

Nonsymptomatic Factors More Strongly Associated with High-Quality End-of-Life Care than Symptomatic Factors for Community-Dwelling Older Adults with Multiple Chronic Conditions

Gayle Kricke, MSW, PhD,¹ Donna Woods, EdM, PhD,²
Alicia Arbaje, MD, MPH, PhD,^{3,4} and Neil Jordan, PhD^{5,6}

Abstract

Background: Information about end-of-life goals and preferences of older adults with multiple chronic conditions (MCCs) is scarce, but necessary for prioritizing resources to care for this population.

Objective: The aim of this study was to determine which end-of-life quality domains are associated with excellent overall end-of-life care quality for older adults with MCCs.

Design: This study involved retrospective cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview.

Measurements: Weighted bivariable analyses determined unadjusted relationships between *overall* care quality and end-of-life care quality. Weighted unadjusted and adjusted multiple logistic regression tested the association of ratings of *overall* care quality with the perception of quality.

Results: The final analytic sample included 477 NHATS participants (weighted: 1,123,887 participants). For older adults with MCC, the rating of *overall* care quality was positively associated with coordination (adjusted odds ratio [aOR] 4.49; 95% confidence interval [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 symptom management (aOR 1.49; 95% CI: 0.81–2.71).

Conclusion: Given that nonsymptomatic domains (*coordination, shared decision making, respect, and spiritual and emotional support*) were most associated with high-quality end-of-life care for older adults with MCC as rated by their proxies, increased attention is needed to strengthen these aspects of care. Symptom management was unrelated to the *overall* quality rating, and further research is needed to illuminate the meaning of this finding.

Keywords: end-of-life care quality; multiple chronic conditions; quality

Introduction

A PROMINENT MODEL developed by Teno et al. (the Teno Model) indicates that high-quality end-of-life care requires assessment and intervention in five domains, regardless of the delivery setting^{1–3}: *coordination, symptom management,*

shared decision making, respect, and spiritual and emotional support. The Teno Model draws from end-of-life standards, institutional guidelines, and provider and family member input.³ However, the Teno Model of end-of-life care quality has not been validated specifically with older adults (defined as individuals aged ≥65) with multiple chronic conditions (MCCs).

¹Division of Quality, Northwestern Memorial HealthCare, Chicago, Illinois.

²Center for Healthcare Studies, Northwestern University Feinberg School of Medicine, Chicago, Illinois.

³Division of Geriatric Medicine and Gerontology, Department of Medicine, Center for Transformative Geriatrics Research, Baltimore, Maryland.

⁴Armstrong Institute Center for Health Care Human Factors, Johns Hopkins University School of Medicine, Baltimore, Maryland.

⁵Department of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine, Chicago, Illinois.

⁶Center of Innovation for Complex Chronic Healthcare, Hines VA Hospital, Chicago, Illinois.

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Two-thirds of older adults lived with MCC in 2012.⁴ 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 health care management, decision-making, or coordination."⁵ 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.⁶ Prognostic uncertainty may lead older adults with MCC to receive fragmented end-of-life care in a general health care system focused on stabilization rather than end-of-life specific needs.³ In addition, 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,⁷ particularly when intervention resources are limited.⁸ 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 needs and demands when intervention resources and time are limited, such as prioritizing care for symptoms such as pain over care for religious or emotional needs.⁸⁻¹⁰

While literature characterizes risks older adults with MCC experience as they approach the end of life, information about their goals and preferences is scarce, yet it is 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.¹¹ However, end-of-life care priorities for older adults with MCC are unknown. In one of the studies of the preferences of older adults with MCC, Clarke et al.¹² demonstrated that the population shared similar end-of-life-related fears with the general public, but did not identify actionable priorities for care improvement.¹³ The study also did not explicitly examine differences between the goals of older adults with MCC and the general older adult 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 health care systems focus limited resources on areas most meaningful to this population within the time constraints that often accompany end-of-life care.

Objective

The objective of this study was to determine which of the recognized end-of-life domains proxy respondents perceive as associated with excellent overall end-of-life care quality for older adults with MCC. Drawing from the competing demands framework⁸ and Maslow's hierarchy of needs,¹⁴ we hypothesized that proxies for dying older adults with MCC would prioritize physiological needs, like symptom management, over other care domains.

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 for deceased Medicare beneficiaries aged ≥ 65 .¹⁵ Collected annually since 2011, NHATS follows a nationally representative sample of >8000 Medicare beneficiaries aged ≥ 65 .

The LMLI provides details on NHATS participants' quality of care in the last month of life using the Teno Model.¹⁶ Before the end of life, NHATS participants designate a proxy (i.e., a family member, friend, etc.) who is contacted to complete the LMLI after the participant dies. The average response rate for the LMLI is 95% in each round.¹⁶ We used NHATS for this study because it is nationally representative of Medicare beneficiaries. Demographic and chronic condition data used in this study were reported directly from the NHATS participant before 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.

All participants were aged ≥ 65 years and were Medicare beneficiaries based on NHATS inclusion criteria. As Medicare beneficiaries account for 93% of Americans aged ≥ 65 years,¹⁷⁻¹⁹ this study describes end-of-life care quality experienced by most community-dwelling older Americans with MCC.

Analysis was limited to individuals with MCC reported before the end of life. Annually, NHATS participants report the presence of heart attack, heart disease, arthritis, diabetes, lung disease, dementia, and cancer.²⁰ For this study, we defined MCC as the presence of two or more of those conditions. Our definition was informed by chronic condition literature, the Agency for Healthcare Research and Quality's chronic condition list, and the NQF MCC definition.^{4,5,20-23}

Measures

Excellent rating of *overall* care quality was this study's primary outcome. In NHATS, proxies rate *overall* end-of-life care quality on a five-point Likert scale ("excellent," "very good," "good," "fair," and "poor").¹⁶ 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." This reclassification approach mirrors that used by Teno et al.¹ in analysis of NHATS, LMLI data.

The aim's independent variables were positive perception of care in the Teno Model's *composite quality domains*, which were informed by different *components*, as described in Table 1. We dichotomized the perception of each *composite quality domain* into "positive" or "not positive." This

TABLE 1. CONCEPTUAL MODEL OF END-OF-LIFE COMPOSITE QUALITY DOMAINS AND INDIVIDUAL COMPONENTS

<i>Composite quality domain</i>	<i>Individual components</i>
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
Respect	Respect Personal care
Spiritual and emotional support	Anxiety and sadness Religious and spiritual needs

reclassification approach mirrors that used by Teno et al.¹ in analysis of NHATS, LMLI data for all community-dwelling older adults, and was defined in consultation with Joan Teno before analysis commenced. 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 to participants who had a need, and whose proxy rated care, for that *composite quality domain*. This approach ensured proxies did not provide ratings for care that a dying individual appropriately did not receive in the last month of life because they did not have a need for that care. For this reason, descriptive analyses examined the entire study sample, while bivariate analyses and multivariable models included only those who had need, and whose proxy rated care, for that *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 perception of care for *composite quality domains*. Next, multiple logistic regression compared ratings of *overall* care quality for older adults whose proxy perceived care as “positive,” compared with those whose proxy perceived care as “not positive.” We ran multiple logistic regression models for each *composite quality domain*, 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 the 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, whereas 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.²⁴ A *p*-value of ≤ 0.05 was considered statistically significant for all analyses. We examined missing data before 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. This study was deemed exempt by an organizational Institutional Review Board.

Results

Descriptive statistics

LMLIs were available for 1223 of 8245 (14.8%) NHATS participants in Rounds 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 ($n=4$; 0.6%); 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 2). The sample was mostly aged 65–84 years (60%), White (77%), not enrolled in Medicaid (80%), and individuals who died at home (44%) or in a hospital (33%). Most proxies were female (75%) and children of the deceased NHATS participants (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 2 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 ($p=0.007$), hospice enrollment ($p=0.04$), and spousal proxies ($p=0.03$). Table 3 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

TABLE 2. WEIGHTED DISTRIBUTION OF UNADJUSTED PROPORTIONS FOR COVARIATES ACCORDING TO OVERALL RATING OF END-OF-LIFE CARE QUALITY ($N_R=477$; $N_W=1,123,887$)

Demographic characteristics	Total sample		Rating of overall care quality		p
	Raw frequency (N=477)	Weight %	Not excellent ($N_R=232$; $N_W=544,929$), frequency (%)	Excellent ($N_R=245$; $N_W=578,958$), frequency (%)	
Age					0.11
65–84	233	60	349,495 (64)	322,363 (56)	
85+	244	40	195,433 (36)	256,595 (44)	
Gender					0.10
Male	213	48	233,165 (43)	303,430 (52)	
Female	264	52	311,764 (57)	275,528 (48)	
White race					0.18
No	176	23	142,578 (26)	116,335 (20)	
Yes	301	77	402,351 (74)	462,623 (80)	
Census region					0.49
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					0.24
No	363	80	419,433 (77)	478,033 (83)	
Yes	114	20	125,496 (23)	100,925 (17)	
Marital status at death					0.007
Not married	306	58	356,350 (65)	290,594 (50)	
Married	171	42	188,579 (35)	288,363 (50)	
Dementia reported					0.38
No	334	76	402,155 (74)	452,247 (78)	
Yes	143	24	142,774 (26)	126,711 (22)	
Cancer reported					0.51
No	267	52	296,789 (55)	292,444 (51)	
Yes	210	48	248,140 (46)	286,514 (50)	

Care and proxy characteristics	Total sample		Rating of overall care quality		p
	Raw frequency (N=477)	Weight %	Not excellent ($N_R=232$; $N_W=544,929$), frequency (%)	Excellent ($N_R=245$; $N_W=578,958$), frequency (%)	
Hospice enrollment					0.04
No	213	43	261,193 (48)	218,662 (38)	
Yes	264	57	283,736 (52)	360,296 (62)	
Place of death					0.06
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					0.03
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					0.41
Male	118	25	124,579 (23)	155,882 (27)	
Female	359	75	420,350 (77)	423,076 (73)	

N_R =raw N; N_W =weighted N.

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 (odds ratio [OR] 1.88; 95% confidence interval [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 0.55; 95% CI: 0.034–0.88).

The proportion of MCC proxies who reported care as “not positive” varied by composite quality domain: coordination (14%), symptom management (27%), shared decision making (21%), respect (25%), and spiritual and emotional support

TABLE 3. ADJUSTED ODDS RATIOS AND 95% CONFIDENCE INTERVALS FOR THE RELATIONSHIPS BETWEEN COVARIATES AND RATING OF OVERALL CARE QUALITY AND BETWEEN COVARIATES AND EACH COMPOSITE QUALITY DOMAIN

	<i>Rating of overall care quality</i>	<i>Coordination</i>	<i>Symptom management</i>	<i>Shared decision making</i>	<i>Respect</i>	<i>Spiritual and emotional support</i>
<i>Demographic factors</i>	(N _R = 477; N _W = 1,123,887) AOR [95% CI]	(N _R = 456; N _W = 1,075,769) AOR [95% CI]	(N _R = 369; N _W = 902,374) AOR [95% CI]	(N _R = 460; N _W = 1,081,297) AOR [95% CI]	(N _R = 466; N _W = 1,099,239) AOR [95% CI]	(N _R = 393; N _W = 954,954) AOR [95% CI]
Age						
65-84	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 [0.99-3.27]	1.22 [0.71-2.08]	1.59 [0.93-2.73]	1.44 [0.90-2.32]	0.59* [0.37-0.95]
Gender						
Male	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Female	0.74 [0.43-1.29]	1.38 [0.60-3.15]	1.15 [0.61-2.17]	1.32 [0.70-2.51]	0.80 [0.46-1.40]	1.00 [0.52-1.92]
White race						
No	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Yes	1.2 [0.65-2.22]	0.49 [0.22-1.10]	0.96 [0.47-1.97]	1.05 [0.59-1.89]	0.94 [0.50-1.76]	0.69 [0.36-1.30]
Census region						
Northeast	1.00 [Ref.]	Not in model	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Midwest	1.15 [0.56-2.33]	—	1.93 [0.80-4.65]	1.57 [0.77-3.20]	1.25 [0.60-2.58]	2.66* [1.21-5.86]
South	0.83 [0.40-1.71]	—	1.49 [0.59-3.72]	1.48 [0.74-2.97]	0.83 [0.40-1.70]	1.13 [0.49-2.61]
West	0.85 [0.45-1.60]	—	1.19 [0.52-2.72]	2.30 [0.94-5.61]	0.75 [0.38-1.50]	1.93 [0.89-4.21]
Medicaid						
No	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Yes	1.09 [0.56-2.13]	1.16 [0.52-2.61]	0.66 [0.34-1.26]	0.57 [0.27-1.18]	0.81 [0.38-1.73]	0.64 [0.31-1.31]
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 [0.82-3.61]	1.67 [0.51-5.45]	2.13 [0.68-6.61]	2.63* [1.06-6.55]	2.15 [0.88-5.26]	1.55 [0.63-3.82]

(continued)

TABLE 3. (CONTINUED)

	<i>Rating of overall care quality</i>	<i>Coordination</i>	<i>Symptom management</i>	<i>Shared decision making</i>	<i>Respect</i>	<i>Spiritual and emotional support</i>
<i>Care and proxy factors</i>	(<i>N_R</i> = 477; <i>N_W</i> = 1,123,887) <i>AOR [95% CI]</i>	(<i>N_R</i> = 456; <i>N_W</i> = 1,075,769) <i>AOR [95% CI]</i>	(<i>N_R</i> = 369; <i>N_W</i> = 902,374) <i>AOR [95% CI]</i>	(<i>N_R</i> = 460; <i>N_W</i> = 1,081,297) <i>AOR [95% CI]</i>	(<i>N_R</i> = 466; <i>N_W</i> = 1,099,239) <i>AOR [95% CI]</i>	(<i>N_R</i> = 393; <i>N_W</i> = 954,954) <i>AOR [95% CI]</i>
Dementia reported						
No	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Yes	0.82 [0.46–1.47]	1.73 [0.75–4.00]	1.05 [0.56–1.98]	0.65 [0.36–1.20]	1.42 [0.81–2.50]	0.87 [0.48–1.57]
Cancer reported						
No	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Yes	1.02 [0.60–1.73]	1.27 [0.65–2.48]	0.52* [0.30–0.91]	0.47* [0.24–0.94]	0.87 [0.54–1.42]	0.73 [0.42–1.26]
Hospice enrollment						
No	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Yes	1.49 [0.94–2.36]	0.66 [0.25–1.71]	1.26 [0.70–2.29]	1.82 [0.95–3.50]	0.92 [0.53–1.61]	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	0.71 [0.40–1.27]	0.39 [0.14–1.10]	0.97 [0.43–2.16]	0.80 [0.39–1.63]	0.69 [0.38–1.25]	0.86 [0.47–1.58]
Other	0.55* [0.34–0.88]	0.31* [0.11–0.90]	1.24 [0.62–2.46]	0.31* [0.14–0.68]	0.54 [0.29–1.00]	0.82 [0.42–1.59]
Proxy relationship						
Spouse	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Child	0.92 [0.42–2.04]	0.85 [0.32–2.25]	1.06 [0.33–3.36]	3.89* [1.62–9.33]	1.64 [0.59–4.58]	1.76 [0.69–4.46]
Other	0.76 [0.30–1.94]	1.41 [0.37–5.35]	1.34 [0.33–5.48]	3.67* [1.13–11.86]	1.48 [0.44–4.99]	1.20 [0.39–3.64]
Proxy gender						
Male	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]	1.00 [Ref.]
Female	0.68 [0.41–1.13]	1.30 [0.61–2.78]	0.66 [0.34–1.29]	1.00 [0.50–2.03]	1.21 [0.69–2.15]	0.98 [0.53–1.82]

*OR significant at $p < 0.05$.AOR, adjusted odds ratio; *N_R* raw *N*; *N_W* = weighted *N*.

(68%). Table 3 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 0.31; 95% CI: 0.11–0.90). Perception of the symptom management *composite quality domain* was significantly negatively associated with the report of cancer (OR 0.52; 95% CI: 0.30–0.91). 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 0.47; 95% CI: 0.24–0.94) and dying in a location other than hospital or home (OR 0.31; 95% CI: 0.14–0.68). 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 0.59; 95% CI: 0.37–0.95).

Relationship between composite quality domains and the rating of overall end-of-life care quality

Table 4 describes the distribution of the rating of *overall* end-of-life care quality according to the perception of care for each *composite quality domain*. A significantly greater proportion of MCC proxies who perceived the coordination *composite quality domain* positively also rated *overall* care quality as “excellent” compared with those who perceived the domain negatively (56% vs. 24%; $p < 0.001$). Significant

positive associations were also present between the rating of *overall* care quality and the perception of care for the following *composite quality domains*: shared decision making (56% vs. 37%; $p = 0.01$); respect (62% vs. 21%; $p < 0.001$); and spiritual and emotional support (63% vs. 46%; $p = 0.006$).

Table 5 reports the unadjusted and multivariable relationships between the perception of care in each *composite quality domain* and the rating of *overall* care quality. Models included all covariates. After adjusting for covariates, the rating of *overall* care quality was significantly positively associated with the perception of care in four *composite quality domains*: coordination (OR 4.49; 95% CI: 1.85–10.86); shared decision making (OR 1.97; 95% CI: 1.12–3.47); respect (OR 6.36; 95% CI: 3.23–12.52); and spiritual and emotional support (OR 2.02; 95% CI: 1.23–3.30).

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: coordination, symptom management, shared decision making, respect, and spiritual and emotional support.³ 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-

TABLE 4. WEIGHTED DISTRIBUTION OF RATING OF OVERALL END-OF-LIFE CARE QUALITY ACCORDING TO THE PERCEPTION OF CARE FOR EACH COMPOSITE QUALITY DOMAIN FOR THOSE WITH A NEED WHO RATED CARE

Perception ($N_R = 477$; $N_W = 1,123,887$)	Not excellent ($N_R = 232$; $N_W = 544,929$)		Excellent ($N_R = 245$; $N_W = 578,958$)		p
	Weighted frequency	% [95% CI]	Weighted frequency	% [95% CI]	
Coordination ($N_R = 456$; $N_W = 1,075,769$)					<0.001
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 ($N_R = 369$; $N_W = 902,374$)					0.10
Not positive	143,355	58 [47–69]	102,686	42 [31–53]	
Positive	305,020	47 [40–53]	351,312	54 [47–60]	
Shared decision making ($N_R = 460$; $N_W = 1,081,297$)					0.01
Not positive	143,882	63 [49–75]	85,662	37 [25–51]	
Positive	379,223	45 [39–50]	472,530	56 [50–61]	
Respect ($N_R = 466$; $N_W = 1,099,239$)					<0.001
Not positive	213,224	79 [69–87]	56,310	21 [13–31]	
Positive	313,429	38 [32–44]	516,276	62 [56–68]	
Spiritual and emotional support ($N_R = 393$; $N_W = 954,954$)					0.006
Not positive	349,837	54 [48–61]	296,838	46 [39–53]	
Positive	114,221	37 [28–48]	194,058	63 [52–73]	

N_R = raw N; N_W = weighted N.

TABLE 5. UNADJUSTED AND MULTIVARIABLE ODDS RATIOS AND 95% CONFIDENCE INTERVALS OF THE RELATIONSHIP BETWEEN “POSITIVE” PERCEPTION OF EACH COMPOSITE QUALITY DOMAIN AND “EXCELLENT” RATING OF OVERALL CARE QUALITY

	Cases			Unadjusted OR		Adjusted OR	
	Raw freq. (N=477)	Weighted freq. (N=1,123,887)	Percentage (N)	OR	95% CI	OR	95% CI
Coordination	456	1,075,769	96	4.08*	1.82–9.13	4.49*	1.85–10.86
Symptom management	369	902,374	80	1.61	0.90–2.86	1.49	0.81–2.71
Shared decision making	460	1,081,297	96	2.09*	1.21–3.63	1.97*	1.12–3.47
Respect	466	1,099,239	98	6.24*	3.26–11.93	6.36*	3.23–12.52
Spiritual and emotional support	393	954,954	85	2.00*	1.24–3.23	2.02*	1.23–3.30

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.

*OR significant at $p < 0.05$ level.

CI, confidence interval; OR, odds ratio.

life care quality for older adults with MCC. Findings further demonstrate the importance of proxy perceived respect, care coordination, spiritual and emotional support, and shared decision making.

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 and Maslow’s hierarchy of needs informing our hypothesis. We found no relationship between MCC proxies’ perception of symptom management and their *overall* end-of-life care quality rating. Our results may indicate that Maslow’s hierarchy may apply differently at the end of life, as findings suggest that dying older adults with MCC may prioritize psychosocial over physiological needs.

We found significant associations between the *overall* end-of-life care quality rating and every other 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. Associations observed 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 that dying older adults with MCC may share similar views as identified by participants in the Teno Model’s foundational study,³ which also indicates that 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 the core function of health care; 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. An examination of end-of-care quality ratings by parents of children who died of cancer found a similar lack of relationship between symptom management and end-of-life care quality ratings, which was similarly attributed to parental expectations of

pain and suffering at the end of life.²⁵ 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. Similarly, being kept informed was positively associated with high ratings of end-of-life care quality in parents of children dying of cancer.²⁵

Current literature offers little detail on caregivers’ expectations of the dying process and how that may impact their perception of care. Historically, studies link expectations for care with satisfaction ratings,^{26–28} but more recent analysis suggests that the relationship between expectation and satisfaction may be more complicated than that previously identified.²⁹ 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.

Limitations

Limitations of the NHATS, LMLI related to its survey items and reliance on proxy rather than direct report limit the generalizability of our findings. This study used NHATS, LMLI data from Rounds 3 to 5 due to differences in each round’s survey items. However, we found no significant differences in participants across rounds, suggesting that results may have been similar if more rounds were included. Despite these concerns, the NHATS, LMLI is the best source for answering our research questions, given it is nationally representative and spans multiple end-of-life care settings.

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. 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.³⁰ Future research could benefit from more innovative approaches for assessing end-of-life care quality that do not rely on proxy report, such as the use of electronic health records, Medicare claims data, or asking the dying individuals directly about their care experiences.

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 aspects of end-of-life care. The domains most associated with high-quality end-of-life care for older adults with MCC were coordination, shared decision making, respect, and spiritual and emotional support. Increased attention is needed to strengthen these aspects of care for older adults with MCC at the end of life. Symptom management was unrelated to the proxy rating of *overall* end-of-life care quality.

Our findings suggest that end-of-life care providers should consider nonsymptomatic domains provided in the Teno Model in addition to symptom management when providing end-of-life care, particularly respect and shared decision making. Enhancing palliative care may be one approach for addressing dying individuals' care coordination, shared decision making, respect, and spiritual and emotional support needs while also attending to their symptoms.

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Author Disclosure Statement

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Address correspondence to:
Gayle Kricke, MSW, PhD
Division of Quality
Northwestern Memorial HealthCare
211 E. Ontario, Suite 1550
Chicago, IL 60611

E-mail: gayle.kricke@nm.org