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# “We want to improve our practices. We want to improve patient outcomes”: An Evaluation of UCLA Health’s Data-Sharing Partnership with 12 Hospice Agencies

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# “We want to improve our practices. We want to improve patient outcomes”: An Evaluation of UCLA Health’s Data-Sharing Partnership with 12 Hospice Agencies

By

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2013

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An executive summary of
a thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Behavioral, Social, and Health Education Sciences
2020

# EXECUTIVE SUMMARY

## Background:

Hospice care is specialized care for people at the end of their life (*End of Life Care*, n.d.) that relieves patient suffering while delivering services often within the home environment (Kumar et al., 2016). The use of hospice services has been linked to improvements in patient outcomes and satisfaction (Meier, 2011). Hospice admissions within the last six months of life are significantly associated with improved patient satisfaction, better pain control, reduced hospital days, and fewer hospital deaths (B. Black et al., 2011; Kleinpell et al., 2019).

UCLA Health, an academic medical center located in Los Angeles, California, has partnerships with 12 local hospice agencies. UCLA Health does not provide its own outpatient hospice care and relies on community-based hospice agencies to provide hospice care. As part of the relationship between UCLA Health and the hospice agencies, monthly data regarding the status of UCLA Health patients who have made contact with any of the hospice agencies are reported by the hospices to UCLA Health.

## Purpose:

Informed by the theory of interorganizational relations, the overall purpose of this thesis is to evaluate the current partnerships between UCLA Health and hospice agencies. This will be achieved through the following aims:

1. Describe the current state of collaboration between hospice agencies and UCLA Health
2. Examine stakeholders' perceptions of the collaboration between hospice agencies and UCLA Health
3. Assess end-of-life quality of care, by hospice agency, for UCLA Health patients

## Methods:

A mixed-methods approach was utilized for this evaluation. In order to determine the current state of collaboration between hospice agencies and UCLA Health, the frequency of monthly data reporting was determined from 2018 to 2019 and trends were compared. In order to examine stakeholders' perceptions of the collaboration between hospice agencies and UCLA Health, key informant interviews were conducted with three hospice stakeholders and two UCLA Health stakeholders. In order to assess end-of-life quality of care for UCLA Health patients by each hospice agency, descriptive statistical analysis was performed on measures such as age, hospice enrollment, reason for non-enrollment, discharge status, and length of stay.

## Results:

The results showed that the majority of hospices remained consistent in their reporting of data between 2018 and 2019. There was one hospice agency who had high reporting rates in 2018, but dropped off in 2019. The key informant interviews revealed five key themes: improving the efficiency and content of the current spreadsheet format, common shared goal of improving quality of care, desire for mutually beneficial collaboration, frequency of receiving feedback, and desire for comparison to other hospices through feedback loop. The quantitative analysis revealed differences in quality of care between the hospice agencies, including in length-of-stay and discharge status.

## Recommendations:

There are a total of five recommendations that emerged from this evaluation:

1. Implement monthly data report back to hospice agencies, including comparisons to the other hospice agencies in partnership with UCLA Health.
2. Schedule a regular quarterly conference call with all of the hospice agencies. In addition to these regularly scheduled calls, communicate with hospice agencies that they can contact UCLA Health about the data-sharing process at any time.
3. Monitor national quality data from Hospice Compare website and evaluate in context of hospice partnerships.
4. Reduce current security features on the spreadsheet to enable hospices to have fewer barriers to data entry.
5. Evaluate the master spreadsheet based on necessity and usefulness of information.

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# ACKNOWLEDGEMENTS

I would like to extend my sincerest gratitude to my Thesis Chair, Dr. Elizabeth Walker, for your mentorship and guidance throughout my time at Rollins. Ever since I had you as my professor during my first semester, I have always appreciated your honesty, warmth, and willingness to help me solve any problem. I would also like to thank my Thesis Committee Member, Dr. Delia Lang, for serving on my committee and as a mentor during my second year at Rollins.

In addition to those at Rollins, I could not have completed my thesis without the support of the team at UCLA Health including Nicole Douglas, Brandy Bryant, Dr. Anne Walling, Dr. Neil Wenger, Jeannie Meyer, and Dr. Peter Phung. I am so appreciative to each of you for your guidance during my Summer 2019 Applied Practicum Experience and for allowing me to continue this important work as part of my thesis.

I would finally like to thank my incredible family and friends for being a sounding board, an editing eye, and my greatest support system.

Lastly, I would like to dedicate my thesis to my grandparents, whose love and light at the end of their lives sparked my passion for this topic.

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# CHAPTER 1: LITERATURE REVIEW

## Landscape of End-Of-Life Care in the United States

End-of-life care is defined as the care provided to seriously ill patients who have a condition that will lead to death (Wiener & Tilly, 2003). End-of-life care may include physical, social, emotional, and spiritual support for patients and their family members (National Cancer Institute, 2011). The goal of end-of-life care is to control symptoms and pain so that patients can be as comfortable as possible during the end of their life (National Cancer Institute, 2011).

In the United States, end-of-life care is often uncoordinated and fragmented (Wiener & Tilly, 2003). At the end of life, patients often experience multiple transitions and suffer the consequences of the resulting discontinuities in care, including medication errors, disruptions in care planning, and failures to coordinate care (Institute of Medicine, 2015). In the last month of life, one in two Medicare beneficiaries visits an emergency department, one in three Medicare beneficiaries is admitted to an intensive care unit (ICU), and one in five Medicare beneficiaries has inpatient surgery (Halpern, 2015). These types of hospital-based approaches to managing patients at the end of their life can inflict unnecessary patient suffering and negatively impact hospital resources (Cardona-Morrell et al., 2016).

During the past century, a major shift occurred in the leading cause of death for older adults, from infectious diseases to chronic and degenerative diseases (Frieden, n.d.). Two out of three older Americans have multiple chronic conditions, and treatment for older Americans accounts for 66% of the country’s health care budget (Frieden, n.d.). Between 2014 and 2060, the population of adults ages 65 and over is expected to grow from 15% to 24% in the United States (Colby & Ortman, 2014). The aging population of the United States has wide-ranging implications for American society, especially on the public health, social service, and health care systems (Frieden, n.d.). It will be the responsibility of society to ensure the aging population lives independently for as long as possible, obtains health care and education when self-managing multiple chronic illnesses, and receives high-quality care in long-term facilities (Grady, 2011). It is imperative that health care services adapt to this demographic change by providing adequate resources for end-of-life care (Etkind et al., 2017).

Improving the quality of end-of-life care has been a growing area of focus, but there are numerous barriers, such as a fragmented healthcare system, difficulties in accurately identifying an individual’s prognosis, and gaining access to vulnerable populations (Kale et al., 2016). Most Americans continue to lack knowledge about available end-of-life care choices; do not engage in a meaningful dialogue with their friends, family, and healthcare professionals about their end-of-life care preferences; and do not demand high-quality and compassionate care from healthcare providers (Meghani & Hinds, 2015). Most individuals approaching the end of life are not mentally, physically, or cognitively able to make decisions about their own care (Meghani & Hinds, 2015). In cases where individuals cannot make their own end-of-life care decisions for themselves, the burden of making medical decisions falls on their families or caregivers (Kale et al., 2016). One out of eight bereaved family members report that the care provided in the last month of life was not consistent with the decedent’s wishes (Khandelwal et al., 2017).

End-of-life care can be provided in a variety of settings and is dependent on factors such as the level of care required, available resources, and patients' goals of care (Bernazzani, 2016). Individuals can receive end-of-life care in settings such as home-based care, long-term care facilities, hospital-based care, and hospice agencies (Bernazzani, 2016). For the purpose of this evaluation, hospice agencies will be the end-of-life care facility focus.

## Hospice Care

Hospice care is specialized care for people at the end of their life (*End of Life Care*, n.d.) that relieves patient suffering while delivering services often within the home environment (Kumar et al., 2016). Hospice care focuses on pain, symptoms, and stress of a serious illness during the terminal phase, typically defined as a life expectancy of six-months or less (National Hospice and Palliative Care Organization, 2019a). Hospices provide support and interdisciplinary care to dying patients and their families by focusing on their physical, spiritual, social, and emotional needs (Cagle, Van Dussen, et al., 2016). The hospice team typically consists of clergy, home health aides, hospice physician, nurses, social workers, volunteers and may include speech therapists, physical therapists, occupational therapists, and the individual's personal physician if needed (National Hospice and Palliative Care Organization, 2019b). The major responsibilities of the hospice care team are to manage the patient's pain and symptoms; provide emotional support; provide needed medications, medical supplies, and equipment; teach family members how to care for the patient; deliver special services when needed; make short-term inpatient care available when symptoms or pain become too difficult to manage at home or respite time is needed; and provide grief support to surviving friends and family (National Hospice and Palliative Care Organization, 2019b).

Hospice care is a form of palliative care at the end of life (Cagle, LaMantia, et al., 2016). Palliative care focuses on symptom management, relieving suffering, and improving quality of life, but does not require a focus on end-of-life care or a particular life expectancy (Resnick, 2012). Hospice care is a specialized and intense form of palliative care that emphasizes quality of life issues, helps in managing disease processes to minimize suffering, and helps patients and families adjust to difficulties brought on by advanced illnesses (National Hospice and Palliative Care Organization & The Center to Advance Palliative Care, 2001).

The idea of hospice care was first introduced in the United States during the 1960s, leading to the global acceptance of the hospice movement in the 1970s (Lutz, 2011). In 1982, Congress decided that the benefits of hospice care were significant enough to create a Medicare hospice benefit, which provided coverage for hospice care (Davis, 1988). Since then, the use of hospice services has grown rapidly over the last two decades (Lupu et al., 2018). In 2017, 1.49 million Medicare beneficiaries received hospice care for at least one day, a 4.5% increase from 2016 (National Hospice and Palliative Care Organization, 2019c). The Institute of Medicine stated in 2014 that there were not enough specialty-trained physicians in hospice and palliative medicine to meet the current patient need, let alone the future need (Committee on Approaching Death: Addressing Key End of Life, 2015).

### *Hospice Utilization*

Much of the data on hospice utilization are from Medicare beneficiaries. Among Medicare beneficiaries in 2017 who used hospice, 58.4% were female, 5.1% were less than 65 years old, and 64.2% were at least 80 years old (National Hospice and Palliative Care Organization, 2019c). The racial breakdown for hospice utilization among Medicare beneficiaries that year was 82.5% Caucasian, 8.2% African American, and 6.4% Hispanic (National Hospice and Palliative Care Organization, 2019c). The top three principal diagnoses for hospice decedents in 2016 and 2017 were cancer (30.1%-31.1%), circulatory/heart (17.6%), and dementia (15.4%-15.6%) (National Hospice and Palliative Care Organization, 2019c). Between 2012 and 2017, hospice patients spent between 74.5 to 79 days in hospice on average (National Hospice and Palliative Care Organization, 2019c). Between 2015 and 2017, 26.2% of hospice patients spent 7 days or fewer in hospice, 35.3% of hospice patients spent between 8 and 60 days in hospice, and 38.5% spent more than 61 days in hospice (National Hospice and Palliative Care Organization, 2019c).

### *Levels of Hospice Care*

The Centers for Medicare and Medicaid Services (CMS) requires four levels of care be available for hospice enrollees: routine home care, continuous home care, inpatient respite care, and general inpatient (GIP) care (Department of Health and Human Services et al., 2010). Hospice patients spend the majority of their time in hospice receiving routine home care, totaling over 97.5% of the days spent in hospice receiving care (National Center for Health Statistics (U.S.), 2019; National Hospice and Palliative Care Organization, 2019a). Most hospices allow the nurse case manager to decide, with the patient and family, what supportive services and personnel are needed and the frequency with which the services should be delivered for routine home care (Berry et al., 2017).

Continuous home care is available for patients who need intensive services during a crisis between 8 and 24 hours, and consists of licensed nursing care that is supplemented by a social worker or home health aide (Berry et al., 2017). The primary goal of continuous home care is to help hospice enrollees stay at home (Wang et al., 2016). Between July and December 2011, 43% of hospices nationally provided continuous home care to at least one patient, and among those hospices, 11.4% of Medicare beneficiaries used continuous home care (Wang et al., 2016). The use of continuous home care on the day before death was associated with an approximately threefold reduction in the rate of inpatient death (Casarett et al., 2015). Furthermore, the use of any continuous health care in hospice decedents reduced their likelihood of experiencing hospice disenrollment or hospitalization after enrollment (Wang et al., 2016). In 2017, only 0.2% of hospice patient days of care was spent utilizing continuous home care (National Hospice and Palliative Care Organization, 2019c).

Inpatient respite care is a short-term stay in an inpatient facility, with the purpose of offering relief for the family caregiver (Berry et al., 2017). Inpatient respite care can be provided in a Medicare-approved facility, such as a hospice inpatient facility, hospital, or nursing home and hospice patients can stay up to 5 days at a time (Department of Health and Human Services, 2019). In 2017, only 0.3% of hospice patient days of care was spent in inpatient respite care (National Hospice and Palliative Care Organization, 2019c). Respite for caregivers is an important component of hospice care for patients and their families (Olsen et al., 2011). One study in the United Kingdom found that among caregivers who received respite care, 85% of those caregivers found the respite care very useful (McKay et al., 2013). Another study found that 45% of caregivers of persons with dementia had unmet mental health needs, most of whom needed emotional support or respite care (B. S. Black et al., 2013).

General inpatient (GIP) care is for patients in hospice who need constant skilled nursing support (Berry et al., 2017). GIP care occurs in nursing homes, hospitals, or hospice-owned facilities that must meet certain requirements for reimbursement (Lysaght Hurley et al., 2015). In 2011, 23% of Medicare hospice beneficiaries received GIP care and 33% of beneficiaries had GIP stays longer than five days, with 11% lasting 10 days or more (Medicare Hospice: Use of General Inpatient Care, 2013). Between 2012 and 2017, the amount of days of care that hospice patients spent in GIP care ranged between 1.8% and 1.3% of total hospice days respectively, with a downward trend over the years (National Hospice and Palliative Care Organization, 2019c).

### ***Measuring Hospice Quality of Care***

Hospice quality is measured both objectively by patient care processes that hospices engage in and subjectively by family/caregiver ratings of care that the deceased hospice patient received (Centers for Medicare and Medicaid Services, 2019). The quality of hospice care varies widely and is sometimes suboptimal, in part due to the growth in hospice services (Broyles et al., 2016). Measuring the quality of hospice care delivery is essential to evaluate and improve the care provided by hospice programs (Dy et al., 2015).

In 2012, CMS implemented the Hospice Quality Reporting Program (HQRP) which is comprised of two reporting requirements: the Hospice Item Set (HIS) and the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS) (Centers for Medicare and Medicaid Services, 2019). The HIS is a standardized, patient-level data instrument developed by CMS to calculate nine quality measures (Zheng et al., 2019): patients treated with an opioid who are given a bowel regimen, pain screening, pain assessment, dyspnea screening, dyspnea treatment, treatment preferences, beliefs/values addressed (if desired by the patient), hospice visits when death is imminent, and a composite measure of all the previous care processes denoted above (Centers for Medicare and Medicaid Services, 2019). For each patient admitted to hospice since July 2014, hospice agencies are required to submit admission and discharge records in order to calculate the HIS measure (NHPCO, 2020).

The Hospice CAHPS is a post-death survey completed by family caregivers, to provide a retrospective understanding of families' and patients' experience with hospice care (Broyles et al., 2016). The Hospice CAHPS consists of 47 questions grouped into the following measures: communication with family, getting timely help, treating patients with respect, emotional and spiritual support, help for pain and symptoms, training family to care for patient, rating of this hospice, willingness to recommend this hospice (Centers for Medicare and Medicaid Services, 2018). The survey is administered several months after the hospice patient is deceased and is administered either through the mail, telephone, or a combination of both modalities (Centers for Medicare and Medicaid Services, 2018).

Much of the data collected through the HQRP are displayed for the public to see. In 2017, CMS created the Hospice Compare website, with the goal of helping individuals compare hospices based on their performances and assist in decision-making (Centers for Medicare and Medicaid Services, 2017). Hospice Compare also serves to allow regulators to monitor hospice quality and for researchers to examine hospice quality improvement (Hsu et al., 2019). The Hospice Compare website allows individuals to search for specific hospice agencies and/or hospice locations in order to access general hospice information, data on family experience of care, and quality of care data (Centers for Medicare and Medicaid Services, 2017). Some example indicators found on the website include the percentage of patients who have received at least one visit in the last three days of life from a registered nurse, physician, nurse practitioner, or physician assistant; percentage of friends or family members who reported the hospice treated the patient with respect; and the percentage of friends or family members who reported the patient received timely help (Centers for Medicare and Medicaid Services, 2017). In order to encourage the participation of hospices to submit their performance data to Hospice Compare, CMS imposed a 2% reduction in reimbursement to hospices that do not participate (Hsu et al., 2019). This has proved to be successful, with 93.7% of hospice agencies in the United States participating in public reporting and measure disclosure (Hsu et al., 2019).

### *Outcomes of Hospice Utilization*

The use of hospice services has been linked to improvements in patient outcomes and satisfaction (Meier, 2011). Hospice admissions within the last six months of life are significantly associated with improved patient satisfaction, better pain control, reduced hospital days, and fewer hospital deaths (B. Black et al., 2011; Kleinpell et al., 2019). Individuals who enroll in hospice within 105 days prior to death have lower Medicare expenditures, rates of hospital and ICU use, 30-day hospital readmissions, and deaths in hospital when compared to non-hospice enrollees (Kelley et al., 2013). In a study of poor-prognosis cancer patients, those who were enrolled in hospice had significantly fewer emergency department visits after hospice enrollment than matched non-hospice patients, despite relatively similar emergency department use prior to hospice enrollment (Obermeyer et al., 2016).

The positive outcomes of hospice care can also extend to the family members of the hospice patients. Bereaved caregivers of advanced cancer patients who died in a hospital or ICU are at an increased risk for developing psychiatric illnesses when compared to those who died at home on hospice (Wright et al., 2010). Caregivers of dementia patients enrolled in hospice were almost twice as likely to rate their satisfaction with care provided as very good or excellent when compared to caregivers of individuals not enrolled in hospice (Shega et al., 2008) and reported fewer unmet needs and concerns with the quality of care for their loved ones (Teno et al., 2011).

## Hospice and Health System Collaboration

Coordinated relationships between organizations can support knowledge exchange and inform organizational practices and planning (Loitz et al., 2017). Collaboration between hospitals and hospice programs, with the goal of improved end-of-life care, can benefit patients, families, hospitals, and hospice agencies (National Hospice and Palliative Care Organization & The Center to Advance Palliative Care, 2001). In order to provide high-quality palliative and end-of-life care, healthcare professionals in hospitals and hospice agencies must collaborate, with an emphasis on clear communication and coordination of treatment and services (Carroll et al., 2007).

Historically, hospices have not participated in data collection or research in collaboration with academic entities or health systems (Abernethy et al., 2011). Hospices typically have been focused on the community aspect of care, which decreases the likelihood that they will interact with traditional research activities (Bull et al., 2010). Formal partnerships between academic health systems and hospices can promote high quality research in the hospice setting and diminish barriers that hospices may face by themselves (Tolley & Payne, 2007). Some of the barriers identified by hospices to conducting research include the hospices not believing that patients/families would be interested in research, a concern that research would increase vulnerability of patients, and having difficulty in obtaining consent to conduct research (Tolley & Payne, 2007). Partnering with academic medical centers, or health entities, that have the resources to collect and manage data, can be utilized in creating a relationship between hospice agencies and health systems (Tolley & Payne, 2007).

There appears to be only a handful of current partnerships between academic medical centers and hospice agencies that engage in relationship-building, data sharing, and provide an avenue for quality improvement. One such partnership is between UCLA Health, which is an academic medical center located in Southern California, and 12 Los Angeles-based hospice agencies. In this arrangement, UCLA Health has partnered with each hospice agency independently without a centralized organization for all the hospice agencies to communicate with one another. This is in contrast to other health systems, who have created a consortium of hospice agencies that communicate with one another and with the medical center as well (Bull et al., 2010; Roscoe et al., 2004).

## Theoretical Framework

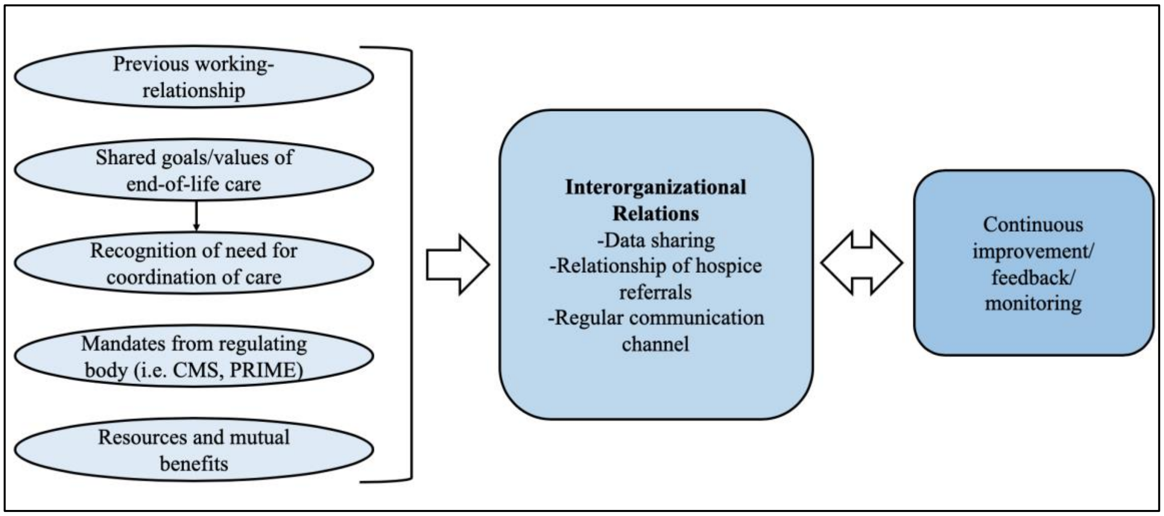
A theory-based approach is useful to better understand the role of collaboration in hospice care, specifically when considering the relationship between UCLA Health and community-based hospice agencies. The idea of interorganizational relations is concerned with understanding the character and pattern, origins, rationale, and consequences of relationships between and among organizations (Cropper et al., 2009). The Interorganizational Relations (IOR) theory is based on the idea that collaboration among organizations can lead to a more comprehensive approach to addressing an issue than what can be accomplished by one organization (Glanz et al., 2014). There are a variety of factors that promote IOR, including the desire for acquiring economic (i.e. funds, materials) and non-economic (i.e. information, legitimacy, support) resources, as well as the pursuit of similar goals and activities (Sofaer & Myrtle, 1991). In practice, the IOR theory consists of determining which organizations in a community are concerned about a given problem and developing strategies to help collaborating organizations overcome barriers at each stage (Glanz et al., 2014). One barrier that continues to influence the development of stable interorganizational relationships is that in addition to benefits gained by collaboration, each organization in the partnership loses some control over its own operation and must invest some of their own limited resources (Bolland & Wilson, 1994).

Interorganizational relations play an important role in the health care setting (Alter, 1987; Kwait, 2001; Miller, 2010; Miller & Mor, 2002). With the emergence of complicated health problems since the late 20th century, addressing these issues through a cooperative approach by multiple organizations became necessary (Sofaer & Myrtle, 1991). Collaboration among professionals and organizations is essential in order to achieve effectiveness in providing person-centered healthcare (Karlsson et al., 2019). Previous literature has detailed the state of interorganizational relations between hospice organizations and nursing homes, with both agencies having shared goals of patient care. In the case of nursing homes and hospice, the purpose of establishing interorganizational relationships is to enhance coordination of care, communication among staff, and allow for merging of care protocols (Miller & Mor, 2002). Ideally, a partnership between these two organizations would allow for the knowledge of hospice staff to be transferred to nursing home staff to be used when taking care of patients at the end of life (Miller & Mor, 2002). Nursing home and hospice partnerships were found to be more successful if the partnerships stemmed from well-planned efforts by hospice leaders and informed by the expectations from nursing home CEOs (Miller, 2010).

Insight from nursing home and hospice interorganizational relations, as well as the literature on the key components of the IOR theory, can help provide insight into the ways that interorganizational relations will play a factor between a large health system, such as UCLA Health, and community-based hospice agencies. Figure 1 details the conceptual model used to guide this evaluation, highlighting the key factors that facilitate interorganizational relations and sustain these relationships over time.

**Figure 1**

*Theoretical Framework*



## Evaluation Aims

The overall purpose of this thesis is to evaluate the current partnerships between UCLA Health and hospice agencies. This will be achieved through the following aims:

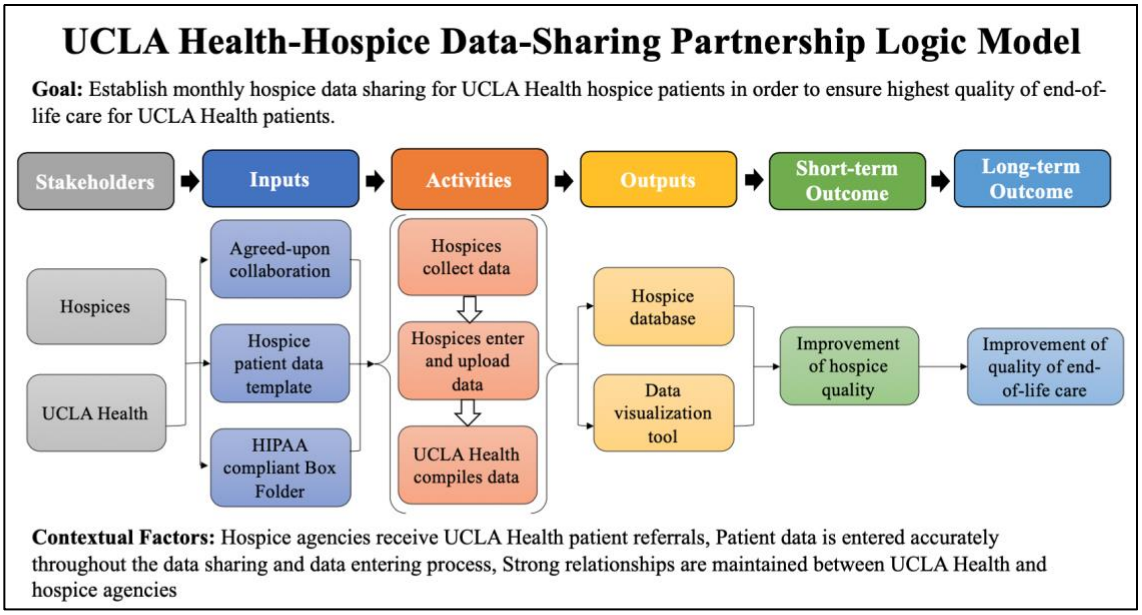
1. Describe the current state of collaboration between hospice agencies and UCLA Health
2. Examine stakeholders’ perceptions of the collaboration between hospice agencies and UCLA Health
3. Assess end-of-life quality of care, by hospice agency, for UCLA Health patients

# CHAPTER 2: PROGRAM DESCRIPTION

This chapter provides a detailed description of the logic model guiding the evaluation (see Figure 2). In addition, this section provides background on the history of the UCLA Health and hospice data-sharing partnership and the Public Hospital Redesign and Incentives in Medi-Cal (PRIME) quality metrics.

**Figure 2**

*Logic Model*



This logic model details a high-level overview of the UCLA Health and hospice data-sharing program. The two main involved stakeholders are the hospice agencies and UCLA Health. Further details on the stakeholders will be provided in Chapter 3. In order for the stakeholders to work together through a partnership, the stakeholders first had to agree on how they would collaborate, create a hospice patient data template to allow for the transfer of data, and create a HIPAA compliant Box Folder to allow for the secure sharing of patient data.

Once the inputs were obtained, the data-sharing partnership required that the hospices actually share the data, enter and upload the data, and then have UCLA Health compile the individual monthly data into a centralized spreadsheet. After the data are compiled into a centralized spreadsheet, this effectively becomes the hospice database and can be used to create a data visualization tool. In this workflow, the data visualization tool took the form of a Tableau dashboard that can display patient metrics from each hospice agency. Ultimately, the hospice database and data visualization tool leads to the short-term outcome objective of an overall improvement of hospice quality and a long-term outcome objective of an overall improvement of the quality of end-of-life care. The following sections will explain the details of the program and logic model with more detail.

## UCLA Health-Hospice Data-Sharing History and Partnership

For over 15 years, healthcare providers at UCLA Health have had relationships with local hospice agencies and informal data sharing between the organizations. In 2016, as part of the UCLA Health Advanced Care Planning Initiative, a formalized process was established to collect UCLA Health hospice patient data through a standardized process using a structured Excel template. The purpose/benefit of data sharing was to collect quality data on UCLA Health patients, as well as to be able to capture patient outcomes for the hospice agencies that may have been missed without data collection. For example, once patients leave UCLA Health and go on hospice, UCLA Health is only aware of when they die if the hospice agency reports this information or if a family/friend reports this information to UCLA Health. By having a regular reporting system by the hospice agencies, previous UCLA Health patient outcomes can be tracked and monitored. This standardized process has grown to include 12 Los Angeles hospice agencies since 2016.

In order to enable hospice agencies to share data with UCLA Health, a contact person was identified at each hospice agency. This contact person was in charge of completing an Excel sheet each month detailing the status of any UCLA Health patient who had made contact with their hospice agency, which included those that enrolled in the hospice and those who did not. Upon completing the form each month, the hospice contact person would upload the Excel sheet into a HIPAA compliant Box Folder to share the file. Once the Excel sheet was uploaded, an employee from UCLA Health would enter the information from each hospice agency into a master spreadsheet. Whoever was in charge of data collection at UCLA Health would send monthly email reminders to the hospice agencies that had not entered and uploaded their monthly data. These emails would be sent as frequently as needed until data were uploaded by the hospice agency.

The master spreadsheet holds all of the hospice monthly data in one local space. The master Excel spreadsheet has a color-coding system to highlight various information. Each hospice agency is assigned a different color to differentiate the 12 agencies. If a patient is entered into the master spreadsheet more than one time, the multiple entries are highlighted in yellow. This would occur if a patient made contact with multiple hospice agencies or revoked hospice, which is a term that refers to when a hospice patient and/or family member decides to withdraw the patient from hospice care, and chooses to enroll in another hospice agency (*Hospice Discharge, Revocation and Transfers*, n.d.).

When the hospice agencies completed their monthly data reporting, they did not have access to the UCLA Health patients' medical record numbers (MRNs). In order to be able to link the hospice patients to UCLA Health, the UCLA Health employee entering the data would have to conduct a manual search in the UCLA Electronic Health Record (EHR) system, Care Connect, for the patients' MRN numbers. This would be important so that information about UCLA Health patients in hospice could be conveyed back to the UCLA Health system (i.e. in the case when a patient died but UCLA Health did not receive notice, this could be followed up by someone from UCLA Health). MRN numbers could only be input into the Excel spreadsheet if the patient's name and date of birth (DOB) matched the record in Care Connect. Once the MRN number was verified and entered into the Excel spreadsheet, a formula was programmed into the master Excel spreadsheet for any duplicate MRN values to turn into a red font. Any red MRNs would be accompanied by a yellow row highlight as well. In general, patients who were in hospice for more than a single month and without a discharge status change remained as one entry in the spreadsheet.

In mid-2019, UCLA Health began to push for a hospice database that could be used to inform hospice quality metrics and improve quality of care for UCLA Health patients in hospice. Prior to this, the master spreadsheet held a wide amount of data, but the data were not reviewed to assess patient outcomes. There were problems with the previous master spreadsheet format, including frequent missing data and data errors, difficulties in analyzing the data, and the inability to function as a database. In order to be able to utilize the vast amount of data UCLA Health had, there was a need to improve the data-sharing process and focus on how to optimize the partnerships between UCLA Health and the hospice agencies to improve patient quality of care.

During the summer of 2019, the evaluator worked on the master spreadsheet in order to standardize the data entries, create a database through Microsoft Access and SQL, and prepare the data to be used to visually display quality metrics in order to be used throughout the UCLA Health system. Throughout the process, informal feedback was gathered from the hospice agencies about the ways in which the data-sharing process could be improved. The purpose of this evaluation is to formalize the feedback and provide concrete recommendations as to the ways that the data-sharing process, visualization, and feedback loop can be optimized going forward.

## PRIME Hospice Quality Measures

UCLA Health is required to report data to California's quality incentive program, called Public Hospital Redesign and Incentives in Medi-Cal (PRIME). PRIME is a pay-for-performance program where California's public health care system and certain hospitals use evidence-based quality improvement methods to achieve performance targets and improve patient outcomes ("Public Hospital Redesign and Incentives in Medi-Cal (PRIME)," 2019). The PRIME federal funding is contingent on health systems (e.g. UCLA Health) meeting the PRIME targets and demonstrating continued improvement ("Public Hospital Redesign and Incentives in Medi-Cal (PRIME)," 2019).

There are five PRIME measures that deal specifically with hospice and end-of-life care. UCLA Health reports on all five measures: 2.7.1. Advance Care Plan, 2.7.3. Inpatient Palliative Care Treatment Preferences, 2.7.4. Outpatient Palliative Care Treatment Preferences, 2.7.5. Palliative Care Services Provided to Patients with Serious

Illness, and 2.7.6. Proportion Admitted to Hospice for Less Than 3 Days. The specific focus of this evaluation is on measure 2.7.6. This measure is important because patients enrolled in hospice for 3 days or less before their death are limited in the benefits they may gain from hospice services (*NQF 0216: Proportion Admitted to Hospice for less than 3 days*, 2016).

The PRIME measurement period occurs on an annual basis and the population consists of UCLA Health patients with at least two primary care encounters or Medi-Cal Managed Care beneficiaries with an assigned UCLA Health primary care provider. Measure 2.7.6 has an eligible population of patients 18 years and older during the measurement period. Patients are included in the denominator, if they were admitted to hospice and died during the measurement period. Patients are included in the numerator, if the patient meets the denominator criteria and spent less than three distinct days in hospice. Since this is an inverse measure, it is considered a numerator success if patients are admitted to hospice three days or longer. UCLA Health receives an incentive of nearly $447,800 from the state, if the PRIME target is met for this measure within the measurement period.

# CHAPTER 3: STAKEHOLDER DESCRIPTION

Due to the nature of the multiple relationships between UCLA Health and the 12 hospice agencies, there are many stakeholders involved. The following section will provide more details into UCLA Health and each of the hospice agency stakeholders.

## UCLA Health

UCLA Health is an academic medical center located in Los Angeles, California and, as of 2019, was ranked #1 in California and #6 in the nation for best hospital (*UCLA Health*, 2019b). UCLA Health is comprised of four hospitals and 180 outpatient clinics located throughout Southern California (*UCLA Health*, 2019b). The mission of UCLA Health is to "deliver leading-edge patient care, research, and education" and its vision is "to heal humankind, one patient at a time, by improving health, alleviating suffering and delivering acts of kindness" (*UCLA Health*, 2019b). UCLA Health has nearly 600,000 unique patient visits per year, with 2.5 million outpatient clinic visits and 40,000 hospital stays per year (*UCLA Health*, 2019b).

### *UCLA Health Palliative Care*

UCLA Health has a palliative care team that visits with chronically, critically, or terminally ill patients and their loved ones in the UCLA Health hospital to better understand what is important to them (UCLA Health, 2019a). The UCLA Health palliative care team provides hospital-based and outpatient palliative care services (UCLA Health, 2019a). The palliative care team at UCLA Health consists of physicians, social workers, nurses, a clinical nurse specialist, and care coordinators (UCLA Health, 2019a). The UCLA Health palliative care team makes frequent referrals to hospice agencies, with 80% of all UCLA Health hospital referrals to hospice between 2018 and

2019 being to one of the 12 hospices that UCLA Health is partnered with. Despite its wide range of healthcare services, especially palliative care services, UCLA Health does not provide any outpatient hospice care directly (UCLA Health, 2019a). In order to inform the palliative care team about the quality of care that the hospice agencies are providing to UCLA Health patients, it will be beneficial to optimize the data sharing and partnerships between UCLA Health and the hospice agencies.

### ***UCLA Health Quality Management Services***

The UCLA Health Quality Management Services Department is comprised of the following teams: patient safety, clinical quality improvement specialists, clinical epidemiology and infection prevention, quality management services, quality informatics and analytics, and quality incentive program management (QIPM) (*UCLA Health | Quality Management Services*, n.d.).. The UCLA Health QIPM team focuses on meeting the state's quality incentive program, PRIME. PRIME is a pay-for-performance program for California's public health care system and certain hospitals and federal funding is contingent on meeting certain performance targets and showing continuous improvement ("Public Hospital Redesign and Incentives in Medi-Cal (PRIME)," 2019). The UCLA Health QIPM team helps to track and monitor the patient data relevant to PRIME measures, including those relating to hospice care, and implement improvement activities to ensure that UCLA Health is making progress to meet their targets.

## **Hospice Agencies**

The following section will detail a brief background on each of the 12 hospice agencies that have a formal data-sharing partnership with UCLA Health. These hospice agencies directly report monthly data to UCLA Health about UCLA Health patients that make contact with their hospice agency. All of the hospice agencies have been de-identified and the information about each of the hospice agencies was retrieved from their respective websites. A summary of the trends of family caregivers' survey score and quality of care is also provided for the 12 hospices based on the Hospice Compare website.

### ***Hospice 1***

Hospice 1 provides services to residents of California and Arizona. Hospice 1 provides home health, palliative care, hospice care, nursing services, and caregiver services to patients and their loved ones.

### ***Hospice 2***

Hospice 2 is located in Southern California and serves the San Fernando Valley and Ventura County areas. Hospice 2 provides home health, palliative care, and hospice services and believes in a team approach for delivering care.

### ***Hospice 3***

Hospice 3 provides care for individuals located throughout the United States. The mission of Hospice 3 is to provide comfort, compassion, and care. Hospice 3 provides hospice, home health, and palliative care services to its patients.

### ***Hospice 4***

Hospice 4 is located in Southern California. Hospice 4's mission is to provide excellence in meeting the end-of-life care needs of the community. Hospice 4 provides emotional support, counseling, home medical equipment and medications, bereavement support, and a team approach for hospice care.

### ***Hospice 5***

Hospice 5 provides services to patients and families throughout Southern California. Hospice 5 provides palliative care, hospice care, and compassionate support to patients and families.

### ***Hospice 6***

Hospice 6 serves residents of the Los Angeles community. Hospice 6’s mission is to provide end-of-life care with honor, respect, and dignity. Hospice 6 provides hospice services and palliative care for patients and bereavement support for family members.

### ***Hospice 7***

Hospice 7 is located throughout the United States, with one of their locations serving the Los Angeles County area. The mission of Hospice 7 is to offer hope and honor life. Hospice 7 provides hospice services and offers music therapy and namaste care.

### ***Hospice 8***

Hospice 8 is located throughout the United States. Specifically in Southern California, Hospice 8 serves the Los Angeles County area. Hospice 8 provides comfort and dignity at the end of life.

### ***Hospice 9***

Hospice 9 serves residents of the San Fernando Valley and Los Angeles. Hospice 9’s mission is to provide high-quality care to patients. Hospice 9 provides services in hospice care, palliative care for pain and symptom management, and bereavement support.

### ***Hospice 10***

Hospice 10 serves the Southern California region. Hospice 10 has a team consisting of a medical director, registered nurses, home health aides, medical social worker, chaplain, pharmacists, and volunteers.

### ***Hospice 11***

Hospice 11 serves the Los Angeles community. The mission of Hospice 11 is to serve patients and their families by providing compassionate care. Hospice 11 provides hospice services for patients and their families, and provides integrative therapies such as art therapy, comfort touch, music activities, and more.

### ***Hospice 12***

Hospice 12 has multiple locations throughout the United States. Specifically in Southern California, Hospice 12 serves the Los Angeles and Ventura County areas. Hospice 12 provides services such as home hospice care, inpatient hospice care, emotional and spiritual care, and support groups.

## **National Metrics of Hospice Agencies**

Each of the 12 hospice agencies that partner with UCLA Health has publicly available reporting metrics, which characterize the quality of care of each hospice agency. This information, found on the national Hospice Compare website, showcases family and caregiver satisfaction and quality metrics for these hospices. Table 1 highlights the specific quality rankings from each hospice agency from the website (Centers for Medicare and Medicaid Services, n.d.).

Through the Hospice Compare website, eight “Family and Caregiver Survey” measures and two “Quality of Patient Care” measures were identified for each hospice agency. Data from the “Family and Caregiver Survey” were collected nationally between 3/31/2017 and 3/30/2019 (Centers for Medicare and Medicaid Services, 2017). Data from the “Quality of Patient Care” were collected nationally between 3/31/2018 and 3/30/2019 (Centers for Medicare and Medicaid Services, 2017). Below is a summary of trends for the family caregivers’ survey results and quality of patient care for the 12 hospice agencies with UCLA Health partnerships, based on the publicly available data found on the website.

### *Family Caregivers’ Survey Scores*

#### *Communication with family:*

The national average of the percentage of family members that rated that the hospice team “always” communicated well is 81%. All ten hospices with data fell below the national average, with a range of 68% and 80%.

#### *Getting timely help:*

The national average of the percentage of family members that rated that the hospice team “always” provided timely help is 78%. One hospice fell at the national average, with the remaining nine hospices with data falling below the national average. The range of scores was between 61% and 78%.

#### *Treating patients with respect:*

The national average of the percentage of family members that rated that the hospice team “always” treated the patient with respect is 91%. One hospice had a score above the national average of 93%, with the remaining nine hospices having data that fell below the national average. The range of scores was between 82% and 93%.

*Emotional and spiritual support:*

The national average of the percentage of family members that rated that the hospice team provided the “right amount” of emotional and spiritual support is 90%. Two hospices had scores above the national average between 91% and 93%, with the remaining eight hospices with data falling below the national average. The range of scores was between 79% and 93%.

*Help for pain and symptoms:*

The national average of the percentage of family members that rated that the patient “always” got the help they needed for pain and symptoms is 75%. Three hospices had scores above the national average between 76% and 78%, one hospice had a score at the national average, and the remaining six hospices had data that fell below the national average. The range of scores was between 63% and 78%.

*Training family to care for patient:*

The national average of the percentage of family members that rated that they “definitely” received the training they needed is 75%. All ten hospices with data fell below the national average, with a range of 61% and 72%.

*Rating of this hospice:*

The national average of the percentage of family members that rated the hospice agency a nine or 10 is 81%. One hospice fell above the national average, with the remaining nine hospices with data falling below the national average. The range of scores was between 67% and 85%.

*Willing to recommend this hospice:*

The national average of the percentage of family members that said YES, they would definitely recommend the hospice is 84%. Two hospices had scores above the national average between 86% and 88%, with the remaining eight hospices with data falling below the national average. The range of scores was between 66% and 88%.

### ***Quality of Patient Care Scores***

The national average of hospices with patients getting at least one visit from a registered nurse, a physician, a nurse practitioner, or a physician assistant in the last three days of life is 82.2%. All 11 hospices with data fell below the national average, with a range of 48.0% and 80.6%.

The national average of hospices with patients who got an assessment of all seven HIS quality measures at the beginning of hospice care to meet the HIS Comprehensive Assessment Measure requirements is 87.1%. Nine hospices had scores above the national average between 89.6% and 100%, and three hospices had scores below the national average. The range of scores was between 78.8% and 100%.

## Table 1

*Hospice Compare Metrics*

| HOSPICE COMPARE | Hospice 1 | Hospice 2 | Hospice 3 | Hospice 4 | Hospice 5 | Hospice 6 | Hospice 7 | Hospice 8 | Hospice 9 | Hospice 10 | Hospice 11 | Hospice 12 | National Average |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Family Caregivers' Survey Results** | | | | | | | | | | | | | |
| **Communication with family** | 80% | 76% | Not available | 78% | 73% | 79% | 73% | 74% | 68% | 76% | Not available | 72% | 81% |
| **Getting timely help** | 78% | 73% | Not available | 75% | 70% | 68% | 61% | 75% | 64% | 69% | Not available | 65% | 78% |
| **Treating patient with respect** | 89% | 88% | Not available | 93% | 86% | 89% | 83% | 88% | 82% | 90% | Not available | 83% | 91% |
| **Emotional and spiritual support** | 93% | 91% | Not available | 88% | 88% | 87% | 81% | 79% | 88% | 90% | Not available | 88% | 90% |
| **Help for pain and symptoms** | 78% | 75% | Not available | 76% | 69% | 70% | 69% | 64% | 63% | 78% | Not available | 69% | 75% |
| **Training family to care for patient** | 71% | 72% | Not available | 69% | 69% | 72% | 66% | 61% | 68% | 67% | Not available | 68% | 75% |
| **Rating of this hospice** | 85% | 80% | Not available | 80% | 75% | 79% | 74% | 67% | 73% | 75% | Not available | 74% | 81% |
| **Willing to recommend this hospice** | 88% | 83% | Not available | 86% | 78% | 82% | 74% | 66% | 80% | 79% | Not available | 76% | 84% |
| **Quality of Patient Care** | | | | | | | | | | | | | |
| **Percentage of patients getting at least one visit from a registered nurse, a physician, a nurse practitioner, or a physician assistant in the last 3 days of life** | 78.6% | 79.4% | 68.9% | Not available due to <20 patient stays | 71.7% | 65.3% | 80.6% | 72.1% | 48.0% | 63.4% | 56.3% | 68.6% | 82.2% |
| **Patients who got an assessment of all 7 HIS quality measures at the beginning of hospice care to meet the HIS Comprehensive Assessment Measure requirements** | 95.6% | 96.8% | 78.8% | 96.0% | 98.1% | 89.7% | 91.9% | 100% | 99.1% | 89.6% | 85.9% | 84.6% | 87.1% |

Blue cell: Hospice agency met or exceeded national average
Green cell: National average

# CHAPTER 4: METHODOLOGY

The evaluation used a mixed-methods approach in order to answer the three evaluation aims. The following sections describe each of the methodologies utilized for this evaluation.

## Evaluation Aim 1 Methodology:

Evaluation Aim 1 was to describe the current state of collaboration between hospice agencies and UCLA Health. This was examined by looking at the frequency of monthly spreadsheet reporting that the hospices completed in the last two years.

### *Frequency of Monthly Spreadsheet Reporting*

In order to determine the frequency of monthly data shared for each hospice agency, monthly records were reviewed from each hospice agency to determine what percentage of monthly reports were successfully submitted throughout 2018 and 2019. Three hospice agencies that did not have partnerships with UCLA Health in 2018 were excluded from the 2018 monthly reporting.

Hospice agencies were considered successful in completing the month's data submission if they uploaded an Excel document for the appropriate month. Late submissions were still considered as a successful submission for the month. Hospices that did not have any UCLA Health patients for the month were instructed to submit a monthly report stating that there were no UCLA Health patients present in their hospice for that month.

This data source was useful in determining the strength of the data-sharing partnership between the hospice agencies and UCLA Health. Data were examined in order to see the two-year reporting trends among hospice agencies.

## Evaluation Aim 2 Methodology:

Evaluation Aim 2 consisted of examining stakeholders' perceptions of the collaboration between hospice agencies and UCLA Health. This evaluation aim was assessed through the use of key informant interviews.

### *Key Informant Interviews*

In order to address Evaluation Aim 2, semi-structured interviews were conducted with key informants, which consisted of stakeholders at the hospice agencies and at UCLA Health. Key informant interviews were deemed appropriate in order to better understand each stakeholders' perspectives on optimizing partnerships between hospices and UCLA Health. Furthermore, qualitative methods are useful for understanding processes and exploring stakeholders' views (Hennink et al., 2011).

### *Sample and Recruitment*

The key informants included stakeholders at hospice agencies and UCLA Health. These categories of informants were chosen based on their direct involvement in the partnerships between UCLA Health and hospice agencies. These informants were also believed to be able to provide suggestions to improve the UCLA Health and hospice partnerships to benefit both organizations.

The evaluator worked directly with the key informants between June and August 2019 through a summer internship position at UCLA Health. Through the internship position, the evaluator made phone and email contact with each of the informants, and retained their contact information after the internship concluded. All informants were contacted by email with a standardized email template (Appendix). The email consisted of reintroducing the evaluator, explaining the purpose of the interviews, and scheduling a time to conduct the interview.

The evaluator contacted a total of 13 stakeholders at the 12 hospice agencies (one hospice agency had two contact people) a total of two times. One hospice informant responded after the initial email and two hospice informants responded after the second email. One stakeholder's email address was invalid and did not deliver. Both UCLA Health informants responded to the initial email that was sent to them.

This evaluation was determined by Emory University's Institutional Review Board (IRB) and UCLA Health's IRB to be a quality improvement and evaluation project and, therefore, not human subjects research. Thus, IRB review was not necessary.

### ***Data Collection***

Two interview guides were developed by the evaluator, with one for the stakeholders at the hospice agency and the other for stakeholders at UCLA Health. The members of the thesis committee, as well as key stakeholders at UCLA Health, reviewed the initial interview guide draft and suggestions were incorporated into the final interview guide. The hospice interview guide consisted of nine questions and the UCLA Health interview guide consisted of eight questions. The general format of the interview guide consisted of: introduction/background questions, perceptions on current data-sharing process, and opinions on the future of the data-sharing relationship between the hospice agencies and UCLA Health. Example interview questions consisted of: "*How can UCLA Health improve its existing partnerships with hospice agencies?*" and "*Is there other information that UCLA Health should be asking for on the monthly patient data* *spreadsheet that would be useful for your hospice agency or quality improvement? If so, can you share an example?"*

The evaluator conducted all five stakeholder interviews over the phone. Data collection occurred in January 2020. The interviews varied from 17 minutes to 37 minutes in length, with an average of 25 minutes. During the interviews, the evaluator was located in a private room with no one else present. The phone call was conducted over speakerphone so the evaluator could record the audio on a password-protected computer for data analysis purposes. Prior to the start of each interview, the evaluator explained the purpose of the interview, the steps taken to ensure confidentiality, and their ability to withdraw from the interview or refuse to answer questions at any time. The evaluator obtained verbal agreement from participants to complete and record the interview. During the interview, the evaluator took notes of important concepts that would be important for later data analysis.

Once the interviews were completed, the audio recordings were saved in a folder on a password-protected computer. Additionally, the audio recordings were temporarily stored in a secure Emory OneDrive folder to ensure the data were accessible on multiple devices. All recordings and interview notes were permanently deleted upon the completion of the project.

### ***Data Analysis***

All interview audio recordings were reviewed and transcribed. The evaluator used the websites Otter, Temi, and OTranscribe to assist with transcribing. After the website-assisted transcription was completed, the evaluator reviewed the transcripts for accuracy. Data analysis was guided by the principles of Interorganizational Relations (IOR) theory.

Transcripts were reviewed for themes that related to the factors that contribute to interorganizational relationships. Transcript coding was noted in the context of themes surrounding what contributes to beneficial partnerships, and how partnerships between the agencies could be optimized to allow for continued organizational relations. Information in the transcripts that was irrelevant to the evaluation aims or to IOR theory was not considered for the purposes of this evaluation. Microsoft Word was used to code the transcripts. A matrix was created that listed the different key informants and themes that emerged from coding in order to assess the similarities and differences in themes across the key informants.

## Evaluation Aim 3 Methodology:

Evaluation Aim 3 was to assess end-of-life quality of care, by hospice agency, for UCLA Health patients. This was achieved through the use of quantitative data analysis from the monthly data reporting by the hospice agencies.

### *Quantitative Data Analysis*

The data were comprised of hospice data that were collected monthly since 2015, although official partnerships were formed in 2016, and compiled into a master spreadsheet. Each hospice agency completed multiple fields of data for each hospice patient, including patient name, referring doctor, hospice diagnosis, discharge status, and type of care received. Based on the data that each hospice agency sent over every month, the individual spreadsheets were combined into a master spreadsheet that housed all of the patient data. The data were cleaned up initially between June 2019 and August 2019 while the evaluator was completing a summer internship with UCLA Health, and once again during the evaluation for any newer data.

The evaluation sample included all UCLA Health patients that presented to any of the 12 hospice agencies between June 2015 and December 2019. Any patient who made contact with one of the hospice agencies, including those who chose not to enroll, were included. Patients who made contact with multiple agencies were included as multiple entries in the spreadsheet. All of the data in the spreadsheet were de-identified and patient names were removed. All entries in the spreadsheet were given a unique patient number that was used during data analysis. All data analysis was conducted within Microsoft Excel. Relevant data for each section of analysis were filtered and analyzed through charts and formulas.

### *Demographics*

The average age of the patients at the time of their hospice referral was calculated for all patients who had a referral date and birthdate listed. An additional patient entry was removed due to having an invalid birthdate listed in the spreadsheet.

### *Enrollment and Non-Enrollment*

The patients in the spreadsheet were categorized as either enrolled or not enrolled into hospice. The total number of patients that made contact with each hospice agency was determined, as well as the number and percentage of patients that actually enrolled into each hospice agency. Among the patients that did not enroll, further analysis was performed to determine the reason for their non-enrollment. A total of 43 patients were excluded from the non-enrollment analysis due to their non-enrollment reasons being left blank. The most common reasons for non-enrollment, based on the total number of patients that did not enroll in hospice, were determined. Additionally, the main reasons for non-enrollment were determined for each hospice agency.

### *Hospice Diagnosis*

Patients were included if they were enrolled in hospice and had a diagnosis documented in the spreadsheet (not left blank). The total number of patients with each diagnosis was calculated for each hospice agency, as well as the percentage of patients with the three most prevalent diagnoses among all of the hospices.

### *Length of Stay*

Only patients who were enrolled in hospice and had a discharge date listed were included in the length of stay analysis. Length of stay was determined by calculating the difference between discharge date and enrollment date to reveal the total enrolled days in hospice. The average length of stay, median length of stay, and length of stay range were determined for each hospice agency and for all patients included in the analysis.

### *Discharge Status*

Analysis for discharge status was comprised of patients in the spreadsheet who were enrolled into hospice and had both a discharge date and discharge status listed. The most common reasons for discharge among all eligible participants were determined, as well as the range of how prevalent each discharge reason was among the individual hospice agencies.

# CHAPTER 5: RESULTS

The following section will summarize the main findings that address each of the three evaluation aims.

## Evaluation Aim 1 Results:

Evaluation Aim 1 is to describe the current state of collaboration between hospice agencies and UCLA Health. This was accomplished through reporting on the frequency of monthly data reporting for the last two years by the 12 hospice partners.

### *Frequency of Monthly Spreadsheet Reporting*

Table 2 showcases the number of months each hospice agency has reported data to UCLA Health for the years 2018 and 2019. Three hospice agencies, Hospice 1, Hospice 2, and Hospice 4 partnered with UCLA Health in 2019 and so they are not counted within the 2018 reporting numbers. Hospice 4 did provide some retrospective data from 2018, but this was not counted for the purposes of this analysis.

**Table 2**

*Hospice Reporting Rate*

| Hospice | 2018 Reporting Rate | 2019 Reporting Rate |
|---|---|---|
| Hospice 1 | Not partnered | 12/12 |
| Hospice 2 | Not partnered | 12/12 |
| Hospice 3 | 12/12 | 12/12 |
| Hospice 4 | Retrospectively reported | 12/12 |
| Hospice 5 | 11/12 | 12/12 |
| Hospice 6 | 12/12 | 12/12 |
| Hospice 7 | 10/12 | 10/12 |
| Hospice 8 | 12/12 | 12/12 |
| Hospice 9 | 12/12 | 12/12 |
| Hospice 10 | 12/12 | 0/12 |
| Hospice 11 | 7/12 | 11/12 |
| Hospice 12 | 12/12 | 12/12 |

Among the nine hospices that reported data in 2018, eight hospices reported for at least 10 out of 12 months and one hospice reported data 7 out of 12 months. Throughout 2019, 11 hospices reported data for at least 10 out of 12 months and one hospice reported data for 0 out of 12 months. Between 2018 and 2019, one hospice increased their reporting from 7 out of 12 months to 11 out of 12 months and one hospice dropped from having high reporting rates in 2018 to having no reporting months in 2019.

### Evaluation Aim 2 Results:

Evaluation Aim 2 is to examine stakeholders' perceptions of the collaboration between hospice agencies and UCLA Health. This was accomplished through conducting key informant interviews.

#### *Key Informant Interview Results*

Key informant interviews were conducted with five stakeholders, three from hospice agencies and two from UCLA Health. Table 3 lists the key informants' position title and how they will be referenced throughout the results section. There were a total of five themes that emerged from the key informant interviews that will be discussed in the results.

**Table 3**

*Key Informants*

| Key Informant | Position |
|---|---|
| Hospice Informant #1 | Intake Coordinator |
| Hospice Informant #2 | Operations Manager |
| Hospice Informant #3 | Admissions Coordinator |
| UCLA Health Informant #1 | Administrative Role |
| UCLA Health Informant #2 | Clinician Role |

*Theme 1: Improving the efficiency and content of the current spreadsheet format*

All key informants discussed the current method of reporting data through the Excel spreadsheet. Two key informants questioned whether the spreadsheet format was the most efficient way to collect and send data. Hospice Informant #3 shared this sentiment:

> As far as for me, I can send in the spreadsheet. That's no problem, but I don't know as far as like when it's received, how that information is utilized. I don't know how efficient it is on UCLA's part because you know, they're getting an Excel spreadsheet and then they have to kind of either input that into their own system.

For this informant, they continue to participate in the spreadsheet system; however, they recognize that the current process may not be the most efficient, especially in terms of later data analysis.

For UCLA Health Informant #1, they shared similar sentiments about the lack of efficiency in the current spreadsheet format. Specifically, they talked about using an online system for the hospice agencies to enter data, instead of relying on the spreadsheet:

> In a perfect world, we wouldn't rely on this spreadsheet…I think it would be ideal to have this data in some type of an online system where a hospice agency has their own profile and their patients are already in a system…and they're able to kind of select on a drop down…I feel like just for the accuracy of data, it will be a lot cleaner.

This quote illustrates the process that UCLA Health would like to move towards in order to streamline data management and data entry, as opposed to the current manual format. Additionally, this informant identifies some problems with the manual format in terms of opportunities for data errors and inconsistencies.

All of the Hospice Informants had suggestions as to the ways that the current spreadsheet could be improved. The three recommendations included two informants suggesting increasing the ease of spreadsheet access and use, one informant suggesting including more quality metrics in the data collection, and two informants suggesting edits to the current spreadsheet categories. A detailed list of suggested improvements are described in Table 4.

**Table 4**

*Suggestions for Spreadsheet Modifications*

| Theme | Definition/Characteristics | Example Quote |
|---|---|---|
| **Increase ease of spreadsheet access and use** | Hospice Informants (2) discussing ways to improve the ease of the current spreadsheet format, specifically the challenges surrounding the password protection and uploading process | “Having the form is so rigid makes it hard because it will error and kick you out and not let you fill things in. I also think that having the document password protected and then having to upload it to Box is a tedious process. Like if the document is secure and we can just send it via email exchange securely…The less barriers make it as easy as it is for people to just get the information over.” |
| **Increase quality measure data collection** | Hospice Informant (1) discussing the potential quality metrics that the spreadsheet could collect data on | “I think that the data they're asking us to provide is really, in my opinion, data that they should be able to pull on their end…It’s not as meaningful as maybe some other data elements…There are very specific general measures that they should be asking…items from patient family satisfaction, like overall rating of care, or timeliness of care…I think other quality measures like improvement of pain within 48 to 72 hours and preventive pain scores.” |

| | | |
|---|---|---|
| **Edits to current spreadsheet format** | Hospice Informants (2) discussing modifications to the current sections in the spreadsheet | **"**The charity or funded to be frank about it, I'd say 99.9% is funded…So I'm just kind of looking at the charity going, yes we do to charity, but not often enough to really mark it." |

*Theme 2: Common shared goal of improving quality of care*

Four out of the five key informants discussed the goal of improving quality of care as an aim of data sharing. UCLA Health Informant #1 noted that data sharing is important to UCLA Health in order to improve quality of care:

> It's important for us because we want to improve our practices, we want to improve patient outcome. And so without the data, we have no idea where we stand…For us, it's just important for us, where our patients are, what are their needs, and how do we improve so that they have…quality end of life care.

Similarly, UCLA Health Informant #2 discussed the importance of reviewing the monthly hospice data in order to monitor patient care:

> I feel like it definitely needs to be collected. It needs to have some form of formal analysis. I do know, you know that in palliative care, I think we're all pretty much drowning, but …We need to have early and you know, loud flags if somebody is falling off the grid and if somebody is not doing well.

For both UCLA Health Informants, being able to monitor the data to assess how UCLA Health patients in hospice are doing is important to ensure adequate care and hospice processes are being provided.

For the hospices, the benefits of using the data to inform quality of care were discussed as well. Hospice Informant #2 believed that the benefits of data reporting would be better realized if there was a collaborative review of the data: "I think it could be valuable if we were all in a room together, sitting down reviewing the data together. And having honest conversations about quality of care and where our opportunities for improvement are in a collaborative manner." For Hospice Informant #1, they recognized how the data reporting system could provide a better understanding of the care their hospice provided:

> I began to realize that it's really good for my job and it's really good for our quality and our [health information system] so it just makes things easier in the long run…It gives us a better overall idea, I can actually run my own reports off of it.

For both of these Hospice Informants, the opportunities that data sharing can have on improving quality of care are either already in progress or have the potential to occur through collaborative efforts with UCLA Health.

*Theme 3: Desire for mutually beneficial collaboration*

All five key informants talked about the desire for greater collaboration between UCLA Health and the hospice agencies. Throughout the interviews, collaboration was discussed in the form of feedback, relationship building, and hospice agency partnerships. For UCLA Health Informant #1, collaboration was something they were actively working towards: “We haven't really done anything with this data at this point, but our next step is for us to really collaborate with the hospice agencies, and provide… them with data on a monthly basis. So that we can, this will be a mutually beneficial collaboration.” This displays UCLA Health’s commitment to provide feedback back to the hospice agencies regularly so that they too will benefit from the data-sharing relationship.

Without currently receiving any feedback from UCLA Health, it can be difficult for the hospice agencies to know what is being done with the data. UCLA Health Informant #2 describes what they have heard from the hospice agencies about receiving feedback: “[The hospices] want to feel like if they are submitting information, it is not, just appearing into a black hole. They want feedback loops. They want [routine] meetings…want opportunities to give and take feedback.” This desire for feeling that the data is being used and knowing what is happening with the data was echoed by Hospice Informant #2: “There’s…other hospitals that we’re partnered with that we meet and annually or biannually and we sit down and review data on both ends together then have a collaborative conversation around service failures. Now, I don't know, kind of where this data lands, is it just for [UCLA] to kind of take a glance at?”

The hospice agency informants all provided recommendations on how they feel the partnership between UCLA Health and their hospice agencies could be strengthened. Hospice Informant #1 suggesting improving relationships and communication channels between the UCLA Health contact and the hospice agency:

> I think it's just trying to create a relationship with the other person that I would be dealing with…Having an opportunity to maybe speak to the individual once in a while and just you know, what's missing? Did I get everything you needed? I could be missing something vital. So having a little bit better communication, I think would be helpful.

Similarly, Hospice Informant #3 also echoed the importance of data feedback: “I do think if we can kind of get a feedback regarding the data that's collected like you were saying that might benefit [hospice].”

For Hospice Informant #2, their suggestions focused around using the data to communicate with UCLA Health and other hospice agencies, as well as to discuss improvements to quality of care:

> I think it could be valuable if we were all in a room together, sitting down reviewing the data together. And having honest conversations about quality of care and where our opportunities for improvement are in a collaborative manner. I think that there's absolutely value in that.

All informants recognized the importance of creating some kind of feedback and communication channel to ensure that both UCLA Health and the hospice agencies are benefiting from data sharing in terms of quality of care.

*Theme 4: Frequency of receiving feedback*

As indicated throughout theme 3, the hospices are interested in receiving feedback from UCLA Health. Each hospice agency reports data to UCLA Health on a monthly basis and all informants were asked how often UCLA Health should report data back to the hospice agencies.

For UCLA Health Informant #1, they would like to aim to provide hospices with data feedback on a monthly basis:

> I think to start off, it would be nice to do it on a monthly basis…at the first of the month….I think [disseminated] in a clean, PDF, so ideally, having their hospice…the purpose of the report, how many community hospice agencies are participating in this type of initiative or collaboration, and then just have hospice agencies data.

UCLA Health Informant #2 believes similarly to UCLA Health Informant #1, when answering how often they think hospices would want data feedback: “Well they would love a monthly meeting, but I think they would settle for quarterly.”

When asking the hospice agencies about how often they would appreciate feedback from UCLA Health, Hospice Informant #3 stated “maybe quarterly” and Hospice Informant #2 said they would like: “A mechanism for maybe more real time feedback really on both sides about how we can partner together better…more of an opportunity to collaborate on how to better serve needs of the community.” For Hospice Informant #2, it appears that they are interested in more of a real time feedback system as needed based on patient care.

*Theme 5: Desire for comparison to other hospices through feedback loop*

UCLA Health has data-sharing relationships with twelve different hospices agencies; however, through this partnership, the other hospices do not formally talk with one another about data sharing or patient care. UCLA Health remains the common link that connects with all of the hospice agencies one-on-one.

When asked about whether the hospice agencies would be interested in receiving data on not only how their hospice agencies are doing, but how they compare with other local hospice agencies, all three Hospice Informants were interested in this. In responding to this question, Hospice Informant #2 stated, “Absolutely. Even if [the hospices] were anonymous, right, so that we could just kind benchmark each other in the community and get a sense, I think that's great.” For Hospice Informant #1, they also believed in the benefit of receiving benchmark data from other hospice agencies that UCLA Health partners with:

> You know, I think my administrator would really like that…We do a yearly report within and let everybody know how we stand as a hospice with other hospices in the area or other hospices in general. Exactly, to what extent or detail, that I will leave to the administrator.

For both UCLA Health Informants, they were able to foresee the benefits of providing data to hospice agencies and benchmarking them with the other hospice agencies. UCLA Health Informant #1 discussed her vision for sharing this data with hospice agencies:

> I think it would be great for them to have within this report, also a comparison of how …they compare to the other hospice agencies, just so they can kind of get an idea in terms of who's also participating and what type of patients they see, how engaged they are. I think it would be helpful for them.

Similar to UCLA Health Informant #1, UCLA Health Informant #2 also discussed the potential unintended benefits of healthy competition that may come as a result of showing hospices how they stand among other hospices:

> I would picture providing them with the data, kind of like the way that we here at UCLA compare quality metrics from unit to unit. Not necessarily because we

> want to encourage competition…But, if somebody has a best practice, the other ones can learn from it.…[I'm hoping] these companies that UCLA selects will work very collaboratively together and there will not be the cutthroat, ruthless competition that you'd see so often with hospice organization.

It is evident that for both UCLA Health Informants, being able to provide data to the hospice agencies about how they are doing, as well as how the other hospices are doing, can lead to discussions about improving care. This ultimately has the opportunity to improve overall hospice care for all UCLA Health patients, no matter what hospice they are enrolled with.

## Evaluation Aim 3 Results:

Evaluation Aim 3 was to assess end-of-life quality of care, by hospice agency, for UCLA Health patients. This evaluation aim was answered through quantitative data analysis of the master spreadsheet containing data from each of the 12 hospice agencies since 2015.

### ***Quantitative Data Analysis***

#### *Demographics*

There were a total of 3,298 unique patient entries between June 2015 and December 2019 in the hospice spreadsheet. All patients (n=3,298) belonged to one of 12 hospice agencies. The average age of all patients who had a birthdate and referral date (n=3,263) was 75 years old at the time of their referral to hospice. The average age of patients at the time of their referral to hospice, broken down by hospice agency, was between 53 and 79 years old.

#### *Enrollment and Non-Enrollment*

The 3,298 unique patient entries in the hospice spreadsheet made contact with one of 12 hospice agencies. Among the 3,298 unique patient entries, there were 1,704 patients enrolled into hospice. The breakdown of the number of patients who enrolled into each hospice agency can be found in Table 5.

**Table 5**

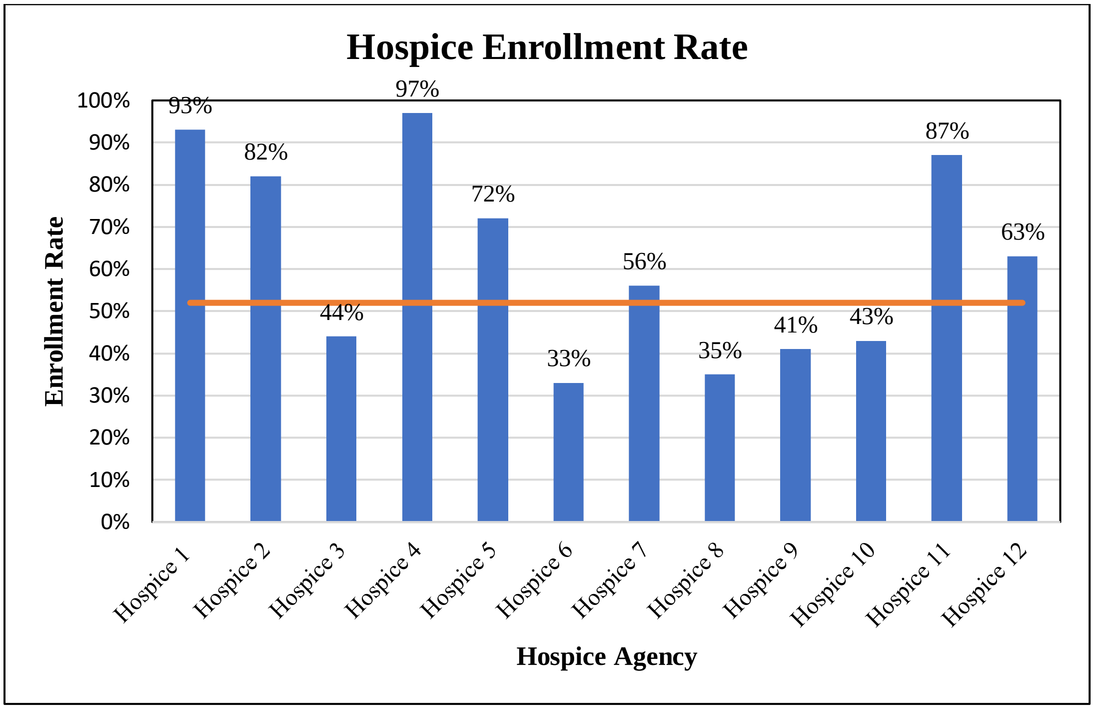
*Hospice Enrollment Status*

| Hospice | Number of patients enrolled | Number of patients not enrolled | Total number of patient entries | % Enrolled |
|---|---|---|---|---|
| Hospice 1 | 100 | 7 | 107 | 93% |
| Hospice 2 | 31 | 7 | 38 | 82% |
| Hospice 3 | 207 | 261 | 468 | 44% |
| Hospice 4 | 36 | 1 | 37 | 97% |
| Hospice 5 | 42 | 16 | 58 | 72% |
| Hospice 6 | 213 | 423 | 636 | 33% |
| Hospice 7 | 9 | 7 | 16 | 56% |
| Hospice 8 | 119 | 222 | 341 | 35% |
| Hospice 9 | 133 | 190 | 323 | 41% |
| Hospice 10 | 6 | 8 | 14 | 43% |
| Hospice 11 | 66 | 10 | 76 | 87% |
| Hospice 12 | 742 | 442 | 1,184 | 63% |
| **Total** | **1,704** | **1,594** | **3,298** | **52%** |

Figure 3 shows the enrollment rate for hospices, which ranged from 33% to 97%. The orange line indicates the average enrollment rate for all patients in the database (n=3,298) which was 52%.

**Figure 3**

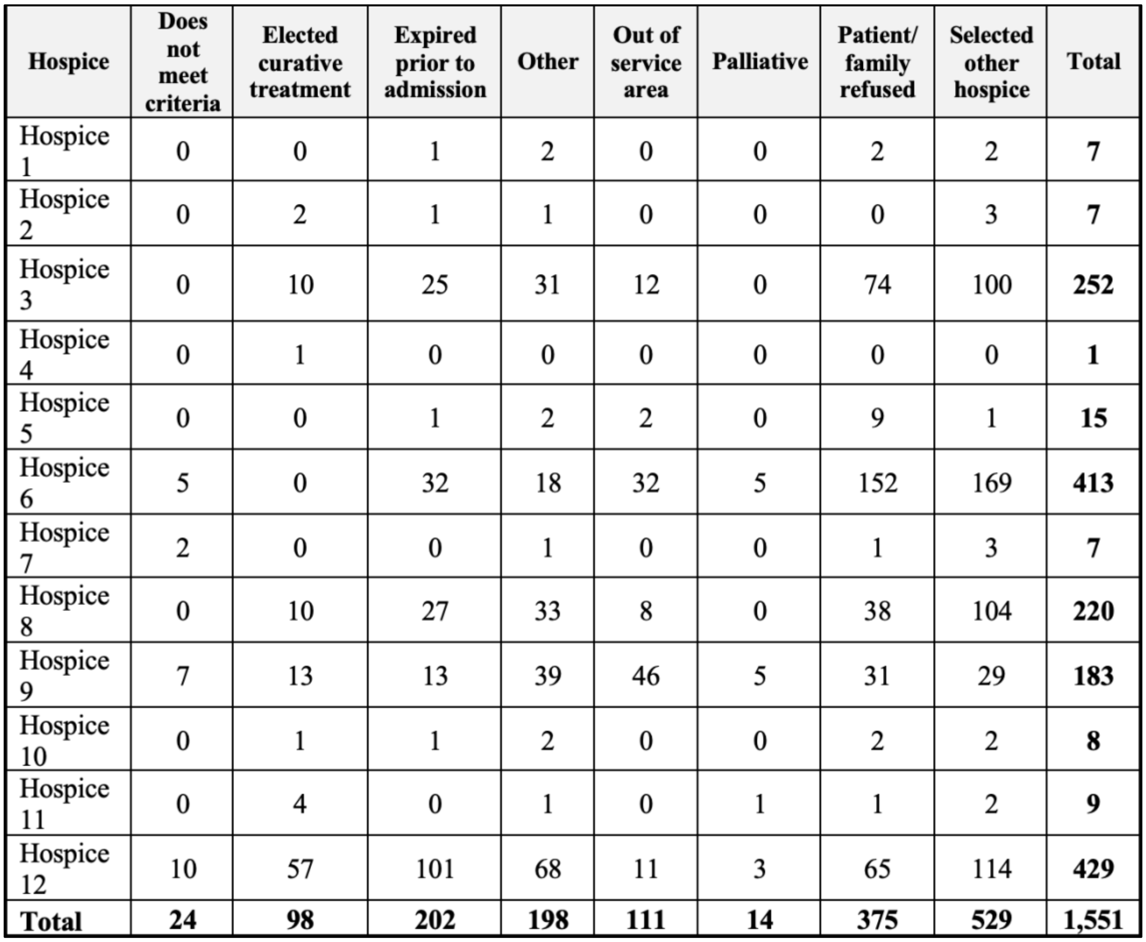
*Hospice Enrollment Rate*



There was a total of 1,551 patients who did not enroll in hospice and had a reason listed for their non-enrollment. The reasons for not enrolling in hospice are presented in Table 6. The most common reason for not enrolling in the hospice was selecting other hospice (n=529, 34%), followed by patient/family refusal (n=375, 24%), and expiring prior to admission (n=202, 13%). For the five hospices that had more than 20 patients not enroll, the percentage of patients that selected other hospices ranged from 16% to 47%, the percentage of patients with patient/family refusal ranged from 15% to 37%, and the percentage with patients that expired prior to admission ranged from 7% to 24%.

**Table 6**

*Hospice Non-Enrollment Reasons*



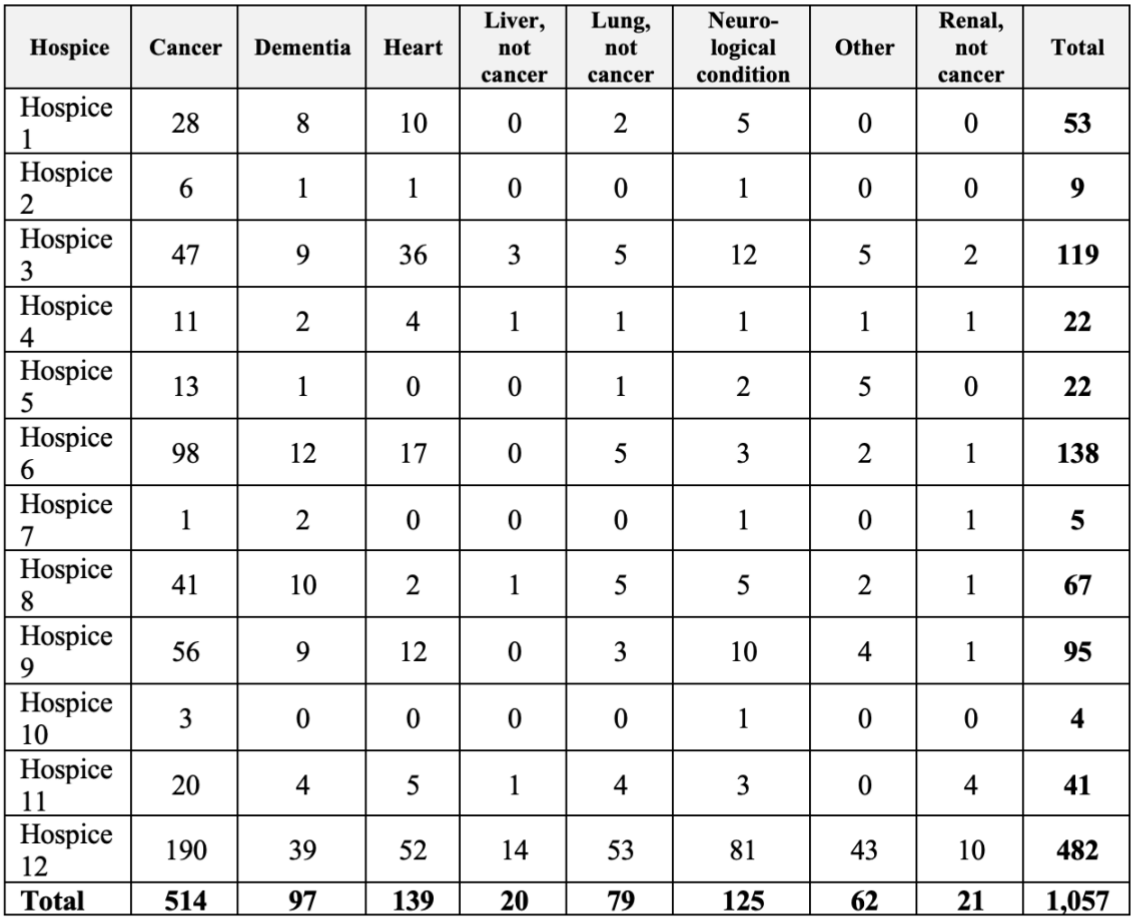
| Hospice | Does not meet criteria | Elected curative treatment | Expired prior to admission | Other | Out of service area | Palliative | Patient/ family refused | Selected other hospice | Total |
|---|---|---|---|---|---|---|---|---|---|
| Hospice 1 | 0 | 0 | 1 | 2 | 0 | 0 | 2 | 2 | **7** |
| Hospice 2 | 0 | 2 | 1 | 1 | 0 | 0 | 0 | 3 | **7** |
| Hospice 3 | 0 | 10 | 25 | 31 | 12 | 0 | 74 | 100 | **252** |
| Hospice 4 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | **1** |
| Hospice 5 | 0 | 0 | 1 | 2 | 2 | 0 | 9 | 1 | **15** |
| Hospice 6 | 5 | 0 | 32 | 18 | 32 | 5 | 152 | 169 | **413** |
| Hospice 7 | 2 | 0 | 0 | 1 | 0 | 0 | 1 | 3 | **7** |
| Hospice 8 | 0 | 10 | 27 | 33 | 8 | 0 | 38 | 104 | **220** |
| Hospice 9 | 7 | 13 | 13 | 39 | 46 | 5 | 31 | 29 | **183** |
| Hospice 10 | 0 | 1 | 1 | 2 | 0 | 0 | 2 | 2 | **8** |
| Hospice 11 | 0 | 4 | 0 | 1 | 0 | 1 | 1 | 2 | **9** |
| Hospice 12 | 10 | 57 | 101 | 68 | 11 | 3 | 65 | 114 | **429** |
| **Total** | **24** | **98** | **202** | **198** | **111** | **14** | **375** | **529** | **1,551** |

*Hospice Diagnosis*

There was a total of 1,057 patients who were enrolled in hospice and had a diagnosis listed (Table 7). The most common diagnosis was cancer (n=514, 49%), followed by heart conditions (n=139, 13%), followed by neurological condition, not cancer or dementia (including stroke) (n=125, 12%). Among the nine hospices that had more than 10 UCLA Health patients enrolled in their hospice, the percentage of those with cancer ranged from 39% to 71%, the percentage of those with heart conditions ranged from 0% to 30%, and the percentage of those with neuro, not cancer or dementia (including stroke) ranged from 2% to 17%.

**Table 7**

*Hospice Diagnosis*



| Hospice | Cancer | Dementia | Heart | Liver, not cancer | Lung, not cancer | Neuro-logical condition | Other | Renal, not cancer | Total |
|---|---|---|---|---|---|---|---|---|---|
| Hospice 1 | 28 | 8 | 10 | 0 | 2 | 5 | 0 | 0 | **53** |
| Hospice 2 | 6 | 1 | 1 | 0 | 0 | 1 | 0 | 0 | **9** |
| Hospice 3 | 47 | 9 | 36 | 3 | 5 | 12 | 5 | 2 | **119** |
| Hospice 4 | 11 | 2 | 4 | 1 | 1 | 1 | 1 | 1 | **22** |
| Hospice 5 | 13 | 1 | 0 | 0 | 1 | 2 | 5 | 0 | **22** |
| Hospice 6 | 98 | 12 | 17 | 0 | 5 | 3 | 2 | 1 | **138** |
| Hospice 7 | 1 | 2 | 0 | 0 | 0 | 1 | 0 | 1 | **5** |
| Hospice 8 | 41 | 10 | 2 | 1 | 5 | 5 | 2 | 1 | **67** |
| Hospice 9 | 56 | 9 | 12 | 0 | 3 | 10 | 4 | 1 | **95** |
| Hospice 10 | 3 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | **4** |
| Hospice 11 | 20 | 4 | 5 | 1 | 4 | 3 | 0 | 4 | **41** |
| Hospice 12 | 190 | 39 | 52 | 14 | 53 | 81 | 43 | 10 | **482** |
| **Total** | **514** | **97** | **139** | **20** | **79** | **125** | **62** | **21** | **1,057** |

*Length of Stay*

There was a total of 1,375 patients that were enrolled in hospice and had a discharge date. The average length of stay was calculated for all patients within each hospice agency (Table 8). The average length of stay ranged from 4 days to 110 days by hospice agency, with the average length of stay for all patients (n=1,375) being 28 days. The median length of stay ranged from 2 days to 32 days by hospice agency, with the median length of stay of all patients (n=1,375) being six days. The total length of stay range was between 0 days and 1,568 days on hospice for all patients (n=1,375).

**Table 8**

*Hospice Length of Stay*

| **Hospice (n=patients)** | **Average of LOS (days)** | **Median LOS (days)** | **Range of LOS (days)** |
|---|---|---|---|
| Hospice 1 (n=62) | 110 | 18.5 | 0-1,568*<br>**outlier or error in reporting* |
| Hospice 2 (n=13) | 13 | 12 | 1-28 |
| Hospice 3 (n=196) | 63 | 16.5 | 0-840 |
| Hospice 4 (n=34) | 85 | 32 | 1-527 |
| Hospice 5 (n=36) | 33 | 16.5 | 1-185 |
| Hospice 6 (n=186) | 23 | 9 | 0-382 |
| Hospice 7 (n=6) | 4 | 3.5 | 2-5 |
| Hospice 8 (n=103) | 34 | 12 | 1-468 |
| Hospice 9 (n=87) | 25 | 12 | 0-180 |
| Hospice 10 (n=3) | 22 | 7 | 3-57 |
| Hospice 11 (n=56) | 13 | 7 | 0-92 |
| Hospice 12 (n=593) | 8 | 2 | 0-372 |
| **Total (n=1,375)** | **28** | **6** | **0-1,568** |

### *Discharge Status*

There was a total of 1,353 patients who were enrolled in hospice and had both a discharge date and discharge status listed (Table 9). The most common reason for discharge was death (n=1,204, 89%), followed by revoked (n=84, 6%). Among the nine hospices with over 20 discharged patients, the percentage of those that died in hospice ranged from 76% to 97%, and the percentage of those that revoked from hospice ranged from 3% to 19%.

**Table 9**

*Hospice Discharge Status*

| Hospice | Death | Discharged to non-contracted facility | Other | Revoked | Transferred to other hospice | Total |
|---|---|---|---|---|---|---|
| Hospice 1 | 60 | 0 | 0 | 2 | 0 | **62** |
| Hospice 2 | 13 | 0 | 0 | 0 | 0 | **13** |
| Hospice 3 | 145 | 0 | 7 | 25 | 15 | **192** |
| Hospice 4 | 32 | 0 | 1 | 1 | 0 | **34** |
| Hospice 5 | 26 | 0 | 3 | 7 | 0 | **36** |
| Hospice 6 | 160 | 1 | 17 | 8 | 0 | **186** |
| Hospice 7 | 5 | 0 | 0 | 1 | 0 | **6** |
| Hospice 8 | 86 | 0 | 5 | 12 | 0 | **103** |
| Hospice 9 | 76 | 0 | 4 | 7 | 0 | **87** |
| Hospice 10 | 2 | 0 | 1 | 0 | 0 | **3** |
| Hospice 11 | 52 | 0 | 0 | 4 | 0 | **56** |
| Hospice 12 | 547 | 0 | 11 | 17 | 0 | **575** |
| **Total** | **1,204** | **1** | **49** | **84** | **15** | **1,353** |

# CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

## Summary and Discussion of Key Findings

Each of the data sources were included in order to evaluate different aims, with the ultimate goal of evaluating the current partnership between the hospice agencies and UCLA Health. The multiple sources of data were reviewed and interpreted in the context of one another. A summary of the findings from each data source, as well as key takeaway from examining all the data sources together, will be discussed below.

The results highlighted trends about the current relationship between UCLA Health and hospice agencies. Reviewing the monthly data provided insight into the data reporting pattern of the hospice partners. Nearly all of the hospice agencies remained consistent in their reporting over the two years; however, one hospice with high reporting rates in 2018 decreased to no reporting in 2019. This significant difference in the hospice agency’s consistency in monthly reporting is important to monitor. Efforts to follow up and engage with hospice agencies to troubleshoot potential challenges before they arise are important to ensure timely data collection. While there may be some drop-offs in reporting that are unavoidable, having UCLA Health work proactively with the hospice agencies to strengthen relationships and communication is important to try and avoid data drop-offs.

The key informant interviews revealed themes relating to the current status of the relationship and suggestions for the ways that the partnership between UCLA Health and hospice agencies could be improved. The sentiments between the hospice agency and UCLA Health informants were similar, and the priorities of the health organizations appeared to align in terms of a desire for the relationship to improve quality of care and the ways that improved collaboration and feedback can improve the partnerships. There was an acknowledgement by both parties regarding how collaboration efforts could be improved in terms of frequency, type, and quality and an agreement on how regular feedback and benchmarking data with other hospice agency data can be used to improve relationships between the organizations.

The quantitative data analysis results revealed vast differences in the number of UCLA Health patients that come into contact with each of the hospice agencies and the different types of care and interactions that patients have at each hospice. The data that were analyzed as part of this evaluation, such as enrollment rate, length of stay, and discharge status, can be used to better understand the care that UCLA Health patients are receiving once they leave the health system and progress into hospice care. Furthermore, this data showcases the wide range of care that hospice patients receive depending on which hospice agency they enroll in. These data, which for the purposes of this analysis were calculated through Excel, are in the process of being displayed in a Tableau dashboard, which can be used to generate similar reports on a regular basis for the hospice agencies to view. Providing this type of feedback to the hospice agencies can give them the means to review potential areas of opportunity for changes.

Reviewing the national hospice quality metrics in the stakeholder description section provided an overview of the quality metrics that are nationally measured, and also how the hospices compare to one another and the national average. While these findings do not specifically pertain to UCLA Health patients, they provide a basis of understanding the quality of care that each hospice provides. Many of the hospice agencies rated at or below the national average for some of the family/caregiver and quality of care measures reported. Although this is not cause for any drastic decisions on the part of UCLA Health to stop partnering with the hospice agencies, looking at national metrics and understanding the overall care provided to patients is important and should continue to be monitored.

Overall, the key takeaways from the results are that there are differences in quality of care provided to patients depending on the hospice agency. In light of the partnership with UCLA Health, providing hospices with feedback regarding the ways that their quality of care differs can be useful for hospice agencies. UCLA Health and the hospice agencies have a goal of working to improve quality of care for patients, and providing regular feedback and opportunities for discussing care delivery are imperative. Providing an avenue for the hospice agencies to regularly talk with UCLA Health and the other hospice agencies can potentially improve reporting rates from hospice agencies as well. Furthermore, the sharing of data and service failures can also allow hospice agencies to share best practices, in order to ensure that hospice quality for all patients, no matter what hospice a patient is located at, is high.

## Strengths

This evaluation had many strengths. The first was its mixed-methods approach, which provided insight into the many ways that the UCLA Health and hospice partnerships operate. This mixed-methods approach also allowed for the broad reach of multiple evaluation aims that not only evaluated the partnerships, but examined the actual quality of care being provided to patients.

Another strength was the theory-based approach that guided this evaluation. By using the principles of interorganizational relations theory to better understand the role of each agency in the data-sharing partnership, this helped to guide the results and analysis sections. This also provided a framework by which interorganizational relations can lay the groundwork for other similar healthcare partnerships working together through data sharing.

## Limitations

This evaluation was not without limitations. The first limitation was in regards to the quantitative data analysis based on the master spreadsheet. Due to the amount of patients UCLA Health refers to each hospice agency, some hospices did not have significant patient data in the database. This made comparisons between the different hospice agencies more difficult in terms of assessing for meaningful differences across the hospice agencies.

Another limitation with the data collected for the evaluation was that only three key informants among 12 hospice agencies were interviewed. Hospices that were more invested in the partnership with UCLA Health may have been more likely to respond to requests for the interview. Perhaps interviewing more individuals from additional hospice agencies would have provided more points of view that were not captured by the three hospice informants included in the evaluation.

## Recommendations

In light of the key findings of the evaluation report, the following five recommendations are proposed:

1. **Implement monthly data report back to hospice agencies, including comparisons to the other hospice agencies in partnership with UCLA Health.**

This step will not only allow the hospices to review their own data and the data of others, this will also make sure that whoever is preparing the data at UCLA Health is looking each month to determine whether there are any concerning cases or service failures. This can open a more real-time communication channel between UCLA Health and the hospice agencies.

2. **Schedule a regular quarterly conference call with all of the hospice agencies. In addition to these regularly scheduled calls, communicate with hospice agencies that they can contact UCLA Health regarding the data-sharing process at any time.**

   This step will provide a chance for the hospice agencies to discuss information from the monthly hospice data-sharing reports, as well as bring up any concerns about the data-sharing process or other topics. The hospice agencies expressed that they would welcome the feedback and are also interested in having open communication channels with UCLA Health. Therefore, showing to the hospice agencies that UCLA Health is available is a crucial step for the hospice agencies to feel as though they have an open communication channel with UCLA Health.

3. **Monitor national quality data from Hospice Compare website and evaluate in context of hospice partnerships.**

   Add a feature on the Tableau hospice dashboard that displays the data from the Hospice Compare website about each hospice agency. Taken in the context of the specific UCLA Health care processes collected by the monthly data collection, the Hospice Compare metrics can showcase trends in all-patient care at each hospice agency. Although it would be difficult for UCLA Health to collect these same quality metrics themselves unless they administered their own survey, using the data from all patients at the hospice agency can provide an estimate into the type of care that UCLA Health patients at each hospice agency are receiving.

4. **Reduce current security features on the spreadsheet to enable hospices to have fewer barriers to data entry.**

   Consider whether the spreadsheet that hospices enter data into each month needs to be uploaded to Box as well as be password protected. The hospice agencies commented on the frustration they have with accessing and opening the spreadsheet, even before entering any data. While UCLA Health must follow appropriate HIPAA procedures to protect the patient data, if there are modifications that can make the process of accessing the spreadsheet easier, these should be considered.

5. **Evaluate the master spreadsheet based on necessity and usefulness of information.**

   Hospice key informants had differing opinions on the usefulness of specific items found in the spreadsheet. Thus, it is important that in light of the suggestions there is a critical evaluation regarding what information in the spreadsheet is necessary based on how the spreadsheet will be utilized and who will utilize the data. For example, one hospice informant described that while asking about charity versus funded care is interesting, nearly all of their patients are on funded care. This comment remained true when the evaluator reviewed the data in the spreadsheet and found virtually all patient entries to be funded as well. This example highlights the potential for determining the most necessary pieces of information to be collected by the spreadsheet, especially in light of the Tableau dashboard which will only be using certain information in its visual displays.

## Conclusions

Sharing data between hospice agencies and health systems is important and necessary in order to critically evaluate end-of-life care being provided to patients no longer at a health system. When establishing a data-sharing relationship between a health system and hospice agencies, creating a regular channel of communication from the beginning can help to ensure that all individuals are collaborating together in a manner that is the most beneficial for all parties involved. This evaluation lays the groundwork to improve the current partnerships between UCLA Health and hospice agencies and ensure continued partnerships. The future of collaboration between the hospice agencies and UCLA Health can be strengthened through the recommendations provided from this evaluation.

Interorganizational relations in regards to end-of-life care are important, but they do require constant evaluation and dialogue in order to make sure that all parties involved are mutually benefitting from the relationship. This evaluation revealed ways that the relationship could be improved during this next iteration of interorganizational relations between UCLA Health and the hospice agencies. By constantly having communication between both partners, this will optimize the partnerships and allow for opportunities to improve care. Working to improve the communication, feedback, and collaboration will help to ensure that data sharing continues between UCLA Health and the hospice agencies, and that end-of-life care is of optimal quality for all.

# REFERENCES

Abernethy, A. P., Wheeler, J. L., & Bull, J. (2011). Development of a health information technology-based data system in community-based hospice and palliative care. *Am J Prev Med*, *40*(5 Suppl 2), S217-24. https://doi.org/10.1016/j.amepre.2011.01.012

Alter, C. F. (1987). Integration in Interorganizational Hospice Care Systems. *The Hospice Journal*, *3*(4), 11–32. https://doi.org/10.1080/0742-969X.1987.11882604

Bernazzani, S. (2016, March 15). *Guide to End-of-Life Care Options*. AJMC. https://www.ajmc.com/contributor/sophia-bernazzani/2016/03/guide-to-end-of-life-care-options

Berry, L. L., Connor, S. R., & Stuart, B. (2017). Practical Ideas for Improving the Quality of Hospice Care. *Journal of Palliative Medicine*, *20*(5), 449–452. https://doi.org/10.1089/jpm.2017.0016

Black, B., Herr, K., Fine, P., Sanders, S., Tang, X., Bergen-Jackson, K., Titler, M., & Forcucci, C. (2011). The Relationships among Pain, Nonpain Symptoms, and Quality of Life Measures in Older Adults with Cancer Receiving Hospice Care. *Pain Medicine*, *12*(6), 880–889. https://doi.org/10.1111/j.1526-4637.2011.01113.x

Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C., & Samus, Q. M. (2013). Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study. *Journal of the American Geriatrics Society*, *61*(12), 2087–2095. https://doi.org/10.1111/jgs.12549

Bolland, J. M., & Wilson, J. V. (1994). Three faces of integrative coordination: A model of interorganizational relations in community-based health and human services. *Health Services Research*, *29*(3), 341–366.

Broyles, I., Li, Q., Zheng, T., Frank, J., Sherif, N., & Rokoske, F. (2016). *The Emerging Picture of Quality of Care in Hospice*. 6.

Bull, J., Zafar, S. Y., Wheeler, J. L., Harker, M., Gblokpor, A., Hanson, L., Hulihan, D., Nugent, R., Morris, J., & Abernethy, A. P. (2010). Establishing a regional, multisite database for quality improvement and service planning in community-based palliative care and hospice. *J Palliat Med*, *13*(8), 1013–1020. https://doi.org/10.1089/jpm.2010.0017

Cagle, J. G., LaMantia, M. A., Williams, S. W., Pek, J., & Edwards, L. J. (2016). Examining Predictors of Preference for Hospice Care among Older Adults. *The American Journal of Hospice & Palliative Care*, *33*(6), 574. https://doi.org/10.1177/1049909115593936

Cagle, J. G., Van Dussen, D. J., Culler, K. L., Carrion, I., Hong, S., Guralnik, J., & Zimmerman, S. (2016). Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. *American Journal of Hospice and Palliative Medicine®*, *33*(1), 27–33. https://doi.org/10.1177/1049909114546885

Cardona-Morrell, M., Kim, J. C. H., Turner, R. M., Anstey, M., Mitchell, I. A., & Hillman, K. (2016). Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem. *International Journal for Quality in Health Care*, *28*(4), 456–469. https://doi.org/10.1093/intqhc/mzw060

Carroll, J. M., Santucci, G., Kang, T. I., & Feudtner, C. (2007). Partners in pediatric palliative care: A program to enhance collaboration between hospital and community palliative care services. *Am J Hosp Palliat Care*, *24*(3), 191–195. https://doi.org/10.1177/1049909106298393

Casarett, D., Harrold, J., Harris, P. S., Bender, L., Farrington, S., Smither, E., Ache, K., & Teno, J. (2015). Does Continuous Hospice Care Help Patients Remain at Home? *Journal of Pain and Symptom Management*, *50*(3), 297–304. https://doi.org/10.1016/j.jpainsymman.2015.04.007

Centers for Medicare and Medicaid Services. (n.d.). *Hospice Compare—Find a Hospice Agency*. Retrieved November 2, 2019, from https://www.medicare.gov/hospicecompare/

Centers for Medicare and Medicaid Services. (2017, August 16). *Hospice Compare Website*. https://www.cms.gov/newsroom/fact-sheets/hospice-compare-website

Centers for Medicare and Medicaid Services. (2018, March 20). *CAHPS Hospice Survey*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/CAHPS%C2%AE-Hospice-Survey

Centers for Medicare and Medicaid Services. (2019, January 14). *Current Measures*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures.html

Colby, S., & Ortman, J. (2014). *Projections of the Size and Composition of the U.S. Population: 2014 to 2060* (p. 13). United States Census Bureau.

Committee on Approaching Death: Addressing Key End of Life. (2015). In *Dying in America: Improving Quality and Honoring Individual Preferences Near the End* *of Life* (25927121). National Academies Press (US) Copyright 2015 by the National Academy of Sciences. All rights reserved. https://doi.org/10.17226/18748

Cropper, S., Ebers, M., Huxham, C., & Ring, P. (2009). Introducing Inter-organizational Relations. *The Oxford Handbook of Inter-Organizational Relations*. https://doi.org/10.1093/oxfordhb/9780199282944.003.0001

Davis, F. A. (1988). Medicare hospice benefit: Early program experiences. *Health Care Financ Rev*, *9*(4), 99–111.

Department of Health and Human Services. (2019). *Medicare Hospice Benefits*. 20.

Department of Health and Human Services, Centers for Medicare &, & Medicaid Services. (2010). *CMS Manual System*. 189.

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., Herr, K., Rotella, J. D., & Casarett, D. J. (2015). Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care From the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management*, *49*(4), 773–781. https://doi.org/10.1016/j.jpainsymman.2015.01.012

*End of Life Care*. (n.d.). Health In Aging. Retrieved October 5, 2019, from https://www.healthinaging.org/age-friendly-healthcare-you/care-what-matters-most/end-life-care

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040?

Past trends, future projections and implications for services. *BMC Medicine, 15*(1), 102. https://doi.org/10.1186/s12916-017-0860-2

Frieden, T. R. (n.d.). *The State of Aging and Health in America 2013*. 60.

Glanz, K., Rimer, B. K., & Viswanath, K. (2014). *Health Behavior: Theory, Research, and Practice*. Wiley. http://ebookcentral.proquest.com/lib/emory/detail.action?docID=2082957

Grady, P. A. (2011). Advancing the health of our aging population: A lead role for nursing science. *Nursing Outlook, 59*(4), 207–209. https://doi.org/10.1016/j.outlook.2011.05.017

Halpern, S. D. (2015). Toward Evidence-Based End-of-Life Care. *New England Journal of Medicine, 373*(21), 2001–2003. https://doi.org/10.1056/NEJMp1509664

Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative Research Methods*. SAGE.

*Hospice Discharge, Revocation and Transfers*. (n.d.). CGS Medicare. Retrieved November 10, 2019, from https://www.cgsmedicare.com/hhh/coverage/coverage_guidelines/discharge_revocations_transfers.html

Hsu, S. H., Hung, P., & Wang, S.-Y. (2019). Factors Associated With Hospices' Nonparticipation in Medicare's Hospice Compare Public Reporting Program. *Medical Care, 57*(1), 28. https://doi.org/10.1097/MLR.0000000000001016

Institute of Medicine. (2015). *The Delivery of Person-Centered, Family-Oriented End-of-Life Care*. National Academies Press (US). http://www.ncbi.nlm.nih.gov/books/NBK285676/

Kale, M. S., Ornstein, K. A., Smith, C. B., & Kelley, A. S. (2016). End-of-Life Discussions with Older Adults. *Journal of the American Geriatrics Society*, *64*(10), 1962–1967. https://doi.org/10.1111/jgs.14285

Karlsson, M., Garvare, R., Zingmark, K., & Nordström, B. (2019). Organizing for sustainable inter-organizational collaboration in health care processes. *Journal of Interprofessional Care*, 1–10. https://doi.org/10.1080/13561820.2019.1638760

Kelley, A. S., Deb, P., Du, Q., Aldridge Carlson, M. D., & Morrison, R. S. (2013). Hospice Enrollment Saves Money For Medicare And Improves Care Quality Across A Number Of Different Lengths-Of-Stay. *Health Affairs*, *32*(3), 552–561. https://doi.org/10.1377/hlthaff.2012.0851

Khandelwal, N., Curtis, J. R., Freedman, V. A., Kasper, J. D., Gozalo, P., Engelberg, R. A., & Teno, J. M. (2017). How Often Is End-of-Life Care in the United States Inconsistent with Patients' Goals of Care? *Journal of Palliative Medicine*, *20*(12), 1400–1404. https://doi.org/10.1089/jpm.2017.0065

Kleinpell, R., Vasilevskis, E. E., Fogg, L., & Ely, E. W. (2019). Exploring the association of hospice care on patient experience and outcomes of care. *BMJ Supportive & Palliative Care*, *9*(1), e13–e13. https://doi.org/10.1136/bmjspcare-2015-001001

Kumar, P., Wright, A. A., Hatfield, L. A., Temel, J. S., & Keating, N. L. (2016). Family Perspectives on Hospice Care Experiences of Patients with Cancer. *Journal of Clinical Oncology*, *35*(4), 432–439. https://doi.org/10.1200/JCO.2016.68.9257

Kwait, J. (2001). Interorganizational Relationships Among HIV/AIDS Service Organizations in Baltimore: A Network Analysis. *Journal of Urban Health:*

*Bulletin of the New York Academy of Medicine*, *78*(3), 468–487. https://doi.org/10.1093/jurban/78.3.468

Loitz, C. C., Stearns, J. A., Fraser, S. N., Storey, K., & Spence, J. C. (2017). Network analysis of inter-organizational relationships and policy use among active living organizations in Alberta, Canada. *BMC Public Health*, *17*(1), 649. https://doi.org/10.1186/s12889-017-4661-5

Lupu, D., Quigley, L., Mehfoud, N., & Salsberg, E. S. (2018). The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *J Pain Symptom Manage*, *55*(4), 1216–1223. https://doi.org/10.1016/j.jpainsymman.2018.01.011

Lutz, S. (2011). The history of hospice and palliative care. *Curr Probl Cancer*, *35*(6), 304–309. https://doi.org/10.1016/j.currproblcancer.2011.10.004

Lysaght Hurley, S., Barg, F. K., Strumpf, N., & Ersek, M. (2015). Same Agency, Different Teams: Perspectives From Home and Inpatient Hospice Care. *Qualitative Health Research*, *25*(7), 923–931. https://doi.org/10.1177/1049732314554091

McKay, E. A., Taylor, A. E., & Armstrong, C. (2013). “What She Told Us Made the world of Difference”: Carers’ Perspectives on A Hospice at Home Service. *Journal of Palliative Care*, *29*(3), 170–177. https://doi.org/10.1177/082585971302900306

*Medicare Hospice: Use of General Inpatient Care*. (2013). 13.

Meghani, S. H., & Hinds, P. S. (2015). Policy brief: The Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. *Nursing Outlook*, *63*(1), 51–59. https://doi.org/10.1016/j.outlook.2014.11.007

Meier, D. E. (2011). Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. *The Milbank Quarterly*, *89*(3), 343–380. https://doi.org/10.1111/j.1468-0009.2011.00632.x

Miller, S. C. (2010). A Model for Successful Nursing Home–Hospice Partnerships. *Journal of Palliative Medicine*, *13*(5), 525–533. https://doi.org/10.1089/jpm.2009.0296

Miller, S. C., & Mor, V. N. T. (2002). The Role of Hospice Care in the Nursing Home Setting. *Journal of Palliative Medicine*, *5*(2), 271–277. https://doi.org/10.1089/109662102753641269

National Cancer Institute. (2011, February 2). *NCI Dictionary of Cancer Terms* [NciAppModulePage]. National Cancer Institute. https://www.cancer.gov/publications/dictionaries/cancer-terms

National Center for Health Statistics (U.S.) (Ed.). (2019). *Long-term care providers and services users in the United States, 2015-2016*. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.

National Hospice and Palliative Care Organization. (2019a). *Palliative Care or Hospice?* https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf

National Hospice and Palliative Care Organization. (2019b). *The Hospice Team*. NHPCO. https://www.nhpco.org/patients-and-caregivers/about-hospice-care/the-hospice-team/

National Hospice and Palliative Care Organization. (2019c). *NHPCO Facts and Figures*.

National Hospice and Palliative Care Organization, & The Center to Advance Palliative Care. (2001). *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service*.

NHPCO. (2020). *Hospice Item Set (HIS)*. NHPCO. https://www.nhpco.org/regulatory-and-quality/quality/hospice-quality-reporting-program-hqrp/hospice-item-set-his/

*NQF 0216: Proportion Admitted to Hospice for less than 3 days*. (2016). 7.

Obermeyer, Z., Clarke, A. C., Makar, M., Schuur, J. D., & Cutler, D. M. (2016). Emergency care utilization and the Medicare hospice benefit for patients with poor-prognosis cancer. *Journal of the American Geriatrics Society*, *64*(2), 323–329. https://doi.org/10.1111/jgs.13948

Olsen, M. L., Bartlett, A. L., & Moynihan, T. J. (2011). Characterizing Care of Hospice Patients in the Hospital Setting. *Journal of Palliative Medicine*, *14*(2), 185–189. https://doi.org/10.1089/jpm.2010.0241

Public Hospital Redesign and Incentives in Medi-Cal (PRIME). (2019). *California Association of Public Hospitals and Health Systems*. https://caph.org/priorities/medi-cal-2020-waiver/prime/

Resnick, B. (2012). Differentiating programs versus philosophies of care: Palliative care and hospice are not equal. *Geriatr Nurs*, *33*(6), 427–429. https://doi.org/10.1016/j.gerinurse.2012.09.008

Roscoe, L. A., Egan, K. A., & Schonwetter, R. S. (2004). Creating an academic-community provider partnership in hospice, palliative care, and end-of-life studies. *Cancer Control*, *11*(6), 397–403. https://doi.org/10.1177/107327480401100607

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2008). Patients Dying with Dementia: Experience at the End of Life and Impact of Hospice Care. *Journal of Pain and Symptom Management*, *35*(5), 499–507. https://doi.org/10.1016/j.jpainsymman.2007.06.011

Sofaer, S., & Myrtle, R. C. (1991). Interorganizational Theory and Research: Implications for Health Care Management, Policy, and Research. *Medical Care Review*, *48*(4), 371–409. https://doi.org/10.1177/002570879104800402

Teno, J. M., Gozalo, P. L., Lee, I. C., Kuo, S., Spence, C., Connor, S. R., & Casarett, D. J. (2011). Does Hospice Improve Quality of Care for Persons Dying from Dementia? *Journal of the American Geriatrics Society*, *59*(8), 1531–1536. https://doi.org/10.1111/j.1532-5415.2011.03505.x

Tolley, D. C., & Payne, R. (2007). Hospice partnerships with academic entities: Philosophical and historical background and assessment of future needs. *J Pain Symptom Manage*, *33*(1), 90–98. https://doi.org/10.1016/j.jpainsymman.2006.10.007

UCLA Health. (2019a). *About Palliative Care*. https://www.uclahealth.org/palliative-care/about-palliative-care

*UCLA Health*. (2019b). https://www.uclahealth.org/

*UCLA Health | Quality Management Services*. (n.d.). Retrieved February 28, 2020, from https://quality.mednet.ucla.edu/pages/

Wang, S.-Y., Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. *Journal of Pain and Symptom Management*, *52*(6), 813–821. https://doi.org/10.1016/j.jpainsymman.2016.05.031

Wiener, J. M., & Tilly, J. (2003). End-of-life care in the United States: Policy issues and model programs of integrated care. *International Journal of Integrated Care*, *3*(2). https://doi.org/10.5334/ijic.81

Wright, A. A., Keating, N. L., Balboni, T. A., Matulonis, U. A., Block, S. D., & Prigerson, H. G. (2010). Place of Death: Correlations With Quality of Life of Patients With Cancer and Predictors of Bereaved Caregivers' Mental Health. *Journal of Clinical Oncology*, *28*(29), 4457–4464. https://doi.org/10.1200/JCO.2009.26.3863

Zheng, N. T., Mukamel, D. B., Rokoske, F. S., Morley, M., Zepeda, S., & Aldridge, M. D. (2019). Have Hospice Costs Increased After Implementation of the Hospice Quality–Reporting Program? *Journal of Pain and Symptom Management*, *58*(1), 48-55.e1. https://doi.org/10.1016/j.jpainsymman.2019.03.013

# APPENDIX

## Email Sent to Hospice Agencies to Conduct Key Informant Interviews

Dear _____,

I hope this email finds you well. My name is Ilana Greenberg and I worked with Nicole Douglas and UCLA Health as a Quality Department Intern, corresponding with you this past summer to collect hospice data. Since concluding my summer internship, I have returned back to Emory University to complete my Masters in Public Health program.

I have continued much of the work I undertook this summer through the form of my Master’s thesis. The purpose of my thesis is to understand the current state of the monthly data-sharing partnership between UCLA Health and hospice agencies, including the ways this partnership can be improved.

As part of my thesis, I am conducting short interviews with hospice agency contacts and UCLA Health employees. If you are interested, please send me some times you would be available in the next two weeks for a 20-30 minute phone call. I very much enjoyed working with you this past summer and I believe you would have a lot of valuable insight to share.

I want to reiterate that I no longer work for UCLA Health, and so my findings will be presented as recommendations to them in an anonymous format that will not link you or your hospice agency to your responses. I also have communicated extensively with the UCLA Health team, so they are aware and have approved of the interview.

Please let me know if you are interested and available and if you have any further questions. I look forward to hearing from you.

Best regards,

Ilana Greenberg