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SOCIAL AND HEALTH DETERMINANTS OF END-OF-LIFE CARE QUALITY:

A MULTIDIMENSIONAL APPROACH

By

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ABSTRACT OF THE DISSERTATION

Social and Health Determinants of End-of-Life Care Quality:

A Multidimensional Approach

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Providing high-quality end-of-life (EOL) care to the nearly 1.9 million older adults who die each year in the U.S. is a pressing concern for policy makers and health care professionals. Medical and public health literature examines the quality of care for dying patients by considering a single measure or a handful of measures separately and in an atheoretical manner. I conduct latent class analysis (LCA) on four waves of National Health and Aging Trends Study data to develop three statistically and conceptually distinct subtypes of proxy reported end-of-life (EOL) care quality that consider multiple dimensions of care simultaneously. I find that between 20 and 25 percent of proxies report that decedents experience EOL characterized by unwanted symptoms and low quality care.

The first analytic chapter uses these categories as an outcome measure to explore the extent to which social determinants of health and mortality extend to proxy perceptions of EOL care quality for 1,046 decedents. I find that the three primary axes of disadvantage in the U.S.-gender, race/ethnicity, and socioeconomic status-do not predict proxy perceptions of EOL care quality. However, hospice involvement, diagnosis with serious illness, dying in a location other than home, and more frequent hospitalization

predict perceptions of care characterized by the presence of unwanted symptoms and poorer assessments on health care encounters and personal care measures. These findings have implications for how EOL care is assessed and suggest that policies to improve EOL care should target place of death, hospice involvement, and the needs of acutely and chronically ill persons.

The second analytic chapter analyzes how proxy reporters' evaluations of EOL care vary based on the decedent's advance care planning (ACP) behavior, attitudes towards religious participation, and social characteristics (race/ethnicity, education, and sex). ACP does not predict EOL care quality using a multidimensional measure of quality. Greater importance of religious participation is associated with higher quality EOL care, and this relationship is stronger among individuals who complete ACP. Proxies for non-Hispanic whites report symptomatic, lower quality EOL care. Proxies for more religious decedents may associate these beliefs with these decedents' increased acceptance of EOL and satisfaction with care. To the extent close family members share decedents' religious attitudes, knowing a loved one's preferences for EOL care may also facilitate increased satisfaction with care.

The third analytic chapter explores how proxy reporters' evaluations of EOL care vary based on the proxy reporters' characteristics (familiarity with care, relationship to decedent). Proxy reporter's familiarity with the decedent's EOL care and relationship to the decedent predict their assessments of care quality. Results suggest caregiving roles and motivations for providing positive assessments should be carefully considered in understanding EOL care assessments, particularly for wives and paid caregivers.

This dissertation uses LCA, a methodological approach to assessing EOL care quality that simultaneously accounts for multiple measures of care and how they co-occur among a sample of older adults. LCA provides an alternative method for assessing how multiple pieces of information move together and is potentially useful for understanding care for a variety of scenarios and settings. Attention to how social characteristics and processes relate to variation in perceptions of care among different subgroups can support practitioners and policy makers in targeting their efforts to improve care in a way that does not create or exacerbate disparities.

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Chapter 1

Introduction

End-of-Life Care for Older Adults: Assessing Quality and Identifying Gaps

Quality End-of-Life Care for Older Adults

High quality end-of-life (EOL) care is a priority for multiple stakeholders, including: dying individuals, their loved ones, caregivers, healthcare providers, and policy makers. Caring well for individuals in the final stages of life is part of a social obligation to honor dying persons and support family members who grieve the loss of a loved one (IOM 2014). As a greater proportion of the US population ages and approaches death, EOL care will affect a growing number of individuals and families. Of the 2.6 million Americans who died in 2014, 1.9 million of those deaths occur to adults aged 65 and older (NCHS 2016). Two-thirds of deaths to older adults are attributed to chronic illnesses such as heart disease, cancer, cerebrovascular diseases, chronic lower respiratory disease, and Alzheimer's disease, although many older adults have multiple chronic illnesses (NCHS 2016). In the final stages of life, these older, chronically ill adults have had multiple encounters with the health care system to manage their illnesses. They are also likely to have complex healthcare needs that may complicate the provision of high quality care at the end of life (EOL). In this dissertation, I examine EOL experiences in older adults, who comprise the majority of decedents in the U.S. and who face potentially complex EOL care scenarios due to increased frailty and multiple health issues, including cognitive impairment which hampers their ability to make decisions about EOL care.

The provision of high-quality EOL care is a concern for multiple stakeholders involved in and affected by death and dying. Providing a “good death” is a long-established and well-recognized part of our social contract with dying individuals (IOM 2014). Historically, death and dying were swift processes, leaving little time for family members to prepare, although care was given to maintaining dying individuals’ emotional and physical comfort as much as possible (Aries 1981). Medicalization of death in the 20th century has prolonged death and dying processes, presenting new challenges for maintaining dying individuals’ physical and emotional comfort, and increasing emphasis on giving them the time and space to put their affairs in order and spend meaningful time with loved ones (Aries 1981). Bereaved family members and caregivers desire high-quality EOL care for their loved ones (Steinhauser et al. 2000, Teno et al. 2001). However, medical advances have shifted the cause, nature, and place of death from relatively quick, home deaths caused by infectious diseases to protracted, institutional and highly medicalized deaths from chronic illness (Carr & Luth 2016). As a result, although health care providers are trained to cure illness and preserve life, they are increasingly involved in EOL care, at times resulting in EOL care that unnecessarily prolongs a dying individual’s life. Despite the tension between clinicians’ training to treat and cure and the distinct comfort and palliation needs of dying individuals, health care professionals have demonstrated an ongoing commitment to improving and providing high quality care to all individuals at the EOL (IOM 2014).

EOL care providers and policy makers also closely monitor care quality. Hospice and palliative care providers, who specialize in EOL care and are responsible for a growing proportion of EOL care services (NHPCO 2015), annually report family

satisfaction with care quality to the Centers for Medicare and Medicaid Services as part of their reimbursement structure (CMS 2016). Although training and approaches may differ, collectively, clinicians and hospice and palliative care providers demonstrate a desire to ensure dying individuals receive high quality care at EOL.

Despite differing approaches to caring for critically ill individuals, and regardless of whether an individual desires all possible treatments until the end of life or prefers to forego invasive treatment that may compromise their quality of life, assessing EOL care quality requires a certain degree of consensus among stakeholders about what constitutes “quality” care. For example, many express a desire to die at home (73%) (Parmalee 2001) and have a chance to say goodbye to loved ones (90%) (Steinhauser et al. 2000). More broadly, dying individuals, bereaved family members, and health care professionals agree that physical and emotional comfort, supportive encounters with health care professionals, and treating the dying individual in a dignified manner are cornerstones of quality EOL care. Physical and emotional comfort is also important to seriously ill individuals, particularly freedom from pain (93%), breathlessness (90%), and anxiety (90%) (Steinhauser et al. 2000).

As older individuals increasingly die from prolonged illness requiring ongoing, and at times complicated, medical care, the location of death has also shifted from nearly all deaths occurring in the home to over half occurring in institutionalized settings such as nursing homes and hospitals (in 2009, 52% of US deaths occurred in these two locations) (Teno et al. 2013). As a result, health care professionals and other caregivers are increasingly involved in EOL care provision. Given that the final months, weeks, and days of life often occur in medical settings, it is not surprising individuals also express a

desire to experience positive encounters with health care providers and remain involved in health care decision-making at EOL. Nearly all seriously ill individuals want to know what to expect about their condition at EOL (96%) (Steinhauser et al. 2000), and bereaved family members indicate it is important to support dying individuals to control medical decision-making (Teno et al. 2001).

Finally, providing dignified care at EOL remains important in a context in which non-family and paid care providers provide a growing proportion of care. Ninety-nine percent of seriously ill individuals, bereaved family members, and health care providers say it is important to be kept clean at the end of life and at least 95% of each of these groups identify maintaining one's dignity as important (Steinhauser 2000). Hospice care, which is predicated on the provision of dignified, comfort care and was involved in 46% (1.2 of 2.6 million) of deaths in 2014 (NHPCO 2015, NHCS 2016), is an important provider of quality EOL care in the US. Moreover, seriously ill individuals, family members, and health care providers identify multiple aspects of care that are important at EOL, including symptom management, dignified care, positive encounters with health care professionals, home death, and hospice involvement.

The multiple factors that are important in assessing EOL care quality fall into two broad categories. The first are objective measures, such as care setting (e.g. place of death) and provider (e.g. hospice). Both home death and hospice involvement are associated with "good deaths" and higher quality EOL care. The second are subjective assessments of care quality, generally reported retrospectively by a proxy involved in or familiar with EOL care, and may be influenced by objective measures. These aspects of care, related to symptom management, quality of encounters with health care providers,

and dignified care, are desired by dying individuals and their loved ones regardless of where the death occurs or what type of provider is involved. This dissertation analyzes EOL care quality using nine measures of subjective proxy-reported assessments of care related to symptom management, encounters with health care providers, and measures of dignified care, while controlling for care setting and provider scenarios.

Gaps in Understanding EOL Care Quality

Despite EOL care being a multifaceted experience, studies of EOL care quality analyze care by looking at individual measures or using a simple additive index (e.g. Teno et al. 2015, Carr 2016). Neither of these approaches captures how subsets of EOL care quality may co-occur or how different subsets of care may represent very different EOL care experiences requiring differing interventions in order to improve care. To address this issue, in the second chapter of this dissertation I use exploratory latent class analysis (LCA) to develop conceptually and statistically different categories of perceived EOL care quality, as reported by the decedent's proxy. In the analysis, LCA takes into account how multiple aspects of EOL care co-occur, reflecting the multiple dimensions terminally ill and older adults identify as important in experiencing a "good death" (Levy and Kutner 2012). This approach allows us to analyze EOL care in a way that more closely aligns with how people think about and experience EOL care. High quality care is generally understood as an amalgamation of several factors—symptom management *and* supportive encounters with health care professionals *and* being treated in a dignified manner—rather than considering each of these factors in isolation. This approach also helps us understand how different aspects of care work together in targeting areas of care for improvement.

In addition to considering how multiple aspects of proxy reporter perceptions of EOL care quality co-occur in older adults, this dissertation identifies the characteristics associated with the type of EOL care an individual receives. The remainder of this section describes how I explore and analyze determinants of perceived EOL care quality in three parts: 1) the extent to which social determinants of health and mortality extend to the case of EOL care quality, 2) the effect of EOL planning and importance of religion on EOL care quality, and 3) how proxy characteristics influence their perceptions of EOL care quality.

In Chapter 2 of this dissertation, I explore the application of Fundamental Causes Theory (FCT) to the case of EOL care quality. FCT identifies social characteristics such as having a higher socioeconomic status (SES) or being a member of a racial or ethnic majority group as a fundamental cause of better health and longer life span (Link and Phelan 1995). Increased income and more education give individuals access to resources such as better health insurance, money to purchase medical services, and an improved ability to access, understand and translate information to health-protecting behaviors (Link and Phelan 1995). Being a member of a racial or ethnic minority group is associated with discrimination in individual health encounters and structural discrimination in the health care system that can negatively impact the type of care an individual receives or cause them to avoid or distrust medical advice. Based on this theorization and the abundance of evidence that supports it, we might expect that SES and race/ethnicity would be fundamental causes of disparities in EOL care quality with individuals with lower SES and members of racial and ethnic minority groups receiving poorer quality EOL care, relative to higher SES persons and whites. On the other hand,

the application of FCT to EOL care quality may be less appropriate for older adults. Some research shows SES-based health disparities attenuate at older ages (Mirowsky and Ross 2008, Phelan et al. 2004), a trend which may be reflected in EOL care quality. The reasons for this attenuation are not entirely clear. Some studies attribute the diminished impact of SES at older ages to selective survival: the negative effects of SES health disparities have already played out in increased mortality among lower SES individuals before old age (Adler and Rehkopf 2008). Other research suggests that social policies such as Social Security and Medicare, which are widely utilized by adults over 65 and provide a basic income and facilitate relatively equal access to health services regardless of SES, effectively diminish SES-based health disparities among older adults (Adler and Rehkopf 2008; Phelan, Link, Tehranifar 2010). Alternatively, SES resources may be of limited use in prolonging life in increasingly frail bodies (Phelan et al. 2004). Economic resources provide health, and by extension, mortality, advantages at many stages of the life cycle (Link and Phelan 1995). However, when a human body nears the end of its natural life span, such as at advanced ages, the limits of scientific knowledge and medical treatment make it simply impossible to extend life any longer, regardless of the amount of resources invested in doing so. Although patient race and ethnicity influence physician behavior (Hoffmann et al. 2016, IOM 2003), an individual's age may simply be a more salient factor than race in EOL scenarios, eliminating variation in EOL care quality. In the second chapter of this dissertation, I begin to address previous inattention to the relationship between fundamental causes of disease and perceptions of EOL care quality.

In addition to considering the underexplored ways in which SES and race/ethnicity might influence EOL care quality, I analyze the effect of advance care

planning for EOL health care needs (“ACP”) and religious beliefs on perceived EOL care quality (Chapter 3). The benefits of informally stating or formally documenting one’s preferences through ACP in terms of avoiding unwanted care at EOL are well documented (Silveira, Kim, Lagana 2010; Detering et al. 2010; Teno et al. 2007; Nicholas et al. 2011). However, the relationship between ACP and perceptions of death quality are less clear, with a retrospective, nationally representative study finding no differences in perceptions of EOL care quality based on ACP or not (Teno et al. 2007) and a prospective longitudinal study of white high school graduates finds increased family conflict when ACP is perceived to be problematic (Khodyakov and Carr 2009). In the third chapter, I add to our understanding of the relationship between ACP and perceptions of EOL care quality using a prospective, longitudinal study of a nationally representative sample of Medical beneficiaries. Moreover, researchers have documented racial/ethnic and SES disparities in ACP. Individuals with higher SES and non-Hispanic whites are more likely to informally state and formally document their preferences than their lower SES, non-Hispanic Black, and Hispanic counterparts. In analyses adjusting for demographic, SES and health characteristics, non-Hispanic blacks have 28% lower odds and Hispanics have 47% lower odds of discussing EOL preferences than non-Hispanic whites (Carr 2012a). Among high-school educated non-Hispanic whites, individuals in the 75th percentile of assets are at least 30% less likely to complete formal ACP and 22% less likely to discuss EOL preferences relative to those in the highest asset quartile (Carr 2012b). The planning gap is smallest between those in the highest and second highest asset quartile, and increases as the amount of assets decreases (Carr 2012b).

Religious beliefs can also play a role EOL treatment and planning, although the relationship between the two is not always clear. Importance of religion has been linked to increased desire for life-sustaining treatments among high school-educated non-Hispanic whites (Sharp, Carr, Macdonald 2012). In a sample of older whites with more mixed education, researchers found no link between religiousness and EOL treatment preferences (Van Ness et al. 2008). Studies of individuals with advanced cancer indicate a link between positive religious coping and increased receipt of mechanical ventilation and resuscitation in the last week of life (Phelps et al. 2009; Maciejewski et al. 2012). However, the relationship between religious beliefs and EOL care quality has received less attention. While physicians tend to negatively view intensive treatment at EOL as futile and preferably avoided (Gallo et al. 2003), religious patients and their family members may be more accepting of the intensive care that can accompany EOL. Moreover, ACP may complicate the relationship between religious attitudes and EOL care quality. The relationship between religious attitudes and ACP is mixed, with some studies finding religious individuals are more likely to discuss EOL preferences (Garrido et al. 2012) or name a health care proxy (Karches et al. 2012), others finding religious coping decreases odds of formal ACP (Phelps et al. 2009; Maciejewski et al. 2012), and others finding no relationship between the two (Smith et al. 2008). In the third chapter of this dissertation, I explore the relationship between ACP, religious attitudes, and EOL care quality, as well as the potentially moderating effects of ACP on the relationship between religious attitudes and perceptions of EOL care quality.

Finally, in Chapter 4 I consider how proxy social characteristics influence their perceptions of EOL care quality. Research links gender and age to the ways in which

individuals respond to stressful situations and negative stimuli. Women are more likely to employ selective ignoring to cope with stressful family interactions (Pearlin and Schooler 1978), and so may provide more positive assessments of EOL care quality as a reflection of coping strategies. Older adults display reduced emotional reactivity and less response to negative stimuli (Carstensen, Fung, and Charles 2003), and may report high-quality EOL care as part of a tendency to focus on the positive aspects of otherwise upsetting events, such as spousal loss. Stress and bereavement research identifies positive appraisal of difficult life events as a useful meaning-making and coping strategy. Bereaved individuals positively appraise the loss of close family members as a way of assigning meaning to the loss and reducing long-term stress associated with the death (Bonanno and Kaltman 1999), and may perceive high-quality EOL care as part of that appraisal process, regardless of the actual nature of care. A similar process may work with respect to proxies who are more familiar with a decedent's care in the last month of life. Familiarity with care may signal actual caregiving responsibilities at EOL. Daughters and wives are likely to provide care for aging, ailing, and dying parents and husbands (NASEM 2016), and they and others familiar with care may be motivated to positively evaluate EOL care in which they were directly involved as a way of making sense of the loss and their role in it.

Data

I use four waves of survey data from the National Health and Aging Trends Study (NHATS) in order to apply an analytically complex technique (LCA) to enhance our understanding of EOL care quality and determine the extent to which: 1) fundamental causes of disease and mortality extend to perceptions of EOL care quality, 2) ACP and

religious attitudes relate to perceptions of care quality, and 3) proxy characteristics influence their perceptions of EOL care quality. NHATS is a prospective, longitudinal study of a nationally representative sample of Medicare-eligible individuals in May 2011. NHATS is ongoing; data are collected annually, beginning with Round 1 in 2011. I analyze a group of NHATS respondents (“decedents”) who met the following criteria: 1) participated in the baseline survey in 2011; 2) died before rounds 2, 3, or 4 of data collection (2012-2014); and 3) had a proxy completed an exit interview about the decedent’s last month of life, including at least one of nine EOL care quality measures. My final analytic sample in each chapter varies based on the variables included in the individual analyses. In the second chapter, I use exploratory latent class analysis (LCA) to identify three conceptually and statistically distinct categories of EOL care quality in the data. I then use these three classes as my outcome measure and perform LCA with covariates to determine which factors significantly predict likelihood of membership in one latent class compared to another. I then run three LCA with covariate models, one each to test the fundamental causes, ACP and religious attitudes, and proxy characteristics questions outlined above. The analytic approach to analyzing EOL care I use in this dissertation examines how multiple elements of EOL care co-occur in a sample of older adults, adding complexity and nuance to how we measure EOL care quality. Additional analyses consider how decedent social characteristics and health behaviors and proxy characteristics shape patterns of EOL care quality, identifying disparities in care provision that can inform efforts to improve EOL care.

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Chapter 2

A Case for Death as Equalizer: Fundamental Causes as non-Predictors of Multidimensional End-of-Life Care Quality

Introduction

Providing quality end-of-life (EOL) care is a priority for dying individuals and their family members, caregivers and healthcare providers, and policy makers. It is part of a social obligation to honor and show respect for individuals in the last stages of life, and for their family members and caregivers who will live with the memory of their loved ones' EOL experience (IOM 2014). Quality EOL care is of particular concern for adults age 65 and older who account for three-quarters of 2.6 million deaths in the United States, 67% of which are attributable to the chronic illnesses heart disease, cancer, stroke, chronic lower respiratory disease, and Alzheimer's disease (2014 data in Kochanek et al. 2016). Caring for older individuals with multiple comorbidities is clinically challenging and costly, particularly in the final stages of life. In 2014, Medicare spent an average of \$69,000 per individual during the last two years of life; just over half of that in the last six months of life alone (Dartmouth Atlas Project 2017b). The relatively common, complex, and costly nature of death among older adults makes understanding and improving EOL care quality among this segment of the population particularly important.

Moreover, experiences with EOL care have lasting effects for bereaved loved ones and caregivers. Bereaved individuals' perceptions of quality of EOL care can affect their long-term health and well-being; widow(er)s who perceive their spouses suffered at EOL report more anger, anxiety, and yearning six months after the loss (Carr 2003).

Those whose spouses received hospice care, considered a source of high-quality EOL care, had reduced risk of mortality (Christakis and Iwashyna 2003).

Bereaved family members and EOL care experts agree that several subjective elements are important at EOL. These include providing physical comfort to dying individuals, helping dying individuals maintain control over medical treatment and daily routine decisions, and easing family members' burdens in advocating for high quality care for their dying loved ones (Teno et al. 2001). These facets of care are subjective in the sense that they rely on family members' assessments of the situation and cannot be easily recorded or verified in a medical record. However, these aspects of care are also more specific than "overall satisfaction" with care and are potentially modifiable (Teno et al. 2001). Questions about family member perceptions of subjective aspects of EOL care have typically been used to assess satisfaction with hospice and palliative care (Teno 2005), and are required by the Centers for Medicare and Medicaid Services (CMS) for reimbursement for these services (NHPCO 2015c). However, these measures are underexplored in studies examining subgroup differences in EOL care. Moreover, their focus on how care is provided makes them relevant for all EOL care scenarios, regardless of setting (e.g. home or hospital) or provider (e.g. hospice worker or nursing home staff member). In this study, I assess family member and caregiver retrospective reports of subjective aspects of EOL care quality among a sample of older adults who died in a variety of care settings and who had different types of care providers in the final stages of life.

Dying is a process that often involves management of complex health conditions, while attending to the needs and preferences of the dying individual and family members,

underscoring the fact that multiple components of care are simultaneously experienced at EOL. However, studies on dying frequently evaluate care quality by assessing single measures separately or by combining several measures into a single index (e.g. Carr 2016; SUPPORT PIs 1995; Teno et al. 2015). I am not aware of any work that systematically explores whether several elements of high quality EOL care are typically experienced, or which elements co-occur most often in the population. Although it is a non-contentious proposition that we should work towards providing good EOL care for all individuals, dying is a complex process. Using nine subjective measures of EOL care simultaneously, I create and use conceptually and analytically distinct subtypes of care quality among older adults. From a care delivery perspective, the measures I use are potentially modifiable and therefore have practical applications in improving EOL care quality in all settings.

In addition to analyzing how multiple components of EOL care quality occur together, this study examines how EOL care quality is distributed among older adults. Although providing high quality EOL care to all individuals is a high priority for providers and policy makers, very little research focuses on how EOL care quality is stratified by different social characteristics of those who experience it. Despite the established link between social disadvantage and increased risk of disease and mortality (Elo 2009; Link and Phelan 1995; Marmot et al. 1991), most research has not explored the possible connection between social disadvantage and EOL care quality (see Carr 2016 for a review and exception). In this paper, I analyze the extent to which fundamental causes theory, a sociological explanation linking health and mortality disparities to social factors such as SES and social support (Link and Phelan 1995), applies to and helps

explain differences in EOL care quality. Using the subtypes of quality care measure that I develop, I investigate the extent to which fundamental causes of illness and mortality (gender, race/ethnicity, and socioeconomic status) also explain differences in EOL care quality among older adults, regardless of where an individual dies, who provided care, and their health status in the year before they died.

This study uses four waves of longitudinal data from the National Health and Aging Trends Study (NHATS) to analyze EOL care quality among adults 65 and older, individuals with complex healthcare needs who are the most likely to die. Using retrospective family member and caregiver reports of the deceased individuals' EOL, this study contributes to our understanding of EOL care quality in two ways. First, rather than looking at how different measures of EOL care quality operate individually, I develop three conceptually and statistically distinct categories of EOL care quality that allow us to understand how multiple components of care co-occur in the final stages of life. This approach allows for a more nuanced understanding of how multiple elements of EOL care might be targeted for improvement simultaneously. Secondly, I explore the extent to which fundamental causes of disparities in health and mortality explain variations in EOL care quality. Understanding the axes along which quality care is stratified has implications for designing effective policies aimed at reducing inequalities in EOL care. In the next section, I describe the components of quality EOL care, explain why it is important to align the multidimensional nature of quality care with how we analyze and assess that care, and outline how existing theories explaining inequalities in health and mortality might help us understand systematic differences in EOL care quality.

Quality End-of-Life Care

Researchers and practitioners consistently identify components of quality EOL care that are important to dying individuals and their loved ones and caregivers in the United States. These include providing physical comfort to dying individuals, helping dying individuals maintain control over medical treatment and daily routine decisions, and easing family members' burdens in advocating for high quality care for their dying loved ones (Teno et al. 2001). However, providing dignified, symptom free, high-quality care is not always an easy endeavor, particularly for older adults. Life expectancy in the United States has increased for the past several decades, in part due to a shift in leading causes of death from acute to chronic illnesses (Carr and Luth 2016). Medical advances allow individuals to live for extended periods of time with multiple chronic illnesses. As human bodies age and become increasingly frail, illness management becomes increasingly complex and costly, making symptom free, high-quality EOL care elusive (Carr and Luth 2016). In this dissertation, I analyze three dimensions of EOL care quality concurrently: physical and emotional symptoms, health care encounters, and dignified treatment. The remainder of this section outlines why these three dimensions are important in considering EOL care quality and the measures I use to address each.

First, freedom from pain, breathlessness, sadness, and anxiety are important factors at EOL for adults, including seriously ill persons and healthcare professionals who care for the dying. In a large study of seriously ill individuals, bereaved family members, physicians, and other health care providers, nine in ten agree or strongly agree that being free from pain, breathlessness, and anxiety is important at EOL (Steinhauser et al. 2000). Just over half of adult respondents indicate they are concerned about the possibility of continued emotional suffering at EOL (Parmalee 2001). While studies

indicate a desire for no pain and other symptoms is common at EOL, complete absence of symptoms is not possible (or even desirable) in every scenario, particularly when people die from protracted chronic illness which can become increasingly severe at the EOL. If a dying individual does not receive enough medication or medical assistance to alleviate symptoms, he or she may continue to suffer. On the other hand, providing complete symptom relief may require heavy sedation, making dying individuals unable to interact with grieving family members. Both outcomes—the perception that an individual continues to suffer when more treatment could be administered and non-responsiveness that results from doses of medication necessary to relieve intractable symptoms that may occur at EOL—can be distressing to family members hoping to share peaceful and meaningful exchanges with dying loved ones. Seriously ill individuals do not want to experience unwanted symptoms at the EOL. Presence of symptoms and ineffective management of those symptoms can negatively impact dying individuals' ability to interact with their family members and caregivers at EOL, and by extension, family members' perceptions of EOL care quality. In developing classes of EOL care quality, I include measures of whether pain, breathlessness, and sadness and anxiety were present and adequately managed in the last month of life.

In addition to physical and emotional comfort, dying individuals' experiences with the health care system are important components of quality EOL care. Longer life span with increasingly complicated health has been accompanied by the medicalization of dying—a cultural shift towards treating death as something to be avoided or delayed, rather than accepted as a natural part of life (Conrad 1992). The combination of complex illness needs and increased medical control over death and dying means that frequent

contact with the health care providers is an inevitable part of dying for many older adults. The nature of that contact is an important component in assessing EOL care quality. While death and dying may occur increasingly under the purview of health care professionals, Americans still expect a degree of autonomy and involvement in personal health care decision-making. Federal law protects a patient's rights to state their EOL health care treatment preferences (U.S. Congress 1990). Recent public opinion polls indicate 80% of people believe doctors and nurses should pay attention to whether or not a patient wants treatment to keep them alive, and 66% believe there are circumstances in which a patient should be allowed to die (PRC 2013). Seriously ill individuals express preferences in support of self-determination: 40% want to control the time and place of death, 84% agree it is important to feel prepared to die, and 96% want to know what to expect about their physical condition at EOL (Steinhauser et al. 2000). The tension between medical providers' increased involvement in EOL and patients' and family members' desire to actively partake in health care decision-making can lead to conflict and confusion in EOL care provision, particularly if the moment of transition from ongoing chronic illness management to dying is not clearly identified, or if a patient's wishes are unclear or in conflict with medical opinion. Clear communication is necessary for healthcare professionals to remain attuned to the care preferences and needs of dying individuals, and to deliver care that is concordant with those desires.

The quality of interactions with health care providers and dying individuals' and their loved ones' participation in health care decisions may be affected by the setting of EOL care and who is providing the care. Doctors may involve dying individuals in care decision-making differently depending on whether they are in a palliative or intensive

care unit. Nurses may also react differently depending on if they are providing hospice care to a newly referred patient or managing medications for a long-term nursing home resident. Similarly, dying individuals' loved ones may assess the quality of interactions with health care providers differently depending on whether they occur in their childhood home or on a bustling hospital unit, and whether care is provided by nursing home staff trained in caring for the aging or by hospice professionals specializing in EOL care specifically. High quality encounters with health care providers should be a goal of quality EOL care, regardless of setting or care provider. As such, I include measures of communication with healthcare professionals, being informed about one's condition, involvement in decision making, and respecting treatment preferences as components of EOL care quality while controlling for care setting and provider.

Finally, in addition to considering the way dying individuals are treated with respect to their physical and health care needs, quality EOL care must also attend to individuals' personal needs. Among seriously ill individuals, 95% say it is important to maintain one's dignity and 99% say being kept clean is important at EOL (Steinhauser et al. 2000). As with interactions with health care providers, loved ones may assess the quality of dying individuals' personal care and treatment differently based on the setting and provider. I include measures of respect and personal care needs to classify types of EOL care while controlling care setting and provider.

When considering EOL care, interventions often target single aspects of care, rather than considering how multiple components of care work together. In practice, it is probably realistic to expect certain sub-dimensions of EOL care occur in tandem. However, we do not have an in depth understanding of how multiple aspects of EOL care

quality co-occur, as most studies examine different aspects of EOL care individually (e.g. Teno et al. 2015). Some studies use a simple index of multiple measures (e.g. Carr 2016). While this approach is an improvement over single-item measures, it does not capture how subsets of measures may co-occur together and how different subsets may describe very different experiences of EOL care. For example, two individuals may have identical index scores, but one's EOL experience may be highly rated in terms of symptom management, while the other's is highly rated on measures of autonomous decision-making. This distinction is important in identifying multiple potential pathways to "good" or "bad" deaths which may require different interventions. In this study, I use latent class analysis (LCA) to develop three conceptually and statistically distinct categories of EOL care quality to consider how multiple aspects of EOL care occur at the same time. This approach allows us to think about EOL care quality in a way that more closely aligns measurement with how people experience and think about EOL care. This approach also helps us understand how different aspects of care work together in order to identify and target specific areas of care for improvement.

Finally, dying individuals and their loved ones desire all aspects of EOL care, or as many as possible, be considered, regardless of where end-of-life occurs and what type of care providers are involved. So, although some aspects of end of life experience such as home death and hospice involvement might be associated with higher quality care, they should not be conflated with *actual* EOL care quality. Home death and hospice involvement are not desired by all individuals, nor are they possible in all EOL scenarios. Family members, caregivers, and health care professionals should, however, aspire to

provide high quality EOL care, by treating dying individuals with respect and dignity and striving to make them as comfortable as possible, regardless of setting or provider.

Studying dying individuals *in situ* is ethically fraught (George 2002), so researchers rely on two types of alternative measures to study EOL care quality. Objective measures, such as Medicare and hospital records and patient charts, are relatively easily verified. Subjective measures rely on another person's assessment of the quality of care. Proxy reports are collected retrospectively and typically are provided by a close family member such as a spouse or child. Hospice and palliative care providers use family member evaluations of EOL care to assess overall satisfaction with care and to identify areas for care improvement, and the CMS use information from these reports in determining reimbursement to hospice and palliative care providers (NHPCO 2015b). However, proxy reports are particularly valuable because they can be utilized regardless of where an individual dies or what type of provider is involved in EOL care. This study uses proxy reports in a sample of older adults who die in a variety of care settings and with different types of EOL care providers. While proxies' assessments may be influenced by their relationship to the decedent, role in caregiving, and/or personal experiences, they remain a necessary and important source of information regarding EOL care quality (George 2002, Lendon et al. 2015). In subsequent analyses, I then control for dying at home versus another setting and whether or not hospice was involved to ensure any observed variation in EOL care quality (as theorized below) is net of EOL care setting or provider. The next section outlines how the fundamental causes theory of health and mortality inequalities might help explain variation in EOL care experiences.

Fundamental Causes Theory and EOL Care Quality

Although providing high quality EOL care to all individuals is a high priority for providers and policy makers, very little research focuses on how EOL care quality is stratified by the different social characteristics of those who experience it. This lack of attention stems, in part, from a historical lack of data regarding EOL experiences among a diverse population of older adults. For example, the Wisconsin Longitudinal Study and its companion study, Wisconsin Study of Family Loss, provide a rich information about EOL care but are limited to relatively high SES (high school educated), non-Hispanic whites, precluding analysis including lower-SES individuals or based on race and ethnicity. There are well-established gradients in life expectancy by gender, race, and socioeconomic status in the United States. For example, women live longer than men (NCHS 2011) and African-Americans have a shorter life expectancy than Whites (NCHS 2016), and those with lower SES have poorer health and premature mortality relative to their higher SES counterparts (Adler et al. 1994; Elo 2009; Marmot et al. 1991). Cause of death is also stratified. Whites and males commit suicide at higher rates than any other race and females (CDC 2015). Until recently, breast cancer was more commonly diagnosed in White women, but it remains more deadly in African American women (ACS 2015; Parker-Pope 2015).

Some of the disparities in mortality outcomes may be linked to disparities in health status across the life course that subsequently impact mortality. Racial and ethnic minorities live longer portions of their lives in poorer health and have less access to health care services than non-Hispanic whites (Elo 2009; Feagin and Bennefield 2014; Marmot et al. 1991; Williams 2012). Similarly, having a higher SES also predicts better health and longer life. Education, specifically, has an independent effect on mortality

(Baker et al. 2011) and accounts for a widening in the gap in self-rated health as adults age (the gap decreases in those over 70 years old, but remains) (Mirowsky and Ross 2008).

The fundamental causes of disease model theorizes the link between social position, health, and mortality by positing health and mortality disparities are rooted in social factors such as SES and social support (Link and Phelan 1995). Higher SES provides greater access to resources such as money, knowledge, power, prestige, and advantageous social networks, which individuals and groups who occupy higher SES utilize to minimize their risk of disease (Link and Phelan 1995: 87). Resources can be employed on two levels. At the individual level, knowing about, having access to, and being able to afford health-enhancing behaviors shape actual health behaviors (Phelan and Link 2005). On a contextual level, resources can give people access to neighborhoods, occupations, and social networks that minimize exposure to health risks and further enhance factors protective of health (Phelan and Link 2005). To the extent that other social categories such as race, ethnicity, and gender are also linked to these risk-reducing resources (such as decreased exposure to discrimination), they too should be considered fundamental causes of disease (Link and Phelan 1995: 87).

While we know a fair amount about social inequalities in health status, disease, and mortality, less is understood about gender, racial/ethnic, and socioeconomic stratification in the quality of EOL care among older adults. Meaningful and effective efforts to improve care for dying persons, and the potential benefits (or reduction in potential harm) to their loved ones and care providers should consider and address stratification in the death and dying experience. To the extent that experiencing quality

care reflects access and resources, fundamental causes theory would suggest that women, members of racial and ethnic minority groups, and individuals with less education, due to their socially disadvantaged positions, may experience poorer quality EOL care.

This analysis evaluates the extent to which fundamental causes theory helps explain inequalities in EOL care. To the extent that inequalities in health and mortality outcomes can be explained by resource, knowledge and network access, it makes sense that the advantages conferred by occupying positions of greater social advantage would translate to access to better EOL care. Following this logic, one might anticipate that men, non-Hispanic whites, and individuals with higher SES would experience higher quality EOL care than women, members of racial and ethnic minority groups, and those with lower SES, and that proxy reports of EOL care quality would reflect these advantages. Conversely, proxy expectations and perceptions of those statuses might influence their reports of EOL care quality in the opposite way. Caregivers, who are likely to be female and, in the case of family caregiving, have similar race/ethnicity and SES to the decedent, might assume that advantages conferred by being male, white, and having higher SES would translate to excellent quality in EOL care, and therefore have higher expectations for care quality. If this is the case, they may hold EOL care quality for male, non-Hispanic White, or higher SES individuals to a higher standard, and have more critical judgments if aspects of care fall short. This paper presents an exploratory analysis of the extent to which fundamental causes of health and mortality disparities—gender, race/ethnicity and SES—can be applied to EOL care quality. To my knowledge, the relationship has not been previously tested, and the mechanisms through which care and perceptions of care operate are not well understood and may, in fact, work in

opposition to one another. The next section describes additional potentially confounding factors between fundamental causes and EOL care quality.

Additional Influences in End-of-Life Care Quality

Care Setting and Provider. My primary focus in this paper is exploring the extent to which social disadvantage influences perceptions of EOL care quality, while accounting for other factors that research indicates may affect perceptions of EOL care quality. Research indicates that location of death and care provider are often associated with high quality EOL care. Opinion polls in the United States indicate that 73% of Americans prefer to die at home (Parmalee 2001), a finding echoed by bereaved individuals (Munn and Zimmerman 2006). However, while people say a home death is important when death is hypothetical or already past, the desire for a home death is less pronounced among seriously ill individuals. In a large study of seriously ill, bereaved family members and health care professionals, only 35% of seriously ill individuals agreed a home death was important, compared to 44% of physicians (Steinhauser et al. 2000). In qualitative studies of older adults and individuals with heart failure, respondents wanted a home death only if it did not cause undue burden for their loved ones (Gott et al. 2004; Gott et al. 2008). This qualification regarding home death may reflect a more accurate perception among those closer to death of the intensity of care required for some illnesses, which may make a home death less desirable in some circumstances.

Hospice care is associated with avoiding intrusive medical treatment such as hospitalization and intensive care unit (ICU) admission at the EOL (Casarett et al. 2005; Stevenson and Bramson 2009). Hospice care is also associated with positive outcomes for bereaved family members. Spouses of individuals who die after receiving hospice

care are at decreased risk of mortality 18 months following the loss compared to spouses of individuals who do not receive hospice (Christakis and Iwashyna 2003) and demonstrate moderately fewer depressive symptoms up to two years following the loss (Ornstein et al. 2015). Family members of individuals who die after receiving hospice care consistently report higher satisfaction with their loved one's EOL care, and that the deceased received better quality EOL care and had fewer unmet needs EOL (Ersek et al. 2015; Rhodes, Xuan, and Halm 2012; Teno et al. 2004; Teno et al. 2011). We should consider the quality of EOL care regardless of where it happens and who is providing the care. However, because home death and hospice involvement are associated with assessments of higher quality EOL care, I control for these factors in models assessing the relationship between fundamental causes factors and EOL care quality.

Health Characteristics. In addition to care setting and provider, health status and illness experience in the final years and months of life can impact the quality and perceptions of EOL care. If death is expected or anticipated, healthcare providers and loved ones can take additional steps to care for the dying individual, leading to higher quality care and increased acceptance of the loss. However, there is considerable variation in the trajectory people follow during their final days, weeks, and months of life. The difference between expected and prolonged death could be the difference between family members accepting a loved one's death is near and perceiving that individual is experiencing unnecessary suffering. Among older adults, multiple chronic illnesses punctuated by acute health crises further complicate care and make it difficult to provide consistently high quality care in the final years of life (President's Council on Bioethics 2005). Living with one or more serious chronic illnesses negatively impacts

health and can accelerate decline in frail older adults, which can lead to complicated care regimes in the time leading up to death. Recent hospitalizations are indicators of acute health episodes and severity of chronic illness, which can increase risk of mortality among older adults and of receipt of intensive medical care in the final months of life. Self-rated health is a reliable predictor of mortality (Idler and Benyamini 1997), and individuals with poorer health may have increased care needs, making it more difficult to provide them with high quality care. I expect proxies of decedents with more illnesses and hospitalizations and who rate overall health worse prior to death will negatively assess EOL care quality because of increased difficulties associated with providing high quality care to individuals with complicated health care needs, particularly when they are at the most vulnerable period before dying.

Other Controls. Finally, I include additional controls that are associated with quality of EOL care. Death is more highly anticipated among older adults, and for the oldest adults in particular. Anticipated or expected death allows time for resource mobilization and higher quality care. Marriage is a marker of social support and potential caregiving resources to attend to a dying individual's needs. Familiarity with EOL is also a marker of closeness to and involvement with a dying individual's care. Knowing about a dying individual's health status and anticipating his death allows time for care arrangements to be made and increases the chances that the dying individual's care needs can be met. I control for older age at death, marital status, and caregiver familiarity with the decedent's last month of life, expecting that being older, married, and more familiarity with care will be associated with more positive proxy assessments of EOL care.

Summary

This study contributes to existing knowledge in two ways. First, research tends to look at a complicated experience such as death using individual measures or an indexed care rating, which obscures different combinations of experiences in individuals' EOL care. This analysis will examine the extent to which individual components of EOL care death co-occur, creating an analytic assessment of care that more closely reflects the way people actually experience it. Moreover, by identifying which aspects of EOL care cluster together, researchers and clinicians can identify aspects of care that require more attention and tailor efforts to target multiple aspects of care simultaneously to meaningfully improve care for the dying.

Second, considering rich research demonstrating important social determinants of health and mortality, this analysis explores whether the notion of structural determinants of health and mortality can be extended to perceptions of EOL care quality. This analysis is exploratory, as the way in which perceptions of care operates are not well understood. To the extent that being male, non-Hispanic White, and having higher SES provides access to resources promoting health and longevity, we would expect individuals in these social positions would also be able to access higher quality EOL care, and proxy reports would reflect this process. On the other hand, proxy reporters may have higher expectations of EOL care for individuals with higher SES and who are non-Hispanic White, and therefore may be more critical in assessing the quality of EOL care.

Data and Methods

Data

I use four waves of data from the 2011-2014 National Health and Aging Trends Study (NHATS).¹ NHATS is a prospective, longitudinal survey administered to a nationally representative sample of 8,245 Medicare beneficiaries over 65 residing in the contiguous United States in May 2011. NHATS includes questions about sociodemographic, health, and disability characteristics. If the respondent dies between waves of data collection, a proxy respondent familiar with the respondent's last month of life completes an exit survey. I use prospective demographic and health information that decedents provided in survey years prior to their deaths and retrospective EOL care measures proxies provided in exit interviews.

Study and Analytic Sample

Of the 8,245 initial NHATS respondents, 1,515 (18%) individuals died between the first and fourth waves of data collection (2011-2014). I include in this study the 1,081 decedents who completed the respondent questionnaire and who have a completed family member or caregiver interview about the decedent's last month of life. I analyze the 1,046 individuals with complete information on eleven independent and control variables and for whom a proxy respondent answered at least one of the nine questions used to assess EOL care quality.² Of the 434 deceased individuals not included in the study, 85 do not have a last month of life interview and 349 were nursing home residents during the

¹ National Health and Aging Trends Study (NHATS) is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by the Johns Hopkins University.

² Sensitivity analysis (Supplementary Analysis 2.A) indicate similar results regardless of the number of LCA items answered. The only exception is with regard to some predictors that lose significance when proxies answer all 9 items. This loss of significance may be due to loss of statistical power as sample size decreases but number of predictors included in the model remains constant.

first wave of data collection. By survey design, these 349 do not have a completed respondent questionnaire. I exclude from the analysis an additional 35 individuals who are missing data on all EOL care quality measures (3) or on any independent or control variable (32).

Measures

EOL Care Quality. I measure quality of EOL care with nine items assessing the NHATS respondent's last month of life as reported by a proxy respondent—usually a spouse (22%) or child (47%). I categorize the responses to these variables into two or three categories to avoid sparseness and facilitate latent class analysis (described below). Table 2.1 provides a summary of the original survey questions and final measures I use in the latent class analysis.

Three of the nine items assess symptoms commonly reported at EOL: pain, breathlessness, and sadness or anxiety. Proxies indicated whether the deceased experienced each of these in the last month of life. If yes, proxies indicated whether the deceased received help dealing with the symptom. If yes, proxies indicated whether the deceased received less help than was needed, more than needed, or about the right amount. I combined these three questions into a single three-category variable for each of pain, breathlessness, and sadness/anxiety: “None” (no reported symptom), “Managed” (experienced a symptom and received “about the right amount of help”), and “Unmanaged” (experienced a symptom and received no help, less help than needed, or more help than needed).

Six questions capture various dimensions of EOL care quality. Two variables measure whether treatment decisions were made without the decedent or her family members' input and the decedent received care she would not have wanted with "No" and "Yes" responses. I categorize whether the decedent was treated with respect, her personal care needs were met, and she and her family were informed about her health condition, as "Always" and "Usually/Sometimes/Never." I dichotomize these three variables because 82%-89% of respondents indicate the decedent's needs were "Always" met. Finally, I measure coordination of care by combining two questions: whether there was more than one doctor involved in care and, if yes, whether it was clear which doctor oversaw care. I divide individuals into two groups: "One doctor/Clear doctor in charge if care" and "Unclear who was in charge of care."

[Table 2.1 about here]

Predictors of End-of-Life Care Quality

Fundamental Causes of Disadvantage. I measure fundamental causes of social disadvantage with three variables. For sex, I code males as 1, females as 0. For race and ethnicity, I compare non-Hispanic whites (coded as 1) with all other racial and ethnic groups (coded as 0). Two supplementary analyses comparing 1) non-Hispanic whites and non-Hispanic blacks only and comparing 2) non-Hispanic whites, non-Hispanic blacks, and Hispanics yield similar results as when Hispanics and "Others" are combined with non-Hispanic blacks.

I choose the most parsimonious treatment of education, dichotomized at the median (more than high school=1, high school or less=0). Analyses categorizing

education into three or four categories do not improve model fit. Education is a persistent and enduring indicator of SES among adults over 65, as income is affected by health and Social Security payments reduce income disparities among older adults, making income a less reliable measure of SES among older adults. Moreover, fundamental causes theory focuses on the relationship between life-long SES and health outcomes, making education a more appropriate indicator of life course SES among retirees than current income.

Care Setting and Provider. I include two dichotomous measures of EOL care setting and provider. I control for EOL care setting (home death=1, all other place of death=0) and whether hospice was involved in care during the last three months of life (coded 1) or not (coded 0).

Health Characteristics. I also control for several aspects of health status that can affect quality of life and predict (expected) mortality among older adults. I control for none (coded as 1) or one or more (coded as 0) previous diagnosis with serious chronic illnesses associated with death in older adults: lung disease, stroke, cancer, or dementia or Alzheimer's disease. I categorize number of hospitalizations in the previous year as none or one (coded as 0) or two or more (coded as 1). I code self-rated health as "Excellent/Very Good" (coded as 1) and "Good/Fair/Poor" (coded as 0).

Other Controls. I control for being married, standardized age at death, and proxy familiarity with the decedent's last month of life as measured with the question: *How familiar were you with the decedent's daily routine in the last month of life?* ("Very familiar"=1 and "Somewhat/A little/Not at all familiar"=0).

Analytic Strategy

First, I present descriptive statistics and discuss bivariate correlations among the items used in the latent class analysis (LCA), indicators of fundamental causes measures, and care location and provider characteristics. I then perform latent class analysis (LCA) to identify statistically and conceptually distinct categories of EOL care quality based on responses to the nine measures outlined above (Figure 2.1). Latent class analysis is a type of modeling that identifies unobserved (latent) subgroups of classes based on patterns of individuals' responses to multiple categorical variables measured in the data. The resulting subgroups, or latent classes, represent discrete categories of EOL care quality. The LCA software I use accounts for missing data using a full information maximum likelihood technique, allowing for inclusion of respondents in the analysis provided the proxy reporter answered at least one item used to determine the latent classes (Collins and Lanza 2010: 80-81; The Methodology Center 2016). As a result, the number of responses to each of the nine items about care in the last month of life varies from 937 to 1,001 (out of 1,046). In exploratory LCA, Bayesian measures of model fit, heterogeneity and latent class separation, average probability of class membership, and predicted latent class size indicate a 3-class solution best fits the NHATS data used in this analysis. In further sensitivity analyses, I perform multiple group LCA on five different subgroups: men and women, non-Hispanic whites and all other racial and ethnic groups, those with high school or less and more than high school educations, home and all other places of death, and hospice and no hospice involvement. In these analyses, multiple group LCA does not significantly improve model fit, and latent classes remain conceptually similar to

the initial three-class solution. I therefore assume measurement invariance for predicted response probabilities (rhos) across groups.

Next, I perform LCA with covariates, which uses multinomial logistic regression to determine the extent to which a single variable (e.g. male) or a block of variables (e.g. male, race, and SES together) predict membership in the three latent classes previously identified.³ Likelihood ratio chi square tests comparing LCA with all covariates to LCA without one or a block of covariates determine whether a single or group of variables significantly predicts latent class membership. This analysis allows me to explore the extent to which fundamental causes of social disadvantage (gender, race/ethnicity, SES), care setting and provider (hospice involvement, home death) and health characteristics (comorbidities, hospitalizations, self-rated health) predict the type of EOL care a decedent receives, either individually, or in the above-mentioned blocks. I conduct all latent class analysis with Stata 14/MP, using the doLCA command (The Methodology Center 2015).

[Figure 2.1 about here]

Finally, in a supplementary analysis I use multinomial or binary logistic regression to regress each of the nine variables used in the LCA on all my predictors to

³ An alternate approach to the “LCA with covariates” approach I use here is “classify/analyze.” In classify/analyze, you perform LCA, assign each case to a resulting latent class based on their highest predicted probability of membership, and then perform multinomial logistic regression to determine significant predictors of latent class membership. While commonly used, “classify/analyze” has been critiqued because it does not account for misclassification error, and therefore can mistakenly identify non-significant predictors as significant (The Methodology Center 2016, Goodman 2007). As the LCA with covariate approach is the most conservative, it is the one I employ here.

determine whether individual predictors operate similarly across individual measures of EOL care quality.

Results

Descriptive Statistics

Table 2.2 provides descriptive statistics of the 1,046 decedents in the sample. Over half of proxies responding to questions about symptoms at EOL reported that the decedent experienced pain, breathlessness, and sadness or anxiety. Proxies reported pain most often (56% managed pain, 15% unmanaged pain). Fifty-six percent reported breathlessness and sadness or anxiety, although breathlessness was more often managed than unmanaged (45% vs 11%) compared to managed and unmanaged sadness (30% and 26%). Overall, proxy reporters rated the remaining aspects of EOL care highly, with at least four-fifths reporting the decedent was “always” treated well and involved in health care decision-making (82-91%).⁴

About 43% of the decedents are male, 70% identify as non-Hispanic White, and 35% have more than a high school degree. Overall, 45% of Medicare beneficiaries are male, 77% are non-Hispanic White, and 50% of adults over 65 in the US have more than a high school education (Cubanski et al. 2015; Ryan and Bauman 2016). The differences in race/ethnicity and education between the NHATS sample and the general Medicare and over 65 population is because NHATS oversampled non-Hispanic blacks and adults over 85 (who have lower levels of education than 65-84 year-olds). Approximately two-

⁴ I do not adjust for survey weights because the analytic program I use drops all cases that are not part of the LCA. As such, when incorporating weights, the LCA software does not correctly adjust standard errors to account for individuals in the complex survey design who are not included in the LCA.

fifths of decedents received hospice (41%) or died at home (38%), similar to the 46% of annual deaths involving hospice (NHPCO 2015a, NHCS 2016) and 34% of Medicare recipients who die at home annually (Teno et al. 2013). Only one in five rated their health as “excellent or very good,” even though just over a quarter reported no serious chronic conditions (27%). Twenty-two percent were hospitalized twice or more in the previous year.

In bivariate correlations (Table 2.3), the six dichotomous items used in the LCA are all positively and significantly correlated. The same categories of symptom variables are also positively and significantly correlated (no pain with no breathlessness with no sadness; managed pain with managed breathlessness with managed sadness, etc.). Unmanaged symptoms are negatively and almost always significantly correlated with the six dichotomous measures of EOL care. Collectively, these bivariate relationships suggest that the variables used in the LCA operate in a similar pattern: positive aspects of EOL care are associated with one another, and unmanaged symptoms are associated with lower care ratings on all measures. With few exceptions, gender, race, and education are not significantly correlated with any of the nine variables used in the LCA. Contrary to what fundamental causes theory would suggest, the directions of association between each fundamental cause and EOL care measure suggest that being a patient who is male, non-Hispanic White, and better educated is associated with more symptoms and less positive treatment at EOL. However, this result is based on direction of association, not significance, and so should be interpreted with caution.

[Tables 2.2 and 2.3 about here].

Three Classes of End-of-Life Care Quality

In the LCA baseline model, without any covariates, three latent classes emerge to represent different types of EOL care quality (Table 2.4). The first class, “no symptoms, high care ratings” is predicted to comprise 45% of the sample. In this class, proxies have a high probability of characterizing decedents as not experiencing pain, breathlessness, and sadness or anxiety. Moreover, proxies have a very high probability of reporting that decedents in this class received the highest quality care in the other six dichotomous measures included in the LCA, relative to the other two classes. For all measures, proxies have over 90% probability of endorsing the more positive assessment of care. The second class, “managed symptoms, high care ratings” comprises 35% of the sample. For this class, proxies have the highest probability of reporting symptoms are present, but managed, in the last month of life. Proxies are also highly likely to report high quality care for the other six areas of care, although proxies have a slightly lower probability of indicating the decedent did not receive any unwanted care in the last month of life, compared to the “no symptoms” class (85%). In this class, symptoms are present, but controlled, and other aspects of EOL care are positively assessed. The third and smallest class, “symptomatic, lower care ratings,” is predicted to account for the remaining 20% of the sample. Proxies are likely to characterize care in this group as mixed in terms of symptom management, and less positively for all other aspects of care. There is about a 50% probability of proxies reporting managed pain or breathlessness, a 40% chance of unmanaged pain, and a 56% chance of unmanaged sadness in this class.

Probability of high quality of care ratings are much lower in the “symptomatic” class than in the other two classes. The likelihoods that proxies report involvement in decisions (78%), having a clear doctor in charge (62%), and not receiving any unwanted

care (76%) are lower in this class than in the other two classes. Personal care needs and respect always being attended to are reported about as often as not in this class, and the likelihood decedents are “always informed” about their medical conditions in less than two fifths (37%). This class represents the “worst” outcome in EOL care: proxies report individuals experience symptoms, often unmanaged, and rate other aspects of care poorly relative to the other two classes.

[Table 2.4 about here.]

Explanatory Mechanisms in Predicted End-of-Life Care Quality

Table 2.5 and Figure 2.2 present odds ratios (exponentiated regression coefficients) and 95% confidence intervals for variables predicting membership in the three latent classes described above. Contrary to what fundamental causes theory would suggest, gender, race/ethnicity, and education are not significant predictors of EOL care quality, when included in the model individually, or as a group. Race/ethnicity is marginally significant ($p=0.09$), but does not operate in the direction expected by fundamental causes theory: in models including all covariates, non-Hispanic whites have higher odds of experiencing “worse” quality EOL care than people of other racial/ethnic backgrounds. Specifically, they have marginally significant lower odds of being in the “no symptoms, high care ratings” group than in the “symptomatic, lower care ratings” group. In supplementary multinomial and binary logistic regression of individual EOL care measures on the variables discussed here, fundamental causes were significant in two instances each for gender and race/ethnicity. Compared to females, males have lower odds of experiencing managed or unmanaged pain (compared to no pain) and of receiving care consistent with their wishes. Non-Hispanic whites have higher odds of

unmanaged sadness or anxiety (compared to none) and lower odds of coordinated care than other racial and ethnic groups (Table 2.6).

In contrast to social characteristics, care setting and provider do significantly predict latent class membership when added to the model individually and together ($p < .0001$). Supporting the common perception that home deaths are preferable to dying in another location, individuals who die at home have higher odds of experiencing no or managed symptoms and higher quality EOL care relative to the odds of having managed or unmanaged symptoms and lower care ratings. Indeed, in supplementary analysis, home death is positively associated with five of the six care measures. Hospice is also a significant predictor of latent class membership, although not always in the expected direction. As expected, hospice recipients have higher odds of being in a group characterized by managed symptoms and high quality care than receiving lower quality care and managed or unmanaged symptoms. However, individuals who received hospice also have lower odds of EOL care without symptoms and with high quality care. If dying individuals are referred to hospice to alleviate their suffering, it makes sense that these individuals would experience “managed” symptoms more often than “no symptoms” (the primary distinguishing factor between these two groups). However, contrary to the idea that hospice care helps manage suffering and provides care aimed at treating the person as an individual, people who receive hospice also have higher odds of experiencing EOL care characterized by unmanaged symptoms and lower rates of quality care relative to either of the other two classes. Supplementary logistic regression indicates hospice is positively associated with having unmanaged (versus none) symptoms.

Finally, health characteristics collectively predict latent class membership ($p < .001$). Consistent with the idea that comorbidities complicate care, particularly at the EOL, those with no chronic illness (compared to one or more) have higher odds of being in the “managed symptoms” or “no symptoms” groups than in the “symptomatic” group. Similarly, more frequent hospitalization, a marker of acute health crises, can also signal presence of symptoms and complicated healthcare needs. As expected, those who report two or more recent hospitalizations (compared to none or one) have higher odds of being in the “managed symptoms” and lower odds of being in the “no symptoms” groups than in the “symptomatic” group. Supplementary logistic regression suggests the relationship between hospitalization and predicted EOL care quality is related to unmanaged symptoms. Self-rated health is not a significant predictor of EOL care quality.

[Table 2.5, Figure 2.2, and Table 2.6 about here.]

Discussion

This study addresses two issues with understanding EOL care quality in older adults. First, while prior studies focus on individual measures of care quality, I use latent class analysis (LCA) to develop a multidimensional measure that simultaneously considers multiple aspects of proxy reports of EOL care quality. Then, using the groups identified in LCA, I analyze how social determinants of health and mortality disparities, EOL care setting and provider, and decedent health characteristics may influence proxies’ assessments of care.

Experiences of EOL care quality fall into three statistically and conceptually different groups, as reported by proxies for a sample of deceased Medicare beneficiaries. The groups are characterized by absence of symptoms and high quality care in all six

domains, managed symptoms and high quality care, and managed and unmanaged symptoms and relatively low quality care. Four-fifths of proxies are likely to rate decedents' EOL experience positively with respect to their interaction with health care providers (informed about condition, involved in decisions, no unwanted treatment, coordinated care) and how they were treated as a person (treated with respect, personal care needs met). Of these 80%, just over half report no symptoms and the remainder report managed symptoms (pain, breathlessness, sadness or anxiety). While adults resoundingly express a desire for "symptom free, excellent care" at EOL (PRC 2013; Steinhauser et al. 2000), these results indicate that caregivers still positively assess quality of EOL care, provided symptoms are managed. Symptoms at EOL are sometimes unavoidable in aging and senescence. However, provided symptoms such as pain and breathlessness are managed, proxies still perceive older adults receive high quality EOL care, even in these circumstances.

In contrast to two classes of high quality EOL care, one in five proxies report a less positive picture of EOL care. They rate decedents' EOL care less positively and indicate decedents experienced managed or unmanaged symptoms. In some instances, more effective symptom management may improve perceptions of health care encounter and personal care. Proxy reports of poor EOL care when symptoms are managed could be an indication of poor psychological adjustment following the loss of a loved one. Alternatively, proxies may be reporting instance of EOL care where, although symptoms were managed, encounters with healthcare providers were unsatisfactory and the decedent was not treated in a dignified manner. Qualitative studies could explore the

circumstances under which proxies report managed symptoms and poor quality care in other areas of EOL care.

Fundamental Causes Do Not Predict End-of-Life Care Quality

Fundamental causes theory proposes that social advantage and disadvantage accumulate in the body and become manifested in health and life expectancy. However, this analysis shows that the mechanisms through which this happens with respect to EOL care in older adults are not clear. Gender, race/ethnicity, and SES do not predict the latent measures of EOL care quality, either jointly or individually. Supplementary analyses suggest this finding is not an artifact of measurement or analytic method. Race and education were not significant in supplementary LCAs comparing non-Hispanic whites and Blacks only and treating education as a 3- or 4-category variable or dichotomizing it at different cut points. My analysis suggests that proxies do not perceive differences in EOL care based on older adults' gender, race/ethnicity, or SES, despite the unequal treatment (differential access to insurance, services, screenings) the decedents have undoubtedly experienced in the healthcare system across the course of their lives (Feagin and Bennefield 2014; Williams 2005). Additional research is needed to unpack the reasons why disparities in treatment over the life course do not correspond to differences in perceptions of EOL care quality among older adults. A deeper understanding of this relationship could inform policies aimed at reducing disparities in other areas.

Although there are racial/ethnic and gender disparities in Medicare utilization, the finding that gender, race/ethnicity, and SES do not influence proxy perceptions of EOL care quality among Medicare recipients suggests the program may be an effective approach to implementing policy that diminishes unequal access to resources such as

EOL care (Phelan, Link, and Tehranifar 2010). The data I analyze were collected before EOL planning sessions were reimbursed by Medicare. To the extent that Medicare successfully equalizes access to quality EOL care, we might expect to see even fewer disparities in EOL care quality among future cohorts of older decedents. The potential equalizing effect of access to EOL planning under Medicare depends on whether planning is still reimbursed by Medicare after expected, but, as of this writing, unknown changes are made to U.S. health care policy. Should Medicare cease to pay physicians for EOL planning sessions, disparities in EOL planning, discussed in the next chapter, may persist or become exacerbated. One way to examine the potentially “equalizing effects” of Medicare would be for future studies to explore how EOL care differs for the less than 10% of individuals over 65 in the United States who are not covered by Medicare. Broadly speaking, coverage is available to anyone over 65 who has been a legal resident for at least five years and has worked for at least ten years. Those outside the Medicare umbrella will be more recent immigrants and individuals who were unemployed for most of their adult lives and not eligible through their spouses.

Phelan and colleagues (2004) find the effects of education and income on mortality weaken among adults over 65 and again among adults after they reach their early 80s. The relationship between SES and mortality is particularly attenuated in adults who die from causes that are not considered “preventable” with the types of resources SES tends to buy, such as early detection, intervention, or treatment, such as dementia and cancers with unknown causes or that do not respond to early detection (i.e. not cancers caused by tobacco consumption, prostate cancer, colorectal cancer, etc.). The authors speculate that frailty in older bodies, and particularly at EOL, may simply

overpower any cumulative benefits accrued by higher SES over the life course. Increasing frailty at older ages may outweigh the benefits of access to preventive screenings, early detection, and expensive treatment, explaining the absence of SES differences in EOL care quality in this analysis.

Another possible explanation for the lack of relationship between gender, race/ethnicity, and SES and EOL care could be that, while social disadvantage accrues and manifests itself in health and mortality outcomes, these factors do not affect perceptions of EOL care quality among proxy reporters. Proxy reporters may be equally motivated to perceive their loved one died well, independent of social characteristics. Indeed, despite the fact that 40% of Medicare decedents are admitted to the ICU during the last six months of life and ICU spending during that same period continues to rise, signaling more intensive and invasive treatment at EOL (Dartmouth Atlas Project 2017a), only 20% of my sample are predicted to experience the “worst” quality EOL care.

Finally, other factors associated with gender, race/ethnicity, and SES, and for which I am unable to account using NHATS data, may affect perceptions of EOL care quality. Social support is protective for health and mortality and may lend itself to improved access to higher-quality EOL care. Although marriage was not a significant predictor of EOL care quality in this analysis, marriage is protective for health and mortality for men, and being married may facilitate access to better EOL care. Men are only 43% of the deceased, but nearly three-quarters of all married individuals in my sample. On the other hand, women tend to have more and stronger social ties, which may lend itself to improved access to quality EOL care, particularly for the 83% of women in the sample who are not married. Alternatively, proxy characteristics may affect their

perceptions of EOL care quality. For example, religiosity has been linked to higher quality of life in the last year of life in general and to better perceptions of health and reduced mortality among African-Americans (Idler, McLaughlin, and Kasl 2009; Idler 2014 p: 17-18). To the extent these trends apply to perceptions of EOL care quality, more religious proxies may assess decedents' EOL care quality more positively.

What Matters: Where You Die, Who Is Involved, and Health Characteristics

In contrast to the weak relationship between fundamental causes and EOL care quality, care provider and setting and health characteristics are strong predictors of perceived care quality. In this analysis, people who die at home are more likely to experience EOL care characterized by an absence of troubling symptoms and receipt of high-quality care. This relationship exists, even when controlling for factors, such as chronic illness, that can potentially complicate home care at EOL. This finding provides support for the general impression among adults and seriously ill individuals that home is the best place to die (Morin 1997; Steinhauser et al. 2000). However, the reason for this relationship remains unclear. For example, higher quality EOL care among people who die at home may be a function of circumstances surrounding these deaths, such as cause and suddenness of death, which are not collected by NHATS. Dying at home often involves family member caregivers who may be motivated to believe they did a good job and therefore positively assess EOL care. Perhaps there is something qualitatively different about dying at home that lends itself to greater physical and psychic comfort and high quality care. People's expectations that dying at home is preferable may also translate to more positive assessments of home deaths.

The relationship between hospice involvement and EOL care quality is mixed. Dying individuals and their loved ones often seek out hospice care specifically for help with pain and symptom management at the EOL, so it makes sense that hospice would predict membership in the “managed symptom” group, which is characterized by symptom management. However, the finding is curious that hospice care also predicts membership in the latent class where unmanaged symptoms are most common and with lowest care ratings across the board, including exceptionally low endorsement of the decedent and family members always being informed about the dying individuals’ health condition. This finding is supported in multinomial regression analyses of the individual measures, which find hospice recipients have significantly higher odds for unmanaged pain, breathlessness, and sadness or anxiety (compared to no symptoms) than those without hospice. Timing of hospice referrals, which is not recorded in NHATS, is also important. Nearly two-thirds of hospice patients receive services for less than a month (NHPCO 2015c), and so proxies may report unmanaged symptoms that occurred in the last month of life prior to hospice involvement. Providing stabilizing comfort care can be an issue if hospice referral comes a few days before death, as is the case for many hospice referrals (Bynum et al. 2016). Moreover, shorter periods of hospice service are associated with bereaved caregivers’ perceptions that their loved ones suffered at EOL and were not prepared for death (Waldrop, Meeker, Kutner 2016). If expectations regarding what hospice services can provide are exceptionally high and not met, care quality may be more harshly assessed. NHATS does not collect information on hospice providers, but certainly not all hospices are created equal, so perhaps variation in quality of hospice care could explain why people who receive hospice care are more likely to experience the

poorest quality EOL care. Finally, while expected death (within six months) is a condition of referral to hospice services, and I control for indicators of prolonged death (presence of chronic illness, recent hospitalizations), the nature of death and the degree to which proxy reporters expected the death could shed light on the unanticipated relationship between hospice receipt and poor EOL care quality.

Health characteristics in the period leading up to death also predict EOL care quality. Specifically, individuals who have one or more chronic illnesses and who have two or more recent hospitalizations have greater odds of experiencing symptoms and lower care ratings than those with no chronic illnesses or one or no hospitalizations. This finding is not surprising, given that increased comorbidity and more frequent hospitalization can signal more complicated health status, which can be increasingly difficult to manage, and eventually devastating, among older, frailer adults. These complex health situations may make it increasingly difficult to manage care at the EOL. While self-rated health, serious illness and hospitalization (as markers of chronic and acute health statuses) can be markers for mortality, only diagnoses and hospitalizations predict EOL care quality. This finding underscores the need for a nuanced understanding of how illness complexity relates to EOL care quality: objective measures of health translate to perceptions of care quality while self-perceptions of health quality do not.

Limitations

This study is among the first I know of to identify latent classes of EOL care quality and explore how fundamental causes of health and mortality disparities may apply to differences in EOL care quality. However, the results are potentially weakened by four limitations. First, the analysis focuses on death among individuals over 65. Premature

mortality among Blacks and individuals with lower SES may leave in the sample a particularly healthy set of individuals with less education and non-Hispanic blacks (who comprise 75% of non-Whites in the sample) who experience relatively symptom free, high-quality EOL care. Moreover, premature death is undesirable, and research indicates health care professionals administer more aggressive EOL care to individuals they consider socially valuable, with younger age being one of the strongest markers of social value (Timmermans 2008). As such, individuals who die before age 65 may receive more aggressive and potentially painful and unwanted EOL care than the older adults in my sample. Future studies might examine SES and racial/ethnic differences in EOL care quality among middle-aged adults, before mortality disparities take effect. However, older adults comprise three-quarters of all deaths in the United States, so understanding EOL care in this segment of the population merits individual attention.

A second limitation is that NHATS data do not capture cause of death or specific information about the dying trajectory. Cause of death will affect certain aspects of the dying experience such as whether it is characterized by pain (as with cancer), breathlessness (as with congestive heart failure), or tends to be swift and asymptomatic (as with an aneurism). A sudden death may be characterized by less medical intervention and fewer symptoms, while a prolonged death may involve complicated care regimens and symptom management. I attempt to address this discrepancy by including variables that approximate chronicity (number of serious diagnoses) and acuity (number of recent hospitalizations) of health conditions as markers of more complicated care needs at EOL. Were it available, including a more accurate measure of dying trajectory may attenuate the effect of chronic illnesses and hospitalizations. Should NHATS data eventually be

linked to the National Death Index, knowledge about EOL trajectories associated with different causes of death might help explain why some individuals experience symptom-free, high quality care EOL and others have an EOL characterized by unmanaged symptoms and poorer quality care.

A third limitation of this study is that the measures of EOL care quality rely on the subjective evaluations of proxy reporters, who may vary systematically in how they assess EOL care quality based on personality or general disposition, prior experience with death, and experience with and knowledge of the death they are evaluating. I control for proxy familiarity with the decedent's last month of life to partially address this issue. Moreover, reliance on second-hand, retrospective reports is a known, but accepted, limitation of studies of EOL (George 2002). Understanding variation in proxy perceptions of EOL care quality is important and merits further study, as these perceptions are linked to bereaved and caregiver health and well-being. Spouses of deceased individuals who receive hospice care have lower risk of mortality (Christakis and Iwashyna 2003). On the other hand, perceptions of poor quality care can negatively affect longer-term mental well-being. Bereaved individuals whose spouses experienced a painful death report greater yearning and intrusive thoughts, and those who perceive substandard care report increased anger six months after the death (Carr 2003). The potentially negative consequences of loss extend to caregivers as well. Nursing home assistants who report distress from grief report lower levels of psychological and physical well-being (Anderson and Ewen 2011). Finally, considering perceptions of specific aspects of EOL care quality provides a more detailed and nuanced perspective on EOL care, helping to answer the question of "How are we doing?" This can be an illuminating

complement to the “Where do we provide care?,” “Who provides care?,” and “How much does care cost?” questions answered by data on place of death, provider type, and Medicare expenditures.

Finally, alternate measures of EOL care might present a different picture, possibly capturing variation based on fundamental causes of advantage and disadvantage.

However, CMS uses the same measures to evaluate hospice provider eligibility for Medicaid and Medicare reimbursement (\$15.1 billion in 2013) (NHPCO 2015b, 2015c), making them a core component in the policy definition of “quality EOL care” and tying them directly to the economy of dying. My analysis extends these measures beyond the hospice context, to a sample of deceased older adults, regardless of whether they received hospice services. A nuanced understanding of how these measures function together, for whom, and under what circumstances is critical for designing effective policy to improve care quality.

Conclusion

This study adds to our understanding of the quality of EOL care for older adults in the United States. Using measures closely connected to EOL care policy, the analysis examines patterns in specific aspects of care in a manner that more closely resembles the multifaceted manner in which people experience the death of a loved one. This analysis reveals EOL care quality varies among older adults, characterized by “no symptoms, highest quality care,” “managed symptoms, high quality care,” and “symptomatic, poor quality care” groups. Moreover, this study explores the relationship between structural determinants of health and mortality and quality of care for the dying. Results suggest that health and mortality advantages accrued across the life course as a result of socially

advantaged positions do not factor significantly into proxy perceptions of EOL. To the extent that Medicare facilitates equal access to quality EOL care regardless of social disadvantage, it plays a meaningful role in reducing healthcare inequalities. It is also possible that circumstances surrounding death, such as place of death, the care provider, and general health, influence the type and quality of care dying individuals receive. Not dying at home, hospice involvement, increased comorbidity and frequent hospitalization do predict poorer EOL care quality. The relationship between cause of death and death trajectory as they relate to hospice involvement and place of death and, ultimately, EOL care quality, merits additional study. Policies aimed at improving EOL care should pay careful attention to how to provide consistent, high-quality care to the chronically and acutely ill.

Table 2.1. Summary of Nine Measures of Quality of End-of-Life Care used in Latent Class Analysis, NHATS, 2011-2014^a

Variable	Measurement Categories	Survey Questions
Pain	1. Unmanaged (yes to Q1, no to Q2; yes to Q1 & Q2, less or more help than needed to Q3)	1. During the last month of life, were there times when [deceased] experienced [pain, trouble breathing, feelings of anxiety or sadness]? (yes/no)
Breathlessness	2. Managed (yes to Q1 & Q2, about right amount of help to Q3)	2. If “yes” to question 1, Did [deceased] get any help in dealing with [symptom]? (yes/no).
Sadness/ Anxiety	3. None (no to Q1)	3. If “yes” to question 2, How much help in dealing with pain did [deceased] receive? (less than needed, more than needed, about right amount).
Involved in Health Care Decisions	1. Yes	During the last month of [deceased]’s life, was there ever a decision made about {his/her} care or treatment without enough input from [deceased] or {his/her} family?
No Unwanted Care	2. No	During the last month of [deceased]’s life, was there any decision made about care or treatment that [deceased] would not have wanted? (yes=0, no=1)
Care Coordination	1. Unclear who was in charge of care (yes to Q1, no to Q2) 2. One doctor/Clear doctor in charge of care (no to Q1; yes to Q1 & Q2)	1. During the last month of [deceased]’s life, was there more than one doctor involved in {his/her} care? (yes/no); 2. If “yes,” During the last month of [deceased]’s life, was it always clear to you which doctor was in charge of {his/her} care? (yes/no).
Informed about Condition	1. Usually, Sometimes, Never	During the last month of [deceased]’s life, how often were you or other family members kept informed about [deceased] condition?
Personal Care Needs Met	2. Always	During the last month of [deceased]’s life, how often were {his/her} personal care needs, such as bathing, dressing, and changing bedding, taken care of as well as they should have been?
Treated with Respect		During the last month of [deceased]’s life, how often were [deceased] treated with respect by those who were taking care of [deceased]?

^a All responses provided by a proxy respondent familiar with decedent’s last month of life.

Table 2.2. Descriptive statistics, 1,046 NHATS decedents, 2011-2014

	Proportion / Mean (sd)	Valid N^b
Death Quality Indicators used in LCA^a		
Pain		971
Unmanaged	0.15	
Managed	0.56	
None	0.30	
Breathlessness		973
Unmanaged	0.11	
Managed	0.45	
None	0.45	
Sadness/Anxiety		937
Unmanaged	0.26	
Managed	0.30	
None	0.44	
Deceased or family involved in decision-making	0.91	971
Family always informed about condition	0.82	999
No unwanted care	0.88	976
Clear doctor in charge of care	0.87	971
Personal care needs always met	0.83	1,001
Always treated with respect	0.89	1,000
Fundamental Causes		
Male	0.43	1,046
Non-Hispanic White	0.70	1,046
More than high school	0.35	1,046
EOL Care Setting and Provider		
Home death	0.38	1,046
Hospice care	0.41	1,046
Health Characteristics		
No serious diagnoses (lung disease, stroke, cancer, dementia/Alzheimer's)	0.27	1,046
2 or more hospitalizations (previous year)	0.22	1,046
Excellent/Very good self-rated health	0.18	1,046
Other Controls		
Married	0.35	1,046

	Proportion / Mean (sd)	Valid N^b
Age at death	85.07	1,046
	(7.88)	
Proxy very familiar with last month	0.79	1,046

a. LCA=Latent class analysis. b. Respondents who answered at least one Death Quality Measure included in LCA.

Table 2.3. Bivariate correlations for EOL care quality and fundamental causes measures, 1,046 NHATS decedents, 2011-2014^a

		1	2	3	4	5	6
1	No pain	1					
2	Managed pain	-0.73	1				
3	Unmanaged pain	-0.27	-0.46	1			
4	No breathlessness	0.18	-0.14	-0.04	1		
5	Managed breathlessness	-0.15	0.22	-0.12	-0.81	1	
6	Unmanaged breathlessness	-0.06	-0.13	0.26	-0.31	-0.31	1
7	No sadness	0.22	-0.11	-0.13	0.18	-0.15	-0.04
8	Managed sadness	-0.15	0.19	-0.08	-0.12	0.16	-0.06
9	Unmanaged sadness	-0.09	-0.08	0.23	-0.08	0.01	0.11
10	Involved in decisions	0.04	0.05	-0.12	0.04	0.03	-0.13
11	Always informed about condition	0.09	0.06	-0.21	0.04	0.05	-0.13
12	No unwanted care	0.13	-0.06	-0.09	0.06	-0.04	-0.03
13	Clear doctor in charge	0.06	0.07	-0.18	0.09	-0.05	-0.06
14	Personal needs always met	0.10	0.05	-0.21	0.08	-0.02	-0.10
15	Always treated with respect	0.10	-0.01	-0.12	0.09	-0.05	-0.07
16	Male	0.08	-0.05	-0.04	-0.04	0.01	0.04
17	Non-Hispanic White	-0.01	.000	0.02	-0.01	-0.02	0.04
18	More than high school	-0.02	-0.01	0.04	-0.01	-0.01	0.04

		7	8	9	10	11	12
7	No sadness	1					
8	Managed sadness	-0.58	1				
9	Unmanaged sadness	-0.52	-0.39	1			
10	Involved in decisions	0.08	0.03	-0.12	1		
11	Always informed about condition	0.10	0.09	-0.2	0.17	1	
12	No unwanted care	0.09	0.01	-0.12	0.16	0.07	1
13	Clear doctor in charge	0.10	0.03	-0.14	0.09	0.27	0.07
14	Personal needs always met	0.12	0.08	-0.22	0.12	0.33	0.12
15	Always treated with respect	0.09	0.03	-0.13	0.14	0.37	0.16
16	Male	0.00	-0.04	0.05	-0.03	-0.01	-0.07
17	Non-Hispanic White	-0.08	0.07	0.02	0.01	-0.04	0.01
18	More than high school	-0.04	0.05	-0.01	-0.01	-0.04	-0.01

		13	14	15	16	17	18
13	Clear doctor in charge	1					
14	Personal needs always met	0.20	1				
15	Always treated with respect	0.20	0.35	1			
16	Male	-0.06	-0.03	0.01	1		

		13	14	15	16	17	18
17	Non-Hispanic White	-0.05	-0.02	-0.01	0.00	1	
18	More than high school	-0.03	0.01	0.00	0.06	0.21	1

a Bold-faced text denotes a statistically significant correlation at the $p < .05$ level.

Table 2.4. Item response probabilities for measures of EOL care (last month of life) used in latent class analysis, 1,046 NHATS decedents, 2011-2014

	No symptoms, high care ratings	Managed symptoms, high care ratings	Symptoms, lower care ratings
End-of-Life Care Measures	45%	35%	20%
Pain			
Unmanaged	0.08	0.08	0.41
Managed	0.38	0.83	0.47
None	0.54	0.09	0.12
Breathlessness			
Unmanaged	0.08	0.06	0.25
Managed	0.27	0.69	0.42
None	0.65	0.25	0.33
Sadness/Anxiety			
Unmanaged	0.17	0.21	0.56
Managed	0.14	0.55	0.21
None	0.69	0.23	0.24
Involved in decision-making	0.95	0.94	0.78
Always informed about condition	0.92	0.96	0.37
No unwanted care	0.96	0.85	0.76
Clear doctor in charge of care	0.94	0.92	0.62
Personal care needs always met	0.94	0.93	0.41
Always treated with respect	0.97	0.97	0.56

Table 2.5. Relative risk ratios (and 95% confidence intervals) of covariates predicting membership in EOL care latent classes, 1,046 NHATS decedents, 2011-2014^a

	Managed symptoms, high care ratings	No symptoms, high care ratings	Sig^b
Fundamental Causes			
Male	0.74	1.19	
	(0.47, 1.18)	(0.70, 2.02)	
Non-Hispanic White	0.73	0.56	
	(0.45, 1.20)	(0.34, 0.95)	
More than high school education	1.08	0.78	
	(0.69, 1.68)	(0.47, 1.29)	
EOL Care Setting and Provider			‡
Home death	2.33	2.95	† ‡
	(1.46, 3.70)	(1.76, 4.93)	
Hospice care	1.76	0.51	† ‡
	(1.14, 2.72)	(0.29, 0.90)	
Health Characteristics			‡
No serious diagnoses (lung disease, stroke, cancer, dementia/Alzheimer's) (1 or more=reference category)	1.08	2.00	† ‡
	(0.64, 1.80)	(1.19, 3.36)	
2+ hospitalizations (0 or 1=reference category)	1.21	0.38	† ‡
	(0.75, 1.95)	(0.18, 0.81)	
Excellent/Very good self-rated health	0.67	0.94	
	(0.38, 1.16)	(0.52, 1.70)	
Other Controls			‡
Married	1.52	1.22	
	(0.93, 2.49)	(0.69, 2.14)	
Age at death (standardized)	1.33	1.52	† ‡
	(1.06, 1.67)	(1.18, 1.96)	
Proxy very familiar with last month	1.99	2.10	† ‡
	(1.20, 3.29)	(1.18, 3.73)	

a Reference category: Symptoms, lower care ratings. b †: variable significantly predicts latent class membership in the model including all covariates ($p < .05$). ‡: including the variable or block of variables significantly improves model fit. Significance based on likelihood ratio chi square tests ($2 * (\Delta \text{ in log likelihood})$).

Table 2.6. Overview of significance of predictors of individual measures of EOL care quality in multinomial and binary logistic regression analyses for NHATS decedents, 2011-2014^a

	1		2		3		4	5	6	7	8	9
	M	U	M	U	M	U						
Fundamental Causes												
Male	-	-							-			
Non-Hispanic White						+				-		
More than High School												
EOL Care Setting and Provider												
Home death ^b				-				+	+	+	+	+
Hospice care ^b		+		+		+						
Health Characteristics												
No serious diagnoses (lung disease, stroke, cancer, dementia/Alzheimer's) ^b					-				+			
2+ hospitalizations (previous year) ^b	+	+		+		+						
Excellent/Very good self-rated health												

a Analysis controls for marriage, age at death, and proxy familiarity with care in last month of life. Relationship significant at $p < .05$. - negative relationship. + positive relationship. b Variable significant in latent class analysis. Column headings: 1 Pain, 2 Breathlessness, 3 Sadness/Anxiety, 4 Involved in decisions, 5 Always informed about condition, 6 No unwanted care, 7 Clear doctor in charge of care, 8 Personal needs always met, 9 Always treated with respect. M Managed pain, breathlessness, or sadness or anxiety; U Unmanaged pain, breathlessness or sadness/anxiety (Reference category=No pain, breathlessness, or sadness or anxiety).

Supplementary Analysis 2.A. Significant predictors of EOL care quality with different LCA item response thresholds, NHATS, 2011-2014

In sensitivity analyses comparing results of LCA with covariate models requiring responses to different numbers of LCA items, increasing the number of items answered for a respondent to be included in the LCA model does not change the overall outcomes regarding the relationship between home death, hospice involvement, or hospitalizations and predicted latent class membership. Serious illness becomes nonsignificant in models requiring all or all but one LCA items be answered. Decrease in significance level and loss of significance may be partially attributed to decreased power, as sample size decreases from 1,046 with at least one item answered to 787 when all nine items are answered. Race varies between marginally significant and significant in the different models and is significant in the models requiring seven and all LCA items be answered, perhaps because members of racial and ethnic minority groups are missing on one or more LCA item more often than expected.

	Number of LCA items answered ^a					
Minimum number of LCA items answered	1	5	6	7	8	9
Fundamental Causes						
Male						
Non-Hispanic white	†	†	†	*	†	*
More than high school education						
EOL Care Setting and Provider						
Home death	****	****	****	****	****	****
Hospice involved	****	****	****	***	***	***
Health Characteristics						
No serious diagnoses (lung disease, stroke, cancer, dementia/ Alzheimer's)	*	*	*	*		
2+ Hospitalizations	**	**	**	**	*	*
Excellent/Very good self-rated health						
Other Controls (not discussed in paper)						
Married						
Age at death (standardized)	**	**	**	**	**	**
Proxy very familiar with last month	**	**	*	†		
N used in LCA	1046	1016	997	940	899	787

†p<.10, *p<.05, **p<.01, ***p<.001, ****p<.0001. a The first column, identifies significant variables in the LCA with covariates model requiring one complete LCA item, and is the model I report and discuss throughout this chapter. The next five columns report significant variables in LCA with covariates models requiring from 5 to 9 complete LCA items.

Supplementary Analysis 2.B. Comparison of odds ratios of covariates predicting membership in death quality latent classes using multinomial LCA with covariates and classify/analyze.^a Significant results for binomial logistic regression using LCA with covariates also shown.^b 1,046 NHATS decedents, 2011-2014 (N=1,046 decedents)

	LCA with Covariates			Classify/Analyze				Significant Results: Binomial Logistic Regression (LCA with Covariates)		
	Class 1 ^d	Class 2 ^d	Sig.	Class 1 ^d	Sig.	Class 2 ^d	Sig.	Class 2 ^d	Class 1 ^d	Class 3 ^d
Fundamental Causes										
Male	0.74	1.19		0.86		1.00				
Non-Hispanic White	0.73	0.56	±	0.74		0.53	**	±		*
More than high school education	1.08	0.78		1.16		0.91				
EOL Care Setting and Provider										
Home death	2.33	2.95	****	1.94	***	2.25	****	**		****
Hospice care	1.76	0.51	****	1.40	±	0.79		***	****	
Health Characteristics										
No serious diagnoses ^c (1 or more=ref. cat.)	1.08	2.00	*	1.02		1.41	±	**		
2+ hospitalizations (0 or 1=ref. cat.)	1.21	0.38	**	0.97		0.54	***	***	*	
Excellent/ Very good self-rated health	0.67	0.94		0.80		0.80				
Other Controls										
Married	1.52	1.22		1.35		1.36				
Age at death (standardized)	1.33	1.52	**	1.75	*	1.35	***	*		***
Proxy very familiar with last month	1.99	2.10	**	1.75	**	2.25	*	±		**

† p<.10, * p<.05, ** p<.01, *** p<.001, **** p<.0001. a Reference category: Symptoms, lower care ratings. b Reference category for each binomial logistic regressions is the other two classes combined. c. Diagnoses are lung disease, stroke, cancer, dementia/Alzheimer's. d. Class 1=Managed symptoms, high care ratings. Class 2=No symptoms, high care ratings. Class 3=Symptoms, lower care ratings.

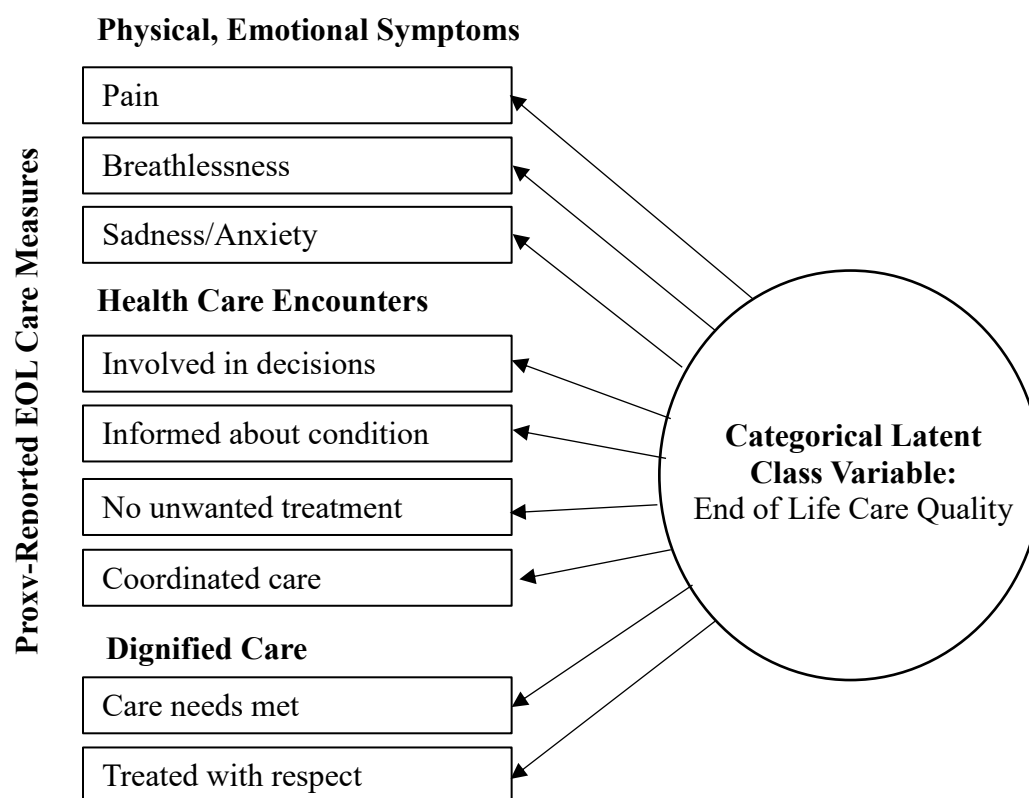
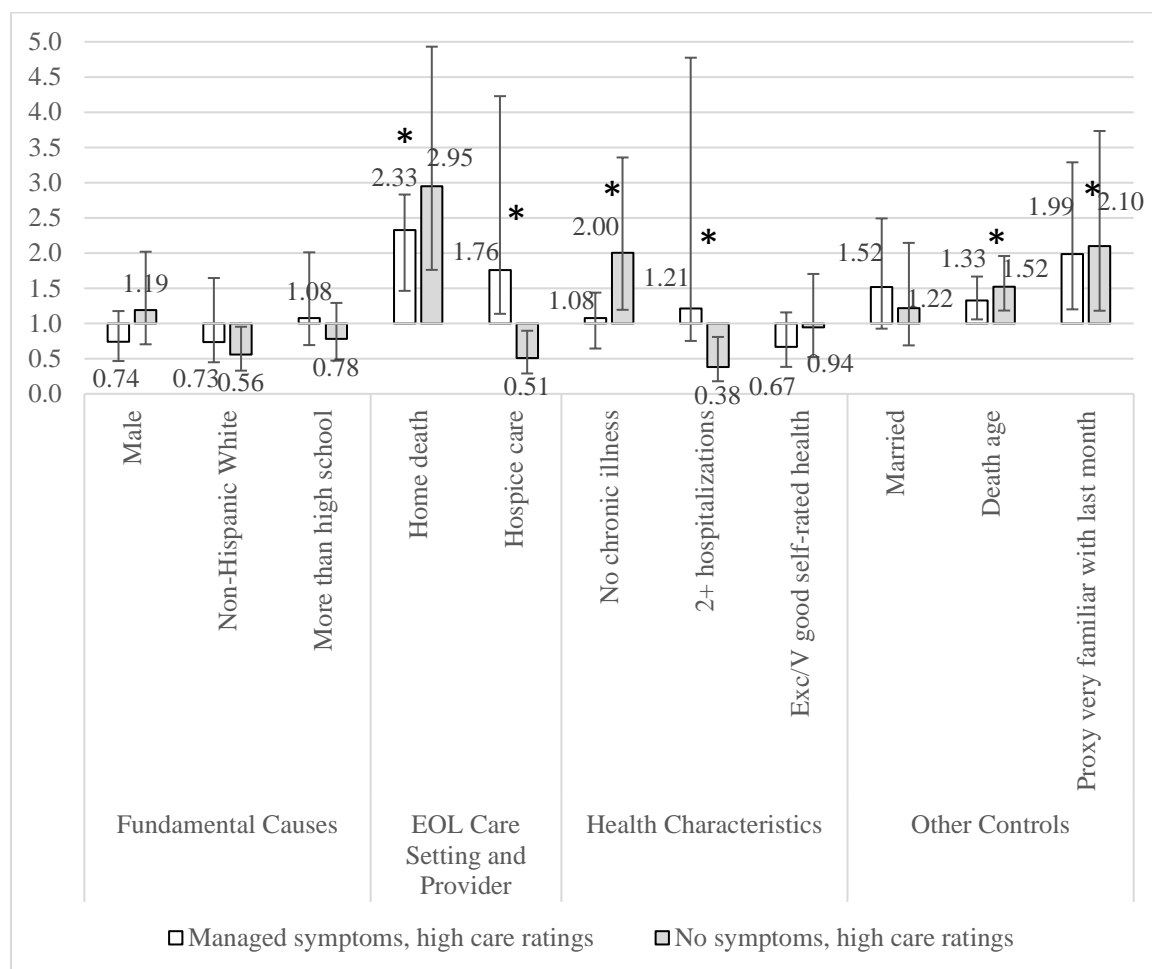
Figure 2.1 Latent Class Analysis Framework

Figure 2.2 Relative risk ratios and confidence intervals of covariates predicting latent class membership, relative to “Symptomatic, lower quality care” class, NHATS, 2011-2014 (N=1,046 decedents)^a



* indicates variable significantly improves model fit at $p < 0.05$.

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Chapter 3

Assessing the Influence of Advance Care Planning and Attitudes towards Religious Participation on Perceptions of End-of-Life Care Quality

Introduction

Dying individuals, their family members, and informal caregivers value the quality of care received at end of life (EOL). Health care providers and policy makers are also concerned with providing high-quality care as part of a social and professional obligation to show respect for dying individuals and for their family members and caregivers who will live with the memory of their loved ones' EOL experiences (Institute of Medicine (IOM) 2015). Quality EOL care is of particular concern for adults over 65 who account for 1.9 million of the 2.6 annual deaths (Kochanek, Murphy, Xu, and Tejada-Vera 2016). Two-thirds of the 1.9 million deaths to older adults are attributable to chronic illnesses such as heart disease, cancer, stroke, chronic lower respiratory disease, and Alzheimer's disease, which require clinically challenging and costly care, particularly in the final stages of life. In 2012, Medicare spent an average of \$70,000 on an individual during the last two years of life; just over half of that in the last six months of life alone (Dartmouth Atlas Project 2017). The complex and costly nature of dying among older adults makes understanding and improving EOL care quality among this segment of the population particularly important.

Seriously ill individuals, bereaved family members and EOL care experts agree medical and psychosocial elements are important at EOL. These elements include providing physical comfort to dying individuals, helping dying individuals maintain control over medical treatment and daily routine decisions, and easing family members'

burdens in advocating for high quality care for their dying loved ones (Teno et al. 2001). These aspects of EOL care are often, and by necessity, provided retrospectively by family members and caregivers and are required by the Centers for Medicare and Medicaid Services (CMS) for reimbursement for hospice and palliative care services (George 2002; NHPCO 2015b; Teno 2005). In this study, I assess family member and caregiver retrospective reports of subjective aspects of EOL care quality among a sample of older adults who died in a variety of care settings and who had different types of care providers in the final stages of life.

Dying is a process that often involves management of complex health conditions, while attending to the needs and preferences of the dying individual and family members, underscoring the fact that multiple components of care are simultaneously experienced at EOL. However, studies on dying frequently evaluate care quality by assessing single measures separately or by combining several measures into a single index (e.g. Carr 2016; Teno et al. 2015). I am not aware of any work that systematically explores whether several elements of high quality EOL care are typically experienced, or which elements co-occur most often in the population. Although it is a non-contentious proposition that we should work towards providing good EOL care for all individuals, dying is a complex process. Without a good sense of how the various dimensions of the experience fit together, we cannot really understand where we should start or how far we must go in making the proposition of high quality EOL care for all a reality. Using nine subjective measures of EOL care simultaneously, I create and use conceptually and analytically distinct subtypes of perceived care quality among older adults, as reported retrospectively by a proxy respondent. From a care delivery perspective, the measures I use are

potentially modifiable and therefore have practical applications in improving EOL care quality in all settings.

In addition to analyzing how multiple components of EOL care quality occur together, this study analyzes the relationship between informally or formally stating one's preferences for EOL healthcare treatment in advance—known as advance care planning (ACP)—and survivors' perceptions of EOL care quality. Research shows that ACP is associated with reduced utilization of invasive and potentially futile treatments at EOL, perceptions that dying individuals maintain control over EOL decision-making, and receipt of care concordant with the dying individual's wishes (Carr and Luth 2016). However, ACP completion varies across subpopulations. Individuals with fewer socioeconomic resources, non-Hispanic blacks, and Hispanics complete ACP at much lower rates than their higher SES, non-Hispanic white counterparts (Carr 2012a, Carr 2012b). So, while ACP completion may contribute to higher quality EOL care on average, the potential benefits may not be evenly distributed across all older adults. In particular, when combined with health disadvantages accrued over the life course, individuals with lower SES and members of racial and ethnic minority groups may be at compounded risk for lower quality EOL care.

Next, this study examines the relationship between religious beliefs and EOL care quality. Prior research has found a mixed relationship between religious beliefs and both attitudes towards EOL care and types of treatment received at EOL. Increased importance of religion in medical decision-making among older, well-educated non-Hispanic whites was associated with higher likelihood of wanting all possible treatment in the case of cognitive impairment or physical pain (Sharp, Carr, MacDonald 2012). Another study of

chronically ill, white, older adults found no relationship between religiosity and willingness to accept risky life-sustaining treatment at EOL (Van Ness, Towle, O’Leary, Fried 2008). Studies of individuals with advanced cancer indicate a relationship between positive religious coping and receipt of life-prolonging care (Maciejewski et al. 2012; Phelps et al. 2009). However, studies exploring the relationship between religious beliefs tend to be limited to specific demographic groups (non-Hispanic whites) or illness populations (cancer patients). Moreover, no study that I know of examines the link between religious attitudes and perceived EOL care quality in a nationally representative sample of older adults.

Finally, I examine how EOL care quality is distributed among older adults. Although providing high quality EOL care to all individuals is a high priority for providers and policy makers, very little research focuses on how EOL care quality is stratified by different social characteristics of those who experience it. Despite the established link between social disadvantage and increased risk of disease and mortality (Elo 2009; Link and Phelan 1995; Marmot et al. 1991), most research has not explored the possible connection between social disadvantage and EOL care quality (see Carr 2016 for a review and exception). As such, I also analyze the extent to which fundamental causes theory, a sociological explanation linking health and mortality disparities to social factors such as socioeconomic status (SES) and social support (Link and Phelan 1995), applies to and helps explain differences in the subtypes of EOL care quality that I develop.

This study uses four waves of longitudinal data from the National Health and Aging Trends Study (NHATS) to analyze EOL care quality among adults 65 and older,

individuals with complex healthcare needs who are the most likely to die. I use family member and caregiver (proxy) retrospective reports of EOL care to develop two conceptually and analytically distinct subtypes of care quality, which show how different components of EOL care co-occur. I then examine the extent to which ACP, attitudes towards religion, and fundamental causes of health disparities explain variations in perceived EOL care quality. In supplementary analysis, I explore how ACP moderates the relationship between fundamental causes of health disparities, attitudes towards religion, and perceived EOL care quality. Understanding how EOL care quality is stratified has implications for designing effective policies aimed at reducing inequalities in EOL care. In the next section I describe the components of quality EOL care, explain why it is important to align the multidimensional nature of quality care with how we analyze and assess that care, and outline how ACP, attitudes towards religion, and sources of inequalities in health and mortality might help us understand systematic differences in EOL care quality.

Quality EOL Care

Beginning in the mid-20th century, medical technological advances contributed to both longer life spans and the medicalization of death, with implications for how we understand EOL care quality. Life-saving technologies hold the potential to prolong life without improving, and in some cases worsening, quality of life. In response, physician thought leaders have reiterated the fundamental responsibility of health care providers to reduce dying patients' physical and psychic suffering and enhance their well-being (Byock 1996, Gawande 2014), a desire echoed by seriously ill individuals, caregivers, and adults more generally (Parmalee 2001, Steinhauser et al. 2000, Teno et al. 2001).

Through medicalization, health care providers and medical institutions have taken over responsibility for aspects of EOL care that were previously the purview of family members and the community (Conrad 1992). Although EOL care increasingly occurs in medical settings, most Americans express a desire to maintain their autonomy and remain involved in medical decision-making, even at EOL (PRC 2013). As such, medical ethicists emphasize the importance of ensuring dying patients maintain their personal dignity and autonomy (Emanuel and Emanuel 1996) and federal law protects patients' rights to state their EOL health care treatment preferences (U.S. Congress 1990). Advances to medical technology that may prolong suffering at EOL and the location of EOL shifting to medical settings have prompted seriously ill individuals, bereaved family members, physicians, ethicists, and policy makers to emphasize multiple components of care as important at EOL including symptom management, control over medical treatment and daily routine decisions, and dignified care.

Adults, including seriously ill persons and healthcare professionals who care for the dying, identify freedom from unwanted symptoms as important at EOL. In a large study of seriously ill individuals, bereaved family members, physicians, and other health care providers, nine in ten agree or strongly agree that being free from pain, breathlessness, and anxiety is important at EOL (Steinhauser et al. 2000). Just over half of adult respondents indicate they are concerned about the possibility of continued emotional suffering at EOL (Parmalee 2001). While physical and emotional symptoms are both important to address at EOL, caregivers may more easily observe and identify physical than emotional symptoms. For example, they may attribute a dying individual's behavior, such as gasping for breath, grimacing, or moaning to breathlessness and pain

rather than sadness or anxiety. Along a similar vein, dying individuals may feel more comfortable expressing physical than emotional discomfort. I include measures of pain, breathlessness, and sadness and anxiety in my analyses of EOL care quality to be able to identify variations in proxy perceptions of dying individuals' experiences with multiple physical and emotional symptoms at EOL.

In an ideal scenario, a dying individual will not experience any unwanted symptoms at EOL. However, complete absence of symptoms is not always possible, particularly when people die from protracted chronic illness which can become increasingly severe at the EOL (Carr & Luth 2016). As such, it is important to consider whether a dying individual received relief from any symptoms that occur, and whether proxies perceive that relief as ultimately beneficial to the dying individual's EOL care. If a dying individual does not receive sufficient medication or medical assistance to alleviate symptoms, he or she may continue to suffer. On the other hand, dying individuals may state a desire for complete symptom relief without understanding its potential consequences. In some instances, providing symptom relief may require heavy sedation, making dying individuals unable to make decisions about their health care or interact in a meaningful way with grieving family members.

Both outcomes—the perception that an individual continues to suffer when more treatment could be administered and non-responsiveness that results from doses of medication necessary to relieve intractable symptoms—can be distressing to family members hoping to share peaceful and meaningful exchanges with dying loved ones. Proxies may associate unsatisfactory symptom management with other aspects of EOL care such as undignified care or not being informed about what to expect about a dying

individual's condition. In order to identify how different experiences with symptoms and their treatment are associated with other aspects of EOL care quality (discussed below), I maintain three categories of symptom management: none, managed, and unmanaged.

In addition to physical and emotional comfort, dying individuals' experiences with the health care system are important components of quality EOL care. Longer life span with increasingly complicated health has been accompanied by a cultural shift towards treating death as something to be avoided or delayed, rather than accepted as a natural part of life (Conrad 1992). The combination of complex illness needs and increased medical control over death and dying means that frequent contact with health care providers is an inevitable part of dying for many older adults. The nature of that contact is an important component in assessing EOL care quality.

While death and dying may occur increasingly under the purview of health care professionals, most Americans still expect a degree of autonomy and involvement in personal health care decision-making. Recent public opinion polls indicate 80% of people believe doctors and nurses should pay attention to whether or not a patient wants treatment to keep them alive, and 66% believe there are circumstances in which a patient should be allowed to die (PRC 2013). Seriously ill individuals express preferences in support of self-determination: 40% want to control the time and place of death, 84% agree it is important to feel prepared to die, and 96% want to know what to expect about their physical condition at EOL (Steinhauser et al. 2000). The tension between medical providers' increased involvement in EOL and patients' and family members' desire to actively partake in health care decision-making can lead to conflict and confusion in EOL care provision, particularly if the moment of transition from ongoing chronic illness

management to dying is not clearly identified, or if a patient's wishes are unclear or in conflict with medical opinion. Clear communication is necessary for healthcare professionals to remain attuned to the care preferences and needs of dying individuals, and to deliver care that is concordant with those desires.

The quality of interactions with health care providers and dying individuals' and their loved ones' participation in health care decisions may be affected by the setting of EOL care and who provides the care. Physicians in intensive care units are trained to use medical technology to save critically ill patients' lives and may be unprepared to shift conversations from focusing on curing a sick patient to determining the best course of action for a dying individual (Chapple 2010). In contrast, hospice workers are trained to help dying individuals and their family members make meaningful decisions about EOL care (NHPCO 2010). Bereaved individuals may assess the quality of healthcare encounters from hospice providers more positively. However, high quality encounters with health care providers should be a goal of quality EOL care, regardless of setting or care provider. As such, I include measures of communication with healthcare professionals, being informed about one's condition, involvement in decision making, and respecting treatment preferences as components of EOL care quality while controlling for care setting and provider.

Finally, in addition to considering the way dying individuals are treated with respect to their physical and health care needs, quality EOL care must also attend to individuals' personal needs. Among seriously ill individuals, 95% say it is important to maintain one's dignity and 99% say being kept clean is important at EOL (Steinhauser et al. 2000). As with interactions with health care providers, loved ones may assess the

quality of dying individuals' personal care and treatment differently based on the setting and provider, I include measures of respect and personal care needs to classify types of EOL care while controlling care setting and provider.

Developing a Multifaceted Measure of End-of-Life Care

Seriously ill individuals, family members, and health care professionals identify multiple components of EOL care as simultaneously important, and it is realistic to assume certain sub-dimensions of EOL care occur in tandem. However, we do not have an in-depth understanding of how multiple aspects of EOL care quality co-occur, as most studies examine different aspects of EOL care individually (e.g. Teno et al. 2015). Some studies use a simple index of multiple measures (e.g. Carr 2016). While this approach is an improvement over single-item measures, it does not capture how subsets of measures may co-occur together and how different subsets may describe very different experiences of EOL care. For example, two individuals may have identical index scores, but one's EOL experience may be highly rated in terms of symptom management, while the other's is highly rated on measures of autonomous decision-making. This distinction is important in identifying multiple potential pathways to "good" or "bad" deaths which may require different interventions. This study addresses the multifaceted nature of EOL care quality by using latent class analysis to analyzing how proxies' assessments of multiple measures of symptom management, health care encounters, and dignified care cluster together into conceptually and statistically distinct categories of EOL care quality.

Advance Care Planning and End-of-Life Care Quality

In addition to exploring whether the social determinants of health and mortality extend to the case of EOL care, this study analyzes the role of advance care planning

(ACP) for future health care needs in predicting perceptions of EOL care quality. ACP consists of discussing one's EOL health care preferences with loved ones or a physician and/or formally stating those preferences in an advance directive, living will, or by naming a durable power of attorney for health care (DPAHC). ACP emerged in the 1980s as a mechanism for providing informed consent for health care providers to withdraw or withhold medical treatments in the event a patient is incapacitated and unable to state their preferences. Federal law mandates hospitals offer patients the opportunity to complete an advance directive or designate a DPAHC upon admission, and the Centers for Medicare and Medicaid Services (CMS) reimburse physicians for time spent discussing EOL treatment preferences with patients (U.S. Congress 1990, Armour 015).

In general, Americans agree maintaining autonomy over decision making at EOL is important. About three-fifths (57%) of adults over 65 would stop treatment if they had an incurable disease and were experiencing painful suffering (PRC 2013). Most engage in some form of ACP: 66% report having discussed with someone else and/or written down their EOL treatment preferences (PRC 2013). However, ACP is not equally distributed across all segments of the population. Older adults participate in ACP at higher rates: over three-quarters report some form of ACP (PRC 2013), a proportion that will grow if patient-physician EOL discussions continue to be reimbursed and become more routine under Medicare. Non-Hispanic whites and individuals with greater SES resources engage in ACP at higher rates than non-Hispanic blacks, Hispanics, and individuals with lower SES (Carr 2012a; Carr 2012b; PRC 2013).

In practice, ACP can be an effective pathway for receiving EOL care that is concordant with a dying individual's wishes. Large studies find individuals who have an

advance directive are less likely to die in an ICU, or be on a respirator or use a feeding tube in the last month of life (Teno et al. 2007) or receive any of six life-sustaining interventions (Nicholas, Langa, Iwashyna, & Weir, 2011). Older, incapacitated adults are more likely to receive comfort care consistent with their preferences than those without an advance directive (Silveira, Kim, and Langa 2010).

Fewer studies have focused on the relationship between ACP and perceptions of EOL care quality, with mixed results. In a study of a small number (n=56) of deceased adults over 80, family members of individuals who received an intervention to facilitate advance care planning reported less stress, anxiety, and depression than family of individuals who did not receive the intervention (Detering et al. 2010). Another larger study did not find any differences in family members' perception of the quality of end-of-life care between individuals with an advance directive and those without one (Teno et al. 2007). Furthermore, if family members consider a living will unhelpful, it may worsen their perceptions of quality of death. In a longitudinal study of older adults, family members reported increased levels of family conflict when they believed the living will was problematic (Khodyakov and Carr 2009). In this study, I examine the relationship between ACP and perceptions of EOL care quality and expect that having completed ACP will be associated with perceptions of higher quality EOL care.

Attitudes towards Religion and EOL Care Quality

Researchers have studied the link between religion and health, with particular attention to the relationship between the two among older adults and at EOL (e.g. Idler 2014; Idler, McLaughlin, and Kasl 2009). Older and seriously ill individuals use religious coping mechanisms to deal with stress and health problems, including in the final stages

of life (Ano and Vasconcelles 2004; Idler et al. 2009; Maciejewski et al. 2012). Overall, positive religious coping is linked to positive outcomes in response to stressful life events (Ano and Vasconcelles 2004).

While researchers consistently report that individuals for whom religion is important draw upon their beliefs in coping with and making decisions about health problems, the nature of the link between religious attitudes and beliefs and EOL preferences is unclear. One study of high school educated, non-Hispanic white older adults found that increased importance of religion in medical decision-making is positively associated with a desire for all life-sustaining treatments at EOL, regardless of cognitive functioning or physical comfort (Sharp et al. 2012). Another study of educationally mixed, non-Hispanic white, older adults found no relationship between being deeply religious and a desire for potentially burdensome life-sustaining treatments at EOL (Van Ness et al. 2008). Studies of African-Americans find a link between spirituality and desiring life-sustaining treatments (Johnson, Elbert-Avila, Tulskey 2005). Studies link this relationship to a variety of factors, including African-Americans' stronger beliefs that life belongs to God and that God knows better than doctors what will happen in the course of an illness, and so doctors should not assist with suicide or decide when to withhold treatment (Blackwell et al. 1999; MacDonald 1998). While the role of religion in determining EOL treatment processes is not fully understood, research collectively suggests more religious individuals desire more extensive treatment at EOL.

In addition to preferring more extensive treatment at EOL, individuals who employ religious coping mechanisms also tend to receive more life-sustaining treatment at EOL. Patients with advanced cancer who reported positive religious coping were more

likely to receive mechanical ventilation or resuscitation in the last week of life (Phelps et al. 2009; Maciejewski et al. 2012). However, researchers have paid less attention to the relationship between religious attitudes and beliefs and *perceptions* of EOL care quality. Exploring this relationship is important given the potential mismatch between religious individuals and their family members' and physicians' expectations for care at EOL. Physicians tend to view intensive life-prolonging treatment at EOL as futile and ultimately harmful, and express a desire to avoid such care at the end of their own lives (Gallo et al. 2003). In contrast, for some patients and their family members, intensive treatment at EOL may be desirable, even if it is futile, because it is consistent with their personal desires and religious beliefs that God should determine what happens with regards to illness and death (Johnson et al. 2005; MacDonald 1998).

Religious beliefs may be associated with greater acceptance of and satisfaction with EOL care, even if such care includes invasive treatment. What may be unacceptable or deemed futile and limiting of quality of life to a physician or other health care professional may not matter to religious individuals at EOL. Close family members, who are likely to share religious beliefs with dying individuals, may report a sense of satisfaction with care. In contrast, proxies for individuals with weaker religious beliefs may be less accepting of EOL and more critical of care. In this study, I analyze the relationship between importance of religious participation (as a marker of general importance of religion) and EOL care quality. I expect greater importance will be associated with more positive assessments of EOL care. Moreover, in contrast to previous studies focusing on non-Hispanic whites or patients with cancer, this study uses a nationally representative sample of older adults who die from any number of causes.

Because non-Hispanic blacks are more religious than non-Hispanic whites and draw more heavily on religious beliefs in explaining desires for life-sustaining treatments, controlling for both race/ethnicity and religious attitudes allows me to identify the distinctive effects of each, without overstating differences of one or the other.

In addition to an equivocal relationship between attitudes towards religion and EOL care, researchers present mixed results with respect to the relationship between religious beliefs and ACP. In a small study of a racially and ethnically diverse group of terminally ill adults, the importance of religion in making medical decisions was associated with increased likelihood of discussing EOL treatment preferences, but not a combination of discussions and formal ACP (Garrido et al. 2012). In another study of mostly African-American general internist patients, increased religiosity was associated with higher odds of naming a DPAHC, but not having an advance directive (Karches et al. 2012). In studies of cancer patients, increased religiosity was linked to no difference in odds of ACP (Smith et al. 2008), lower odds of having a living will (Maciejewski et al. 2012; Phelps et al. 2009) and lower odds of designating a DPAHC (Phelps et al. 2009). Fewer studies look at the relationship of attitudes towards religion and ACP together on EOL care. One study of cancer patients finds that having a living will attenuates the relationship between positive religious coping and mechanical ventilation or resuscitation in the last week of life (Maciejewski et al. 2012). In supplementary analysis, I explore the potential for ACP to moderate the relationship between importance of religious participation and EOL care quality.

Fundamental Causes Theory and EOL Care Quality

In addition to exploring the relationship between ACP, attitudes towards religion and EOL care quality, I also control for decedents' sociodemographic characteristics that may influence perceptions of care quality. There are well-established gradients in life expectancy by race, gender, and socioeconomic status in the United States. African-Americans have a shorter life expectancy than Whites (NCHS 2016), and those with lower SES have poorer health and premature mortality relative to their higher SES counterparts (Adler et al. 1994; Elo 2009; Marmot et al. 1991). Some of the disparities in mortality outcomes may be linked to disparities in health status across the life course that subsequently impact mortality. Racial and ethnic minorities live longer portions of their lives in poorer health and have less access to health care services than non-Hispanic whites (Elo 2009; Feagin and Bennefield 2014; Marmot et al. 1991; Williams 2012). Similarly, having a higher SES also predicts better health and longer life. Education, specifically, has an independent effect on mortality (Baker et al. 2011) and accounts for a widening in the gap in self-rated health as adults age (the gap decreases in those over 70 years old but remains) (Mirowsky and Ross 2008).

Fundamental causes theory posits that disparities in health and mortality outcomes can be explained by greater access to socioeconomic resources and structurally advantageous positions that are protective of health and mortality (Link & Phelan 1995). Relative to women, ethnic minorities and those with fewer socioeconomic resources, men, non-Hispanic whites, and those with richer socioeconomic resources typically have greater access to and the ability to activate additional resources that are protective of health and mortality across the life course, (Link and Phelan 1995). To the extent that access to quality EOL care reflects discrimination-free access to resources, fundamental

causes theory would suggest that racial and ethnic minorities, individuals with less education, and women, due to their socially disadvantaged positions, may experience poorer quality EOL care. As such, we may expect that dying males, non-Hispanic whites, and individuals with more education would have greater access to higher quality EOL care, and proxies would reflect that access in their assessments of EOL care quality. On the other hand, proxies for non-Hispanic whites, individuals with higher SES, and men, having internalized the privileged social position of individuals with these characteristics, may have higher expectations for quality of EOL care, and may therefore assess care more harshly if it fails to meet those expectations.

Summary

This study contributes to existing knowledge in two ways. First, this analysis will examine the extent to which individual components of EOL care death co-occur, creating a multidimensional assessment of care that more closely reflects the manner in which people actually experience it. Moreover, by identifying which aspects of EOL care cluster together, we can identify aspects of care that require more attention and tailor efforts to target multiple aspects of care simultaneously to meaningfully improve care for the dying. Second, this analysis explores the extent to which ACP, attitudes towards religion, and the interaction between the two predict EOL care quality, while controlling for sociodemographic determinants of health and mortality. I expect proxies for individuals who complete ACP and indicate religious participation is important to them will report decedents received better EOL care.

Data and Methods

Data

To identify classes of EOL care quality and determine how ACP, attitudes towards religion, and fundamental causes of health and mortality influence proxy perceptions of care quality, I use four waves of data from the 2011-2014 National Health and Aging Trends Study (NHATS). NHATS is a prospective, longitudinal survey administered annually to a nationally representative sample of 8,245 Medicare beneficiaries over 65 residing in the contiguous United States in May 2011. NHATS includes questions about sociodemographic, health, and disability characteristics. If the respondent dies between waves of data collection, a proxy respondent familiar with the respondent's last month of life completes an exit survey. For the sample analyzed in this study, proxy exit surveys occurred, on average, within six months of the NHATS respondent's death, making their responses less susceptible to recall bias introduced when the time between death and reporting about that death is lengthy. I use prospective demographic and health information respondents provided in survey years prior to their deaths and retrospective EOL care measures proxies provided in exit interviews. I also use questions on ACP behavior that were administered during Round 2 (2012) to a random one-third subsample of individuals who completed the Rounds 1 and 2 surveys in 2011 and 2012.

Study and Analytic Sample

The 8,245 initial NHATS respondents had to meet three criteria to be included in this analysis. First, 1,081 individuals completed the respondent questionnaire at Round 1 and have a completed family member or caregiver exit interview about the decedent's last month of life. The respondent questionnaire records sex, race/ethnicity, education, and religious attitudes. Second, 725 of the 1,081 deceased respondents died after Round

2, when questions about ACP were asked. Third, 253 of the 725 respondents who died after Round 2 and before Round 3 or 4 (2013-2014) were randomly selected to complete questions about ACP at Round 2. Of the 253 eligible for inclusion in this study, I analyze the 222 individuals with complete information on all independent and control variables and for whom a proxy respondent answered at least one of the nine questions used to assess EOL care quality. I exclude from the analysis an additional 31 individuals who were missing data on an independent or control variable. Of these 31, 30 were missing information on one or more of the three ACP questions I analyze. The 30 individuals missing data on ACP questions do not significantly differ from the 222 with information on ACP in terms of gender, race/ethnicity, education, or importance of religious participation.

Measures

I measure quality of EOL care with nine items assessing the NHATS respondent's last month of life as reported by a proxy respondent—usually a spouse (19%) or child (45%). I categorize the responses to these nine items into two or three categories to avoid sparseness and facilitate latent class analysis (described below). Table 4.1 provides a summary of the measures I use in the latent class analysis.

Three of the nine items assess symptoms commonly reported at EOL: pain, breathlessness, and sadness or anxiety. Proxies indicated whether the deceased experienced each of these in the last month of life. If yes, proxies indicated whether the deceased received help dealing with the symptom. If yes, proxies also indicated whether they believe the deceased received less help than was needed, more than needed or about the right amount. I combined these three questions into a single three-category variable

for each of pain, breathlessness, and sadness/anxiety: “None” (no reported symptom), “Managed” (experienced a symptom and received “about the right amount of help”), and “Unmanaged” (experienced a symptom and received no help, less help than needed, or more help than needed).

Six questions capture dimensions of EOL care quality related to encounters with health care providers and dignified care. Two variables measure whether treatment decisions were made without the decedent or their family members’ input and the decedent received care she would not have wanted with “No” and “Yes” responses. I categorize whether the decedent was treated with respect, had their personal care needs were met, and they and their family were informed about her health condition, as “Always” and “Usually/Sometimes/Never.” I dichotomize these three variables because 80%-90% of respondents indicate the decedent’s needs were “Always” met. Finally, I measure coordination of care by combining two questions: whether there was more than one doctor involved in care and, if yes, whether it was clear which doctor oversaw care. I divide individuals into two groups: “One doctor/Clear doctor in charge if care” and “Unclear who was in charge of care.”

[Table 3.1 about here]

Predictors of End-of-Life Care Quality

Advance Planning Behavior. I measure end-of-life planning with three questions from the NHATS survey: *Have you talked to anyone about the types of medical treatment you want or don’t want if you become seriously ill?*, *Do you have a living will or advance directive?*, and *Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself?* (yes=1,

no=0). I also construct two dummy variables. One measures formal ACP with a “yes” response to either or both questions about a living will and DPAHC. The other measures any ACP with a “yes” response to any of the three NHATS survey questions.

Importance of Religious Participation. I measure the importance of religious participation to decedents with the question *How important is it to you to attend religious services?* I code “very important” as 1 and “somewhat important” and “not so important” as 0.

Fundamental Causes of Advantage. I measure fundamental causes of social disadvantage with three variables. For sex, I code males as 1, females as 0. For race and ethnicity, I compare non-Hispanic whites (coded as 1) with all other racial and ethnic groups (coded as 0). Two supplementary analyses comparing 1) non-Hispanic whites and non-Hispanic blacks only and comparing 2) non-Hispanic whites, non-Hispanic blacks, and Hispanics yield similar results as when Hispanics and “Others” are combined with non-Hispanic blacks. I choose the most parsimonious treatment of education, dichotomized at the median (more than high school=1, high school or less=0). Analyses categorizing education into three or four categories do not improve model fit.

Analytic Strategy

Latent Class Analysis: Two-Class Solution. The analytic approach I use in this chapter differs from Chapters 2 and 4 in three ways. First, the sample size in this chapter (222) is considerably smaller than in chapters 2 and 4 (1,046). The smaller sample size is because I include questions about ACP in the analysis, which were subject to specific timing and skip pattern restrictions in the NHATS survey design that limited the number of individuals who answered them. The ACP questions were only asked in Round 2

(excluding the 503 individuals who participated in Round 1 and died prior to Round 2) and, by study design, to a random one-third subset of NHATS respondents who did not live in a nursing home in Round 1 (excluding an additional 427 individuals). I do not report results of multiple imputation because the procedure required imputation on an exceptionally high percentage (80%) of “missing not at random” cases.

Second, the exploratory latent class analysis (LCA) identified a two-class solution best fit the data in this chapter, rather than the three-class solution used in Chapters 2 and 4. Because the sample size is small and I wanted to preserve predictive power, I use a two-class solution in this chapter. As I describe below, the two-class solution essentially collapses the “no symptoms, high quality care” and “managed symptoms, high quality care” classes used in Chapters 2 and 4 into a single class (see Supplementary Analysis 2.B. on p. 64, last column for a comparison). The comparison of “symptomatic, lower quality care” to “no or managed symptoms, high quality care” in this chapter is conceptually similar to the comparison between “symptomatic” and “managed symptoms, high quality care” and “no symptoms, high quality care” classes in Chapters 2 and 4.

Third, the LCA with covariates models in this chapter include only key independent variables: race/ethnicity, education, gender, and ACP types. In this chapter I exclude additional controls used in Chapters 2 and 4 (number of chronic illnesses, number of recent hospitalizations, place of death, and hospice involvement) in order to preserve estimation power with the smaller sample analyzed here (222 compared to 1,046 in Chapters 2 and 4). Moreover, cross tabulations between illnesses, hospitalizations, place of death, and hospice involvement with independent variables (various types of

ACP, importance of religious attendance, gender, race/ethnicity, and education) reveals small cell sizes (less than 40), which can complicate model estimation and make it difficult to detect subgroup differences.

Table 3.2 presents the results of exploratory LCA using the nine quality of EOL care measures, which indicated that a two-class solution best describes the quality of EOL care among decedents in my sample as reported by their proxies. The largest class, “managed or no symptoms, high quality care” is predicted to comprise 77% of the sample. In this class, proxies have a very high probability of reporting that members of this class received the highest quality care in the other six measures included in the LCA, relative to the second latent class. For all measures in this class, proxies have over a 92% probability of endorsing the desirable response. Moreover, proxies have a 17% or less probability of characterizing decedents as having unmanaged symptoms, particularly pain (8%) and breathlessness (5%). The other latent class, “symptoms, lower quality care” is predicted to comprise 23% of the sample. In this class, probability of high quality care ratings are much lower than in the first class. The likelihood proxies will report the decedent and family were involved in decision making (70%) and the decedent received care concordant with their wishes (68%) are lower than in the other latent class, although they are still relatively high. Ratings for care coordination (53%), having personal care needs met (43%) and being treated with respect (50%) are predicted to be considerably lower in this class than in the first class. Proxies have only a 28% probability of reporting the decedent was always informed about their condition (compared to 96% in the other class). Moreover, proxies are likely to provide mixed reports of symptoms in the “lower quality care, symptomatic” class. Proxies have low probabilities of reporting no pain

(10%) and no or managed sadness or anxiety (14% and 21%, respectively). Proxies in this class have the highest probability of reporting managed breathlessness (52%) and unmanaged sadness or anxiety (65%).

[Table 3.2 about here]

Next I perform LCA with covariates, which uses binomial logistic regression to determine the extent to which a single variable (e.g. having a living will or race/ethnicity) predicts membership in the two latent classes previously identified. Likelihood ratio chi square tests comparing LCA with all covariates to LCA without a covariate determine whether a variable significantly predicts latent class membership. This analysis allows me to explore the extent to which ACP, attitudes towards religion, and fundamental causes of social disadvantage (decendent race/ethnicity, gender, SES) predict the type of EOL care a decendent receives. To test the predictive power of ACP on latent class membership, I run five separate LCA with covariate analyses, one each for: informal discussions, living will, DPAHC, formal planning (living will and/or DPAHC), and any type of ACP. I conduct all latent class analysis with Stata 14/MP, using the doLCA command (The Methodology Center 2015).

Moderation. I conduct supplementary analysis to test whether ACP moderates the relationship between importance of religion and EOL care quality. I first assign individuals to a type of EOL care quality based on which class they have the highest probability of belonging to in the baseline LCA model. I then use three-way cross tabulations to explore how attitudes towards religion might facilitate EOL care quality, regardless of ACP.

Results

Descriptive Statistics

Table 3.3 provides descriptive statistics of the 222 decedents in the sample. Over half of proxies responding to questions about symptoms at EOL reported that the decedent experienced pain, breathlessness, and sadness or anxiety. Seven in ten proxies reported pain (54% managed pain, 17% unmanaged pain). Fifty-nine percent of proxies reported breathlessness and 65% reported sadness or anxiety, although breathlessness was almost always managed (50% compared to 9% unmanaged), and sadness or anxiety were more evenly split between managed (37%) and unmanaged (28%). Overall, proxy reporters rated the remaining aspects of EOL care highly, with at least four-fifths reporting the decedent was “always” treated well and involved in health care decision-making (80-90%).

Just over two-fifths (41%) of decedents were male, 69% identified as non-Hispanic White, and 37% had more than a high school education. Over 60% of decedents report completing each type of ACP, and 80% report having completed at least one type of planning (informal discussions, living will, and/or DPAHC). About half (52%) of decedents reported religious participation was “very important” to them.

In bivariate correlations (Table 3.4), the six dichotomous items used in the LCA were all positively and significantly correlated. The same categories of symptom variables are also positively and significantly correlated (no pain with no breathlessness with no sadness; managed pain with managed breathlessness with managed sadness, etc.). Unmanaged pain and sadness/anxiety are negatively and almost always significantly correlated with the six dichotomous measures of EOL care (exception: unmanaged pain is not significantly correlated with no unwanted care). Collectively, these bivariate

relationships suggest that the variables used in the LCA operate in a similar pattern: positive aspects of EOL care are associated with one another, and unmanaged symptoms are associated with lower care ratings on all measures. Having a living will and a DPAHC are significantly and negatively correlated with no sadness or anxiety at end of life. Importance of religious participation is significantly and negatively associated with unmanaged pain and significantly and positively associated with managed sadness or anxiety, being informed about one's condition, and the two measures of dignified care. Being non-Hispanic white is significantly and positively correlated with informal and formal ACP.

[Tables 3.3 and 3.4 about here]

Table 3.5 presents odds ratios (exponentiated regression coefficients) and 95% confidence intervals for variables predicting membership in the “symptomatic, lower quality care” class compared to the “no or managed symptoms, high quality care” class for each of the five models analyzing different types of ACP. Of the five variables included in each model- a type of ACP, attitude towards religion, gender, race/ethnicity, and education-only religious attitudes and race/ethnicity significantly predict latent class membership and significantly improve model fit ($2*(\Delta \log \text{likelihood})$). Indicating that reporting attendance at religious services as “very important” is associated with 63%-65% lower odds of being in the “symptomatic, lower quality care” class than in the “no or managed symptoms, high quality care” class. Being non-Hispanic white is associated with over 200% higher odds of being in the “symptomatic, lower quality care” class than in the “no or managed symptoms, high quality care” class. The relationship between

importance of religious participation and race/ethnicity and EOL care quality is similar, regardless of the type of ACP included in the LCA with covariates model.

Small cell sizes preclude testing an interaction term for ACP and attitudes towards religion using LCA with covariates. However, as shown in Table 3.6, three-way cross tabulations for ACP, attitudes towards religion, and EOL care quality suggest a relationship between ACP, the importance of attending religious services, and EOL care quality together. However, this relationship only exists among those who complete ACP. Among those who completed ACP, proxies for those for whom church attendance is very important report higher quality EOL care in higher than expected proportions. Proxies for those for whom church attendance is not as important report lower quality EOL care in higher than expected proportions. These relationships are consistent across all types of ACP. However, importance of religious attendance is not significant for EOL care quality among individuals with no ACP.

Discussion

This study addresses two core questions regarding EOL care quality among older decedents. First, while prior studies focus on individual measures of care quality, I use latent class analysis (LCA) to develop a multidimensional measure that simultaneously considers multiple aspects of proxy reports of EOL care quality. Then, using the groups identified in LCA, I analyze how ACP, attitudes towards religion, and fundamental causes of disease relate to assessments of EOL care quality.

Experiences of EOL care quality fall into two statistically and conceptually different groups, as reported by proxies for a sample of deceased Medicare beneficiaries. The groups are characterized by (1) no or managed symptoms and high quality care and

(2) symptoms and lower quality care. Over three-quarters of proxies are likely to rate decedents' EOL experiences positively with respect to their interaction with health care providers (informed about condition, involved in decisions, no unwanted treatment, coordinated care) and how they were treated as a person (treated with respect, personal care needs met). In this class, there is a low probability proxies report unmanaged symptoms, particularly pain and breathlessness. Decedents in this class are likely to experience high quality EOL care. In an ideal scenario, decedents will experience the "symptom free, excellent care" desired at EOL (PRC 2013; Steinhauser et al. 2000). However, if symptoms are unavoidable, provided they are managed, proxies are likely to positively assess a decedent's health care encounters and personal care. The positive relationship between symptom management and perceptions of other dimensions of EOL care suggests that careful attention to managing dying individuals' symptoms may improve satisfaction with other aspects of care.

In contrast to this class of high quality EOL care, over one in five proxies are likely to report a less rosy picture of EOL care. They rate decedents' EOL care less positively and indicate decedents experienced managed or unmanaged symptoms, most likely managed breathlessness and unmanaged sadness. To the extent that symptom management is associated with positive perceptions of other aspects of EOL care quality, focusing on alleviating unmanaged symptoms may be an effective strategy for shifting towards more positive perceptions of health care encounters and personal care. Additional research is needed to better understand what is happening in cases where proxies report managed symptoms and negative assessments of care. Proxy reports of poor EOL care when symptoms are managed could be an indication of poor psychological adjustment

following the loss of a loved one. Alternatively, proxies may be reporting on instances of EOL care where, although symptoms were managed, encounters with healthcare providers were unsatisfactory and the decedent was not treated in a dignified manner. Qualitative studies could explore the circumstances under which proxies report managed symptoms and poor quality care in other areas of EOL care.

ACP does not Predict Perceived EOL Care Quality

Research suggests that ACP for EOL healthcare needs is associated with better quality EOL care in some respects: individuals who plan for end of life are less likely to receive futile treatments (Mack, Paulk, Viswanath, & Prigerson 2010; Nicholas et al. 2011; Teno et al. 2007; Wright et al. 2008), or receive treatments that are not concordant with their wishes (Detering et al. 2010). Following this line of scholarship, I expected that individuals who completed advanced planning would experience higher quality EOL care than individuals those who did not. Contrary to these expectations, I found that ACP did not predict proxies' assessments of EOL care quality, which could mean that ACP has little effect on perceived EOL care quality. Although not a significant predictor of EOL care quality, any type of advance planning is associated with lower odds of receiving lower quality EOL care. The sample size is relatively small (222), so a larger sample may provide additional power necessary to detect significant differences based on ACP. Alternatively, decedents in this sample could have had EOL experiences where ACP did not come into play. A large proportion had no symptoms and high quality care, which could mean death was sudden, requiring little decision-making about EOL care. Future research can explore the relationship between ACP, cause of death, and EOL care quality should NHATS be linked to the National Death Index.

Another possible reason for the lack of relationship between ACP and EOL care quality is that ACP may be effective at targeting specific aspects of EOL care quality, but not multiple dimensions of care simultaneously. For example, in bivariate relationships (Table 3.3), having completed any type of ACP is significantly and positively correlated with being involved in decision-making regarding EOL care. The relationship between any type of ACP and involvement in decision-making suggests one of the intentions of ACP—to ensure patients maintain their autonomy—works among older adults. Moreover, having a living will and/or DPAHC or any type of ACP is significantly and negatively correlated with no sadness or anxiety, and significantly or marginally significantly and positively correlated with managed sadness or anxiety. Prior work has shown that individuals with indeterminate/uncertain time horizons are more likely to complete ACP than those with limited or expansive horizons, possibly due to increased anxiety about the uncertainty of when they may be faced with a health crisis in which ACP is helpful (Luth 2016). If individuals who complete ACP tend to be more anxious than those who do not, having plans in place may help alleviate sadness and anxiety at EOL. While asking about sadness and anxiety in a single question is common practice in assessing EOL care quality (e.g. CMS 2016), they are related, but not identical, constructs. Additional research differentiating between dying individuals' experiences of sadness and anxiety might elucidate the possible effect of ACP on reducing anxiety among dying individuals.

Importance of Religious Participation Predicts EOL Care Quality

Although ACP does not predict EOL care quality, individuals for whom attendance at religious services is very important experienced EOL characterized by no or

managed symptoms and high quality care. One explanation for the relationship between attitudes towards religious participation and EOL care quality is that family members of religious decedents, who are also likely to be religious and comprise a majority of proxies in this analysis, may activate religious coping mechanisms, allowing them to more successfully deal with the stress of losing a loved one (Ano and Vasconcelles 2004). This effective coping may result in more positive assessments of EOL care quality. Strong religious beliefs may cause dying individuals and their loved ones to be more accepting of death as part of God's plan or as a pathway to an afterlife, similarly resulting in positive assessments of EOL care quality. To the extent that positive proxy assessments of EOL care quality reflect peace with their loved one's death, my findings support research finding religiousness and spirituality positively influence the bereavement process (Becker et al. 2007). Additional research is needed to unpack the relationship between religious beliefs, perceptions of EOL care, and bereavement, specifically the extent to which positive assessments of care reflect a certain state in the bereavement process facilitated through religious coping, and how religious coping might influence perceptions of EOL care that facilitate bereavement.

Alternatively, individuals who value church attendance tend to have more active social support networks (Idler et al. 2009), members of which may provide emotional comfort to the dying individual or trusted assistance with routine care activities, contributing to higher quality EOL care. Bivariate analyses indicate increased importance of religious participation is significantly and positively associated with receipt of dignified care (personal care needs being met, being treated with respect). While NHATS data do not allow me to analyze how religious support networks contribute to EOL care,

additional research could explore in greater detail the circumstances under which and how religious support networks translate to EOL care provision.

I found no direct association between ACP and importance of church attendance or EOL care quality in bivariate analysis. However, supplemental analyses showed that proxies for individuals who completed ACP and who valued church attendance reported high quality EOL care in higher than expected proportions. Although these analyses include small cell sizes, and so results should be interpreted with caution, this finding suggests that ACP may further facilitate access to high quality EOL care among individuals for whom church attendance is important. One possible explanation is that close family members, who are likely to share religious beliefs with decedents, may have also discussed EOL treatment preferences and/or be the designated health care proxy for older adults' whose EOL care they evaluate. As such, they may be more familiar and agree with the dying individuals' preferences, and therefore may be more effective advocates for better EOL care, or may have a more positive assessment of care. To the extent the relationship between ACP, importance of religious participation, and EOL care quality persists in larger or different samples, religious networks may be a useful mechanism for encouraging ACP completion and facilitating better EOL care.

Fundamental Causes of Health and Mortality Disparities do not Consistently Predict Perceived EOL Care Quality

Based on the well-established link between lower SES and racial/ethnic minority status and poor health outcomes and premature mortality (Elo 2009; Link and Phelan 1995; Marmot et al. 1991), I expected that individuals with less education or who identify as a racial or ethnic minority would receive poorer quality EOL care. Moreover, given

that older women are also in a position of social disadvantage and tend to outlive their spouses—and the potential health-protective benefits of marriage—relative to men, I expected women would receive worse quality EOL care than men. However, in a sample of deceased older adults, these three “fundamental causes” of disease and mortality are not associated with EOL care quality as expected. Education and sex do not predict EOL care quality. Race/ethnicity do predict EOL care quality, but not in the direction expected by fundamental causes theory. Proxies have greater odds of reporting non-Hispanic whites experienced symptomatic, lower quality EOL care.

There are multiple possible explanations for the lack of significant findings related to education. Studies have found that SES health disparities attenuate at older ages, although the reason for such attenuation is not well understood (Phelan et al. 2004). On one hand, health and mortality disparities caused by social disadvantage may already have already played out in the NHATS sample. While the NHATS sample is representative of Medicare recipients, study participants must live to age 65 and be well enough to participate in at least one round of a lengthy survey. As a result, NHATS participants may represent a particularly healthy subset of older adults who have similar, relatively high quality EOL experiences. Supplementary analyses show a quarter of respondents in my sample do not report having lung or kidney problems, cancer, or Alzheimer’s which are common among adults over 65, and there are no differences in illnesses by education. Moreover, as three quarters of all deaths in the US occur to individuals 65 and older, it is important to understand what happens at EOL among this group.

Conversely, Link and Phelan (Phelan et al. 2004) postulate reductions in health disparities could be due to frailty in old age for which additional resources and other advantages fail to compensate. This study focuses on care in the last month of life, when individuals are expected to be at their most fragile, and so advantages accrued over the life course may not apply to failing bodies. Were information about decedents' EOL trajectories and causes of death available, we could control for some of the "messiness" associated with EOL that may mask SES inequalities in EOL care. Finally, fundamental causes theorists explain that policy initiatives that equalize access to healthcare resources can offset disparities linked to social disadvantage. All the respondents in my sample are Medicare recipients, a universal program designed to facilitate access to healthcare. Lack of SES differences in access to quality EOL care could signify that Medicare is an effective mechanism for ensuring relatively equal access to high quality EOL care. A possible indicator of the relatively equitable access to high quality care through Medicare is the fact that individuals in the sample are equally likely to receive hospice care, which is both associated with high quality care and paid for by Medicare.

Similarly to education, there is no relationship between gender and EOL care in this sample. In supplementary analysis, men and women are equally likely to receive hospice care and have no chronic illnesses, and have similar numbers of hospitalizations in the year before death, signaling relatively similar EOL trajectories. However, we know older men and women have very different health experiences. Compared to men, women occupy a structurally disadvantageous position in society and have higher levels of cognitive impairment than men (NCHS 2016), so it is somewhat surprising they do not receive higher quality EOL care. On the other hand, men tend to experience more acute

illness, have a shorter lifespan than women and higher rates of morbidity on most of the leading causes of death (NCHS 2016). Greater illness severity may make men's EOL care more complicated, precluding high quality care provision and evoking negative assessments among proxy reporters, and close family members in particular. Additional research is needed to better understand how and why different health trajectories for older men and women converge in similar EOL care quality.

Contrary to what fundamental causes theory would predict, proxies report non-Hispanic whites are more likely to experience symptomatic, low quality care than no or managed symptoms and high quality care. This finding is surprising, given that health and mortality outcomes are generally better for non-Hispanic whites (Feagin and Bennefield. 2014; Williams 2012). It is unlikely that non-Hispanic whites receive systematically poorer care at the end of life, given they receive better care in so many other aspects of medical care (Hoffman et al. 2016; IOM 2003). One explanation is that the non-Hispanic whites in this sample may have less frequent contact with health care providers, which may negatively affect their ability to access high quality EOL care. Chi square tests (not shown) indicate non-Hispanic whites have fewer hospitalizations than expected, but also report not being informed about care more often than expected. However, it is not clear why non-Hispanic whites would have fewer hospitalizations or poorer communication with health care providers as non-Hispanic whites and non-whites do not differ in the number of chronic illnesses they have. Nor do they differ in hospice involvement, or home death. Perhaps proxies for non-Hispanic white decedents hold higher expectations for care quality than proxies for non-whites, and therefore evaluate EOL care more harshly when it falls short of their expectations. While NHATS data do

not contain information on proxy race, given that over 70% of proxies are spouses or children, in most cases proxies are likely the same race as the decedent whose care they evaluate. As such, findings may reflect their own expectations for EOL care. Proxy relationship to the decedent may also affect their assessments of EOL care quality. Non-whites have distant family proxies more often than expected, who may tend to provide more positive assessments of EOL care quality.

Limitations

This study is among the first I know of to identify latent classes of EOL care quality and explore how social determinants of health and mortality disparities and advance care planning behavior may apply to differences in EOL care quality. However, the results are potentially weakened by four limitations. First, the analysis focuses on death among individuals over 65. Premature mortality among individuals with lower SES may explain the lack of socioeconomic disparities in EOL care quality in my sample. Premature mortality among Blacks and individuals with lower SES may leave in the sample a particularly healthy set of individuals with less education and non-Hispanic blacks (who comprise 75% of non-Whites in the sample) who go on to experience relatively symptom free, high-quality EOL care. Moreover, premature death is undesirable, and research indicates health care professionals administer more aggressive EOL care to younger individuals whom they consider socially valuable (Timmermans 2008). As such, individuals who die before age 65 may receive more aggressive and potentially painful and unwanted EOL care than the older adults in my sample. Future studies might examine SES differences in EOL care quality among middle-aged adults, before mortality disparities take effect. However, older adults comprise three-quarters of

all deaths in the United States, so understanding EOL care in this segment of the population merits individual attention.

A second limitation is that the analysis focuses exclusively on social determinants of health and mortality and ACP behavior, without controlling for other factors that may affect actual or perceptions of death quality. This includes health and illness trajectory, place of death, and hospice involvement in EOL care. Sample size and model instability limited my ability to include these factors in the current analysis. As NHATS respondents continue to die and the sample of individuals who can be analyzed increases, it will be possible to include additional control variables in future analyses. As such, findings related to racial and ethnic differences in perceived EOL care quality should be interpreted with caution.

A third limitation of this study is that the measures of EOL care quality rely on the subjective evaluations of proxy reporters, who may vary systematically in how they assess EOL care quality based on personality or general disposition, prior experience with death, and experience with and knowledge of the death they are evaluating. Reliance on second-hand, retrospective reports is a known, but accepted, limitation of studies of EOL (George 2002). Understanding variation in proxy perceptions of EOL care quality is important and merits further study, as these perceptions are linked to bereaved and caregiver health and well-being (Anderson and Ewen 2011; Carr 2003; Christakis and Iwashyna 2003).

Finally, alternate measures of EOL care might present a different picture, possibly capturing variation based on fundamental causes of advantage and disadvantage. However, CMS uses the same measures to evaluate hospice provider eligibility for

Medicaid and Medicare reimbursement (\$15.1 billion in 2013) (NHPCO 2015a, 2015b), making them a core component in the policy definition of “quality EOL care” and tying them directly to the economy of dying. My analysis extends these measures beyond the hospice context to a sample of deceased older adults, regardless of whether they received hospice services. A nuanced understanding of how these measures function together, for whom, and under what circumstances is critical for designing effective policy to improve care quality.

Conclusion: Implications for Understanding Perceived EOL Care Quality

This paper examines the extent to which ACP, religious attitudes, and fundamental causes of health and mortality determine perceived EOL care quality in a sample of older adults. One-quarter of the sample experienced undesirable symptoms and lower quality care in the last month of life. ACP was not related to EOL care quality, which could be an indication that ACP is effective in limiting EOL treatment, but not in affecting perceptions of EOL care. However, individuals who value attending religious services received higher quality EOL care, possibly reflecting increased acceptance of EOL and satisfaction with care, regardless of the level of futility associated with it. Future research is needed to understand how perceptions of EOL care, which may be modifiable based on targeted efforts to improve care quality, may work in tandem with religious beliefs and coping mechanisms to facilitate bereavement, and how the relationship between religious beliefs and perceptions of care may be applicable to other situations such as coping with chronic illness or caregiving responsibilities. The association between attitudes towards religious participation and EOL care quality may

be particularly strong among individuals who complete ACP, which may reflect benefits of caregiver knowledge of and agreement with EOL care preferences.

Contrary to existing sociological theory and empirical research suggesting otherwise, social characteristics such as gender and SES, are not related to EOL care quality. One explanation is that fundamental causes of disadvantage may apply to health and mortality, but may not be applicable to the middle stage: end of life care quality. It is also possible that the end of life is uncertain enough that socioeconomic advantages accrued over the life course disappear in the last stages of life. Proxy reporters may just evaluate/perceive quality of EOL care to be similar, regardless of the social advantage or disadvantage the deceased individual experienced over the course of his or her life. Proxies report lower quality EOL care for non-Hispanic whites than for non-whites, which is surprising given the health advantages non-Hispanic whites accrue over the life course. Proxies also tend to report a relatively rosy picture of quality of EOL care, with over 80% reporting the highest quality care on any given measure. Proxy reporters may be directly involved in providing care at the end of life, wish to remember a loved one's death in a positive light, or otherwise motivated to report care was good, inflating reports of actual quality. Regardless, to the extent that positive perceptions of care influence facilitate bereavement, improving EOL care quality could enable bereaved individuals to better cope with loss. The next chapter investigates this final theme, exploring in detail how proxy characteristics might influence perceptions of EOL care quality.

Table 3.1. Summary of Nine Measures of Quality of End-of-Life Care used in Latent Class Analysis, NHATS, 2011-2014^a

Variable	Measurement Categories	Survey Questions
Pain	1. Unmanaged (yes to Q1, no to Q2; yes to Q1 & Q2, less or more help than needed to Q3)	1. During the last month of life, were there times when [deceased] experienced [pain, trouble breathing, feelings of anxiety or sadness]? (yes/no)
Breathlessness	2. Managed (yes to Q1 & Q2, about right amount of help to Q3)	2. If “yes” to question 1, Did [deceased] get any help in dealing with [symptom]? (yes/no).
Sadness/ Anxiety	3. None (no to Q1)	3. If “yes” to question 2, How much help in dealing with pain did [deceased] receive? (less than needed, more than needed, about right amount).
Involved in Health Care Decisions	1. Yes	During the last month of [deceased]’s life, was there ever a decision made about {his/her} care or treatment without enough input from [deceased] or {his/her} family?
No Unwanted Care	2. No	During the last month of [deceased]’s life, was there any decision made about care or treatment that [deceased] would not have wanted? (yes=0, no=1)
Care Coordination	1. Unclear who was in charge of care (yes to Q1, no to Q2) 2. One doctor/Clear doctor in charge of care (no to Q1; yes to Q1 & Q2)	1. During the last month of [deceased]’s life, was there more than one doctor involved in {his/her} care? (yes/no); 2. If “yes,” During the last month of [deceased]’s life, was it always clear to you which doctor was in charge of {his/her} care? (yes/no).
Informed about Condition	1. Usually, Sometimes, Never	During the last month of [deceased]’s life, how often were you or other family members kept informed about [deceased] condition?
Personal Care Needs Met	2. Always	During the last month of [deceased]’s life, how often were {his/her} personal care needs, such as bathing, dressing, and changing bedding, taken care of as well as they should have been?
Treated with Respect		During the last month of [deceased]’s life, how often were [deceased] treated with respect by those who were taking care of [deceased]?

^a All responses provided by a proxy respondent familiar with decedent’s last month of life.

Table 3.2. Item response probabilities for measures of EOL care (last month of life) used in latent class analysis, 222 NHATS decedents, 2011-2014

	Managed or no symptoms, high quality care	Symptomatic, lower quality care
Death Quality Measures	77%	23%
Pain		
Unmanaged	0.08	0.46
Managed	0.57	0.44
None	0.35	0.10
Breathlessness		
Unmanaged	0.05	0.24
Managed	0.50	0.52
None	0.45	0.24
Sadness/Anxiety		
Unmanaged	0.17	0.65
Managed	0.42	0.21
None	0.42	0.14
Involved in decision-making	0.95	0.70
Always informed about condition	0.96	0.28
No unwanted care	0.96	0.68
Clear doctor in charge of care	0.94	0.53
Personal care needs always met	0.92	0.43
Always treated with respect	0.98	0.50

Table 3.3. Descriptive statistics for 222 NHATS decedents, 2011-2014

	Proportion / Mean (sd)	Valid N^b
Death Quality Indicators used in LCA^a		
Pain		211
Unmanaged	0.17	
Managed	0.54	
None	0.29	
Breathlessness		208
Unmanaged	0.09	
Managed	0.50	
None	0.40	
Sadness/Anxiety		205
Unmanaged	0.28	
Managed	0.37	
None	0.35	
Deceased or family involved in decision-making	0.90	212
Always informed about condition	0.80	218
No unwanted care	0.90	213
Clear doctor in charge of care	0.84	214
Personal care needs always met	0.81	218
Always treated with respect	0.87	215
End-of-Life Planning		
Informal discussions	0.61	222
Living will	0.63	222
Durable power of attorney for health care (DPAHC)	0.67	222
Living will or DPAHC	0.74	222
Any end-of-life planning	0.80	222
Religious attendance very important	0.52	222
Fundamental Causes		
Male	0.41	222
Non-Hispanic White	0.69	222
More than high school	0.37	222

a. LCA=Latent class analysis. b. Respondents who answered at least one end-of-life care quality included in LCA.

Table 3.4. Bivariate correlations for EOL care quality and proxy characteristics, 222 NHATS decedents, 2011-2014^a

		1	2	3	4	5	6
1	No pain	1.00					
2	Managed pain	-0.69	1.00				
3	Unmanaged pain	-0.29	-0.49	1.00			
4	No breathlessness	0.16	-0.07	-0.10	1.00		
5	Managed breathlessness	-0.09	0.12	-0.06	-0.83	1.00	
6	Unmanaged breathlessness	-0.12	-0.10	0.28	-0.26	-0.32	1.00
7	No sadness	0.26	-0.13	-0.15	0.14	-0.08	-0.12
8	Managed sadness	-0.10	0.17	-0.11	-0.09	0.10	-0.01
9	Unmanaged sadness	-0.17	-0.05	0.28	-0.05	-0.03	0.14
10	Involved in decisions	0.08	0.03	-0.14	0.09	-0.02	-0.11
11	Always informed about condition	0.13	0.13	-0.32	0.09	0.05	-0.24
12	No unwanted care	0.15	-0.05	-0.11	0.03	-0.06	0.05
13	Clear doctor in charge	0.17	0.09	-0.32	0.12	-0.07	-0.09
14	Personal needs always met	0.07	0.12	-0.24	0.11	-0.02	-0.15
15	Always treated w respect	0.14	0.01	-0.17	0.10	-0.08	-0.04
16	Informal EOL discussions ^b	0.01	-0.09	0.11	0.02	-0.03	0.02
17	Living will	-0.02	-0.05	0.09	0.00	-0.04	0.07
18	DPAHC ^b	0.03	-0.05	0.03	0.07	-0.03	-0.06
19	Living will or DPAHC ^b	0.01	-0.02	0.02	0.03	-0.03	0.00
20	Any advance care planning (ACP)	-0.04	-0.02	0.07	0.00	-0.02	0.03
21	Religious attendance very important	-0.02	0.13	-0.15	-0.01	-0.01	0.03
22	Male	0.14	-0.12	-0.02	0.03	-0.04	0.01
23	Non-Hispanic White	-0.04	0.02	0.03	0.02	-0.10	0.13
24	More than high school	-0.12	0.06	0.06	0.00	-0.02	0.03

		7	8	9	10	11	12
7	No sadness	1.00					
8	Managed sadness	-0.56	1.00				
9	Unmanaged sadness	-0.46	-0.48	1.00			
10	Involved in decisions	0.10	0.02	-0.13	1.00		
11	Always informed about condition	0.21	0.11	-0.34	0.30	1.00	
12	No unwanted care	0.15	0.13	-0.29	0.29	0.27	1.00
13	Clear doctor in charge	0.08	0.11	-0.21	0.13	0.36	0.11
14	Personal needs always met	0.16	0.14	-0.33	0.21	0.36	0.22
15	Always treated w respect	0.18	0.08	-0.28	0.33	0.54	0.37
16	Informal EOL discussions ^b	-0.11	0.06	0.06	0.07	-0.05	0.05

		7	8	9	10	11	12
17	Living will	-0.14	0.14	0.00	0.10	-0.03	0.10
18	DPAHC ^b	-0.17	0.13	0.03	0.06	0.08	0.07
19	Living will or DPAHC ^b	-0.15	0.12	0.02	0.13	0.04	0.09
20	Any ACP	-0.16	0.18	-0.01	0.14	0.07	0.07
21	Religious attendance very important	-0.09	0.16	-0.08	0.10	0.16	0.05
22	Male	0.12	-0.09	-0.03	-0.04	-0.03	0.02
23	Non-Hispanic White	-0.14	0.08	0.06	0.08	-0.18	-0.02
24	More than high school	-0.11	0.16	-0.06	-0.03	-0.03	-0.09

		13	14	15	16	17	18
13	Clear doctor in charge	1.00					
14	Personal needs always met	0.27	1.00				
15	Always treated w respect	0.19	0.39	1.00			
16	Informal EOL discussions ^b	-0.06	-0.08	-0.02	1.00		
17	Living will	-0.04	0.00	0.05	0.55	1.00	
18	DPAHC ^b	0.02	0.00	0.03	0.48	0.60	1.00
19	Living will or DPAHC ^b	0.01	0.03	0.04	0.45	0.77	0.84
20	Any ACP	0.04	-0.01	-0.01	0.63	0.64	0.70
21	Religious attendance very important	0.00	0.19	0.21	-0.09	0.01	-0.03
22	Male	-0.09	0.02	0.06	-0.02	-0.03	-0.08
23	Non-Hispanic White	-0.08	-0.05	-0.11	0.33	0.38	0.21
24	More than high school	0.02	0.14	0.04	0.04	0.17	0.05

		19	20	21	22	23	24
19	Living will or DPAHC ^b	1.00					
20	Any ACP	0.84	1.00				
21	Religious attendance very important	-0.01	0.00	1.00			
22	Male	-0.07	-0.12	-0.09	1.00		
23	Non-Hispanic White	0.27	0.28	-0.05	-0.01	1.00	
24	More than high school	0.08	0.08	-0.06	0.06	0.17	1.00

a **Bolded** text denotes relationship is significant at $p < 0.05$. b DPAHC=durable power of attorney for health care. EOL=end-of-life

Table 3.5 Binomial logistic regressions: Odds ratios (and 95% confidence intervals) of covariates predicting membership in “Symptomatic, lower care quality” EOL care latent classes by five types of advance care planning, 222 NHATS decedents, 2011-2014^a

Type of Advance Care Planning					
	Model 1: Informal discussions	Model 2: Living will	Model 3: DPAHC	Model 4: Living will and/or DPAHC	Model 5: Any ACP
Advance Care Planning (ACP)	0.69	0.72	0.52	0.55	0.58
	(0.31, 1.54)	(0.32, 1.61)	(0.24, 1.13)	(0.24, 1.27)	(0.23, 1.48)
Religious attendance very important ^b	0.35	0.36	0.36	0.37	0.37
	(0.17, 0.74)	(0.18, 0.76)	(0.17, 0.76)	(0.18, 0.76)	(0.17, 0.77)
Male	0.77	0.77	0.76	0.76	0.77
	(0.36, 1.62)	(0.37, 1.64)	(0.35, 1.61)	(0.36, 1.61)	(0.26, 1.63)
Non-Hispanic white ^b	3.66	3.56	3.66	3.71	3.64
	(1.36, 9.89)	(1.34, 9.46)	(1.42, 9.43)	(1.42, 9.71)	(1.36, 9.72)
More than high school	0.68	0.72	0.71	0.70	0.71
	(0.31, 1.45)	(0.33, 1.55)	(0.33, 1.53)	(0.33, 1.51)	(0.33, 1.53)

a. Reference class: “No or managed symptoms, high quality care.” b. Variable always a significant predictor of EOL care quality at $p < .01$.

Table 3.6 Proportion and number of individuals who receive each class of EOL care quality by ACP and importance of religious participation, 222 NHATS decedents, 2011-2014.

Type of ACP	Importance of religious attendance	High quality care with managed or no symptoms		Lower quality care with pain, managed breathlessness, and sadness/anxiety		Pearson's χ^2 (p value)
		%	n	%	n	
No discussions	Not/somewhat	72.22	26	27.78	10	1.75 (0.185)
	Very	84.00	42	16.00	8	
Discussions	Not/somewhat	70.00	49	30.00	21	5.29 (0.021)
	Very	86.36	57	13.64	9	
No living will	Not/somewhat	72.50	29	27.50	11	0.93 (0.335)
	Very	81.40	35	18.60	8	
Living will	Not/somewhat	69.70	46	30.30	20	6.78 (0.009)
	Very	87.67	64	12.33	9	
No DPAHC	Not/somewhat	67.65	23	32.35	11	0.90 (0.342)
	Very	77.50	31	22.5	9	
DPAHC	Not/somewhat	72.22	52	27.78	20	7.17 (0.007)
	Very	89.47	68	10.53	8	
No formal planning	Not/somewhat	70.37	19	29.63	8	0.37 (0.541)
	Very	77.42	24	22.58	7	
Formal planning	Not/somewhat	70.89	56	29.11	23	7.67 (0.006)
	Very	88.24	75	11.76	10	
No ACP	Not/somewhat	71.43	15	28.57	6	0.27 (0.601)
	Very	78.26	18	21.74	5	
Any ACP	Not/somewhat	70.59	60	29.41	25	7.35 (0.007)
	Very	87.10	81	12.90	12	

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Chapter 4

The Influence of Proxy Reporter Characteristics on Perceptions of Older Adults'

End-of-Life Care Quality

Introduction

Dying individuals, their family members, and informal caregivers place a high value on the quality of care received at the end of life. Health care providers and policy makers also are concerned with providing high-quality care. It is part of a social obligation to honor and show respect for individuals in the last stages of life, and for their family members and caregivers who will live with the memory of their loved ones' EOL experience (Institute of Medicine (IOM) 2014). Quality EOL care is of particular concern for adults over 65, who account for three-quarters of 2.6 deaths in the United States, 67% of which are attributable to the chronic illnesses heart disease, cancer, stroke, chronic lower respiratory disease, and Alzheimer's disease (Kochanek et al. 2016). Caring for older individuals with multiple comorbidities is clinically challenging and costly, particularly in the final stages of life. In 2014, Medicare spent an average of \$69,000 per individual during the last two years of life; just over half of that in the last six months of life alone (Dartmouth Atlas Project 2017). The complex and costly nature of dying among older adults makes understanding and improving EOL care quality among this segment of the population particularly important.

Bereaved family members and EOL care experts agree that medical and psychosocial elements are important at EOL. These include providing physical comfort to dying individuals, helping dying individuals maintain control over medical treatment and daily routine decisions, and easing family members' burdens in advocating for high

quality care for their dying loved ones (Teno et al. 2001). Understanding the nature and quality of these aspects of EOL care necessarily relies on proxy or caregivers' retrospective appraisals of the decedent's experiences. These appraisals of care also are subjective in the sense that they reflect family members' assessments of the situation and cannot be easily recorded or verified in a medical record. Studying these specific aspects of care may be more productive than focusing on more general assessments such as the proxy's "overall satisfaction" with care because the former are potentially modifiable via interventions (Teno et al. 2001). Moreover, most proxy reporters for older adults are also older adults, who tend to provide positively biased appraisals (Mather and Carstensen 2005).

Family member perceptions of subjective aspects of EOL care have typically been used to assess satisfaction with hospice and palliative care (Teno 2005), and are used by the Centers for Medicare and Medicaid Services (CMS) to determine reimbursement eligibility for these services (National Hospice and Palliative Care Organization (NHPCO) 2015b). However, these measures are underexplored in studies identifying variations in the quality of EOL care. Moreover, these measures assess aspects of care important to dying individuals and caregivers in all EOL care scenarios, regardless of setting (e.g. home or hospital) or who provides care (e.g. hospice worker or nursing home staff member).

Although studies of EOL care rely on proxy reports, they often fail to consider how proxy characteristics, and the lived experiences that accompany those characteristics, influence their perceptions of care. Research indicates women are more likely to employ selective ignoring to cope with stressful family interactions (Pearlin and

Schooler 1978), and older adults are less likely to both recall and respond to negative stimuli (Carstensen, Fung, and Charles 2003). Bereaved family members and those who are more directly involved in care at EOL may positively assess EOL care as a way of making sense of the loss (Bonanno and Kaltman 1999; Park 2010). This analysis explores how proxy familiarity with care, relationship to the decedent, gender, and age influence proxy perceptions of EOL care quality.

I use family member and caregiver (proxy) retrospective reports of EOL care to develop three conceptually and analytically distinct subtypes of care quality, which show how different components of EOL care co-occur. I then examine the extent to which proxy characteristics (familiarity with EOL care, relationship to decedent) influence assessments of EOL care quality. I then evaluate the extent to which these effects persist after controlling for 1) decedent sociodemographic and health characteristics that affect health and mortality, and 2) care setting and provider characteristics that may affect proxy perceptions of EOL care quality. I use four waves of longitudinal data from the National Health and Aging Trends Study (NHATS) to analyze EOL care quality among adults 65 and older, individuals with complex healthcare needs who are the most likely to die. In the next section I describe the components of quality EOL care, and explain the importance of a multidimensional analysis of care quality.

Quality EOL Care

Beginning in the mid-20th century, medical technological advances contributed to both longer life spans and the medicalization of death, with implications for how we understand EOL care quality. Life-saving technologies hold the potential to prolong life without improving, and in some cases worsening, quality of life. In response, physicians

and thought leaders have reiterated the fundamental responsibility of health care providers to reduce dying patients' physical and psychic suffering and enhance their well-being (Byock 1996, Gawande 2014), a desire echoed by seriously ill individuals, caregivers, and adults more generally (Parmalee 2001, Steinhauser et al. 2000, Teno et al. 2001). Through medicalization, health care providers and medical institutions have taken over responsibility for aspects of EOL care that were previously the purview of family members and the community (Conrad 1992).

Although EOL care increasingly occurs in medical settings, most Americans express a desire to maintain their autonomy and remain involved in medical decision-making, even at EOL (PRC 2013). As such, medical ethicists emphasize the importance of ensuring dying patients maintain their personal dignity and autonomy (Emanuel and Emanuel 1996), and federal law protects patients' rights to state their EOL health care treatment preferences (U.S. Congress 1990). Advances to medical technology that may prolong suffering at EOL and the location of EOL shifting to medical settings have prompted seriously ill individuals, bereaved family members, physicians, ethicists, and policy makers to emphasize multiple components of care as important at EOL including symptom management, control over medical treatment and daily routine decisions, and dignified care.

Adults, including seriously ill persons and healthcare professionals who care for dying individuals, identify freedom from unwanted symptoms as important at EOL. In a large study of seriously ill individuals, bereaved family members, physicians, and other health care providers, nine in ten agree or strongly agree that being free from pain, breathlessness, and anxiety is important at EOL (Steinhauser et al. 2000). Just over half

of adult respondents indicate they are concerned about the possibility of continued emotional suffering at EOL (Parmalee 2001). While physical and emotional symptoms are both important to address at EOL, physical symptoms are generally easier to identify than emotional symptoms. Dying individuals may feel more comfortable expressing physical than emotional discomfort. Similarly, caregivers and health care providers may find it easier to identify physical than emotional symptoms. They may attribute a dying individual's behavior, such as gasping for breath, grimacing, or moaning to breathlessness and pain rather than sadness or anxiety. I include measures of pain, breathlessness, and sadness and anxiety in my analyses of EOL care quality to be able to identify variations in proxy perceptions of dying individuals' experiences with multiple physical and emotional symptoms at EOL.

In an ideal scenario, a dying individual will not experience any unwanted symptoms at EOL. However, complete absence of symptoms is not always possible, particularly when people die from protracted chronic illness which can become increasingly severe at the EOL (Carr & Luth 2016). As such, it is important, and perhaps more realistic, to consider whether a dying individual received relief from any symptoms that occur, and whether proxies perceive that relief as ultimately beneficial to the dying individual's EOL care. If a dying individual does not receive sufficient medication or medical assistance to alleviate symptoms, he or she may continue to suffer.

On the other hand, dying individuals may state a desire for complete symptom relief without understanding its potential consequences. In some instances, providing symptom relief may require heavy sedation, making dying individuals unable to make decisions about their health care or interact in a meaningful way with grieving family

members. Both outcomes—the perception that an individual continues to suffer when more treatment could be administered and non-responsiveness that results from doses of medication necessary to relieve intractable symptoms—can be distressing to family members hoping to share peaceful and meaningful exchanges with dying loved ones. Proxies may associate unsatisfactory symptom management with other aspects of EOL care such as undignified care or not being informed about what to expect about a dying individual's condition. While symptoms at EOL may be unavoidable, clear communication with dying individuals and family members about what to expect with different approaches to symptom management may improve perceptions of care quality. In order to identify how different experiences with symptoms and their treatment are associated with other aspects of EOL care quality (discussed below), I maintain three categories of symptom management: none, managed, and unmanaged.

In addition to physical and emotional comfort, dying individuals' experiences with the health care system are important components of quality EOL care. Longer life span with increasingly complicated health has been accompanied by a cultural shift towards treating death as something to be avoided or delayed, rather than accepted as a natural part of life (Conrad 1992). The combination of complex illness needs and increased medical control over death and dying means that frequent contact with the health care providers is an inevitable part of dying for many older adults. The nature of that contact is an important component in assessing EOL care quality. While death and dying may occur increasingly under the purview of health care professionals, most Americans still expect a degree of autonomy and involvement in personal health care decision-making. Recent public opinion polls indicate 80% of people believe doctors and

nurses should pay attention to whether or not a patient wants treatment to keep them alive, and 66% believe there are circumstances in which a patient should be allowed to die (PRC 2013). Seriously ill individuals express preferences in support of self-determination: 40% want to control the time and place of death, 84% agree it is important to feel prepared to die, and 96% want to know what to expect about their physical condition at EOL (Steinhauser et al. 2000).

The tension between medical providers' increased involvement in EOL and patients' and family members' desire to actively partake in health care decision-making can lead to conflict and confusion in EOL care provision. Conflict and confusion may be more likely if the moment of transition from ongoing chronic illness management to dying is not clearly identified, or if a patient's wishes are unclear or in conflict with medical opinion. Clear communication is necessary for healthcare professionals to remain attuned to the care preferences and needs of dying individuals, and to deliver care that is concordant with those desires.

The quality of interactions with health care providers and dying individuals' and their loved ones' participation in health care decisions may be affected by the setting of EOL care and who provides the care. Physicians in intensive care units are trained to use medical technology to save critically ill patients' lives and may be unprepared to shift conversations from focusing on curing a sick patient to determining the best course of action for a dying individual (Chapple 2010). In contrast, hospice workers are trained to help dying individuals and their family members make meaningful decisions about EOL care (NHPCO 2010). Bereaved individuals' may assess the quality of healthcare encounters from hospice providers who focus on psychological and spiritual needs, in

addition to physical comfort more positively than encounters with physicians who provide care in a medicalized setting and are trained to prevent death. However, high quality encounters with health care providers should be a goal of quality EOL care, regardless of setting or care provider. As such, I include measures of communication with healthcare professionals, being informed about one's condition, involvement in decision making, and respecting treatment preferences as components of EOL care quality while controlling for care setting and provider.

Finally, in addition to considering the way dying individuals are treated with respect to their physical and health care needs, quality EOL care must also attend to individuals' personal needs. Among seriously ill individuals, 95% say it is important to maintain one's dignity and 99% say being kept clean is important at EOL (Steinhauser et al. 2000). As with interactions with health care providers, loved ones may assess the quality of dying individuals' personal care and treatment differently based on the setting and provider. I include measures of respect and personal care needs to classify types of EOL care while controlling care setting and provider.

Developing a Multifaceted Measure of End-of-Life Care

Seriously ill individuals, family members, and health care professionals identify multiple components of EOL care as simultaneously important, and it is realistic to assume certain sub-dimensions of EOL care occur in tandem. However, we do not have an in depth understanding of how multiple aspects of EOL care quality co-occur, as most studies examine different aspects of EOL care individually (e.g. Teno et al. 2015). Some studies use a simple index of multiple measures (e.g. Carr 2016). While this approach is an improvement over single-item measures, it does not capture how subsets of measures

may co-occur together and how different subsets may describe very different experiences of EOL care. For example, two individuals may have identical index scores, but one's EOL experience may be highly rated in terms of symptom management, while the other's is highly rated on measures of autonomous decision-making. This distinction is important in identifying multiple potential pathways to "good" or "bad" deaths which may require different interventions. This study addresses the multifaceted nature of EOL care quality by using latent class analysis to analyzing how proxies' assessments of multiple measures of symptom management, health care encounters, and dignified care cluster together into conceptually and statistically distinct categories of EOL care quality.

Proxy Characteristics and EOL Care Quality

Studying dying individuals *in situ* is ethically fraught (George 2002), so researchers rely on two types of alternative measures to study EOL care quality. Objective measures, such as Medicare and hospital records and patient charts, provide information about treatments and medications administered at EOL and are relatively easily verified. Subjective measures rely on another person's assessment of care quality. Proxy reports are collected retrospectively and typically are provided by a close family member such as a spouse or child.

Proxy reports are important sources of information about EOL care (Lendon et al. 2015). Hospice and palliative care providers use family member evaluations of EOL care to assess overall satisfaction with care and to identify areas for care improvement, and the CMS use information from these reports in determining reimbursement to hospice and palliative care providers (NHPCO 2015a, CMS 2016). Unlike Medicare data which provide information on hospital care or hospice services, proxy reports can be utilized

regardless of where an individual dies or what type of provider is involved in EOL care. This study uses proxy reports of EOL care for a sample of older adults who die in a variety of care settings and with different types of EOL care providers.

Although proxy perceptions of EOL care provide valuable insights into the nature and quality of EOL care, research tends to disregard the way in which proxy characteristics, such as their gender, age, relationship to the decedent, and familiarity with decedent care, may influence their perceptions of EOL care quality. Researchers tend to accept proxy appraisals without taking into consideration psychosocial influences on their perceptions (Lendon et al. 2015). Individuals respond to stressors in different, patterned ways, which may influence the way in which they assess that stressor. Death is a stressful event and proxy reporters' perceptions of EOL care may be influenced as part of the coping process of dealing with the stress associated with death and dying. Compared to men, women are more likely to employ selective ignoring to cope with stress related to family relationships (Pearlin & Schooler 1978). In selective ignoring, individuals identify and focus on the positive aspect of a stressful situation, in the process downplaying, or ignoring, the negative facets of the stressor (Pearlin & Schooler 1978: 6). As such, we might expect that, as part of coping with the loss of a close family member, mothers and daughters may selectively ignore negative aspects of EOL care and provide more positive assessments.

In addition to gendered patterns in responses to the stress of loss due to death, proxies' perceptions of EOL care quality may also be affected by differing ways in which individuals respond to stimuli over the life course. Compared to younger individuals, older adults show less emotional response overall to negative stimuli (Carstensen et al.

2003) and less intense negative reactions to stressful situations (Birditt and Fingerman 2003; Birditt, Fingerman and Almeida 2005). Research suggests that, while younger and older adults both experience negative emotions in response to stressful situations, older adults focus less on the negative aspects of these situations, feel negative emotions for less time, and don't feel the negative emotions as strongly as younger adults (Birditt 2013, Mather and Carstensen 2005). Applied to the case of perceptions of EOL care quality, we might expect that older proxy reporters, such as spouses, would respond to and remember positive aspects of EOL care and be less affected by negative aspects, providing more positive assessments of care overall.

In addition to age and gender affecting how proxies assess EOL care quality, proxy relationship to the decedent and nature of involvement in EOL may also influence their perceptions of EOL care. Bereaved family members engage in a variety of strategies to cope with their loss which may impact their perceptions of EOL care quality. Positive appraisals of EOL care may help family members assign a positive meaning to the loss, reducing the extent to which they experience the loss as a long-term stressor (Bonanno and Kaltman 1999). EOL care proxy reporters are often close family members, such as spouses and children, who may still be processing their personal losses at the time they assess care quality. Individuals closely involved in EOL care may use similar strategies to deal with loss. Caregiving responsibilities become more intensive at EOL, however, caregivers also report they find meaning and purpose in providing EOL care (NASEM 2016). The sense of meaning and purpose among individuals who provide direct care for their loved ones near the end of life may motivate them to positively assess the quality of their efforts (Bonanno and Kaltman 1999; Park 2010). Increased familiarity with EOL

care may signal caregiving responsibilities, and so we might expect that proxies who report being “very familiar” with EOL care would provide more positive assessments of that care. Caregivers report fewer depressive symptoms after the person receiving care dies (Li 2005), particularly among spousal caregivers who report higher levels of strain (Schulz et al 2001), and may therefore positively assess EOL care.

In this study I examine how proxy gender, age relationship to the decedent, and familiarity with EOL care influence their assessments of EOL care quality, with special attention to spouses and children, who are most likely to be involved in EOL care and are expected to be the most affected by decedents’ deaths. However, smaller nuclear families, geographical distance between parents and adult children, and increased reliance on nursing home care for older, frail adults means that a growing number of more distant family members and non-family are involved in EOL care, and so I include these individuals in my study to incorporate their perceptions of care quality.

Controls

The focus of this study is exploring how proxy characteristics influence perceptions of EOL care quality. In keeping with the theme in this dissertation of exploring the relationship between fundamental causes of health disparities and EOL care quality, I also control for decedent sociodemographic characteristics. Building upon previous findings (see Chapter 2) suggesting health characteristics and EOL care setting and provider also influence proxy perceptions of care quality, I control for these factors as well. Fundamental causes theory posits that disparities in health and mortality outcomes can be explained by greater access to socioeconomic resources and structurally advantageous positions that are protective of health and mortality (Link & Phelan 1995).

Relative to women, ethnic minorities and those with fewer socioeconomic resources, men, non-Hispanic whites, and those with richer socioeconomic resources typically have greater access to and the ability to activate additional resources that are protective of health and mortality across the life course, (Link and Phelan 1995). As such, we may expect that dying males, non-Hispanic whites, and individuals with more education would have greater access to higher quality EOL care, and proxies would reflect that access in their assessments of EOL care quality.

Declining health in the period before death can complicate care provision. Symptoms accompanying chronic illnesses can often be successfully managed through ongoing contact and coordination with doctors. However, as bodies age and become increasingly frail, chronic illnesses can become increasingly difficult to manage (Carr and Luth 2016), potentially complicating the provision of high quality EOL care. Acute illness episodes in older adults may require hospitalization. These episodes usually involve adverse symptoms and hospitalization involves intense interaction with health care providers. As individuals near EOL, hospitalization can signal an overall decline in health and complex care needs (Carr and Luth 2016). Proxies may report lower quality EOL care for older decedents as well as those with chronic illness or frequent hospitalization in the year before death.

Finally, proxies may have different expectations of care quality depending on where the care occurs and who provides it. Adults in the general population and caregivers of seriously ill individuals express a desire to die at home (PRC 2013; Steinhauser et al. 2000), indicating a general assumption that home deaths are preferable to deaths in other locations. Proxy reporters for individuals who died at home may have

provided care for the dying individual and may therefore be motivated to positively evaluate their role. Hospice was founded on the premise of and generally enjoys a reputation for providing high quality EOL care. Hospice referrals must be made within the last six months of life (although, on average, individuals are in hospice a much shorter period), implying family members of hospice patients have been informed that death is imminent. In contrast, family members of individuals who die without hospice care may not anticipate the death or may expect medical attention will prevent their loved one's death. In general, family members of individuals receiving hospice services are more satisfied with care than those who die without hospice care (Teno et al. 2004). The general preference for home death and assumption hospice care is high quality may lead proxies to provide more positive assessments of EOL care in these two contexts. In this paper, I apply latent class analysis to determine how proxy perceptions of multiple aspects of EOL care combine into conceptually and statistically distinct categories of EOL care quality. I then explore how proxy characteristics influence their perceptions of care quality, controlling for decedent social and health characteristics and EOL care setting and provider that may also influence EOL care quality.

Data and Methods

Data

To identify classes of EOL care quality and determine how proxy characteristics influence their perceptions of care quality, I use four waves of data from the 2011-2014 National Health and Aging Trends Study (NHATS). NHATS is a prospective, longitudinal survey administered annually to a nationally representative sample of 8,245 Medicare beneficiaries over 65 residing in the contiguous United States in May 2011.

NHATS includes questions about sociodemographic, health, and disability characteristics. If the respondent dies between waves of data collection, a proxy respondent familiar with the respondent's last month of life completes an exit survey. For the sample analyzed in this study, proxy exit surveys occurred, on average, within seven months of the NHATS respondent's death, making their responses less susceptible to recall bias introduced when the time between death and reporting about that death is lengthy. I use prospective demographic and health information respondents provided in survey years prior to their deaths and retrospective EOL care measures proxies provided in exit interviews.

Study and Analytic Sample

Of the 8,245 initial respondents, 1,515 (18%) individuals died between the first and fourth waves of data collection (2011-2014). I include in this study the 1,081 individuals who completed the respondent questionnaire and who have a completed family member or caregiver interview about the decedent's last month of life. I analyze the 1,046 individuals with complete information on nine independent and control variables and for whom a proxy respondent answered at least one of the nine questions used to assess EOL care quality. Of the 434 deceased individuals not included in the study, 85 do not have a last month of life interview and 349 were nursing home residents during the first wave of data collection, and, by survey design, do not have a completed respondent questionnaire. I exclude from the analysis an additional 35 individuals who are missing data on all EOL care quality measures (3) or an independent or control variable (32).

Measures

EOL Care Quality. I measure quality of EOL care with nine items assessing the NHATS respondent's last month of life as reported by a proxy respondent—usually a spouse (22%) or child (47%). I categorize the responses to these variables into two or three categories to avoid sparseness and facilitate latent class analysis (described below). Table 4.1 provides a summary of the measures I use in the latent class analysis.

Three of the nine items assess symptoms commonly reported at EOL: pain, breathlessness, and sadness or anxiety. Proxies indicated whether the deceased experienced each of these in the last month of life. If yes, proxies indicated whether the deceased received help dealing with the symptom. If yes, proxies also indicated whether they believe the deceased received less help than was needed, more than needed or about the right amount. I combined these three questions into a single three-category variable for each of pain, breathlessness, and sadness/anxiety: “None” (no reported symptom), “Managed” (experienced a symptom and received “about the right amount of help”), and “Unmanaged” (experienced a symptom and received no help, less help than needed, or more help than needed).

Six questions capture dimensions of EOL care quality related to encounters with health care providers and dignified care. Two variables measure whether treatment decisions were made without the decedent or their family members' input and the decedent received care she would not have wanted with “No” and “Yes” responses. I categorize whether the decedent was treated with respect, had their personal care needs were met, and they and their family were informed about her health condition, as “Always” and “Usually/Sometimes/Never.” I dichotomize these three variables because 82%-89% of respondents indicate the decedent's needs were “Always” met. Finally, I

measure coordination of care by combining two questions: whether there was more than one doctor involved in care and, if yes, whether it was clear which doctor oversaw care. I divide individuals into two groups: “One doctor/Clear doctor in charge of care” and “Unclear who was in charge of care.”

[Table 4.1 about here]

Factors Predicting EOL Care Quality

Proxy Characteristics. Proxy familiarity with the decedent’s last month of life is measured with the question: *How familiar were you with the decedent’s daily routine in the last month of life?* (“Very familiar”=1 and “Somewhat/A little/Not at all familiar”=0). I dichotomize proxy familiarity with the decedent’s care because of the large proportion of proxies (79%) who indicated they are “very familiar” with care. The high percentage of “very familiar” proxies reflects NHATS protocol to attempt to identify and interview proxies who are familiar with EOL care. I measure proxy relationship to the decedent using a series of dummy variables for husband, wife, daughter, and other family/non-family member, omitting son (reference category). This categorization of proxy relationship to the decedent allows me to examine how close family members’ age, gender, and relationship to the decedent affects their perceptions of EOL care quality. As people tend to marry someone who is similar in age, I assume husbands and wives represent older respondents (relative to children), wives and daughters are women, and other family/non-family members signify more distal proxy-decedent relationships. In a supplementary analysis, male and female other family/non-family members’ perceptions of EOL care quality were not significantly different from one another, and so I collapse these individuals into the same group.

Respondent Characteristics. This analysis controls for respondent characteristics, including fundamental causes of social disadvantage (education, race/ethnicity, and gender), age at death, and health in the year before death, that may influence EOL care quality. I compare non-Hispanic whites (coded 1) with all other racial and ethnic groups (coded 0).⁵ I also include measures for sex (males=1, females=0) and education, dichotomized at the median (more than high school=1, high school or less=0). I control for age at death, which I standardize so it can be included in the LCA model (the software I use does not support continuous covariates). I compare individuals with no chronic illness (coded 1) to those with one or more of the following illnesses: lung disease, kidney problems, cancer, and/or dementia/Alzheimer's (coded 0). I also control for hospitalization in the year before death (two or more hospitalizations=1, no or one hospitalization=0).

EOL care setting and provider. I control for EOL care setting (home death=1, all other place of death=0) and whether hospice was involved in care during the last three months of life (coded 1) or not (coded 0).

Analytic Strategy

Latent Class Analysis: Three-Class Solution. Table 4.2 presents the results of exploratory LCA (details described in Chapter 2) using the nine EOL care quality measures, which indicated that a three-class solution best describes the quality of EOL care among decedents in my sample, as reported by their proxies. The first class, “no symptoms, highest quality care ratings” is predicted to comprise 45% of the sample. In

⁵ Supplementary analysis comparing non-Hispanic Whites and non-Hispanic Blacks only yield similar results as when Hispanics and “Others” are combined with non-Hispanic Blacks.

this class, proxies have a high probability of characterizing decedents as having an absence of pain, breathlessness, and sadness or anxiety. Moreover, proxies have a very high probability of reporting that members of this class received the highest quality care in the other six domains included in the LCA, relative to the other two classes. For all measures in this class, proxies have over 90% probability of endorsing the more desirable response. The second class, “managed symptoms, high quality care ratings” comprises 35% of the sample. For this class, proxies have the highest probability of reporting symptoms are present, but managed, in the last month of life. Proxies are also highly likely to report high quality care for the other six areas of care, although proxies report a slightly lower probability the decedent did not receive unwanted care in the last month of life compared to the first class (85%). In this class, symptoms are present, but controlled, and other aspects of EOL care are positively assessed. The third and smallest class, “symptomatic, poor care ratings,” accounts for the remaining 20% of the sample. Proxies characterize care in this group as mixed in terms of symptom management, and less positively for all other aspects of care. There is a 47% probability of proxies reporting managed pain in this class. The chance of unmanaged pain and managed breathlessness is about 40% and unmanaged sadness in 56% in this class. Proxies are less likely to report involvement in decisions (78%), having a clear doctor in charge (62%), and not receiving any unwanted care (76%) than in the other two classes. Personal care needs and respect “always” being attended to are reported about as often as not in this class, and the likelihood decedents are “always informed” about their medical conditions is less than two fifths (37%). This class represents the “worst” outcome in EOL care: proxies report

individuals experience symptoms, often unmanaged, and rate other aspects of care poorly relative to the other two classes.

[Table 4.2 about here]

Next I perform LCA with covariates, which uses multinomial logistic regression to determine the extent to which a single variable (e.g. familiarity with last month of life) or a block of variables (e.g. all proxy characteristics) predict membership in the three latent classes previously identified. Likelihood ratio chi square tests comparing LCA with all covariates to LCA without one or a block of covariates determine whether a single or group of variables significantly predicts latent class membership. This analysis allows me to explore the extent to which proxy characteristics (proxy familiarity with last month of life, relationship to decedent, and gender) and control variables (decedent race/ethnicity, gender, education, age at death, illnesses, and recent hospitalizations; home death and hospice involvement) predict the type of EOL care a decedent receives, either individually, or in the above-mentioned blocks. I conduct all latent class analysis with Stata 14/MP, using the doLCA command (The Methodology Center 2015).

Results

Descriptive Statistics

Table 4.3 provides descriptive statistics of the 1,046 decedents in the sample. Over half of proxies responding to questions about symptoms at EOL reported that the decedent experienced pain, breathlessness, and sadness or anxiety. Seven in ten proxies reported (56% managed pain, 15% unmanaged pain). Fifty-six percent (56%) reported breathlessness and sadness or anxiety, although breathlessness was more often managed than unmanaged (45% vs 11%) compared to managed and unmanaged sadness (30% and

26%). Overall, proxy reporters rated the remaining aspects of EOL care highly, with at least four-fifths reporting the decedent was “always” treated well and involved in health care decision-making (82-91%).

Nearly 79% of proxies reporting on the decedent’s EOL care quality said they were very familiar with care in the decedent’s last month of life, and nearly 70% of proxies reporting on the decedent’s EOL care quality were close family members (5% husbands, 17% wives, 33% daughters, 14% sons). Just over one-third (35%) of decedents had more than a high school education, 70% identify as non-Hispanic White, and 43% are male.

In bivariate correlations (Table 4.4), the six dichotomous items used in the LCA were all positively and significantly correlated. The same categories of symptom variables are also positively and significantly correlated (no pain with no breathlessness with no sadness; managed pain with managed breathlessness with managed sadness, etc.). Unmanaged symptoms are negatively and almost always significantly correlated with the six dichotomous measures of EOL care (exception: unmanaged breathlessness is not significantly correlated with no unwanted care and having a clear doctor in charge). Collectively, these bivariate relationships suggest that the variables used in the LCA operate in a similar pattern: positive aspects of EOL care are associated with one another, and unmanaged symptoms are associated with lower care ratings on all measures.

Proxy characteristics generally are not associated with symptoms, although wives are more likely to report no pain, and daughters to report managed sadness. Being involved in decision making about care is not associated with any proxy characteristics. Proxy familiarity with EOL care is positively and significantly correlated with four

measures of care quality (informed about condition, care coordination, personal care, and respect), suggesting a relationship between involvement in and more positive assessments of EOL care. In contrast, sons show negative, significant correlation with the same measures. These results suggest proxy evaluations of EOL care may differ based on their familiarity with care and relationship to the decedent, with individuals familiar with care providing positive care assessments and sons being more negative in their evaluations.

[Tables 4.3 and 4.4 about here]

Proxy Predictors of EOL Care Quality

Table 4.5 and presents odds ratios (exponentiated regression coefficients) and 95% confidence intervals for variables predicting membership in the three latent classes described above. Figure 4.1 presents odds ratios and 95% confidence intervals for proxy familiarity with care and relationship to the decedent. Proxy characteristics, when added to the LCA with covariates model as a block, significantly improve model fit ($2*(\Delta \log \text{likelihood})$). Familiarity with care in the last month of life and proxy relationship to deceased also significantly improve model fit. Individuals whose proxies report being very familiar with care in last month of life have 121% higher odds of being in the no symptoms, high care ratings and managed symptoms (OR=2.21, CI: 1.21-4.02), or high care ratings classes relative to the symptomatic, low are ratings class (OR=2.21, CI: 1.30-3.78). Compared to individuals with son proxies, those with wife and other family/non-family proxies have over 100% higher odds of being in the no symptoms, high quality care or managed symptoms, high quality care latent classes (compared to symptoms, lower quality care).

Control Variables

Age at death and absence of chronic illness are associated with higher odds of being in the no symptoms class relative to symptoms, lower quality care class. More frequent hospitalization is associated with lower odds of no symptoms, high quality care. Contrary to what fundamental causes theory would suggest, SES, race/ethnicity, and gender are not significant predictors of latent class membership, although being non-Hispanic white is associated with lower odds of being in the no symptoms, high quality care class than in the symptoms, lower quality care class. Finally, EOL care setting and provider are significant predictors of latent class membership. Home death is associated with higher odds of being in the no symptoms or managed symptoms classes. Hospice care is associated with higher odds of being in the managed symptoms, high quality care class and lower odds of being in the no symptoms, high care class than in the symptoms, lower quality care class.

[Table 4.5, Figure 4.1 about here]

Discussion

This study addresses two core questions regarding EOL care quality among older decedents. First, while prior studies focus on individual measures of care quality, I use latent class analysis (LCA) to develop a multidimensional measure that simultaneously considers multiple aspects of proxy reports of EOL care quality. Then, using the groups identified in LCA, I analyze how proxy characteristics and experiences may influence their assessments of care, while controlling for decedent sociodemographic and health factors and EOL care setting and provider.

Experiences of EOL care quality fall into three statistically and conceptually different groups, as reported by proxies for a sample of deceased Medicare beneficiaries.

The groups are characterized by (1) absence of symptoms and high quality care in all six domains, (2) managed symptoms and high quality care, and (3) managed and unmanaged symptoms and relatively low quality care. Four-fifths of proxies are likely to rate decedents' EOL experiences positively with respect to their interaction with health care providers (informed about condition, involved in decisions, no unwanted treatment, coordinated care) and how they were treated as a person (treated with respect, personal care needs met). Of these 80%, just over half are likely to report no symptoms and the remainder are likely to report managed symptoms (pain, breathlessness, sadness or anxiety).

These results suggest two possible pathways to high quality EOL care, which proxies are likely to report for four-fifths of older adults. First, nearly half of older adults are likely to be fortunate and experience a death described by their proxies as "symptom free, excellent care" desired at EOL (PRC 2013; Steinhauser et al. 2000). However, symptoms are not always completely avoidable in every EOL scenario. The encouraging news is that, when proxies report symptoms are present and managed, they are also likely to positively assess a decedent's health care encounters and personal care. The positive relationship between symptom management and perceptions of other dimensions of EOL care suggests that careful attention to managing dying individuals' symptoms may improve satisfaction with other aspects of care.

In contrast to two classes of high quality EOL care, one in five proxies are likely to report a less rosy picture of EOL care. They rate decedents' EOL care less positively and indicate decedents experienced managed or unmanaged symptoms. To the extent that symptom management is associated with positive perceptions of other aspects of EOL

care quality, focusing on alleviating unmanaged symptoms may be an effective strategy for shifting towards more positive perceptions of health care encounters and personal care. Additional research is needed to better understand what is happening in cases where proxies report managed symptoms and negative assessments of care. For example, lower satisfaction with care that includes effective symptom management may be an indication of poor psychological adjustment following the loss of a loved one. Alternatively, proxies may be reporting instance of EOL care where, although symptoms were managed, encounters with healthcare providers were unsatisfactory and the decedent was not treated in a dignified manner. Additionally, proxies report about care over a one-month period, during which time the decedent's symptoms and care needs may have fluctuated, and proxies may be providing assessment based on the most intense or final points of care over the one-month period (Kahneman, et al. 1993).

The Role of Proxy Characteristics in EOL Care Quality Assessments

I find that certain proxy attributes—proxy familiarity with care in the last month of life and relationship to the decedent—are associated with different assessments of EOL care quality, even when controlling for other factors that might affect perceptions of EOL care such as decedent sociodemographic and health characteristics and EOL care setting and provider. Proxies who are very familiar with the decedent's care in the last month of life are more likely to report no or managed symptoms and higher quality EOL care. Proxies may report they are familiar with the decedent's EOL care because they were informed about the decedent's condition or involved in decision making: being very familiar with care is positively and significantly correlated with all six measures of care quality. Alternatively, the relationship between familiarity with care and high probability

(over 90%) of giving positive assessments of care quality aligns with previous work showing that bereaved individuals make positive appraisals of the loss as a way of dealing with it (Michael and Snyder 2005). Seven in ten proxies in this sample are close family members, who are also the individuals most likely to take on caregiving roles for aging, infirm, and dying adults. To the extent that positive perceptions of EOL care quality are associated with better long-term health and well-being (Carr 2003; Christakis and Iwashyna 2003), remembering the final days and weeks with a loved one in a positive light can be a protective mechanism.

Relative to son proxies, wife proxies are more likely to characterize decedents' EOL care as symptom free or with managed symptoms and of high quality. Wives are likely to be primary caregivers of ailing spouses and may therefore tend to rate their care positively for the same reasons discussed above. To the extent that women selectively ignore negative aspects of familial interactions as a way of coping with stressful events (Pearlin and Schooler 1978), wives may tend to focus on the positive aspects of EOL care when providing evaluations. Wives may also assess EOL care quality more positively because they are older than sons. Increased emotional regulation at older ages and closer proximity to their own deaths may cause spouses to assess their loss with more equanimity (Carstensen et al. 2003). Consistent with research showing that EOL caregiving brings satisfaction and meaning to one's life (NASEM 2016), wives who are deeply engaged in the caregiving process may also have an objectively high quality experience providing EOL care to their dying spouses than sons, who tend to provide less caregiving and are also less likely to live with a dying parent. Only 72% of son proxies report being very familiar with the decedent's EOL care, compared to 94% of wives.

Although husbands and daughters tend to assess EOL care more positively than sons, the differences are not statistically significant for husbands, and are only marginally significant for daughters, suggesting that age and gender effects on their own do not significantly shift proxy perceptions of EOL care. However, the difference in EOL care evaluations between sons and wives suggests older age and female gender may work in tandem to influence perceptions of EOL care.

Compared to sons, other family members and non-family members are also likely to characterize decedents' EOL care as free from or with managed symptoms and of high quality. Sons and other proxies report being "very familiar" with EOL care in statistically similar proportions, so the difference in perceptions is not related to familiarity with care, although it could be related to the nature of involvement in EOL care and what proxies assess in their evaluations of EOL care. Sons are less likely to be involved in family caregiving (NASEM 2016), although they may stay abreast of their parents' statuses at EOL. "Other proxies" include distant family members (58%), individuals unrelated to the decedent (24%), as well as proxies who worked in the facility where the decedent lived or were paid to provide in-home help to the decedent ("paid caregivers") (18%). Paid caregivers, in particular, may be motivated to positively assess care they were compensated to provide. In this sample, paid caregivers report dignified care and positive encounters with health care providers at significantly higher rates than sons (exception: decedent/family was informed about decedent's condition). In fact, all paid caregivers in this sample report the decedent/family was always involved in decision-making (n=56), the decedent received no unwanted treatment (n=54), and there was a clear doctor in charge of care (n=51). We rely increasingly on paid caregivers for the growing number of

aging and dying adults who live in residential care and nursing home facilities (Teno et al. 2013). While studies have found paid caregivers can provide accurate accounts of patient health (Boyer et al. 2004), future studies should pay careful attention to how paid caregivers assess EOL care quality and how their assessments might influence our overall understanding of care quality.

Other Predictors of EOL Care Quality

In addition to proxy relationship to the decedent and familiarity with death, decedent health and EOL care setting and provider predict EOL care quality. Contrary to what fundamental causes theory would predict, according to proxy reporters, non-Hispanic whites are less likely to experience no symptoms and high quality care than symptomatic, low quality care. This finding is surprising, given that health and mortality outcomes are generally better for non-Hispanic whites (Feagin and Bennefield. 2014, Williams 2012). It is unlikely that non-Hispanic whites receive systematically poorer care at the end of life, given they receive better care in so many other aspects of medical care (Hoffman et al. 2016; IOM 2003). One explanation is that the non-Hispanic whites in this sample have more complex health needs than members of other racial and ethnic minority groups. Chi square tests (not shown) indicate non-Hispanic whites report having one or more chronic illness at significantly higher rates than would be expected, which could complicate their EOL care quality.

On the other hand, non-Hispanic whites and non-whites do not differ in hospitalization frequency, hospice involvement, or home death. Perhaps proxies for non-Hispanic white decedents hold higher expectations for care than proxies for non-whites, and therefore evaluate EOL care more harshly when it falls short of their expectations.

While NHATS data do not contain information on proxy race, given that over 70% of proxies are spouses or children, in most cases proxies are likely the same race as the decedent whose care they evaluate. As such, findings may reflect their own expectations for EOL care. Non-Hispanic black caregivers tend to report fewer depressive symptoms than non-Hispanic white caregivers (NASEM 2016), and so their more positive appraisals of EOL care quality may reflect overall better mental well-being.

In contrast to the finding for non-whites, increased age at death is associated with having one's death assessed as symptom free and with high quality EOL care. The oldest adults' tendency towards higher quality EOL care could be related to how their health issues manifest themselves in old age. Supplementary analysis indicates age is not a factor in whether or not someone is diagnosed with a chronic illness, but is related to illness severity. Adults with two or more hospitalizations in the year before death are, on average, two years *younger* than adults with no or one hospitalization. Older adults who can avoid hospitalization towards the end of life are more likely to experience less complicated (i.e. "no symptoms") EOL care. Alternatively, health care providers may forego heroic attempts to extend the lives of older adults, resulting in less intrusive and potentially quality-limiting care at EOL. Indeed, supplementary analysis indicates hospice recipients are, on average, 14 months older than non-hospice decedents. Additional research is required to better understand the mechanisms that explain the link between living to older ages and increased likelihood of experiencing symptom free, high quality EOL care.

Finally, EOL care setting and provider matter for perceptions of EOL care quality. Home death is associated with no or managed symptoms, and high quality care. Most

adults express a desire to die at home and so may be predisposed to positively evaluate the quality of loved ones' home deaths. Alternatively, individuals who died at home may have more sudden deaths that are not accompanied by symptoms or require little EOL care. If the death is not sudden, individuals who die at home may have less complicated EOL care needs, allowing them to stay at home through the end of life. Hospice is associated with managed symptoms and high quality care and, surprisingly, with managed and unmanaged symptoms and low quality care. The relationship between hospice and low quality care could reflect variation in quality of hospice services. Similar to expectations for non-Hispanic whites, proxies may anticipate high quality hospice care in accordance with the service's reputation and may assess care particularly harshly if it fails to meet their expectations. Finally, hospice recipients often include the most complicated EOL care cases, and it may not be possible to provide high quality care and adequate symptom management before an individual dies in these most complex instances.

Limitations

This study is among the first I know of to identify latent classes of EOL care quality and explore how proxy characteristics influence their perceptions of EOL care quality. However, the results are potentially weakened by four limitations. First, I am unable to test how alternate or additional proxy characteristics might influence EOL care quality or the effect of some of my significant measures. For example, for proxies who provided caregiving, intensity of care or additional caregiving experience may give proxies a distinct perspective on care quality. Similarly, accounting for proxy well-being or grief at the time of the exit interview, or long-standing relationship dynamics between

the decedent and proxy might help elucidate whether one's perceptions of EOL care reflect their current affective states, resulting in biased assessments. Future research might use the subsample of caregivers in the National Study of Caregiving companion study to NHATS to unpack how aspects of caregiving and the caregiver-recipient relationship affects perceptions of EOL care quality.

Second, the analysis focuses on death among individuals over 65. Premature mortality among individuals with lower SES may explain the lack of economic disparities in EOL care quality in my sample. In short, the most disadvantaged might have died prior to age 65, thus those in the NHATS sample would represent a particularly healthy subset of lower SES individuals who have less complicated EOL care needs and therefore receive higher quality EOL care. Future studies might examine SES differences in EOL care quality among middle-aged adults, before mortality disparities take effect. However, older adults comprise three-quarters of all deaths in the United States, so understanding EOL care in this segment of the population merits individual attention.

A third limitation is that NHATS data do not capture cause of death or specific information about the dying trajectory. Cause of death will affect certain aspects of the dying experience such as whether it is characterized by pain (as with cancer), breathlessness (as with congestive heart failure), or tends to be swift and asymptomatic (as with an aneurism). A sudden death may be characterized by less medical intervention and fewer symptoms, while a prolonged death may involve complicated care regimens and symptom management. Whether a death is sudden or anticipated, characterized by symptoms and medical intervention or lack thereof, might explain why proxies provide rosy, or negative, assessments of EOL care quality. Should NHATS data eventually be

linked to the National Death Index, future research could also consider cause of death in understanding EOL care quality.

Finally, alternate measures of EOL care might present a different picture, possibly capturing additional variation based on fundamental causes of advantage and disadvantage. However, CMS uses the same measures to evaluate hospice provider eligibility for Medicaid and Medicare reimbursement (\$15.1 billion in 2013) (NHPCO 2015b), making them a core component in the policy definition of “quality EOL care.” My analysis extends these measures beyond the hospice context, to a sample of deceased older adults, regardless of whether they received hospice services. A nuanced understanding of how these measures function together, for whom, and under what circumstances is critical for designing effective policy to improve care quality.

Conclusion

This study adds to our understanding of the quality of EOL care for older adults in the United States. Using measures closely connected to EOL care policy, the analysis examines patterns in how specific aspects of care occur in tandem, more closely resembling the multidimensional way people experience the death of a loved one. Considering multiple measures of EOL care quality simultaneously provides a gestalt picture of care for older adults consistent with multifactorial approaches to understanding psychosocial and health-related processes elsewhere in aging research. This analysis reveals EOL care quality varies among older adults, characterized by “no symptoms, highest quality care,” “managed symptoms, high quality care,” and “symptomatic, poor quality care” groups. Moreover, this study explores the relationship between proxy characteristics and structural determinants of health and mortality and quality of care for

the dying. Results suggest that, to the extent familiarity with care is stand-in for actual caregiving responsibilities, individuals involved in caregiving provide more positive assessments of EOL care. Among close family members, proxy age and gender together lead to more positive assessments of EOL care. Paid caregivers, whose role in EOL care is growing, add both value and potential bias in their assessments of care. EOL care improvement efforts and policies using proxy ratings to determine EOL care reimbursement eligibility must attend to and account for the different potential biases proxies incorporate into their assessments.

Table 4.1. Summary of Nine Measures of Quality of End-of-Life Care used in Latent Class Analysis, NHATS, 2011-2014^a

Variable	Measurement Categories	Survey Questions
Pain	1. Unmanaged (yes to Q1, no to Q2; yes to Q1 & Q2, less or more help than needed to Q3)	1. During the last month of life, were there times when [deceased] experienced [pain, trouble breathing, feelings of anxiety or sadness]? (yes/no)
Breathlessness	2. Managed (yes to Q1 & Q2, about right amount of help to Q3)	2. If “yes” to question 1, Did [deceased] get any help in dealing with [symptom]? (yes/no).
Sadness/ Anxiety	3. None (no to Q1)	3. If “yes” to question 2, How much help in dealing with pain did [deceased] receive? (less than needed, more than needed, about right amount).
Involved in Health Care Decisions	1. Yes	During the last month of [deceased]’s life, was there ever a decision made about {his/her} care or treatment without enough input from [deceased] or {his/her} family?
No Unwanted Care	2. No	During the last month of [deceased]’s life, was there any decision made about care or treatment that [deceased] would not have wanted? (yes=0, no=1)
Care Coordination	1. Unclear who was in charge of care (yes to Q1, no to Q2) 2. One doctor/Clear doctor in charge of care (no to Q1; yes to Q1 & Q2)	1. During the last month of [deceased]’s life, was there more than one doctor involved in {his/her} care? (yes/no); 2. If “yes,” During the last month of [deceased]’s life, was it always clear to you which doctor was in charge of {his/her} care? (yes/no).
Informed about Condition	1. Usually, Sometimes, Never	During the last month of [deceased]’s life, how often were you or other family members kept informed about [deceased] condition?
Personal Care Needs Met	2. Always	During the last month of [deceased]’s life, how often were {his/her} personal care needs, such as bathing, dressing, and changing bedding, taken care of as well as they should have been?
Treated with Respect		During the last month of [deceased]’s life, how often were [deceased] treated with respect by those who were taking care of [deceased]?

^a All responses provided by a proxy respondent familiar with decedent’s last month of life.

Table 4.2. Item response probabilities for measures of EOL care (last month of life) used in latent class analysis, 1,046 NHATS decedents, 2011-2014

	No symptoms, high quality care ratings	Managed symptoms, high quality care ratings	Symptomatic, poor quality care ratings
EOL Care Measures	0.45	0.35	0.20
Pain			
Unmanaged	0.08	0.08	0.41
Managed	0.38	0.83	0.47
None	0.54	0.09	0.12
Breathlessness			
Unmanaged	0.08	0.06	0.25
Managed	0.27	0.69	0.42
None	0.65	0.25	0.33
Sadness/Anxiety			
Unmanaged	0.17	0.21	0.56
Managed	0.14	0.55	0.21
None	0.69	0.23	0.24
Involved in decision-making	0.95	0.94	0.78
Always informed about condition	0.92	0.96	0.37
No unwanted care	0.96	0.85	0.76
Clear doctor in charge of care	0.94	0.92	0.62
Personal care needs always met	0.94	0.93	0.41
Always treated with respect	0.97	0.97	0.56

Table 4.3. Descriptive statistics for 1,046 decedents, NHATS, 2011-2014

	Proportion / Mean (sd)	N^b
Death Quality Indicators used in LCA^a		
Pain		971
Unmanaged	0.15	
Managed	0.56	
None	0.30	
Breathlessness		973
Unmanaged	0.11	
Managed	0.45	
None	0.45	
Sadness/Anxiety		937
Unmanaged	0.26	
Managed	0.30	
None	0.44	
Involved in decision-making	0.91	971
Always informed about condition	0.82	999
No unwanted care	0.88	976
Clear doctor in charge of care	0.87	971
Personal care needs always met	0.83	1,001
Always treated with respect	0.89	1,000
Proxy Characteristics		
Very familiar with care in last month of life	0.79	1,046
Proxy relationship to deceased		1,046
Husband	0.04	
Wife	0.17	
Daughter	0.33	
Son (reference)	0.14	
Other family / Non-family	0.32	
Controls		
Decedent sociodemographic and health characteristics		
More than high school	0.35	1,046
Non-Hispanic White	0.70	1,046
Male	0.43	1,046
Age at death	85.07 (7.88)	1,046
No serious illness (lung disease, stroke, cancer, dementia/Alzheimer's)	0.27	1,046
2 or more hospitalizations (previous year)	0.22	1,046

	Proportion / Mean (sd)	N^b
End-of-life care setting and provider		
Home death	0.38	1,046
Hospice care	0.41	1,046

a. LCA=Latent class analysis. b. Respondents who answered at least one end-of-life care quality included in LCA.

Table 4.4. Bivariate correlations for EOL care quality and proxy characteristics, 1,046 NHATS decedents, 2011-2014^a

		1	2	3	4	5	6	7
1	No pain	1.00						
2	Managed pain	-0.73	1.00					
3	Unmanaged pain	-0.27	-0.46	1.00				
4	No breathlessness	0.18	-0.14	-0.04	1.00			
5	Managed breathlessness	-0.15	0.22	-0.12	-0.81	1.00		
6	Unmanaged breathlessness	-0.06	-0.13	0.26	-0.31	-0.31	1.00	
7	No sadness	0.22	-0.11	-0.13	0.18	-0.15	-0.04	1.00
8	Managed sadness	-0.15	0.19	-0.08	-0.12	0.16	-0.06	-0.58
9	Unmanaged sadness	-0.09	-0.08	0.23	-0.08	0.01	0.11	-0.52
10	Involved in decisions	0.04	0.05	-0.12	0.04	0.03	-0.13	0.08
11	Always informed about condition	0.09	0.06	-0.21	0.04	0.05	-0.13	0.10
12	No unwanted care	0.13	-0.06	-0.09	0.06	-0.04	-0.03	0.09
13	Clear care coordination	0.06	0.07	-0.18	0.09	-0.05	-0.06	0.10
14	Personal needs always met	0.10	0.05	-0.21	0.08	-0.02	-0.10	0.12
15	Always treated with respect	0.10	-0.01	-0.12	0.09	-0.05	-0.07	0.09
16	Proxy very familiar with care	0.02	0.01	-0.05	-0.01	0.02	-0.01	0.00
17	Proxy husband	-0.06	0.04	0.02	-0.01	-0.01	0.02	0.04
18	Proxy wife	0.12	-0.09	-0.03	-0.03	0.04	-0.02	-0.01
19	Proxy daughter	-0.02	-0.01	0.04	0.03	-0.03	-0.01	-0.09
20	Proxy son	-0.04	0.05	-0.02	-0.02	0.03	-0.02	0.00
21	Proxy other family/non-family	-0.02	0.03	-0.02	0.00	-0.02	0.03	0.08

		8	9	10	11	12	13	14
8	Managed sadness	1.00						
9	Unmanaged sadness	-0.39	1.00					
10	Involved in decisions	0.03	-0.12	1.00				
11	Always informed about condition	0.09	-0.20	0.17	1.00			
12	No unwanted care	0.01	-0.12	0.16	0.07	1.00		
13	Clear care coordination	0.03	-0.14	0.09	0.27	0.07	1.00	
14	Personal needs always met	0.08	-0.22	0.12	0.33	0.12	0.20	1.00
15	Always treated with respect	0.03	-0.13	0.14	0.37	0.16	0.20	0.35
16	Proxy very familiar with care	-0.02	0.03	0.00	0.21	-0.10	0.10	0.08
17	Proxy husband	-0.03	-0.02	-0.04	-0.02	0.02	-0.01	0.01
18	Proxy wife	0.01	0.00	-0.05	0.03	-0.11	-0.02	0.02
19	Proxy daughter	0.07	0.03	0.04	0.03	0.00	0.04	0.01
20	Proxy son	-0.05	0.06	-0.02	-0.07	0.00	-0.08	-0.10
21	Proxy other family/non-family	-0.03	-0.06	0.03	0.01	0.08	0.03	0.04

		15	16	17	18	19	20	21
13	Clear care coordination							
14	Personal needs always met							
15	Always treated with respect	1.00						
16	Proxy very familiar with care	0.07	1.00					
17	Proxy husband	0.02	0.02	1.00				
18	Proxy wife	0.06	0.17	-0.10	1.00			
19	Proxy daughter	-0.02	0.17	-0.15	-0.31	1.00		
20	Proxy son	-0.07	-0.07	-0.09	-0.18	-0.28	1.00	
21	Proxy other family/non-family	0.02	-0.26	-0.15	-0.31	-0.48	-0.28	1.00

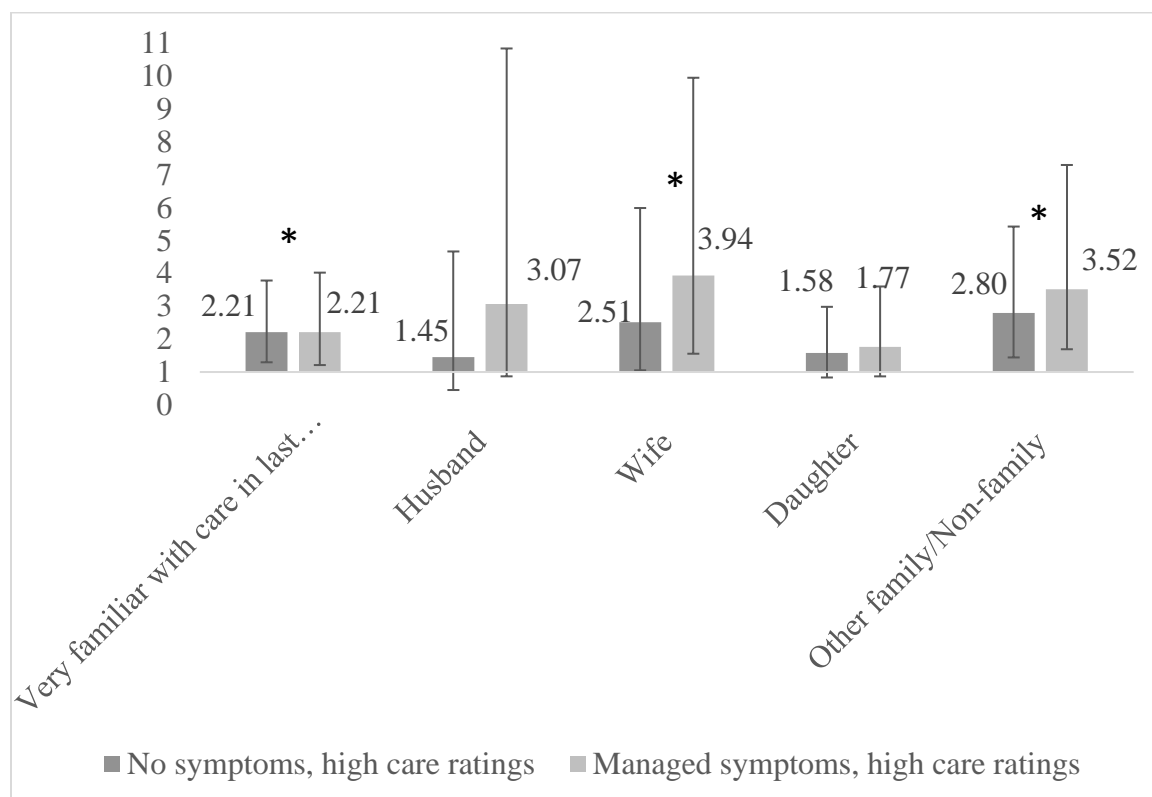
a Bold-faced text denotes a statistically significant correlation at the $p < .05$ level

Table 4.5. Multinomial logistic regression: Odds ratios (and 95% confidence intervals) of covariates predicting membership in EOL care latent classes, 1046 NHATS decedents, 2011-2014^a

	No symptoms, high care ratings	Managed symptoms, high care ratings	Sig ^b
Proxy Characteristics			‡
Very familiar with care in last month of life	2.21 (1.30, 3.78)	2.21 (1.21, 4.02)	†‡
Proxy relationship to deceased			‡
Husband	1.45 (0.45, 4.67)	3.07 (0.87, 10.85)	
Wife	2.51 (1.05, 5.99)	3.94 (1.56, 9.96)	†
Daughter	1.58 (0.83, 2.98)	1.77 (0.86, 3.60)	
Other family / Non-family	2.80 (1.44, 5.43)	3.52 (1.69, 7.30)	†
Controls			
<i>Decedent sociodemographic characteristics</i>			‡
More than high school	1.11 (0.71, 1.74)	0.79 (0.48, 1.31)	
Non-Hispanic White	0.75 (0.45, 1.25)	0.53 (0.31, 0.89)	
Male	0.72 (0.44, 1.18)	1.00 (0.57, 1.74)	
Standardized age at death	1.26 (1.00, 1.60)	1.55 (1.20, 2.00)	†‡
No serious diagnoses (lung disease, stroke, cancer, dementia/Alzheimer's)	1.08 (0.64, 1.81)	2.02 (1.20, 3.41)	†‡
2 or more hospitalizations (previous year)	1.18 (0.74, 1.91)	0.38 (0.18, 0.77)	†‡
<i>EOL care setting and provider</i>			†‡
Home death	2.53 (1.59, 4.04)	2.99 (1.78, 5.02)	†‡
Hospice care	1.81 (1.16, 2.82)	0.52 (0.29, 0.91)	†‡

a Reference category: Symptomatic, low care ratings. b †: variable significantly predicts latent class membership in the model including all covariates ($p < .05$). ‡: including the variable or block of variables significantly improves model fit. Significance based on likelihood ratio chi square tests ($2*(\Delta\text{loglikelihood})$).

Figure 4.1 Relative risk ratios and confidence intervals of proxy characteristics predicting latent class membership, relative to “Symptomatic, lower quality care” class, NHATS, 2011-2014 (N=1,046 decedents)^a



a. Reference category for relationship to decedent is “Son.” * indicates variable significantly improves model fit at $p < 0.05$.

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Chapter 5

Conclusion

Introduction

This dissertation uses four waves of survey data from the National Health and Aging Trends Study (NHATS) to examine perceived quality of end-of-life (EOL) care in a sample of older adults on Medicare. In doing so, it adds to our understanding of EOL care quality in four ways. First, I use latent class analysis (LCA) to develop conceptually and statistically distinct categories of EOL care quality. LCA allows me to identify how multiple factors important in EOL care co-occur, preserving nuances in different EOL care experiences with respect to symptoms, supportive encounters with health care providers, and receipt of dignified care. Understanding how individual components of EOL care work together, or in contrast to one another, can help us design interventions that improve multiple aspects of EOL care simultaneously. For example, I find that proxy reports of unmanaged symptoms are likely to be accompanied by an especially low likelihood of family members always being informed about the decedent's condition and the decedent's personal care needs always being met, indicating efforts to improve symptom management should also attend to communication and personal care needs. Second, I extend theoretical work on social determinants of health and mortality disparities to the case of perceived EOL care quality. Using the fundamental causes of disease framework, I analyze the relationship between socioeconomic status, race/ethnicity, and gender and perceived EOL care quality. Third, I investigate how advance care planning (ACP) affects perceptions of EOL care quality. I tested for, but did not find moderating effects of ACP on the relationship between race/ethnicity and EOL

care quality. Finally, I consider how proxy characteristics affect their perceptions of EOL care quality. I pay particular attention to the ways in which gender, age, relationship to the decedent, and familiarity with care relate to differences in perceived care quality. My work employs a novel analytic lens for examining existing data on EOL care and for designing efforts to improve care quality. By using an approach (LCA) that considers how multiple aspects of EOL care quality co-occur among various subgroups, policy makers and clinicians can identify which aspects of EOL care which aspects of care to target concurrently to improve overall care. By looking at subgroup differences in EOL care experiences, policy makers and clinicians can tailor care improvement efforts to meet the varied needs and experiences of particular subgroups without creating or exacerbating inequalities in care receipt.

Classes of End-of-Life Care Quality

This dissertation is the first analysis that I know of to use latent class analysis (LCA) to consider how multiple measures of EOL care quality co-occur in a sample of older adults. I utilize nine measures of EOL care quality that are commonly identified as important facets of EOL care, and which EOL care providers and the Centers for Medicare and Medicaid Services rely upon to assess care quality among hospice and palliative care organizations (NHPCO 2015; Parmalee 2001; Steinhauser et al. 2000; Teno et al. 2001). These include measures of physical and emotional symptom management (pain, breathlessness, sadness or anxiety), quality of encounters with health care providers (informed about condition, involvement in decision-making, receipt of care concordant with preferences, clear coordination of care), and receipt of dignified care (personal needs met, respectful treatment). Analyses of a large sample of NHATS

decedents who participated in at least one wave of the survey and for whom a proxy completed an exit interview (n=1,046) and smaller sub-sample (n=222) of decedents who also completed a module on ACP reveal that proxies perceive a majority of older adults (80% and 75%, respectively) receive high quality EOL care, characterized by no or managed symptoms. An absence of symptoms is typically aspired to as an “ideal” way to experience EOL (Parmalee 2001; Steinhauser et al. 2000). However, as symptoms are unavoidable in some EOL scenarios, it is an encouraging sign that proxies still assess care positively in many instances where symptoms are well-managed. The tendency for some proxies to positively assess EOL care in the presence of managed symptoms could signal that these individuals will have positive bereavement outcomes or are finding supportive relationships to alleviate grief.

On the other hand, 20%-25% of adults are likely to receive poorer quality EOL care. For these individuals, proxies assess encounters with health care providers and the personal treatment the decedent received less positively. Proxies also report either managed or unmanaged symptoms for this group. A substantial subset of proxies (35% in sample where n=1,046) report high quality care when symptoms are managed, so effectively managing symptoms in cases where proxies report unmanaged symptoms may also positively shift their perceptions of health care encounters and dignified care. Additional information and research is required to understand why some proxies are likely to report poorer quality EOL care even if symptoms are well-managed. Perhaps the lower quality ratings reflect something different about the decedent’s EOL trajectory that is not captured in NHATS data. Proxies may be reporting about objectively “worse” EOL experiences, where although the decedent’s symptoms were managed, they did not have

supportive encounters with health care professionals and/or were not treated in a dignified manner. Alternatively, proxies' negative assessments of EOL care quality in a context of managed symptoms may be an indication of poor psychological adjustment following the loss of a loved one.

Patients experience care as a holistic experience that is greater than the sum of individual components. LCA is a useful technique for researchers, clinicians, and policy makers interested in evaluating how multiple subcomponents of care, such as symptom management, care coordination, and patient-clinician interactions, collectively contribute to an overall concept of "quality EOL care" in different patient populations. Gaining a better understanding of how individual aspects of care work in tandem with, or in opposition to, one another can provide insights about which aspects of care should be targeted together to improve the level of overall care. For example, researchers and clinicians may find incorporating assessments of sadness or anxiety and offering options for support may cause patients and their loved ones to also feel they are being treated with dignity and respect. Alternatively, making changes to care protocol that increase emphasis on personal dignified care may lead to fewer reports of sadness and anxiety among patients and caregivers. LCA, which accounts for how multiple components cooccur in a sample allows us to more closely align analytic techniques with global understandings patient and caregiver experience of care while preserving the characteristics of the individual measures (in contrast to aggregated measures that obfuscate such distinctions). Service delivery changes and improvements can then be made based on a multifaceted understanding of how various components of care fit together to form an overall assessment of care.

Determinants of Perceived EOL Care Quality

The remainder of my dissertation investigates how decedent characteristics, experiences with ACP, EOL care setting and provider, and proxy characteristics influence proxy evaluations of EOL care quality, as identified by the latent classes described in the previous section. Across three separate analyses, I find the following with respect to perceived EOL care quality: 1) decedent education and gender are not significant predictors; 2) being non-Hispanic white predicts poorer EOL care quality in some cases; 3) decedent's chronic illnesses and recent hospitalizations are associated with EOL care quality; 4) dying at home and hospice involvement predict EOL care quality; 5) ACP does not predict EOL care quality, importance of religious participation does, and ACP appears to moderate the relationship between importance of participation and EOL care quality; and 6) proxy familiarity with care, relationship to the decedent, and age and gender together among close family member proxies predict EOL care quality. In the remainder of this section, I summarize my results, offer possible explanations, and identify areas for additional research.

Equivocal Relationship between Fundamental Causes of Health Disparities and EOL Care Quality

Fundamental causes theory (Link and Phelan 1995) posits that social disadvantage produces well-documented SES and racial/ethnic health and mortality disparities (Elo 2009; Marmont 1991; Williams 2012). However, I found mixed results with respect to the applicability of fundamental causes theory to perceptions of EOL care quality. Education, a reliable indicator of lifetime SES in older adults (Elo 2009), does not predict EOL care quality. There are several possible explanations for this lack of association.

Some research suggests health disparities related to SES attenuate at older ages (Phelan et al. 2004; Mirowsky and Ross 2008), which could explain the lack of relationship between education and EOL care quality in my analyses. Additional research is needed to unpack the mechanisms that contribute to this attenuation and lack of association. For example, the lack of relationship between SES and EOL care quality could reflect selection into a sample of older adults: the sickest individuals with low SES may die before reaching age 65. To the extent this is true, participants in the NHATS study are, by nature of having lived to age 65, relatively hardy and healthy, and may not exhibit the SES variation in health, and EOL care, we might observe in a study that includes middle-aged adults. Additionally, the lack of association may signal that Medicare is effective at reducing health disparities among older adults by equalizing access to high quality care, regardless of SES advantage previously accrued over the life course (Phelan, Link, and Tehranifar 2010).

Similar to education, a decedent's gender is not related to proxy reports of EOL care quality. While I expected men's socially advantageous position in society would translate to higher quality EOL care, there was no difference in men and women's EOL care. This lack of association could reflect the complex relationship between gender and health. On average, men live shorter lives than women and have higher morbidity from chronic illnesses that are common causes of death (NCHS 2016), indicating that they experience more severe versions of chronic illnesses, which may manifest as complex health care needs that make it difficult to provide high quality EOL care. On the other hand, women experience greater depression and anxiety than men and experience higher rates of cognitive decline (Alzheimer's Association 2016; Rosenfield and Mouzon 2013),

which also present challenges in providing high quality EOL care. In contrast, most of the sample are members of the “Silent Generation,” and so may be less likely to disclose otherwise unobservable physical discomfort or anxiety to loved ones (DeGiacomo et al. 2013), resulting in relatively positive assessments of EOL care quality. Additional research on the effects of illness severity and cognitive decline on actual and perceptions of EOL care quality may reveal gender differences in EOL care quality.

Alternatively, social support may also explain the lack of differences in EOL care quality between deceased men and women. Because wives outlive their husbands, men are more likely to be cared for at EOL by a spouse. Marriage can be a protective factor for older adults’ health (Carr and Springer 2010), and wives may effectively advocate for high quality care for their husbands. Wives are also likely to provide care to their husbands at EOL (NASEM 2016). To the extent that wives find satisfaction in caring for their husbands (NASEM 2016), they may report positive perceptions of EOL care quality. While women are not as often cared for by their husbands, they do benefit from larger, more connected social networks outside of marriage (Cornwell and Schafer 2016; Fiori, Antonucci, and Cortina 2006). These networks may facilitate direct access to high quality EOL care, or lead the individuals reporting on women’s EOL care quality to perceive that care to be of higher quality because of the supportive role members of women’s social networks provide at EOL. Supportive marital relationships may facilitate quality EOL care among men, while larger and connected extramarital relationships may facilitate similar care among women, obscuring gender differences in EOL care quality in the sample. Studies that can also account for the type and quality of social support individuals receive at EOL may reveal gender differences in EOL care quality.

Finally, race and ethnicity predict EOL care quality, but only in some analyses, and in counterintuitive ways. Health disparities research would suggest that non-whites would receive higher quality EOL care than non-Hispanic whites based on their shorter life spans and poorer health (IOM 2003; NCHS 2016) and experiences of discrimination in health care encounters (Hoffman et al. 2016; IOM 2003). However, decedent's race/ethnicity are only a marginal predictor of EOL care quality in more fully specified analyses with a larger sample (Chapters 2 and 4), and a significant predictor in a more targeted analysis with a smaller sample (Chapter 3). Moreover, in models where race/ethnicity is statistically significant, proxies perceive non-Hispanic whites receive poorer quality EOL care compared to others. This surprising finding could be the result of a mismatch between expectations and care: proxies for non-Hispanic whites could have higher expectations for EOL care and judge more harshly when care fails to meet their expectations.

Conversely, non-Hispanic blacks and Latinos, accustomed to more negative encounters with health care providers, may provide overly positive assessments of EOL care quality if a family member receives high quality EOL care. A third explanation is that proxies for ethnic minority decedents, who, because of the large proportion of family member proxies, are likely to be the same race/ethnicity as the decedent, may be more inclined to make positive assessments of EOL encounters, regardless of whether they are of high or low quality. Moreover, members of racial and ethnic minority groups are more likely to engage in family caregiving and report greater satisfaction with caregiving than non-Hispanic whites (NASEM 2016). Generally positive assessments of EOL care quality for racial and ethnic minority decedents are understandable if their proxy reports

are a reflection of family caregivers' assessments of their own care provision. Additional research should explore whether there are racial/ethnic differences in proxies' *expectations* for EOL care and how those translate to differences in *perceptions* of actual EOL care quality.

The analysis in this dissertation is motivated by the idea that non-Hispanic blacks and Hispanics are groups that are both socially disadvantaged, relative to non-Hispanic whites, and so, to the extent that social disadvantage and discrimination operate similarly for non-Hispanic blacks and Hispanics, both groups would have similar experiences with respect to perceived EOL care quality. Moreover, small sample size precluded analysis of non-Hispanic whites, non-Hispanic blacks, and Hispanics as three separate groups. However, it is important to note that Hispanics enjoy longer lives and better health than non-Hispanic whites (NCHS 2016). To the extent that health characteristics influence EOL care quality (as I discuss below), future analyses should account for differences in Hispanics' and non-Hispanics blacks' health. A three-way comparison of non-Hispanic whites, non-Hispanic blacks, and Hispanics should be possible as the number of NHATS decedents grows. Interestingly, marginal significance disappeared in one analysis comparing non-Hispanic whites and non-Hispanic blacks (Chapter 2), suggesting that proxies for Hispanic decedents may be determining the small differences in EOL care quality that are observed.

Contrary to what fundamental causes theory would suggest (Link and Phelan 1995), fundamental causes of social advantage that predict better health and longer life, do not map onto perceived EOL care quality. The lack of gender and SES differences in EOL care quality could be a result of measurement limitations in the data. Alternatively,

the absence of gender and SES differences could suggest that for older adults, in the final month of life, experience and care do not discriminate with respect to symptom management, supportive encounters with health care professionals, and receipt of dignified care: four-fifths of dying individuals experience high quality care and no or managed symptoms, regardless of their gender or class. To the extent the lack of differences is attributable to equitable access to relatively high quality EOL care, we might consider Medicare, which, other than deceased status, is the single common denominator among everyone in the analyses, to be effective in minimizing health and healthcare access disparities otherwise observed in the broader population. Racial and ethnic differences in EOL care quality do emerge. Contrary to tendencies for non-Hispanic whites to receive better health care and enjoy superior health across the life course, proxies perceive that non-Hispanic whites receive poorer quality care than members of racial and ethnic minority groups, which may be the result of a mismatch between expectations for and perceptions of care.

Decedent Health Characteristics and EOL Care Setting and Provider Predict

Perceptions of EOL Care Quality

Decedent health was a significant predictor of EOL care quality. Proxies for healthier individuals reported no symptoms and higher quality EOL care than proxies for decedents who reported at least one of four chronic illnesses or two or more hospitalizations in the year before death. Older adults who experience relatively good health may have shorter EOL trajectories and less complicated care needs at EOL. Increased comorbidity and more frequent hospitalization can signal more complicated health status, which can be difficult to manage, and eventually devastating, among older,

frailer adults. Complex health situations may complicate EOL care. While self-rated health, serious illness and hospitalization (as markers of chronic and acute health statuses) can be markers for mortality, only diagnoses and hospitalizations predict EOL care quality. This finding underscores the need for a nuanced understanding of how illness complexity relates to EOL care quality. Objective measures of health map onto proxy perceptions of care quality while self-perceptions of health quality do not, suggesting the importance of including in studies of EOL both subjective measures of health, which can predict timing of death, and objective measures of health, which can predict the quality of EOL care.

Home death and hospice involvement are also significant predictors of EOL care quality. Home death, which is typically associated with a “good” death (Byock 1996; Parmalee 2001), is associated with positive proxy assessments of EOL care and no or managed symptoms. One explanation is that proxies’ assessments reflect an expectation that a home death is high quality. Another is that certain EOL trajectories lend themselves to allowing an individual to die at home. For example, a relatively healthy individual with uncomplicated health needs may have a shorter and uncomplicated EOL trajectory that allows them to die at home, although the effect of home death was independent of illnesses and hospitalization. Access to caregiving resources may also facilitate home death. Although marital status was not a significant predictor of EOL care quality in supplemental analysis, married individuals and those with rich social networks may find the support they need to stay, and die, in their homes. Not having a caregiver in the home is an exclusion criteria for enrollment for 12% of hospices, further underscoring the relationship between social support and access to high quality EOL care (Aldridge

Carlson et al. 2012). Alternatively, there may be something qualitatively better about home deaths that makes them of higher quality relative to deaths occurring in other locations.

Hospice involvement also predicts EOL care quality. The purpose of hospice care is to provide high quality comfort care to dying individuals and their families. As such, it is not surprising that hospice is associated with proxy reports of managed symptoms and high quality care at EOL. Interestingly, hospice is also associated with symptomatic, lower quality EOL care. These results could be capturing variation in quality of hospice providers. Timing of referral to hospice is linked to satisfaction with care (Schockett et al. 2005), and late referrals to hospice may influence perceptions of EOL care in this sample as well. Hospice referrals are also made in complicated EOL scenarios, and it may not be possible to effectively manage symptoms if the referral is made just a few days before death (Bynum et al. 2016). Finally, proxy reports may reflect their recollections of the most intense and recent aspects of the last month of life rather than an overall average or most common experience (Kahneman et al. 1993). Given that hospice stays are generally a few days in duration, proxies may be reporting on EOL care that occurred in the last month of life, prior to hospice involvement. Information about the length of time an individual was in hospice services might elucidate why, in some cases, proxies perceived deaths where hospice was involved to be of relatively poor quality.

Benefits of Advance Care Planning and Religious Beliefs for EOL Care Quality

While research establishes a link between ACP and receipt of fewer invasive and futile treatments at EOL, (e.g. Teno et al. 2007), the relationship between ACP and perceptions of EOL care is less clear (Detering et al. 2010; Khodyakov and Carr 2009;

Teno et al. 2007). My analysis of a small sample of individuals (n=222) who completed ACP indicates that ACP has no effect on proxies' multidimensional perceptions of EOL care quality. The direction of the relationship between different types of ACP and EOL care quality suggests ACP may be associated with positive perceptions of EOL care, and so a larger sample size may provide sufficient power to detect significant differences in EOL care quality based on ACP behavior. To the extent individuals complete ACP to alleviate uncertainty or anxiety about EOL (Luth 2016), this study finds that completing any type of ACP may continue to help keep anxiety at bay at EOL. On the other hand, ACP can be considered unhelpful if family members perceive that it causes confusion or conflict at EOL, or did not positively impact quality of EOL care (Khodyakov and Carr 2009), underscoring potentially competing effects of ACP that obscure the effect of ACP on EOL care quality.

Although religiosity is generally associated with a desire for and receipt of more invasive, life-prolonging treatment at EOL (e.g. Phelps et al. 2009; Sharp, Carr, and Macdonald, 2012), religious coping is also linked to better adjustment to stressful situations such as illness and death (Ano and Vasconcelles 2005). I find importance of religious participation is associated with no or managed symptoms and high quality EOL care. This association may be the result of proxies reporting religious decedent's, or their own, increased acceptance and satisfaction with EOL care. My analysis finds the relationship between religious attitudes and EOL care quality may be stronger among individuals who have completed ACP, suggesting communicating one's EOL treatment preferences in the context of religiosity may facilitate access to better EOL care. Alternatively, close family members who share decedent's religious values and are aware

of decedent's EOL preferences may feel more confident and comfortable advocating for loved one's EOL care or more satisfied with care in retrospect.

Proxy Characteristics Predict EOL Care Quality

Overall, the NHATS data paint a rather positive view of EOL care quality. Proxy characteristics, including familiarity with EOL and relationship to the decedent, affect their perceptions of care quality. Proxy familiarity with EOL is associated with perceptions of higher quality care. To the extent that individuals familiar with EOL care also provided care, their positive evaluations may be assessments of their own care provision. If they were particularly emotionally invested in caregiving, they may positively appraise the decedent's EOL as a way of coming to terms with the loss (Michael and Snyder 2005). Alternatively, their positive perceptions may be a relatively accurate appraisal of an objectively meaningful and high-quality caregiving experience (NASEM 2016).

Proxy relationship to the decedent is also associated with more positive perceptions of EOL care quality. Relative to sons, distant family and non-family members assess EOL care more positively. These assessments from individuals more distally related to the decedent may reflect more objective assessments of EOL care quality, particularly from paid caregivers who may be accustomed to caring for dying individuals and may have a less emotion-infused reaction to EOL. Paid caregivers could also be motivated to positively assess care for which they were compensated. Finally, wives, relative to sons, provide more positive assessments of EOL care quality. Wives' positive evaluations may present an example of how age-based and gendered reactions to negative stimuli and difficult situations work together to result in positive recollections of

EOL care (Carstensen, Fung and Charles 2003; Pearlin and Schooler 1978). Studies using proxy reports of EOL care quality should control for familiarity with care and proxy relationship to decedent in ways that account for age and gender differences among close family members. Moreover, additional research is needed to better understand the mechanisms through which proxy reporters' characteristics and lived experience shape their perceptions of EOL care quality.

We cannot directly ask deceased individuals about their past experiences and there are ethical considerations that make it difficult to conduct research with dying individuals. As such, researchers and service providers necessarily rely on proxy reports for important information about EOL (George 2002). While proxy reporters tend to be close family members of decedents, researchers and service providers do not typically pay attention in their analyses to how proxy reporters' experiences, characteristics, and relationship with decedents inform and affect the reports they provide on EOL care (Lendon et al. 2015). However, I find a link between proxy familiarity with care in the last month of life and relationship to the decedent and perceptions of EOL care quality, implying that *who* you ask matters for the response you obtain. The measures I analyze are similar to questions the Centers for Medicare and Medicaid Services uses to assess the quality of hospice services in the U.S. Without careful attention to who is answering the questions and how their own experiences and characteristics might affect their perceptions, we obtain an incomplete understanding of the state of EOL care. Moreover, efforts to improve EOL care for deceased individuals and their caregivers will only be as successful as the extent to which they consider and address heterogeneity in caregiver experiences and perceptions of care.

Conclusion

As the Baby Boomer generation, the 75 million persons born between 1946 and 1964, continues to age and die, EOL care will touch the lives of a growing number of individuals and families. As a society, we have a social contract to provide dignified care to individuals in the most vulnerable, and final, stages of life. Growth in hospice services and the emergence of palliative care as a medical subspecialty signal the health care field's commitment to improving quality of care for dying individuals. However, much work remains in order to ensure all dying individuals receive high quality care at EOL. At least one in five individuals receives poorer quality care, and determinants of perceived EOL care quality are not well understood. This dissertation takes steps to identify determinants of EOL care quality and finds that religious attitudes, proxy social and health characteristics, EOL care setting and provider, and proxy characteristics to perceptions of care quality. Effective improvement of EOL care and support for dying individuals and their caregivers will require a detailed understanding of the nuanced and varied manners in which deceased individuals and their caregivers' characteristics and experiences affect their experiences and perceptions of EOL care.

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