How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways

Kristin Litzelman, Erin E. Kent, Michelle Mollica, and Julia H. Rowland

ABSTRACT

Purpose

Perceived quality of care (QOC) is an increasingly important metric of care quality and can be affected by such factors among patients with cancer as quality of life and physician trust. This study sought to evaluate whether informal caregiver well-being was also associated with perceived QOC among patients with cancer and assessed potential pathways that link these factors.

Methods

This study used data from the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium. Patients with lung and colorectal cancer enrolled in CanCORS (N = 689) nominated an informal caregiver to participate in a caregiving survey. Both groups self-reported sociodemographic, psychosocial, and caregiving characteristics; cancer characteristics were obtained from the CanCORS core data set. Multivariable logistic regression was used to assess the association between caregiver psychosocial factors and subsequent patient-perceived QOC, controlling for earlier patient-perceived QOC and covariates. Secondary analysis examined potential pathways that link these factors.

Results

Patients whose informal caregiver had higher levels of depressive symptoms were significantly more likely to report fair or poor QOC (odds ratio, 1.06; 95% CI, 1.01 to 1.13). When caregivers reported fair or poor self-rated health, patients were more than three times more likely to report fair or poor perceived QOC (odds ratio, 3.76; 95% CI, 1.76 to 9.55). Controlling for patient psychosocial factors and physician communication and coordination of medical care reduced the effect size and/or statistical significance of these relationships.

Conclusion

Informal caregivers are an important part of the care team and their well-being is associated with patient-perceived QOC. Engaging informal cancer caregivers as part of the care team and conducting ongoing risk stratification screening and intervention to optimize their health may improve patient-reported outcomes and QOC.

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INTRODUCTION

Patient-reported experiences with care are an increasingly important quality metric in the health care setting. Not only is patient experience a component of care quality¹ and a key patient-reported outcome,² it is also increasingly used in pay for performance metrics^{3,4} and Medicare reimbursement rate determinations.⁵ Previous research suggests that 40% to 60% of patients with cancer report excellent quality of care.^{6,7} Predictors of less-than-excellent perceived quality of

care among survivors of cancer include poor psychosocial factors—that is, quality of life—unmet treatment needs, and low physician trust⁶⁻⁸; qualitative work also highlights the importance of patient-provider communication in perceived quality of care.⁹

One key factor that has not been explored in relation to perceived quality of care is the role of informal caregiving. Informal caregivers—family members or friends who provide unpaid care—play a critical role in supporting and caring for patients with cancer.¹⁰⁻¹³ This includes not only provision of emotional, financial, and functional

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support, but also, increasingly, active involvement in home medical treatments, patient appointments, and care coordination.^{14,15} Caregivers make up an important part of the care team, with approximately 60% providing medical and/or nursing tasks in the home.¹⁵ Recent research and theory have also shown that caregiver and patient well-being are intertwined,¹⁶⁻²² which further highlights the importance of this role; therefore, caregiver well-being may also be related to patient clinical outcomes, such as perceived quality of care. This has not yet been examined empirically.

To address this gap, the current study examined the association of family caregiver depressive symptoms and self-rated health with the perception of medical care quality by patients with cancer. In exploratory secondary analyses, we also evaluated the effect of controlling for several confounders that may potentially link caregiver well-being and patient outcomes, including patient health-related quality of life (previously associated with perceived quality of care⁷ and caregiver well-being¹⁸), patients' report of communication with their physician and coordination of care (previously associated with perceived quality of care^{6,9} and which we theorize may be influenced by caregiver participation in patient appointments and care coordination), and the number of medical and/or nursing tasks in which caregivers engage. We hypothesized that more depressive symptoms and worse self-rated health in the caregiver would be associated with worse patient perceptions of quality of care.

METHODS

This study used data collected by the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium between 2003 and 2006.²³⁻²⁵ In brief, the CanCORS consortium consisted of seven study sites that ascertained newly diagnosed patients with lung and colorectal cancer. The resulting sample was demographically representative within the CanCORS regions.²⁶ Patients completed baseline and follow-up surveys administered approximately 4 months after diagnosis and approximately 11 to 13 months after diagnosis, respectively. This study also used survey data from informal caregivers who were identified after the patients' baseline survey. Caregivers were nominated by patients with cancer in the core CanCORS survey and were contacted for participation via mail, which included a self-administered questionnaire, information about the study, a postage-paid return envelope, and a \$20 incentive. Caregiver data were collected approximately 5 to 6 months after the patient's diagnosis. The study was approved by the institutional review boards of each study site, and full informed consent was obtained from all participants. The current study is a secondary analysis of these data.

Measures

Dependent variable: patient-perceived quality of care. Patients were asked to report "Overall, how would you rate the quality of your health care since your [cancer] diagnosis?" Responses were recorded on a 5-point Likert scale and dichotomized to fair/poor versus excellent/very good/good quality of care, hereafter referred to as poor versus good. Although more robust, validated measures of perceived quality of care exist, single-item assessments have been used previously.^{6,8,27} The dependent variable was measured at the follow-up survey.

Independent variables: caregiver psychosocial characteristics. Caregiver symptoms of depression were assessed by using the 10-item version of the Center for Epidemiologic Studies Depression scale (CESD).^{28,29} Caregivers reported how often during the past 4 weeks they experienced each of 10 items, for example, "felt depressed" and "could not get going," on a 4-point Likert scale: rarely or none of the time to most or all of the time. Item responses were summed (range, 0 to 30), with higher scores indicating

more depressive symptoms. The CESD-10 has good test-retest reliability (0.71).²⁹ Caregivers also reported their overall self-rated health on a 5-point Likert scale. As a result of category size, caregivers were then categorized as having excellent/very good, good, or fair/poor self-rated health.

Confounders. At baseline and follow-up surveys, patients reported on their depressed mood by using an eight-item version of the CESD coded as yes (1) versus no (0) that was summed to give a score that ranged from 0 to 8 (higher scores indicated more depressive symptoms), as well as on their health-related quality of life (HRQoL) by using the Short-Form 12³⁰ (Mental Component Score [MCS] and Physical Component Score [PCS]; higher scores indicated better health). Patients also responded at baseline and follow-up to 11 questions adapted from the Consumer Assessment of Healthcare Providers and Systems survey³¹ that assessed their perceptions of physician communication (five items) and coordination of care (six items) during their cancer treatment (scored on a 4-point Likert scale: always [1] to never [4]; summed scores were converted to a 100-point scale, with 0 representing the worse possible care and 100 representing optimal care, as published previously³²). Finally, caregivers reported whether they participated in each of eight medical and/or nursing tasks: administering medication, making decisions about whether the patient needed a medication, keeping track of or watching for adverse effects, helping manage or control the patient's symptoms, changing bandages, providing lung treatments, deciding when to call a doctor, and accompanying the patient to appointments. The total number of tasks was summed.

Covariates. Patient-perceived quality of care, measured as above, was assessed at the baseline survey and included as a covariate. Patient sociodemographic characteristics were also assessed, including age (≤ 54 , 55 to 64, 65 to 74, or ≥ 75 years), sex, race (white non-Hispanic v other), region of the United States (Midwest, South, or West), income ($< \$20,000$, $\$20,000$ to $\$40,000$, $\$40,000$ to $\$60,000$, or $> \$60,000$), education (high school or less v some college or more), marital status (married or partnered v divorced, widowed, separated, or never married), employment status at the follow-up interview (no v yes), and insurance status (any public v private only; seven individuals without health insurance were collapsed into the any public group).

Cancer characteristics. Type of cancer (lung v colorectal), stage at diagnosis (0 to I, II to III, or IV to V), and time since diagnosis at the follow-up survey (days) were obtained from CanCORS core data. Patients self-reported the type(s) of treatment they had received by the time of the survey (surgery, radiation, and/or chemotherapy).

Caregiver sociodemographic characteristics. Informal caregivers also reported their sociodemographic characteristics, including age (20 to 50, 51 to 60, 61 to 70, or ≥ 71 years), sex, race/ethnicity (white-non-Hispanic v other), household income (categorized into quartiles), education status (high school or less v some college or trade school or more), employment status (does not work for pay, < 35 hours/week, ≥ 35 hours/week), and marital status (married or partnered v divorced, widowed, separated, or never married) in the questionnaire.

Caregiving characteristics. Amount of care provided to the care recipient (one half or less than one half, most, all or almost all), relationship to the patient with cancer (spouse or partner, child, parent or sibling, or other), coresidence with the patient (yes or no), hours per week of care provided, and number of household tasks for which help was provided, including basic or instrumental activities of daily living, were collected in the caregiver questionnaire.

Of 825 baseline informal caregivers identified by CanCORS, 689 (83.5%) had complete information on the dependent variable (patient's perceived quality of care) and were therefore eligible for this study. Missing data on other covariates were dealt with by using multiple imputation as described below. Covariate missing data ranged from 0% to 19%, with the exception of patient income, with 45% missing responses.

Statistical Analyses

All analyses were conducted by using R (v3.2.4; The R Foundation, Vienna, Austria). Multiple imputation with predictive mean matching and a donor-sampling weight of 0.2 were used to predict values of

Table 1. Characteristics of Survivors of Lung and Colorectal Cancer and Their Caregivers in the Cancer Care Outcomes Research and Surveillance Study (2003 to 2006; N = 689)

Characteristic	Total Sample	Excellent, Very Good, or Good Perceived Quality of Care*	Fair or Poor Perceived Quality of Care*	P
Fair/poor perceived quality of care, No. (%)				
Baseline (nonmissing, n = 646)	23 (3.56)			
Follow-up (nonmissing, n = 689)	41 (5.95)			
Caregiver depressive symptoms, No. (mean ± SD)	672 (8.60 ± 5.78)	633 (8.45 ± 5.70)	39 (11.06 ± 6.62)	.01
Caregiver self-rated health, No.	681	641	40	< .001
Excellent/very good, %	43.61	44.62	27.50	
Good, %	34.80	35.10	30.00	
Fair/poor, %	21.59	20.28	42.50	
Patient characteristics				
Patient age, years, No.	689	648	41	.82
0 to 54, %	13.93	14.20	9.76	
55 to 64, %	31.35	31.02	36.59	
65 to 74, %	32.22	32.25	31.71	
≥ 75, %	22.50	22.53	21.95	
Patient sex, No.	689	648	41	.89
Male, %	68.07	68.21	65.85	
Female, %	31.93	31.79	34.15	
Patient race, No.	689	648	41	.80
Other, %	23.95	23.77	26.83	
White (non-Hispanic), %	76.05	76.23	73.17	
Region, No.	689	648	41	.64
Midwest, %	17.85	17.59	21.95	
South, %	60.23	60.19	60.98	
West, %	21.92	22.22	17.07	
Income, USD, No.	558	528	30	.22
< 20,000, %	31.72	31.06	43.33	
20,000 to 40,000, %	36.02	36.74	23.33	
40,000 to 60,000, %	16.31	15.91	23.33	
> 60,000, %	15.95	16.29	10.00	
Education, No.	648	611	37	.21
High school or less, %	53.55	49.85	58.54	
Some college or more, %	46.45	44.44	31.71	
Marital status, No.	600	566	34	.81
Divorced, widowed, separated, never married, %	32.00	27.78	29.27	
Married or partnered, %	68.00	59.57	53.66	
Employment status at follow-up, No.	590	560	30	.32
No, %	77.63	66.67	63.41	
Yes, %	22.37	19.75	9.76	
Insurance status, No.	636	599	37	.59
Any public, [†] %	76.10	70.06	73.17	
Private only, %	23.90	22.38	17.07	
Cancer characteristics				
Type of cancer, No.	689	648	41	.03
Lung, %	51.09	50.00	68.29	
Colorectal, %	48.91	50.00	31.71	
Stage at diagnosis, No.	689	648	41	.04
0 to I, %	32.08	31.17	46.34	
II to III, %	48.04	49.23	29.27	
IV to V, %	19.88	19.60	24.39	
Time since diagnosis at follow-up survey, days, No. (mean ± SD)	689 (387 ± 58)	648 (387 ± 59)	41 (383 ± 56)	.48
Treatment received (not mutually exclusive), No.	648	611	37	.08
Surgery, %	29.32	28.48	43.24	
Radiation therapy, %	72.07	71.69	78.38	
Chemotherapy, %	36.27	36.17	37.84	
Caregiver sociodemographic characteristics				
Age, years, No.	669	630	39	.12
20 to 50, %	26.91	26.83	28.21	
51 to 60, %	28.40	27.46	43.59	
61 to 70, %	24.36	24.92	15.38	
≥ 71, %	20.33	20.79	12.82	

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Table 1. Characteristics of Survivors of Lung and Colorectal Cancer and Their Caregivers in the Cancer Care Outcomes Research and Surveillance Study (2003 to 2006; N = 689) (continued)

Characteristic	Total Sample	Excellent, Very Good, or Good Perceived Quality of Care*	Fair or Poor Perceived Quality of Care*	P
Sex, No.	671	632	39	.78
Male, %	21.01	20.68	17.07	
Female, %	78.99	76.85	78.05	
Race/ethnicity, No.	689	648	41	.33
Other, %	28.74	28.24	36.59	
White (non-Hispanic), %	71.26	71.76	63.41	
Income, USD, No.	378	353	25	.08
< 12,000, %	29.10	16.83	10.26	
12,000 to 26,999, %	26.98	14.29	30.77	
27,000 to 47,999, %	24.07	13.49	15.38	
≥ 48,000, %	19.84	11.43	7.69	
Education, No.	679	640	39	.59
High school or less, %	40.80	39.97	43.90	
Some college or more, %	59.20	58.80	51.22	
Marital status, No.	675	636	39	.49
Divorced, widowed, separated, never married, %	18.22	18.21	12.20	
Married or partnered, %	81.78	79.94	82.93	
Employment status, No.	646	607	39	.68
Does not work for money, %	50.31	50.74	43.59	
Works for money, < 35 h/wk, %	15.33	15.16	17.95	
Works for money, 35+ h/wk, %	34.37	34.10	38.46	
Caregiving characteristics				
Amount of care provided, No.	655	614	41	< .001
Half or less than half, %	22.75	21.34	43.90	
Most, %	22.60	22.80	19.51	
All or almost all, %	54.66	55.86	36.59	
Relationship to patient, No.	687	646	41	.75
Spouse/partner, %	62.15	62.54	56.10	
Child, %	14.70	14.40	19.51	
Parent, %	15.43	15.48	14.63	
Other, %	7.71	7.59	9.76	
Live with patient, No.	686	645	41	.02
No, %	28.86	29.15	46.34	
Yes, %	71.14	75.90	53.66	
Hours per week, No.	641	602	39	.38
≤ 1, %	20.59	19.35	17.07	
1 to 10, %	27.61	25.08	36.59	
11 to 35, %	29.64	28.17	19.51	
> 35, %	22.15	20.59	21.95	
Caregiving tasks, No. (mean ± SD)	689 (4.54 ± 3.77)	648 (4.50 ± 3.78)	41 (5.10 ± 3.62)	.23

NOTE. Descriptive statistics were calculated in the unimputed data; for each characteristic, No. refers to the total N of nonmissing data points on which the descriptive statistics are calculated.

Abbreviations: SD, standard deviation; USD, US dollars.

*At follow-up.

†Includes a small number of individuals who reported having no insurance.

missing data (Harrell's aregimpute³³⁻³⁵); five imputations were conducted. All multivariable analyses were conducted by using the imputed data sets. Estimates and standard errors were combined by using Rubin's rules.³⁶

All variables were examined by using descriptive statistics in the original unimputed data³⁷; values were nearly identical to those calculated by using imputed data. Those with good perceived quality of care were compared with those with poor quality of care by using χ^2 and Kruskal-Wallis tests. Multivariable logistic regressions were used to assess the association between each caregiver health factor—depressive symptoms and self-rated health—and patient-perceived quality of care in the imputed data. Models controlled for perceived quality of care at baseline, as well as sociodemographic, cancer, and caregiving characteristics. Only those characteristics significantly or borderline associated with outcome in bivariable regressions ($P < .10$) were included as control variables. A sensitivity analysis controlling for all caregiver sociodemographics, cancer characteristics, caregiving characteristics,

and patient age and sex produced consistent results (Appendix Tables A1 and A2, online only).

Secondary analyses added three blocks of additional confounders to the models: patient psychosocial factors, patient assessment of communication and care coordination, and caregiver medical and/or nursing tasks. Attenuation of the regression coefficient and CI of the key independent variable—depressive symptoms or self-rated health—were examined. Formal mediation tests were not conducted as a result of the exploratory nature of these secondary analyses.

In a complementary analysis, we also evaluated mental and physical HRQoL, measured by using the MCS and PCS of the Short Form-12,³⁰ as independent variables (Appendix Tables A3 and A4, online only). In a sensitivity analysis, we also added depressive symptoms to the regression for self-rated health. Finally, to understand whether the observed effects were consistent for those with and without clinically significant levels of depressive symptoms, we reran the analyses stratifying by CESD scores of ≥ 10 (clinically significant) versus < 10 .²⁹

RESULTS

Table 1 depicts the characteristics of patients and caregivers. The majority of patients were older (age > 65 year) and male. Most (76%) were white non-Hispanic, had an income below \$40,000 per year (68%), and were married or partnered (68%), unemployed or retired (78%), and on public insurance (76%). Type of cancer was evenly distributed among patients (51% lung and 49% colorectal) and nearly one half had been diagnosed at stage II or III.

Informal caregivers, by contrast, varied in age: more than one quarter were between age 20 and 50 years, and 20% were age > 70 years. Most caregivers were female (80%), white non-Hispanic (70%), married or partnered (80%), and unemployed (> 50%). Caregiver incomes were low, with 29% making less than \$12,000 per year. More than one half of caregivers provided nearly all patient care (55%), were the patient's spouse or partner (62%), lived with the patient (70%), and provided > 10 hours of care per week (> 50%).

Approximately 6% of patients reported fair/poor perceived quality of care at follow-up. Type of cancer, stage at diagnosis, surgical cancer treatment, caregiver income, amount of care provided, and patient-caregiver coresidence differed for patients who reported good versus poor quality of care ($P < .10$).

Tables 2 and 3 show the results of the staged multivariable regressions.

Caregiver Depressive Symptoms

Higher caregiver depressive symptoms was associated with an increased likelihood that patients would report poor quality of care (odds ratio [OR], 1.06; 95% CI, 1.01 to 1.13; **Table 2**). For each 1-point increase in caregiver depressive symptoms, patients were

6% more likely to report poor quality of care. For example, patients of caregivers who reported “moderately” to all items in the CESD would be 85% more likely to report fair/poor quality of care than patients of caregivers who reported “some/a little” to all items. Controlling for patient psychosocial factors—depressive symptoms, MCS, and PCS—decreased the effect size of this association. Controlling for assessment of care—physician communication and coordination of care—reduced the statistical significance (95% CI crossed 1.00). When we stratified by levels of caregiver depressive symptoms, the association between depressive symptoms and patient-perceived quality of care held among those with clinically significant levels of depressive symptoms (OR, 1.13; 95% CI, 1.02 to 1.28), but not in those with lower levels of depressive symptoms (OR, 0.91; 95% CI, 0.75 to 1.11; Appendix **Table A5**, online only).

Caregiver Self-Rated Health

When caregivers reported fair/poor self-rated health, patients were almost four times more likely to report poor quality of care (OR, 3.76; 95% CI, 1.76 to 9.55; **Table 3**). This association was considerably attenuated, but still statistically significant, after controlling for patient psychosocial factors (OR, 2.85; 95% CI, 1.39 to 8.42) and physician communication and coordination of care (OR, 3.10; 95% CI, 1.18 to 9.43), and was somewhat attenuated after controlling for caregiver medical and/or nursing tasks (OR, 3.54; 95% CI, 1.65 to 9.06). These associations were robust to controlling for depressive symptoms. When we stratified by levels of caregiver depressive symptoms, the association between self-rated health and patient-perceived quality of care held among those with clinically significant levels of depressive symptoms (OR, 4.84, 95% CI, 1.38 to 25.32), but not in those with lower levels of depressive symptoms (OR, 2.40; 95% CI, 0.52 to 9.05; Appendix **Table A5**, online only).

Table 2. Associations Between Informal Caregiver Depressive Symptoms and Poor Perceived Quality of Care Among Patients With Lung and Colorectal Cancer (multivariable logistic regressions; Cancer Care Outcomes Research and Surveillance study, 2003 to 2006; N = 689)

Variable	Model*			
	1	2	3	4
Caregiver depressive symptoms	1.06 (1.01 to 1.13)	1.04 (0.99 to 1.11)	1.06 (0.99 to 1.13)	1.06 (1.00 to 1.13)
Confounders				
Patient psychosocial factors (spillover)				
Follow-up				
Depressive symptoms		1.33 (1.06 to 1.57)		
Mental HRQoL		1.00 (0.96 to 1.04)		
Physical HRQoL		0.98 (0.96 to 1.04)		
Baseline				
Depressive symptoms		0.86 (0.67 to 1.00)		
Mental HRQoL		0.96 (0.90 to 0.98)		
Physical HRQoL		0.98 (0.92 to 1.00)		
Patient assessment of care				
Follow-up				
Communication			0.96 (0.94 to 0.97)	
Coordination			0.95 (0.95 to 0.96)	
Baseline				
Communication			0.99 (0.97 to 1.02)	
Coordination			1.00 (0.98 to 1.04)	
Caregiver medical and/or nursing tasks				1.10 (0.94 to 1.29)

NOTE. Data are presented as OR (95% CI). Fair/poor perceived quality of care, 1; good/very good/excellent perceived quality of care, 0.

Abbreviations: HRQoL, health-related quality of life; OR, odds ratio.

*All models control for perceived quality of care at baseline, cancer type, stage at diagnosis, amount of caregiving provided by the caregiver, coresidence of the caregiver and survivor, caregiver income, and whether the survivor received surgery for his/her cancer.

Table 3. Associations Between Informal Caregiver Self-Rated Health and Poor Perceived Quality of Care Among Patients With Lung and Colorectal Cancer (multivariable logistic regressions; Cancer Care Outcomes Research and Surveillance study, 2003 to 2006; N = 689)

Variable	Model*			
	1	2	3	4
Caregiver self-rated health				
Excellent/very good	Ref	Ref	Ref	Ref
Good	1.50 (0.59 to 3.46)	1.25 (0.49 to 3.17)	2.24 (0.90 to 7.52)	1.46 (0.58 to 3.39)
Fair/poor	3.76 (1.76 to 9.55)	2.85 (1.39 to 8.42)	3.10 (1.18 to 9.43)	3.54 (1.65 to 9.06)
Confounders				
Patient psychosocial factors (spillover)				
Follow-up				
Depressive symptoms		1.34 (1.07 to 1.59)		
Mental HRQoL		1.00 (0.96 to 1.05)		
Physical HRQoL		0.98 (0.96 to 1.03)		
Baseline				
Depressive symptoms		0.86 (0.68 to 1.01)		
Mental HRQoL		0.96 (0.90 to 0.98)		
Physical HRQoL		0.97 (0.92 to 1.00)		
Patient assessment of care				
Follow-up				
Communication			0.96 (0.94 to 0.97)	
Coordination			0.95 (0.95 to 0.96)	
Baseline				
Communication			1.00 (0.97 to 1.03)	
Coordination			1.00 (0.97 to 1.03)	
Caregiver medical and/or nursing tasks				1.11 (0.95 to 1.30)

NOTE. Data are presented as OR (95% CI). Fair/poor perceived quality of care, 1; good/very good/excellent perceived quality of care, 0.

Abbreviations: HRQoL, health-related quality of life; OR, odds ratio; Ref, reference.

*All models control for perceived quality of care at baseline, cancer type, stage at diagnosis, amount of caregiving provided by the caregiver, coresidence of the caregiver and survivor, caregiver income, and whether the survivor received surgery for his/her cancer.

DISCUSSION

This study assessed the association between informal caregiver health factors—depressive symptoms and self-rated health—and perceived quality of care among patients with lung and colorectal cancer in a large, multisite study. Findings suggest that caregiver health and well-being are correlated with how patients with cancer perceive their care, with implications for quality metrics and provider reimbursement. Exploratory analyses showed that patient psychosocial factors, communication with clinical staff and care coordination, and/or caregivers' ability to take on medical and/or nursing tasks attenuated these relationships. Further research is needed to confirm these findings by using more robust measures of perceived quality of care and to determine whether these factors may be mediators in the pathway that links caregiver factors and patient-perceived quality of care.

To our knowledge, this was the first study to assess the association between informal caregiving and quality of care. Although patient experience and perceived quality of care have been incorporated into quality measures,^{1,38} empirical research suggests that it does not always line up with medically objective quality of care.⁶ This suggests that numerous other factors may influence perceived quality of care.

There are several potential explanations for these findings. Informal caregivers provide support to the patient, including coordination of care. Caregivers with worse mental or physical health may have diminished capacity to coordinate care, attend clinical visits, hear, understand, or recall treatment instructions, or support the patient in evaluating information and making

decisions. Evidence supports this potential pathway: in one study, communication with clinical staff was the most prevalent theme related to satisfaction and quality of care.⁹ Trust in the physician, which can be affected by a physician's ability to effectively communicate information and facilitate decision making, is also associated with better perceived quality of care.⁶ Furthermore, survivors of cancer with unmet service needs are more likely to report less-than-excellent quality of care,²⁷ which is possibly related to breakdowns in care coordination. Additional research is needed to better elucidate the role caregivers may have in successful coordination and clinical communication and may inform best practices.

Recent research into perceived quality of care among patients with cancer has reported a strong cross-sectional association between better patient quality of life and better perceived quality of care.⁷ Caregiver and patient adjustment and mental health are interrelated,¹⁶⁻²² and caregiver depression may have a tangible influence on patient outcomes. However, research has not yet reached consensus on the directionality of these associations. In particular, one study in the CanCORS population indicated that patient depressive symptoms were associated with their caregivers' mental and physical HRQoL, rather than the reverse.³⁹ Future longitudinal research is needed to elucidate whether a pathway may exist that links caregiver well-being, patient well-being, and perceived quality of care or other clinical outcomes, as well as more comprehensive measures to parse the drivers of such effects.

Patients may also take inclusion of caregivers and/or family members into account when assessing quality of care.⁴⁰ If family caregivers with depressed mood or poor self-rated health elicit less

help from the clinical care team—or, conversely, if caregivers who receive less support are more likely to become depressed or develop health issues—this may adversely impact patient reporting of their care. Although we controlled for perceived quality of care at the baseline survey, poor-quality medical care may contribute to poor caregiver outcomes.

The findings from this study, if confirmed, highlight the importance of incorporating the caregiver into the care team. Caregiver well-being can potentially exert a tangible influence on reported quality of care by patients with cancer, with possible consequences for quality metrics and any linked provider reimbursement rates. Supporting informal caregivers and facilitating their continued health could improve the care that they can provide to the patient, as well as these important quality outcomes. Involving family and friends is one of the Institute of Medicine's dimensions of quality patient-centered care.⁴¹ Future longitudinal research, including randomized controlled trials, will be critical to informing policy and provider team best practices. Emerging models of psychosocial service provision to caregivers of patients with cancer may inform whether offering comprehensive caregiver support can improve patient outcomes.⁴²

The findings of this study should be considered in light of several potential limitations. First, although this study had longitudinal data on patients with cancer (two data points), only one data point was available on caregivers. Second, patients who died before the follow-up survey were not included (potential survival bias). Third, the measure of perceived quality of care consisted of a single unvalidated item; however, CanCORS survey tools were thoroughly pilot tested.²⁴ More comprehensive and nuanced measures of perceived quality of care are needed to confirm the

findings and to better understand this relationship. Fourth, the statistical significance of the results is not robust to a Bonferroni correction; future confirmatory studies are needed. Strengths include the large, multisite population, rich longitudinal data, and the focus on caregivers for survivors of lung and colorectal cancer, two groups for whom limited survivorship research currently exists. Although the findings will need to be confirmed, these data present an initial portrait of the potential for caregiver well-being to play a role in patient perceptions in a clinically meaningful way.

In conclusion, this study found that caregiver depressive symptoms and self-rated health were associated with patients' reports of poor quality of care. Engaging informal cancer caregivers as part of the care team and conducting ongoing risk stratification screening and intervention to optimize their health may improve patient-reported outcomes and quality of care.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at www.jco.org.

AUTHOR CONTRIBUTIONS

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Data analysis and interpretation: All authors

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REFERENCES

- Centers for Medicare & Medicaid Services: 2015 National impact assessment of the Centers for Medicare & Medicaid Services (CMS) quality measures report. <https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/qualitymeasures/downloads/2015-national-impact-assessment-report.pdf>
- Tzelepis F, Sanson-Fisher RW, Hall AE, et al: Development and psychometric evaluation of the Quality of Patient-Centered Cancer Care measure with hematological cancer survivors. *Cancer* 121: 2383-2392, 2015
- Robinson JC, Shortell SM, Rittenhouse DR, et al: Quality-based payment for medical groups and individual physicians. *Inquiry* 46:172-181, 2009
- Stawiski S, Bavin S, Fulton B: Impact of patient satisfaction on pay-for-performance in medical practices. http://helpandtraining.pressganey.com/Documents_secure/Medical%20Practices/White%20Papers/Med_Practice_P4P_6-08.pdf
- Centers for Medicare & Medicaid Services: HCAHPS: Patients' perspectives of care survey. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-instruments/HospitalQualityInits/HospitalHCAHPS.html>
- Bickell NA, Neuman J, Fei K, et al: Quality of breast cancer care: Perception versus practice. *J Clin Oncol* 30:1791-1795, 2012
- Zafar SY, McNeil RB, Thomas CM, et al: Population-based assessment of cancer survivors' financial burden and quality of life: A prospective cohort study. *J Oncol Pract* 11:145-150, 2014
- John DA, Kawachi I, Lathan CS, et al: Disparities in perceived unmet need for supportive services among patients with lung cancer in the Cancer Care Outcomes Research and Surveillance Consortium. *Cancer* 120:3178-3191, 2014
- Seccareccia D, Wentlandt K, Kevork N, et al: Communication and quality of care on palliative care units: A qualitative study. *J Palliat Med* 18:758-764, 2015
- Given BA, Given CW, Sherwood PR: Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol* 10:57-64, 2012
- Levine C, Halper D, Peist A, et al: Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Aff (Millwood)* 29:116-124, 2010
- Olson RE: Is cancer care dependant on informal carers? *Aust Health Rev* 36:254-257, 2012
- Ockerby C, Livingston P, O'Connell B, et al: The role of informal caregivers during cancer patients' recovery from chemotherapy. *Scand J Caring Sci* 27:147-155, 2012
- Feinberg L, Reinhard SC, Houser A, et al: Valuing the invaluable: 2011 update—The growing contributions and costs of family caregiving. <https://assets.aarp.org/rgcenter/ppi/lc/i51-caregiving.pdf>
- National Alliance for Caregiving: Caregiving in the U.S. 2015. <http://www.caregiving.org/caregiving2015/>
- Northouse LL, Katapodi MC, Schafenacker AM, et al: The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs* 28:236-245, 2012
- Litzelman K, Yabroff KR: How are spousal depressed mood, distress, and quality of life associated with risk of depressed mood in cancer survivors? Longitudinal findings from a national sample. *Cancer Epidemiol Biomarkers Prev* 24:969-977, 2015
- Litzelman K, Green PA, Yabroff KR: Cancer and quality of life in spousal dyads: Spillover in couples with and without cancer-related health problems. *Support Care Cancer* 24:763-771, 2016
- Kershaw TS, Mood DW, Newth G, et al: Longitudinal analysis of a model to predict quality of life in prostate cancer patients and their spouses. *Ann Behav Med* 36:117-128, 2008
- Galbraith ME, Pedro LW, Jaffe AR, et al: Describing health-related outcomes for couples experiencing prostate cancer: Differences and similarities. *Oncol Nurs Forum* 35:794-801, 2008
- Ejem DB, Drentea P, Clay OJ: The effects of caregiver emotional stress on the depressive symptomatology of the care recipient. *Aging Ment Health* 19:55-62, 2014
- Segrin C, Badger TA: Psychological and physical distress are interdependent in breast cancer survivors and their partners. *Psychol Health Med* 19: 716-723, 2014
- Ayanian JZ, Chrischilles EA, Fletcher RH, et al: Understanding cancer treatment and outcomes: The Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22:2992-2996, 2004
- Malin JL, Ko C, Ayanian JZ, et al: Understanding cancer patients' experience and

outcomes: Development and pilot study of the Cancer Care Outcomes Research and Surveillance patient survey. *Support Care Cancer* 14:837-848, 2006

25. van Ryn M, Sanders S, Kahn K, et al: Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psychooncology* 20:44-52, 2010

26. Catalano PJ, Ayanian JZ, Weeks JC, et al: Representativeness of participants in the cancer care outcomes research and surveillance consortium relative to the surveillance, epidemiology, and end results program. *Med Care* 51:e9-e15, 2013

27. Weaver KE, Aziz NM, Arora NK, et al: Follow-up care experiences and perceived quality of care among long-term survivors of breast, prostate, colorectal, and gynecologic cancers. *J Oncol Pract* 10:e231-e239, 2014

28. Radloff LS: The CES-D scale: A self-report depression scale for research in the general population. *Appl Psychol Meas* 1:385-401, 1977

29. Andresen EM, Malmgren JA, Carter WB, et al: Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for

Epidemiologic Studies Depression Scale). *Am J Prev Med* 10:77-84, 1994

30. Ware J Jr, Kosinski M, Keller SD: A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 34:220-233, 1996

31. Hays RD, Shaul JA, Williams VS, et al: Psychometric properties of the CAHPS 1.0 survey measures. *Med Care* 37:MS22-MS31, 1999 (suppl 3)

32. Ayanian JZ, Zaslavsky AM, Arora NK, et al: Patients' experiences with care for lung cancer and colorectal cancer: Findings from the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 28:4154-4161, 2010

33. Harrell FE Jr: Package Hmisc. <https://cran.r-project.org/web/packages/Hmisc/Hmisc.pdf>

34. Yu L-M, Burton A, Rivero-Arias O: Evaluation of software for multiple imputation of semi-continuous data. *Stat Methods Med Res* 16:243-258, 2007

35. Horton NJ, Kleinman KP: Much ado about nothing: A comparison of missing data methods and software to fit incomplete data regression models. *Am Stat* 61:79-90, 2007

36. Rubin DB: Multiple imputation after 18+ years. *J Am Stat Assoc* 91:473-489, 1996

37. Jochen H, Herke M, Brian T, et al: Multiple imputation of missing data: A simulation study on a binary response. *Open J Stat* 3:370-378, 2013

38. Klazinga N, Fischer C, ten Asbroek A: Health services research related to performance indicators and benchmarking in Europe. *J Health Serv Res Policy* 16:38-47, 2011 (suppl 2)

39. Kim Y, van Ryn M, Jensen RE, et al: Effects of gender and depressive symptoms on quality of life among colorectal and lung cancer patients and their family caregivers. *Psychooncology* 24:95-105, 2014

40. Tzelepis F, Sanson-Fisher RW, Hall AE, et al: The quality of patient-centred care: Haematological cancer survivors' perceptions. *Psychooncology* 24:796-803, 2014

41. Institute of Medicine: Crossing the quality chasm: A new health system for the 21st century. <http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>

42. Applebaum AJ, Kulikowski JR, Breitbart W: Meaning-centered psychotherapy for cancer caregivers (MCP-C): Rationale and overview. *Palliat Support Care* 13:1631-1641, 2015

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways

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Appendix

Table A1. Association Between Informal Caregiver Depressive Symptoms and Perceived Quality of Care (poor v good) of Patients With Lung and Colorectal Cancer (CanCORS, 2003-2006; multivariable logistic regressions; N = 689), Controlling for All Caregiver Sociodemographic Characteristics, Cancer Characteristics, Caregiving Characteristics, and Patient Age and Sex

Variable	Unadjusted*	Model			
		1†	2‡	3§	4¶
Caregiver depressive symptoms	1.06 (1.01 to 1.12)	1.06 (1.00 to 1.13)	1.04 (0.99 to 1.12)	1.03 (0.94 to 1.10)	1.06 (1.00 to 1.12)
Confounders					
Patient psychosocial factors (spillover)					
Follow-up					
Depressive symptoms			1.38 (1.11 to 1.68)		
Mental HRQoL			1.00 (0.96 to 1.05)		
Physical HRQoL			0.97 (0.95 to 1.03)		
Baseline					
Depressive symptoms			0.84 (0.61 to 0.97)		
Mental HRQoL			0.95 (0.88 to 0.98)		
Physical HRQoL			0.98 (0.92 to 1.01)		
Patient assessment of care					
Follow-up					
Communication				0.95 (0.91 to 0.96)	
Coordination				0.94 (0.94 to 0.94)	
Baseline					
Communication				1.00 (0.97 to 1.04)	
Coordination				1.00 (0.96 to 1.03)	
Caregiver medical and/or nursing tasks					1.06 (0.86 to 1.27)

NOTE. Data are presented as OR (95% CI).

Abbreviations: CanCORS, Cancer Care Outcomes Research and Surveillance; HRQoL, health-related quality of life; OR, odds ratio.

*Controls only for patient-perceived quality of care at baseline.

†Model 1 controls for patient-perceived quality of care at baseline; caregiver age, sex, race/ethnicity, income, education, marital status, and employment status; cancer type, stage, time since diagnosis, and receipt of treatment (surgery, radiation, and/or chemotherapy); proportion of care provided by the caregiver, relationship to the patient, coresidential status with the patient, and hours per week of care; and patient age and sex.

‡Model 1 plus patient psychosocial factors.

§Model 1 plus patient assessment of care.

¶Model 1 plus number of caregiver medical and/or nursing tasks.

Table A2. Association Between Informal Caregiver Self-Rated Health and Perceived Quality of Care (poor v good) of Patients With Lung and Colorectal Cancer (CanCORS, 2003-2006; multivariable logistic regressions; N = 689), Controlling for All Caregiver Sociodemographic Characteristics, Cancer Characteristics, Caregiving Characteristics, and Patient Age and Sex

Variable	Unadjusted*	Model			
		1†	2‡	3§	4¶
Caregiver self-rated health					
Excellent/very good	Ref	Ref	Ref	Ref	Ref
Good	1.50 (0.60 to 3.31)	1.52 (0.57 to 3.69)	1.29 (0.46 to 3.65)	3.94 (1.00 to 11.18)	1.49 (0.57 to 3.66)
Fair/poor	3.23 (1.54 to 7.61)	3.70 (1.61 to 11.20)	3.23 (1.47 to 12.86)	3.64 (0.83 to 12.14)	3.63 (1.59 to 11.08)
Confounders					
Patient psychosocial factors (spillover)					
Follow-up					
Depressive symptoms			1.40 (1.11 to 1.70)		
Mental HRQoL			1.00 (0.96 to 1.05)		
Physical HRQoL			1.97 (0.95 to 1.04)		
Baseline					
Depressive symptoms			0.83 (0.61 to 0.97)		
Mental HRQoL			0.94 (0.88 to 0.97)		
Physical HRQoL			0.97 (0.91 to 1.00)		
Patient assessment of care					
Follow-up					
Communication				0.95 (0.91 to 0.95)	
Coordination				0.94 (0.94 to 0.94)	
Baseline					
Communication				1.00 (0.97 to 1.04)	
Coordination				1.00 (0.96 to 1.02)	
Caregiver medical and/or nursing tasks					1.08 (0.88 to 1.30)

NOTE. Data are presented as OR (95% CI).

Abbreviations: CanCORS, Cancer Care Outcomes Research and Surveillance; HRQoL, health-related quality of life; OR, odds ratio; Ref, reference.

*Controls only for patient-perceived quality of care at baseline.

†Model 1 controls for patient-perceived quality of care at baseline; caregiver age, sex, race/ethnicity, income, education, marital status, and employment status; cancer type, stage, time since diagnosis, and receipt of treatment (surgery, radiation, and/or chemotherapy); proportion of care provided by the caregiver, relationship to the patient, coresidential status with the patient, and hours per week of care; and patient age and sex.

‡Model 1 plus patient psychosocial factors.

§Model 1 plus patient assessment of care.

¶Model 1 plus number of caregiver medical and/or nursing tasks.

Caregiver Well-Being and Patient-Reported Quality of Care

Table A3. Association Between Informal Caregiver Mental HRQoL and Perceived Quality of Care (poor v good) of Patients With Lung and Colorectal Cancer (CanCORS, 2003-2006; multivariable logistic regressions; N = 689)

Variable	Unadjusted*	Model			
		1†	2‡	3§	4¶
Caregiver mental HRQoL	0.97 (0.94 to 1.00)	0.97 (0.94 to 1.00)	0.98 (0.95 to 1.01)	0.98 (0.94 to 1.02)	0.97 (0.95 to 1.01)
Confounders					
Patient psychosocial factors (spillover)					
Follow-up					
Depressive symptoms			1.33 (1.06 to 1.57)		
Mental HRQoL			0.99 (0.96 to 1.04)		
Physical HRQoL			1.98 (0.96 to 1.03)		
Baseline					
Depressive symptoms			0.86 (0.67 to 1.00)		
Mental HRQoL			0.96 (0.90 to 0.98)		
Physical HRQoL			0.97 (0.92 to 1.00)		
Patient assessment of care					
Follow-up					
Communication				0.96 (0.94 to 0.97)	
Coordination				0.95 (0.95 to 0.96)	
Baseline					
Communication				1.00 (0.97 to 1.02)	
Coordination				1.00 (0.98 to 1.04)	
Caregiver medical and/or nursing tasks					1.12 (0.96 to 1.31)

NOTE. Data are presented as OR (95% CI).

Abbreviations: CanCORS, Cancer Care Outcomes Research and Surveillance; HRQoL, health-related quality of life; OR, odds ratio.

*Controls only for patient-perceived quality of care at baseline.

†Model 1 controls for perceived quality of care at baseline, cancer type, stage at diagnosis, amount of caregiving provided by the caregiver, coresidence of the caregiver and survivor, caregiver income, and whether the survivor received surgery for his/her cancer.

‡Model 1 plus patient psychosocial factors.

§Model 1 plus patient assessment of care.

¶Model 1 plus number of caregiver medical and/or nursing tasks.

||Mental component score from the Short Form-12.

Table A4. Association Between Informal Caregiver Physical HRQoL and Perceived Quality of Care (poor v good) of Patients With Lung and Colorectal Cancer (CanCORS, 2003-2006; multivariable logistic regressions; N = 689)

Variable	Unadjusted*	Model			
		1†	2‡	3§	4¶
Caregiver physical HRQoL	0.98 (0.95 to 1.00)	0.97 (0.94 to 1.00)	0.97 (0.94 to 1.00)	0.97 (0.94 to 1.00)	0.97 (0.94 to 1.00)
Confounders					
Patient psychosocial factors (spillover)					
Follow-up					
Depressive symptoms			1.35 (1.07 to 1.59)		
Mental HRQoL			1.00 (0.96 to 1.04)		
Physical HRQoL			0.98 (0.96 to 1.03)		
Baseline					
Depressive symptoms			0.87 (0.68 to 1.01)		
Mental HRQoL			0.96 (0.90 to 0.98)		
Physical HRQoL			0.97 (0.92 to 1.00)		
Patient assessment of care					
Follow-up					
Communication				0.96 (0.94 to 0.97)	
Coordination				0.95 (0.95 to 0.96)	
Baseline					
Communication				1.00 (0.97 to 1.02)	
Coordination				1.00 (0.98 to 1.03)	
Caregiver medical and/or nursing tasks					1.12 (0.96 to 1.30)

NOTE. Data are presented as OR (95% CI).

Abbreviations: CanCORS, Cancer Care Outcomes Research and Surveillance; HRQoL, health-related quality of life; OR, odds ratio.

*Controls only for patient-perceived quality of care at baseline.

†Model 1 controls for perceived quality of care at baseline, cancer type, stage at diagnosis, amount of caregiving provided by the caregiver, coresidence of the caregiver and survivor, caregiver income, and whether the survivor received surgery for his/her cancer.

‡Model 1 plus patient psychosocial factors.

§Model 1 plus patient assessment of care.

¶Model 1 plus number of caregiver medical and/or nursing tasks.

||Physical component score from the Short Form-12.

Table A5. Association Between Informal Caregiver Health Characteristics and Perceived Quality of Care (poor v good) of Patients With Lung and Colorectal Cancer, Stratified by Clinically Significant Level of Depressive Symptoms (CanCORS, 2003-2006; multivariable logistic regressions; N = 689)

	Clinically Significant Depressive Symptoms*			Not Clinically Significant Depressive Symptoms		
	OR	95% CI		OR	95% CI	
		Lower	Upper		Lower	Upper
Caregiver depressive symptoms	1.13	1.02	1.26	0.91	0.75	1.11
Self-rated health						
Excellent/very good	Ref			Ref		
Good	2.67	0.50	12.39	0.83	0.22	2.64
Fair/poor	4.84	1.38	25.32	2.40	0.52	9.05

NOTE. Dependent variable: fair/poor perceived quality of care, 1; good/very good/excellent perceived quality of care, 0. Caregiver depressive symptoms and self-rated health were assessed in separate models. All models were controlled for perceived quality of care at baseline, cancer type, stage at diagnosis, amount of caregiving provided by the caregiver, coresidence of the caregiver and survivor, caregiver income, and whether the survivor received surgery for his/her cancer.

Abbreviations: CanCORS, Cancer Care Outcomes Research and Surveillance; OR, odds ratio; Ref, reference category.

*Defined as a score of 10+ on the 10-item Centers for Epidemiology Studies Depression Scale (CESD-10).