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The Association between Multiple Chronic Conditions, Domains of End-of-Life Care Quality, Care Coordination, and the Perception of High Quality End-of-Life Care for Older Adults

A DISSERTATION

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By

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Abstract

While literature indicates that fewer than half of older adults aged 65 years or older receive high quality end-of-life care,[1] less is known about the quality of end-of-life care experienced by the segment of that population with multiple chronic conditions (MCC).[2] A prominent and widely accepted conceptual model created by Joan Teno and colleagues with older adult and caregiver input (Teno Model) indicates that high quality end-of-life care requires assessment and intervention in five domains: *coordination, symptom management, shared decision-making, respect,* and *spiritual and emotional support*.[1,3,4] *Coordination*, one of the identified quality domains, may be of particular importance to older adults with MCC given its success in addressing care fragmentation for older adults with MCC prior to the end of life.[5–7]

Drawing upon the Teno Model of high quality end-of-life care, the *goals* of this study were to advance the understanding of the quality of end-of-life care experienced by older adults with MCC and how that care may be improved. The study's two *objectives* were to assess the presence of MCC as a potential driver of poor end-of-life care quality, and to inform end-of-life care improvements that meet the needs of older adults with MCC and their informal caregivers. Three *specific aims* addressed the study's objectives: (1) to identify disparities in end-of-life care quality by MCC status; (2) to determine which dimensions of end-of-life care quality were associated with high quality end-of-life care for older adults with MCC; and (3) to assess the association between care coordination and high quality end-of-life care for older adults with MCC. This retrospective cross-sectional cohort study utilized the nationally representative National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI).[8]

In this study, we found that only 52% of community-dwelling Medicare beneficiaries with MCC received “excellent” care in the last month of life. The greatest unmet need for older adults with MCC was in the spiritual and emotional support *composite quality domain*, where only 31% of MCC proxies perceived care positively. Among older adults included in this study, individuals with MCC experienced significantly greater anxiety and sadness in the last month of life compared to those without MCC.

We found no association between MCC status and rating of *overall* care quality. MCC proxies had higher odds of perceiving care positively for breathing issues and being informed about care, but care perception did not differ by MCC status for any other dimensions of quality. For several dimensions of quality, proxies’ perception of care was related to the setting where the older adult’s death occurred and hospice enrollment.

Specifically, dying at home was the only factor significantly associated with an “excellent” rating on the measure of *overall* care quality for this study’s sample. Positive perception of care in the coordination, shared decision-making, and respect *composite quality domains* were also higher for older adults who died at home. In our study, we also found dying at home was significantly associated with hospice enrollment for dying individuals.

Among those with MCC, perception of care in the coordination, shared decision-making, respect, and spiritual and emotional support *composite quality domains* were significantly associated with the rating of *overall* care quality. Symptom management, the fifth *composite quality domain* identified in the Teno Model, was not associated with the rating of *overall* care quality provided by MCC proxies in this study. Relationships between how proxies perceived dimensions of end-of-life care and how they ultimately rated the *overall* care experience of dying older adults with MCC were complex. For many recognized end-of-life quality domains, perceiving care negatively appeared to have a stronger association with the overall care quality rating than perceiving care as “positive”.

The presence of cancer appeared to be a driver of the care older adults with MCC experienced in the last month of life. A greater proportion of proxies perceived end-of-life care quality negatively in the symptom management and shared decision-making *composite quality domains* for individuals dying with MCC that included cancer. We found that MCC proxies perceived *overall* care quality, spiritual and emotional support, and religious and spiritual care positively for individuals with cancer enrolled in hospice, while MCC proxies perceived shared decision-making and care for anxiety/sadness more positively for individuals without cancer enrolled in hospice.

Prior to the end of life, coordination is associated with better quality of care as well as improved health and utilization outcomes for older adults with MCC.[5–7] Proxies of older adults with MCC who perceived coordination positively in the last month of life also perceived care as “positive” for the following dimensions: symptom management, pain management, respectful treatment, personal care, and the extent to which the dying individual was kept informed in the last month of life. Findings suggested that coordination may be associated with highly rated end-of-life care, but the study was not able to establish causation between receiving coordinated care and receiving high quality care in other end-of-life care dimensions. This study demonstrated the need to more thoroughly examine care coordination, including specific coordination tasks, as an approach for ensuring high quality end-of-life care.

Results indicated that end-of-life care quality does not differ significantly by MCC status, but meaningful gaps in care exist for all older adults, particularly relating to spiritual and emotional support. We also identified that dying at home was significantly associated with higher rates of hospice enrollment, better ratings of *overall* end-of-life care quality, and a "positive" perception of care for several quality dimensions for the general older adult population and for older adults with MCC. In this study, ratings of *overall* end-of-life care quality for older adults with MCC were associated with their experience in the coordination, shared decision-making, respect, and spiritual and emotional support domains, but not their experience with symptom management. Findings also suggested that older adults with MCC who do not have cancer may experience different benefits from hospice, Medicare's primary end-of-life care program and the gold standard for end-of-life care quality, than dying older adults with MCC that does not include cancer. Study findings identified care coordination as an end-of-life care improvement approach worth further investigation. Additionally, this study confirmed the need to improve end-of-life care quality research approaches, which currently limit the ability to improve end-of-life care quality meaningfully.

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Chapter 1: Introduction

Study Summary and Aims

While literature indicates that fewer than half of older adults aged 65 years or older receive high quality end-of-life care,[1] less is known about the quality of end-of-life care experienced by the segment of that population with multiple chronic conditions (MCC).[2] MCC is defined as the presence of 2 or more chronic conditions that together impact health status and require complex management.[9] Two-thirds of older adults lived with MCC in 2012.[10] Prior to the end of life, having MCC is associated with fragmented, ineffective and inefficient care, and higher healthcare costs and utilization.[5,9,11,12] Approaching the end of life, most older adults with MCC lack a linear trajectory to death, and instead experience frequent cycles of decline and improvement that pose a challenge for planning and delivering care.[13] As a result, it is difficult to determine when end-of-life-specific interventions should be started. Therefore, older adults with MCC may receive low quality end-of-life care in a general healthcare system unprepared to address their end-of-life-specific needs. In addition to impacting the dying individual, low quality end-of-life care is associated with increased Medicare costs,[14] as well as poor mental health outcomes for care providers[15] and informal caregivers.[16–18] In 2014, the Institute of Medicine identified improvement in end-of-life care as a national priority.[19]

A prominent and widely accepted conceptual model created by Joan Teno and colleagues with older adult and caregiver input (Teno Model) indicates that high quality end-of-life care requires assessment and intervention in five domains: *coordination, symptom management, shared decision-making, respect,* and *spiritual and emotional support*.[1,3,4]

However, the Teno Model has not been validated with the population of older adults with multiple chronic conditions. Knowing which end-of-life quality domains (*coordination, symptom management, shared decision-making, respect,* and *spiritual and emotional support*) are most important to older adults with MCC would help providers, payers, and healthcare systems focus limited resources on areas most meaningful to this population within the time restraints that often accompany end-of-life care. *Coordination*, one of the identified quality domains, may be of particular importance to older adults with MCC given its success in addressing care fragmentation for older adults with MCC prior to the end of life.[5–7] Studies outside the US indicate coordination's potential for improving end-of-life care quality,[20–22] but coordination's influence on quality within US policies and care delivery systems lacks evidence. Understanding the end-of-life quality domains most valued by older adults with MCC and identifying strategies for improving care in those domains could inform patient-centered interventions and policies aligned with the populations' priorities.

Drawing upon the Teno Model of high quality end-of-life care, the *goals* of this study were to advance understanding of the quality of end-of-life care experienced by older adults with MCC and how that care may be improved. This retrospective cross-sectional cohort study utilized the nationally representative National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI).[8] In the LMLI, proxies report their perception of care within each of the 5 end-of-life quality domains noted above by indicating if the deceased older adult experienced needs in that domain and whether needs were met when identified. Proxies also report a separate rating of *overall* end-of-life care quality. Using proxy-reported information for deceased community-dwelling Medicare beneficiaries aged 65 or older, this study addressed two *objectives*: to assess the presence of MCC as a potential driver of poor end-of-life care quality, and to inform end-of-life care improvements that meet the needs of older adults with MCC and their informal caregivers. Three *aims* addressed the objectives:

Aim 1: Identify disparities in proxy-reported end-of-life care quality for older adults with MCC compared to those without MCC

Hypothesis: Proxies for older adults with MCC will be less likely to rate *overall* care quality as "excellent" than proxies for older adults without MCC.

Aim 2: Determine which of the 5 recognized end-of-life quality domains are associated with excellent *overall* end-of-life care quality for older adults with MCC

Hypothesis: Proxies for older adults with MCC who perceived care as "positive" in the symptom management *composite quality domain* will be more likely to rate *overall* end-of-life care quality as "excellent".

Aim 3: Evaluate the relationship between positive perception of care in the coordination *composite quality domain* and positive perception of care in other recognized quality dimensions for older adults with MCC

Hypothesis: Proxies for older adults with MCC who perceived care as "positive" in the coordination *composite quality domain* will be more likely to perceive care as "positive" other dimensions of quality.

Findings from this study's aims: (1) identify whether end-of-life care quality for older adults differs by MCC status, (2) contribute information for prioritizing patient-centered end-of-life care quality improvements, and (3) suggest whether *coordination*, a strategy that has shown promise for improving care quality prior to end-of-life, also improves the perception of end-of-life care quality for older adults with MCC.

Literature Review

Fewer than half of older adults aged 65 years or older receive high quality end-of-life care,[1] however not much is known about the quality of end-of-life care experienced by the segment of that population with multiple chronic conditions (MCC).[2] Older adults with MCC face unique challenges at the end of life, but few studies explicitly examine their end-of-life care quality. Failure to address the gap in knowledge regarding end-of-life care quality for older adults with MCC could lead to ineffective improvements or policies mismatched with the populations' needs and priorities. This section will describe the history and importance of end-of-life care quality for older adults, present the need for examining end-of-life care quality for older adults with MCC, and discuss a potential strategy for improving end-of-life care quality for older adults with MCC.

High Quality End-of-Life Care for Older Adults

Scope, Outcomes, and Cost Associated with End-of-Life Care for Older Adults

The Institute of Medicine identifies end-of-life care, or the humane care for individuals approaching death, as a social obligation and national priority given its widespread impact on individuals, families, and society.[23] Over 2.5 million people die annually in the United States,[24] of which over 80% are individuals age 65 and older.[25] The quality of end-of-life care experienced by older adults impacts the dying individual, their caregivers, and their medical providers. Studies demonstrate associations between poor quality end-of-life care and major depressive disorders,[16,17] poor quality of life,[17] and increased burden[18] among informal caregivers. Poor quality end-of-life care has also been linked to moral distress and job dissatisfaction among healthcare providers.[15] Additionally, poor quality end-of-life care for older adults impacts society by increasing Medicare costs. In every year since 1970, over 25% of Medicare's expenditures went to care for older adults in the last year of life.[26] Medicare Payment Advisory Commission (MedPAC) analysis indicates Medicare's end-of-life spending increased 1.1 percentage points per decade since its creation as a result of a national trend toward more aggressive end-of-life care.[14,26]

History of End-of-Life Care for Older Adults

Medicare's policies shape the country's end-of-life care landscape given 93% of older adults are enrolled in Medicare and that older adults account for a high proportion of deaths each year.[25,27,28] Understanding current end-of-life care quality requires examining the history of Medicare's end-of-life care policies and strategies, including hospice and palliative care.

In 1982, Medicare enacted policy to address shortcomings in end-of-life care at the time, creating a hospice benefit that has changed little in the 34 years since its inception.[29] *Hospice* is a method of care delivery focused on comfort and closure for dying individuals and their families that can be delivered at home or in a healthcare facility. Eligibility for Medicare's hospice benefit requires individuals to forego curative treatment and to have a 6-month prognosis to death. Appropriate hospice use is defined as enrollment for greater than 1 week, but less than 6 months.[30] Literature indicates appropriate hospice use is associated with fewer unmet needs and greater satisfaction with quality when compared to other care approaches.[1,31] For example, a nationally representative survey conducted in 2000 identified that over 70% of proxies for hospice enrollees rated end-of-life care as excellent, compared to less than 50% of proxies for individuals who died in other settings.[3]

While many consider hospice the gold standard of end-of-life care, eligibility criteria for Medicare's hospice benefit limits its accessibility for a growing number of older adults. Medicare's hospice eligibility requirement of a 6-month prognosis to death was developed to reflect the experience of individuals with cancer in the 1980s, as cancer was a common end-of-life diagnosis for older adults at the time. However, medical advances decreased the cancer mortality rate by 22% between 1991 and 2011[32] while concurrently enabling older adults to live longer with chronic conditions.[33] Older adults dying of conditions other than cancer often lack the 6-month prognosis required to access Medicare's hospice benefit.[30] However, Medicare failed to change hospice eligibility rules in response to the population's changing needs as fewer older adults died from cancer and more died as a result of chronic conditions.

The palliative care movement emerged as a way to circumvent Medicare's hospice policy in response to limitations for seriously, chronically, but not terminally ill individuals.[34] *Palliative care* provides support for symptoms and psychosocial needs in any care setting, typically in consultation with a palliative care team.[34] Unlike hospice, palliative care can be delivered concurrently to curative care at any point across the lifespan. However, unlike for hospice, Medicare lacks specific palliative care policy or payment to incentivize its delivery, and instead includes palliative care as a part of general healthcare services. The absence of explicit Medicare palliative care policy results in unclear parameters for what palliative care entails and undefined standards for how it should be provided, which therefore impedes its capacity to markedly improve end-of-life care quality.[33] Older adults, ineligible for hospice served in a location without palliative care capabilities, may receive end-of-life care within the general acute care system, such as hospitals or intensive care units (ICU). Death within a hospital or in intensive care is associated with poor outcomes for older adults due to differences between acute and end-of-life goals of care.[33,35]

Definition of High Quality End-of-Life Care for Older Adults

Differences in acute and end-of-life goals, preferences, and priorities necessitate different definitions of high quality care.[4] A prominent and widely accepted conceptual model developed by Joan Teno and colleagues (Teno Model) indicates that high quality end-of-life requires assessment and intervention in five domains, regardless of the delivery setting or approach:[1,3,4]

- *Coordination:* Designated professionals take responsibility for overseeing the care team and organizing consistent care across care settings.
- *Symptom Management*: Dying individuals receive their desired level of support for symptoms such as pain and difficulty breathing.
- *Shared Decision-Making*: Decisions reflect dying individuals' goals and values and include their input.
- *Respect*: Dying individuals are treated with respect and receive support for personal care needs.
- *Spiritual and Emotional Support:* Dying individuals and their families receive their desired amount of support for their spiritual and emotional needs.

Other studies confirm the domains included in the Teno Model,[36–38] but additionally recommend the quality definition include trust in providers[37] and accessibility.[38] Details on the model's creation can be found in **Chapter 2.**

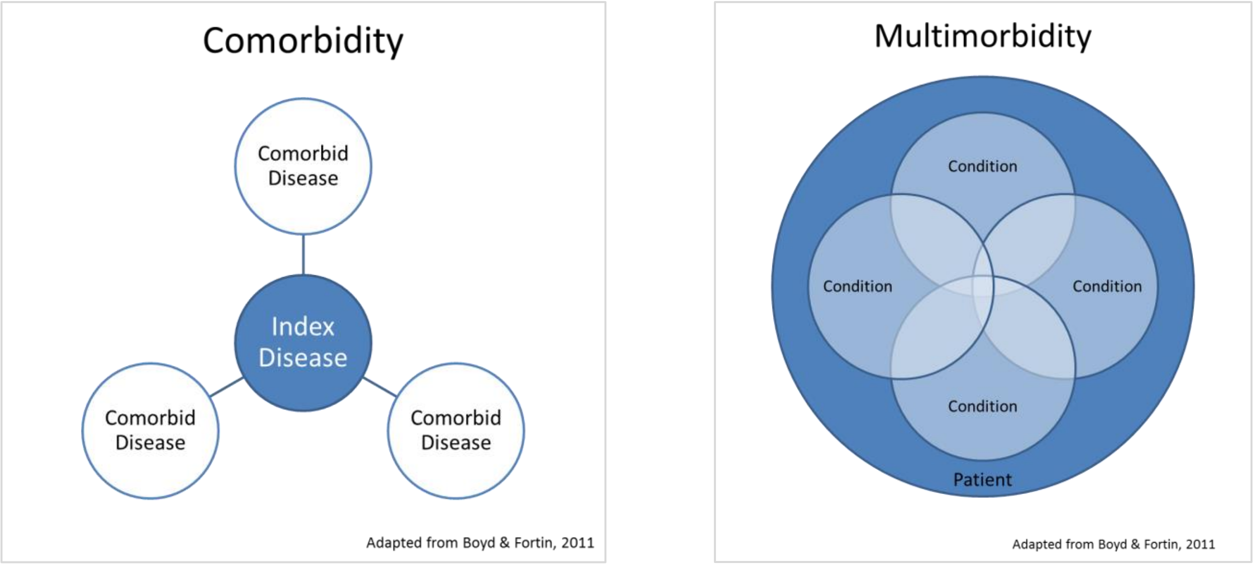
The Teno Model informed a nationally representative study conducted in 2000 with proxies for recently deceased individuals. In the study, approximately 25% of all dying individuals experienced unmet symptom needs, 25% lacked shared decision-making, 21% experienced issues with respect, 50% did not receive enough emotional support, and 15% felt medical providers did not know enough about the dying individual to provide the best care.[3] Additionally, proxy ratings of overall end-of-life care quality declined from 57% in the 2000 survey to 47% in a more recent analysis.[1]

End-of-Life Care Quality for Older Adults with Multiple Chronic Conditions

While literature identifies that only 47% of older adults aged 65 years and older receive high quality end-of-life care, the end-of-life care quality experienced by the growing population of older adults with MCC has yet to be defined.[2] Older adults with MCC experience known medical complexity,[39] barriers accessing high quality health care,[6] and unique end-of-life challenges.[4,40,41] Defining the end-of-life care quality experienced by older adults with MCC is a necessary step toward identifying needed improvements and minimizing suboptimal outcomes associated with poor end-of-life care quality in this subpopulation.

Multiple Chronic Conditions

Two-thirds of older adults lived with MCC in 2012.[10] Also called multimorbidity, the National Quality Forum defines MCC as: "…two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination.”[9] Multimorbidity differs from the similarly-named comorbidity, as seen in **Figure 1-1**.[39,42] Comorbidity focuses on a single condition as the index disease around which all others are understood and managed.[39] However, multimorbidity introduces a patient-centered framework where all conditions interact and impact each other, managed in the context of the patient’s goals and preferences. The multimorbidity, or MCC, framework acknowledges nuance and complexity omitted from the comorbidity model. As modern care delivery approaches shift away from the comorbidity framework toward multimorbidity, gaps in care can be seen.



Adapted from Boyd & Fortin, 2011

Adapted from Boyd & Fortin, 2011

Figure 1-1. Comorbidity and multimorbidity frameworks showing the difference in orientation between two models for organizing care of two or more chronic conditions.

Chronic conditions can be *concordant* or *discordant*, which contributes to MCC’s complexity. *Concordant chronic conditions* share pathophysiologic similarities that can be managed through the same care plan, while *discordant chronic conditions* differ in their pathophysiology and require unique and sometimes conflicting care plans.[43] As a result, individuals with discordant chronic conditions may possess multiple care plans directed by many providers, which place them at risk for poor outcomes.[43] Poor health outcomes associated with MCC include mortality, low functional status, and poor quality of life.[42] Prior to the end of life, individuals with MCC experience fragmented, ineffective, and inefficient care; high healthcare utilization and costs; avoidable hospital admissions; and preventable complications associated with hospitalization, polypharmacy, and post-operative complications.[5,9,11,12]

Due to the complexity of medical needs for older adults with MCC, care providers must actively prioritize services to address each individual's most pressing needs,[39] particularly when time and intervention resources are limited, such as at the end-of-life.[44] In an attempt to resolve care fragmentation and determine care priorities for the MCC population, healthcare providers increasingly turn to *care coordination*, or the deliberate organization of care to ensure appropriate service delivery.[45] Care coordination models demonstrate promise for addressing poor outcomes associated with MCC, including hospitalizations and readmissions,[46–49] skilled nursing facility placement,[6,50] inefficient care,[51] healthcare utilization costs,[47,48,52] and medication adherence.[52] Additionally, a growing number of Medicare policies provide financial support for care coordination activities.

Multiple Chronic Conditions at the End of Life

End-of-life literature identifies risks older adults with MCC face as they approach death,[41,53–55] but does not define the end-of-life care quality experienced by older adults with MCC. End-of-life experts identify the trajectory to death for older adults with MCC as a source of risk. Four illness trajectories encompass the experience of 92% of Medicare beneficiaries.[56] Three of those trajectories describe patterns of decline associated with progressive illness.[13] **Figure 1-2** depicts the three trajectories described below:

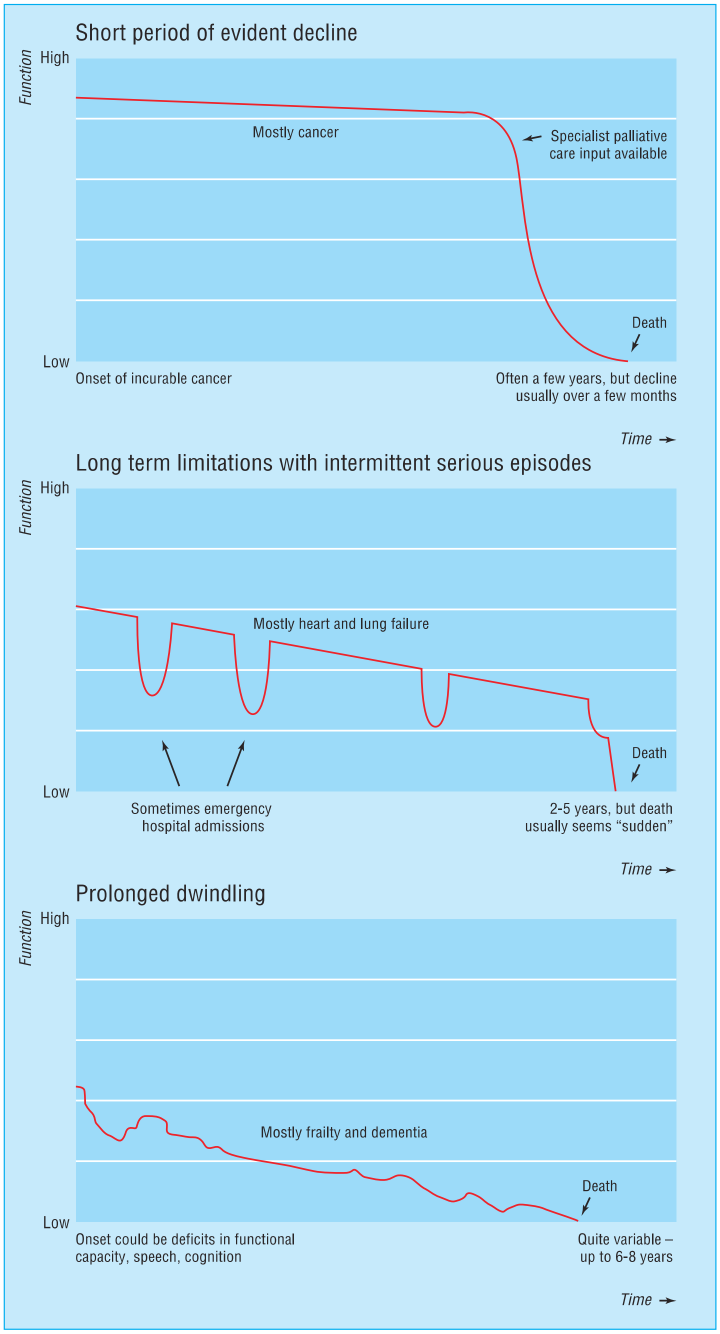


Figure 1-2. Typical trajectories to death for people with progressive illness. Figure derived from Murray et al's[13] examination of palliative care provision by illness trajectory.

- *Short period of evident decline*: Typical of older adults with cancer, individuals experience a predictable decline for potentially years until experiencing a steep drop-off in the last months of life. Individuals can typically predict future needs and plan accordingly, such as for hospice enrollment.[13]
- *Long-term limitations with intermittent serious episodes*: Typical of older adults with chronic conditions, individuals experience a steady decline over many years with periods of acute exacerbation and improvement. Each point of exacerbation may require hospitalization, often with intensive care, and may result in death. As a result, long-term planning is more difficult for older adults experiencing this trajectory.[13]
- *Prolonged dwindling:* Typical of older adults with dementia or frailty (failure of multiple body systems often associated with older age), individuals experience progressive decline accompanied by increasing needs for supportive services. Death often results from an acute condition or injury that taxes the system, such as pneumonia or a fall.[13]

As described above, when approaching the end of life, most older adults with MCC lack a linear trajectory to death and instead experience frequent cycles of decline and improvement that pose a challenge for planning and delivering care.[13] As a result, it is difficult to determine when end-of-life-specific interventions should be started. For example, the 6-month prognosis required by Medicare for hospice enrollment may be impossible to determine for older adults with MCC as a result of their illness trajectory.[41]

Prognostic uncertainty may lead older adults with MCC to receive fragmented end-of-life care in a general healthcare system focused on stabilization and one which is unprepared to address end-of-life specific needs.[4] However, little is known about how risks match reality since few studies have explicitly examined the end-of-life care quality experienced by older adults with MCC.[54,57,58] One available investigation, a case study of challenges for providing high quality end-of-life care to older adults with MCC, identified that in an effort to stabilize a patient, acute care providers may miss complications occurring to conditions other than the admitting diagnosis.[57] Additionally, the study described the unpredictability of MCC, stating that deaths occurring during the case study frequently caught acute care staff off guard; in many cases where the older adult died in the hospital, the acute care providers thought the older adult was in fact improving. Defining the end-of-life care quality experienced by older adults with MCC is a necessary step toward identifying needed improvements and minimizing suboptimal outcomes associated with poor end-of-life care quality.

Improving End-of-Life Care for Older Adults with Multiple Chronic Conditions

Regardless of whether older adults with MCC experience end-of-life care quality different than other populations, patient-centered end-of-life care improvement priorities and strategies for older adults with MCC need development. Improving end-of-life care quality for older adults with MCC requires a two-pronged approach: (1) investigating the populations' end-of-life care preferences, and (2) identifying strategies for care improvement.

Care preferences at end-of-life for older adults with MCC. As described previously, care for older adults with MCC requires active prioritization.[39] Investigation of illness trajectories and associated care patterns indicates that individuals' end-of-life care priorities may differ based on their illness experience, which suggests the need to examine the end-of-life care preferences of the MCC population explicitly based on their unique trajectory-based challenges.[41] However, just as little is known about the quality of end-of-life care experienced by older adults with

MCC, the populations' end-of-life care priorities are unknown. In a study of Canadian older adults with MCC, Clarke et al[59] identified the population shared similar end-of-life goals with the general public, including fear of prolonged pain and suffering, institutionalization, and loss of mental acuity, and loss of independence. However, while the study identified common fears, it did not identify actionable priorities for care improvement.[38] The study also did not explicitly examine differences between the goals of older adults with MCC and the general older adult population.

The Teno Model, described previously, provides a framework for high quality care provision,[4] but has not been validated with the MCC population. Knowing which end-of-life quality domains (*coordination, symptom management, shared decision-making, respect,* and *spiritual and emotional support*) are most important to older adults with MCC would help providers, payers, and healthcare systems focus limited resources on areas most meaningful to this population within the time restraints that often accompany end-of-life care.

End-of-life care quality improvement strategies for older adults with MCC. *Coordination*, one of the identified quality domains, may be of particular importance to older adults with MCC given its success in addressing care fragmentation for older adults with MCC prior to the end of life.[5–7] However, evidence of the influence of coordination on end-of-life care quality is limited to case studies of particular delivery models,[57,60,61] qualitative assessment of the need for coordination,[59,62] and evaluation of policies and systems outside the US.[20,22,63,64] Findings from these studies demonstrate potential end-of-life quality improvements that may be associated with coordination, such as decreased symptom distress,[60] increased hospice enrollment,[61] decreased late-life ICU and hospital use,[61] and more efficient use of healthcare resources.[65]

Investigation into the relationship between coordination and the other recognized quality domains may offer an approach for improving end-of-life care quality for older adults with MCC.

Significance

This study advances the understanding of the quality of end-of-life care experienced by older adults with MCC and how that care may be improved. The Institute of Medicine and Centers for Medicare and Medicaid Services call for a national effort to improve end-of-life care quality.[66,67] However, failure to first address the gap in knowledge regarding end-of-life care quality for older adults with MCC could lead to ineffective improvements or policies mismatched with the populations' needs and priorities. Findings from this study: (1) identify whether end-of-life care quality for older adults differs by MCC status, (2) contribute information for prioritizing patient-centered end-of-life care quality improvements, and (3) suggest whether *coordination*, a strategy that has shown promise for improving care quality prior to the end of life, also improves the perception of end-of-life care quality for older adults with MCC.

Innovation

- *Focus on older adults with MCC*: Most existing end-of-life studies examine single conditions in isolation,[41] which overlooks the unique needs of the two-thirds of older adults with MCC.
- *Multidisciplinary team:* The study team's expertise spans health services research, clinical geriatrics, social work, and quality. Blending multiple perspectives ensures this study's scientific and practical relevance.

- *Novel dataset:* This study is the first to use the nationally representative NHATS, LMLI to examine end-of-life care quality for older adults with MCC.[68] Unlike other site-specific datasets, NHATS includes information across multiple end-of-life settings, including home, hospice, and the hospital.

Chapter 2: Approach and Methodological Considerations

Study Design and Methods

Study Design

This study was a retrospective, cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). The NHATS, LMLI was administered to designated proxies, such as family or friends, for deceased Medicare beneficiaries aged 65 or older.[8] The LMLI provides details on NHATS participants' location, daily activities before death, and quality of care in the last month of life. Study objectives were to assess the presence of MCC as a potential driver of poor end-of-life care quality, and to inform end-of-life care improvements that meet the needs of older adults with MCC and their informal caregivers. The Teno Model includes the following domains of end-of-life care quality: *coordination*, *symptom management, shared decision-making, respect,* and *spiritual and emotional support.* The Teno Model informed the study design and variables.[4] Three aims addressed the study objectives, guided by the conceptual framework depicted in **Figure 2-1**. Aim 1 identified disparities in proxy-reported *overall* end-of-life care quality for older adults with MCC compared to those without MCC. Aim 2 determined which of the 5 recognized end-of-life *composite quality domains* were associated with "excellent" *overall* end-of-life care quality for older adults with MCC. Aim 3 evaluated the relationship between positive perception of care within the *coordination* quality domain and positive perception of care within other recognized quality domains for older adults with MCC.

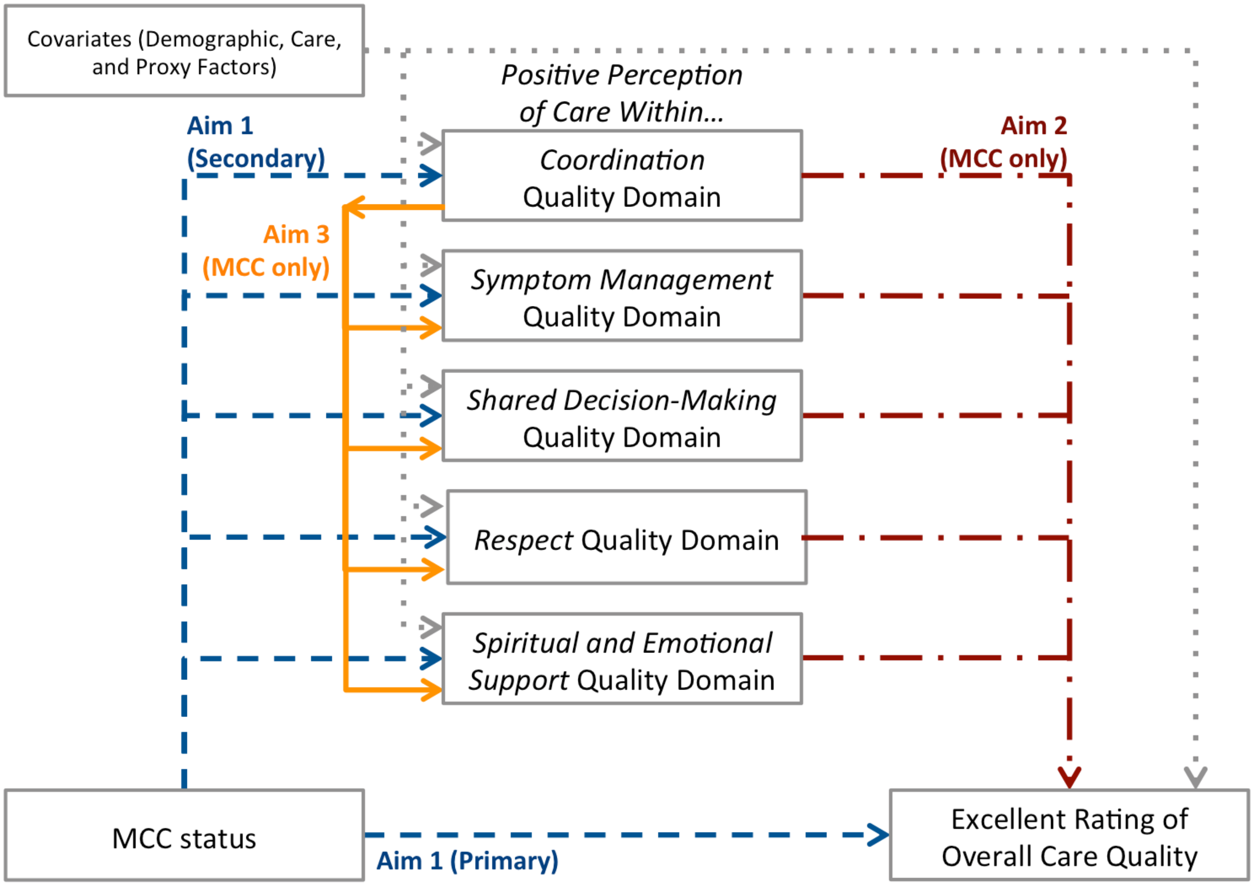


Figure 2-1. Conceptual framework of study aims. Aim 1 examined the association between MCC status and overall care quality rating (primary) and between MCC status and each quality domain (secondary). Aim 2 examined the association between each quality domain and overall care quality rating. Aim 3 examined the relationship between the *coordination* quality domain and each of the other 4 quality domains.

Conceptual Model

The Teno Model informed NHATS, LMLI questions and formed the basis of this study. The Teno Model's creation occurred in two phases: (1) literature review, and (2) focus groups.[4] While prior definitions of high quality end-of-life care relied on expert opinion and literature alone, the Teno Model introduced input from patients, families, and practitioners.[4] Literature review involved a Medline search for end-of-life guidelines and standards published between

1986 and 1999, supplemented by the assembly of unpublished institutional guidelines from practice experts across multiple end-of-life settings. Thirty distinct sets of guidelines yielded 14 major end-of-life quality domains. Findings from the literature review then informed six focus groups conducted with 42 participants between January and April 1999. Focus group participants included family members 3 to 12 months post-loss recruited through hospices, hospitals, nursing homes, and home health care agencies. Focus group moderators led open-ended and focused discussion about what participants would consider high quality end-of-life care without seeking group consensus. Five themes emerged from these focus groups.

Teno and colleagues then created a preliminary conceptual model by combining their literature review and focus group findings, and they identified five end-of-life quality domains: (1) provides dying individuals with desired physical comfort and emotional support, (2) promotes shared medical decision-making, (3) provides health care and related services that are focused on the needs and values of the dying individual, (4) attends to the needs and values of those who care for and love the dying individual, and (5) coordinates health care and related services to smooth transitions among sites and types of service.[4] Teno and colleagues then created and validated a survey tool to assess each domain.[3] Further validation and refinement resulted in the final Teno Model used in this study:[1,4] *coordination*, *symptom management, shared decision-making, respect,* and *spiritual and emotional support.*

Data Source

All data used in this study came from the National Health and Aging Trends Study (NHATS), a longitudinal study collected annually since 2011. NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG032947) through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health.[8] The purpose of NHATS is to be a research tool that reduces disability, maximizes health and independence, and enhances quality of life for older adults.[8] The following sections describe the NHATS design, data collection, and data availability.

National Health and Aging Trends Study design

NHATS follows a nationally representative sample of over 8,000 Medicare beneficiaries aged 65 and older.[68] Participants were initially interviewed in 2011 and are re-interviewed annually. Five rounds of NHATS data were available at the time of this study. The original NHATS participant sample, drawn from the Medicare enrollment file, was limited to beneficiaries aged 65 or older, alive on September 30, 2010, and residing in the contiguous US. Sampling followed a three-stage design: (1) selected 95 primary sampling units (counties and groups of counties); (2) selected 655 secondary sampling units (ZIPs and ZIP fragments); and (3) selected eligible beneficiaries residing within the secondary sampling units. Sampling identified 12,411 individuals potentially eligible for NHATS, but 774 were deemed ineligible prior to fieldwork.[68] Of the 11,637 eligible for inclusion upon contact, 8,245 responded for a weighted response rate of 71%. Sample replenishment began in 2016 with NHATS Round 5.

NHATS weighting

NHATS oversampled older individuals (85+) and Black individuals to achieve targeted sample sizes for age and racial/ethnic groups.[68] NHATS aimed to enroll a large enough sample to allow for analysis of trends relating to 5-year age groups and race/ethnicity. NHATS provides survey weights for all NHATS data, including replicate tracker weights and analytic weights. Tracker weights represent all Medicare beneficiaries age 65+ alive on September 30, 2010 in the contiguous US who could have been sampled. Analytic weights represent only those alive and eligible during the fieldwork period for each round. Weights account for probability of selection and can be used to adjust for non-response.

NHATS tracker weights were applied to all analyses in this study to account for data being drawn from multiple rounds based on the participants' year of death. Weights for individual participants are calculated relative to other participants in their strata. The tracker weight was used so that participants were assigned a weight relative to the other members of the study sample rather than relative to only those alive in the round when their LMLI was collected.

National Health and Aging Trends data collection and availability

NHATS has two data collection components, both using validated and original tools: the Sample Person Interview (SPI) and the Last Month of Life Interview (LMLI). The SPI collects information on physical and cognitive capacity, activities of daily living, social, physical, technological environment, and participation in activities. NHATS collects SPI data for each participant from one of three sources: directly from the participant, from a designated proxy for participants unable to communicate, or from a facility employee for participants residing in a nursing home or custodial care (called "residential care" by NHATS). The SPI contains demographic and chronic condition data used in this study.

The LMLI provides details on NHATS participants' location, daily activities before death, and quality of care in the last month of life using the Teno Model.[68] Prior to the end-of-life, NHATS participants designate a proxy (i.e., family, friends, etc.) who is contacted to complete the LMLI after the participant dies. Facility employees can serve as proxies for participants who die in a facility without a designated proxy available. The average weighted response rate for the LMLI has been 95% in each round (Round 2: 95.6%; R3: 93.8%; R4: 95.2% R5: 97.1%).[68] NHATS was selected for use in this study because it is nationally representative of Medicare beneficiaries, who account for the vast majority of older adults with MCC who die each year.

Study Sample Inclusion and Exclusion Criteria

NHATS participants eligible for this study met the following criteria: deceased with an LMLI completed in NHATS Round 3 (2014), 4 (2015), or 5 (2016); had a proxy who was not an employee of the setting where the individual died; with complete chronic condition data reported before death; community-dwelling in the last month of life; and received care in the last month of life with a proxy rating the *overall* quality of that care. All participants were 65 or older and Medicare beneficiaries based on NHATS inclusion criteria. As Medicare beneficiaries account for 93% of Americans aged 65 and older,[25,26,28] this study describes end-of-life care quality experienced by the majority of community-dwelling older Americans with MCC. The following sections describe the rationale for each criterion. **Table 2-1** describes significant differences in key groups we compared while defining our inclusion and exclusion criteria, which are explained in detail in the following sections.

Deceased with an LMLI completed in NHATS Rounds 3, 4, or 5

NHATS participants must have a completed LMLI available for end-of-life care quality to be assessed. We compared deceased NHATS participants with an LMLI completed to those without and found no differences in demographics reported prior to the end of life. However, we could not assess differences at the end of life, as no information was available for deceased participants without an LMLI.

NHATS participants could have an LMLI completed in Round 2 (2013), Round 3 (2014), Round 4 (2015), or Round 5 (2016). No LMLIs were completed in Round 1 (2012). We excluded NHATS participants with an LMLI completed in Round 2 due to changes in survey questions between Rounds 2 and 3 relating to hospice enrollment, a key covariate in this study. In the LMLI, proxies report whether the NHATS participant died at home, in a hospital, in a nursing home, in a hospice resident, in transit, or elsewhere. The proxy then reports whether the participant received hospice if they died in a hospital or a nursing home. However, Round 2 proxies did not report whether individuals who died at home, in transit, or elsewhere received hospice care, which resulted in missing hospice enrollment information for individuals in one of those three locations. NHATS designers amended the LMLI after Round 2 to include more complete hospice enrollment data.

Because hospice enrollment cannot be determined for Round 2 LMLI participants, prior studies using the LMLI excluded Round 2 participants in any hospice-related analyses. We experimented with imputing the hospice variable for Round 2 participants through multiple imputation methods based on participants’ age, gender, race, and place of death. However, imputation resulted in an unstable dataset, particularly when survey weights were applied to analysis. After consulting with Joan Teno, we dropped Round 2 participants from the study sample and used participants from Rounds 3, 4, and 5 only. To assess potential for bias, we compared individuals who died in Round 2 to those who died in other rounds and found Round 2 participants differed by proxy gender, dementia reported, and place of death, as shown in **Table 2-1, Line 1**. After removing Round 2 participants, our study participants differed across rounds on two factors: age and proxy type, as shown in **Table 2-1, Line 2**.

Non-facility employee proxy

We excluded participants whose LMLI was completed by a facility employee due to potential for bias in quality reporting, as the care provider could also be the person rating the quality of care. Participants with a facility proxy were also most frequently older, female, white, widowed, and most frequently died in a nursing home (**Table 2-1, Line 3**). Prior studies using the LMLI also excluded facility employee proxies due to the same issue.[1]

Sufficient chronic condition data reported before death

Sufficient chronic condition data were required for determining MCC status. Each year, NHATS participants report the presence of a list of chronic conditions collected by NHATS. After reporting specific chronic conditions, NHATS participants respond to an open-ended follow-up question of whether a doctor has ever told them they have another serious disease or illness. The follow-up question attempts to identify any conditions missed in the close-ended, condition-specific questions.

NHATS only collects chronic conditions through direct report from the participant, rather than from a proxy. As a result, participants may lack chronic condition data for rounds prior to their death if a proxy completed the survey for that round. **Appendix A** describes the process for determining the presence or absence of each chronic condition reported in the NHATS, which forms the basis of the MCC variable determination.

Missing chronic condition data were more prevalent for residential care-dwelling participants than community-dwelling participants due to a higher rate of proxy-completed NHATS surveys prior to the end of life. Only 1% of the community sample lacked sufficient chronic condition data to determine their MCC status, compared to 20% of the residential care-dwelling sample. For NHATS participants missing any chronic condition data, 398 lacked all chronic condition data, while 1,254 had some chronic condition data present. There was no pattern for which chronic conditions lacked information for those who had some, but not all, chronic condition data.

Community-dwelling in the last month of life

We also excluded participants who primarily dwelled in residential care in the last month of life due to differences in demographic and care factors; however, to ensure we did not overlook the end-of-life experience of residential care-dwelling individuals, we examined this subgroup in a separate analysis. We stratified analysis by residential status after determining that combining the groups may mask important findings. Participants dwelling primarily in residential care in the last month of life differed significantly from those dwelling in the community on 10 of 12 demographic, care, and proxy factors of interest at the p<.05 level (**Table 2-1, Line 5**). Even when limited to participants with non-facility proxies (see **Study Sample**), community-dwelling and residential care-dwelling participants still differed significantly at the p<.05 level for most factors (**Table 2-1, Line 6**).

Since residential care-dwelling older adults are an understudied group that may experience unique end-of-life challenges, we repeated all analyses with the residential care-dwelling sample, reported in **Chapter 6**. Findings from the residential care analysis have limited generalizability, however, as 71% of deceased residential care-dwelling NHATS participants were excluded from the study sample. We excluded 40.1% due to the use of a facility employee proxy. We excluded 21.1% due to inconclusive MCC status. The remaining 6.0% were excluded because their LMLI was collected during Round 2. Residential care participants with a facility proxy only differed on marital status at death and proxy gender with those with a non-facility proxy (**Table 2-1, Line 4**). However, residential care-dwelling participants with an inconclusive MCC status differed from those with conclusive MCC status on several factors (**Table 2-1, Line 7**).

Study Sample

Appendix B includes a flowchart of NHATS participant inclusion in this study. 1,824 of 8,245 NHATS participants died during the first five NHATS rounds, representing 4,070,978 Medicare beneficiaries when weighted. LMLIs were available for 1,726 deceased participants, while 98 died and did not have an LMLI completed (30 in Round 2, 33 in Round 3, 22 in Round 4, and 13 in Round 5). As previously discussed, deceased participants without an LMLI did not differ from those with an LMLI on demographic factors reported prior to the end of life.

Community-dwelling sample

Of the 1,726 participants with completed LMLIs, 985 dwelled primarily in the community in the last month of life (298 in Round 2, 288 in Round 3, 237 in Round 4, and 162 in Round 5), representing 2,359,776 Medicare beneficiaries when weighted. 320 community-dwelling participants (787,609 when weighted), or 32% of all deceased community-dwelling NHATS participants with an LMLI (33% when weighted), did not meet study inclusion criteria: 8 had a facility proxy; 10 had an inconclusive MCC status; 290 died in Round 2; and 12 were missing key covariate data (3 were missing Medicaid status, 4 were missing hospice enrollment status, 1 was missing proxy relationship to the deceased, and 4 were missing proxy gender). Excluded participants did not differ significantly from those included with the exception of the 290 dying in Round 2, as described in the previous section.

The final community-dwelling analytic sample included 665 NHATS participants, representing 1,572,166 Medicare beneficiaries when weighted. The final sample includes 98% of all community-dwelling NHATS participants who died in Rounds 3, 4, or 5 (97% when weighted). Aim 1 analyzed data for the entire final community-dwelling analytic sample, but the samples for Aim 2 and 3 vary slightly based on specific exclusion criteria unique to each aim. **Table 2-2** describes the study samples used in each aim as well as their difference from the final community-dwelling analytic sample.

Of note, multiple LMLI items offer NHATS proxies the response option of “No care in the last month of life,” which resulted in small inconsistencies across LMLI items in the reported presence of care (see **Variables** for detail on LMLI items). We used the *rating of overall care quality* item to define the Aim 2 sample and the *coordination* item to define the Aim 3 sample. One proxy reported care was present for the *coordination* item but not present for the *rating of overall care quality* item. This discrepancy accounts for the small difference in the participants who did not receive care in the last month of life in Aim 2 compared to Aim 3.

Residential care-dwelling sample

Of the 1,726 participants with completed LMLIs, 741 dwelled primarily in residential care (205 in Round 2, 235 in Round 3, 167 in Round 4, and 134 in Round 5), representing 1,513,556 Medicare beneficiaries when weighted. Exclusion criteria applied to 536 residential care-dwelling participants (1,073,458 when weighted), or 72% of all deceased residential care-dwelling NHATS participants (71% when weighted): 306 had a facility proxy; 163 had an inconclusive MCC status; 48 died in Round 2, and 19 were missing key covariate data (2 were missing Medicaid status, 5 were missing hospice enrollment, 11 were missing proxy gender, and

1 was missing both hospice and proxy gender). Excluded participants did differ significantly from those included in analysis, as described in the previous sections and **Table 2-1**.

The final residential care-dwelling analytic sample included 205 NHATS participants, representing 440,098 Medicare beneficiaries when weighted. The final sample includes 38% of all residential care-dwelling NHATS participants who died in Rounds 3, 4, or 5 (40% when weighted).

Variables

The study's independent and dependent variables varied by aim, as shown in **Table 2-3** and defined in the following sections.

Definition of the multiple chronic conditions status variable

MCC status was an independent variable in Aim 1 and defined the subgroup analyses that comprised Aims 2 and 3. For this study, we defined MCC as the presence of 2 or more of the following conditions: heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer. MCC status was a dichotomous binary variable (present/absent). **Appendix A** describes the process for determining MCC status for each participant.

Defining the MCC status variable was a critical decision during the planning of this study, as the MCC definition drives this study's results and interpretation. The Agency for Healthcare Research and Quality (AHRQ) defines a chronic condition as: "A condition that lasts 12 months or longer and meets one or both of the following tests: (1) it places limitations on self-care, independent living, and social interactions; and (2) it results in the need for ongoing intervention with medical products, services, and special equipment."[69] AHRQ maintains a list of conditions it recognizes as chronic, which was developed by a panel of physician experts.[70]

Annually, NHATS participants report the presence of the following AHRQ-recognized chronic conditions: heart attack, heart disease, hypertension, arthritis, diabetes, lung disease, dementia, and cancer.[70]

While the list of chronic conditions has been well-developed and validated, the MCC literature lacks an official, universally applied definition of MCC. As discussed in the prior chapter, the National Quality Forum (NQF) defines MCC as: "…two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination."[71] Researchers apply that definition differently across studies of MCC based on their interpretation of which conditions yield adverse effects in combination. For example, as discussed in the prior chapter, Piette and Kerr define MCC in terms of concordant and discordant conditions based on conditions' pathophysiologic similarities and ability to be managed through the same care plan.[43] Similarly, the MCC definition used by Wolff et al groups conditions by impacted organ system, under the rationale that such conditions could be managed by the same physician specialty.[72] Meanwhile, others advocate an MCC definition that clusters conditions based on their severity, cost, and overall priority to the healthcare system.[73] Still other studies simply count the presence of chronic conditions without consideration of conditions' similarities, severity, or contribution to complexity.[74] Prominent researchers in the field cite the nearly infinite condition combinations that can define MCC as a major barrier to developing a coherent body of literature on the topic.[75]

In planning this study, we examined six different potential MCC definitions using the AHRQ-recognized chronic conditions collected by NHATS before selecting the study definition.

Table 2-4 displays the candidate definitions we examined, while **Table 2-5** presents the distribution of MCC status for each candidate MCC definition. The study's resulting MCC definition was the presence of 2 or more of the following conditions: heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer. Three issues were considered in defining MCC for this study: (1) whether to include hypertension, a highly prevalent condition in the older adult population; (2) whether to collapse similar conditions; and (3) whether to include dementia and cancer in the definition. The following sections discuss each issue we considered.

Inclusion of hypertension. While hypertension is an AHRQ-recognized chronic condition that lasts longer than 12 months and typically requires medical intervention in the form of medication and lifestyle changes, we questioned whether it met NQF's definition of MCC due to the relative simplicity of its management. Approximately 75% of participants eligible for this study reported the presence of hypertension (74% of community-dwelling participants; 75% of residential care-dwelling participants), which inflated the MCC group without contributing meaningfully to the complexity of care. We considered three different approaches for handling hypertension in the sample: (1) including hypertension (Definitions 1 and 2); (2) including hypertension only in combination with stroke, which was considered to be a complication of severe hypertension that may contribute meaningfully to complexity (Definition 3); and (3) excluding hypertension from the MCC definition (Definitions 4, 5, and 6). We ultimately decided to exclude hypertension from the study's MCC definition for clinical and analytic reasons.

Table 2-6 describes the distribution of the presence of hypertension and other chronic conditions in this study's community-dwelling and residential care-dwelling analytic samples. Of the 8 chronic conditions captured by the NHATS, hypertension was reported as the only chronic condition for 3.5% of the community-dwelling and 1.7% of the residential care-dwelling participants, while 60.3% of the community-dwelling and 64.6% of the residential care-dwelling participants had hypertension and at least two more conditions. Deciding to include or exclude hypertension did not change the MCC status of those groups. The hypertension-only group would not have MCC regardless of its definition due to the presence of only one chronic condition, while the group with hypertension and at least two more conditions would meet the MCC definition even with hypertension excluded.

Including or excluding hypertension from the MCC definition impacted the 10.4% of community-dwelling and 9.0% of residential care-dwelling participants who had hypertension and only one other condition. We examined differences in demographic, care, and proxy factors for participants whose MCC status would change when hypertension was excluded compared to those whose MCC status would not change. The groups differed significantly at the p<.05 level for four factors: race/ethnicity, dementia reported, cancer reported, and place of death. We also examined the impact of including hypertension in the MCC definition only if the participant had also suffered a stroke (16.9% of the community-dwelling sample; 29.2% of the residential care-dwelling sample). The combination of stroke and hypertension was thought to reflect more severe hypertension that might add more complexity to managing the condition, making it meet NQF's MCC criteria.

We determined that the overall study outcomes did not differ significantly when hypertension was excluded from the MCC definition or when hypertension and stroke were considered together. Additionally, we deemed that complications of more severe hypertension would be reflected in the other cardiovascular conditions included in the study's MCC definition, such as heart disease or heart attack.[76,77]

Collapsing similar conditions. As discussed previously, Piette and Kerr's MCC typology identifies that conditions can either be concordant or discordant.[43] Following that typology, we examined the impact of collapsing heart attack, heart disease, and hypertension into one cardiovascular condition category, as they are concordant conditions managed through similar care plans.[43] We examined the impact of collapsing concurrent conditions in three different ways: collapsing heart attack, heart disease, and hypertension (**Table 2-4, Definition 1**); collapsing heart attack, heart disease, and hypertension only if the participant also reported stroke (**Table 2-4, Definition 3**); and collapsing heart attack and heart disease while excluding hypertension (**Table 2-4, Definition 4**). Sensitivity analysis showed that findings varied little when cardiovascular conditions were collapsed compared to when they were each counted separately in the MCC definition since most participants who had cardiovascular conditions also had other chronic conditions. As such, most participants' MCC status did not change when cardiovascular conditions were counted individually compared to when they were collapsed. As a result, we decided to count each cardiovascular condition separately when determining MCC status.

Treatment of dementia and cancer. While AHRQ recognizes dementia and cancer as chronic conditions, notable differences exist between dementia, cancer, and other chronic conditions that challenge whether they should be included in the MCC definition. As described in **Chapter 1**, older adults with dementia or cancer experience different end-of-life challenges from individuals with other chronic conditions[41] due to their unique trajectories to death.[40] In the presence of dementia and cancer, typical clinical management strategies may differ, as well. While some chronic cancers, such as prostate cancer, can be managed similarly to other chronic conditions, they cannot be separated from acute cancers in the NHATS.

We ultimately decided to include dementia and cancer in our MCC definition due to their inclusion in AHRQ's chronic condition list. However, to ensure our analysis reflected the potential influence of dementia and cancer, we considered both conditions as covariates. Notably, our community-dwelling sample may contain a lower prevalence of individuals with dementia than the general population. As 70% of Medicare beneficiaries with dementia die in a nursing home,[78] the prevalence of dementia in this study's primary, community-dwelling sample may be lower than in the nation's older adult population overall.

Definition of excellent overall end-of-life care quality rating variable

Excellent rating of *overall* care quality is a dependent variable in Aims 1 and 2. In NHATS, proxies rate *overall* end-of-life care quality on a 5-point Likert scale ("excellent", "very good", "good", "fair", "poor").[68] The LMLI asks for a rating of *overall* care quality as a unique question and not a summation of the experience in end-of-life quality domains ("Overall, how would rate [participant]'s care in the last month of life? Would you say it was: excellent, very good, good, fair, or poor?"). Since this study was interested in high quality care, rating of *overall* care quality was dichotomized into "excellent" or "not excellent", which collapsed "very good", "good", "fair", and "poor" ratings. This reclassification approach mirrors that used by Teno et al[1] in analysis of NHATS, LMLI data for all community-dwelling older adults. The reclassification also aligns with the top-box score method often used when analyzing patient satisfaction data for performance improvement.[79] **Appendix C** contains a flowchart showing the process for defining the excellent rating of *overall* care quality variable.

Definition of positive perception of care within each quality domain variables

Positive perception of care in the Teno Model's *composite quality domains* and each domains' individual *components*, as described in **Table 2-7**, were dependent variables in Aim 1, independent variables in Aim 2, and both independent and dependent variables in Aim 3. We dichotomized the perception of each *composite quality domain* and individual *component* into "positive" or "not positive." **Appendix C** contains a flowchart of the processes for defining each individual *component* and *composite quality domain* variable and coding NHATS, LMLI item responses into "positive" or "not positive" for each variable.

We defined positive perception of care for the individual *components* of a *composite quality domain* as a proxy reporting that the participant had a need within the *component* and that the participant received the desired level of support for that need. We defined positive perception of care for the *composite quality domains* as a proxy reporting that the participant received the desired level of support for each individual *component* in the *composite quality domain* where a need was identified, with the exception of the coordination *composite quality domain*. We defined the perception of the coordination *composite quality domain* as "positive" if a proxy reported only one doctor was involved in the participants' care, or that someone was in charge of care if more than one doctor was involved. We defined the perception of the coordination *composite quality domain* as "not positive" if more than one doctor was involved in care without someone designated as in charge. We based our coordination definition after consultation with Joan Teno.(Joan M. Teno, MD, e-mail communication, November 2015)

Because we were interested in perception of quality, we limited analysis for each *component* or *composite quality domain* to participants who had a need, and whose proxy rated care, for that *component* or *composite quality domain*. However, because some proxies did not know whether the deceased participant had a need or received care in certain *components*, we assessed each outcome to determine if the reason for not rating care differed by MCC group. We identified no significant differences in proxies' awareness of participants' end-of-life needs by MCC status, so we felt confident excluding those without both a reported need and a care rating from the multivariable analysis.

Covariate Assessment

We considered potential covariates derived from clinical experience and existing literature on end-of-life care quality: age, gender, race/ethnicity, Census region, Medicaid enrollment, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy gender and proxy relationship to the deceased.

We examined *gender* and *age* as covariates based on literature suggesting differences in treatment across demographic groups. For example, in their study of Medicare spending in the last year of life, Bird et al[80] identified an interaction between age and gender: spending patterns revealed a tendency to treat men more aggressively, particularly at older ages, while treating women less aggressively across all age groups.

We considered *race/ethnicity* based on literature suggesting differences in care preferences and outcomes across racial and ethnic groups. In their survey of Medicare beneficiaries from multiple racial and ethnic groups, Barnato et al[81] identified a preference for intensive end-of-life treatment among Hispanic and African American older adults compared to

White individuals. Fishman et al[82] found a similar finding in their study, which identified stronger preference for continuing curative treatment rather than transitioning to hospice among African American individuals with cancer compared to White individuals. Abdollah et al[83] identified racial and ethnic differences in the aggressiveness of care provided to older adults dying of prostate cancer, suggesting that African American older adults receive less frequent diagnostic and therapeutic interventions, while receiving higher intensity, more aggressive end-of-life care. Additionally, Welch et al[84] reported that older African-American individuals are less likely than White individuals to report receiving excellent care adherent to their treatment wishes and more likely to report poor communication with end-of-life providers. NHATS, LMLI public use data combine race and ethnicity into a single variable, which limited our ability to draw meaningful conclusions about race and ethnicity in this study.

We also considered *cancer reported, hospice enrollment,* and *place of death* as covariates. However, studies suggest these factors may be related to each other. End-of-life quality literature suggests that individuals enrolled in hospice are the most likely to report end-of-life care quality as excellent.[3,31] However, individuals with a cancer diagnosis are the most likely to experience appropriate hospice use.[85–87] Conversely, individuals with non-cancer diagnoses are most likely to experience long[86] or short [87] hospice enrollment, thought to be attributable to prognostic challenges for individuals without cancer.[88] However, investigation by Teno et al[89] identified that even short hospice stays can be beneficial to the overall end-of-life quality experience. In their analysis of the Family Evaluation of Hospice Care survey, they identified that family perception of the timing of hospice referral as “too late” was more highly associated with poor satisfaction and quality ratings than the actual length of hospice enrollment. Deaths in a hospital or an intensive care unit are associated with poorer quality of care than deaths in hospice, including poorer communication with medical providers, decreased likelihood of being treated with respect, and lower overall rating of care quality.[1,3]

We considered *proxy gender* and *relationship to the participant* based on literature suggesting quality ratings differ by proxy type.[90,91] For example, studies indicate that due to wide variation in practices for identifying proxies across retrospective end-of-life care quality surveys, proxy reliability cannot be currently defined.[90,91] Additionally, family caregiving configurations often change as an individual approaches death, such that no individual proxy has the full picture of the end-of-life care delivered.[90] However, one study suggests that proxy report is typically accurate for objective measures like care received but less accurate for subjective measures, such as degree of pain.[92] A different study showed proxies and patients give similar reports of healthcare quality.[93]

We examined four additional covariates – *dementia reported, Census region, Medicaid enrollment,* and *marital status at death* – because of their potential association with our dependent variables. We considered dementia reported due to differences in trajectories to death among persons with dementia [40] and due to unique needs among this population. We also included Census region to assess for geographic variation.[94] While all participants were Medicare beneficiaries due to NHATS inclusion criteria, we also included Medicaid enrollment as a proxy for socioeconomic status.[95] Lastly, we examined marital status at death as a potential proxy for the presence of a support network, which may be associated with quality of end-of-life care.[96]

Analysis Plan

We used STATA Version 12 for data management and to conduct all analyses, applying NHATS-supplied tracker weights where appropriate.[97] We examined missing data prior to analysis to assess for potential bias, and excluded participants missing covariate data, after determining they did not differ significantly from participants with complete covariate data available. A p-value of ≤.05 was considered statistically significant for all analyses. The following chapters (**Chapters 3 through 5**) describe each aims' specific analysis approach.

Power Calculations

We performed power calculations for all aims prior to analysis based on findings from a 2000 national follow-back survey of end-of-life care, which asked participants the same questions as the NHATS, LMLI.[3] We based estimations for older adults with MCC on older adults who died in the hospital and estimations for older adults without MCC on those who died in hospice, given literature identifying barriers to hospice use for older adults with MCC. Although the community-dwelling sample represented 1,572,166 Medicare beneficiaries and the residential care-dwelling sample represented 440,098 when weighted, we used a conservative approach and based all power calculations on the raw sample. We pooled all LMLI rounds to increase power. All aims were powered to detect meaningful differences at 80% power where α=.05.

Chapter 3: The Association between the Presence of Multiple Chronic Conditions and the Experience of High-Quality End-Of-Life Care for Community-Dwelling Older Adults

Objective

(1) To describe the end-of-life care experienced by older adults with multiple chronic conditions (MCC)

(2) To evaluate the relationship between MCC status and proxy-reported rating of *overall* end-of-life care quality and specific quality-related subdomains.

Methods

Retrospective cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). Bivariable analyses were conducted using the Wald statistic to determine unadjusted relationships between MCC status and the following outcomes: (1) excellent rating of *overall* care quality, and (2) perception of care for recognized dimensions of quality. Multiple logistic regression compared unadjusted and adjusted ratings of care quality for older adults with MCC to those without MCC. Appropriate survey weights were applied to all analysis.

Results

The final analytic sample included 665 participants, which represented 1,572,166 Medicare beneficiaries when weighted (77% with MCC, 23% without). MCC was associated with reporting greater breathing issues (aOR 1.60; 95% CI: 1.05-2.43) and more anxiety or sadness (aOR 1.59; 95% CI: 1.02-2.46) in the last month of life. *Overall* end-of-life care quality was rated as “not excellent” by 49% of MCC proxies. The proportion of MCC proxies who reported care as “not

positive" varied by *composite quality domain*: coordination (15%), symptom management (29%), shared decision-making (22%), respect (25%), and spiritual and emotional support (69%). MCC was not significantly associated with the rating of *overall* care quality in unadjusted or adjusted models.

Conclusion

While end-of-life care quality does not differ significantly for older adults based on their MCC status, end-of-life care quality is lacking for all older adults, particularly for spiritual and emotional support. Findings indicate older adults with MCC experience greater end-of-life care needs than those without MCC.

Introduction

The quality of end-of-life care experienced by community-dwelling Medicare beneficiaries aged 65 and older impacts the dying individual, their caregivers,[16,18,93] their medical providers,[15] and society as a whole.[14,26] While literature identifies that only 47% of older adults aged 65 years and older receive high quality end-of-life care, the end-of-life care quality experienced by the growing population of older adults with multiple chronic conditions (MCC) has yet to be defined.[2] Older adults with MCC experience known medical complexity,[39] barriers accessing high quality health care,[6] and unique end-of-life challenges.[4,40,41] Defining the end-of-life care quality experienced by older adults with MCC is a necessary step toward identifying needed improvements and minimizing suboptimal outcomes associated with poor end-of-life care quality in this subpopulation.

Two-thirds of older adults lived with MCC in 2012.[10] The National Quality Forum (NQF) defines MCC as: "…two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination."[9] When approaching the end of life, most older adults with MCC lack a linear trajectory to death and instead experience frequent cycles of decline and improvement that pose a challenge for planning and delivering care.[13] As a result, it is difficult to determine when end-of-life-specific interventions should be started. For example, the 6-month prognosis required by Medicare for hospice enrollment may be impossible to determine for older adults with MCC as a result of the type of illness trajectory.[41] Prognostic uncertainty may lead older adults with MCC to receive fragmented end-of-life care in a general healthcare system focused on stabilization and one which is unprepared to address end-of-life specific needs.[4] However, little is known about how risks match reality since few studies have explicitly examined the end-of-life care quality experienced by older adults with MCC.[54,57,58]

A prominent and widely accepted conceptual model developed by Joan Teno and colleagues (Teno Model) indicates that high quality end-of-life requires assessment and intervention in five domains, regardless of the delivery setting or approach:[1,3,4]

- *Coordination:* Designated professionals take responsibility for overseeing the care team and organizing consistent care across care settings.
- *Symptom Management*: Dying individuals receive their desired level of support for symptoms such as pain and difficulty breathing.
- *Shared decision-making*: Decisions reflect dying individuals' goals and values and include their input.

- *Respect*: Dying individuals are treated with respect and receive support for personal care needs.
- *Spiritual and Emotional Support:* Dying individuals and their families receive their desired amount of support for their spiritual and emotional needs.

The Teno Model informed a nationally representative study conducted in 2000 with proxies for recently deceased individuals.[3] In the study, approximately 25% of all dying individuals experienced unmet symptom needs, 25% lacked shared decision-making, 21% experienced issues with respect, 50% did not receive enough emotional support, and 15% felt medical providers did not know enough about the dying individual to provide the best care. Additionally, proxy ratings of *overall* end-of-life care quality declined from 57% in the 2000 survey to 47% in a more recent analysis.[1]

While there is literature describing end-of-life care quality for the general older adult population using the Teno Model, we do not know whether older adults with MCC experience end-of-life care that meets specified domains of quality, or whether end-of-life care for older adults with MCC differs from care for those without MCC. Without information on end-of-life care quality for older adults with MCC, it is impossible to determine whether current end-of-life policies and care approaches adequately meet the needs of this subpopulation. Meaningfully improving end-of-life care quality for older adults with MCC requires understanding the care quality they experience and how care differs for this population when compared to older adults generally.

Objective

Drawing upon the Teno Model,[3] the objectives of this study were: (1) to describe the end-of-life care experienced by older adults with MCC, and (2) to evaluate the relationship between MCC status and proxy-reported rating of *overall* end-of-life care quality and specific quality-related dimensions. Based on previous literature cited above about challenges older adults with MCC experience accessing high quality care prior to the end-of-life, we hypothesized that proxies for older adults with MCC would rate care quality as lower than proxies for older adults without MCC.

Design and Methods

Study Design and Data Source

This study was a retrospective, cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). The NHATS, LMLI was administered to designated proxies, such as family or friends, for deceased Medicare beneficiaries aged 65 or older.[8] Collected annually since 2011, NHATS follows a nationally representative sample of over 8,000 Medicare beneficiaries aged 65 and older.

The LMLI provides details on NHATS participants' location, daily activities before death, and quality of care in the last month of life using the Teno Model.[68] Prior to the end-of-life, NHATS participants designate a proxy (i.e., family, friends, etc.) who is contacted to complete the LMLI after the participant dies. Facility employees can serve as proxies for participants who die in a facility without a designated proxy available. The average response rate for the LMLI is 95% in each round.[68] We used NHATS for this study because it is nationally representative of

Medicare beneficiaries, who account for the vast majority of older adults with MCC who die each year. Demographic and chronic condition data used in this study were reported directly from the NHATS participant prior to the end-of-life.

Sample

NHATS participants eligible for this study met the following criteria: deceased with an LMLI completed in NHATS Rounds 3 (2014), 4 (2015), or 5 (2016); community-dwelling in the last month of life; had a proxy who was not an employee of the setting where the individual died; with complete chronic condition data reported before death; and received care in the last month of life with a proxy rating the *overall* quality of that care. We excluded NHATS participants with an LMLI completed in Round 2 due to changes in survey questions between Rounds 2 and 3 relating to hospice enrollment, a key covariate in this study. We also excluded participants who primarily dwelled in residential care in the last month of life due to differences in demographic and care factors; however, we examined this subgroup in a separate analysis (see **Chapter 6**). We excluded community-dwelling participants whose LMLI was completed by a facility employee due to potential for bias in quality reporting, as the care provider could also be the person rating the quality of care. We excluded 12 NHATS participants for whom chronic condition data was missing rather than attempting imputation in an effort to preserve the validity of the study's survey weights.

All participants were aged 65 years or older and were Medicare beneficiaries based on NHATS inclusion criteria. As Medicare beneficiaries account for 93% of Americans aged 65 years and older,[25,27,28] this study describes end-of-life care quality experienced by the majority of community-dwelling older Americans with MCC.

Measures

MCC status was this study's primary independent variable (operationalized as "present" or "absent"). Annually, NHATS participants report the presence of the following chronic conditions: heart attack, heart disease, hypertension, arthritis, diabetes, lung disease, dementia, and cancer.[70] For this study, we defined MCC as the presence of 2 or more of the following conditions: heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer. We excluded hypertension from the MCC definition for analytic and conceptual reasons. 74% of eligible participants reported the presence of hypertension, which inflated the MCC group without contributing meaningfully to the complexity of care. To be included in this study's MCC definition, individuals with hypertension had to have at least two other chronic conditions We deemed that complications of more severe hypertension would be reflected in the other cardiovascular conditions included in the study's MCC definition (heart attack and heart disease). Our sensitivity analysis included six different definitions of MCC informed by chronic condition literature,[9,10,12,43,70,73] and found the definition of MCC did not alter our significant results. We selected this study's MCC definition based on its representation of AHRQ-recognized conditions and its alignment with the NQF MCC definition, described at the outset of this paper.[9]

Excellent rating of *overall* care quality was this aim's primary outcome. In NHATS, proxies rate *overall* end-of-life care quality on a 5-point Likert scale ("excellent", "very good", "good", "fair", "poor").[68] The LMLI asks for a rating of *overall* care quality as a unique question and not a summation of the experience in end-of-life quality domains. Since this study was interested in high quality care, rating of *overall* care quality was dichotomized into "excellent" or “not excellent”, which collapsed “very good”, “good”, “fair”, and “poor” ratings. This reclassification approach mirrors that used by Teno et al[1] in analysis of NHATS, LMLI data for all community-dwelling older adults.

Secondary outcomes were positive perception of care in the Teno Model’s *composite quality domains* and each domains’ individual *components*, as described in **Table 2-7**. We dichotomized the perception of each *composite quality domain* and individual *component* into “positive” or “not positive” following processes defined in **Appendix C**. We defined positive perception of care for the individual *components* of a *composite quality domain* as a proxy reporting that the participant had a need within the *component* and that the participant received the desired level of support for that need. We defined positive perception of care for the *composite quality domains* as a proxy reporting that the participant received the desired level of support for each individual *component* in the quality domain where a need was identified, with the exception of the coordination *composite quality domain*. We defined the perception of the coordination *composite quality domain* as “positive” if a proxy reported only one doctor was involved in the participants’ care, or that someone was in charge of care if more than one doctor was involved. We defined the perception of the coordination *composite quality domain* as “not positive” if more than one doctor was involved in care without someone designated as in charge.

Because we were interested in perception of quality, we limited analysis for each *component* or *composite quality domain* to participants who had a need, and whose proxy rated care, for that *component* or *composite quality domain*. However, because some proxies did not know whether the deceased participant had a need or received care in certain *components*, we assessed each outcome to determine if the reason for not rating care differed by MCC group. We identified no significant differences in proxies' awareness of participants' end-of-life needs by MCC status, so we felt confident excluding those without both a reported need and a care rating from the multivariable analysis.

Statistical Methods

First, we used descriptive analysis of demographic, care, and proxy factors to characterize the study sample. Next, we conducted bivariable analyses using the Wald statistic to determine the unadjusted relationships between MCC status and the following outcomes: (1) excellent rating of *overall* care quality, (2) perception of care for *composite quality domains*, and (3) perception of care for individual *components*. We examined the bivariable analyses to describe the end-of-life care experienced by the MCC population. We examined the association between demographic, care, and proxy characteristics and each outcome of interest, to assess factors associated with excellent care in that population. Next, multiple logistic regression compared ratings of *overall* care quality for older adults with MCC to those without MCC, both unadjusted and adjusted for covariates.

Covariates derived from existing literature on end-of-life care quality were included in all multivariable models: age, gender, race/ethnicity, Census region, Medicaid enrollment, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy gender and proxy relationship to the deceased. Age, race/ethnicity, Census region, marital status at death, place of death, and proxy relationship to the deceased were all categorical variables, while gender, Medicaid enrollment, dementia reported, cancer reported, hospice enrollment, and proxy gender were all binary variables. NHATS, LMLI public use data combines race and ethnicity into a single variable. Marital status at the time of death was dichotomized into married and not married, which also included widowed individuals.

We used STATA Version 12 to conduct all analyses, applying NHATS-supplied tracker weights where appropriate.[97] A p-value of ≤.05 was considered statistically significant for all analyses. We examined missing data prior to analysis to assess for potential bias, and excluded participants missing covariate data, after determining they did not differ significantly from participants with complete covariate data available. The Northwestern University Institutional Review Board deemed this study exempt.

Results

Descriptive and Bivariable Analysis

LMLIs were available for 1,223 of 8,245 (14.8%) NHATS participants in Round 3, 4, or 5. Of those, 687 (56%) were community-dwelling in the last month of life. However, after verifying no difference from other participants on the reported covariates, we excluded 22 (3.2%) community-dwelling NHATS participants with a Round 3, 4, or 5 LMLI for the following reasons: ineligibility due to a facility employee proxy (n=4; .6%); inconclusive MCC status (n=7; 1.0%); and missing covariate information (n=11; 1.6%). The final analytic sample included 665 participants (96.8% of community-dwelling participants), which represented 1,572,166 Medicare beneficiaries when weighted (**Table 3-1**). The sample was mostly white (78%), married (43%) or widowed (43%) at the time of death, and died at home (43%) or in a hospital (37%). The sample was fairly evenly distributed by gender (48% men vs. 52% women). Half of the sample received hospice care in the last month of life. Most proxies were female (73%) and children of the deceased NHATS participants (54%).

After weighting, 77% of the sample met the study's MCC criteria, representing 1,211,208 individuals (raw N=503), while 23% did not, representing 360,958 individuals (raw N=162). **Table 3-1** shows differences in the participants' demographic, care, and proxy factors by MCC status. The MCC group had significantly higher prevalence of hospice enrollment (54% vs. 38%; p = .005), dementia (23% vs. 8%; p<.001), and cancer (46% vs. 9%; p<.001). However, odds of hospice enrollment did not differ significantly by MCC status after controlling for differences in the report of dementia and cancer between groups (data not shown). Hospice enrollment was significantly higher among those with cancer reported, regardless of MCC status (59% vs. 45%; p=.003; data not shown). Additionally, more than one doctor was involved in care for 72% of the sample, which did not differ significantly by MCC status (data not shown).

Differences in Need by Multiple Chronic Condition Status

Proxies for individuals with MCC (referred to as MCC proxies) reported a higher prevalence of need in all *composite quality domains* and *components* where needs could vary compared to proxies for participants without MCC (**Figure 3-1**). Among MCC proxies with awareness of participants' need, 85% reported symptom management needs, which included 75% with pain and 58% with breathing issues. MCC proxies also reported spiritual and emotional support needs for 82% of deceased participants, including 65% with anxiety/sadness and 49% desiring religious or spiritual support. MCC was significantly associated with reporting breathing issues (OR 1.60; 95% CI: 1.05-2.43) and anxiety/sadness (OR 1.59; 95% CI: 1.02-2.46) after adjusting for covariates (data not shown).

Differences in the Rating of *Overall* End-of-Life Care Quality by Multiple Chronic Condition Status

Overall end-of-life care quality was rated as "not excellent" by 49% of MCC proxies (**Table 3-2**). The proportion of MCC proxies who reported care as "not positive" varied by *composite quality domain*: coordination (15%), symptom management (29%), shared decision-making (22%), respect (25%), and spiritual and emotional support (69%). **Table 3-2** reports results from bivariable analysis of rating of *overall* care quality and perception of care in each *composite quality domain*. MCC proxies perceived the shared decision-making *composite quality domain* significantly less positively than non-MCC proxies (79% vs. 86%, p=.03). Significantly more MCC proxies reported receiving unwanted care (16% vs. 8%, p=.02), but more MCC proxies reported being kept informed about care (83% vs. 74%, p=.03). A significantly greater percentage of MCC proxies perceived of care for anxiety/sadness positively when compared to proxies for participants without MCC (53% vs. 37%, p=.02).

MCC was not significantly associated with the rating of *overall* care quality in unadjusted or adjusted models (**Table 3-3**). However, MCC was significantly associated with "positive" perception of breathing care (OR 3.13; 95% CI: 1.34-7.31), which was attributable to the greater proportion of individuals with lung disease in the MCC group (data not shown). MCC was also significantly associated with being informed about care (OR 2.05; 95% CI: 1.18-3.55).

Differences in Covariates by Perception of Care in Domains of End-of-Life Care Quality

Rating of *overall* care quality and perception of care in each *composite quality domain* were significantly associated with several covariates (**Table 3-4**). Dying in a hospital (OR .56; 95% CI: .34-.92) or in a setting other than home or a hospital, such as a nursing home (OR .42;

95% CI: .28-.64), were negatively associated with rating of *overall* care quality. Perception of the coordination *composite quality domain* was positively associated with dying at age 75 to 84 (OR 2.02; 95% CI: 1.09-3.76) or age 85+ (OR 2.62; 95% CI: 1.25-5.48) and black race (OR 2.73; 95% CI: 1.14-6.54), and negatively associated with dying in a hospital (OR .24; 95% CI: .11-.52) or in a setting other than home or a hospital, such as a nursing home (OR .19; 95% CI: .07-.49). Perception of the symptom management *composite quality domain* was positively associated with black race (OR 1.92; 95% CI: 1.06-3.49) and hospice enrollment (OR 2.19; 95% CI: 1.25-3.84). It was negatively associated with having cancer (OR .54; 95% CI: .35-.83) or a female proxy (OR .56; 95% CI: .32-.98). Perception of the shared decision-making *composite quality domain* was positively associated with having a child (OR 3.46; 95% CI: 1.67-7.17) or other relative proxy (OR 2.61; 95% CI: 1.02-6.67), and it was negatively associated with being never/not married (OR .37; 95% CI: .17-.83) or widowed (OR .50; 95% CI: .26-.98) at the time of death. Perception of the respect *composite quality domain* was positively associated with black race (OR 2.22; 95% CI: 1.31-3.76), and it was negatively associated with dying in a hospital (OR .47; 95% CI: .27-.83) or other setting (OR .37; 95% CI: .23-.60). Perception of the spiritual and emotional support *composite quality domain* was positively associated with hospice enrollment (OR 1.89; 95% CI: 1.15-3.11) or dwelling in the Midwest (OR 2.96; 95% CI: 1.43-6.11) or the West (OR 2.39; 95% CI: 1.12-5.11) in the last month of life.

Discussion

We know little about the end-of-life care quality experienced by older adults given the scarcity of studies on the topic. However, we know even less about the end-of-life care quality experienced by older adults with MCC. This study sought to fill a gap in existing knowledge by examining the end-of-life care quality experienced by older adults with MCC and how that differed from care experienced by those without MCC.

From this study, we learn that end-of-life care quality is poor for most older adults, including those with MCC. Less than half of proxies for dying older adults rated end-of-life care quality as “excellent” in this study. Our results align with Teno et al’s finding that less than half of older adults receive high quality end-of-life care.[1] The finding is also reminiscent of McGlynn et al’s[98] finding that only approximately half of adults experience guideline concordant healthcare. Results from our study suggest this gap in care quality may also be present at the end of life.

Of note, our study found no significant difference in end-of-life care quality experienced by older adults with MCC compared to those without, contrary to our hypothesis that older adults with MCC would experience poorer quality care. The finding was surprising given literature identifying gaps in care quality for older adults with MCC prior to the end of life, as well as literature suggesting older adults with MCC are susceptible to receiving poor quality care at the end-of-life. Prior to the end of life, individuals with MCC experience fragmented, ineffective, and inefficient care; high healthcare utilization and costs; avoidable hospital admissions; and preventable complications associated with hospitalization, polypharmacy, and post-operative complications.[9,11,12,99] At the end of life, older adults with MCC face prognostic uncertainty resulting from frequent cycles of physical decline and improvement,[13] placing them at risk of receiving fragmented end-of-life care in a general healthcare system focused on stabilization and unprepared to address end-of-life specific needs.[4] We based our hypothesis on the literature suggesting older adults with MCC were at risk for poorer quality end-of-life care than older adults without MCC, but our study found dimensions of end-of-life care where MCC proxies perceived care better than non-MCC proxies. For example, MCC proxies rated care for breathing issues better than non-MCC proxies, and more MCC proxies reported feeling informed about care. The findings did not align with what we anticipated to find based on available literature on MCC and care quality, but suggest the end-of-life care experience may differ by MCC status. The findings also indicates the need for more investigation into the reasons why older adults with MCC experience lower quality care prior to the end of life, but do not appear to experience differences in quality at the end of life.

Our study also demonstrated that dimensions of quality requiring medical or technical skills such as pain management, breathing care, and personal care were perceived most positively for older adults in the study, while gaps were present in care that required softer skills, such as spiritual and emotional support and shared decision-making. Most notably, this study indicated that only a quarter of dying older adults received their desired level of spiritual and emotional support in the last month of life. The poor care for spiritual and emotional support identified by this study is cause for concern, as dying individuals' spiritual beliefs and emotional state guide many of their end-of-life care decisions.[100] Additionally, literature shows that the receipt of spiritual and emotional support at the end of life is associated with higher quality care and other positive outcomes, including higher rates of hospice enrollment, fewer aggressive treatments, increased quality of life, and lower costs.[100–103] The low proportion of proxies rating end-of-life care quality as "excellent" and the lack of spiritual and emotional support identified by this study indicate a need for improving end-of-life care quality for dying older adults.

Digging deeper into our data, we see that a significantly higher proportion of older adults with MCC were enrolled in hospice in the last month of life due to the higher rate of cancer in the MCC group, which may drive some of our findings. The hospice model of care makes a deliberate attempt to address recognized dimensions of end-of-life care quality, including coordination, symptom management, shared decision-making, respect, and spiritual and emotional support.[104] Appropriate hospice use, defined as enrollment for greater than one week but less than six months,[30] is associated with fewer unmet needs and greater satisfaction with end-of-life quality when compared to other care approaches.[1,31] Our findings reinforce the association between hospice and higher quality care by demonstrating that dying with hospice care was associated with higher rates of symptom management and spiritual and emotional support. However, we still found gaps in spiritual and emotional support when hospice was present, suggesting that even within a setting where care was significantly better for spiritual and emotional support, there was room for improvement. In addition, NHATS does not provide information about the duration of time spent in hospice, which would be necessary to better understand the relationship between hospice and quality for older adults with MCC specifically.

A closer look at our data also showed dying at home was the only factor significantly associated with an “excellent” rating on the measure of *overall* care quality for this study’s sample. Positive perception of care in the coordination, shared decision-making, and respect *composite quality domains* were also higher for older adults who died at home. While public opinion polls indicate a general preference to die at home,[105] findings from this study suggest proxies perceive care as better when the individual died at home. However, more investigation is needed into whether care was technically better at home, or whether proxies perceived care as better because of its alignment with their preferences.

Looking further into our findings, we see an interesting story about how the perception of shared decision-making differed by the proxy's relationship to the dying individual. In our study, we found that spousal proxies rated shared decision-making the worst when compared to children or other family proxies. The finding may relate to the dying individuals' social support network; in our study, 44% of the sample was widowed and 15% was unmarried at the time of death, suggesting a spouse was not available to serve as proxy. The finding may also relate to the proxies' caregiving experience, as literature suggests spousal caregivers face unique barriers that put them at heightened risk for stress [106] and depression,[107] which may influence their perception of care quality.[93] For example, spousal caregivers may be more likely to live with the dying individual, have no choice in taking the caregiver role, experience less support for their caregiving role, and be more vulnerable to limitations based on their own age and health.[106,108,109] In a survey comparing different types of informal caregivers' experiences, spousal caregivers were the most skeptical of formal and professional services and the least likely to ask for help when compared to adult children and other caregivers.[109] That reluctance to engage and skepticism of formal care providers may influence spousal caregivers' perception of shared decision-making, which involves active input from care providers, care receivers, and family members. Additionally, spousal caregivers of older adults experience the highest rates of depression,[107] which is associated with lower satisfaction with care among caregivers.[93] While literature identifies differences in the caregiving experience by relationship to the dying individual, it offers little insight into the differences in caregivers' perceptions of care quality by their relationships to the dying individual. The difference in the perception of shared decision-making by proxy relationship identified by this study is a provocative finding that needs more investigation to determine how the perception of end-of-life care quality is influenced by the dying individuals' social support networks or their relationship to their caregiver.

Our study also identified a lack of agreement among shared decision-making *components*, suggesting more work needs to be done in this area. The majority of MCC proxies felt the dying individual had input into care (91%) or did not receive unwanted care (84%), but only 75% of proxies felt positively about both *components* of the shared decision-making *composite quality domain*. This indicates that dying individuals with MCC may have received care that addressed one *component* of shared decision-making without addressing the other. For example, 16% of MCC proxies felt the dying individual gave input into care that was not translated into action. Examining the intersection of each *composite quality domains' components* indicates that dying individuals may have received care that addresses one *component* of need without addressing all needs within a *composite quality domain*. This suggests a need for care providers to consider the multiple dimensions of care quality present in each *composite quality domain* when delivering care.

While care did not differ significantly for older adults by MCC status, findings from this study demonstrate notable differences in end-of-life care needs by MCC status. Among older adults included in this study, individuals with MCC experienced greater anxiety and sadness in the last month of life compared to those without MCC. Prior to the end of life, older adults with MCC are at an elevated risk for anxiety, particularly as the number of chronic conditions increases.[110] Our findings suggest that older adults with MCC may also experience greater anxiety and sadness at the end of life compared to older adults without MCC. Given the increased prevalence of anxiety and sadness for older adults with MCC at the end of life and the gaps in spiritual and emotional support identified in this study, our findings suggest a vital need to enhance care in this area, particularly for older adults with MCC.

Limitations

This study should be interpreted in light of its limitations. Limitations of the NHATS, LMLI related to its survey items, reliance on proxy rather than direct report, and approach to collecting data from residential care-dwelling participants all limit the generalizability of our findings. Despite these concerns, the NHATS, LMLI is the best source for answering our research questions given it is nationally representative, spans multiple end-of-life care settings, and uses a recognized conceptual model to assess end-of-life care quality.

First, our analysis was limited to data available through the NHATS, LMLI as of Round 5 (2016). We were unable to leverage the longitudinal nature of NHATS due to the small size of the current LMLI sample. The study was unable to meaningfully assess differences in end-of-life care quality by racial and ethnic groups with the current sample, however future rounds of LMLI data may provide the sample needed for such analysis. The study’s MCC definition was also limited to conditions collected by NHATS; as a result, the MCC definition lacks nuance that would help explain the study’s outcomes. Additionally, NHATS lacks details about care that could have provided context for findings, such as the length of time in hospice before death.

Next, this study relied on proxy report rather than direct report from the dying individual. Literature suggests proxy report is typically accurate for objective measures like care received, but less accurate for subjective measures, such as degree of pain.[92] A different study showed proxies and patients give similar reports of healthcare quality.[93] To address this limitation, we investigated aspects of care received and overall satisfaction, which literature suggests are most reliable when rated by a proxy, rather than the extent specific symptoms were experienced.

Lastly, the study only investigates community-dwelling older adults due to differences between community-dwelling and residential care-dwelling populations. Therefore, findings can only be generalized to community-dwelling Medicare beneficiaries. To ensure the end-of-life experience of residential care-dwelling older adults was not overlooked, we assessed outcomes for residential care-dwelling older adults in a separate analysis not reported in this paper.

Despite these limitations, this study identifies relevant and important information about this understudied population of older adults with MCC.

Improving End-of-Life Care Quality for Older Adults with MCC

Our study showed a vital need to address the spiritual and emotional needs of dying individuals with MCC while still attending to their symptom management needs. Older adults with MCC in this study experienced both greater breathing issues and more emotional needs than older adults without MCC, suggesting a high level of demand for care that attends to physical and emotional needs among dying individuals with MCC. This new information may pose a challenge to end-of-life care providers with limited resources to be allocated to physical and emotional care. The National Consensus Project for Quality Palliative Care guidelines, the National Quality Forum Preferred Practices, and a recent consensus report offer recommendations for improving spiritual and emotional support. Recommendations include focusing on personal and professional development among healthcare providers to enhance their self-confidence discussing sensitive topics; changing processes to include standardized assessment of all patients' spiritual needs; establishing a palliative care focus for serving individuals approaching the end of life; and leveraging non-physician professionals trained in spiritual and emotional support, such as chaplains and social workers, to reduce the time and task burden on the medical team.[111] Findings from our study suggest that while potentially difficult, shifting resources toward better spiritual and emotional support provision would address a glaring gap in the care experienced by dying older adults with MCC.

Hospice care may be one approach healthcare providers can draw upon for addressing both physical and emotional needs, but our study suggested that dying individuals may face challenges accessing hospice care. In our study, hospice enrollment was associated with both better symptom management and better spiritual and emotional support. However, only about half of older adults with MCC in this sample died while enrolled in hospice, suggesting the remaining half a million dying individuals with MCC did not have access to the benefits of hospice care. Our findings suggest a need to either enhance hospice enrollment in the last month of life or to develop approaches for providing hospice-like care outside the formal hospice model, such as through palliative care services.

Our findings also suggested an opportunity to improve shared decision-making at the end of life by ensuring dying individuals' wishes are translated into care providers' treatment decisions and that the shared decision-making process is sensitive to caregivers' unique challenges based on their relationship to the dying individual. Shared decision-making is considered a core element of patient-centered care[112] that requires input from both patients and care providers that is then implemented through treatment decisions.[113] Without two-way communication and the translation of input into care, treatment decisions do not meet the requirements of the shared decision-making model. Additionally, the goals of shared decision-making differs for every dying individual and should incorporate the input of their informal caregivers.[113] Findings from our study indicate current shared decision-making processes may adequately address the needs of children and other family caregivers, but not spousal caregivers. Our study suggests that medical providers may benefit from changing communication processes or implementing tools that strengthen shared decision-making in practice, such as the use of advance care planning or guided goals of care conversations through formal models, such as Respecting Choices [114] or Honoring Choices Minnesota.[115] However, more evidence is needed to support such models' ability to impact shared decision-making and care quality at the end of life. Additionally, more information is needed on how the effectiveness of such shared decision-making models differ by the caregivers' relationship to the dying individual.

Conclusions

Findings from this study show that while end-of-life care quality does not differ significantly for older adults based on their MCC status, end-of-life care quality is lacking for all older adults, particularly for spiritual and emotional support. Findings from this study confirm previous analysis, which showed that end-of-life care quality for older adults needs to be improved. This study contributes important information for key stakeholders such as end-of-life care providers, hospital administrators, and policymakers on the specific care needs of dying older adults with MCC and gaps in care that exist for dying older adults with MCC. As a growing number of older adults reach the end of life with MCC, it is important to be mindful of the population’s specific needs and allocate resources to meet them.

Chapter 4: Factors Associated with Proxy-Reported High-Quality End-Of-Life Care for Community-Dwelling Older Adults with Multiple Chronic Conditions

Objective

Drawing on a prominent model of end-of-life care quality, the objective of this study was to determine which of the recognized end-of-life quality domains are associated with excellent overall end-of-life care quality for older adults with multiple chronic conditions (MCC).

Methods

Retrospective cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). Bivariable analyses were conducted using the Wald statistic to determine unadjusted relationships between excellent rating of *overall* care quality and perception of care for recognized dimensions of quality. Unadjusted and adjusted multiple logistic regression tested the association of ratings of *overall* care quality (operationalized as “excellent” and “not excellent”) with the perception of care for each dimension of quality (operationalized as “positive” or “not positive”). Appropriate survey weights were applied to all analysis.

Results

The final analytic sample included 477 NHATS participants, representing 1,123,887 Medicare beneficiaries with MCC when weighted. For older adults with MCC, the rating of *overall* care quality was positively associated with the perceptions of coordination (aOR 4.49; 95% CI: 1.85-10.86), shared decision-making (aOR 1.97; 95% CI: 1.12-3.47), respect (aOR 6.36; 95% CI: 3.23-12.52) and spiritual and emotional support (aOR 2.02; 95% CI: 1.23-3.30). We found no

significant association between the rating of *overall* care quality and the perception of symptom management for dying older adults with MCC (aOR 1.49; 95% CI: .81-2.71).

Conclusion

This study identified variation in how proxies of older adults with MCC rated *overall* end-of-life care quality based on their perception of several aspects of end-of-life care. The end-of-life care quality domains most associated with high quality care for older adults with MCC were coordination, shared decision-making, respect, and support, while symptom management was unrelated to the rating of *overall* end-of-life care quality. Findings suggest healthcare systems seeking to improve end-of-life care for older adults with MCC may consider allocating greater resources to address dying individuals' non-symptomatic needs.

Introduction

A prominent and widely accepted conceptual model developed by Joan Teno and colleagues (Teno Model) indicates that high quality end-of-life care requires assessment and intervention in five domains, regardless of the delivery setting or approach:[1,3,4]

- *Coordination:* Designated professionals take responsibility for overseeing the care team and organizing consistent care across care settings.
- *Symptom Management*: Dying individuals receive their desired level of support for symptoms such as pain and difficulty breathing.
- *Shared decision-making*: Decisions reflect dying individuals' goals and values and include their input.

- *Respect*: Dying individuals are treated with respect and receive support for personal care needs.
- *Spiritual and Emotional Support:* Dying individuals and their families receive their desired amount of support for their spiritual and emotional needs.

The Teno Model draws from end-of-life guidelines and standards, unpublished institutional guidelines, input from end-of-life care practitioners, and focus groups comprised of bereaved family members.[4] However, the Teno Model of end-of-life care quality has not been validated with the population of older adults with multiple chronic conditions (MCC).

Two-thirds of older adults lived with MCC in 2012.[10] The National Quality Forum (NQF) defines MCC as: "…two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination."[9] At the end of life, most older adults with MCC lack a linear trajectory to death and instead experience frequent cycles of decline and improvement that pose a challenge for planning and delivering care.[13] Prognostic uncertainty may lead older adults with MCC to receive fragmented end-of-life care in a general healthcare system focused on stabilization and one which is unprepared to address end-of-life specific needs.[4] Additionally, due to the complexity of medical needs for older adults with MCC, care providers must actively prioritize services to address each individual's most pressing needs,[39] particularly when intervention resources are limited.[44] For example, care for older adults with MCC at the end of life may be informed by the competing demands framework, which posits that individuals must actively prioritize their demands when intervention resources and time are limited, such as prioritizing care for symptoms like pain over care for religious or emotional needs.[44,116,117]

While literature identifies risks older adults with MCC experience as they approach the end of life, information about this population's goals and preferences is scarce, but necessary for prioritization. Investigation of illness trajectories and associated care patterns indicates that individuals' end-of-life care priorities may differ based on their illness experience, which suggests the need to examine the end-of-life care preferences of the MCC population explicitly based on their unique trajectory-based challenges.[41] However, end-of-life care priorities for older adults with MCC are unknown. In one of the only studies of the preferences of older adults with MCC, Clarke et al[59] demonstrated the population shared similar end-of-life goals with the general public, including fear of prolonged pain and suffering, institutionalization, loss of mental acuity, and loss of independence. However, while the study identified common fears, it did not identify actionable priorities for care improvement.[38] The study also did not explicitly examine differences between the goals of older adults with MCC and the general older adult population.

The Teno Model, described previously, provides a framework for high quality care provision,[4] but has not been validated with the MCC population. Knowing which end-of-life quality domains (*coordination*, *symptom management*, *shared decision-making*, *respect*, and *spiritual and emotional support*) are most important to older adults with MCC would help providers, payers, and healthcare systems focus limited resources on areas most meaningful to this population within the time restraints that often accompany end-of-life care.

Objective

Drawing upon the Teno Model,[4] the objective of this study was to determine which of the recognized end-of-life quality domains proxy respondents perceive as associated with excellent overall end-of-life care quality for older adults with MCC. Drawing from the competing demands framework[44] and Maslow's hierarchy of needs,[118] we hypothesized that proxies for dying older adults with MCC would prioritize physiological needs over other domains. Therefore, we hypothesized that proxies who perceived care as positive in the symptom management *composite quality domain* would be more likely to rate *overall* end-of-life care quality as "excellent".

Design and Methods

Study Design and Data Source

This study was a retrospective, cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). The NHATS, LMLI was administered to designated proxies, such as family or friends, for deceased Medicare beneficiaries aged 65 or older.[8] Collected annually since 2011, NHATS follows a nationally representative sample of over 8,000 Medicare beneficiaries aged 65 and older.

The LMLI provides details on NHATS participants' location, daily activities before death, and quality of care in the last month of life using the Teno Model.[68] Prior to the end-of-life, NHATS participants designate a proxy (i.e., family, friends, etc.) who is contacted to complete the LMLI after the participant dies. Facility employees can serve as proxies for participants who die in a facility without a designated proxy available. The average response rate for the LMLI is

95% in each round.[68] We used NHATS for this study because it is nationally representative of Medicare beneficiaries, who account for the vast majority of older adults with MCC who die each year. Demographic and chronic condition data used in this study were reported directly from the NHATS participant prior to the end-of-life.

Sample

NHATS participants eligible for this study met the following criteria: deceased with an LMLI completed in NHATS Rounds 3 (2014), 4 (2015), or 5 (2016); community-dwelling in the last month of life; had a proxy who was not an employee of the setting where the individual died; with complete chronic condition data reported before death; and received care in the last month of life with a proxy rating the *overall* quality of that care. We excluded NHATS participants with an LMLI completed in Round 2 due to changes in survey questions between Rounds 2 and 3 relating to hospice enrollment, a key covariate in this study. We also excluded participants who primarily dwelled in residential care in the last month of life due to differences in demographic and care factors; however, we examined this subgroup in a separate analysis (see **Chapter 6**). We excluded community-dwelling participants whose LMLI was completed by a facility employee due to potential for bias in quality reporting, as the care provider could also be the person rating the quality of care. We excluded 12 NHATS participants for whom chronic condition data was missing, rather than attempting imputation, in an effort to preserve the validity of the study's survey weights.

All participants were aged 65 years or older and were Medicare beneficiaries based on NHATS inclusion criteria. As Medicare beneficiaries account for 93% of Americans aged 65 years and older,[25,27,28] this study describes end-of-life care quality experienced by the majority of community-dwelling older Americans with MCC.

Additionally, this analysis only included individuals with MCC reported prior to the end of life. Annually, NHATS participants report the presence of the following chronic conditions: heart attack, heart disease, hypertension, arthritis, diabetes, lung disease, dementia, and cancer.[70] For this study, we defined MCC as the presence of 2 or more of the following conditions: heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer. We excluded hypertension from the MCC definition for analytic and conceptual reasons. 74% of eligible participants reported the presence of hypertension, which inflated the MCC group without contributing meaningfully to the complexity of care. To be included in this study's MCC definition, individuals with hypertension had to have at least two other chronic conditions We deemed that complications of more severe hypertension would be reflected in the other cardiovascular conditions included in the study's MCC definition (heart attack and heart disease). Our sensitivity analysis included six different definitions of MCC informed by chronic condition literature,[9,10,12,43,70,73] and found the definition of MCC did not alter our significant results. We selected this study's MCC definition based on its representation of AHRQ-recognized conditions and its alignment with the NQF MCC definition, described at the outset of this paper.[9]

Measures

Excellent rating of *overall* care quality was this aim's primary outcome. In NHATS, proxies rate *overall* end-of-life care quality on a 5-point Likert scale ("excellent", "very good", "good", "fair", "poor").[68] The LMLI asks for a rating of *overall* care quality as a unique question and not a summation of the experience in end-of-life quality domains. Since this study was interested in high quality care, rating of *overall* care quality was dichotomized into "excellent" or "not excellent", which collapsed "very good", "good", "fair", and "poor" ratings. This reclassification approach mirrors that used by Teno et al[1] in analysis of NHATS, LMLI data for all community-dwelling older adults.

The aim's independent variables were positive perception of care in the Teno Model's *composite quality domains* and each domains' individual *components*, as described in **Table 2-7**. We dichotomized the perception of each *composite quality domain* and individual *component* into "positive" or "not positive" following processes defined in **Appendix C**. We defined positive perception of care for the individual *components* of a *composite quality domain* as a proxy reporting that the participant had a need within the *component* and that the participant received the desired level of support for that need. We defined positive perception of care for the *composite quality domains* as a proxy reporting that the participant received the desired level of support for each individual *component* in the *composite quality domain* where a need was identified, with the exception of the coordination *composite quality domain*. We defined the perception of the coordination *composite quality domain* as "positive" if a proxy reported only one doctor was involved in the participants' care, or that someone was in charge of care if more than one doctor was involved. We defined the perception of the coordination *composite quality domain* as "not positive" if more than one doctor was involved in care without someone designated as in charge. Because we were interested in perception of quality, we limited analysis for each *component* or *composite quality domain* to participants who had a need, and whose proxy rated care, for that *component* or *composite quality domain*.

Statistical Methods

First, we used descriptive analyses of demographic, care, and proxy factors to characterize the study sample. Next, we conducted bivariable analyses using the Wald statistic to determine unadjusted relationships between *overall* care quality rating and the following outcomes: (1) perception of care for *composite quality domains*, and (2) perception of care for individual *components*. Next, multiple logistic regression compared ratings of *overall* care quality for older adults whose proxy perceived care as “positive”, compared to those whose proxy perceived care as “not positive”. We ran multiple logistic regression models for each *composite quality domain* and each individual *component*, both unadjusted and adjusted for covariates. We also examined the association between demographic, care, and proxy characteristics and (1) the rating of *overall* end-of-life care quality, and (2) perception of care for *composite quality domains* to assess factors associated with excellent care for older adults with MCC.

Covariates derived from existing literature on end-of-life care quality were included in all multivariable models: age, gender, White race, Census region, Medicaid enrollment, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy gender and proxy relationship to the deceased. Age, Census region, marital status at death, place of death, and proxy relationship to the deceased were all categorical variables, while gender, White race, Medicaid enrollment, dementia reported, cancer reported, hospice enrollment, and proxy gender were all dichotomous variables. Marital status at the time of death was dichotomized into married and not married, which also included widowed individuals.

We used STATA Version 12 to conduct all analyses, applying NHATS-supplied tracker weights where appropriate.[97] A p-value of ≤.05 was considered statistically significant for all analyses. We examined missing data prior to analysis to assess for potential bias, and excluded participants missing covariate data, after determining they did not differ significantly from participants with complete covariate data available. The Northwestern University Institutional Review Board deemed this study exempt.

Results

Descriptive Statistics

LMLIs were available for 1,223 of 8,245 (14.8%) NHATS participants in Round 3, 4, or 5. Of those, 687 (56%) were community-dwelling in the last month of life. However, after verifying no difference from other participants on the reported covariates, we excluded 22 (3.2%) community-dwelling NHATS participants with a Round 3, 4, or 5 LMLI for the following reasons: ineligibility due to a facility employee proxy (n=4; .6%); inconclusive MCC status (n=7; 1.0%); and missing covariate information (n=11; 1.6%). Of the 665 remaining community-dwelling participants, 504 (75.8%) met this study's MCC definition. However, we excluded 27 (5.4%) participants with MCC from the study sample because they did not receive care in the last month of life (n=21; 4.2%) or their proxy did not rate *overall* care quality (n=6; 1.2%). The final analytic sample included the remaining 477 NHATS participants with MCC who received care in the last month of life and had that care rated by their proxy (94.6% of community-dwelling sample with MCC).

The final analytic sample represented 1,123,887 Medicare beneficiaries when weighted (**Table 4-1**). The sample was mostly aged 65 to 84 years (60%), white (77%), not enrolled in

Medicaid (80%), and individuals who died at home (44%) or in a hospital (33%). The sample was fairly evenly distributed by gender (48% male vs. 52% female). Most proxies were female (75%) and children of the deceased NHATS participant (55%).

Proxies of NHATS participants with MCC (referred to as MCC proxies) rated *overall* care quality as “excellent” for 52% of NHATS participants and “not excellent” for the remaining 48%. **Table 4-1** shows the differences in participants’ demographic, care, and proxy factors by rating of *overall* care quality. Characteristics significantly associated with “excellent” *overall* care quality were marriage at the time of death (p=.007), hospice enrollment (p=.04), and spousal proxies (p=.03). **Table 4-2** reports the adjusted relationships between the rating of *overall* care quality and demographic, care, and proxy factors. The *overall* care quality rating was not significantly associated with marital status at death, hospice enrollment, or proxy relationship to the deceased after controlling for covariates. After adjustment, the *overall* care quality rating was significantly positively associated with older age (OR 1.88; 95% CI: 1.17-3.02) and significantly negatively associated with dying in a setting other than a hospital or home, such as a nursing home (OR .55; 95% CI: .34-.88).

The proportion of MCC proxies who reported care as “not positive” varied by *composite quality domain* (data not shown): coordination (14%), symptom management (27%), shared decision-making (21%), respect (25%), and spiritual and emotional support (68%). **Table 4-2** shows the adjusted relationships between demographic, care, and proxy factors and the perception of care in the five *composite quality domains*. After adjusting for covariates, dying in a setting other than hospital or home was significantly negatively associated with the perception of care in the coordination *composite quality domain* (OR .31; 95% CI: .11-.90).

Perception of the symptom management *composite quality domain* was significantly negatively associated with the report of cancer (OR .52; 95% CI: .30-.91). Perception of the shared decision-making *composite quality domain* was significantly positively associated with being married at the time of death (OR 2.63; 95% CI: 1.06-6.55) or having a child proxy (OR 3.89; 95% CI: 1.62-9.33) or other proxy (OR 3.67; 95% CI: 1.13-11.86), while it was significantly negatively associated with the report of cancer (OR .47; 95% CI: .24-.94) and dying in a location other than hospital or home (OR .31; 95% CI: .14-.68). Perception of the respect *composite quality domain* was not significantly associated with any demographic, care, or proxy factors. Perception of the spiritual and emotional support *composite quality domain* was significantly positively associated with residing in the Midwest in the last month of life (OR 2.66; 95% CI: 1.21-5.86) or hospice enrollment in the last month of life (OR 1.96; 95% CI: 1.08-3.54) and significantly negatively associated with older age (OR .59; 95% CI: .37-.95).

We examined the intersection of MCC, cancer, place of death, and hospice enrollment in post hoc analysis (data not shown). Dying at home was significantly associated with hospice enrollment after adjusting for demographic, care, and proxy factors (OR 4.24; 95% CI: 2.71-6.62). Among those who did not die at home, hospice enrollment was significantly associated with the report of cancer after adjustment (OR 2.03; 95% CI: 1.30-3.17). Among older adults whose MCC included cancer, hospice enrollment was significantly associated with “excellent” rating of *overall* care quality (OR 1.86; 95% CI: 1.08-3.21) and with the positive perception of the spiritual and emotional support *composite quality domain* (OR 2.52; 95% CI: 1.17-5.40) and the religious and spiritual needs *component* (OR 2.52; 95% CI: 1.32-4.82). Among those without cancer, hospice enrollment was significantly associated with the positive perception of the shared decision-making *composite quality domain* (OR 2.31; 95% CI: 1.18-4.50) and the anxiety and sadness *component* (OR 2.67; 95% CI: 1.19-5.99).

Relationship between *Composite Quality Domains*, Individual *Components*, and the Rating of *Overall* End-of-Life Care Quality

Table 4-3 describes the distribution of the rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain* and each individual *component*. A significantly greater proportion of MCC proxies who perceived the coordination *composite quality domain* positively also rated *overall* care quality as "excellent" compared to those who perceived the domain negatively (56% vs. 24%; p<.001). Significant positive associations were also present between the rating of *overall* care quality and the perception of care for the shared decision-making *composite quality domain* (56% vs. 37%; p=.01) and its input into care (56% vs. 16%; p<.001) and informed about care (59% vs. 9%; p<.001) *components*; the respect *composite quality domain* (62% vs. 21%; p<.001) and its respect (57% vs. 8%; p<.001) and personal care (60% vs. 22%; p<.001) *components*; and the spiritual and emotional support *composite quality domain* (63% vs. 46%; p=.006) and its anxiety/sadness (55% vs. 35%; p=.002) *component*.

Table 4-4 reports the unadjusted and multivariable relationships between the perception of care in each *composite quality domain* and each individual *component* and the rating of *overall* care quality. Models included all covariates, with the exception of those with raw cell counts less than ten, which were excluded from each model. After adjusting for covariates, the rating of *overall* care quality was significantly positively associated with the perception of care in the coordination *composite quality domain* (OR 4.49; 95% CI: 1.85-10.86), the shared decision-making *composite quality domain* (OR 1.97; 95% CI: 1.12-3.47) and its input into care (OR 6.92; 95% CI: 2.40-19.91) and informed about care (OR 19.57; 95% CI: 6.29-60.86) *components*; the respect *composite quality domain* (OR 6.36; 95% CI: 3.23-12.52) and its respect (OR 14.67; 95% CI: 4.59-46.91) and personal care (OR 4.98; 95% CI: 2.39-10.38) *components*; and the spiritual and emotional support *composite quality domain* (OR 2.02; 95% CI: 1.23-3.30) and its anxiety/sadness (OR 1.90; 95% CI: 1.14-3.18) *component*. However, three individual *components* that yielded significant odds ratios included small raw sample sizes (input into care, informed about care, and respect). The trends detected in the multivariable models should be noted, but the resulting odds ratios should be interpreted with caution.

Discussion

Little is known about which dimensions of care matter to older adults with MCC at the end of life. The widely-accepted Teno Model of high quality end-of-life care identifies five key domains of care: coordination; symptom management; shared decision-making; respect; and spiritual and emotional support.[4] However, the model has not been validated with the MCC population to determine whether it reflects their unique end-of-life needs, preferences, and experiences. This study applies the Teno Model to dying older adults with MCC and provides evidence to confirm and question aspects of the model.

Only 52% of MCC proxies rated *overall* end-of-life care quality as “excellent” in our study, suggesting a need to improve care for dying older adults with MCC. Examining the dimensions of quality associated with excellent end-of-life care quality for older adults with MCC offers information to guide improvement. This study determined that all *composite quality domains* identified in the Teno Model except symptom management mattered when rating *overall* end-of-life care quality for older adults with MCC. Pain management and breathing management, *components* of symptom management, were also not significantly associated with the rating of *overall* care quality.

The lack of significant association between symptom management and the rating of *overall* end-of-life care quality is surprising because it is counter to the competing demands framework, which informed our hypothesis. The competing demands framework posits that patients must actively prioritize their demands when intervention resources are limited.[44,116,117] Applying the competing demands framework to Maslow's hierarchy of needs,[118] we anticipated that MCC proxies would prioritize the dying individual's physiological needs, such as symptom management, over needs further up Maslow's hierarchy, such as spiritual and emotional support, when rating *overall* end-of-life care quality. On the contrary, we found no relationship between MCC proxies' perception of symptom management and their *overall* end-of-life care quality rating. The results of our study could indicate that Maslow's hierarchy of needs may not apply at the end of life, as our findings suggest that dying older adults with MCC may prioritize their psychosocial needs over their physiological needs.

We did find significant associations between the *overall* end-of-life care quality rating and every other *composite quality domain* recognized in the Teno Model: coordination, shared decision-making, respect, and spiritual and emotional support. For each of those domains, MCC proxies rated *overall* end-of-life care quality better when needs in the domain were met, which suggests agreement between dying older adults with MCC and participants in the Teno Model's foundational study.[4] In the Teno Model's foundational study, bereaved family members identified that the presence of a designated physician in charge ensured continuity across settings and aided in communication of the care plan, particularly when many multidisciplinary team members were involved in care. Within the respect and personal care domain, Teno Model study participants also expressed the value of maintaining personhood, dignity, and a sense of control at the end-of-life. They also shared their need to feel emotionally supported through services that promote closure and psychological well-being. Within the shared decision-making domain, Teno Model study participants valued active relationships with end-of-life medical providers in order to feel involved and confident in the treatment decision-making process. Associations seen in this study between the *overall* end-of-life care quality rating and four of the Teno Model's domains (coordination, shared decision-making, respect, and spiritual and emotional support) suggest dying older adults with MCC may share similar views as identified by participants in the Teno Model's foundational study, which also indicates the model may have value for guiding care provision to dying older adults with MCC.

Our findings made us contemplate the relationship between proxies' expectations and their quality ratings and how that relationship may have influenced our findings. For example, addressing symptoms is a core function of healthcare, therefore proxies may expect symptom management needs to be met. Proxies may not consider care to be "excellent" when it simply meets their expectations of symptom management without exceeding them. Alternatively, proxies may expect pain and breathing troubles to be part of the dying experience, and may therefore be more tolerant of unmet symptom management needs when rating *overall* care quality. However, proxies may also expect to be involved in the treatment decision-making process and for the dying individuals to be treated with respect, which were two dimensions of care highly related to proxies' *overall* care quality rating in our study.

Current literature offers little detail on caregivers' expectations of the dying process and how that may impact their perception of care, thus additional research is needed in this area. Given our study used proxy report to assess end-of-life care quality, our findings are reliant on proxy perception, which may be influenced by their expectations for care. Historically, studies link expectations for care with satisfaction ratings,[119–121] but more recent analysis suggests the relationship between expectation and satisfaction may be more complicated than previously identified.[122] We know of no study specifically examining the relationship between expectations for end-of-life care and satisfaction with that care. Further research should investigate the relationship between proxy expectations and satisfaction within the particular context of end-of-life care quality, particularly given the extent to which studies of end-of-life care quality rely on proxy report.

Our study not only showed that shared decision-making was highly related to the *overall* rating of end-of-life care quality, but also indicated that dying older adults with MCC and cancer experienced lower quality care within the shared decision-making *composite quality domain*. Dying older adults with MCC and cancer also experienced lower quality care in the symptom management *composite quality domain*. Evidence suggests older adults dying with cancer may experience high symptom burden, which may result in greater need for late-life symptom management.[123] In acknowledgement of cancer's high symptom burden, experts endorse symptom management as the highest priority service item for palliative oncology care, followed by shared decision-making,[124] but our study suggests symptom management may not be as vital as other domains of care to dying older adults with MCC and cancer.

Literature also suggests individuals dying with terminal cancer may have different informational needs not being met than individuals dying with other conditions. For example, in a systematic review, Matsuyama et al identified that individuals dying with terminal cancer may be more willing to choose treatments with little potential benefit, due in part to the lack of information about their prognosis or treatments' likelihood of success.[125] Our study reinforces that the needs of individuals dying with cancer may be unique by showing dying older adults with MCC that includes cancer experience lower quality symptom management and shared decision-making than those without cancer. Future studies should investigate how the presence of other chronic conditions in addition to cancer may impact symptom burden, symptom management, or shared decision-making at the end of life.

Our study also suggested that the presence of a cancer diagnosis might influence hospice access and outcomes for dying older adults with MCC. In our study, dying at home was significantly associated with hospice enrollment for all participants, but among individuals who did not die at home, hospice enrollment was significantly greater among individuals whose MCC included cancer. Cancer-based differences in hospice enrollment align with the hospice's history as well as known challenges for older adults with MCC approaching the end of life. First, Medicare's hospice eligibility requirement of a 6-month prognosis to death was developed to reflect the experience of individuals with cancer in the 1980s, as cancer was a common end-of-life diagnosis for older adults at the time.[32] Next, older adults dying with MCC experience a unique trajectory to death when compared to older adults with cancer, which makes it difficult to determine when to initiate end-of-life specific interventions, such as hospice.[40] As a result, older adults with a cancer diagnosis may have different access to hospice care than those without cancer, which our findings appear to confirm. Findings from our study indicate a need to determine ways to increase hospice accessibility for dying older adults with MCC or to provide hospice-like care outside formal hospice programs.

Our findings also suggest that the benefits of hospice may be different for older adults with MCC who had cancer as one of their chronic conditions. We found that MCC proxies perceived *overall* care quality, spiritual and emotional support, and religious and spiritual care significantly more positively for individuals with cancer enrolled in hospice, while MCC proxies perceived shared decision-making and care for anxiety/sadness significantly more positively for individuals without cancer enrolled in hospice. The discrepancies in hospice-related outcomes we found indicate that older adults with MCC that includes cancer may be a unique population with different end-of-life needs and experiences than older adults whose MCC does not include cancer. Further investigation is necessary to understand the mechanisms that underlie the discrepancies in hospice-related outcomes by cancer diagnosis.

Limitations

This study should be interpreted in light of its limitations. Limitations of the NHATS, LMLI related to its survey items, reliance on proxy rather than direct report, and approach to collecting data from residential care-dwelling participants all limit the generalizability of our findings. Despite these concerns, the NHATS, LMLI is the best source for answering our research questions given it is nationally representative, spans multiple end-of-life care settings, and uses a recognized conceptual model to assess end-of-life care quality.

First, our analysis was limited to data available through the NHATS, LMLI as of Round 5 (2016). We were unable to leverage the longitudinal nature of NHATS due to the small size of the current LMLI sample. The study was unable to meaningfully assess differences in end-of-life care quality by racial and ethnic groups with the current sample, however future rounds of LMLI data may provide the sample needed for such analysis. The study's MCC definition was also limited to conditions collected by NHATS; as a result, the MCC definition lacks nuance that would help explain the study's outcomes. Additionally, NHATS lacks details about care that could have provided context for findings, such as the length of time in hospice before death.

Next, this study relied on proxy report rather than direct report from the dying individual. Literature suggests proxy report is typically accurate for objective measures like care received, but less accurate for subjective measures, such as degree of pain.[92] A different study showed proxies and patients give similar reports of healthcare quality.[93] To address this limitation, we investigated aspects of care received and overall satisfaction, which literature suggests are most reliable when rated by a proxy, rather than the extent specific symptoms were experienced.

Lastly, the study only investigates community-dwelling older adults due to differences between community-dwelling and residential care-dwelling populations. Therefore, findings can only be generalized to community-dwelling Medicare beneficiaries. To ensure the end-of-life experience of residential care-dwelling older adults was not overlooked, we assessed outcomes for residential care-dwelling older adults in a separate analysis not reported in this paper.

Despite these limitations, this study identifies relevant and important information about this understudied population of older adults with MCC.

Improving End-of-Life Care Quality for Older Adults with MCC

Our findings suggest that end-of-life care providers should consider non-symptomatic dimensions of quality in addition to addressing individuals' symptom management needs when providing end-of-life care. Specifically, end-of-life care providers may find value in prioritizing interventions that address *components* of respect and shared decision-making when treating dying individuals with MCC. *Components* highly associated with the rating of *overall* end-of-life care quality in our study included respectful treatment and the extent to which dying individuals and their caregivers had input into care and were kept informed of treatment decisions. Other dimensions, including coordination and spiritual and emotional support, were also important to MCC proxies when rating *overall* care quality for dying older adults with MCC.

Enhancing palliative care may be one approach for addressing dying individuals' coordination, shared decision-making, respect, and spiritual and emotional support needs while also attending to their symptoms. Palliative care may be particularly meaningful for dying older adults with MCC who experience challenges accessing hospice care as a result of prognostic uncertainty.[41] Palliative care provides support for symptoms and psychosocial needs in any care setting, typically in consultation with a palliative care team.[34] Unlike hospice, palliative care can be delivered concurrently to curative care at any point across the lifespan, which means older adults with MCC may access palliative care services without needing the 6-month prognosis required for hospice eligibility. Early evidence suggests palliative care may be able to attend to the unique needs of dying older adults with MCC.[55] Available NHATS, LMLI data did not identify aspects of palliative care provided to dying participants in the last month of life, so we could not assess the impact of palliative care on outcomes for this study's sample. Additional investigation is necessary to demonstrate palliative care’s impact on domains identified in the Teno Model of high quality end-of-life care, particularly those most associated with high quality care for the population.

Conclusions

Findings from this study identified variation in how proxies of older adults with MCC rated *overall* end-of-life care quality based on their perception of several aspects of end-of-life care. The end-of-life care *composite quality domains* most associated with high quality care for older adults with MCC were coordination, shared decision-making, respect, and support, while symptom management was unrelated to the rating of *overall* end-of-life care quality. Findings suggest healthcare systems seeking to improve end-of-life care for older adults with MCC may consider allocating greater resources to address dying individuals’ non-symptomatic needs.

Chapter 5: The Influence of Care Coordination on Other Factors Associated with High-Quality End-Of-Life Care for Community-Dwelling Older Adults with Multiple Chronic Conditions

Objective

Drawing on a prominent model of end-of-life care quality, the objective of this study was to evaluate the relationship of perception of care in the coordination *composite quality domain* with the perception of care for other recognized quality domains for older adults with multiple chronic conditions (MCC).

Methods

Retrospective cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). In this study, a "positive" perception of coordination was operationalized as only one doctor was involved in the participants' care, or that one doctor was in charge of care if more than one doctor was involved. Bivariable analyses were conducted using the Wald statistic to determine unadjusted relationships between positive perception of the coordination *composite quality domain* and perception of care for the other recognized dimensions of quality in the Teno Model of end-of-life care quality. Unadjusted and adjusted multiple logistic regression tested the association of the perception of care for the coordination *composite quality domain* (operationalized as "positive" or "not positive") with the perception of care in each *composite quality domain* and each individual *component*. Appropriate survey weights were applied to all analysis.

Results

The final analytic sample included 466 NHATS participants, representing 1,102,484 Medicare beneficiaries with MCC when weighted. Eighty-five percent of MCC proxies perceived the coordination *composite quality domain* as positive. Coordinated care was positively associated with the perception of symptom management (aOR 2.34; 95% CI: 1.07-5.14), pain (aOR 3.60; 95% CI: 1.43-9.10), being informed about care (aOR 8.94; 95% CI: 3.87-20.65), respect (aOR 3.21; 95% CI: 1.55-6.62), and personal care (aOR 3.49; 95% CI: 1.56-7.77).

Conclusion

This study identified that proxies for older adults with MCC who perceived end-of-life care to be coordinated also reported receiving high quality care in other end-of-life care domains, which should be cautiously interpreted due to the cross-sectional nature of the analysis.

Introduction

Two-thirds of older adults lived with multiple chronic conditions (MCC) in 2012.[10] The National Quality Forum (NQF) defines MCC as: "…two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination."[9] In an attempt to resolve care fragmentation and determine care priorities for the MCC population, healthcare providers increasingly turn to *care coordination*, or the deliberate organization of care to ensure appropriate service delivery.[45] Care coordination models demonstrate promise for addressing poor outcomes associated with MCC, including hospitalization and readmission,[46–49] skilled nursing facility placement,[6,50] inefficient care,[51] healthcare utilization costs,[47,48,52] and medication adherence.[52] Additionally, a growing number of Medicare policies provide financial support for care coordination activities.

Due to the complexity of medical needs for older adults with MCC, care providers must actively prioritize services to address each individual's most pressing needs,[39] particularly when time and intervention resources are limited, such as at the end-of-life.[44] Approaching the end of life, most older adults with MCC lack a linear trajectory to death and instead experience frequent cycles of decline and improvement that pose a challenge for planning and delivering care.[13] Prognostic uncertainty may lead older adults with MCC to receive fragmented end-of-life care in a general healthcare system focused on stabilization and one which is unprepared to address end-of-life specific needs.[4]

A prominent and widely accepted conceptual model developed by Joan Teno and colleagues (Teno Model) indicates that high quality end-of-life requires assessment and intervention in five domains, regardless of the delivery setting or approach:[1,3,4]

- *Coordination:* Designated professionals take responsibility for overseeing the care team and organizing consistent care across care settings.
- *Symptom Management*: Dying individuals receive their desired level of support for symptoms such as pain and difficulty breathing.
- *Shared decision-making*: Decisions reflect dying individuals' goals and values and include their input.
- *Respect*: Dying individuals are treated with respect and receive support for personal care needs.

- *Spiritual and Emotional Support:* Dying individuals and their families receive their desired amount of support for their spiritual and emotional needs.

Coordination, one of the identified quality domains, may be of particular importance to older adults with MCC given its success in addressing care fragmentation for older adults with MCC prior to the end of life.[5–7] However, evidence of the influence of coordination on end-of-life care quality is limited to case studies of particular delivery models,[57,60,61] qualitative assessment of the need for coordination,[59,62] and evaluation of policies and systems outside the US.[20,22,63,64] Findings from these studies demonstrate potential end-of-life quality improvements that may be associated with coordination, such as decreased symptom distress,[60] increased hospice enrollment,[61] decreased late-life ICU and hospital use,[61] and more efficient use of healthcare resources.[65] Findings from Aim 2 of this study identified a significant association between coordination and the *overall* rating of care quality in the last month of life for older adults with MCC (**Chapter 4**). Investigation into the relationship between coordination and the other recognized quality domains may offer an approach for improving end-of-life care quality for older adults with MCC.

Objective

Drawing upon the Teno Model,[4] the objective of this study was to evaluate the relationship of perception of care in the coordination *composite quality domain* to the perception of care for other recognized quality domains for older adults with MCC. Based on the literature discussed previously showing the promise of coordination for improving outcomes for the MCC population prior to the end of life, we hypothesized that proxies for older adults with MCC who perceived care as positive in the coordination domain would be more likely to perceive care as positive in other dimensions of quality.

Design and Methods

Study Design and Data Source

This study was a retrospective, cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI). The NHATS, LMLI was administered to designated proxies, such as family or friends, for deceased Medicare beneficiaries aged 65 or older.[8] Collected annually since 2011, NHATS follows a nationally representative sample of over 8,000 Medicare beneficiaries aged 65 and older.

The LMLI provides details on NHATS participants' location, daily activities before death, and quality of care in the last month of life using the Teno Model.[68] Prior to the end-of-life, NHATS participants designate a proxy (i.e., family, friends, etc.) who is contacted to complete the LMLI after the participant dies. Facility employees can serve as proxies for participants who die in a facility without a designated proxy available. The average response rate for the LMLI is 95% in each round.[68] We used NHATS for this study because it is nationally representative of Medicare beneficiaries, who account for the vast majority of older adults with MCC who die each year. Demographic and chronic condition data used in this study were reported directly from the NHATS participant prior to the end-of-life.

Sample

NHATS participants eligible for this study met the following criteria: deceased with an LMLI completed in NHATS Rounds 3 (2014), 4 (2015), or 5 (2016); community-dwelling in the last month of life; had a proxy who was not an employee of the setting where the individual died; with complete chronic condition data reported before death; and received care in the last month of life with a proxy rating their perception of care for the coordination quality domain. We excluded NHATS participants with an LMLI completed in Round 2 due to changes in survey questions between Rounds 2 and 3 relating to hospice enrollment, a key covariate in this study. We also excluded participants who primarily dwelled in residential care in the last month of life due to differences in demographic and care factors; however, we examined this subgroup in a separate analysis (see **Chapter 6**). We excluded community-dwelling participants whose LMLI was completed by a facility employee due to potential for bias in quality reporting, as the care provider could also be the person rating the quality of care. We excluded 12 NHATS participants for whom chronic condition data were missing rather than attempting imputation in an effort to preserve the validity of the study's survey weights.

All participants were aged 65 years or older and were Medicare beneficiaries based on NHATS inclusion criteria. As Medicare beneficiaries account for 93% of Americans aged 65 years and older,[25,27,28] this study describes end-of-life care quality experienced by the majority of community-dwelling older Americans with MCC.

Additionally, this analysis only included individuals with MCC reported prior to the end of life. Annually, NHATS participants report the presence of the following chronic conditions: heart attack, heart disease, hypertension, arthritis, diabetes, lung disease, dementia, and cancer.[70] For this study, we defined MCC as the presence of 2 or more of the following conditions: heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer. We excluded hypertension from the MCC definition for analytic and conceptual reasons. 74% of eligible participants reported the presence of hypertension, which inflated the MCC group without contributing meaningfully to the complexity of care. To be included in this study's MCC definition, individuals with hypertension had to have at least two other chronic conditions We deemed that complications of more severe hypertension would be reflected in the other cardiovascular conditions included in the study's MCC definition (heart attack and heart disease). Our sensitivity analysis included six different definitions of MCC informed by chronic condition literature,[9,10,12,43,70,73] and found the definition of MCC did not alter our significant results. We selected this study's MCC definition based on its representation of AHRQ-recognized conditions and its alignment with the NQF MCC definition, described at the outset of this paper.[9]

Measures

This aim's explanatory variable was positive perception of care in the *coordination composite quality domain*. Two NHATS, LMLI items describe aspects of coordination experienced in the last month of life: (1) whether more than one doctor was involved in care, and (2) whether a particular doctor was in charge of care if more than one doctor was involved. We defined the perception of the coordination *composite quality domain* as "positive" (referred to as "positive perception of coordination") if a proxy reported only one doctor was involved in the participants' care, or that someone was in charge of care if more than one doctor was involved. We defined the perception of coordination as "not positive" if more than one doctor was involved in care without someone designated as in charge.

This aim's outcomes were the positive perception of care in the Teno Model's other *composite quality domains* and each domains' individual *components*, as described in **Table 2-7.**

We dichotomized the perception of each non-coordination *composite quality domain* and individual *component* into “positive” or “not positive” following processes defined in **Appendix C**. We defined positive perception of care for the individual *components* of a *composite quality domain* as a proxy reporting that the participant had a need within the *component* and that the participant received the desired level of support for that need. We defined positive perception of care for the non-coordination *composite quality domains* as a proxy reporting that the participant received the desired level of support for each individual *component* in the quality domain where a need was identified. Because we were interested in perception of quality, we limited analysis for each *component* or *composite quality domain* to participants who had a need, and whose proxy rated care, for that *component* or *composite quality domain*.

Statistical Methods

First, we used descriptive analyses of demographic, care, and proxy factors to characterize the study sample. Next, we conducted bivariable analyses using the Wald statistic to determine unadjusted relationships between positive perception of coordination and the following outcomes: (1) perception of care for each of the other *composite quality domains*, and (2) perception of care for each of the individual *components*. Next, multiple logistic regression analyses tested the association of the perception of the *coordination composite quality domain* (operationalized as “positive” or “not positive”) with the perception of care in each *composite quality domain* and each individual *component*, both unadjusted and adjusted for covariates.

Covariates derived from existing literature on end-of-life care quality were included in all multivariable models, including: age, gender, White race, Census region, Medicaid enrollment, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy gender and proxy relationship to the deceased. Age, Census region, marital status at death, place of death, and proxy relationship to the deceased were all categorical variables, while gender, White race, Medicaid enrollment, dementia reported, cancer reported, hospice enrollment, and proxy gender were all dichotomous variables. Marital status at the time of death was dichotomized into married and not married, which also included widowed individuals.

We used STATA Version 12 to conduct all analyses, applying NHATS-supplied tracker weights where appropriate.[97] A p-value of ≤.05 was considered statistically significant for all analyses. We examined missing data prior to analysis to assess for potential bias, and excluded participants missing covariate data, after determining they did not differ significantly from participants with complete covariate data available. The Northwestern University Institutional Review Board deemed this study exempt.

Results

Descriptive Statistics

LMLIs were available for 1,223 of 8,245 (14.8%) NHATS participants in Round 3, 4, or 5. Of those, 687 (56%) were community-dwelling in the last month of life. However, after verifying no difference from other participants on the reported covariates, we excluded 22 (3.2%) community-dwelling NHATS participants with a Round 3, 4, or 5 LMLI for the following reasons: ineligibility due to a facility employee proxy (n=4; .6%); inconclusive MCC status (n=7; 1.0%); and missing covariate information (n=11; 1.6%). Of the 665 remaining community-dwelling participants, 504 (75.8%) met this study’s MCC definition. However, we excluded 38 (7.5%)

participants with MCC from the study sample because they did not receive care in the last month of life (n=20; 4.0%) or their proxy did not know whether the participant received coordination in the last month of life (n=18; 3.5%). The final analytic sample included the remaining 466 NHATS participants with MCC who received care in the last month of life and whose proxy reported their perception of coordination (92.5% of community-dwelling sample with MCC).

The final analytic sample represented 1,102,484 Medicare beneficiaries when weighted (**Table 5-1**). The sample was mostly white (78%), not enrolled in Medicaid (79%), and without dementia reported (76%). The sample was fairly evenly distributed by age (41% aged 85+), gender (53% female), and hospice enrollment (57% enrolled). Most proxies were female (75%) and were not the spouse of the deceased NHATS participant (71%).

Proxies of NHATS participants with MCC (referred to as MCC proxies) perceived the coordination domain as “positive” for 85% of the NHATS participants and “not positive” for the remaining 15%. **Table 5-1** shows the difference in participants’ demographic, care, and proxy factors by the perception of coordination. Participants whose proxy perceived coordination as “positive” differed significantly from participants whose proxy perceived coordination as “not positive” on one demographic factor in unadjusted analyses, White race (p=.049). After adjustment, perception of coordination was negatively associated with dying in a setting other than a hospital or home, such as a nursing home (OR .32; 95% CI: .15-.92; data not shown). The proportion of MCC proxies who reported care as “not positive” varied by *composite quality domain* for the non-coordination *composite quality domains* (data not shown): symptom management (22%), shared decision-making (20%), respect (24%), and spiritual and emotional support (58%).

Relationship between *Composite Quality Domains*, Individual *Components*, and the Perception of Care in the Coordination *Composite Quality Domain*

Table 5-2 identifies whether MCC proxies with a "positive" perception of coordination, defined as only one doctor involved in the participants' care, or that one doctor was in charge of care if more than one doctor was involved, differed from those with a "not positive" perception of coordination with respect to their perception of each other *composite quality domain* and each individual *component*. Compared to MCC proxies who perceived coordination as "not positive," a significantly greater proportion of MCC proxies who perceived coordination as "positive" also perceived care as "positive" for the following *composite quality domains* and individual *components*: the informed about care *component* (90% vs. 52%; p=.001); the respect *composite quality domain* (79% vs. 53%; p=.003) and its respect (93% vs. 72%; p=.007) and personal care (83% vs. 56%; p=.005) *components*; and the spiritual and emotional support *composite quality domain* (35% vs. 15%; p=.03).

Table 5-3 reports the unadjusted and multivariable relationships between the perception of coordination with the perception of care in each *composite quality domain* and each individual *component*. After adjusting for covariates, the perception of coordination was positively associated with the perception of the following *composite quality domains* and *components*: the symptom management *composite quality domain* (OR 2.34; 95% CI: 1.07-5.14) and its pain *component* (OR 3.60; 95% CI: 1.43-9.10); the informed about care *component* (OR 8.94; 95% CI: 3.87-20.65); and the respect *composite quality domain* (OR 3.21; 95% CI: 1.55-

6.62) and its respect (OR 5.64; 95% CI: 2.49-12.79) and personal care (OR 3.49; 95% CI: 1.56-7.77) *components*. Due to small raw samples sizes for some analyses, the trends detected in the multivariable models should be noted, but the resulting odds ratios should be interpreted with caution.

Discussion

Coordination is one of five key domains recognized in the Teno Model of high quality end-of-life care, accompanied by symptom management, shared decision-making, respect, and spiritual and emotional support (**Table 2-7**). Prior to the end of life, coordination is associated with better quality of care as well as improved health and utilization outcomes for older adults with MCC.[6,7,99] However, studies examining care coordination at the end of life for older adults with MCC are limited to case studies and modest evaluations of small pilot programs. This study advances our understanding of coordinations' influence on the perception of end-of-life care quality for older adults with MCC by determining whether MCC proxies who reported coordinated care in the last month of life also reported high quality care in other recognized end-of-life quality domains.

This study found that perceiving care as coordinated care in the last month of life was significantly associated with also perceiving care as "positive" for several other dimensions of quality, including symptom management, being kept informed about care, and feeling respected. In this study, a "positive" perception of coordination was operationalized as only one doctor was involved in the participants' care, or that one doctor was in charge of care if more than one doctor was involved. Findings from this study support our hypothesis that MCC proxies who reported that care was coordinated – that one doctor was in charge of care – would be more likely to perceive care positively for other dimensions of quality.

The association we found between coordination and symptom management aligns with findings from a small evaluation of the PhoenixCare demonstration project, which found lower rates of symptom distress among older adults with chronic conditions who received coordinated case management along with palliative care.[60] However, we lacked information about whether dying individuals in this study received care following a formal care coordination framework like PhoenixCare. Our finding suggests that the relationship between coordination and symptom management may persist outside formal care coordination models like PhoenixCare, but assessing this relationship requires more information than available for this study.

Our study also demonstrated that dying older adults with MCC who received coordinated care also received more respectful treatment in the last month of life, including attendance to personal care needs. A recent systematic review indicates that respect and care coordination are both key elements of person-centered care,[126] but current literature does not indicate a clear relationship between receiving coordinated care and feeling respected or with having personal needs met. Findings from this study suggest that the relationship between coordination and respect may be an area for further research, particularly as it relates to high quality end-of-life care.

Additionally, our findings showed that proxies for dying individuals with MCC perceived that they were kept more informed about care when care was coordinated in the last month of life. In the Teno Model’s foundational study, bereaved family members identified that the presence of a designated physician in charge ensured continuity across settings and aided in communication of the care plan, particularly when many multidisciplinary team members were involved in care.[4] The connection between coordination and the extent to which individuals felt informed about care reflects a core goal of coordination activities. Wagner's Chronic Care Model, a highly-regarded model for organizing care for people with chronic conditions that forms the conceptual foundation for many care coordination programs, identifies the transfer of information between patients and care teams as a hallmark of coordinated care.[127] Findings from our study suggest that care coordination and being informed about care may also be related at the end of life.

Limitations

This study should be interpreted in light of its limitations. The NHATS's questions asked regarding coordination in the last month of life, retrospective nature, and reliance on proxy rather than direct report from the dying individual limit the generalizability of our findings. Despite these concerns, the NHATS, LMLI is the best source for answering our research questions given it is nationally representative, spans multiple end-of-life care settings, and uses a recognized conceptual model to assess end-of-life care quality.

First, NHATS asks proxies whether more than one doctor was involved in care during the last month of life, and whether someone was in charge of care if more than one doctor was involved. While these questions identify one key element of care coordination – that someone was in charge of care – they do not fully reflect the breadth of activities involved in coordinating care. As a result, this study cannot draw broad conclusions about care coordination at the end-of-life. More information about specific coordination tasks such as connection to community services or transfer of information across care providers would be necessary to provide a nuanced evaluation of coordination and end-of-life care quality.

Next, NHATS, LMLI is only collected once after a NHATS participant dies, and thus can only provide cross-sectional data about care provided in the last month of life without any temporal dimension. As a result, this study can only assess correlation between coordination and other recognized quality domains, rather than causation. Using available NHATS data, we cannot know whether high quality care for symptom management, respect, and other dimensions resulted from coordination, or whether coordination is a marker of generally higher quality care overall. Additional research with some temporal dimension to data collection would be necessary to assess the causal pathways between coordination and high quality care in other end-of-life quality domains.

Other limitations included the study's reliance on proxy rather than direct report from the dying individual. Literature suggests proxy report is typically accurate for objective measures like care received, but less accurate for subjective measures, such as degree of pain.[92] A different study showed proxies, and patients gave similar reports of healthcare quality.[93] To address this limitation, we investigated aspects of care received and overall satisfaction, which literature suggests are most reliable when rated by a proxy, rather than the extent specific symptoms were experienced.

Lastly, the study only investigates community-dwelling older adults due to differences between community-dwelling and residential care-dwelling populations. Therefore, findings can only be generalized to community-dwelling Medicare beneficiaries. To ensure the end-of-life experience of residential care-dwelling older adults was not overlooked, we assessed outcomes for residential care-dwelling older adults in a separate analysis not reported in this paper.

Despite these limitations, this study identifies relevant and important information about this understudied population of older adults with MCC.

Coordination as a Strategy for Improving End-of-Life Care for Older Adults with MCC

Findings from this study suggest that efforts to provide coordinated care may be related to more positive care in other end-of-life quality domains, specifically symptom management, respect, and the extent to which individuals are informed about care. For the sake of this study, we defined coordination as the presence of someone in charge of care during the last month of life. The presence of someone in charge of care is only one of several aspects of coordinated care. For example, a systematic review identified four critical domains that coordination models must meet to support adequate chronic care: patient self-management, decision support, delivery system design, and clinical information systems.[128] Similarly, the Agency for Healthcare Research and Quality (AHRQ) determined nine tasks to be integral to care coordination in their effort to develop systematic, comprehensive measures of care coordination: establishing accountability or negotiating responsibility; communicating (interpersonal and information transfer); facilitating transitions; assessing needs and goals; creating a proactive plan of care; monitoring, following up, responding to change; supporting self-management goals; linking to community resources; and, aligning resources with patient and population needs.[45] While many formal care coordination models offer additional services such as linkage to community services or individualized care planning,[129] the presence of someone in charge of care is a key element to care coordinated through a formal model or coordinated informally. Findings from our study suggested that even without additional coordination services, the presence of a central authority managing the care team and observing the dying individuals' needs may be an important dimension of end-of-life care.

Other studies have found similar results. For example, a pilot study in a palliative care unit found that designating an entity in charge of care for individuals led to cost reductions as a result of fewer duplicated services and greater adherence to patient preferences.[130] While more information is needed to assess whether high quality end-of-life care for older adults with MCC resulted from care being coordinated, findings from this study suggest care coordination may be a strategy for end-of-life care improvement worth further investigation.

Conclusions

This study identified that proxies for older adults with MCC who perceived end-of-life care to be coordinated also reported receiving high quality care in other end-of-life care domains. However, this study could not draw conclusions about causal relationship between coordination and high quality care. Despite our limited definition of coordination, results from this study indicated that coordination could be a strategy for improving end-of-life care quality for older adults with MCC, particularly in the dimensions of symptom management, respect, and the extent to which individuals are informed about care.

Chapter 6: Conclusion

While literature indicates that fewer than half of older adults aged 65 years or older receive high quality end-of-life care,[1] less is known about the quality of end-of-life care experienced by the segment of that population with multiple chronic conditions (MCC).[2] A prominent and widely accepted conceptual model created by Joan Teno and colleagues with older adult and caregiver input (Teno Model) indicates that high quality end-of-life care requires assessment and intervention in five domains: *coordination, symptom management, shared decision-making, respect,* and *spiritual and emotional support*.[1,3,4] *Coordination*, one of the identified quality domains, may be of particular importance to older adults with MCC given its success in addressing care fragmentation for older adults with MCC prior to the end of life.[5–7]

Drawing upon the Teno Model of high quality end-of-life care, the *goals* of this study were to advance the understanding of the quality of end-of-life care experienced by older adults with MCC and how that care may be improved. The study's two *objectives* were to assess the presence of MCC as a potential driver of poor end-of-life care quality, and to inform end-of-life care improvements that meet the needs of older adults with MCC and their informal caregivers. Three *specific aims* addressed the study's objectives: (1) to identify disparities in end-of-life care quality by MCC status; (2) to determine which dimensions of end-of-life care quality were associated with high quality end-of-life care for older adults with MCC; and (3) to assess the association between care coordination and high quality end-of-life care for older adults with MCC. This retrospective cross-sectional cohort study utilized the nationally representative National Health and Aging Trends Study (NHATS), Last Month of Life Interview (LMLI).[8]

Key Findings

Aim 1 Key Findings

In this study, only 52% of community-dwelling Medicare beneficiaries with MCC received “excellent” care in the last month of life. The greatest unmet need for older adults with MCC was in the spiritual and emotional support *composite quality domain*, where only 31% of MCC proxies perceived care positively. Among older adults included in this study, individuals with MCC experienced significantly greater anxiety and sadness in the last month of life compared to those without MCC.

We found no association between MCC status and rating of *overall* care quality. MCC proxies had higher odds of perceiving care positively for breathing issues and being informed about care, but care perception did not differ by MCC status for any other dimensions of quality. For several dimensions of quality, proxies’ perception of care was related to the setting where the older adult’s death occurred and hospice enrollment.

Specifically, dying at home was the only factor significantly associated with an “excellent” rating on the measure of *overall* care quality for this study’s sample. Positive perception of care in the coordination, shared decision-making, and respect *composite quality domains* were also higher for older adults who died at home. In our study, we also found dying at home was significantly associated with hospice enrollment for dying individuals.

Aim 2 Key Findings

Among those with MCC, perception of care in the coordination, shared decision-making, respect, and spiritual and emotional support *composite quality domains* were significantly associated with the rating of *overall* care quality. Symptom management, the fifth *composite* *quality domain* identified in the Teno Model, was not associated with the rating of *overall* care quality provided by MCC proxies in this study. Relationships between how proxies perceived dimensions of end-of-life care and how they ultimately rated the *overall* care experience of dying older adults with MCC were complex. For many recognized end-of-life quality domains, perceiving care negatively appeared to have a stronger association with the *overall* care quality rating than perceiving care as "positive".

The presence of cancer appeared to be a driver of the care older adults with MCC experienced in the last month of life. A greater proportion of proxies perceived end-of-life care quality negatively in the symptom management and shared decision-making *composite quality domains* for individuals dying with MCC that included cancer. We found that MCC proxies perceived *overall* care quality, spiritual and emotional support, and religious and spiritual care positively for individuals with cancer enrolled in hospice, while MCC proxies perceived shared decision-making and care for anxiety/sadness more positively for individuals without cancer enrolled in hospice.

Aim 3 Key Findings

Prior to the end of life, coordination is associated with better quality of care as well as improved health and utilization outcomes for older adults with MCC.[5–7] Proxies of older adults with MCC who perceived coordination positively in the last month of life also perceived care as "positive" for the following dimensions: symptom management, pain management, respectful treatment, personal care, and the extent to which the dying individual was kept informed in the last month of life. Findings suggested that coordination may be associated with highly rated end-of-life care, but the study was not able to establish causation between receiving coordinated care and receiving high quality care in other end-of-life care dimensions. This study demonstrated the need to more thoroughly examine care coordination, including specific coordination tasks, as an approach for ensuring high quality end-of-life care.

Limitations

This study relied on secondary data, which limited the generalizability of our findings. The four most significant limitations included reliance on proxies rather than direct report, the timing of NHATS, LMLI data collection, the use of self-reported MCC status, and the exclusion of nursing home residents. Despite these concerns, the NHATS, LMLI is the best source for answering our research questions given it is nationally representative, spans multiple end-of-life care settings, and uses a recognized conceptual model to assess end-of-life care quality. The following sections describe each limitation and its implications for the outcomes of this study.

Reliance on Proxy Rather than Direct Report

This study relied on proxy report rather than direct report from the dying individual. While proxies could describe symptoms experienced and care received by the dying NHATS participant in the last month of life, the accuracy of that information could not be validated with the person who experienced those symptoms or received that care. While numerous end-of-life studies use proxy report, researchers question the strength of proxies' responses. For example, studies indicate that due to wide variation in practices for identifying proxies across retrospective end-of-life care quality surveys, proxy reliability cannot be currently defined.[90,91] Additionally, family caregiving configurations often change as an individual approaches death, such that no individual proxy has the full picture of the end-of-life care delivered.[90] However, one study suggests that proxy report is typically accurate for objective measures like care received, but less accurate for subjective measures, such as degree of pain.[92] A different study showed proxies and patients give similar reports of healthcare quality.[93]

In an attempt to limit proxy issues, we did not use proxy report of the extent to which dying individuals experienced specific symptoms, which proxies cannot reliably report. We only investigated whether symptoms were present, features of the care received, and overall satisfaction, which literature suggests can be reliably reported by a proxy.[92]

Timing of Data Collection

Report from bereaved proxies may bias our results. In our study, we relied on proxies' perception of care quality in the last month of life. It is possible that proxies' perception of care quality may be influenced by their feelings of grief and loss relating to the NHATS participants' death. Literature disagrees whether or to what extent caregiver bereavement impacts their rating of quality.[91] However, a systematic review of end-of-life satisfaction cautions that measures of satisfaction may be biased by grief and anger.[38] Additionally, a different study on end-of-life quality measurement identifies that proxy-reported assessment of end-of-life quality must balance immediate bereavement with memory.[92] All proxies were surveyed within 12 months of participant's death for this study, but it is impossible to assess their bereavement with information available in the NHATS dataset. In an effort to identify any proxy-related confounding, we included proxy gender and proxy relationship to the deceased as covariates during analysis.

Self-Reported MCC Status

The use of self-reported chronic conditions, rather than official diagnoses, represents a study limitation. Conditions included in the study were limited to those identified by NHATS in their data collection tools. While some conditions may be missed, the NHATS attempts to collect chronic condition data as thoroughly as possible. For example, NHATS participants first report their chronic conditions through close-ended questions about specific chronic conditions. Data collectors then ask an open-ended follow-up question about whether a doctor has ever told the participant they have another serious disease or illness to identify any conditions missed in the original questions.

Another condition-based limitation is that proxies do not update the participants' condition list during the LMLI. As a result, NHATS does not capture any conditions diagnosed between the participants' last interview and the LMLI. Therefore, it is possible that participants who did not meet this study's MCC definition at the last interview prior to death may have met the MCC definition at the point of death. However, such a change in MCC status cannot be detected with available data.

To control the potential for bias based on conditions selected by NHATS and their collection method, we defined MCC as a binary variable, coded into absent or present. We chose not to consider the number of chronic conditions due to that numbers' dependence on conditions identified during NHATS data collection. Examining only the absence and presence of MCC also minimized issues related to new conditions acquired during the last year of life. While our approach allowed us to examine MCC broadly as a concept, we were unable to perform a more nuanced analysis based on specific chronic condition combinations. Future studies examining end-of-life care quality for older adults with MCC may consider different approaches to collecting chronic condition information that provides more detail, such as medical record review.

Exclusion of Nursing Home Residents

This study only investigates community-dwelling older adults, which limits our ability to generalize the findings to older adult living in residential care in the last month of life, including skilled nursing facilities. We chose to stratify analysis by dwelling status (community versus residential care) due to differences in the two populations on key demographic, care, and proxy factors (see **Chapter 2**). However, concerns over the generalizability and quality of the residential care-dwelling data led us to exclude the residential care-dwelling subpopulation from the study entirely. Specifically, 71% of deceased residential care-dwelling NHATS participants were excluded from the study sample. We excluded 40.1% due to the use of a facility employee proxy. We excluded 21.1% due to inconclusive MCC status. The remaining 6.0% were excluded because their LMLI was collected during Round 2, which was an exclusion criteria of this study due to changes in NHATS, LMLI survey items between Rounds 2 and 3.

Since residential care-dwelling older adults are an understudied group that may experience different end-of-life care quality than community-dwelling older adults, we attempted to examine their end-of-life care quality experience in a separate analysis. We repeated the study's analysis with the residential care-dwelling sample, but found the results to be highly unstable and therefore unreliable (see **Appendix D**). For example, most crosstabs in the residential care-dwelling sample analysis contained raw cell sizes less than 10, which resulted in large confidence interval ranges for weighted proportions. The small raw cell sizes also impacted the multivariable regressions. We attempted to exclude all covariates with small cell sizes from multivariable models. For comparison, we ran all multivariable models unadjusted, adjusted for all covariates, and then adjusted for only covariates where raw cell sizes were greater than 10. The results were vastly different, including some changes in the odd ratios' direction, based on which covariates were in the model. Additionally, wide confidence intervals resulted from some multivariable regressions, while other models could not be run at all. We determined the data to be too volatile for any meaningful conclusions to be drawn from analysis.

While currently available in NHATS, the LMLI data do not allow for analysis of the residential care-dwelling older adult population using our study protocol, we still find the population to be of high importance. Our analysis should be repeated and compared to the community-dwelling population once additional NHATS rounds provide a sufficient residential care-dwelling sample. Additionally, researchers should consider other approaches for studying end-of-life care quality among residential care-dwelling older adults, particularly those who do not have family available to serve as proxies.

Implications and Recommendations

This section describes our findings' most notable implications for practice, policy, and future research. Results indicated that while end-of-life care quality did not differ significantly by MCC status, gaps in care exist for all dying older adults, particularly related to spiritual and emotional support. Findings also suggested that hospice, Medicare's primary end-of-life care program and the gold standard for end-of-life care quality, may not adequately meet the needs of older adults with MCC unless they also have cancer. Additionally, this study confirmed the need to improve end-of-life care quality research approaches, which currently limit the ability to improve end-of-life care quality meaningfully. The following sections describe each implication in more depth.

Implication for Practice: Enhance Spiritual and Emotional Support

In our study, end-of-life care quality did not differ significantly for those with MCC and those without, but care was not of high quality for either group, particularly for spiritual and emotional support needs. Participants with MCC experienced significantly higher rates of anxiety and sadness in the last month of life when compared to participants without MCC, which may make gaps in spiritual and emotional support especially relevant for dying older adults with MCC. Additionally, how MCC proxies perceived spiritual and emotional support in the last month of life was associated with how they rated *overall* end-of-life care quality, suggesting care in this area was meaningful to their overall care quality experience. Our findings indicate that spiritual and emotional support is a priority for dying older adults with MCC, yet care rarely addressed the population's spiritual and emotional needs adequately.

Other studies have found a similar linkage between spiritual and emotional support and the end-of-life care quality. Dying individuals' spiritual beliefs and emotional state guide many of their end-of-life care decisions, thus attending to spiritual and emotional needs may have implications for other aspects of end-of-life care.[100] For example, in one study, individuals with advanced cancer receiving *spiritual support* from their medical team experienced higher rates of hospice enrollment and fewer aggressive treatments at the end of life.[100] Similar results were seen among individuals with advanced cancer who received *emotional support* from their medical team.[131] Other studies also identify an association between spiritual and emotional support and *overall* end-of-life care quality, in addition to other important outcomes such as increased quality of life, decreased use of aggressive care, and lower costs.[100,102,103] While literature does not identify the specific impact of spiritual and emotional support on dying individuals with MCC, our findings suggest spiritual and emotional support are important to the population and therefore worthy of intervention.

Healthcare providers struggle to deliver spiritual and emotional support effectively, despite accreditation standards that require such care (The Joint Commission Provision of Care, Treatment, and Services standards). As in our study, others have found evidence that dying individuals' spiritual and emotional support needs often go unmet.[132,133] For example, in their assessment of spiritual care for older adults dying with advanced cancer, Balboni et al concluded that while 88% of participants found spiritual support important at the end of life, 72% felt the healthcare system was not meeting their spiritual and religious needs.[134] Additionally, Teno et al found that 50% of older adults did not receive enough emotional support in the last month of life.[1] Evidence from other studies suggests that while spiritual and emotional support are seen as vital components of end-of-life care by patients and other stakeholders, significant gaps in care still exist in those areas.[134]

Literature identified barriers that may prevent healthcare providers from addressing spiritual and emotional support needs at the end-of-life. Barriers to effective spiritual support included lack of time, cultural factors, institutional limitations, and professional education needs.[135] Similar barriers impact the provision of emotional support at the end-of-life. For example, in focus groups, physicians expressed concern that providing emotional support would complicate their already complex schedules by forcing them to take on an additional role of counselor for their patients.[136] Other barriers to providing emotional support include patients withholding emotional concerns out of fear of embarrassment, and care providers failing to initiate supportive conversations due to lack of time or low confidence in their own interpersonal skills.[137] Eliminating the identified barriers may improve spiritual and emotional support provision at the end of life, but requires significant investment and culture change within healthcare systems.

Literature also identifies facilitators and recommendations that may be leveraged to improve spiritual and emotional support at the end-of-life. Facilitators of effective spiritual support provision include reciprocal relationships between patients and providers, family engagement in care, and the fostering of a friendly environment where dying individuals feel safe communicating about their thoughts and feelings.[135] The National Consensus Project for Quality Palliative Care guidelines, the National Quality Forum Preferred Practices, and a recent consensus report compiled by experts provide detailed recommendations to inform spiritual and emotional support provision at any time in the life course and overcome identified barriers within healthcare.[111] Recommendations include focusing on personal and professional development among healthcare providers to enhance their self-confidence discussing sensitive topics; changing processes to include standardized assessment of all patients' spiritual needs; establishing a palliative care focus for serving individuals approaching the end of life; and leveraging non-physician professionals trained in spiritual and emotional support, such as chaplains and social workers, to reduce the time and task burden on the medical team.[111] Others advocate for creating new roles for non-physician experts that can attend to dying individuals spiritual and emotional support at the end-of-life as a method for reducing physician burden and enhancing patients' comfort discussing their thoughts and feelings.[137] Additionally, improving access to hospice care may also lead to better spiritual and emotional support, as individuals who receive hospice care receive better spiritual and emotional support than those who die in other settings (although our study identified opportunities to improve spiritual and emotional support for those dying with hospice, as well).[3] Devoting greater resources toward providing spiritual and emotional support, designing new processes, and creating new roles for non-physician experts could result in greater spiritual and emotional support for dying individuals, which may contribute to better overall end-of-life care quality, particularly for older adults with MCC.

In summary, despite the existence of accreditation standards incentivizing and guidelines informing spiritual and emotional support provision, care in these areas fails to adequately meet the needs of the majority of dying older adults. Fixing the problem will require culture change, rethinking the way spiritual and emotional support is provided, and additional research to inform and evaluate such changes. This study identified gaps in spiritual and emotional support provided to dying older adults with MCC and also provides evidence that spiritual and emotional support are integral components of end-of-life care quality for the population and thus should be an improvement priority.

Implications for Policy: Strengthen Hospice Policy

In our Aim 1 analysis, we identified that individuals with cancer and those who died at home were more likely to receive hospice care in the last month of life. In our Aim 2 analysis, which was limited to older adults with MCC, we similarly found that dying at home was positively associated with hospice enrollment. However, for those who died outside the home, cancer was significantly positively associated with hospice enrollment. Additionally, we found discrepancies in MCC proxies' perception of care for individuals enrolled in hospice based whether the dying individual reported cancer as one of their chronic conditions. Our findings indicate a need to strengthen Medicare's hospice policy in a way that enhances accessibility for individuals who do not die at home and do not have cancer, and reduces variability in hospice-related outcomes for individuals who do not have cancer.

This study identified a significant association between dying with cancer and hospice enrollment. Cancer-based differences in hospice enrollment align with the hospice's history as well as known challenges for older adults with MCC approaching the end of life. First, Medicare's hospice eligibility requirement of a 6-month prognosis to death was developed to reflect the experience of individuals with cancer in the 1980s, as cancer was a common end-of-life diagnosis for older adults at the time.[32] Next, older adults dying with MCC experience a unique trajectory to death when compared to older adults with cancer, which makes it difficult to determine when to initiate end-of-life specific interventions, such as hospice.[40] For example, Medicare's current hospice eligibility criteria require a 6-month prognosis to death, which may only be determinable for older adults with cancer. As a result, older adults with a cancer diagnosis may have different access to hospice care than those without cancer, which our findings appear to confirm.

Our findings also suggest that the benefits of hospice may be different for older adults with MCC who had cancer as one of their chronic conditions. We found that MCC proxies perceived *overall* care quality, spiritual and emotional support, and religious and spiritual care significantly more positively for individuals with cancer enrolled in hospice, while MCC proxies perceived shared decision-making and care for anxiety/sadness significantly more positively for individuals without cancer enrolled in hospice. The discrepancies in hospice-related outcomes we found indicate that older adults with MCC that includes cancer may be a unique population with different end-of-life needs and experiences than older adults whose MCC does not include cancer. Due to NHATS limitations, our study was unable to identify reasons why the MCC population did not experience the same benefits from hospice enrollment as the general older adult population or why hospice-related benefits differed by cancer diagnosis among older adults with MCC. We suspect the discrepancies may have resulted from the duration of hospice care received by the MCC population. Appropriate hospice use is defined as enrollment for greater than 1 week, but less than 6 months.[30] Literature indicates appropriate hospice use is associated with fewer unmet needs and greater satisfaction with quality when compared to other care approaches.[1,31] However, studies on hospice outcomes suggest that strong positive outcomes require early hospice enrollment.[131] If our suspicion is true, older adults with MCC may be enrolling in hospice, but not for a meaningful duration, which may not allow the benefits of hospice to be fully experienced.

If further investigation confirms differences we found in hospice-related outcomes for older adults with MCC who do not have cancer compared to those who do, discrepancies in hospice-related benefits may warrant adjusting Medicare policy to meet the needs of the latter group. Changes in policy would be necessary to promote hospice enrollment among those who do not have cancer or to enhance palliative care as a way to make the benefits of hospice available for individuals who are ineligible for hospice enrollment. A recent Medicare pilot project attempts to fix shortcomings of the Medicare hospice policy, but the pilot may not produce improvements for older adults with MCC who do not appear to be experiencing meaningful benefits from the traditional hospice model. The Medicare Care Choices Model allows individuals to receive hospice-like supportive services while also receiving curative treatment. However, the Care Choices Model does not eliminate the 6-month prognosis requirement that may be acting as a barrier for older adults with MCC. Medicare policies that would potentially improve end-of-life care quality for older adults with MCC would be those that either improve hospice accessibility by eliminating the 6-month prognosis requirement for individuals willing to forego curative treatment, or those that strengthen palliative care delivered outside a formal hospice model.

In summary, our study found that individuals with cancer and those who died at home were more likely to receive hospice care in the last month of life. We also found variability in hospice-related outcomes for older adults with MCC based on whether they had cancer as one of their chronic conditions. The differences in hospice-related outcomes we found indicate that older adults with MCC that includes cancer may be a unique population with different end-of-life needs and experiences than older adults whose MCC does not include cancer. Further investigation is necessary to understand the mechanisms that underlie the discrepancies in hospice-related outcomes by cancer diagnosis. Results from such investigation should inform improvements to Medicare’s hospice policy to enhance accessibility for older adults with MCC who do not have cancer or to strengthen palliative care for those ineligible for hospice.

Implication for Future Research: Innovate End-of-Life Research Methods

Lastly, findings from this study highlight a need for new approaches to studying end-of-life care quality, particularly for older adults with MCC. Our study suffered from limited details about specific aspects of end-of-life care provided to dying older adults, such as care coordination activities and duration of hospice enrollment. However, such limitations are not unique to this study, and are related to issues inherent to most studies of end-of-life care quality. Currently, researchers typically follow two approaches for assessing end-of-life care quality: they gather prospective information from people suspected to die soon, or they gather retrospective information from proxies. Both approaches are limited in generalizability given neither measures the experience of dying individuals directly.

Researchers typically use the first approach, gathering information prospectively from individuals expected to die soon, to assess the needs and opinions of dying individuals at a moment in time. Recent examples of studies using this approach include Kastbom, Milberg, and Karlsson's[138] interviews with palliative cancer patients to assess themes associated with a good death; Li et al's[139] investigation of the linkage between radiation therapy and aggressive care among terminal cancer patients; and Delgado-Guay et al's[140] randomized controlled trial of advanced cancer patients' wishes for end-of-life care. Major limitations of this approach are that it requires the identification and recruitment of individuals approaching the end of life.[141] Identifying individuals likely to die relies on the strength of prognostic tools and places physicians into the role of gatekeeper for research participant identification and enrollment.[141] As a result, prospective studies often focus on conditions such as advanced cancer where a prognosis to death can be identified and an individual has enough time remaining to be recruited and participate in a study before death.[100,141] As discussed in previous chapters, individuals with MCC rarely experience a clear prognosis to death, and as a result, their perspective may be left out of prospective studies. Additionally, it is impossible to know how long a participant will survive at the point of recruitment and data collection, thus information from prospectively enrolled participants may not actually reflect end-of-life experience if individuals recruited live longer than anticipated. Prospective studies can therefore often tell more about what individuals anticipate wanting at the end of life than their actual end-of-life experience.

Proxies offer an alternative to prospective data collection,[92] which allows end-of-life care assessment for individuals who cannot be identified prior to death, such as older adults with MCC. Two large national follow-back surveys, including the NHATS, rely on proxy report of end-of-life care quality.[3,8] In a systematic review of end-of-life measurement tools, Lendon et al[91] found that the vast majority (93%) of survey-based end-of-life care assessments target proxies rather than the dying individual. Commonly utilized, validated tools for proxy assessment include the After Death Bereaved Family Member Interview,[142] Family Satisfaction with Advanced Cancer Care,[143] and the Family Evaluation of Hospice Care,[144] among others. The approach for defining who can serve as a proxy, identifying that proxy, and collecting data from proxies varies widely across studies and limits the comparability of studies, including those using the same survey tool.[91] As discussed in the **Limitations** section of this chapter, proxy report may be subject to bias based on time, relationship, and proxy's awareness of the end-of-life experience. Proxy report may say more about caregivers' experience with a dying individuals' end-of-life care than it says about the care itself, which while important, may not tell vital information about improving end-of-life care quality for dying individuals.

Gathering information prospectively from individuals expected to die soon and retrospectively from proxies share some common limitations, as well. Both approaches are limited in their capacity to allow follow-up questions. When data are collected prospectively, dying individuals may be unwilling to follow up if their condition is worsening, or they may be unavailable for or unable to follow-up. When data are collected retrospectively, proxies are limited by their memory, which limits their ability to accurately recall details and rate care.[91,145] In both situations, detailed information about the sort of care received by a dying individual may be inaccessible to researchers.

Assessing end-of-life care quality directly requires accurately identifying dying individuals and for those dying individuals to be willing to engage in research, which represent major barriers to end-of-life research that necessitate innovation. The ability to accurately identify dying individuals may in itself inform end-of-life care improvement, as knowing the moment end-of-life begins could indicate when end-of-life-specific interventions should start. Once identified, while many research participants may be motivated by a sense of altruism, individuals aware they have a limited time left in life may be unwilling to spend that time engaging in research. Given such limitations, understanding the quality of end-of-life care experienced by older adults with MCC and translating that understanding into improvement will require innovation. Three potential approaches to improving end-of-life care quality research include leveraging electronic health record (EHR) data, utilizing claims data and other population-level datasets, and applying ethnographic data collection approaches.

First, emerging studies demonstrate the feasibility of EHR data for studying end-of-life care quality. For example, Seaman et al[146] used EHR data to perform a retrospective assessment of palliative consultation orders among critically ill ICU patients at high risk of dying, showing that palliative consultation orders typically occur late in the life course for such patients.

Wachterman et al[147] utilized medical records to assess the end-of-life care quality experienced by individuals dying within a Veteran's Administration inpatient facility. EHRs' contribution to research will grow as this technology expands within clinical settings, potentially allowing for the prospective identification of research participants and retrospective review of the end-of-life care provided.

Next, studies on end-of-life for older adults could benefit from Medicare claims data to identify services delivered during the last month, including addressing the lack of data on hospice utilization that this study faced. End-of-life cost and utilization studies often use claims data to quantify the type of care provided to dying individuals, but recent studies from outside the US demonstrate that claims data can provide information for quality improvement, particularly when coupled with clinical registries. Maetens et al[148] identified approaches for using Belgian claims data and clinical registries to assess end-of-life care quality, while Ohlen et al[149] linked clinical registries and claims data to assess the quality of pain management among palliative care patients in Sweden. Similar approaches may be useful within the US, particularly to examine particular demographic and care characteristics in combination with healthcare utilization.

Lastly, the use of ethnographic data collection tools might offer a new approach for engaging dying individuals and their caregivers in meaningful research about end-of-life care quality. The Australian 'Caring at the End of Life' project utilizes photo-voice and participatory network mapping to understand the end-of-life experience for dying homebound individuals and their caregivers.[150] In that study, dying individuals were invited to photograph moments from their day and discuss those photos with the researchers.[150] In a different Australian study, Collier, Sorenson, and Iedema[151] used video-reflexive ethnographic methods to identify patient safety risks in a hospital and at home for dying individuals. In that study, researchers shadowed dying individuals and video recorded their daily healthcare experiences. Researchers then watched the videos with the dying individuals to gather their perspective on their end-of-life care.[151] Additionally, others have applied narrative research methods to study individuals' end of life experience[152] and bereavement among family members.[153] The strength of such approaches is their ability to facilitate change[154] and their ability to engage non-typical research participants who may find traditional research methods challenging, including individuals from marginalized communities and those with communication issues.[155] Ethnographic research methods also provide more granular and specific data directly from dying individuals through their own perspective, rather than filtering dying individuals' experiences through survey responses gathered from the researcher's perspective. While the application of ethnographic tools to end-of-life care quality research has been limited, early evidence suggests innovative and participatory approaches may have promise for contributing new information to understand end-of-life care quality and inform quality improvement.

In summary, this and other similar study suffer from limitations based on current methods for studying end-of-life care quality that do not measure the experience of dying individuals directly. Specifically, most studies of end-of-life care rely on prospective identification of individuals likely to die, which results in literature skewed toward individuals with cancer, or rely on retrospective data collection from proxies, which rely heavily on memory and perception. New, innovative research approaches leveraging electronic health record (EHR) data, utilizing claims data and other population-level datasets, and applying ethnographic methods may help strengthen future end-of-life research.

Conclusion

This study sought to advance understanding of the quality of end-of-life care experienced by older adults with MCC and how that care may be improved using the nationally representative NHATS, LMLI. We identified that end-of-life care quality does not differ significantly by MCC status, but meaningful gaps in care exist for all older adults, particularly relating to spiritual and emotional support. We also identified that dying at home was significantly associated with higher rates of hospice enrollment, better ratings of *overall* end-of-life care quality, and a “positive” perception of care for several quality dimensions for the general older adult population and for older adults with MCC. In this study, ratings of *overall* end-of-life care quality for older adults with MCC were associated with their experience in the coordination, shared decision-making, respect, and spiritual and emotional support domains, but not their experience with symptom management. Findings also suggested that older adults with MCC who do not have cancer may experience different benefits from hospice, Medicare’s primary end-of-life care program and the gold standard for end-of-life care quality, than dying older adults with MCC that does not include cancer. Study findings identified care coordination as an end-of-life care improvement approach worth further investigation. Additionally, this study confirmed the need to improve end-of-life care quality research approaches, which currently limit the ability to improve end-of-life care quality meaningfully.

Chapter 7: Supplemental Materials

Table 2-1. Significant differences in key comparison groups at the p<.05 level for demographic, care, and proxy factors

		Demographic						**Care**				**Proxy**	
#	**Comparison**	**Age**	**Gender**	**Race/Ethnicity**	**Census Region**	**Medicaid**	**Marital Status at Death**	**Dementia Reported**	**Cancer Reported**	**Hospice Enrollment**	**Place of Death**	**Proxy Relationship**	**Proxy Gender**
By Round													
1	By death in Round 2 vs. other rounds							x			x		x
2	By round, excluding Round 2	x										x	
By Facility Proxy Status													
3	By facility proxy, regardless of dwelling in last month	x	x	x			x				x		x
4	By facility proxy, residential care-dwelling only						x						x
By Dwelling													
5	By dwelling in last month, regardless of facility proxy	x	x	x		x	x	x		x	x	x	x
6	By dwelling in last month, non-facility proxy only	x	x	x			x	x		x	x	x	
By Conclusive MCC Status													
7	By inconclusive MCC status, res. care & non-facility proxy only	x	x		x						x	x	

**Unless noted, all comparisons include Round 2 data

Table 2-2. Raw and weighted study samples with differences from the final community-dwelling analytic sample

Aim	Raw Sample (Weighted)	Difference from Final Community-Dwelling Analytic Sample
1	665 (1,572,166)	No difference
2	477 (1,123,877)	MCC only, excluding participants who did not receive care in the last month of life, based on the LMLI *overall* care quality rating item (n=21), or whose proxy did not rate *overall* care quality (n=6)
3	466 (1,102,484)	MCC only, excluding participants who did not receive care in the last month of life, based on the LMLI coordination item (n=20), or whose proxy did not know whether the participant received coordination in the last month of life (n=18)

Table 2-3. Sample populations and variables by study aim

Aim	Pop.	Covariates	Independent/ Explanatory Variable	Dependent Variable
1	All subjects	Age, gender, race/ethnicity, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship, proxy gender	MCC status	Excellent *overall* end-of-life care quality rating (primary)
				Positive perception of care within each *composite quality domain* (secondary)
				Positive perception of care within each individual *component* (tertiary)
2	MCC only	Age, gender, White race, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship, proxy gender	Positive perception of care within each *composite quality domain* (primary)	Excellent *overall* end-of-life care quality rating
			Positive perception of care within each individual *component* (secondary)	Excellent *overall* end-of-life care quality rating
3	MCC only	Age, gender, White race, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship, proxy gender	Positive perception of care within coordination *composite quality domain*	Positive perception of care within symptom management, shared decision-making, respect, and spiritual and emotional support *composite quality domains* (primary)
				Positive perception of care within each individual *component* (secondary)

Table 2-4. Candidate multiple chronic condition definitions considered during study planning

<table>
<tr><th>Def</th><th>Interp.</th><th>Heart Disease</th><th>Heart Attack</th><th>Hypertension</th><th>Arthritis</th><th>Diabetes</th><th>Lung Disease</th><th>Dementia</th><th>Cancer</th></tr>
<tr><td>1</td><td>Complexity-based</td><td colspan="3">x
[Cardiovascular Condition]</td><td>x</td><td>x</td><td>x</td><td></td><td></td></tr>
<tr><td>2</td><td>AHRQ recognized</td><td>x</td><td>x</td><td>x</td><td>x</td><td>x</td><td>x</td><td>x</td><td>x</td></tr>
<tr><td>3</td><td>Severity-based</td><td colspan="3">x
[Cardio. w/ Stroke]</td><td>x</td><td>x</td><td>x</td><td></td><td></td></tr>
<tr><td>4</td><td>Complexity-based w/o hypertension</td><td colspan="2">x
[Cardio.]</td><td></td><td>x</td><td>x</td><td>x</td><td></td><td></td></tr>
<tr><td>5*</td><td>AHRQ recognized w/o hypertension</td><td>x</td><td>x</td><td></td><td>x</td><td>x</td><td>x</td><td>x</td><td>x</td></tr>
<tr><td>6</td><td>AHRQ recognized w/o hypertension, dementia, cancer</td><td>x</td><td>x</td><td></td><td>x</td><td>x</td><td>x</td><td></td><td></td></tr>
</table>

*Study MCC definition

Table 2-5. Weighted percentage of sample with and without MCC by MCC definition strategy for LMLIs in Rounds 3, 4, 5

	Community-Dwelling		**Residential Care-Dwelling**	
Definition	**MCC Absent**	**MCC Present**	**MCC Absent**	**MCC Present**
1	24%	76%	22%	78%
2	13%	87%	6%	94%
3	37%	63%	30%	71%
4	39%	61%	36%	64%
5	23%	77%	15%	85%
6	37%	63%	35%	65%

Table 2-6. Distribution of the presence of hypertension and other chronic conditions among NHATS participants included in the analytic sample

	Community-Dwelling			Residential Care-Dwelling		
Group	**Raw # (N=665)**	**Weighted # (N=1,572,166)**	**%**	**Raw # (N=205)**	**Weighted # (N=440,098)**	**%**
No hypertension	167	406,280	25.8	44	96,007	21.8
Hypertension	498	1,165,886	74.2	155	331,690	75.4
Only	23	54,989	3.5	3	7,364	1.7
+1 condition*	82	163,097	10.4	19	39,819	9.0
+2 or more conditions	393	947,800	60.3	133	284,507	64.6
Hypertension + stroke	128	265,118	16.9	57	128,426	29.2

*Participants with hypertension and one other condition are the only group impacted by the exclusion of hypertension from the MCC definition

Table 2-7. Conceptual model of end-of-life *composite quality domains* and *individual components*

Composite Quality Domain	Individual Components
Coordination	>1 doctor involved in care
	1 doctor in charge of care
Symptom Management	Pain
	Breathing
Shared Decision-Making	Input into care
	Receipt of unwanted care
	Informed about care*
Respect	Respect
	Personal care
Spiritual and Emotional Support	Anxiety and sadness
	Religious and spiritual needs

*While being informed about care is a *component* of the shared decision-making *composite quality domain*, it is not included in the Teno Model's composite shared decision-making *composite quality domain* calculation.

Table 3-1. Weighted distribution of unadjusted proportions for covariates according to multiple chronic condition (MCC) status (N=1,572,166)

	Total Sample		MCC Status		
Demographic Characteristics	**Raw Freq. (N=665)**	**Weight. %**	**Absent (N=360,958) Freq. (%)**	**Present (N=1,211,208) Freq. (%)**	**p-value**
Age					.71
65 to 74	82	22	79,298 (22)	262,027 (22)	
75 to 84	245	39	129,337 (36)	477,469 (39)	
85+	338	40	152,323 (42)	471,712 (39)	
Gender					.31
Male	297	48	188,171 (52)	565,189 (47)	
Female	368	52	172,787 (48)	646,019 (53)	
Race/ethnicity					.66
White	426	78	276,287 (77)	946,521 (78)	
Black	181	12	49,739 (14)	138,142 (11)	
Hispanic/other	58	10	34,932 (10)	126,545 (10)	
Census region					.30
Northeast	116	17	80,607 (22)	186,680 (15)	
Midwest	151	25	86,163 (24)	299,145 (25)	
South	256	35	123,669 (34)	423,747 (35)	
West	142	24	70,519 (20)	301,637 (25)	
Medicaid					.57
No	506	80	293,636 (81)	960,302 (79)	
Yes	159	20	67,322 (19)	250,907 (21)	
Marital status at death					.45
Married	242	43	163,302 (45)	508,358 (42)	
Not Married	98	15	58,181 (16)	171,724 (14)	
Widowed	325	43	139,474 (39)	531,127 (44)	
Dementia reported					<.001
No	508	81	333,979 (93)	936,920 (77)	
Yes	157	19	26,979 (8)	274,289 (23)	
Cancer reported					<.001
No	429	62	328,238 (91)	649,607 (54)	
Yes	236	38	32,719 (9)	561,602 (46)	

Table 3-1. Weighted distribution of unadjusted proportions for covariates according to multiple chronic condition (MCC) status (N=1,572,166) (Continued)

	Total Sample		**MCC Status**		
Care and Proxy Characteristics	**Raw Freq. (N=665)**	**Weight. %**	**Absent (N=360,958) Freq. (%)**	**Present (N=1,211,208) Freq. (%)**	**p-value**
Hospice enrollment					.005
No	337	50	223,951 (62)	556,306 (46)	
Yes	328	50	137,007 (38)	654,903 (54)	
Place of death					.06
Home	269	43	143,447 (40)	527,268 (44)	
Hospital	249	37	166,142 (46)	412,828 (34)	
Other	147	21	51,368 (14)	271,112 (22)	
Proxy relationship					.59
Spouse	154	29	88,621 (25)	361,470 (30)	
Child	382	54	203,083 (56)	641,946 (53)	
Other relative	95	12	41,168 (11)	147,384 (12)	
Non-relative	34	6	28,085 (8)	60,409 (5)	
Proxy gender					.82
Male	172	27	98,779 (27)	319,411 (26)	
Female	493	73	262,178 (73)	891,797 (74)	

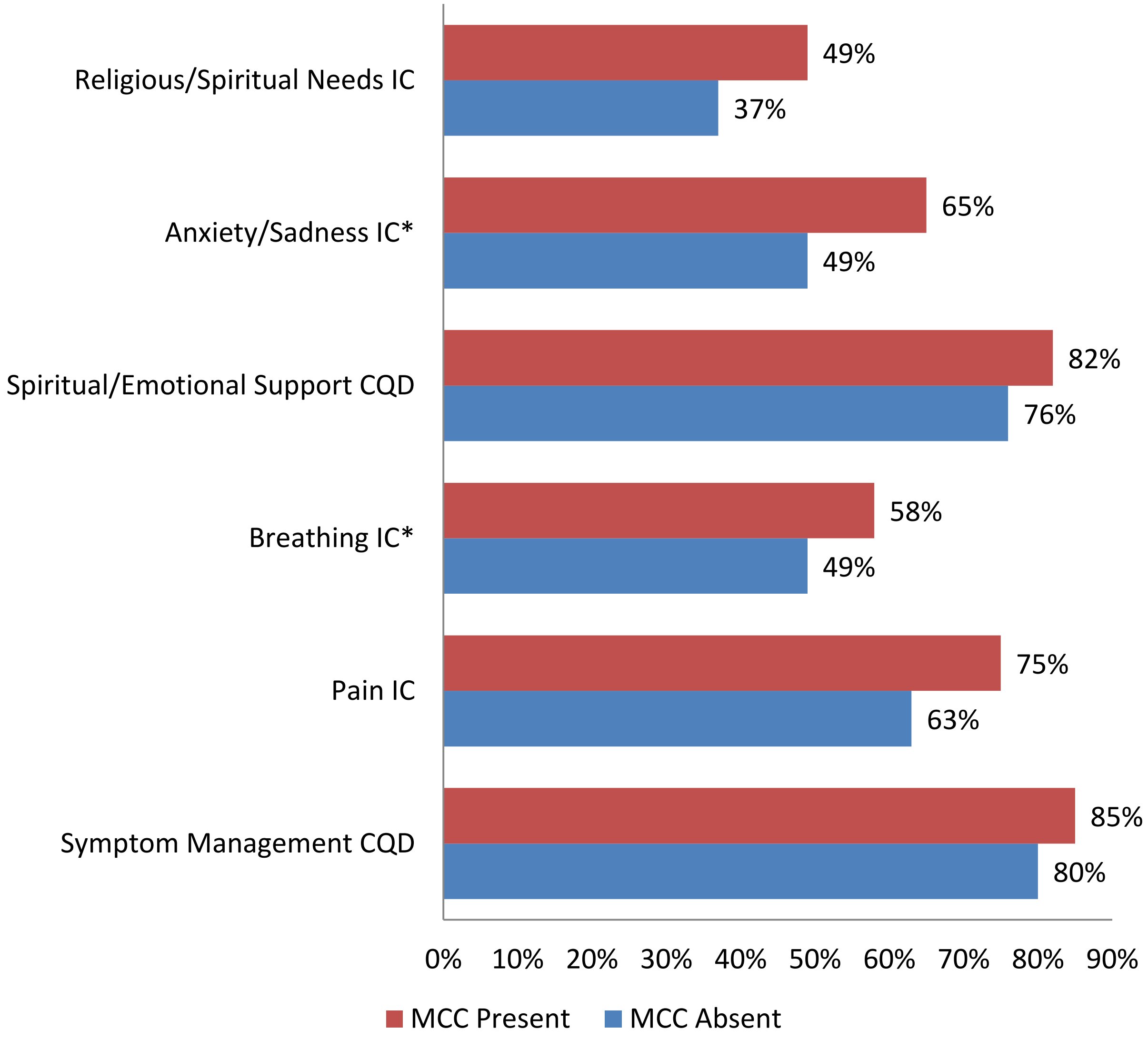


Figure 3-1. Percentage of study sample with need in each *composite quality domain* (CQD) and individual *component* (IC) where needs could vary by multiple chronic condition (MCC) status (*OR significant at p<.05 after adjusting for age, gender, race/ethnicity, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and place of death)

Table 3-2. Weighted distribution of rating of *overall* end-of-life care quality and perception of care in *composite quality domains* (CQD) and individual *components* (IC) for those with a need in the domain who rated care according to MCC status

Perception (Total N=1,572,166)	MCC Absent (Total N=360,958)		MCC Present (Total N=1,211,208)		p-value
	Freq.	Weighted % [95% CI]	Freq.	Weighted % [95% CI]	
Rating of *Overall* Care Quality (N=1,446,522)					.15
Not Excellent	186,596	58 [47,68]	544,929	49 [43,54]	
Excellent	136,039	42 [32,53]	578,958	52 [46,57]	
Coordination CQD (N=1,423,759)					.38
Not Positive	61,002	19 [13,28]	161,379	15 [11,19]	
Positive	260,273	81 [72,88]	941,105	85 [81,89]	
Symptom Management CQD (N=1,195,769)					.45
Not Positive	82,870	33 [23,44]	271,187	29 [24,34]	
Positive	169,248	67 [56,77]	672,463	71 [66,76]	
Pain IC (N=1,026,612)					.45
Not Positive	58,267	29 [19,41]	202,940	25 [20,30]	
Positive	142,462	71 [59,81]	622,943	75 [70,80]	
Breathing IC (N=808,615)					.07
Not Positive	50,989	33 [20,48]	124,913	19 [14,25]	
Positive	105,114	67 [52,80]	527,599	81 [75,86]	
Shared decision-making CQD (N=1,444,182)					.03
Not Positive	46,080	14 [9,21]	239,841	22 [18,26]	
Positive	283,765	86 [79,91]	874,496	79 [75,82]	
Input into Care IC (N=1,414,223)					.90
Not Positive	30,408	10 [5,16]	100,027	9 [7,12]	
Positive	289,195	91 [84,95]	994,593	91 [88,93]	
Receipt of Unwanted Care IC (N=1,442,776)					.02
Not Positive	27,430	8 [4,16]	175,748	16 [13,19]	
Positive	299,904	92 [84,96]	939,694	84 [81,87]	
Informed about Care IC (N=1,468,612)					.03
Not Positive	86,601	26 [19,35]	188,808	17 [13,21]	
Positive	241,560	74 [65,81]	951,643	83 [79,87]	

Table 3-2. Weighted distribution of rating of *overall* end-of-life care quality and perception of care in *composite quality domains* (CQD) and individual *components* (IC) for those with a need in the domain who rated care according to MCC status (Continued)

	MCC Absent (Total N=360,958)		**MCC Present (Total N=1,211,208)**		
Perception (Total N=1,572,166)	**Freq.**	**Weighted % [95% CI]**	**Freq.**	**Weighted % [95% CI]**	**p-value**
Respect CQD (N=1,458,195)					.20
Not Positive	99,772	32 [24,41]	280,460	25 [21,29]	
Positive	215,507	68 [59,76]	862,457	76 [71,79]	
Respect IC (N=1,439,827)					.25
Not Positive	44,120	14 [9,21]	111,589	10 [8,13]	
Positive	270,097	86 [77,91]	1,014,022	90 [87,92]	
Personal Care IC (N=1,436,593)					.31
Not Positive	80,688	26 [19,35]	233,847	21 [17,25]	
Positive	230,185	74 [65,81]	891,872	79 [71,83]	
Spiritual and Emotional Support CQD (N=1,250,700)					.24
Not Positive	194,500	74 [64,82]	679,244	69 [64,73]	
Positive	68,677	26 [18,36]	308,279	31 [27,36]	
Anxiety/Sadness IC (N=830,589)					.02
Not Positive	89,974	63 [51,74]	321,472	47 [40,54]	
Positive	51,905	37 [26,49]	367,238	53 [46,60]	
Religious/Spiritual Needs IC (N=1,184,887)					.06
Not Positive	157,414	65 [55,74]	515,112	55 [49,60]	
Positive	84,541	35 [26,45]	427,820	45 [40,51]	

Table 3-3. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between MCC status and "excellent" rating of *overall* care quality and with positive perception in each *composite quality domain* (CQD) and individual *component* (IC)

	Cases		**Unadjusted OR**		**Adjusted OR**	
Outcomes	**Weighted Freq. (N=1,572,166)**	**% of N**	**OR**	**[95% CI]**	**OR**	**[95% CI]**
Rating of *Overall* Care Quality	1,446,522	92	1.46	[.87,2.44]	1.42	[.79,2.55]
Coordination CQD	1,423,759	91	1.37	[.70,2.67]	1.07	[.55,2.08]
Symptom Management CQD	1,195,769	76	1.21	[.74,2.00]	1.53	[.90,2.58]
Pain IC	1,026,612	65	1.26	[.71,2.22]	1.57	[.88,2.81]
Breathing IC	808,615	51	2.05*	[1.08,3.91]	3.13*	[1.34,7.31]
Shared decision-making CQD	1,444,182	92	.59	[.35,1.00]	.82	[.48,1.41]
Input into Care IC	1,414,223	90	1.05	[.53,2.08]	1.06	[.47,2.41]
Receipt of Unwanted Care IC	1,442,776	92	.49	[.23,1.05]	.78	[.37,1.63]
Informed about Care IC	1,468,612	93	1.81*	[1.11,2.96]	2.05*	[1.18,3.55]
Respect CQD	1,458,195	93	1.42	[.85,2.39]	1.54	[.84,2.81]
Respect IC	1,439,828	92	1.48	[.80,2.77]	1.47	[.73,2.97]
Personal Care IC	1,436,593	91	1.34	[.78,2.28]	1.43	[.79,2.59]
Spiritual & Emotional Support CQD	1,250,700	80	1.29	[.83,1.99]	1.08	[.63,1.85]
Anxiety/Sadness IC	830,589	53	1.98*	[1.10,3.55]	1.68	[.83,3.41]
Religious/Spiritual Needs IC	1,184,887	75	1.55	[.98,2.45]	1.36	[.83,2.24]

All models include age, gender, race/ethnicity, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and place of death

*OR significant at p<05

Table 3-4. Adjusted odds ratios (OR) and 95% confidence intervals (CI) for the relationships between covariates and rating of *overall* care quality and between covariates and each *composite quality domain* (CQD)

Demographic Characteristics	Rating of *Overall* Care Quality (N=1,446,522) AOR [95% CI]	Coordination CQD (N=1,423,759) AOR [95% CI]	Symptom Management CQD (N=1,195,769) AOR [95% CI]	Shared decision-making CQD (N=1,444,182) AOR [95% CI]	Respect CQD (N=1,458,195) AOR [95% CI]	Spiritual and Emotional Support CQD (N=1,250,700) AOR [95% CI]
MCC status						
Absent	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Present	1.42 [.79,2.55]	1.07 [.55,2.08]	1.53 [.90,2.58]	.82 [.48,1.41]	1.54 [.84,2.81]	1.08 [.63,1.85]
Age						
65 to 74	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
75 to 84	.77 [.45,1.30]	2.02* [1.09,3.76]	1.11 [.54,2.28]	.45 [.17,1.16]	.87 [.47,1.59]	.80 [.41,1.55]
85+	1.34 [.76,2.35]	2.62* [1.25,5.48]	1.37 [.70,2.71]	.85 [.32,2.24]	1.20 [.70,2.05]	.57 [.31,1.05]
Gender						
Male	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Female	.85 [.51,1.44]	1.4 [.74,2.64]	.92 [.52,1.62]	1.22 [.68,2.18]	.95 [.55,1.65]	1.11 [.66,1.86]
Race/ethnicity						
White	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Black	1.35 [.75,2.44]	2.73* [1.14,6.54]	1.92* [1.06,3.49]	1.56 [.90,2.70]	2.22* [1.31,3.76]	1.44 [.78,2.64]
Hispanic/other	.64 [.28,1.47]	1.39 [.48,4.00]	1.03 [.41,2.60]	.74 [.36,1.52]	.93 [.43,2.02]	1.97 [.88,4.41]
Census region						
Northeast	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Midwest	.96 [.55,1.69]	.77 [.45,1.34]	1.20 [.53,2.74]	1.08 [.62,1.89]	1.04 [.59,1.83]	2.96* [1.43,6.11]
South	.56 [.31,1.04]	.93 [.44,1.97]	1.13 [.48,2.66]	.97 [.55,1.72]	.60 [.36,1.02]	1.22 [.56,2.66]
West	.82 [.48,1.38]	1.17 [.59,2.30]	.74 [.34,1.61]	1.80 [.81,3.99]	.65 [.39,1.07]	2.39* [1.12,5.11]

*OR significant at p<05

Table 3-4. Adjusted odds ratios (OR) and 95% confidence intervals (CI) for the relationships between covariates and rating of *overall* care quality and between covariates and each *composite quality domain* (CQD) (Continued)

Demographic and Care Characteristics	**Rating of *Overall* Care Quality (N=1,446,522) AOR [95% CI]**	**Coordination CQD (N=1,423,759) AOR [95% CI]**	**Symptom Management CQD (N=1,195,769) AOR [95% CI]**	**Shared decision-making CQD (N=1,444,182) AOR [95% CI]**	**Respect CQD (N=1,458,195) AOR [95% CI]**	**Spiritual and Emotional Support CQD (N=1,250,700) AOR [95% CI]**
Medicaid						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.24 [.75,2.05]	1.70 [.77,3.73]	.64 [.35,1.17]	.81 [.43,1.54]	.65 [.39,1.09]	.63 [.33,1.18]
Marital status at death						
Married	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Not married	.53 [.23,1.22]	.37 [.11,1.24]	.42 [.15,1.16]	.37* [.17,.83]	.70 [.29,1.65]	.73 [.31,1.75]
Widowed	.81 [.40,1.62]	1.01 [.41,2.53]	.73 [.29,1.82]	.50* [.26,.98]	.63 [.30,1.32]	.67 [.30,1.49]
Dementia reported						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	.89 [.49,1.59]	1.81 [.86,3.81]	.95 [.50,1.82]	.60 [.34,1.06]	1.53 [.93,2.54]	.89 [.52,1.52]
Cancer reported						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.18 [.75,1.87]	1.35 [.79,2.31]	.54* [.35,.83]	.62 [.34,1.11]	.90 [.58,1.40]	.78 [.47,1.30]
Hospice enrollment						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.25 [.83,1.87]	.76 [.39,1.48]	2.19* [1.25,3.84]	1.54 [.81,2.93]	.77 [.49,1.21]	1.89* [1.15,3.11]
Place of death						
Home	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Hospital	.56* [.34,.92]	.24* [.11,.52]	1.38 [.75,2.53]	.66 [.35,1.26]	.47* [.27,.83]	.79 [.47,1.34]
Other	.42* [.28,.64]	.19* [.07,.49]	1.20 [.70,2.07]	.26* [.12,.57]	.37* [.23,.60]	.81 [.44,1.47]

*OR significant at p<05

Table 3-4. Adjusted odds ratios (OR) and 95% confidence intervals (CI) for the relationships between covariates and rating of *overall* care quality and between covariates and each *composite quality domain* (CQD) (Continued)

Proxy Characteristics	**Rating of *Overall* Care Quality (N=1,446,522) AOR [95% CI]**	**Coordination CQD (N=1,423,759) AOR [95% CI]**	**Symptom Management CQD (N=1,195,769) AOR [95% CI]**	**Shared decision-making CQD (N=1,444,182) AOR [95% CI]**	**Respect CQD (N=1,458,195) AOR [95% CI]**	**Spiritual and Emotional Support CQD (N=1,250,700) AOR [95% CI]**
Proxy relationship						
Spouse	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Child	.84 [.41,1.69]	.64 [.26,1.57]	.96 [.41,2.25]	3.46* [1.67,7.17]	1.04 [.47,2.31]	1.64 [.70,3.82]
Other relative	.80 [.31,2.07]	1.02 [.27,3.85]	1.15 [.36,3.70]	2.61* [1.02,6.67]	1.02 [.38,2.74]	1.07 [.37,3.09]
Non-relative	.59 [.21,1.67]	.78 [.12,4.90]	.69 [.22,2.11]	3.22 [.73,14.16]	1.07 [.29,4.03]	.38 [.06,2.52]
Proxy gender						
Male	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Female	.80 [.54,1.20]	1.11 [.59,2.07]	.56* [.32,.98]	1.00 [.55,1.84]	1.08 [.65,1.80]	1.12 [.66,1.91]

*OR significant at p<05

Table 4-1. Weighted distribution of unadjusted proportions for covariates according to *overall* rating of end-of-life care quality (N=1,123,887)

Demographic Characteristics	Total Sample Raw Freq. (N=477)	Weight. %	Rating of *Overall* Care Quality Not Excellent (N=544,929) Freq. (%)	Excellent (N=578,958) Freq. (%)	p-value
Age					.11
65 to 84	233	60	349,495 (64)	322,363 (56)	
85+	244	40	195,433 (36)	256,595 (44)	
Gender					.10
Male	213	48	233,165 (43)	303,430 (52)	
Female	264	52	311,764 (57)	275,528 (48)	
White race					.18
No	176	23	142,578 (26)	116,335 (20)	
Yes	301	77	402,351 (74)	462,623 (80)	
Census region					.49
Northeast	79	15	81,044 (15)	91,820 (16)	
Midwest	111	25	118,393 (22)	161,511 (28)	
South	186	36	218,032 (40)	182,345 (32)	
West	101	24	127,459 (23)	143,282 (25)	
Medicaid					.24
No	363	80	419,433 (77)	478,033 (83)	
Yes	114	20	125,496 (23)	100,925 (17)	
Marital status at death					.007
Not married	306	58	356,350 (65)	290,594 (50)	
Married	171	42	188,579 (35)	288,363 (50)	
Dementia reported					.38
No	334	76	402,155 (74)	452,247 (78)	
Yes	143	24	142,774 (26)	126,711 (22)	
Cancer reported					.51
No	267	52	296,789 (55)	292,444 (51)	
Yes	210	48	248,140 (46)	286,514 (50)	

Table 4-1. Weighted distribution of unadjusted proportions for covariates according to *overall* rating of end-of-life care quality (N=1,123,887) (Continued)

Care and Proxy Characteristics	**Total Sample**		**Rating of *Overall* Care Quality**		**p-value**
	Raw Freq. (N=477)	**Weight. %**	**Not Excellent (N=544,929) Freq. (%)**	**Excellent (N=578,958) Freq. (%)**	
Hospice enrollment					.04
No	213	43	261,193 (48)	218,662 (38)	
Yes	264	57	283,736 (52)	360,296 (62)	
Place of death					.06
Home	193	44	202,293 (37)	287,473 (50)	
Hospital	163	33	200,669 (37)	175,092 (30)	
Other	121	23	141,967 (26)	116,393 (20)	
Proxy relationship					.03
Spouse	115	30	131,352 (24)	203,669 (35)	
Child	275	55	311,552 (57)	304,549 (53)	
Other	87	15	102,025 (19)	70,739 (12)	
Proxy gender					.41
Male	118	25	124,579 (23)	155,882 (27)	
Female	359	75	420,350 (77)	423,076 (73)	

Table 4-2. Adjusted odds ratios (OR) and 95% confidence intervals (CI) for the relationships between covariates and rating of *overall* care quality and between covariates and each *composite quality domain* (CQD)

Demographic Factors	**Rating of *Overall* Care Quality (N=1,123,887) AOR [95% CI]**	**Coordination CQD (N=1,075,769) AOR [95% CI]**	**Symptom Management CQD (N=902,374) AOR [95% CI]**	**Shared decision-making CQD (N=1,081,297) AOR [95% CI]**	**Respect CQD (N=1,099,239) AOR [95% CI]**	**Spiritual and Emotional Support CQD (N=954,954) AOR [95% CI]**
Age						
65 to 84	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
85+	1.88* [1.17,3.02]	1.80 [.99,3.27]	1.22 [.71,2.08]	1.59 [.93,2.73]	1.44 [.90,2.32]	.59* [.37,.95]
Gender						
Male	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Female	.74 [.43,1.29]	1.38 [.60,3.15]	1.15 [.61,2.17]	1.32 [.70,2.51]	.80 [.46,1.40]	1.00 [.52,1.92]
White race						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.2 [.65,2.22]	.49 [.22,1.10]	.96 [.47,1.97]	1.05 [.59,1.89]	.94 [.50,1.76]	.69 [.36,1.30]
Census region						
Northeast	1.00 [ref]	not in model	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Midwest	1.15 [.56,2.33]	--	1.93 [.80,4.65]	1.57 [.77,3.20]	1.25 [.60,2.58]	2.66* [1.21,5.86]
South	.83 [.40,1.71]	--	1.49 [.59,3.72]	1.48 [.74,2.97]	.83 [.40,1.70]	1.13 [.49,2.61]
West	.85 [.45,1.60]	--	1.19 [.52,2.72]	2.30 [.94,5.61]	.75 [.38,1.50]	1.93 [.89,4.21]
Medicaid						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.09 [.56,2.13]	1.16 [.52,2.61]	.66 [.34,1.26]	.57 [.27,1.18]	.81 [.38,1.73]	.64 [.31,1.31]
Marital status at death						
Not married	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Married	1.72 [.82,3.61]	1.67 [.51,5.45]	2.13 [.68,6.61]	2.63* [1.06,6.55]	2.15 [.88,5.26]	1.55 [.63,3.82]

*OR significant at p<.05

Table 4-2. Adjusted odds ratios (AOR) and 95% confidence intervals (CI) for the relationships between covariates and rating of *overall* care quality and between covariates and each *composite quality domain* (CQD) (Continued)

Care and Proxy Factors	**Rating of *Overall* Care Quality (N=1,123,887) AOR [95% CI]**	**Coordination CQD (N=1,075,769) AOR [95% CI]**	**Symptom Management CQD (N=902,374) AOR [95% CI]**	**Shared decision-making CQD (N=1,081,297) AOR [95% CI]**	**Respect CQD (N=1,099,239) AOR [95% CI]**	**Spiritual and Emotional Support CQD (N=954,954) AOR [95% CI]**
Dementia reported						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	.82 [.46,1.47]	1.73 [.75,4.00]	1.05 [.56,1.98]	.65 [.36,1.20]	1.42 [.81,2.50]	.87 [.48,1.57]
Cancer reported						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.02 [.60,1.73]	1.27 [.65,2.48]	.52* [.30,.91]	.47* [.24,.94]	.87 [.54,1.42]	.73 [.42,1.26]
Hospice enrollment						
No	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Yes	1.49 [.94,2.36]	.66 [.25,1.71]	1.26 [.70,2.29]	1.82 [.95,3.50]	.92 [.53,1.61]	1.96* [1.08,3.54]
Place of death						
Home	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Hospital	.71 [.40,1.27]	.39 [.14,1.10]	.97 [.43,2.16]	.80 [.39,1.63]	.69 [.38,1.25]	.86 [.47,1.58]
Other	.55* [.34,.88]	.31* [.11,.90]	1.24 [.62,2.46]	.31* [.14,.68]	.54 [.29,1.00]	.82 [.42,1.59]
Proxy relationship						
Spouse	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Child	.92 [.42,2.04]	.85 [.32,2.25]	1.06 [.33,3.36]	3.89* [1.62,9.33]	1.64 [.59,4.58]	1.76 [.69,4.46]
Other	.76 [.30,1.94]	1.41 [.37,5.35]	1.34 [.33,5.48]	3.67* [1.13,11.86]	1.48 [.44,4.99]	1.20 [.39,3.64]
Proxy gender						
Male	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]	1.00 [ref]
Female	.68 [.41,1.13]	1.30 [.61,2.78]	.66 [.34,1.29]	1.00 [.50,2.03]	1.21 [.69,2.15]	.98 [.53,1.82]

*OR significant at p<.05

Table 4-3. Weighted distribution of rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care

Perception (Total N=1,123,887)	**Not Excellent (Total N=544,929)**		**Excellent (Total N=578,958)**		
	Freq.	**% [95% CI]**	**Freq.**	**% [95% CI]**	**p-value**
Coordination CQD (N=1,075,769)					<.001
Not Positive	115,454	76 [61,86]	36,460	24 [14,39]	
Positive	403,860	44 [38,50]	519,995	56 [50,62]	
Symptom Management CQD (N= 902,374)					.10
Not Positive	143,355	58 [47,69]	102,686	42 [31,53]	
Positive	305,020	47 [40,53]	351,312	54 [47,60]	
Pain IC (N=787,096)					.16
Not Positive	110,905	61 [47,73]	71,912	39 [27,53]	
Positive	292,761	48 [41,56]	311,518	52 [44,59]	
Breathing IC (N=636,853)					.33
Not Positive	67,410	60 [43,75]	45,166	40 [25,57]	
Positive	271,209	52 [45,59]	253,068	48 [41,56]	
Shared decision-making CQD (N=1,081,297)					.01
Not Positive	143,882	63 [49,75]	85,662	37 [25,51]	
Positive	379,223	45 [39,50]	472,530	56 [50,61]	
Input into Care IC (N=1,069,317)~					<.001
Not Positive	84,516	85 [67,94]	15,511	16 [6,33]	
Positive	430,627	44 [39,50]	538,662	56 [50,61]	
Receipt of Unwanted Care IC (N= 1,082,401)					.39
Not Positive	90,387	55 [38,70]	75,064	45 [30,62]	
Positive	435,216	48 [42,53]	481,734	53 [47,58]	
Informed about Care IC (N=1,109,293)~					<.001
Not Positive	156,104	91 [78,97]	15,452	9 [3,22]	
Positive	384,923	41 [36,47]	552,814	59 [53,64]	
Respect CQD (N=1,099,239)					<.001
Not Positive	213,224	79 [69,87]	56,310	21 [13,31]	
Positive	313,429	38 [32,44]	516,276	62 [56,68]	
Respect IC (N=1,098,896)~					<.001
Not Positive	98,789	92 [78,97]	8,828	8 [3,22]	
Positive	427,521	43 [37,49]	563,757	57 [51,63]	
Personal Care IC (N=1,084,499)					<.001
Not Positive	172,984	78 [65,86]	49,937	22 [14,35]	
Positive	349,226	41 [34,47]	512,351	60 [53,66]	

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Table 4-3. Weighted distribution of rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care (Continued)

Perception (Total N=1,123,887)	**Not Excellent (Total N=544,929)**		**Excellent (Total N=578,958)**		**p-value**
	Freq.	**% [95% CI]**	**Freq.**	**% [95% CI]**	
Spiritual and Emotional Support CQD (N=954,954)					.006
Not Positive	349,837	54 [48,61]	296,838	46 [39,53]	
Positive	114,221	37 [28,48]	194,058	63 [52,73]	
Anxiety/Sadness IC (N=674,490)					.002
Not Positive	199,154	65 [55,74]	108,098	35 [26,45]	
Positive	166,916	46 [37,54]	200,323	55 [46,63]	
Religious/Spiritual Needs IC (N=916,797)					.13
Not Positive	251,978	51 [44,59]	241,442	49 [41,57]	
Positive	177,026	42 [33,52]	246,351	58 [48,67]	

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Table 4-4. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between "positive" perception of each *composite quality domain* (CQD) and individual *component* (IC) and "excellent" rating of *overall* care quality

	Cases		**Unadjusted OR**		**Adjusted OR**	
	Weighted Count (N=1,123,887)	**% of N**	**OR**	**[95% CI]**	**OR**	**[95% CI]**
Coordination CQD[c]	1,075,769	96%	4.08*	[1.82,9.13]	4.49*	[1.85,10.86]
Symptom Management CQD	902,374	80%	1.61	[.90,2.86]	1.49	[.81,2.71]
Pain IC	787,096	70%	1.64	[.81,3.34]	1.59	[.72,3.52]
Breathing IC [cp^]	636,853	57%	1.39	[.67,2.89]	1.34	[.62,2.88]
Shared decision-making CQD	1,081,297	96%	2.09*	[1.21,3.63]	1.97*	[1.12,3.47]
Input Into Care IC[c^#~]	1,069,317	95%	6.82*	[2.51,18.50]	6.92*	[2.40,19.91]
Receipt of Unwanted Care IC[p]	1,082,401	96%	1.33	[.68,2.60]	1.20	[.60,2.41]
Informed About Care IC~	1,109,293	99%	14.51*	[4.80,43.84]	19.57*	[6.29,60.86]
Respect CQD	1,099,239	98%	6.24*	[3.26,11.93]	6.36*	[3.23,12.52]
Respect IC [c^~]	1,098,896	98%	14.76*	[4.64,46.91]	14.67*	[4.59,46.91]
Personal Care IC	1,084,499	96%	5.08*	[2.49,10.38]	4.98*	[2.39,10.38]
Spiritual & Emotional Support CQD	954,954	85%	2.00*	[1.24,3.23]	2.02*	[1.23,3.30]
Anxiety/Sadness IC	674,490	60%	2.21*	[1.36,3.60]	1.90*	[1.14,3.18]
Religious/Spiritual Needs IC	916,797	82%	1.45	[.90,2.36]	1.45	[.88,2.40]

All models include age, gender, White race, Census region, Medicaid, marital status at death, hospice enrollment, proxy relationship to the deceased, dementia reported, cancer reported, and place of death unless otherwise noted

[c] Census region excluded from model

[p] Proxy relationship to the deceased excluded from the model

^Place of death excluded from the model

[#] Dementia reported excluded from the model

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*OR significant at p<.05 level

Table 5-1. Weighted distribution of unadjusted proportions for covariates according to the perception of the coordination *composite quality domain* (CQD) (N=1,102,484)

	Total Sample		**Perception of Coordination CQD**		
Demographic Characteristics	**Raw Freq. (N=466)**	**Weight. %**	**Not Positive (N=161,379) Freq. (%)**	**Positive (N=941,105) Freq. (%)**	**p-value**
Age					.16
65 to 84	224	59	107,978 (67)	543,048 (58)	
85+	242	41	53,401 (33)	398,057 (42)	
Gender					.87
Male	205	47	77,695 (48)	439,267 (47)	
Female	261	53	83,684 (52)	501,838 (53)	
White race					.049
No	166	22	20,199 (13)	223,522 (24)	
Yes	300	78	141,180 (88)	717,582 (76)	
Medicaid					.94
No	355	79	128,775 (80)	746,485 (79)	
Yes	111	21	32,604 (20)	194,620 (21)	
Marital status at death					.37
Not married	299	58	105,170 (65)	532,776 (57)	
Married	167	42	56,209 (35)	408,329 (43)	
Dementia reported					.10
No	325	76	134,419 (83)	703,198 (75)	
Yes	141	24	26,960 (17)	237,907 (25)	
Cancer reported					.92
No	265	54	87,787 (54)	504,620 (54)	
Yes	201	46	73,592 (46)	436,484 (46)	
Hospice enrollment					.94
No	207	43	68,393 (42)	405,627 (43)	
Yes	259	57	92,986 (58)	535,478 (57)	
Place of death					.10
Home	193	44	44,474 (28)	443,306 (47)	
Hospital	161	34	64,663 (41)	311,668 (33)	
Other	112	22	52,242 (32)	186,131 (20)	
Proxy relationship					.42
Not spouse	112	71	121,321 (75)	656,089 (70)	
Spouse	354	30	40,057 (25)	285,016 (30)	
Proxy gender					.18
Male	114	25	55,152 (34)	225,416 (24)	
Female	352	75	106,227 (66)	715,689 (76)	

Table 5-2. Weighted distribution of the perception of coordination according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care

Perception (Total N=1,102,484)	Not Positive (Total N=161,379) Freq.	Not Positive (Total N=161,379) % [95% CI]	Positive (Total N=941,105) Freq.	Positive (Total N=941,105) % [95% CI]	p-value
Symptom Management CQD (N=881,596)					.11
Not Positive	55,010	39 [24,57]	181,711	25 [20,30]	
Positive	84,708	61 [43,76]	560,165	76 [70,80]	
Pain IC (N=774,969)					.07
Not Positive	47,532	38 [22,57]	123,454	19 [15,24]	
Positive	77,754	62 [43,78]	526,229	81 [76,85]	
Breathing IC (N=628,304)					.39
Not Positive	28,315	24 [13,40]	88,233	17 [12,25]	
Positive	89,934	76 [60,87]	421,822	83 [75,88]	
Shared decision-making CQD (N=1,071,602)					.87
Not Positive	32,120	22 [12,36]	191,908	21 [17,25]	
Positive	115,039	78 [64,88]	732,535	79 [75,83]	
Input into Care IC (N=1,062,182)~					.36
Not Positive	18,494	13 [6,25]	71,623	8 [5,11]	
Positive	128,665	87 [75,94]	843,400	92 [89,95]	
Receipt of Unwanted Care IC (N=1,071,712)					.63
Not Positive	27,141	18 [10,31]	138,260	15 [12,19]	
Positive	124,865	82 [69,91]	781,445	85 [81,88]	
Informed about Care IC (N=1,091,212)					.001
Not Positive	78,241	49 [33,64]	91,799	10 [7,13]	
Positive	83,137	52 [36,67]	838,034	90 [87,93]	
Respect CQD (N=1,086,066)					.003
Not Positive	74,059	47 [35,61]	192,770	21 [16,26]	
Positive	82,353	53 [40,65]	736,884	79 [74,84]	
Respect IC (N=1,079,167)					.007
Not Positive	42,288	28 [17,42]	61,514	7 [5,9]	
Positive	109,680	72 [58,83]	865,684	93 [91,95]	
Personal Care IC (N=1,077,756)					.005
Not Positive	69,147	44 [31,59]	158,856	17 [13,23]	
Positive	87,265	56 [41,69]	762,488	83 [78,87]	

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Table 5-2. Weighted distribution of the perception of coordination according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care (Continued)

Perception (Total N=1,102,484)	**Not Positive (Total N=161,379)**		**Positive (Total N=941,105)**		**p-value**
	Freq.	**% [95% CI]**	**Freq.**	**% [95% CI]**	
Spiritual and Emotional Support CQD (N=940,458)~					.03
Not Positive	99,665	85 [66,94]	536,957	65 [60,70]	
Positive	17,974	15 [6,34]	285,862	35 [30,40]	
Anxiety/Sadness IC (N=659,236)					.28
Not Positive	51,007	53 [38,68]	245,434	44 [36,51]	
Positive	44,727	47 [32,62]	318,068	56 [49,64]	
Religious/Spiritual Needs IC (N=913,933)					.11
Not Positive	77,205	70 [47,87]	413,351	51 [45,57]	
Positive	32,422	30 [13,53]	390,955	49 [43,55]	

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Table 5-3. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between “positive” perception of each *composite quality domain* (CQD) and individual *component* (IC) and “positive” perception of coordination

	Cases		Unadjusted OR		Adjusted OR	
	Weighted Count (N=1,102,484)	% of N	OR	[95% CI]	OR	[95% CI]
Symptom Management CQD	881,596	80%	2.00	[.91,4.40]	2.34*	[1.07,5.14]
Pain IC	774,969	70%	2.61*	[1.07,6.33]	3.60*	[1.43,9.10]
Breathing IC [g,p,d]	628,304	57%	1.51	[.61,3.70]	1.70	[.58,4.94]
Shared decision-making CQD	1,071,602	97%	1.07	[.50,2.26]	.97	[.45,2.07]
Input Into Care IC~	1,062,182	96%	1.69	[.63,4.57]	1.54	[.47,5.01]
Receipt of Unwanted Care IC[p]	1,071,712	97%	1.23	[.55,2.76]	1.16	[.53,2.52]
Informed About Care IC	1,091,212	99%	8.59*	[3.86,19.14]	8.94*	[3.87,20.65]
Respect CQD	1,086,066	99%	3.44*	[1.71,6.90]	3.21*	[1.55,6.62]
Respect IC [p]	1,079,167	98%	5.43*	[2.36,12.46]	5.64*	[2.49,12.79]
Personal Care IC	1,077,756	98%	3.80*	[1.76,8.21]	3.49*	[1.56,7.77]
Spiritual & Emotional Support CQD~	940,458	85%	2.95	[.98,8.87]	3.10	[.97,9.85]
Anxiety/Sadness IC	659,236	60%	1.48	[.74,2.93]	1.31	[.60,2.85]
Religious/Spiritual Needs IC	913,933	83%	2.25	[.80,6.30]	2.57	[.86,7.73]

All models include age, gender, White race, Medicaid, marital status at death, hospice enrollment, proxy relationship to the deceased, dementia reported, cancer reported, place of death, and proxy gender unless otherwise noted

[g] Proxy gender excluded from the model

[p] Proxy relationship to the deceased excluded from the model

[#] Dementia reported excluded from the model

~Contains raw cell count <10

*OR significant at p<.05 level

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Appendix A: Determining the Presence of Chronic Conditions and Multiple Chronic Condition Status Variable

Step 1: Determine the presence or absence of each medical condition reported in NHATS for each LMLI participant

For each medical condition, participant must meet the following criteria for classification:

- "Yes": Participant reported "Yes" to medical condition in any living round (**Table A-1**)
- "No": Participant either (**Table A-2**):
  - Reported "No" to LAST living round for cumulative conditions
  - Reported "No" to EVERY living round for episodic conditions
  - "Inconclusive": Participant response did not fit either the "Yes" or "No" criteria

Table A-1. NHATS rounds with information available about participants' medical conditions based on the round in which a proxy completed a LMLI

Medical Condition Reporting Round	LMLI Round			
	Round 2	Round 3	Round 4	Round 5
Round 1	x*			
Round 2	x	x*		
Round 3	x	x	x*	
Round 4	x	x	x	x*

*Last Living Round

Table A-2. Classification of conditions reported in NHATS based on characteristics of data for variable

Cumulative	Episodic
Heart Disease* High Blood Pressure* Arthritis* Osteoporosis Diabetes* Lung Disease* Dementia*	Heart Attack* Stroke Cancer*

*AHRQ-recognized chronic condition

Step 2: Examine inconclusive conditions to assess patterns

- **Table A-3** shows the presence of each medical condition for NHATS, LMLI participants
- **Figure A-1** shows the frequency of LMLI participants by their number of inconclusive medical conditions for the ten medical conditions reported in the NHATS
    - There were no patterns in which conditions were inconclusive for those with between 1 and 9 inconclusive conditions
    - Only 1% of the community sample did not have sufficient chronic condition data such that their MCC status could be determined, compared to 20% of the residential care-dwelling sample

Table A-3. Presence of medical condition diagnosis for all NHATS participants with an LMLI, including Round 2

Condition	Yes	No	Inconclusive
Heart Attack	385	907	434
Heart Disease	475	820	431
Hypertension	974	338	414
Arthritis	915	406	405
Osteoporosis	362	930	434
Diabetes	388	914	424
Lung Disease	346	957	423
Stroke	327	962	437
Dementia	349	951	426
Cancer	484	809	433

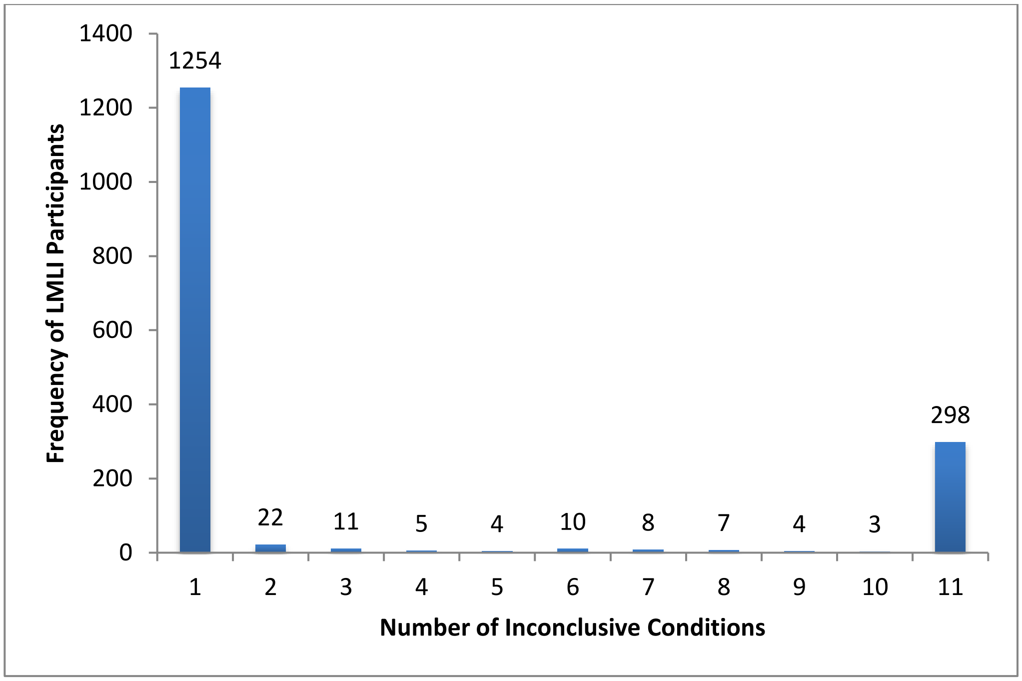


Figure A-1. Frequency of LMLI participants by number of inconclusive conditions

Step 3: Combine report for each condition in the MCC definition to assess MCC status

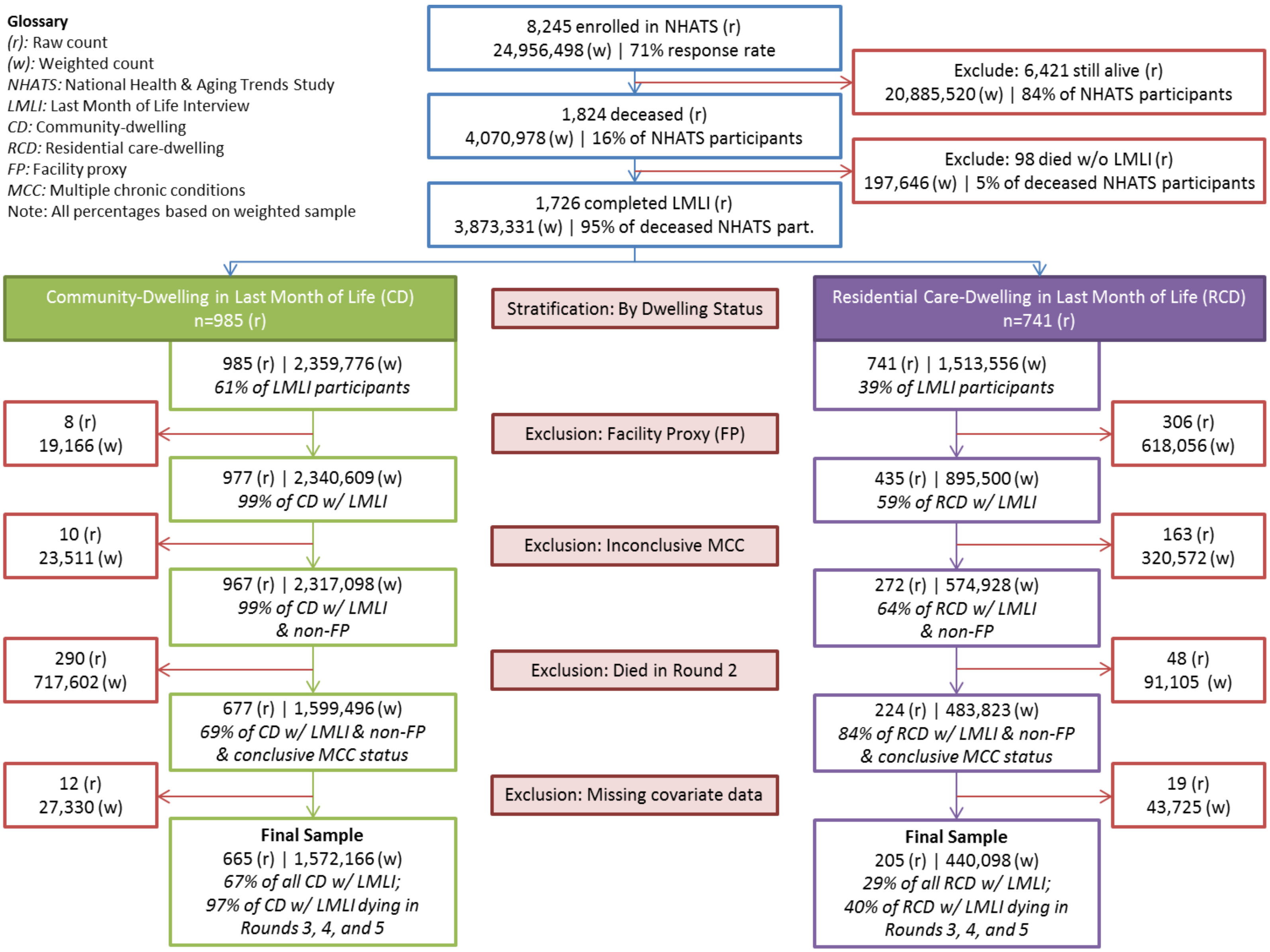
Participant must meet the following criteria for classification:

- "Present": Participant reports "Yes" to at least two conditions in the definition
- "Absent": Participant reports "No" to every condition in the definition
- "Inconclusive": Participant reports inconclusive to more than one condition without two or more other conditions reported as "Yes"

Table A-4. Scenarios and their corresponding MCC status designation by the number of conditions reported as yes, no, or inconclusive

# Yes	# No	# Inconclusive	MCC Status
None	All	None	Absent
One	All remaining	None	Absent
Two or more	Any	Any	Present
None	Any	More than one	Inconclusive

Appendix B: Flowchart of Sample Inclusion and Exclusion



Glossary
(r): Raw count
(w): Weighted count
NHATS: National Health & Aging Trends Study
LMLI: Last Month of Life Interview
CD: Community-dwelling
RCD: Residential care-dwelling
FP: Facility proxy
MCC: Multiple chronic conditions
Note: All percentages based on weighted sample

Appendix C: Process for Determining Positive Perception of Care in Quality Domains

Table C-1 describes the *composite quality domains* and individual *components* used in this study.

Table C-1. Conceptual model of end-of-life *composite quality domains* and individual *components*

Composite Quality Domain	Individual Components
Coordination	>1 doctor involved in care
	1 doctor in charge of care
Symptom Management	Pain
	Breathing
Shared Decision-Making	Input into care
	Receipt of unwanted care
	Informed about care*
Respect	Respect
	Personal care
Spiritual and Emotional Support	Anxiety and sadness
	Religious and spiritual needs

*While being informed about care is a *component* of the shared decision-making *composite quality domain*, it is not included in the Teno Model's composite shared decision-making *composite quality domain* calculation.

The following charts describe the process for defining study variables, in the order presented:

- Rating of *overall* end-of-life care quality (**Figure C-1**)
- Coordination *composite quality domain* (**Figure C-2**)
- Pain individual *component* (**Figure C-3**)
- Breathing individual *component* (**Figure C-4**)
- Symptom management *composite quality domain* (**Figure C-5**)
- Input into care individual *component* (**Figure C-6**)
- Receipt of unwanted care individual *component* (**Figure C-7**)

- Informed about care individual *component* (**Figure C-8**)
- Shared decision-making *composite quality domain* (**Figure C-9**)
- Respect individual *component* (**Figure C-10**)
- Personal care individual *component* (**Figure C-11**)
- Respect *composite quality domain* (**Figure C-12**)
- Anxiety/sadness individual *component* (**Figure C-13**)
- Religious and spiritual needs individual *component* (**Figure C-14**)
- Spiritual and emotional support *composite quality domain* (**Figure C-15**)

All NHATS, LMLI questions derived from the NHATS Round 5 Last Month of Life Interview Guide.

Figure C-1. Rating of *Overall* End-of-Life Care Quality

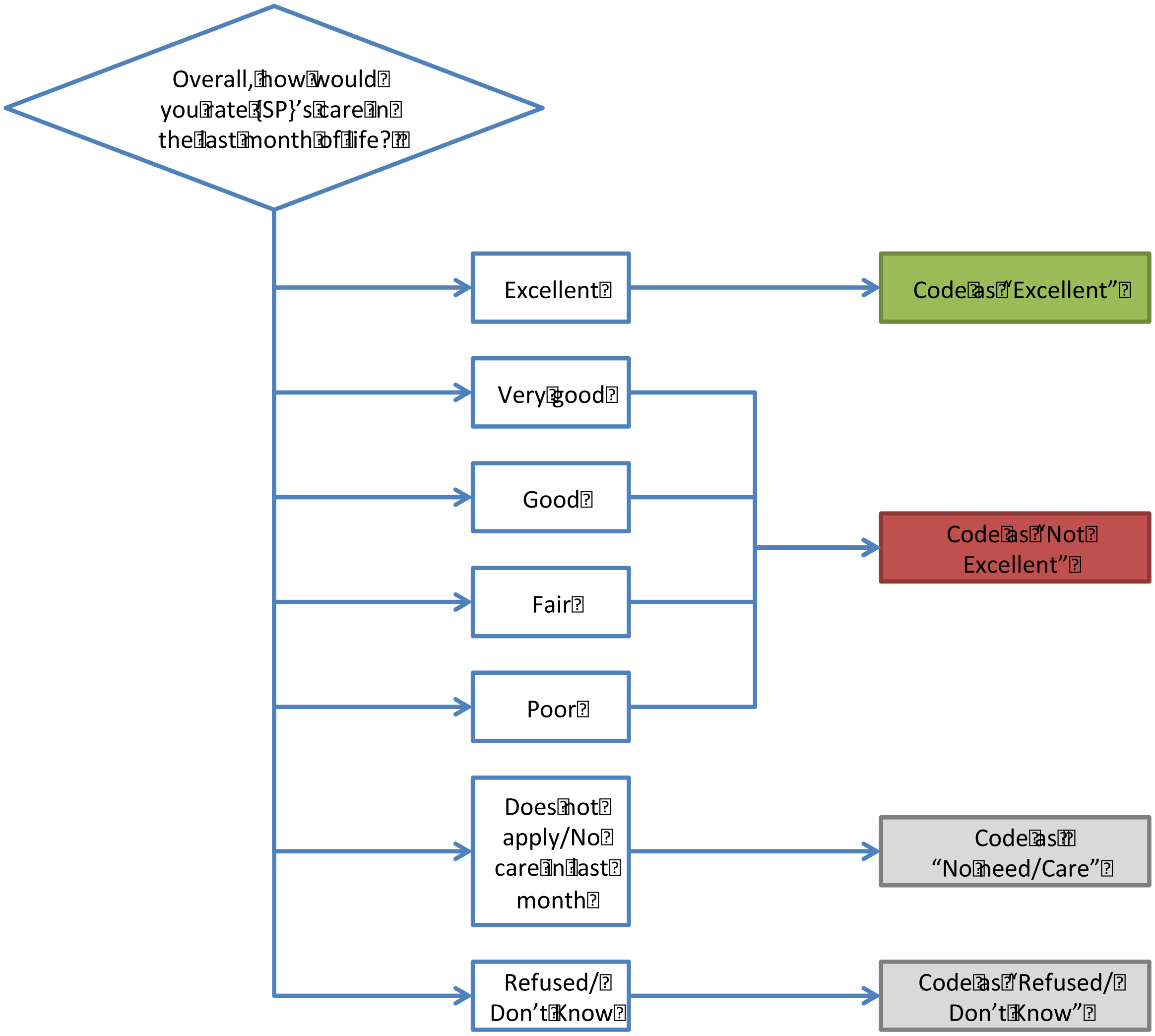


Figure C-2. Coordination *Composite Quality Domain*

During the last month of life…

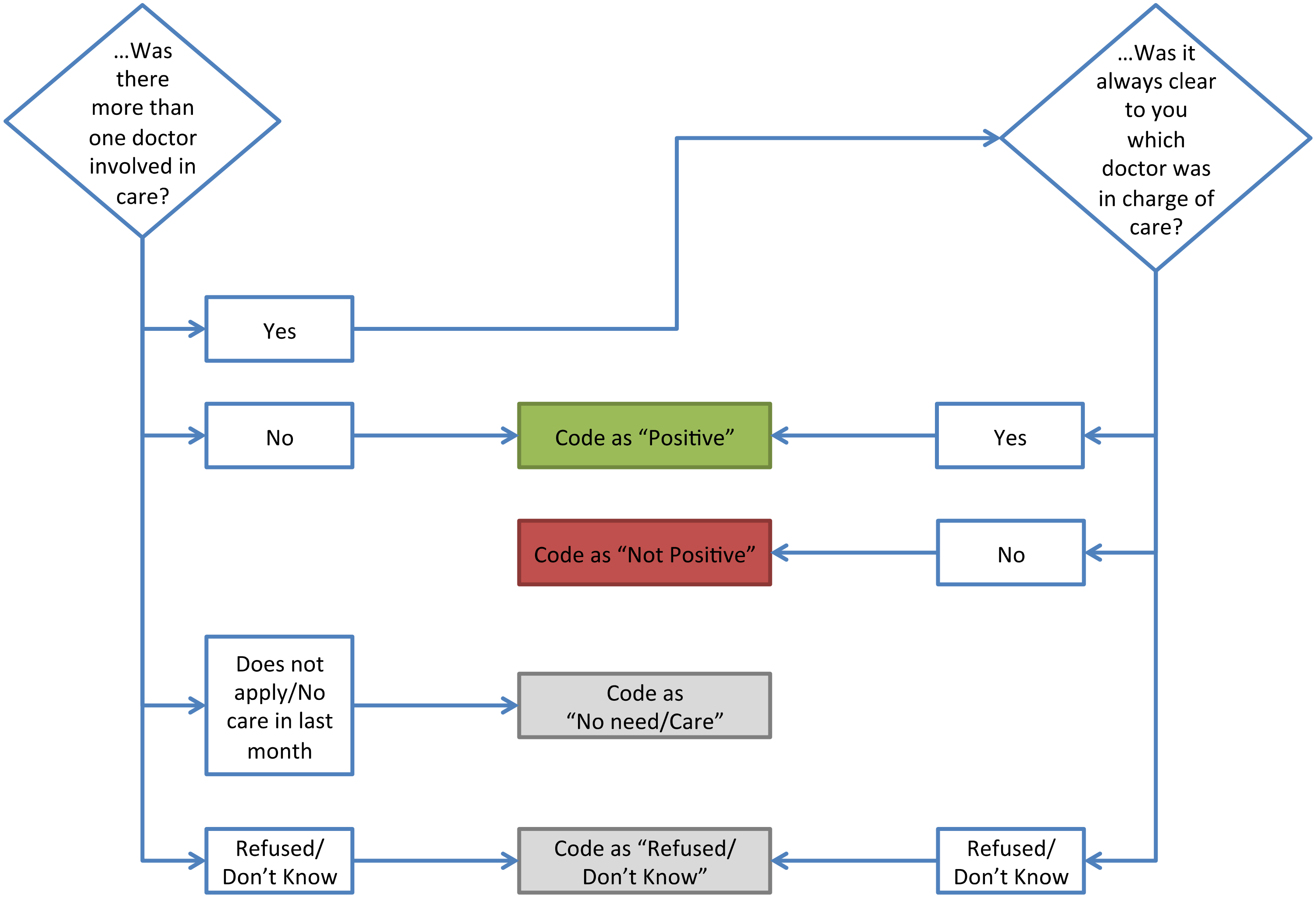


Figure C-3. Pain Individual *Component*

During the last month of life…

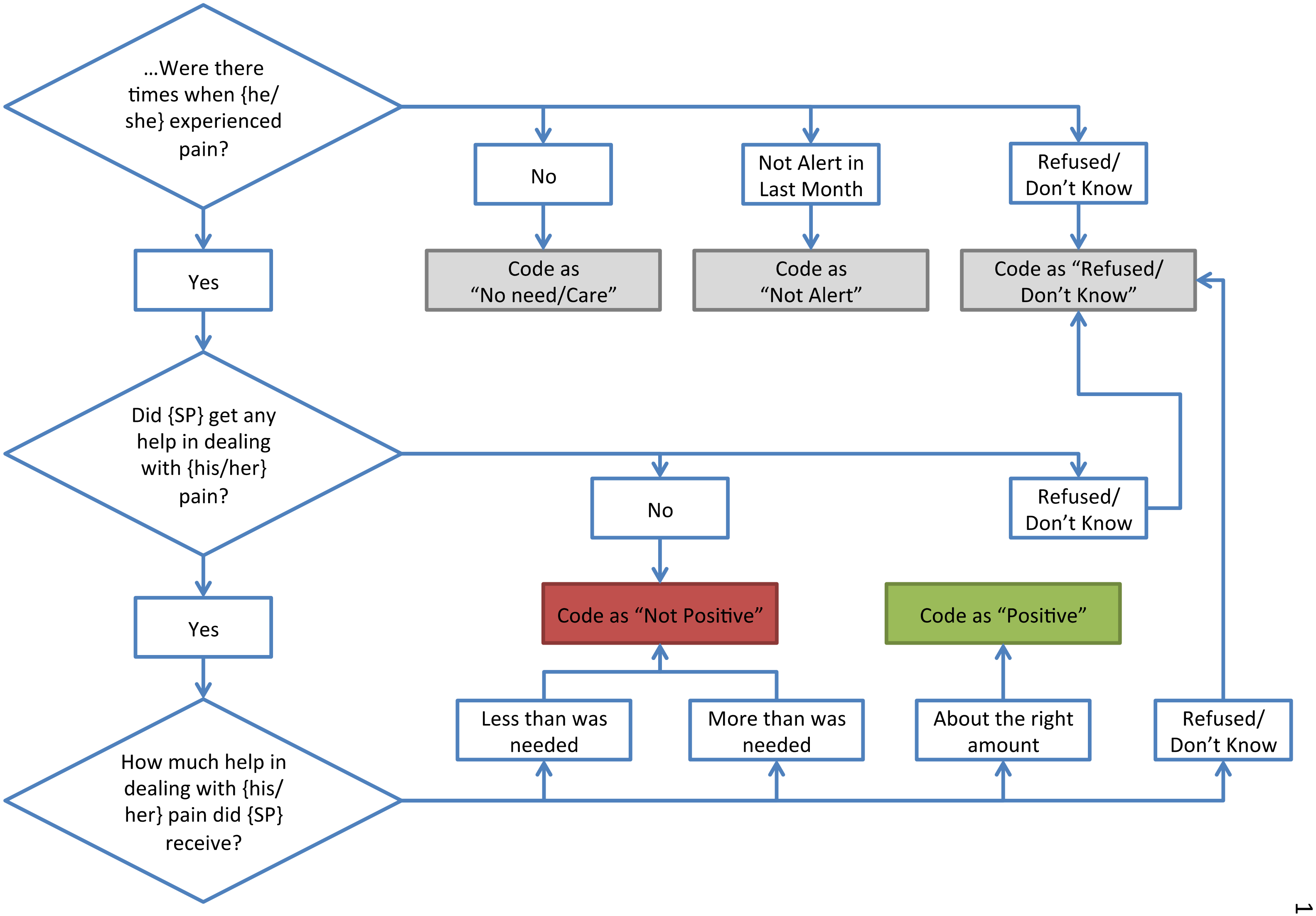


Figure C-4. Breathing Individual *Component*

During the last month of life…

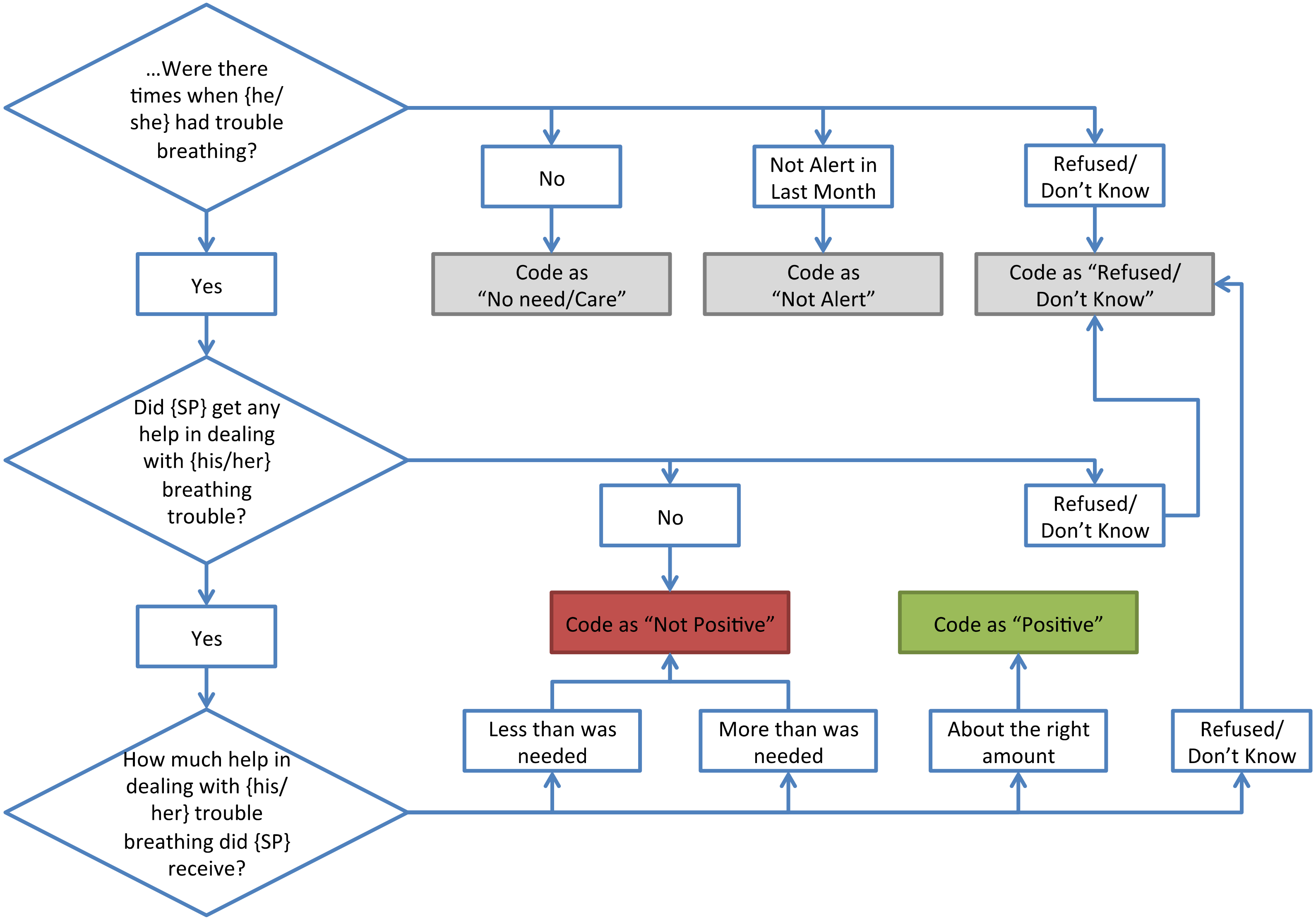


Figure C-5. Symptom Management *Composite Quality Domain*

		Breathing Individual Component				
		Positive	Not Positive	No Need/Care	Don’t Know/ Refused	Not Alert
Pain Individual Component	Positive	Positive	Not Positive	Positive	Inconclusive	
	Not Positive	Not Positive	Not Positive	Not Positive	Inconclusive	
	No Need/Care	Positive	Not Positive	No Need/Care	Inconclusive	
	Don’t Know/ Refused	Inconclusive	Inconclusive	Inconclusive	Inconclusive	
	Not Alert					Not Alert

Figure C-6. Input Into Care Individual *Component*

During the last month of life…

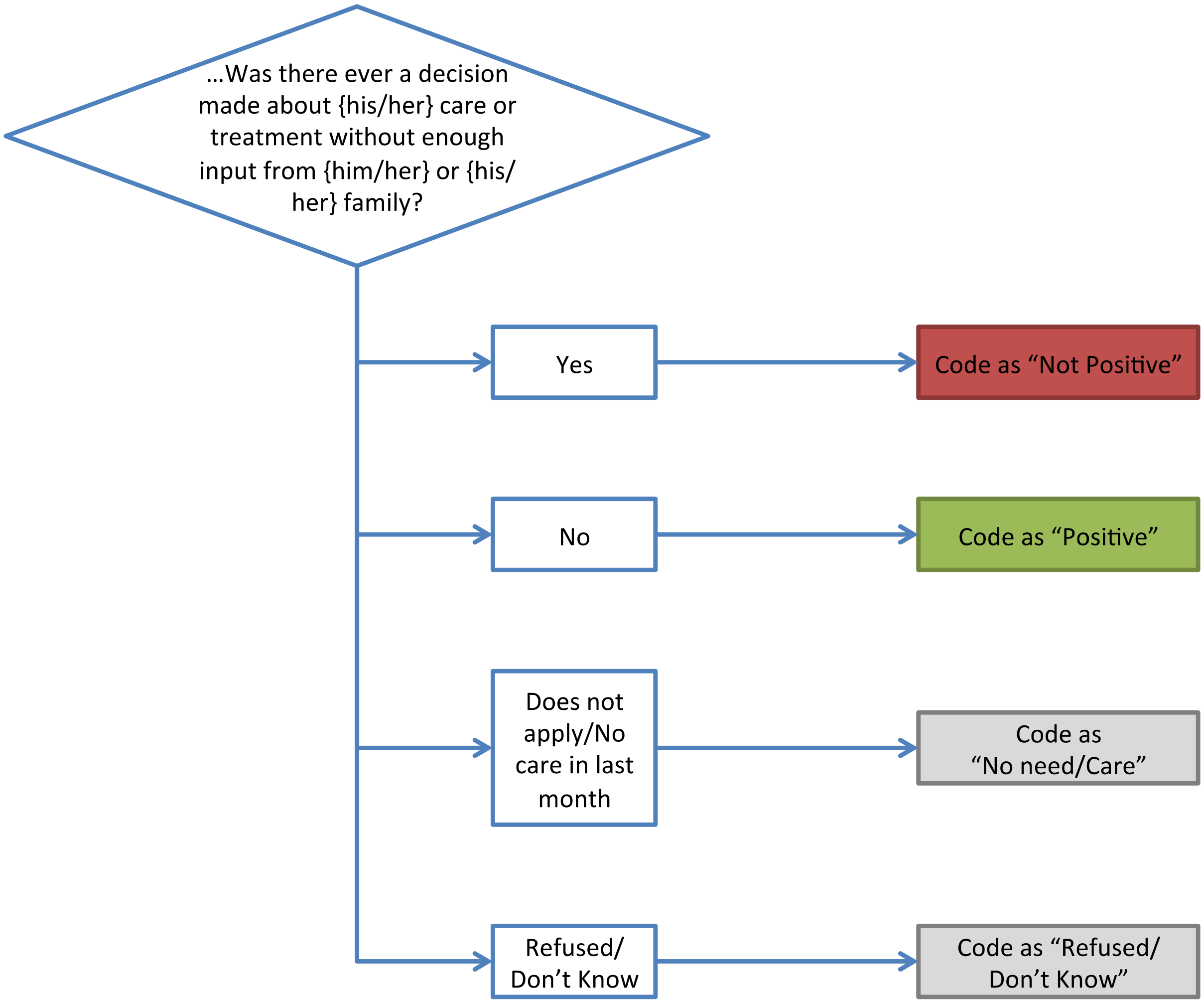


Figure C-7. Receipt of Unwanted Care Individual *Component*

During the last month of life…

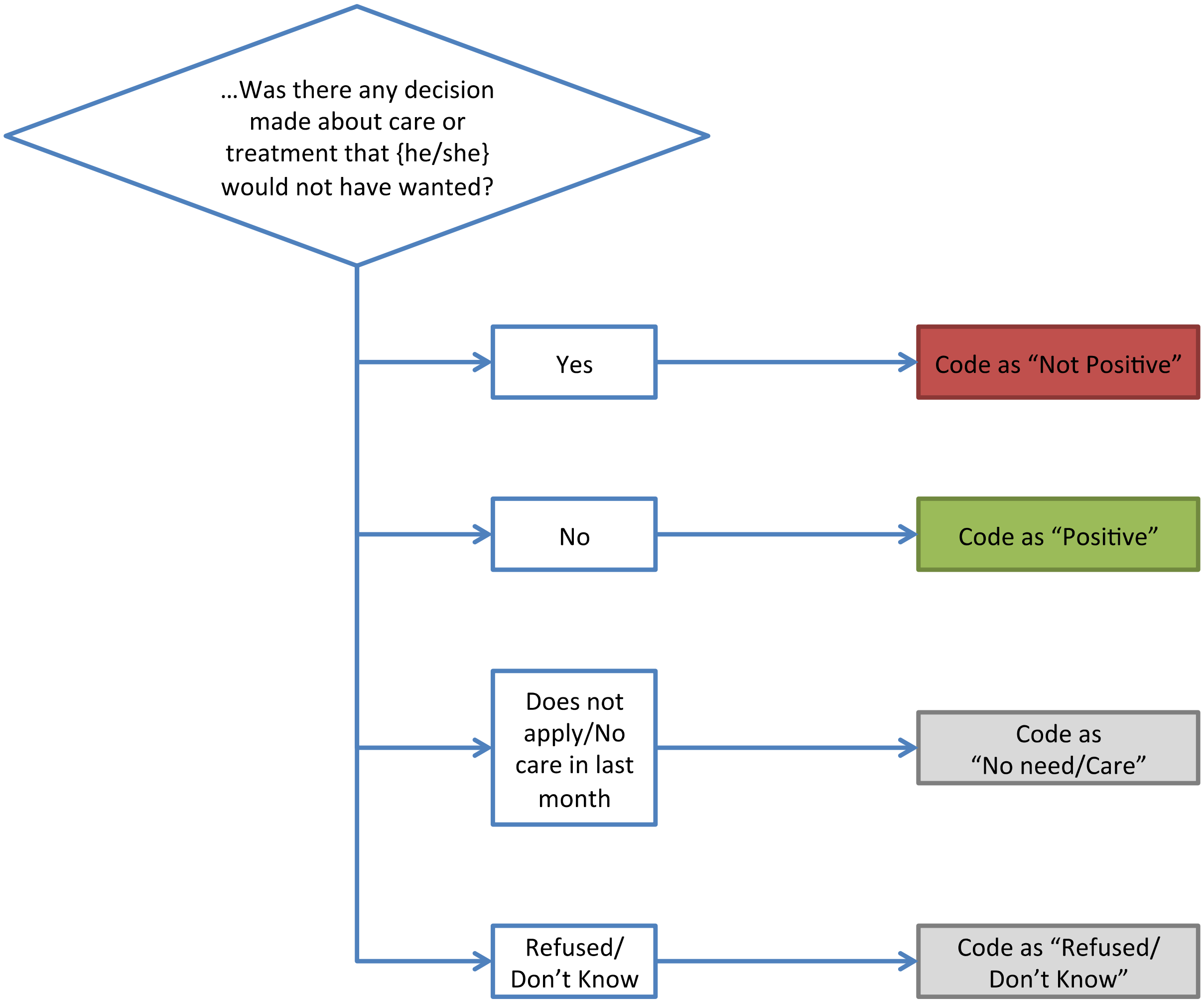


Figure C-8. Informed About Care Individual *Component*

During the last month of life…

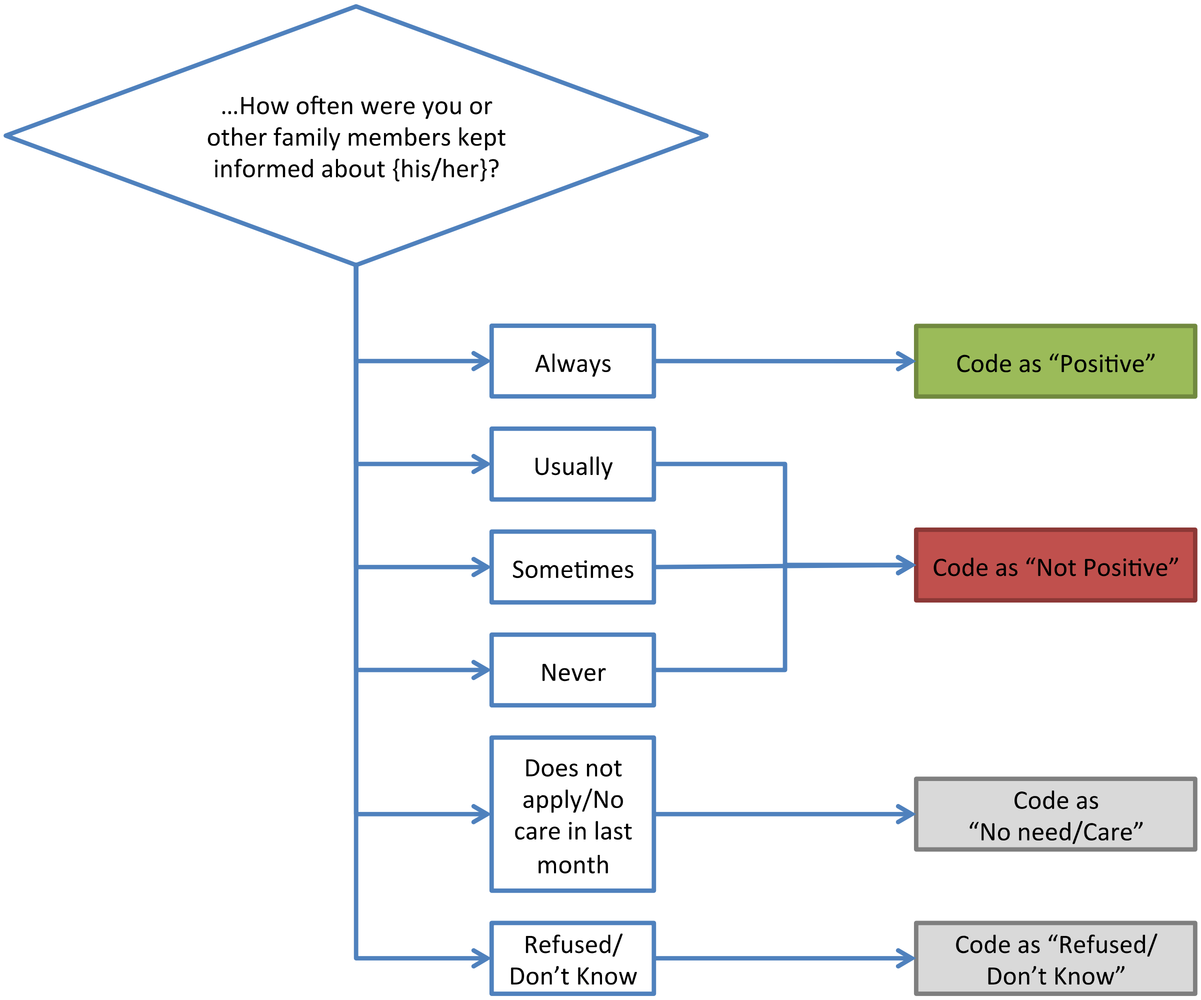
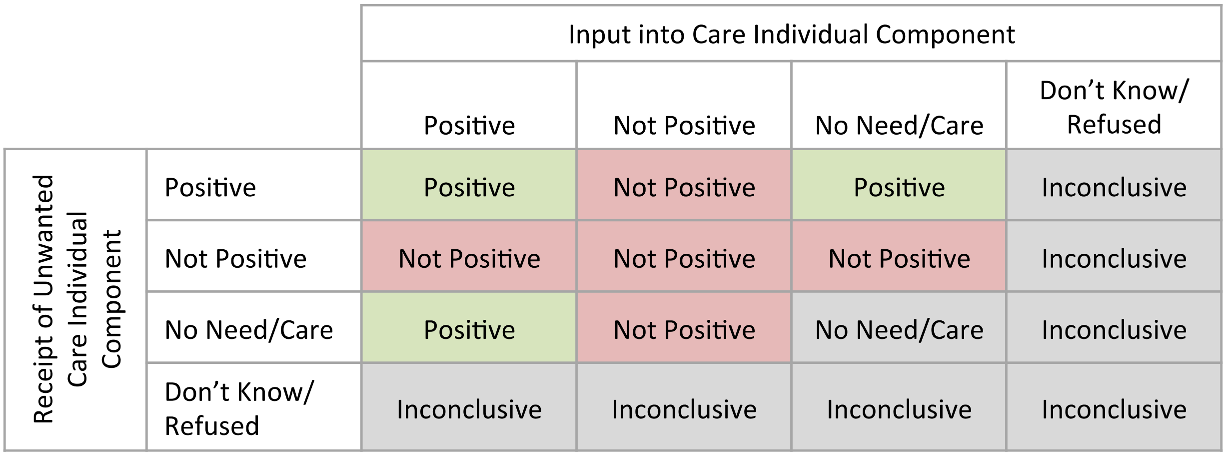


Figure C-9. Shared Decision-Making *Composite Quality Domain*



		Input into Care Individual Component			
		Positive	Not Positive	No Need/Care	Don’t Know/ Refused
Receipt of Unwanted Care Individual Component	Positive	Positive	Not Positive	Positive	Inconclusive
	Not Positive	Not Positive	Not Positive	Not Positive	Inconclusive
	No Need/Care	Positive	Not Positive	No Need/Care	Inconclusive
	Don’t Know/ Refused	Inconclusive	Inconclusive	Inconclusive	Inconclusive

Figure C-10. Respect Individual *Component*

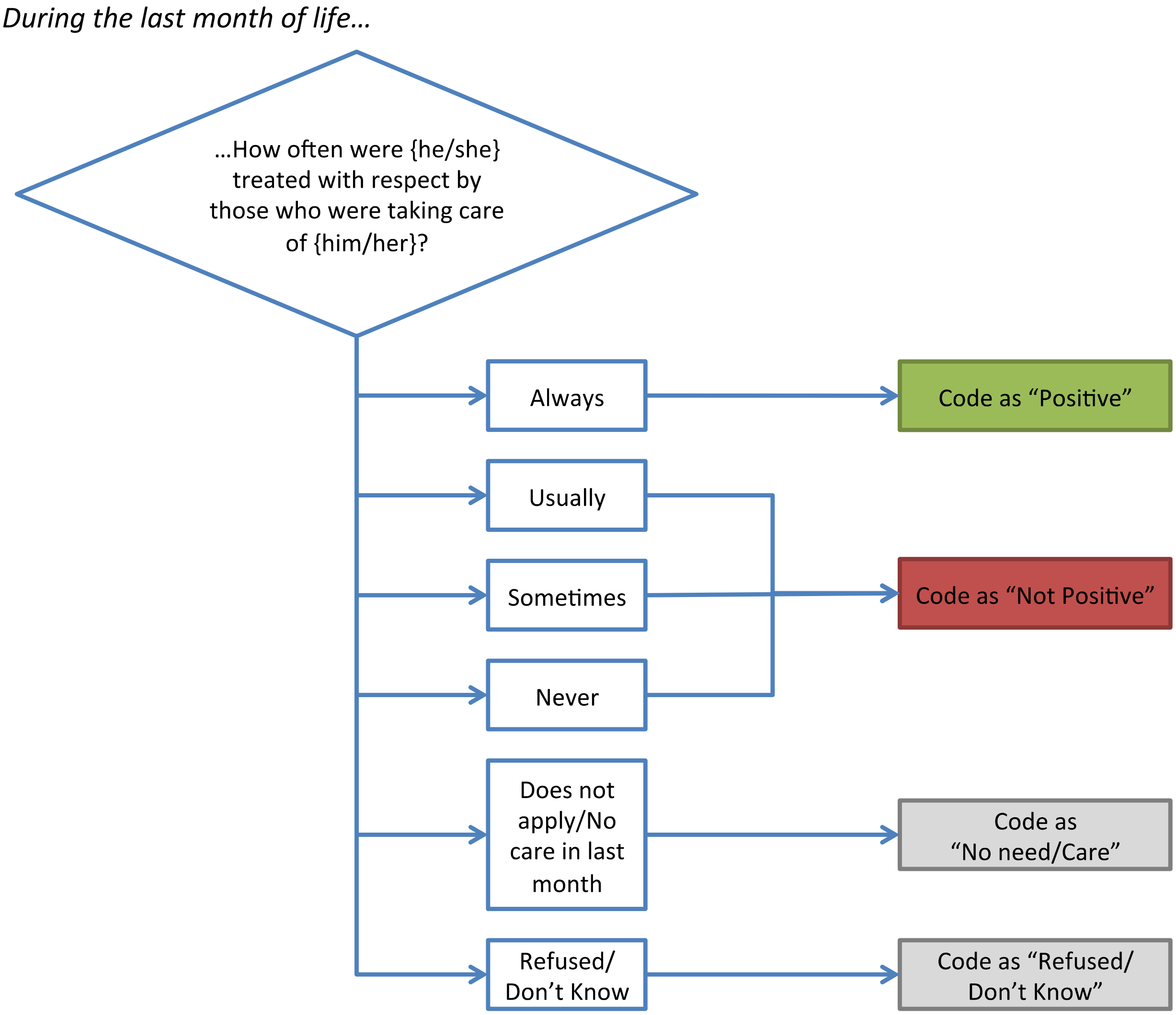


Figure C-11. Personal Care Individual *Component*

During the last month of life…

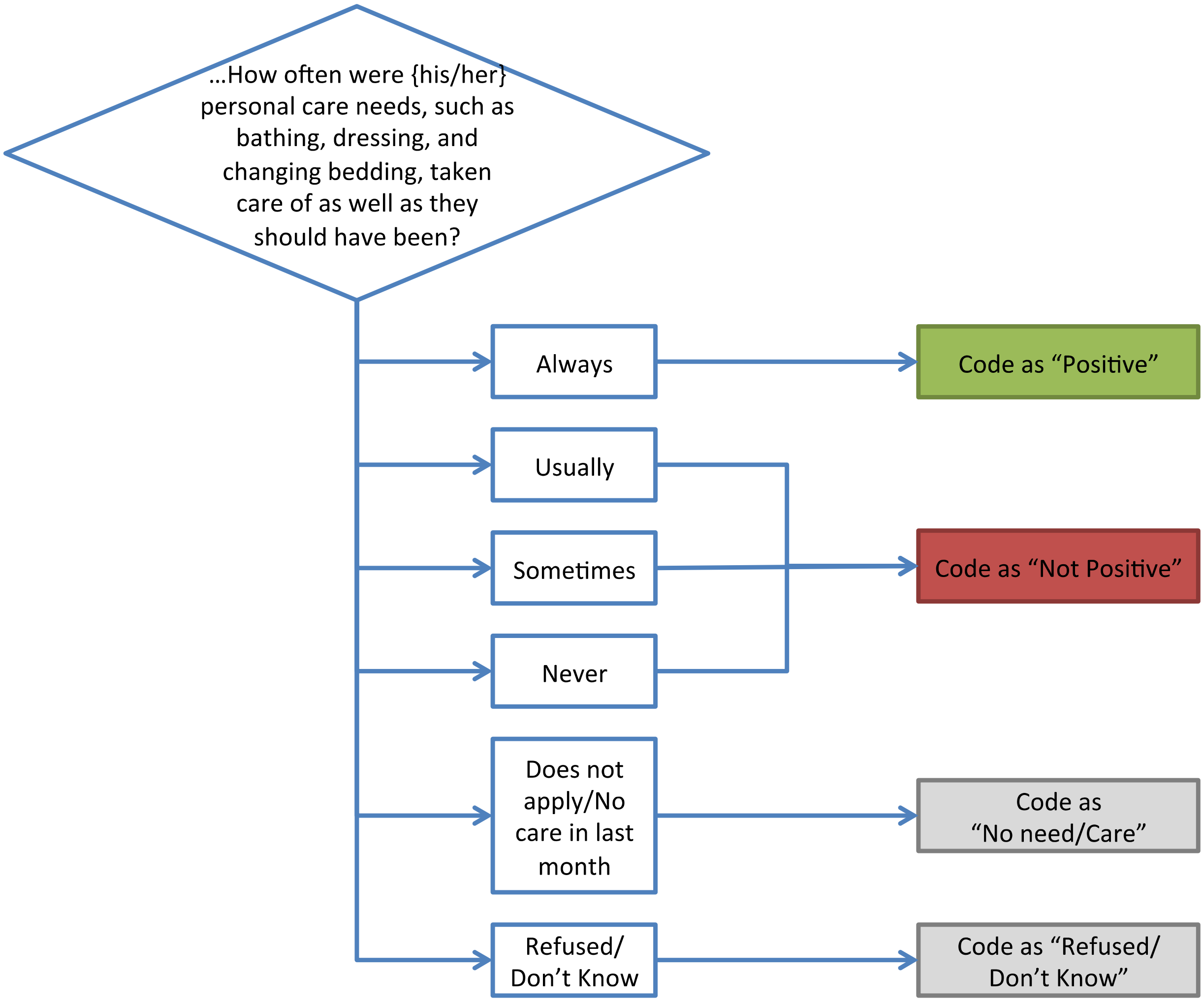


Figure C-12. Respect *Composite Quality Domain*

		Personal Care Individual Component			
		Positive	Not Positive	No Need/Care	Don’t Know/ Refused
Respect Individual Component	Positive	Positive	Not Positive	Positive	Inconclusive
	Not Positive	Not Positive	Not Positive	Not Positive	Inconclusive
	No Need/Care	Positive	Not Positive	No Need/Care	Inconclusive
	Don’t Know/ Refused	Inconclusive	Inconclusive	Inconclusive	Inconclusive

Figure C-13. Anxiety/Sadness Individual *Component*

During the last month of life…

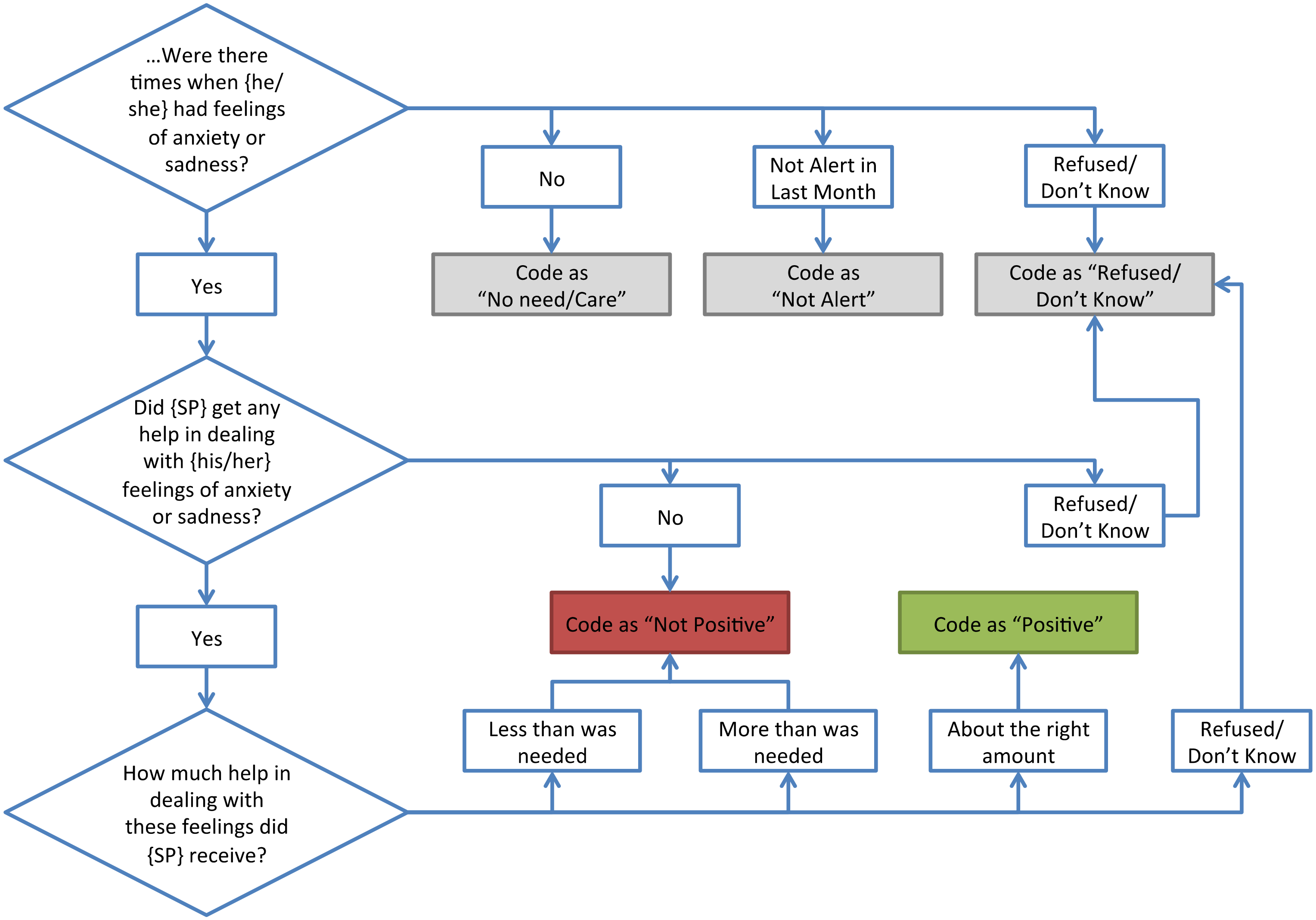


Figure C-14. Religious and Spiritual Needs Individual *Component*

During the last month of life…

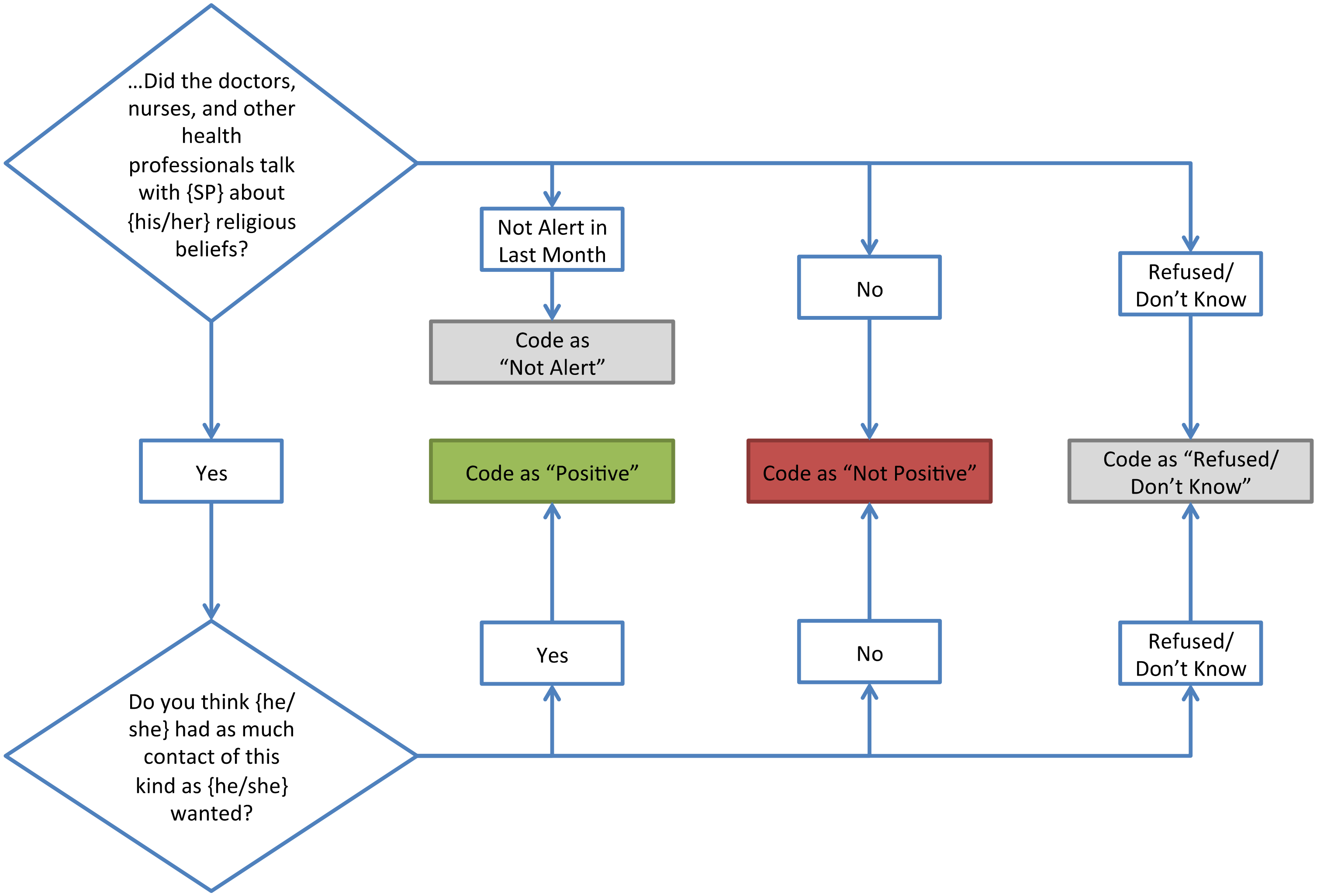


Figure C-15. Spiritual and Emotional Support *Composite Quality Domain*

		Religious and Spiritual Needs Individual Component				
		Positive	Not Positive	No Need/Care	Don’t Know/ Refused	Not Alert
Anxiety/Sadness Individual Component	Positive	Positive	Not Positive	Positive	Inconclusive	
	Not Positive	Not Positive	Not Positive	Not Positive	Inconclusive	
	No Need/Care	Positive	Not Positive	No Need/Care	Inconclusive	
	Don’t Know/ Refused	Inconclusive	Inconclusive	Inconclusive	Inconclusive	
	Not Alert					Not Alert

Appendix D: Residential Care-Dwelling Analysis

The following tables contain results from analysis of the residential care-dwelling sample. **Tables D-1 to D-3** present results from Aim 1 analysis. **Tables D-4 to D-6** present results from Aim 2 analysis. **Tables D-7 to D-9** present results from Aim 3 analysis.

Results from the residential care-dwelling analyses indicate that the NHATS, LMLI cannot support analysis of this study's aims with the sample available from Rounds 2 through 5. Analysis of the residential care-dwelling sample produced highly unstable and therefore unreliable results. For example, most crosstabs in the residential care-dwelling sample analysis contained raw cell sizes less than 10, which resulted in large confidence interval ranges for weighted proportions. The small raw cell sizes also impacted the multivariable regressions. We attempted to exclude all covariates with small cell sizes from multivariable models. For comparison, we ran all multivariable models unadjusted, adjusted for all covariates, and then adjusted for only covariates where raw cell sizes were greater than 10. The results were vastly different, including some changes in the odd ratios' direction, based on which covariates were in the model. Additionally, wide confidence intervals resulted from some multivariable regressions, while other models could not be run at all. We determined the data to be too volatile for any meaningful conclusions to be drawn from analysis.

Table D-1. Weighted distribution of unadjusted proportions for covariates according to multiple chronic condition (MCC) status for residential care-dwelling older adults

	Total Sample		**Multiple Chronic Condition Status**				
			Absent (N=65,098)		**Present (N=375,000)**		
Characteristic	**Raw # (N=205)**	**Wgtd % (N=440,098)**	**Raw # (N=31)**	**Wgtd # (%)**	**Raw # (N=172)**	**Wgtd # (%)**	**p-value**
Age							.72
65 to 84	46	33	8	23,243 (36)	38	121,734 (33)	
85+	159	67	24	41,855 (64)	135	253,266 (68)	
Gender							.79
Male	77	43	11	29,073 (45)	66	157,857 (42)	
Female	128	58	21	36,025 (55)	107	253,169 (58)	
White race							.43
No	38	12	6	11,977 (18)	32	40,508 (11)	
Yes	141	88	26	53,121 (82)	141	334,492 (89)	
Census region							.12
Northeast	36	17	6	11,859 (18)	30	64,501 (17)	
Midwest	50	24	6	13,632 (21)	44	93,677 (25)	
South	65	30	7	8,446 (13)	58	124,825 (33)	
West	54	28	13	31,162 (48)	41	91,997 (25)	
Medicaid							.44
No	146	73	26	52,325 (80)	120	270,418 (72)	
Yes	59	27	6	12,774 (20)	53	104,582 (28)	
Marital status at death							.03
Not married	155	70	28	57,155 (88)	127	249,150 (66)	
Married	50	30	4	7,943 (12)	46	125,850 (34)	

Table D-1. Weighted distribution of unadjusted proportions for covariates according to multiple chronic condition (MCC) status for residential care-dwelling older adults (Continued)

	Total Sample		Multiple Chronic Condition Status				
			Absent (N=65,098)		Present (N=375,000)		
Characteristic	**Raw # (N=205)**	**Wgtd % (N=440,098)**	**Raw # (N=31)**	**Wgtd # (%)**	**Raw # (N=172)**	**Wgtd # (%)**	**p-value**
Dementia reported							.04
No	119	60	24	49,972 (77)	95	213,510 (57)	
Yes	86	40	8	15,126 (23)	78	161,490 (43)	
Cancer reported							.02
No	113	52	26	48,845 (75)	87	180,788 (48)	
Yes	92	48	6	16,253 (25)	86	194,212 (52)	
Hospice enrollment							.65
No	78	38	15	27,798 (43)	63	139,889 (37)	
Yes	127	62	17	37,300 (57)	110	235,111 (63)	
Place of death							.27
Home	32	17	5	10,180 (16)	27	62,743 (17)	
Hospital	50	23	13	25,929 (4)	37	76,124 (2)	
Other	123	60	14	28,989 (45)	109	236,134 (63)	
Proxy relationship							.04
Not spouse	171	77	30	60,076 (92)	141	279,310 (75)	
Spouse	34	23	2	5,022 (8)	32	95,690 (26)	
Proxy gender							.44
Male	52	25	12	20,435 (31)	40	87,851 (23)	
Female	153	75	20	44,663 (69)	133	287,149 (77)	

Table D-2. Weighted distribution of rating of *overall* end-of-life care quality and perception of care in *composite quality domains* (CQD) and individual *components* (IC) for those with a need in the domain who rated care according to MCC status for residential care-dwelling older adults

Perception (Total N=440,098)	MCC Absent (Total N=65,098)			MCC Present (Total N=375,000)			p-value
	Raw #	Wgtd #	Wgtd % [95% CI]	Raw #	Wgtd #	Wgtd % [95% CI]	
Rating of *Overall* Care Quality (N=436,812)							.99
Not Ex.	19	33,045	52 [33,71]	91	194,448	52 [45,59]	
Excellent	12	30,593	48 [30,67]	81	178,726	48 [41,55]	
Coordination CQD (N=418,726)							.95
Not Positive	3	5,377	9 [2,26]	14	31,955	9 [5,15]	
Positive	27	57,451	91 [74,98]	149	323,944	91 [85,95]	
Symptom Management CQD (N=332,347)							.69
Not Positive	6	10,808	23 [12,40]	23	59,748	21 [15,29]	
Positive	15	35,315	77 [60,88]	106	226,475	79 [71,85]	
Pain IC (N=285,890)							.43
Not Positive	4	7,888	19 [8,41]	13	31,208	13 [7,22]	
Positive	14	32,804	81 [59,92]	98	213,990	87 [78,93]	
Breathing IC (N=242,094)							.74
Not Positive	3	5,432	19 [5,47]	12	31,863	15 [8,25]	
Positive	9	23,969	82 [53,95]	81	180,830	85 [75,92]	
Shared decision-making CQD (N=428,700)							.42
Not Positive	1	4,443	8 [1,37]	23	47,728	13 [8,20]	
Positive	27	54,814	93 [63,99]	146	321,715	87 [80,92]	
Input into Care IC (N=426,817)							.91
Not Positive	1	4,443	7 [1,36]	13	28,612	8 [4,15]	
Positive	29	57,735	93 [64,99]	154	336,028	92 [86,96]	
Receipt of Unwanted Care IC (N=425,457)							.01
Not Positive	0	-	0 [0,0]	13	25,543	7 [4,12]	
Positive	28	59,257	100 [100,100]	154	340,656	93 [88,96]	
Informed about Care IC (N=426,986)							.48
Not Positive	9	17,069	26 [14,44]	34	73,735	20 [14,28]	
Positive	23	48,029	74 [56,86]	133	288,153	80 [72,86]	

Table D-2. Weighted distribution of rating of *overall* end-of-life care quality and perception of care in *composite quality domains* (CQD) and individual *components* (IC) for those with a need in the domain who rated care according to MCC status for residential care-dwelling older adults (Continued)

Perception (Total N=440,098)	MCC Absent (Total N=65,098) Raw #	Wgtd #	Wgtd % [95% CI]	MCC Present (Total N=375,000) Raw #	Wgtd #	Wgtd % [95% CI]	p-value
Respect CQD (N=434,301)							.86
Not Positive	9	14,791	23 [13,39]	41	91,561	25 [19,32]	
Positive	22	48,847	77 [61,88]	130	279,101	75 [68,81]	
Respect IC (N=430,957)							.39
Not Positive	2	4,967	8 [2,27]	24	47,042	13 [8,20]	
Positive	29	58,671	92 [73,98]	146	320,278	87 [80,92]	
Personal Care IC (N=434,301)							.71
Not Positive	9	14,791	23 [13,39]	33	74,790	20 [14,28]	
Positive	22	48,847	77 [61,88]	138	295,873	80 [73,86]	
Spiritual and Emotional Support CQD (N=344,786)							.97
Not Positive	17	32,570	65 [37,85]	85	188,948	64 [55,72]	
Positive	7	17,749	35 [15,63]	46	105,519	36 [28,45]	
Anxiety/Sadness IC (N=239,687)							.50
Not Positive	7	11,273	29 [13,53]	31	74,834	37 [29,47]	
Positive	11	28,025	71 [48,87]	58	125,556	63 [54,71]	
Religion IC (N=321,742)							.73
Not Positive	15	29,649	61 [32,84]	66	152,069	56 [47,64]	
Positive	8	19,209	39 [17,68]	55	120,815	44 [36,53]	

Table D-3. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between MCC status and “excellent” rating of *overall* care quality and with “positive” perception in each *composite quality domain* (CQD) and individual *component* (IC) for residential care-dwelling older adults

	Cases (N=440,098)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR***	**[95% CI]**	**OR***	**[95% CI]**
Rating of *Overall* Care Quality[1]	436,812	99%	.99	[.43,2.30]	1.11	[.45,2.71]
Coordination CQD~[1]	418,726	95%	.95	[.20,4.43]	.72	[.12,4.25]
Symptom Management CQD~[2]	332,347	76%	1.16	[.55,2.46]	1.12	[.50,2.53]
Pain IC~[1b]	285,890	65%	1.65	[.52,5.19]	3.06	[.64,14.76]
Breathing IC~[1b]	242,094	55%	1.29	[.30,5.55]	.70	[.08,5.90]
Shared decision-making CQD~[3]	428,670	97%	.55	[.08,3.69]	.61	[.10,3.56]
Input into Care IC~[1b]	426,817	97%	.90	[.14,5.68]	will not run	--
Receipt of Unwanted Care IC~[1b]	366,199	83%	1.00	--	1.00	--
Informed about Care IC~[4]	426,986	97%	1.39	[.58,3.31]	1.21	[.48,3.06]

*OR significant at p<.05

~Contains raw cell count <10

[1] Model includes age, gender, White race, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and proxy gender

[1b] Model includes age, gender, White race, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and proxy gender, but small cells in all

[2] Model includes gender, Medicaid, cancer reported, hospice enrollment, and proxy gender

[3] Model includes gender, dementia reported, cancer reported, and hospice enrollment

Table D-3. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between MCC status and “excellent” rating of *overall* care quality and with “positive” perception in each *composite quality domain* (CQD) and individual *component* (IC) for residential care-dwelling older adults (Continued)

	Cases (N=440,098)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR***	**[95% CI]**	**OR***	**[95% CI]**
Respect CQD~[5]	434,301	99%	.92	[.38,2.24]	.86	[.38,1.95]
Respect IC~[6]	430,957	98%	.58	[.13,2.58]	.50	[.11,2.19]
Personal Care IC~[7]	434,301	99%	1.20	[.45,3.16]	1.23	[.41,3.64]
Spiritual & Emotional Support CQD~[8]	344,786	78%	1.02	[.32,3.24]	1.05	[.36,3.12]
Anxiety/Sadness IC~[9]	239,687	54%	.67	[.21,2.14]	.53	[.17,1.66]
Religion IC~[8]	321,742	73%	1.23	[.36,4.12]	1.23	[.38,3.95]

*OR significant at p<.05

~Contains raw cell count <10

[5] Model includes age, gender, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, and proxy gender

[6] Model includes cancer reported and hospice enrollment

[7] Model includes age, gender, Medicaid, dementia reported, hospice enrollment, and proxy gender

[8] Model includes age, gender, White race, Medicaid, dementia reported, cancer reported, hospice enrollment, place of death, and proxy gender

[9] Model includes age, gender, Medicaid, marital status at death, dementia reported, cancer reported, and hospice enrollment

Table D-4. Weighted distribution of unadjusted proportions for covariates according to *overall* rating of end-of-life care quality for residential care-dwelling older adults

	Total Sample		**Rating of *Overall* Care Quality**				
			Not Excellent (N=194,448)		**Excellent (N=178,726)**		
Characteristic	**Raw # (N=172)**	**Wgtd % (N=372,174)**	**Raw # (N=91)**	**Wgtd # (%)**	**Raw # (N=81)**	**Wgtd # (%)**	**p-value**
Age							.85
65 to 84	37	32	18	60,976 (31)	19	58,932 (33)	
85+	135	68	73	133,472 (69)	62	119,795 (67)	
Gender							.31
Male	65	42	33	73,293 (38)	32	82,737 (46)	
Female	107	58	58	121,154 (62)	49	95,989 (54)	
White race							.37
No	31	10	20	24,221 (13)	11	14,460 (8)	
Yes	141	90	71	170,226 (88)	70	164,266 (92)	
Census region							.03
Northeast	30	17	12	21,310 (11)	18	43,191 (24)	
Midwest	44	25	24	47,505 (24)	20	46,172 (26)	
South	57	33	36	81,279 (42)	21	41,720 (23)	
West	41	25	19	44,353 (23)	22	47,644 (27)	
Medicaid							.98
No	119	72	62	139,833 (72)	57	128,759 (72)	
Yes	53	28	29	54,615 (28)	24	49,967 (28)	
Marital status at death							.70
Not married	127	67	66	126,621 (65)	61	122,529 (69)	
Married	45	33	25	67,826 (35)	20	56,197 (31)	

Table D-4. Weighted distribution of unadjusted proportions for covariates according to *overall* rating of end-of-life care quality for residential care-dwelling older adults (Continued)

	Total Sample		**Rating of *Overall* Care Quality**				
			Not Excellent (N=194,448)		**Excellent (N=178,726)**		
Characteristic	**Raw # (N=172)**	**Wgtd % (N=372,174)**	**Raw # (N=91)**	**Wgtd # (%)**	**Raw # (N=81)**	**Wgtd # (%)**	**p-value**
Dementia reported							.88
No	94	57	52	111,380 (57)	42	100,304 (56)	
Yes	78	43	39	83,068 (43)	39	78,422 (44)	
Cancer reported							.70
No	86	48	48	96,190 (50)	38	82,772 (46)	
Yes	86	52	43	98,258 (51)	43	95,954 (54)	
Hospice enrollment							.60
No	62	37	35	75,981 (39)	27	62,083 (35)	
Yes	110	63	56	118,467 (61)	54	116,644 (65)	
Place of death							.06
Home	27	17	11	22,360 (12)	16	40,382 (23)	
Hospital	36	20	22	45,915 (24)	14	28,383 (16)	
Other	109	63	58	126,172 (65)	51	109,962 (62)	
Proxy relationship							.57
Not spouse	140	74	72	140,710 (72)	68	136,774 (77)	
Spouse	32	26	19	53,738 (28)	13	41,952 (24)	
Proxy gender							.64
Male	40	24	22	48,651 (25)	18	39,200 (22)	
Female	132	77	69	145,796 (75)	63	139,526 (78)	

Table D-5. Weighted distribution of rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care for residential care-dwelling older adults

	Not Excellent (Total N=194,448)		**Excellent (Total N=178,726)**		
Perception (Total N=373,174)	**Raw #**	**Wgtd % [95% CI]**	**Raw #**	**Wgtd % [95% CI]**	**p-value**
Coordination CQD (N=354,073)					.39
Not Positive	10	63 [32,86]	4	37 [14,68]	
Positive	73	50 [42,57]	75	51 [43,58]	
Symptom Management CQD (N=284,398)					.16
Not Positive	15	66 [43,84]	7	34 [16,58]	
Positive	51	46 [35,58]	55	54 [42,65]	
Pain IC (N=245,198)					.06
Not Positive	11	84 [53,96]	2	16 [4,47]	
Positive	51	51 [40,62]	47	49 [38,60]	
Breathing IC (N=210,867)					.98
Not Positive	6	52 [22,81]	5	48 [19,78]	
Positive	40	51 [39,63]	41	49 [37,61]	
Shared decision-making CQD (N=369,443)					.10
Not Positive	15	69 [49,84]	8	31 [16,51]	
Positive	73	49 [41,57]	73	51 [43,59]	
Input into Care IC (N=364,629)					.04
Not Positive	11	86 [54,97]	2	14 [3,46]	
Positive	75	48 [40,56]	79	52 [44,60]	
Receipt of Unwanted Care IC (N=366,199)					.56
Not Positive	7	58 [36,77]	6	42 [23,65]	
Positive	79	51 [43,58]	75	49 [42,57]	
Informed about Care IC (N=361,888)					<.001
Not Positive	31	90 [74,97]	3	10 [3,26]	
Positive	56	42 [33,51]	77	58 [49,67]	
Respect CQD (N=370,663)					<.001
Not Positive	38	90 [72,97]	3	10 [3,28]	
Positive	52	39 [30,49]	78	61 [51,70]	
Respect IC (N=367,320)					<.001
Not Positive	23	95 [72,99]	1	5 [1,28]	
Positive	67	46 [38,54]	79	54 [46,62]	
Personal Care IC (N=370,663)					<.001
Not Positive	31	91 [68,98]	2	9 [2,32]	
Positive	59	42 [33,51]	79	58 [49,67]	

Table 6-5. Weighted distribution of rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain* (CQD) and individual *component* (IC) for those with a need who rated care for residential care-dwelling older adults (Continued)

	Not Excellent (Total N=194,448)		**Excellent (Total N=178,726)**		
Perception (Total N=373,174)	**Raw #**	**Wgtd % [95% CI]**	**Raw #**	**Wgtd % [95% CI]**	**p-value**
Spiritual and Emotional Support CQD (N=294,467)					.08
Not Positive	50	58 [45,70]	35	42 [30,55]	
Positive	21	42 [28,57]	25	58 [43,72]	
Anxiety/Sadness IC (N=200,389)					.047
Not Positive	21	68 [46,83]	10	32 [17,54]	
Positive	26	44 [31,57]	32	56 [43,69]	
Religion IC (N=272,884)					.21
Not Positive	37	57 [42,70]	29	43 [30,58]	
Positive	27	45 [32,59]	28	55 [41,68]	

Table D-6. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between "positive" perception of each *composite quality domain* (CQD) and individual *component* (IC) and "excellent" rating of *overall* care quality for residential care-dwelling older adults

	Cases (N=373,174)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR***	**[95% CI]**	**OR***	**[95% CI]**
Coordination CQD~[1]	354,073	95%	1.73	[.46,6.56]	1.71	[.38,7.78]
Symptom Management CQD~[1]	284,398	76%	2.29	[.70,7.44]	2.27	[.57,9.03]
Pain IC~[1]	245,198	66%	5.02	[.88,28.52]	11.84	[.63,223.56]
Breathing IC~[1]	210,867	57%	1.02	[.25,4.17]	.70	[.13,3.74]
Shared decision-making CQD~[2]	369,443	99%	2.32	[.94,5.70]	2.35	[.94,5.85]
Input Into Care IC~[1]	364,629	98%	6.72*	[1.26,35.86]	will not run	
Receipt of Unwanted Care IC~[1]	366,199	98%	1.33	[.52,3.35]	.96	[.29,3.15]
Informed About Care IC~[3]	361,888	97%	12.37*	[3.60,42.52]	12.68*	[3.84,41.85]

*Significant at p<.05 level

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[1] Model includes age, gender, White race, Census region, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and proxy gender, but all contain raw cell counts <10

[2] Model includes dementia reported, cancer reported, and hospice enrollment

[3] Model includes gender, Medicaid, dementia reported, cancer reported, and hospice enrollment

Table D-6. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between "positive" perception of each *composite quality domain* (CQD) and individual *component* (IC) and "excellent" rating of *overall* care quality for residential care-dwelling older adults (Continued)

	Cases (N=373,174)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR***	**[95% CI]**	**OR***	**[95% CI]**
Respect CQD~[4]	370,663	99%	13.46*	[3.38,53.64]	15.65*	[4.32,56.72]
Respect IC~[5]	367,320	98%	2.80*	[2.67,162.16]	2.58*	[2.65,159.80]
Personal Care IC~[3]	370,663	99%	13.63*	[2.63,7.59]	16.56*	[3.55,77.16]
Spiritual & Emo. Support CQD[6]	294,467	79%	1.94	[.95,3.97]	2.03	[.98,4.20]
Anxiety/Sadness IC[7]	200,389	54%	2.70	[.99,7.36]	2.92*	[1.03,8.28]
Religion IC[8]	272,884	73%	1.61	[.76,3.38]	1.61	[.76,3.43]

*Significant at p<.05 level

~Contains raw cell count <10

[4] Model includes gender, Medicaid, marital status at death, dementia reported, cancer reported, and hospice enrollment

[5] Model includes cancer reported

[6] Model includes age, gender, Medicaid, dementia reported, and cancer reported

[7] Model includes age, gender, Medicaid, cancer reported, and hospice enrollment

[8] Model includes age, gender, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, and proxy gender

Table D-7. Weighted distribution of unadjusted proportions for covariates according to the perception of the coordination *composite quality domain* for residential care-dwelling older adults

	Total Sample		Coordination Quality Domain				
			Not Positive (N=31,955)		Positive (N=323,944)		
Characteristic	Raw # (N=163)	Wgtd % (N=355,899)	Raw # (N=14)	Wgtd # (%)	Raw # (N=149)	Wgtd # (%)	p-value
Age							.48
65 to 84	35	32	4	13,641 (43)	31	100,017 (31)	
85+	128	68	10	18,314 (57)	118	223,928 (69)	
Gender							.70
Male	64	43	7	15,494 (49)	57	136,509 (42)	
Female	99	57	7	16,461 (52)	92	187,436 (58)	
White race							.79
No	29	11	3	3,999 (13)	26	33,497 (10)	
Yes	134	90	11	27,956 (88)	123	290,447 (90)	
Census region							.86
Northeast	26	16	3	7,364 (23)	23	50,713 (16)	
Midwest	43	26	3	5,778 (18)	40	85,387 (26)	
South	55	33	5	11,390 (36)	50	106,191 (33)	
West	39	25	3	7,423 (23)	36	81,653 (25)	
Medicaid							.57
No	115	73	9	24,980 (78)	106	234,152 (72)	
Yes	48	27	5	6,974 (22)	43	89,793 (28)	
Marital status at death							.42
Not married	119	66	11	24,190 (76)	108	211,714 (65)	
Married	44	38	3	7,765 (24)	41	112,230 (35)	

Table D-7. Weighted distribution of unadjusted proportions for covariates according to the perception of the coordination *composite quality domain* for residential care-dwelling older adults (Continued)

	Total Sample		**Coordination Quality Domain**				
			Not Positive (N=31,955)		**Positive (N=323,944)**		
Characteristic	**Raw # (N=163)**	**Wgtd % (N=355,899)**	**Raw # (N=14)**	**Wgtd # (%)**	**Raw # (N=149)**	**Wgtd # (%)**	**p-value**
Dementia reported							.47
No	90	57	9	21,429 (67)	81	182,496 (56)	
Yes	73	43	5	10,526 (33)	68	141,448 (44)	
Cancer reported							.95
No	81	48	7	15,549 (49)	74	154,194 (48)	
Yes	82	52	7	16,406 (51)	75	169,751 (52)	
Hospice enrollment							.01
No	57	36	2	3,916 (12)	55	123,876 (38)	
Yes	106	64	12	28,038 (88)	94	200,068 (62)	
Place of death							.52
Home	27	18	1	2,456 (8)	26	60,287 (19)	
Hospital	33	19	4	8,939 (28)	29	57,359 (18)	
Other	103	64	9	20,560 (64)	94	206,299 (64)	
Proxy relationship							.72
Not spouse	133	75	11	22,489 (70)	122	243,574 (75)	
Spouse	30	25	3	9,466 (30)	27	80,370 (25)	
Proxy gender							.27
Male	40	25	6	13,063 (41)	34	74,788 (23)	
Female	123	75	8	18,892 (59)	115	249,156 (77)	

Table D-8. Weighted distribution of perception of care for the coordination *composite quality domain* (CQD) according to the perception of care for each CQD and individual *component* (IC) for those with a need who rated care for residential care-dwelling older adults

	Not Positive (Total N=31,955)		**Positive (Total N=323,944)**		
Perception (Total N=355,899)	**Raw #**	**Wgtd % [95% CI]**	**Raw #**	**Wgtd % [95% CI]**	**p-value**
Symptom Management CQD (N=278,591)					.38
Not Positive	4	14 [5,34]	18	86 [66,95]	
Positive	7	7 [3,16]	95	93 [84,97]	
Pain IC (N=241,537)					.24
Not Positive	3	20 [6,49]	9	80 [51,94]	
Positive	5	6 [2,15]	91	94 [85,98]	
Breathing IC (N=203,989)					.80
Not Positive	1	8 [1,42]	11	92 [58,99]	
Positive	7	10 [05,19]	70	90 [81,95]	
Shared decision-making CQD (N=351,802)					.67
Not Positive	1	6 [1,36]	19	94 [64,99]	
Positive	12	9 [05,16]	128	91 [84,95]	
Input into Care IC (N=351,152)					.04
Not Positive	0	0 [0,0]	11	100 [100,100]	
Positive	13	9 [5,16]	136	91 [84,95]	
Receipt of Unwanted Care IC (N=351,070)					.77
Not Positive	1	12 [1,58]	10	88 [42,99]	
Positive	12	8 [5,15]	136	92 [85,95]	
Informed about Care IC (N=348,219)					.04
Not Positive	8	23 [13,38]	22	77 [62,87]	
Positive	6	6 [3,13]	124	94 [87,98]	
Respect CQD (N=354,073)					.11
Not Positive	8	18 [9,34]	32	82 [66,92]	
Positive	6	6 [3,13]	116	94 [87,97]	
Respect IC (N=350,730)					.12
Not Positive	5	23 [10,44]	18	77 [56,90]	
Positive	9	7 [3,14]	129	93 [86,97]	
Personal Care IC (N=354,073)					.15
Not Positive	7	19 [8,38]	25	81 [62,92]	
Positive	7	7 [3,13]	123	94 [87,97]	

Table D-8. Weighted distribution of perception of care for the coordination *composite quality domain* (CQD) according to the perception of care for each CQD and individual *component* (IC) for those with a need who rated care for residential care-dwelling older adults (Continued)

Perception (Total N=355,899)	**Not Positive (Total N=31,955)**		**Positive (Total N=323,944)**		**p-value**
	Raw #	**Wgtd % [95% CI]**	**Raw #**	**Wgtd % [95% CI]**	
Spiritual and Emotional Support CQD (N=282,440)					.21
Not Positive	8	12 [6,24]	72	88 [76,94]	
Positive	2	5 [1,17]	43	95 [84,99]	
Anxiety/Sadness IC (N=189,435)					.25
Not Positive	4	17 [6,40]	23	83 [60,94]	
Positive	4	7 [2,17]	51	93 [83,98]	
Religion IC (N=264,829)					.22
Not Positive	7	13 [6,27]	57	87 [73,94]	
Positive	3	5 [2,15]	50	95 [85,98]	

Table D-9. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between "positive" perception of each *composite quality domain* (CQD) and individual *component* (IC) and positive perception of the coordination CQD for residential care-dwelling older adults

	Cases (N=355,899)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR**	**[95% CI]**	**OR**	**[95% CI]**
Symptom Management CQD~[1]	278,591	78%	2.34	[.72,7.63]	2.90	[.61,13.84]
Pain IC~[2]	241,537	68%	4.84	[.85,27.70]	2.95	[.49,17.65]
Breathing IC~[2]	230,989	65%	1.12	[.28,4.46]	2.30	[.14,37.48]
Shared decision-making CQD~[2]	351,802	99%	1.92	[.71,5.19]	.51	[.04,7.38]
Input Into Care IC~[2]	351,152	99%	6.02*	[1.10,33.07]	will not run	
Receipt of Unwanted Care IC~[2]	351,070	99%	.90	[.30,2.72]	1.00	[.06,16.01]
Informed About Care IC~[3]	348,219	98%	1.70*	[3.10,36.95]	5.04*	[1.41,18.03]

*Significant at p<.05 level

~Contains raw cell count <10

[1] Model includes hospice enrollment

[2] Model includes age, gender, White race, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, place of death, proxy relationship to the deceased, and proxy gender, but containing raw cell count <10

[3] Model includes gender, dementia reported, cancer reported, and hospice enrollment

Table D-9. Unadjusted and multivariable odds ratios (OR) and 95% confidence intervals (CI) of the relationship between "positive" perception of each *composite quality domain* (CQD) and individual *component* (IC) and positive perception of the coordination CQD for residential care-dwelling older adults (Continued)

	Cases (N=355,899)		**Unadjusted OR**		**Adjusted OR**	
	Wgtd Freq	**% of N**	**OR**	**[95% CI]**	**OR**	**[95% CI]**
Respect CQD~[4]	354,073	99%	14.33*	[3.65,56.33]	3.43	[.94,12.55]
Respect IC~[5]	350,730	99%	21.21*	[2.72,165.63]	4.02*	[1.28,12.61]
Personal Care IC~[6]	354,073	99%	14.28*	[2.80,72.72]	3.45	[.85,14.08]
Spiritual & Emo. Support CQD~[7]	282,440	79%	1.96	[.93,4.13]	2.83	[.58,13.77]
Anxiety/Sadness IC~[8]	189,435	53%	2.41	[.89,6.51]	2.53	[.63,1.20]
Religion IC~[9]	264,829	74%	1.71	[.78,3.77]	3.37	[.76,14.96]

*Significant at p<.05 level

~Contains raw cell count <10

[4] Model includes gender, Medicaid, marital status at death, dementia reported, cancer reported, and hospice enrollment

[5] Model includes cancer reported

[6] Model includes gender, Medicaid, dementia reported, cancer reported, and hospice enrollment

[7] Model includes gender, dementia reported, and cancer reported

[8] Model includes age, gender, Medicaid, and cancer reported

[9] Model includes age, gender, Medicaid, marital status at death, dementia reported, cancer reported, hospice enrollment, and proxy gender