in increased recruitment and participation (Meert et al., 2008). The benefits will not directly impact the participants; however, their participation could have positive impacts on care delivery in the future.

Privacy and Confidentiality

To protect the privacy and confidentiality of the participating hospitals, any publications or presentations will describe the demographics (i.e., size, geographic location, number of community members served) of the hospital but will not include the name. The participants were assured of privacy and confidentiality. Full disclosure was provided about the PI's requirement to report unethical practices that are disclosed if there is a risk to safety (Shamoo & Resnik, 2015). Additionally, clear boundaries were set related to interactions outside of the research study (Shamoo & Resnik, 2015).

Confidentiality was provided to all participants. Data were only accessible by the PI and those assisting with future analyses (Polit & Beck, 2017). The data were stored in a password-protected computer with access allowed only to the PI and authorized personnel (Polit & Beck, 2017). Hospital administration was not involved in the data

collection or analysis (Molyneux et al., 2016; Shamoo & Resnik, 2015). Lastly, the plan for dissemination was provided to participants (Peter, 2015).

Additional Ethical Considerations Related to Mixed Methods Research

The use of mixed methods research requires additional ethical considerations, especially with the use of a concurrent design, addressing: (a) quantitative and qualitative ethical concerns, (b) collection of identifying information, and (c) participant burden (Creswell et al., 2011). The ethical issues for both the quantitative and qualitative strands were addressed by the PI (Creswell et al., 2011) as noted in the previous paragraphs. Personal information was collected (e.g., name, contact information, job information, professional experience) during initial recruitment (Creswell et al., 2011). Contact information was collected in order to request participation in the study and understand how participants' job background may have impacted their interaction with patients with serious illness. This was discussed during initial introductions. Lastly, the use of a mixed methods approach may have increased participant burden within the study, especially for senior hospital managers who assisted with survey completion. All potential participants were informed that the research was voluntary (as stated previously) and that if they chose not to participate there would be no negative consequences (Creswell et al., 2011).

Chapter 3 Summary

The use of a mixed methods case study design offered the most appropriate fit to successfully complete the purpose and aims of this study. Case selection included four Alabama hospitals based upon HRR and HCI, existence/non-existence of palliative care, hospital size, and geographic location. A senior hospital manager was recruited at each

hospital to act as the survey coordinator and to complete an adapted CAPC National Palliative Care Registry survey via paper form and pencil. The adapted National Palliative Care Registry survey provided a general picture of palliative care programs, services, staffing mix, funding, and patient populations within the four selected Alabama hospitals. The survey sections were broken down so that appropriate staff were able to complete pertinent sections. The quantitative data were analyzed using descriptive statistics.

Multiple sources of qualitative data included interviews and information from document reviews. The purposefully recruited sample for the qualitative strand included the senior hospital managers, clinician leaders, and frontline clinicians. Senior hospital managers were key to recruitment of other hospital staff, and every effort was made to create rapport. The initial hospital senior manager was asked to participate in the interview and recommend clinician leaders and frontline clinicians to participate; snowball sampling was thus utilized when needed. Continuous thematic data analysis of interviews provided a portion of the qualitative data using strategies of segmenting, reassembling, and interpreting data. Coding of the document reviews was included within the qualitative analysis. Analysis of each case was completed using explanation building. Comparative-case synthesis was completed across all cases, along with the creation of a meta-matrix. The meta inferences created with both strands of data yielded a rich, in-depth understanding of serious illness care within community hospitals in Alabama.

Conventional methods were followed to provide rigor, reliability, and trustworthiness to the study procedures. Lincoln and Guba's trustworthiness criteria were used to ensure rigor within the study. In addition, ethical approval was obtained from the

University of Alabama at Birmingham Institutional Review Board and by all the hospitals where the study was conducted. Finally, informed consent was reviewed with participants for the survey and interviews.

CHAPTER 4

RESULTS

The purpose of this mixed methods multiple case study was to develop a thorough description of access to palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. This chapter presents the study results in two sections, first providing a mixed methods within-case analysis for each hospital, including a summary of quantitative environmental factors, hospital characteristics and processes related to serious illness and palliative care, in addition to qualitative themes from interviews of administrators, clinician leaders, and frontline clinicians. Then, the results for the cross-case analysis of the four hospitals are compared for environmental factors, hospital characteristics, and processes related to serious illness and palliative care across four Alabama hospitals.

The results are organized around three common themes that were identified during the analysis. The three themes, or categories, that emerged are (a) history and evolution of serious illness care, (b) providing patient-centered serious illness care, and (c) serious illness care impact. The theme of history and evolution of serious illness care is supported by the integration of results from the quantitative environmental factors and survey data along with the qualitative interviews and document analysis at each hospital.

The themes of providing patient-centered serious illness care and serious illness care impact emerged from qualitative interviews and document analysis at each hospital.

Case One: Hospital A

Description of Hospital A—Large, Urban Hospital With Palliative Care

Hospital A was established in 1916 through a “grassroots effort to meet a need in the community for healthcare that did not require long periods of travel for residents” (A-A1). The not-for-profit hospital is licensed for 583 beds. The hospital is established in an urban community and serves an additional six surrounding counties that consist of mainly rural geography with limited access to healthcare services, such as primary care and tertiary care hospitals. To best serve these communities, the hospital has two satellite hospitals, one in the populated area of the same county and the other in a rural county. One county that is served by the hospital was impacted by the closure of its rural hospital, whereas the additional four counties have small hospitals with limited resources that may face financial constraints. Three additional independently owned hospitals within the hospital-defined catchment area of Hospital A serve the rural counties.

Designated by Medicare as the Sole Community Provider, the hospital serves as the hospital hub for multiple counties and is the only hospital offering palliative care within the catchment area. Inpatient services include labor and delivery, neonatal intensive care unit, surgical services, and catheterization laboratory. In addition to inpatient services at the main hospital, the hospital offers a large cancer center, outpatient surgical center, diabetes education center, home health services, and home medical

equipment. Palliative care services are currently only offered at the main hospital, with hopes to expand the practice in the future. The hospital established the palliative care program through a “grassroots effort with the support of a few clinician advocates that expressed the need for this service to serve the community better.” The palliative care program began seeing patients in 2016 utilizing a part-time board-certified physician. The program has grown rapidly since that time; the staff now consists of a part-time board-certified physician, two full-time certified nurse practitioners, and a full-time social worker who serves as the coordinator and educator.

Demographic Hospital Information

Hospital A had a total of 19,526 patient admissions in 2021. This included an average daily census of 339 patients. The total number of annual inpatient deaths was 1,077 patients. Most of the patient population included adults aged 18-64 years old (56.3%, $n = 11,270$ patients) and adults 65 years old and older (42.0%, $n = 8,410$ patients). The racial makeup of the population served was mainly African American (25.5%) and Caucasian (68%). The most common discharge dispositions included: home without any services (60.5%), home with home health or palliative care (10%), and death (10%). All payments (100%) that were received for the Hospital A budget were from fee-for-service clinician billing (including Medicare Part B billing). Appendix H provides demographic details of Hospital A.

Description of Hospital A Participants

A total of nine current employees from Hospital A participated in an individual face-to-face interview and represented a diverse range of job classification, experience, and time with the hospital. The participants included four males (45%) and five females (55%), eight of them Caucasian (89%) and one African American (11%). Participants were further classified based upon their length of employment at Hospital A with a range of 2 years to 38 years. Participants were assigned pseudonyms based on their role in relation to the interview and were designated by A-A1, administrator, A-L1 through A-L4, clinician leaders, and A-F1 through A-F4, frontline clinicians. Table 11 provides participants' demographic information.

Table 11*Hospital A Participant Demographics*

Part. ID	Participant Role	Gender	Race	Professional Education or Training	Years at Hospital	Years in Current Role	Current Position
A-A1	Hospital Administrator	female	Caucasian	Master of Accountancy	11 years	7 years	Chief Financial Officer
A-L1	Clinician Leader	male	Caucasian	BSN, MSN	11 years	1 year	Interim CNO
A-L2	Clinician Leader	male	African American	BSN	6 years	1 year	Medical ICU Nurse Manager
A-L3	Clinician Leader	male	Caucasian	MD, Palliative Care Fellowship	10 years	6 years	Palliative Care Medical Director
A-L4	Clinician Leader	female	Caucasian	MSW	4 years	2 years	Director of Case Management
A-F1	Frontline Clinician	female	Caucasian	MSW	2 years	2 years	Palliative Care Coordinator
A-F2	Frontline Clinician	female	Caucasian	ADN	6 years	3 years	Medical ICU Registered Nurse
A-F3	Frontline Clinician	female	Caucasian	ADN	38 years	38 years	Medical ICU Registered Nurse
A-F4	Frontline Clinician	male	Caucasian	Master of Divinity	10 years	10 years	Nurse Chaplain

Theme One: History and Evolution of Serious Illness Care

The theme of history and evolution of serious illness care encompassed the characteristics of the hospital and the community, the history and evolution of serious

illness and palliative care within the hospital, and the perceptions and beliefs of staff about serious illness and palliative care that impact care. The theme was supported by the weaving of results from the quantitative environmental factors and survey data along with the qualitative interviews and document analysis at each hospital. The theme was comprised of three subthemes: (a) developing a mindset towards serious illness care, (b) developing a financially feasible, mission-focused approach to serious illness care that was impactful for patients and families, and (c) changing perceptions about serious illness and palliative care through trust and education.

Subtheme: Developing a Mindset Towards Serious Illness Care

Developing a mindset towards serious illness care included hospital and community characteristics such as the environmental factors, staffing, and the population served (Table 12 presents a joint display of the quantitative and qualitative results for this subtheme).

Table 12

Hospital A Joint Display for Subtheme: Developing a Mindset Towards Serious Illness Care

History and Evolution of Serious Illness Care: Developing a Mindset Towards Serious Illness Care		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - Passion within administration for providing services for the <u>benefit of the community</u> 	<ul style="list-style-type: none"> - “I spent two days learning all about palliative care and how to measure it and what it does, and it was very intriguing, and something that I felt pretty passionate about once I heard about it and understood that it's not just hospice care and understood moving up the food chain so to speak.” (A-A1) 	<ul style="list-style-type: none"> - Access to community and inpatient hospice services within the catchment area - Limited community palliative care services - Sole Community Hospital Status, community-focused assessments
<ul style="list-style-type: none"> - Focus on providing <u>best quality care</u> for patients 	<ul style="list-style-type: none"> - “Typically, especially nursing, we’re pretty geared towards what’s best for the patient. And so, anything that’s new or new service or something that we’re perceiving as it’s gonna be a benefit for ’em, we’re all for it.” (A-L2) 	<ul style="list-style-type: none"> - Cancer mortality rate higher in four counties and an ACS cancer center to establish quality care for patients with cancer
<ul style="list-style-type: none"> - <u>“Seeing” the impact</u> of serious illness care for the patient 	<ul style="list-style-type: none"> - “Truly seeing was believing in the use of the services: “Sometimes the best teacher of it is really them seeing it and participating.” (A-F1) 	<ul style="list-style-type: none"> - Top chronic illness diagnoses: cardiac (18.6%, $n = 4,001$), GI/hepatic (9.2%, $n = 1989$), and pulmonary (7.3%, $n = 1,583$)

Qualitative Findings. All participants provided comments related to developing a mindset towards providing care for patients with serious illness. The hospital administrator spoke about the passion for providing such a beneficial service for patients within the community, even though reimbursement was lacking. The administrator reflected on why palliative care is a service that benefits patients, "We feel good, we know anecdotally it's good for our patients, so we view it more as a community service than anything" (A-A1). It was the passion of providers, administration, and even the board that initiated the possibility of building a palliative care program that would impact the care for patients and their families in years to come. The administrator spoke about the support for the program despite the lack of reimbursement: "We do not collect as much as it costs for the director's services, or the two nurse practitioners, or any other support that they get to run their consult service, so it is something that we feel is a community benefit" (A-A1).

Clinicians commented a great deal on transparency of the services that could be offered to patients and their families. Educating staff on how impactful the services would be for patients with serious illness helped to develop a mindset towards use of the palliative care services and growth within the program. One palliative care clinician leader stated, "I think it's education and then repetition. Once they see what we do—and then I think they trust us to do a good job, but I think it takes hands-on experience" (A-L3).

Clinicians appreciated the education. However, the mindset shift occurred through seeing patients who might previously have had unrealistic goals and received futile

treatments; now they benefitted from having a holistic, supportive approach to care that honors their wishes. One frontline clinician described the ability to

facilitate somebody to live in a good way, in a positive way, regardless of what's going on, regardless of the illness, regardless of where the emotions are. To move 'em through that and get 'em the resources they need to live better. (A-F2)

Quantitative Findings. This section presents data related to supportive quantitative data for the subtheme of developing a mindset towards serious illness care.

Environmental Factors. Hospital A included six counties within the hospital-defined catchment areas. These included one urban county and five rural counties. The average cancer mortality rate, which is an indicator of overall health, was higher than the overall Alabama average. The mean mortality rate for the six counties in Hospital A's catchment area is similar to the overall Alabama cancer mortality rate; however, two counties within the catchment area are higher and this could indicate poor health within these two counties.. The hospital is an ACS cancer center with a goal of providing quality cancer care for patients, which was a diagnosis considered with the implementation of palliative care. The mean household income was below the Alabama average (\$54,943) in all except one county. The only urban county had a median household income above that of the remaining five rural counties. Table 13 provides data of environmental factors for Hospital A.

Table 13*Environmental Factors*

	Median	Range	Mean	Alabama Comparison
Population of Catchment Area				
Population	18,116	201,244	48,457	4,903,185
SDH: Economic Stability				
Median Household Income	\$43,675	\$28,682	\$43,389	\$54,943
SDH: Healthcare Access				
Cancer Mortality Rate (measure of health) *per 100,000	199.85	135.1	206.2	209.3

Hospital A was the only hospital case that had received the Medicare sole community hospital status. Hospitals with sole community status have been found to have a lower adoption of hospital palliative care programs when compared to those that do not carry this status. However, this is not the case for Hospital A, which has established and grown the hospital palliative care program since it was started in 2016. Community-based palliative care was limited within the hospital-based catchment area, with only two of the six counties having access to these services. Access to community hospice and home health was available within the entire catchment area. The Hospital Referral Region (HRR) where this case is located had the highest Hospital Care Intensity (HCI) of all four cases, and this hospital had the highest HCI of all four hospitals. Interestingly, the case had a strong hospital palliative care program that continued to grow in the number of patients seen. However, the high HCI could indicate that

medically ineffective treatments may be received more frequently prior to a palliative care consult. These data are displayed in Table 14.

Table 14

Factors Relevant to the Adoption or Closure of Hospital Palliative Care Programs

Sole Community Hospital Status	Yes
ACGME Approved Residency	Yes
ACS Cancer Center	Yes
Community-Based Hospice Access within Catchment Area	Yes
Inpatient Hospice Access (within 60 miles of hospital)	Yes, hospice house and GIP
Community-Based Palliative Care Access within Catchment Area	Yes, Tuscaloosa & Bibb
Community-Based Home Health Care Access within Catchment Area	Yes
Hospital Care Intensity (HCI) with Hospital Referral Region (HRR)	83.9%
Hospital Care Intensity (HCI) at the Hospital	75.3%

Primary Hospital Admission Diagnoses. The top admission diagnosis was “other,” which includes a variety of hospital services. However, the diagnoses that followed “other” were diagnoses related to chronic illness; therefore, palliative care services could be beneficial for these patients. The three top chronic illness admission diagnoses included: cardiac (18.6%, $n = 4,001$), GI/hepatic (9.2%, $n = 1,989$), and pulmonary (7.3%, $n = 1,583$). Table 15 provides information about primary admission diagnoses for Hospital A.

Table 15*Primary Hospital Admission Diagnoses*

Admissions Based Upon Primary Diagnosis	
Cardiac	4,001 (18.6%)
Pulmonary	1,583 (7.3%)
Cancer	639 (3.0%)
Renal	1,067 (5.0%)
Neurologic/Neuromuscular/ Neurodegenerative	624 (2.9%)
GI/Hepatic	1,989 (9.2%)
Traumatic	1,540 (7.1%)
Other (ENT, OB/GYN, Endo, Spine, Neonate, surgery)	10,110 (46.9%)

Subtheme: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care

Developing a financially feasible, mission-focused approach to serious illness care that was impactful for patients and families emerged through understanding the factors and resources that the hospital used to develop an approach to care for patients with serious illness (i.e., palliative care program development through clinician leaders). Table 16 presents a joint display of the quantitative and qualitative results for this subtheme.

Table 16

Hospital A Joint Display for the Subtheme: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care That Was Impactful for Patients and Families

History and Evolution of Serious Illness Care: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care That Was Impactful for Patients and Families			
Qualitative	Illustrative Quote	Quantitative	
<ul style="list-style-type: none"> - <u>Champions</u> found within administration and physicians for serious illness care 	<ul style="list-style-type: none"> - “I think [previous hospital doctors] just saw the need that there was another layer that needed to be added in order for patients to make informed decisions. I think that was probably the impetus for it.” (A-L4) 	<ul style="list-style-type: none"> - Contracted with one or more hospice agencies to provide serious illness care for patients - Palliative care budget 100% supported by the hospital 	
<ul style="list-style-type: none"> - <u>Palliative care education</u> for administration <u>prior</u> to starting palliative care 	<ul style="list-style-type: none"> - “I think that was what really sent us over the edge was going to that [CAPC PCLC training] and understanding it made it very possible, but it was our team that championed it.” (A-A1) 	<ul style="list-style-type: none"> - N/A 	
<ul style="list-style-type: none"> - Establishing palliative care was a <u>mission fit</u> for the hospital and a need for the community 	<ul style="list-style-type: none"> - “We really tried to stay true to the mission, impact as many people as possible with the benefit, and then try to stay financially viable or use our foundation to help subsidize it.” (A-A1) 	<ul style="list-style-type: none"> - Established palliative care program in 2016 as an embedded model - Currently utilized 3.5 FTE staffing to provide the services to patients, no plans to expand at this time 	
<ul style="list-style-type: none"> - Physician experience and training 	<ul style="list-style-type: none"> - “I think he [palliative care trained internal medicine physician] was the catalyst in it, 	<ul style="list-style-type: none"> - Program is led by 0.5 FTE board certified physician, 2.0 FTE nurse 	

but I think the interest the rest of us took”
(A-A1).

practitioners, and 1.0 FTE social
worker/coordinator

Qualitative Findings. Administration and clinician leaders felt that multiple advocates helped to build the foundation of serious illness care within Hospital A. Several medical doctors with hospital privileges and a long-standing practice within the community were the initial champions for consideration of the program. This passion helped to support administrator buy-in and provision of additional education on palliative care. One clinician leader reflected on the upstream thought process in caring for patients and families during serious illness:

I think they [previous hospital physicians] were early champions as, “Hey, this is a way to provide that type of care for really sick people,” again, upstream in the disease process kind of before they leave the hospital, ’cause I think it is telling that a lot of the early physician champions here were hospice docs. (A-L3)

Administration felt that, though there was a passion among administrators and the board of directors for great patient care, knowledge about the benefits of a palliative care service was lacking. The administrator commented on the impact of the Center to Advance Palliative Care (CAPC) Palliative Care Leadership Centers (PCLC) training: “If we had not gone there and spent that two days getting that level of a deep dive and understanding what it is and what it could be more than we thought, maybe we wouldn’t have done the program” (A-A1).

Additionally, a new practicing internal medicine doctor who had completed a palliative care fellowship served as the first champion and director of the program. Ultimately, the service was an opportunity to provide upstream care for patients with serious illness in the community and, in addition, would possibly impact the bottom line. The potential for cost savings while providing improved care was particularly attractive

to the administration and the board of directors. One clinician leader commented about the impact of one of the champions, “I just feel like his knowledge, his palliative care fellow, his knowledge, his passion for hospice and end-of-life care, his affiliation with hospice here, his family’s involvement, I just think that’s a passion of his” (A-L4). The administrator felt that the program fit the three areas that are evaluated before initiating a new service line: financially feasible, impactful for patients, and mission focused. The administrator stated, “We really tried to stay true to the mission, impact as many people as possible with the benefit, and then try to stay financially viable or use our foundation to help subsidize it” (A-A1).

Quantitative Findings. This section presents data related to supportive quantitative data for the subtheme of developing an approach to serious illness care.

Hospital’s Palliative Care Resources. The resources for Hospital A included access to hospice services through a contract with community hospice agencies to provide inpatient care and a relationship with community hospice agencies that offered informal collaboration related to patient care. Two of the hospitals’ champions served as hospice medical directors within the community.

Palliative Care Program Characteristics and Structure. Hospital A offered the provision of palliative care through an embedded staffing model that is established internally within the hospital. This staffing model includes 3.5 FTE, represented by a part-time physician, two full-time nurse practitioners, and one social worker who served

in a full-time role as both coordinator and educator. The program is funded 100% through the hospital because the administration sees this as a “mission fit” and meeting the community’s needs. Table 17 provides all the details that were collected regarding Hospital A’s palliative care program.

Table 17*Palliative Care Program Characteristics and Structure*

Year the palliative care program was established	2016
Inpatient palliative care staffing model	
Embedded: program is internal to the hospital	Yes
Partial: program partially internal with additional contracted services	n/a
Contracted: program is administered by an outside, contracted agency	n/a
Status of staffing with the program over the last year	
Stable: not currently recruiting or requesting additional staff	Yes, 3.5 FTE
Reduced staff in the past two years: not currently recruiting or requesting additional staff	n/a
Short-staffed: requesting and recruiting additional staff for current patient load	n/a
Requesting staff to manage anticipated future growth	n/a
Disciplines represented within palliative care team	
Physician	0.5
Advanced Practice Registered Nurse	2.0
Physician Assistant	
Registered Nurse/Licensed Practical Nurse	
Social Worker	
Chaplain/Spiritual Care Provider	
Pharmacist	
Other	1.0
Inpatient Palliative Care Program Budget (%)	
Financial support from hospital or another parent organization	100%

Subtheme: Changing Perceptions about Serious Illness and Palliative Care Through Trust and Education

Changing perceptions about serious illness and palliative care through trust and education included the perceptions from staff about how care is to be provided and buy-in to providing serious illness care (Table 18 presents a joint display of the quantitative and qualitative results for this subtheme).

Table 18

Hospital A Joint Display for Subtheme Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education

History and Evolution of Serious Illness Care: Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education			
Qualitative	Illustrative Quote	Quantitative	
- Obtaining “buy-in” to serious illness care; buy-in came easiest with hospitalists and intensivists	- “When we did our interview at the Board, my kind of pitch, I suppose, to them was that this is the rare opportunity in medicine where we can practice good medicine, because the majority of hospitals our size nationwide do have a palliative care program, so we practice good medicine.” (A-L3)	- Most of the consults were from hospitalists (46.8%, $n = 619$) and the pulmonary/critical care team (38.7%, $n = 512$).	
- Shift in believing in <u>“upstream” care</u>	- “It’s [palliative care] extended medical care for patients that might not be end of life, which I think the term has become end-of-life care now, extension of hospice, kind of non-hospice.” (A-F2)	- N/A	
- Trust and education were to establish and grow the PC program	- “Once they see what we do—and then I think they trust us to do a good job, but I think it takes hands-on experience. Trust that we are not going to just give everybody a bunch of morphine and shovel ’em to the inpatient hospice unit. I think that just takes time (speaking about initial reluctance of oncology).” (A-L3)	- The most common primary diagnosis for which the consult was received was pulmonary (41.9%, $n = 439$) and cancer (22.3%, $n = 233$).	

Qualitative Findings. Administration and clinician leaders found that early training with both administrators and clinician leaders impacted the ability and buy-in to start a program.

When we did our interview at the Board, my kind of pitch, I suppose, to them was that this is the rare opportunity in medicine where we can practice good medicine, because the majority of hospitals our size nationwide do have a palliative care program, so we practice good medicine. (A-L3)

Administration commented on the importance of a PCLC program training that helped to educate administrators and clinician leaders on palliative care and the impact that can be seen for patients and families.

Learning all about palliative care and how to measure it and what it does, and it was very intriguing, and something that I felt pretty passionate about once I heard about it and understood that it's not just hospice care and understood moving up the food chain so to speak. (A-A1)

Clinician leaders and frontline clinicians commented about the initial hesitancy that was found with a shift in early goals of care conversations and consulting palliative care services. They felt that hesitancy was improved with education and building trust among the care team. One clinician leader stated, "You know, the practice before was more so people just use them as that last ditch effort before DNR. Just something like, I've done everything; let's get them on board. I think we've kind of exhausted all options" (A-L2). Another commented,

A lot of those physicians just naturally felt like, "I know Jane Doe or John Doe better than anybody else. I'm going to be the one that's going to help see them

through this whole process." It was hard getting those physicians to see the benefit, as I think they all just naturally felt like palliative care should be something they do. (A-L1)

However, it did take time to increase consults and build a stable palliative care team. Initially, palliative care was seen as the “pull the plug team” and were often not involved until late in the disease process.

We’re just the pull-the-plug team or the send you to you’re-not-gonna-make-it team, that kinda thing. We still very much fight that battle, not just with families, but with some of the physicians and a lot of the nursing—or I shouldn’t say a lot—with a larger-than-you-would-expect portion of the nursing staff and medical staff that think palliative care is the exact same thing as hospice, where palliative care is only needed in the final days of life. But once we kind of overcome that barrier, I think people—the program sells itself. (A-L3)

A shift in believing and seeing the service as “upstream care” within the disease process assisted with growth of the use of palliative care services for patients with serious illness. As one frontline clinician commented, “It’s [palliative care] extended medical care for patients that might not be end of life, which I think the term has become end-of-life care now, extension of hospice, kind of non-hospice” (A-F2). A clinician leader said of palliative care providers,

They just wanted to support them, identify what their wishes were, give them like where they were, how things were lookin', and from there just set a goal and just work towards it. It wasn't that they thought all people should be DNRs. You

know, that's not their purpose. Their purpose was just being that supportive of group for the patients and patients' families. (A-L2)

Quantitative Findings. This section presents supportive quantitative data for the subtheme of perceptions about serious illness care.

Palliative Care Program Consults. Most of the consults were from hospitalists (46.8%, $n = 619$) and the pulmonary/critical care teams (38.7%, $n = 512$). The first groups to “buy-in” included hospitalists and intensivists, who continue to be the most frequently admitting physicians. The most common primary diagnoses for which a consult was received were pulmonary (41.9%, $n = 439$) and cancer (22.3%, $n = 233$). Oncologists were more reluctant to refer cancer patients initially, but establishing trust was an important step for the palliative care team. Table 19 displays additional details of palliative care consults at Hospital A.

Table 19*Hospital A Palliative Care Program Consults*

Annual Initial Palliative Care Consults by Clinician Specialty	
Hospitalist	619 (46.8%)
Oncologist	39 (3.0%)
Cardiologist	21 (1.6%)
Nephrologist	20 (1.5%)
Pulmonary and/or Critical Care	512 (38.7%)
Surgery	9 (0.7%)
Neurologist	3 (0.2%)
Internal Medicine	99 (7.5%)
Family Medicine	0 (0.0%)
Unsure/Unknown	0 (0.0%)
Other	0 (0.0%)
Number of Consults Based Upon Primary Diagnosis	
Cancer	233 (22.3%)
Cardiac	158 (15.1%)
Pulmonary	439 (41.9%)
Renal	77 (7.4%)
Neurologic/Neuromuscular/ Neurodegenerative	140 (13.4%)

Summary of History and Evolution of Serious Illness Care

Management of patients with serious illness was a passion for a handful of early champions to create a palliative care program within Hospital A. This was the initial driving force behind seeking out additional education, which then ignited a passion within the hospital administration, clinician leaders, and the board. The hospital initially supported and continues to support the palliative care program through 100% hospital funding. Program growth was slow at times, due to initial hesitancy and the desire of many providers to provide care directly to their patients. However, education and witnessing the benefits for patients and their families have helped the program expand and shift the mindset within Hospital A. Hospitalists and intensivists were supporters of

the early palliative care program and continued to be the primary sources of consults for the palliative care program. Additionally, younger generations of providers are receiving palliative care education and are more open to the idea of including this service as a part of the patient's care team. Though reimbursement is limited, the development and growth of palliative care meets the hospital's mission and impacts the patients who are served within the community.

Theme Two: Providing Patient-Centered Serious Illness Care

All participants commented on the process of providing care for patients with serious illness, whether from direct patient contact or care management. The theme of providing patient-centered serious illness care emerged through understanding the processes that were essential to providing care to patients with serious illness and their families. The theme was comprised of five subthemes that describe how care was provided: (a) basics of providing care, (b) building trust and relationships among clinicians and the palliative care team, (c) empowerment through leadership support of serious illness care, (d) the importance of clinician training when providing serious illness care, and (e) multidisciplinary communication focused on patient-centered care.

Subtheme: Basics of Providing Care

Clinician leaders and frontline clinicians spoke about access to policies and procedures related to serious illness care that were located within the intranet. Table 20 provides a graphic organizer for the subtheme of basics of providing care.

Table 20

Hospital A Graphic Organizer for Subtheme: Basics of Providing Care

Providing Patient-Centered Serious Illness Care: Basics of Providing Care			
Participant Perspectives	Associated Codes	Illustrative Quotes	
- Policy use related to serious illness care was limited	- utilizing policies and procedures in serious illness - assessment tools used in practice	- “I think we kinda look to the future as someone that comes in and may need palliative care.” (A-F3)	
- Policies and procedures are often not utilized by staff due to intensivists’ involvement and experience of nurses for caring for patients with serious illness	- physician-driven referral process	- “Well, if it’s the nurse who recognizes the need, then we just communicate with our intensivist, and most of the time, they specifically place the order—of course, if they agree.” (A-F4)	
- Limited knowledge of the National Consensus Project Guidelines though they sought out quality metrics for palliative care program assessment	- NCP usage with practice	- “I have utilized that when we've had our team meetings.” (A-F1)	

While basic policies for comfort care and organ donation could be found on the hospital intranet, policies and procedures for serious illness care were not easy to locate (and were rarely used). One frontline clinician reflected on the openness to palliative care within the ICU, despite the lack of easy access to such policies: “I think probably back here in critical care, we’re just a little more forward thinking. I think we kinda look to the future as someone that comes in” (A-F3).

However, rounding on patients with palliative care providers present seemed to be impactful for clinicians. One frontline clinician reflected on having the palliative care team present compared to using policies in practice, “We do have like a scoring system to go by, but we’re also rounding every day, and our palliative care coordinators are within those rounds. I’m sure all of that’s within a policy” (A-F4).

When the palliative care program first began, there was a “cheat sheet” that allowed the nurses to look for indications that palliative care might be considered. A clinician leader said that the cheat sheet included language such as, “Ask these questions. If you got two or more points, then that was supposed to prompt you to ask the physician to do it. That’s how nursing initially started bringing in palliative care and incorporating them” (A-L1).

However, when the intensivists began, the cheat sheet was no longer needed due to their underlying inclination to refer for palliative care when indicated and their intimate involvement in the patient care within the unit. One frontline clinician commented on the involvement of intensivists, “They really push for palliative care and have a close understanding of where the patient is at and what the needs may be early on” (A-F4).

Frontline clinicians indicated that they could request consults with palliative care if they felt a need but trusted the intensivist to manage the care and consult when needed. Clinician leaders were not familiar with the National Consensus Guidelines for Quality Palliative Care, even within the palliative care staff: “I’m not familiar with that” (A-L4).

Subtheme: Building Trust and Relationships Among Clinicians and the Palliative Care Team

The subtheme of building trust and relationships among clinicians and the palliative care team emerged through interviews and reflections with the interdisciplinary team (IDT) members. IDT rounding and evolving relationships among the care team had an impact on palliative care referral, despite challenges that the IDT aimed to overcome. Table 21 provides a graphic organizer for the subtheme of building trust and relationships among clinicians.

Table 21

Hospital A Graphic Organizer for Subtheme: Building Trust and Relationships Among Clinicians and the Palliative Care Team

Providing Patient-Centered Serious Illness Care: Building Trust and Relationships Among Clinicians and the Palliative Care Team		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Inclusion of <u>all staff</u> within IDT (nurses, therapy services, intensivists, spiritual care, pharmacist, dietary, and a palliative care team member)	- The importance of IDT work	- “Anybody that goes to the bedside and has direct patient care, needs to be involved in that care's interdisciplinary team. If we're gonna have holistic care, it's all brought to the table.” (A-F2)
- Multidisciplinary rounds <u>build trust and established relationships</u> among the team including palliative care	- Understanding the roles of the IDT - Relationships and trust among the care team	- “We got to understand each and everybody's side a lot more as each one reported out kind of what we were lookin' at and what we were seein' from our end and what we were lookin' to do. It went a long way towards relationship-wise, professionally.” (A-L2)
- Palliative care had a <u>positive impact</u> with participation in rounding	- Rounding impact on palliative care	- “We have had great success with interdisciplinary team rounds in the ICUs.” (A-L3)
- The care team didn't feel that they were working in “silos” with rounds	- Putting the pieces together to provide palliative care	- “Before it was like, you might have one physician or nurse kinda had some bits and pieces of what was goin' on here and

		there. But a huge change for us was havin' intensive care doctor that kinda managed all things.” (A-L2)
- PC team <u>challenges</u> with not having a <u>dedicated full IDT</u>	- Care challenges	- “We were able to get plenty of champions. We have tried to do interdisciplinary team meetings it’s been difficult. By the time the message went from our team meeting to champions our message got muddled.” (A-L3)

The administrator commented that trust was built through the inclusion of both clinical and nonclinical staff within the interdisciplinary team: “To me interdisciplinary is all stakeholders, and so for that it’s clinical, it’s each department, anybody that might touch that patient or that type of condition at the table with operational non-clinical folks—that could include all the way down to revenue cycle” (A-A1).

Clinicians felt that relationships and trust had been built through the introduction and continued use of daily multidisciplinary rounds. These rounds included intensivists, nurses, spiritual care, case management, respiratory therapists, palliative care, therapy services (physical and occupational), and dietary services. Rounding offered an opportunity for all disciplines to be involved and provide updates on patients. One clinician leader reflected, “Strike up conversation and gettin' to know more of the people for who they were, outside of that we were starting to see a little bit more as far as what they consult on and brought in earlier on” (A-L2).

Clinicians reported they felt many of the disciplines that work with patients with serious illness were previously “working in silos,” but rounding has allowed all disciplines to share their roles and how they can impact patient care, thereby building a professional relationship among the care team. One clinician leader stated, “Our rounds went a long way towards—even with care just not siloing out things” (A-L2).

The palliative care team felt that rounding with the intensivists increased the number of consults they received, and the team felt free to make suggestions while rounding on patients who might benefit from the service. One frontline clinician stated, “Almost every single round, they're saying something to the palliative care representative

standing there, the coordinator. ‘Have y'all seen this patient? What are y'all doing?’ That used to come to us [spiritual care], but that's how integrated they have become” (A-F2).

During interviews, the participants reflected on some of the remaining challenges to building relationships. Clinicians felt that workloads and short staffing impacted the care that they were able to provide. One frontline clinician observed, “As a care team as a whole, I guess, the needs are all over the place—short staffed, not having the resources that we need” (A-F4).

There was even a feeling among some providers that doctors and nurses were the “bread and butter” for the hospital and other disciplines (e.g., social workers, chaplains) were not “essential.” The pressures and unrealistic expectations could even come from families. One frontline clinician reflected on the challenges of working in the current healthcare climate:

I'm really struggling because I just feel like I'm getting mean sometimes, 'cause I see, and I feel like I know what the outcome's gonna be most of the time, but I just get so aggravated in families that, it's just the climate of the country right now. We're stupid and they Google something on Google, and they know that they have the answers. (A-F3)

The palliative care team also reflected on challenges of not having a dedicated full interdisciplinary team: “I think our team is interdisciplinary as much as we can be” (A-F1). The team reflected on past attempts to create a team that had palliative care experience; however, funding and staffing changes did not allow for a dedicated fully interdisciplinary team with all appropriate disciplines. One clinician leader said, “We

can't afford to have our own chaplain, and we can't afford to have our own case manager" (A-L3).

Subtheme: Empowerment Through Leadership Support of Serious Illness Care

The subtheme of empowerment through leadership support of serious illness care emerged through interviews and reflected the impact of leadership within Hospital A on caring for patients and families with serious illness. Table 22 provides a graphic organizer for the subtheme of empowerment through leadership support of serious illness care.

Table 22

Hospital A Graphic Organizer for Subtheme: Empowerment Through Leadership Support of Serious Illness Care

Providing Patient-Centered Serious Illness Care: Empowerment Through Leadership Support of Serious Illness		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Variety of leadership styles	- Mixture of leadership styles that complement each other	- “You typically see a pretty good variety, and I think that’s a good thing. You have different people that lead different ways. You have some that are much more quiet. Me, I’m gonna typically be much more quiet. I don’t mind voicing an opinion. And you have yours that are a lot more lead by example. You have some that are just really good cheerleaders, motivators. You have some that are really good at the background stuff, inner workings of whatever that aren’t personable at all.” (A-L2)
- Transparent leadership with a <u>“hands on” approach</u> to serious illness care	- Transparent leadership - Top-down approach to leadership	- “I would say I see more transparency in the mid to lower-range management in terms of being more communicative about what’s going on.” (A-F1)
- Critical care nurses felt that they relate to direct managers, but did not always feel supported by upper administration	- Hands on approach to leading	- “Just, we get told that they hear us and they see the need, but we just don’t see a change [reflecting on upper management].” (A-F4)

Comments related to hospital leadership were made by all participants.

Administration and clinician leaders felt it was important to be a “more hands-on” leader while avoiding micromanaging the care team. This was noted with the development of the palliative care program. Administration offered support and worked to get the program off the ground, such as providing advertising and training. However, once uptake of the services began to increase, administration turned over the reins to the director and coordinator of palliative care. One clinician leader reflected, “Administration helped to nurture the palliative care program in a hands-on approach in its infancy, and then as it has grown, they have not micromanaged it” (A-L3).

Clinicians felt that a good variety of leadership styles were seen within the hospital and offered the right amount of support for moving the hospital and programs forward. One clinician leader stated, “All of them are, they work in their own ways and they're really good. So, I'm happy of that because we kind of have—just that variety, I think, helps” (A-L2).

Clinicians felt that their voices were heard by direct management through open and transparent communication. One clinician leader stated, “It is being transparent, I should say. It's hearing people's concerns, trying to help find out where maybe they have hesitancy or doubt or questions, and trying to explain the why behind things” (A-L1).

Clinicians commented that many of the direct managers of clinical care areas were not far removed from the bedside, so they were more relatable and approachable when a challenge arose. One clinician leader stated,

A lot more people [middle management] aren't as removed from the bedside or the manager leadership. Kinda like anything, anybody management-wise is not so

far removed from who's reportin' to 'em, so a lot more understanding of things and little nuances. What works now versus what doesn't anymore kind of thing. So, I think it goes a long, long way for overall happiness with jobs and who we report to. (A-L3)

Subtheme: The Importance of Clinician Training When Providing Serious Illness Care

The subtheme of the importance of clinician training when providing serious illness care emerged through reflections of participants on topics related to training at Hospital A. Table 23 provides a graphic organizer for the subtheme of improving clinician training in serious illness care.

Table 23

Hospital A Graphic Organizer for Subtheme: The Importance of Clinician Training When Providing Serious Illness Care

Providing Patient-Centered Serious Illness Care: The Importance of Clinician Training When Providing Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Mandatory <u>orientation</u> includes <u>serious illness training</u>	- Orientation for new staff - Identifying education gaps	- “As far as that week of ICU orientation they first start, yes it’s mandatory. After that, what you see—it's a little bit more voluntary.” (A-L2)
- Mandatory serious illness care education for the entire staff is limited post-orientation	- Serious illness training - Training attendance expectations - Need for palliative care education is great	- “If it's something that has to do with our credentialing, like Joint Commission, CMS, something like that, yeah, they're gonna put out a mandatory.” (A-F2)
- Serious illness training focused towards ICU nurses	- Support for serious illness education - Specific palliative care training	- “I teach the RN orientation. I teach the critical care orientation and then I have those four classes that are open to the hospital but required for critical care nurses. The next phase is probably applying for the CE credits for social workers too.” (A-F1)

Clinicians commented on the impact of clinician training on providing care within Hospital A. The comments related to orientation, annual training, and areas of identified focus. Serious illness care training and an introduction to the palliative care program were mandatory for clinician orientation, especially for nursing staff; in contrast, training was limited for other care providers, including physicians. One clinician leader stated, “I don’t know how much continuing education there is from a hospital standpoint. Some of it is informal. From a physician standpoint I’m not aware that there’s any training” (A-L3).

Clinician leaders felt that the training that focused on caring for patients with serious illness had improved since the establishment of the palliative care program. One clinician leader said of the increased training opportunities facilitated by the palliative care coordinator, “Our coordinator meets with and provides education for all of our incoming nurses during nursing orientation. She provides outreach to staff, lunch and learn, things like that. She teaches an OLLI class” (A-L3).

Clinicians commented that serious illness and palliative care training for clinicians has improved greatly within formal education programs and may be taken into consideration when training new staff: “A significant part of that training every year for me is that it's goals of care, end-of-life care” [speaking on the role of a chaplain] (A-F2).

The palliative care coordinator has recently begun offering specific classes for intensive care registered nurses (RNs) that are linked to annual evaluations. RNs are required to attend two of four classes offered within an annual period. The more classes that nurses attend, the better they score on annual evaluations. One clinician leader

explained, “As part of their goals that they'll be evaluated on at the end of the fiscal year, it was about for palliative-care focused and communication-focused classes” (A-L1).

Subtheme: Multidisciplinary Communication Focused on Patient-Centered Care

The subtheme of multidisciplinary communication focused on patient-centered care emerged through reflections of participants related to communication between administration and staff and the impact communication makes in the care that is provided to patients with serious illness and their families within Hospital A. Table 24 provides a graphic organizer for the subtheme of patient-centered communication.

Table 24

Hospital A Graphic Organizer for Subtheme: Multidisciplinary Communication Focused on Patient-Centered Care

Providing Patient-Centered Serious Illness Care: Multidisciplinary Communication Focused on Patient-Centered Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Open and honest communication with the staff 	<ul style="list-style-type: none"> - Honest communication - Communication challenges 	<ul style="list-style-type: none"> - “I mean, we're shootin' for stars, and hopefully we land on clouds. You know, this is what we're shootin' for; however; we're probably gonna end up more here. And they're a lot more open to that.” (A-L2)
<ul style="list-style-type: none"> - Multidisciplinary rounding has made a <u>huge impact connecting patients to services</u> 	<ul style="list-style-type: none"> - Multidisciplinary rounding communication - Palliative care communication with the care team 	<ul style="list-style-type: none"> - “Just me even being there [referring to multidisciplinary rounds], I think it flags for them like, oh, they would be a good one for that.” (A-F1)
<ul style="list-style-type: none"> - The <u>PC team</u> has been <u>instrumental in leading conversations</u> on goals of care for patients with serious illness 	<ul style="list-style-type: none"> - Approaches to communication with patients and families - Communication partnership with palliative care - Palliative care communication with the care team 	<ul style="list-style-type: none"> - “When palliative comes in, they're like, "Don't talk to 'em, don't ask 'em anything," so then you know, we just go in and talk about the weather. Some families just cannot—don't wanna talk about it. They know, but they just don't wanna talk about it. You just kinda have to feel them out and see where the conversation leads you.” (A-F3)

All participants commented on the impact of communication on care for patients with serious illness. Administration and clinician leaders commented on the impact that open, honest communication with staff had in building relationships: “The trust part of it, like I said, is just being as open as possible, as honest as possible, and welcoming whatever it is” (A-L2).

One clinician felt that open, early communication about impactful changes is important. The participant stated, “Employees that when they're frustrated by things that are happening, that they don't know about, then it's harder for them to defend anything the hospital is doing. I think it would go a long way to have more transparency” (A-F1).

Additionally, monthly management team meetings allow for upper and middle management to discuss upcoming changes, challenges, and other important information that is then taken back and shared with frontline clinicians. The administrator stated,

We have a big management team [meeting] each month, about 120 people, where we present monthly our financials, our quality metrics, just a whole slew of things, and then those directors and managers that are there are supposed to then disseminate that at their department meetings. (A-A1)

Clinicians discussed the positive impact of multidisciplinary rounding and communication on the care for patients with serious illness. One clinician leader stated, “We’ve seen probably the most growth in our service over the last few years has been in the ICUs, and I think that’s directly related to the multidisciplinary team rounds” (A-L3).

Frontline clinicians feel that this offers an avenue for open communication to discuss how to best care for their patients and whether other services, such as palliative care, will positively impact each patient and family. One frontline clinician reflected that

“The palliative care team has impacted the way frontline clinicians are able to interact with patients and families related to goals of care conversations: they have been very instrumental in helping lead the conversation. Or helping us lead the conversation” (A-F3).

However, clinicians did not have a specific approach to communication with patients and families. One frontline clinician said of her experience building her confidence to have conversations, “I don’t have a specific approach. I will say, just from experience, I’ve gotten more comfortable with having those conversations” (A-F4).

Summary of Providing Patient-Centered Serious Illness Care

Many of the participant interviews focused on providing care to patients with serious illness at Hospital A. The care of patients with serious illness was greatly impacted by the intensivist and multidisciplinary rounds, in turn resulting in increased palliative care use. Frontline clinicians often felt that policies were available but not readily utilized. Often frontline clinicians leaned on their experience, the intensivists’ close involvement with their patients, and the multidisciplinary rounds rather than written policies to provide care for patients with serious illness.

Participants felt that trust and communication among the care team had the greatest impact on care for patients with serious illness. Inclusion of a large multidisciplinary team within rounds helped to build professional relationships and increase communication among the care team. Prior to interdisciplinary rounds, participants reported feeling as though they were working in silos. The relationships and trust established during interdisciplinary rounds extended to the palliative care team, thus

creating earlier referrals for patients and families. In contrast, frontline clinicians reflected on short staffing, increased workloads, and underappreciation in some roles. Frontline clinicians stated that they did not always feel that upper management understood the challenges of providing care for patients with serious illness. However, they often felt that direct management had their best interest at heart and knew the struggles of caring for patients since they were not as far removed from providing care. Additionally, members of the palliative care team commented on the challenges of not having a full interdisciplinary team to provide care.

An increased focus on care for seriously ill patients was recently directed toward ICU RNs, and appropriate training was reflected in the annual staff evaluation.

Theme Three: Serious Illness Care Impact

All participants addressed the impact of serious illness care for the patients, families, hospital, and community. The theme of serious illness care impact emerged through understanding the impact of care for patients, families, the hospital, and the community. Participants also described perceived limitations to providing serious illness care. The theme was comprised of three subthemes: (a) focus on patient-centered care, (b) palliative care closing the gap in fulfilling a need for patients with serious illness, and (c) limitations to providing serious illness and palliative care.

Subtheme: Focus on Patient-Centered Care

The subtheme of focus on patient-centered care emerged through participant interviews. Participants reflected on ways patient-centered care has been impacted within

Hospital A, as well as on how they continued to honor the patients' and families' wishes during serious illness. Table 25 provides a graphic organizer for the subtheme of focus on patient-centered care.

Table 25

Hospital A Graphic Organizer for Subtheme: Focus on Patient-Centered Care

Serious Illness Care Impact: Focus on Patient-Centered Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Opportunity to honor patients' and families' wishes, even with poor prognoses 	<ul style="list-style-type: none"> - Family experience during serious illness care - Patient is more than a disease 	<ul style="list-style-type: none"> - "There's good outcomes. There is gonna be some bad. Also just being that support person for the family or that patient through all of it, and, as they transition, go through that, and you go through that with 'em is a big thing all itself." (A-L2)
<ul style="list-style-type: none"> - Staffing challenges have impacted care for patients 	<ul style="list-style-type: none"> - Ultimately, we are here for patients 	<ul style="list-style-type: none"> - "We're in a time now where travel nursing is a big thing. You have people that all say, well, we deserve a pay raise. Honestly, great. You know what, I do not get paid nearly enough for what I do. I love what I do, but, you know, the thing is, none of us got into this profession for the money." (A-L2)

Clinicians described providing care to patients who received early palliative care. They noted that early palliative care resulted in more open communication between the staff and the family, allowing patients' wishes to be honored, and futile or unwanted treatments to be avoided. One frontline clinician described using honest communication that helped family members understand patients' prognoses: "They were like this would really help my so-and-so family member to understand, to hear it from a third party, not hear it from me, so there's no bias" (A-F4).

Clinicians spoke about a shift in the staffing environment related to travel nursing, understaffing, and extremely sick patients. One clinician leader stated, "We're in a time now where travel nursing is a big thing, and the staffing environment is changing along and our patients are sicker" (A-L2). However, keeping the focus on honoring the patient goes a long way in managing serious illness, even if the outcome is not what the family or staff wanted for this patient. Providing care to each patient based on the person and turning the focus away from just the disease offers dignity through the hospitalization and beyond. One clinician leader spoke about the care provided to patients with a poor prognosis:

Just are going to have poor prognoses or people that are going to have terminal prognoses, and maybe they're going to make it out of the hospital, but they needed that plan of how do we take care of more than just the disease process. How do we take care of the person, their family, those relationships? They [palliative care clinicians] were able to just be that resource. (A-L1)

Subtheme: Palliative Care Closing the Gap in Fulfilling a Need for Patients with Serious Illness

The subtheme of palliative care closing the gap in fulfilling a need for patients with serious illness emerged through participant interviews about how the care that was provided to patients with serious illness met the needs of those patients and their families within Hospital A. Table 26 provides a graphic organizer for the subtheme of meeting the needs of patients with serious illness.

Table 26

Hospital A Graphic Organizer for Subtheme: Palliative Care Closing the Gap in Fulfilling a Need for Patients with Serious Illness

Serious Illness Care Impact: Palliative Care Closing the Gap in Fulfilling a Need for Patients with Serious Illness		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Impact for <u>care continuation</u> through the use of intensivists, case management, multidisciplinary rounds, and PC services 	<ul style="list-style-type: none"> - Investing in patients and families - Program impact related to other factors 	<ul style="list-style-type: none"> - “When they implemented intensivists, a lot of them. They really push for palliative care. I think it just goes to—they’re up here with the 16 patients, and so they, I guess, get to spend more time with each individual patient and kind of look, okay, we’re on day 6 of being on the ventilator. It’s not lookin’ like we’re gonna come off. We may need to either move towards comfort measures or move towards trach, and just discussing—having them involved from the beginning.” (A-F4)
<ul style="list-style-type: none"> - <u>PC offered a “soft service”</u> to patients while nurses were focused on physical care, especially during COVID 	<ul style="list-style-type: none"> - Program impact related to COVID 	<ul style="list-style-type: none"> - “I’m speaking from the nurse leader on our unit’s point of view and just the relationship we’ve had with them ... they were integral in essentially providing that kind of soft care that maybe we lost touch with, especially during COVID, just due to the huge mortality rates and just the amount of extra work that taking care of COVID patients

			brought. It was an extremely, extremely strained time.” (A-L1)
- Discharge plans and continuation of care for patients with serious illness can be put into place	- Providing options	-	“I feel confident when they’re going home with something like home healthcare because then if we’ve initiated conversations here to talk about the trajectory of illness and then we put them in the hands of a service that can continue to check in on them and then also continue those conversations should they need to lead to something like hospice.” (A-F1)
- <u>Referrals to PC expanded</u> to include multiple serious illnesses, not just cancer	- Filling a gap and need - Viewing from a different perspective	-	“I will tell you, our hospitalist group now, it’s starting to broaden so much it’s hard to outside of oncology say which things are the most diagnosis that we are seeing used because they’ve learned how to use it properly.” (A-A1)

Administration felt that the palliative care service impacted the community surrounding this full-service hospital. One administrator stated, “There is not the financial support from the payers to provide this type of service, and so it's dependent on nonprofit hospitals who believe that's their mission to provide palliative care” (A-A1). Though palliative care was often used for patients with cancer or congestive heart failure, the impact has expanded into other disease categories to fill a need in providing holistic care to patients and their families. The administrator observed, “It is now being used across a lot of different types of diagnosis, but oncology for us is really honestly number one” (A-A1).

Palliative care provided “soft services” (i.e., goals of care conversations and family meetings) for patients and families, allowing critical care staff to focus on providing physical care while still understanding the emotional and spiritual needs of the patient and family. This meant staff could better connect with families and understand their point of view. One clinician leader said of palliative care providers, “They were integral in essentially providing that kind of soft care that maybe we lost touch with” (A-L1).

The service was especially impactful during the height of the COVID-19 pandemic, when clinicians were so focused on the physical aspects of care that goals of care and communicating with the family became less of a priority. The palliative care service stood in the gap for the patients and families, providing holistic care where wishes were honored for the best possible medical outcome. One clinician leader reflected on this time,

They just could tie all of the little loose ends together with family members.

Whether it was connecting them with the right nurse, doctor, consult, they were able to do a lot of those pieces. In addition to that, especially the coordinator, just spending time at the patient's bedside that maybe the nurse couldn't always do, because we're having to go prone another patient or we're having to code another patient. It was just nonstop for 18 months. They helped so much in that supportive role like that (A-L1).

Clinicians have witnessed the impact for patients and families who are at a crossroads in care. They have witnessed palliative care clinicians serve as a "guide" providing options and education towards the next steps in care. One frontline clinician stated, "It's like almost being the headmaster and helping direct care and just put it all under one tent, or one umbrella, I guess, just to help guide the family" (A-F3).

The intensivists and multidisciplinary rounds have impacted the use of palliative care services and the "buy-in" by staff. One clinician leader noted, "I think a lot of trust is built through just the relationships you have with them. It's through the everyday stuff" (A-L1).

Additionally, case management and palliative care have been able to work together on discharge plans that impact the continuity of care for patients and families upon hospital discharge. One frontline clinician referred to the care coordination, saying, "I feel good about that continuum" (A-F1).

Subtheme: Limitations to Providing Serious Illness and Palliative Care

The subtheme of limitations to providing serious illness and palliative care emerged through participant reflections related to challenges that have been experienced when caring for patients with serious illness at Hospital A. Table 27 provides a graphic organizer for the subtheme of limitations to providing serious illness care.

Table 27

Hospital A Graphic Organizer for Subtheme: Limitations to Providing Serious Illness and Palliative Care

Serious Illness Care Impact: Limitations to Providing Serious Illness and Palliative Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Limited funding and reimbursement for PC</u> , hospital doing this for the benefit of constituents	- Payment streams	- “Number one is the fact that there is not the financial support from the payers at all to provide this type of service, and so it’s dependent on nonprofit hospitals who believe that that’s probably their mission to provide, and that’s what I think has really slowed down the growth of palliative care.” (A-A1)
- <u>Concerns for metrics comparison for PC program; unknown existence of NCP Guidelines for Quality Palliative Care</u>	- Challenges to measuring success	- “There are other programs that—like when palliative care started you couldn’t just get out there and go to some resource—even the Hospital Association didn’t have, “Here’s the five standards you should be trying to meet and here’s comparative databases.” (A-A1)
- <u>Delayed PC referrals and goals of care conversations due to misunderstanding of symptom management vs. end-of-life care</u>	- Delayed timing	- “They’re [the palliative care team] not very useful when it’s the day we’re supposed to extubate. It’s more so from the beginning to help talk the family through it.” (A-C4)

<ul style="list-style-type: none"> - Generational differences among providers impacted uptake 	<ul style="list-style-type: none"> - Generational differences 	<ul style="list-style-type: none"> - “I think it’s a lot of generational—there’s discrepancies in the perception of palliative care from generation to generation. The older physicians in the hospital, the people who are in their 50s and 60s, were the ones who we felt like we had to overcome the biggest barriers in educational palliative care. The physicians who—and I think that’s because they didn’t come up when they were in their training—palliative care didn’t exist. The physicians in their 40s and 50s I think are, or in my experience have been, much more open to it, more familiar with palliative care. Then the physicians in their 30s and 40s coming out of training, they consult us without hesitation.” (A-L3)
<ul style="list-style-type: none"> - Delayed goals of care conversations due to hesitation 	<ul style="list-style-type: none"> - Clinician hesitancy to palliative care referral 	<ul style="list-style-type: none"> - “You know, the practice before was more so people just use them as that last ditch effort before DNR. Just something like, I've done everything; let's get them on board. I think we've kind of exhausted all options.” (A-L2) -

Administration is focused on funding for hospitals, and cost savings can be anticipated to result from use of palliative care services. The administrator felt that “what hampers I think the growth of palliative care is the lack of reimbursement for it” (A-A1).

Additionally, program success is difficult to measure without national or state metrics that can be utilized to show the impact of the program. One administrator felt that it was challenging to assess the program without national metrics describing, “What is it we’re trying to accomplish? And what is the point of this program?” (A-A1).

Clinicians felt that delayed timing and misunderstanding impacted access to palliative care; as a result, conversations that focused on goals of care and honoring the patients’ wishes were also impacted.

I think the biggest problem was early on and maybe to this day, you still have some people who see it more as kind of that later consult when it happens. And we’ve all been guilty of just overlooking it, or just kind of seein’ ’em [palliative care] as a little bit late. (A-L2)

Clinician leaders also spoke about a generational shift among clinicians and the increased use of palliative care services for patients with serious illness. Younger clinicians often receive training in palliative care and managing serious illness within their professional educational programs. This impact can be seen in the use of the services and belief in their benefits for patients.

I think it’s a lot of generational—there’s discrepancies in the perception of palliative care from generation to generation. The older physicians in the hospital, the people who are in their 50s and 60s, were the ones who we felt like we had to overcome the biggest barriers in educational palliative care. The physicians

who—and I think that’s because they didn’t come up when they were in their training—palliative care didn’t exist. The physicians in their 40s and 50s I think are, or in my experience have been, much more open to it, more familiar with palliative care. Then the physicians in their 30s and 40s coming out of training, they consult us without hesitation. (A-L3)

Summary of Serious Illness Care Impact

Clinician leaders and frontline clinicians discussed the impact of early access to palliative care that helped manage the patient’s illness while honoring the patient’s wishes, even if the final outcomes were negative. Administration reflected on the palliative care program being available to those with multiple serious health conditions and the impact of care. This was especially important to the clinician leaders and frontline clinicians during the pandemic; during that time they were overwhelmed with providing physical care, while the palliative care team facilitated much-needed conversations regarding goals of care and kept the family informed of changes. However, barriers to offering this service included limited reimbursement, difficulty with evaluation and comparison of the program to programs in other hospitals, delayed referrals, and need for education among staff, patients, and families of palliative care.

Key Findings From Hospital A

Hospital A was nonprofit, located in an urban area, and serving a large rural catchment area. The palliative care program was established in 2016. The current model of care was a 0.5 FTE board-certified physician, 2.0 certified nurse practitioners, with a

1.0 social worker-coordinator. The following areas were important findings related to serious illness and palliative care at Hospital A:

- Supportive administration and clinician champions initiated palliative care after attending CAPC PCLC training
- Sole Community Hospital, that initiated palliative care
- Buy-in for the program was completed through education and the constituents “seeing” the results of palliative care
- Multidisciplinary rounding was important for building trust and relationships, especially with the palliative care team
- Intensivists were utilized within the ICU and were supporters of palliative care
- Serious illness training was required in orientation and offered through voluntary continuing education session
- Palliative care training was linked to critical care nurses’ annual evaluations
- Focus was honoring patients’ and families’ wishes, despite poor prognosis
- Limitation to palliative care existed with a major limitation being reimbursement and funding
- Generational differences in buy-in and referrals and also staffing shortages were further limitations to providing serious illness care

Case Two: Hospital B

Description of Hospital B—Large, Urban Hospital with Palliative Care

Hospital B was established in 1957. The nonprofit hospital is licensed for 387 beds, according to the Alabama Hospital Association, and serves seven rural Alabama counties. There are seven additional Alabama hospitals within the hospital-defined catchment area. Hospital B serves as a receiving hospital for the smaller county hospitals within the catchment area to manage patients with critical care needs. Designated by Medicare as a Rural Referral Center, the hospital serves as the hospital hub for multiple counties and is the only hospital to provide palliative care within the catchment area. The hospital offers inpatient maternal care, is a certified comprehensive stroke center, surgical center, and has a neonatal intensive care unit. In addition to inpatient services, the hospital offers an outpatient cancer center, heart and vascular center, wound care, home health, and cardiovascular and pulmonary rehabilitation. Hospital B established a palliative care program in 2014. The palliative care program utilizes 2.5 FTE with a nurse practitioner, a social worker, and a part-time chaplain. The palliative care program does not have physician represented on the care team.

Demographic Hospital Information

Hospital B admitted 18,569 patients in 2021, with an average daily census of 270.34 patients. Similar to the previous case, most of the patient population included adults aged 18-64 years old (55.2%, $n = 10,241$ patients) and adults 65 years and older (42.1%, $n = 7,819$ patients). The most common discharge dispositions included: home

without any services (65.6%), home with home health (13.9%), and long-term care facility (12.8%). Appendix H provides demographic details of Hospital B.

Hospital B provided information on financial incentives related to payments it receives. Budgeting sources came from fee-for-service clinician billing that included Medicare Part B billing (12.05%), philanthropic and foundation support (0.02%), and other revenue from patient and nonpatient sources (87.93%).

Description of Case Participants for Hospital B

Six employees from Hospital B participated in an interview. Participants were diverse within their job classification, experience, and employment duration. The participants included one male (16.7%) and five females (83.3%), with all identifying as Caucasian (100%). Participants were further classified based upon years of employment at the hospital, with a range of 6 to 29 years. Hospital B's staff reported the longest employee duration of the four cases. Participants were assigned pseudonyms based on their role in relation to the interview and were designated as B-A1, administrator, B-L1 and B-L2, clinician leaders, and B-F1 through B-F3, frontline clinicians. Table 28 provides participant demographic information.

Table 28*Hospital B Participant Demographics*

Part. ID	Participant Role	Gender	Race	Professional Education or Training	Years at Hospital	Years in Current Role	Current Position
B-A1	Hospital Administrator	female	Caucasian	Master of Business Administration	8 years	5 years	VP of Marketing and Strategic Planning
B-L1	Clinician Leader	female	Caucasian	MSN, Clinical Nurse Specialist	29 years	5 years	VP Patient Care Services & CNO
B-L2	Clinician Leader	female	Caucasian	MSN, Clinical Nurse Specialist	26 years	1 year	Director, Critical Care Services
B-F1	Frontline Clinician	male	Caucasian	Master of Divinity	6 years	6 years	Chaplain, Director of Spiritual Care
B-F2	Frontline Clinician	female	Caucasian	MD	13 years	3 years	Hospitalist, previous Director of Palliative Care
B-F3	Frontline Clinician	female	Caucasian	BSN	15 years	2 years	ICU Staff Nurse

Theme One: History and Evolution of Serious Illness Care

The theme of history and evolution of serious illness care encompassed how the care was provided to patients and families at Hospital B, how it has evolved over time, and the perceptions and beliefs of staff about serious illness and palliative care.

Participants within each category provided comments related to the theme of history and evolution of serious illness care within the hospital. The theme was comprised of three subthemes: (a) developing a mindset towards serious illness care, (b) developing a financially feasible, mission-focused approach to serious illness care that was impactful for patients and families, and (c) changing perceptions about serious illness and palliative care through trust and education.

Subtheme: Developing a Mindset Towards Serious Illness Care

Developing a mindset towards serious illness care included hospital and community characteristics such as environmental factors, staffing, and the population served. Table 29 presents a joint display of the quantitative and qualitative results for this subtheme. All participants commented on the subtheme of developing a mindset towards serious illness care.

Table 29

Hospital B Joint Display for Subtheme: Developing a Mindset Towards Serious Illness Care

History and Evolution of Serious Illness Care: Developing a Mindset Towards Serious Illness Care		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - Creating programs that meet the community needs and have buy-in from the community 	<ul style="list-style-type: none"> - “We actually created it along the quality-of-care perspective. Just are we doing the best we can to provide the best quality of care, outcome-wise, for the patients.” (B-L1) 	<ul style="list-style-type: none"> - Access to community and inpatient hospice services within the catchment area - Limited community palliative care services - Rural Referral Center, community-focused assessments
<ul style="list-style-type: none"> - Focus on <u>providing quality serious illness care</u> to patients and their families 	<ul style="list-style-type: none"> - “In order for palliative care to really thrive in an environment, you need administrators and supervisors and managers who really understand value-based care, meaning care that may not generate green dollar revenue but does generate revenue savings, which ultimately produces more opportunity for positive revenue growth.” (B-L2) 	<ul style="list-style-type: none"> - Cancer mortality rate was higher when compared to Alabama, began as a quality of care service for oncology patients - Top chronic illness diagnoses: cardiac (20.4%, $n = 3,791$), GI/hepatic (10.3%, $n = 1,904$), and pulmonary (8.5%, $n = 1,585$)
<ul style="list-style-type: none"> - <u>Education</u> and providing care to certain patients helped to shift the mindset of the hospital and see the 	<ul style="list-style-type: none"> - “We did education with our cancer committee. We did lots of education through the community, and through media relations. I would even do coffee talks. I did talks at the Rotary Club for Dothan. 	<ul style="list-style-type: none"> - ACGME Approved Residency for Internal Medicine, palliative care

benefit of palliative care
services

Talks at the senior center. A lot of the foundation
dinners and charity events that they had, I would do
talks there. That was kind of that first year, lots of
marketing.” (B-F1)

education included in the
curriculum

Qualitative Findings. Hospital B focused on providing quality care for patients within their catchment area. Palliative care was seen to provide high-quality care and decrease unnecessary readmissions, at least initially. The administrator reflected on meeting community needs through programs that may not be as “profitable.” “If it's not viable and we think there's still a great community need for it, we might still enter into that service based on the community need, knowing that it may be a service that's not profitable for us” (B-A1).

Staff involvement in planning any new programs was considered important at Hospital B. Participants noted that early staff involvement produced greater buy-in of new programs and allowed clinicians to see their benefits for patients. One clinician leader stated, “They need to understand the need for it as well. They want to see that it will benefit their patients, not just benefit the hospital” (B-L2).

Palliative care clinicians worked to educate hospital clinicians and the community about the benefits of using palliative care services. This included educational sessions within the hospital and through outside agencies. Additionally, caring for high-profile patients helped to increase the acceptability of the palliative care program. One clinician leader reflected on caring for patients and the impact of growth within the program: “Kind of after taking care of certain patients, kind of helped network into other ways to provide palliative care education, and kind of get this area—get the word out” (B-L1).

Administration and clinician leaders also worked to develop buy-in for all new programs by showing the benefits to patients; their approach was no different when earning the buy-in for the palliative care program. One frontline clinician recalled, “Definitely the hospitalist, and the ICU nurses, and the oncology nurses were on board

pretty quickly. That was the majority of our consults to begin with. They saw that the focus on quality of care for the patients” (B-L1).

Quantitative Findings. This section presents data related to supportive quantitative data for the subtheme of developing a mindset towards serious illness care.

Environmental Factors. Hospital B’s catchment area included seven rural Alabama counties, three counties in Florida, and two counties in Georgia. The mean household income was below the Alabama average and the cancer mortality rate for the hospital catchment area was higher than the overall state rate, with only one county having a lower than expected cancer mortality rate. This could indicate poor health within these counties as compared to the state of Alabama as a whole. The palliative care program started as a service line for quality of care for oncology patients. The environmental factors for Hospital B counties are included in Table 30.

Table 30*Hospital B Environmental Factors*

	Median	Range	Mean	Alabama Comparison
Population of the Catchment Area				
Population	37,049	88,677	46,291	4,903,185
SDH: Economic Stability				
Median Household Income	\$50,052	\$18,928	\$49,293	\$54,943
SDH: Healthcare Access				
Cancer Mortality Rate (measure of health) *per 100,000	219.6	106.4	227.1	209.3

Though in a rural community, Hospital B did not have the designation of Medicare Sole Community Hospital status. Still, they were considered a Rural Referral Center that focused heavily on the needs of surrounding communities, due to the presence of another hospital within 35 miles. Community-based home health and hospice were accessible within the hospital-based catchment area.

However, community palliative care was only provided in one of the Alabama counties within the catchment area. There was no inpatient hospice house located within 60 miles of the hospital, though the hospital did offer general inpatient (GIP) services. The HCI for the hospital was higher than the HCI for the HRR. These data are displayed in Table 31.

Table 31*Factors Relevant to the Adoption or Closure of Hospital Palliative Care Programs*

Sole Community Hospital Status	No
ACGME Approved Residency	Yes
ACS Cancer Center	No
Outpatient Hospice Access within Catchment Area	Yes
Inpatient Hospice Access (within 60 miles of hospital)	Yes, GIP only
Outpatient Palliative Care Access within Catchment Area	Yes, only in one county
Outpatient Home Health Care Access within Catchment Area	Yes
Hospital Care Intensity (HCI) with Hospital Referral Region (HRR)	40.5%
Hospital Care Intensity (HCI) at the Hospital	68.0%

Primary Hospital Admission Diagnoses. The top admission diagnosis was “other,” which includes a variety of hospital services. However, the diagnoses that followed “other” were diagnoses related to chronic illness; therefore, palliative care services could be beneficial for these patients. Three chronic illness admission diagnoses included: cardiac (20.4%, $n = 3,791$), GI/hepatic (10.3%, $n = 1,904$), and pulmonary (8.5%, $n = 1,585$). Table 32 provides primary admission diagnoses of Hospital B.

Table 32*Primary Hospital Admission Diagnoses*

Admissions Based Upon Primary Diagnosis	
Cardiac	3,791 (20.4%)
Pulmonary	1,585 (8.5%)
Cancer	406 (2.2%)
Renal	1,053 (5.7%)
Neurologic/Neuromuscular/ Neurodegenerative	1,537 (8.3%)
GI/Hepatic	1,904 (10.3%)
Traumatic	587 (3.2%)
Other (OB/GYN, surgeries, ENT, ophthalmology)	7,706 (41.5%)

Subtheme: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care

Developing a financially feasible, mission-focused approach to serious illness care that was impactful for patients and families involved consideration of hospital resources and the factors in place to develop an approach to care for patients with serious illness. Table 33 presents a joint display of the quantitative and qualitative results for this subtheme. All participants commented on the subtheme of developing an approach to serious illness care.

Table 33

Hospital B Joint Display for the Subtheme: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care that Was Impactful for Patients and Families

History and Evolution of Serious Illness Care: Developing a Financially Feasible, Mission-Focused Approach to Serious Illness and Palliative Care That Was Impactful for Patients and Families		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - <u>Champions</u> found within administration, physicians, and nursing for serious illness care 	<ul style="list-style-type: none"> - “Chief Nursing Officer, she was the Director for our oncology floor. She had already kind of been working behind the scenes, trying to get palliative care started for about a year or two before I even came into it. I had also been working separately to get our CMO to get a palliative care service started. Finally he was like, “Well, you know, there's a nurse that's really interested in this too, on oncology.” She had approached our radiation oncologist, but he wasn't interested in kind of spearheading it. I kind of became the physician champion for it.” (B-F1) 	<ul style="list-style-type: none"> - Contracted with one or more hospice agencies for GIP care - Palliative care budget 100% supported by the hospital, though grant funding was initially used to start palliative care
<ul style="list-style-type: none"> - Service line goals that focused on <u>providing quality care</u> and grant funding assisted in getting the program implemented 	<ul style="list-style-type: none"> - “We also might look to our foundation if we needed support financially to launch a service or service line that wasn't gonna be as profitable or not profitable and see what they can do to help us, so that is something we've done in the past. They've provided a lot of support to our palliative care program in the past, so to support that.” (B-A1) 	<ul style="list-style-type: none"> - Established palliative care program in 2014 as an embedded model - Currently utilized 2.5 FTE staffing to provide the services to patients, no plans to expand at this time

- A changing hospital environment and goals required a restructuring of the palliative care program staff

- “I know that the model has changed over time, and we've explored other models for palliative care. I'm sure that you've heard already that we had a palliative care physician, and now we run our program with a nurse practitioner, social worker, and chaplain.” (B-A1)

- Program is led by 1.0 FTE board-certified nurse practitioner, 1.0 social worker, and 0.5 FTE board-certified chaplain

Qualitative Findings. Champions for palliative care were found with an oncology nurse and internal medicine doctor. Additionally, the CEO and CFO at the time were supportive of palliative care. One clinician leader described the champions within the hospital: “An internal medicine physician, that was kind of a passion for her, also, in her role as a hospitalist is having the ability to provide, not necessarily hospice care, but more symptom management. Other physicians that were really advocating for it were our oncology physicians” (B-L1).

The program was modeled after UAB’s palliative care program. Participation in education through UAB impacted the knowledge needed for startup of the program. Staff at Hospital B received a great deal of encouragement from the opportunities to visit with UAB staff when developing the program. One frontline clinician recalled attending a training program prior to program startup: “The Clinical Training Academy. The CTA. Clinical Training Academy with UAB and did all of that before we started the program” (B-F1).

Training through the Center to Advance Palliative Care (CAPC) for the nurse advocate and the previous CEO and CFO impacted the startup and support for the program on the C-suite side. One clinician leader commented on the education, “Melissa had already gone to CAPC once. Our former CEO, CFO had gone through that training, through CAPC. They had the manuals, and everything, how to start it up” (B-L2).

Funding of the program startup was supported through the hospital foundation and other small grants. The hospital initially supported a portion of the program, but has since taken over full funding once the initial benefits for the patients were demonstrated. One frontline clinician reflected on grant funding and the impact of start up, “Without the

foundation's help, we wouldn't have been able to start. Actually, they supported about 75% of the program for the first year, and about 50% of the program for the second year” (B-F1).

The program was initially taken on a service line to assist with readmission of cancer patients due to uncontrolled symptoms. One clinician leader stated, “We actually created it along the quality-of-care perspective. Just, are we doing the best we can to provide the best quality of care, outcome-wise, for the patients?” (B-L1). Participating in a federal grant program to implement a lay navigator role in cancer care to avoid unnecessary emergency department admissions further illuminated the need for the development of a palliative care program. The clinician leader spoke about how this served as an impetus of the palliative care program:

The grant program was centered on implementing lay navigators into cancer care for Medicare beneficiaries to—in an attempt to mitigate the usage of emergency departments, readmissions, having someone that could follow along from cancer diagnosis to either treatment and/or death so that patients could have someone to navigate. (B-L1)

Bringing on a board-certified chaplain was a significant step for both the hospital and the palliative care program. The palliative care team initially included a physician and a nurse who served as a coordinator. Due to budgeting and growth, the current program comprises a nurse practitioner model with a social worker and chaplain. One clinician leader stated, “We're really pioneers in our system. I'm the first board-certified chaplain here. Palliative care is 6 or 7 years old here. We're really here building a culture of spiritual care and palliative care” (B-L2).

Quantitative Findings. This section presents supportive quantitative data for the subtheme of developing an approach to serious illness care.

Hospital's Palliative Care Resources. The resources for Hospital B did not include an existing relationship with a hospice agency; however, they did provide GIP care for patients who were served by a community hospice service.

Palliative Care Program. Hospital B offers palliative care through an embedded staffing model that is established internally within the hospital. This staffing model includes a 2.5 FTE that is represented by a full-time nurse practitioner, a full-time social worker, and a part-time chaplain. The program is funded 100% through the hospital. Palliative care services are available during day shift on weekdays. Table 34 provides all the details that were collected regarding Case B's palliative care program.

Table 34*Palliative Care Program Characteristics and Structure*

Year the palliative care program was established	2014
Inpatient palliative care staffing model	
Embedded: program is internal to the hospital	Yes
Partial: program partially internal with additional contracted services	n/a
Contracted: program is administered by an outside, contracted agency	n/a
Status of staffing with the program over the last year	
Stable: not currently recruiting or requesting additional staff	n/a
Reduced staff in the past two years: not currently recruiting or requesting additional staff	n/a
Short-staffed: requesting and recruiting additional staff for current patient load	Yes, 2.5 FTE
Requesting staff to manage anticipated future growth	n/a
Disciplines represented within palliative care team	
Physician	
Advanced Practice Registered Nurse	1.0
Physician Assistant	
Registered Nurse/Licensed Practical Nurse	
Social Worker	1.0
Chaplain/Spiritual Care Provider	0.5
Pharmacist	
Other	
Inpatient Palliative Care Program Budget (%)	
Financial support from hospital or another parent organization	100%

Subtheme: Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education

Changing perceptions about serious illness and palliative care through trust and education included the perceptions from staff about how care is to be provided and buy-in to providing serious illness care. Table 35 presents a joint display of the quantitative and qualitative results for this subtheme. All participants commented on the subtheme of perceptions of serious illness care.

Table 35

Hospital B Joint Display for Subtheme: Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education

History and Evolution of Serious Illness Care: Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education		
Qualitative	Illustrative Quote	Quantitative
	<ul style="list-style-type: none"> - “Some physicians I think are—depending on where they were trained and what education, what experience they've had of palliative care before they came to our facility or at our facility—are more likely to consult palliative care for symptom management and far upstream, closer to the diagnosis. Others may be more likely to consult palliative care at the point in which it's time to have the conversation about transitioning to comfort. For the palliative care team, of course, it's always more effective for us when we're consulted earlier in the medical narrative.” (B-F2) - “We really the first couple years kind of struggled for buy-in, and lots of palliative care education, community education, hospital education, staffing education. Quickly within a year, we were running full speed, wanting more help, thinking of 	<ul style="list-style-type: none"> - Most of the consults were from hospitalists (62.7%, $n = 605$) and the pulmonary/critical care team (23.5%, $n = 227$). However, this group initially was hesitant to palliative care. - The most common primary diagnosis for which the consult was received was cancer (32.7%, $n = 194$) and cardiac (21.2%, $n = 126$). - N/A

ways to expand the program, things like
that.” (B-F1)

Qualitative Findings. The perceptions of palliative care and serious illness care varied among the non-clinician and clinician staff. Overall, the focus was on symptom management and holistic care for patients with serious illness; however, attitudes about end-of-life versus early referrals varied. One clinician leader reflected on the overall goals of palliative care:

Palliative and supportive care is largely concerned ideally with the management of symptoms and disease processes, helping people to negotiate their illness and the changes to their lives, manage their symptoms so that they can have more time and better time in life and with their loved ones. (B-L2)

Another clinician leader reflected on palliative care as end-of-life care support:

When the palliative care team comes in, they can explain to the patient, "We want you to be comfortable, but you have to understand, we have to work within these boundaries unless you know you're comfortable with signing maybe I do not resuscitate." (B-L3)

Clinician hesitancy was cited as an issue, especially with older physicians and those not employed by the hospital who have privileges. One clinician leader stated, "A subset of physicians, they've cared for these patients and families. They feel that in asking another provider that's not familiar with their case to come in and have those conversations, I think, is a little difficult for them" (B-L1).

The palliative care program has helped to change the viewpoint regarding serious illness care for many clinicians, especially nursing staff, but also patients and families that were cared for at Hospital B. This is attributable to both educational opportunities and direct experience with the palliative care services. One clinician said of the changes

in perceptions of palliative care by nurses within Hospital B, “Until we established a specific palliative care program here, that’s when we began to see the nurses’ perception of what it is and how it can be successful and beneficial” (B-L2).

Quantitative Findings. This section presents supportive quantitative data for the subtheme of perceptions about serious illness care.

Palliative Care Program Consults. Most of the referrals were from hospitalists (62.7%, $n = 605$) and the pulmonary/critical care team (23.5%, $n = 227$). Hesitancy or resistance to palliative care was the initial reaction of the hospitalist and intensivists; however, through building of trust and relationships they have become a large source of referrals for the palliative care team. The most common primary diagnoses for which the consult was received were cancer (32.7%, $n = 194$) and neurologic disorders (26.3%, $n = 156$). Table 36 shows information about who facilitated palliative care program consults and why.

Table 36*Hospital B Palliative Care Program Consults*

Disciplines Represented Within Palliative Care Team	
Physician	n/a
Advanced Practice Registered Nurse	1.0
Physician Assistant	n/a
Registered Nurse/Licensed Practical Nurse	n/a
Social Worker	1.0
Chaplain/Spiritual Care Provider	0.5
Pharmacist	n/a
Other	1.0
Annual Initial Palliative Care Consults by Clinician Specialty	
Hospitalist	605 (62.7%)
Oncologist	24 (2.5%)
Cardiologist	8 (0.8%)
Nephrologist	8 (0.8%)
Pulmonary and/or Critical Care	227 (23.5%)
Surgery	41 (4.2%)
Neurologist	5 (0.5%)
Internal Medicine	38 (3.9%)
Family Medicine	0 (0.0%)
Unsure/Unknown	0 (0.0%)
Other	9 (0.09%)

Summary of History and Evolution of Serious Illness Care

Champions for palliative care were the driving force behind development of the palliative care program at Hospital B. Initially, the program was built as a service line for patients with cancer; the program was designed to provide comprehensive cancer services and to increase the patients' quality of life, manage symptoms, and avoid readmissions. However, the program expanded to include many other serious illnesses. Administration was supportive of palliative care and education, which was initially obtained through the CAPC PCLC program. There has been a shift in models that the palliative care program

has utilized based upon changes in administration and cost savings. During the early years of the program, funding was provided through foundation and other small grants. However, the hospital currently funds 100% of the program staff. Although the program was slow to get buy-in, this was combatted with education within the hospital and community. Additionally, the patient and clinician experience with the program further encouraged growth. Clinician hesitancy was found among hospitalists and intensivists during program implementation. Upon clinician experience with the palliative care program, this view shifted; currently, the hospitalists and intensivists were the sources of the greatest number of consults.

Theme Two: Providing Patient-Centered Serious Illness Care

All participants commented on the process of providing care for patients with serious illness, whether this be from direct patient contact or managing the care that was provided. The theme of providing patient-centered serious illness care emerged through understanding the processes that were essential to providing patient-centered care for those with serious illness. The theme was comprised of five subthemes that impacted how care was provided: (a) basics of providing care, (b) building trust and relationships among clinicians and the palliative care team, (c) empowerment through leadership support of serious illness care, (d) the importance of clinician training when providing serious illness care, and (e) multidisciplinary communication focused on patient-centered care.

Subtheme: Basics of Providing Care

The basics of providing care included assessment, charting, consultations by other specialists, and policies that are utilized for patients with serious illness. All participants commented on basics of providing care. Table 37 provides a graphic organizer for the subtheme of basics of providing care.

Table 37

Hospital B Graphic Organizer for Subtheme: Basics of Providing Care

Providing Patient-Centered Serious Illness Care: Basics of Providing Care			
Participant Perspectives		Associated Codes	Illustrative Quotes
- Policy use related to serious illness care was limited		- assessment tools used in practice	- “We have policies that cover it. However, staff aren’t always looking up policies. In as far as a checklist goes, we don’t have a specific checklist. Our palliative care team is present, very present, in the unit.” (B-L2)
- Symptoms and consult triggers were considered but never implemented due to the organic growth of the palliative care program & limited PC workforce		- utilizing policies and procedures in serious illness	- “Those would all be reasonable triggers for palliative care. We don't use them here currently. Our staffing is such that I don't know if, at our current levels of staffing, we could handle those kinds of automatic triggers.” (B-F2)
- Physicians are required to consult palliative care and other services related to serious illness care; however, clinicians and family members can make the request		- Physician-driven referrals process	- “Mostly physician consulted. Nurses often would kind of request it in the ICU and on the cancer floor, our oncology floor. They would request it a lot. Particularly the ICU. The ICU nurses would request it, but it had to be a physician order. It could even be a verbal order.” (B-F1)
- Unaware of NP Guidelines to guide quality palliative care		- NCP usage with practice	- “Yes, but we don’t currently use them.” (B-F1)

Hospital B has policies in place for serious illness care; however, clinicians typically did not utilize the policies. Often palliative care staff were present, but the clinicians did not look towards the policies. One frontline clinician stated, “I don’t know right off hand if there is a policy or not for just consulting palliative care, but it’s one of those things where if we get it” (B-F3).

Physicians are required to make the initial palliative care consult. It is common practice for ICU and oncology nurses to make the request, especially early in the development of the palliative care program. One frontline clinician stated,

I think in order for palliative care to follow up on a consult, they need a physician consult, so the attending physician. Oftentimes, physicians may be responding to a nurse advocate, a nurse, a bedside nurse who sees the need for palliative care and speaks to the physician. Families can request palliative care visitation. (B-F2)

Consult triggers have been considered for palliative care services. The palliative care team administered surveys to different departments to determine the need and interest in symptom triggers for referrals to palliative care. However, palliative care clinicians felt that official triggers were not needed, granted the growth of the program and the number of referrals that are consistently entered for patients. One frontline clinician reflected on the consideration for the triggers, “I think like most programs did where, we first started out, and we were only getting the dying patient consults. Then quickly kind of morphed into, more consults than we could keep up with” (B-F1).

Clinician leaders were familiar with the NCP guidelines; however, the guidelines were utilized initially but not much after the program was established. One clinician leader stated, “Yes, I’m familiar with them but we don’t often utilize them” (B-L1).

Subtheme: Building Trust and Relationships Among Clinicians and the Palliative Care Team

The subtheme of building trust and relationships among clinicians and the palliative care team emerged through interviews and reflections based upon the IDT members, the impact on care, evolving relationships among the care team, and challenges that the IDT would work to overcome. All participants commented on the subtheme of building trust and relationships among clinicians. Table 38 provides a graphic organizer for the subtheme of building trust and relationships among clinicians.

Table 38

Hospital B Graphic Organizer for Subtheme: Building Trust and Relationships Among Clinicians and the Palliative Care Team

Providing Patient-Centered Serious Illness Care: Building Trust and Relationships Among Clinicians and the Palliative Care Team		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Multidisciplinary rounds <u>built trust and established relationships</u> among the team 	<ul style="list-style-type: none"> - Building relationships through multidisciplinary rounds - Putting the pieces together to provide palliative care 	<ul style="list-style-type: none"> - “Oh yes, 'cause it's a team thing. I update them, like they come up, and I tell them what's happened that morning, give 'em update what's happened that evening, then the pharmacist. Like the doctor will say any needs from pharmacy, and they'll discuss antibiotics or their platelets are low. It just allows us to build upon each other's strength as clinicians.” (B-F3)
<ul style="list-style-type: none"> - Palliative care had a <u>positive impact</u> with participation in rounding 	<ul style="list-style-type: none"> - Established palliative care relationships with staff 	<ul style="list-style-type: none"> - “Our palliative care team is very present in the ICUs and has an extremely good relationship with our critical care nurses. I do think the nurses feel very comfortable—because our program is successful and established.” (B-L2)
<ul style="list-style-type: none"> - The palliative care team <u>model</u> had been impacted by <u>changes</u> in the past 	<ul style="list-style-type: none"> - The importance of interdisciplinary work 	<ul style="list-style-type: none"> - “We would have interdisciplinary rounds with us, plus the RN for palliative care,

-
- Understanding the role of the IDT

who was at the time also considered the coordinator. That eventually morphed into the social worker, who is with them now. Instead of an RN, it's a social worker, and then the chaplain. As a social worker, she also works as sort of the case manager, but she's not an RN. She is actually a social worker. We had tried to incorporate a case manager previously before we had her actual position. We had a job description through HR for a case manager, but we're never able to fill that role, so it morphed into a social worker.” (B-L1)

Multidisciplinary rounding has impacted the relationships of the care team and allowed for increased discussions on managing patients with serious illness. The relationships that were built through multidisciplinary rounding have facilitated referrals and discussions of patients' wishes for next steps in care. One clinician leader stated, "I think that multidisciplinary rounding promotes more of a team atmosphere" (B-L1).

The palliative care team has been involved in multidisciplinary rounding and had the opportunity to build and nurture relationships with staff. One clinician leader spoke of the team structure: "Really, a good example of interdisciplinary team planning and team management is our current huddle process that allows active participation including members of the palliative care team" (B-L1). The structure of the palliative care team has shifted due to changing administration and funding since the adoption of the program; however, this shift included hiring a full-time board-certified chaplain (0.5 FTE with the palliative care team). The administrator stated, "One area that we have expanded is our spiritual care. I feel like the spiritual care and the palliative care go hand in hand, they often work together with patients, and support each other. He's really enriched the organization" (B-A1).

Awards and recognition are provided within Hospital B. Awards are available for both clinicians and unlicensed staff. The hospital foundation also offers awards for staff. One clinician leader described the awards available. "We have nursing awards, the DAISY. We have a BEE award, which is for nonclinical caregivers who perform effectively or excellently" (B-L2). Recently, the palliative care nurse practitioner was recommended and received an award from the Legacy of Hope, which is a state-level award. One frontline clinician stated, "The current nurse practitioner for palliative care,

she was recently recognized by Legacy of Hope for her help with Legacy of Hope at our hospital” (B-F1).

The hospital provides resiliency training for all staff during orientation and additional training for ICU nursing staff. One clinician leader reflected on the establishment of resiliency training post COVID to assist with staff mental health in caring for patients with serious illness. “Our chaplain provides resiliency training. That focuses on well-being, mental health, how to step away from a bad situation or a difficult patient, particularly related to one that’s not gonna have a good outcome and how to process that” (B-L1).

Empowerment Through Leadership Support of Serious Illness Care

The subtheme of empowerment through leadership support of serious illness care for patients and families emerged through interviews. All participants commented on the subtheme of empowerment through leadership support of serious illness care. Table 39 provides a graphic organizer for the subtheme of empowerment through leadership support of serious illness care.

Table 39

Hospital B Graphic Organizer for Subtheme: Empowerment Through Leadership Support of Serious Illness Care

Providing Patient-Centered Serious Illness Care: Empowerment Through Leadership Support of Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Transparent and <u>engaged leadership</u> team impacts care within Hospital B 	<ul style="list-style-type: none"> - Transformational leadership - Hands-on approach to leading 	<ul style="list-style-type: none"> - “I would say, probably now, it’s more addressing looking at the problem, diving into it, understand the data, and just getting staff and others’ feedback. Our CEO actually served as the COO for a hospital. He is extremely operational. He is very, very engaged. He will oftentimes bring, even if he already knows what he wants to do— he’ll oftentimes bring ideas or discussion topics to our—we have an executive huddle every morning at 8:00 a.m.” (B-L1)
<ul style="list-style-type: none"> - Leadership is <u>focused on quality improvement</u> and strategic goals to impact serious illness care 	<ul style="list-style-type: none"> - Focused leadership towards quality improvement - Strategic focused leadership 	<ul style="list-style-type: none"> - “We have a CEO who is very transparent, and sets the tone for where we’re going, sets the strategic direction for the organization.” (B-A1)
<ul style="list-style-type: none"> - Shift in leadership led to a <u>shift in expectations for palliative care due to funding concerns</u> 	<ul style="list-style-type: none"> - Leadership changes that impact palliative care 	<ul style="list-style-type: none"> - “It was costing more money without the foundation being able to provide salaries, we

were more closely looked at for revenue generation rather than cost savings. It definitely kind of morphed into the feeling of we're doing this to provide needed help and care to our patients and our community to every service has to prove their worth." (B-L1)

Leadership is focused on quality improvement and the strategic direction of the hospital. One strategy to improve the quality of care within the hospital is the employment of a health care engineer who works to assess trends and process improvements to improve care. One clinician leader stated that the health care engineer “helps us dive into understanding trends and patterns and data and really works with us from a PI perspective: process improvement, really helping us to understand data and making sure that we’re targeting the right problem” (B-L1).

The physicians, board, and leadership team work together on strategic goals and the hospital direction at annual leadership retreats. This allows for input across different clinician levels and discussions related to feasibility of the strategic goals and the direction of serious illness care within the hospital. The administrator spoke about the leadership retreats that are conducted annually.

First, we have a physician retreat, we take our physicians off-site, and that is a leadership team retreat for our medical staff, and so we get their input at that particular meeting. Then a couple of months later, we take the board off-site—and we are governed by a not-for-profit hospital, but we’re an authority hospital, and so we’re governed by a volunteer board that’s made up of 12 members of the community and the president of the medical staff—so we take that board off and we do a strategic planning session with them and get their input. Then following that we do the same thing with our leadership team. (B-A1)

Leadership changes have impacted the structure and expectations of the palliative care program and shifted the focus away from a physician-run program and towards

expectation of a revenue-generating rather than a cost-savings program. One frontline clinician said of the change,

The old CEO that was very, very supportive of palliative care had actually gone to the palliative care leadership by CAPC, the leadership conference by CAPC, was no longer part of the program, was no longer with the hospital. The new CEO was coming from Banner Health out in Colorado. He was familiar with palliative care, but of course on a much larger system-wide scale (inpatient, outpatient, and community palliative care under the hospital system). (B-F1)

Frontline clinicians felt supported in their individual roles. One critical care nurse (frontline clinician) commented on the support within the ICU, “I’ve been at this hospital for a very long time, and I’ve gone through several CEOs and CNOs, and right now I feel the most supported than I’ve felt, I would say almost ever” (B-F3).

Subtheme: The Importance of Clinician Training When Providing Serious Illness Care

The subtheme of the importance of clinician training when providing serious illness care emerged through reflections of participants related to the importance of serious illness care training as it is provided within Hospital B. Clinician leaders and frontline clinician participants commented on the subtheme. Table 40 provides a graphic organizer for the subtheme of improving clinician training in serious illness care.

Table 40

Hospital B Graphic Organizer for Subtheme: The Importance of Clinician Training When Providing Serious Illness Care

Providing Patient-Centered Serious Illness Care: The Importance of Clinician Training When Providing Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Mandatory <u>orientation</u> includes <u>serious illness training</u> for critical care nurses and residents 	<ul style="list-style-type: none"> - Orientation for new staff 	<ul style="list-style-type: none"> - “We have a formal clinical education program that the designated—not a training and development—it’s an actual core-clinical-nursing education program. All employees go through that program, particularly nursing, nursing students, nursing staff, PTAs, all that, where we cover the care of the critically-ill patient as well as palliative patients. That’s part of their orientation onboarding. Those things are really around patient rights, advanced directive care, from a critical care—acuity of the patient.” (B-L1)
<ul style="list-style-type: none"> - Education gaps and needs are identified through multiple methods (i.e., staff surveys, chart reviews, ICU educator) 	<ul style="list-style-type: none"> - Identifying education gaps - Support for serious illness education 	<ul style="list-style-type: none"> - “We have incorporated an educator role now, have shifted him from being in education department just to critical care. One of the biggest needs that was voiced by staff was, the continued education or lack of. Having him

			be present, be visible, all the education opportunities just for our department, just by a critical care educator.” (B-L2)
- <u>Education on palliative care</u> was important at the <u>initiation</u> of the program for the community and clinicians	- Specific palliative care training - Need for palliative care education	-	“We did do education with hospital clinicians. For sure. We did education with them. We did some CMEs. We did education with our cancer committee. We did lots of education through the community, and through media relations. I would even do coffee talks. I did talks at the Rotary Club for Dothan. Talks at the senior center. A lot of the foundation dinners and charity events that they had, I would do talks there. That was kind of that first year, lots of marketing.” (B-F1)
- Annual required training for the staff does not include serious illness care training	- Serious illness training - Training attendance expectations	-	“Contemplated adding a CBL for that because we have CBLs for lots of other things, but it was difficult to get buy-in from administration, to add an additional module on palliative care.” (B-L1)
- Hospital B is a teaching hospital that offers <u>palliative care and serious illness education to residents</u>	- Residency programs	-	“We still do didactics with the resident physicians on palliative care. That's part of their curriculum. We had started a lecture series on care of the serious

illness patient, difficult conversations. Then we did another one on end-of-life measures, including things like PEG tubes.” (B-F1)

Orientation offers a brief introduction to palliative care, with a more detailed approach on caring for those with serious illness for ICU nurses. One clinician leader stated, “Well, it’s critical care orientation, so in as far as managing—teach the withdrawal process, managing patients going through that” (B-L2). Residents receive education and training on palliative care, while new physicians to the hospital receive a general overview of the palliative care department and the services that are available. The administrator spoke on the resident training, “Those residents all come through the hospital, and they all do an intensivist training. They get that palliative care training right there. They get to see that firsthand” (B-A1).

Surveys have been conducted to explore perceived educational gaps of clinicians. For example, nursing staff surveys identified a need for more education on providing palliative care for patients with serious illness. Newer staff nurses, in particular, provided feedback that they are not as comfortable with difficult conversations or managing symptoms as more experienced nurses. One clinician leader recalled feedback from a recent survey: “One of the questions is what do you feel like you need more help on, more training on, what have you. She said exactly that. She said: I would like more help in knowing what to expect when patients begin the dying process” (B-L2).

Palliative care and serious illness care education was important upon initiating the program and continues now. This education is for both clinicians and community members. One frontline clinician reflected that education is needed for “even existing physicians and physicians who may not be new doctors but are new to our system. Providing education regarding the benefits of palliative care, when palliative care intervention is most effectively beneficial” (B-F2). Required training at Hospital B

consists of orientation and annual education that is focused on basic patient care and specific skills. However, one frontline clinician stated, “We have basic refresher things to complete annually. This often doesn’t include palliative care information” (B-F3).

Subtheme: Multidisciplinary Communication Focused on Patient-Centered Care

The subtheme of multidisciplinary communication focused on patient-centered care emerged through reflections of participants related to communication from administration and staff, and the impact communication makes in the care that is provided to patients with serious illness and their families within Hospital B. All participants commented on the subtheme of patient-centered communication. Table 41 provides a graphic organizer for the subtheme of patient-centered communication.

Table 41

Hospital B Graphic Organizer for Subtheme: Multidisciplinary Communication Focused on Patient-Centered Care

Providing Patient-Centered Serious Illness Care: Multidisciplinary Communication Focused on Patient-Centered Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - The <u>palliative care team leads</u> conversations with patients with serious illness and their families; other clinicians often rely on their expertise in this area to assist in patient care 	<ul style="list-style-type: none"> - Approaches to communication with patients and families - Palliative care communication with the care team 	<ul style="list-style-type: none"> - “SPIKES is what I had learned at the Clinical Training Academy with Dr. Tucker. That was pretty much what I always tried to go by.” (B-F1)
<ul style="list-style-type: none"> - <u>Multidisciplinary rounding</u> has made a <u>huge impact</u> on connecting patients to palliative care services 	<ul style="list-style-type: none"> - Multidisciplinary rounding communication - Palliative care communication with the care team 	<ul style="list-style-type: none"> - “Being physically present, that was the most that we were able to incorporate into our interdisciplinary rounds.” (B-F1)

The palliative care team utilized SPIKES and Vital Talk for conversations with patients and families regarding healthcare decisions. One frontline clinician noted the use of specific communication tools. “SPIKES is what I had learned at the Clinical Training Academy with Dr. Tucker. That was pretty much what I always tried to go by” (B-F1).

Due to their extensive experience, the palliative care team can often help get the patient and family on the same page and facilitate family meetings. One frontline clinician reflected on the ability of the palliative care team to lead difficult conversations:

I had a patient, there was lots of family dynamics, and the family was really battling over making the decisions because there was some guilt over not being there for the patient over the years. I was like, "We need palliative care here. They'll be able to take care of this.” (B-F3)

Multidisciplinary rounding occurs at the patient bedside every day with intensivists, nurses, case management, and ancillary services. The palliative care team also tries to be present during daily ICU rounding. This occurs on the floors as well, which includes nursing staff, case management, and ancillary services; palliative care is consulted through the discussion among the staff on the floors. One clinician leader reported of the multidisciplinary rounding, “We have a discussion about each patient. During those discussions, if there’s a patient has maybe a difficult transition, or there’s a barrier to discharge, then the palliative care department is consulted at that point in time too” (B-L1).

Summary of Providing Patient-Centered Serious Illness Care

Participants from Hospital B spoke about the processes that are in place to care for patients with serious illness and their families, in partnership with the clinician team and hospital administration. The experience of clinicians often prevailed without the use of policies for serious illness care. Triggers for palliative care referrals were considered; however, the growth of the program demonstrated that triggers were not needed.

Multidisciplinary rounding that included the entire interdisciplinary team and palliative care providers proved helpful in building trust and growing the program. Though the palliative care team model has changed since its inception in 2014, the trust of the clinicians in assisting with managing symptoms and leading conversations has continued to make an impact on the care of patients with serious illness at Hospital B. Clinicians felt supported by hospital leadership within their roles, and the administration was engaged with staff through employee rounding and staff council.

Clinician orientation and annual education were mandatory and covered the core clinician care needs and technology requirements. Nursing staff orientation included more specific training related to caring for patients with serious illness. Hospital B is a teaching hospital and offers didactic residency training by the palliative care team. Additionally, palliative care team members were able to be involved in multidisciplinary rounds and witness the use of palliative care for certain patients with serious illness. The palliative care team utilized SPIKES and Vital Talk for difficult conversations with patients and families.

Theme Three: Serious Illness Care Impact

All Hospital B participants discussed how impactful providing serious illness care was to the patients, families, hospital, and community. Although the comments focused on the idea of patient-centered care to fulfill identified needs, barriers to providing this care would sometimes occur. The theme of serious illness care impact emerged through understanding the impact of care for patients, families, the hospital, and the community. The theme was comprised of three subthemes: (a) focus on patient-centered care, (b) palliative care closing the gap in fulfilling a need for patients with serious illness, and (c) limitations to providing serious illness and palliative care.

Subtheme: Focus on Patient-Centered Care

The subtheme of focus on patient-centered care emerged through participant interviews, reflecting how patient-centered care has been implemented within Hospital B. Participants reflected on their goal of honoring the patients' and families' wishes during serious illness. Table 42 provides a graphic organizer for the subtheme of focus on patient-centered care.

Table 42

Hospital B Graphic Organizer for Subtheme: Focus on Patient-Centered Care

Serious Illness Care Impact: Focus on Patient-Centered Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - <u>Palliative care</u> works to meet the patient <u>where they are in the disease process</u>, even if this includes an acute traumatic event. 	<ul style="list-style-type: none"> - Palliative care where the patient is in the disease process - Family experience during serious illness care 	<ul style="list-style-type: none"> - “We approach palliative care from a service line for cancer care. Only after that approach that we realized that we could open it up to patients with diagnosis like CHF and COPD and HIV, and just all the—dialysis—there’s a whole wide range of people.” (B-L1)
<ul style="list-style-type: none"> - <u>Connecting</u> patients to <u>community services</u> to manage their serious illness 	<ul style="list-style-type: none"> - Care coordination and community resources 	<ul style="list-style-type: none"> - “Recently in our region, we've had more providers of in-home palliative care. Not just hospice care, but palliative care, so we have a little more access to that now than we did, say, five years ago, which is really good.” (B-F2)

All participants commented on the subtheme of focus on patient-centered care. The administrator focused on the “nice to-have” service for patients and their families that included personal care items and spiritual support (B-A1). Frontline clinicians spoke about meeting the patients where they are in the disease process. Early access to palliative care services is ideal; however, some patients may experience a traumatic event, such as a stroke, and the care may be just as impactful. One frontline clinician stated,

We do get consults from our neurosurgeons and from our—we have a neuro ICU. We see patients there. Usually, it's in those cases—it's almost hard to say downstream because strokes are traumatic events. It's not like a person who's had oftentimes a long and chronic illness, so you don't really have a lot of opportunity there to get consults far upstream. Not really upstream consults, but I do think they use us effectively when it's appropriate. (B-F2)

Subtheme: Palliative Care Closing the Gap in Fulfilling a Need for Patients with Serious Illness

The subtheme of palliative care closing the gap in fulfilling a need for patients with serious illness emerged through participant reflections about whether the care that was provided to patients with serious illness met their needs. Table 43 provides a graphic organizer for the subtheme of focus on meeting the needs of patients with serious illness.

Table 43

Hospital B Graphic Organizer for Subtheme: Palliative Care Closing the Gap in Fulfilling a Need for Patients With Serious Illness

Serious Illness Care Impact: Palliative Care Closing the Gap in Fulfilling a Need for Patients With Serious Illness		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Hospital B serves as a <u>major hospital partner</u> for many rural hospitals within the catchment area, so <u>assessment of needs and expansion of services</u> are important 	<ul style="list-style-type: none"> - Community impact - Filling a gap and need - Providing options 	<ul style="list-style-type: none"> - “Obviously, we’re gonna look at viability of the program, profitability of the program, but, also, how is it going to affect our patient outcomes? We typically look at starting a new program. We look at what the need is from the community perspective and how is that going to assist us, either providing better outcomes to our patients and increased quality of care for what we’re providing for and then profitability.” (B-L2)
<ul style="list-style-type: none"> - Palliative care provides symptom management and avoidance of unnecessary hospital admissions 	<ul style="list-style-type: none"> - Goals of decreasing readmissions 	<ul style="list-style-type: none"> - “We actually realized that there was a lot to offer from the perspective of being able to prevent readmissions for patients.” (B-L1)
<ul style="list-style-type: none"> - The initiation of the <u>intensivists and rounding impacted the use of palliative care services</u> 	<ul style="list-style-type: none"> - Program impact related to other factors 	<ul style="list-style-type: none"> - “We got an intensivist service. I think it was around 2016. They started doing more formal kind ICU rounds in the morning. That includes the case managers, and a lot of times the chaplain. It includes the pharmacist, and

everybody that's doing ICU rounds. The palliative care nurse started doing rounds with the ICU team as well, and that would help trigger a lot of consults.” (B-F1)

All participants commented on the subtheme of fulfilling a need for patients with serious illness. Administration and clinician leaders spoke on the array of services offered at Hospital B due to the surrounding communities' limited ability to provide extensive, serious illness care. There is a continued focus on assessment of what the surrounding community needs in terms of serious illness care and how palliative care can help those patients with serious illness. The administrator stated, "Usually the counties that do have a hospital have very small hospitals that offer limited services, so we work with them in a really collaborative way when they need to transfer a patient to us for that care" (C-A1).

The onset of the intensivists' program impacted care of patients with serious illness by allowing one main physician to oversee the care of each patient. The intensivists are present for daily rounding, integrated within the care team, and have established relationships with the ICU nursing staff. The intensivists program is very supportive of initiating palliative care for patients with serious illness. One frontline clinician commented on the relationship between intensivists and palliative care usage, "Especially in critical care we see the need, I think a lot of the nurses and the intensivists, will reach out for palliative care. We feel we're partners and we know our strengths and we know theirs" (B-F3).

Hospital readmissions due to a need for symptom management was one of the gaps that the palliative care program was able to help fill, especially for those patients with cancer. Patients with other serious illnesses, such as CHF and COPD, were also seen to benefit from the start of the program. One frontline clinician described the goal of keeping the patients out of the hospital:

There are occasionally patients that we see across multiple admissions. Part of our goal and our hope is to help people to avoid multiple admissions where those admissions are unnecessary and only serve to interrupt the patient's ability to inhabit their own preferences, patients who want to stay home, patients who want to have time with their family. (B-F2)

Subtheme: Limitations to Providing Serious Illness and Palliative Care

The subtheme of limitations to providing serious illness and palliative care emerged through participant reflections related to challenges they have experienced when caring for patients with serious illness at Hospital B. Table 44 provides a graphic organizer for the subtheme of limitations to providing serious illness care.

Table 44

Hospital B Graphic Organizer for Subtheme: Limitations to Providing Serious Illness and Palliative Care

Serious Illness Care Impact: Limitations to Providing Serious Illness and Palliative Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Limited reimbursement</u> and revenue stream from palliative care service created challenges for sustainability and model changes	- Payment streams	- “One challenge was just the reimbursement challenges that people have everywhere. I did all the things that a consultant told me to do as we were every year trying to keep our palliative service going, and justify why we were still needed. It was every single year at budget time, I felt like I was fighting for why the hospital needed us. All the cost savings analyses that I did, there's all kinds of—there's toolkits through CAPC, and things like that. Trying to get other ways to plead our case for why we were needed. Cost savings wasn't enough. That was considered funny money.” (B-F1)
- Profitability of hospitals, specifically in rural areas, has impacted serious illness care within Hospital B	- Challenges to serving rural communities	- “We do pay attention to what's going on to our rural hospitals because we are oftentimes at capacity, and so we want those hospitals to thrive and be successful as well because their communities need them. We are

		seeing some hospital closures in our catchment area and services being eliminated.” (B-A1)
- A <u>knowledge deficit</u> within the community and clinicians still limits access to early palliative care services	- Stigma with palliative care - Community education gaps	- “I think that in our state, and particularly in our community now, palliative care is still associated with end-of-life care. I’m sure that there has been very diligent efforts to try to change that perspective, but in the South, particularly where we are, when you think of palliative care, people think of on hospice, even providers.” (B-L1)
- <u>Staffing challenges</u> remain a limitation within serious illness care	- Staffing challenges	- “We have just become inundated in just this workforce issue where I don’t really get a chance to think about anything else except where—how am I gonna staff these units in the ICU? Where are we gonna find this? We don’t have a whole lot.” (B-L1)
- <u>Hesitation</u> with the use of palliative care services is seen with some physicians due to <u>NP led PC model</u>	- Clinician hesitancy to NP led model - PC certification factors	- “There’s definitely physicians that just refuse to consult her. They don’t feel like they need help from a nurse practitioner, right? Those are the ones that you’re never gonna fix or change.” (B-F1)
- Generational differences among providers impacted uptake	- Generational differences in the use of palliative care	- “I think the younger generations embrace it more because they’re

		taught in their medical programs about it. It's actually included as part of their curriculum." (B-L1)
- Challenges impacted the palliative care program	- Varying views of what PC encompasses	- "It was only after we had had the program for about four years that we actually start seeing that our intensivists in the ICU start trying to advocate a little bit for it. To tell you the truth, when we first started it, they were totally against it. Intensivists and our critical care department wanted nothing to do it. Hospitalists, some of our hospitalist program, wanted nothing to do with it, like, "It's just a hospice program. We'll call you when they make the decision to withdraw care." Well, we'll call you then." (B-L1)

All participants commented on the subtheme of limitations to providing serious illness care. Lack of reimbursement and revenue-generating service streams were challenging when starting the program and still remain somewhat of a challenge with expansion of palliative care within Hospital B. The use of grants and foundation money helped to supplement hospital funding at the beginning of the program; however, sustainability is still a concern and one reason for changes in the palliative care model over time. One frontline clinician stated,

With the initial wave of optimization, affected the foundation to where they were no longer allowed to provide grants to support salaries. That hit our program kind of hard. That was around 2016 for the first wave of optimization, and so my entire salary, plus the nursing salary. We couldn't support our salaries for the foundation, and so the hospital had to take over those salaries. (B-F1)

Profitability of Alabama hospitals is low, and the initiation of a program like palliative care may be a difficult decision for hospitals that are attempting to keep afloat. Closures of “feeder” hospitals are impacting serious illness care within Hospital B, as rural hospitals seek partnerships or assistance in providing care within rural communities. One clinician leader stated, “Over half of Alabama hospitals are not profitable. Do a better job of telling the story about the incentive won’t make a ton of money off this program, patients have better quality of life, even if their quantity is not long” (B-L1).

There still remains a lack of knowledge about the distinction between palliative care versus hospice care that creates hesitancy and limits the use of the program early in the disease process. One frontline clinician reported what he sometimes hears from patients and families:

When they hear palliative care, what they're thinking is, "Y'all want me to stop trying. Y'all are giving up on me" rather than thinking of us as a service line that can come alongside them and strengthen them as they go through these changes. (B-F2)

Lack of nursing staff and travel nursing costs remain a limitation to serious illness care. Hospital B had built an additional ICU but was unable to staff the beds due to limited nursing staff available for the unit. Additionally, the use of travel nurses affected the staffing and budget within the hospital post-COVID. One frontline clinician said of the impact of care related to nursing staffing, "They've also put a lot of capital into the hospital. They added on a third ICU, which we haven't been able to open yet because we don't have the staff for it. It's just kinda sitting there right now" (B-F1).

Much quicker buy-in may occur with younger clinicians because they often have been exposed to palliative care within residency programs or formal education. One frontline clinician noticed the earlier buy-in from younger physicians and the hospitalists currently working in Hospital B. "There was definitely much quicker buy-in from the younger physicians. The younger ones definitely have more buy-in for palliative care, for sure. That's most of the hospitalist group anymore" (B-F1).

Acceptance of the use of palliative care was impacted by the first physician director's lack of certification and an initial lack of support by the intensivist within the ICU. A clinician leader, remembering this challenge, stated, "The most difficult thing to get buy-in from, especially from specialists was that, I was not fellowship-trained, and didn't have enough experience in training to grandfather in, and take the palliative care board certification exam" (B-L1).

The strategic plan for the hospital did not include palliative care or serious illness care goals for the previous 5 years. The administrator noted the lack of goals for palliative care: “Palliative care has not been a service line that has been on our strategic plan that I can recall in the last 5 years. I can’t think of any specific goals” (B-A1).

Summary of Serious Illness Care Impact

The community hospital serves as a partner for many rural hospitals and often will admit patients who have experienced a traumatic, acute event where recovery might not be possible (i.e., stroke). Palliative care was able to step into these situations to assist patients and families going through acute, traumatic, life-altering illnesses. Participants reflected on the ability of palliative care to assist with symptom management, decreasing unnecessary readmissions, and honoring patients’ and families’ wishes. Limited funding remained a challenge for the palliative care program and required adjustments to models of delivery. A knowledge deficit and hesitation remain within the community and among some clinicians; consequently, continued education and engagement will be required. Staffing challenges within the hospital, especially within nursing care, have continued to impact the ability to expand care.

Key Findings From Hospital B

Hospital B was nonprofit, located within an urban area, and served a large rural catchment area. The palliative care program was established in 2014. The current model of care was a 1.0 FTE board-certified nurse practitioner-led model, with a 1.0 FTE social

worker-coordinator, and 0.5 FTE chaplain. The following areas were important findings related to serious illness and palliative care at Hospital B:

- Supportive administration and clinician champions initiated palliative care after attending CAPC PCLC training
- Rural Referral Center focused towards surrounding rural hospitals and how best to serve the community
- Multidisciplinary rounding was important for building trust and relationships, especially with the palliative care team
- Intensivists were utilized within the ICU and were supporters of palliative care
- Serious illness training was required in orientation and offered through voluntary continuing education sessions, though the voluntary sessions were nursing focused
- Residents were offered educational sessions on palliative care
- Focus was honoring patients' and families' wishes, despite poor prognosis
- Limitations to palliative care existed, with a major limitation being reimbursement and funding
- Generational differences in terms of buy-in and referrals and also staffing shortages were another limitation to providing serious illness care

Case Three: Hospital C

Description of Hospital C—Small, Rural Hospital Without Palliative Care

Hospital C was established in 1925 by community residents who wanted local access to health services. The for-profit hospital is licensed for 112 beds, according to the Alabama Hospital Association, and is owned and overseen by a large hospital management company. Located in a rural community, Hospital C serves only the county that it resides within and offers a satellite emergency room within the same county. There are numerous competing hospitals within the catchment area, including three that had a palliative care program. Hospital C focuses on surgeries and maternal/child care. In addition to inpatient services at the main hospital, the hospital offers a wound care and hyperbaric oxygen center, outpatient women's imaging center, and an urgent care facility. Hospital C does not have a palliative care program, operating under the assumption that their hospitalists "all provide palliative care" (C-F1) for all patients. Recently, Hospital C broke ground on an expansion that will offer the opportunity to expand surgical services, intensive care services, and a long-term care facility.

Demographic Hospital Information

Hospital C admitted a total of 7,139 patients in 2021. This included an average daily census of 84 patients. The adult patient population was equally comprised between ages 18-64 years old (44%, $n = 3,141$ patients) and 65 years old and older (44%, $n = 3,141$ patients). The most common discharge dispositions included: home without any services (59%) and home with community home health services (20%). Hospital C

provided information on financial incentives related to payments to the hospitals, including bonus payments for quality measures (12%) and financial contracts with other providers and vendors (98%). Additionally, Hospital C participated in alternative payment models. Appendix H provides demographic details of Hospital C.

Description of the Hospital C Participants

A total of six employees from Hospital C participated in an interview. Participants were diverse within their job classification, experience, and time employed by the hospital. The participants included one male (16.7%) and five females (83.3%), and all six were Caucasian (100%). Participants were further classified based upon their length of time at the hospital, with a range of 3 to 15 years. Participants were assigned pseudonyms based on their role in relation to the interview and were designated by C-A1, administrator, C-L1 through C-L3, clinician leaders, and C-F1 through C-F2, frontline clinicians. Table 45 provides participant demographics information.

Table 45*Hospital C Participant Demographics*

Part. ID	Participant Role	Gender	Race	Professional Education or Training	Years at Hospital	Years in Current Role	Current Position
C-A1	Hospital Administrator	female	Caucasian	Master of Accountancy	13 years	3 years	Chief Financial Officer
C-L1	Clinician Leader	female	Caucasian	MSW	5 years	3 years	Director of Case Management
C-L2	Clinician Leader	female	Caucasian	MSN	3 years	3 years	Director of Quality
C-L3	Clinician Leader	female	Caucasian	BSN	14 years	3 years	Senior Nurse Leader
C-F1	Frontline Clinician	female	Caucasian	MD	8 years	8 years	Hospitalist
C-F2	Frontline Clinician	male	Caucasian	BSN	15 years	3 years	ICU Staff Nurse

Theme One: History and Evolution of Serious Illness Care

The theme of history and evolution of serious illness care encompassed the characteristics of the hospital and the community, the history and evolution of serious illness care within the hospital, and the perceptions and beliefs of staff about serious illness that impacts care provided at Hospital C. The theme was comprised of three subthemes: (a) developing a mindset towards serious illness care, (b) limited approach to serious illness care, and (c) narrow perceptions about serious illness care.

Subtheme: Developing a Mindset Towards Serious Illness Care

Developing a mindset towards serious illness care included hospital and community characteristics such as the environmental factors, staffing, and the population

served. Table 46 presents a joint display of the quantitative and qualitative results for this subtheme.

Table 46

Hospital C Joint Display for Subtheme: Developing a Mindset Towards Serious Illness Care

History and Evolution of Serious Illness Care: Developing a Mindset Towards Serious Illness Care		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - Focus was on end-of-life <u>care</u> rather than earlier within the serious illness trajectory - Limitations to expansion of services were due to <u>physical infrastructure</u> of hospital - Creating programs that meet the community needs and have buy-in from the community; the <u>community includes older populations</u> 	<ul style="list-style-type: none"> - “A lot of our patients come into the hospital, and they have conditions that are—they’re not gonna survive from, or they’re not gonna survive long enough.” (C-F1) - “Our hospital, given our restraints as far as bed capacity currently, we don’t have the beds to be able to do something.” (C-A1) - “I think as the community has expanded, our role has expanded, and our leadership has always tried to expand with the community. Since this hospital started years ago, there have been many changes—many editions. We’re building another edition as it is. We try to grow with the community. Our leadership always tries to do that. Our corporation looks at that as well.” (C-L2) 	<ul style="list-style-type: none"> - Access to community and inpatient hospice services within the catchment area - Access to community palliative care services - N/A - Median household income greater than overall Alabama, hospital was also for-profit with a focus on more profitable services - Three main primary admission diagnoses: cardiac (32.6%, $n = 2,330$), GI/hepatic (29.6%, $n = 2,115$), and pulmonary (12.4%, $n = 886$); often associated with chronic illness, these diagnoses could be related to the older population that is served

Qualitative Findings. All participants commented on the development of a mindset towards serious illness care. Many of the discussions focused more on end of life and goals of care management and not on managing serious illness earlier in the disease trajectory. Hospice use was frequently mentioned by participants due to the age of the clientele within the catchment area. One clinician leader stated, “We do deal a lot with hospice. We do have older clientele, especially here in South Alabama. A lot of people come down to retire, so we do deal a lot with hospice” (C-L1).

When discussing changes to care or initiation of new service programs, clinician leaders commented on the need for transparency and involvement of staff who would be impacted by changes or new services. The administrator reflected on the planning of new services, “We bring everybody to the table. It takes the entire leadership team here at this hospital, directors, managers, everybody to accomplish somethin’ and to have success with it” (B-A1).

Administration and clinicians would like to see program expansion that fits the community, but they want to have the space and be prepared to offer services that will benefit patients and families with serious illness. The administrator stated, “Even with consideration of expansion of services, it is not possible due to current bed capacity and space within the hospital” (C-A1).

Community palliative care was utilized for patients upon discharge and was accessible to patients outside of the hospital. One clinician leader stated, “I think that we tend to use palliative a lot more when the families actually need to go onto hospice but maybe they're just not ready for that yet” (C-L1).

Clinicians would like to see additional services offered in the future, but it was important that any new services meet a community need and are well planned prior to implementation. One frontline clinician reflected on expansion of services to include palliative care, “I don't want 'em to start one and then just stop it. I wanted something, but I think the community's gonna have to get more involved, too” (C-F2).

Quantitative Findings. This section presents supportive quantitative data for the subtheme of developing a mindset towards serious illness care.

Environmental Factors. Hospital C included one rural county within the hospital-defined catchment areas. The mean household income was above the Alabama average. Hospital C was for-profit and focused on services that were more profitable, such as surgeries. The cancer mortality rate, which is an indicator of overall health, was higher in the county than in the state as a whole. This could indicate poor health within this county, as compared to the state of Alabama, or it could reflect the older age of residents. Data of environmental factors for Hospital C is provided in Table 47.

Table 47

Hospital C Environmental Factors

	Total (one county)	Alabama Comparison
Total Population		
Population	223,234	4,903,185
SDH: Economic Stability		
Median Household Income	\$64,346	\$54,943
SDH: Healthcare Access		
Cancer Mortality Rate (measure of health) *per 100,000	215.0	209.3

Hospital C did not have the designation of Medicare Sole Community Hospital status due to its for-profit status. Community-based palliative care, home health, and hospice were accessible within the hospital-based catchment area. Additionally, a hospice house was available within 60 miles of the hospital. These data are displayed in Table 48.

Table 48*Factors Relevant to the Adoption or Closure of Hospital Palliative Care Programs*

Sole Community Hospital Status	No
ACGME Approved Residency	Yes
ACS Cancer Center	No
Outpatient Hospice Access within Catchment Area	Yes
Inpatient Hospice Access (within 60 miles of hospital)	Yes, hospice house and GIP
Outpatient Palliative Care Access within Catchment Area	Yes
Outpatient Home Health Care Access within Catchment Area	Yes
Hospital Care Intensity (HCI) with Hospital Referral Region (HRR)	71.8%
Hospital Care Intensity (HCI) at the Hospital	59.3%

Primary Hospital Admission Diagnoses. Three main primary admission diagnoses made up the total number of admissions to the hospital: cardiac (32.6%, $n = 2,330$), GI/hepatic (29.6%, $n = 2,115$), and pulmonary (12.4%, $n = 886$). Interestingly, the hospital had a significant focus on areas of chronic illness, though qualitatively it was reported that surgeries and maternal/child were significant service lines. Table 49 provides details of Hospital C's primary admission diagnoses.

Table 49*Primary Hospital Admission Diagnoses*

Admissions Based Upon Primary Diagnosis	
Cardiac	2,330 (32.6%)
Pulmonary	886 (12.4%)
Cancer	150 (2.1%)
Renal	503 (7.0%)
Neurologic/Neuromuscular/ Neurodegenerative	543 (7.6%)
GI/Hepatic	2,115 (29.6%)
Traumatic	359 (5.0%)
Other	253 (3.5%)

Subtheme: Limited Approach to Serious Illness Care

Limited approach to serious illness care encompassed hospital resources and the factors in place that may help to develop approaches to care for patients with serious illness. Table 50 presents a joint display of the quantitative and qualitative results for this subtheme.

Table 50

Hospital C Joint Display for the Subtheme: Limited Approach to Serious Illness Care

History and Evolution of Serious Illness Care: Limited Approach to Serious Illness Care			
Qualitative	Illustrative Quote	Quantitative	
<ul style="list-style-type: none"> - <u>Hospitalists</u> are typically the clinicians who <u>have goals of care conversations</u>; opportunities for difficult conversations are not present for other staff 	<ul style="list-style-type: none"> - “All the hospitalists actually are able to perform palliative and hospice care.” (C-F1) - “We typically leave those conversations for the hospitalists or primary physician.” (C-F2) 		
<ul style="list-style-type: none"> - <u>Inpatient hospice</u> patients are admitted and comanaged with an outside agency 	<ul style="list-style-type: none"> - “We have hospice patients and palliative care patients that we care for with the help of outside agencies.” (C-L3) 	<ul style="list-style-type: none"> - Contracted with one or more hospice agencies to provide serious illness care for patients and an informal relationship of collaboration with a community hospice agency 	
<ul style="list-style-type: none"> - Case management is involved and present from the beginning of the hospitalization to assist with <u>discharge planning</u> and connect patients with resources 	<ul style="list-style-type: none"> - “Case management looks at every patient that's admitted and rounds in the ICUs to talk about discharge plans.” (C-F2). 		

Qualitative Findings. All participants in Hospital C commented on the approach to serious illness care within the hospital. Many participants commented on the growth of the hospital with new services being based upon community needs and staff input. Additionally, a risk analysis and resources assessment are completed prior to adding a new service. One clinician leader commented,

We look at many things. We look at the need in the community. We look at the resources we have available. We look at if it's a specific—like surgical palliative, whatever service, what expertise we have available, we do a risk analysis. (C-L2)

Patients are admitted for symptom management through local partnerships with hospice agencies. One frontline clinician reflected on the partnership, “We do have hospice companies that we’ll work with their hospital and come in to provide hospice care if the patient meets general inpatient criteria” (C-F1).

Clinicians commented on gathering an understanding of patients’ needs and goals early in the hospitalization. One frontline clinician commented, “My goal is meeting my patients’ goals. If my patients’ goals are comfort and quality for the remainder part of their life, that’s my goal. If their goal is to live as long as possible, regardless of comfort, that’s my goal” (C-F1).

Additionally, case management is involved, beginning with an initial assessment of what services may be needed upon discharge. Clinicians discussed discharge planning as an important part of serious illness management. One frontline clinician noted, “We will call a case manager to let them look at the case and talk to us about what kind of services and care they can get once they leave the hospital to help take care of 'em” (C-F2).

Quantitative Findings. This section presents data related to supportive quantitative data for the subtheme of developing an approach to serious illness care.

Hospital's Palliative Care Resources. The resources for Hospital C included access to hospice services through a contract with community hospice agencies to provide inpatient care and less formal relationships with community hospice agencies that offered informal collaboration related to patient care.

Subtheme: Narrow Perceptions about Serious Illness Care

Narrow perceptions about serious illness care included perceptions from staff about how care for serious illness is to be provided and about gaining buy-in from constituents. Table 51 presents a graphic organizer of the qualitative results for this subtheme.

Table 51

Hospital C Graphic Organizer for Subtheme: Narrow Perceptions About Serious Illness Care

History and Evolution of Serious Illness Care: Narrow Perceptions About Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Varied opinions on what encompasses palliative care, majority felt the <u>focus was on end of life/hospice</u> 	<ul style="list-style-type: none"> - Beliefs in care - Clinician hesitancy - Initial reactions by clinicians 	<ul style="list-style-type: none"> - “It's more like comfort care for the patient and to provide—I don't want to say more resources—support for the family as they're going through an illness or end of life for a patient. It's not quite hospice, but it's, I would say comfort care.” (C-L2)
<ul style="list-style-type: none"> - Community palliative care was used as a next step for patients that were appropriate for hospice 	<ul style="list-style-type: none"> - History of serious illness 	<ul style="list-style-type: none"> - “I think it's (community palliative care) a good option for families that are on the cusp of making a decision. They're too medical for home health really and they need that extra help (like hospice).” (C-L1)
<ul style="list-style-type: none"> - Focus on <u>accreditation and quality improvement</u> of the hospital and services that are provided 	<ul style="list-style-type: none"> - Hospital focus on accreditation and disease-specific quality 	<ul style="list-style-type: none"> - “The quality initiatives, all the regulatory compliance, monitoring the PII, the CMS, the Leapfrog, all of that stuff falls under the quality side”. (C-L2)

Qualitative Findings. Various opinions of serious illness care were discussed by all participants at Hospital C, indicating an uncertain definition of providing palliative care. Many clinicians felt that there was greater emphasis on end-of-life care, while some felt that palliative care was a “bridge” to honoring patients’ and families’ wishes. One clinician leader described it as, “For palliative care, I would say comfort care prior to them passing away” (C-L3). However, a frontline clinician felt it was more towards a focus on comfort: “It’s a person that has been discharged from a hospital setting or whatever to go home to try to keep comfortable” (C-F2). Another clinician leader, who had personal experience of palliative care, said, “I feel like palliative care is sort of a bridge for some people between regular care and hospice” (C-L2).

Occasionally, palliative care was used as a resource for patients or families who were hospice appropriate, but not ready to stop treatments or certain services. One clinician leader reflected on her personal experience, “I think that we tend to use (community) palliative care a lot more when the families actually need to go onto hospice but maybe they’re just not ready for that yet” (C-L1).

Participant interviews revealed a focus on quality and accreditation within the hospital. Administration made comments related to focus on quality ratings for the hospital. For instance, the administrator stated, “We’re Stroger-credited. There’s also our heart center. We have accreditation. We’re also a Leapfrog A on the score and have been for 13 consecutive quarters, which is incredible. I think one of the few in Alabama” (C-A1).

Although Hospital C employs a variety of providers, there is a push to bring in providers from other hospitals who may impact the care of patients with serious illness or have been at hospitals that offer palliative care. The administrator stated,

I think one of the good things is our medical staff here. We have a lot of seasoned and experienced doctors on our staff. We're able to recruit seasoned physicians, some of 'em coming from UAB and these other places. I think it's gonna be great for us to continue to improve outcomes. (C-A1)

However, it was unknown if the new "seasoned" providers had experience with providing palliative care or were hesitant to use palliative care.

Summary of History and Evolution of Serious Illness Care

One approach that is often used for patients with serious illness is discharge planning upon hospital admission. Additionally, goals of care are discussed by the hospitalists when a patient is admitted. Participants reflected on a focus towards end-of-life care and hospice use due to the older demographics of the community the hospital serves. Perceptions of serious illness care varied among staff, based upon their roles. Various opinions on the management of serious illness were voiced by participants. Some participants felt palliative care was geared towards end of life, while others felt it was directed towards managing care anywhere in the disease trajectory.

Space limitations remain a challenge for adding services. However, the hospital is expanding and will assess the situation for expansion based upon community and staff input. Participants reflected on preparation and space for service expansion in the future. Future expansion of the hospital will include an additional ICU to expand care for

patients with serious illness, though a consideration of establishing palliative care was not presented by the administrators or clinician leaders. There has been a push for the hospital to bring in more seasoned physicians who may have experience caring for those with serious illness, especially with the upcoming hospital expansion.

Theme Two: Providing Patient-Centered Serious Illness Care

All participants from Hospital C commented on providing serious illness care. Hospital C does not have an established palliative care program; however, it does provide care within the ICU and in partnership with local hospice agencies for hospice GIP patients admitted for symptom management. The theme of providing patient-centered serious illness care emerged through understanding the processes that were essential to such care. The theme was comprised of five subthemes that impacted how care was provided: (a) basics of providing care, (b) building trust and relationships among clinicians, (c) empowerment through leadership support of serious illness care, (d) limited clinician training in serious illness care despite the need, and (e) hospital-focused communication.

Subtheme: Basics of Providing Care

The basics of providing care included assessment, charting, consultations by other specialists, and policies that are utilized for patients with serious illness. Clinician leaders and frontline clinicians commented on basics of providing care. Table 52 provides a graphic organizer for the subtheme of basics of providing care.

Table 52

Hospital C Graphic Organizer for Subtheme: Basics of Providing Care

Providing Patient-Centered Serious Illness Care: Basics of Providing Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Charting</u> takes away from serious illness care	- Assessment tools used in practice	- “I’m not saying it’s not a good thing to do or have the knowledge of doin’, but everything they add is one thing that takes away from the care of the patient.” (C-F2)
- <u>Policies</u> for serious illness care (i.e., comfort care) are most commonly <u>used by physicians or hospitalists</u>	- Physician-driven referral process - Goals of care conversations - Utilizing policies and procedure in serious illness	- “They [ICU nurses] haven’t been instructed [on policy use]. There’s also additional paperwork if the patient wants comfort care measures. I automatically have goals of care conversations with every patient.” (C-F1)

Assessment was frequently completed in the ICU; however, a frontline clinician commented on the time commitment that is required for charting and its possible impact on patient care:

If you have the computer that takes your vital signs, monitors at the bedside should flow into charts. The system is capable, and we did get the gateway to hook it up to our charting system, but it just hasn't been done yet. It would cut down on 30 or 40 percent of our charting. (C-F2)

Consultations for other specialty services were most commonly completed by the physician; however, case management or the ICU nurse could make the request for specialty referrals.

The comfort care policy was utilized by hospitalists, though other procedures such as goals of care guidelines were not readily utilized. It was reported that policies were utilized more frequently by case management. One frontline clinician completed goals of care conversations with every patient upon admission regardless of triggers or policies in place. One frontline clinician reflected on the involvement of case management:

Many times, the doctors will make the referral for community palliative care or hospice. Sometimes, we will talk with the doctor and the doctor will put the order in for a referral. Every now and then, we will call a case manager to let them look at the case. (C-F2)

Participants were not familiar with or did not utilize the National Consensus Guidelines for Palliative Care. One clinician leader commented, "I've heard of them, but we don't use them" (C-L1).

Subtheme: Building Trust and Relationships Among Clinicians

The subtheme of building trust and relationships among clinicians emerged through interviews and reflections based upon the IDT members, the impact on care, evolving relationships among the care team members, and challenges that the IDT would work to overcome. Table 53 provides a graphic organizer for the subtheme of building trust and relationships among clinicians.

Table 53

Hospital C Graphic Organizer for Subtheme: Building Trust and Relationships Among Clinicians

Providing Patient-Centered Serious Illness Care: Building Trust and Relationships Among Clinicians		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - <u>Positive staff relationships</u> impact the care that is provided 	<ul style="list-style-type: none"> - Building a team through mentorship - Support within their role 	<ul style="list-style-type: none"> - “A representative from the hospitalist group, they come in, and we talk about every patient on that floor, what their plan is, and what we're lookin' at. Of course, the physicians are really open and accessible. They always come up to my case management offices. We'll go over the list in the mornin' with 'em just, "What are we lookin' for this? What are we lookin' for that?" (C-L1)
<ul style="list-style-type: none"> - <u>Outside resources were utilized</u> for some care team members (i.e., outside clergy and pastors); however, clinicians sometimes felt overwhelmed with not having additional care team members available 	<ul style="list-style-type: none"> - Care challenges - Limited IDT staffing for the entire hospital 	<ul style="list-style-type: none"> - “Without the structure in place to have a unit secretary or someone to answer the phone or even like a consistent tech. 'Cause the patient ratio's two-to-one and sometimes three-to-one. When it's a true one-to-one situation, four nurses take care of that one patient and we all kind of take care of each other's patients, so it really does impede the care—I mean, 'cause

<hr/>			one patient can suck us all in.” (C-F2)
- Reflection on <u>relationships built</u> through the <u>small hospital</u> and community atmosphere	- Relationships built through hospital size	-	“We're very involved with staff, and it's such a small hospital too that you can walk down the hall and say, “Hey, there’s Ricky,” and “Hey, there’s Karen.” Everybody kind of knows everybody, so I think it's really good relationship.” (C-L3)
<hr/>			

All participants commented on trust and relationships within Hospital C. All participants felt that the hospital staff had a good working relationship, as seen within patient care, mentorship, recognition, and interdisciplinary rounding. Clinician leaders spoke about informal mentorship relationships that have developed with the staff, allowing more seasoned staff to mentor those who are newer to the field. One clinician leader stated, “My newer ones [case managers] will reach out to my older ones if they have a question or something. I pair them on a unit so they can work together to build that relationship and to learn as you go” (C-L1).

Interdisciplinary rounding has impacted patient care and relationships among the staff who are able to participate. Interdisciplinary rounding is completed with a focus towards discharge planning for patients in the ICU. One frontline clinician reported,

I think we do a really good job here at the hospital, because we're not so big. I think that makes a big difference in a lot of different ways. In my opinion, I think we do really good with our interdisciplinary care. (C-F2)

The typical attendees at the meetings include case management, ICU nurses, dietary, therapy services, and a manager. Physicians are invited to meetings if there is concern about a patient; otherwise they meet with case management directly to discuss the patient. “If there’s a concern I have about a patient, yes” (C-F1). Chaplain services are not provided within the hospital structure of the interdisciplinary team; however, spiritual care can be addressed by outside clergy as needed: “We don't have an in-house chaplain or anything” (C-L3).

Frontline clinicians felt the leadership team members were supportive of nursing, given the options that nurses have throughout the community, with more than five

hospitals within 60 miles. Staff recognition through awards and “shouts outs” are another way Hospital C works to build relationships among the care team. One clinician leader stated,

Administration tries to do a lot to recognize staff. We do Employee of the Month and Employee of the Year. We started a bucket list program where you can give people points as they do things, and leaders can give that to anybody in the hospital. They try very hard to recognize staff (C-L2).

Subtheme: Empowerment Through Leadership Support of Serious Illness Care

The subtheme of empowerment through leadership support of serious illness care emerged through interviews and reflected the support of leadership, though not a strong focus on serious illness care. Table 54 provides a graphic organizer for the subtheme of empowerment through leadership support of serious illness care.

Table 54

Hospital C Graphic Organizer for Subtheme: Empowerment Through Leadership Support of Serious Illness Care

Providing Patient-Centered Serious Illness Care: Empowerment Through Leadership Support of Serious Illness		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Variety of leadership styles that allows strengths of each to be utilized	- Mixture of leadership styles that complement each other	- “I think our leadership styles actually play off of each other with that because some of us are really strong in one. I will say that a lot of times when we come to this table or in one of our other conference rooms, sometimes putting our heads together and brainstorming, we are able to come up with great ideas, great next steps, and strategic decisions because it’s not just one person making a decision. We’re playing off the strengths of everybody, and when you do that, I think you can be extremely successful.” (C-A1)

Administration and clinician leaders spoke about leadership within Hospital C and how this impacts empowerment within the hospital. The administrator commented on the various leadership styles that were found within the hospital and how this allowed leaders to pull upon each other's strengths to improve care and the direction of the hospital. The administrator stated, "I think all of us are different in our own way, which is good because you're gonna have some that have strengths that are really strong in certain things where maybe somebody else is strong in something else" (C-A1).

The small hospital size has allowed management to build relationships with staff through working on the various units and serving as house supervisors. A clinician leader said of the small hospital size, "We're very involved with staff, and it's such a small hospital too that you can walk down the hall and say, 'Hey, there's Ricky,' and 'Hey, there's Karen.' Everybody kind of knows everybody, so I think it's really good relationship" (C-L3).

Subtheme: Limited Clinician Training in Serious Illness Care Despite the Need

The subtheme of limited clinician training in serious illness care despite the need for it emerged through reflections of participants during interviews. Table 55 provides a graphic organizer for the subtheme of improving clinician training in serious illness care at Hospital C.

Table 55

Hospital C Graphic Organizer for Subtheme: Limited Clinician Training in Serious Illness Care Despite the Need

Providing Patient-Centered Serious Illness Care: Limited Clinician Training in Serious Illness Care Despite the Need		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Mandatory orientation and annual education include nursing education and tech education, which may vary depending on the hospital unit; <u>mandatory serious education is not required</u>	- Orientation for new staff	- “A lot of it's like our yearly clinical training that we do on the computers and stuff like that, but it doesn't—I wouldn't say it's specific on end-of-life.” (C-F3)
- <u>Expansion of serious illness care is needed</u> due to the new care units with the hospital expansion	- Need for serious illness education is great - Specific serious illness training - Need for palliative care education is great	- “Because we're expanding, there needs to be—it needs to be ramped up considerably, to get us to a point where we can manage a 24-bed ICU, and a surgical ICU, and a medical ICU and what we're gonna grow into. But it has gotten better.” (C-F2)
- <u>Voluntary training related to serious illness is provided through partnerships with local agencies</u>	- Training attendance expectations - Serious illness training	- “I have recently partnered with a hospice company. After the first of the year, we were gonna get on the books for them to come in and do a class about taking care of GIP patients. We have a lot of new nurses. A lot of 'em are new grads. I think that just

giving them—and may not always feel comfortable taking care of a hospice patient. We do a fair share of inpatient hospice here. We are looking at getting somethin' together and get that on the books so that we can start rollin' that out.” (C-L2)

Clinician leaders and frontline clinicians all commented on clinician training at Hospital C. Hospital staff complete a mandatory orientation to the hospital, a specific unit orientation, and training associated with requirements related to accreditation; however, no training is provided related to caring for seriously ill patients. One clinician leader described “mandatory annual education that is on nursing education and tech education. It's kind of geared a little bit differently depending on what unit you're working on, but those conversations are done and had, and they have that in their orientation” (C-L3).

Voluntary education for nursing staff related to goals of care and communication was offered by a local hospice agency. This training is currently not mandatory or a requirement of new employee orientation. A clinician leader said of education provided through local partnerships with outside agencies, “We have had certain companies come in and give education for different things. I think hospice was one before, and that was kind of the, ‘Hey, if y'all want to be involved in it, you can’” (C-L3).

Frontline clinicians spoke about how training has improved for nurses who are caring for seriously ill patients, stating that the hospital has made organizational changes to include hiring an ICU trainer. One frontline clinician remembered their own training related to seriously ill patients:

In my time in the hospital, in the beginning, because of staffing and several other issues, we didn't. We now have a trainer for ICU now who is a longtime experienced nurse in the ICU and well-respected in the hospital and he's now moved into that role. He's kind of creating the job description for that as he goes along, so it has helped us because it's very focused for us, from his standpoint.

I've seen that change, and the hospital's made a structure change in order for that to happen. (C-F2)

Much of the training is nursing focused, with limited training for other specialties. However, the hospital does provide a residency program and biannual meetings for medical staff. One clinician leader stated, “We have a medical staff meeting twice a year and anything that's required through some of the organizations like Leapfrog and CMS and Joint Commission that we do need to provide. We do that during general medical staff meetings” (C-L2).

Subtheme: Hospital-Focused Communication

The subtheme of hospital-focused communication emerged through reflections of participants related to communication between administration and staff and the impact of communication related to discharge planning within Hospital C. Table 56 provides a graphic organizer for the subtheme of patient-centered communication.

Table 56

Hospital C Graphic Organizer for Subtheme: Hospital-Focused Communication

Providing Patient-Centered Serious Illness Care: Hospital-Focused Communication		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - <u>Goals of care</u> conversations are typically <u>completed by hospitalists</u> 	<ul style="list-style-type: none"> - Approaches to communication with patients and families - Honest communication with patients and families 	<ul style="list-style-type: none"> - “If we know somebody's gonna be probably a terminal extubation, we call the Alabama Organ Center. If they feel like it's necessary, they will actually come over and talk with the family.” (C-F2)
<ul style="list-style-type: none"> - <u>Discharge planning</u> through case management rounding is impactful for continuation of care 	<ul style="list-style-type: none"> - Case management round communication - Serious illness communication with the care team 	<ul style="list-style-type: none"> - “We try to coordinate with the restraints of the insurances and family wishes and physicians and their medical needs and coordinate a discharge plan that's the best option for them for when they leave the hospital.” (C-L1)

All participants commented on the impact of communication at Hospital C that was focused towards discharge planning and limited goals of care conversations. Physicians typically have goals of care conversations with patients upon admission to the hospital; however, palliative treatment was not discussed with patients who wanted everything done to prolong life. One frontline clinician reflected on goals of care conversations, “If they tell me their code status is completely full code, do everything they can, ‘Yes, I’d want my life going on with the machine,’ I’m not talking about palliative care anymore” (C-F1).

Discharge planning discussions begin early in the admission process and include many members of the interdisciplinary team. Multidisciplinary rounds within the ICU bring all the specialties together that may impact patient care and discharge on a daily basis. Clinicians felt that this communication related to patient care was impactful and built relationships among the care team. One clinician leader explained,

The goal is to start looking at the patient early. Ideally, figuring out how long they're gonna be there for discharge planning, what their needs are going to be after they leave the hospital, what we need to accomplish that day, what's still outstanding, as far as tests, or labs, or whatever. It's just a brief rundown of each patient. (C-L2)

Summary of Providing Patient-Centered Serious Illness Care

All participants commented on the process of providing serious illness care to patients and families. The basics of providing this care included referrals, to community palliative care or hospice, were initiated by physicians or case management. Discussions

focused on limited use of policies for caring for patients with serious illness. Frontline clinicians expressed that more frequent assessments increased the burden of charting.

Relationships and trust were built within Hospital C through interdisciplinary rounding and staff recognition. However, the interdisciplinary team did not always include all members of the care team. Leadership within Hospital C provides empowerment to staff by transparency and an open-door policy. The leadership team is willing to step in to provide care, and they are involved in interdisciplinary rounding. Additionally, leaders make efforts to include staff in discussions of upcoming changes or new service lines.

Clinician training within Hospital C includes both mandatory education and optional opportunities for staff in relation to caring for patients with serious illness. Participants felt that some of the educational programs were more geared towards nursing and not necessarily appropriate for other specialties, though frontline clinicians spoke of improvements in terms of the breadth of education available. Additionally, Hospital C offered a residency program for physicians that included a focus on family medicine. Clinician leaders and frontline clinicians commented that physicians and case management most commonly initiated goals of care and end-of-life conversations with patients and families; it was rare for any other member of the critical care team to have difficult conversations with patients or families. All participants had positive comments about interdisciplinary rounding and the impact it has made in caring for patients with serious illness. The leadership team commented on communication through rounds and information sharing with staff.

Theme Three: Serious Illness Care Impact

All participants discussed the positive impact within Hospital C of serious illness care on patients, families, hospital, and community. The comments focused on the idea of patient-centered care to fulfill identified needs, although barriers would sometimes hinder the best possible provision of this care. The theme of serious illness care impact emerged through understanding the impact of care for patients, families, the hospital, and the community. The theme was comprised of two subthemes: (a) fulfilling a need for patients with serious illness utilizing hospice and (b) limitations to providing serious illness care.

Subtheme: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice

The subtheme of fulfilling a need for patients with serious illness utilizing hospice emerged through participant interviews about whether the care that was provided to patients with serious illness met the needs of those patients and their families. Table 57 provides a graphic organizer for the subtheme of meeting the needs of patients with serious illness.

Table 57

Hospital C Graphic Organizer for Subtheme: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice

Serious Illness Care Impact: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Expansion of services and staff specialties focused on community needs and support for programs 	<ul style="list-style-type: none"> - Community impact - Experienced staff to provide serious illness care - Filling a gap or need 	<ul style="list-style-type: none"> - “Trying to determine what you need in order to be able to provide the service, what resources we need to have available, and what benefit that would provide to our community and to the hospital?” (C-L1)
<ul style="list-style-type: none"> - Hospice services were available within the hospital thorough a partnership; patients were connected to community resources upon discharge to expand available services for continuation of care 	<ul style="list-style-type: none"> - Outside resources that provide palliative care or hospice - Limited inpatient options 	<ul style="list-style-type: none"> - “We have a couple of home health agencies that offer palliative programs. They have nurse practitioners that come out to the house and can see them and treat them.” (C-L2)

All participants commented on fulfilling needs for patients with serious illness. Clinician leaders and administration felt that the hospital continues to focus on community needs as new services and programs are initiated. One clinician leader reflected on growth within the community, “I think as the community has expanded, our role has expanded, and our leadership has always tried to expand with the community” (C-L2).

The health care authority, corporate office, assists the hospital in assessing community needs and providing resources for growth and care of patients with serious illness. The administrator commented on the ability to “tap” into outside resources. One clinician leader made the connection to “the health care authority, which is also a stakeholder. They're very active and involved in helping us make sure we provide what the community needs” (C-L2).

Clinician leaders spoke on positive outcomes, such as decreased length of stays and readmissions, attributable to daily interdisciplinary rounding with nurses, case management, therapy services, and the nurse manager within the ICU. One clinician leader stated, “It really has rounded out. We all know. We're all in the same guidelines on what we need to do for the patient. That really has helped” (C-L3).

Additionally, the use of community resources helps to expand patient care upon discharge or during hospitalization for symptom management while on hospice. One clinician leader described the ability to provide serious illness care within a partnership approach: “We do have hospice companies that we'll work with their hospital and come in to provide hospice care if the patient meets general inpatient criteria” (C-F1).

Frontline clinicians focused on working with families to honor patients' wishes and offering hope for families in the care that is provided. One frontline clinician stated, They find comfort when you give them the option of, 'Let's focus on your quality of life instead of prolonging it.' I think sometimes it's reassuring to patients and reassuring to family members. They're just focusing on what the patient wants or just wants. (C-F1)

Subtheme: Limitations to Providing Serious Illness Care

The subtheme of limitations to providing serious illness care emerged through participant reflections related to challenges experienced when caring for patients with serious illness at Hospital C. Table 58 provides a graphic organizer for the subtheme of limitations to providing serious illness care.

Table 58

Hospital C Graphic Organizer for Subtheme: Limitations to Providing Serious Illness Care

Serious Illness Care Impact: Limitations to Providing Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Limited space and capacity of support services limit the expansion of services at this time (focused on expansion of ICU and not education) 	<ul style="list-style-type: none"> - Building and space constraints to providing serious illness care 	<ul style="list-style-type: none"> - “We’re havin’ to expand in order to have the real estate to do more services because if you think about it, even if we offered a service, our lab is not even in a space that’s conducive for our current—we need a new lab. Our dietary makes the patient meals and does all of that, so you add all this—well, we gotta have a bigger that. That’s part of our hospital expansion project. Anything we do that would be a support department, the impact of that, well, they’re not gonna be able to support that in our current situation.” (C-A1)
<ul style="list-style-type: none"> - Unrealistic expectations of families and delayed goals of care conversations have impacted serious illness care; though resistance to palliative care by hospitalists 	<ul style="list-style-type: none"> - Delayed timing - Impeding provider in the development of palliative care - Unrealistic expectations of patients and families 	<ul style="list-style-type: none"> - “He [community family doctor] was one to take care of ‘em his self, maybe not transitioning to hospice as soon as—or palliative as soon as they could. Maybe just because he was so vested in those patients. I know it’s probably hard once you’ve carried those patients for a long time to do that. He’s

<ul style="list-style-type: none"> - Limited IDT, short staffing, and unrealistic expectations within the ICU setting may impact care 	<ul style="list-style-type: none"> - Missed opportunities in providing serious illness care - Staffing challenges 	<p>since retired. I think we're coming into more of an acceptance to that type of medicine.” (C-L2)</p> <ul style="list-style-type: none"> - “Literally, we just pray that there's no codes —if we have two patients, if we have two patients that are true one-to-one patients, are critical, on drips and declining, then we're to our knees, seriously, 'cause if there's a code blue in the hospital, if there's a code gray in the hospital, rapid response, anything in the hospital, we can't go. It really does impact us. We've now staffed both this unit and the stepdown unit, but for a long time, we couldn't do that. We were just patching the holes with somebody else, which made it even worse, and I think travel nursing situation. Something's got to give with nursing compensation across the board because you got all this, this huge inequity because people leave here because they can go make more money elsewhere. It really does impact care.” (C-L2)
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Participants from all three categories commented on limitations related to providing serious illness care. The administrator spoke to physician infrastructure and limitations in the capacities of the current facilities (e.g., lab equipment limitations) to provide serious illness care. The administrator observed, “We’re havin’ to expand in order to have the real estate to do more services” (C-A1). The administrator or other participants did not feel that palliative care could be considered until the expansion was completed, despite the importance of the impact on education for current staff.

Clinicians spoke about delayed goals of care discussions with patients and families that often are not completed with the primary care clinician prior to hospital admission. One clinician leader stated,

We have doctors that do a great job of approaching hospice. It may be a little later than what it should have been or even palliative because when our hospitalists see 'em in the hospital, it's usually because they're sick. It hasn't been done on that primary care basis. (C-L1)

Another clinician leader spoke about the unrealistic expectations of patients and families upon admission to the hospital regarding progression of serious illness. One frontline clinician commented on the unrealistic expectations, “I think a lot of times people have unrealistic expectations. Patients and their family members have unrealistic expectations. As a culture, people seem surprised that people don’t get all of a sudden, all the way better” (C-F1). Goals of care conversations are completed with “all patients,” though there is no mention of difficult conversations and discussing disease progression if “the patient wants everything done” (C-F1).

Clinicians spoke on short staffing that was related to the current nursing climate and travel nursing. One frontline clinician stated,

Older nurses, they get to a place and stay. They like the people they work with.

To the younger nurses that are just startin' out—they don't care where they go.

They're looking for the money and who can pay 'em the most money, that's where they're gonna go. (C-F2)

Summary of Serious Illness Care Impact

All participants commented on the impact of serious illness care within Hospital C. The hospital has continuously grown with the community to fulfill the needs of patients with serious illness, gathering input from the community when considering expansion and the addition of new programs. Clinician leaders and administration for Hospital C felt that they had a wealth of resources from their home office to assist in developing hospital service lines; however, these have not related to providing serious illness care. The recruitment of seasoned physicians from larger healthcare facilities was making an impact on the care provided at the hospital, as were the outside community resources available to community members.

The serious illness care provided to patients within the community of Hospital C has limitations. All participants spoke about the physical limitations of the hospital; although expansion is coming, the current space limits what services and types of patients can be managed within the hospital. Additionally, frontline clinicians spoke of the unrealistic expectations of patients and families. Often goals of care conversations or discussions of disease trajectory had not occurred within primary care settings. Lastly, the

change in nursing staffing had impacted how patient care was carried out. Frontline clinicians commented on the challenges of understaffing and staff turnover and the resulting impact on patient care.

Key Findings From Hospital C

Hospital C is a for-profit hospital, located within a rural community, with a one-county catchment area. Palliative care is not offered at this hospital, though they do take care of patients with serious illness. The staff did not feel that they had the capacity to add or expand any service, including palliative care, and felt that it was adequate to have hospice to assist when needed and goals of care conversations. The following areas were important findings related to serious illness and palliative care at Hospital C:

- Higher income than average for the state of Alabama as a whole; there was a qualitative focus on more profitable services such as surgeries, though this was not reflected in admitting diagnoses
- Emphasis by the leadership team on meeting accreditation and quality standards
- Hospitalists were responsible for conducting goals of care conversations with patients upon admission
- A partnership with community hospice was utilized to manage end-of-life patients within the hospital
- Case management rounding was utilized with a focus on discharge planning and did not include the entire patient care team

- Serious illness training was not provided during orientation, and voluntary opportunities were offered on occasion by an outside agency, despite verbalized requests from clinical staff
- Care coordination upon discharge was an important focus for case management when caring for patients with serious illness
- Limitations were related to infrastructure and staffing; this was a concern from the administrator in expanding any service during the time of the study

Case Four: Hospital D

Description of Hospital D—Large, Urban Hospital without Palliative Care

Hospital D was established in 1965. The for-profit hospital is licensed for 177 beds, according to the Alabama Hospital Association. Serving a three-county catchment area, Hospital D is owned and overseen by a large hospital management company. There are six competing hospitals within Hospital D's catchment area, including two that have a palliative care program. The inpatient services that are provided at the hospital include maternal/child care, cancer care services, and surgical services. Additional outpatient services provided by Hospital D include wound care, occupational health, diabetes center, an ALS center, community primary care offices, and a soon-to-open freestanding emergency room. The hospital provides serious illness care through intensive care units and the inpatient oncology unit but does not have palliative care. Hospital D also offers an acute care unit for the hospitalized elderly population. This program is accredited through Nurses Improving Care for Healthsystem Elders (NICHE), which offers nurses

additional geriatric training on older adult health issues that include physical care in addition to initiating patient and family involvement in advanced directives.

Demographic Hospital Information

Hospital D had total annual patient admissions of 8,686 patients in 2021. This included an average daily census of 110 patients. Most of the patient population included adults aged 18-64 years old (4,128 patients) and adults 65 years old and older (4,115 patients). The most common discharge dispositions were home with any services (69.55%) and home with home health (10.94%). Appendix H provides demographic details of Hospital D.

Hospital D provided information on financial incentives related to payments to the hospital. The budget for Hospital D was based upon fee-for-service clinician billing that included Medicare Part B billing (95%) and bonus payments for quality measures (5%).

Description of the Case Participants for Hospital D

A total of six current employees from Hospital D participated in interviews. Participants were diverse within their job classification, experience, and time with the hospital. The participants included four males (66.7%) and two females (33.3%), and all six identified as Caucasian (100%). Participants were further classified based upon their length of time at the hospital with a range of 1 year to 4 years. The participants at Hospital D had the least time with their organization of any of the four cases. Participants were assigned pseudonyms based on their role in relation to the interview and were

designated by D-A1, administrator, D-L1 through D-L3, clinician leaders, and D-F1 through D-F2, frontline clinicians. Table 59 provides participant demographic information.

Table 59

Hospital D Participant Demographics

Part. ID	Participant Role	Gender	Race	Professional Education or Training	Years at Hospital	Years in Current Role	Current Position
D-A1	Hospital Administrator	male	Caucasian	Masters of Healthcare Administration	1 year	1 year	Director of Acute Care Services
D-L1	Clinician Leader	male	Caucasian	BSN	4 years	1 year	Director of Oncology
D-L2	Clinician Leader	male	Caucasian	MSN	1 year	1 year	CNO
D-L3	Clinician Leader	female	Caucasian	BSN, Masters in Leadership and Healthcare Systems	1 year	1 year	Director of Critical Care
D-F1	Frontline Clinician	male	Caucasian	BSN	3 years	1 year	Oncology, Charge Nurse
D-F2	Frontline Clinician	female	Caucasian	BSN	4 years	1 year	ICU and Oncology Clinical Educator

Theme One: History and Evolution of Serious Illness Care

All participants reflected on the theme of history and evolution of serious illness care at Hospital D, how it has evolved over time, and the perceptions and beliefs of staff about serious illness and palliative care. The theme was comprised of three subthemes:

(a) developing a mindset towards serious illness care, (b) developing an approach to serious illness care, and (c) perceptions about serious illness care.

Subtheme: Developing a Mindset Towards Serious Illness Care

All participants commented on the theme of developing a mindset towards serious illness care. Developing a mindset towards serious illness care involved the hospital and community characteristics such as the environmental factors, staffing, and the population served. Table 60 presents a joint display of the quantitative and qualitative results for this subtheme.

Table 60

Hospital D Joint Display for Subtheme: Developing a Mindset Towards Serious Illness Care

History and Evolution of Serious Illness Care: Developing a Mindset Towards Serious Illness Care		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - Administration feels that <u>staff engagement</u> is important in <u>understanding the needs</u> of the hospital and the community 	<ul style="list-style-type: none"> - “I will casually mention it to some of the leaders within the department like the charge nurses or the coordinator or something or the clinical educator. I'd say, "You know what would be cool is if we had this or that," and just bring—put it out there and just get some casual conversation flowing about it and some excitement.” (D-L3) 	<ul style="list-style-type: none"> - Access to community and inpatient hospice services within the catchment area - Access to community palliative care services - Hospital Care Intensity (HCI) 72.5% in Hospital Referral Region (HRR)
<ul style="list-style-type: none"> - Patients with serious illness are admitted to the ICUs and oncology floor; however, <u>surgery and maternal/child services are a large focus for the hospital</u> 	<ul style="list-style-type: none"> - One frontline clinician stated that the hospital is known for these services. “This hospital is built on surgeries and babies. Oncology is important, but it’s expensive” (D-F1) 	<ul style="list-style-type: none"> - Median household income greater than overall Alabama, focus on more profitable services - Three main primary admission diagnoses were related to chronic illness: cardiac (28.0%, $n = 2,432$), pulmonary (25.4%, $n = 2,207$), and GI/hepatic (11.5%, $n = 1,002$). This is divergent from the qualitative findings

Qualitative Findings. The administration and leaders of the hospital are engaged and reach out to staff for feedback on needs of the hospital. One clinician leader reflected on the expansion of the oncology unit and inclusion of staff feedback with the move, “We have really tried to create that teamwork culture buy-in, scratch your back, scratch my back type of environment. I’m really proud of the way our staff works together in that nature” (D-L1).

Currently, the hospital provides serious illness care through ICUs and an oncology treatment unit. However, services that are a large part of the hospital include mother/baby and various surgeries. The administrator commented on the surgery focus of the hospital, “We have a very robust total joint program. Our bariatric surgery program is doing very well. Those are both certified or they have the, in the certification.” (D-A1)

Quantitative Findings. This section presents supportive quantitative data for the subtheme of developing a mindset towards serious illness care.

Environmental Factors. Hospital D included three urban counties within the hospital-defined catchment area. The mean household income was above the Alabama comparison in all three counties. The hospital was for-profit and qualitative interviews found that the hospital focused on “surgeries and babies,” which would be more profitable services. The three-county average cancer mortality rate was lower than the rate for Alabama as a whole; however, one county had a greater cancer mortality rate than the overall rate for Alabama. The environmental factors for Hospital D counties are included in Table 61.

Table 61*Hospital D Environmental Factors*

	Median	Range	Mean	Alabama Comparison
Population for Catchment Area				
Population	119,679	273,994	197,168	4,903,185
SDH: Economic Stability				
Median Household Income	\$70,736	\$15,025	\$66,006	\$54,943
SDH: Healthcare Access				
Cancer Mortality Rate (measure of health) *per 100,000	173.2	51.1	186.6	209.3

As a for-profit hospital, Hospital D did not have the designation of a Medicare Sole Community Hospital status. Community-based home health, hospice, and palliative care were accessible within the entire hospital-based catchment area. An inpatient hospice house was available within 60 miles of the hospital, and the hospital offered GIP services. The hospital HCI was 68%; however, the HRR HCI was higher at 72.5%, indicating that medically ineffective care may occur at other hospitals within the HRR. The data are presented in Table 62.

Table 62*Factors Relevant to the Adoption or Closure of Hospital Palliative Care Programs*

Sole Community Hospital Status	No
ACGME Approved Residency	Yes
ACS Cancer Center	No
Outpatient Hospice Access within Catchment Area	Yes
Inpatient Hospice Access (within 60 miles of hospital)	Yes, hospice house and GIP
Outpatient Palliative Care Access within Catchment Area	Yes
Outpatient Home Health Care Access within Catchment Area	Yes
Hospital Care Intensity (HCI) with Hospital Referral Region (HRR)	72.5%
Hospital Care Intensity (HCI) at the Hospital	68.0%

Primary Hospital Admission Diagnoses. Three main primary admission diagnoses comprised the total number of admissions to the hospital: cardiac (28.0%, $n = 2,432$), pulmonary (25.4%, $n = 2,207$) and GI/hepatic (11.5%, $n = 1,002$). Interestingly, through qualitative interviews “surgeries and babies” were the biggest service for the hospital, though this is not found within the quantitative data. Table 63 provides details of Hospital D’s primary admission diagnoses.

Table 63

Primary Hospital Admission Diagnoses

Admissions Based Upon Primary Diagnosis	
Cardiac	2,432 (28.0%)
Pulmonary	2,207 (25.4%)
Cancer	275 (3.2%)
Renal	716 (8.2%)
Neurologic/Neuromuscular/ Neurodegenerative	598 (6.9%)
GI/Hepatic	1,002 (11.5%)
Traumatic	334 (3.8%)
Other	1,118 (12.9%)

Subtheme: Limited Approach to Serious Illness Care

Administration and clinician leaders commented on the theme of limited approach to serious illness care, including hospital resources and other factors already in place. Table 64 presents a joint display of the quantitative and qualitative results for this subtheme.

Table 64

Hospital D Joint Display for the Subtheme: Limited Approach to Serious Illness Care

History and Evolution of Serious Illness Care: Limited Approach to Serious Illness Care		
Qualitative	Illustrative Quote	Quantitative
<ul style="list-style-type: none"> - The <u>corporate office</u> is instrumental in <u>assisting</u> with the development of programs and connecting the hospital with resources for program development, though this <u>did not include PC</u> at this time - <u>Palliative care</u> is provided on a <u>case-by-case basis</u> (pain and symptom management; similar to GIP) - Programs will be considered if they are <u>beneficial for a patient population and fit the mission of the hospital</u> 	<ul style="list-style-type: none"> - “We have a corporate agency, and they usually—we can pull from a resource there to come over and talk with the staff or to the leadership about that particular program.” (D-L3) - “I know of three patients off the top of my head that we’ve done palliative treatment on, or our version of it. So it’s not— We haven’t had a robust— I guess what I’m saying is, we haven’t had to do it a lot.” (D-A1) - “So they do make considerations on return of investment, revenue and things but they also make decisions based on what our patient population needs. So we do have a dialysis program which quite frankly is not a money maker, and they went through with it anyway.” (D-A1). 	<ul style="list-style-type: none"> - Informal collaboration with community hospice agencies to provide serious illness care for patients

Qualitative Findings. When Hospital D looked to develop or expand a service, the corporate office assisted them in gaining insight into the needs of the community and provided guidance that allowed for the growth of serious illness care. Often the corporate office would connect Hospital D administration with a hospital that had already instituted the program that was being considered, though this did not include serious illness or palliative care programs at the time of this study. One clinician leader said of the resources available through the corporate office, “We are able to use our corporate office to network with other hospitals that may have been successful in certain programs we are considering” (D-A1).

Palliative care was offered on a case-by-case basis, and the resources of an outside hospice agency was available as needed. One frontline clinician reflected on the use of symptom management within the oncology unit, “It’s like a team approach when it comes to pain—when it comes to palliative care. There’s not one size fits all. Everyone is a case-by-case basis” (D-F1).

Hospital D offers a program called Nurses Improving Care for Healthsystem Elders (NICHE), a program that provides additional training for nurses who care for older adults. The administrator conveyed the excitement of the physician who leads the program: “Our primary doctor for that unit is a big believer in it. We are excited that we have expanded that unit to 18 beds. We are looking forward to helping that population with their needs” (D-A1).

Programs were considered based upon the hospital mission, revenue stream, community needs, and community resources. One clinician leader noted that sometimes programs were implemented out of necessity for patients. “We do have a very small

dialysis unit. It was contracted out, even though it probably is not a very good return on investment as far as revenue wise. However, they made that decision based on the needs of the patient” (D-L2).

Quantitative Findings. This section presents supportive quantitative data for the subtheme of developing an approach to serious illness care.

Hospital’s Palliative Care Resources. Hospital D’s palliative care resources included an informal collaboration with community hospice agencies to care for patients with serious illness.

Subtheme: Narrow Perceptions About Serious Illness Care

All participants commented on the theme of narrow perceptions about serious illness care, including the perceptions from staff about how care is to be provided and how buy-in to providing serious illness care can be achieved. Table 65 presents a graphic organizer of the qualitative results for this subtheme.

Table 65

Hospital D Graphic Organizer for Subtheme: Narrow Perceptions About Serious Illness Care

History and Evolution of Serious Illness Care: Narrow Perceptions About Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Clinicians had <u>similar beliefs in palliative</u> or serious illness care being a <u>supportive service</u> 	<ul style="list-style-type: none"> - Beliefs in care from the viewpoint of the clinicians 	<ul style="list-style-type: none"> - “It involves not just the patient. It’s the family, too, in terms of more comfort. It’s similar to hospice where you just want it to be more comfortable for the patient. There’s what’s called palliative radiation, especially—it’s not treating to cure. It’s more about preventing further—it’s slowing down a progression of disease but not fixing the problem.” (D-F1)
<ul style="list-style-type: none"> - Though clinicians reflected <u>favorably towards palliative care</u> benefits, it is <u>not currently being considered</u> 	<ul style="list-style-type: none"> - History of serious illness care within the hospital 	<ul style="list-style-type: none"> - “I think the number one thing that may be impeding it is there is no discussion. That hasn’t even been a topic that we’ve discussed in any scenario. The benefit of this interaction with you and I is that it made me start thinking about, hey, that might be a good thing to add.” (D-A1)

Qualitative Findings. Clinicians had similar beliefs on what encompassed palliative or serious illness care. One of the clinician leaders, remembering a past experience with palliative care, said, “I would say palliative care/supportive care is for those patients with long-term illnesses that need support, not necessarily for end of life, but for—to help manage their symptoms, keep them as comfortable as possible” (D-L1).

The administrator and clinicians discussed the benefits of palliative care in managing serious illness. However, instituting a palliative care program has not been discussed recently. One clinician leader spoke about the use of hospice agencies to provide serious illness care. “We do have some that come in to work on a consultant basis that would help assist us in end of life” (C-L2).

Summary of History and Evolution of Serious Illness Care

Hospital D found that staff engagement in understanding the needs of patients and the community was important during the consideration of new services. Though serious illness care was provided through ICUs and the oncology unit, the hospital was focused on surgical services and mother/baby services. Participants spoke about the access to corporate office resources and other hospitals when considering the creation of new services to benefit patients with serious illness and their families. Palliative care was provided to patients on a case-by-case basis by their admitting doctor. Palliative care was not a program that Hospital D considered during this study; however, participants felt that it may be beneficial to patients with serious illness.

Theme Two: Providing Patient-Centered Serious Illness Care

All participants commented on the process of providing care for patients with serious illness, whether this be from direct patient contact or managing the care that was provided. The theme of providing patient-centered serious illness care emerged through understanding the processes that were essential to caring for those with serious illness. The theme was comprised of four subthemes that impacted how care was provided: (a) basics of providing care, (b) empowerment through leadership support of serious illness care, (c) limited clinician training in serious illness care despite the need, and (d) hospital-focused communication.

Subtheme: Basics of Providing Care

Clinician leaders and frontline clinicians shared their thoughts on the basics of providing care, including assessment, charting, consultations by other specialists, and policies that are utilized for patients with serious illness. Table 66 provides a graphic organizer for the subtheme of basics of providing care.

Table 66

Hospital D Graphic Organizer for Subtheme: Basics of Providing Care

Providing Patient-Centered Serious Illness Care: Basics of Providing Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Policy use related</u> to serious illness care was <u>limited</u>	- Utilizing policies and procedures in serious illness	- “We don’t have much a handwritten policy or procedures for serious illness care, besides the comfort care orders. Typically, we can reach out to case management for assistance with connecting them to any resources outside of the hospital.” (D-F1)
- <u>Physicians</u> typically begin the <u>consult process</u> ; however, nurses or families can request a consult for any specialty service	- Physician-driven referral process	- “They also have a history of CHF, a lot of times, they’ll just do them—okay, let’s go ahead and consult, even just do a courtesy consult for their cardiologist so that we can agree on how much fluid is too much fluid or getting a happy medium. They do consults quite a lot here, whether it’s nephrology or urology. It’s just a case by case.” (D-F2)

Policy use related to serious illness was limited, except for comfort care order sets that are implemented upon physician orders. One frontline clinician stated, “They’ve got an order set that’ll say yes to this and no to this, but it’s not necessarily a document that we keep with us” (D-F2).

Physicians request the consults or referrals. This may be a referral for a new condition or a courtesy consult to let another physician know that their patient is under the care of a hospitalist. One frontline clinician stated, “Usually, it’s at their discretion and say, ‘Okay, do you wanna do a courtesy consult out to them?’ Just reach out. It also depends on if that specific doctor actually has privileges in the hospital” (D-F1).

Clinicians were not familiar with the National Consensus Guidelines for Quality Palliative Care. One clinician leader reflected, “I wouldn’t say I’m familiar with it” (D-L1).

Subtheme: Empowerment Through Leadership Support of Serious Illness Care

All participants reflected on empowerment through hospital leadership. The subtheme of empowerment through leadership support of serious illness care emerged through interviews and reflected the impact of leadership within Hospital D on caring for patients and families with serious illness. Table 67 provides a graphic organizer for the subtheme of empowerment through leadership support of serious illness care.

Table 67

Hospital D Graphic Organizer for Subtheme: Empowerment Through Leadership Support of Serious Illness Care

Providing Patient-Centered Serious Illness Care: Empowerment Through Leadership Support of Serious Illness		
Participant Perspectives	Associated Codes	Illustrative Quotes
- Variety of leadership styles	<ul style="list-style-type: none"> - Mixture of leadership styles that complement each other - Bottom-up leadership - Servant leadership style - Transactional leadership style 	- “I would say it’s a good mix of leadership styles. It varies from person to person.” (D-L1)
- Leadership presence has been impactful for building trust	<ul style="list-style-type: none"> - Hands-on approach to leading - Transparent leadership - Top-down approach to leadership 	- “I feel very supported by the general management staff. He sees the CEOs and CNOs a bit more than I do, but I do appreciate that they round more. For a long time, it was like, well, there is a CEO somewhere, and they’re in a room somewhere. That’s how it was for a while, but I think they’re changing that dynamic and having them actually be present and there to help.” (D-F2)

There were a variety of leadership styles throughout the hospital. The administrator reflected on his leadership style, “I always say I am a bottom-up kind of guy. I have tried not to do any massive changes without involving my frontline staff and discussing with it first” (D-A1). A clinician leader described his own leadership style as, “I’d say I’m more of a servant leader. Giving staff what they need to be successful” (D-L1).

Clinicians discussed engagement of hospital leadership through rounding and staff council. Typically rounding occurs on a daily basis and staff council occurs once to twice a month. One clinician leader described rounding as a nurse leader:

We round in the ICUs, and we round on the floor. Each leader currently has about 10 to 20 beds depending on what you got going on. Our goal is every day, which we meet, every day is every single patient gets rounded on by a nurse leader or somebody that’s a leader here. (D-L3)

Nurse leaders were engaged with staff and on occasion would step into care for patients when staffing was overwhelmed. The same clinician leader reflected on her ability to assist in certain situations.

They’ve seen that over and over again with me when things have gone awry or we’re getting a patient that’s very, very sick. I’ll just put on my scrubs and go to the unit, and I’ll say—especially if it’s someone like they’ve never had this particular patient. (D-L3)

Subtheme: Limited Clinician Training in Serious Illness Care Despite the Need

Clinician leaders and frontline clinicians commented on clinician training. The subtheme of limited clinician training in serious illness care despite the need emerged through reflections of participants related to the importance of the serious illness care training that is provided within Hospital D. Table 68 provides a graphic organizer for the subtheme of improving clinician training in serious illness care.

Table 68

Hospital D Graphic Organizer for Subtheme: Limited Clinician Training in Serious Illness Care Despite the Need

Providing Patient-Centered Serious Illness Care: Limited Clinician Training in Serious Illness Despite the Need		
Participant Perspectives	Associated Codes	Illustrative Quotes
<ul style="list-style-type: none"> - Mandatory orientation and annual training are focused on “basics of care”; <u>no required training related to serious illness care</u> 	<ul style="list-style-type: none"> - Orientation for new staff - Identifying education gaps - Training attendance expectations 	<ul style="list-style-type: none"> - “We’ve been doing is back to basics because we’ve had so many travelers and, after COVID, so much turnaround that a lot of the basic stuff that we would assume everyone was doing hadn’t been getting done.” (D-F2)
<ul style="list-style-type: none"> - <u>Lack of serious illness training</u>, though they are trained to identify patient needs and utilize care plans to fulfill those needs 	<ul style="list-style-type: none"> - Lack of serious illness training 	<ul style="list-style-type: none"> - “I do not know that there are specific serious illness programs from our nurse educator department.” (D-L1)

Orientation and annual training were required and typically were focused on basics of care. One frontline clinician explained, “Training on the computer system and skills is typically what is offered” (D-F1).

Training on care plans and understanding how to build the care plan by identifying patient needs was discussed during interviews. One clinician leader stated, “We train them how to do their care plans, not just to click boxes, to actually think about what are the things this patient needs” (D-L3). However, there was not specific training offered on caring for patients with serious illness. Another clinician leader confirmed, “not that I'm aware of” (D-L2).

Subtheme: Hospital-Focused Communication

Clinician leaders and frontline clinicians commented on hospital-focused communication. The subtheme of hospital-focused communication emerged through reflections of participants related to communication between administration and staff, as well as the impact communication makes on the care that is provided to patients with serious illness and their families within Hospital D. Table 69 provides a graphic organizer for the subtheme of patient-centered communication.

Table 69

Hospital D Graphic Organizer for Subtheme: Hospital-Focused Communication

Providing Patient-Centered Serious Illness Care: Hospital-Focused Communication		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Physicians</u> are typically charged with having <u>goals of care conversations</u>	- Approaches to communication with patients and families	- “Typically the physician handles goals of care conversations. Occasionally case management will talk with the family.” (D-F2)
- <u>Case management rounds</u> are utilized to discuss patient care and connect patients to needed services; <u>discharge planning focus with limited case team attendance</u>	- Case management rounding communication	- “We have the interdisciplinary rounds every day. In that meeting, the whole meeting’s pretty much completely about goal of care for the patient, and that’s a daily thing.” (D-L3)

Goals of care conversations are typically led by the hospitalists or admitting doctor. Nurses will often note that the timing for the conversations is right and inform their admitting physician. One frontline clinician reflected on the physician having the conversation,

I see the doctors enough to know to tell them, “Hey, I think it’s time to have this conversation. They’re usually agreeable to having the conversation. Typically, it’s the physician that the family trusts more, if it’s either the hospitalist or a consult. (D-F1)

Multidisciplinary rounding is utilized within the ICU and oncology units. Case management typically led the discussion about the patient based upon conversations with the physician. The rounding allowed for decreased opportunities for miscommunication among disciplines. One frontline clinician noted of the rounding, “I like it because it cuts down on some of the miscommunications of, ‘Oh, I didn’t know that’s what they’re here for. I didn’t know they’d seen them’” (D-F2). The rounds included staff from multiple disciplines: “It’s without the doctors. It involves case management, the pharmacy, the dietitian, the nurses, physical therapy, occupational therapy” (D-F2).

Summary of Providing Patient-Centered Serious Illness Care

Clinicians at Hospital D did not utilize particular policies related to serious illness care. However, comfort care orders were available for the hospitalist or admitting doctor to initiate. Typically, physicians were required to order consults, but nurses felt empowered to request them based on the patient. Multidisciplinary rounding was utilized within the ICU and oncology unit. Case management led the rounding conversations that

included the nurse and other members of the interdisciplinary team. The discussion typically focused on discharge planning and care coordination. Physicians did not participate in rounding; however, they had prior discussions with case management regarding the status of the patient. Leadership was engaged with staff through rounding and multiple avenues of communication and feedback. Nurse leaders rounded on particular units and assisted in patient care when needed. Orientation and mandatory annual training focused on basic skills and charting; limited serious illness training was provided to staff. Physicians were charged with goals of care conversations with patients and families.

Theme Three: Serious Illness Care Impact

All participants within Hospital D discussed how impactful providing serious illness care was to the patients, families, hospital, and community. The comments focused on the idea of patient-centered care to fulfill identified needs, although barriers to providing this care would sometimes occur. The theme of serious illness care impact emerged through understanding the impact of care for patients, families, the hospital, and the community. The theme was comprised of two subthemes: (a) fulfilling a need for patients with serious illness utilizing hospice and (b) limitations to providing serious illness care.

Subtheme: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice

All participants commented on fulfilling needs for patients with serious illness utilizing hospice. The subtheme of fulfilling a need for patients with serious illness

emerged through participant interviews about whether this care met the needs of patients and families within Hospital D. Table 70 provides a graphic organizer for the subtheme of meeting the needs of patients with serious illness.

Table 70

Hospital D Graphic Organizer for Subtheme: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice

Serious Illness Care Impact: Fulfilling a Need for Patients With Serious Illness Utilizing Hospice		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Case management</u> is utilized to assist in identifying and <u>fulfilling patient's and family's needs</u>	- Discharge planning	- "Discharge planning starts when they're admitted. It's at a certain stage to start reaching out to other facilities about how they would reach out to the family and how the family would reach out to a hospice company or other palliative care measures, how the doctors will talk to the family about what their needs are. Are they gonna go home? Are they gonna go to patient rehab? Are they gonna go—basically, any needs on radiation at home. Then finding out a way—how are they gonna get to their treatments? How are they gonna see a doctor? How are they gonna make their referrals?" (D-F1)
- <u>Symptom management</u> is treated by the admitting <u>physician or hospitalist or through a partnership with hospice</u>	- Filling a gap or need	- "We have had one or two quote unquote palliative patients (needing symptom and pain management), but they were individually driven, or driven by

an individual physician and not a
program.” (D-A1)

Clinicians reflected on fulfilling needs for hospitalized patients with serious illness through the use of case management. One clinician leader said of case management, “We’ve got a very robust case management program, and they work really well on identifying patients’ and families’ needs during the hospital stay and when discharged home” (D-L2).

Symptoms for patients with serious illness are treated by the hospitalist or admitting doctor. One frontline clinician described the approach when it comes to managing symptoms for patients:

It’s like a team approach when it comes to pain or symptoms—when it comes to palliative care. There’s not one size fits all. Everyone is a case-by-case basis. If it’s one nurse that recognizes it, if it’s the doctor that recognizes it, it is addressed when it happens. (D-F1)

Subtheme: Limitations to Providing Serious Illness Care

All participants commented on the limitations to providing serious illness care within Hospital D. The subtheme of limitations to providing serious illness care emerged through participant reflections related to challenges that have been experienced when caring for patients with serious illness at Hospital D. Table 71 provides a graphic organizer for the subtheme of limitations to providing serious illness care.

Table 71

Hospital D Graphic Organizer for Subtheme: Limitations to Providing Serious Illness Care

Serious Illness Care Impact: Limitations to Providing Serious Illness Care		
Participant Perspectives	Associated Codes	Illustrative Quotes
- <u>Leadership changes</u> have been challenging in moving forward with changes or new program implementation	- Leadership changes	- “We’ve had, basically, a revolving door with administrators that all care. They all have good ideas. They’re all likeable. We love them a lot. It’s just their stresses can make us stressed. They’ll all have a goal and direct towards having something done. Things move slowly.” (D-F2)
- <u>Short staffing and turnover</u> have negatively impacted serious illness care.	- Staffing limitations	- “I think that really the main issue has been staffing and leadership frame as well. We’ve had a lot of turnover. Everybody blames everything on COVID and all of our staffing woes. During COVID, during a lot of the staffing woes, managers and directors were pulled into staffing, and they were required to work sometimes 24 hours a day and things to cover their own job and then kept going to staffing to help take care of patients. That always will impede any type of new program 'cause the director or manager just

doesn't have the bandwidth to take on anything else. We're seeing a little bit of a change. Our staffing is getting better. We still are short-staffed every day, and we have to meet and work and ask people to work extra shifts, and it's not a lot of fun to get all of those things accomplished. We've already had a meeting about that this morning, and we've gotten some things done there, but it definitely what it would impede would be the force, the workforce that it would take to do something like that. It's not that we don't believe in it or we don't wanna something like that to happen. That's such a wonderful thing. It's that the workforce hasn't been present for us." (D-L3)

Leadership changes have been significant for Hospital D over the last year. Clinicians felt that this may have caused delays in getting programs or services started for patients with serious illness. The administrator reflected on the changes, “Full disclosure, I wouldn’t say 100 percent, a huge change in our leadership. A new director of critical care and cardiac services was brought on board. A new CEO was brought on board. We now have a new CNO” (D-A1). However, the administrator did hope to see some new ideas and positive changes for the hospital in the future: “My understanding is, hoping that a new leadership change, bring new ideas from people from different aspects of healthcare, different areas, different hospitals, to help facilitate change” (D-A1).

In addition to leadership changes, nurse staffing has been challenging, with a great deal of turnover. One frontline clinician reflected on staffing challenges and the lack of time to sufficiently train a new nurse before beginning care for patients. “The issue with that is it’s such a high turnover where you—if you were to train somebody who’s a full-time staff, the orientation was 90 days. You don’t have that. You have about two weeks or less” (D-F1).

Summary of Serious Illness Care Impact

Hospital D utilized case management to assist with assessing patient and family needs within and outside of the hospital. Hospitalists or the admitting physicians typically initiated care for patients’ symptoms; a few physicians have provided a form of palliative care for a limited number of patients. Hospital D did experience challenges when providing care to serious ill patients and their families. For example, significant leadership changes over the last year have resulted in delays in obtaining equipment or

meeting the needs of staff. However, administration hopes that the changes will offer positive changes and new ideas soon. Additionally, a staffing shortage has caused challenges with providing needed coverage and training within the ICU and oncology unit.

Key Findings From Hospital D

Hospital D is a for-profit hospital, located within a urban community, serving an urban three-county catchment area. Palliative care is not offered at this hospital, though the staff report it has been done a handful of times by the hospitalists. They felt that palliative care has not occurred at this hospital because the discussion is not happening and the service focus was said to be surgeries and maternal/child. The following areas were important findings related to serious illness and palliative care at Hospital C:

- Higher income than average for the state of Alabama as a whole, qualitative focus on more profitable services such as surgeries and maternal/child, though this was not reflected in admitting diagnoses
- Hospitalists were responsible for conducting goals of care conversations with patients upon admission
- Reported a “case-by-case” approach to palliative care by hospitalists that consisted of symptom management
- A partnership with community hospice was utilized to manage end-of-life patients within the hospital
- Case management rounding was utilized with a focus on discharge planning and did not include the entire patient care team

- Serious illness training was not provided during orientation and voluntary opportunities were offered on occasion by an outside agency, despite verbalized requests from clinical staff
- Care coordination upon discharge was an important focus for case management when caring for patients with serious illness
- Limitations were related to leadership changes and staffing challenges

Cross-Case Analysis Among Alabama Hospitals

Comparison of themes and subthemes across cases uncovered emergence of the same three themes: history and evolution of serious illness care, providing patient-centered serious illness care, and serious illness care impact. However, the subthemes that emerged differed across the four cases. The commonalities and differences among the cases are discussed in three sections: (a) hospitals with palliative care, (b) hospitals without palliative care, and (c) hospitals with and without palliative care. A graphic organizer of all four hospitals is presented in Appendix I.

Cross-Case Analysis One: Comparisons of Hospitals With Palliative Care

Hospitals with palliative care had similarities in themes and subthemes; however, some of the characteristics among the hospitals and palliative care programs differed. The two hospitals with palliative care were Case One (Hospital A) and Case Two (Hospital B).

Commonalities and Differences in Hospital Descriptions

The hospitals with palliative care had many similarities related to ownership status, location, and the initial steps to starting palliative care. Both hospitals were located in an urban area, though they both served patients residing in multiple rural counties within the hospital-defined catchment areas. Hospital A opened its palliative care program in 2016, while Hospital B's opened in 2014. Prior to initiation of the palliative care program, administrators and clinician leaders attended the CAPC Palliative Care Leadership Centers training sessions. Additionally, both hospitals had a limited interdisciplinary palliative care team. The hospitals with palliative care programs were both nonprofit hospitals that were overseen by a board of directors.

Commonalities and Differences in Theme One

This section summarizes commonalities and differences among the three subthemes of theme one for hospitals with palliative care (Hospitals A and B): (a) developing a mindset towards serious illness care, (b) developing an approach to serious illness care, and (c) perceptions about serious illness care.

Developing a Mindset Towards Serious Illness Care. Participants at both hospitals had similar responses about the development of a mindset towards serious illness care. Administration was supportive of the expansion of serious illness care and focused on providing quality care for patients within the community despite the challenges of funding. The median household income for populations served by both hospitals were less than the Alabama average. Community services were similar for both

hospitals, with access within the entire catchment area to community hospice and home health. However, palliative care access was limited to one to two counties within the catchment area. Both hospitals had a residency training program that was ACGME approved. The hospitals had similar primary admission diagnoses: cardiac, GI/hepatic, and pulmonary.

Hospital A participants felt that a mindset shift was seen by staff and community members who had witnessed the use of palliative care, whereas Hospital B participants felt that education within the hospital and community had caused the greatest shift in mindsets. Despite increased buy-in to palliative care, Hospital A was located within an HRR with the highest overall HCI for Alabama at 83.9%, while Hospital B was located within an HRR with the lowest overall HCI for Alabama at 68.0%. It should be noted, though, that the HCIs reflect data from 2017 and likely have changed over the last 6 years.

Developing a Financially Feasible, Mission-Focused Approach to Serious Illness Care That Was Impactful for Patients and Families. The palliative care programs were established at both hospitals through champions for palliative care services. Though the impetus for each program was different, both hospitals had to shift the models of delivery over the years. This was due to the limited funding for palliative care. Currently, programs at both hospitals are funded 100% through the hospital.

The impetus for the programs was different between the hospitals. Hospital A aimed to create a program to better serve patients who were admitted to the ICU with serious illness. The clinician support initially was provided by two hospice medical

directors. The director of the palliative care program at Hospital A completed a fellowship and board certification as a palliative care and internal medicine physician. The impetus of the program at Hospital B was a service line within the comprehensive cancer center that was originally developed for cancer patients with a focus on quality care; however, it later expanded to include other serious illnesses. Hospital A has a 3.5 FTE model that includes a social worker who coordinates consults and services, two nurse practitioners, and a part-time physician who serves as the director. Hospital B has a 2.5 FTE model that utilizes a nurse practitioner, social worker, and chaplain. Challenges to buy-in were seen at Hospital B with lack of a board-certified palliative care physician; these challenges continue despite the change to a model led by a board-certified nurse practitioner. The palliative care program at Hospital A has been funded through the hospital since inception, while the program at Hospital B was initially funded through the hospital foundation and small grants.

Changing Perceptions About Serious Illness and Palliative Care Through Trust and Education. Hospitals A and B had to grow “buy-in” to the program through education with the board of directors and clinicians. There are still physicians at both hospitals who are hesitant about palliative care, feeling that the service is needed only for comfort measures. Additionally, both hospitals noted generational differences in the early use of their palliative care services. Physicians who had been practicing a longer period of time often had more hesitancy in consulting the service or would choose to perform palliative care independently. Participants at both hospitals felt that “younger” physicians were less hesitant because of training and education within their professional studies.

Palliative care programs at both hospitals received the majority of consults from hospitalists or intensivists/pulmonary care physicians.

The initial acceptance of the palliative care program by hospitalists and intensivists differed between the two hospitals with palliative care. Hospitalists and intensivists at Hospital A were the first to begin consulting the palliative care program. In contrast, hospitalists and intensivists at Hospital B were initially against the program, though they now are the specialties that most frequently request palliative care consults. The two hospitals had a similar common primary diagnosis for palliative care referrals: cancer. The most common primary diagnoses for consults at Hospital A were pulmonary and cancer. The most common primary diagnoses for consults at Hospital B were cancer and cardiac.

Commonalities and Differences in Theme Two

This section summarizes commonalities and differences among the five subthemes of theme two for Hospitals A and B: (a) basics of providing care, (b) building trust and relationships among clinicians, (c) empowerment through leadership support of serious illness care, (d) improving clinician training in serious illness care, and (e) patient-centered communication.

Basics of Providing Care. Neither hospital reported using written policies in making decisions regarding palliative care. Neither hospital had official triggers for initiating a palliative care consultation. Participants felt that often their experience of caring for patients with serious illness helped them to be aware of when to consult

palliative care. Physicians were required to make the initial consult; however, participants at both hospitals, including nurses, felt comfortable requesting the physicians initiate a consult.

Building Trust and Relationships Among Clinicians and the Palliative Care Team. The use of multidisciplinary rounding within the ICUs at both hospitals helped to provide patient-centered care and establish relationships among the care teams. These rounds included the intensivists, nurses, dietary, case management, therapy services, and palliative care. Palliative care team members at both hospitals felt this helped to build trusting relationships with the care team and may have assisted in triggering early consults for patients with serious illness. Hospitals A and B both recognized staff performance with awards and provided staff support.

Hospital A participants reflected on the challenges of having a limited interdisciplinary care team whose members were specific to the palliative care program. They felt that the connection with spiritual care and coordination of discharge planning were challenging. In contrast, Hospital B's care team included a chaplain who provided spiritual care and a social worker who worked closely with case management on care coordination. Hospital B also provided resiliency training to assist ICU staff with self-care.

Empowerment Through Leadership Support of Serious Illness Care. A variety of leadership styles were seen within both hospitals. Participants reflected on the

transparency and open communication with hospital leadership at both hospitals.

Participants at both hospitals felt that, overall, they had a supportive administration.

Hospital A had a consistent leadership team throughout the development and continuation of the palliative care program; however, several administrators were transitioning to retirement during this study. Hospital B was affected by changes in the leadership team after the establishment of the palliative care program, which impacted the palliative care team model. Despite changes in hospital administration, support for palliative care remained strong despite the impact of funding challenges on the model of care.

The Importance of Clinician Training When Providing Serious Illness Care.

Orientation and annual training were mandatory for clinicians at both hospitals.

Orientation provided specific training related to caring for patients with serious illness.

Voluntary serious illness training was also available at both hospitals, though Hospital A had a more structured training program.

The palliative care coordinator at Hospital A provided educational sessions for clinicians. The annual evaluations for ICU nurses were tied to attendance at these educational sessions, based upon the number of sessions attended. Hospital B provided didactic education on palliative care for medical residents; they also attended multidisciplinary rounding with the intensivists.

Multidisciplinary Communication Focused on Patient-Centered Care.

Participants felt that open and honest communication was provided to staff by the

leadership team. Both hospitals employed multiple avenues for staff communication. Participants reflected on the benefits of using the palliative care team to help with difficult conversations.

The palliative care team at Hospital B employed specific communication strategies with patients and families that included SPIKES and Vital Talk. The palliative care team at Hospital A did not utilize a formal communication tool.

Commonalities and Differences in Theme Three

This section summarizes commonalities and differences among the three subthemes of theme three for Hospitals A and B: (a) focus on patient-centered care, (b) fulfilling a need for patients with serious illness, and (c) limitations to providing serious illness care.

Focus on Patient-Centered Care. Participants at both hospitals expressed that palliative care allowed patients and families to have their care needs met. This was true for patients with varying serious illnesses and even those in acute traumatic situations.

Palliative Care Closing the Gap in Fulfilling a Need for Patients With Serious Illness Care. Intensivists' services within ICUs at both hospitals impacted the care that was received by patients with serious illness.

Though both hospitals have rural catchment areas, administration at Hospital B focused on needs of rural community hospitals. This included services that may be needed by patients who are transferred from the rural hospitals to Hospital B, including

palliative care services. Participants at Hospital A reflected on the “soft services” that are provided by palliative care, while the ICU clinicians focused on the physical needs of the patient; this was especially beneficial during the COVID pandemic.

Limitations to Providing Serious Illness and Palliative Care. Limited reimbursement for palliative care services has impacted programs at both hospitals. This has created shifts in the care models for the palliative care programs over the years. A knowledge deficit about palliative care among clinicians and community members will continue to impact early access to palliative care.

Hospital A was impacted by difficulty assessing program impact due to the absence of existing measures for evaluating palliative care success.

Cross-Case Analysis Two: Comparisons of Hospitals Without Palliative Care

Hospitals without palliative care had similarities in themes and subthemes; however, some of the characteristics among the hospitals and their strategies for providing serious illness care differed. The two hospitals without palliative care were Case Three (Hospital C) and Case Four (Hospital D).

Commonalities and Differences in Hospital Descriptions

Hospital C was in a rural location, while Hospital D was located in an urban setting. Hospital C had a one-county catchment area, while Hospital D had a three-county catchment area. Both hospitals were for-profit and overseen by a large hospital management company, and both hospitals had a focus on more profitable services:

surgical and maternal/child services. Hospital C provided serious illness care within the ICU, while Hospital D provided serious illness care within the ICUs and oncology unit.

Commonalities and Differences in Theme One

This section includes commonalities and differences among the three subthemes for theme one for hospitals without palliative care (Hospitals C and D): (a) developing a mindset towards serious illness care, (b) developing an approach to serious illness care, and (c) perceptions about serious illness care.

Developing a Mindset Towards Serious Illness Care. Participants at both hospitals reflected on the importance of assessing the community for needs related to new services. Access to community hospice, home health, and palliative care were available within the catchment area of the hospital. The median household income in both hospitals' catchment areas was higher than the Alabama average. Both hospitals had a medical residency program that was ACGME approved, which has been associated with increased prevalence of a palliative care program. However, neither hospital provided serious illness or palliative care training for residents.

Limited Approach to Serious Illness Care. Participants reflected that hospitalists and the admitting physician typically have goals of care conversations with patients and families upon admission. Hospital C partnered with local hospice agencies to provide inpatient care for patients with serious illness. While Hospital D did provide some GIP care, hospitalists had provided palliative care and symptom management for

patients on a case-by-case basis. Hospital D participants felt that they had several resources of support from the management corporation if they chose to expand services for serious illness in the future. The admitting diagnoses, though, were more related to chronic illness; however, the qualitative interviews were divergent from this finding in that the services that the hospitals focused on were more profitable services.

Narrow Perceptions About Serious Illness Care. Participants at Hospital C had varying opinions as to the services that palliative care encompassed. Some participants felt that palliative care was only used for end of life, while other participants felt it was focused on goals of care for patients. Participants at Hospital D had similar beliefs on palliative care, stating that it was a holistic, supportive service for patients with serious illness and their families who may continue to seek aggressive care measures. Administrators at Hospital C were focused on the recruitment of physicians from larger hospitals and an ongoing hospital expansion to better care for patients with serious illness and their families.

Commonalities and Differences in Theme Two

This section includes commonalities and differences among the five subthemes of theme two for Hospitals C and D: (a) basics of providing care, (b) building trust and relationships among clinicians, (c) empowerment through leadership support of serious illness care, (d) improving clinician training in serious illness care, and (e) patient-centered communication.

Basics of Providing Care. Participants at both hospitals reflected on the limited use and availability of policies related to serious illness, though comfort care orders were available at both hospitals. At both hospitals, physicians were the only team member authorized to initiate a consult or referral. However, other clinicians caring for seriously ill patients felt comfortable requesting that the appropriate physician make a referral.

Clinicians at Hospital C reflected on the amount of charting related to serious illness and its negative impact on time available for on patient care.

Building Trust and Relationships Among Clinicians. Participants at Hospital C reflected on the use of multidisciplinary rounding and the establishment of relationships among the care team. Additionally, participants discussed the roles of the small size of the hospital and the importance of consistent staff in building relationships and establishing trust. Hospital C did not have a chaplain on staff to provide spiritual care; however, relationships were established with community clergy to provide spiritual care to patients with serious illness. Additionally, participants at Hospital C commented on the team-building activities and recognition for staff. Participants at Hospital D did not have comments related to building trust and establishing relationships.

Empowerment Through Leadership Support of Serious Illness Care.

Participants at both hospitals commented that their leadership team members had diverse styles and that this diversity was beneficial. The leadership teams at both hospitals are engaged with staff through transparent communication and employee rounding.

Limited Clinician Training in Serious Illness Care Despite the Need.

Orientation and annual training within both hospitals focus on basics of care and documentation. Both hospitals have critical care educators who focus on specific needs of nursing staff. Voluntary training on caring for patients with serious illness is provided for Hospital C's employees through partnerships with local hospice agencies.

Hospital-Focused Communication. Goals of care conversations are typically completed by hospitalists or the admitting physician at both hospitals. Multidisciplinary rounding was implemented within critical care units at both hospitals to assist with discharge planning; the rounds are led by the case management staff. Typically, physicians are not involved in the multidisciplinary rounding, but the case management team has been informed regarding the needs of the patients.

Commonalities and Differences in Theme Three

This section includes commonalities and differences among the two subthemes of theme three for hospitals without palliative care: (a) fulfilling a need for patients with serious illness and (b) limitations to providing serious illness care.

Fulfilling a Need for Patients with Serious Illness Care Utilizing Hospice.

Case management helped to connect patients with community services for continuation of care at home. Hospital C coordinated inpatient symptom management and care with outside hospice agencies, while at Hospital D physicians managed symptoms and care for patients approaching the end of life. The administration at Hospital C were currently

focused on expanding physician staff, so that services could be expanded to meet the community demand.

Limitations to Providing Serious Illness Care. Participants at both hospitals felt that short staffing continued to be a challenge in providing serious illness care.

Participants at Hospital C felt that unrealistic job expectations made it challenging to have time to provide care to patients and families. Participants at Hospital C felt patients and families had unrealistic expectations related to disease progression, impacting goals of care discussions. The physical building size limited any additional services for patients until an expansion is complete. Hospital D had significant leadership changes over the last year, and participants felt this impeded any new service growth to care for patients with serious illness.

Cross-Case Analysis Three: Comparisons of Hospitals With and Without Palliative Care

Commonalities and differences between hospitals with and without palliative care are presented within this section.

Hospitals with and without palliative care had similarities and differences among themes and subthemes. All four hospitals are compared here: the two with palliative care, Case One (Hospital A) and Case Two (Hospital B), and the two without palliative care, Case Three (Hospital C) and Case Four (Hospital D).

Commonalities and Differences in Hospital Descriptions

Hospitals with palliative care were nonprofit and managed by a board of directors. Hospitals without palliative care were for-profit hospitals and overseen by a large hospital management company. The catchment areas for hospitals with palliative care covered large geographic areas that included multiple rural counties, while hospitals without palliative care included smaller catchment areas.

Commonalities and Differences in Theme One

This section includes commonalities and differences among variations in subthemes for theme one between hospitals with and without palliative care: (a) developing a mindset towards serious illness care, (b) approach to serious illness care, and (c) perceptions about serious illness care. Table 72 provides an overview and meta inferences related to Theme One.

Table 72

Graphic Organizer for Cross-Case Comparison: Theme One

Subthemes	Hospitals with PC	Areas of Similarities	Hospitals Without PC	Meta Inferences
Developing a mindset towards serious illness care	<ul style="list-style-type: none"> - Mission Fit - Limited community PC access - Lower household income 	<ul style="list-style-type: none"> - Access to community home health and hospice - ACGME Residency Program 	<ul style="list-style-type: none"> - Community needs assessment; though this did not include PC - Community PC access - Higher household income 	<ul style="list-style-type: none"> - <u>Mission fit</u> important for PC establishment - <u>Residency program did not impact PC access</u> - <u>Household income may be impactful in focus of hospital</u> (i.e., higher income, focused on profit-generating services)
Developing a financially feasible, mission-focused approach to serious illness care that was impactful for patients and	<ul style="list-style-type: none"> - Clinician champions - Supportive administration - PCLC education prior to implementation - 100% hospital-funded PC 	<ul style="list-style-type: none"> - None 	<ul style="list-style-type: none"> - N/A 	<ul style="list-style-type: none"> - PC was developed through <u>initial education and supportive administration and clinician champions</u>

families (Hospitals with PC)	- PC model changes			- <u>Hospital without PC</u> did not have serious illness care but <u>utilized hospice</u> as needed
Limited approach to serious illness (Hospitals without PC)	- N/A	- None	- Hospitalists' goals of care conversations - "All hospitalists perform palliative care" - Utilization of hospice partnership for inpatient EOL care - Hospital D performed "their version" of PC	
Changing perceptions about serious illness and palliative care through trust and education (Hospitals with PC)	- "Buy-in" through education and "seeing" palliative care - Hospitalists and intensivists were the biggest supporters of PC as reflected through the number of PC referrals	- None	- N/A	- A <u>differing understanding</u> of palliative care existed - <u>EOL and goals of care</u> were important to <u>hospitals without PC</u>

Limited perceptions about serious illness care (Hospitals without PC)	- N/A	- None	<ul style="list-style-type: none"> - Goals of care conversations were the area of serious illness care - Hospital C focused more on EOL, while Hospital D focused on symptoms management; however, hospice was their serious illness service
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Developing a Mindset Towards Serious Illness Care. Administration at hospitals with palliative care were supportive of the initial development of palliative care with the focus being towards mission fit for the community members, despite the challenges of funding. Participants at hospitals without palliative care reflected on the need to assess the community for needs related to new services and focused on surgical and mother/baby services.

Hospitals with palliative care had access within the entire catchment area to community hospice and home health but had limited access to community palliative care. Community hospice, home health, and palliative care were available within the catchment areas of both hospitals without palliative care and were a utilized resource for inpatient and outpatient care. All hospitals had a residency program that was ACGME approved, though hospitals with palliative care did have residency education sessions on palliative care.

All hospitals had admitting diagnoses that focused on chronic illness, despite the focus of for-profit hospitals on more profitable services (based upon the qualitative interviews).

The median household income was higher than the Alabama average in the catchment areas of both hospitals without palliative care, while the hospitals with palliative care had a lower than average median household income. Based on the qualitative interviews, the higher household income in hospitals without palliative care may be supported by the focus on more profitable services that were offered.

Approach to Serious Illness Care. Two separate subthemes emerged when comparing hospitals with and without palliative care, and there were no similarities, but instead areas of divergence, in how serious illness care was provided at the hospitals. At hospitals with palliative care, clinician champions were the driving force behind implementation, along with supportive administrators. The model of delivery and the care team members had shifted over the years due to funding. Currently, programs at both hospitals are funded 100% through the hospital.

Hospitalists or the admitting physician at hospitals without palliative care were charged with having goals of care conversations with patients and families upon admission. Hospitals without palliative care partnered with local hospice agencies to provide inpatient care or utilized hospitalists to manage symptoms for patients with serious illness.

Perceptions About Serious Illness Care. Two separate subthemes emerged when comparing hospitals with and without palliative care. Again, there were no similarities, but instead areas of divergence, related to the perceptions of how serious illness care is provided at the hospitals. Hospitals with palliative care had to grow “buy-in” to the program through education with the board of directors and clinicians, though some hesitancy still exists. Hospitals with palliative care programs received the majority of consults from hospitalists or intensivists/pulmonary care physicians.

Participants at hospitals without palliative care had varying views on the timing and role of palliative care. Both hospitals felt that goals of care conversations were

important, while participants at Hospital C focused on end of life and those at Hospital D focused on symptom management.

Commonalities and Differences in Theme Two

This section includes commonalities and differences among the subthemes of theme two for hospitals with and without palliative care: (a) basics of providing care, (b) building trust and relationships among clinicians, (c) leadership support, (d) clinician training, and (e) communication. Table 73 provides an overview and meta inferences related to Theme Two.

Table 73

Graphic Organizer for Cross-Case Comparison: Theme Two

Subthemes	Hospitals with PC	Areas of Similarities	Hospitals Without PC	Meta Inferences
Basics of providing care	<ul style="list-style-type: none"> - Intensivist and hospitalist made referrals - Triggers were not utilized, but symptom assessment and rounding were used for referral to PC 	<ul style="list-style-type: none"> - Comfort care policies existed at all hospitals 	<ul style="list-style-type: none"> - Hospitalists and case management made outpatient referrals as needed 	<ul style="list-style-type: none"> - <u>Policies were in place at all hospitals</u> - Hospitalist/Intensivists were required to consult other services
Building trust and relationships among clinicians and the palliative care team (Hospitals with PC)	<ul style="list-style-type: none"> - Multidisciplinary rounding included the entire care team (including PC) - Reflections on the relationships and trust that were built increased the use of PC 	<ul style="list-style-type: none"> - None 	<ul style="list-style-type: none"> - N/A 	<ul style="list-style-type: none"> - Hospitals with PC felt that <u>rounding was important to meet the needs of the patients and families</u> with a focus on connecting to services - PC became a trusted voice that was present during meeting through the establishment of trust
Building trust and relationships	<ul style="list-style-type: none"> - N/A 	<ul style="list-style-type: none"> - None 	<ul style="list-style-type: none"> - Rounding focused on 	<ul style="list-style-type: none"> - Hospitals <u>without PC</u> were focused on <u>care</u>

among clinicians (Hospitals without PC)			discharge planning - A limited care team was included within the daily rounds - - Leadership support was limited for serious illness care	<u>coordination</u> for the patient outside of the hospital - Leadership support was a <u>key factor in initiating PC</u> and will likely be a <u>factor with changes in leadership</u>
Empowerment through leadership support of serious illness care	- Administration supported PC through program implementation, funding, and education - Changes in leadership could potentially impact support of PC or require changes in the model -	- Variety of leadership styles existed		
The importance of clinician training when providing serious illness care (Hospitals with PC)	- Serious illness training was mandatory for all staff during orientation; critical care staff had additional training	- None	- N/A	- Serious illness <u>training</u> <u>was a priority for</u> <u>hospitals with PC</u> - Serious illness education was not a priority for hospitals <u>without PC</u> ; <u>instead, the focus was on</u>

	<ul style="list-style-type: none"> - Hospital A required continuing serious illness training for critical care nurses that was linked to annual evaluations - Required annual training had a narrower focus at Hospital D (not including annual computer-based training modules) 			<u>“basics of care” and accreditation standards</u>
Limited clinician training in serious illness care despite the need (Hospitals without PC)	- N/A	- None	<ul style="list-style-type: none"> - Serious illness care education was not required, nor offered by the hospitals - Outside agencies would conduct serious illness care education - Staff were uncomfortable in managing 	

				seriously ill patients at Hospital C	
Multidisciplinary communication focused on patient- centered care (Hospital with PC)	- Critical daily conversations on the day-to-day patient care while also looking forward into future needs	- None	- N/A		- The focus on the communication was different among hospitals with and without PC - Understanding the <u>patient's and family's current and future needs</u> <u>is</u> important in providing serious illness care
Hospital-focused community (Hospitals without PC)	- N/A	- None	- Hospital focused and looking towards the future rather than focused on current needs		

Basics of Providing Care. Policy use was limited at all hospitals, though comfort care orders were available. Hospitals with palliative care did not use triggers, but typically felt clinicians were aware when a consult was needed. Hospitals without palliative care relied on physicians or case management to request consults within or outside of the hospital.

Building Trust and Relationships Among Clinicians. Multidisciplinary rounding was utilized within all hospitals, though the models were different between hospitals with and without palliative care. The rounding team at hospitals with palliative care included the intensivists, nurses, dietary, case management, therapy services, and palliative care. Palliative care teams at both hospitals felt this helped to build trusting relationships with the care team and may have assisted in early consults for patients with serious illness. The rounding model that hospitals without palliative care utilized was led by case management staff and included nurses, pharmacy, dietary, and therapy services.

Leadership Support. All hospitals had a variety of staff leadership styles. Participants at all hospitals felt that their leadership team was supportive and offered transparency. Additionally, leadership at all hospitals was engaged and interactive with staff through rounding or staff councils.

Clinician Training. Orientation at hospitals with palliative care offered specific training related to caring for patients with serious illness. Orientation at hospitals without palliative care focused on basics of care and documentation and did not provide training

specifically on caring for patients with serious illness. Voluntary serious illness care training, though limited, was available at all four hospitals. Interestingly, serious illness care training at one hospital with palliative care was a portion of critical care nurses' annual evaluation.

Communication. Hospitals with palliative care utilized the palliative care team to have goals of care conversations with patients and families; however, some intensivists and critical care nursing staff felt empowered to have these conversations as well. Hospitals without palliative care utilized hospitalists or the admitting physician for goals of care conversations; occasionally a member from the case management team would have these conversations. All hospitals had multiple avenues for communication with staff and gaining an understanding of staff needs.

Commonalities and Differences in Theme Three

This section includes commonalities and differences among subthemes for theme three for hospitals with and without palliative care: (a) developing a mindset towards serious illness care, (b) developing an approach to serious illness care, and (c) perceptions about serious illness care. Table 74 provides an overview and meta inferences related to Theme Three.

Table 74

Graphic Organizer for Cross-Case Comparison: Theme Three

Subthemes	Hospitals with PC	Areas of Similarities	Hospitals Without PC	Meta Inferences
Focus on patient-centered care (Hospitals with PC)	- PC for all serious illness	- None	- Did not have comments related to this subtheme	- <u>Focused on serious illness at any stage in the disease trajectory</u>
Palliative care closing a gap in fulfilling a need for patients with serious illness (Hospitals with PC)	- Intensivists and multidisciplinary rounding helped to connect patients with PC to meet needs	- None	- N/A	- Hospitals with PC focused on inpatient and outpatient care services - Hospitals without PC focused on discharge plans and outpatient resources
Fulfilling a need for patients with serious illness utilizing hospice (Hospitals without PC)	- N/A	- None	- Case management rounding was focused on discharge planning	
Limitations to providing serious illness or palliative	- Lack of program funding - Staffing challenges	- Staffing challenges	- N/A	- Funding was not a topic of discussion for

care (Hospitals with PC)

- Hesitation with use of PC (generational and others that wanted to care for “their patients”)

Limitations to providing serious illness care (Hospitals without PC)

- N/A

- Staffing challenges

- PC programs were not discussed; therefore, funding was not discussed
- Staffing, leadership changes, and infrastructure were limitations

hospitals without PC since it was not on their “radar”

- Staffing was a challenge for all hospitals

Focus on Patient-Centered Care. Participants at hospitals with palliative care expressed that palliative care allowed patients with a wide range of illnesses and their families to have their needs met. Participants from hospitals without palliative care did not have any comments that specifically focused on patient-centered care.

Fulfilling a Need for Patients With Serious Illness. Intensivists' services within ICUs at hospitals with palliative care impacted the care that was received by patients with serious illness. At hospitals without palliative care, case management was utilized for connecting patients to needed services.

Limitations to Providing Serious Illness Care. Participants at all hospitals reflected on the challenges in providing serious illness care due to the continued staffing shortage, especially within nursing staff. Hospitals with palliative care reflected on the lack of funding, which required changes in the model of palliative care within each hospital.

Key Findings From the Cross-Case Analysis

The cross-case analysis revealed areas of similarities and areas of divergence among all cases. The following areas were important findings related to serious illness and palliative care within Alabama hospitals:

- Hospitals with palliative care delivered care via an interdisciplinary palliative care team (though they were limited in staffing), whereas hospitals without palliative care delivered serious illness care that focused on end-of-life care through

partnerships with local hospice agencies and through symptom management by hospitalists

- Hospitals with palliative care had a lower household income and focused on community and mission fit, while hospitals without palliative care had higher household income and verbalized a focus on more profitable services that met the community's needs
- Palliative care champion clinicians and supportive administration were a common finding that distinguished between hospitals with and without palliative care
- Community palliative care services were available in the catchment areas of Hospitals C and D but not in the catchment areas of Hospitals A and B
- Hospitals with a palliative care program noted a generational difference in physician buy-in and timely consults to palliative care; frequently younger physicians would consult earlier and more frequently when compared to physicians with longer practice histories
- Multidisciplinary rounding occurred at hospitals with palliative care and included the intensivists and palliative care team, while hospitals without palliative care were focused on discharge planning and rounding did not include the entire care team, though there were differences among the goals and disciplines in attendance
- Serious illness training was provided during orientation and on a voluntary basis at hospitals with a palliative care program, while voluntary offerings at hospitals without palliative care were limited and only offered by outside agencies

- All hospitals discussed the knowledge deficit and stigma associated with palliative care, which often created hesitancy and delayed consults to palliative care or referrals to community services
- Participants at hospitals with palliative care spoke on the challenges of limited reimbursement for palliative care consults, though they felt the service improved the quality of patient care
- All hospitals reported challenges with staffing that impacted the hospitals' ability to extend or begin hospital services

Chapter 4 Summary

The four hospitals presented in this study offered a comparison of cases to explore how serious illness care is provided to patients and families within Alabama. Hospitals that had a palliative care program served a larger geographic population that included rural counties, were nonprofit, and were larger than the two hospitals without palliative care. The driving force behind the initiation of palliative care at the two hospitals was clinician champions who worked with a supportive hospital administration, despite the limited opportunity for reimbursement. The two hospitals that did not have palliative care provided serious illness care to patients and families through hospitalists and partnerships with local hospice agencies. All hospitals used rounding, though hospitals with palliative care were focused on goals of care, assessment of needed services, and discharge planning with the entire care team; meanwhile, hospitals without palliative care focused on discharge planning and care coordination with a limited patient care team. However, the disciplines that were included in the rounds differed. Hospitals with palliative care

felt funding and reimbursement were the biggest barriers to implementation and sustaining palliative care. All hospitals expressed concern over the impact of staffing shortages on providing serious illness care for patients and families.

CHAPTER 5

CONCLUSIONS

Overview

The purpose of this mixed methods multiple case study was to develop a thorough description of access to palliative care in Alabama hospitals by integrating results related to environmental factors and hospital characteristics and processes from the quantitative and qualitative study aims. A total of four hospitals were selected for this study based on previously identified criteria. In the quantitative phase of the study, environmental factors were collected by the PI through publicly available sources, while the hospital descriptive data were collected using a paper survey that was provided to a hospital administrator. In the qualitative phase, the PI conducted interviews with staff members holding a variety of positions at each hospital and completed a document analysis. Three themes, or categories, emerged during the within- and cross-case analysis: (a) history and evolution of serious illness care, (b) providing patient-centered serious illness care, and (c) serious illness care impact.

Discussion

Palliative care access is limited in Alabama hospitals, despite the extensive care that is provided for patients with serious illness. According to the Center to Advance Palliative Care (CAPC, 2019a), Alabama was ranked a D in access to hospital palliative

care (with a scale of A being best, and F being the worst). This study explored the factors within four hospitals, two with a palliative care program and two without a palliative care program, to understand environmental factors and hospital characteristics and processes that may impact the presence or absence of hospital palliative care for seriously ill patients and their families. The significant findings of this study were presented within the structure and processes of the adapted conceptual framework for the Evaluation of Integrated Palliative Care Networks (Bainbridge et al., 2010; Donabedian, 1966).

Through the cross-case analysis environmental factors, hospital characteristics and processes emerged that are seen in hospitals with and without palliative care. These are described below.

Hospitals with palliative care were more likely to have (a) nonprofit tax status, (b) a greater number of staffed beds, (c) a smaller mean population size and lower socioeconomic status within their catchment area, (d) care for populations that reside in rural counties, (e) a CMS classification (i.e., sole community hospital or rural referral center), (f) administration that supported palliative care due to mission fit, (g) palliative care clinician champions, (h) critical care units staffed by intensivists, (i) multidisciplinary rounding that includes the entire care team, and (j) serious illness training for critical care staff.

Hospitals without palliative care were more likely to have (a) for-profit tax status, (b) a smaller number of staffed beds, (c) a larger population size and higher socioeconomic status within their catchment area, (d) smaller hospital-defined catchment areas, (e) hospice and end-of-life care within the hospital, (f) access to community palliative care, (g) a mission focus towards surgery and maternal/child services, (h)

hospitalists performing goals of care conversations, and (i) rounding using a case management and discharge planning focus.

Environmental Factors and Hospital Characteristics

Within this study, hospitals with palliative care were nonprofit, while hospitals without palliative care were for-profit. This finding is consistent with those of previous studies comparing palliative care access in nonprofit and for-profit hospitals (Dumanovsky et al., 2016; Rogers et al., 2020; Rogers et al., 2021). Similarly, for-profit hospitals were less likely to open and sustain a palliative care program (Rogers et al., 2021). Historically, for-profit hospitals have needed to provide evidence of profitability of services to continue to satisfy stakeholders' goals, which can be challenging when providing palliative care (May et al., 2018).

The need for a sustainable payment stream for palliative care may impact the initiation of palliative care within nonprofit and for-profit hospitals. A limitation that impacted hospitals with palliative care was related to funding and reimbursement challenges. This required consideration of grant funding and even changing models of care. Ultimately, for the two hospitals with palliative care, the benefit for the community and mission fit were seen as a greater impact than funding.

In previous studies, it was found that for-profit hospitals were more likely to focus on profitable services and more likely to close unprofitable services when compared to nonprofit and government-owned hospitals (Bayindir & Schreyogg, 2021; Horwitz & Nichols, 2022). Although both for-profit and nonprofit hospitals value profitable services (such as surgical services) more than unprofitable (such as palliative care), larger

nonprofit hospitals provide more unprofitable services when compared to smaller nonprofit hospitals (Bayindir, 2019). This may have been a factor in the decision to provide palliative care at the two nonprofit, larger hospitals included in this study. Hospitals with palliative care were the only hospitals offering palliative care within the catchment area, while hospitals without palliative care had multiple competing hospitals and multiple hospitals within the catchment area that offered palliative care. Lastly, Alabama has a greater percentage of for-profit hospitals (33.3%) when compared to U.S. hospitals as a whole (23.9%), which may impact access to palliative care (Kaiser Family Foundation, 2021).

Cost savings benefits from initiation and sustenance of hospital palliative care are difficult to demonstrate. Unless the financial aspects of providing palliative care are addressed, expansion in Alabama will be challenging. It is possible that nonprofit hospitals will recognize that palliative care is needed for optimal patient care, and this could result in maintenance or expansion of services regardless of potential cost savings.

The hospitals with palliative care had a greater quantity of staffed beds compared to hospitals without palliative care. This aligns with the literature, which indicated that hospitals with a larger numbers of beds are more likely to open and sustain a program than hospitals with fewer beds (Dumanovsky et al., 2016; Rogers et al., 2020; Rogers et al., 2021). It is important to note that hospital size (greater than 50 beds), tax status (nonprofit vs. for-profit), and geographic location (rural vs. urban) were important predictors of the existence of palliative care in previous studies (Dumanovsky et al., 2016; Rogers et al., 2020; Rogers et al., 2021). The hospitals with palliative care within this study reflected these characteristics of number of beds, nonprofit tax status, and

urban communities. However, it is interesting to note that the hospitals with palliative care provided care for patients who resided within rural communities based upon the hospital-defined catchment areas.

Hospitals with palliative care had a smaller mean population size (per hospital-defined catchment area) when compared to hospitals without palliative care. It would be expected that larger populations would increase the likelihood of specialty services, such as palliative care, though this was not found within this study. It is of note that the hospitals without palliative care were each one of multiple hospitals within their hospital-defined catchment areas, some of which did offer palliative care. In contrast, hospitals with palliative care had smaller, rural hospitals within their hospital-defined catchment area. One study found that nonprofit hospitals that operate in a catchment area with a high for-profit market often will operate more like for-profit hospitals, offering profitable services more frequently than unprofitable services (Bayindir & Schreyogg, 2021; Horwitz & Nichols, 2009). This may explain one factor in relation to the existence of palliative care within the nonprofit hospitals since they operated in a low for-profit market. Nevertheless, an association between access to palliative care and hospital availability was not identified in the literature.

Patients in the hospitals with palliative care had a lower socioeconomic status (as represented by the median household income) within their hospital-defined catchment area when compared to Alabama as a whole; in contrast, hospitals without palliative care had a higher socioeconomic status. One study supported the finding that palliative care exists in areas of lower socioeconomic status (Currow et al., 2012). Another study found that larger, nonprofit hospitals were more likely to address community needs and have

the financial, infrastructure, and human resources capital to support these needs (Noh et al., 2022). However, typically, lower socioeconomic status has resulted in decreased access to palliative care (Gardner et al., 2019; Hoerger et al., 2019; Nelson et al., 2021; Santos Salas et al., 2019). This may be related to hospitals without palliative care focusing on other more profitable services and serving a community with a higher socioeconomic status. This is an interesting finding when compared to current literature that should be explored further.

All hospitals had access to community home health and hospice in their hospital-defined catchment areas. Interestingly, hospitals with palliative care did not have access to community palliative care within the entire hospital-defined catchment area, while hospitals without palliative care did have this service available. Community services were often utilized as a discharge resource for patients and would occasionally provide care within the hospitals without palliative care. Use of community palliative care post-discharge has been associated with use of hospital palliative care for patients with serious illness (Webber et al., 2022). The use of community palliative care and hospice services has been associated with fewer hospital readmissions and emergency department visits (McCarroll et al., 2022; Saunders et al., 2019). It is unknown if there is an association between the availability of community palliative care and access to hospital palliative care; this may be a factor related to hospitals with a palliative care program covering a larger, rural catchment area than the hospitals without palliative care. Historically, access to community palliative care has been limited in rural communities, though some innovative interventions have been implemented to improve rural access (Bakitas, Elk, et al., 2015; Gaudet et al., 2014; Rogers et al., 2020). Since hospitals with palliative care

had a primarily rural catchment area, this is likely the reason for limited access to community palliative care.

Varying models of palliative care, including community palliative care, offer a continuation in care for patients with serious illness. Often inpatient palliative care is used for patients who may be acutely ill and require symptom management, while outpatient or community palliative care is used to manage mild to moderate symptoms and assist with coordination of services (Hui & Bruera, 2020). Having this resource assists in providing the continuation of care through serious illness to end of life with hospice.

The two hospitals with palliative care had Centers for Medicare and Medicaid Services (CMS) designation, while the two hospitals without palliative care did not have CMS classifications, though they did specialize in surgery and maternal/child services. The purpose of the Sole Community Provider (Hospital A) and the Rural Referral Center (Hospital B) classifications is to provide access to health services for patients residing in rural communities who may not have access to specialty services at their local rural hospital, while providing a financial incentive to the hospitals to offer those services (CMS, 2015). Typically, hospitals with CMS designations are operating in markets with better health outcomes, better financial conditions, and are more profitable when compared to rural hospitals without a designation (Thomas et al., 2017). Hospitals with Sole Community Provider status have been found to have palliative care services, though their adoption and closure rates are lower than those of nonprofit hospitals (Rogers et al., 2021). However, the geographic locations (urban) and the tax status (nonprofit) of the hospitals may also have played a role in palliative care availability.

Mission and Community Focus

Administrators at hospitals with palliative care felt strongly that palliative care supported the mission of the hospital and was a needed service for the community despite limited funding sources. Hospitals that are nonprofit, such as the two hospitals with palliative care within this study, are required to complete community assessments, implementing programs that benefit the community, though reimbursement may be limited. Evidence that nonprofit hospitals more frequently initiate palliative care when compared to for-profit hospitals is present in the literature; therefore, this finding within the study may support the increased likelihood of nonprofit hospitals having palliative care more frequently based upon community needs (Dumanovsky et al., 2016; Rogers et al., 2021; Rogers et al., 2021).

The funding support for the two palliative care hospitals differed at the start of their programs. One hospital utilized foundation and grant funding to continue the program. However, both hospitals were fully funded by their nonprofit hospitals at the time of this study. Sustainability of palliative care programs has been impacted by monetary inputs, in addition to workforce availability in relation to specialist training and education (Cassel, 2013; Roberts & Hurst, 2013). This particular program at one of the hospitals has been growing for the last 9 years with the support of the administration. Successful and sustainable hospital service programs require alignment of strategic goals and mission along with the capacity to provide the care (in infrastructure, staff, and resources) in addition to supportive leadership teams (Azevedo et al., 2021; Cowie et al., 2020). Although the hospitals with palliative care did reflect that the development of the program was “mission fit,” there were no strategic goals for the program, and it was

considered a “nice to have” service. These factors likely played a role in the implementation and sustainability of these two programs thus far.

Nonprofit hospitals have a charge to support community needs through community assessments every 3 years and to invest their profits back into the identified needs of the population they serve (Internal Revenue Service, 2021; Noh et al., 2022; Rapfogel & Gee, 2019). The nonprofit hospitals choose how much to spend on community benefits in relation to program planning or activities, though nationally the contributions vary widely (Rapfogel & Gee, 2019). As noted by administrators at hospitals with palliative care, these programs fit both the mission of the hospital and the needs of the community. Administrators at hospitals without palliative care had a focus towards surgeries and maternal/child services, although funding challenges could have been a deterrent to initiating a palliative care service, and infrastructure limitations and staffing limitations were also reported. However, one hospital without palliative care stated that palliative care did not exist because administration or clinicians did not consider it as a need. Meanwhile, the other hospital without palliative care felt that “all hospitalists could perform palliative care” and did so through goals of care conversations, though limited discussions about disease progression were provided by hospitalists or other staff; therefore, it was truly conversations that reflected palliative care. Another challenge was the varying beliefs in care, as some felt that palliative care and hospice were the same while others felt that palliative care was more supportive. Numerous studies have shown hesitancy with the use of palliative care due to the confusion with hospice and end-of-life care (Beasley et al., 2019; Flieger, Chui, & Koch-Weser, 2020; Zimmermann et al., 2014). While both for-profit and nonprofit hospitals have a mission

to address community needs, for-profit hospitals must satisfy investors as well (Cheney, 2019). As previously discussed, for-profit hospitals will often opt for more profitable programs, such as surgery, when compared to nonprofit hospitals (Horwitz & Nichols, 2022).

Clinician Champions and Supportive Administration

Hospitals with palliative care had champion clinicians and supportive administration for instituting palliative care. Champions and supportive leadership have been shown to garner support for the initiation of new hospital services, including palliative care (Cowie et al., 2020; Johnson et al., 2019; Shoemaker & McInnes, 2022), whereas less support from administration and hospital leaders (such as champions) may negatively impact the sustainability and buy-in to new hospital services (Geerligs et al., 2018). Participants at hospitals with palliative care reflected on the impact of training by administrators and clinician champions attending CAPC's Palliative Care Leadership Center (PCLC) training. The training and mentorship that is provided allowed for 80% of participating hospitals to establish a program within 2 years of attendance (Cassel et al., 2018).

Though hospitals with palliative care had supportive leadership from the initiation of the program, leadership changes impacted the palliative care model at one hospital due to funding. Therefore, consideration should be given to sustaining programs through the support of administration.

One hospital with palliative care faced hesitation at the start of the palliative care program by some physicians due to the lack of board certification of the palliative care

medical director. Though the model has changed to a nurse practitioner-led program and the nurse practitioner is board certified, hesitation of some physicians remains due to the lack of a palliative care physician represented within the program. The other palliative care hospital has maintained a board-certified medical director throughout the existence of the program and did not experience this same hesitation.

Meanwhile, hospitalists at hospitals without palliative care performed goals of care conversations and managed symptoms on a case-by-case basis, with hospice GIP occurring if patients met the inpatient hospice criteria. Participants at hospitals without palliative care felt that this was sufficient serious illness care. Though physicians and other clinicians have the ability to perform components of palliative care, many do not have palliative training to address certain issues for patients with serious illness and their families, such as symptom management and psychosocial support (Hughes & Smith, 2014). Due to the limited availability of trained palliative care specialists, primary palliative care may be necessary as the U.S. population continues to age, living longer with serious illness (Hughes & Smith, 2014; Meier et al., 2017).

Intensivists

Hospitals with palliative care utilized intensivists in the critical care units, whereas hospitals without palliative care utilized hospitalists or admitting physicians to manage patient care within the critical care units. The use of intensivists has been found in larger, urban, and nonprofit hospitals, though hospitals located within competitive markets had increased incidence as well (Liddle et al., 2022). Clinicians at hospitals with palliative care felt that the intensivists allowed for open communication related to

patients' wishes and requests for palliative care. One study found that the use of intensivists within the critical care unit reduced hospital mortality and ICU length of stay for patients with advanced lung cancer (Song et al., 2019). Fewer than 20% of U.S. hospitals have intensivists within the critical care units, despite evidence of improved outcomes such as reduced mortality rates and hospital lengths of stay (American Hospital Association, n.d.; Society of Critical Care Medicine, 2021).

Participants at hospitals with palliative care reported that intensivists increased the rate of referral, often had basic palliative care training during medical school, and were believers in the use of palliative care. Though intensivists at one hospital with palliative care were not supporters initially, participants at both hospitals reflected on the belief that intensivists have in palliative care and the support it brings to patients. Though evidence is limited on the association between palliative care use and intensivist presence in the critical care units, it appears that the intensivists at the hospitals with palliative care were considered champions for the services that were provided. The use of champions to bridge the gap between the palliative care team and staff is important in promoting high-quality palliative care and growth in use of this service (Kamal et al., 2019).

Multidisciplinary Rounding

Multidisciplinary rounding was employed at all the hospitals; however, the rounding models were different between hospitals with and without palliative care. Hospitals with palliative care took a holistic approach to rounding that included care coordination, goals of care reviews, progress of the patient, and addressing spiritual or psychosocial needs. The time spent rounding allowed time for patients and families to be

informed of progress as well. Rounding in hospitals without palliative care focused on discharge planning and goals of care reviews that were addressed by case management. The disciplines that attended varied between hospitals with and without palliative care. All hospitals included staff nurses, case management, unit nurse managers, therapy services, pharmacy, and dietary services. The hospitals with palliative care also included intensivists and chaplains, in addition to a member of the palliative care team. Multidisciplinary rounding has been found to be an effective method of communication, though some disciplines may experience the processes differently (Lui et al., 2021; Walton et al., 2019). The presence of palliative care staff was preferred to the use of triggers to prompt palliative care referrals and allowed critical care teams to build trust and relationships with the palliative care staff (McDarby & Carpenter, 2019; Stey et al., 2020; Wysham et al., 2017).

Palliative and Serious Illness Care Training

Palliative and serious illness care training differed across the hospitals with and without palliative care. Hospitals with palliative care provided mandatory palliative care education for critical care nurses, and one hospital with palliative care provided additional palliative care training to critical care staff that was directly linked to annual evaluations. Hospitals without palliative care provided advanced care planning training and utilized hospice agencies to provide training on caring for patients at end of life, though this training was limited and clinicians requested additional education on caring for patients with serious illness. Palliative care education is important in increasing access for patients with serious illness and their families. While some clinicians receive

education in their professional programs, a gap remains in understanding and providing primary palliative care services (Meier et al., 2017; Vaughn and Salas, 2022). As discussed previously, it is important to educate all clinicians on providing primary palliative care to support the growing population with serious illness, especially in light of the lack of trained specialist palliative care clinicians (Hall et al., 2016; McDarby & Carpenter, 2019; Spetz et al., 2016).

All hospitals had limited to no knowledge of the National Consensus Project Guidelines for Quality Palliative Care. One hospital even felt a limitation to the growth of palliative care was a lack of metrics to measure their palliative care program against, though these guidelines could have served in that capacity. Education is needed to increase the knowledge of these guidelines when establishing and sustaining a palliative care program.

Implications and Recommendations

This study provided a better understanding of the environmental factors and hospital structures and processes between hospitals with and without palliative care programs. The integration of quantitative and qualitative findings allowed for the development of meta inferences in understanding factors that may impact access to palliative care within hospitals. Although this study adds to the literature in understanding factors that impact access to hospital palliative care in Alabama, implications were identified during this study that could inform clinical practice, future research, and policy.

Clinical Practice

This study highlighted the importance of palliative care clinician champions, multidisciplinary rounding in building trust among the care team, and palliative care education as core factors of hospital palliative care. Though research is limited on the impact of clinician champions for palliative care, these clinicians often act as a bridge to building trust for the palliative care team. It is important for leadership in critical care units to consider developing palliative care champions who may assist in increasing palliative care referrals for patients with serious illness. Multidisciplinary rounding with the care team that included intensivists and palliative care clinicians helped to develop relationships and increased referrals to palliative care. Additionally, an established interdisciplinary communication process allows for better patient outcomes. Lastly, palliative care education is important for all care team members. As the Baby Boomer population continues to age, it will be necessary for clinicians to be confident in providing primary palliative care, which may include difficult conversations or management of symptoms. This will allow specialty palliative care to become accessible for patients and families with more complex needs.

Future Research

While this study provided a better understanding of factors that impact access to hospital palliative care in Alabama, additional studies are needed to further assess these factors and the impact on access. The study supported previous evidence that palliative care is implemented and sustained more frequently in nonprofit, urban hospitals (Dumanovsky et al., 2016; Rogers et al., 2020; Rogers et al., 2021). Previous studies have

not fully addressed the impact of clinician champions on the development and sustenance of hospital palliative care or offered comparison among states that have readily accessible hospital palliative care (i.e., CAPC rating of an A) versus states that do not (i.e., CAPC rating of a D or F), such as Alabama (CAPC, 2019).

In this study, palliative care impetus was influenced by clinician champions, who were able to obtain buy-in from hospital administrators to attend additional training and in turn were able to build and sustain a palliative care program. Current research is limited in understanding palliative care clinician champions as the catalyst to organizational buy-in and development of palliative care.

This study was limited to four hospitals within Alabama (whose hospital palliative care access is limited). Further research is needed that would allow comparisons among hospitals with and without palliative care between states with readily accessible palliative care versus states that have limited palliative care. This would allow further evaluation of factors and conditions that need to be present to establish hospital palliative care.

Policy

This study yielded policy implications, including the need for primary palliative care education among clinicians within their professional educational programs and the need for changes to the current fee-for-service payment system for palliative care.

Although palliative care education has improved within professional educational programs, a lack of awareness of palliative care remains, and the ability to provide primary palliative care is limited. Currently, there is no national framework for formal

palliative care education within nationally accredited educational programs for physicians, nurses, or social workers. National hospice and palliative care organizations should consider lobbying for university-accrediting bodies to require this basic education.

In 1982, the Centers for Medicare and Medicaid (CMS) established a hospice payment stream that has allowed access to hospice services for patients with a terminal illness within the last 6 months of life. Currently, a fee-for-service payment stream is available for non-hospice palliative care and typically does not provide enough funding to cover an interdisciplinary palliative care team's salary. Therefore, a new payment stream similar to that of the hospice payment model should be considered. This would allow for increased access to palliative care within hospitals, outpatient facilities, and the community in which the patient resides.

Limitations and Strengths

This section identifies limitations and strengths of the study.

Limitations

As with any research study, this one is not without its limitations. This study of four Alabama hospitals has limitations that should be considered when interpreting the findings. The hospitals initially selected fit the intended characteristics: (a) palliative care versus no palliative care, (b) rural versus urban location, (c) nonprofit versus for-profit, and (d) small versus large number of beds. Unfortunately, rurality could not be assessed within the study, due to the limited number of hospitals with palliative care in Alabama and the inability of the only rural hospital with palliative care to opt into the study.

However, the participating hospitals with palliative care did include rural counties within the hospital-defined rural catchment area.

Secondly, the study was not conducted pre-COVID as initially planned. Therefore, the impressions presented within the quantitative hospital survey and qualitative interviews are post-COVID impressions. The impact of COVID on hospitals and staff has been documented in relation to both burnout and patient experience (Koontalay et al., 2021). During the interviews, participants spoke of the impact on care that COVID created within the hospital. Therefore, this may have impacted their view of palliative or serious illness care within their hospital.

The homogeneity of the hospital participants presented a limitation in the study; perspectives may have been different with a more heterogeneous participant pool. Additionally, the participants and those who provided care do not reflect the patient population that they are likely caring for within the hospitals. Therefore, this should be taken into consideration when reviewing the study findings and planning future studies.

The survey that was utilized for this study was adapted from a widely used Center to Advance Palliative Care survey and was pilot tested; it did come with the limitation of being a self-reported survey by hospital administrators. This should be taken into consideration when looking at the overall results of the descriptions and statistics of each hospital.

Lastly, potential for bias exists within the qualitative interviews and document analysis in the collection, analysis, and interpretation of the results. Strategies that were utilized to reduce research bias in the qualitative portion of the study included the use of field notes and member checking. The PI made field notes during interviews and utilized

memoing during review of the transcripts. Additionally, the PI used member checking to verbally confirm the understanding of participants' perspectives at the completion of the interviews; the PI also emailed a summary to interview participants at each hospital to ask for feedback on the description of hospital palliative care. An email or verbal response was received from each administrator who participated, though feedback from clinician leaders and frontline clinicians varied. This should be taken into consideration when interpreting these results.

Strengths

Though limitations exist within this mixed methods study, to our knowledge, this is the first study to assess environmental factors, structures, and processes associated with hospitals with and without palliative care within Alabama. The study team included a diverse group of experts in palliative care, health services research, and mixed methods research who assisted in development of the study procedures and interpretation of results.

The use of a mixed methods multiple case study offered a novel and comprehensive approach to assessing factors that impact hospital palliative care access within Alabama hospitals. The use of this method provided multiple comparisons of environmental characteristics, structures, and processes of care among multiple hospitals. To our knowledge, this is the first study to utilize this methodology in palliative care access research. The inclusion of more than one hospital and comparison of hospitals with and without palliative care offered opportunities for comparison among different characteristics and processes that impact palliative care within Alabama hospitals.

An in-depth description of serious illness care was obtained through qualitative interviews of diverse representation of hospital administrators, clinician leaders, and frontline clinicians at each hospital. Additionally, data collection and analysis occurred for each hospital. The multiple perspectives allowed for a thorough and in-depth understanding of palliative and serious illness care within Alabama hospitals.

Chapter 5 Summary

The aim of this study was to explore the environmental factors, structures, and processes that are present in hospitals with and without palliative care. The environmental factors, such as socioeconomic status, and hospital structures, such as tax status, support the findings of previous literature on hospital palliative care. Palliative care champions, mission fit, intensivists, and multidisciplinary rounding have all been shown within this study to impact palliative care existence and practice in Alabama hospitals.

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APPENDIX A
LITERATURE MATRIX

Literature Matrix

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Bakitas et al. (2009)	U.S.	Quant	Telehealth	<ul style="list-style-type: none"> improved QOL, symptoms, and mood in advanced cancer patients
Bakitas, Tosteson, et al. (2015)	U.S.	Quant	Telehealth	<ul style="list-style-type: none"> improved survival for early admission for patients with advanced cancer
Butler & O'Brien (2018)	New Zealand	Quant	Community based	<ul style="list-style-type: none"> those with mental health are less likely to receive timely palliative care services
Bowman et al. (2019)	U.S.	Qual	Community based	<ul style="list-style-type: none"> difficulty keeping IDT due to funding differ in understanding of palliative care, education offered, and resources available understanding clinical quality unknown difficulty due to limited funding with current payment models; limited staffing due to this different staffing needs in home-care compared to hospital staffing
Brant et al. (2019)	Global	Quant	Various	<ul style="list-style-type: none"> lack of trained providers community awareness lacking: lack of time, funding, and availability were barriers to education satisfaction with pc varied, symptom management and communication funding is a barrier on continuing pc services policy changes can be challenging as well as access in general

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Brazil et al. (2009)	Canada	MMR	Not specified	<ul style="list-style-type: none"> • barriers to palliative care: language, transportation; psych and social support lacking • more community outreach needed
Cahill et al. (2020)	Australia	Qual	Hospital	<ul style="list-style-type: none"> • themes that were identified included: a patient-set agenda giving the patient a voice, patient-set agenda enhanced an understanding of what issues were most important, having a set meeting model was helpful for patients and families, and the medical team didn't always see the meeting model as appropriate for all patients (such as those with complex health issues or family dynamics)
Castleden et al. (2010)	Canada	Qual	Various	<ul style="list-style-type: none"> • lack of awareness among vulnerable populations and different cultures; cultural training will be important • culture plays a role in the use of pc
Ceronsky et al. (2013)	U.S.	MMR	Community based	<ul style="list-style-type: none"> • collaboration of other community providers; difficulty with recruiting and keeping pc specialist • education needed among community • challenge with funding; fee for service model not appropriate; external resources and support are needed for success • educational intervention • recommends to redesign care delivery

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Cotterell et al. (2007)	UK	Qual	Hospital	<div>362</div> <ul style="list-style-type: none"> • providers wanted to make a difference in the life of patient and peers • nurses work to educate others • focus on patient-oriented care • increased nursing skills impacted patient care • time and dissemination issues with influencing palliative care
Crooks et al. (2018)	Canada	Qual	Not specified	<ul style="list-style-type: none"> • lack of community awareness of palliative care • locally developed educational tools and training sessions are more successful
Currow et al. (2012)	Australia	Quant	Various	<ul style="list-style-type: none"> • high socioeconomic status: less palliative care (differing results compared to other studies)
Dionne-Odom et al. (2021)	U.S.	Quant	Telehealth	<ul style="list-style-type: none"> • caregiver needs vary widely • common problems included managing the patients' condition/symptoms, work, time for patients' ADLs, coordinating services, and future planning
Dionne-Odom et al. (2019)	U.S.	Qual	Not specified	<ul style="list-style-type: none"> • caregivers are often involved in decision making such as treatment options, "what if" scenarios, facilitate shared-decision making and illness discussions
Dionne-Odom et al. (2015)	U.S.	Quant	Telehealth	<ul style="list-style-type: none"> • decreased stress burden and lower depression scores for caregivers with early palliative care
Dudley et al. (2019)	U.S.	Qual	Various	<ul style="list-style-type: none"> • lack of palliative care specialists • lack of familiarity with palliative care by primary care providers • increased community may help to improve uptake

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Dumanovsky et al. (2016)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • larger hospitals the more likely to have palliative care • non-profit and public hospitals were more likely to have palliative care compared to for-profit hospitals
Fink et al. (2013)	U.S.	MMR	Hospital	<ul style="list-style-type: none"> • providers are more familiar with the term of palliative care • education provided annually; need additional education; communication with families and patients • lack of palliative care policies & procedures; consider work with larger urban hospitals for training and policies • effective transitions of care, pain and symptom management, advance directive • personalized attention due to small hospital size
Gardner et al. (2019)	U.S.	Qual	Community based	<ul style="list-style-type: none"> • few had utilized pc services despite unmet needs surrounding symptoms burden • barriers that were identified included lack of familiarity with pc, limited access, and financial concerns
Gaudet et al. (2014)	Canada	Qual	Community based	<ul style="list-style-type: none"> • good lines of communication are necessary; may rely on too much informal communication; autonomy is beneficial; ongoing work relationships help to improve use • understanding the role of the provider will assist with uptake • the goals of providers are shared (improve QOL for patient)

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Glasgow et al. (2019)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • limited funding and staff stretched thin trying to fulfill many roles • advocate for resources for the community • hospital pc consultation continues to be associated with reduced hospitalization charges • this study found that improvements were seen related to value-based reimbursement outcomes; seen through reduced hospital readmissions
Goldsmith et al. (2008)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • palliative care is significantly correlated to lower Medicare hospital death rates, fewer ICU/CCU days per participant in the last 6 months of life
Greer et al. (2016)	U.S.	Quant	Various	<ul style="list-style-type: none"> • cost less per day with patient on early palliative care compared to those admitted later in the disease trajectory • Palliative care doesn't increase costs
Hall et al. (2016)	U.S.	Qual	Various	<ul style="list-style-type: none"> • interdisciplinary team is important part of the team; some primary providers felt they could provide the care • integration of palliative care is important • funding available for palliative care physicians • consider "standing orders" to increase use of palliative care services
Heitner et al. (2021)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • early referral to pc was through referral criteria or guidelines for triggers for referral to pc

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
				<ul style="list-style-type: none"> • however, using the referral criteria would yield patients that were not a “good fit” for services • recommendations were made to create the referral criteria as a team effort between the hospital staff and pc team
Higginson et al. (2014)	UK	Quant	Not specified	<ul style="list-style-type: none"> • improved symptom burden and QOL, decreased resource use and lower costs • benefits begin to be seen at 6 weeks
Hoerger et al. (2019)	U.S.	Quant	Not specified	<ul style="list-style-type: none"> • increased access to palliative care in states with older population, increased socioeconomic status, white (less racially diverse), politically liberal
Horton et al. (2016)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • hospitals with pc programs were more likely to be “higher” volume (increased number of Medicare discharges), more likely to be an ACGME member, nonprofit, and have oncology services. • hospitals less likely to have pc programs were hospitals located within southern states, rural areas, or be sole community providers
Hua et al. (2018)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • hospitals with and without pc programs showed to have similar length of stays for patients • patients in hospital with pc programs were more likely to be discharged to hospice
Hui et al. (2018)	Global	Delphi	Outpatient	<ul style="list-style-type: none"> • automatic referral with predefined criteria may be

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Jansky et al. (2019)	Germany	Qual	Not specified	<ul style="list-style-type: none"> beneficial for collaboration and pt. coordination of care cultural differences (migrant status), legal status, distrust of medical community, and language barriers were common barriers for palliative care uptake
Jeyasingam (2008)		Quant	Hospital	<ul style="list-style-type: none"> caregivers may have more unmet than patients screening for unmet needs should be completed with any inpatient admission
Johnson et al. (2011)	Australia	Qual	Hospital	<ul style="list-style-type: none"> collaboration with other providers in the community created positive relationships and increased referrals lack of knowledge of palliative care among community and providers; lack of hope and forgoing active treatment related to decreased use maximizing quality of life "sell" using symptom management; holistic care; earlier referral offered better benefits cultural barriers and mistrust decreased usage in some populations
Kamal et al. (2019)	-	-	-	<ul style="list-style-type: none"> specialty pc workforce shortage remains a concern for caring for an aging population consideration must be given to training for non-palliative care specialists to provide pc services, such as goals of care conversations consider these palliative care champions that stand between

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Kavalieratos et al. (2014)	U.S.	Qual	Various	<ul style="list-style-type: none"> the clinical care and palliative care specialists building trust and rapport is important for palliative care referrals; CHF unpredictable knowledge gap among cardiologists
Keim-Malpass et al. (2015)	U.S.	Qual	Various	<ul style="list-style-type: none"> coordination of care was challenging due to scheduling rural patients often driving long distances and need visits on the same days common community misconceptions of palliative care trigger points for palliative care referral are not clear demand for services exceeded supply, which makes initial visits challenging
Kelley et al. (2011)	Canada	Qual	Not specified	<ul style="list-style-type: none"> staffing was a difficult piece for those establishing palliative care communities that had begun palliative care had a greater commitment to collaboration, community empowerment, and obtaining resources local team works better; however, physician involvement from a distance would work innovative models of care are needed; take risks for the better of the care funding was a large barrier for those trying to start programs communities that had not established palliative care

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
				<p>were more likely to see barriers</p> <ul style="list-style-type: none"> • antecedents for palliative care establishment include infrastructure, vision for change, promotion of collaborating practice and enhancing comm empowerment; innovative models of care are needed; take risks for the better of the care
Kilaru et. al. (2015)	U.S.	Quant	Not specified	<ul style="list-style-type: none"> • this study assessed if HSAs or HRRs defined where patients would receive care; these areas vary in the ability to predict where care will occur • less movement occurred within HRR boundaries as compared to HSA boundaries • patients living in populous, urban HSAs with multiple large hospitals often remained for inpatient care
Lancaster et al. (2018)	England	MMR	Hospital	<ul style="list-style-type: none"> • 24/7 call varies among providers, not all had pain mgt or specialist palliative care available • variation in education provided, some formal education and other occasional education days • limited correlation between palliative care needs and allocated budget
May et al. (2017)	U.S.	Quant	Various	<ul style="list-style-type: none"> • cost less per day with patient on early palliative care compared to those admitted later in the disease trajectory

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
McDarby & Carpenter (2019)	U.S.	Qual	Hospital	<ul style="list-style-type: none"> • reduced length of stay and treatment intensity = cost savings • care coordination is a challenge and inconsistent, superficial, and limiting deeper collaboration • confusion of palliative care among families and non-palliative care providers • limited educational opportunities • palliative care specialist role is perceived to be for pain and symptom control only and not to assist with patient-centered care and planning
Meier (2011)	-	-	-	<ul style="list-style-type: none"> • need for policy changes that focus on increasing palliative care workforce and the availability of services within hospitals and nursing homes in the U.S.
Meier (2013)	-	-	-	<ul style="list-style-type: none"> • a shift is the approach to healthcare in the U.S. • changes in funding streams are needed to support access to palliative care • increased clinician education is needed to advance palliative care
Morrison, Augustin, et al. (2011)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • smaller hospitals less likely to have palliative care • 4% in Alabama
Nathanson et al. (2016)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • states with sicker populations and more preventable hospitalizations had fewer palliative care providers
Nelson et al. (2021)	-	-	-	<ul style="list-style-type: none"> • provides a framework that goes beyond the traditional pc

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Pearce (2016)	-	-	-	<p>model; access to pc is not created equal</p> <ul style="list-style-type: none"> multiple layers of providing pc that addresses cultural differences, socioeconomic differences, and access must be considered a new framework of pc was presented using the socioecological model those aged 80 and older are the fastest growing demographic in the U.S. limited full IDT within palliative care programs expansion of policy will assist with education of IDT palliative care team members
Reyes-Gibby et al. (2012)	U.S.	Quant	Outpatient	<ul style="list-style-type: none"> disparities found among symptom burden (black & Hispanic had little improvement when compared to whites) referral to palliative care was not different among races
Rogers et al. (2020)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> common characteristics associated with palliative care include urban setting and larger hospital size (esp. over 300 beds) teaching hospitals more likely to offer pc
Rogers et al. (2021)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> between 2009-2017, overall pc adoption rate in hospitals was 34.9%, while the overall closure rate was 15% factors relevant to the adoption included being a nonprofit hospital, hospitals with an American College of Surgeons cancer program,

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Santos Salas et al. (2019)	Canada	Qual	Various	<p>hospitals with 300 or more beds, hospitals with residency training programs approved by the Accreditation Council of Graduate Medical Education, and a location within New England</p> <ul style="list-style-type: none"> • factors relevant to the closure included nonprofit hospital, rural hospitals, hospitals with fewer than 50 beds, sole-provider hospitals, and hospitals located within the East South Central U.S. • social determinants of health impact symptom burden in cancer patients due to income (affordability), education (understand symptom control), less social support, language barrier more of an issue than cultural differences • unnecessary hospital admission due to lack of housing
Schellinger et al. (2018)	U.S.	Qual	Community based	<ul style="list-style-type: none"> • goals of care were evaluated based upon discussion among patients with serious illness; medical and nonmedical (social, ethical, caregiving, financial) goals were discussed equally • this study reflected the importance of whole-person goals to fulfill not only physical aspects of care for patients with serious illness
Shipman et al. (2005)	England	Quant	Not specified	<ul style="list-style-type: none"> • 24/7 coverage varies • care satisfaction was good • access to care not always available

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Silbermann et al. (2015)	Middle Eastern countries	MMR	Various	<ul style="list-style-type: none"> • personnel and time varied • community awareness of palliative care lacking • training for staff varies • most healthcare professionals wish to acquire additional knowledge about pc • satisfied most with pain and symptom management
Smith et al. (2013)	U.S.	MMR	Outpatient	<ul style="list-style-type: none"> • staffing rotations vary; often too many referrals for staff to see in timely manner • impetus of starting is patients were "falling through the cracks" upon discharge • multiple funding sources to stay afloat: institutional revenue, billing, philanthropy, research funding, and foundation support
Spetz et al. (2016)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • full interdisciplinary team was limited among a majority of hospitals due to lack of funding • chaplain was most often member missing followed by SW • only 25% of hospitals had a complete funded interdisciplinary team
Tasneem et al. (2019)	U.S.	Qual	Telehealth	<ul style="list-style-type: none"> • most did not feel that the patient and provider relationship would be impacted; offer inpatient visits in addition to telehealth • videoconferencing and WiFi available for most; privacy is not of concern • reduced risk of discomfort from not sitting in waiting room

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
Temel et al. (2010)	U.S.	Quant	Outpatient	<ul style="list-style-type: none"> • cost savings and travel time benefits • improved symptom burden, QOL, and less depression for patients with lung and GI cancer admitted for early palliative care • more Advance Planning documentation • longer life expectancy
Temel et al. (2017)	U.S.	Quant	Outpatient	<ul style="list-style-type: none"> • improved QOL and mood for patients with non-metastatic non-cell lung cancer admitted for early palliative care
Torke et al. (2010)	U.S.	MMR	Community based	<ul style="list-style-type: none"> • Interdisciplinary team is the most important for "whole" patient care • lack of public knowledge of palliative care • payment and policy challenges for non-cancer patients (dementia patients within this study)
Tschirhart et al. (2014)	U.S.	Quant	Hospital	<ul style="list-style-type: none"> • intensive services occur within the last 6 months of life, approximately 18% of subjects underwent at least one intensive service within the last 6 months of life • lower odds of receiving an intensive service included older age, Alzheimer's disease, cancer, nursing home resident, and having an advance directive in place • higher odds of having an intensive procedure was associated with residing in an HRR with a higher HCI Index as well as ethnicity (black and Hispanic)

Author(s), Year	Country or Region	Study Design	Models of Care	Findings
van Riet Paap et al. (2014)	Europe	Delphi	Not specified	<ul style="list-style-type: none"> • 24/7 availability needed; IDT importance and needed • well-structured medical record is needed
Woitha et al. (2014)	Europe	Delphi	Not specified	<ul style="list-style-type: none"> • multi professional team needed; 24/7 availability • need infrastructure in place
Zimmermann et al. (2014)	Canada	Quant	Various	<ul style="list-style-type: none"> • improved symptom burden, QOL for patients with advanced cancer admitted to early palliative care

APPENDIX B

ADAPTED SURVEY (HOSPITALS WITH PALLIATIVE CARE)

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

You are invited to participate in a research project being conducted by Amy Beasley, a PhD student at the University of Alabama at Birmingham School of Nursing. The purpose of this mixed methods study is to explore two Alabama hospitals that offer palliative care programs and two that do not. These hospitals have been chosen based on size and geographic location.

DIRECTIONS FOR COMPLETING THIS SURVEY

- The paper survey included in this envelope asks for information about [insert Hospital Name] and the factors that impact the care that you provide (i.e., staffing, budgeting).
- The entire survey should take approximately 30 minutes to complete.
- The survey consists of four sections and each section is intended to be completed by the most appropriate staff person, based upon the best judgment of the hospital administration (see suggestions in the table below).
- The survey should be completed by hand.
- Please place completed survey pages within the provided envelope.
- Contact Amy Beasley, Principal investigator, upon completion of the survey.
 - You may contact her by email at beasl029@uab.edu or phone at 205-361-1649.
 - Upon completion of this survey, Amy Beasley will retrieve the documents from your location.

SURVEY SECTION	SURVEY FOCUS	SUGGESTED STAFF PERSON	SURVEY PAGE NUMBERS
HOSPITAL STRUCTURE	Focuses on the community and the patient population that your hospital serves.	Chief Operating Officer	2 – 5
HOSPITAL RESOURCES	Focuses on resources provided by outside agencies	Chief Financial Officer	6
FINANCIAL INCENTIVES	Focuses on hospital funding and budgeting	Chief Financial Officer	7
PALLIATIVE CARE PROGRAMS	Focuses on palliative care program information	Palliative Care Program Coordinator or Director	8 - 11

If you have any questions about this study, you may call me at 205-361-1649, or my advisor, Dr. Bakitas, at 205-996-0093. The study has been reviewed and approved by the University of Alabama at Birmingham Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at 205-934-3789.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

REPORTING PERIOD

1. Is the most recently compiled reporting period used for this report on a full 12 months of data (either calendar year or fiscal year)?

☐ Yes ☐ No

2. If no, how many months of data are you reporting?

HOSPITAL STRUCTURE

3. What is the ownership or tax status of the hospital?

☐ For-Profit ☐ Non-Profit ☐ Public

4. Is this hospital located in an urban, suburban, or rural area?

☐ Urban ☐ Suburban ☐ Rural

5. Is this hospital a teaching hospital?

☐ Yes ☐ No

6. Total number of annual hospital admissions during the reporting period?

7. Total number of hospital beds (setup and staffed for use)?

8. If able to obtain, please provide the following metrics about your hospital for the reporting period.

Average daily census for the hospital	
Total hospital discharges (including deaths)	
Total hospital inpatient deaths	

9. Indicate the number of hospital admissions by age group.

Birth To 17 Years Old	
18-64 Years Old	
>65 Years Old	

10. Indicate the breakdown of hospital admissions by the following ethnicity categories.

Ethnicity	Breakdown by Percentage/Count
Black/African American non-Hispanic	
White/Caucasian non-Hispanic	

Asian non-Hispanic	
American Indian/Alaskan Native non-Hispanic	
Hawaiian Native/Pacific Islander non-Hispanic	
Hispanic/Latino	
Other, specify	

11. Indicate the number of hospital admissions based on the following primary underlying diagnosis groupings.

Primary Underlying Diagnosis Groupings	Number of Hospital Admissions
Cardiac	
Pulmonary	
Cancer	
Renal	
Neurologic/Neuromuscular/Neurodegenerative	
GI/Hepatic	
Traumatic	
Other, specify	

12. Please provide the percentage by discharge disposition on the day of hospital discharge, during the reporting period.

Discharge Disposition	%	Discharge Disposition	%
Home without any services		Other Health Care Facility (e.g. LTACH, VA)	
Home with hospice		Death	
Home with home health		Left Against Medical Advance/AMA	
Home with palliative care		Unable to Determine (UTD)	
Hospice-Health Care Facility		Not Discharged from the Hospital during Reporting Period	
Acute Care Facility			

13. Do you have a dedicated inpatient unit for patients with serious or complex illness?

☐ Yes ☐ No

14. If yes, are there floor nurses dedicated to this inpatient unit to care for patients with serious or complex illness? If so, do they receive any specialized training?

Thank you for completing the Hospital Structure portion of the survey.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

HOSPITAL RESOURCES

15. What is your hospital's relationship to a hospice?
(check all that apply)

- ☐ No relationship exists
- ☐ The hospital/health system owns its own hospice.
- ☐ We have a contract with one or more community hospice agencies
- ☐ We informally collaborate with community hospice agencies
- ☐ Other, specify

Thank you for completing the Hospital Resources portion of the survey.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

FINANCIAL INCENTIVES

16. Approximately what percent of your hospital budget comes from the following sources (should add to 100%):

%	
	Fee for service clinician billing (including Medicare Part B)
	Bonus payments for quality measures
	Subsidy from partner organizations
	Financial contracts/service agreements with other providers or vendors (where you did not bill the payer directly)
	Philanthropic and foundation support
	Other, specify
100%	Total

17. Does your organization participate in alternative payments (such as case rates or bundled episode payments)?

☐ Yes ☐ No ☐ Not sure

Thank you for completing the Financial Incentives portion of the survey.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

PALLIATIVE CARE PROGRAM QUESTIONS

18. In what year was your palliative care program established at this hospital?

PROGRAM STRUCTURE

19. How is your inpatient palliative care program staffed?

Number of Staff	
	Embedded: Program is internal to the hospital (all palliative care team members are employed by the hospital)
	Partial: Program is partially internal with additional contracted services
	Contracted: Program is administrated by an outside, contracted agency

20. Considering the staffing of your palliative care team over the past year, how would you describe your staffing?

Number of Staff	
	Stable-not currently recruiting or requesting additional staff
	Reduced staff in the past two years-not currently recruiting or requesting additional staff
	Short-staffed and requesting or recruiting additional staff for current patient load
	Requesting staff to manage anticipated future growth

21. Which of the following disciplines constitute your patient care team within your palliative care program? Place a checkmark by each discipline that is represented within the program.

Discipline	✓	Discipline	✓
Physician		Social Worker	
Advanced Practice Registered Nurse		Chaplain/Spiritual Care Provider	
Physician's Assistant (PA)		Pharmacist	
Registered Nurse (RN)/Licenses Practical Nurse (LPN)		Other, specify	

22. Provide the number of annual initial palliative care consults by specialty of referring clinician. If unable to provide the number of consults, please provide a ranking (1 being the most consults) or an approximate percentage of consults from each area.

Palliative Care Consults		Palliative Care Consults	
Hospitalist		Neurologist	
Oncologist		Internal Medicine	
Cardiologist		Family Medicine	
Nephrologist		Don't know/Not sure	
Pulmonary and/or critical care		Other, specify	
Surgery			

23. Indicate the number of initial palliative care consults by age group seen by your program during the reporting period.

Birth To 17 Years Old	
18-64 Years Old	
>65 Years Old	

24. Indicate the number of initial palliative care consults seen by your program in the following ethnicity categories:

Ethnicity	Breakdown by Percentage/Count
Black/African American non-Hispanic	
White/Caucasian non-Hispanic	
Asian non-Hispanic	
American Indian/Alaskan Native non-Hispanic	
Hawaiian Native/Pacific Islander non-Hispanic	
Hispanic/Latino	
Other, specify	

25. Indicate the number of initial palliative care consults seen in the following primary underlying diagnosis groupings.

Number of Consultants	Underlying Diagnosis Groupings
	Cancer
	Cardiac
	Pulmonary
	Renal
	Neurologic/Neuromuscular/Neurodegenerative

26. Do you have a dedicated inpatient palliative care unit?

☐ Yes

☐ No

FINANCIAL RESOURCES

27. Approximately what percent of your inpatient palliative care program budget comes from the following sources (should add to 100%):

%	
	Financial support from hospital or another parent organization (including salary stipends, not including philanthropy)
	Fee for service clinician billing (including Medicare Part B)
	Bonus payments for quality measures
	Subsidy from partner organizations
	Financial contracts/service agreements with other providers or vendors (where you did not bill the payer directly)
	Philanthropic and foundation support
	Not funded
	Other, specify
100%	Total

CAPACITY FOR 24/7 CARE

28. Does your inpatient palliative care program provide 24/7 coverage for patients and families?

☐ Yes ☐ No

29. If no, what times do you have coverage within the palliative care program? (Check all that apply)

- ☐ Weekday, days
☐ Weekday, nights
☐ Weekend, days
☐ Weekend, nights

Thank you for completing the Palliative Care Program portion of the survey.

APPENDIX C

ADAPTED SURVEY (HOSPITALS WITHOUT PALLIATIVE CARE)

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

You are invited to participate in a research project being conducted by Amy Beasley, a PhD student at the University of Alabama at Birmingham School of Nursing. The purpose of this mixed methods study is to explore two Alabama hospitals that offer palliative care programs and two that do not. These hospitals have been chosen based on size and geographic location.

DIRECTIONS FOR COMPLETING THIS SURVEY

- The paper survey included in this envelope asks for information about [insert Hospital Name] and the factors that impact the care that you provide (i.e., staffing, budgeting).
- The entire survey should take approximately 30 minutes to complete.
- The survey consists of three sections and each section is intended to be completed by the most appropriate staff person, based upon the best judgment of the hospital administration (see suggestions in the table below).
- The survey should be completed by hand.
- Please place completed survey pages within the provided envelope.
- Contact Amy Beasley, Principal investigator, upon completion of the survey.
 - You may contact her by email at beasl029@uab.edu or phone at 205-361-1649.
 - Upon completion of this survey, Amy Beasley will retrieve the documents from your location.

SURVEY SECTION	SURVEY FOCUS	SUGGESTED STAFF PERSON	SURVEY PAGE NUMBERS
HOSPITAL STRUCTURE	Focuses on the community and the patient population that your hospital serves.	Chief Operating Officer	2 – 3
HOSPITAL RESOURCES	Focuses on resources provided by outside agencies	Chief Financial Officer	4
FINANCIAL INCENTIVES	Focuses on hospital funding and budgeting	Chief Financial Officer	5

If you have any questions about this study, you may call me at 205-361-1649, or my advisor, Dr. Bakitas, at 205-996-0093. The study has been reviewed and approved by the University of Alabama at Birmingham Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at 205-934-3789.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

REPORTING PERIOD

1. Is the most recently compiled reporting period used for this report on a full 12 months of data (either calendar year or fiscal year)?
☐ Yes ☐ No
2. If no, how many months of data are you reporting?

HOSPITAL STRUCTURE

3. What is the ownership or tax status of the hospital?
☐ For-Profit ☐ Non-Profit ☐ Public
4. Is this hospital located in an urban, suburban, or rural area?
☐ Urban ☐ Suburban ☐ Rural
5. Is this hospital a teaching hospital?
☐ Yes ☐ No
6. Total number of annual hospital admissions during the reporting period?
7. Total number of hospital beds (setup and staffed for use)?
8. If able to obtain, please provide the following metrics about your hospital for the reporting period.

Average daily census for the hospital	
Total hospital discharges (including deaths)	
Total hospital inpatient deaths	

9. Indicate the number of hospital admissions by age group.

Birth To 17 Years Old	
18-64 Years Old	
>65 Years Old	

10. Indicate the breakdown of hospital admissions by the following ethnicity categories.

Ethnicity	Breakdown by Percentage/Count
Black/African American non-Hispanic	
White/Caucasian non-Hispanic	
Asian non-Hispanic	

American Indian/Alaskan Native non-Hispanic	
Hawaiian Native/Pacific Islander non-Hispanic	
Hispanic/Latino	
Other, specify	

11. Indicate the number of hospital admissions based on the following primary underlying diagnosis groupings.

Primary Underlying Diagnosis Groupings	Number of Hospital Admissions
Cardiac	
Pulmonary	
Cancer	
Renal	
Neurologic/Neuromuscular/Neurodegenerative	
GI/Hepatic	
Traumatic	
Other, specify	

12. Please provide the percentage by discharge disposition on the day of hospital discharge, during the reporting period.

Discharge Disposition	%	Discharge Disposition	%
Home without any services		Other Health Care Facility (e.g. LTACH, VA)	
Home with hospice		Death	
Home with home health		Left Against Medical Advance/AMA	
Home with palliative care		Unable to Determine (UTD)	
Hospice-Health Care Facility		Not Discharged from the Hospital during Reporting Period	
Acute Care Facility			

13. Do you have a dedicated inpatient unit for patients with serious or complex illness?

☐ Yes ☐ No

14. If yes, are there floor nurses dedicated to this inpatient unit to care for patients with serious or complex illness? If so, do they receive any specialized training?

Thank you for completing the Hospital Structure portion of the survey.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

HOSPITAL RESOURCES

15. What is your hospital's relationship to a hospice?
(check all that apply)

- ☐ No relationship exists
- ☐ The hospital/health system owns its own hospice.
- ☐ We have a contract with one or more community hospice agencies
- ☐ We informally collaborate with community hospice agencies
- ☐ Other, specify

Thank you for completing the Hospital Resources portion of the survey.

Survey to Access to In-Hospital Palliative Care Services in Alabama Hospitals

FINANCIAL INCENTIVES

16. Approximately what percent of your hospital budget comes from the following sources (should add to 100%):

%	
	Fee for service clinician billing (including Medicare Part B)
	Bonus payments for quality measures
	Subsidy from partner organizations
	Financial contracts/service agreements with other providers or vendors (where you did not bill the payer directly)
	Philanthropic and foundation support
	Other, specify
100%	Total

17. Does your organization participate in alternative payments (such as case rates or bundled episode payments)?

☐ Yes
 ☐ No
 ☐ Not sure

Thank you for completing the Financial Incentives portion of the survey.

APPENDIX D
INTERVIEW PROTOCOLS

Senior Hospital Manager Interview Protocol

PC Access in Alabama: Assessing Access to Care for Serious Illness

Time of interview: _____
Date: _____
Place: _____
Interviewer: _____
Interviewee: _____
Position of interviewee: _____

Introduction

(Participant name), I want to thank you for taking the time out of your schedule to speak with me today. The purpose of this study is to explore access to PC or care for patients with serious illness at Alabama hospitals. We are assessing hospitals' structures and processes to provide serious illness care to patients while in the hospital. This will allow for an in-depth understanding of what factors impact the creation and sustainability of PC services. Which will assist in developments of better care interventions for patients and caregivers in Alabama in the future. This study will be conducted by myself, a PhD student, from the University of Alabama at Birmingham's School of Nursing. You have been invited to participate in this study due to your involvement and experience within {insert hospital name}. I know your insight will provide an in-depth look into your hospital and provide details on the care that is provided to patients with serious illness. Everything we say is on record unless you request otherwise during the interview. I will be audio recording as well as taking notes during our discussion with your permission. Audio recordings will be transcribed in their entirety for review by the principal investigator s involved in this study. The findings of this study will be reported in aggregate.

Do I have permission to proceed?

[Obtain Informed Consent]

Icebreaker

Please share a little about yourself and your role at {insert hospital name}.

Let's begin with a question to help guide my understanding of your viewpoint on palliative care.

1. In your own words, how would you personally define palliative care or supportive care?

For administrators that completed the descriptive survey: Questions would be presented to seek clarification on the descriptive survey as needed.

First, we will discuss hospital- and community-related factors that may impact the care provided within {hospital name}. {Environmental Factors}

1. Will you share your thoughts on the specific aspects that impact care within your hospital's catchment area?
2. What unique characteristics is your hospital known for the in community?
 - a. Probe: such as, cardiac care, mother/baby care, other specialty care

In the next few questions, we will discuss hospital and leadership characteristics. {Hospital Characteristics/Organizational Factors}

3. What factors that are taken into consideration when considering a new program within your hospital? {Hospital Structure}
 - a. Do you conduct a needs assessment? If so, what data do you consider most important?
 - b. If a program is undertaken, how do you go about setting strategic goals for the program?
4. Thinking back to your hospital's history, is there anything that you feel may have contributed or impeded the development of palliative care? {History/Evolution}
5. How does your hospital build trust among team members? What specific strategies do you use? {Trust and Respect}
 - i. Probe: For example, do you use townhalls, newsletters, publish annual reports, or offer office hours for clinical leaders?
6. What leadership style do you most often see within the hospital? {Leadership}
 - a. Or can you provide an example of how you lead?

I would like to hear about collaboration among the care team. {Collaboration Among Providers}

7. Share your thoughts with me when you hear the term "interdisciplinary team."
 - a. What team members would you expect to be on an interdisciplinary team that cares for seriously ill patients [palliative care patients]? {Interdisciplinary Teamwork; Interdisciplinary Team}
 - i. Probe: For example, a physician, nurse, social worker, chaplain.

We are approaching the end of the interview.

8. Is there anything that you would like to add that we have not discussed? This would be concerning care of patients with serious illness at your hospital.

That was my last question that I have prepared for you today. Thank you so much for your time. I will be shutting off the recorder now.

Thank you again for your time and have a good day.

Clinician Leader Interview Protocol

PC Access in Alabama: Assessing Access to Care for Serious Illness

Time of interview: _____

Date: _____

Place: _____

Interviewer: _____

Interviewee: _____

Position of interviewee: _____

Introduction

(Participant name), I want to thank you for taking the time out of your schedule to speak with me today. The purpose of this study is to explore access to PC or care for patients with serious illness at Alabama hospitals. We are assessing hospitals' structures and processes to provide serious illness care to patients while in the hospital. This will allow for an in-depth understanding of what factors impact the creation and sustainability of PC services which will assist in developments of better care interventions for patients and caregivers in Alabama. This study will be conducted by myself, a PhD student, from the University of Alabama at Birmingham's School of Nursing. You have been invited to participate in this study due to your involvement and experience within {insert hospital name}. I know your insight will provide an in-depth look into your hospital and provide details on the care that is provided to patients with serious illness. Everything we say is on record unless you request otherwise during the interview. I will be audio recording as well as taking notes during our discussion with your permission. Audio recordings will be transcribed in their entirety for review by the principal investigator s involved in this study. The findings of this study will be reported in aggregate.

Do I have permission to proceed?

[Obtain Informed Consent]

Icebreaker

1. Please share a little about yourself and your role at {insert hospital name}.

Let's begin with a couple questions to help guide my understanding of your viewpoint on palliative care.

2. In your own words, how would you personally define palliative care or supportive care?

As we go through additional questions today, please keep in mind your previous responses on palliative or supportive care.

In the next questions, we will discuss {insert hospital name} characteristics and as well as the hospital leadership. {Hospital Characteristics/Organizational Factors}

3. What factors are considered when {insert hospital name} is implementing a new program? {Hospital Structure}
 - a. Probes: Is there a formal needs assessment? What stakeholders impact the decision to consider a new program?
4. Thinking back to your hospital's history, is there anything that you feel may have contributed or impeded the development of palliative care? {History/Evolution}
 - a. Probes: Administration driven? Clinician driven? Patient driven?
5. How do you get "buy in" from the staff when a new program is implemented?
 - a. Probes: Is there a formal training or communication process (such as townhalls, newsletters, staff meetings) that are enacted when the new program or service is implemented?
6. How do you build trust among team members? Do you have specific strategies that you utilize? {Trust and Respect}
 - a. Probes: For example, team building activities, offering office hours for clinician leaders, soliciting and acting on informal or formal feedback from staff, awards or recognition for innovation or excellence in caring for patients with serious illness, or formal appreciation events/gestures.
7. What leadership style do you most often see within the hospital? {Leadership}
8. Will you provide an example of the working relationship among administration and clinical staff?

To change gears a little bit, let's discuss specific clinician training at the hospital.
{Provider Characteristics}

9. Does your hospital provide training that focuses on care of seriously ill patients? {Specialty Training & Experience}
 - a. Probe: For example, goals of care conversations, communication, symptoms, and pain management.
10. Is there an expectation for attendance for all clinical staff or do you have a specific target audience? {Specialty Training & Experience; Educational Opportunities}
11. Are you familiar with the National Consensus Project Guidelines for Quality Palliative Care?
 - a. (IF YES) Is training or continuing education that is offered to clinical staff based upon the NCP Guidelines?

Now that we have talked about clinician training, I would like to hear about collaboration among the care team. {Collaboration Among Providers}

12. Share your thoughts with me when you hear the term "interdisciplinary team."

13. What team members would you expect to be [are included] on an interdisciplinary team that cares for seriously ill patients [palliative care patients]?
{Interdisciplinary Teamwork; Interdisciplinary Team}

We are approaching the end of the interview.

14. Is there anything that you would like to add that we have not discussed? This would be concerning care of patients with serious illness at your hospital.

That was my last question that I have prepared for you today. Thank you so much for your time. I will be shutting off the recorder now.

Thank you again for your time and have a good day.

Frontline Clinician Interview Protocol

PC Access in Alabama: Assessing Access to Care for Serious Illness

Time of interview: _____

Date: _____

Place: _____

Interviewer: _____

Interviewee: _____

Position of interviewee: _____

Introduction

(Participant name), I want to thank you for taking the time out of your schedule to speak with me today. The purpose of this study is to explore access to PC or care for patients with serious illness at Alabama hospitals. We are assessing hospitals' structures and processes to provide serious illness care to patients while in the hospital. This will allow for an in-depth understanding of what assists with the creation and sustainability of PC services which will assist in developments of better care interventions for patients and caregivers in Alabama. This study will be conducted by myself, a PhD student, from the University of Alabama at Birmingham's School of Nursing. You have been invited to participate in this study due to your involvement and experience within {insert hospital name}. I know your insight will provide an in-depth look into your hospital and provide details on the care that is provided to patients with serious illness. Everything we say is on record unless you request otherwise during the interview. I will be audio recording as well as taking notes during our discussion with your permission. Audio recordings will be transcribed in their entirety for review by the principal investigator s involved in this study. The findings of this study will be reported in aggregate.

Do I have permission to proceed?

[Obtain Informed Consent]

Icebreaker

Please share a little about yourself and your role at {insert hospital name}.

Let's begin with a question to help guide my understanding of your viewpoint on palliative care.

1. In your own words, how would you personally define palliative care or supportive care?

**The next few questions ask for your thoughts about the hospital and its leadership.
{Hospital Characteristics/Organizational Factors}**

2. Tell me about any policies or symptom triggers for referrals to specialty services that you have in place that are used for patients with a serious illness. {Policy/Procedures}
3. Are there any documents that use frequently during the care for patients with serious illness? {Policy/Procedures}
4. Will you share how a specialty referral is made for a patient with serious illness? May any team member or even a family member make this request? {Power Equity}
5. Tell me about awards or recognition that your hospital provides for innovation or excellence for patients with serious illness? {Incentives}
 - a. Share your feelings about formal recognition vs. informal recognition.
 - b. Does your hospital promote staff support related to self-care and resilience?
6. Will you share about how supported you feel by administration within your role? {Leadership & Role Recognition}
7. What clinical area do you feel that administration is more focused towards and why? {Leadership & Role Recognition}

To change gears a little bit, let's discuss how is the clinician training done within the hospital. {Provider Characteristics}

6. What aspects of care (i.e. communication, symptom management, care coordination, etc.) do you believe that impacts care for patients with serious illness? {Beliefs/Attitudes}
7. Does your hospital provide training that focuses on care of seriously ill patients? For example, goals of care, communication, symptoms, and pain management. {Specialty Training & Experience}
 - a. Is there an expectation for attendance for all clinical staff or do you have a specific target audience? {Specialty Training & Experience; Educational Opportunities}

Now that we have talked about the care providers, I would like to hear about collaboration among the care team. {Collaboration Among Providers}

8. Thinking back over the time you have worked at {insert hospital name}. Will you provide an example of a patient that you cared for that could have or did benefit from palliative care? Share your thoughts on what went well and what could have been different.
9. Share your thoughts with me when you hear the term “interdisciplinary teamwork.” {Interdisciplinary Teamwork; Interdisciplinary Team}
10. Thinking back to the previous example you described, what team members were included in the care team. How did the team work together to provide care? {Role Recognition/Trust/Respect}

11. What challenges were you faced with as a care team? {Shared Decision Making and Problem Solving}

Let's now talk about how communication and assessment is done at your hospital. {Information Transfer}

12. Do you have a usual approach to leading difficult conversations with patients and families with serious illness? Tell me more about it. {Communication}
13. Thinking about your day-to-day practice, can you discuss some of the standardized patient assessments that are used? {Standardized Assessments}

We are approaching the end of the interview.

14. Is there anything that you would like to add that we have not discussed? This would be concerning care of patients with serious illness at your hospital.

That was my last question that I have prepared for you today. Thank you so much for your time. I will be shutting off the recorder now.

Thank you again for your time and have a good day.

APPENDIX E

DATA SOURCES STRENGTHS AND WEAKNESSES

Data Sources Strengths and Weaknesses

Data Source	Description	Strengths	Weaknesses
Interview	Face-to-Face Semi-Structured Interviews with administrators, Chief Medical Officer, Chief Nursing Officer, hospitalists, front-line registered nurses	<ul style="list-style-type: none"> • In-depth information • Opportunity to ask targeted questions • Gain perceptions and attitudes 	<ul style="list-style-type: none"> • Reflexivity—saying the “correct things” • Expensive • Time consuming for data collection and analysis
Document Review	Documents related to serious illness care with the hospital	<ul style="list-style-type: none"> • Unobtrusive • View around researchers schedule • Ability to look for specific and broad topics 	<ul style="list-style-type: none"> • Access withholding • Bias by documents author • Bias selectivity, collection of data may be insufficient
Surveys	Qualtrics-based surveys using a portion of National PC Registry Hospital survey and quality measures survey	<ul style="list-style-type: none"> • Inexpensive • Quick timeframe needed • Selection of descriptive data to answer study questions 	<ul style="list-style-type: none"> • Survey burnout—must keep them short • Missing or incomplete data • Low response rates

APPENDIX F
DOCUMENTATION REVIEW

Documentation Review

Documentation reviews included viewing of documents that entail the hospitals mission, vision, and policies and procedures related to serious illness care. The documents that were not available publicly was requested by the principal investigator and obtained from a senior hospital manger or a clinician leader. The documents were assessed for a focus on palliative care or serious illness care. The documents that were reviewed included a) annual reports (assessing history and growth), b) hospital mission and vision (and program as applicable), c) any hospital policies and procedures related to management of a patient with serious illness (and program as applicable), and d) specialty referral or consult documents. Additionally, documents that were present through publicly electronic sources (i.e. hospital website) were reviewed.

Hospital Document List	
Hospital Mission	We serve to improve the health of our patients and community.
Hospital Vision	To be the provider of choice in our market by delivering excellent care to patients and families in West Alabama.
Program Mission, as applicable	
Program Vision, as applicable	
Annual Reports (assessing history and growth)	
Strategic Plan	
Hospital Policies and Procedures <ul style="list-style-type: none">• Goals of care• Advanced care planning• Comfort care orders• Discharge Planning	
Specialty Referrals	

APPENDIX G

IRB APPROVAL LETTER



Office of the Institutional Review Board for Human Use

470 Administration
Building 701 20th
Street South
Birmingham, AL
35294-0104
205.934.3789 | Fax 205.934.1301 |
irb@uab.edu

APPROVAL LETTER

TO: Beasley, Amy M

FROM: University of Alabama at Birmingham Institutional Review Board Federalwide Assurance #
FWA00005960

IORG Registration # IRB00000196 (IRB 01)

IORG Registration # IRB00000726 (IRB 02)

IORG Registration # IRB00012550 (IRB 03)

DATE: 14-Jun-2022

RE: IRB-300007594
IRB-300007594-004

Exploring the Facilitators and Barriers to Palliative Care Access in Alabama Hospitals

The IRB reviewed and approved the Revision/Amendment submitted on 06-Jun-2022 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Exempt

Exempt Categories: 2

Determination: Exempt

Approval Date: 14-Jun-2022

APPENDIX H
HOSPITAL RESULTS

Additional Hospital Characteristics and Structure for Hospital A

Annual Hospital Admissions	19,526
Total Staffed Hospital Beds	490 beds
Average Daily Census	339
Total Hospital Discharges	20,291
Total Inpatient Deaths	1,077
Admissions by Age	
Birth to 17 y/o	339 (1.7%)
18-64 y/o	11,270 (56.3%)
>65 y/o	8,410 (42.0%)
Admissions by Ethnicity	
Black/African American	4,172 (25.5%)
White/Caucasian	11,131 (68%)
Asian	96 (0.6%)
American Indian/Alaskan Native	5 (0.03%)
Hawaiian Native/Pacific Islander	9 (0.05%)
Hispanic/Latino	338 (2.1%)
Other	619 (3.8%)
Discharge Disposition	
Home without any services	60.5%
Home with hospice	4.0%
Home with home health	10.0%
Home with palliative care	3.0%
Hospice-home health facility	4.0%
Acute care facility	2.0%
Acute care facility (e.g., LTACH)	5.0%
Death	10.0%
Left against medical advice	1.0%
Unable to determine	0.0%
Not discharged from the hospital during the reporting period	0.5%
Hospital Budget Sources	
Fee-for-service clinician billing (including Medicare Part B)	100%

Additional Hospital Characteristics and Structure of Hospital B

Ownership of the Hospital	Nonprofit
Geographical Location	Rural
Hospital Teaching Status	Yes
Annual Hospital Admissions	18,569
Total Staffed Hospital Beds	336 beds
Average Daily Census	270.34
Total Hospital Discharges	18,576
Total Inpatient Deaths	752
Admissions by Age	
Birth to 17 y/o	509 (2.7%)
18-64 y/o	10,241 (55.2%)
>65 y/o	7,819 (42.1%)
Admissions by Ethnicity	
Black/African American	5,353 (28.8%)
White/Caucasian	12,477 (67.2%)
Asian	37 (0.2%)
American Indian/Alaskan Native	22 (0.1%)
Hawaiian Native/Pacific Islander	7 (0.0%)
Hispanic/Latino	162 (0.9%)
Other	511 (2.8%)
Discharge Disposition	
Home without any services	65.6%
Home with hospice	1.4%
Home with home health	13.9%
Home with palliative care	0%
Hospice-home health facility	0.5%
Acute care facility	0.4%
Acute care facility (e.g., LTACH)	12.8%
Death	3.4%
Left against medical advice	2.0%
Unable to determine	0%
Not discharged from the hospital during the reporting period	0.01%
Existence of Dedicated Inpatient Unit for Patients with Serious Illness	No

Additional Hospital Characteristics and Structure for Hospital C

Ownership of the Hospital	For-profit
Geographical Location	Rural
Hospital Teaching Status	Yes
Annual Hospital Admissions	7,139
Total Staffed Hospital Beds	112 beds
Average Daily Census	84
Total Hospital Discharges	7,118
Total Inpatient Deaths	188
Admissions by Age	
Birth to 17 y/o	857 (12%)
18-64 y/o	3141 (44%)
>65 y/o	3141 (44%)
Admissions by Ethnicity	
Black/African American	578 (8.1%)
White/Caucasian	6,011 (84.2%)
Asian	65 (0.9%)
American Indian/Alaskan Native	41 (0.6%)
Hawaiian Native/Pacific Islander	4 (0.1%)
Hispanic/Latino	407 (5.7%)
Other	33 (0.5%)
Discharge Disposition	
Home without any services	59.0%
Home with hospice	2.0%
Home with home health	20.0%
Home with palliative care	2%
Hospice-home health facility	1%
Acute care facility	3%
Acute care facility (e.g., LTACH)	2%
Death	2%
Left against medical advice	1%
Unable to determine	6%
Not discharged from the hospital during the reporting period	2%
Existence of Dedicated Inpatient Unit for Patients with Serious Illness	Yes

Additional Hospital Characteristics and Structure of Hospital D

Ownership of the Hospital	For-profit
Geographical Location	Urban
Hospital Teaching Status	No
Annual Hospital Admissions	8,686
Total Staffed Hospital Beds	130 beds
Average Daily Census	110
Total Hospital Discharges	8,712
Total Inpatient Deaths	190
Admissions by Age	
Birth to 17 y/o	443 (5.0%)
18-64 y/o	4,128 (48.0%)
>65 y/o	4,115 (47.0%)
Admissions by Ethnicity	
Black/African American	1,726 (19.7%)
White/Caucasian	6,696 (76.4%)
Asian	46 (0.5%)
American Indian/Alaskan Native	3 (0.0%)
Hawaiian Native/Pacific Islander	142 (1.6%)
Hispanic/Latino	77 (0.9%)
Other	69 (0.8%)
Discharge Disposition	
Home without any services	69.5%
Home with hospice	0.06%
Home with home health	10.94%
Home with palliative care	1.72%
Hospice-home health facility	0.38%
Acute care facility	2.3%
Acute care facility (e.g., LTACH)	0.08%
Death	2.2%
Left against medical advice	2.4%
Unable to determine	0%
Not discharged from the hospital during the reporting period	0%
Existence of Dedicated Inpatient Unit for Patients with Serious Illness	No

APPENDIX I

CROSS-CASE ANALYSIS GRAPHIC ORGANIZER

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Hospital Description	<ul style="list-style-type: none"> - Urban, serving multiple rural counties - Nonprofit hospital - PC opened in 2016 	<ul style="list-style-type: none"> - Urban, serving multiple rural counties - Nonprofit hospital - PC opened in 2014 	<ul style="list-style-type: none"> - Rural, serving one rural county - For-profit hospital - Overseen by corporate headquarters 	<ul style="list-style-type: none"> - Urban, serving three urban counties - For-profit hospital - Overseen by corporate headquarters
History and Evolution of Serious Illness Care: Developing a mindset towards serious illness care	<p>Qualitative Supportive administration for serious illness care, despite funding limitations</p> <ul style="list-style-type: none"> - Starting the conversation - Opportunity for growth <p>“Seeing” is believing for staff</p> <ul style="list-style-type: none"> - “seeing” it - Staff buy-in 	<p>Qualitative Supportive administration for serious illness care, despite funding limitations</p> <ul style="list-style-type: none"> - Staff buy-in - Opportunity for growth - Mission focused - Starting the conversation <p>Education within the hospital and community were key</p> <ul style="list-style-type: none"> - Approaching it from a different perspective 	<p>Qualitative Creating programs that meet the community needs and have buy-in from the community</p> <ul style="list-style-type: none"> - Buy in to new programs - Approaching it from EOL perspective <p>Limitations to expansion of services were due to constraints on hospital</p> <ul style="list-style-type: none"> - Negative factors that impact serious illness 	<p>Qualitative Administration feels that staff engagement is important in understanding the needs of the hospital and the community</p> <ul style="list-style-type: none"> - Buy in to new programs - Opportunity for growth in the future <p>Serious illness care was provided within the ICUs and oncology floor</p>

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
		<ul style="list-style-type: none"> - Buy-in to new programs by clinicians - Value-based care mindset 		<ul style="list-style-type: none"> - Starting the conversation for serious illness
	Quantitative <ul style="list-style-type: none"> - Median household income less than overall Alabama - Sole Community Hospital Designation - Limited community palliative care services 	Quantitative <ul style="list-style-type: none"> - Median household income lower than overall Alabama - Rural Referral Center Designation - Limited community palliative care services 	Quantitative <ul style="list-style-type: none"> - Access to community palliative care services - Median household income greater than overall Alabama - Cancer mortality rate was higher when compared to Alabama 	Quantitative <ul style="list-style-type: none"> - Access to community palliative care services - Median household income greater than overall Alabama - Cancer mortality rate was lower when compared to Alabama
History and Evolution of Serious Illness Care: Changing Perceptions about	Qualitative Varying views of the services that are encompassed within palliative care <ul style="list-style-type: none"> - Beliefs in care 	Qualitative Varying views of the services that are encompassed within palliative care <ul style="list-style-type: none"> - Beliefs in care 	Qualitative Varied opinions on what encompasses palliative care, majority felt the focus was on end of life	Qualitative Clinicians had similar beliefs in palliative or serious illness care being a supportive service

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Serious Illness and Palliative Care Through Trust and Education (Hospitals with PC)	- Supportive role	- Initial reactions by clinicians	- Beliefs in care - Clinician hesitancy - Initial reactions by clinicians	- Beliefs in care from the viewpoint of the clinicians
Narrow Perceptions about Serious Illness Care (Hospitals without PC)	Obtaining “buy-in” to serious illness care through education - Initial reactions by clinicians	Obtaining “buy-in” to serious illness care through education - Strategic direction of palliative care	Recruitment of staff from other larger hospitals to impact serious illness care - Drawing in new medical staff with a wealth of experience - Generational differences	Though clinicians reflected favorably towards palliative care benefits, it is not currently being considered - History of serious illness care within the hospital
	Quantitative - The majority of the consults were from hospitalists (46.8%, $n = 619$) and the pulmonary/critical care team (38.7%, $n = 512$).	Quantitative - The majority of the consults were from hospitalists (62.7%, $n = 605$) and the pulmonary/critical care team (23.5%, $n = 227$).	Quantitative No quantitative data was applicable for hospitals without palliative care	Quantitative No quantitative data was applicable for hospitals without palliative care

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Providing Patient-Centered Serious Illness Care: Basics of Providing Care	Limited policy use, no formal trigger use due to program growth <ul style="list-style-type: none"> - utilizing policies and procedures in serious illness - assessment tools used in practice Intensivists involvement <ul style="list-style-type: none"> - physician-driven referral process 	Limited policy use, no formal trigger use due to program growth <ul style="list-style-type: none"> - intensivists involvement - utilizing policies and procedures in serious illness Intensivists involvement <ul style="list-style-type: none"> - physician-driven referral process 	Policies and referrals are most commonly used by physicians or hospitalists <ul style="list-style-type: none"> - Physician-driven referral process - Goals of care conversations - Utilizing policies and procedure in serious illness Charting takes away from serious illness care <ul style="list-style-type: none"> - Assessment tools used in practice 	Policy use related to serious illness care was limited <ul style="list-style-type: none"> - utilizing policies and procedures in serious illness Physicians typically begin the consult process; however, nurses or families can request a consult <ul style="list-style-type: none"> - Physician-driven referral process
Providing Patient-Centered Serious Illness Care: Building Trust and Relationships Among Clinicians and the Palliative Care Team	Multidisciplinary rounds built trust and established relationships among the team <ul style="list-style-type: none"> - Relationships and trust among the care team 	Multidisciplinary rounds built trust and established relationships among the team <ul style="list-style-type: none"> - Building relationships through 	Reflection on relationships build through the small hospital and community atmosphere <ul style="list-style-type: none"> - Relationships built through hospital size 	Participants did not provide perspectives related to building trust and relationships among clinicians

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
(Hospitals with PC)	The care team didn't feel that they were	multidisciplinary rounds	Outside resources were utilized for some care	
Building Trust and Relationships	working in "silos" with rounds	- Putting the pieces together to provide palliative care	team members (i.e., outside clergy and pastors); however, clinicians sometimes felt overwhelmed with not having additional care team members available	
Among Clinicians (Hospitals without PC)	- Putting the pieces together to provide palliative care	Leaders worked to build trust with the staff and to better understand their needs by implementing employee rounding and unit council	- Care challenges - Limited IDT staffing for the entire hospital	
	PC team challenges with not having a dedicated full IDT			
	- Care challenges	- Established palliative care relationships with staff		
		Palliative care had a positive impact with participation in rounding		
		- The importance of interdisciplinary work		
		- Understanding the role of the IDT		

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Providing Patient-Centered Serious Illness Care: Empowerment through Leadership Support of Serious Illness Care	<p>Variety of leadership styles</p> <ul style="list-style-type: none"> - Mixture of leadership styles that complement each other <p>Transparent leadership with a “hands on” approach to serious illness care</p> <ul style="list-style-type: none"> - Transparent leadership - Top-down approach to leadership 	<p>Leadership is focused on quality improvement and strategic goals to impact serious illness care</p> <ul style="list-style-type: none"> - Focused leadership towards quality improvement - Strategic focused leadership <p>Transparent and engaged leadership team impacts care within Hospital B</p> <ul style="list-style-type: none"> - Transformational leadership - Hands-on approach to leading 	<p>Variety of leadership styles that allows strengths of each to be utilized</p> <ul style="list-style-type: none"> - Mixture of leadership styles that complement each other 	<p>Variety of leadership styles</p> <ul style="list-style-type: none"> - Mixture of leadership styles that complement each other - Bottom-up leadership - Servant leadership style - Transactional leadership style <p>Leadership presence has been impactful for building trust</p> <ul style="list-style-type: none"> - Hands-on approach to leading - Transparent leadership - Top-down approach to leadership
Providing Patient-Centered Serious Illness Care: The	<p>Mandatory orientation includes serious illness training</p> <ul style="list-style-type: none"> - Orientation for new staff 	<p>Mandatory orientation includes serious illness training for critical care nurses and residents</p>	<p>Mandatory orientation and annual education include nursing education and tech education, which may</p>	<p>Mandatory orientation and annual training are focused on “basics of care”</p>

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Importance of Training Clinicians when caring for Seriously Illness Patients (Hospitals with PC)	- Identifying education gaps Serious illness training focused towards ICU nurses, evaluation focused	- Orientation for new staff Hospital B is a teaching hospital that offers palliative care and serious illness education to residents	vary depending on the hospital unit - Orientation for new staff Voluntary training related to serious illness is provided through local partnerships with local agencies	- Orientation for new staff - Identifying education gaps - Training attendance expectations Lack of serious illness training, though they are trained to identify patient needs and utilize care plans to fulfill those needs
Limited Clinician Training in Serious Illness Care Despite the Need (Hospitals without PC)	- Support for serious illness education - Specific palliative care training	- Residency programs	- Training attendance expectations - Serious illness training	- Lack of serious illness training
Providing Patient-Centered Serious Illness Care: Multidisciplinary Communication Focused on Patient-Centered Care (Hospitals with PC) Hospitals-Focused Community	Open and honest communication with the staff - Honest communication - Communication challenges The PC team has been instrumental in leading conversations on goals of care for patients with serious illness	The palliative care team leads conversations with patients with serious illness and their families; other clinicians often rely on their expertise in this area to assist in patient care - Approaches to communication with patients and families	Goals of care conversations are typically completed by physician hospitalists, or the Alabama Organ Center - Approaches to communication with patients and families - Honest communication	Physicians are typically charged with having goals of care conversations - Approaches to communication with patients and families Case management rounds are utilized to discuss patient care and connect patients to

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
(Hospitals without PC)	<ul style="list-style-type: none"> - Approaches to communication with patients and families - Communication partnership with palliative care - Palliative care communication with the care team 	<ul style="list-style-type: none"> - Palliative care communication with the care team 	<p>with patients and families</p> <p>Discharge planning through case management rounding is impactful for continuation of care</p> <ul style="list-style-type: none"> - Case management round communication - Serious illness communication with the care team 	<p>needed services; discharge planning focus with limited case team attendance</p> <ul style="list-style-type: none"> - Case management rounding communication
Serious Illness Care Impact: Focus on Patient-Centered Care	<p>Opportunity to honor patients' and families' wishes, even with poor prognoses</p> <ul style="list-style-type: none"> - Family experience during serious illness care - Patient is more than a disease 	<p>Palliative care works to meet the patient where they are in the disease process, even if this includes an acute traumatic event</p> <ul style="list-style-type: none"> - Palliative care where the patient is in the disease process - Family experience during serious illness care 	<p>Participants did not provide perspectives related to building trust and relationships among clinicians</p>	<p>Participants did not provide perspectives related to building trust and relationships among clinicians</p>

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
Serious Illness Care Impact: Palliative Care Closing the Gap in Fulfilling a Need for Patients with Serious Illness (Hospitals with PC) Fulfilling a Need for Patients with Serious Illness Utilizing Hospice (Hospitals without PC)	PC offered a “soft service” to patients while nurses were focused on physical care, especially during COVID <ul style="list-style-type: none"> - Program impact related to COVID Impact for care continuation through the use of intensivists case management, multidisciplinary rounds, and PC services <ul style="list-style-type: none"> - Filling a gap and need - Investing in patients and families - Program impact related to other factors 	Serves as a major hospital partner for many rural hospitals within the catchment area, so assessment of needs and expansion of services are important <ul style="list-style-type: none"> - Community impact - Filling a gap and need - Providing options The initiation of the intensivists and rounding impacted the use of palliative care services <ul style="list-style-type: none"> - Program impact related to other factors - Providing options 	Hospice services were available within the hospital thorough a partnership; Patients were connected to community resources upon discharge to expand available services to offer patients a continuation in care <ul style="list-style-type: none"> - Outside resources to planning new service lines - Limited to inpatient PC Expansion of services and staff specialties focused on community needs and support for programs <ul style="list-style-type: none"> - Community impact - Experienced staff to provide 	Case management is utilized to assist in identifying and fulfilling patient’s and family’s needs <ul style="list-style-type: none"> - Discharge planning Symptom management is treated by the admitting physician or hospitalist <ul style="list-style-type: none"> - Filling a gap or need

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
			serious illness care - Filling a gap or need	
Serious Illness Care Impact:				
Limitations to Providing Serious Illness and Palliative Care (Hospitals with PC)	Limited funding and reimbursement for PC, hospital doing this for the benefit of constituents - Payment streams	Limited reimbursement and revenue stream from palliative care service created challenges for sustainability and model changes - Payment streams	Limited IDT, short staffing, and unrealistic expectations within the ICU setting may impact care - Missed opportunities in providing serious illness care	Short staffing and turnover have negatively impacted serious illness care. - Staffing limitations
Limitations to Providing Serious Illness Care (Hospitals without PC)	Delayed PC referrals and goals of care conversations due to misunderstanding of symptom management vs. end-of-life care - Delayed timing Delayed goals of care conversations due to hesitation - Clinician hesitancy Generational differences among	A knowledge deficit within the community and clinicians still limits access to early palliative care services - Stigma with palliative care - Community education gaps Hesitation with the use of palliative care services is seen with some physicians	- Staffing challenges Unrealistic expectations of families and delayed goals of care conversations have impacted serious illness care - Delayed timing - Impeding provider in the development of palliative care	Leadership changes have been challenging in moving forward with changes or new program implementation - Leadership changes

Theme/Subtheme	Hospital A (+PC)	Hospital B (+PC)	Hospital C (-PC)	Hospital D (-PC)
	providers impacted uptake	- Clinician hesitancy	- Unrealistic expectations of patients and families	
	- generational differences in use of palliative care	Generational differences among providers impacted uptake		
		- generational differences in use of palliative care		