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ABSTRACT

Title of Document:

QUALITY AND QUALITY IMPROVEMENT
IN END-OF-LIFE CARE: PERCEPTIONS OF
HOSPICE PROVIDERS

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Hospice is both a philosophy of care and a system for delivering care to patients near the end of life. The goals of hospice are to provide comfort care around the process of dying and to support the dying individual and his/her family members. Hospice care focuses not only on physical aspects of care, but also on social, emotional, spiritual, cultural, and ethical aspects.

In recent years, there has been increasing interest among clinicians, researchers, and others to improve the quality of care provided through hospice. Yet relatively little research has focused on the perceptions of quality improvement (QI) among hospice staff, even though such perceptions may influence both their engagement in, and the ultimate success of, agencies' QI efforts.

The goal of this study was to examine how hospice staff perceive efforts to improve quality of care in the hospice setting. This qualitative study employed an ethnographic and phenomenological approach to elicit narratives and meanings of end-of-life (EOL) care quality and its improvement from 19 directors, nurses, chaplains, and social workers from five hospice agencies in Maryland. Study participants articulated five interrelated meanings of QI: formal

processes, learning on the part of hospice providers, changes in documentation to support compliance, “doing better,” and activities that positively impact patients and families. They agreed that the quality of EOL care can be improved, and, for the most part, their views of QI were positive. Yet they also expressed skepticism about QI efforts. Front-line hospice workers had fairly broad, generalized knowledge regarding the QI efforts of their agencies, but limited familiarity with how those efforts were chosen. Participants reported engaging in improvement activities, although not all of those activities were part of their agencies’ formal QI efforts. Furthermore, they identified education as a key mechanism to help them more effectively improve the quality of care they provide. Finally, this study found that participants’ perceptions of quality EOL care and QI were linked to their occupational roles, but not to the characteristics of their agencies. Implications of these findings for hospice policy and practice are discussed, as are ideas for future research.

QUALITY AND QUALITY IMPROVEMENT IN END-OF-LIFE CARE:
PERCEPTIONS OF HOSPICE PROVIDERS

By

Karen E. Johnson

Dissertation submitted to the Faculty of the Graduate School of the
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Dedication

This dissertation is dedicated to my mentor and friend, Karen Pace; my wonderful husband, Steve Johnson; my parents, Danny and Faye Campbell; and my parents-in-law, Joe and Ann Johnson.

Karen: It was you who first introduced me to the field of quality improvement, and taught me so much over the years. You encouraged me to begin the doctoral program. You suggested that hospice might be an interesting area of study. You even agreed to serve on my dissertation committee! Although you had to resign from the committee before I completed the dissertation, you continued to offer much-needed support and encouragement. But more importantly, somewhere along the way, we forged a friendship that has endured. I am truly blessed.

Steve: Along with me, you learned about telomeres and the social construction of reality. You put up with armloads of books about death and dying, even though they stacked up around the house and messed up your Amazon search history. But somehow, you always believed in me. You convinced me (over and over again) that I could do this. You deserve the “phud” almost as much as I do (although not quite as much, because you didn’t read all those books!). You are absolutely the best, and I know I can always count on you. I love and respect you more than I can ever put into words.

Mom and Dad: You always encouraged me to do my best. You never discouraged me from reaching for more. Plus, you provided so much practical help, without which, I’d never have made it so far. I’ll never forget those early morning breakfasts, rides to the bus at the end of the hollow, and the pick-ups at the end of a long

day. Without those, I would never have been able to go to—or finish—my first two years of college. It never occurred to any of us back then that I'd eventually earn a doctorate. Your love and support helped make it possible. I hope you are proud.

Mom and Dad Johnson: You welcomed me into your family from the start. I love being around you, and I am so grateful to have you in my life.

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I would also like to thank the other members of my dissertation committee: Ann Gruber-Baldini, John Cagle, Nancy Miller, Sean Morrison, and, until recently, Karen Pace. Each gave unselfishly of their time to aid me in this endeavor, and each provided unique insights that helped me improve the study and this final product.

In addition, I would like to thank the 24 hospice agency staff members who participated in this study. These include the 19 agency directors, nurses, social workers, and chaplains whose narratives I formally analyzed for the study, as well as the 5 quality improvement coordinators who facilitated recruitment of interviewees and provided much-needed contextual information about their agencies and their QI endeavors. Without exception, all of these study participants shared generously of their time and

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Chapter 1: Introduction

The goals of hospice care are (1) to provide comfort care around the process of dying and (2) to support the dying individual and his/her family members so as to optimize their quality of life. Hospice care focuses not only on physical aspects of care, but also on social, emotional, spiritual, cultural, and ethical aspects of care. Accordingly, this paradigm of care is a complex, yet morally essential, component of healthcare.

Hospice care exists within a context of both internal (e.g., motivational, cultural) and external (e.g., regulatory) environments that shape its structures, practices, and accomplishments. In recent years, there has been an increasing interest among clinicians, researchers, and other stakeholders in improving the quality of care in the hospice setting. In 2008, this interest was codified when the Centers for Medicare and Medicaid Services (CMS) revised the Conditions of Participation for hospice agencies to require quality assessment and improvement (Centers for Medicare & Medicaid Services, 2008). Subsequently, the 2010 Affordable Care Act mandated that hospices submit data on selected quality indicators to CMS or face reductions in reimbursement (Office of the Legislative Council, 2010).

The major goal of this study was to examine how staff members from selected hospice agencies in Maryland perceive efforts to improve quality of care in the hospice setting. The study utilized an ethnographic and phenomenological approach to elicit narratives and meanings of the quality improvement (QI) experience from multiple perspectives within the hospice setting. The work commenced by exploring how participating hospice employees characterized end-of-life (EOL) care quality. It then

focused on how participants perceived efforts to improve the quality of that care, including how they defined QI in the hospice setting more generally, and how they viewed QI efforts in terms of advantages, disadvantages, barriers, and facilitators. The study also examined participants' awareness and views of external drivers for improving EOL care quality, as well as their knowledge and insights of both agency-specific and personal QI efforts.

This chapter lays the groundwork for the study and its findings. It begins by illustrating the importance of improving the quality of care near the end of life. It then presents the specific research question and aims of the study. The chapter concludes by describing the underlying theory and conceptual framework used for considering QI efforts in the hospice setting.

Importance of Improving End-of-Life Care

A variety of factors necessitate a continued focus on improving the quality of EOL care. Some of these factors, discussed more fully below, include the anticipated increase in demand for hospice care as the U.S. population ages, the effect of chronic illness on the dying process, evidence of poor-quality EOL care, and a healthcare policy environment that is increasingly focused on improving the quality of care while decreasing its cost.

Increasing Demand for Hospice Care

Enrollment in hospice in the United States has increased more than nine-fold since 1985, from 158,000 to more than 1.49 million as of 2017 (Connor, 2009, p. 130; National Hospice and Palliative Care Organization, 2018a). This increase in hospice

utilization has been driven, in part, by the expansion of the Medicare hospice benefit in terms of access, services, and reimbursement, a shift among hospice agencies to provide care for chronic terminal conditions in addition to cancer, and a greater awareness of the benefits of hospice care among the general public (Person, 2004). However, even in the absence of these influences, the demand for hospice care almost certainly will continue to increase as the U.S. population ages. In 2017, 94.9% of the 1.49 million Medicare beneficiaries enrolled in hospice were 65 years of age or older, and 47.5% were 85 years of age or older (National Hospice and Palliative Care Organization, 2018a). Furthermore, in 2017, approximately 48% of Medicare beneficiaries who died were enrolled in hospice at the time of death (National Hospice and Palliative Care Organization, 2018a). By 2030, the numbers of those 65 and older in the U.S. are projected to increase 30.3% to 73.1 million and the numbers of those 85 and older will increase 35.8% to 9.1 million from 2020 levels (Vespa, Lauren, & Armstrong, 2020). This expected increase in the over-65 population will translate to an increase in the number of Medicare beneficiaries overall, as well as in the number of those enrolled in hospice (Medicare Payment Advisory Commission, 2019).

Increasing Prevalence of Chronic Conditions

There also has been an increase in the number and percentage of Americans with chronic conditions—trends that likely will continue with the aging of the U.S. population (Hung, Ross, Boockvar, & Siu, 2011). Data from 2014 indicate that 60% of adults in the U.S. have at least one chronic condition, while 42% have more than one, and 12% have five or more (Buttorff, Ruder, & Bauman 2017). Further, CMS estimates that 69% of

fee-for-service Medicare beneficiaries had at least two chronic conditions in 2017 (Centers for Medicare & Medicaid Services, 2019b). Moreover, in 2017, 10 of the 15 leading causes of death in the United States, which accounted for 68% of all deaths, were due to chronic disease (Kochanek, Murphy, Xu, & Arias, 2019).

As posited by Lynn and demonstrated empirically by Lunney and colleagues, three trajectories describe the functional status and dying process for those with serious chronic disease (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Lynn, 2001). The first trajectory results in “short term, expected deaths” from conditions such as terminal cancer. In this illness trajectory, the course of illness is relatively predictable and functional abilities are maintained throughout the majority of the trajectory. The second illness trajectory reflects chronic conditions that result in organ system failure (e.g., heart failure, chronic obstructive pulmonary disease, and cirrhosis). The third trajectory reflects dementia or frailty. The second and third trajectories differ markedly from the first: declines in function are more gradual and prolonged, and often, they are relatively less predictable, where periods of stability alternate with illness exacerbations or crises.

In the illness trajectories of those with organ failure, dementia, and frailty, the dying process is extended, often over years. This is due, in part, to modern medical care, which has become adept in treating other potentially fatal conditions (e.g., pneumonia or kidney failure) that often accompany these chronic conditions (Institute of Medicine, 1997). Connor suggests that hospice care may modify these illness trajectories by reducing the severity of the exacerbations and helping to improve or maintain patients’ functional abilities (Connor, 2009, p. 41). For example, hospice care may facilitate

maintenance of adequate diet and medication management and/or enable detection of early sign or symptoms of potential exacerbations and then provide treatment to limit their effects (Lorenz, Shugarman, & Lynn, 2006). Regardless, this “prolonging of death” due to chronic disease mandates a system of care that will provide physical comfort as well as emotional, spiritual, and practical support for dying individuals and their families (Institute of Medicine, 1997, p. 37).

Evidence of Poor-Quality End-of-Life Care

The landmark study demonstrating the need for improvements in EOL care began in 1989 with the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). As summarized by Conner, the goal of SUPPORT was to “improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying” (Connor, 2009, p. 93).

SUPPORT included two phases: a prospective observational study conducted from 1989 to 1991, and a controlled clinical trial conducted from 1992 to 1994, both of which were performed in five teaching hospitals in the U.S. Phase 1 of SUPPORT described the decision-making process and related outcomes of 4,301 hospitalized patients who were dying. Findings from this phase of SUPPORT indicated that advance directives did not influence patients’ resuscitation decision, nor hospitals’ use of resources (Teno et al., 1994). The study also found that physicians’ perceptions of their patients’ preferences regarding resuscitation often were at odds with actual patient desires (Teno et al., 1995). This increased the use of medical resources, even after adjustment for patient age, diagnosis, and illness severity. Phase 2 of SUPPORT assigned a total of

4,804 dying patients to a control group and an intervention group (Connor, 2009; Connors Jr. et al., 1995; Murphy et al., 2000; Teno, 1999). The control group received usual medical care. Members of the intervention group were queried about their preferences and then educated about treatment options and prognosis by specially trained nurses. These nurses then facilitated the sharing of this information between the patients and their physicians. Unfortunately, the intervention was not successful. Specifically, the median time until a do-not-resuscitate order was written did not change, the agreement between patient and physician regarding CPR preferences did not increase, the number of days spent in an ICU, comatose, or on mechanical ventilation did not decrease, the level of reported pain did not decrease, and, finally, there was no reduction in the amount of hospital resources utilized (Teno et al., 1995) .

Although much progress has been made to improve the quality of care near the end of life in the years since the SUPPORT study, particularly in the hospice setting, recent studies indicate that additional improvement is needed. For example, in 2009, Carlson and colleagues conducted a national survey of 591 randomly selected hospice programs to determine the extent to which hospices in the U.S. had implemented 17 of the 38 preferred practices endorsed by the National Quality Forum (Carlson et al., 2011; National Quality Forum, 2006). The 38 preferred practices promote use of key structures and processes of care needed in high-quality palliative care and hospice programs. Results from this study indicated that only 10% of hospices reported adherence to all 17 of the preferred practices. The preferred practices that were implemented least frequently included: using a standardized assessment tool for pain and system management (66%)

and incorporating the goals of the patient and family in the care planning process (55% and 45%, respectively). Implementation of preferred practices was associated with infrastructure support (e.g., on-call physicians at night and on weekends), and was more likely among larger and chain-affiliated agencies. Finally, the study authors uncovered geographic variation in practice patterns among U.S. hospices, with hospices in New England more likely than those in other census regions to have implemented the preferred practices.

More recent literature also suggests that, even though pain management is a key focus of care in the hospice setting, there continues to be opportunity for improvement in the management of pain for those near the end of life. Pain, a multidimensional construct that includes physical, emotional, cognitive, and spiritual components, is one of the most frequent symptoms faced by those nearing the end of life (Cagle & Altilio, 2011; Wilkie & Ezenwa, 2012). Physical pain near the end of life has been described as complex, variable, present in multiple locations in the body, and as moderate or severe in intensity (Wilkie & Ezenwa, 2012). Fiscal year 2015 data from the CMS Hospice Quality Reporting Program indicate that a comprehensive assessment of pain was conducted within one day (in those who screened positive for pain) only 73.9% of time in Medicare-certified hospices (Zheng et al., 2018). In a study of patients with cancer, chronic obstructive pulmonary disease (COPD), and dementia, who were admitted to an inpatient hospice facility, fewer than half of the first two patient groups reported adequate control of their moderate or severe pain within 24 hours of its onset (Romem et al., 2015). These authors also found that those with COPD were given significantly less

opioid medication to control their pain, even though they reported similar levels of moderate-to-severe pain intensity as those with cancer. In a study of 94 cancer patients receiving home hospice care, two-thirds of patients reported having at least mild pain, and patients also reported having an average 1-2 hours of severe pain daily (Black et al., 2011). In another study of older cancer patients receiving home hospice care, researchers found that evidence-based practices for pain assessment and management were not consistently implemented or documented (Herr et al., 2010). This study also found that only 15.8% of patients reporting severe pain had their medication increased within 24 hours of their second such report, and only 5.3% of those reporting moderate-to-severe pain had a reassessment of their pain within 24 hours. Finally, in a study of patients with both cancer and dementia who were receiving hospice care in a nursing home, 40% were not given any opioid medication during their last two weeks of life (Monroe, Carter, Feldt, Dietrich, & Cowan, 2013).

A few studies also have indicated a need for improvement in the management of symptoms other than pain for those enrolled in hospice. For example, studies from the early 2000s that focused on care of dementia patients found inadequate management of dyspnea (i.e., shortness of breath), as well as other symptoms including loss of appetite and incontinence (Black et al., 2011; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2008; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Black and colleagues found that, although there was a decrease in several symptoms (i.e., tiredness, nausea, depression) and a corresponding increase in degree of comfort and overall quality of life for cancer patients two weeks after admission to home hospice care, the differences were

not statistically significant (Black et al., 2011). In a study of Veteran's Administration patients with solid tumor cancers between 2006 and 2008 who were enrolled in the hospice program, researchers found that patients received only 61% of the recommended care for depression or other psychosocial symptoms, 71% of the recommended care for dyspnea, and 38% of the recommended care for other symptoms (Malin et al., 2011). Some of the most common non-pain symptoms encountered by persons near the end of life include dyspnea, fatigue, anxiety, depression, nausea, agitation, confusion, anorexia, and incontinence, and fortunately, these are symptoms that are most amenable to management through high-quality hospice care (Cagle & Altilio, 2011; Medicare Payment Advisory Commission, 2012; Singer et al., 2015; Wilkie & Ezenwa, 2012). Not unexpectedly, symptom management (including assessment, education, treatment, and outcome) is a key domain of care that is now measured in hospices nationwide (Zheng, Rokoske, Kirk, Lyda-McDonald, & Bernard, 2014).

Moreover, a recent study examining differences in perceived quality of hospice care among caregivers across various settings of care found that the agency-level average scores reflecting the highest positive ratings of quality were less than 90% for measures of getting help for symptoms, getting emotional and spiritual support, getting timely care, and hospice team communication (Quigley et al., 2020). Importantly, this study also found that hospice agencies' scores were significantly lower when care was provided in hospitals and nursing homes, as compared to the patients' home.

Finally, the U.S. Office of Inspector General recently found evidence of care deficiencies across most U.S. hospice agencies. Specifically, 87% of Medicare-certified

hospice agencies that were surveyed between 2012 and 2016 failed to meet at least one requirement for participating in the Medicare program (Office of Inspector General, 2019). Most of these deficiencies related to shortcomings in care planning, training and supervision of hospice aides, and completion of required assessments. However, 20% of the surveyed agencies had at least one deficiency that indicated lack of capacity to provide adequate care or practices that jeopardized the health or safety of enrollees.

Current Healthcare Policy

Healthcare policymakers continue to focus on the unsustainable growth in healthcare costs—growth that will be exacerbated by the aging of the U.S. population (Institute of Medicine, 2013; Keehan et al., 2011). More and more, policymakers, both public and private, are relying on pay-for-performance programs that provide payment incentives to healthcare providers in an effort to increase healthcare quality, reduce healthcare costs, or both (Institute of Medicine, 2013; Kinney, 2013), although thus far, it is unclear whether this approach will yield the desired results ("Pay-for-performance," 2012). Over the past 18 years, CMS has launched various QI programs for hospitals, nursing facilities, home health agencies, and individual physicians. These programs typically progress from payment incentives for voluntary reporting of quality metrics, to payment for required submission and public reporting of quality metrics, to payment incentives or penalties based on the results of the quality metrics (i.e., pay-for-performance) (Kinney, 2013). This focus on increasing quality and reducing costs, often referred to as a move to “value-based care,” is now being implemented in the hospice setting. For hospices, submission and eventual public reporting of quality metrics was

mandated by the 2010 Affordable Care Act. Accordingly, CMS now penalizes, financially, those hospice agencies that do not collect and submit quality performance data. If CMS follows its pattern of moving toward paying for performance (Centers for Medicare & Medicaid Services, 2020), it eventually may penalize those hospice agencies that provide poor quality care and/or reward those agencies that provide the highest quality care.

Research Question and Aims

As demonstrated above, improving the quality of care delivered through hospice is, and will continue to be, a necessary and vital objective for the U.S. healthcare system. While there is research on preparedness for QI implementation and on specific QI interventions, there is a lack of basic research from the qualitative perspective about the nature and circumstances of QI within hospice.

Accordingly, the overall research question addressed in this study is how providers in the hospice industry perceive QI efforts. To answer this question, I explored how hospice providers who participated in the study characterized and defined quality care near the end of life. I also examined their knowledge and perceptions of external drivers for improving quality of care (e.g., specific legislative and regulatory requirements) and their perceptions of internal QI efforts (both agency-specific and personal). The specific aims for this study were as follows:

Aim 1: To identify and describe the meanings of quality care at the end of life, as perceived by hospice providers

Aim 2: To identify and describe how hospice providers perceive the potential for improving quality of care near the end of life

Aim 3: To identify and describe hospice providers' familiarity with and perceptions of external drivers to improve quality of care near the end of life

Aim 4: To identify and describe the internal (agency-specific) QI efforts of hospice providers participating in the study

Aim 5: To identify and describe the perceptions of hospice providers concerning their own QI efforts

Aim 6: To describe how the above meanings and perceptions might differ according to provider role and/or agency characteristics

As a point of clarification, throughout this document, I have used the phrase “hospice provider” as an umbrella term that represents individual staff members in various roles (most usually, agency directors, nurses, social workers, and chaplains), as well as the hospice agency as a whole (i.e., the organization itself). At times, I have used the terms “hospice provider,” “agency staff,” or agency “employees” synonymously, primarily to provide variety in the text. When specificity is needed (e.g., to distinguish between individuals versus agencies or provider roles), I have used exact language, not the umbrella term.

Theoretical Underpinnings

At its core, healthcare QI requires *change*, including change by individuals as well as healthcare teams, organizations, and systems (Ferlie & Shortell, 2001). A range of theories, frameworks, and models have been applied to the improvement of healthcare

quality (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007; Shojanian, McDonald, Wachter, & Owens, 2004). These run the gamut from “grand theories” that describe or explain all or part of the QI process or those that provide some indications of how to accelerate the process, “mid-range” theories that are less abstract and are used to guide empirical research or practice, and “micro” theories that are narrowly focused on particular fields or populations (Shojanian et al., 2004).

In the science of QI, the theoretical framework that is almost always invoked, either explicitly or implicitly, is that of Diffusion of Innovations (DOI). DOI, as defined by Rogers, is “*essentially a social process in which subjectively perceived information about a new idea is communicated from person to person. The meaning of an innovation is thus gradually worked out through a process of social construction*”(Rogers, 2003, pp. xx-xxi).

Initially proposed by Everett Rogers in 1962, this social change “grand theory” has evolved over time to include, among many new insights, descriptions of how networks and new communications technologies influence the spread of new ideas and how diffusion occurs within and between organizations. Although not the first to study the topic, Rogers’ initial contributions to the field argued that the diffusion of innovations is a *general* or *universal* process that holds true regardless of the type of innovation or the context of the diffusion in terms of geographical location and culture, an assertion that has been borne out over time (Rogers, 2003, p. xvi, 2004).

The DOI theory, described in detail in the next section, is particularly applicable to healthcare and healthcare improvement because of the length of time it takes for

findings from research (e.g., new drugs, devices) to be incorporated into standard practice (Balas & Boren, 2000). Moreover, while QI efforts seek to disseminate healthcare innovations, *QI itself can be considered an innovation* that can be diffused among individuals and within and across organizations and systems. In his seminal article on disseminating innovations in healthcare, Berwick illustrated that uptake of proven process improvements also can be protracted (Berwick, 2003). In this article, he provided examples of improvements that were embraced by relatively few practitioners, but which substantially decreased cesarean section delivery rates, decreased hospitalization rates for asthma patients, and increased patient safety during surgery while simultaneously saving millions of dollars.

Diffusion of Innovations

Rogers formally defines diffusion of innovations as the “*process in which an innovation is communicated through certain channels over time among the members of a social system*” (Rogers, 2003, p. 5). The diffusion of innovations ultimately results in a decision of whether to adopt or to reject an innovation. As used by Rogers, the term “diffusion” is applied to both the spontaneous or unplanned spread of new ideas, as well as the directed or planned spread (which is sometimes called dissemination).

Rogers posited four main elements of his theory: (1) innovation, (2) communication, (3) time, and (4) the social system. These are described more fully below. Unless otherwise indicated, the source for this information is the fifth edition of Rogers’ *Diffusion of Innovations* (Rogers, 2003).

Innovation

The first main element of the Diffusions of Innovations (DOI) theory is the innovation itself. An innovation is something—an idea, intervention, or practice—that potential adopters or users (e.g., individuals, organizations, communities) perceive as new. Innovations in healthcare include new procedures, new medications, new guidelines for practice, and new care delivery process, among others. Varkey and colleagues describe innovations in healthcare as typically related to healthcare products, processes, or structures that are either *nondisruptive* or *disruptive* (Varkey, Horne, & Bennet, 2008). Nondisruptive innovations are incremental in effect, allowing for improvement of something that already exists. Disruptive innovations are *transformational* in effect, resulting in the participation of new players (e.g., models of care, products, processes, markets) and the marginalizing of old ones. Varkey and colleagues characterize QI efforts in general as “most closely linked” to non-disruptive innovation, because improvement efforts often simply extend current practices (Varkey et al., 2008). However, sometimes QI efforts result in complete redesign of healthcare processes or structures. For example, many QI efforts endeavor to ensure implementation of standards of care (e.g., assessments of pain and other symptoms). These would be considered non-disruptive innovations. In contrast, some QI activities seek to redefine how care is delivered. Examples of such disruptive efforts include the rise of hospice and palliative care as models of care delivery.

Rogers described five steps of the *innovation-decision process* among individuals.¹ These typically occur in the order shown below:

- Knowledge. When the potential adopter learns about and gains understanding of the innovation
- Persuasion. When the potential adopter forms an initial opinion about whether or not to adopt an innovation
- Decision. When the potential adopter “engages in activities” that lead to adoption or rejection of the innovation
- Implementation. When the adopter actually puts the innovation into practice
- Confirmation. When the adopter seeks feedback on or evaluation of the adoption decision, which may be reversed if that feedback is negative

The rate of adoption of a particular innovation depends to a large extent on the characteristics of the innovation, *as perceived by* those who may or may not adopt it. As much as 49%- 87% of the variance in the rate of adoption is explained by the following five characteristics of the innovation: relative advantage, compatibility, complexity, trialability, and observability. These characteristics are discussed more fully below.

RELATIVE ADVANTAGE

The first characteristic of an innovation that is highly correlated with the rate of adoption is its relative advantage. Relative advantage is the extent to which the innovation is perceived to be better than the status quo (e.g., in terms of economics,

¹ There are similar, but different, stages of the innovation process within organizations.

convenience, satisfaction, prestige). In general, the greater the perceived relative advantage, the faster the rate of adoption will be. In some cases, however, it may be difficult to convince potential adopters of the relative advantage of an innovation. Such is the case for preventive innovations, such as those that decrease the likelihood of some future undesired event (e.g., taking a flu shot to avoid catching the flu). Persuading potential adopters of the benefit of these types of innovations can be difficult, because of the uncertainty that the undesired event will occur and the potential long lag time between adoption and the future event. Thus, for preventive innovations, the rate of adoption may be particularly slow. At least some QI efforts in the hospice setting are, in essence, preventive innovations, as they generally are geared towards preventing undesired outcomes near the end of life (e.g., interventions geared toward improving pain management). However, the lag time between adoption and realization of the benefit may be relatively short.

Two ways to increase the relative advantage of an innovation, and thus to increase the rate of adoption, are to mandate adoption or attach incentives to its adoption. Incentives can be offered to individuals or the system itself; these can be monetary or not, positive or negative, and immediate or delayed. While use of incentives can promote adoption, or quicker adoption, among those who might be less inclined towards adoption at all, such adopters might have less motivation to continue use of an innovation after the incentive is discontinued. Both mandates (i.e., through the CMS Conditions of Participation rules) and negative monetary incentives (i.e., through the Hospice Quality

Reporting Program) have been used to promote adoption of QI efforts in the hospice setting.

COMPATIBILITY

The second characteristic of an innovation that is highly correlated with the rate of adoption is its compatibility. Compatibility is the extent to which the innovation is perceived to align with the values, beliefs, past experiences, and current needs of the potential adopter. In general, the greater the perceived compatibility, the faster the rate of adoption will be.

Compatibility with cultural values and beliefs is most salient, because innovations that are perceived as incompatible with these may not be adopted at all. In contrast, compatibility with past innovations can either hinder or help the rate of adoption. For example, a new innovation that is similar to existing ideas may be more quickly adopted because the shift from old to new might be perceived as easier. On the other hand, a negative experience with an earlier innovation might retard the rate of adoption of a similar innovation. Finally, while seemingly straightforward, understanding whether or how an innovation is compatible with current needs can be problematic if the need for a particular innovation is not recognized or not accurately assessed.

Some research has indicated that there may be a reluctance to implement QI efforts in hospice because of the perceived uniqueness of the setting. In a qualitative study of perceived barriers and facilitators of QI in the hospice setting, Durham and colleagues identified three such barriers (Durham, Rokoske, Hanson, Cagle, & Schenck, 2011). These included: (1) concerns about adequacy of quality measurement for

spiritual, psychological, and cultural needs, (2) the potential for inaccurately reflecting quality of care if performance metrics cannot take into account individual patient or family goals for care, and (3) the potential for QI efforts to *medicalize* death, which is in direct opposition to the humanistic philosophy of hospice. Each of these can be interpreted as issues of compatibility of the innovations.

COMPLEXITY

The third characteristic of an innovation that is highly correlated with the rate of adoption is its complexity. Complexity is the extent to which the innovation is perceived too difficult to understand or implement. In general, the greater the perceived complexity, the slower the rate of adoption will be. In contrast to other medical settings (e.g., hospitals, nursing facilities, and home health agencies), QI in the hospice setting is a relatively new endeavor, and many organizations have limited experience and/or resources available for proficient engagement. Potential difficulties in adopting and implementing QI activities in the hospice setting include identifying appropriate areas for improvement efforts, selecting the best metrics to measure improvement, ensuring adequate and appropriate data collection techniques, and providing sufficient staff education and training.

TRIALABILITY

The fourth characteristic of an innovation that is highly correlated with the rate of adoption is its trialability. Trialability is the extent to which the innovation is perceived to be amenable to implementation on a small scale, for learning purposes, prior to

widespread adoption. In general, the greater the perceived trialability, the faster the rate of adoption will be.

It should be noted that in the hospice setting, for agencies certified for Medicare/Medicaid participation, trialability for “overall” QI efforts was an option only prior to the 2008 change in the CMS Conditions of Participation, which mandated establishment of quality assurance and performance improvement programs. However, QI efforts for particular areas of interest almost always are (or should be) implemented on a trial basis. This is because implementing “small tests of change” prior to widespread adoption and implementation is a standard part of the QI process (Moen & Norman, 2010).

OBSERVABILITY

The fifth characteristic of an innovation that is highly correlated with the rate of adoption is its observability. Observability is the extent to which the outcome of an innovation is perceived to be visible to potential adopters. In general, the greater the perceived observability, the faster the rate of adoption will be. Observability is almost possible for QI in the hospice setting, as improvement often can be demonstrated via use of well-vetted performance measures. However, the degree of, and ease of access to, performance measurement results varies across hospice organizations.

Communication channels

The second main element of the DOI theory is the communication channels through which information about innovations is created and then shared. Rogers describes several communication channels, including mass media (e.g., radio, television),

interpersonal exchanges, and technology-based mediums (e.g., the internet). Of these, communication through interpersonal networks is more conducive to persuasion (for or against) about an innovation than is mass communication, which typically is used to spread knowledge about the innovation among potential adopters. Rather than relying on the technical merits of the intervention, potential adopters tend to judge an innovation based on the information received via interpersonal exchanges from previous adopters who are similar to themselves. Such similarity enhances communication, in part because the exchange of ideas is easier when the “players” share common understandings. Typically, however, when communication regarding an innovation is limited to those who are similar, the rate of adoption will be relatively slow.

Time

The third main element of the DOI theory is time. Time in the diffusion process can be reflected in several ways, including:

- the time needed to complete the steps of the innovation-decision process from knowledge through adoption or rejection;
- the rate of adoption of an innovation (usually, the number potential adopters who adopt the innovation within a given time period); and
- the relative “earliness” or “lateness” of adoption by a particular adopter (described by Rogers as “*innovativeness*”).

Rogers described the innovativeness of adoption using five categories: innovators, early adopters, early majority, late majority, and laggards. When the number of adopters is plotted against time, the resulting distribution typically is a bell-shaped (normal) curve.

These adopter categories are determined by partitioning this adoption curve according to the number of standard deviations from the average adoption time. Of course, the ability to identify the various adopter categories is possible only when the innovation has been fully diffused among a set of individuals.

- Innovators. Comprising 2.5% of adopters, these are the risk-takers who “launch” the innovation in a new system. They often have substantial financial resources, high levels of technical expertise, and ability to live with the uncertainty of an innovation untried in a particular context. Described by Rogers as “cosmopolite,” their interpersonal networks extend beyond the boundaries of their own social system.
- Early adopters. Comprising 13.5% of adopters, these are the opinion leaders in the local system. They are respected by their peers, triggering a critical mass of adoption as they communicate their own evaluation of the innovation to their peers through interpersonal exchanges.
- Early majority. Comprising 34% of adopters, these are the followers who adopt just ahead of the “average” adopter. Berwick describes them as “local” in their perspective, making them interested in innovations that are most relevant to their own particular needs rather than in those that are may be applicable more generally (Berwick, 2003).
- Late majority. Comprising 34% of adopters, these are the more skeptical adopters who delay adoption until peer pressure is brought to bear. They may have financial reasons to delay adoption until it is “safe” to do so.

- Laggards. Comprising 16% of adopters, these are the traditionalists who look to the past when making decisions and are resistant to change, often due to financial pressures.

Berwick, in his conceptual “prescription” for diffusing innovations in healthcare, suggests identifying, and then supporting, innovators and early adopters by providing time and resources to “scout out” innovations, communicate with innovators, and try new QI initiatives on a small scale (Berwick, 2003).

Social system

The fourth main element of the DOI theory is the social system. In this theory, a social system is made up of members (e.g., individuals, organizations, sub-systems) working to solve a common problem and accomplish a common goal. Social systems can be structured both formally (i.e., when norms define the behavior that is expected from members of the system, such as in a hierarchy) and informally (i.e., members belong to various interpersonal networks). Both types of social structures can affect the diffusion of innovations either positively or negatively.

Opinion leaders, who are central players in interpersonal communication networks, regularly influence other members of the system, either to promote or discourage adoption of an innovation. The influence of opinion leaders is not due to their role in the formal social structure, but instead is merited because of their “technical competence, social accessibility, and conformity to the system’s norms” (Rogers, 2003, p. 27). Opinion leaders look outside of their own system, bringing in new ideas and knowledge.

The decision whether to adopt or reject an innovation can be made optionally, by each individual members of the social system, or jointly. Joint decisions can be made either through a *collective* decision (arrived at by consensus of the members) or by an *authority* decision (made by a small number of individuals in the system, with little input from other members of the system). For this study, the social system of primary interest is the individual hospice agency. Thus, diffusion of innovations within organizations is of interest. This is discussed next.

Diffusion of Innovations Within Organizations

Diffusion of innovations within an organization is similar to, but more complex than, diffusion among individuals. As with diffusion among individuals, diffusion within organizations is a *process* rather than a one-time event (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004; Rogers, 2003). Specifically, Rogers describes diffusion within organizations as a two-part process. First is *initiation* (i.e., gathering information, conceptualization, and planning for adoption, leading up to the decision to adopt). This is then followed by *implementation* (i.e., the actions involved in putting the innovation into operation).

In general, decisions regarding adoption are more likely to be collective or authority decisions rather than optional decisions made by individuals in the organization (Rogers, 2003). Rogers asserts that while authority decisions typically will result in a faster rate of adoption than optional decisions, actual implementation of the innovation can be retarded if individual members of the organization have not “bought in” to the decision.

Some research has assessed how organizational characteristics affect diffusion. One general finding is that larger organizations tend to be more innovative—possibly because of the relatively greater availability of financial and human capital resources (Rogers, 2003). Other structural characteristics of organizations also have been shown to be related to organizational innovativeness (Rogers, 2003). These are described below:

- **Centralization.** The degree to which control in the organization is concentrated among few members or dispersed among many. More centralized organizations may be slower to adopt initially but be better at implementation.
- **Complexity.** A reflection of members' knowledge and expertise (i.e., via formal education or training and occupational specialization). More complex organizations may be more likely to adopt, but members may be less likely to come to consensus about how to implement.
- **Formalization.** The degree to which members' adherence to rules and procedures is expected. More formalized organizations may be slower to adopt, but be better at implementation.
- **Interconnectedness.** The level of interpersonal linkages between members of an organization. Organizations with higher levels of interconnectedness tend to be more innovative.
- **Organizational slack.** The level of “uncommitted” resources that are available to the organization (i.e., resources that are not needed simply to maintain the organization). Higher levels of organizational slack are positively associated with innovativeness.

Certain individuals within an organization (i.e., those who excel in interpersonal relationships and in the arts of persuasion and compromise) also may support the adoption of an innovation and, in so doing, influence others to do so as well. These *champions* within an organization are similar to opinion leaders who promote diffusion among individuals. Organizational adoption of an innovation is more likely when there is a champion supporting the innovation (Greenhalgh et al., 2004).

Organizational characteristics and availability of champions can vary substantially across hospice agencies. Although research on these characteristics in relation to QI in hospice is limited, there is some empirical evidence that larger agencies, those with multiple locations, and those with a designated champion have greater capacity for QI efforts (Hanson et al., 2010).

Consolidated Framework for Implementation Research

Aims 4 and 5 of this study specifically address implementation of QI efforts (i.e., agency-specific and personal efforts, respectively). Thus, a basic understanding of implementation science is needed to place the findings related to these aims into context.

Implementation science (sometimes called *implementation research*) is the study of factors that influence the translation of innovations from basic research to broad application (Demiris, Oliver, Capurro, & Wittenberg-Lyles, 2014). Many elements of the DOI theory are incorporated into implementation science. However, as the name implies, implementation science itself focuses less on the *initial adoption* of innovations (Demiris et al., 2014; Rabin & Brownson, 2012). Instead, it considers various factors, such as

organizational, geographic, political, and cultural contexts, that influence the *sustained adoption* of innovations in specific settings.

Various frameworks have been developed to describe, and potentially influence, the implementation process (Demiris et al., 2014). For this study, I utilized the domains articulated in the *Consolidated Framework for Implementation Research* (CFIR) to guide its aims and develop the interview guide. The CFIR was established by Damschroder and colleagues in 2009 to synthesize existing implementation theories (Damschroder et al., 2009). Since its introduction, the CFIR has been used as a guiding framework in a variety of studies. Notably, this framework builds on Greenhalgh and colleagues' contributions regarding diffusion of innovations in service organizations (Greenhalgh et al., 2004). The CFIR, described by its authors as “meta-theoretical,” includes common constructs from existing theories, but does not try to describe interrelationships between the constructs, nor does it address specific hypotheses related to implementation (Damschroder et al., 2009). The CFIR consists of five major domains, as follows:

- The intervention (i.e., the innovation). Characteristics of the intervention include its source, underlying evidence, relative advantage, adaptability, trialability, complexity, design/packaging, and cost.
- Inner setting. The structural, political, and cultural context of the organization in which implementation occurs, as well as the nature and quality of its social network and communications, its capacity for change, and readiness for implementation.

- Outer setting. The economic, political, and social context of the organization in which implementation occurs. This includes external policies and regulations, as well as patient needs and external peer pressure.
- Individuals involved in the implementation. These can hail from both the inner and outer settings, and includes those who implement the intervention or are affected by the intervention.
- Process of the implementation. The implementation process incorporates planning, engaging, executing, and evaluating (although not necessarily in this linear order).

Importantly, each of the five domains of the CFIR includes specific constructs that influence implementation, some of which flow directly from the DOI theory. Appendix A, taken directly from a supplemental file accompanying Damschroder and colleagues' seminal article on the CFIR, provides a short description of each of its constructs (Damschroder et al., 2009).

Individuals within organizations play an active role in the adoption and implementation processes. However, when the CFIR was established, there was little research focusing on the interaction between individuals and the organizations in which they work, and how this interaction influences changes in individual and organizational behavior (Damschroder et al., 2009). Because for this study, the primary unit of analysis is the individual hospice staff member, it is instructive to review additional details about the characteristics of individuals, as related to their influence on implementation, that are

recognized in the CFIR. Descriptions of these constructs are taken from Damschroder, et al. (2009), who cite supportive literature as available.

- Knowledge and beliefs about the intervention. This component of the CFIR incorporates both attitudes about the intervention—often acquired subjectively from peers—as well as more the objective familiarity with facts about the intervention. The authors note that effective implementation often is a function of individuals' *skilled* and *enthusiastic use* of the intervention. The level of skilled use can be increased through effective education and training. However, the level of enthusiastic use in an individual often is influenced from communication with peers about their personal experiences with the intervention.
- Self-efficacy. This component of the CFIR reflects individuals' beliefs in their own ability to do the things necessary to implement the intervention. Damschroder and colleagues suggest that higher levels of self-efficacy are associated with both adoption and sustained implementation.
- Stage of change. This component of the CFIR reflects the stage of an individual in the progression towards skilled, enthusiastic, and sustained implementation.
- Individual identification with the organization. This component of the CFIR incorporates individuals' perceptions of, and commitment to, the organization. Damschroder and colleagues argue that those who are committed to the organization likely will put extra effort into the implementation process and positively influence peers regarding the implementation. Similarly, they suggest

that those who feel that the organization is “fair” may be more likely to more fully engage in the implementation process.

- Other personal attributes. These include other traits such as intellectual ability, learning style, motivation, values, competence, etc. Damschroder and colleagues note that little research to date has focused on these characteristics.

In 2015, Kirk and colleagues conducted a systematic review to determine the number and types of studies that have used the CFIR, the ways in it has been applied, and its contribution to implementation research (Kirk et al., 2016). Across the 26 qualitative, quantitative, and mixed-methods studies identified in this review, the authors identified the investigation of many types of innovations, including QI activities. The main objective of most of the identified studies was to gain insight into providers’ experiences with implementation, including processes used and barriers and facilitators to implementation. Based on these studies, Kirk and colleagues reported that some researchers specifically noted that the CFIR constructs were easy to understand and use. They noted that although a few authors suggested a need for clarification of the constructs, and even potential gaps in the framework, work to date had not necessitated substantial changes to the current framework. Finally, Kirk and colleagues noted that few of the study authors had actually used the CFIR to compare across studies, and none appeared to use it to further develop implementation theory. Results of a brief review of several studies published subsequent to Kirk, et al.’s 2015 review echo most of these conclusions regarding use and utility of the CFIR (e.g., (Abrahamson, DeCrane, Mueller, Davila, & Arling, 2015; Gesell et al., 2018; Selick, Durbin, Casson, Lee, & Lunsky,

2018; White et al., 2019), although some studies have also been used to strengthen the framework (e.g., (Strehlenert, Hansson, Nystrom, & Hasson, 2019; Varsi, Ekstedt, Gammon, & Ruland, 2015; Warner et al., 2018).

Importantly, the organizational components of the CFIR were adapted by Alexander and Hearld in their systematic review of implementation of QI initiatives in healthcare organizations (Alexander & Hearld, 2011).² Findings from this review indicate that the external context (i.e., outer settings) and QI processes themselves are relatively more likely to have a positive effect on implementation than does the content of the innovation or the internal context (i.e., the inner settings). However, these findings were tempered by the fact that substantially less research on external context and innovation content had been conducted to date. Because they focused only on the organizational correlates of implementation, Alexander and Hearld's work did not evaluate studies' findings vis-à-vis the fifth major domain of the CFIR (i.e., the individuals involved in the implementation).

Summary of Chapter 1

This chapter began by describing the current and ongoing demand for hospice care and the increasing prevalence of chronic disease in the U.S. population. It also cited critical evidence of provision of poor-quality EOL care, and stressed the concept of value (i.e., higher quality and lower cost) as the focus of current U.S. healthcare policy. These factors demonstrate and highlight the importance of improving the quality of care near

² This article was not included in the 2015 Kirk, et al systematic review because that review was limited to empirical studies.

the end of life. Nonetheless, there has been relatively little research to date focusing on QI within the hospice setting. This has prompted me to address the question of how hospice providers perceive QI efforts, which I believe has implications not only for participation in QI efforts, but also in the ultimate success of these efforts. The specific aims of the study address this overall research question in a progressively focused manner, from exploring overall meanings of quality EOL care and its improvement overall, to an exploration of perceptions of external drivers of QI, to a more narrowly focused examination of hospice providers views of agency-specific and personal QI efforts. Ideally, the findings regarding provider perceptions of QI efforts will contribute to a better understanding of QI implementation in general and QI in the hospice setting in particular.

The remainder of the chapter described the theoretical underpinnings of the study (i.e., the DOI theory, the application of the DOI theory to organizational diffusion, and the CFIR). Chapters 5 and 6 will present the findings of the study, and Chapter 7 will synthesize the findings and provide recommendations for practice, policy, and future research. But in order to adequately understand the findings and conclusions that will be presented in later chapters, background information on hospice and QI is required, as is a review of published literature regarding perceptions of EOL care quality and its improvement. Chapters 2 and 3, respectively, focus on these topics.

Chapter 2: Background

In order to understand the context and goals of this study, a familiarity with hospice is required: what it is, who provides it, who receives it, and how it operates in the United States. A basic understanding of how healthcare quality is defined, measured, and improved, both in general, and in the hospice setting specifically, also is required.

This chapter comprises two sections. The first section provides a brief history of hospice, and then describes the main components of U.S. hospice programs. Next, it summarizes the main requirements and provisions of the Medicare hospice benefit, so that the hospice care system in the U.S. can be further understood. The first section concludes by presenting the most currently available hospice statistics for the United States as a whole, and for the state of Maryland.

The second section of this chapter provides contextual information on healthcare quality and its improvement. It begins by providing a general definition of healthcare quality. It then presents discusses several dimensions, components, domains, and frameworks of quality of EOL care. Next, this section presents a brief introduction to healthcare quality measurement, describes several methodological challenges in measuring the quality of EOL care, and identifies key performance measures used in assessing care quality and improvement in the hospice setting. The section then goes on to briefly describe a common method used in improving healthcare quality. Finally, the section concludes by discussing key policy actions that have spurred QI activities in the hospice setting, and then reporting results of several national QI measures.

Hospice

Hospice is both a philosophy of care and a system for delivering care to patients near the end of life. According to the National Hospice and Palliative Care Organization, the philosophy of hospice is to provide family-centered care for persons nearing the end of life that minimizes their suffering and supports living in a way that is both meaningful and congruent with their values (National Hospice and Palliative Care Organization, 2016). Patient determinism (the idea that patients have the right to determine their own course of treatment, make key decisions about the end of life, and have the opportunity to prepare for death) is one of the basic tenets of this philosophy (Connor, 2009, pp. 9-10).

As a healthcare delivery system, hospice invokes an interdisciplinary approach to provide holistic care (i.e., physical, psychological, social, and spiritual care) for terminally ill patients and their families. In the U.S., both patients and their families view hospice care as high-quality, compassionate care (Taylor, Ostermann, Van Houtven, Tulskey, & Steinhauser, 2007). Hospice often is considered a setting of care, although the actual location of care delivery can include private residences, assisted living facilities, nursing facilities, hospitals, and inpatient hospice facilities.

Brief History of Hospice

The first hospices were created in the 11th century as places of shelter and refreshment for travelers during the Crusades, as signified by the Latin word *hospitium*, meaning “hospitality,” from which the word “hospice” is derived (Connor, 2009, pp. 1-5). However, the modern hospice movement began in the late 1950’s by Dame Cicely Saunders, an English nurse, social worker, and physician, who pioneered an

interdisciplinary and holistic approach for care of the dying. Dame Saunders went on to found the first modern hospice—St. Christopher’s, located just outside of London—in 1967.

In the U.S., Florence Wald, Dean of the Yale School of Nursing, co-founded the first U.S. hospice in New Haven, Connecticut in 1974 (National Hospice and Palliative Care Organization, 2013). She did this after inviting Dame Saunders to give a series of lectures in 1965, and then taking a sabbatical in 1968 to work at St. Christopher’s and learn about hospice. As of 2017, 4,488 hospice agencies provided services to U.S. Medicare beneficiaries (Medicare Payment Advisory Commission, 2019).

Components of U.S. Hospice Programs

The following ten characteristics reflect the essential components of hospice programs in the United States (Connor, 2009, pp. 7-8).

1. The patient and family together comprise the unit of care. The family includes those bonded with the patient through blood or emotional ties.
2. Care is provided in the home (i.e., in private homes as well as group homes or assisted living facilities) and in inpatient facilities (i.e., residential or inpatient hospice facilities, hospitals, or nursing homes).
3. Symptom management is the focus of treatment. This includes the management of pain as well the management of as other types of symptoms such as nausea and vomiting, shortness of breath, diarrhea and constipation, and confusion.

4. The care that is provided treats the whole person. Services may vary between programs but typically include nursing care, medical social services, physician services, spiritual support and counseling, home care services, companionship services, physical, occupational, and/or speech therapy, respite care, provision of medical supplies (including medications), and bereavement support.
5. Services are available 24 hours a day, 7 days per week.
6. The care that is provided is interdisciplinary. The care team includes physicians, nurses, social workers, chaplains, other mental health professionals, physical/occupational/speech therapists, pharmacists, and volunteers, among others.
7. The care that is provided is physician-directed. Hospice care is ordered by the attending physician, who must certify that the patient has limited life expectancy (typically 6 months); the hospice medical director oversees the care of all hospice patients.)
8. Volunteers are an integral part of the care team. Volunteers provide non-skilled care to patients (e.g., sitting with a patient, providing help with activities of daily living such as toileting and bathing, homemaker assistance, errands), bereavement support, office assistance, facility maintenance, etc.
9. The care that is provided is community-based and is not contingent on the patient's or family's ability to pay.
10. Bereavement services are provided to families of the basis of need. Typically, grief counseling is begun prior to the patient's death and bereavement support is

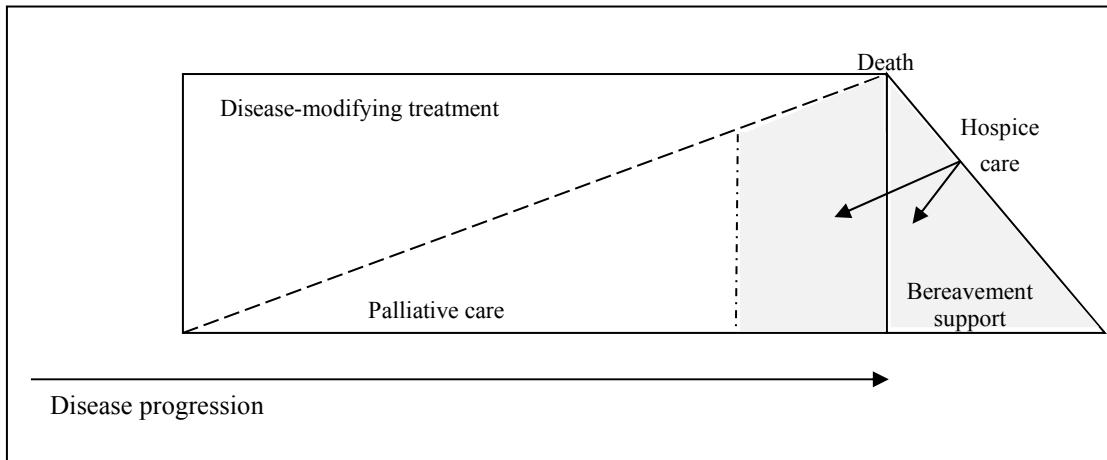
offered for up to a year following the death. Often hospice programs will offer bereavement support programs that are open to the entire community.

The care provided via hospice is palliative in nature, but hospice care is not synonymous with palliative care. The term “palliative” means reducing the effects or symptoms of a medical condition without curing it (palliative, 2014). In the United States, palliative care³—unlike hospice care—may be provided to those with any serious illness (terminal or not) at any stage of the illness (Center to Advance Palliative Care, 2014).⁴ Thus, hospice care is palliative care that is provided near the end of life. As described by Connor (2009, p. 6), “all hospice care is palliative; however, not all palliative care is hospice care.” Figure 1 illustrates how hospice care fits into the full continuum of care, beginning relatively near the end of life and continuing (for the family) beyond the patient’s death in the form of bereavement support.

³ Defined by the National Quality Forum (National Quality Forum (NQF), 2006) as “patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering; palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.” Like hospice care, palliative care has evolved in the United States into both a philosophy of care and a formalized system for delivery of healthcare, most often provided in an inpatient setting.

⁴ Note that outside of the United States, the term “palliative care” often is considered a care approach for those with life-threatening illness (World Health Organization, 2014).

Figure 1. Care Continuum for Palliative and Hospice Care



Adapted from National Quality Forum (NQF), 2006

The Medicare Hospice Benefit

The Medicare hospice benefit was introduced in 1982 as part of the Tax Equity and Fiscal Responsibility Act of 1982 (Gage et al., 2000). In terms of healthcare policy, creation of this benefit was relatively rapid, beginning 10 years earlier with a 1972 U.S. Senate Special Committee on Aging hearing on death with dignity (National Hospice and Palliative Care Organization, 2013). Dr. Elizabeth Kubler-Ross, author of the 1969's *On Death and Dying*, testified at this hearing. Up until this time, death and dying had been considered taboo subjects. However, with the publication of Dr. Kubler-Ross' best-selling book, this public attitude began to change (Newman, 2004).

Two years after the initial hearing, in 1974, Senators Frank Moss and Frank Church introduced legislation to grant federal funds to hospice programs, although the proposed legislation did not pass (Hospice Association of America, 2014). By the late 1970's, however, both government-led and private interests spurred the spread of hospice

care in the United States. In 1978, the National Cancer Institute awarded demonstration grants to study how, and at what cost, hospices provided care (Gage et al., 2000). The next year, the Health Care Financing Administration (HCFA) was authorized by Congress, and jointly funded by The Robert Wood Johnson Foundation and the John A. Hartford Foundation, to conduct a demonstration study to examine the feasibility of a Medicare-funded hospice benefit (Gage et al., 2000). In 1980, the Joint Commission on the Accreditation of Hospitals developed accreditation⁵ standards for hospices through a grant by the W.K. Kellogg Foundation (Gage et al., 2000). Finally, in 1982, Congress created the Medicare hospice benefit. This benefit had two restrictions: (1) a 4-year sunset provision was established, such that the benefit would expire unless Congress intervened and (2) the benefit had to be evaluated (Gage et al., 2000). In 1986, with the passage of the Consolidated Omnibus Budget Reconciliation Act, the Medicare hospice benefit was made permanent (Gage et al., 2000). Since its initial creation, Congress has modified the Medicare hospice benefit substantially, including increasing the benefit period, changing service provisions, and increasing reimbursements, and modifying the payment structure (Hospice Association of America, 2014; Medicare Payment Advisory Commission, 2019).

⁵ Accreditation is a way for hospice programs to signal to the community at large that they are meeting pre-defined standards of quality care. Hospice agencies that are accredited by an approved national accreditation organization are exempt from routine state surveys to assess compliance with Medicare conditions. Currently, CMS has approved (or “deemed”) three organizations to fulfill this function for hospice agencies: The Joint Commission, the Community Health Accreditation Partner (CHAP), and the Accreditation Commission for Health Care, Inc (ACHC).

To be eligible for the Medicare hospice benefit, a patient who qualifies for Medicare Part A⁶ must meet two additional eligibility criteria (Medicare Payment Advisory Commission, 2019). First, two physicians (the patient's regular physician and a hospice physician) must certify that the patient's life expectancy is six months or less if the disease progresses as expected. Second, the patient must agree to discontinue Medicare-funded curative treatment for the terminal disease. The amount of time a patient can receive hospice care under the benefit is unlimited, assuming the patient still meets the eligibility requirements. However, the first two 90-day benefit periods, the beneficiary must be recertified via a face-to-face visit with a physician or nurse practitioner every 60 days (Marrelli, 2018). Most care under the Medicare benefit is provided in the patient's place of residence (e.g., a private residence, group home, nursing facility, or assisted living facility), but care also can be provided in hospice inpatient facilities or in hospitals (National Hospice and Palliative Care Organization, 2018a). Payment is made on a per-diem basis. This means that a daily rate is paid to the provider, regardless of how many or what types of services (if any) are provided on a particular day. The actual per-diem payment depends on the patient's location (residence vs. inpatient) and the intensity of care needed (e.g., routine vs. continuous care) on that particular day (Medicare Payment Advisory Commission, 2019). Beginning in 2016,

⁶ Adults aged 65 or older automatically qualify for Medicare Part A if he/she is a U.S. citizen or legal resident, and if he/she (or spouse) has made payroll tax contributions for at least 10 years. Adults under age 65 who are disabled qualify for Medicare Part A after 24 months of entitlement to Social Security Disability Insurance (SSDI). Those with end-stage renal disease (ESRD) or Lou Gehrig's disease qualify once they begin receiving SSDI payments. ESRD is tied to dialysis/kidney transplant and not SSDI. Those aged 65 and older who do not automatically qualify for Medicare Part A may receive those benefits if they pay the monthly Part A premium. (source: <http://cms.hhs.gov/Medicare/Eligibility-and-Enrollment/OrigMedicarePartABEligEnrol/index.html>)

CMS modified the payment structure for routine home care, such that the per-diem payment for days 1-60 is higher than for days 61 onward; as part of this change, CMS also instituted a service intensity adjustment that pays an additional \$42 per hour (up to four hours per day) for visits by registered nurses and social workers during the patient's last week of life (Medicare Payment Advisory Commission, 2019). Although the Medicare hospice benefit provides only palliative care for a patient's terminal condition, the Medicare program will continue to provide coverage (including curative treatment) for other conditions when necessary.

National Hospice Statistics

Table 1 presents patient-level information for U.S. Medicare beneficiaries who received hospice Services through the Medicare hospice benefit in 2017, as provided by the National Hospice and Palliative Care Organization (National Hospice and Palliative Care Organization, 2018a).⁷ Table 2 presents information on hospice agencies that provided care to U.S. Medicare beneficiaries in 2017, as provided by the National Hospice and Palliative Care Organization and the Medicare Payment Advisory Commission.

⁷ In previous years, NHPCO provided data on hospice patients from all payers, not just Medicare, using information provided voluntarily to their National Data Set and member databases. However, beginning with the 2015 data year, they began publishing data for Medicare beneficiaries only.

Table 1. Characteristics of Medicare Beneficiaries Who Received Hospice Care, 2017

Characteristic	Value	Characteristic	Value
Number of patients	1.49 million	Level of care (% of days)	
Average length of stay	76.1 days	Routine home care	98.2%
Median length of stay	24 days	General inpatient care	1.3%
Sex		Continuous home care	0.2%
Female	58.4%	Inpatient respite care	0.3%
Male	41.6%	Discharges and Transfers	
Age		Death	82.9%
Less than 65	5.1%	Revocation	6.5%
65-69	7.4%	Transfers	2.1%
70-74	10.3%	No longer terminally ill	6.7%
75-79	12.9%	Moved out of service	1.4%
80-84	16.7%	Discharges for cause	0.3%
85+	47.5%	Location at death	
Race		Home	48.2%
White	82.5%	Nursing facility ^a	31.8%
Black	8.2%	Hospice inpatient facility	11.2%
Hispanic	6.4%	Acute care hospital	7.0%
Asian	1.7%	Other	1.7%
Other	1.2%		
Principle diagnosis (decedents only)			
Cancer	30.1%		
Circulatory/heart disease	17.6%		
Dementia	15.6%		
Respiratory disease	11.0%		
Stroke	9.4%		
Chronic kidney disease	2.3%		
Other	13.9%		

Note. Source: National Hospice and Palliative Care Organization (2018a).

^aIncludes skilled nursing facilities, nursing facilities, assisted living facilities, and long-term care facilities.

Table 2. Characteristics of U.S. Hospice Agencies that Provided Services to Medicare Beneficiaries in 2017

Characteristic ^a	Value	Characteristic ^b	Value
Number of agencies	4,488	Daily census	
Agency type		Mean	68.9
Free-standing/independent	78.4%	Median	33.2
Part of hospital system	10.5%	Number of patients	
Part of home health agency	10.6%	1-49	62.2%
Part of nursing home	0.0%	50-199	31.0%
Organizational tax status		200-499	5.7%
Not-for-profit	27.4%	>= 500	1.1%
For-profit	69.0%		
Government-owned	3.6%		
Geographic location			
Urban	79.9%		
Rural	19.6%		

Note. Source: ^aMedicare Payment Advisory Commission (2019); ^bNational Hospice and Palliative Care Organization (2018a).

The majority of hospice care in the U.S. is provided through the Medicare hospice benefit, which, in 2017, covered approximately 1.49 million Medicare beneficiaries and more than 90% of days spent in hospice in the U.S. in 2017 (Medicare Payment Advisory Commission, 2019). An estimated 1.1 million of these patients died while under hospice care, representing approximately 39.1% of all U.S. deaths (Kochanek et al., 2019; National Hospice and Palliative Care Organization, 2018a).

In the U.S., women are more likely to use hospice than men, a trend that has continued since the mid-1990's (Connor, Tecca, Lund Person, & Teno, 2004; Han, Remsburg, McAuley, Keay, & Travis, 2006; National Hospice and Palliative Care Organization, 2018a). Hospice utilization increases with age, with the lowest rates of use among those under age 65 and the highest among those aged 85 and above (National

Hospice and Palliative Care Organization, 2018a). Whites are disproportionately more likely to use hospice than other minorities (Han, Remsburg, & Iwashyna, 2006; Johnson, Kuchibhatla, Tanis, & Tulsky, 2007; National Hospice and Palliative Care Organization, 2018a). Potential reasons behind lower utilization of the Medicare hospice by Black Americans may include lack of availability of services, less knowledge about the services offered by hospice, greater distrust of the medical system, a greater reluctance to communicate treatment preferences, more unwillingness to accept the imminence of death, or a greater desire to pursue curative treatment (Johnson et al., 2007; Moulton, 2000).

Cancer was the predominant terminal disease among U.S. hospice patients in earlier years (e.g., in 1992, 80% of hospice patients had cancer) (Connor, 2009, p. 3). This likely was due to the increasing demand of cancer patients to participate in their treatment decisions as well as the relatively predictable course of swift decline over a short period of time that is characteristic of terminal cancer (Lynn, 2001). By 2014, however, cancer patients accounted for only 36.6% of new hospice admissions (National Hospice and Palliative Care Organization, 2015). This was due, in part, to policy recommendations from the National Hospice and Palliative Care Organization regarding admission of non-cancer patients (Connor, 2009; Connor, Elwert, Spence, & Christakis, 2007; Han, Remsburg, McAuley, et al., 2006). As of 2017, those with circulatory/heart disease (17.6%), dementia (15.6%), respiratory disease (11.0%), and stroke (9.4%) made up a substantial proportion of Medicare-enrolled hospice decedents (National Hospice

and Palliative Care Organization, 2018a). In contrast, those with cancer comprised only 30.1%.

The average length of service (LOS) for Medicare hospice patients in 2017 was 76.1 days, well below the 6-month eligibility timeframe allowed by Medicare; however, the median length of service was only 24 days (National Hospice and Palliative Care Organization, 2018a). The large gap between the average and median length of stay suggests that many patients spend relatively little time in hospice care. According to the National Hospice and Palliative Care Organization, 27.8% of Medicare hospice patients either died or were discharged⁸ from hospice within 7 days of admission (National Hospice and Palliative Care Organization, 2018a). Possible reasons for these very short hospice stays include physician reluctance to discuss or refer their patients to hospice, unwillingness of patients and/or families to accept a terminal diagnosis, the prohibition against concurrent curative and palliative care under the Medicare hospice benefit, and the fee-for-service payment system that incentivizes higher volumes of services for those near the end of life (Medicare Payment Advisory Commission, 2019). The concern with short lengths of stay is that those patients with very short episodes may not have enough time to benefit optimally from the various palliative and supportive services that are available through hospice. The large gap between the average and median lengths of stay also suggests that some patients spend substantially more time under hospice care than

⁸ Not all patients die while under hospice care; “live discharges” may occur for a variety of reasons. For example, the patient may choose to revoke the hospice benefit in order to receive curative treatment, the patient’s condition may improve, making him/her ineligible for the benefit under Medicare’s 6-month life expectancy rules, or the patient may move away from the hospice service area (Medicare Payment Advisory Commission, 2019). In 2017, the rate of live discharges among Medicare hospice patients was 17.1 percent (National Hospice and Palliative Care Organization, 2018a).

might be expected given the 6-month life expectancy (if the disease progresses as expected) that is typical for hospice eligibility. In 2017, 14.1% of patients remained in hospice care for more than 6 months (National Hospice and Palliative Care Organization, 2018a). However, the 6-month eligibility rule can be problematic because of the difficulty in accurately predicting time of death for many conditions, particularly for those with diagnoses such as dementia or heart failure that, unlike most cancers, have uncertain courses (Fox et al., 1999; Schonwetter et al., 2003; von Gunten, Ferris, D'Antuono, & Emanuel, 2002). The inability to accurately forecast time of death is further complicated by the possibility that hospice care itself may actually extend the life of certain patients (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007). However, there is concern that some hospice providers, particularly for-profit agencies, may purposively enroll patients likely to have long lengths of stay, but who may not actually meet the 6-month life expectancy requirement for eligibility, because long stays tend to be more profitable for the hospice agency⁹ (Medicare Payment Advisory Commission, 2019; Wachterman, Marcantonio, Davis, & McCarthy, 2011).

According to the Medicare Payment Advisory Commission, 4,488 hospice agencies in the U.S. provided services to Medicare beneficiaries in 2017 (Medicare Payment Advisory Commission, 2019). Of these, the majority (78.4%) comprised freestanding, independent agencies, while the remaining included mixed agencies (i.e.,

⁹ Analyses have shown that the resource needs and costs for hospice care are higher at the beginning of an episode (i.e., when a patient is first enrolled, due to assessment, stabilization, etc.) and near the end of the episode when death is imminent. Beginning in 2016, the Medicare payment structure changed from a simple per diem rate for routine home care of the patient, to a per diem rate that is less \$42 per day less after the first 60 days of care, coupled with a service intensity adjustment for nurse/social worker visits during the last 7 days of life (Medicare Payment Advisory Commission, 2019).

part of a hospital system (10.5%), home health agency (10.6%) or a nursing home (<0.1%). The majority of these are for-profit agencies (69.0%), while 27.4% are not-for-profit agencies, and 3.6% are government-owned agencies. Between 2000 and 2017, the growth in the number of Medicare-certified hospice agencies in the U.S. (from 2,255 in 2000 to 4,488 in 2012) is entirely attributable to the increase in the number of for-profit agencies (from 672 in 2000 to 3,079 in 2017) (Medicare Payment Advisory Commission, 2019).

Finally, data from the National Hospice and Palliative Care Organization indicate that hospice agency size varies considerably: approximately 62.2% of agencies, served, on average, between 1-49 Medicare patients per day, 31.0% served 50-199 patients per day, and 6.8% served 200 or more patients per day (National Hospice and Palliative Care Organization, 2018a).

Maryland Hospice Statistics

Hospices in Maryland fall under the state's Certificate of Need (CON) program. CON programs originally were legislated at the federal level to regulate hospital and NF capacity, in the belief that excess capacity would result in higher costs (National Conference of State Legislatures, 2015; Smith & Forgione, 2009). Although no longer federally mandated, many states continue to enforce CON programs. According to the Maryland Health Care Commission (MHCC), the objectives of the Maryland CON program are to ensure that new healthcare facilities and services are developed only when needed, and that such facilities/services are cost-effective, of high quality, geographically and financially accessible, financially viable, and will not negatively impact already-

established facilities or services (Maryland Health Care Commission, 2015). Need for hospice services is projected for each Maryland jurisdiction, which is defined as the each of the 23 Maryland counties and Baltimore City, and is calculated as a function of jurisdiction population and death rate, state hospice utilization, and the national hospice utilization rate (Maryland Health Care Commission, 2013). All but seven of the jurisdictions in Maryland have at least two hospice programs in operation, and the largest jurisdictions have seven to 10 hospice programs in operation.

Maryland hospice data are obtained from the Maryland Hospice Survey. This survey, conducted annually by the MHCC, is a legislatively mandated requirement for licensed hospices in Maryland. Data collected via the survey is used to support planning and policy development for hospice services in the state, including CON decisions (Maryland Health Care Commission, 2018a).

According to data from the 2018 Maryland Hospice Survey (Maryland Health Care Commission, 2018b), 28,373 patients received hospice care from 26 licensed hospice providers in the state. The majority of the patients were female (56.5%), White (72.6%), and aged 85 or older (43.7%). The smallest hospice agency in Maryland served 85 patients in 2018, while the largest served 5,244. The facility-level average length of stay for the 30 agencies was 67.3 days (min=32 days, max=211 days), and the facility-level average median length of stay was 25.1 days (min=8 days, max=138 days). The majority of agencies were free-standing (n=20) and not-for-profit (n=22).

Healthcare Quality and Its Improvement

The need for improvement in the safety and quality of the entire U.S. healthcare system was brought to the forefront of public awareness with the publication of the Institute of Medicine's (IOM's) *To Err is Human* in 1999 (Institute of Medicine, 2000). Two years later, the IOM issued a follow-up report, *Crossing the Quality Chasm*, which more completely described the shortcomings in quality in the U.S. healthcare system (Institute of Medicine, 2001). That report offered a multi-level framework for health system redesign that incorporates patient experience, team-based “microsystems” of care, the organizations that support these microsystems, and the environmental “macrosystem” of policies and regulations that influence those organizations (Berwick, 2002; Institute of Medicine, 2001).

Defining Healthcare Quality

In 1990, the IOM defined healthcare quality as “*the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge*” (Institute of Medicine, 1990, p. 4). This definition continues to be widely used and accepted (Panzer et al., 2013). Chassin and Galvin elaborate on this definition as follows (Chassin & Galvin, 1998):

- “health services” denotes various types, settings, and providers of care;
- “individuals and populations” reflects the need for quality of care during individual patient-provider interactions as well as at the overall system level, where issues of access and population health come into play;

- “desired health outcomes” emphasizes the need for person-centered care that welcomes a broad array of clinical and non-clinical outcomes (e.g., engagement, satisfaction, functional abilities);
- “increases the likelihood of desired health outcomes” interjects a cautionary note that sometimes poor outcomes occur even with high quality care; and
- “consistent with current professional knowledge” underscores the fact that knowledge—of medicine, about people, organizations, and systems, and of improvement itself—is not static and that changes in thinking and in healthcare delivery structures and processes will be necessary.

In 2001, with the publication of *Crossing the Quality Chasm*, the IOM expanded its concept of quality by articulating the following six dimensions of healthcare quality (Institute of Medicine, 2001):

- Safety. Avoiding injuries to patients from the care that is intended to help them
- Effectiveness. Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse)
- Patient-centeredness. Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions
- Timeliness. Reducing waits and sometimes harmful delays for both those who receive and those who give care

- Efficiency. Avoiding waste, in particular waste of equipment, supplies, ideas, and energy
- Equity. Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status

Defining End-of-Life Care Quality

There is no overarching definition of high-quality EOL care. However, numerous researchers and organizations have articulated various dimensions, domains, and frameworks that describe various facets of quality of EOL care. Several of these efforts are described more fully below.

IOM dimensions and components of care

In 1993, the IOM began exploring the feasibility of conducting a study of end of life care. Four years later, a series of workshops and meetings culminated in the groundbreaking publication of *Approaching Death: Improving Care at the End of Life* (Institute of Medicine, 1997). Members of the IOM Committee on Care at the End of Life who authored this report noted four overarching deficiencies in the care of the dying at that time: failure to provide effective care, with concomitant provision of ineffective or even harmful care; legal, organizational, and economic barriers; inadequate education and training of healthcare professionals; and lack of knowledge and research to support evidence-based EOL care. Committee members argued that care for the dying involves four key elements: (1) understanding the four dimensions of the illness experience, (2) identifying and communicating diagnosis and prognosis, (3) establishing person-centered

goals and plans for EOL care, and (4) adapting care to these goals and plans by attending to the four dimensions of illness.

The four dimensions of the illness experience, as described by the 1997 IOM Committee, include the following:

- Physical. This dimension incorporates the prevention and relief of symptoms and therefore requires a working knowledge of symptoms associated with underlying disease and how these symptoms interact.
- Psychological. This dimension incorporates the physical aspects of cognition as well as the emotional needs of the dying person and his/her family. As such, care involves both clinical and non-clinical interventions and extends beyond death in the form of bereavement support.
- Spiritual. This dimension incorporates the search for hope or meaning, often supported by religious or philosophical beliefs. As with the psychological dimension, spiritual care is needed for the dying person as well as for the family, and extends beyond death most visibly with facilitation for desired EOL rituals (e.g., last rites, specific burial practices).
- Practical. This dimension incorporates the day-to-day burdens associated with illness and as such overlaps with the physical, psychological, and spiritual dimensions.

Importantly, members of this Committee noted that the importance of these dimensions to the dying person and his/her family will vary over time. Its members also

noted that the provision of good quality care for one dimension likely will affect the other dimensions as well. For example, offering practical care such as help with estate planning may alleviate emotional distress, which, in turn, may improve physical symptoms.

In 2013, the IOM once again embarked upon a study of EOL care. The aim of this new effort was to report on the current state of care in the U.S. for those approaching death. The 18-month effort was spearheaded by a 21-member committee that included individuals with expertise in a variety of subjects including aging, palliative care, pediatrics, and finance, among many others. The resulting report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, was published in 2015 (Institute of Medicine, 2015). As part of this report, the 2013 IOM Committee proposed a set of 12 core components of quality EOL care, all of which are applicable in hospice, palliative care, and other healthcare settings (see Table 3).

Table 3. IOM’s Proposed Core Components of Quality EOL Care

Proposed core components	
1	Frequent assessment of patient’s physical, emotional, social, and spiritual well-being.
2	Management of emotional distress
3	Offer referral to expert-level palliative care
4	Offer referral to hospice if the patient has a prognosis of 6 months or less
5	Management of care and direct contact with patient and family for complex situations by a specialist-level palliative care physician
6	Round-the-clock access to coordinated care and services
7	Management of pain and other symptoms
8	Counseling of patient and family
9	Family caregiver support
10	Attention to the patient’s social context and social needs
11	Attention to the patient’s spiritual and religious needs
12	Regular personalized revision of the care plan and access to services based on the changing needs of the patient and family

Note. Source: *Dying in America* (IOM, 2015).

Framework based on a “good death”

An early framework concerning quality of EOL care was developed in 1998 as a way to understand and evaluate a “good death” and to serve as a guide for future research, training, and healthcare system design and reimbursement (Emanuel & Emanuel, 1998). At this time, a death was considered “good” if it had (or did not have) certain attributes.¹⁰ For example, in its 1997 report on improving EOL care, the IOM defined a good death as “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Institute of

¹⁰ Perceptions of what makes a death “good” have evolved considerably over time. This evolution is discussed more fully in Chapter 3.

Medicine, 1997, p. 4). The framework conceptualized by Emanuel and Emanuel (1998) includes four components:

- Fixed characteristics of the patient. These include clinical condition and prognosis and sociodemographic factors such as age, educational level, and race/ethnicity.
- Modifiable dimensions of the patient's experience. These include physical symptoms, psychological and cognitive symptoms, social relationships and support, economic demands and caregiving needs, hopes and expectations, and spiritual and existential beliefs.
- Potential interventions of the care system. These include those by family and friends, social interventions such as spiritual activities, support groups, and insurance coverage, medical-provider interventions, and healthcare institutional interventions.
- Overall outcome. This reflects the experience of the dying process.

The authors envisioned the framework as helpful in improving the quality of EOL care by emphasizing the multi-dimensional and inter-connected aspects of the dying experience; stressing that the death experience is not just a medical phenomenon, and providing a systematic approach for defining, measuring, and relieving suffering.

Domains of care

In 1997, under the aegis of the American Geriatrics Society (AGS), 41 organizations issued a statement of principles for measuring quality of care at the end of life (Lynn, 1997). In this statement, these organizations suggested 10 general domains of

care for which measurement is required (see table 3). For the most part, these domains are self-explanatory. The domain of “aggressive care near death” was included because many patients prefer not to receive aggressive care (e.g., hospitalization, CPR) when death is imminent. The “survival time” domain was included because this varies across care systems and therefore monitoring of this domain may provide insight into various systems, including priorities and potential tradeoffs between survival time and elements included under the other domains.

These 10 AGS domains provided foundational context for defining the domains of EOL quality medical care used in the “Toolkit Project”—an effort to identify and develop person-centered, clinically meaningful, administratively manageable, and scientifically sound measurement instruments to facilitate improvement in EOL quality of care (Teno, 1996, 1999; Teno, Byock, & Field, 1999). The measures in the Toolkit are organized by 10 domains of care (see Table 4). As would be expected, most of the domains included in the Toolkit are similar to those articulated by the AGS.

In 2004, the National Consensus Project (NCP) for Quality Palliative Care, a collaborative effort of the five major U.S. hospice and palliative care organizations at that time, released their first set of clinical practice guidelines for palliative care. The purpose of these guidelines was to promote consistent, high-quality palliative care, as well as to provide guidance for the development of new palliative care services (National Consensus Project for Quality Palliative Care, 2004). Eight domains of quality palliative care comprise the organizing framework for these guidelines (see Table 4). The guidelines have been updated three times since 2004, with the most current version of the

guidelines released in 2018 (National Consensus Project for Quality Palliative Care, 2018). While the guidelines themselves have been updated substantially to reflect changes in research, practice, and the policy environment for palliative care in the U.S., the domains have stayed relatively constant.

Table 4. Domains of End-of-Life Care, by Source

American Geriatrics Society ^a	Toolkit Project ^b	National Consensus Project ^c
Physical and emotional symptoms	Physical symptoms Emotional symptoms	Structure and processes of care Physical aspects of care
Support of function and autonomy	Functional status	Psychological and psychiatric aspects of care
Advance care planning	Advance care planning	Social aspects of care
Aggressive care near death—site of death, CPR, and hospitalization	Satisfaction	Spiritual, religious, and existential aspects of care
Patient and family satisfaction	Quality of life	Cultural aspects of care
Global quality of life	Caregiver well-being	Care of the patient nearing the end of life
Family burden	Spirituality	Ethical and legal aspects of care
Survival time	Continuity of care	
Provider continuity and skill	Grief and bereavement	
Bereavement		

Note. Sources: ^aLynn, 1997; ^b<http://www.chcr.brown.edu/pcoc/toolkit.htm>; ^c National Consensus Project for Quality Palliative Care, 2018.

As mentioned, there is quite a bit of overlap between the AGS domains and the Toolkit domains. However, the domains in the Toolkit do not explicitly focus on aggressive care near the end of life or survival time. Also, unlike the AGS domains, spirituality is emphasized. The labels of the Toolkit domains also reflect a somewhat more holistic point of view. For example, rather than highlighting need for measures and QI for caregiver burden, the focus is on caregiver well being. The NCP domains differ quite a bit from the AGS and Toolkit domains, perhaps because they do not focus exclusively on care near the end of life. Unlike the AGS and Toolkit domains, the NCP

domains specifically call out structures and processes of care. NCP clinical practice guidelines associated with this domain reflect the need for assessments to inform a person- and family-centered plan of care, involvement of both an interdisciplinary care team as well as volunteers in the care, provision of adequate support, education, and training to the care team, and ongoing data-driven quality assurance and performance improvement efforts. Also, the NCP domains explicitly include social, cultural, and ethical and legal aspects of care.

National Quality Forum Framework for end-of-life care

In 2006, the National Quality Forum (NQF) convened a multi-stakeholder panel of palliative and EOL care experts to develop a framework to support future quality measure development and research for palliative and hospice care (National Quality Forum, 2006). This framework specified:

- Scope of hospice and palliative care. This included the populations served, settings of care, and levels of healthcare professionals (i.e., primary and specialty care).
- Structural and programmatic elements of care. These included interdisciplinary teams, models of care delivery, bereavement programs, educational programs, volunteers, quality assessment and performance improvement, community outreach programs, administrative policies, information technology, ethical dilemma policy, and “self-care” initiatives for those caring for the dying.
- Domains of care. These included the eight domains identified in the NCP clinical practice guidelines.

The initial NQF framework provided a basis for the identification of 38 preferred practices endorsed by NQF for both hospice and palliative care. These evidence-based “best practices” can be used as building blocks for high-quality programs of care across multiple settings and as guides for the development of quality measures.

In 2016 and in 2017, NQF’s Palliative and End-of-Life Care Standing Committee revisited the initial measurement framework. The newly simplified measurement framework comprises a series of concentric circles that places the patient, family, and caregivers at the center of care (National Quality Forum, 2017). Additional rings of the framework include (1) most of the domains of care articulated in the NCP Guidelines (e.g., psychological aspects, physical aspects), as well as two additional domains (safety and financial), (2) healthcare settings in which palliative care can be provided, and (3) types of palliative care. Notably, this committee differentiated between four types of palliative care: (1) curative palliative care, which is provided alongside curative care to help manage side effects of treatment, (2) chronic palliative care, which is provided to those who are not near the end of life, but have non-curable conditions, (3) EOL care, and (4) bereavement care.

National Hospice and Palliative Care Organization components of quality

The National Hospice and Palliative Care Organization, a membership organization that represents hospice and palliative care programs and professionals in the U.S., has identified nine components of quality care for hospice care. These components serve as the organizational framework for its *Standards of Practice for Hospice Programs* (National Hospice and Palliative Care Organization, 2018b).

- Patient- and family-centered care. Providing care and services established through partnerships between patients, their families, and hospice care providers
- Ethical behavior and consumer rights. Upholding high ethical standards and advocating for the rights of patients and their families
- Clinical excellence and safety. Incorporating patient- and family-centered care and promoting patient safety and security
- Inclusion and access. Promoting inclusiveness so that quality hospice care is available to patients, families, and communities regardless of sociodemographic factors, beliefs, traditions, or cultural backgrounds
- Organizational excellence. Building an organizational culture of quality and improvement that values communication and collaboration as well as ethical business practices
- Workforce excellence. Fostering a collaborative, interdisciplinary environment that meets the needs of clients as well as the staff, volunteers, and the organization as a whole
- Standards. Representing excellence in hospice practice and reflecting the full scope of hospice care in the U.S.
- Compliance with laws and regulations. Ensuring compliance with all applicable laws, regulations, and professional standards of practice, and implementing systems and processes that prevent fraud and abuse

- Stewardship and accountability. Developing a qualified and diverse governance structure and senior leadership who share the responsibilities of fiscal and managerial oversight
- Performance measurement. Collecting, analyzing, and actively using performance measurement data to foster quality assessment and performance improvement in all areas of care and services.

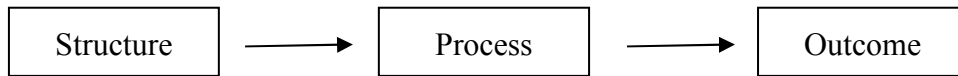
Measuring Healthcare Quality

Measurement of healthcare quality is needed in order to understand the level of quality that is provided by particular practitioners, in particular settings, for particular conditions, and for particular subgroups of patients. Measurement also is necessary in order to assess the success (or not) of QI efforts. The primary goal underlying healthcare performance measurement is to improve the quality of care for patients.

The accepted paradigm for assessing quality of care was first proposed by Avedis Donabedian in 1966 (Donabedian, 2005, [Reprinted from The Milbank Memorial Fund Quarterly, Vol. 44, No. 3, Pt. 2, 1966]). Figure 2 depicts the presumed “flow of causation” between the structures, processes, and outcomes of care (Donabedian, 1988). Structures of care refer to characteristics of the settings in which care is provided and the characteristics of those providing the care (e.g., facilities; equipment; operating hours; use of electronic medical records; staff qualifications and training; workforce utilization) (Donabedian, 2005; Institute of Medicine, 2006). Processes of care are those things that are actually done for patients during the delivery of care (e.g., provision of anticoagulants

to stroke patients; medication reconciliation after a hospital discharge). Outcomes reflect the results of care (e.g., survival, relief of symptoms; functional improvement).

Figure 2. Donabedian's Model for Assessing Quality of Care



Healthcare performance measures aggregate individual-level data in order to quantify the performance of different aspects of the healthcare system (e.g., an individual clinician, hospital, nursing facility, or hospice agency). In addition to their use in assessing and improving quality of care, healthcare performance measures also are used to inform healthcare consumers and other stakeholders about healthcare quality and, increasingly, to influence payment for care that is provided. Types of healthcare performance measures include measures of quality (i.e., structure, process, and outcome measures), as well as measures of access, resource use, cost, and efficiency.¹¹ Healthcare performance measures may be relatively simple (e.g., percentage of diabetic patients who receive a foot exam during the measurement year) or they can be more complex (e.g., composite measures that aggregate multiple individual performance measures into a single performance measure, measures that require risk-adjustment to account for differences in patient case mix, or measures that are created from data obtained from multi-item instruments or scales).

¹¹ The NQF defines efficiency measures as those that measure the cost of care that is associated with a specified level of quality of care (See <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=76880>).

Data used for performance measurement can include information taken from patients' medical records (paper-based or electronic); information obtained from patient assessments conducted in specific healthcare settings (e.g., assessment data from patients residing in nursing facilities or receiving Medicare home health benefits); data from specialized clinical registries; data obtained directly from the patient, typically from questionnaires or surveys; and data from other electronic sources such as pharmacy and laboratory data or data from healthcare claims data submitted for payment purposes.

Measuring End-of-Life Care Quality

Identifying the various facets of high-quality EOL care is a preliminary step in measuring quality of care near the end of life because these guide researchers and QI experts in determining what should be measured. Yet measuring the quality of EOL care can be especially challenging for a number of reasons. Nonetheless, many performance measures are available for measuring the quality of care in hospice.

Methodological challenges

Methodological challenges in measuring the quality of EOL care include identifying those who are nearing the end of life (e.g., due to difficulties in prognosticating time of death for most conditions), determining which entities should be held accountable for high-quality EOL care (e.g., individual providers, care teams or programs, or "higher-level" entities such as health plans or accountable care organizations), developing measures that can be used in various care settings (e.g., hospitals, nursing facilities, hospices), and aligning measures of care quality across settings of care (Morrison, Siu, Leipzig, Cassel, & Meier, 2000; Teno, 2005).

But even within hospice there are many challenges in measuring care quality. One key challenge is that those near the end of life may not be able or willing to participate in measurement activities, particularly if multiple measurements are desired. For example, they may be unable to provide information regarding their pain or other symptoms (making assessments more difficult) and may be unable to provide patient-reported feedback regarding quality of care. Use of proxy respondents is one potential solution to this challenge. However, research has shown that while proxy responses often are concordant with patient responses for more objective areas (e.g., dyspnea, nausea and vomiting), they may not be consistent with patient responses in more subjective areas such as pain, depression, and treatment preferences (Teno, 2005; Yabroff, Mandelblatt, & Ingham, 2004). Also, while retrospective assessment of hospice care quality from the perspective of the bereaved family member is common, there is concern that the bereavement process itself can impair recall and that perceptions of quality may change over time as grief diminishes (Teno, 2005).

Another challenge concerns the timing of measurement, specifically regarding when and how often measurement is needed. For example, many processes of care are required on an on-going basis (e.g., pain assessment and treatment) but quality measures may focus on a specific timeframe such as admission to hospice or last three days of life. A complicating factor is the likelihood that the priorities of patients and their families will change as death approaches (e.g., spirituality may become more important over time), yet there is a need to be sensitive to the burden of data collection for the patient, family, and the hospice staff (Teno et al., 1999).

Finally, determining appropriate outcomes of care for those in hospice and developing reliable and valid performance measures for these outcomes is not always straightforward. Outcome measures often are preferred over other types of measures because they reflect what patients really care about and encourage a holistic approach to improving care rather than one that is restricted to certain providers or processes. However, outcomes that typically are used in healthcare performance measurement (e.g., mortality, improvement in functional status) may not be appropriate for assessing the quality of care provided to those near death. Instead, outcomes such as quality of life, spiritual well-being, and patient and family experience of or satisfaction with care are more salient for the hospice setting, although collecting patient- and family-reported outcomes can be difficult in this setting, as noted above (Donaldson & Field, 1998).

Performance measures used in hospice

Even though there are significant challenges in measuring quality of care in the hospice setting, many performance measures for assessing care quality and improvement are available. Some of these include:

- Assessing Care of Vulnerable Elders (ACOVE) measures. The ACOVE project is an on-going effort by RAND researchers to develop and use measures that assess care provided to vulnerable elders (those 65 years of age or older who are increased risk of death or functional decline) (Wenger & Shekelle, 2001). Most recently updated in 2007, the full suite of ACOVE measures includes 392 measures that address 26 medical conditions. Twenty-one of these pertain to palliative and EOL care and include measures related to advance care planning,

documentation of care preferences (including life-sustaining treatment), gastrostomy tube placement, assessment, treatment, and management of dyspnea, pain management, caregiver stress, and bereavement (Lorenz, Rosenfeld, & Wenger, 2007). These measures can be used in various settings including hospice.

- National Association of Home Care pain and symptom management measures. This set of 14 measures addresses pain, dyspnea, and constipation. The pain and dyspnea measures are computed from data collected via the Edmonton Symptom Assessment System, an instrument used extensively by palliative care and hospice providers (Pace, 2007). This measure set was initially developed to aid hospices in meeting the Quality Assessment and Performance Improvement (QAPI) requirements of the Medicare Conditions of Participation (COPs).
- QAPI structural measure. This is a structural measure that assesses whether a hospice has participated in a QAPI program that includes at least three quality indicators related to patient care. The intent is to use the data from this measure to inform CMS about the scope and content of hospice QAPI programs (Centers for Medicare & Medicaid Services, 2012).
- Prepare, Embrace, Attend, Communicate, Empower (PEACE) measures. Funded by CMS, researchers from The Carolinas Center for Medical Excellence conducted an environmental scan to identify quality measures that were applicable for palliative care and hospice settings and addressed any of the NCP domains. Using a consensus-based approach and criteria similar to those used by

NQF to evaluate measures for potential endorsement, a technical expert panel identified 34 quality measures that address pain, dyspnea, nausea, bowel function, depression, anxiety, spiritual concerns, family education, translator services, advance directives, and several adverse events including falls and medication errors (Schenck, Rokoske, Durham, Cagle, & Hanson, 2010).

- Comfortable Dying measure. Developed by the National Hospice and Palliative Care Organization, this measure assesses the percentage of patients who report being uncomfortable because of pain at the initial assessment (after admission to hospice services) who report pain was brought to a comfortable level within 48 hours (National Quality Forum, 2012).
- Family Evaluation of Hospice Care. Developed by the National Hospice and Palliative Care Organization and researchers from Brown University, this measure is based on a 61-item survey fielded to bereaved family members between 1-3 months after the death of the patient. The survey queries family members about the hospice's success in the following five topic areas: meeting the family's need for information and support, coordinating care, managing the patient's pain and dyspnea, and providing emotional support to the patient and the family. The survey also includes a global question regarding the overall quality of care received by the patient while under the care of the hospice (Connor, Teno, Spence, & Smith, 2005; National Quality Forum, 2012). Two separate performance measures are calculated from the items in this survey: a "composite" measure that assesses the five topic areas listed above and a measure reflecting the

number of responses that included a response of “excellent” to the global question regarding overall quality.

- Hospice Experience of Care Survey (Hospice CAHPS) measures. Part of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) family of surveys, the Hospice Experience of Care survey is a 47-item survey that is completed by the primary caregiver after the death of his/her loved one in hospice (Centers for Medicare & Medicaid Services, 2019a; Medicare Payment Advisory Commission, 2019). Topic areas addressed in this survey include communication with the family, timeliness of care, treating the patient with respect, emotional and spiritual support, pain and symptom management, and training the family to care for the patient. The survey also includes an item to assess the caregiver’s overall rating for the care that was provided, and an item regarding willingness to recommend the hospice to friends and family. Data from this survey are used to calculate performance measures that reflect family experience with care for the above topics.
- Hospice Item Set (HIS) measures. The HIS is a standardized set of items that allows hospices to collect patient-level data for each hospice admission (Centers for Medicare & Medicaid Services, 2018a). Medicare-certified hospice agencies are required to report HIS data to CMS or face a payment penalty (see the regulation section that appears later in this chapter). Data collected through the HIS can be used to calculate the following seven quality measures (most of which come from the PEACE measure set):

- Patients Treated with an Opioid who are Given a Bowel Regimen (NQF #1617)
- Pain Screening (NQF #1634)
- Pain Assessment NQF #1637)
- Dyspnea Screening (NQF #1639)
- Dyspnea Treatment (NQF #1638)
- Treatment Preferences (NQF #1641)
- Beliefs/Values Addressed (if desired by the patient) (modified version of NQF #1647)
- Hospice and Palliative Care Composite Process Measure – Comprehensive Assessment at Admission (NQF #3235)
- Hospice Visits when Death is Imminent (a pair of measures that are not NQF-endorsed)

Improving Healthcare Quality

As noted earlier, change is required to improve the quality of healthcare. However, not all changes are improvements (Batalden & Davidoff, 2007). When conceptualizing this study, I defined QI as *systematic changes that result in improved structures, processes, and outcomes of care* (Alexander & Hearld, 2009, 2011).

Although many approaches and methods are used in QI efforts, perhaps the best-known and most utilized approach is the Plan-Do-Study-Act (PDSA) cycle, which was first introduced by W. Edwards Deming in the 1950's. In 1994, the PDSA cycle was

combined with three fundamental questions to form the *Model for Improvement*, a tool designed to accelerate improvement (Moen & Norman, 2010). The three questions emphasize the need to set measurable aims for improvement, identify performance measures that can be tracked across time, and select the types of changes needed to drive improvement. The change can then be tested on a small scale in a real-world environment using the PDSA cycle. Several PDSA cycles may be needed to refine a particular change before broad implementation. This model, popularized by organizations such as the Institute on Healthcare Improvement and CMS Quality Improvement Organizations, is widely used in healthcare QI efforts, including those in the hospice setting (Oxenham, Finucane, Arnold, & Russell, 2013). Other methodologies often used for healthcare QI include Lean, Six Sigma, Lean Six Sigma, and the DMAIC (Define-Measure-Analyze-Improve-Control) framework (Minami, Bilimoria, & Yang, 2017).

Improving End-of-Life Care Quality

Efforts to improve the quality of EOL care are not new, although the combined effects of more general efforts to improve the quality of the U.S. healthcare system overall, along with legislative and regulatory actions specifically directed towards hospice programs, have accelerated the pace of QI efforts in this setting.

Policy drivers for quality improvement

The two key regulatory and legislative actions mandating QI initiatives in the hospice setting are the CMS Conditions of Participation for hospice programs and the 2010 Affordable Care Act. These are described below.

CMS HOSPICE CONDITIONS OF PARTICIPATION

Conditions for Participation (COPs) are criteria that healthcare organizations must meet in order to participate in Medicare and/or Medicaid. The original hospice COPs were published in 1983, but largely remained unchanged except for some limited amendments made in 1990 (Centers for Medicare & Medicaid Services, 2008). For the most part, those COPs included specific staffing, services, and supplies requirements (Connor, 2009, p. 128). However, in June 2008, CMS published revised hospice COPs, which became effective as of December 2, 2008 (Centers for Medicare & Medicaid Services, 2008, p. 32088). As stated in the final rule for the new COPs, “this revision is part of a larger effort to bring about *improvements in the quality of care* furnished to hospice patients and their families through an outcome-oriented approach to patient care” [emphasis added]. Three of the six principles underlying the revised COPs reflect this emphasis on improving the quality of care provided by hospice agencies.

Specifically, the earlier condition around quality assurance was replaced with the Quality Assessment and Performance Improvement (QAPI) requirement. This condition states that the hospice “must develop, implement, and maintain an effective, ongoing, hospice-wide data driven quality assessment and performance improvement program.” To fulfill this condition, a hospice QAPI program must demonstrate measureable improvement in palliative outcomes and support services; use quality indicator data; focus on high risk, high volume, and problem-prone topics; conduct annual performance improvement projects; and be overseen by the hospice governing body (Centers for Medicare & Medicaid Services, 2008, p. 32117; Ross, 2011). Beyond these general

requirements, however, the QAPI COPs are not prescriptive about the clinical topic areas or number and types of improvement activities that should be pursued.

AFFORDABLE CARE ACT

In March 2010, Congress enacted the Affordable Care Act (Cannan, 2013).¹² Some of the key provisions of the Act (also known as the ACA, healthcare reform law, and “Obamacare”), included expanding access to health insurance coverage, increasing protections for consumers who purchase insurance coverage, and enabling improvements in the quality, performance, and costs of the U.S. healthcare system (National Conference of State Legislatures, 2011). More specifically, this Act authorized the CMS Hospice Quality Reporting Program (HQRP). Per section 3004 of the Act, hospice agencies are required to submit quality data for measures specified by HHS, or face a 2-percent reduction in their market basket increase (Office of the Legislative Council, 2010, pp. 284-285). The law also directs that these quality measure results be publicly reported on the CMS website. Payment reductions began as of October 1, 2013 (the beginning of fiscal year 2014). The payment reductions mandated by the ACA for hospice agencies that do not submit quality data to CMS could—depending on the amount of the market basket increase for a particular year—result in payment rates that are less than those of the preceding fiscal year.

The timeline and selected reporting requirements of the CMS Hospice Quality Reporting Program (HQRP) are shown in Table 5. CMS began publicly reporting results

¹² Per Cannan (2013), the ACA is a combination of the initial Patient Protection and Affordable Care Act (PPACA) and the Health Care and Education Reconciliation Act of 2010. The latter, which amended the PPACA, was passed shortly afterwards.

of some of the HQRP measures in 2017 on its Hospice Compare website (Medicare Payment Advisory Commission, 2019).

STATE OF MARYLAND REGULATIONS

According to the Maryland State Health Plan, the Maryland Health Care Commission (MHCC) will select and publicly report hospice quality measures on their online Consumer Guide to Long Term Care (Maryland Health Care Commission, 2013). However, to my knowledge, the MHCC has not yet implemented this effort. Although the MHCC website links to its Maryland Health Care Quality Reports webpage, hospice measures are not included as yet. However, the MHCC site also links to the Hospice Compare webpage.

Hospice quality measurement results

In 2016, 86% of Medicare-certified hospices that provided services to Medicare enrollees reported data on the QI metrics required in the HQRP (Medicare Payment Advisory Commission, 2018). Thus, because the bulk of hospice programs in the U.S. are Medicare-certified, it is clear that most hospices are now engaged in QI efforts. Data from Medicare-certified hospice agencies for 2017 indicate high levels of performance on six of the seven original process measures included in the HIS (see table 6 (Medicare Payment Advisory Commission, 2019)).

Table 5. CMS Hospice Quality Reporting Program Reporting: Requirements and Timeline

Performance Measures	Data collection	Data submission	Use
QAPI structural measure	CY2011	Jan 31, 2012 (voluntary reporting only)	Information gathering; dry run of submission process
QAPI structural measure NQF #0209: Comfortable Dying	Oct-Dec, 2012	QAPI: Jan 2013 NQF #0209: Apr 2013	FY2014 payment determination
Same as above, except list of quality indicators not required	CY2013	Apr 1, 2014	FY2015 payment determination
Hospice Item Set (HIS) (7 initial measures)	Jul - Dec, 2014	Ongoing electronic submission for each patient at admission and discharge	FY2016 payment determination
Hospice Item Set (7 initial measures) Hospice CAHPS	HIS: CY2015 CAHPS: One month only, Jan-Mar 2015; Monthly, April-Dec 2015	HIS: Ongoing submission CAHPS: Quarterly deadlines	CAHPS dry run using Q1 data HIS & CAHPS Q2-Q4: FY2017 payment determination; Hospice Compare (HIS measures only)
Hospice Item Set (7 initial measures) Hospice CAHPS	CY2016	HIS: Ongoing submission CAHPS: Quarterly deadlines	FY2018 payment determination; Hospice Compare
Hospice Item Set (7 initial measures, composite measure, plus visits when death is imminent pair) Hospice CAHPS	CY2017	HIS: Ongoing submission CAHPS: Quarterly deadlines	FY2019 payment determination; Hospice Compare (7 initial measures and composite, CAHPS measures)
Hospice Item Set (7 initial measures, composite measure, plus visits when death is imminent pair) Hospice CAHPS	CY2018	HIS: Ongoing submission CAHPS: Quarterly deadlines	FY2020 payment determination; Hospice Compare (7 initial measures and composite, measure #1 of pair, CAHPS measures)

Note. Source: Centers for Medicare & Medicaid Services, 2018b.

Table 6. Scores on Selected Quality Measures, Medicare-Certified Hospice Agencies

Measure	2017 Patient-level average	Measure	2016-2017 Caregiver-level average
Treatment preferences	99.1%	Emotional support	90%
Beliefs and values	96.3%	Respect	91%
Dyspnea screening	98.7%	Pain and symptoms	75%
Dyspnea treatment	97.3%	Team communication	80%
Pain screening	96.7%	Timely help	78%
Pain assessment	87.5%	Caregiver training	75%
Bowel regimen	96.5%	Rates hospice as 9 or 10	81%
Comprehensive assessment (composite, all 7 measures)	86.0%	Recommends hospice	85%

Note. Source: Medicare Payment Advisory Commission, 2019.

The scores presented in Table 6 reflect patient or caregiver averages, not agency-level averages. Nonetheless, these results suggest that hospices, in general, are providing high-quality care as measured by the majority of these process measures. Nonetheless, these results also indicate that there is still room for improvement in terms of assessing patients' pain and conducting a comprehensive patient assessment at hospice admission, as well as for caregiver experience with care.

Summary of Chapter 2

This chapter has provided needed background and context for the study. It began by describing the history of hospice and then explaining how it operates within the U.S. healthcare system. It then went on to discuss several important facets of healthcare quality and its improvement, including various definitions of healthcare quality in general and for EOL care specifically, as well as discussions related to measurement of healthcare quality. The chapter also provided contextual information on key policies

related to improving care quality in the hospice setting. Finally, it concluded by providing national-level results for several QI measures used in the hospice setting. The next chapter continues the presentation of background information by providing a summary of the published literature that has focused on perceptions of EOL care quality and its improvement.

Chapter 3: Literature Review

Despite the IOM's broad definition of healthcare quality and the numerous dimensions, domains, and frameworks of quality EOL care that have been articulated, the actual concept of healthcare quality, particularly that provided near the end of life, remains abstract. As such, its true meanings are subjective. As described by Sutherland and Dawson, quality is:

"...defined by individual actors according to their particular experiences, value systems, and deeply held assumptions...we must accept that quality is multifaceted and recognize that when we speak of quality, we touch different meanings in different audience."(Sutherland & Dawson, 1998, pp. S20-S21).

This subjectivity may be especially significant in the hospice setting, where physical, psychological, social, and spiritual care is provided by an inter-disciplinary care team. While the meanings of what constitutes good quality of care near the end of life are subjective and based on individuals' experiences, values, and beliefs, there is substantial agreement among hospice stakeholders on key elements of high-quality EOL care. In contrast to the amount of research focusing on hospice providers' perceptions and meanings of quality EOL care, very little research has explored hospice providers' perceptions of QI. This chapter summarizes the published literature regarding perceptions of EOL care quality and its improvement. It begins with the concept of the "good death," and then proceeds to a review of what is currently known regarding hospice providers' perceptions of quality EOL care and their perceptions of QI.

The Good Death

The concept of a “good death” is a key tenet of the modern hospice movement (Hart, Sainsbury, & Short, 1998; Walters, 2004). It is not, however, a new concept, nor is it a static one. In Western cultures prior to the advent of modern medical science, the prevalent view of a good death was primarily religious in nature. A good death was one in which a person died at peace with God and with others (Walters, 2004). This conceptualization of a good death corresponds, according to Walters, to what the French historian Ariés called a “tamed death,” namely, one occurring in the presence of family, friends, and neighbors, with proper ceremonial and sacerdotal regard (Hart et al., 1998). Walters goes on to describe the modern ideal of the good death, beginning in the mid-1700s, as one that is unimagined, hidden, and sudden. It is one in which, because of the advent of effective medical intervention, death began to be seen as preventable, and, when it ultimately occurred, as failure.

However, in the past fifty years, the concept of a good death has evolved substantially. With the publication of Kubler-Ross’ *On Death and Dying* in 1969, the concept of a good death came to be viewed as one of *acceptance*¹³ (Hart et al., 1998). With this view of a good death as acceptance, the “emotional struggle” to resist death has ended, and appropriate preparation and goodbyes have been made.

Relatively soon afterwards, however, the conceptualization of a good death changed to one of *control*. This has been labeled by Walters as the “post-modern” view

¹³ This is the final stage of grief, as posited by Kubler-Ross; earlier stages include denial, anger, bargaining, and depression. It should be noted that Kubler-Ross’s theory of stages of grief is not without criticism (Hart, et al., 1998).

(Walters, 2004). Walters distinguished between two views of control, one in which control of death lay primarily with the dying, and one in which control of death lay primarily in the hands of others (Kehl, 2006; Walters, 2004). The former conceptualization of a good death became synonymous with euthanasia. This was a primary interpretation from the 1960s through the mid-1990s (Kehl, 2006). The latter conceptualization of a good death—control by the non-dying—began to focus on the key *attributes* of a good death. This view centered attention on how unwanted symptoms associated with death can be controlled, typically through efforts of healthcare providers and particularly hospice providers (Kehl, 2006; Walters, 2004). This viewpoint has been criticized to some extent, however, because it can emphasize the medicalization of death, and has thus come to be viewed as another means of social control of the dying (Hart et al., 1998).

Since the mid-1990s, the idea that certain attributes define a good death has become the dominant cultural conceptualization. For example, in its 1997 report on improving EOL care, the Institute of Medicine defined a good death as “*one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards*” (Institute of Medicine, 1997, p. 4). Kehl summarized the 1995-2004 research literature pertaining to a good death from the perspectives of patients, family members, and healthcare professionals (Kehl, 2006). Based on this review, Kehl notes that what is considered a good death is “highly individual, changeable over time, and based on perspective and experience” (Kehl, 2006, p. 281). Nonetheless,

there was substantial agreement from the various perspectives as to the attributes of a good death, even though there were differing opinions as to the relative importance or weight of the various attributes. Kehl's research identified the following attributes of a good death:

- Being in control. This includes having choices; having wishes honored; making decisions; having the option of euthanasia; and the location, timing, and presence of others.
- Being comfortable. This includes lack of distress; management of physical, psychological, emotional, and spiritual symptoms; receiving physical comfort such as hugging; and hope.
- Sense of closure. This includes saying goodbye; resolving unfinished business, such as work, family, financial, and legal business; and preparing for death.
- Affirmation of the dying person. This includes dignity; recognizing the whole person, including physical, emotional, social, and spiritual aspects; quality of life, including living fully; and individuality.
- Trust in care providers. This includes access to care; good communication; knowing the patient and/or family well; strong patient advocacy; and non-judgmental attitudes.
- Recognition of impending death. This includes both awareness and acceptance.
- Beliefs and values honored. These include beliefs, values, and practices of a personal, cultural, or spiritual nature.

- Burden minimized. This includes, particularly, family burden when caring for the dying individual; it also includes financial burden and independence of the dying to the extent possible.
- Relationships optimized. This includes enough time; good communication; reconciliation and forgiveness; and social support of the dying.
- Appropriateness of death. This encompasses the age of the dying person, and appropriate use or non-use of technology.
- Leaving a legacy. This includes being remembered and contributing to others.
- Family care. This includes involvement in care and death of the dying person; family preparedness for death; and the family as recipients of care.

Thus, in these studies of patients, family members, and healthcare providers, being in control was found to be both the most important, and the most common, attribute of a good death, while being comfortable was the attribute that both patients and healthcare professionals most often agreed upon. In contrast, having beliefs and values honored was found to be more salient for ethnic and religious minority groups (Tong et al., 2003).

Provider Perceptions of Quality of Care Near the End of Life

Relatively little recent research has examined the perceptions of quality EOL care from the perspective of healthcare providers, with even fewer studies focusing on quality of care near the end of life. One of the aims of this study is to describe perceptions of quality of care near the end of life from the perspective of hospice providers in various roles (i.e., executive director, front-line nurse, social worker, and chaplain). Thus, in this

section, I synthesize previous research on perceptions of quality of care from the perspectives of those whose role is to provide that care. The majority of this research has focused on nursing care, although a few studies have focused on care provided by physicians. Very little research has explored such perceptions from the perspectives of other providers of hospice care, including chaplains and social workers, and none has explored this topic from the perspectives of hospice directors.

Nurses' Perceptions

Spanning more than 25 years, various studies have explored the lived meaning of quality nursing, including perceptions, understandings, and definitions of effective quality palliative and EOL care; behaviors, processes, competencies, and activities that promote or are inherent in quality EOL care; and barriers to, and facilitators of, quality EOL care. These studies have run the gamut of viewpoints and care settings in the U.S. and abroad, including those of generalist nurses in acute care hospitals (Burhans & Alligood, 2010; Lynn, McMillen, & Sidani, 2007; Thompson, McClement, & Daeninck, 2006), nurse executives (Garner, Goodwin, McSweeney, & Kirchner, 2013), palliative care and hospice nurses (Degner, Gow, & Thompson, 1991; Johnston & Smith, 2006; Zerwekh, 1995), intensive care and critical care nurses (Crump, Schaffer, & Schulte, 2010; McClement & Degner, 1995; Todaro-Franceschi, 2013; Zomorodi & Lynn, 2010), oncology nurses (Beckstrand, Collette, Callister, & Luthy, 2012; Steeves, Cohen, & Wise, 1994), and community nurses (Austin, Luker, Caress, & Hallett, 2000).

Nonetheless, several common themes of quality nursing care have emerged across these disparate studies. The overarching theme voiced by nurses in describing quality

nursing care near the end of life is the idea of *connection*, that is, of “being there” physically and emotionally for both patients and the family (Burhans & Alligood, 2010; Johnston & Smith, 2006; Lynn et al., 2007; Thompson et al., 2006; Zerwekh, 1995). Also voiced in several studies was the concept of *active listening* (Crump et al., 2010; Garner et al., 2013; Johnston & Smith, 2006; Todaro-Franceschi, 2013; Zerwekh, 1995; Zomorodi & Lynn, 2010). This concept includes not only the ability to provide needed information regarding health status, prognosis, and treatment options, but also the ability to encourage questions and to both facilitate and participate in conversations about the end of life itself and goals for end of life care. The theme of *advocacy*—or acting on the patient’s behalf—also emerged in several studies (Austin et al., 2000; Burhans & Alligood, 2010; Degner et al., 1991; Garner et al., 2013; Lynn et al., 2007; Thompson et al., 2006; Zerwekh, 1995; Zomorodi & Lynn, 2010). This theme incorporates actions taken to “get what is needed” and to ensure that the care that is provided conforms to the wishes of the patients. Although related to the theme of advocacy, the *provision of comfort* emerged as a distinct theme across many of these studies (Degner et al., 1991; Johnston & Smith, 2006; McClement & Degner, 1995; Zerwekh, 1995; Zomorodi & Lynn, 2010). This theme incorporates the provision of physical comfort, particularly relief from pain, as well as management of other symptoms and provision of emotional support. *Supporting the family* also was considered a critical component of quality EOL care (Austin et al., 2000; Beckstrand et al., 2012; Degner et al., 1991; McClement & Degner, 1995; Thompson et al., 2006; Zerwekh, 1995; Zomorodi & Lynn, 2010). Facets of this theme include establishing a trusting relationship with the family, providing both

informational and emotional support, alleviating the caregiving burden and/or enhancing coping abilities, and adapting the physical environment so as to facilitate peace, dignity, and privacy, both before and after death. Finally, the theme of effective *teamwork* with and between various healthcare providers (e.g., nurses, palliative care team, physicians, chaplains, social workers) emerged in several studies as a requirement for quality EOL care (Austin et al., 2000; Lynn et al., 2007; Zerwekh, 1995).

Physicians' Perceptions

The physician perspective about quality EOL care is relevant to this study, even though physicians were not included as participants. This is because, like agency directors, hospice medical directors (who typically are physicians) may have substantial influence in guiding the hospice quality agenda. Surprisingly few studies have explored physician perceptions of quality care near the end of life. Blumenthal, in the first of six articles in the *New England Journal of Medicine* exploring care quality, summarized previous conceptualizations of quality of care from the physician perspective (Blumenthal, 1996; Donabedian, 1988; Palmer, 1991). Perceived quality of physician care was, at that time, manifested in two ways. First, it was seen as being contingent on the *technical aspects* of care—both in terms of the appropriateness of care (signifying good decision-making skills) and the skill and timeliness with which the care was delivered. Second, it was based on the *interaction* between physicians and their patients. This latter conceptualization incorporated various aspects of that interaction, including communication, trust, empathy, honesty, and sensitivity (Donabedian, 1988).

The emphasis on the importance of physician skill in determining quality of EOL care is revealed in a subsequent qualitative study designed to identify skill domains that exemplify quality care provided by physicians to their dying patients (Curtis et al., 2001). Overall, patients, family members, nurses, social workers, and physicians who participated in this study identified 12 domains of physician skills. This research supported the importance of technical and interpersonal skills for physicians providing EOL care, as reported by Blumenthal (1996). Interestingly, however, neither competence nor pain and symptom management were ranked, by frequency, in the top half of the domains by physicians. In this study, however, Curtis and colleagues found that communication, respect, and humility were the top-ranked domains (Curtis et al., 2001). Unlike the previous research on physician perceptions of quality physician care, skills in facilitating teamwork with other providers and encouraging family participation were identified as needed in the provision of quality EOL care by physicians, as were skills in engaging the patient in the care process, including incorporating their values and goals (Curtis et al., 2001).

In an effort to gain a better understanding of factors considered important for a good death, Steinhauser and colleagues (2000) asked patients, their families, physicians, and other care providers to rate the importance of 44 attributes of the EOL experience. Attributes rated as very important by practically all of the physicians in the study included physical aspects of the EOL experience, such as cleanliness and freedom from pain, as well as maintaining dignity, having someone to listen, and having trust in the physician. Although not rated quite so highly as these factors, physicians also perceived

the naming of a decision maker, being able to say goodbye to important people, and having the family present near death as very important. Although this study did not directly assess perceptions of quality care among physicians, it is reasonable to infer that care that facilitates the attainment of these factors would be considered by physicians to be high quality care.

Finally, in an effort specifically designed to discover physician perceptions of quality EOL care, Farber and colleagues interviewed 32 family practice faculty members from six sites across three states (Farber, Egnew, & Herman-Bertsch, 1999). Five themes emerged from this research. Three of the themes (consensus, planning, and caregiving) reflected, to a great extent, the desired skills related to provision of EOL care. The themes of consensus and planning encompassed the need for acceptance of the seriousness of the illness and agreeing on a care management plan that would facilitate a comfortable death. In their discussion of concepts underlying the caregiving theme, informants emphasized the importance of identifying a primary caregiver, assembling a care team comprised of the patient, family members, other community members, and healthcare professionals to support the patient near the end of life, as well as directing this care team in such a way as to ensure that the care is provided smoothly. Two additional themes that emerged from the study—relationship and personal domain—focused less on technical skills. Instead, these themes reflected informants' perceptions of the importance of making a commitment to “stay the course” with their dying patients, building an intimate connection with them, and being mindful of the transcendent and spiritual nature of the EOL stage, while at the same time acknowledging the stresses

involved in caring for someone near the end of life. Results from this study were re-interpreted to some extent to reflect findings from additional interviews with patients and caregivers (Farber, Egnew, Herman-Bertsch, Taylor, & Guldin, 2003). As part of this reexamination of physicians' perspectives, the study authors noted that the theme of relationship varied according to the physician's experience. Less experienced physicians (<5 years) tended to describe relationships with their patients as delivering technically appropriate care and ensuring patient autonomy. In contrast, physicians with greater experience (>10 years), described relationship in terms of the shared experience between themselves and their patient, particularly one that allows for discussion of any topic of interest or importance to the patient or family, even if not strictly medical in nature.

Chaplains' Perceptions

A few studies have explored chaplains' perceptions of care quality, either directly or as part of research addressing improving the quality of spiritual care. For example, in a collaborative effort between The Hastings Center and The HealthCare Chaplaincy, researchers conducted a qualitative study to obtain information about chaplains' experiences with, and understandings of, quality and QI in spiritual care (Lyndes, Fitchett, Thomason, Berlinger, & Jacobs, 2008). Data for the study were obtained from four focus groups with 39 healthcare chaplains located in New York, Illinois, Arizona, and California. The majority of the chaplains in this study worked in hospitals, but a few worked in hospices or other healthcare settings; thus, the findings do not apply exclusively to EOL care. Study participants identified three major roles of the healthcare chaplain: (1) providing spiritual care to patients and their families, (2) promoting the

institutional mission and building staff morale, and (3) acting as change agent when necessary to integrate spirituality into the organizational culture. Their conceptions of providing quality care encompassed only the first two of these roles. Chaplains were seen as providing quality care in these roles in three ways: by being present, by providing holistic care, and helping to create a safe space. Key skills and activities referenced by participants included listening and communicating, taking others seriously, and respecting diversity. While for the most part agreeing that improving quality of care delivered by chaplains is important, study participants were skeptical about the QI metrics typically associated with their provision of bedside care (e.g., number of patients seen within 24 hours of admission; patient satisfaction scores).

Two other studies are somewhat informative regarding the perceptions of care quality as perceived by chaplains. The first is a qualitative study of five Christian chaplains who provided EOL care to veterans in a Veteran's Administration medical center through their role as members of a palliative care consult team (Chang et al., 2012). The goal of the study was to understand the process and content of the care provided by the chaplains. Results from this study revealed a systematic effort to refer all palliative care patients to a chaplain and to discuss each patient in weekly palliative care team meetings. The chaplains noted that, although the process of patient referral was successful, there was no corresponding effort to refer family members for spiritual care. The chaplains reported a variety of spiritual care services offered to their patients, including performing religious rituals and ceremonies, making funeral arrangements, providing religious materials, praying, listening, helping the patient to reconnect with

God, enabling communication with family members, and providing presence. The chaplains in this study conveyed several distinctive characteristics of the veterans they served (i.e., experience in combat, social isolation, mental health problems such as post-traumatic stress disorder, and lack of connection to a religious community) that necessitated provision of more specialized spiritual care than might be needed in other settings. They particularly noted patients' need for forgiveness and/or help with the guilt associated with participation in war efforts. Ideas for improving the quality of spiritual care included having more time to spend with patients, inclusion of the family in provision of bereavement or other supportive services, being able to contact and connect with patients' personal spiritual advisors if from a different (i.e., non-Christian) religious tradition, providing support groups for family members prior to the patient's death, and having a memorial service with staff after the death of the patient.

A second study also is somewhat informative in understanding chaplains' perceptions of spiritual care quality. That effort entailed a systematic examination of the causes underlying a decrease in referrals for spiritual care in a large, non-profit hospice in the Northwest. This was followed by a staff educational effort aimed at increasing referrals (Hall, Shirey, & Waggoner, 2013). Two barriers to referral were identified in this study. First, other care team members thought that the chaplains were too overworked and couldn't handle additional referrals. Second, staff had an incomplete understanding of nature of spiritual care (specifically in how it differs from religious support) and the roles of the chaplains in their agency.

Social Workers' Perceptions

While several researchers have explored the expanding role of social workers in EOL care, particularly their contributions to EOL discussions and management of pain and other symptoms (e.g., Altilio, Gardia, & Otis-Green, 2007; Cagle & Altilio, 2011; Gwyther et al., 2005; Reese, 2011), little research to date has considered the quality of care provided by social workers, and no research was identified that explicitly focused on social workers' perceptions of quality EOL care. Only one exploration of social workers' perceptions can be considered at least somewhat germane to this study. Parker-Oliver and colleagues examined the perceived interdisciplinary collaboration (i.e., teamwork) between social workers and other hospice team members using the Index of Interdisciplinary Collaboration (IIC) instrument (Parker-Oliver, Bronstein, & Kurzejeski, 2005). Study participants included 77 hospice social workers in one Midwestern state. Although the level of perceived collaboration was high among the study participants, it was not statistically significantly associated with hospice quality, as measured by the presence or absence of program compliance deficiencies in its most recent certification report. However, three individual items from the IIC were significantly correlated with hospice quality, suggesting that some aspects of collaboration, specifically, resolving conflict, creating processes to facilitate teamwork between hospice workers, and making interdisciplinary referrals, are associated with the quality of care provided in hospice (Parker-Oliver et al., 2005).

Hospice Directors' Perceptions

For this study, hospice directors of interest are the lead administrators of the program (e.g., CEO, president, executive director). I was unable to locate research that has explored the meanings of EOL care quality from the perspective of hospice directors.

Provider Perceptions of Quality Improvement for End-of-Life Care

To date, research focusing on perceptions of QI among those who provide EOL care in the U.S. is sparse. Furthermore, to my knowledge, beyond the recent work by Singh and colleagues (Singh, Sillerud, & Omar, 2019), no research explicitly focused on the meanings of QI in EOL care has been conducted to date. Specifically, these authors (Lyndes et al., 2008) interviewed seven leaders in a hospice agency in the Midwest region of the U.S. regarding their perceptions of QI (Singh et al., 2019). These leaders included the directors/managers of quality, education, clinical operations, patient care, medical/nursing, critical care nurses/CNAs, and quality, compliance, and human resources. The focus of this study was to elicit attitudes of hospice leaders regarding how they define quality and how they view QI efforts in their organization. Five themes emerged from this study, as follows:

- Patient-centered care. Participants defined quality care as timely and efficient, and emphasized coordination and communication between team members and with patients/families.
- Continuous quality improvement. Participants described their formalized processes for QI (e.g., tracking data, particularly patient/family satisfaction,

soliciting input from staff, regular QI meetings, and use of Lean and Six Sigma methods).

- Leadership involvement and commitment. Participants emphasized support for QI by agency leadership, particularly in the provision of training and resources for QI activities. They also mentioned a recognition program for staff involved in QI efforts.
- Communication as a foundation for QI. Participants spoke of the need to listen to staff feedback and concerns, and to share their own feedback with staff. They noted the need for interactive forms of communication with staff that rely on various modalities (e.g., face-to-face, not just e-mail). They also spoke about their education efforts to help staff better communicate with their patients.
- Perceived barriers. A main barrier that emerged from this series of interviews was the acceptance of the QI department by staff. One manager specifically contrasted the perception of the QI department as just pointing out mistakes in a negative manner versus being a collaborative team member. Two other staff-related barriers that were mentioned included resistance to change and lack of time for participating in QI efforts.

Other relevant literature has centered primarily on perceptions of specific QI efforts or on barriers and facilitators of QI efforts. For example, as noted earlier, Lyndes and colleagues, as part of their focus group study of chaplains who worked in a variety of healthcare settings including hospice, found divergent views of QI efforts (Lyndes et al., 2008). Specifically, some focus group participants expressed skepticism about the

metrics being used and their ultimate utility in driving improvement, others saw at least some potential for benefit, and still others embraced the concept of QI efforts, seemingly convinced that such activities would produce meaningful improvement in care quality.

Additionally, one study focused explicitly on barriers to and facilitators of QI efforts in the hospice setting. In 2006-2007, researchers from the Carolinas Center for Medical Excellence interviewed 32 hospice and palliative care providers, along with leaders of relevant professional and managed care organizations, researchers, quality measurement experts, and a consumer advocate, in an effort to identify barriers and facilitators to the implementation of QI activities (Durham et al., 2011). These researchers presented the results of this study in light of four major themes, as summarized below:

- External factors constrain QI implementation. At the time of these interviews, informants noted a lack of standards, guidelines, and best practices that could be used as a gauge to assess, and ultimately improve, care. They also cited organizational and environmental barriers, perceiving that larger hospice agencies and those affiliated with hospitals as more likely to successfully engage in QI activities, in contrast to hospices that are smaller, independent, and/or operating in rural areas. They also perceived the lack of incentives to improve quality—particularly financial incentives—as a barrier. Conversely, they identified policy incentives, including regulatory mandates for QI and public reporting of quality metrics, as facilitators of QI.

- Internal factors limit capacity for QI implementation. Respondents in this study perceived cost and resource issues, insufficient technology, including electronic systems to facilitate medical record keeping, billing, and reporting, and lack of expertise to most efficiently use such systems when they were available as barriers to implementing QI activities. These participants also described poor planning (e.g., in selecting tools and priorities for improvement efforts) and insufficient knowledge and expertise in QI methodologies (such as data collection, analysis, and use of results) as barriers. Perhaps most interestingly, these study respondents perceived organizational culture as a barrier when the goals of QI are neither understood nor well articulated, particularly by leadership. They also perceived both external funding (e.g., through grants or federal programs) and internal funding (i.e., through budget allocation for QI activities) as facilitators to QI implementation. In addition, they identified specific leadership activities as facilitators. These included tangibly supporting QI efforts by incorporating them into daily activities (rather than as “extra” work), fully engaging staff, funding staff specifically for these activities, and providing training for the full QI enterprise.
- Research on best practices is limited. This study’s participants perceived a lack of evidence to show that particular care processes can actually lead to improved outcomes. They also perceived flaws in the various tools available for QI activities (including data structures, assessment instruments, and quality measures). Perceived facilitators that would address these barriers included

development of easy-to-use measures and availability of benchmarking so as to compare results and obtain guidance on how to improve.

- Traditional QI may not be a good fit for hospice. In this study, the respondents believed that many of the aspects of hospice care, including the spiritual, psychological, and cultural aspects, are too nuanced for quality measurement. They noted the challenges with measurement, including those related to patient preferences, multiple care settings, and data collection as significant barriers. These respondents also were concerned particularly with whether the measures that were available could accurately reflect quality of care, citing the differences in patient acuity levels that may not be adequately accounted for and the trade-offs that often are made in symptom treatment (e.g., some patients will tolerate more pain when medication leads to lack of lucidity). Interestingly, a few of this study's participants considered the application of QI efforts in the hospice setting as a medicalization of death.

It is unclear whether the perceptions regarding barriers and facilitators of QI implementation identified in this study also are held by today's hospice providers. The NCP clinical practice guidelines for palliative care had been available for only two years by the time of this study in 2006-2007, and the NQF framework for palliative and hospice care had just been developed. Moreover, relatively few quality measures were available and none had obtained NQF endorsement, the revised Medicare hospice COPs had not yet been finalized, and the legislatively-mandated reporting of hospice quality metrics as part of the ACA was still four years in the future.

Results from two studies of perceived barriers to quality hospice care also may provide insight on possible provider perceptions of QI, even though neither was designed to explore these perceptions per se. The first, a 2002 survey of 867 hospice nurses, identified several perceived key barriers to effective symptom management, as follows (Johnson, Kassner, Houser, & Kutner, 2005).

- Family caregivers or patients are unable or unwilling to implement or maintain treatment. This barrier was identified in reference to the more “concrete” physical symptoms such as pain, shortness of breath, nausea, and constipation. Respondents also perceived this as significant barrier in managing symptoms such as depression or irritability.
- Some symptoms result from other treatments, and more distressing symptoms may limit the ability to treat other symptoms. For symptoms such as weakness, fatigue, confusion, depression, and irritability, these nurses perceived that trade-offs are sometimes unavoidable.
- Family caregivers or patients do not perceive a symptom as problematic. Clearly related to the first barrier, nurses perceived this barrier as significant particularly for symptoms such as depression and irritability.

In a more recent study of perceived barriers, researchers interviewed 22 hospice nurses, physicians, and social workers. This study sought to identify: (1) perceived barriers regarding their relationships with other care providers in the nursing home and home settings and (2) how poor relationships may impede optimum medication management (Lau, Masin-Peters, Berdes, & Ong, 2010). Perceived barriers articulated

by those in the study included *attitudinal* barriers such as: (1) “turf wars,” (2) perceptions of knowing what is best for a patient despite hospice advice, (3) distrust of hospice, either due to professional skepticism or prior negative experiences, and (4) emotional responses, such as fear of opioid medications, or poor coping mechanisms, such as being emotionally distant or overwhelmed with grief. Study respondents also noted *site-readiness* barriers, including poor communication; disagreements between care providers; and responsibility overload. Finally, they noted *alignment* barriers, including differences in priorities for care across the two groups of providers, and differences in their education and training.

Additional recent research also sheds some light on perceptions of QI in EOL care, although again, these studies were not designed to elicit these data, per se. First, Lindley and colleagues reported results of a survey designed to inform researchers of: (1) the QI environment in general, and (2) more specifically, the needs of hospice and palliative care clinicians relative to implementing the set of *Measuring What Matters* quality measures (Lindley, Rotella, Ast, Matzo, & Kamal, 2017). The survey was completed by 1,050 members of the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. The key barriers to QI implementation identified through this survey included time constraints and lack of “financial, human, or technology” resources. Respondents to the survey indicated that both higher caseloads and greater documentation demands aggravated the issue of time constraints. The need for training, education, and coaching on QI methods, data collection, and implementation was highlighted by the authors, as was the need for

systems to better collect quality measurement data. In a second study, Dy and colleagues recently developed a survey (the Measuring and Improving Quality in Palliative Care survey) to evaluate barriers and facilitators of quality measurement and improvement in palliative care programs (Dy et al., 2017). As part of their content validation of the survey, the authors conducted cognitive interviews with six palliative care providers (three physicians with measurement expertise, two nurses, and a social worker). One key finding from this effort included the lack of knowledge regarding the QI initiatives in their programs (necessitating inclusion of a “Not Sure” response option). In a follow-up study to establish the reliability and content validity of that survey, investigators administered the survey to 103 respondents in 11 palliative care programs in the U.S. and Canada (Dy et al., 2018). As part of this effort, Dy and colleagues convened discussion groups with respondents from eight of the participating palliative care programs to further validate the survey. Key results from these discussions included: (1) the utility of the survey and the discussions to assess programs’ QI efforts, (2) differences in how survey respondents conceptualized quality, compared to how it is conceptualized via program standards, (3) for some programs, QI efforts were leadership-driven, while in others, they were more “grassroots-driven,” which resulted in lack of awareness among many respondents of ongoing QI efforts, and (4) respondents had difficulty in “anchoring” responses, such as identifying who should be considered quality leadership, and reflecting multiple QI efforts.

It is unknown whether hospice staff perceive the barriers identified in the above studies as insurmountable. If so, one could infer that they may have less favorable

perceptions of QI activities, particularly if interventions focus primarily on the hospice provider's clinical behavior. If not, then one could infer they might have more favorable perceptions, particularly if the measures and interventions used in quality activities address these barriers and are relatively inclusive in nature (e.g., incorporating training, education, communication).

Summary of Chapter 3

This chapter began by describing the concept of the “good death.” It then summarized literature focused on perceptions of care quality near the end of life from the perspective of nurses, physicians, chaplains, and social workers. The chapter concluded by summarizing available literature on provider perceptions regarding improvement of EOL care. With the exception of nurses, there has been relatively little research regarding perceptions of EOL care quality or its improvement from those in other occupational roles. Much of what is available vis-à-vis improvement in EOL care quality has focused on barriers and facilitators of QI efforts. The following chapter turns from a consideration of previous literature regarding perceptions of QOL care quality and its improvement to focus on the methodological approaches used to collect, analyze, and present the data in this study.

Chapter 4: Methods and Study Participants

For this study, I sought to identify and describe the meanings and perceptions of quality of care and QI efforts, as defined and perceived by hospice staff who participated in the study. To do so, I employed an ethnographic and phenomenological approach to data collection and analysis. To obtain data for the study, I conducted 19 face-to-face semi-structured interviews with hospice directors, nurses, social workers, and chaplains from five hospice agencies in Maryland. The data collection period spanned from March 2016 to April 2017. I used qualitative content and narrative analysis to identify key themes in participants' statements regarding EOL care quality and QI efforts in the hospice setting. To provide contextual information for the study, I also talked with participating agencies' QI coordinators, acquired written data on QI initiatives, and observed an internal QI meeting at each of the participating agencies.

This chapter begins with an overview of the methodological approaches and the assumptions that I brought to the study. Next, it outlines the sampling procedures used to recruit five hospice agencies and 19 of their employees for the study. The chapter continues by explaining the study's data collection procedures, including the approaches used to ensure the protection of human subjects participating in the study. The chapter concludes by describing the analytic processes used to address the aims of the study.

Methodology and Study Assumptions

The key goal of the study, to elicit hospice providers' perceptions and meanings of QI efforts, mandated a qualitative research methodology. I conducted this research by

collecting data via ethnographic interviewing and analyzing the findings via a phenomenological approach.

Qualitative Research

Qualitative research refers to systematic inquiry that does not depend on quantification or statistical procedures to discover, interpret, and organize findings (Strauss & Corbin, 1998). It focuses on the “meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things” (Berg, 2009, p. 3). Qualitative research crosses interpretive paradigms and academic disciplines and, as such, encompasses a plethora of methods, although none of them are considered inherently superior (Denzin & Lincoln, 1998; Richards & Morse, 2007). Hallmarks of qualitative research include a “real-world” research setting, absence of a priori hypotheses, detailed “thick” description that reflects context, nuance, and complexities in all interpretations that emerge from the data, and an expectation that the design of the study will evolve as data are collected and analyzed (Patton, 1990).

Ethnographic and Phenomenological Approaches

I used focused ethnographic interviewing as both the primary methodology and the main data-gathering tool for this study. Focused ethnographic interviewing allows for the study of culture, broadly understood as the shared values, beliefs, behaviors, norms, and worldviews, within a cohesive or defined group of people, as pertaining to a particular topic or shared experience (Richards & Morse, 2007). Hughes (1992) and Spradley (1979) have described ethnographic interviews as “a series of friendly

conversations” that incorporate a give-and-take approach where the interviewer is “responsive to the information and cues provided by the informant” (Hughes, 1992, p. 444; Spradley, 1979, p. 58). More specifically, the ethnographic interview employs a set of “entry questions” that are designed to facilitate conversation on key topics. Each entry question is followed by more detailed questions designed to uncover specific information needed to more fully understand the topic areas.

For this study, I utilized a phenomenological approach from the anthropological tradition. By this, I mean that I have endeavored to examine and describe cultural and personal meanings and lived experiences underlying individual behavior of hospice providers. I have done this by analyzing the stories they told and the conversations we had during the interviews. These stories and conversations reveal their perceptions of, and experiences related to providing care for patients near the end of life and improving the quality of that care.

Ethnographic research does not assume that a “reality” exists that can be understood to a greater or lesser degree by researchers who are “objective” to a greater or lesser extent (Guba & Lincoln, 1998). Instead, ethnographic research assumes that there are multiple realities, each of which is socially constructed (and therefore mutable), and that these realities can be elicited only through the interaction of the researcher and the individual informants through the qualitative methods described above.

Study Assumptions

Importantly, ethnographic research assumes, implicitly, that the researcher brings to the study his/her own “voice,” including values, beliefs, perceptions, and biases. These

cannot be set aside, but instead, must be acknowledged. To that end, I recognized at the outset of the study the following assumptions regarding QI for EOL care:

- The quality of care provided to patients who are near the end of life is not always optimal.
- The quality of care that is provided to those near the end of life can be improved.
- Working to improve the quality of care for those near the end of life is a worthy endeavor.
- Efforts to improve the quality of care for those near the end of life should result in better outcomes for patients and their families (e.g., better control of physical symptoms, alleviation of social, spiritual, or psychological distress, improved quality of life).
- Efforts to improve EOL care are not all “equal:” some are more relevant and successful than others.
- Not everyone agrees that the quality of care near the end of life needs to be improved.
- Perceptions of “quality improvement,” writ large, influence motivation to engage in QI efforts.
- Perceptions of “quality improvement,” writ large, influence success in actually improving the quality of EOL care.

Sampling Procedures and Study Participants

The overall goal for this study was to identify and describe the meanings and narratives of the QI experience within hospice from multiple perspectives. Because hospice care is, by definition, a multi-disciplinary effort, I believed it was essential to investigate the perceptions of QI from hospice staff who serve in different roles. Moreover, I wanted to include staff from different types of hospice agencies, because the culture of an organization affects the perceptions and actions of its members and may be associated with specific characteristics of the organization. Because this study uses a qualitative approach, statistical representativeness of study participants and generalizability of results to all provider types across all agency characteristics was neither anticipated nor required.

Sampling Procedures

Individual hospice providers (i.e., study participants) were the primary units of analysis. The sampling strategy incorporated a two-stage design, with the selection of hospice agencies as the first stage and the selection of hospice providers within each chosen agency as the second stage. First, I used a purposive sampling approach to identify those hospice agencies that represent the diversity of hospice programs in the state of Maryland in terms of size (small, medium, or large, based on average daily census), type of agency (free-standing or part of a hospital, home health, or nursing facility), organizational tax status (for-profit or not-for-profit) and service area locality¹⁴

¹⁴ To be clear, the urban, rural, or both “locality” refers to the catchment area of the patients enrolled by the agency, not to the administrative office(s) or residential locations of the agency.

(urban, rural, or both). Second, using both purposive and random sampling, I recruited informants from four different roles (agency director, direct-care nurse, social worker, and chaplain) from within each identified agency. I wanted to explore the perceptions of nurses, social workers, and chaplains because individuals in these roles are key members of the hospice interdisciplinary team who implement the physical, social, and spiritual components of the hospice philosophy. I wanted to explore the perceptions of hospice directors because they provide the strategic direction for QI efforts in their agencies and are ultimately responsible for the results of those efforts. Below, I provide details on how each of these stages of sampling was implemented to recruit participants into the study.

Recruiting Hospice Agencies

I constructed the hospice agency sampling frame for this study using two sources: (1) hospice licensing information from the Maryland Department of Health and Mental Hygiene Office of Health Care Quality, and (2) hospice agency data from the 2014 Maryland Hospice Survey (see Appendix B). The state of Maryland fields its hospice survey annually to support planning for hospice services in the state (Maryland Health Care Commission, 2018a). The 2014 dataset included the most current, publicly available information on the 27 hospice agencies licensed in Maryland during the recruitment phase of this study. To allow for inclusion in the study of at least one hospice agency with each of the above-referenced agency characteristics, at the start of the study, I identified five agencies for recruitment.

To recruit hospice agencies for the study, I contacted the executive director of each agency via e-mail. This initial e-mail included an invitation to participate in the

study, both organizationally and personally. It also included a description of the goals of the study and the requirements for participation (see Appendix C). The sampling plan for the study was designed such that, if the executive director did not allow agency participation, another agency with the desired characteristic(s) (or combination of characteristics) was invited to participate instead. Recruitment of agencies was continued until at least one agency with the relevant characteristics agreed to participate or until no additional agencies with those characteristics remained.

Four of the five agencies that I initially targeted for inclusion agreed to participate. However, the fifth agency did not respond to repeated contacts. Per the sampling plan, I selected another agency with similar characteristics for recruitment. The director of that agency also did not respond to repeated contacts. I then identified a third agency with similar characteristics for recruitment. Initially, a representative of this agency agreed to participate. Subsequently, a more senior administrator withdrew this agreement, although without providing a reason for this reversal. I then identified a fourth agency for potential participation, although due to the small number of hospice agencies in Maryland, it lacked one of the desired characteristics. This agency agreed to participate in the study. Thus, after contacting a total of eight hospice agencies, I was able to complete recruitment of five agencies for the study. These five agencies met most, but not all, of my requirements for variety in terms of size, type, organizational tax status, and service locality. I cannot disclose specific characteristics of the participating hospice agencies, given only 27 eligible agencies operating in Maryland during the recruitment phase of this study. Due to this small number, such a disclosure could allow

for their identification, and, by extension, the identification of those agency staff who participated in the study. I can disclose that, compared to their distribution in Maryland overall, small agencies, non-freestanding agencies, and agencies that serve only urban areas were relatively under-represented.

Recruiting Individual Hospice Staff

My goal for this study was to enroll four staff members from each participating hospice, with each individual fulfilling one of the four roles in the agency (i.e., director, direct-care nurse, social worker, and chaplain). I relied on the person identified by the agency director (often, although not always, the agency's quality coordinator) to provide a listing of eligible employees and their contact information. I defined "eligible employees" as those who worked full-time for the agency and who had been employed by the agency for at least six months. If a particular agency did not have a full-time employee for a particular role, part-time employees who had worked at the agency for at least six months also were considered eligible for participation. Per the sampling plan for the study, when more than one individual fulfilled a particular role of interest, I randomly selected one individual for recruitment (see Appendix C). I continued recruitment for individual participants from each agency until an individual from each of the four provider roles agreed to participate or until the pool of potential informants in each role was depleted. Per the sampling plan, if I had been unable to recruit individuals from at least three of the four roles from a particular agency, I would have recruited a sixth agency with similar characteristics. This contingency plan was, ultimately, unnecessary.

I also planned to recruit additional participants if thematic saturation was not achieved. This, too, proved unnecessary.

A total of 19 informants from five participating agencies were enrolled in the study (see Table 7). Sixteen enrollees agreed to participate after only one recruitment contact. Three initially-selected potential participants refused to participate (a chaplain from agency B and social workers from agencies C and E). The chaplain cited time pressure as the reason for refusal; however, neither social worker provided a reason. In these instances, I randomly selected another individual from the lists provided by the agency. In each case, this second person agreed to participate. Finally, although Agency C employed more than 10 direct care nurses, and I reached out to each one in turn, ultimately I was unable to recruit any of the nurses from that agency. In fact, none of those nurses responded to my recruitment e-mails. This was an unexpected reaction, given the positive response regarding participation from other providers in Agency C, as well as from nurses employed by the other participating agencies.

Of the 19 informants who participated in this study, 12 were women and 7 were men. Because differences in responses according to demographic characteristics were not a focus of the study, I did not ask informants to self-identify on other demographic characteristics such as age, race, or ethnicity. However, there was diversity among participants according to these characteristics.

Table 7. Final Participation in the Study, by Agency and Role

Agency	Director	Nurse	Social worker	Chaplain	Total participants
Agency A	✓	✓	✓	✓	4
Agency B	✓	✓	✓	✓	4
Agency C	✓	No response	✓	✓	3
Agency D	No response	n/a	n/a	n/a	n/a
Agency E	✓	✓	✓	✓	4
Agency F	No response	n/a	n/a	n/a	n/a
Agency G	Refusal	n/a	n/a	n/a	n/a
Agency H	✓	✓	✓	✓	4
Total	5	4	5	5	19

Note. In total, five hospice agencies and 19 individuals participated in the study. All participating hospice agencies employed more nurses than social workers, and more social workers than chaplains. The two smallest agencies employed only one chaplain, although the other agencies had at least four to select from. All participating agencies had at least 3 social workers and at least 10 nurses for potential recruitment.

Data Collection Procedures

I collected data for this study via face-to-face interviews conducted between March 2016 and April 2017. I used semi-structured interviews to facilitate the dialogue with the participants (see Appendix D). The formation of interview questions was, for the most part, informed by the literature and by theory. Initially, I considered developing different interview guides for the different staff roles. Ultimately, this was not necessary, as I wanted to explore the same topics with participants in all roles. Also, the interview guide was designed to provide a starting point for conversation with study participants, and this gave me the freedom to deviate from the questions as needed.

Interview duration varied from about 50 minutes to just over two hours, with most lasting from 75 to 90 minutes. For two directors, I conducted the interview in two sessions, due to time constraints on their part. In general, interviews with agency

directors were the longest, while interviews with nurses were the shortest. I conducted the interviews at each participant's time and location of choice. Most participants chose to meet at the agency's administrative office, but a few chose an alternative location (i.e., local library and Starbucks). Almost all of the participants were "on the clock" during the interviews, although one nurse and one social worker specifically noted that they were meeting on their day off. At the beginning of each interview, I obtained permission from the participant to audio-record the session. I also took written notes during the interview, and audio-recorded my thoughts and impressions immediately following.

Protection of Human Subjects

The protocol for this study was approved by UMBC's Institutional Review Board via an expedited review, because it was deemed to involve research described under IRB expedited category 7,¹⁵ and because it presented only minimal risk to study participants. To meet the additional requirements for IRB expedited review, I developed a statement of informed consent. However, my initial dissertation director encouraged pursuit of a waiver that would allow verbal consent to participation, without requiring interviewees to sign a consent form. The rationale for pursuing this waiver was that that obtaining signed consent can hinder establishment of rapport with informants in qualitative and ethnographic research and compromise the interviewing process. Ultimately, the UMBC IRB waived the requirement for written documentation of informed consent.

¹⁵ IRB expedited category 7 includes research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Consequently, I obtained consent orally (which I audio-recorded), and provided an information sheet to participants describing the consent process (see Appendix E).

Prior to final agreement to participate in the study, three of the five agencies that participated in the study required additional internal review and approval of the study protocol to ensure human subjects protection, in addition to the IRB approval granted by UMBC.

Per the UMBC IRB protocol, at the beginning of the interview, each participant gave verbal consent for participation in the study, as well as permission to audio-record the interview. I stored electronic copies of the audio-recorded interviews and transcriptions of these interviews on a password-protected computer. Access to these files was limited to me and the dissertation director.

Data Validation

In order to strengthen the basic study design, I asked each agency to provide written information on their current QI efforts. These data, as well as information elicited from informal conversations with each agency's QI coordinator (see Appendix C and Appendix E), helped to provide a context from which to understand the perspectives articulated by the various participants from each agency. They also aided the interviewing process (e.g., to identify additional questions for discussion or to refine already-formulated questions). The volume and content of the contextual information provided by each agency was left to the discretion of the agency's director and/or QI coordinator. This contextual information included quality metric trend reports, data collection instruments, minutes of previous QI meetings or board meetings, and formal

performance improvement planning documents. While I used these materials, along with the conversations with the QI coordinators, as background information to help me better understand and validate participant responses, I did not formally code or otherwise analyze them.

I also attended and observed an internal QI meeting for each agency. These observations provided additional context (e.g., frequency, attendance, length, approach) regarding each agency's internal QI efforts. My attendance at these meetings typically was preceded by a brief introduction of me and this study by the meeting leader (usually the QI coordinator). I collected field notes during these observational meetings but did not audio-record them. As with the contextual materials from each agency, I used these field notes as background information, but did not formally analyze those data.

Finally, during the in-person interview, I asked each informant if he/she would be willing to review and provide feedback on the initial findings of the study, a process known as "member checking" (Saldana, 2016). At the time of the interviews, all participants agreed to provide this feedback. Ultimately, however, only four did so (two chaplains, one nurse, and one director, from three of the five participating agencies). This lack of response likely was due to the lag time between the interviews, which were conducted between March 2016 and April 2017, and my request for feedback, which was solicited in October 2018. All four participants who provided feedback agreed with the initial findings as presented. Two highlighted the need for educational efforts both within and outside of the hospice setting, a subject that I will raise in Chapter 7 as part of the discussion of practice implications from the study.

Data Analysis

I conducted a content analysis to identify key themes from study participants' narratives. Content analysis applies systematic qualitative and quantitative analysis and interpretation of the contents of a body of data with the goal of identifying "patterns, themes, biases, and meanings" (Berg, 2009, p. 338; Saldana, 2016, p. 300). To conduct this analysis, I used both first-cycle and second-cycle coding methods (Saldana, 2016). Saldana describes first-cycle coding as a way to "initially summarize segments of data" (p. 236) and second-cycle coding as "advanced ways of reorganizing and reanalyzing data coded through first cycle methods," (p.234) the primary goal of which is "to develop a sense of categorical, thematic, conceptual, and or theoretical organization from your array of first cycle codes" (p. 234). A code is simply a "word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldana, 2016, p. 4).

During the first-cycle coding phase, I utilized a number of coding methods, including attribute coding, structural coding, descriptive coding, and in vivo coding. Saldana (2016) describes these types of coding as the following:

- Attribute coding. Notation of basic descriptive information
- Structural coding (also known as "utilitarian" coding). Applies a content-based or conceptual phrase representing a topic of inquiry to a segment of data that relates to a specific research question used to frame the interview
- Descriptive coding. Summarizes in a word or short phrase the basic topic of a passage of qualitative data

- In vivo coding. Word or short phrase from the actual language found in the qualitative data record

During the second-cycle phase of the analysis, I employed pattern coding. Pattern coding groups initial codes into a smaller number of categories that are conceptually related. See Appendix F for an example of first- and second-cycle codes assigned to portions the interviews.

The patterns that emerged during the second phase of coding often became the themes that are presented in chapters 5 and 6. As noted by Saldana (2016, p 198), a theme is an “outcome of coding, categorization, or analytic reflection.” For this study, I have defined a theme as a label that describes the most important patterns that have emerged from the data.

I used Atlas.ti software (versions 7 and 8) to code the data from the interviews. Atlas.ti is a Computed Assisted Qualitative Data Analysis Software (CADQAS) package designed to facilitate analysis of textual, graphical, audio, and video data. Atlas.ti licenses the full version of the software to students at a markedly reduced price. I also used this software to create and organize analytic memos to document my thoughts about the codes and the coding process itself, as well as my reflections about concepts, ideas, and patterns that emerged as I immersed myself in the data.

My initial dissertation director, an expert in qualitative analysis, read all interviews from the first agency and provided guidance for conducting future interviews and for coding the material. Discussion of results of the content analysis with that

dissertation director and other committee members continued throughout the data collection and analysis phases of the study.

I accomplished a significant portion of the analysis of the data collected in this study through the process of writing. More specifically, the writing process itself suggested new ways to categorize the findings and refine the themes. For example, some findings that I initially viewed as separate categories or themes coalesced or merged with other themes as I and my dissertation director reflected on various versions of this document.

As a reminder, the overall research question for the study asks how providers in the hospice industry perceive QI efforts. Importantly, another of my assumptions regarding QI became increasingly clear as I analyzed the data collected in this study and summarized the findings. This assumption reflects the meaning that I, personally, assign to the term “quality improvement” and how I use this term in both my thinking and in my language. As noted earlier, for this study, I defined QI as *systematic changes that result in improved structures, processes, and outcomes of care*. This formal definition matches the theoretical models from the literature, as well as my own personal conceptualization of QI that I have reached through more than 10 years of work in the field of healthcare QI. In conducting this research, I have not changed my mind about this formal definition of QI. However, I did realize through the research process that when I use the term “quality improvement,” I almost always think of the entire *QI enterprise*. This overall enterprise involves the numerous efforts and activities involved in the actual process of QI (including measurement), the infrastructure underlying these processes, including the

science of QI, as well as the outcomes of QI efforts. Each of these facets are, in my view, subsumed in the formal definition that I have used for this study.

Yet my adherence to this understanding of the entire *enterprise of QI*, along with my use of language in calling it, simply “quality improvement,” resulted in some confusion. The confusion arose in how I articulated the aims of the study (particularly Aim 2) and, in some cases, how I asked particular questions during the interviews. As I analyzed the data, I came to realize that often, although not always, I was specifically interested in study participants’ perceptions of QI *efforts*, as opposed to the *outcomes* of those efforts (i.e., better quality of care received by patients and their families). Interviewees’ narrative responses indicate that this former interpretation was how they often heard and responded to my questions. Thus, when summarizing those findings, I explicitly refer to “*quality improvement efforts*” to make this understanding clearer to the reader. At other times, however, I and/or my study participants were thinking of other facets of the QI enterprise (often, its outcomes). This sometimes resulted in a conflation among the concepts of care quality and improvement in care quality. In these cases, I note the conflation briefly, but rely primarily on the context of the narrative to reflect these understandings and to summarize the findings. I will return to this conflation of concepts in Chapter 7.

Finally, in analyzing the data from this study, I realized that the formal wording of Aim 2 does not reflect the entirety of the concepts that I sought to understand. Aim 2, as stated when the study was initiated, was to identify and describe how participants perceive the potential for improving quality of care near the end of life. However, the

interview questions that I posed to address this aim involved much more than just the potential (i.e., the capacity) for improvements in care. These questions also covered topics such as the meanings of QI, advantages and disadvantages of QI efforts, barriers and facilitators of QI efforts, factors influencing perceptions of QI efforts, and ideas for QI efforts. Thus, the participant responses that I summarize under this aim reveal a broader and richer dialogue regarding perceptions of QI in the hospice setting than might be expected from Aim 2 as initially articulated.

Presentation of Findings

When initially conceptualizing the study, I focused on six distinct lines of inquiry and these became the six aims of the study. The questions that I used as jumping off points for discussion were structured and ordered in congruence with the study aims. However, in analyzing the data, I discovered that the key findings did not always lend themselves to a strict aim-by-aim reporting of results. Thus, I have presented the major findings that emerged from the study in two separate chapters. Chapter 5 focuses on the meanings of quality EOL care as defined by study participants, and how these meanings differ according to provider role and associated agency characteristics (Aims 1 and 6). Chapter 6 presents the bulk of the findings from this study. It focuses on findings related to participants' perceptions of QI efforts and how these perceptions differ by provider role and agency characteristics (Aims 2-6). Chapter 6 is organized according to major sections that summarize key discussion points from the interviews. Within each section, I indicate how the major findings address the study aims and identify the relevant themes that emerged from the participant responses. Finally, Chapter 7 synthesizes the major

findings from the study, along with its strengths and limitations, discusses the implications of these findings for policy and practice, and provides ideas for future research.

The themes in chapters 5 and 6 generally are ordered according to the number of participants who discussed a particular idea. Often, but not always, the ordering of themes by number of participants parallels the ordering according to number of coded instances about a particular topic. In some cases, however, the themes that I have highlighted reflect ideas that were discussed by relatively few participants. Reasons for such inclusions vary, but typically these signify what I considered to be particularly interesting or unexpected findings, or because strains of the idea permeated throughout the set of interviews.

To illustrate the themes and key findings presented herein, I have included many direct quotations from study participants. These are displayed using indented, italicized font. For the most part, the quotations are presented verbatim. However, to enhance clarity, for some quotes, I have made minor spelling, punctuation, or grammatical changes, or deleted verbal ticks (e.g., “you know” or “like”). Also, I have added explanatory text within brackets for some quotations. Attribution for quotations is based on agency identifier and role (e.g., a quotation by the nurse informant from Agency A is indicated by the descriptor *Nurse A*).

Summary of Chapter 4

This chapter described the methodological approaches used in the study and articulated the assumptions that I held when first conceptualizing the study. It also

detailed the procedures used to recruit participants, conduct the interviews, and analyze the resulting narrative data. Chapter 5 turns to the findings from the qualitative analysis of participants' meanings of quality EOL care and any variations by staff role or agency characteristics.

Chapter 5: Meanings of Quality End-of-Life Care

The overarching goal of this study was to gain insight on how those providing hospice care perceive efforts to improve EOL care. When conceptualizing the study, I believed that to adequately understand participants' perceptions about QI in the hospice setting, I would first need to understand the meanings they attach to quality EOL care more generally. Thus, Aim 1 of the study sought to identify and describe the meanings of quality care at the end of life, as perceived by the hospice providers participating in the study. The study also sought to discover whether and how these meanings vary according to provider role and/or agency characteristics (Aim 6). This chapter summarizes the findings that address these two aims. The chapter begins by describing the most salient meanings that study participants ascribed to quality care near the end of life. It then delves more deeply into these perceived meanings by examining how participants differentiated between levels of care quality (i.e., how they viewed high-quality EOL care, versus care that is of moderate and low quality).

To elicit responses from participants about how they conceptualize quality EOL care, I began by asking the question “*When I say ‘quality care near the end of life,’ what do you think about? How would you describe or define this term?*” Each of the 19 participants discussed this concept, via a total of 111 coded instances. Most of these coded instances reflect narrative offered in direct response to this question. However, some came from discussion that occurred later in the interviews. Because this question was fairly general, many participants' descriptions also were general in nature, rather than specific or discrete.

After discussing their views of quality of EOL care in general, I then turned my attention to exploring whether and how participants differentiate between high-quality care, low-quality care, and “middle of the road” care. I approached this line of inquiry by asking three separate questions. First, I asked, “*What makes for high-quality end-of-life care?*” I sometimes proffered this question as, “*When you think about high-quality end-of-life care, what comes to mind?*” Next, I asked, “*When you think about end-of-life care that isn’t of the highest quality, what comes to mind?*” Finally, I asked, “*When you think about end-of-life care that is neither excellent nor or poor, what comes to mind?*” For each question, I invited study participants to provide examples to illustrate their ideas. Asking for such examples allowed interviewees to be more specific in their descriptions, as compared to their responses to my first, more general, question about quality EOL care.

Although most of the study participants answered all three of these follow-up questions, they verbalized more than twice as many coded instances describing high-quality care than moderate- or low-quality care. Specifically, 18 participants described how they perceive high-quality EOL care, via 88 coded instances. Sixteen participants, via 37 coded instances, described how they view EOL care that is neither excellent nor or poor (i.e., moderate-quality care). Finally, 18 participants, via 42 coded instances, described their perceptions of care that isn’t of the highest quality (i.e., low-quality care).

Addressing Aim 1 of the study, key findings indicate that the most salient meanings of quality EOL care held by study participants reflect: (1) effective symptom management, and (2) individualized care that aligns with patient and family wishes.

However, interviewees focused primarily on individualized care and holistic care when describing high-quality EOL care, and specifically discussed the lack of these attributes when defining moderate- and low-quality EOL care. In addition, some participants highlighted care provided outside of the hospice setting when they described low-quality care. For these participants, low-quality care means the patient is getting either too much or not enough care. Addressing Aim 6 of the study, the findings also indicate that these meanings of quality EOL care are influenced by provider role but are not associated with agency characteristics. Each of these key findings are supported below through narratives that are drawn directly from participant interviews.

Theme 1: Quality EOL Care Addresses Symptoms and Aligns with Patient and Family Wishes

The 19 study participants verbalized a broad array of meanings of quality EOL care. Perhaps not surprisingly, participants described these meanings primarily in terms of the activities they perform for their patients in their day-to-day work in hospice. These included relational activities such as: (1) spending time, listening, and showing love; (2) providing education about hospice itself and/or treatment options; and (3) “*going over and above*” minimum standards when providing care. However, some of these participants also portrayed meanings in terms of the organizational structures through which they operate, or through the lens of patient/family outcomes. Examples of these more structural meanings include effective teamwork among the hospice care providers and availability of the resources needed to provide EOL care. Examples of meanings of quality EOL care from the perspective of patient and family outcomes include elements

such as family engagement in the care process, a sense of confidence in the choice of hospice care, and a lack of fear and sense of hope, even in the face of death.

However, as detailed below, two meanings of quality EOL care verbalized most frequently and by the most participants were: (1) effective management of patient symptoms and (2) individualized care that is aligned with patient and family wishes. Only four of the 19 participants did not articulate at least one of these meanings.

Effective Management of Patient Symptoms

Ten participants (five chaplains, three social workers, one nurse, and one director), via 22 coded instances, described quality EOL care as effectively addressing symptoms that patients encounter near the end of life. Pain was the symptom mentioned most frequently.

If they have pain issues, making sure that it's been diagnosed and the pain is dealt with in the manner that the patient and the family are comfortable.

Chaplain B

*Like I said, I think for the most part...pain management...is the first thing..., whether it's in the hospital or in the home....But I think the main thing is just managing the pain symptoms. **Social Worker H***

Notably, several of the chaplains pointed to the management of spiritual and emotional pain. However, in some cases, they didn't explicitly use the word "pain," but instead spoke of offering emotional and spiritual support and comfort.

*From my perspective...quality of life is making sure...the person's spirituality, spiritual life, spiritual pain is taken care of. You don't want the person to be in pain spiritually. As much as our counterpart, nursing, don't want the patient to be in pain physically. **Chaplain H***

*And, of course, that [clinical support] is not enough, and so I think the psychosocial spiritual support is very important as well. It's a... part of that whole picture of the care at the end of life...[W]e are there to support their struggles, emotional, psychological struggles...I'm there to help them process those feelings and their experiences, you know, spiritual and religious experiences. And hope to bring them peace. So, I think that comfort and peace, both physical and spiritual and psychosocial is, I consider that as the quality of care. **Chaplain E***

In addition to pain, a few participants also referred to other symptoms, sometimes specifically (e.g., shortness of breath) and sometimes more generally (e.g., ensuring that patients are comfortable).

*You know, specifically pain control is something that pops in my head. How can you say you're giving quality care if you're not controlling people's symptoms, and even the most distressing of them. **Social Worker***

B

So, the quality issues is the listening, the first thing, listening to patients. And, of course, you focus on comfort care...some of our patients are in

horrific pain and we have... so many patients who have COPD [Chronic Obstructive Pulmonary Disease] and...they have... shortness of breath.

*So, symptom management is so important at the end of life. **Chaplain C***

Individualized Care that Aligns with Patient and Family Wishes

Ten study participants (four social workers, three chaplains, two nurses, and one director), via 21 coded instances, defined quality EOL care as care that is individualized for each patient and family, in alignment with their wishes. Participants described such care as providing opportunities to patients and families to determine which services or treatments they do or do not want, and tailoring treatment to suit individual needs and desires. In addition to the word “wishes,” interviewees also used the words “desires,” “goals,” and “wants” to reflect this patient- and family-centric aspect of care.

*We try to do as best we can, what the family wishes, what the patient wishes. I guess that would be quality end of life care, to be able to carry out what they wish. **Chaplain A.***

*I mean you have to walk into the house and you have to assess that house. Every person, every family is different. Every death is different. And it has to be individualized....It should be different, what I do for you, as for what I do for somebody else. **Social Worker E***

Whatever the patient...However the patient defines that [quality care]. That's gonna vary as far as desires, as far as wishes...Individualized.

Social Worker A

*I guess because it still goes back to the, you know, how do you fully define quality end-of-life care? Does it mean giving them really the best environment possible? Does that mean honoring their wishes?...You know, it, it becomes subjective...[A]nd is it just number of visits, or is it who's going? ...Because certainly...if you got a nursing visit every single day, you might think that's really quality care. But if you have a ton of psychosocial and other factors going on and you never see your social worker, well, it's probably not quality care then for you. So ... Well, I guess what I'm saying... that quality care should be individualized based on your needs. **Social Worker B***

*The quality of care needs also to be defined in collaboration with the patient's vision of life. Because we always ask the patient "how do you want to spend your last day?" And many will tell you. **Chaplain H***

Well...each family has their own definition... I don't set the definition as to what quality of life is. I ask them, "What is it that you want for your mother or father?" Some people will say, I just want her to...breathe better...not have this respiratory distress all the time...Some people say, I don't want mom to be knocked off with narcotics,...I want her to be more alert. ...[S]ome people say, I want my mom to be comfortable and not suffer at all. So, based on their needs, we try to meet their goals....[A]ll end-of-life quality is defined by the family or the... patient....They say,

look, I want this, I don't want that. Okay, we're not going to do any of that if you don't want it. Nurse E

Importantly, the above quotations also illustrate the notion that the quality of EOL care is subjective. That is, different patients and families will have different views of what constitutes quality EOL care. In fact, five participants explicitly verbalized this idea, albeit in various ways.

Theme 2: Holistic Care is High-Quality EOL Care

Participants' narratives about different levels of EOL care quality provided additional insight regarding the meanings they ascribed to this concept. As already noted, participants were able to differentiate between levels of care quality, although they focused more on their perceptions of high-quality care than on their perceptions of moderate- or low-quality care. Most of the meanings that study participants ascribed to high-quality EOL care were similar to those they described as quality EOL care more generally. In other words, when asked initially to describe quality EOL, participants were also describing what they later identified as *high-quality* EOL care. However, the emphasis placed on certain meanings shifted somewhat. For example, when describing their views of high-quality EOL care, participants again frequently alluded to individualized care that aligns with patient and family wishes. However, they spoke relatively less about symptom management. Most notably, however, the importance of holistic care emerged as a salient meaning of high-quality EOL care. By holistic care, I am referring to care that addresses the various domains of palliative care, including the social, psychological, and spiritual aspects, not just the physical. While this meaning was

articulated by three participants when describing quality EOL care, it was alluded to by these and five other participants when they described their views of high-quality EOL care.

*[There is] always good medication management, comfort, ...spiritual care, support from our social work department. **Nurse A***

*I think exceptional...I hear a lot of nurses who stayed with the family for hours during a transition [death]. I've heard of chaplains who'll come in the middle of the night. There are social workers that can walk into a situation and put out all the fires, that make everybody calm enough to go to that next stage. And the music therapists are phenomenal, they really are. **Social Worker E***

Chaplain E provided a detailed example to illustrate the provision of high-quality care provided to a U.S. veteran. This example included references to full provider engagement, teamwork, and coordination, a “pinning” ceremony attended by friends, family, and the hospice care team, and collaboration between the nurse and social worker that minimized hospitalization of the patient and provided peace for the patient’s wife when moving the patient to a DNR (do not resuscitate) status. This chaplain ended the story by saying,

*I think that was a good case there. And we have many of these cases that, that the whole team worked together to provide...that whole person care. Clinical, spiritual, psychosocial. Uh-huh. **Chaplain E***

Importantly, when describing what I have classified as holistic care as a key meaning of high-quality EOL care, several of the study participants referred to care of both the patient and the family.

*It [high-quality care] should be the same consistent, very skilled, very competent person every time, and that team, together, should be providing for that whole holistic care of that patient and family. **Director C***

*I would say that high-quality end of life care means, basically, a full menu of the services that hospice provides. You want the patient and family have access to all the help needed. Because...dying doesn't happen in isolation. Death has an effect not only on the patient, but also on those left behind. So, the anticipation of death involves everyone who's involved in the care of the patient. The patient suffers physically. Caregivers, family members suffer emotionally. So the high quality of care...is not just caring for the patient who's laying in the bed. You want also to care for the patient[s] who are standing....[H]igh quality of care is making sure that everyone involved in the patient care is being taken care of....[S]o, to me, the quality of care is really attending to all these people. **Chaplain H***

Theme 3: Lack of Care Characterizes Moderate- and Low-Quality EOL Care

As noted earlier, study participants were relatively less able to verbalize meanings of moderate- or low-quality care. However, almost all participants described these levels of care in terms of deficiencies in care processes or in the outcomes of care. For

example, Director H indicated that moderate-quality care lacks consistency, while Social Worker C focused on the lack of individualized care and attention to patient wishes.

Inconsistent, I guess, would be a good word for middle of the road.

Director H

*You know, and when I think of middle of the road care, you know, I just think of somebody getting average care, their needs are being met, the family is receptive to the staff, but they're missing that personalization of, you know, who we are and who they are and how we can help them achieve their goals. **Social Worker C***

Chaplain A described middle-quality care as a lack of holistic care, and as care that does not result in effective symptom management, saying,

*I guess physically, it would be being in pain. Emotionally and spiritually, [it] would be unsupported. Let's see. Middle of the road...Yeah, I guess not being supported as a family, and any tension between family....Yeah, so tension within the family. **Chaplain A***

Perhaps most interestingly, while some participants viewed such deficiencies as moderate-quality care, others viewed them as low-quality care. This interpretation as low-quality care is illustrated by the following narratives by Director A and Chaplain E.

Well, low quality of care would be, to me, that you weren't responsive when somebody needed you. That you didn't give the adequate amount of

*support to the patient and family, because it's a holistic approach to care. [To] give you an example of that, somebody gets admitted to a hospice program...They'll see an admission nurse, they'll get admitted, and they won't see another nurse for a week. **Director A***

*Low quality would be if, let me think of...a recent experience...so, recently we had a patient,...they had this expectation that hospice would be there [at the patient's home] 24/7....And when we said we could not, because the patient really at the time was asymptomatic, you know ...his symptoms were managed fairly well at home. It was just the family was overwhelmed... they just couldn't pull it together to...provide care on a constant basis...and then when they were asking for us to help them decide...what to do, see I don't get into that kind of work. I guess that would be the case that, I feel like, you know, sometimes chaplains could be...more integrated into the team [at this agency]. **Chaplain E***

Nurse A described moderate-quality EOL care as a lack of both holistic and individualized care. Interestingly, this participant, and four others, characterized moderate-quality EOL care as a sort of “bare bones” care.

In the center setting, it may be, still the right medications...but not so much support spiritually or from social work. Or from nurses, not so much support.... Just kind of doing the bare minimum. Like, "Here's your pills, here's your pain medicine, we'll see you in two hours." ... I'd say bare

*minimum, still doing their jobs, nothing illegal but, this is what you're gonna get, and don't ask for anything more. **Nurse A***

*Middle of the ground to me...would be that you might see a patient one time a week, give him a phone call. Just like the social aspects of help with the family is just okay. You're just skating through. You're just giving the bare bones of what you feel like you need to give. **Director A***

But again, such a lack of holistic care was viewed by Director H as low-quality care.

*Low-quality care would be sort of a cookie-cutter approach, providing sort of the minimum, without doing anything extra, and then not necessarily tailoring your care to the individual. But basically, giving sort of blanket [of] things, well everybody gets this or everybody gets that, without consideration of the patient's care. Not being responsive to the needs of the family....So, they're sort of checking the box without necessarily putting their heart into the work that they're doing. **Director H***

Finally, Social Worker E described moderate-quality care somewhat differently, suggesting that with this level of care, patients do get what they need. But this participant went on to contrast this level of care with “exceptional” care in which providers go above and beyond when providing care for their patients (e.g., by spending hours at the

deathbed, per a quotation included in the preceding section). This idea also was reflected in comments by Director E.

*...they [patients] got the support, they got the information, they got the tangibles, the medication, the bed, whatever that they needed. And that somebody was available to them, 24 hours. 9 times out of 10, that's what I hear. And I think, I think that's the basic. **Social Worker E***

Middle of the line is...it's probably the 80/20 rule....[W]e're not reaching for the opportunity to be great, it's the day in and day out grind of end-of-life care. And sometimes what we see is just, I don't want to call it mediocre, right, but it's just,...sometimes, going through the motions.

Director E

Theme 4: Low-Quality EOL Care Often Occurs Outside of the Hospice System

A final meaning of low-quality EOL care quality that emerged from discussion by six participants reflects care that is provided outside of the hospice system. As a reminder, care provided within the hospice system most often occurs at the patients' home, whether a private residence or another type of long-term care facility such as an assisted living facility or nursing home. Hospice care also may be provided in inpatient settings, such as in a stand-alone hospice facility.¹⁶ Thus, by care provided "outside of the hospice system," I mean care of patients who are not enrolled in hospice and/or care

¹⁶ The extent of family involvement in hospice care varies substantially, depending on the location of care. As a group, study participants provided care in all of these locations.

that is not provided by hospice agency staff. Of the six participants who discussed this “non-hospice” care, three discussed low-quality EOL care in terms of a lack of care, and three discussed it in terms of too much care. For example, Social Worker H and Chaplain H equated lack of enrollment in hospice to low-quality EOL care. Both posited families’ lack of understanding about how hospice can help as the underlying reason for not using hospice services.

*I think low quality would be a situation where you have a family that’s maybe struggling to grasp that hospice is here to make your loved one comfortable. And a lot of times, ...they can’t come to that conclusion because, maybe there’s one family member who is like “I don’t want to do hospice.” ...[A]nd so the family is struggling to come to that agreement, [and] the patient unfortunately is left to be in pain, not get that comfort care... **Social Worker H***

*And the low-level quality of care is basically where there is no attention given even to those services [addressing the physical symptoms]. Where people are overwhelmed about the shock of dying. Or where people don’t think that it’s [hospice] worth it, it’s worth doing anything, because she’s [the patient] dying anyway. ... [P]eople give up. Family members give up. Because there’s just nothing that is worth investing [in] or going through... because the person will die anyway. **Chaplain H***

Two participants also referred to sub-optimal care that is sometimes provided to patients who reside in nursing homes.

*Low-quality end of life care is when a person is placed in a facility, and the facility does the bare minimum. You know... they work on a time schedule instead of caring for the patient's needs. **Chaplain B***

Additionally, Chaplain A and Social Worker C identified too much care when describing low-quality EOL care that is provided outside of the hospice system. The allusion to too much care encompassed drastic and/or futile measures done to extend life.

*[Low-quality EOL care is being] in a hospital hooked up to machines...being resuscitated even if there's no reason to be. **Chaplain A***

*What I would consider to be low quality care, I think about oncologists that just chemotherapy people until there is no other option except they have to pass away in the hospital. **Social Worker C***

Later in the interviews, several participants suggested increasing access to hospice care as a way to improve EOL care quality. Thus, I believe this meaning of low-quality care is important to present, even though it was identified by only a small number of participants.

As an aside, one additional participant (Social Worker A) described too much care as low-quality care, but recognized that this can also occur within the hospice setting.

*... I found that lately they've [agency leadership] been saying we get paid more when it's within seven days of death, and if we [visit the patient] each day, we get more reimbursement....That's great, BUT I'm not going to push myself on them and go in their house each day, if that's not what they want and that's not what they need.¹⁷ **Social Worker A***

Meanings of EOL Care Quality by Provider Role and Agency Characteristics

To address Aim 6 of the study, I analyzed whether, and how, the above meanings of quality EOL care vary according to provider role (i.e., director, nurse, social worker, or chaplain) and agency characteristics (i.e., size, type, tax status, and locality). Results of this analysis indicate that these meanings are associated with provider role but not with agency characteristics.

Meanings of EOL Care Quality by Provider Role

As a group, chaplains were relatively more vocal in their narratives regarding meanings of EOL care quality. Specifically, this group of providers had more coded instances of meanings than those in other roles (n=41, for an average of 8.2), followed by directors (average=5.4), social workers (average=5.2), and nurses (average=4.3). But more importantly, the meanings ascribed to EOL care also varied by provider role. As indicated in Table 8, all participating chaplains and social workers verbalized at least one

¹⁷ This understanding of the payment structure for the Medicare hospice benefit is not entirely correct. As described earlier, the per-diem payment for days 1-60 is higher than for days 61 onward. However, CMS does provide a service intensity adjustment that pays an additional \$42 per hour (up to four hours per day) for visits by registered nurses and social workers during the patient's last week of life.

of the two most common meanings of quality EOL care, while only three directors and two nurses did so.

Table 8. Number of Study Participants Holding Most Common Meanings of Quality EOL Care, by Provider Role

Meaning	Directors	Nurses	Social workers	Chaplains
Symptom management	1	1	3	5
Individualized care that follows wishes	1	2	4	3
At least one (symptom management, individualized care that follows wishes)	2	3	5	5
Both meanings	0	0	2	3

However, the minority meanings of quality EOL care (e.g., relational activities, education, teamwork, and patient/family engagement in the care process) were verbalized primarily by the agency directors.

As a group, agency directors discussed high- and moderate-quality care relatively more than those in the other roles, while chaplains discussed low-quality care relatively more. Fewer directors than those in other roles defined high-quality EOL care as holistic, but more directors described lack of individualized care that aligns with patient and family wishes as moderate-quality EOL care. In contrast, identification of low-quality care outside of the hospice system was discussed almost exclusively by chaplains and social workers.

Meanings of EOL Care Quality by Agency Characteristics

There were differences in the density of narrative regarding meanings of EOL care quality across the five participating agencies, with the average number of coded

instances ranging from 9 to 16. However, the agency with the fewest coded instances (Agency A) differed from the agency with the most only in that it is a smaller agency.

There were also differences across the agencies in terms of the two key meanings of quality EOL care. However, these did not appear to be linked to specific agency characteristics. As shown in Table 9, all four providers from Agency B defined quality EOL care in terms of symptom management, but only one from that agency referenced individualized care that aligned with patient and family wishes. However, no particular characteristic of Agency B stood out in comparison to the other agencies. Similarly, three participants from agencies A and E referenced individualized care that aligns with wishes, while only one participant from agencies B and C did so. However, these agencies differed only in that Agency A is the smallest.

Table 9. Number of Study Participants Holding Most Common Meanings of Quality EOL Care, by Agency Characteristics

Meaning	Agency A	Agency B	Agency C	Agency E	Agency H
Symptom management	1	4	1	2	2
Individualized care that follows wishes	3	1	1	3	2
At least one (symptom management, individualized care that follows wishes)	3	4	2	4	2
Both meanings	1	0	0	1	2

As group, employees of Agency H discussed high- and moderate-quality care relatively less than those from other agencies, but their density of discussion regarding low-quality care was similar to that of employees from the other agencies. This agency differed from the others only in terms of type (i.e., not free-standing vs. free-standing).

Only participants from Agency B did not reference holistic care as a meaning of high-quality EOL care; however the characteristics of this agency were similar to the other agencies whose participants defined holistic care as high-quality care. Finally, only participants from Agency E did not discuss low-quality care in terms of care provided outside of the hospice system. Again, however, the characteristics of this agency were similar to those agencies with employees who did discuss this meaning of low-quality EOL care.

Summary of Chapter 5

This chapter summarized the findings regarding the meanings of quality EOL care that emerged during conversations with 19 hospice employees in Maryland. These findings address Aims 1 and 6 of the study.

Analyses of participants' narratives demonstrate a strong ability to verbalize meanings of quality EOL care and to differentiate between various levels of care quality. While interviewees defined quality EOL care primarily in terms of actions they, as healthcare providers, perform for their patients, they also described it through the lens of structures of care (e.g., teamwork/adequate resources) and outcomes of care (e.g., confidence and hope in patients and families).

Addressing Aim 1 of the study, when defining quality EOL care more generally, participants most frequently spoke of effective symptom management and individualized care that adheres to the wishes of patients and families. The concept of holistic care, or care of the whole person, also emerged when participants focused more specifically on definitions of high-quality EOL care. These meanings persisted during discussions of

moderate- and low-quality EOL, although for these levels of care quality, participants spoke about the lack of care (e.g., the lack of care that is individualized). A final meaning that emerged from these narratives is that of non-hospice care, which some participants equated to low-quality EOL care. Interestingly, they described this low-quality non-hospice care as a lack of care (e.g., suboptimal EOL care in nursing homes) as well as too much care (e.g., hospitalization or other futile treatments). Addressing Aim 6 of the study, the findings also indicate that meanings of quality EOL care differed by provider role, but were not linked to agency characteristics. These findings serve as a backdrop for those presented in the next chapter, which turns from meanings of quality EOL care to meanings and perceptions of QI within the hospice setting.

Chapter 6: Perceptions of Quality Improvement Efforts

The research question underlying this study asked how participating hospice staff perceive efforts to improve quality of care near the end of life. Aims 2-5, progressing from the abstract to the concrete, and from the general to the personal, addressed that question. These aims sought an understanding of participants' perceptions of the potential for improving EOL care quality, their perceptions of external drivers of QI efforts in hospice, their agencies' QI efforts, and finally, their own QI efforts. The interview questions mirrored the sequence of ideas laid out in these aims.

This chapter comprises eight sections that summarize findings that address Aims 2-6 of the study. Table 10 indicates the section of the chapter that addresses each study aim.

Table 10. Organization of Chapter 6 by Study Aim

Study aims	Chapter section
Aim 2: To identify and describe how hospice providers perceive the potential for improving quality of care near the end of life	Multiple meanings of QI Advantages and disadvantages of QI efforts Internal barriers to, and facilitators of QI efforts Influences on positive/negative views of QI efforts Potential of, and ideas for improvement
Aim 3: To identify and describe hospice providers' familiarity with and perceptions of external drivers to improve quality of care near the end of life	External forces that drive QI efforts
Aim 4: To identify and describe the internal (agency-specific) QI efforts of hospice providers participating in the study	Agency-specific QI efforts
Aim 5: To identify and describe the perceptions of hospice providers concerning their own QI efforts	Personal participation in QI efforts

Aim 6 of the study sought to describe how participants' meanings and perceptions of QI efforts might differ according to provider role and/or agency characteristics. This aim is addressed in each of the eight chapter sections listed above.

Multiple Meanings of Quality Improvement

I began the process of gathering narrative data about perceptions of QI efforts in the hospice setting by asking study participants a number of questions relating to this underlying topic of interest. The initial question was, "*What do you think of when you hear the term quality improvement in your line of work?*" This question focused on the meanings of QI perceived by those hospice workers who participated in the study. It was the first of several that I posed to address Aim 2 of the study, which, as initially stated, was to identify and describe how hospice providers perceive the potential for improving quality of care near the end of life.

Most informants were able to answer this question without additional prompting. Of the 19 participants in the study, 18 responded to this question and identified at least one meaning of QI though a total of 63 coded instances. In these 63 quotations, eight participants identified one meaning, nine identified two meanings, and one identified three meanings. While they offered the majority of these statements in response to the initial question noted above, some of the relevant statements occurred during subsequent discussions throughout the interviews. One person seemingly conflated the term "quality improvement" with improving patient quality of life, and therefore did not articulate a meaning of QI. The conflation among the concepts of care quality and improvement in

care quality surfaced multiple times with multiple participants throughout the interviews. This was alluded to in Chapter 4 and is addressed more fully in Chapter 7.

The initial findings that address Aim 2 indicate that hospice providers ascribed a variety of meanings to QI, some of which I did not anticipate. Specifically, informants' responses revealed five related, yet distinct, meanings of QI: (1) formal processes, (2) learning on the part of hospice providers, (3) changes in documentation to support compliance, (4) "doing better," and (5) activities that positively impact patients and families. Additionally, findings that address Aim 6 of the study, to describe how the above meanings and perceptions might differ according to provider role and/or agency characteristics, indicate that these meanings were associated with provider role but not with agency characteristics. Each of the five meanings is described more fully below, with direct supporting evidence from the interviews.

Theme 1: QI as Formal Processes within an Organizational Department

Nine of the 19 study participants (all five directors, two social workers, one nurse, and one chaplain) described QI as the formalized processes and activities undertaken by an agency's QI department and its personnel, making this the most common conceptualization of QI voiced in this study. This meaning of QI was verbalized through 16 coded instances.

Three of the specific formal activities mentioned by study informants included: a) calculating performance metrics and listening to customer feedback, b) using this information to determine areas to target for improvement, and c) putting processes in place to address those areas.

*You know, identifying areas where we are not performing to the standard we'd like to be. And evaluating why, and what can be done to change that. And when I hear quality improvement or performance improvement, I always think of a formalized process of doing that. **Director C***

*But in a nutshell, for me, quality improvement is looking at every area of your organization and developing a process and a plan to ensure that you are demonstrating that you are improving different parts of your organization through a strategic plan. **Director A***

Basically, improving the processes and...the ways that things are done that will ultimately serve the customers better, or patients in this case.

Nurse B

Some participants specifically alluded to their agency's QI department, their QI coordinator or manager, and formalized approaches or tools for improvement.

*In my last job, we used to have to meet each month for QI. And we would review data, and come up with a plan to either improve or expand, so that's how I view it. **Social Worker A***

*Well I... automatically go to...the quality department, Lean,¹⁸ you know, those sorts of things, quality improvement. **Director B***

¹⁸ Lean is a quality improvement methodology that seeks to maximize value by minimizing waste. Initially developed for the manufacturing industry, lean principles are now used in healthcare quality improvement. See www.lean.org.

*I'm blessed that this organization has a director of quality...I trust [this person] ...on watching adverse events, working with clinical leadership, working with leadership all across the organization, monitoring trends, understanding where our gaps are or our opportunities are at, and then sitting down in a very honest and open way to discuss what we need to do as an organization to eliminate that gap. **Director E***

Perceptions such as these, which portrayed QI as formalized activities of the hospice organization, was one of the three meanings articulated by study participants that aligns with my initial, working definition of QI (i.e., systematic changes that result in improved structures, processes, and outcomes of care). Participants who ascribed to this meaning of QI spoke of QI in terms of calculating and using quality measures, applying specialized improvement methodologies, and fulfilling these activities under the auspices of a specialized organizational structure (i.e., the agency's QI department). Each of these characterizations of QI as formal processes within the organization corresponds to the methodical and organized approach to QI that is inherent in the word “*systematic*” from my working definition of QI.

Theme 2: QI as Learning

The second most common meaning of QI voiced by study participants encompassed that of learning on the part of hospice providers. This meaning was verbalized by 7 of the 19 study participants (three directors, two social workers, one nurse, and one chaplain) through 17 coded instances. Five of the study participants

described QI as learning from past experiences, including mistakes in care, and using that knowledge to ensure that customer needs are met and mistakes are not repeated. In contrast, three participants discussed QI in terms of learning that is accomplished via agency educational activities for staff. One participant, Director E, verbalized both viewpoints.

Learning from past mistakes

Two participants (a chaplain and social worker) explicitly discussed QI as a method of learning from past mistakes. The past mistakes referred to in these instances included those made by the participants themselves, as well as those made by other hospice employees. In both cases, these individuals viewed QI as not only recognizing the quality problems (the learning), but also taking action so as not to repeat those mistakes going forward.

*That we would not avoid the mistakes that we have made, face it, and work as a team, and come up with concrete steps in how to improve the...care and not to make the same mistakes again....Those cases that I mentioned to you, ...I had to enter adverse events...and so I think... [the agency takes] those cases very seriously...We would talk about it at team [meetings], and so it's a very open and transparent process...that we face those situations and try not to...repeat the same mistake. **Chaplain E***

...There's always a need for quality improvement. Absolutely. ...[Y]ou learn from the mistakes, you really do. And they're dreadful, and they're

*horrible to remember. There are still things that will make me cry, that happened ten years ago. **Social Worker E***

Although acknowledging previous shortcomings in care provided by their agencies, two of the directors focused their discussion on the learning process itself and its future impact. These participants spoke of QI as more than just a one-time assessment of care quality. Instead, both described it as an ongoing process that occurs in response to evolving customer needs.

*So just to say we're doing a good job today does not necessarily imply that a month from now, or a year from now, you're still going to be doing a good job, because conditions change. And it's...important to continuously, sort of, adapt the services that you're providing, in order to meet the needs and accomplish the mission. **Director H***

Director B took this conceptualization a little further, identifying QI as a way to facilitate continuous learning, a significant personal philosophy.

*But I really do believe that it's really about continuous learning. I do. ...And I think those [the quality department and QI techniques] are structures and infrastructures that support that continuous learning. And I think they give visibility and, I guess, communicate the value of that to individuals, and to the organization, and to the community, that quality is at the forefront of what we are doing. **Director B***

Staff learning through agency educational efforts

Three participants (one director, one nurse, and one social worker) described QI in terms of the knowledge that hospice staff obtain through structured educational efforts that an agency implements as a part of its QI efforts.

Every quality manager does it differently. They might spin their audits a different way, monitor different things, educate in a different way to improve things... [The quality manager] uses it as an educational tool, where we need to improve on this aspect. Nurse A

Learning through staff educational efforts was portrayed less strongly than the idea of learning from past experiences to impact future care, appearing in only 4 of the 17 coded instances related to learning. While I could have included this aspect of meaning under the first theme of QI as formal processes, I have chosen to locate it within this separate theme of learning for two reasons. First, I wanted to highlight its importance as an integral part of hospice agencies' operations. Second, I wanted to underscore its salience to select study participants, who discussed hospice educational activities in response to numerous questions throughout the interviews.

Taken together, the perception of QI as learning by seven study participants represents what I consider to be an expansion of my own working definition of QI. It brings to light learning as a latent factor in my definition that is worth highlighting. Specifically, my working definition of QI (*systematic changes that result in improved structures, processes, and outcomes of care*) presupposes, but does not state explicitly,

that one must discover quality problems before implementing improvement activities, and that one must understand the effects of those activities to know whether the changes are actually improvements.

Theme 3: QI as Changes in Documentation to Support Compliance

Other participants defined QI more narrowly by focusing on agency-initiated processes that are geared toward improvements in documentation to support compliance with state or federal regulations, to meet requirements for agency accreditation, or to meet their agency's own internal standards. Director C provided the following examples of required documentation needed to demonstrate compliance:

An example of compliance is getting our certifications of terminal illness signed on time and turned in, our notices of election¹⁹ are filed within five days, the quality measures that we have to report to Medicare within those prescribed timeframes...double checking those things, are compliance.

Director C

This meaning of documentation to support compliance was expressed by six study participants (two nurses, two social workers, one director and one chaplain) through 20 coded instances. Statements by these participants suggest that this meaning of QI reflects a strongly-held perception for those who ascribed to it. Participants specifically

¹⁹ A notice of election is a Medicare-required form that each patient or his/her representative must sign to indicate understanding of the palliative nature of hospice care and to waive curative treatment for the terminal illness. See <https://www.nhpco.org/election-hospice>

referenced the auditing of patient medical records²⁰ as a time-consuming and labor-intensive, yet effective, way to assess documentation deficiencies. They also noted that QI coordinators use audit results as a tool for educating agency staff about requirements for compliance, as well as for monitoring both changes and improvements in documentation practices and compliance activities.

In answering the question “*What do you think about when you hear the term quality improvement?*” participants who defined QI as documentation to support compliance said:

Honestly I think about a lot of audits, monitoring, or documentation.

Nurse A

*I also think of just very practically adding a new question into your assessment (laughs). Yeah, obviously documentation is what it [QI] makes me think of in general. **Social Worker B***

*Also, we look at the standards that we have to follow for Medicare and JCAHO and to keep our certifications, or that kind of thing. **Nurse H***

And another buzz word I would say when I think about quality improvement is "compliance." Ensuring that you're compliant not only

²⁰ Medical record auditing is a quality improvement tool whereby one reviews a set of patient records in reference to a particular topic, for example, to verify correct use of coding schemas or adherence to agency policies and procedures. More complex audits can be used to ascertain whether particular clinical processes have been conducted or whether particular outcomes have been achieved. Goals of medical record audits can include identifying problems with documentation or care quality, as well demonstrating that such problems have decreased after improvement efforts have been implemented.

with external things like healthcare quality and Medicare and things like that, but compliant with your own standards that you have internally.

Director A

Once again, this theme of QI as documentation to support compliance overlaps that of QI as formal processes and is also intertwined with the meaning of QI as learning through staff educational opportunities. Yet this idea of QI as primarily associated with improvements in documentation, particularly to comply with regulatory, accreditation, or other agency-specific standards, came up repeatedly throughout the interviews. Thus, it merits recognition as a distinct meaning of QI. However, I do not view it as aligning with my own working definition of QI, although others might.

Theme 4: QI as “Doing Better”

A fourth meaning of QI, voiced by four participants (two social workers and two chaplains, through seven coded instances), reflects the somewhat amorphous (and even circular) idea of “doing better.” This conceptualization of QI, as described by these participants, reflects both optimism (i.e., it is possible to improve) and pragmatism (i.e., there is always room for improvement).

*Just always striving to do better. Yeah, I think we do an excellent job of caring here, but we could always do better. **Chaplain A***

*Areas which we could grow upon or improve. We always have room to grow. **Social Worker A***

How we can do our jobs better. How we can serve our patients more effectively. Social Worker C

Unlike previously discussed meanings of QI, this meaning, as expressed by participating social worker and chaplains, was curiously lacking in specificity. The connotation was continual improvement, although participants did not say this explicitly and did not offer evidence of actual improvement. Neither did they offer a comparator: while they implied improvement compared to the past, they did not specify a timeframe (e.g., better than last year or last month) or an object (e.g., better than a competitor or better than oneself). Similarly, except for Social Worker C, who referenced tasks associated with care or other aspects of the job, they did not explicitly discuss what could be done better. Nonetheless, I have chosen to highlight this meaning as a separate theme, rather than subsuming it elsewhere, because it reflects the ultimate goal of QI (i.e., care improvement), rather than focusing on the processes and activities of QI. Accordingly, this meaning is the second of three articulated by study participants that aligns with my working definition of QI when I began the study (i.e., systematic changes that result in improved structures, processes, and outcomes of care).

Theme 5: QI as Activities that Positively Impact Patients and Families

Finally, three participants (one nurse, one social worker, and one chaplain, through three coded instances) described QI as activities that ultimately lead to better care and better outcomes for patients and their families. This conceptualization is the third meaning articulated by study participants that aligns with my initial definition of QI.

Basically, improving the processes and, and the ways that things are done that will ultimately serve the customers better, or patients in this case.

Nurse B

*Quality improvement, what comes to my mind is, when I hear the term, it's finding or doing anything possible so that the life of the patient can improve....Improve here means in no way curing whatever symptom they have but improve, meaning, make that experience of living with illness a humane experience. **Chaplain H***

Although identified by only a small number of participants, this meaning of QI demonstrates that at least some hospice providers construed QI, at its most basic level, through the lens of the patient and family. Moreover, this conceptualization shows they did so in a very specific or concrete way, as opposed to more generally by “doing better” or “learning from mistakes.” Both of these meanings are agency- or staff-based, rather than patient-focused, and can occur without concomitant improvement in patient and family outcomes. This, of course, is not meant to imply that hospice providers do not keep patient and family outcomes in mind as they do their work. The fact that they do came through clearly throughout the interviews. But it does suggest that perhaps only a minority overtly link QI to better patient and family outcomes.

Meanings of QI by Provider Role and Agency Characteristics

Aim 6 of this dissertation sought to describe how study participants' meanings and perceptions of QI differ according to provider role (i.e., director, nurse, social worker, or chaplain) and agency characteristics (i.e., size, type, tax status, and locality). A key finding relating to that aim is that perceptions in this thematic area were associated with provider role but not with agency characteristics. Specific differences in meanings by provider role and agency characteristics are described more fully below.

Meanings of QI by provider role

The most striking differences in meanings of QI by provider role were those of directors compared to front-line staff (i.e., nurses, social workers, and chaplains). Directors, as a group, verbalized fewer meanings overall (three, compared to four verbalized by nurses and five by both social workers and chaplains). But more importantly, they verbalized a different set of meanings compared to those in other roles, as described below.

More directors identified QI as formal processes within the organization than did those in the other three roles. Each of the five agency directors in the study expressed this conceptualization of QI, via a total of 11 coded instances. In contrast, only two social workers, one nurse, and one chaplain verbalized this meaning of QI, through a total of five coded instances. QI as formal processes within an organization may be a particularly salient meaning of QI for directors, in part because some of the primary responsibilities of the director role include overseeing and approving organizational structures, procedures, and personnel.

Also, more directors than those in other roles viewed QI as learning. Three of the five agency directors viewed QI as learning, as evidenced through 7 of the 17 coded instances that reference learning. Conversely, only two social workers, one nurse, and one chaplain articulated this meaning of QI. Within this meaning of QI, the directors focused on the learning process itself, which they see as an ongoing activity, as well as on learning by staff that occurs through formalized processes of the agency. Two directors in this study explicitly referenced continuous learning as a salient, personal philosophy. It is therefore not surprising that these two informants, in particular, perceived this meaning (i.e., learning) of QI.

Although only six study participants described QI in terms of changes in documentation to support compliance, they portrayed this meaning of QI via 20 coded instances, making this the most frequently mentioned meaning of QI across all of the participants' narratives. However, only one agency director verbalized this meaning of QI. Four of the six participants who viewed QI in terms of documentation to support compliance were nurses and social workers, along with a single chaplain. The four nurses and social workers provided 17 of the 20 coded instances of this meaning of QI, indicating that this meaning of QI was particularly salient for individuals serving in these two roles. The significance of this meaning of QI for nurses and social workers could derive from occupants in these roles (particularly the nursing role) being more likely to bear the brunt in terms of medical record audits and requirements for compliance in their day-to-day activities.

None of the directors who participated in this study verbalized QI as “doing better.” Instead, this meaning of QI was articulated explicitly only by chaplains and social workers. Although the participating directors alluded to the concept of doing better later in their interviews, this did not appear to be a way that directors actually define QI.

Finally, none of the directors in this study verbalized QI as a tool for impacting patients and families. With only three participants expressing this meaning of QI overall, it is difficult to conclude whether or not the provider role is relevant for this theme. However, it is worth noting that the participants who held this meaning of QI (i.e., one nurse, social worker, and chaplain) spend a majority of their time in direct contact with patients and families, while agency directors typically do not. This “immediacy” with patients and families may explain, to some extent, why this meaning of QI was verbalized by front-line staff but not by agency directors.

Meanings of QI by agency characteristics

In contrast to the clear differences in meanings of QI by provider role, agency characteristics did not appear to be strongly linked to the meanings that study participants ascribe to QI. Two participants in four of the five participating agencies and one in the fifth agency discussed QI as formal processes within an organization, suggesting that it is a meaning that is unrelated to agency characteristics.

Similarly, at least one participant from four of the five agencies that participated in the study viewed QI as learning (specifically, by three participants from one agency, two from another, and one each from the remaining two agencies). The single agency

with no participants who verbalized this meaning of QI had no characteristics that were unique to the participating agencies.

The six participants who viewed QI as changes in documentation to support compliance were employed across four of the five participating agencies. While the agency without participants who verbalized this meaning differed from the others in terms of its profit status, there is no readily apparent rationale for a linkage between profit status and this meaning of QI. Of potential significance, however, the three individuals from that particular agency defined QI only in terms of formal processes and learning.

Participants from three of the five participating agencies (although not the same three agencies) described the remaining two meanings of QI (i.e., “doing better” and as activities that positively impact patients and families). Yet because these were the minority meanings in terms of both number of participants and frequency of coded instances, I could not draw reliable conclusions about how or why specific agency characteristics may be associated with the meanings of QI held by their employees.

Summary: The Multiple Meanings of QI

Addressing Aim 2 of the study, participants’ narratives in response to the question about what they think of when they hear the term “quality improvement” revealed five distinct meanings of QI. The most commonly verbalized meaning was that of *formalized processes and activities* undertaken by an agency’s QI department and its personnel. Study participants also defined QI as *learning*, both informally, through past experiences, as well as more formally, through educational activities engaged in by hospice staff. Some study participants defined QI much more narrowly, seeing it as *efforts to improve*

documentation of care, primarily for the purpose of meeting regulatory or accreditation requirements. For a minority of study participants, QI simply meant “*doing better.*” Finally, a few study participants overtly equated QI to *activities that result in better care and better outcomes* for patients and their families.

Addressing Aim 6 of the study, the narratives also indicated that study participants’ definitions of QI varied according to their role in the agency, but not according to characteristics of the agency in which they were employed. Directors overwhelmingly viewed QI in terms of formalized agency processes and as learning, while nurses and social workers were more apt to define QI in terms of activities geared toward documentation and compliance. Interestingly, agency directors collectively verbalized fewer meanings of QI than those in front-line role (i.e., nurses, social workers, and chaplains).

When initiating this study, I defined QI as *systematic changes that result in improved structures, processes, and outcomes of care*. However, the findings described above indicate that participating hospice providers, as a group, viewed QI more broadly, although their perceptions were likely shaped, at least in part, by their occupational roles.

Advantages and Disadvantages of Quality Improvement Efforts

Turning from the meanings of QI, I asked participants to share what they perceive as the advantages and disadvantages of QI efforts. This query provided another way to address the overall research question of how hospice providers view QI efforts, and, more specifically, to explore participants’ perceptions regarding the potential for improving quality of care near the end of life (Aim 2 of the study).

I often linked the two queries about advantages and disadvantages in one question (e.g., “*Can you talk about some advantages of those QI efforts, and then some disadvantages?*”), while at other times I first asked about advantages, provided an opportunity for participant responses, and then went on to ask about disadvantages. I did not qualify these questions by asking about advantages or disadvantages toward certain groups (e.g., patients), as I did not want to channel participants’ thoughts in any preconceived way. Although for the most part I did not have to rephrase the questions, I noticed that several participants seemed somewhat surprised that I would ask about potential disadvantages of QI efforts.

In response to these questions, 9 of the 19 participants verbalized advantages of QI efforts through 12 coded instances, while 12 verbalized disadvantages through 39 coded instances. Interestingly, although several participants initially said—when asked directly—that they could see no disadvantages to activities related to QI, they actually went on to describe at least one disadvantage as the discussion of this topic, and the interview, progressed. Four individuals who identified disadvantages were able to name more than two.

Only five participants verbalized both advantages and disadvantages. I had expected informants to mention several examples of each, but I now realize I should have asked all participants the two questions separately. This would have ensured they realized that the question had two parts. Combining the questions was intended to avoid signaling any particular expectations on my part. On balance, it is not clear whether the lack of discussion of both advantages and disadvantages of QI efforts by most of the

study participants is a noteworthy finding or simply an artifact of my interviewing approach.

Addressing Aim 2 of this study, key findings are that (1) participants voiced disadvantages of QI efforts substantially more often than advantages, and (2) many of the advantages and disadvantages of QI were viewed through a self-centric lens. When describing advantages of QI efforts, participants articulated specific benefits for hospice staff, hospice agencies, and patients and families. When describing disadvantages of QI efforts, participants primarily discussed organizational and staff-related issues, including negative staff emotions that can result from QI efforts. They also discussed the potential for counter-productivity of QI efforts. Each of these advantages and disadvantages of QI efforts, as described by study participants, is discussed more fully below, supported through quotations taken from the participant interviews. Addressing Aim 6 of this study, findings indicate that perceptions of advantages and disadvantages of QI efforts vary according to provider role, but are not linked to agency characteristics.

Theme 1: QI Benefits Staff, Agencies, and Patients and Families

Through 12 coded instances, nine study participants (four nurses, two directors, two chaplains, and one social worker) described advantages of QI efforts in terms those who benefit from those efforts. These beneficiaries include: (1) the hospice staff who provide care to patients, (2) the hospice agency itself, and (3) patients and families. Interestingly, only two of the nine participants (one director and one social worker) described QI efforts as beneficial for more than one of these groups.

Five of these nine participants (three nurses, one social worker, and one chaplain), via six coded instances, referenced benefits to the hospice staff. These participants viewed QI as advantageous to hospice care providers because it enables them to learn, and thus, to improve their own professional performance.

Everybody can improve... when those audits come out. We see where we messed up and I feel that's better in that sense...so, it's room to grow and learn, and improve in that aspect when you see where you made a mistake.

Nurse A

*I think advantages would be just wanting to do better, wanting to achieve a higher level. Because I think for the most part, the goal is that you want to be at your best, you want to be viewed as your best... **Social Worker H***

Three participants (two directors and one social worker) considered QI to be beneficial to the agency as a whole. These individuals expressed three distinct advantages of QI to hospice agencies. First, Director A described QI a way to help fulfill the mission of the agency.

*The advantage of QI is... ensuring that your organization is doing the best that they can and that we're meeting the needs of the community. **Director***

A

In contrast, Director B viewed QI as beneficial to agencies because it underscores the intrinsic importance of working to enhance care quality and serves as a tangible way to demonstrate the agency's commitment to providing high quality care.

*It keeps in front of all of us what we can do better, without beating ourselves up for not doing it as well as we could, and not shirking the responsibility to change that. **Director B***

Finally, Social Worker H viewed QI as a way to showcase agency performance, particularly to competing agencies.

*... you want to be viewed as your best. You want to be seen by the competition, well, we want to be like them. So just kind of being at the cutting edge, being looked at an example. **Social Worker H***

Notably, only two of the nine participants who described advantages of QI efforts in terms of its beneficiaries (a chaplain and a nurse) spoke of benefits to patients and families. Chaplain A focused on QI as a way to help to increase the ability of both patients and families to cope with impending death.

*The advantages would be, being able to help the patients and the families deal with this. Death is never easy. **Chaplain A***

Nurse E described QI as beneficial to patients, because it can result in better symptom management and better quality of life.

When you improve quality of these last days, I think the patients would be more comfortable. And that's what's important, you know, being comfortable, enjoying your daily living activities as long as possible. And that can be done with a good education and management. Nurse E

In the above quotation, Nurse E linked QI with the agency's educational and management functions, and thus provided additional context to explain the relationship between QI and patient-related benefit. Once again, however, the responses from both Chaplain A and Nurse E suggest a conflation between QI and quality of care, an issue that I will explore further in Chapter 7.

Two aspects of study participants' perceptions of the advantages of QI merit commentary. First is the overall range of entities that participants viewed as benefiting from QI efforts. Second is the relative strength of the self-centric viewpoint. I expected participants to speak primarily about advantages to patients and families, and, to a lesser extent, to hospice agencies. However, their view of QI efforts as advantageous to hospice staff was new to me. Moreover, the fact that more study participants verbalized QI efforts as beneficial to staff than as beneficial to patients and families was both surprising and striking.

Theme 2: QI Can Generate Negative Emotions in Staff and Become Counter-Productive

Twelve study participants (all five directors, three social workers, two nurses, and two chaplains) described disadvantages of QI efforts through 39 coded instances. As

noted earlier, interviewees articulated many more instances of disadvantages of QI than its advantages, although initially, some seemed surprised to be asked about disadvantages in the interview.

The disadvantages of QI discussed by participants centered primarily on two topics: 1) negative staff emotions, such as feelings of dread, fear, stress, or discouragement, and 2) the potential for counter-productivity, including both wasted effort and unintended deterioration in the quality of the care provided. These views were widespread, as at least one person from each provider role and each participating agency voiced these two types of disadvantages of QI.

QI efforts can generate negative emotions in hospice staff

A total of 10 participants in the study discussed a variety of negative emotions that can be engendered in hospice staff by QI activities. Six of these (three directors, two nurses, and one chaplain) noted that dread, anger, or even fear can result when the messaging or corrective activities associated with QI are, or are perceived to be, punitive in nature.

*... we had somebody in QI who was not the right match for the position, who made staff feel...they hated conversations about it, because it felt very punitive....I think that the way in which information is presented and the way that staff get the feedback is key...you can't make people feel bad about it, or they want to run from you, and they want to run from QI, and they want to run from any discussions about it. **Director C***

*It can be more on the negative side, and then that just sours the whole thing. I had a manager one time that presented it in a very negative tone, you know, you do this or this 'll happen. **Nurse H***

*I guess, often the dread or the fear that you have, you know, not fulfilling the QI assessments. You know... like when you make a mistake and...I guess the...terrible fear of the documentation sometimes. **Chaplain C***

Four of the 10 participants who linked QI efforts to negative staff emotions (two directors and two social workers) believed that QI can increase staff members' feelings of stress. This can happen when hospice staff perceive QI efforts as adding to an already-stressful and demanding workload.

*“Oh, don't forget to do this and don't forget to do that.”... It's just a stressful event. I mean, what we do is a little stressful at times anyway. So, when you're saying quality improvement, it's like oh, gosh, what else are you going to add to my plate? **Social Worker H***

Finally, two of the 10 participants who believed that QI efforts can spur negative emotions in hospice staff (one social worker and one nurse) saw QI efforts as potentially leading to feelings of discouragement. They expressed this idea of discouragement in two distinct ways. Nurse H referred to the feeling that is engendered when a desired change hasn't happened, and therefore directives have to be repeated.

I think...quality improvement can kind of knock you down, because a lot of times... if you've got somebody like our PI [performance improvement] nurse... you can feel a little bit discouraged. So, it's... all the way the message gets out there... yeah...it can be discouraging. Like I said, when you're being told "don't do this, do this," and you hear it over and over.

Nurse H

In contrast, Social Worker E discussed discouragement that happens when there is a perception that a particular problem cannot be improved upon (e.g., due to lack of resources).

*I would say that we have battles that we just haven't found the answer to yet. And they're the same old battles...you know, doesn't matter what agency it is...some of these things, it does not seem like there'll ever be resolution, so that's frustrating. **Social Worker E***

Once again, with their discussion of potential negative emotions that can result from QI efforts, study participants evidenced a self-centric focus in their perceptions of QI. Unlike my reaction to the inward focus that emerged during their discussions of the advantages of QI, this self-centric viewpoint regarding disadvantages of QI was not surprising. However, I expected study participants to discuss perceived (and actual) overwork that often comes with QI efforts. Instead, they clearly emphasized the negative emotions they sometimes associate with QI efforts. I believe this is an important finding from the study.

QI efforts can become counter-productive

Six study participants (two directors, two chaplains, one nurse, and one social worker) described several ways that QI can be—or become—counter-productive for hospice agencies and staff, as well as for patients and families. For example, Chaplain C cautioned against becoming too focused on the details of documentation and compliance, believing this could stifle holistic and individualized EOL care.

*That you be so obsessed with your statistics, because, I guess, you throw out a lot of the purpose, the meaning, the wholeness, the holistic approach when you just focus so much on the little details...When you become so concerned with documentation. **Chaplain C***

Three participants (a director, nurse, and social worker) described the organizational disadvantage caused by using hospice resources in activities that do not actually result in better care. They suggested that this can happen if QI efforts are not well-defined and well-managed.

Quality improvement doesn't do anything unless you're actually improving quality...you could set up a department...and then never do anything with it. Our challenge here is, how do you keep that moving, how do you keep that focus, and how do you keep...a positive approach to it? And how do you not have it become punitive, or micromanaging, or critical, in the sense of derogatory? [I]f you don't really think through

*what quality means for you as an organization, it can become something that isn't helpful. **Director B***

*The only disadvantage is if you're just beating one thing to death and not moving forward, to get tangled up in something that doesn't get you anywhere, so to speak. **Nurse H***

Social Worker C provided an example of this type of counter-productivity by referring to education or training efforts that are geared toward improvement but are actually ineffective.

*I would say the biggest disadvantage is they [hospice leadership] put you through these trainings because they've heard that this training is effective or that training is effective. But they've got no basis in knowing how to incorporate it into our populations that we're working with. **Social Worker C***

Importantly, three participants (a director, chaplain, and social worker) described an even more serious type of counter-productivity that can arise from QI efforts: unintentionally encouraging attitudes or actions that can lead to *poorer quality care* for patients and families. These informants provided three specific examples of this potential disadvantage, describing QI efforts that are particularly focused on compliance. For example, Chaplain B noted the inability to see more patients in a day due to the time required for documentation.

*[B]ecause of so many rules and regulations ...my paperwork limits me to four, on a good day five, patients, as opposed to in the hospital I could see 15 to 20, because you didn't have to do any regimented write-up of each patient...[M]y heart goes out to [the nurses] because I understand what they have to go through, when [you] have to sit down and do all this [typing on a] computer after finishing seeing your patients. **Chaplain B***

Social Worker C described use of computers to document care at the bedside as impeding rapport with patients.

*They talk to us about documentation all the time, about how to document and when to document, and their big thing is point of care documentation. I'm not doing it. To me that is totally uncompassionate. How are you ever supposed to develop rapport with somebody with a computer between you? I'm not going to put a wall between me and a patient that I'm trying to build a relationship with. **Social Worker C***

In the third example, Director C suggested that a QI effort focused on completing the required comprehensive assessment within five days may be interpreted as giving permission to wait the full five days to complete the various component assessments, even though taking that much time might not be good for the patient.

Now that we're trying to [have] a comprehensive assessment completed within five days,[that] has kind of given permission for that nursing assessment not to be completed for five days. Well, if you go out on

*admission and you evaluate pain, and then the nurse doesn't go out until day four, you don't have improvement on day three. **Director C***

Study participants' perceptions of QI as potentially counter-productive for themselves, hospice agencies, and most especially, for patients and families, is yet another mostly-unexpected finding from this study. I would not have been surprised if they had focused on time management difficulties or even the opportunity costs associated with specific QI activities. Instead, their emphasis on the potential for deterioration in the quality of care provided to patients and families signals the need for QI experts and others to consider these potential drawbacks when deciding on when and how to implement various QI efforts.

More than half of participants interviewed for this study described disadvantages of QI efforts, and they did so with more than three times the number of coded instances used to describe advantages. This occurred, even though, initially, several seemed surprised that I asked about disadvantages. Informants focused primarily on negative staff emotions and potential detriments in care that could result from certain QI efforts. The discourse related to negative staff emotions (dread, fear, stress, and discouragement) reflects a self-centric perspective (i.e., something that participants experience or observe in others). In contrast, participants' discussions of potential counter-productivity of QI, including declines in care quality, reflects a more outward-facing perception that is geared primarily toward patients and families.

Advantages and Disadvantages of QI by Provider Role and Agency Characteristics

In addressing Aim 6 of the study, I explored how perceptions of advantages and disadvantages of QI varied according to provider role (i.e., director, nurse, social worker, or chaplain) and agency characteristics (i.e., size, type, tax status, and locality). As seen with the meanings of QI perceived by study participants, a key finding from this set of themes is that perceptions of the advantages and disadvantages of QI were associated with provider role but not with agency characteristics. This is described more fully below.

Perceived Advantages and Disadvantages by Provider Role

Compared to those in other roles, more nurses in the study verbalized advantages of QI. While at least one participant from each provider role articulated such advantages, all four participating nurses did so. However, the advantages these nurses perceived were limited to those for patients, families, and hospice staff. In contrast, and unlike those in other roles, when answering specifically about advantages of QI, directors spoke only about advantages to the agency.

Compared to those in other roles, more agency directors and social workers in the study verbalized one or more disadvantages of QI. All five of the agency directors voiced disadvantages of QI, as did three of the participating social workers. In contrast, only two nurses and two chaplains discussed disadvantages of QI. Nonetheless, participants from each of the four provider roles discussed both negative staff emotions and possible counter-productivity as disadvantages of QI.

Perceived Advantages and Disadvantages by Agency Characteristics

There were no clear differences in perceptions of advantages or disadvantages of QI according to agency characteristics examined in this study. Multiple participants from four of the five participating agencies voiced advantages of QI. Only participants from Agency C failed to indicate any advantages. However, this agency lacked a participating nurse, and all other nurses in this study discussed advantages of QI.

Similarly, two to three participants from all five agencies voiced disadvantages of QI. Also, participants from all five agencies discussed both negative staff emotions and counter-productivity as disadvantages of QI.

Half of the 12 participants who named disadvantages of QI were employed by medium-sized hospice agencies, and their responses made up a majority of the statements related to disadvantages. Beyond this relatively higher number of instances of disadvantage being voiced by employees of from medium-sized agencies, there were no notable differences in responses linked to agency type.

Summary: The Advantages and Disadvantages of QI Efforts

Addressing Aim 2 of the study, participants verbalized both advantages and disadvantages of QI efforts. A key finding of the study is that more participants discussed disadvantages than advantages, and they did so through a substantially higher number of responses. This was somewhat unexpected, as one might expect a hesitancy to criticize aspects of their workplace to an outsider. However, these interviewees may simply be accustomed to discussing positive aspects of QI, and perceived an opportunity

to voice negative aspects. Nonetheless, this pattern likely reflects strongly-held and widely-shared reservations regarding QI efforts.

Regarding advantages of QI efforts, study participants described QI as beneficial for hospice staff, hospice agencies, and patients and families, in that order. Regarding disadvantages of QI efforts, study informants primarily emphasized negative staff emotions, including dread, anger, fear, stress, and discouragement. They also identified the potential for counter-productivity of QI efforts as a disadvantage of QI efforts. The concept of counter-productivity arose, in part, in participants' references to wasted effort and resources on the part of hospice agencies and staff, as well as actual declines in the quality of care provided to patients and families. A few participants also identified the time needed for QI efforts, as well as the challenges of communicating to staff about both changes in processes and the results of those changes, as disadvantages. The self-centric nature of informants' perceived advantages and disadvantages of QI efforts is a second key finding that addresses Aim 2 of this study.

Addressing Aim 6 of the study, participants' discussions of advantages and disadvantages of QI efforts suggest that, once again, perceptions of QI varied according to staff role, but were not linked to specific agency characteristics. More nurses were verbalized advantages of QI efforts than did participants in other roles, while more directors and social workers verbalized disadvantages of QI. The association with staff role was most evident with perceived advantages of QI efforts. Specifically, nurses discussed benefits of QI efforts to hospice staff and to patients and families, while directors spoke only about benefits to hospice agencies.

Internal Barriers and Facilitators of Quality Improvement Efforts

As a third way of addressing the overall research question of how hospice providers view QI efforts, I explored what study participants identify as barriers to, and facilitators of, QI efforts in the hospice setting. This line of inquiry also addresses Aim 2 of the study, which sought to identify and describe participants' perceptions regarding the potential for improving quality of care near the end of life.

To begin this dialogue, I asked study participants, typically through a single question, to describe "*the kinds of things that either help or hinder QI efforts in hospice.*" For the most part, they were able to answer this question as posed, although a few did not initially understand the question. For those individuals, I rephrased the question by using the terms "facilitators" and "barriers" in place of "help" and "hinder." For one person, I further defined the word "facilitator" as "things that make QI easier to do." These rephrasings were successful, as all were then able to address the question.

Overall, 16 of the 19 study participants verbalized at least one barrier or facilitator of QI efforts. Perhaps not surprisingly, more participants (n=16) were able to identify barriers than were able to identify facilitators (n=12). All 12 of the participants who identified facilitators also mentioned barriers during their interviews, and thus, none of the participants identified facilitators only. During the interviews, study participants verbalized a total of 39 coded instances of barriers, compared to 31 coded instances of facilitators.

As in a previous study of barriers to and facilitators of QI efforts in the hospice setting (Durham et al., 2011), participants verbalized both internal and external barriers to

QI efforts, as well as internal and external facilitators. By *internal*, I mean activities and attitudes that exist or operate within a particular hospice agency, such as various aspects of organizational culture and processes. *External* includes activities, attitudes, regulations, or organizations that exist or operate outside of an individual hospice agency.

Turning first to barriers to QI efforts, among the 16 participants who identified them, 14 identified internal barriers, while only seven identified external barriers. Similarly, of the 12 participants who identified facilitators of QI efforts, 11 identified internal facilitators, while only three identified external facilitators. Five participants (two directors, one nurse, one social worker, and one chaplain) identified both internal and external barriers to QI. Only two participants (one director and one social worker) identified both internal and external facilitators of QI.

Before delving into the findings in this area, three contextual notes are in order. First, when developing the question about barriers and facilitators of QI efforts, I did not distinguish between the actual work of hospices in *implementing the activities* of QI versus *achieving the goals* of QI, a distinction that informants nonetheless articulated in their responses. Moreover, when fielding the question, I did not specify which of these two concepts I was interested in, vis-à-vis barriers and facilitators. For the most part, study participants spoke about barriers and facilitators associated with conducting QI activities, although some participants also discussed barriers and facilitators of achieving successful QI (e.g., improved outcomes for patients and families). Second, although participants' responses to these questions were sometimes similar to those regarding advantages and disadvantages of QI efforts, I view these as distinct lines of inquiry and

have summarized the findings separately. Third, as a part of this study on perceptions of QI in the hospice setting, I wanted to understand participants' familiarity with external drivers to improve the quality of care near the end of life, and their perceptions of those drivers (Aim 3 of the study). However, after analyzing their narratives regarding external barriers and facilitators of QI efforts, I found that there was substantial overlap with their discussion of external drivers of QI efforts, particularly in areas related to regulations. Thus, in the remainder of this section, I have presented only the findings related to internal barriers and facilitators of QI efforts. I have described findings related to external barriers and facilitators of QI efforts, as well as the findings related to perceptions of the external drivers of QI efforts, in a subsequent section.

Fourteen study participants (all five directors, four social workers, three nurses, and two chaplains) identified internal *barriers* to QI efforts via 30 coded instances. Eleven participants (four directors, three nurses, three social workers, and one chaplain) identified internal *facilitators* of QI efforts via 27 coded instances. Thus, more study participants described internal barriers to QI efforts than internal facilitators of QI efforts. Addressing Aim 2 of the study, three themes captured participants' perceptions of internal barriers and facilitators of QI efforts. These included: (1) agency leadership's approaches to QI, (2) educational activities, and (3) staff attitudes. Often, although not always, participants discussed particular activities and attitudes as a barrier/facilitator "pair," with one aspect viewed as helpful to QI efforts and its opposite viewed as a hindrance. For example, as will be discussed shortly, several participants talked about the tone used by hospice leadership when communicating about QI efforts. Some of

these participants spoke about use of a positive tone as a facilitator of QI efforts, while others spoke about use of a negative tone as a barrier to QI efforts. Addressing Aim 6 of the study, participants' perceptions of internal barriers and facilitators of QI efforts were associated to some extent with provider role, but were not linked to agency characteristics.

Theme 1: Approaches to QI by Hospice Agency Leadership as Internal Barriers and Facilitators

Eleven study participants (four directors, three social workers, two nurses, and two chaplains), via 32 coded instances, identified various approaches to QI activities by hospice agency leadership as either internal barriers to, or facilitators of QI efforts. Their discourse primarily focused on: (1) staff involvement in QI efforts, (2) the tone that is used in communication about QI efforts, and (3) having a punitive mindset regarding QI efforts. Both the positive and negative dimensions of these items, when they occurred in participant narratives, are described below.

Staff involvement in QI efforts

Five of the eight participants who discussed approaches to QI by agency leadership (two social workers, one director, one nurse, and one chaplain), through 11 coded instances, pointed to staff involvement in QI as either an internal barrier to, or facilitator of QI efforts. First, three of these interviewees viewed QI efforts as supported when agency leadership values and includes the perspectives of front-line staff in the QI efforts of their agency. Specifically, Nurse B and Social Worker C suggested that front-line staff can help to identify quality issues that should be addressed by the agency.

*I think if they [agency leadership] would listen to staff a little bit more about issues that staff runs into, and can correlate it to improving the overall quality of care, I would think that would help greatly. **Social Worker C***

Likewise, Director C thought that QI efforts should not be limited to agency leaders or others specifically tasked with QI as a key responsibility. Instead, leaders should actively include front-line staff in hands-on improvement activities. This director suggested that such inclusions would encourage learning and acceptance of change, as well as provide a means of building rapport among interdisciplinary team members.

*I think involving the frontline people is also key, not only to their learning in an accepting environment...But it's kind of participatory, it's part of that whole team concept that we're supposed to be. I think the more frontline staff you can involve in the auditing is both educational and gives you a better outcome in the end. **Director C***

Stating this same point in reverse, Nurse B indicated that not listening to staff ideas (a type of staff *non-involvement*) is a barrier to QI efforts. This perception from Nurse B emerged through a discussion of staff members' self-initiated QI activities and the support of those activities by their fellow team members.

They [front-line staff] are very supportive. And they know that I'll listen, I listen to their ideas. [One colleague] had mentioned that, once before that it had come up, she'd given her input, and nobody listened to her. I was

like, well, I'm asking for your input because I really respect your thoughts.

Nurse B

Another staff-related internal barrier to QI efforts identified by study participants is having too few front-line staff overall. This barrier was verbalized by two social workers and one chaplain.

*I think sometimes there's a lot of hurdles that have to be jumped through to say that you've done quality improvement. But I think when we have less patients, we're able to do a better job. When we're able to have that individualized time with them and really get to know them. **Social Worker***

C

What can be a danger to the quality of care is the shortage of staff members, when you have not enough staff caring for the patient.

*Somewhere people will just be checking boxes. **Chaplain H***

Note that the above quotations again illustrate what seems to be a conflation between *providing* high-quality care to patients with efforts to *improve* the quality of care that is provided. Interestingly, two of the interviewees who identified staff shortages as a barrier to QI efforts were employed by an agency that had experienced substantial staff turnover and shortages near the time of the interviews. However, participants from another agency with similar staffing shortages did not explicitly identify having too few staff as a barrier to QI. Nevertheless, some participants at that site discussed increasing staff numbers as a way to improve quality of care within their agency. Interestingly,

none of the interviewees explicitly identified having adequate numbers of front-line staff as a *facilitator* of QI efforts.

Tone used in communications

Four participants identified the tone that is used in communications to agency staff about QI processes and feedback as either a barrier to, or a facilitator of internal QI efforts. Through four coded instances, two directors and one nurse identified the use of a negative tone as a barrier. These participants discussed the interplay between agency leadership (i.e., senior leadership, QI leadership, or both) and front-line staff.

The way the message is portrayed. I would say that is the number one [barrier], just having seen good and bad examples over time....[Y]ou can't make people feel bad about it or they want to run from you, and they want to run from QI, and they want to run from any discussions about it.

Director C

*It's all in how the message is sent and perceived, and perception, as you know, is reality. So, I think it's always got to be on a positive light. This is where we want to get, so in order, it's got to be kept in a positive type of tone. [I]f the message is received in a negative way, then people just shut down and get pissed. **Nurse H***

Conversely, in four coded instances, three participants (one director, one nurse, and one social worker) identified the use of a positive tone in QI communications as a facilitator of QI efforts. Director C and Nurse H specifically contrasted positive

messaging that can facilitate QI efforts with negative messaging that hinders those efforts, as shown in the quotations above. In describing positive tone in communications as a facilitator, these participants alluded to communications that (1) explain, in a positive way, why particular QI efforts are being implemented, and (2) offer feedback on mistakes that is constructive in nature. Social Worker H also intimated that a more positive tone could ameliorate staff frustration with QI efforts.

*Say if there is something that's not done correctly, you get a nice e-mail, not a negative e-mail...I think if you can kind of give an example and how it's addressed, I think, just kind of how you give out the information, you'll probably get a better result. **Social Worker H***

Interestingly, the topic of tone in communications directed toward agency staff also emerged in the discussion of advantages and disadvantages of QI efforts, although the focus of that narrative was the impact of tone on staff emotions.

Punitive mindset

Three participants specifically spoke about a punitive mindset on the part of agency leadership as a barrier to QI efforts. In the following quotation, Director H articulated two ways in which agency leadership displays a punitive mindset: (1) by “policing” staff and assigning blame (whether real or perceived) and (2) exacerbating, rather than alleviating, a dysfunctional view of QI by agency staff.

If you look at QI in an adversarial way, that can hinder. PIs [performance improvement coordinators] are a truly valuable component to an

*organization, but they tend to be sort of “the cop on the beat.” So, when the cop’s around, “Shhh, quiet, look who’s here.” Proper leadership, it can either make it worse or make it better. If you have the leader of the organization reinforcing the negatives, and everybody sees it as a negative, then improvement becomes all the more difficult, because no one’s seeing it as an opportunity. They’re seeing it as just another rock that’s tossed at them, and they resent it. **Director H***

Thus, this director viewed a punitive mindset on the part of hospice agency leadership as a barrier to QI efforts because it promotes a negative connotation of QI among hospice agency staff.

More specifically, both the director and the chaplain from Agency E blamed a punitive mindset on the part of agency leadership for failure in the reporting of adverse events. These participants saw a punitive mindset as a barrier to QI efforts because it promotes a lack of transparency, which makes it harder to identify where care should be improved.

Certainly a hindrance is the potential that it [QI activities] could be punitive. And what happens with that is, adverse events don’t get put in [by agency staff], and the organization does not get the clear picture [of what is really happening]. I need pure adverse event reporting. I tell them that we need to look at that so we know where to support. No one’s getting

*called out, it's just to make us a better organization. So please, if it's an adverse event, put it in. **Director E***

*Lack of transparency [in the] process, you know, in a company, if somebody's trying to hide something then, then that would hinder the QI process. **Chaplain E***

Notably, only Director E explicitly identified the converse of a punitive mindset as facilitator of QI efforts, although arguably it was implicit in the discourse regarding positive tone in communication by agency leadership.

*I think helping the QI efforts are just to put it out there. It's not the vice principal's office, it's not punitive, it's something we have ongoing in the organization, so just to make it part of our fabric and what we stand for, and that is to always get better. **Director E***

Other approaches to QI efforts by agency leadership

While discussed by a minority of participants, a few additional approaches to QI by agency leadership as barriers or facilitators of QI bear mentioning. For example, Director B saw the lack of integration and collaboration between the QI department and other departments within the agency as a hindrance to QI.

[Another] hindrance of it would be not connecting. If quality is an isolated department and isn't interfacing with the other departments. You

know, “we’ve got a problem here, go fix it”... “Clinical team, you really screwed up here, fix it.” **Director B**

Social Worker E described “going overboard” on certain activities as a barrier to QI, even if such activities are important to overall quality of care. This participant described a requirement for discussing, at each patient visit, evacuation processes in the event of an emergency.

...everybody has to now put it in their documentation, every single time you meet somebody, that you discussed evacuation. So that kind of thing, I think, gets in the way of what the whole purpose of quality improvement is. It becomes... just something more to do. Now, obviously, evacuating hospice patients is important. But...it does not need to be in every repetitive documentation. Because after a while, you stop wanting to document what needs to be documented. You’re too busy checking off the boxes and making the organization happy. **Social Worker E**

Finally, Directors B and E referenced specific attitudes held by hospice leadership about QI more broadly as either a barrier to, or facilitator of QI efforts. Both noted that QI efforts are helped when QI is perceived as a core value of the organization, one that is seamlessly woven into everyday operations of the agency in a non-punitive way.

I think holding it [quality improvement] out as a core value. And holding it out as an integral part of the organization. And that it is what helps inform education... so if we’re just educating and we’re not informed by

*the quality areas that we need to pay attention to, well those should feed each other. **Director B***

Director B also contrasted the view of QI as a short-term exercise (i.e., a barrier to QI efforts), rather than a continuous and dynamic process that must be well-defined, coordinated, and reinforced.

Barriers are if you think of it only as “fix it and you’re done.” You know, a fix-it program. That doesn’t get you very far. [Another] hindrance is if it’s [QI] not well-defined and continually reinforced with a philosophy and approach that is more fluid and ongoing and productive in nature.

Director B

As demonstrated above, study participants identified various aspects of organizational culture that are shaped by agency leadership as barriers to, and facilitators of QI. They considered certain approaches to QI by agency leaders to either help or hinder QI efforts, depending on how those efforts are put into practice. This was particularly apparent in the discussion of the tone used in communications with agency staff about QI efforts, in that participants highlighted a negative tone as a barrier but a positive tone as a facilitator. Finally, although the concept regarding a punitive mindset emerged as a distinct idea in the relevant discussions, and is thus discussed separately above, it is intertwined with the concept of tone in communication about QI efforts.

Theme 2: Educational Activities as Internal Barriers and Facilitators

When responding to my question about the things that either help or hinder QI efforts in hospice, a total of seven study participants, via 16 coded instances, identified various educational activities as internal barriers to, or facilitators of QI efforts. Through four coded instances, three study participants (all social workers) identified educational activities as internal barriers to QI efforts, while six study participants (two directors, two social workers, one nurse, and one chaplain) identified educational activities as internal facilitators of QI through 12 coded instances. Although six of the seven participants focused on education *received* by hospice staff, one discussed education *provided* by agency staff that is geared toward both caregivers and physicians.

Educational activities as barriers to QI efforts

Of the three social workers who identified educational activities as an internal barrier to QI efforts, two focused on inconsistent and ineffective training. When asked what kinds of things might hinder QI in hospice, Social Worker H said:

*Lack of training, like an actual training manual. So, if you're having folks trained without a manual, you're going to train me, [then] someone else is going to start [and] someone else is going to train that person. So just consistency, just having a formal training program. So that everyone's learning the same things. **Social Worker H***

Social Worker C described ineffective training as either perfunctory or irrelevant to the work at hand, which then may be easily ignored. This participant alluded to training that is provided via a computer video as an example.

*Pointless trainings that you can't correlate into your day-to-day work [can hinder QI]. Just kind of distract from what we really need to be doing, I feel like....A QI person brings the computer and then you watch it [a training video] on the internet. But I don't think that there's a whole lot of paying attention that goes on. **Social Worker C***

In contrast, the third social worker discussed the failure of staff educational efforts to clearly articulate the connection between particular QI efforts and how those activities can improve care quality.

I think how the education is rolled out around any issue [matters for QI]. And [this education is] always bringing whatever the issue is, back to how it is actually gonna improve our quality of care. Because I feel like sometimes that does get lost in the rollout of some things, that there is a reason we're doing this. It's not just to make things harder for you and it's not just for those surveyors. It's really about the patients and families.

Social Worker B

Educational activities as facilitators of QI efforts

When discussing educational activities as a facilitator of QI efforts, some of the participants' dialogue centered explicitly on how staff education and training could

support QI activities in the hospice setting. For example, Chaplain E noted that educational efforts can help staff understand how to look for opportunities for improvement and how to contribute to QI efforts.

*... if we could have good education [on] how to look for QI, how to contribute our efforts into QI, I think that would be a big help. **Chaplain E***

As noted earlier, when discussing inconsistent and ineffective training as a barrier to QI efforts, participants referred to a wide variety of training and educational activities, from in-person sessions conducted by the agencies' QI staff to "pre-packaged" training videos and the like. As part of their discussion, participants also pointed to a good orientation curriculum that is comprehensive, yet not overwhelming, and ongoing training that imparts up-to-date best practices.

*I guess the other thing is that affects quality [improvement] is a good strong orientation. And we have swung the pendulum in both directions. We started to make our orientation so long and so laborious, trying to cover so much, that we made it almost impossible for people to absorb that information...and part-timers, they could never complete it. Then we cut it down to the point where people weren't getting enough. **Director C***

I think training needs to be continual. Because with any discipline, things are always changing, new things always coming out, oh this is a better way to do this...So I just think that training is key. If you don't train your

*people, they're not going to stay up-to-date with the latest. **Social Worker***

H

Finally, one nurse also considered the education *provided* by hospice staff to families, caregivers, and physicians, to be an internal facilitator of QI efforts. Specifically, Nurse E alluded to the provision of information to the family or other informal caregivers about the probable outcomes of treatment choices, as well as explaining to physicians what hospice can offer.

*I think to educate caregivers, the family members, as to what is real and what would be the outcome of each of those processes they want to proceed with. I think education is critical for them to understand the reality of the situation. I think a lot of physicians need education also regarding hospice care. And some old-timers [physicians], they won't accept it [the utility of hospice care]. **Nurse E***

This idea of educating physicians about the value of hospice also came up later in the interviews as a way of increasing access to hospice care, which some of the participants viewed as a way to improve the quality of EOL care more broadly.

As described above, study participants more often viewed educational activities as facilitators of QI efforts, although some also saw them as potential barriers. For the most part, participants discussed educational activities in terms of specific *content* that is offered to agency staff. For example, they viewed content that is inconsistent or unhelpful as hindering QI efforts, but saw content that is comprehensive, up-to-date, and

relevant as helpful to QI efforts. These discussions reflect earlier findings. For example, the failure to “connect the dots” from a particular QI effort to its intended improvement result reflects a perceived deficiency in staff education. But such a deficiency also pertains to agency and leadership communication, although this time in relation to content, rather than tone. Similarly, participants’ views of education as a conduit that facilitates agency staff’s ability to identify improvement opportunities and contribute to QI efforts links to the previously-discussed idea of staff involvement as a facilitator of QI efforts. The role of education in hospice QI efforts emerged in various ways throughout the interviews; I will explore this concept more fully in Chapter 7.

Theme 3: Staff Attitudes as Internal Barriers and Facilitators

Five study participants, through 7 coded instances, identified various staff attitudes as either internal barriers to, or facilitators of QI efforts. Four participants (two nurses and two social workers) discussed staff attitudes as barriers to QI efforts, while one nurse and one chaplain discussed them as facilitators. Only one nurse identified staff attitudes as both barriers and facilitators.

The four interviewees who identified staff attitudes as a barrier to QI efforts spoke specifically about attitudes toward change. Lack of openness to change may be an especially salient barrier to QI efforts, given that QI is, by definition, change. Two of these participants intimated that disgruntled workers are less open to change, and that other workers are particularly sensitive to change.

*There's some nurses that kind of have a chip on their shoulder and may not want to learn, and they know that their way's the right way...[N]ot everybody's as open to change and learning, and if there's a new way to document something, some nurses might not want to change the way she's done it for 30, 25 years, or whatever. [T]he wrong personality is not going to want to change to better the situation. **Nurse A***

*People's attitudes...people's feeling about change. I think we, as a people, don't like change. I know I used to be that way and, ever since working in hospice, I have a whole different view on pretty much everything. **Nurse B***

On the flip side, Nurse B also viewed “good” attitudes of staff to be a facilitator of QI efforts, believing that those with positive attitudes are more open to QI efforts.

*I think if you have good attitudes you have a better chance of people accepting “let's try this.” **Nurse B***

Chaplain E pointed more specifically to the attitude of willingness to learn from mistakes as a facilitator of QI efforts.

...not avoid the mistakes that we have made, face it and work as a team and come up with concrete steps in how to improve the care and not to make the same mistakes again....The openness, transparency to accept the mistakes that we have made is very important in [the] QI process. So that

that attitude would be something that could help with the QI process.

Chaplain E

As demonstrated above, study participants identified attitudes of hospice staff as both barriers to, and facilitators of QI efforts. Lack of openness to change on the part of agency staff emerged as a key internal barrier to QI efforts, while staff positivity, openness, and willingness to learn from mistakes emerged as key facilitators of QI efforts.

Internal Barriers and Facilitators by Role and Agency Characteristics

As noted previously, Aim 6 of this study sought to describe whether and how participants' meanings and perceptions of QI vary according to provider role (i.e., director, nurse, social worker, or chaplain) and/or agency characteristics (i.e., size, type, tax status, and locality). As another way to address this aim, I explored how study participants' perceptions of barriers to, and facilitators of QI efforts varied according to these characteristics.

Based on findings summarized above, it appears that perceptions related to barriers and facilitators of QI efforts were associated with provider role, with stronger associations for barriers than for facilitators. In contrast, there were no clear associations between agency characteristics and study participants' perceptions of barriers and facilitators. These differences are described more fully below.

Perceived barriers and facilitators by provider role

Provider role appeared to be somewhat associated with participants' responses regarding internal barriers to QI efforts, although this was primarily with respect to the types of barriers they perceived. Only three nurses and two chaplains identified internal barriers, although four social workers and five directors did so. Regarding the type of barriers, four of the five directors identified approaches to QI by hospice agency leadership as internal barriers to QI efforts, compared with only three social workers, two chaplains, and two nurses. Moreover, participating directors referred to these barriers in substantially more coded instances than did those in other roles (n=11, compared to three each by those in other roles). Yet only social workers identified educational activities as internal barriers to QI efforts, and only social workers and nurses identified staff attitudes as internal barriers to QI efforts.

There also appeared to be modest differences across provider roles in responses regarding internal facilitators of QI efforts. Four of the five directors who participated in this study identified facilitators of QI efforts through 13 coded instances. In contrast, only three nurses, three social workers, and one chaplain identified internal facilitators through a total of 14 coded instances. As with barriers to QI efforts, more directors perceived attitudes and activities of hospice agency leadership as internal facilitators of QI than did those in other. Specifically, three directors identified these as facilitators via seven coded instances, compared to only two nurses via two coded instances, and two social workers via three coded instances. However, provider role did not appear to be associated with the identification of the other internal facilitators of QI efforts (i.e.,

educational activities or staff attitudes), except that relatively fewer chaplains identified these types of facilitators. The above findings support the conclusion that study participants' perceptions of barriers to, and facilitators of QI efforts differed according to provider role.

Perceived barriers and facilitators by agency characteristics

There did not appear to be strong associations between perceptions of internal barriers to, and facilitators of QI efforts and agency characteristics. Findings indicate that at least three participants from three of the five participating agencies identified internal barriers to QI efforts, although only two participants from Agency A (the smallest participating) agency did so. The pattern was similar in terms of internal facilitators. For the most part, there were no other discernible patterns according to type of barrier or facilitator, other than staff attitudes, which were not named by any participants from Agency C. However, characteristics of this agency were shared with other participating agencies in terms of size, type, tax status, and locality. The only noteworthy finding in terms of differences linked to agency characteristics was that individuals from Agency A articulated fewer coded instances of either barriers or facilitators overall, compared to participants from other agencies. Because this was the first site in which I interviewed, my inexperience with interviewing may have contributed to this result.

Summary: Internal Barriers and Facilitators of QI Efforts

Addressing Aim 2 of the study, when study participants responded to my question about the things they believe either help or hinder QI efforts in hospice, they identified more barriers than facilitators. They also differentiated between internal versus external

barriers and facilitators. The narrative discourse regarding external barriers of QI efforts was similar to the discussion of external drivers of QI efforts later in the interviews. Thus, this section focused on findings regarding their perceptions of internal barriers to, and facilitators of QI efforts. Three overall themes emerged that reflect participants' views of internal barriers and facilitators. These included various activities and attitudes of agency leadership, educational activities of the agency, and staff attitudes. Yet whether aspects of these three overarching concepts are viewed by study participants as barriers or facilitators depends on how they are implemented within the hospice agency. Overall, participants were more apt to perceive educational activities as facilitating QI efforts. But the reverse was true for the themes of leadership approaches to QI efforts, where discussion of barriers outweighed facilitators.

It is worth noting that I expected many study participants to identify electronic medical records (EMRs) as a key barrier to QI efforts, given that they have been the subject of study and published literature on barriers and facilitators of QI in the hospice setting. However, only Director A spoke about EMRs in this context. This participant noted that hospice-specific EMR systems make it time-intensive to document the care that is provided, but also recognized their utility in QI activities by supporting continuity of care. Thus, what is most interesting about EMRs vis-à-vis helping or hindering QI efforts is that they did not emerge as a major theme in this study.

Finally, addressing Aim 6 of the study, once again, provider role was associated, at least to some extent, with participants' perceptions of internal barriers to, and

facilitators of QI efforts. However, there was no clear linkage between these perceptions and agency characteristics.

Influences on Positive/Negative Views of Quality Improvement Efforts

As has been discussed above, Aim 2 of this study focused on how participating hospice staff perceive the potential for improving care near the end of life. Two interview questions generated responses regarding participants' perceptions of this potential, as well as their positive and/or negative views of QI efforts more broadly. Specifically, I asked study participants the question, "*What has influenced your thinking about quality improvement?*" Also, after discussing what they perceive as the advantages and disadvantages of QI, I asked whether their views of QI had changed over time, and if so, what factors had contributed to the change(s) in their perceptions ("*Would you say that you've always felt this way, or have your perceptions changed over time?*")." If they answered "yes," I followed with "*What has contributed to this change in your in perceptions?*" I was interested in factors that participants thought had influenced their current views about QI, although I did not state this directly in the first question. Similarly, for the follow-up question, I was interested in changes in their perceptions of QI efforts up to the current time. Participants' responses indicated that they understood these in the intended ways. While these questions represented two distinct lines of inquiry, the themes that emerged from them overlapped substantially, and thus I have summarized them jointly in this section.

Fourteen of the 19 study participants (four directors, four nurses, three social workers, and three chaplains) discussed, via 14 coded instances, factors that have

influenced their current perceptions of QI. Through an additional 11 coded instances, 9 participants (four directors, three nurses, and two social workers) discussed how and why their perceptions of QI had evolved over time. Again addressing Aim 2 of the study, these participants articulated two main factors that have influenced their current assessment of QI: (1) previous experiences with QI efforts, and (2) personal or professional maturation. Moreover, among those who described an evolution in their perceptions regarding QI efforts, the shift was uniformly toward a more positive view. Pertaining to Aim 6 of the study, it is clear that factors influencing positive or negative views of QI are associated with provider role. However, consistent with the majority of findings, these factors do not appear to be linked to agency characteristics.

Theme 1: Previous Experience with QI Efforts Shapes Current Perceptions of QI

Through 14 coded instances, 11 participants (all four nurses, three social workers, three chaplains, and one director) described their previous experience with QI efforts as influential in shaping their current perceptions. This is, therefore, the factor most frequently identified in terms of influencing study participants' current perceptions. This theme of prior experience also emerged in three of the 14 coded instances wherein participants discussed how their perceptions have evolved. For the most part, these interviewees discussed previous experiences with QI efforts that took place in the hospice setting, although at least one harkened back to experiences in a different care setting.

They primarily described their previous influential experiences with QI by either providing (1) examples of specific QI activities in which they had engaged, or (2) examples of what they viewed as positive results from QI efforts. Most of these

participants portrayed a positive perception of QI efforts. However, those who described QI activities that centered on changes in documentation portrayed a relatively negative view of QI efforts.

Prior QI activities can generate positive or negative views of QI efforts

Three participants, via 5 coded instances, viewed their contemporary perceptions of QI as rooted in previous QI activities in which they participated. These responses appeared in three statements by one nurse, and in additional references by a chaplain and a social worker. For all three, their underlying narrative connoted a positive perception of QI. For example, Nurse B first spoke about a well-received innovation designed to enhance efficiencies for hospice nurses who visit patients in their homes on weekends (i.e., “runners”).

*When you're out there doing things, you know, you see that, oh, this could be done differently. ...Here's a good example...Phone calls [i.e., those made to check-in with patients] are not made by the runners [weekend nurse who isn't a case manager] anymore. [They are] made by us in the office. Because...of the weather in Maryland...[while making calls in the car], runners either run AC or heat. Either way, they are wasting gas. They are just sitting in their car to make calls, or driving out of their way to come here just to make phone calls, and that doesn't make sense. Yeah...all the runners are happy with it, everyone's happy with it, because nobody likes to make phone calls in their car. **Nurse B***

Nurse B then went on to talk about QI as a dynamic process that, in itself, can improve over time.

*There's always going to be somebody who's not going to like it [QI]. You're never going to make everybody happy. But I think I've learned over the years that yeah... at least give it [a particular QI effort] a shot, and then you can always tweak things as you go along. It's trial and error. **Nurse B***

Social Worker A harkened back to a job in a different care setting. This participant's view of QI, which included ideas related to teamwork, regularity, a fixed objective, and the resulting work product, stemmed directly from those earlier experiences.

*In my last job, we used to have to meet each month for QI, and we would review data, and come up with a plan to either improve or expand, so that's how I view it [QI]. **Social Worker A***

However, four participants (two social workers and two chaplains) called out a particular type of previous experience with QI as influencing their current views of QI: improvement efforts that focused on documentation. Unlike those discussed previously, these study participants portrayed a negative perception of QI. For example, Chaplain B pointed to requirements for timeliness of documentation, which must be met to comply with accreditation standards, as negatively impacting the number of patients who can be served in a typical day.

But we're obstructed because of the paperwork and the deadlines. You used to be able to...you had 24 hours to complete your paperwork. If that were the case, I could see seven, eight patients a day. But now you have to complete your paperwork two hours after your visit. And if you don't, then the agency gets dinged. So, I have to limit my patients, you know?

Chaplain B

Social Worker H spoke about payment penalties that are levied against hospice agencies when documentation is inadequate.

It's basically... if you don't have your documentation, they [Medicare/CMS] take back money. We've all been told that we leave all this money out there because certain things aren't done. So...if you don't document correctly, and dot your I's and cross your T's...they're going to go through with a fine-tooth comb, and kind of ding you on things.

Social Worker H

Social Worker B expressed concern about changes in documentation without concomitant change in the quality of care.

I guess if I felt it [changes in documentation] ever translated to...actually doing something radically different..., I would feel like there's more value to it. But I find very often it's not that I'm doing anything different, it's that I'm writing about it differently. That there's a new assessment

*screen, that I'm checking a new box that wasn't there before. That's how it normally feels. **Social Worker B***

Finally, in perhaps one of the most interesting responses to the questions on factors influencing perceptions of QI efforts, Chaplain C described having “see-sawing” perceptions of QI that vary depending on the specific outcome of the QI effort. This participant portrayed a generally negative view of QI when discussing the burden associated with QI efforts that focus on documentation. Yet Chaplain C also credited the spiritual assessment, which is required as part of federal quality measurement activities, as helping to solidify the chaplaincy role in the hospice setting. In describing this more fluid view of QI efforts related to documentation, this chaplain said,

*I guess the seesaw that I've shared with you. You know, the forest and the trees, you know? How obsessive do we become with our documentation? On the other hand, I thank God I have that spiritual assessment, even with my questions about it, because that's the only way that chaplains have so much support in hospice system. So...I go back and forth. **Chaplain C***

Experiencing positive results of QI efforts generates positive perceptions of QI

Five participants (three nurses, one social worker, and one director), via one coded instance each, spoke about the positive results they have witnessed from QI efforts, and how these have influenced their current, fairly positive perceptions of QI. For example, the results of medical record audits have colored Nurse A's perceptions of QI efforts. This participant spoke about the utility of these audits, because they can

illuminate deficiencies in care quality. By extension, this participant viewed QI auditing activities as helping to pinpoint where improvement activities are needed.

When audits come out, it shows us what, where we need to improve.

Nurse A

In contrast, the other two nurses in this group pointed to their interactions with patients, and what such interactions can teach them, as having influenced their current perceptions of QI.

I think, you know, with each patient you learn what is real quality, you know, what you read in the books is one thing, but what you see in real life is a totally different thing. Nurse E

Well, I mean just by, you know, patient care, what works, what doesn't work, what, you know, trying to do the best, best thing for each and every patient. That's the bottom line [for QI], in my view anyway. Nurse H

Although clearly responding to questions about QI, the answers from these two participants seem, once again, to reflect perceptions about quality of care rather than, or perhaps in addition to, perceptions about QI, a subject that I will discuss further in Chapter 7.

The social worker who referenced positive results of QI described them in broader terms than audit results or patient outcomes, although this participant was not particularly explicit about what these positive results entailed.

*Well, originally, you know, again, 20 years ago, I would have been telling you it [QI] is just a big pain in the butt, that they have to have these meetings, and we have to whatever, QAPI [Quality Assurance and Performance Improvement], yadda yadda, yadda. But if you can get better practice out of it, then it really does serve its purpose. If it's really just there because Medicare demands it, or you know, the agency, and this is what we do, then it's a waste of time. But if you can get something accomplished from it, changes that need to be made [then QI is worthwhile]. **Social Worker E***

Finally, the director who discussed positive results of QI spoke about improved communication between patients and agency staff as an outcome of adverse event reporting. Specifically, Director E viewed adverse event reporting as a QI activity that drives necessary and constructive conversations with patients and families, which itself was perceived as an improvement in care.

*What I've discovered through adverse event reporting and just talking with families, in a very open and honest conversation where I'm here to listen. Help me, tell me what I need to know to make us better. **Director E***

Overall, previous experiences with QI, including specific activities and outcomes of QI efforts, were the central factor that study participants identified as influencing their current perceptions of QI. For these participants, QI experiences related to documentation yielded a primarily negative perception of QI.

Interestingly, one participant revealed a mixed perception of QI, seeing both positive and negative aspects of required documentation.

Theme 2: Personal and Professional Maturation Generates Positive Views of QI

Their own maturation, both personal and professional, was the second most frequently referenced factor that promoted a positive view of QI among study participants. This theme was discussed by six of the study participants. For all six, their perceptions of QI have changed from less to more positive over time.

Two nurses, each with one coded instance, described personal maturity as having swayed their assessment of QI toward a more positive view. Nurse A couched this idea in terms of an increased willingness to learn, while Nurse H described it as fostering an evolving openness to the QI enterprise.

*I know that when I was younger, I used to be like just like any young person; you know everything, and you're perfect, and you didn't make a mistake. And I can remember back then I would think, even in nursing school, like, "I was right. I don't care what she said." But now it's like, "Nope. I messed up, and thank you for showing me and I'll do better next time." **Nurse A***

*Well, I think I'm more open to it [QI], you know...it can be discouraging...when you're being told "don't do this, do this," and you hear it over and over. I try not to do that anymore. **Nurse H***

In contrast, four of the five participating directors, each with one coded instance, described their own professional growth as having positively influenced their perceptions about QI efforts. These directors attributed expansion in their job responsibilities as they advanced in their careers to the director role as an impetus for changes in their perceptions of QI, which included an increased awareness of the importance of QI. More specifically, these directors indicated that they currently viewed QI in a broader or more comprehensive way compared to how they evaluated it earlier in their careers.

The more I've taken on higher level areas of responsibility and more comprehensive responsibility, the more I've, I guess, appreciated the importance and need to stay on top of that [QI]. **Director B**

Two of the directors contrasted their current perceptions of QI to earlier, narrower views. In those past views, they saw QI only in terms of how it affected their workload or their own specific responsibilities.

When I was... right out of school I didn't think of it as important. And I think when you're hands-on... the quality that you think about is, "Is my patient comfortable? Am I managing their symptoms?" ...But then when you're a director, it's so much more global. When I think of quality now, I have to think about every aspect of our organization. It's so much broader.

Director A

I think there's been a maturation of my perceptions. You know, as you, as you grow in responsibility, your field of vision expands. So, I think when

*we start off, we're much more limited in terms of our areas of responsibility. And then you see everything as affecting that one area and it's either an aid in achieving your job or some sort of impedance, right? So more often than not, people tend to see it as like oh, just another thing I have to do. **Director H***

Although one would assume that these nurses and directors have matured both personally *and* professionally over the years, the nurses focused their discussion on their personal maturity as driving positive perceptions of QI, while the directors focused on their professional growth.

Additional Factors that Influence Views of QI among Agency Directors

Four of the agency directors briefly described two other factors as having influenced their perceptions of QI, which were not noted by staff in other work roles. First, Directors A and E, through three coded instances, pointed to Medicare's quality measurement policy (i.e., the quality measures that are used in the CMS Hospice Quality Reporting Program) as a factor that has influenced their views of QI. Specifically, Director A viewed the quality measurement and reporting enterprise as a way of increasing staff awareness of QI, as well as a way to achieve improvement in hospice quality of care.

I think in the past, people knew they had to do some quality, and so they did the bare minimum and it really wasn't a smooth, efficient process ...that really was looking at things that you needed to improve on... to get

*to... better quality. Now we have so many quality indicators in the hospice industry, that are tied to our reimbursement...HIS [Hospice Item Set], we have the CAHPS [Consumer Assessment of Healthcare Providers and Systems], we have all kinds of different things that we have to abide by now. And so I think that people are getting more and more aware of quality improvement and what you have to do. **Director A***

However, Director E held a more nuanced view, and portrayed unease about QI efforts when discussing Medicare's quality measurement policy. This participant expressed concern about potential negative effects on staff morale when quality measurement results are made available for use by consumers to compare between hospice agencies.

*You're surely aware that in 2017 under Medicare.gov there's going to be a Hospice Compare. So my energy now is, I have all these proud healthcare providers and they're magnificent people. And we do really good work. And I'm speaking to them about how personal it's going to get if we're on a Medicare.gov Compare site and the consumer can go in, needing to pick hospice for their mom in the State of Maryland, and they can look at us versus two or three other competitors and see how we stack up. **Director E***

Additionally, Directors B and H, through one coded instance each, described their positive views of QI as an outgrowth of their own personal philosophies, particularly with respect to continuous learning.

Influences on Positive/ Negative Views of QI by Provider Role and Agency

Characteristics

The above sections summarized findings regarding contributing factors that were associated with study participants' positive and negative perceptions of QI. An analysis of these findings with respect to provider role (i.e., director, nurse, social worker, or chaplain) indicates that these factors were associated with provider role. However, analysis of the findings with respect to agency characteristics (i.e., size, type, tax status, and locality) indicates that contributing factors were, once again, not linked to agency characteristics. These findings, which address Aim 6 of this study, are described below.

Factors that influence perceptions of QI by provider role

When discussing what had influenced their perceptions about QI, agency directors cited, almost exclusively, either their own personal philosophies or Medicare quality measurement policy. In contrast, those in the other provider roles referred exclusively to their previous experiences with QI. Among those who identified previous experience with QI as influencing their current views, participating nurses named QI activities and positive results of QI. However, they did not refer to QI efforts that focus on documentation. In contrast, the social workers and chaplains more commonly referenced documentation when discussing experience with QI.

Four of the five directors and three of the four nurses who participated in the study reported evolving evaluations of QI. However, only two social workers (and no chaplains) did so. During their narratives, all four of the directors attributed these changes in perceptions of QI to professional maturity, while the two of the three nurses credited personal maturity. In contrast, the social workers who discussed changes in their views of QI primarily referenced past experience with QI as a contributing factor.

Factors that influence perceptions of QI by agency characteristics

There were no clear differences that can be linked to agency characteristics vis-à-vis factors that participants identified as influencing their current evaluations of QI. At least two employees from four of the participating agencies and one from the fifth participating agency discussed factors that influenced their views of QI, and at least one employee from four participating agencies discussed factors they associated with changes in their views of QI.

Experience with QI, which was the most commonly cited influencing factor, was articulated by at least one participant from each agency. Personal or professional maturation, the second most-commonly cited factor, was mentioned by at least one employee from four of the five participating agencies. The other two factors, personal philosophy and Medicare quality measurement policy, were cited by directors from four of the five participating agencies.

Summary: Influences on Positive/ Negative Views of QI Efforts

As another way to address the overall research question for the study—how providers in the hospice industry perceive QI efforts—and to address Aim 2 of the study

(i.e., how hospice providers perceive the potential for improving care near the end of life), I asked study participants to discuss those factors they identify as influencing their views of QI. The most commonly-cited factors included previous experiences with QI and personal or professional maturity. Evaluations of QI were primarily positive, except for those participants who focused on previous experiences related to documentation as an influencing factor. Just under half of the study participants noted an evolution in their perceptions about QI. For these individuals, the shift was toward a more positive, and oftentimes more comprehensive, view of QI. Finally, addressing Aim 6 of the study, these findings indicate that factors that influenced perceptions of QI were associated with provider role. However, these factors did not appear to be linked to agency characteristics.

Potential for, and Ideas for Improving EOL Care Quality

Two additional lines of inquiry enabled me to explore how study participants perceive the potential for improving quality of care near the end of life (Aim 2 of the study). When I began exploring their general perceptions regarding QI, I posed the following questions: “*Thinking about quality of care in hospice, do you think it can be improved? How or in what ways?*” These questions explicitly address Aim 2 of the study. Later in the interview, I shifted attention to a discussion of agency-specific QI efforts and how each participant viewed those specific efforts (Aim 4 of the study). In that portion of the interview, I asked participants the following question: “*Are there any other things would you like for your agency to do to improve the quality of care here?*”

As noted earlier, when developing the interview questions, my intention was to mirror the progression of ideas established via the specific aims of the study. To answer the overall research question of how participants' perceive efforts to improve quality of care near the end of life, I began with a set of rather abstract questions about QI (e.g., what do you think of when you hear the term "quality improvement," what do you think of as advantages and disadvantages of QI efforts). I then channeled the questions so that I could focus more narrowly on participants' perceptions of external drivers of QI, then on their perceptions of their respective agency's QI efforts, and finally, on perceptions of their own personal QI efforts. However, when analyzing the responses from the questions on participants' ideas for improvement, I realized they did not necessarily answer the questions as I had intended. I had expected them to provide ideas for improvement for EOL care, writ large, in response to the initial questions, and then to draw on what they perceive as "missing" from their agency's QI efforts to answer the later question regarding agency-specific improvements. Instead, participants provided both general and agency-specific ideas for improvement in their responses to both questions. Not surprisingly, the themes from the two sets of responses were quite similar, and therefore, I have combined and summarized these findings in this section.

Sixteen of the 19 study participants responded directly to the first question regarding the potential for improving quality of care in hospice. However, 18 of the 19 study participants, through 86 coded instances, responded to the two questions regarding ideas for improvement. Only nine of those interviewed provided ideas for improvement in response to the initial, more general question. However, 17 of the participants

provided ideas for improvement when responding to the second, agency-specific question.

Addressing Aim 2 of the study (i.e., to identify and describe how hospice providers perceive the potential for improving quality of care near the end of life), all of the participants agreed that EOL care can be improved. Moreover, they articulated various strategies to affect such improvement, thus also addressing Aim 4 (i.e., to identify and describe the agency-specific QI efforts of study participants). Specific ideas for improving the quality of EOL care fell into five major themes: (1) increasing access to hospice services, (2) ensuring sufficient numbers of agency staff, (3) increasing staff skills, (4) promoting the emotional well-being of staff, and (5) modifying QI activities of the agency. I have described these themes more fully below, supported with participant quotations. Addressing Aim 6 of this study, findings indicate that participants' ideas for improvement in EOL care varied somewhat by provider role. Again, as will be detailed later, there was little evidence of differences according to agency characteristics.

Theme 1: Unanimous Agreement on Potential to Improve End-of-Life Care

Across the 16 study participants who directly answered the first question during the interviews, there was unanimous agreement that quality of care in hospice can be improved. For the most part, participants answered this question fairly succinctly, but often rather generally. Typical quotations included sentiments such as the following from Nurse A and Social Worker E, respectively: “*there’s always room for improvement*” and “*there’s always something that can be done better.*” Notably, of those who did not answer this question directly, all three verbalized ideas for improving EOL

care either in response to the second question or in other parts of the interview. Thus, I have concluded they, too, believed that the quality of hospice care can be improved.

Theme 2: Improvement via Increasing Access to Hospice Services

Nine study participants, via 27 coded instances, voiced their belief that increasing access to hospice services will improve EOL care. Nineteen of these instances related to increasing enrollment in hospice more generally. The remainder focused on ways to expand or otherwise enhance the services that are offered to patients who are already enrolled in a hospice program.

Ideas for increasing hospice enrollment, which were discussed by six study participants, primarily centered on educating the public about the benefits of hospice care. One key element within this category involved educating physicians about how hospice can be a better alternative for terminally ill patients than futile attempts at curative care.

Gosh, one of the biggest challenges...is just getting the word out there and getting people to think about hospice care as a treatment plan. A lot of education, community education and awareness [is needed]. Nurse H

The public still knows very, very little about hospice care...But people should know what hospice does. That it's about symptom management. And I guess it's just hard to have that discussion...So, the ways of really giving that information out, that we are about symptom management, that hospice relieves difficult symptoms better than anyone else...that's what

*hospice is about.... Not many know anything about medications that are out there to make individuals feel comfortable at the end of life. So, I would like to see much more...education...even about what I do, what chaplaincy supports in a hospice setting. **Chaplain C***

This chaplain also mentioned the public's lack of understanding of hospice's capacity to treat other terminal medical conditions, not just cancer.

*The community needs to be educated... By education, I mean, explaining to them what are the benefits of having those services. We need to be talking with the doctors...It isn't easy for [the primary physician] to let their patient go to hospice, because they see that as a failure. So, we try to build that relationship with them [physicians], to let them know...it's okay. You want the best for that patient, and clinically, you come to a point where you see that...disease will lead them to death. The best thing you can do, if you care for them, is to direct them to a place where they will receive the care they need. **Chaplain H***

Nurse E connected the dots between enrollment in hospice and improving EOL care by equating fewer "back-and-forth" visits for curative care to a higher degree of comfort and a better quality of life over what would be achieved without hospice.

So, if you take my mother to a specialist, their purpose is to make things better, fix things. Whereas hospice, we say "we cannot fix it, so let us do whatever is more comfortable for you." A lot of people don't realize

hospice can do more than comfort care...you can improve the quality of the last 60 days or last 90 days of somebody... "I think quality is more important than quantity. And if you agree with me, then this is what we should do, rather than go and sending you back and forth for all these procedures, let's make you comfortable." Nurse E

Director H indicated that one of the biggest challenges for hospice is lack of access. This participant spoke about several elements that can drive under-utilization of hospice care.

I think access is one...of our biggest challenges, because we're dealing with a population that's really undereducated when it comes to what hospice is and what it offers. There's a lot of misunderstandings about it... stigmas that we have to confront and overcome. These are services that are really valuable to a much broader population than is currently being made available. Right now, it's the last six months of life. But there are many cases where patients earlier could really benefit...If we were able to start this early on, and be able to continue with some of these aggressive therapies...there would be fewer people hesitant to take on the challenge of going into hospice care...Really, there isn't going to be any positive change in the form of a cure for most of these things, they're just going through the motions...and for whatever reason, the families perhaps either don't know, or are unwilling to accept, the hospice care. Director H

Six study participants suggested, via nine coded instances, that expanding or otherwise enhancing the services offered to patients who are already enrolled in a hospice program would improve EOL care. Their ideas for expanding services included things like creating tailored programs for patients with specific conditions (such as Alzheimer's disease), offering music therapy, and providing inpatient options in certain geographic regions. They voiced these ideas in response to the question about agency-specific ideas for improving EOL care.

*Yeah, I want to continue to provide enhancements in the care that we provide our patients... There are also some specialty programs that I want to bring that are based on disease processes. For example, a cardiac program, a COPD program, an Alzheimer's program, where care is tailored to the needs of that specific population... cardiac patients are an underserved community in terms of hospice... you can tailor what you're doing, to make enhancements here and there that make it more appealing to those particular populations. **Director H***

*Music therapy is another big one. I've seen firsthand the miraculous impact of music therapy, especially on patients with dementia. **Director H***

A lot of times our patients, when they hear about going [for inpatient hospice care] they say no. [Contracting with a local hospital would] improve the service to our patients. And it's travel time for the families too, to visit their loved ones... that's the first thing when you hear about,

*that it's no. And that's why they would rather send them to the [local] hospital. **Chaplain E***

In response to the agency-specific question on ideas for improvement, participants also suggested ways to enhance currently-offered hospice services. These included contracting with additional ambulance services and ensuring that a continuous-care option is always available (i.e., 8-24 hours per day of crisis care provided primarily by hospice nurses in the patient's home).

At one point...they [this participant's agency] had some issues with the ambulance companies, they couldn't get enough ambulances to support transporting our patients...Sometimes we have to transport a patient from here to our inpatient unit, then a lot of times they had to wait for like three hours, four hours, you know, plus the traffic and all that [to get there].

Chaplain E

We had what's called continuous care. And, due to, I guess, a nursing shortage or employee shortage, they had to discontinue it for a little while. But during [that] time, it was very frustrating. You know, this is something we say we offer, [and] we're not offering it right now. And it's a really wonderful thing that we do, because there are people that are too fragile to move, and the family is not equipped in whatever capacity to take care of them at that stage...It was infuriating when we didn't have it.

Social Worker E

Another idea for enhancing currently-offered services, voiced by Chaplain A, is to allow chaplains to offer bereavement care. In Chaplain A's agency, bereavement care is provided to the family after the death of the patient by a specialized "bereavement team" within the agency, rather than by the chaplain. However, Chaplain A suggested that chaplain-provided bereavement care would be a service enhancement, because it would improve continuity of care, and consequently, improve overall EOL care quality.

*One of the reasons why I liked doing bereavement also was for continuity. Because with hospice, we get the nurse, the social worker, and the chaplain. Then, when that person dies, the social worker and nurse and chaplain all go away, and it's about bereavement. You're now with a whole new team in this vulnerable moment. [But] if I had connections beforehand, I like, at least, to have that bridge from the first few weeks or whatever. Yeah, kind of a continuity of care. **Chaplain A***

Perhaps not surprisingly, study participants articulated specific ways in which their agencies could expand or enhance existing services, and thus improve EOL care. But what I found most interesting was that several participants offered a broader vision for improving EOL care than I had expected. Instead of focusing only on patients and families receiving care from their own or other hospice agencies, these participants focused on patients who are not currently enrolled in hospice at all. Specifically, these participants believed that making hospice services available for more patients overall, as well as earlier in their illness trajectory, will improve EOL care. The underlying assumption for this belief, which was conveyed by the majority of participants in the

study, is that key attributes of hospice care, such as following patient wishes, providing individualized care, providing holistic care, and addressing pain or other symptoms, defines high-quality EOL care.

Theme 3: Improvement via Ensuring the Agency has Sufficient Staff

Six study participants viewed either increasing staff size or, alternatively, more effectively addressing staff turnover, as ways to improve EOL care. This approach for improvement was identified through 11 coded instances. Notably, it was verbalized by at least one participant from all five of the agencies included in the study.

*Well, we're trying to hire more staff. And then, when a nurse is sick, somebody has a back-up to fill in, [that] would be nice...A little bit more staff would be good. And I know they're trying to hire....They're in the works with it. **Social Worker A***

*And another thing is, I know the bottom line is to increase our patient load. But when it reaches a certain point, and the workers are being overworked trying to handle the patients, it sometimes can reduce the quality of care. **Chaplain B***

*We have a high [staff] turnover. I don't know why. ... So, I think whatever [the issue] is, if they can resolve that, that would help to maintain continuity of care for the patients. Being a team member for a longer time, you know who's what, who can help you if you're striking out or something. **Nurse E***

Theme 4: Improvement via Increasing Staff Skills

Six study participants, via 13 coded instances, identified increasing the skills of hospice agency staff as an approach for improving EOL care. For the most part, these individuals focused on various educational efforts aimed at current employees. However, two also discussed increasing the overall skills of staff by hiring new staff members with certain types of expertise. The identification of educational activities as a specific way to improve EOL care quality should not be surprising, given that earlier in the interviews, several participants not only named educational activities as facilitators of QI (or as barriers, if not conducted well), but also identified “learning” as one of the meanings of QI.

When discussing educational efforts to enhance staff skill, participants mentioned both formal certification as well as the continuing education required for licensure. For example, Director C believes that discipline-specific certification would improve staff expertise.

*I would love to see our staff all become certified. There are now social work and chaplaincy certifications. But I think that education, and having to meet those standards, is a wonderful thing for bringing up the level of professionalism...and then you know the expertise of your staff. **Director C***

In a similar vein, Social Worker B acknowledged the value of continuing education, but suggested that such efforts be more targeted to the work done in hospice.

*I would also say just general education stuff. We're [social workers] required to do our 40 hours of continuing education just to maintain our license. But...[i]f you don't want to [focus on hospice social work], you could take all classes on, you know, marriage counseling or welfare for children...I think, obviously, we want to do a good job, and...having more education on topics that are specifically related to this [hospice] is always good. **Social Worker B***

Study participants also suggested a few specific ideas for enhancing the skills of current hospice staff. These included focusing on orientation programs and mentoring, ensuring that staff have shared access to informational resources that patients and families would find useful, and having more instruction and structure on how to best provide care during patient visits.

*Oh, I would focus on staff development, and orientation, and precepting, and that kind of thing. **Nurse H***

*We have social workers that work with the families...and they have a bag of tricks, they've got everything. I just think maybe it's not shared as much as it could be. Whether it's during your orientation or in general, so everybody has this list or a spot on our shared drive where, here, this is there. **Nurse B***

Director C suggested preparing nurses to conduct an “optimal visit” via a visit template.

*...helping nurses conduct an “optimal visit,” where you talk about what’s your pre-visit preparation, what are the steps you need to go through when you do your visit, what do you need to remember when you’re doing your assessment, what do you need to remember before you leave, how do you walk out the door when people are following you out the door, how do you frame your timeframe so that you’re not spending three hours in one family when you’ve got five visits to do that day.... But [we need it] for all disciplines. **Director C***

Two directors also spoke about enhancing the skills of agency staff overall by hiring individuals with particular expertise or skills. Director A talked about bringing nurse practitioners aboard, while Director C discussed hiring individuals with customer service skills.

We’ve never had a nurse practitioner on staff before, and things had changed [in] years recently...nurse practitioners can do a lot more. They can follow patients, they can be the attending, they can write orders.

Director A

And then you’ve got to have the right hiring of people with customer service skills. There are some people that you just cannot teach that to.

Director C

Theme 5: Improvement via Promoting Emotional Well-Being of Staff

Five participants, via 18 coded instances, pointed to activities to enhance the emotional well-being of staff as a way to improve EOL care. Ideas ranged from general support for staff and allowing time for staff to reflect on patients who have died, to augmenting leave to better support staff mental health. This idea of promoting staff well-being as a mechanism for QI was perhaps the most novel and interesting of those identified by study participants.

*I think that support is a big piece. Our jobs are hard. It's very emotional. We need the support, but it's kinda like...To set up a day, a time to get together, is the tough piece. But I think there is a need. **Social Worker A***

*I think, because of the work we do...we talk to each other, but you also need to have support, emotional support. Whether it's team building or... just like [a] mental health day for staff. Kind of a day like, what they used to do was, every month at a staff meeting they would read all the names of everybody who died and then say "do you have something that you remember about somebody?" And I think that's nice. So, I just think like some kind of reflective something, you know...I just think that was a nice idea to give, you know a fun story about whoever. **Social Worker H***

I think that the administration really needs to kind of take a walk in the line staff's shoes, see what we go through in a day...it's not this walk in the park like I think it's sometimes perceived as. That our jobs are very

*emotionally draining and...understanding that this is a mentally taxing job....[W]e don't get any personal days [off]. None. You get three weeks of vacation, but that's your sick time, too. You're not really supposed to call out unless you're sick. So, it's not like I can call my supervisor in the morning and say "I'm having a really hard time, I just can't come in today." **Social Worker C***

Both Chaplain B and Social Worker C highlighted the need for hospice staff to be able to talk about their feelings. However, both also voiced a reluctance to rely solely on their peers for this release, due to concern that it would add more stress to their peers' lives.

*This is going to sound selfish but more...think of more ways to decompress...I would like to have someone who's full-time where you can just, if you've had a tough visit, you can just go see them. And they'd be available, you could call them up and say hey, I'm on the way, this is what's happened and I need to talk about this. **Chaplain B***

Chaplain B went on to describe a visit to a state park, with hiking or biking and a time to meet and talk over refreshments, away from the agency. Chaplain B added:

I do this for my team or anybody in the agency, I've been pulled to the side several times "hey, I just need to talk." But there are days when I need to talk. And there's no person for me to talk to other than another chaplain.

*But then I feel guilty because...now I'm interrupting their day. So, I would like to have someone whose job it is to do that. **Chaplain B***

*I wouldn't say that I talk to our chaplain a whole lot, I talk to one of the nurses that I'm pretty close to, that I work with consistently. But the chaplains all have another job, because they all have church, even if they're full-time, they're doing something else. And they are dealing with the same things you are, so there's really nobody that's not going through the same stuff to talk to...Then you kind of feel like you're adding more stress to them. **Social Worker C***

In summary, these participants emphasized the stressful nature of their jobs in hospice and talked about ways their agencies could help alleviate that stress. The implication from these responses is that such stress reduction would enable hospice staff to provide better care.

Theme 6: Improvement via Modifying Approaches to QI Efforts

Finally, four study participants, through 11 coded instances, suggested that EOL care could be improved if their agencies made changes to their QI activities. Once again, these suggestions were consistent with earlier narratives from the interviews regarding staff involvement and ineffective implementation of QI efforts as a facilitator of, and barrier to, QI efforts, respectively.

For example, Director B talked about embedding the Lean philosophy and practice (i.e., efforts to improve by removing waste in the system) throughout the agency.

*What I'd like to do is make better use of what we've learned from Lean. Have it [Lean] be more infused as a philosophy and practice throughout the agency...As well as other quality improvement models...[J]ust get better at using the good tools that are available. And having it more part and parcel the fabric of the organization. **Director B***

Both Director C and Chaplain E suggested that EOL care would be improved if the agency's front-line staff played a larger role in the QI process, from making recommendations for improvement activities to doing chart audits.

*I would love to see more staff involved in the actual auditory (sic) process...[W]ay back when...we used to do all our own chart audits. We didn't have a QI person, we were too small to do that. And I never learned so much in my life as I did when I was auditing charts, when we were auditing each other's charts. **Director C***

*Maybe that's one thing [my agency] can improve that the QI is everybody's responsibility...even field staff...like me could receive more professional training....[I]f only the people in the office is doing the QI, how would they know how to improve QI? Because I don't always feel that the field staff has enough voice when the management is trying to make some kind of decision. **Chaplain E***

Although couched in different terms, these participants essentially referenced a belief that a “culture of quality,” where all agency staff engage in QI activities, would result in improved EOL care for their patients and families.

Ideas for Improvement by Provider Role and Agency Characteristics

All participants either explicitly agreed that there is potential for improving quality of care in hospice, or provided specific ideas for improvement. However, an analysis of the above findings revealed that ideas for improving EOL care differed somewhat according to provider role (i.e., director, nurse, social worker, or chaplain). There was less evidence that these ideas for improvement were related to the characteristics of the agencies in which they work (i.e., size, type, tax status, and locality). Additional details of the provider- and agency-specific analyses are described below.

Ideas for improvement by provider role

There were a few notable differences across provider roles in terms of ideas for improving EOL care. First, nurses provided substantially less commentary on this topic than those in other roles (nine coded instances, compared to 20, 26, and 25 by directors, social workers, and chaplains, respectively). The ideas for improvement also varied by provider role. Specifically, none of social workers in the study suggested improving access to hospice care or enhancing existing hospice services as a way to improve EOL care, nor did they suggest improvements in QI practices. However, as a group, they provided three times as much narrative on staff-focused ideas for improvement than those in other roles. While at least one person from each role discussed staff numbers and staff

skill sets, only social workers and chaplains discussed improving the emotional well-being of agency staff as a way to improve EOL care quality. These groups' representatives believed that their agencies can improve EOL care for their patients and families by both recognizing, and then helping to alleviate, the stresses associated with hospice work for their staff.

Ideas for improvement by agency characteristics

While specific ideas for improvement varied across participants from the various agencies, there was little systematic variation in the overall topics voiced by participants according to agency characteristics. For example, at least one participant from four of the five agencies spoke of improving access to hospice as a way to improve EOL care, either by increasing enrollment or expanding or enhancing services,. However, each of the characteristics of the remaining agency (i.e., size, type, tax status, and locality) matched at least one of the characteristics of the other four agencies. That said, only two of those four agencies had at least three employees who mentioned access, but again, no specific agency characteristic stood out. Similarly, individuals from all five agencies identified adequate staffing and increasing staff skills as ideas for improvement. Participants from four of the five agencies identified promoting the emotional well-being of agency staff as an approach for improving EOL care quality. The fifth agency, in which no one mentioned emotional well-being, was similar to others in the characteristics of interest. Finally, participants from four of the five agencies made reference to improving QI processes as a way to improve EOL care. The remaining agency, none of whose

employees identified modifying QI efforts as an approach for improving care quality, differed from the others only in that it was the smallest of the five.

Summary: Potential for, and Ideas for Improving EOL Care Quality

Not surprisingly, all study participants agreed that there is potential for improving the quality of care provided through hospice. Also, as expected, nearly all participants were able to offer specific ideas for improving EOL care, either for the industry more broadly or for their agencies in particular. Relatively more participants discussed staff-focused ideas for improvement, including suggestions to increase staff numbers, advance staff skills, and promote the emotional well-being of staff. But participants also viewed increasing access to hospice services as a way to improve EOL care, both for those who are, and who are not, currently enrolled in hospice. Finally, a few participants suggested that modifying agencies' QI efforts ultimately would improve EOL care. An example of such a modification would be including all front-line staff in QI efforts. As with most of the perceptions discussed earlier in this chapter, it appears that ideas for improving EOL care were associated to some extent with provider role, but were not linked to agency characteristics.

External Forces that Drive Quality Improvement Efforts

In a previous section, I described what study participants perceive as barriers to, and facilitators of, QI efforts that exist within a particular hospice agency (i.e., internal barriers and facilitators). These findings emerged during the interviews as I asked participants to describe “*the kinds of things that either help or hinder QI efforts in hospice.*” However, as part of this discourse, participants also described things outside

their own hospice agency that they believe help or hinder QI efforts (i.e., external barriers and facilitators). Exploring what study participants perceive as external barriers and facilitators is another way to understand their perceptions regarding the potential for improving quality of care near the end of life (Aim 2 of the study). Narrative in this area also addresses one aspect of the overall research question regarding how hospice providers view QI efforts more generally.

However, when analyzing participants' discussion of external barriers and facilitators, I realized their responses about external facilitators of QI efforts also address, in part, what I wanted to learn when I articulated Aim 3 of the study (i.e., to identify and describe hospice providers' familiarity with, and perceptions of external drivers to improve quality of care near the end of life). I had formulated Aim 3 when I first began this study, because I was curious about how much hospice employees know about legislative and regulatory efforts that have spurred formalized QI efforts within the hospice industry. To elicit the information to address this aim, I crafted two interview questions as follows: a) *What do you think are the things or forces that are driving efforts to improve the quality of care in hospice?* and b) *In general, what do you think about those efforts?* For the latter question, I typically followed up with probing questions to explore whether participants viewed these efforts as good or bad, although for a couple of participants, my probing questions assessed perceptions regarding the efficacy of the drivers they had identified. In response to the first question listed above, 18 of the 19 interviewees (i.e., all but one of the nurses) discussed, via a notable 80 coded instances, what they viewed as external forces that drive QI efforts in the hospice setting. Of these

18 participants, 13 answered the second question regarding their thoughts about the drivers they had identified, via 21 coded instances.

Thus, to address Aim 3 of the study, I have summarized in this section the findings that emerged from participants' responses to the above questions that explicitly asked about external drivers of QI efforts, as well as the findings that emerged from their responses regarding external facilitators of QI efforts. For completeness, I have also summarized the participants' responses about external barriers to QI efforts.

Addressing Aim 3 of the study, analysis of the narrative responses revealed four key external forces that participants viewed as driving hospice QI efforts. These included: (1) the regulatory environment, (2) the hospice industry, (3) competition, and (4) thought leaders and peers in healthcare. Each of these themes is described more fully below, along with quotations from the interviews that support them. In addressing Aim 6 of the study, these findings also indicate participants' perceptions were associated with provider role, as well as with agency size.

Theme 1: The Regulatory Environment Drives Hospice QI Efforts

When asked directly about the forces they saw as driving efforts to improve the quality of care in hospice, 15 of the 18 study participants (five directors, five social workers, three chaplains, and two nurses) identified regulations and their associated effects on reimbursement. These participants spoke about these two interrelated facets of the healthcare regulatory environment through 41 coded instances. Of these, six (two directors, two nurses, one social worker, and one chaplain) discussed only regulations, three (two directors and one social worker) discussed only reimbursement, and the

remaining six (three social worker, two chaplains, and one director) discussed both. I have described participants' perceptions of these drivers below, using supporting quotations from the interviews to illustrate the various views.

Regulations

Participants who identified regulations as a driver of QI efforts in hospice often spoke about them in fairly general terms, referring primarily to those entities they viewed as making or enforcing the regulations (e.g., using words such as “*Medicare*,” “*CMS*,” “*the state*,” or “*the government*”). For the most part, these participants did not discuss specific regulations or their content. In addressing my question on the forces that are driving efforts to improve the quality of care in hospice, Social Worker A said: *I'm sure some government. Well, somebody is. In my last job, it was the state.* In terms of regulations, other participants said:

Yeah, it was about five to eight years ago when Medicare started more of the “Wait a minute, we have to look at this; we need to start doing more, reviewing the chart audits, more taking back payment.” **Director B**

Some of it is Medicare and regulations. **Director C**

And then, of course, the very, very important, three-month bereavement assessment...so that's all from CMS, about getting the spiritual assessment. **Chaplain C**

Interestingly, only Director B mentioned the Affordable Care Act (ACA) by name. This director viewed the ACA as having both positive and negative effects on the hospice industry as a whole.

*There's a lot of improvement we can make. I [don't] think the challenges with the Affordable Care Act are ... any bigger than the benefits that have come with it as well. Some of it has adversely affected us. But some of it also has helped. **Director B***

In addition, Social Worker C and Nurse H referred specifically to results from the required post-death CAHPS survey as a driver of hospice QI initiatives. As a reminder, the Hospice CAHPS questionnaire is completed by the primary caregiver after the death of their loved one in hospice. It covers many topics, including hospice team communication, timeliness of care, respect for family members, and symptom management.

*I would say all the surveying that people do about the quality of care loved ones receive. I know we send out a survey...a couple months after a loved one dies. [T]hey [CMS and the hospice agency] take information and they get their results and then they bring it to you, to talk to you about things that they feel need to be improved upon. I think that...some of the Medicare reimbursement depends on patient experience, I could be wrong about that, but I'm pretty sure that I am right. **Social Worker C***

*Well, I think it should ultimately come back from surveys. I mean we send all of our families a survey at the end. So that has to be looked at. Those results of those surveys definitely should drive it. **Nurse H***

I have included these two participants' discussion of the CAHPS survey results as a driver of QI efforts under the regulatory environment theme, because the fielding of the survey and reporting of results is now required by the CMS Hospice Quality Reporting Program for most hospice agencies.

Reimbursement

Most of the participants who spoke of reimbursement in their discussions of external drivers of QI efforts explicitly associated it with regulatory requirements. For example, Chaplain E and Social Worker H mentioned incentives or penalties that affect hospice reimbursement, including the reimbursement and payment policies under CMS Medicare rules.

*So...what I have heard, from my position, is Medicare. So, this is a very heavily Medicare-driven industry. And so all the QI, I guess I can imagine, is trying to meet the Medicare guidelines and standards. Make sure, so that we can be reimbursed. And I think that's another driver as well. Because if we don't meet those standards, then there will be issues in getting reimbursed by Medicare. **Chaplain E***

Oh,...it's basically...Medicare, Medicaid, someone paying. So, if you don't have your documentation, they take back money. Medicaid,

*Medicare, it doesn't matter, you know what I mean. I've been told, we've all been told, that we leave all this money out there, because certain things aren't done. So, it's just a situation where if you don't document correctly, and dot your I's and cross your T's, basically it's going to come back to a point where they're going to go through with a fine-tooth comb and kind of ding you on things. So, I mean, that's just the way it is. **Social Worker H***

Director E pointed more specifically to the [at the time of the interview] expected public reporting of performance measure results and the link to payment.

*So certainly, the new CAHPS environment [Consumer Assessment of Healthcare Providers and Systems: surveys used to gauge patient experience of care] in this era of public transparency. I just think that type of accountability in a public fashion is...that's a wonderful opportunity. And again, it's all mandated, and it's all related to how we get paid, and how we'll be rated, and all of those ways that hospice is going where everything else has already been going....Everybody else already has the stars.²¹ We'll get the stars soon. The stars are coming. The stars are coming. **Director E***

²¹ CMS has implemented a “star ratings” system for several types of delivery systems (e.g., hospitals, nursing homes, Medicare Advantage plans, Part D drug plans, etc.), although this has not yet been implemented for hospice. In these systems, each entity receives a rating of one to five stars, where the number of stars is meant to reflect an overall summary of care quality. The star rating essentially is the result of a composite performance measure that is computed based on results from various quality and,

Even more specifically, two participants linked their ideas of regulations and financial considerations to efforts by CMS to reduce fraud.

*All the Medicare fraud things that you hear, it's like every time you hear it on the news, and it's like, okay, that means something is going to be tightened. **Social Worker B***

*Another one is, you know, financial, because, with changes in healthcare, I think the government is looking for a reason to take money back. It's almost like a lot of the mechanisms they have in place right now don't really care about whether or not the patient's getting better care. They're just looking for reasons they can claw money back from you or perhaps not pay you to begin with. So, it's forcing organizations to be all the more careful about how they do things...So, I think that's a big driving force and sometimes...to such a degree that it, I think it hinders the ability of organizations to really deliver really good services. **Director H***

Others who discussed matters of reimbursement, or financial considerations more broadly, alluded to the overall shift in U.S. healthcare payment policy from paying for volume to paying for value, and the attendant, perceived, focus on cost containment.

...What's changing in the healthcare environment overall, moving from volume-based reimbursement to value-based. Even though that's not

possibly, cost measures. However, the methods used to assign the stars (i.e., the choice of component measures, and the aggregation and weighting rules) vary across programs.

*directly applied here yet, it will be. And it's going to be in a different way than with hospitals and such, because of the way we're reimbursed and all that. But it's coming. And with already that movement in other parts of the healthcare system, wow, we've got to pay attention to this....If we're going to be viable in the community and really believable in the community, our outcomes have to demonstrate that we have quality. So, anyway, that's what I think [is] another external driver. **Director B***

The almighty dollar. The Wall Street Journal has had articles about hospice care. Yes, in the Wall Street Journal. Because it's cost containment. So that's what's really, I think, the primary factor.

Chaplain C

Regulations and other mandates as barriers to QI efforts

Of note, when discussing perceptions of barriers and facilitators of QI efforts, four study participants (two directors, one social worker, and one chaplain) identified regulations as external barriers to QI efforts.

These participants highlighted three regulatory scenarios they perceive as barriers. The first was requirements related to compliance, which demand substantial resources and often are needed to receive payment for services or to achieve accreditation of the hospice program. The second was the Medicare hospice benefit, which requires formally identifying a terminal diagnosis. The third was other externally mandated QI efforts,

even when improvement efforts target issues that are not a problem within a particular agency.

In terms of the resources required to ensure compliance, both directors who spoke about this topic discussed the fiscal aspect. One specifically noted the direct costs associated with the time and resources used to achieve regulatory compliance, and the other referred to the potential loss of revenue if an agency runs afoul of governmental oversight standards.

*I would also say that regulators are a barrier, because they continue in the hospice industry to...[add] new regulations that we all have to follow. And it's not only taking a lot of time to implement them, it's taking a lot of money. **Director A***

*It's almost like a lot of the mechanisms they [the government] have in place right now don't really care about whether or not the patient's getting better care...Because you're putting so much time and energy into making sure that every "i" is dotted and every "t" is crossed, so you're not giving an opening to the government. And they might be delivering very, very good care. But despite that, it might still cost you a lot of money, if you're not taking care of...the fine print, so to speak. **Director H***

Director A spoke about patients' eligibility for receiving hospice care under current Medicare regulations, which require a diagnosis of terminal illness.

*And what's happening now is that people are not getting hospice that really should have hospice, because nobody can find a diagnosis. That 100-year-old that's really dying, because they're old and because they have several different co-morbidities. ... [I]f you can't find a terminal diagnosis, what do you do? That's been a challenge, too. A barrier? Oh, yeah. **Director A***

Social Worker E suggested that regulators often require hospice agencies to focus attention on issues that may not be a problem within a particular agency, which, in turn, can hamper efforts to address issues that do need attention. This participant saw this as a lack of awareness on the part of regulators regarding potential unintended consequences of mandatory QI efforts.

Well, I think a lot of QI stems from, you get evaluated by the state, or you get evaluated by JHACO, so I think that's where a lot of the issues stem from. So, again, it's just whatever somebody else decides is quality.

Social Worker E

This participant went on to discuss requirements for documenting discussions about evacuating in an emergency, as reported earlier in the discussion about “going overboard” on certain QI activities. Although Social Worker E pointed to regulatory requirements mandated by the state or those that arise from the accreditation process, this type of scenario also could be driven by other regulatory bodies such as CMS or even parent companies (in the case of national or regional chain-owned agencies).

Interestingly, when discussing the regulatory environment as an external force driving QI efforts in hospice, the tone and the content of participants' narratives that focused on regulations in general seemed fairly neutral. However, the tone and the content of the narratives regarding reimbursement seemed quite negative. As noted, four interviewees also discussed regulations as an external barrier to QI efforts, but not as an external facilitator of QI efforts. Further analysis indicated that three of these four participants viewed regulations as a "driver," but not as a facilitator. In other words, these participants do not equate "driving forces" of QI efforts with "things that help QI efforts." It is unclear, however, if this is a genuine distinction in meaning or simply an artifact of my word choices during the interviews, or perhaps the ordering of the questions in the interviews.

Theme 2: The Hospice Industry Drives Hospice QI Efforts

Twelve participants (four directors, three nurses, three chaplains, and two social workers) discussed, through 22 coded instances, how the hospice industry itself, and in some cases, changes in the industry, act as drivers of QI efforts in hospice. By the "hospice industry," I mean the collective of hospice programs operating in the U.S., the leadership and employees thereof, as well as the various industry organizations that interact in various ways with the hospice programs (e.g., advocacy and accrediting organizations).

Although acknowledging the impact of regulatory scrutiny that has been caused, in part, by shady practices of some hospice providers, Director B believes there is pressure for the hospice industry overall to "prove" itself. This participant believes this

can be done, in part, by demonstrating the quality of care that is being provided and improving that care.

*I think just the need for us, as an industry, to prove ourselves, to be able to clearly articulate and demonstrate value to healthcare... So, we have to address those critiques [regarding regulatory requirements and financial management] and we've been doing that as an industry... The hospice industry now is to take its rightful place in the continuum of care, it's responsible place... [We] can say, "We are very responsible providers, we get the regulations, we in no way want to abuse the system or the resources that we need and that are given to us to do the job, that we do it responsibly and we need to move forward." **Director B***

When responding to my question about the forces that are driving efforts to improve the quality of care in hospice, four participants (two chaplains, one nurse, and one director) described, more specifically, the role of professional organizations within the hospice industry, and their associated activities, as external drivers of QI efforts. Director C provided an example of how industry-specific organizations support QI efforts by recognizing the National Hospice and Palliative Care Organization's (NHPCO's) Quality Partners program. This is a national performance improvement program that provides background materials and other resources and tools to facilitate measurement and QI efforts for hospice.

*Some of it is the professional organizations. Like NHPCO-- they have their quality commitment thing... And we use that with our employees too. So, some of it is the professional organizations driving improvement in quality. **Director C***

These participants also referred to educational opportunities provided through state or professional organizations.

*...We [Nurse E's agency] have two symposiums a year...and there they talk about all different aspects [of care]. You know, how do you manage this, how do you manage different aspects, psychosocial issues, medical issues and everything. And I think attending those kinds of seminars also helps you to learn what you might not come across in the field. **Nurse E***

Five participants (two social workers, two chaplains, and one nurse) specifically discussed accreditation as a driver of QI efforts.

*And, anybody who comes in and observes us, and makes recommendations, and charges us if we don't do it right...all of those companies.... **Social Worker E***

I think they [JCAHO] are a necessary component. Because of the abuses of the past in hospice, I think that they make sure that you are doing things in a quality manner. Because that's what the patient and families deserve. And I think, even though it's stressful and intense when they come, they

are very much necessary, very much needed. You know JCAHO... They're coming (laughs). And so, you have to keep all facets of the agency, you know, [my agency] has to be on point, so to speak, in every part.

Chaplain B

Theme 3: Competition Drives Hospice QI Efforts

Four study participants (two social workers, one director, and one chaplain), through eight coded instances, identified competition as another external driver of QI efforts in the hospice setting. Specifically, they described the provision of poor-quality care as a potential reason for loss of customers to other agencies.

We certainly don't want quality to be an excuse for someone else [another hospice agency] to come into our area. Oh, yeah, but that hospice isn't very good, let's get a better one in. So, competition certainly drives quality...If you're not the best, doing the best for your patients and families, somebody else may come in and do it better. And so they should.

Director C

*Competition. You know, maybe because if I do it better than you, then maybe I can get your business. **Social Worker H***

While I could have located these quotations about competition under the hospice industry theme above, the perception of inter-agency competition as an external driver of QI efforts seems qualitatively different. This may be because

“the hospice industry” as a driver of QI efforts connotes a sense of camaraderie and purpose, while competition in some ways connotes the opposite.

Theme 4: Thought Leaders and Peers in Healthcare Facilitate Hospice QI Efforts

When discussing things that help or hinder QI efforts in hospice, three study participants also identified various types or groups of people as external facilitators of QI efforts. Through five coded instances, two directors and one social worker pointed to: (1) peers from other hospice agencies or other healthcare entities and (2) well-known experts outside of the hospice industry.

Director H and Social Worker H identified peers who provide healthcare both inside and outside of the hospice industry as external facilitators of QI, because they believed hospice staff can both collaborate with, and learn from these individuals. Director H pointed to learning from those who work in other hospice agencies by identifying and duplicating “best practices,” as well as by identifying, and avoiding, practices that are less successful.

*You know, opportunities to collaborate with peers within the industry..., are, I think, helpful.... We can learn from each other what others are doing and sort of emulate what's going well and... obviously avoid what's not going so well. **Director H***

Social Worker H suggested that non-hospice peers can provide an “outside the box” view of potential areas for improvement, such as when hospice staff provide care to a patient who lives in a nursing home.

*[W]hen you're...working in the facilities, they'll [staff in those facilities] say well, [agency X] does this [some particular activity] and you guys don't. But I just think that you have to kind of think outside of the box, because obviously they're [agency X] doing it [that particular activity]. So how is that possible? We should be able to be doing that [particular activity] too, right? **Social Worker H***

Director B identified a second group of people as an external facilitator of QI efforts: knowledgeable individuals who are not formally associated with the hospice industry, but who can reach a broad audience, including both the lay public and healthcare professionals.

*...there are people outside of our industry who are realizing that [hospice] has an important place in the healthcare continuum. So, you've got people like Atul Gawande, you've got Ellen Goodman with the Conversation Project...people that aren't steeped in hospice trying to say, pay attention to us [hospice], ... give us your patient, because they need us. **Director B***

In the above quote, Director B points to a surgeon (Dr. Gawande) and a journalist (Ms. Goodman), both of whom have used their influence to draw attention to EOL care in general, and, by extension, to hospice care. This is a novel, yet insightful, perception regarding external facilitators of QI efforts. It reflects the importance of education and opinion leadership in conveying that

hospice care, itself, offers improvement over the “status quo” in EOL healthcare. By making healthcare providers and the general public more aware of the benefits of hospice, the number of people who choose hospice care will increase. Thus, the care for those patients is improved, in comparison to traditional, often hospital-based, cure-focused care. This idea was alluded to on multiple occasions throughout the interviews. It represents a much broader view of improving EOL care than the narrower version of systematic change implemented within a particular agency.

External physicians as barriers to QI efforts

When discussing perceptions of external barriers and facilitators of QI efforts, three study participants (two nurses and one chaplain) identified some “outside” physicians (e.g., patients’ primary care physicians or specialists who have primary responsibility for a particular aspect of the patient’s care) as barriers to hospice QI efforts. They viewed such physicians as a barrier to QI efforts because of their lack of knowledge or understanding about the benefits of hospice and/or their reluctance to “give up” their own efforts at treatment. Both of these shortcomings can result in the unwillingness of the outside physicians to refer patients to hospice in a timely manner.

Yes, it is not obvious to the primary physician, it isn't easy for them to let their patient go to hospice, because they see that as a failure. Imagine a doctor telling them that there is nothing we can do. You feel abandoned. So, we try to build that relationship with them [doctors] to let them know, no it's okay. You want the best for that patient and clinically, you come to

*a point where you see that disease will lead them to death. The best thing you can do, if you care for them, is to direct them to a place where they will receive the care they need instead of you holding them or trying to try chemo or something that will just weaken the patient and then leave no result. **Chaplain H***

I think it's a lot of things. I think it's their [non-hospice physicians'] perception that they can just keep on treating. I think there's a monetary element to it. If they're not coming to me, I'm not getting reimbursed. I hate to say it. But also, a feeling like they're giving up on their patient.

Nurse H

It is possible, however, that with these responses, these study participants were conflating barriers to QI efforts with barriers to providing high quality EOL care. As mentioned earlier, this is a subject that I will return to in Chapter 7.

External Drivers of QI Efforts by Provider Role and Agency Characteristics

The above sections have summarized the findings of factors that interviewees perceived as external forces that drive QI efforts in hospice, addressing Aim 3 of the study. Turning to Aim 6 of the study, I explored whether participants' perceptions of external drivers of QI efforts in hospice differ according to provider role (i.e., director, nurse, social worker, or chaplain) and/or agency characteristics (i.e., size, type, tax status, and locality). These analyses indicate that participants' perceptions of external drivers of QI efforts were strongly associated with provider role. Their perceptions also appeared to

be at least somewhat associated with agency size, although not with other agency characteristics. Specific differences according to provider role and agency characteristics are described below.

Perceived external drivers of QI efforts by provider role

As with the perceptions previously summarized (i.e., meanings of QI, advantages and disadvantages of QI efforts, and internal barriers and facilitators.), study participants' perceptions of external drivers of QI efforts varied according to provider role. Directors and social workers offered substantially more narrative about external drivers of QI efforts than did nurses and chaplains (57 coded instances versus 23, respectively). All of the directors and social workers identified facets of the regulatory environment as external drivers, although only three chaplains and two nurses did so. Similarly, four of the five directors spoke of the hospice industry as an external driver of QI, compared to only two nurses, two chaplains, and one social worker. Accreditation (a specific facet of the hospice industry) was identified specifically as an external driver of QI efforts only by the front-line staff. However, among the four staff roles included in the study, only nurses did not identify competition as an external driver.

Perceived external drivers of QI efforts by agency characteristics

Unlike previously summarized perceptions relating to QI efforts, participants' perceptions of external drivers of QI efforts appear to be associated, at least to some extent, by agency size. Employees of the smallest participating agency did not identify reimbursement/financial considerations as driving QI efforts, although two of the four participating employees of this agency did discuss regulations more generally as a driver

of QI efforts. Also, none of the employees from the smallest, or the largest, of the participating agencies identified competition as an external driver of hospice QI efforts. There were no clear associations with other agency characteristics.

Summary: External Forces that Drive QI Efforts

In this section, I have described the findings that emerged from my discussion with study participants regarding their familiarity with, and perceptions of, external forces that drive efforts to improve the quality of care provided near the end of life (Aim 3 of the study). These discussions occurred in response to direct questions about these external drivers of QI efforts, and to questions about things that help or hinder QI efforts in hospice.

Interviewees recognized a broad array of external factors as driving QI efforts in hospice. Regulations and their attendant effects on hospice reimbursement emerged as the most frequently identified drivers, although participants did not identify specific regulations by their formal names (e.g., the Affordable Care Act). However, study participants also pointed to several additional drivers of improvement activities. These included the hospice industry itself, competition among hospice agencies, healthcare providers in other hospice agencies and in other settings, and thought leaders who have expanded the national conversation about EOL care.

Finally, addressing Aim 6 of the study, findings indicate that participants' perceptions of external factors that drive QI efforts in hospice were associated with provider role and, possibly, with agency size. The most striking differences by provider role were those of directors and social workers compared to nurses and chaplains, both in

terms of total narrative regarding external drivers, as well as the types of drivers they identified. The most striking differences in responses associated with agency size were: a) the lack of discussion of reimbursement or financial considerations by those from the smallest represented agency, and b) the lack of narrative mentioning competition by those from the largest and smallest agencies.

Perceptions of Agency–Specific Quality Improvement Efforts

The overall research question for this study was how hospice care providers perceive QI efforts. As noted earlier, the aims of the study were structured to proceed from the general to the specific. In particular, I wanted to learn about participants' perceptions about quality of EOL care and QI efforts broadly (Aims 1 and 2), and then to focus more narrowly on their perceptions of external drivers of QI efforts (Aim 3), their own agencies' efforts (Aim 4), and their own personal efforts to improve care quality (Aim 5). More specifically, Aim 4 of this study sought to identify and describe the internal (i.e., agency-specific) QI efforts of hospice providers participating in the study. To address this aim, I asked study participants a series of questions about what their agencies' efforts entail, how or why their agencies focused on those particular efforts, and what they think about the results of those efforts.

It should be noted that Aim 4 recognizes the variety and diversity of potential QI endeavors across hospice agencies. QI efforts involve systematic changes that result, ideally, in improved structures, processes, and/or outcomes of care. While there is much similarity how different hospice agencies operate, notable differences in their structures, processes, and outcomes exist. Thus, effective improvement efforts must be tailored to

each specific agency. This is true even given the regulatory environment that requires data collection and reporting of standardized measures of hospice quality. For example, as part of the Hospice Item Set under CMS's HQRP, participating agencies report on treatment of dyspnea. Some agencies perform well on this process of care, and therefore QI efforts are not necessary. Other agencies do not perform as well, and may (or may not) choose to invest in efforts to improve in this area. Those that choose to focus on dyspnea treatment may determine that, for example, improvements in documentation, medication reconciliation, or care coordination (or any combination of these or other areas) are needed to effect change in their dyspnea treatment rates.

Three key findings address Aim 4 of this study. First, study participants had general knowledge of at least some agency-specific QI efforts, although this knowledge was more widespread and specific among agency directors. Second, front-line staff had relatively little knowledge about how their agencies selected particular topics or activities for QI efforts. Third, most, but not all, study participants believed their agencies' QI efforts have had a positive effect. Addressing Aim 6 of the study, these findings suggest that participants' knowledge and perceptions regarding their own agency's QI efforts were associated with their provider roles. Once again, however, they were not linked to agency characteristics. I have elaborated on each of the themes below, using quotations from the interviews to support my interpretation of the findings.

Theme 1: Widespread, Yet Fairly General, Knowledge of Agency-Specific QI

Efforts

I began this portion of the interview by asking “*Are you familiar with the QI efforts that that your agency has been or is currently engaged in? Can you please describe those?*” Sixteen of the 19 study participants described, through 66 coded instances, at least one activity they viewed as a QI activity of their agency. The number of activities described per participant ranged from one to nine. These descriptions of agency-specific QI efforts varied from very general to quite specific, with half of the 16 participants reporting both general and detailed descriptions.

Fifteen of the study participants (all five directors, all four nurses, three social workers, and three chaplains) described their agency’s QI efforts in broad or general terms, through 40 coded instances. The majority of responses referenced documentation efforts, educational efforts, performance measurement done per CMS mandate or for agency accreditation, and the conduct of internal QI meetings as part of their agency’s formal QI activities. As illustrated below, the responses varied considerably in focus and detail.

*In the past...there were audits, for wounds and for just general documentation of the admission visits. **Nurse A***

A significant portion of her [the agency’s QI coordinator] time is spent reviewing the charts. So, every patient chart is reviewed from admission on, so that we can identify any issues or problems that might exist in the

*way we're delivering the care or in the way that the documentation is happening. **Director H***

Yes, I know what they [agency QI staff] look at....I know that they do monitor, like if we're putting certain kind of data in, like the HIS data [Hospice Item Set: measures reported to CMS as part of its Hospice Quality Reporting Program] that's reported back, that type of stuff.

Nurse B

*They have training courses, ...they call it Muffins for something [“Muffins for Maniacs” are educational webinars provided by the Hospice and Palliative Care Network of Maryland]. Basically, it is to educate the nurses who are in the field as to what are some of the changes that are taking place and to improve the quality of life for the patients. And our [agency] also encourages all the nurses to become board-specialty certified. **Nurse E***

*Yeah, I am familiar with them...we have our internal operational quality, our QAPI program, and our QAPI meetings. **Director B***

Six of the study participants who gave relatively broad descriptions of QI activities described some of the clinical aspects of EOL care, including symptom management, psychological and spiritual care, and topics related to patient safety.

*We've done a lot in the past, pain and symptom management ones... We've done things on meeting the emotional needs of the families. Oh, we're working on our [Human Resources] process. That's a huge one..., it's about our recruitment and orientation. **Director A***

A lot of them [the agency's QI efforts] are more nurse-y in focus. I'm thinking back to wounds were a big one and measuring wounds. That was a big push at one point. CNA supervision was a big push at one point.

Social Worker B

Nine study participants (four directors, two social workers, two chaplains, and one nurse), via 26 coded instances, described their agency's QI efforts in relatively more specific terms. In these instances, participants not only named a specific QI activity, but also included additional details, such as explaining why the agency focused on that activity, how the activity was conducted, or how the effort was working. For example, Director C talked about their efforts to decrease visit delay times in the evenings.

*We do have an issue with staffing on the evenings, and we're trying to hire another evening nurse. Although we do have back-up people scheduled, they [the evening staff] hate to bother the back-up nurse...because [he/she] has worked all day. Why have a back-up schedule if you're not going to call them? **Director C***

Chaplain B referenced an effort that encourages all front-line staff (not just nurses) to enter information into the patient's chart.

*One of the things I like now is that we're all able to enter notes, clinical care notes, into a patient's chart. We're doing it in our IDT [interdisciplinary team] meetings, we're all taking turns entering notes and everybody has their input. ... [I]t used to be only the nurses that would do it. And now everybody on the team gets to tell the computer. And that creates an awareness, when you go see a patient, you know that from social work they're worried about this, so you're able to better minister to them. **Chaplain B***

Also, Nurse E described agency-driven social gatherings that promote staff members' willingness ask for help from, and provide help to, their colleagues.

*Well, we do have social gatherings...to become more friendly and all that. So, we have cookouts, social gatherings in the company headquarters...to know each other better the way, you know, if I call you after 5 o'clock, I know you're not going to get pissed off. Because things happen, and you want an answer, so who should I call? [It improves care quality for patients] because you want an answer, you want to give them an answer. ... Sometimes I pick up the phone at 7 in the evening, when I'm not supposed to, I say hey, you're fine, don't worry about it, I'll get somebody to come and see you tomorrow, Saturday. **Nurse E***

Based on the interview responses, it seems clear that study participants were familiar with at least some of the QI efforts of their agencies, even those reaching beyond

their specific roles. However, they described the majority of the efforts in very general ways. Yet half of those who described at least one QI effort were able to include some detail regarding the QI efforts they identified. Importantly, even though many of the descriptions of their agencies' QI efforts were fairly general in nature, they were consistent with the meanings of QI held by study participants, as described earlier in this chapter (i.e., formal processes, learning, changes in documentation to support compliance, "doing better," and activities that positively impact patients and families).

Theme 2: Limited Familiarity with How Agency QI Efforts are Chosen

To identify and describe agency-specific QI efforts of study participants (Aim 4), I also asked study participants two follow-up questions about their agency's QI efforts. The first of these asked: "*Can you tell me how or why your agency decided to focus on those particular efforts?*"

Ten participants (all 5 directors, two nurses, two social workers, and one chaplain) were able to verbalize, to some extent, how they believed their agencies selected the QI efforts that they had described. When responding to this first follow-up question, Director A provided detail about the strategic and operational processes that drive the agency's QI efforts.

We have a leadership meeting once a month. We do a lot of brainstorming [and] strategic planning...at the board level. Our leaders and our board get together annually, to look at our strategic plan....[L]eadership really is the driver of [everything]. And then from leadership, it trickles down

*into quality...and clinical operations....The leaders are here and everybody who's clinical meets monthly too, to specifically talk about quality and clinical and what's going on. **Director A***

Director B referenced performance measurement results, including those conducted for CMS and The Joint Commission and their own internal tracking of adverse events, as the impetus for the selection of QI activities for the agency.

*We have a quality plan that is based on both our outcomes of our Joint Commission survey, that's identified areas for improvement, and the measures that we're focused on by Medicare and other oversight, you know, other State oversight and things like that...as well as our own tracking of occurrence reports, things like that....It could be a service failure, it could be a systems failure, it could be a fall, it could be medication errors, you know, so those [are] where we track those incidents. **Director B***

Although less detailed in their descriptions of how QI priorities were selected, other participants also pointed to performance measurement results (e.g., from the post-death CAHPS survey) or accreditation reports as tools that help in the selection of their agencies' QI activities.

Survey results definitely. There is a survey that gets handed out, I think it's two months after any patient's discharge. [Interviewer: Yeah, the CAHPS survey.] Yeah, that one, yeah. So, certainly, sometimes our

*quality, I know it stems from the feedback on that, but also when JCAHO comes through and those kinds of surveys as well. **Social Worker B***

Notably, however, five study participants (two nurses, two chaplains, and one social worker) indicated they did not know how or why their agencies selected specific activities for their QI efforts. Three of the five stated this explicitly when asked how or why their agency focused on particular efforts:

*No. I'm not privy to that information. **Chaplain A***

*No. I guess management thinks that is what is best for our future nurses and all that. **Nurse E***

*They don't communicate that stuff. I think that there are (sic) other stuff they don't communicate particularly well. **Social Worker E***

Nurse H noted that some QI activities are regulated, but when asked if the agency also conducts non-regulated QI activities, this participant was less sure.

*I know that there's some [activities] that are regulated, and when they're regulated, they do 'em, you know? I guess there probably are [some QI activities being conducted] that are not regulated. I'm not [familiar with those]. **Nurse H***

The responses described above indicate an overall lack of definitive knowledge among a number of study participants regarding how particular topic areas or process were chosen for QI efforts. This was particularly true for front-line staff.

Theme 3: Mixed Feelings Regarding Agency-Specific QI Efforts

As noted above, I asked study participants two follow-up questions to solicit their knowledge of their agency's QI efforts (Aim 4 of the study). The second of these asked: "*In what ways, if any, have these quality improvement efforts made a difference so far?*" This question was designed to elicit hospice staff members' awareness and perception of the results of their agencies' QI efforts, whether positive, negative, or neutral.

In responding to this question, 11 of the 19 interviewees indicated an overall belief in the success of at least some of those efforts. While some of these participants answered rather vaguely (e.g., two participants answered with "*I think so*"), most provided at least one example of what he or she considered an improvement in the quality of care provided. For example, Director A spoke of improved timeliness for patient admissions, as well as improvements in pain control.

This organization would sit on referrals and not admit people...for days, if they didn't have staff to do it or they didn't think they did. And that was one of the things I immediately changed. We admit 24/7, period. ...Well, I think [the] HIS [Hospice Item Set] and other things that we've had to do have helped the patients and their families, because you have to keep seeing the patient if they're not comfortable. Back in the day, if you got

really busy and you started a medication on somebody that had pain, they might not get a visit, truthfully, [until] the next day. They do now.

Director A

Nurse B discussed how improving their medication reconciliation processes had helped to identify potentially dangerous drug interactions.

*The med recs [medication reconciliations], those are important, because if I have a patient who's doing holistic... or ... herbal medications, those can interact with certain other medications. So yeah, the nurses, when they put that all in, it's so we can make sure we don't have any interactions. **Nurse B***

While others did not describe actual improvements in care, they did make some allusion to how or why they viewed certain QI efforts as successful. For example, Nurse A linked improvements in documentation to better communication between team members.

*Because with those [QI efforts mentioned previously], our documentation improves, so it's better communication between the nurses and between the social workers. **Nurse A***

Similarly, Social Worker B linked activities to improve medication reconciliation with increased patient safety.

*Things like medication rec [reconciliation], I absolutely I see that that's safety, that's really important. **Social Worker B***

Even so, four study participants verbalized a degree of skepticism as to whether their agency's QI efforts had made a positive difference in care provided to patients. Notably, all four of these participants who expressed skepticism spoke about QI efforts that center on improvements in documentation. One of these four (Social Worker B) indicated both belief in the effectiveness of QI efforts regarding medication reconciliation, as well as skepticism regarding documentation.

*Well, I would say definitely it's better charting. Whether that's an improvement for us as an agency I don't know, if it's necessarily an improvement to patient care. But if we want to continue to operate and be a viable organization, we do have to continue to be accredited by these agencies and so, ... in that sense ... it's good. (laughs) But I think you can tell I'm not always sure that quality improvement actually ends up in better care in the home. That, I'm not always one hundred percent sure of. **Social Worker B***

*To me that [point of care, computerized documentation] is totally uncompassionate. How are you ever supposed to develop rapport with somebody with a computer between you? Now, I will take in pen and paper and jot notes, but I'm not going to put a wall between me and a patient that I'm trying to build a relationship with. **Social Worker C***

*Taking more time to chart. That's another thing, you know. Like even for my chaplain's profile, there are a lot of questions that do not pertain to what we really do, and questions [that are] very, very redundant that actually none of us really fill them out. **Chaplain E***

The findings from these interviews, as described above, suggest that most study participants saw value in the QI efforts undertaken by their agencies, although some remained skeptical, particularly regarding QI efforts that primarily emphasize improvements in documentation.

Perceptions of Agency-Specific QI Efforts by Provider Role and Agency

Characteristics

To address Aim 6 of this study, I explored whether study participants' knowledge of their own agency's QI efforts varied according to provider role and/or agency characteristics. As with most of the earlier findings regarding perceptions of QI efforts, study participants knowledge and perceptions regarding their own agency's QI efforts were associated with provider role, but not with agency characteristics. Specific differences in findings by provider role and agency characteristics are described more fully below.

Perceptions of agency-specific QI efforts by provider role

More agency directors identified one or more of their agencies' QI efforts than did those in the other three roles. Moreover, agency directors, as a group, identified many more efforts than did any of the front-line staff participating in the study.

Specifically, all five directors in the study identified at least one agency-specific QI effort (a total of 26 efforts overall). In contrast, although all four participating nurses identified at least one agency-specific QI effort, as a group, they described only eight QI efforts overall. Furthermore, four of the five participating chaplains identified eight QI efforts, and three of the five participating social workers identified nine efforts.

In terms of familiarity with the processes involved in selecting their agencies' topics for QI activities, all five participating directors were able describe them in at least some detail. However, only two nurses, two social workers, and one chaplain were able to do so.

Finally, agency directors and nurses were more apt to view their agencies' QI efforts as successful, at least in part, compared to social workers or chaplains. Specifically, all five directors and three of the four nurses provided narrative indicating belief in the success of their agencies' QI efforts, in comparison to only two social workers and two chaplains. Interestingly, however, three of the five participating social workers expressed some skepticism regarding the efficacy of their agency's QI efforts specifically in relation to documentation. A similar skepticism was expressed only by one other participant (a nurse).

Perceptions of agency-specific QI efforts by agency characteristics

Differences in familiarity with, and perceptions of agency-specific QI efforts were not clearly linked to agency characteristics. At least two participants from each agency identified at least one QI effort conducted by their agency. For two agencies, all four participating employees identified at least one QI effort. However, the various

characteristics of these two agencies were similar to those of agencies with fewer employees who identified QI efforts. Interestingly, agency size did not seem to be linked to study participants' familiarity with their agencies' processes in selecting QI efforts. Similarly, perceptions of the effectiveness of agency-specific QI efforts also did not appear to be linked to agency characteristics, as at least one participant from each agency reported a favorable perception. Moreover, the four participants who expressed skepticism regarding results of QI efforts were equally distributed across four of the five participating agencies. Only the smallest of the participating agencies had no one verbalize skepticism of the effectiveness of QI in that portion of the interview.

Summary: Perceptions of Agency-Specific QI Efforts

Overall, study participants were aware of at least some of their agencies' QI efforts. Yet, for the most part, those interviewed described these efforts in general, rather than specific, ways. These QI efforts, as described, corresponded well with the meanings of QI that were expressed by study participants earlier in their interviews. Fewer social workers were able to describe specific QI efforts than were those in other roles. But as a group, agency directors, those ultimately responsible for completion of QI tasks, named many more QI efforts than did front-line staff. These agency directors were intimately familiar with how their agencies select focal areas for their QI efforts, and appeared to have a key role in the decision-making. In contrast, the front-line staff were much less familiar with how QI efforts were selected, typically pointing either to post-death survey results, findings from the accreditation process, or, in some interviews, explicitly stating they did not know. Participants' views of the ultimate effectiveness of their agencies' QI

efforts also were mixed. Just over half indicated a belief in the success of those efforts, although their descriptions were fairly abbreviated and, in some cases, quite vague. A few others used this opportunity to express some skepticism regarding QI efforts, particularly those having to do with documentation.

Personal Participation in QI Efforts

I concluded the process of gathering narrative data by asking study participants a series of questions regarding their personal QI efforts. This included asking them to describe their involvement in their agency's QI activities and to identify what might help them be more effective in improving care quality. These questions were designed to address Aim 5 of this study (i.e., to identify and describe the perceptions of hospice providers concerning their own QI efforts). To address Aim 6 of the study, I also analyzed the findings from this portion of the interviews according to provider role (i.e., director, nurse, social worker, or chaplain) and agency characteristics (i.e., size, type, tax status, and locality).

Two key themes emerged from analysis of participants' discussions of these three questions that address Aim 5 of the study: (1) activities discussed as personal QI efforts were not limited to the formal QI efforts of their respective agencies and (2) participants overwhelmingly perceived increased educational opportunities as the best means of making their own QI efforts more effective. Addressing Aim 6 of the study, findings indicate that perceptions of their own personal QI efforts varied according to provider role. Data also suggested these perceptions may be linked to agency tax status.

Theme 1: Personal QI Efforts Not Limited to Formal QI Efforts of the Agency

The first question that I asked the participants regarding their own personal QI efforts was “*In what ways have you been involved in this agency’s quality improvement efforts?*” Sixteen of the 19 study participants, via 72 coded responses, answered this question. Interestingly, while many of these responses described efforts in improving EOL care quality, many also described efforts to provide high quality care more generally. I have noted this conflation between providing high-quality care versus improving quality of care earlier, and will explore it more deeply in Chapter 7. It is worthwhile noting that this conflation was most noticeable in participants’ discussion of their personal efforts, as compared to their discussions about general or agency-specific efforts. Putting aside those responses regarding providing care more generally, 15 participants (all five directors, four social workers, three nurses, and three chaplains), via 53 coded instances, identified various personal activities they viewed as methods for improving the quality of care they provide.

Some described their personal QI activities in a very general way, such as attending QAPI meetings (which are mandated for agency participation in Medicare), helping to facilitate QI meetings, and attending various training efforts. However, many described more specifically how they, personally, participated in their agencies’ QI efforts, even when also speaking about the more general activities listed above. For example, as Nurse A provided examples of agency-specific QI efforts related to documentation, this participant also described personal efforts that included providing

input on changes in documentation practices and adhering to directives regarding pressure ulcer documentation.

*They've [agency QI staff] done email surveys, and with nursing meetings and stuff—they've asked what our thoughts were on this matter or that matter, as far as if we like that documentation or "should we get back to this way?" or "Sorry, but this is just the way it's gonna be." They want our input. ... [Pressure ulcers], there's so many and it's so frequent, they can become such a problem so fast. Malnutrition, patients aren't eating. Those things are breaking down. I always made it part of my job but [now] I'm more careful with wound assessments, just to make sure I do it the right way. **Nurse A***

Similarly, Social Worker B described efforts to be more timely and comprehensive when documenting patient care.

*So, I started paying a little bit more attention to that section of the assessment [oxygen safety] and, you know, actually writing things in, like "nephew is a smoker, but always goes outside onto the back porch to smoke," things like that. ... Well, I will not say that my documentation is always perfect, so certainly I'm always trying to push myself to be more timely in doing things. And trying to get better at using the computer during my visit in a way that isn't going to destroy a therapeutic relationship. **Social Worker B***

However, many of the study participants' own QI activities did not align seamlessly with the formalized, agency-specific activities they reported earlier in the interview. For example, when describing engagement in educational-related activities, Nurse E described reading journal articles.

Well, I do continuing education, I read articles. I read the National Hospice Palliative Journal, I get that one. And that always has research studies. Nurse E

Nurse A described going to more senior colleagues as way to improve clinical knowledge.

I'll go to [the QI Coordinator], I'll go to my boss, I'll go to [the agency director] and say, "What should I have done in this case?" or "What should I do? 'Cause I don't know, I'm stuck. I've never been faced with this question or that issue." Nurse A

Social Worker B referred to a previous agency-sponsored effort to learn about best practices from other hospice programs.

At one point I was part of a committee that was trying to look at different ways, it wasn't necessarily just quality improvement, it was also just general best practices, how do other hospices do things? Is that something we can bring here? That kind of thing. Social Worker B

Interviewees in varied staff roles also reflected the previously-described QI meaning of “doing better,” particularly in communicating, listening, and observing patients and their families.

Communication, that’s been my messaging.... [W]e must figure out how to take the time to communicate, in ways that sons and daughters and spouses want to be communicated with. So that they’re educated, and I never hear the phrase, “I wish I would have known or expected that.”

Director E

*I had another patient who was a junk food junkie (laughs). So, it was Doritos and potato chips when I went to see him. And those are some of the things that you do, you’re a listener, you’re an observer. My quality improvement is just always trying to be a better listener. Always trying to make sure that I’m servicing them the way they want to be serviced, as opposed to my preconceived notions. **Chaplain B***

The most important thing I can do is listen. [Interviewer: Have you gotten better at listening over the years?] I think I have, because I’m now less concerned about ...other things...you know, I’m not doing the documentation there [at the bedside], I’m not worrying about every single box, name, and number and things like that. From the documentation perspective, I’ve not improved at all. And I would say I’ve declined, enormously. However, on the clinical, I can’t help but believe that by

*focusing and listening and observing and learning the best ways to communicate with the family and the patient, that I am giving them better care. **Social Worker E***

Interestingly, two innovations were described by Chaplain A as QI efforts because they opened the door for future contact by this chaplain that may not have been pursued by the patient or family otherwise.

*Most of the time, the nurse will ask [if somebody is interested in chaplaincy services] on intake. When I first got here, [the intake nurses] were asking whether the [patient/family] wanted the chaplain. Now, [the intake nurses] just say, "The chaplain will call you." I'll call, and sometimes they decline over the phone, which is fine. Then I'll say, "Do you mind if I check back with you in about a month or so?" Usually they agree with that. [Interviewer: That actually is a change from going and saying, "Do you want a chaplain?" to "The chaplain will call."? Do you see that as a quality improvement activity?] Yeah, I do, [it has increased the] number of contacts. That just reminded me, sometimes when the admitting nurses get bogged down, I'll go and do the consent signing. That kind of gets me in the door, at least for initial contact. And then I'll say, "Is it okay if I come back and talk?" That's something that started with me. I think [that actually helps patients and families], again, because that initial contact, they see who I am. So that when I call them a week later, they already have a face. **Chaplain A***

The majority of the remaining personal QI activities were reported by agency directors. For the most part, these reflected various efforts for which they have authority as director of the agency, even if they were not specifically identified as formal QI efforts of the agency. Examples include hiring “*the right person*” for the QI Coordinator position and enhancing service offerings, such as music therapy, dialysis for end-stage renal disease patients, and shortening the time from referral to admission.

As expected, many of the activities described by study participants as personal QI efforts harkened back to those previously identified as agency-specific QI initiatives, and many were consistent with the meanings of QI that were held by study participants, as described earlier in this chapter. Yet, as illustrated above, not all of the efforts perceived as QI activities align strictly with the formal QI efforts of the agencies included in the study. Regardless, participants generally believed their QI efforts have had a positive impact for their patients.

Theme 2: Education Perceived as Key in Making Personal QI Efforts More Effective

As noted earlier, Aim 5 of the study was to identify and describe the perceptions of participating hospice staff concerning their own QI efforts. One of the final questions that I posed to address this aim was “*What might help you to be more effective in improving care quality?*” Through a total of 23 coded instances, 11 study participants (three directors, three nurses, three social workers, and two chaplains), responded to this question. Of these, eight voiced the desire for education (two individuals from each provider role). Each of these participants signaled their desire for additional learning

opportunities that could be provided by, or facilitated by, their agency. While such opportunities could include more formal training, some participants also expressed their belief that dialogue and collaborative learning with their colleagues would help them provide better care for their patients.

*So, for me personally, I'm a one-on-one person, I'd rather be told "you really suck at this, you need to work on you" versus go to a meeting that's ... about that topic and wondering if I'm the reason is this a whole group thing. (laughs) So yeah, like knowing when it's a specific failing on my part versus...something that everybody needs to work on. **Social Worker***

B

*I think at this agency... there's not a whole lot of guidance on how to improve your care...there's not a lot of feedback. But I feel like there's a lot of room for improvement on collaborating, you know, on how the nurses could do their jobs better and the social workers could do their jobs better and the chaplains could do their jobs better.... **Social Worker***

C

*...I would like to get together with my colleagues, my chaplain staff colleagues to talk about our work and how we can improve it, and to give each other feedback, and for consultation as well. Like if I have a tough case, you know, what can I do about it? **Chaplain E***

*I think, you know, attending some of these seminars would help me to educate myself better from somebody who's been in the field for many years...like a cardiology nurse or something like that. And that might be something also that might... sway me to further my skills in one particular organ system. **Nurse E***

A few participants suggested that educational opportunities could be facilitated to a greater extent if their agency would (a) allow more work time to be devoted to educational activities, and/or (b) provide financial support that would allow individuals to pursue learning (e.g., formal continuing education, pursuit of certification) on their own time.

*Well, I would love to go to the continuing education; however, [my agency] only provides two days. So, if I do, then I have to take my own vacation time. **Chaplain E***

*Well, they could always promote continuing education more. I don't think they promote it. They could always help with reimbursement. I think that's a downfall of this particular [agency]. I don't think they focus on the continuing education like they should. **Nurse H***

This focus on education as a fundamental way to improve care quality was not limited to front-line staff, as Director B and Director H also spoke about staff education in this context.

*So, I would put the staff as sort of my number one concern in terms of ... how we could do things better, have more qualified people and more opportunities for improving their capabilities and their level of understanding, their expertise, their education. All that would be positive to improving the care that we deliver. **Director H***

*I think probably the key thing would be to really identify what's the best resource and support we can give to the people who are delivering the care. Whether it be in education, tools, time, or thinking differently about how they do their jobs, so that it is more effective and efficient...in delivering that care. Staying abreast of...[best] practices that other organizations are doing....So, to me, bringing back, or even just having, those conversations with other people who are doing it differently, or thinking about it differently, helps inform how I think about what we can do differently and better here. **Director B***

As illustrated above, the participants focused on education as the primary means of helping them improve care quality. This theme of education has emerged throughout these findings, in terms of meanings of QI, barriers and facilitators of QI efforts, factors that influence perceptions of QI efforts, and in various ways, as a way to improve quality of care. I will discuss this overarching theme of education more fully in Chapter 7.

Personal Participation in QI Efforts by Provider Role and Agency Characteristics

The above discussion summarized study participants' perceptions of their own QI efforts, including the ways in which they viewed their participation, their beliefs regarding the impact of those efforts, and what they thought would help them to improve the care they provide. As with the majority of perceptions explored in this study, responses regarding personal QI efforts were associated with provider role. These findings also indicated that the tax status of the agency (but not size, type, or locality) may be associated with the number and types of personal QI efforts that were reported by participants. These specific differences address Aim 6 of the study, and are described more fully below.

Perceptions of personal QI efforts by provider role

Differences in perceptions of the number and types of personal QI efforts varied to some extent based on provider role. For example, all five directors provided examples of their own personal contributions to QI efforts, compared to four social workers, three nurses, and three chaplains who did so. Moreover, directors spoke of more personal QI efforts, on average, than those in other roles. In terms of the types of personal QI efforts described, at least one participant in each role, except that of chaplain, mentioned participation in formal QI activities, such as attendance in agency QI meetings. However, only nurses and social workers described QI efforts related to documentation and compliance (e.g., working to improve timeliness or comprehensiveness of documentation). Participating agency directors also were more apt to describe activities that did not strictly align with meanings of QI that emerged in the earlier portion of the

interviews (i.e., formal QI activities, documentation, learning, and “doing better”). In fact, all five directors described such “other” QI efforts (e.g., specific hiring decisions and extension of services offered by the agency), while only two chaplains and one social worker did so. As noted earlier, many of these “other” types of efforts that were described by the directors stem from their authority within the agency. Notably, the view of education as a primary means of increasing the effectiveness of personal QI efforts did not vary according to provider role.

Perceptions of personal QI efforts by agency characteristics

Interviewees’ responses regarding personal QI efforts cannot be linked definitively to specific agency characteristics. However, individuals from one participating agency, which differed from the others in terms of its tax status, were relatively less likely than those from the other four agencies to describe personal QI efforts. Specifically, only two of the four employees of this agency described their own QI efforts via six coded instances. In contrast, 3-4 participants from three other agencies described their personal QI efforts via 11 to 18 coded instances (depending on the agency), while two participants from the remaining agency, which had only three participants, described their personal efforts via six coded instances. However, because each agency had at least two participants who described their personal QI efforts, a conclusive link to agency tax status was not supported in this study.

Summary: Personal Participation in QI Efforts

The perceptions voiced in these narratives regarding personal QI efforts were somewhat, but not completely, aligned with the agency-specific efforts described earlier

in the interviews. At least some of those interviewed saw themselves as involved in QI efforts that are uniquely their own, rather than operating solely through the more formalized agency-specific efforts. Many, although not all, of the efforts that study participants viewed as QI activities corresponded to the meanings of QI that emerged through this study. Education, or more specifically, furthering their education in various ways, emerged as the key approach for making participants' own QI efforts more effective. Some staff members in the study were interested in more long-term educational efforts (e.g., to achieve certification). Others wanted agency-led one-on-one training, seminars, or other forms of continuing education, and/or financial support to pursue these types of educational endeavors. Finally, perceptions of personal QI efforts clearly were associated with provider role. Specifically, agency directors identified their own involvement in many more QI efforts than did front-line providers. While there was some indication that agency tax status may be linked to personal QI activities, the data from this study were not strong enough to assert a definitive association.

Summary of Chapter 6

This chapter summarized the findings regarding perceptions of EOL QI efforts in hospice from interviews of 19 hospice employees in Maryland. These findings addressed both the overall research question of how providers in the hospice industry perceive QI efforts, as well as Aims 2-6 of the study.

Analyses revealed five key insights that emerged from dialogue pertaining to Aim 2 of the study, which considered perceptions of QI efforts through the lens of meanings, advantages and disadvantages, barriers and facilitators, influences, potential, and ideas

for improvement. First, QI meant different things to different people. Participants in this study described five distinct meanings of QI, including formal processes undertaken by hospice agencies, learning by hospice staff, implementing changes in documentation to support compliance, “doing better,” and participating in activities that positively impact patients and families. Second, when invited to discuss advantages and disadvantages of QI efforts, participants did so primarily through a self-centric lens, and they focused more on QI’s disadvantages than advantages. Third, study participants identified both internal and external barriers to, and facilitators of QI efforts. As a whole, however, they identified more barriers than facilitators. Importantly, interviewees collectively perceived various aspects of agency leadership activities and attitudes, educational activities, and staff attitudes, as both barriers and facilitators. Fourth, participants most frequently credited their own previous experiences with QI efforts or their own maturation (either personal or professional) as having influenced their current perceptions of QI efforts, whether positive or negative. Of those who described a change in how they have perceived QI efforts over time, the shift was from a less positive to a more positive view. Fifth, all study participants agreed that the quality of EOL care can be improved, and most had concrete suggestions for improvement. These suggestions included increasing access to hospice services, ensuring the agency has sufficient staff, building employee skills, promoting staff members’ emotional well-being, and improving the way QI activities are implemented.

Regarding perceptions of external forces that drive QI efforts in hospice (Aim 3 of the study), participants recognized four key drivers. They most frequently alluded to

the regulatory environment, including requirements related to reimbursement. Other external drivers identified by study participants included the hospice industry itself, inter-agency competition, and thought leaders and peers in healthcare.

Regarding perceptions of their own agency's QI efforts (Aim 4 of the study), data from this study indicated that participants had some knowledge about these activities. However, for all participant roles except directors, this knowledge was fairly general. Front-line staff appeared to have relatively little insight about how specific activities are selected for QI efforts within their agencies. Yet, for the most part, they viewed their agencies' efforts in a positive light, believing they result in actual improvements in patient care.

Regarding participants' perceptions about their own QI efforts (Aim 5 of the study), two key themes arose from the interviewees' narrative. First, they saw many things they do as QI activities, including things that are not part of their agencies' formal QI activities. Second, they identified additional educational efforts as the primary way to make their own personal QI efforts more effective.

Finally, addressing Aim 6 of the study, findings from the interviews indicate that, without exception, participants' perceptions of QI efforts varied according their professional role in the organization (i.e., director, nurse, social worker, or chaplain). For the most part, however, these perceptions were not linked to characteristics of the participants' agency.

Chapter 7: Conclusion

This study has attempted to answer the overarching question of how providers in the hospice industry perceive QI efforts. Core assumptions underlying the study included the belief that perceptions of QI influence: (1) the motivation to engage in improvement efforts, and (2) the level of success in actually improving care quality. Testing these assumptions is far beyond the scope of this study. However, by focusing on narratives and personal meanings from the 19 participating hospice agency directors, nurses, social workers, and chaplains, this study provides a novel lens for examining QI efforts in the hospice setting.

Overall, study participants agreed that the quality of EOL care can be improved, and in general, most conveyed a positive, yet realistic view, of efforts to improve that care. Participants' perceptions of both EOL care quality and its improvement were associated with their professional roles in the organization. However, for the most part, their perceptions did not appear to be linked to the characteristics of the agency that employs them. Many of the perceptions that emerged from participant conversations throughout the interviews aligned with previous literature on perceptions of EOL care quality and its improvement. Original contributions from this study include insights on the meanings of QI held by hospice staff and how occupational roles of staff members were tied to differences in perceptions of quality EOL and its improvement.

This final chapter synthesizes the results of the study, first providing a synopsis of key findings, then elaborating on cross-cutting themes that appeared throughout the narrative data. The chapter continues by noting how the findings align with previous

research and linking the study findings to the underlying theory. The chapter then goes on to identify several strengths and limitations of this study. Finally, the chapter concludes by discussing implications of the study findings on both policy and practice, and providing ideas for future research.

Synthesis of Study Results

As detailed in chapters 5 and 6, many findings emerged that addressed the specific aims of the study. Below, table 11 outlines the study's key findings by study aim.

Table 11. Key Findings by Study Aim

Aim 1: Meanings of quality care at the end of life

- The most salient meanings of quality EOL care held by study participants reflect: (1) effective symptom management, and (2) individualized care that aligns with patient and family wishes.
- When specifically describing high-quality EOL care, interviewees focused primarily on individualized care and holistic care.
- When describing moderate- and low-quality EOL care, participants specifically discussed the lack of those attributes they view as markers of high-quality EOL care (e.g., individualized and holistic care).
- Some participants focused on non-hospice care (i.e., traditional medical/family care not provided by hospice staff) when describing low-quality care. For these participants, low-quality could mean the patient is getting either too much or not enough care.

Aim 2: Perceptions of improving quality of care near the end of life

- Multiple meanings of QI
 - Participant responses revealed five related, yet distinct, meanings of QI: (1) formal processes, (2) learning on the part of hospice providers, (3) changes in documentation to support compliance, (4) “doing better,” and (5) activities that positively impact patients and families.
- Advantages and disadvantages of QI efforts
 - Study participants verbalized substantially more disadvantages than advantages of QI efforts.
 - Many of the advantages and disadvantages of QI were viewed through a self-

centric lens.

- Specific benefits enjoyed by hospice staff, hospice agencies, and patients and families were seen as the key advantages of QI.
- Disadvantages of QI were characterized by study participants primarily in terms of negative staff emotions and as having the potential for counter-productivity.
- Internal barriers to, and facilitators of QI efforts
 - Often, although not always, participants discussed particular activities and attitudes as a barrier/facilitator “pair,” with one aspect viewed as helpful to QI efforts and its opposite viewed as a hindrance.
 - Internal barriers/facilitators include various activities and attitudes of agency leadership (e.g., staff involvement, tone in communications, punitive mindset), educational activities of the agency, and staff attitudes.
 - Study participants more often saw educational activities as facilitators than as barriers.
- Factors that influence perceptions about QI efforts
 - Previous experiences (i.e., prior QI activities and positive results of QI efforts) affect current perceptions.
 - Personal and professional maturation shape current perceptions.
 - For those who described an evolution in their perceptions of QI efforts, the shift was uniformly toward a more positive view.
- Potential of, and ideas for improving the quality of EOL care
 - All participants agreed that EOL care can be improved.
 - Specific ideas for improvement included: (1) increasing access to hospice services, (2) ensuring sufficient numbers of agency staff, (3) increasing staff skills, (4) promoting the emotional well-being of staff, and (5) modifying QI activities of the agency.

Aim 3: External forces that drive QI efforts

- Participants identified four external forces that drive hospice QI efforts: (1) the regulatory environment, (2) the larger hospice industry, (3) competition, and (4) thought leaders and peers in healthcare.

Aim 4: Agency-specific QI efforts

- Participants had general knowledge of at least some agency-specific QI efforts. This knowledge was more widespread and specific among agency directors.
- Front-line staff had relatively little knowledge about how their agencies select particular topics or activities for QI efforts.
- Most, but not all, study participants believed their agencies’ QI efforts have had a positive effect.

Aim 5: Personal participation in QI efforts

- Participants view their personal QI efforts as not limited to the formal QI efforts of their respective agencies.
- Participants believe that more education is the primary mechanism for making their own QI efforts more effective.

Aim 6: Differences in perceptions by provider role and agency characteristics

- Meanings and perceptions were associated with provider role.
 - For the most part, meanings and perceptions were not linked to agency characteristics (although agency size was associated with views of external drivers, and perceptions of personal participation in QI efforts appeared to be associated with agency tax status)
-

Cross-Cutting Themes

After reflecting on the key findings of the study, I identified five cross-cutting themes that summarize important aspects of participants' perceptions of quality EOL care and its improvement. Specifically, participating providers' perceptions of EOL care quality and improvement were: (1) expansive, (2) pragmatic, (3) conflated, (4) fragmented, and (5) self-centric. Although all of these are inter-related in various ways, I have discussed them separately below.

Hospice providers' views of quality EOL care and QI were expansive

This study demonstrated that the perceptions of participating hospice providers regarding quality EOL care and its improvement were expansive. By this, I mean their perceptions were wide-ranging and sometimes unexpected. This was evidenced by the meanings they ascribed to these concepts, their views of EOL care provided outside of the hospice setting, the ideas they suggested for improving EOL care, and the advantages of QI that they described.

As discussed in Chapter 5, the most salient meanings that study participants ascribed to quality EOL care included effective symptom management and individualized care that aligns with the wishes of patient and their families. Study participants portrayed these meanings of quality EOL in terms of actions they perform as part of their day-to-day work, as well as the ways in which they conduct these actions. However, some study participants also defined quality EOL care by describing activities and outcomes of patients and families (e.g., family engagement in the care process, sense of confidence and hope and lack of fear). Moreover, some participants also recognized that EOL care also is provided in settings other than hospice, and is therefore outside of their sphere of influence. More specifically, a number of participants described at least a portion of such care as low-quality care, which can manifest as either too much care (e.g., continuing futile treatments) or not enough care (e.g., lack of holistic, person-centered care). Furthermore, when offering ideas for how EOL care could be improved, study participants underscored their recognition of this low-quality non-hospice care by recommending education for the community at large about the value of hospice and by expanding access to hospice.

The meanings ascribed to QI by participants in this study also were quite expansive. By this, I mean the meanings covered more and different topics than those I expected, given my own definition of QI as “systematic changes that result in improved structures, processes, and outcomes of care.” The two meanings of QI that I did not anticipate included that of learning by hospice providers, and as changes in documentation done primarily for the purposes of compliance. Both of these meanings

have implications for practice, particularly with respect to educational efforts on the part of hospice agencies and other stakeholders, as will be discussed below.

Finally, the expansive view of QI perceived by study participants also is demonstrated by the advantages of QI they articulated. As expected, they pointed to improved outcomes for patients and families (e.g., better symptom management and coping skills). Surprisingly, this was the minority perspective. The advantages of QI that were more frequently recognized by participating providers included increased professional knowledge and growth for agency staff, as well as benefits to the agency itself by facilitating fulfillment of the organization's mission and allowing demonstration of competitive advantage.

Hospice providers' views of QI were pragmatic

Participants in this study also exhibited a pragmatic view of QI efforts. By this, I mean that, although participants' evaluations of QI were positive overall, they were able to identify and articulate attendant disadvantages of QI efforts, as well as potential for unintended consequences. Stated differently, while maintaining a positive perception of QI in general, these hospice providers were not blind to its negative aspects. This pragmatic view was exemplified by the relatively high volume of narrative regarding disadvantages of QI efforts as compared to its advantages. It was also demonstrated through the skepticism voiced by participants about QI efforts that focus primarily on changes to documentation practices, particularly those implemented in response to requirements for compliance with state licensure, industry, or accreditation standards. For example, participants noted the possibility that focusing too narrowly on

documentation or other compliance activities could divert attention from providing high-quality care or otherwise prevent focus on improvement activities that would have greater positive impact on patients and families. Some participants were particularly skeptical about activities posited as improvements in care that, conversely, they viewed as decrements in care. One such example is the requirement for completing documentation within two hours of making a visit, which can preclude making additional visits to other patients in a typical workday. Another example is the requirement to document care at the bedside, which was seen as impeding provider-patient rapport.

Hospice providers' views of QI were conflated

As already noted several times in Chapter 6, this study also revealed conflation between the concepts of care quality, QI, and quality assurance in the narratives of some study participants. The conflation between care quality and QI emerged most often when I asked about participants' personal QI efforts. In several cases, their responses reflected the actual provision of care (i.e., the things they actually do for patients and families, which they believe is of good quality), rather than the actual things they do, specifically, to make that care better. This conflation also emerged in discussions about barriers to QI efforts, when participants talked about things that make providing high-quality care difficult (e.g., staff shortages) rather than things that make improvement in that care difficult. Of course, such conflation is understandable, given that it is not possible to completely decouple quality from its improvement. In fact, as noted earlier, I also realized that I was not as clear in my language as I might have been for some questions,

such as using the term “quality improvement” to connote both the activities to effect improvement, as well as the desired outcome of those activities.

Some study participants also conflated quality assurance (QA) activities (i.e., activities done to ensure compliance with industry standards) with QI activities. This was alluded to in the previous section that discussed participants’ skepticism with activities that focus on documentation and compliance. Conflation between QA and QI is particularly understandable, given that, ideally, changing documentation processes and conforming to standards of practice ultimately will result in better outcomes for patients and their families. Also, it is not uncommon for the same hospice staff (or department) to be responsible for both QI and QA (i.e., for improvement activities as well as for compliance). While this muddiness in concepts and terminology did not emerge as a finding in the literature that I reviewed, it may have if my review had focused on implementation of QI initiatives or evaluations of such initiatives, rather than on provider perceptions of QI initiatives.

Hospice providers’ views of QI were fragmented

Findings from this study also illuminated several important ways in which knowledge or views of QI were fragmented. First, the meanings of QI held by study participants indicate that most did not explicitly view QI through the lens of the patient and family, even though their perceptions of quality EOL care were almost uniformly person-centered.

Expanding on this idea, there also appeared to be a disconnect between participants’ meanings of quality EOL care and their ideas for improvement. These ideas

for improvement fell broadly into areas of improving access to hospice care, ensuring sufficient numbers of staff to provide care, increasing staff skills, promoting the emotional well-being of staff, and enhancing approaches to QI in terms of methods and participants. While each of these areas of improvement make sense conceptually, participants often did not explicitly “connect the dots” between what they believed to be deficiencies in care quality (e.g., non-holistic care due to a lack of spiritual support) with their ideas for improvement (e.g., hire more chaplains). It is unknown whether this disconnect reflects a true conceptual gap in linking problems in quality with mechanisms to address the problems and with desired outcomes of those efforts, or if the disconnect is one of articulating the connections, particularly given that I did not explicitly ask them to describe quality problems and then offer ideas for improvement. Also, there was an apparent inability on the part of some participants to further “connect the dots” between ongoing QI activities and how such activities will result in improved care for patients and families. Once again, some participants, at minimum, either did not, or were unable to articulate these connections. However, some understood the desired connection, but were skeptical that the activities would actually result in improved care.

Findings from this study also revealed incomplete knowledge of their agencies’ formalized QI activities among participating front-line staff, as well as in their knowledge of the results of those activities (i.e., whether or not the improvement activities were actually spurring better care). This was evidenced by the lack of specificity on the part of some participants when discussing their agencies’ QI efforts and/or in explaining how

those efforts were decided upon. Also, only about half of the participants were able to opine about the success of those efforts.

Hospice providers' views of QI were self-centric

Finally, this study revealed that many participating hospice providers' perceptions regarding efforts to improve EOL care were self-centric. By this, I mean that their views of QI efforts were shaped in many ways through the lens of the self. Not surprisingly, when describing the most influential factors on their current views of QI, study participants focused primarily on the self (i.e., via discussion of their previous QI experiences and personal and professional growth). However, the self-centric nature of perceptions played out in several other ways throughout the participant interviews. It was particularly prominent during discussions about advantages and disadvantages of QI efforts, barriers and facilitators of QI efforts, and in their views of both education and staff wellness as ways to enhance QI activities and outcomes.

Regarding perceived advantages of QI, recall that one of the most frequently mentioned was the increase in professional knowledge and growth for agency staff. When discussing disadvantages of QI efforts, interviewees spoke about the negative emotions of dread, anger, fear, and discouragement, as well as increased stress. Interestingly, these participants did not speak about positive emotions that might be spurred via QI efforts, although it seems these also could be evoked when working to improve EOL care quality (e.g., satisfaction, joy, interest, pride). The self-centric lens also came into play when participants discussed staff attitudes as barriers and facilitators of QI efforts. In these discussions, participants identified the attitudes of openness

toward change, willingness to learn, and positivity as facilitators, and their opposites as barriers.

Perhaps most interesting, however, study participants often applied a self-centric lens in their thoughts on how to improve the quality of EOL care. Recall that improving staff skills and promoting emotional well-being of staff (particularly by helping to reduce stress) were two of the most frequently mentioned ideas for improvement. Moreover, many study participants viewed additional education and training as the most effective way for them, personally, to effect improved care quality.

It is important to note, however, that this finding regarding a self-centric viewpoint should not be construed in a negative way. It does not mean that participating hospice providers were focused primarily on their own comfort, particularly at the expense of the patients and families they care for. In fact, many of the participants emphasized the mission of hospice and their commitment to that mission.

Alignment with Previous Literature and Theory

Although there are multiple frameworks that describe domains of quality EOL care, there is no consensus-based definition of high-quality EOL care. Moreover, recent research examining the perceptions of quality EOL care from the perspective of healthcare providers is limited, with even fewer studies targeted to EOL care quality.

Although some studies have examined perceptions of quality care among various types of providers, the majority comes from the nursing perspective. Similarly, literature focusing on perceptions of QI among those providing EOL care is sparse. The majority of this

research has centered primarily on barriers and facilitators of QI, and to my knowledge, none has explored the meanings of QI held by EOL care providers.

Nonetheless, many of the study findings on provider perceptions of quality aligned with available literature. Specifically, the most common meanings that study participants ascribed to quality EOL care (i.e., effective symptom management and individualized care that aligns with the wishes of patient and their families) have been previously reported in the literature (Johnston & Smith, 2006; Zomorodi & Lynn, 2010). Also, study participants' descriptions of meanings of quality EOL care as actions they perform for their patients, and in the ways in which they conduct these actions, are congruent with previous literature (Austin et al., 2000; Parker-Oliver et al., 2005).

Findings from this study regarding barriers and facilitators also aligned to a large extent with previous research findings. For example, the perception of activities and attitudes as barrier/facilitator "pairs" has been previously recognized (Alexander & Hearld, 2011), as has a differentiation between internal versus external barriers and facilitators (Durham et al., 2011). Also, previous research identified lack of knowledge, lack of staff involvement, a punitive mindset, and negative tone in communications as barriers to QI efforts, which aligns with some of the key barriers identified in this study (Davies, Powell, & Rushmer, 2007; Durham et al., 2011; Lindley et al., 2017; Singh et al., 2019). Again, aligning with the work of Durham and colleagues, participants in this study identified regulatory mandates as facilitators of QI (Durham et al., 2011). Of note, although insufficient technology and lack of adequate performance measures were identified as barriers to QI efforts in previous research (Cagle et al., 2012; Durham et al.,

2011), these topics did not emerge as key barriers to QI by participants in this study. This likely is due to significant changes in technology and healthcare performance measurement since those earlier studies were conducted.

As described in Chapter 1, the theoretical underpinnings of this study include Rogers' Diffusion of Innovations (DOI) theory, extensions of that theory relevant to diffusion within organizations, and the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009; Greenhalgh et al., 2004; Rogers, 2003). Recall that the CFIR includes constructs from the DOI theory and its extensions, as well as those from other implementation frameworks. The domains from the CFIR proved useful in guiding the aims of the study and developing the interview guide. Because testing the utility of the CFIR was not the purpose of this study, its results were not located within that framework. Nonetheless, the findings from this study support its domains and many of its constructs, as shown in Appendix G.

Strengths and Limitations

As with all research studies, this effort has both strengths and limitations. However, before discussing these, it is important to provide support to demonstrate the trustworthiness of the participant responses that formed the basis for the study findings. First, I was able to achieve good rapport with study participants, which enabled an environment in which they felt comfortable enough to relate their thoughts and feelings about quality improvement, even when these were less than positive. To establish this rapport, I began the interviews by getting to know the participants better through an informal discussion prior to asking the interview questions that addressed the study aims.

In addition to asking them about their roles, titles, and certification, I also inquired about their previous occupational experiences and what led them to work in hospice. Many offered stories of family experiences with death and/or hospice care that gave them exposure to the hospice philosophy and mission. This introductory portion of the interviews often lasted 15 minutes or more.

In addition, the study utilized a sampling plan with random selection of participants within in occupational role (when more than one individual was employed in those roles), which minimized possible selection bias. Without this random recruitment, it would have been possible for the agency directors or quality improvement coordinators to ensure participation of staff who they knew would relate only positive responses to the study questions. Relatedly, I made it a point to reaffirm to each participating nurse, social worker, and chaplain that, not only would I keep their responses confidential, but that I would also keep their participation private. This ensured that the agency directors or quality improvement coordinators did not know who participated in the study, unless this information was shared by the participants.

Confidence in the trustworthiness of participant responses also is bolstered by obtaining both positive and negative views of QI from most interviewees. In particular, if the responses had been heavily weighted toward only positive responses, I would have questioned whether participants had been directed by agency leaders on how to respond. Furthermore, many of the responses corresponded to previous findings from the literature and also align with implementation science theory, as previously noted.

Finally, the results of the member checking exercise further validated not only the trustworthiness of the data used in the study, but also the findings based on those data. Specifically, those participants who provided feedback did not disagree with any of the findings that I related to them. Moreover, they also noted interest, and sometimes surprise, regarding some of the findings. Some also provided specific examples of things that particularly interested or surprised them, indicating a critically and thoughtful consideration of the findings, rather than a cursory review.

The key strengths of this study, beyond the trustworthiness of the participant responses, include the novelty of the topic area and the participation of those in occupational roles that reflect the multidisciplinary nature of hospice care, social work and chaplaincy in particular. As previously mentioned, little research has focused on perceptions of QI among those who provide EOL care. Moreover, while not all roles of the hospice interdisciplinary team were represented in this study due to feasibility concerns (e.g., medical director, aides, volunteers), the inclusion of social workers and chaplains provides insight from key hospice team perspectives that have been, to date, mostly untapped.

The primary limitation of the study is that the results cannot be generalized to all hospice providers in the U.S. However, it is possible that the results may be transferable to other groups of hospice providers. Support for this potentiality, and for the strength of the findings more generally, comes from the methods and underlying assumptions for the study, which have been stated clearly, the inclusion of participant narrative to support the findings and their interpretations, the review of initial results by a subset of participants,

which, as noted, did not reveal concerns, and the fact that many of the findings align with previous research and also conform to underlying theory.

A second limitation is the study's small size. Participants included only 19 staff members from five hospice agencies in the state of Maryland. Even so, the data gathered from this small group generated approximately 475 pages of text (more than 200,000 words). More importantly, the participants included both social workers and chaplains, provider groups that have been included in similar research relatively less often than other types of providers such as nurses or physicians. Also, while recruitment of agencies was conducted via purposive sampling, recruitment of individuals was done via random selection when multiple individuals were eligible for inclusion, thus minimizing potential selection bias. Additionally, limiting the sample to agencies operating in Maryland ensured uniformity in that all are operating under the same Certificate of Need rules, and all have access to the same state hospice and palliative care organization.

A third limitation, related to sample size, is potentially more serious. Given the small number of agencies included in the study, there was not enough variation in agency characteristics to allow for a robust examination of how differences in participant perceptions might vary by agency characteristics. Frequently, when a particular agency had a markedly different response pattern for a particular topic, it often had one or more characteristics in common with agencies that did not have that response pattern. This made it almost impossible to associate an unusual response pattern with a specific agency characteristic. Thus, although the range of desired agency characteristics was mostly achieved, there was limited capacity to link differences to agency characteristics. In

reality, given the small number of hospice agencies in Maryland and the relative lack of variation in terms of size, tax status, and agency type, a robust examination of differences by agency characteristic may not have been possible, even if participants from all agencies had been included in the study.

A fourth limitation concerns the likely conflation on the part of some participants in QI efforts and compliance activities. As discussed, some defined QI specifically in terms of changes in documentation to support compliance efforts. Also, participants often described other compliance activities (e.g., conversations about oxygen safety) as QI efforts. This conflation was exacerbated by the way that participating hospice agencies structure their QI and compliance departments and/or personnel (i.e., within the same departments, and especially for smaller agencies, overseen by the same individual). It is certainly possible that some of the perceptions conveyed by participants were, in fact, perceptions about compliance activities rather than QI activities. Nonetheless, the very demonstration of this conflation is an important finding of the study.

Finally, had this study been conceptualized as a post-implementation study, with attendant use of the CFIR to guide both development and analysis (i.e., with implementation of QI itself as the innovation), its results may have contributed to refinements of the CFIR. Even so, as discussed earlier, results of this study support the utility of the domains and constructs of the CFIR.

Implications for Policy and Practice

Several implications for both policy and practice can be derived from the findings from of study, as described below.

Implications for Policy

One of the goals of this study was to explore participants' familiarity with, and perceptions of external forces that spur QI efforts in hospice. I expected study participants, particularly agency directors, to have a general knowledge of Medicare's Conditions of Participation (COPs) for hospice and of the CMS Hospice Quality Reporting Program. I also expected them to have at least some idea of how these policy levers have compelled QI efforts in hospice, even if they did not know specific details of the regulations or even its formal terminology. These expectations were only partially borne out. Study participants in fact did identify regulations and their associated effects on reimbursement as the most important driver of QI efforts in hospice, although they may not have completely understood those regulations. Also as expected, agency directors were more conversant with these federal policy drivers than were the participants in the other front-line roles. Study participants also demonstrated awareness of other external factors, including requirements associated with accreditation and/or adherence to other practice standards. However, most of the participants described the various regulations or policies in general terms. For example, they did not specifically mention or describe the COPs or HQRP, or any other regulatory requirements by name. Instead, these participants described the governmental entity that they perceived as the entity implementing the requirements, with "*CMS*," "*Medicare*," "*the state*," and "*the government*" as the most commonly mentioned. This approach to focusing on the regulating entity, as opposed to the policy or program, was true even for agency directors.

Specific knowledge of various regulatory or legislative details is not necessary for most hospice staff members carry out their duties effectively. However, agency directors and those leaders charged with directing QI efforts and ensuring compliance were expected to express more specific knowledge, including using the names of specific initiatives. It may be instructive for policy makers to know that, for most participants in this study, knowledge among front-line hospice staff regarding details of policy is not extensive. Also, although participating leaders expressed familiarity with various policies, they did not convey that knowledge using formal language. More importantly, although viewed as drivers of QI in hospice, many study participants also had a rather negative view of many of the policies. For example, the government's focus on fraud reduction was seen by some as, in the words of Director H, "*reasons they can claw money back from you or perhaps not pay you to begin with.*"

Similarly, a vocal minority of study participants expressed strong skepticism toward a number of QI activities they perceived as geared only toward improving documentation and compliance. They viewed these activities as extra work with little added benefit other than to ensure continued reimbursement. Industry stakeholders, as well as federal and state policy makers and representatives of accrediting bodies, should critically examine existing compliance standards, including how organizations interpret adherence to the standards and how they react when adherence is not optimal. Depending on those findings, stakeholders may need to provide guidance to the field on how best to ensure compliance with industry standards, without demoralizing staff, wasting resources in pursuits that do not ultimately maintain or improve patient well-

being, or otherwise result in detriments in care. In addition, policy makers should exercise restraint before adding new requirements, particularly when the evidence base underlying them is not strongly linked to better outcomes for patients and their families.

At several points throughout the interviews, participants discussed the under-utilization of hospice, driven in large part by a lack of understanding of the benefits of hospice by the general public, as well as by some healthcare practitioners. To address this issue, policymakers, payers, and other stakeholders should, at minimum, re-examine the two key eligibility criteria required for coverage under the Medicare hospice benefit (i.e., requirements to forego curative treatment for the terminal condition and documentation of the six-month prognosis of death), and alter the benefit as needed. CMS is formally evaluating the first criterion through its 5-year *Medicare Care Choices Model* demonstration (Sheedy et al., 2020). This demonstration project, which is slated to conclude in December, 2020, allows enrollees to receive hospice benefits in addition to curative care for their terminal condition. The six-month prognosis of death requirement was, arguably, a reasonable criterion when the benefit was first established and cancer patients comprised the majority of enrollees (although many would disagree). However, cancer is no longer the prevailing diagnosis among hospice enrollees, making prognosis of death within six months much less of a certainty. This call for a re-examination of the eligibility requirements of the Medicare hospice benefit is echoed in a recent study that found substantial under-utilization of hospice care, particularly among decedents without cancer (Cagle, Lee, Ornstein, & Guralnik, 2020).

Implications for Practice

The information on the perceptions and meanings of QI derived from this study of hospice providers in Maryland provides insights that can be used to inform, develop, facilitate, and implement future QI activities. The practice implications discussed below focus primarily on attitudes about QI, communication and education about QI, and actual implementation of QI activities. Importantly, although couched as recommendations for hospice agencies, most of these also apply to palliative care organizations more broadly, as well as to other healthcare settings. Moreover, although for the most part directed to individual agencies, successful uptake of these recommendations will require contribution and commitment from a wide variety of industry stakeholders, such as researchers, QI and measurement experts, and advocacy, membership, and professional organizations.

Early in the interviews, several participants discussed the punitive approach that can be used in relation to QI efforts. They spoke about this inaccurate and damaging view of QI as an issue in prior jobs or with former employees in their own agencies, highlighting its negative effects on staff morale. Going forward, hospice agencies should work to abandon and replace this punitive mindset regarding QI with something more positive, and recognize the critical role of QI in achieving the mission of hospice. It was clear that the participating agencies represented have already made this transition. However, this critical change may not be characteristic for most/all hospice agencies.

This study also highlighted the need for leaders in hospice organizations to be vigilant regarding the tone used in communications to staff regarding QI efforts. This

attention to tone in messaging is particularly important because, by definition, QI efforts are needed to address problems in care delivery or deficiencies in care quality. Agency leaders should recognize the critical role of their communications in motivating staff in efforts to continuously improve the care they provide. Specifically, agency leaders should take particular care not to reflect negative attitudes, such as distrust or blame. Instead, they should ensure that messaging to staff regarding QI be positive and affirming. One such approach would be to highlight the various benefits of QI efforts. Examples of benefits of QI articulated by participants in this study include the ability to showcase their agencies' commitment to their patients and families, the gains in professional growth of their staff, and direct benefits to patients and families.

Results from this study illuminated the value that agency staff places on education and training as the best available way to help them improve the quality of care they provide. But the study also shed light on deficiencies in the content of education and training that is offered to agency staff. Participants specifically called out education or training that is irrelevant to their work. In addition, they noted the need for agencies, as part of their educational activities, to more effectively explain how the QI efforts they have undertaken will actually result in improved structures, processes, and outcomes of care. Accordingly, agency leaders should emphasize the ultimate goal of QI efforts, which is to optimize the well-being of their patients and families.

Moreover, in this study, front-line staff had only limited knowledge of the QI activities of their agencies, and very little knowledge about the ultimate success (or not) of those efforts. This suggests that agency leaders should purposively educate their staff

about what QI efforts are being made, why they were selected, and how those efforts are being assessed. Moreover, they should ensure that staff can both access, and understand, the results of those improvement activities. Finally, as already discussed, findings from this study indicate that hospice agency staff often equate QI activities with activities done primarily for compliance to industry standards. As part of their education regarding QI for their staff, agency leaders should clearly differentiate between these types of activities.

Importantly, given this study's identification of differences in perceptions regarding QI by occupational role, agencies should be prepared to tailor both their communications and their educational efforts as needed for their various audiences. Notably, enhancing education about QI may be beyond the scope of many hospice agencies, given the time required to develop effective communication strategies and curriculum, as well as the specialized knowledge and expertise that also may be needed. Therefore, industry leaders (e.g., the National Hospice and Palliative Care Organization, the National Coalition for Hospice and Palliative Care) should collate existing materials and/or develop new ones as needed, and provide guidance for their use.

Results from this study not only underscore the need for hospice agencies to engage front-line staff in their QI activities, it also revealed the desire of many participating staff to engage in those efforts. Agencies can facilitate "passive" engagement by offering information on QI efforts and results, as described above. But active participation of front-line staff also is needed. One way that agencies can facilitate this engagement is to routinely and systematically ask staff to identify quality problems

that should be addressed by the agency. Another approach is to include front-line staff as team members in more formal QI efforts (e.g., a project using Lean methodology), to provide input on problems, processes, and potential solutions.

As revealed in this study, there are many potential barriers to effective QI implementation in the hospice setting. Consequently, hospice agencies should actively investigate barriers to QI implementation in their own organizations. This can be done as part of the Plan-Do-Study-Act approach in ongoing QI initiatives, as well as via more formal evaluations of QI efforts post-implementation. Organizations can also ask staff to respond to surveys that are designed to identify barriers to QI. Researchers and industry stakeholders should provide guidance to organizations about the availability and utility of such surveys.

Finally, hospice agencies should not only collect data about barriers to implementing QI efforts, but actually act on those data. As already noted, this study found that participating hospice staff crave effective education and training opportunities that will enhance their skills, believing this ultimately will lead to improved quality in the care they provide. In addition, participants in this study linked their own emotional well-being with their ability to provide high-quality care for their patients/families and to improve that care. Thus, hospice providers should ensure access to appropriate education and training, as well as focus on ways to alleviate staff stress and other negative emotions.

Ideas for Future Research

The results of this study indicate several avenues for additional research to inform the topics of EOL care quality and its improvement. First, to my knowledge, this was the first study that specifically explored the meanings of QI among hospice providers. Moreover, while exploring the published literature on this topic, I did not see similar research targeted to other healthcare settings or providers. However, as discussed above, the meanings that study participants ascribed to “quality improvement” were broader than I expected, based on the working definition used in the study. Given the importance of QI efforts in healthcare, future studies should explore this topic in other healthcare settings, and in other stakeholder groups, such as QI experts and policy makers.

This study also identified conflation in the concepts and language around care quality, QI, and quality assurance/compliance. Further research to clarify these conflated concepts by more precisely articulating their similarities, differences, and interrelationships would be helpful to the field, as would consideration of the implications of this conflation.

This study also found that the emotions, attitudes, skills, and desires of hospice staff impact their perceptions of QI efforts. Researchers should revisit existing instruments that elicit information about staff attitudes and satisfaction (e.g., the National Hospice and Palliative Care Organization’s Survey of Team Attitudes and Relationships survey) to ensure that relevant domains are covered. In addition, they should use such instruments to examine whether and how staff attitudes are associated with measures of care quality and QI efforts.

Another area that deserves attention is the potential incompatibility in the meanings of high-quality EOL care as both holistic care and care that is aligned with patient/family wishes. Narratives from a small number of participants alluded to the cognitive and emotional dissonance they experience when they want to provide the full range of hospice services to their patients as needed (e.g., physical, social, emotional, psychological, and spiritual support), but the patients and/or families reject these services. In such cases, the meanings of high-quality EOL care are in conflict. This paradox has not, to my knowledge, been reported or discussed as such in the literature pertaining to QI in the hospice or palliative care settings, although it may have been explored in other literature. Future studies should explore the prevalence of this paradox, and its effects on the emotional well-being of hospice providers.

Finally, as is always the case in qualitative studies, participants verbalized a variety of ideas that ultimately proved tangential to the aims of this study. Yet many of these may be worthwhile to consider in future EOL care quality and QI research. Two that were particularly intriguing included: (1) an allusion to the isolation of hospice team members, many of whom interact with their colleagues in very limited ways in their day-to-day work, and (2) QI innovations conceived and implemented informally by front-line staff.

Summary

This qualitative study employed an ethnographic and phenomenological approach to elicit narratives and meanings of EOL care quality and QI from 19 directors, nurses, chaplains, and social workers from five hospice agencies in Maryland. Overall, the

meanings that study participants ascribed to quality EOL care aligned with previous literature, although in some ways, their views were more expansive than expected. A novel finding was the five interrelated meanings of QI that were articulated by study participants (i.e., formal processes; learning on the part of hospice providers; changes in documentation to support compliance; “doing better;” and activities that positively impact patients and families). Study participants agreed that quality of EOL care can be improved, and for the most part, their perceptions about QI were positive. Yet they also expressed skepticism about QI efforts, as evidenced by their reflections about its disadvantages and barriers. This study also revealed that front-line hospice workers had fairly broad, generalized knowledge regarding the QI efforts of their agencies, but limited familiarity regarding how those efforts were chosen. In addition, the study found that participants engaged in improvement activities, although not all of those activities were part of their agencies’ formal QI efforts. Moreover, participants identified education as a key mechanism to help them more effectively improve the quality of care they provide to their patients and families. Finally, this study found that participants’ perceptions of quality EOL care and QI were associated with their occupational roles in the organization, but were not linked to the characteristics of the agency that employs them.

Appendix A: CFIR Constructs with Short Definitions

Source: Electronic Supplementary Materials (Additional File 3):

<https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-4-50#Sec39>, from Damschroder, L.J., Aron, D.C., Keith, R.E. et al. Fostering

implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science*, 4, 50 (2009).

<https://doi.org/10.1186/1748-5908-4-50>

Intervention characteristics

Intervention Source. Perception of key stakeholders about whether the intervention is externally or internally developed

Evidence Strength and Quality. Stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have desired outcomes

Relative Advantage. Stakeholders' perception of the advantage of implementing the intervention versus an alternative solution

Adaptability. The degree to which an intervention can be adapted, tailored, refined, or reinvented to meet local needs

Trialability. The ability to test the intervention on a small scale in the organization, and to be able to reverse course (undo implementation) if warranted

Complexity. Perceived difficulty of implementation, reflected by duration, scope, radicalness, disruptiveness, centrality, and intricacy and number of steps required to implement

Design Quality and Packaging. Perceived excellence in how the intervention is bundled, presented, and assembled.

Cost. Costs of the intervention and costs associated with implementing the intervention including investment, supply, and opportunity costs.

Outer setting

Patient Needs and Resources. The extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization

Cosmopolitanism. The degree to which an organization is networked with other external organizations

Peer Pressure. Mimetic or competitive pressure to implement an intervention; typically because most or other key peer or competing organizations have already implemented or are in a bid for a competitive edge

External Policy and Incentives. A broad construct that includes external strategies to spread interventions, including policy and regulations (governmental or other central

entity), external mandates, recommendations and guidelines, pay-for-performance, collaboratives, and public or benchmark reporting

Inner setting

Structural Characteristics. The social architecture, age, maturity, and size of an organization

Networks and Communications. The nature and quality of webs of social networks and the nature and quality of formal and informal communications within an organization

Culture. Norms, values, and basic assumptions of a given organization

Implementation Climate. The absorptive capacity for change, shared receptivity of involved individuals to an intervention, and the extent to which use of that intervention will be rewarded, supported, and expected within their organization

- **Tension for Change.** The degree to which stakeholders perceive the current situation as intolerable or needing change.
- **Compatibility.** The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems.
- **Relative Priority.** Individuals' shared perception of the importance of the implementation within the organization.
- **Organizational Incentives and Rewards.** Extrinsic incentives such as goal-sharing awards, performance reviews, promotions, and raises in salary, and less tangible incentives such as increased stature or respect.
- **Goals and Feedback.** The degree to which goals are clearly communicated, acted upon, and fed back to staff, and alignment of that feedback with goals.
- **Learning Climate.** A climate in which: a) leaders express their own fallibility and need for team members' assistance and input; b) team members feel that they are essential, valued, and knowledgeable partners in the change process; c) individuals feel psychologically safe to try new methods; and d) there is sufficient time and space for reflective thinking and evaluation.

Readiness for Implementation. Tangible and immediate indicators of organizational commitment to its decision to implement an intervention

- **Leadership Engagement.** Commitment, involvement, and accountability of leaders and managers with the implementation.
- **Available Resources.** The level of resources dedicated for implementation and on-going operations, including money, training, education, physical space, and time.
- **Access to Knowledge and Information.** Ease of access to digestible information and knowledge about the intervention and how to incorporate it into work tasks.

Characteristics of individuals

Knowledge and Beliefs about the Intervention. Individuals' attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to the intervention

Self-Efficacy. Individual belief in their own capabilities to execute courses of action to achieve implementation goals

Individual Stage of Change. Characterization of the phase an individual is in, as he or she progresses toward skilled, enthusiastic, and sustained use of the intervention

Individual Identification with Organization. A broad construct related to how individuals perceive the organization, and their relationship and degree of commitment with that organization

Other Personal Attributes. A broad construct to include other personal traits such as tolerance of ambiguity, intellectual ability, motivation, values, competence, capacity, and learning style

Process

Planning. The degree to which a scheme or method of behavior and tasks for implementing an intervention are developed in advance, and the quality of those schemes or methods.

Engaging. Attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities.

- Opinion Leaders. Individuals in an organization who have formal or informal influence on the attitudes and beliefs of their colleagues with respect to implementing the intervention.
- Formally Appointed Internal Implementation Leaders. Individuals from within the organization who have been formally appointed with responsibility for implementing an intervention as coordinator, project manager, team leader, or other similar role.
- Champions. "Individuals who dedicate themselves to supporting, marketing, and 'driving through' an [implementation]" [101] (p. 182), overcoming indifference or resistance that the intervention may provoke in an organization.
- External Change Agents. Individuals who are affiliated with an outside entity who formally influence or facilitate intervention decisions in a desirable direction.

Executing. Carrying out or accomplishing the implementation according to plan.

Reflecting and Evaluating. Quantitative and qualitative feedback about the progress and quality of implementation accompanied with regular personal and team debriefing about progress and experience.

Appendix B: Hospice Agency Sampling Frame

Table B1. Hospice Agencies and their Characteristics, 2014 Maryland Hospice Survey

Name	Agency type	Tax status	Locality	Size
Amedisys Hospice of Greater Chesapeake	Freestanding	For-profit	Urban	Medium
Calvert Hospice, Inc.	Freestanding	Not-for-profit	Urban	Small
Capital Caring	Freestanding	Not-for-profit	Urban	Medium
Carroll Hospice, Inc.	Freestanding	Not-for-profit	Rural	Small
Chester River Home Care & Hospice, LLC	Freestanding	Not-for-profit	Both	Small
Coastal Hospice, Inc.	Freestanding	Not-for-profit	Rural	Medium
Evercare Hospice and Palliative Care	Freestanding	For-profit	Both	Medium
Gilchrist Hospice Care	Hospital-based	Not-for-profit	Both	Large
Heartland Hospice - Beltsville	Freestanding	For-profit	Urban	Medium
Heartland Hospice Services	Home health	For-profit	Both	Medium
Holy Cross Home Care and Hospice	Hospital-based	Not-for-profit	Urban	Medium
Hospice of Charles County, Inc.	Freestanding	Not-for-profit	Rural	Small
Hospice of Frederick County	Hospital-based	Not-for-profit	Both	Medium
Hospice of Garrett County, Inc.	Freestanding	Not-for-profit	Rural	Small
Hospice of Queen Anne's, Inc.	Freestanding	Not-for-profit	Rural	Small
Hospice of St. Mary's County / Hospice of St. Mary's, Inc.	Hospital-based	Not-for-profit	Rural	Small
Hospice of the Chesapeake, Inc.	Freestanding	Not-for-profit	Both	Large
Hospice of Washington County, Inc.	Freestanding	Not-for-profit	Both	Large
Jewish Social Service Agency Hospice	Freestanding	Not-for-profit	Both	Medium
Montgomery Hospice, Inc.	Freestanding	Not-for-profit	Both	Large
Professional Healthcare Resources of Baltimore	Freestanding	For-profit	Urban	Small
Seasons Hospice and Palliative Care of MD	Home health	For-profit	Both	Large
Shore Home Care and Hospice	Home health	Not-for-profit	Rural	Small
Stella Maris, Inc.	Nursing home	Not-for-profit	Both	Medium

Name	Agency type	Tax status	Locality	Size
The Community Hospice of Maryland	Freestanding	Not-for-profit	Both	Medium
The Joseph Richey House	Freestanding	Not-for-profit	Urban	Small
Western Maryland System Hospice Services	Hospital-based	Not-for-profit	Urban	Small

Note. Source: Maryland Health Care Commission, 2014 Maryland Hospice Survey.

Table B2. Hospice Sampling Frame: Agency Characteristics

Agency Characteristic	Number	Percentage
Agency type		
Freestanding	18	66.7
Not freestanding	9	33.3
Tax status		
For-profit	6	22.2
Not-for-profit	21	77.8
Locality		
Rural	7	25.9
Urban	8	29.6
Both	12	44.4
Size		
Small	11	40.7
Medium	11	40.7
Large	5	18.5

Note. Source: Maryland Health Care Commission, 2014 Maryland Hospice Survey.

Appendix C: Recruitment Letters

Month, DD, 2015

First M. Last

Title

Agency Name

Street Address

City, Maryland xxxxx-xxxx

Dear Ms. Last,

My name is Karen Johnson. I am a student at the University of Maryland, Baltimore County (UMBC), working on my doctoral degree in Gerontology.

My dissertation research is focused on perceptions of quality improvement efforts in the hospice setting. I plan to explore how hospice providers characterize quality care near the end of life and how they perceive efforts to improve care quality. I am also interested in providers' knowledge and perceptions of external drivers of quality improvement efforts (e.g., specific legislative and regulatory requirements) as well as their perceptions of agency-specific quality improvement efforts and their own personal efforts to improve care quality.

The design of the study is qualitative in nature, meaning that I will obtain data for the study primarily through interviews and informal observations and conversation. Because hospice care is, by definition, a multi-disciplinary effort, I want to include providers in various roles, including leadership, nursing, social work, and chaplaincy. Also, because I expect that organizational culture will affect the perceptions of hospice providers, I want to include providers from different agencies that represent the diversity of hospice programs in the state of Maryland in terms of size, agency type, organizational tax status, and locality.

I am writing to ask whether your agency would be willing to participate in my study.

As a [INSERT SMALL/MEDIUM/LARGE, FREE-STANDING/HOSPITAL-BASED/NURSING HOME-BASED/HOME HEALTH-BASED, FOR-PROFIT/NOT-FOR-PROFIT, RURAL/URBAN/BOTH RURAL AND URBAN] agency, the perspectives of you and your staff would be very valuable.

Participation in the study would include:

- An initial meeting with your quality improvement coordinator so that I can learn more about your organizational approach to quality improvement.
- Provision of information about your agency's current quality improvement efforts. This information could include things such as quality metric trend reports, data collection instruments, minutes of previous quality improvement meetings, etc., at your discretion. This would NOT include any patient-level data.
- Separate face-to-face interviews with you, as well as with a direct-care nurse, social worker, and chaplain from your agency (assuming each is willing to participate).
- Allowing me to observe at least one quality improvement meeting at your agency, at your discretion.

I will solicit formal informed consent for participation in the study from each participant. Each interview will take between 1-2 hours but could be spread over 1-2 sessions if needed. I would come to your office for the interviews or meet with participants at a location of their choice. With permission of the participants, I will audio-record the interviews. These interviews likely will be scheduled within 2-12 weeks of our initial meeting. Any materials provided as part of the study, including the content of the interviews, meetings, and conversations, will be kept confidential. The identity of your agency and the participants from your agency also will be kept confidential.

To date, there has been relatively little basic research about the nature and circumstances of quality improvement within hospice, particularly from a qualitative perspective. Although foundational in nature, it is my hope that insights gained from this study can be used to inform future improvement activities in the hospice setting.

I would be happy to discuss the goals and requirements of the study in more detail, so please do not hesitate to contact me via e-mail or phone if you have any questions or concerns. Please feel free to share this letter with any potential participants from your agency.

I look forward to your response regarding participation in the study, and thank you, in advance, for your time.

Sincerely,

Karen Johnson
[e-mail address]
home: 410-XXX-XXXX
cell: 443-XXX-XXXX

Month, DD, 2015

First M. Last

Title

Agency Name

Street Address

City, Maryland xxxxx-xxxx

Dear Ms. Last,

My name is Karen Johnson. I am a student at the University of Maryland, Baltimore County (UMBC), working on my doctoral degree in Gerontology.

The focus of my research is on perceptions of quality improvement efforts in the hospice setting. As part of my proposed research, and because hospice care is interdisciplinary in nature, I would like to interview hospice directors, nurses, social workers, and chaplains from several hospice agencies in Maryland.

[INSERT NAME OF HOSPICE DIRECTOR], the director of your agency, has agreed to participate in the study and to allow me to recruit a [INSERT DIRECT-CARE NURSE, SOCIAL WORKER, CHAPLAIN] within your agency to participate in my study. You were randomly selected for potential participation from a list of full-time [INSERT DIRECT-CARE NURSES, SOCIAL WORKERS, CHAPLAINS] who have been employed with your agency for at least six months. I am writing to ask whether you would be willing to participate in my study.

If you agree to participate in the study, I will conduct one face-to-face interview with you. This interview will take between 1-2 hours, but could be spread over 1-2 sessions if needed and more convenient for you. I would come to your office for the interview (assuming a quiet and private space is available) or meet with you at a location of your choice, as long as it is conducive to the interviewing process (i.e., adequate privacy, minimal distractions, and low noise level so that conversations can be recorded). I will solicit formal informed consent for your participation in the study at the beginning of the interview. I will take detailed notes of our conversation and, with your permission, audiotape the interview. Data collected through your participation in the study will, of course, be kept confidential.

I would be happy to discuss the goals and requirements of the study in more detail, so please do not hesitate to contact me via e-mail or phone if you have any questions or concerns.

I look forward to your response regarding participation in the study, and I thank you, in advance, for your time and consideration.

Sincerely,

Karen Johnson

[e-mail address]

home: 410-XXX-XXXX

cell: 443-XXX-XXXX

Month, DD, 2015

First M. Last

Title

Agency Name

Street Address

City, Maryland xxxxx-xxxx

Dear Ms. Last,

My name is Karen Johnson. I am a student at the University of Maryland, Baltimore County (UMBC), working on my doctoral degree in Gerontology.

The focus of my research is on perceptions of quality improvement efforts in the hospice setting. As part of my research, I will be interviewing hospice directors, nurses, social workers, and chaplains from several hospice agencies in Maryland. As the Quality Improvement Coordinator for your agency, you would be able to provide invaluable information about the quality improvement efforts that are underway within your agency, allowing me to put the information I glean from the interviews into proper context. I would be grateful for your help with this matter.

[INSERT NAME OF HOSPICE DIRECTOR], the director of your agency, has agreed to the participation of your agency in my study. I am writing to ask whether you, personally, would be willing to participate in the study.

If you agree to participate, I will have an initial informal conversation with you about the quality improvement efforts of your agency. This conversation should take no more than one hour. I will ask you to provide electronic or hard copies of documents that illustrate your agency's quality improvement efforts and to explain those documents as needed. This information could include things such as quality metric trend reports, data collection instruments, minutes of previous quality improvement meetings, etc., at your discretion and/or at the discretion of [INSERT NAME OF HOSPICE DIRECTOR]. These documents should NOT include any patient-level data. I will take detailed notes of our conversations and also audio record the conversation if you agree. All data that you provide (via documentation or through our conversation) will be kept confidential and no specific names will ever appear in connection with the research. I will solicit formal informed consent for your participation in the study at the beginning of our initial conversation. Follow-up conversations (likely via phone or e-mail, but also potentially in-person) also may be required.

I would be happy to discuss the goals and requirements of the study in more detail, so please do not hesitate to contact me via e-mail or phone if you have any questions or concerns.

I look forward to your response regarding participation in the study, and thank you, in advance, for your time and consideration.

Sincerely,

Karen Johnson

[e-mail address]

home: 410-XXX-XXXX

cell: 443-XXX-XXXX

Appendix D: Interview Guide

These questions are entry ways into discussion and conversation of the topics at hand.

Start with consent (plan for 10 minutes on this section)

Basic descriptive information (aim for about 5 minutes on this section):

- What is your role in hospice?
- What is your title?
- What kind of certification(s) do you have?
- How long have you been a (nurse, social worker, chaplain, hospice director)?
- Can you tell me a little bit about your history of work in this industry? How long have you worked in hospice? What led you to get involved with hospice? What did you do before that?
- How long have you worked in this agency? Was all that time full time/part time?

Perceptions about quality of care near the end of life (plan for about 15 minutes on this section):

- How would you describe or define the term “quality care near the end of life”?
- When you think about high quality end-of-life care what comes to mind?
(Alternative ways to phrase: what does high quality of care near the end of life look like? What makes high quality of care?)
- In your experience of working in hospice, have you ever seen any problems with the quality care provided? Can you please give me an example or two of that?
 - Alternative: When you think about end-of-life care that isn't of the highest quality, what comes to mind?
- Would you say there is a mid-level of quality of care, care that is neither excellent nor or poor. Can you think of any examples of that that you have experienced or know about?
- Who would you describe as the main customer or client here? (expected options are the dying person, the family, or both)
- Is there anything else I need to know about what quality end-of-life care is like?

Perceptions about quality improvement (plan for about 15 minutes on this section):

- What do you think of when you hear the term “quality improvement”?
- What has influenced your thinking about quality improvement?
- Thinking about quality of care in hospice, in your opinion, do you think it can be improved? If so, how, or in what ways? (please be specific)

- In your mind, what are the advantages of QI efforts?
- What are the disadvantages of QI efforts?
- What kinds of things, in your opinion, either help or hinder quality improvement efforts in hospice?

Perceptions about external drivers of QI (plan for about 10-15 minutes on this section):

- What do you think are the things that are driving efforts to improve the quality of care in hospice? (please be specific)
 - PROBE if necessary to see if respondents know of any external drivers.
- In general, what do you think about those efforts? What's your opinion of them, if any?
 - PROBE: One at a time: Are they a good thing? A bad thing? Why do you say that?
- Would you say that you've always felt this way, or have your perceptions changed over time?
 - If yes, then ask what has contributed to their change in perceptions

Perceptions about internal QI efforts (plan for about 20-30 minutes on this section):

- Are you familiar with the QI efforts that that your agency has been or is currently engaged in? Can you please describe those?
 - If not familiar, then switch to asking if they:
 - believe QI efforts are needed
 - what makes them think so
 - what should those efforts be
 - how they think such efforts would make a difference
 - why agency hasn't yet initiated efforts or perhaps why they don't know about them
- Can you tell me how or why your agency decided to focus on those particular efforts?
- What do you think about these efforts? Are they a good thing? A bad thing? Why do you say that?
 - PROBE for information about each of the efforts they named above
- Do you think these QI efforts have made a difference so far?
 - PROBE: In what ways, if any, have these efforts made a difference for your patients or their families?
 - PROBE: In what ways, if any, have these efforts impacted your job?
- How have you reached these conclusions about these efforts?

- PROBE: Possible answers might be personal anecdotes, performance data, agency communications, communications with others (if the latter, probe to see who—others in same role, etc.).
- What, if any, other things would you like for your agency to do to improve the quality of care that is being provided?
 - What do you think might be keeping your agency from doing this?
- Is there anything else I need to know about your agency's QI efforts?

Perceptions about personal QI efforts (plan for about 15-20 minutes for this section):

- In what ways, if any, have you contributed to this agency's QI efforts?
 - PROBE: If yes, try to tie to specific projects or programs
 - PROBE: If no, try to find out why not; find out if have contributed to another agency's efforts
- What things can you do (personally, as an employee) to improve quality of care near the end of life for your clients?
- Do you believe that your personal activities in this agency's QI efforts have made a positive difference?
 - PROBE: If yes, in what ways? How have your efforts improved patient/family outcomes?
 - PROBE: If no, then why do you think so?
- In your opinion, what, if anything, would help you to be even more effective in improving care quality?
- Is there anything else I need to know about your personal QI efforts?

Follow-up

- Would you be willing to review and provide feedback on my initial findings?
Obtain e-mail address

Appendix E: Informed Consent Information Sheets

Whom to Contact about this study:

Principal Investigator: Karen Johnson

Department: Doctoral Program in Gerontology (Department of Sociology and Anthropology)

Telephone number: XXX-XXX-XXXX

[ON DEPARTMENTAL LETTERHEAD]

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Title: Quality improvement in end-of-life care: Perceptions of hospice providers

I. INTRODUCTION/PURPOSE:

I am being asked to participate in a research study. The purpose of this study is to identify and describe how hospice providers in different roles perceive efforts to improve the quality of end-of-life care. I am being asked to volunteer because I am the Director of a hospice agency. My involvement in this study will begin when I agree to participate and will continue potentially through the summer of 2016. In total, about 25 persons from several hospice agencies will be invited to participate.

II. PROCEDURES:

I will be asked to allow participation of my agency in the study. Participation of my agency in the study will include:

- allowing the principal investigator to meet with my agency's quality improvement coordinator to learn more about the agency's approach to quality improvement, with the option of follow-up meetings, calls, or e-mails as needed
- allowing the provision of information about my agency's current quality improvement efforts
- facilitating the identification and contact of a direct-care nurse, social worker, and chaplain from my agency to participate in the study (each would be randomly selected when more than one individual fulfills the role)
- permitting the principal investigator to observe at least one quality improvement meeting at my agency, at my discretion

I will also be asked to participate in an interview at the location of my choice. My participation in this study will last for approximately 1-2 hours, spread over 1-2 sessions as needed and convenient for me. I will be asked to allow audio recording of the interview and detailed note-taking by the interviewer. I understand that no personal or agency identifying information will be attached to the audio recording or to the files transcribed from the recording. I also understand that any responses that are shared either externally or internally will not be linked to me or to my agency.

III. RISKS AND BENEFITS:

My participation in this study does not involve any significant risks and I have been informed that my participation in this research will not benefit me personally. Insights gained from this study may be used to inform future quality improvement activities in hospice care.

IV. CONFIDENTIALITY:

Any information learned and collected from this study in which I might be identified will remain confidential and will be disclosed ONLY if I give permission. The investigator will make every effort to keep my personal and agency information confidential. To help protect my confidentiality, no personal or agency information other than my role in the agency and my credentials (e.g., RN) will be recorded. If applicable, (1) my name will not be included on the interview and other collected data; (2) a code number will be placed on the interview and other collected data as the only identifying feature; (3) through the use of an identification key, only the researcher will be able to link my interview to my identity; and (4) only the researcher and her dissertation mentor will have access to the identification key. All information collected in this study will be stored in a locked room or drawer and/or in electronic files accessed only via a secure password.

Only the investigator and her dissertation mentor will have access to these records. If information learned from this study is published, I will not be identified by name, nor will my agency. By signing this form, however, I allow the research study investigator to make my records available to the University of Maryland Baltimore County (UMBC) Institutional Review Board (IRB) and regulatory agencies as required to do so by law.

Consenting to participate in this research also indicates my agreement that all information collected from me individually may be used by current and future researchers in such a fashion that my personal and agency identity will always be protected. Such use may include sharing anonymous information with other researchers or doctoral committee members for checking the accuracy of

study findings and for future approved research that has the potential for improving human knowledge.

Although my confidentiality in this study is protected, confidentiality may not be absolute or perfect. If the investigators have reasonable cause to believe or suspect that a person has been abused, they are required by Maryland State law and University System of Maryland policy to file a report with the police department or social services department in the locality in which my agency is located, as well as with the appropriate individuals or department at UMBC. Similarly, if I report abuse that has happened in the past, the interviewer will also have to file a report.

I give permission to record my voice or image.

I do not give permission to record use my voice or image.

V. COMPENSATION/COSTS:

My participation in this study will involve no cost to me.

VI. CONTACTS AND QUESTIONS:

The principal investigator, Karen Johnson, or her dissertation committee chair, Dr. Robert L. Rubinstein, has offered to and has answered any and all questions regarding my participation in this research study. If I have any further questions, I can contact I can contact Karen Johnson via phone (XXX-XXX-XXXX) or e-mail (XXX@XXX) or Dr. Rubinstein via phone (XXX-XXX-XXXX) or e-mail (XXX@XXX).

If I have any questions about my rights as a participant in this research study, contact the Office for Research Protections and Compliance at (410) 455-2737 or compliance@umbc.edu.

VII. VOLUNTARY PARTICIPATION

I have been informed that my participation in this research study is voluntary and that I am free to withdraw or discontinue participation at any time, for any reason. I have been informed that data collected for this study will be retained by the principal investigator and analyzed even if I choose to withdraw from the research. If I do choose to withdraw, the investigator and I will have discussed my withdrawal and the investigator may use my information up to the time I decide to withdraw.

I will be given a copy of this consent form to keep.

Whom to Contact about this study:

Principal Investigator: Karen Johnson

Department: Doctoral Program in Gerontology (Department of Sociology and Anthropology)

Telephone number: XXX-XXX-XXXX

[ON DEPARTMENTAL LETTERHEAD]

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Title: Quality improvement in end-of-life care: Perceptions of hospice providers

I. INTRODUCTION/PURPOSE:

I am being asked to participate in a research study. The purpose of this study is to identify and describe how hospice providers in different roles perceive efforts to improve the quality of end-of-life care. I am being asked to volunteer because I work in a hospice agency and provide nursing, social work, or chaplaincy services to patients and their families as part of my role in this agency. My involvement in this study will begin when I agree to participate and will continue potentially through the summer of 2016. About 25 persons from several hospice agencies will be invited to participate.

II. PROCEDURES:

As a participant in this study, I will be asked to participate in an interview at the location of my choice. My participation in this study will last for approximately 1-2 hours, spread over 1-2 sessions as needed and as convenient for me. I will be asked to allow audio recording of the interview and detailed note-taking by the interviewer. I understand that no personal or agency identifying information will be attached to the audio recording or to the files transcribed from the recording. I also understand that any responses that are shared either externally or internally will not be linked to me.

III. RISKS AND BENEFITS:

My participation in this study does not involve any significant risks and I have been informed that my participation in this research will not benefit me personally. Insights gained from this study may be used to inform future improvement activities in hospice care.

IV. CONFIDENTIALITY:

Any information learned and collected from this study in which I might be identified will remain confidential and will be disclosed ONLY if I give

permission. The investigator will make every effort to keep my personal information confidential. To help protect my confidentiality, no personal information other than my role in the agency and my credentials (e.g., RN) will be recorded. If applicable, (1) my name will not be included on the interview and other collected data; (2) a code number will be placed on the interview and other collected data as the only identifying feature; (3) through the use of an identification key, the researcher will be able to link my interview to my identity; and (4) only the researcher and her dissertation mentor will have access to the identification key. All information collected in this study will be stored in a locked room or drawer and/or in electronic files accessed only via a secure password.

Only the investigator and her dissertation mentor will have access to these records. If information learned from this study is published, I will not be identified by name, nor will my agency. By signing this form, however, I allow the research study investigator to make my records available to the University of Maryland Baltimore County (UMBC) Institutional Review Board (IRB) and regulatory agencies as required to do so by law.

Consenting to participate in this research also indicates my agreement that all information collected from me individually may be used by current and future researchers in such a fashion that my personal identity and agency will be protected. Such use may include sharing anonymous information with other researchers for checking the accuracy of study findings and for future approved research that has the potential for improving human knowledge.

Although my confidentiality in this study is protected, confidentiality may not be absolute or perfect. If the investigators have reasonable cause to believe or suspect that a person has been abused, they are required by Maryland State law and University System of Maryland policy to file a report with the police department or social services department in the locality in which my agency is located, as well as with the appropriate individuals or department at UMBC. Similarly, if I report abuse that has happened in the past, the interviewer will also have to file a report.

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- I do not give permission to record use my voice or image.

V. COMPENSATION/COSTS:

My participation in this study will involve no cost to me.

VI. CONTACTS AND QUESTIONS:

The principal investigator, Karen Johnson, or her dissertation committee chair, Dr. Robert L. Rubinstein, has offered to and has answered any and all questions regarding my participation in this research study. If I have any further questions, I can contact I can contact Karen Johnson via phone (XXX-XXX-XXXX) or e-mail (XXX@XXX) or Dr. Rubinstein via phone (XXX-XXX-XXXX) or e-mail (XXX@XXX).

If I have any questions about my rights as a participant in this research study, contact the Office for Research Protections and Compliance at (410) 455-2737 or compliance@umbc.edu.

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I have been informed that my participation in this research study is voluntary and that I am free to withdraw or discontinue participation at any time, for any reason. I have been informed that data collected for this study will be retained by the investigator and analyzed even if I choose to withdraw from the research. If I do choose to withdraw, the investigator and I will have discussed my withdrawal and the investigator may use my information up to the time I decide to withdraw.

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Whom to Contact about this study:

Principal Investigator: Karen Johnson

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Telephone number: XXX-XXX-XXXX

[ON DEPARTMENTAL LETTERHEAD]

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Title: Quality improvement in end-of-life care: Perceptions of hospice providers

I. INTRODUCTION/PURPOSE:

I am being asked to participate in a research study. The purpose of this study is to identify and describe how hospice providers in different roles perceive efforts to improve the quality of end-of-life care. I am being asked to volunteer because I serve as the quality improvement coordinator in a hospice agency. My involvement in this study will begin when I agree to participate and will continue potentially through the summer of 2016. About 25 persons from several hospice agencies will be invited to participate.

II. PROCEDURES:

As a participant in this study, I will be asked to have at least one informal conversation with the primary investigator regarding the quality improvement efforts of my agency. I will also be asked to provide electronic or hard copies of agency documents that illustrate my agency's quality improvement efforts and to explain these documents to the interviewer as needed. My participation in this study will last for approximately one hour for the initial conversation, but may also include follow-up conversations via phone or e-mail, or in-person, as needed and as convenient for me. I will be asked to allow audio recording and detailed note-taking by the interviewer. I understand that no personal or agency identifying information will be attached to interviewer notes. My name and the name of the agency will never be attached to any writing or publications that may come out of this research. I also understand that any responses that are shared either externally or internally will not be linked to me or my agency.

III. RISKS AND BENEFITS:

My participation in this study does not involve any significant risks to me and I have been informed that my participation in this research will not benefit me personally. Insights gained from this study may be used to inform future improvement in hospice care.

IV. CONFIDENTIALITY:

Any information learned and collected from this study in which I might be identified will remain confidential and will be disclosed ONLY if I give permission. The investigator will attempt to keep my personal information confidential. To help protect my confidentiality, no personal information other than my role in the agency and my credentials (e.g., RN) will be recorded. If applicable, (1) my name will not be included on interview notes or other collected data; (2) a code number will be placed on the interview notes and other collected data as the only identifying feature; (3) through the use of an identification key, the researcher will be able to link data collected from me to my identity; and (4) only the researcher and her dissertation mentor will have access to the identification key. All information collected in this study will be stored in a locked room or drawer and/or in electronic files accessed only via a secure password.

Only the investigator and her dissertation will have access to these records. If information learned from this study is published, I will not be identified by name, nor will my agency. By signing this form, however, I allow the research study investigator to make my records available to the University of Maryland Baltimore County (UMBC) Institutional Review Board (IRB) and regulatory agencies as required to do so by law.

Consenting to participate in this research also indicates my agreement that all information collected from me individually may be used by current and future researchers in such a fashion that my personal and agency identity will be protected. Such use will include sharing anonymous information with other researchers for checking the accuracy of study findings and for future approved research that has the potential for improving human knowledge.

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If I have any questions about my rights as a participant in this research study, contact the Office for Research Protections and Compliance at (410) 455-2737 or compliance@umbc.edu.

VII. VOLUNTARY PARTICIPATION

I have been informed that my participation in this research study is voluntary and that I am free to withdraw or discontinue participation at any time, for any reason. I have been informed that data collected for this study will be retained by the investigator and analyzed even if I choose to withdraw from the research. If I do choose to withdraw, the investigator and I will have discussed my withdrawal and the investigator may use my information up to the time I decide to withdraw.

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Appendix F: Examples of First- and Second-Cycle Codes

Table F1. Meanings of QI: Examples of First- and Second-Cycle Codes

First-cycle coding: Structured and descriptive codes	Second-cycle coding: Pattern codes
QI meaning: best practices	Formal processes
QI meaning: compliance	QI meaning: measurement
QI meaning: continuous learning	QI meaning: done via strategic plan
QI meaning: documentation	QI meaning: monthly process
QI meaning: done via strategic plan	QI meaning: QI coordinator
QI meaning: education	Learning
QI meaning: learn from mistakes	QI meaning: continuous learning
QI meaning: measurement	QI meaning: learn from mistakes
QI meaning: minimum standards	QI meaning: education
QI meaning: monthly process	Compliance/documentation
QI meaning: QI coordinator	QI meaning: minimum standards
	QI meaning: best practices
	QI meaning: compliance
	QI meaning: documentation

Appendix G: Crosswalk of Study Aims and Topics to CFIR Domains and Constructs

Table G1. Study Aims and Topic Areas, with Associated CFIR Domains and Constructs

Aims and study topic areas	CFIR domains	CFIR constructs
Aim 1: Meanings of quality care at the end of life	Characteristics of individuals	Knowledge and beliefs
Aim 2: Perceptions of improving quality of care near the end of life		
<ul style="list-style-type: none"> • Multiple meanings of QI 	Characteristics of individuals	Knowledge and beliefs
<ul style="list-style-type: none"> • Advantages and disadvantages of QI efforts 	Intervention characteristics	Relative advantage
	Characteristics of individuals	Knowledge and beliefs
<ul style="list-style-type: none"> • Internal barriers to, and facilitators of QI efforts 	Characteristics of individuals	Knowledge and beliefs Other personal attributes
	Inner setting	Networks and communications Culture Learning climate Access to knowledge and information
<ul style="list-style-type: none"> • Factors that influence perceptions about QI efforts 	Characteristics of individuals	Knowledge and beliefs State of change
<ul style="list-style-type: none"> • Potential of, and ideas for improving the quality of EOL care 	Characteristics of individuals	Knowledge and beliefs
	Inner setting	Available resources Learning climate
	Process	Planning Engaging
Aim 3: External forces that drive QI efforts	Outer setting	External policy and incentives Cosmopolitanism Peer Pressure
Aim 4: Agency-specific QI efforts	Characteristics of individuals	Knowledge and beliefs
	Inner setting	Networks and communications
Aim 5: Personal participation in QI efforts	Characteristics of individuals	Knowledge and beliefs
	Inner setting	Available resources
Aim 6: Differences in perceptions by provider role and agency characteristics	Characteristics of individuals	Knowledge and beliefs Self-efficacy
	Inner setting	Structural characteristics

Note. CFIR: Consolidated Framework for Implementation Research.

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