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Patient Characteristics Associated with the Level of Patient-Reported Care Coordination among Male Colorectal Cancer Patients in the Veterans Affairs Healthcare System

George L. Jackson, Ph.D., MHA^{1,2}, Leah L. Zullig, Ph.D., MPH^{1,2}, Sean M. Phelan, Ph.D., MPH³, Dawn Provenzale, MD, MS^{1,2}, Joan M. Griffin, Ph.D.³, Steven B. Clauser, Ph.D., MPA⁴, David A. Haggstrom, MD, MPH^{5,6}, Rahul M. Jindal, MD, Ph.D., MBA⁷, and Michelle van Ryn, Ph.D., MPH³

¹ Durham Veterans Affairs Medical Center, Durham, NC

² Duke University, Durham, NC

³ Mayo Clinic, Rochester, MN

⁴ Patient Centered Outcomes Research Institute, Washington, DC

⁵ Roudebush Veterans Affairs Medical Center, Indianapolis, IN

⁶ Indiana University, Indianapolis, IN

⁷ Walter Reed National Military Medical Center, Bethesda, MD

Abstract

Background—We sought to determine if patient characteristics, including race/ethnicity, were associated with patient-reported care coordination for colorectal cancer (CRC) patients treated in the Veterans Affairs (VA) healthcare system, with the goal of better understanding potential goals of quality improvement efforts aimed at improving coordination.

Methods—The nationwide Cancer Care Assessment and Responsive Evaluation (C-CARES) survey involved VA CRC patients diagnosed in 2008 (response rate=63%). The survey included a 4-item scale of patient-reported frequency (never, sometimes, usually, always) of care coordination activities (scale score range=1-4). Among 913 CRC patients providing information on care coordination, demographics, and symptoms, multivariable logistic regression was used to examine odds of patients reporting optimal care coordination.

Results—VA CRC patients report high levels of care coordination (mean scale score=3.50 (standard deviation=0.61). Eighty-five percent of patients report a high level of coordination, including the 43% reporting optimal/highest-level coordination. There was no difference in the

Corresponding Author: George L. Jackson, Ph.D., MHA Address: Durham VA Medical Center, 508 Fulton Street (152), Durham, NC, 27705 Phone: 919-286-0411, ext. 7091 | Fax: 919-416-5836 | george.l.jackson@duke.edu.

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odds of reporting optimal coordination by race/ethnicity. Patients with early-stage disease (OR: 0.60; 95% CI: 0.45-0.81), greater pain (OR: 0.97 for 1-point increase in pain scale; 95% CI: 0.96-0.99) and greater levels of depression (OR 0.97 for 1-point increase in depression scale; 95% CI: 0.96-0.99) were less likely to report optimal coordination.

Conclusion—CRC patients in the VA report high levels of care coordination. Unlike what has been reported in settings outside the VA, there appears to be no racial/ethnic disparity in reported coordination. However, challenges remain in ensuring coordination of care for patients with less advanced disease and high symptom burden.

Keywords

Colorectal Cancer; Care Coordination; Health Disparities; Veterans

INTRODUCTION

Cancer care involves a range of clinical and psychosocial issues that must be coordinated among members of the healthcare team,^{1, 2} the patient, and caregivers.³⁻⁵ Based on a review of 48 published definitions of care coordination, McDonald et al. noted five elements involved in care coordination, all of which are applicable to cancer care: 1) involvement of numerous individuals or teams; 2) individuals and/or teams dependent on one another to do their jobs; 3) need for adequate knowledge of role of those involved in care; 4) information exchange among patients and healthcare teams; and 5) an overall goal of facilitating appropriate care.⁶

Lack of care coordination has been associated with compromised patient safety, unneeded or inappropriate care, conflicting information provided to patients, increased healthcare costs, and lower patient satisfaction.^{4, 6} Poor coordination is more common among patients with chronic illnesses, including cancer.^{7, 8} Further, racial and ethnic disparities in coordination have been reported,^{9, 10} although the presence of such self-reported disparities is not universal.¹¹ One key dimension of care coordination is whether patients perceive information exchange and knowledge to be adequate among healthcare staff and the patient so that appropriate care can be delivered.^{6, 12}

The VA is the largest provider of cancer care in the United States, treating approximately 3% of all cancer cases in the United States.¹³ Quality of cancer care is generally equivalent to or better than that provided outside the VA.^{14, 15} In contrast to other settings,¹⁶ studies have generally shown racial equity in the quality of CRC care provided to VA patients.^{17, 18} We examined whether there are disparities in patient-reported coordination of care within the VA. Additionally, we examined the association between care coordination and patient-reported outcomes expected to be impacted by the degree of coordination.

METHODS

The Cancer Care Assessment and Responsive Evaluation (C-CARES) survey methods have been previously described.^{19, 20} Briefly, the primary purpose of C-CARES was to assess patient-reported experience with the VA healthcare system, including both clinical and non-

clinical care, among recently diagnosed CRC patients (diagnosed in 2008). Question domains included evaluating diagnosis and access to care, cancer treatments, symptoms, hospice care, primary care, and barriers to care, as well as care coordination. Questions were written at or below an 8th grade reading level. The study was approved by the Institutional Review Boards (IRB) of the Minneapolis VA Medical Center and University of Minnesota School of Medicine. The Durham VA Medical Center IRB approved retrospective data analysis.

Patient Sample and Survey Administration

Patients were identified through the VA Central Cancer Registry (VACCR). Based on abstraction of the VA electronic health record (EHR) by certified cancer registrars, the VACCR seeks to identify all cancer cases diagnosed and treated within VA. It has been estimated that VACCR captures approximately 90% of cancer cases treated in VA.^{14, 15}

To be included in the survey cohort, patients had to meet the following eligibility criteria: 1) newly diagnosed with stage 1-4 colorectal cancer during calendar year 2008, 2) received over half of their cancer care at any medical center in the VA healthcare system, and 3) alive at the time of the mailing. After obtaining a list of potentially-eligible patients from the VACCR, a research assistant manually reviewed patients' electronic health record to confirm eligibility and identify the patient's mailing address. A self-administered paper survey was mailed to 2,090 patients' homes between August and November 2009. A \$10 incentive was included in the initial survey packet to encourage participation. Individuals who reported that most of their cancer care was received outside of the VA were excluded from analysis. Additionally, the small number of women, reflecting CRC prevalence in the VA,^{13, 15} made gender comparisons statistically infeasible.

Outcome

Care coordination was measured with a scale based on four items from a measure designed by the Picker Institute and used in prior studies of quality of patient-centered colorectal cancer care.²¹ Respondents were asked about VA care since January 1, 2008 at the VA facility where they received most of their cancer care. The scale has a Cronbach's alpha coefficient of 0.845. Respondents were asked to report on the frequency of the following four care coordination topics using a 4 point response scale (1="never," 2=sometimes", 3="usually," 4=always"): a) familiarity of the care team with medical history [factor loading=0.87, item-scale correlation=0.75]; b) familiarity with information from other providers [factor loading=0.86, item-scale correlation=0.72]; c) clinicians have information needed to provide care [factor loading=0.83, item-scale correlation=0.69]; and d) knowing to whom to direct questions [factor loading=0.78, item-scale correlation=0.60] (see table 3 for exact question wording). The scale score was calculated as the mean of the scores reported for each question. To have a score calculated, a respondent had to answer three of the four questions.

Explanatory Variables

Measures of patient characteristics, disease characteristics, and symptoms were included as explanatory/independent variables. Patient characteristics included age at CRC diagnosis,

race (derived from VACCR if not reported on survey), employment status, educational level, and social support (based on the individual reported as most likely to help take care of the respondent. See table 2 for more detail on variable categories used in the regression analysis.

We also controlled for disease characteristics and symptoms. Stage at diagnosis, a binary variable, was included in the model. Stage of disease was aggregated into early stage (i.e., stage I or II) versus late stage (i.e., stage III or IV). To assess symptom severity within the last six months, C-CARES used validated PROMIS scales for fatigue, pain, and depression.^{22, 23} For each scale, higher scores indicated greater severity of symptoms. In order for PROMIS scales to be meaningful, patients must respond to all survey items, thus surveys with missing information on any PROMIS symptom survey item were excluded from analysis.

A t-score for each scale was calculated for every respondent. PROMIS scale t-score distributions are standardized for the general U.S. population with a mean of 50 and a standard deviation of 10.^{22, 23} The PROMIS scale t-scores were then calculated separately for pain, fatigue, and depression.²³

The C-CARES survey also contained a measure of bowel or defecation problems in the previous six months for respondents who did not have a stoma. The measure was a subset of six questions from the European Organization for Research and Treatment of Cancer (EORTC) Colorectal Cancer Quality of Life Questionnaire.²⁴ These items were aggregated to determine whether patients reported a bowel problem based on a continuous scale.

Analysis

Statistical analyses were performed using Stata (StataCorp. 2009. *Stata Statistical Software: Release 11*. College Station, TX: StataCorp LP). We assessed descriptive statistics to examine the composition of the analysis cohort. We conducted multivariable logistic regression analysis to determine the likelihood that respondents with specific patient, disease, and symptom characteristics would report optimal (scale score of 4/endorsing highest level of coordination for each answered question) cancer care coordination. Finally, to examine the association of the care coordination scale with patient outcomes expected to be impacted by the degree of coordination, multivariable logistic regression equations including covariates described above, were used to examine the odds of a patient reporting he: 1) had never been given contradictory information; 2) never went to an emergency room or urgent care for cancer related problems; 3) never experienced symptoms or problems between visits; and 4) always got needed help for symptoms or problems between visits. The terms never or always refer to the time period since January 1, 2008.

RESULTS

Among 2,511 potentially eligible subjects identified through the cancer registry, 421 were determined to be ineligible based on registry data and medical record review, leading to 2,090 mailed surveys. Surveys were returned by 1,409 (67% response rate). Eliminating patients who self-reported information indicating they were not eligible for the survey (e.g., received less than half of care in the VA), 1,147 surveys were available for analysis. After

dropping information for 30 females, 21 individuals with missing stage information, and 157 other individuals with missing information on coordination of care or other covariates, the final dataset for the present analysis included 913 individuals. The 157 individuals with missing covariates did not significantly differ from other male respondents who provided information on those variables in terms of key demographic and disease characteristics, including: age, race, employment, income, social support, stage at diagnosis, and reported symptoms.

Characteristics of the survey respondents are summarized in Table 1. Patients were, on average, 67.5 years old, non-Hispanic white (76%), not currently employed (80%), and had a high school education or higher (84%). The majority (64%) had incomes < \$20,000 per year. Sixty-two percent of respondents had early stage disease (i.e., stage I or II).

Cancer patients in this VA study reported high levels of care coordination. The mean care coordination scale score was 3.50 (standard deviation (SD)=0.61). Eighty-five percent of cancer patients reported a high level of cancer care coordination (score 3 on 1-4 scale) and 43% reported the highest possible level of care coordination on the scale (i.e. optimal care coordination)

As detailed in table 2, no differences in reported coordination of care exist by patients' race/ethnicity or other sociodemographic characteristics (i.e., income employment, or education). However, patients with early-stage disease were significantly less likely to report receiving highly coordinated care (OR: 0.60; 95% CI: 0.45-0.81). At the same time, patients with greater pain (OR: 0.97 for 1-point increase in the t-score of the pain scale; 95% CI: 0.96-0.99) and greater levels of depression (OR: 0.97 for 1-point increase in the t-score of the depression scale; 95% CI: 0.96-0.99) were significantly less likely to report the highest levels of care coordination. While not statistically significant, fatigue and bowel problems were also negatively associated with care coordination.

Descriptive data on individual survey questions assessing care coordination as well as expected outcomes of coordination are presented in table 3. Patients with a cancer care coordination score of 4 had significantly greater odds of never being given contradictory information about their health or care (OR: 2.22; 95% CI: 1.73-2.86; p-value: <0.001), not experiencing symptoms between visits (OR: 1.48; 95% CI: 1.12-1.95; p-value: 0.005), and always getting needed help between visits (OR: 5.53; 95% CI: 4.04-7.56; p-value: <0.001). While the association was not statistically significant, the direction of the point estimate of the odds ratio comparing the association between highly coordinated care and never going to the emergency department or urgent care for a cancer-related issue was in the expected direction (OR: 1.12; 95% CI: 0.87-1.44; p-value: 0.385).

DISCUSSION

Our findings indicate that CRC patients in the VA report high levels of care coordination, with 85% reporting high levels and 43% reporting optimal coordination based on the measure used in this study. This measure focuses on patients and healthcare teams having and sharing the information needed to manage cancer. Unlike studies conducted in non-VA

settings,⁹ reported care coordination was not associated with patients' race/ethnicity or other sociodemographic factors. While we recognize that measures of coordination across studies vary, the present finding reflects previous research that has found a lack of clinically meaningful racial/ethnic disparities in CRC care in the VA.^{17, 18, 25} We did find, however, that having less advanced cancer was associated with reduced odds of reporting optimum coordination. However, so were having higher levels of pain and depression.

It appears that the relationship between stage and coordination is somewhat confounded toward the null by patient symptoms. When symptoms are not included in the model, the odds ratio for early-stage disease is 0.73 (p-value: 0.25) as opposed to 0.60 (p-value: 0.25) for the fully adjusted model. The unadjusted odds ratio is 0.75 (p-value: 0.39). These results point toward the simultaneous possibility that: 1) those with greater psychosocial burden, as indicated by higher levels of depression and pain, may have unmet needs for support and 2) patients with early-stage disease may have underappreciated needs that require more coordination. Utilizing the data from the present survey, we have also learned that patients with lower stage disease are less likely to report receiving wanted supportive care for a variety of symptoms.²⁰ While our data does not allow us to fully unpack the relative contributions of patient and health system characteristics to this association, it is an important area for future research. Models of care that include enhancements such as patient navigators may both help to address the needs of patients with higher levels of symptoms and ensure that the needs of patients with early, as well late-stage disease are recognized and addressed.³

Since 1995, the VA has focused on efforts to improve the quality and coordination of healthcare services, including the use of a fully integrated EHR.²⁶ Also during the 2008-2009 time period covered by the survey, there were several initiatives to measure and improve the quality of CRC diagnosis and treatment ongoing in the VA,^{2, 14, 15} potentially enhancing care coordination.

Our study has important limitations and considerations. This study was conducted among male patients in the VA healthcare system. However, as an integrated delivery system with a fully functional EHR, the VA mirrors staff/group model health maintenance organizations,²⁷ integrated cancer services provided by non-federal academic medical centers,²⁸ and the accountable care organizations that are currently being established under the Affordable Care Act.²⁹ Furthermore, it has been hypothesized that the eligibility structure of the VA reduces the likelihood that any disparity, if found, is attributable to patient differences in insurance status or ability to pay.^{17, 30} Additionally, the low number of female CRC survivors in the VA means that we were not able to include women in the study. While there may be differences between the experiences of men and women, other large survey studies of CRC patients have not found differences in reported care coordination by gender.^{4, 9}

We assessed care coordination from the perspective of the patient. While this assessment represents how the patient interprets the degree to which both healthcare staff and patients have adequate knowledge of the patient's treatment and disease, the perspective of healthcare staff may differ.^{31, 32} While the response rate was 67%, it is still possible that those individuals who returned the survey may have been more engaged in their healthcare

(potentially being more likely to report good coordination) or identify gaps in care coordination (potentially being less likely to report good coordination). Addressing these potential scenarios represents an opportunity for future research. Additionally, our measure of care coordination focuses on appropriate availability of patient and care information. Our examination of the association of the care coordination variable and expected outcomes of high levels of coordination indicated that having a higher score on the care coordination measure is associated with getting needed help with symptom care.

High levels of patient-reported care coordination and lack of disparities in coordination represent important factors that may contribute to both the high quality of care^{2, 26} and relative lack of racial/ethnic disparities VA cancer care^{14, 15, 17, 18} in the VA. Future research, however, should focus on the perceived gap in care coordination for those who are symptomatic and at earlier disease stage. Methods to enhance care coordination and receipt of care for VA patients with early-stage disease and greater symptom burden should be evaluated. Specific contributors such as equal access, well-defined performance measures linked to cancer treatment outcomes, and an integrated EHR that may enhance the quality of care delivery in the VA, should be explored in other settings.

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Table 1

Characteristics of survey respondents (n=913)

	Percent/Mean	SD	Min	Max
Patient Characteristics				
Age	67.48	9.74	26	90
Male	100.0	--	--	--
White race	76.34	--	--	--
Black race	13.14	--	--	--
Hispanic	5.48	--	--	--
Other race	5.04	--	--	--
Employment and Educational Status				
Employed	19.61	--	--	--
Not employed	80.39	--	--	--
High school or higher education	84.12	--	--	--
Less than high school education	15.88	--	--	--
Annual Income				
< \$10,000	15.66	--	--	--
\$10,000 - \$20,000	48.63	--	--	--
\$20,001 - \$40,000	24.75	--	--	--
> \$40,000	10.95	--	--	--
Social Support				
Spouse	52.35	--	--	--
Family and friends	40.64	--	--	--
No one	4.82	--	--	--
Stage at Diagnosis				
Early stage (i.e., Stage I or II)	61.99	--	--	--
Late stage (i.e., Stage III or IV)	38.01	--	--	--
Symptoms				
Fatigue	52.95	9.75	32.5	82.7
Pain	51.32	10.74	41.0	78.3
Depression	50.57	11.00	37.1	81.1
Bowel problems	0.67	0.47	0.0	1.0

Table 2

Multivariate logistic regression results reflecting the odds of patients reporting the highest level care coordination (n=913)

	OR	95% CI	p
Patient Characteristics			
Age [continuous variable, per 1 year increase]	1.01	0.99–1.02	0.40
White, Non-Hispanic Race/Ethnicity [referent-non-white]	0.98	0.82–1.15	0.73
Not employed [referent-part- or full-time employment]	0.92	0.63–1.32	0.64
Less than high school education [referent- high school]	0.97	0.65–1.45	0.89
Annual Income			
< \$10,000	1.36	0.78–2.37	0.28
\$10,000 - \$20,000	1.23	0.76–1.97	0.40
\$20,001 - \$40,000	1.01	0.61–1.67	0.97
>\$40,000 [referent]	--	--	--
Social Support			
Spouse as caregiver [referent]	--	--	--
Family and friends	0.81	0.61–1.08	0.16
No one	0.57	0.28–1.14	0.11
Disease Characteristics & Symptoms			
Early-stage [referent-late stage] [†]	0.60 [*]	0.45–0.81	0.00
Fatigue [continuous variable, per 1 point increase]	0.99	0.97–1.01	0.38
Pain [continuous variable, per 1 point increase]	0.97 [*]	0.96–0.99	0.00
Depression [continuous variable, per 1 point increase]	0.97 [*]	0.96–0.99	0.00
Bowel problems [continuous variable, per 1 point increase]	0.94	0.69–1.27	0.67

* Indicates statistical significance at the $p < 0.05$ level.

[†] Early stage of disease is a dichotomous variable where early stage=1 if Stage I or II and early stage=0 if Stage III or IV disease.

Table 3

Coordination of cancer care survey items

Items In Care Coordination Scale					
	Always % of those that responded (n)	Usually % of those that responded (n)	Sometimes % of those that responded (n)	Never % of those that responded (n)	Mean Score for each Question^{**} (SD)
Familiar With Medical History					
How often were the doctors, nurses, and other health care providers who cared for you familiar with your most recent medical history? (n=909)	62.38 (567)	29.81 (271)	6.71 (61)	1.10 (10)	3.5 (0.67)
Aware of Treatment Changes					
How often were your providers aware of changes in your treatment that other providers recommended? (n=904)	58.74 (531)	29.20 (264)	8.63 (78)	3.43 (31)	3.4 (0.79)
Providers have Needed Information					
Do you think your providers had all of the information they needed, such as test results, to make decisions about your treatment? (n=911)	68.06 (620)	23.71 (216)	7.03 (64)	1.21 (11)	3.59 (0.68)
Know to Whom to Ask Questions					
How often did you know who to ask when you had questions about your health problems? (n=912)	60.09 (548)	25.77 (235)	11.62 (106)	2.52 (23)	3.43 (0.79)
Care Coordination Scale Results					
Care Coordination Scale (n=913)_	1.97 (18) (score = 1-<2)	13.03 (119) (score = 2-<3)	42.06 (384) (score = 3-<4)	42.94 (392) (score = 4)	3.50 (0.61)
Items Used To Examine the Association between the Care Coordination Scale and Outcomes Potentially Associated with High Levels of Coordination					
Given Contradictory Information					
How often were you given contradictory information about your health or treatments? * (n=884)	12.22 (108)	5.54 (49)	17.53 (155)	64.71 (572)	1.65 (1.04)
Association between optimum care coordination (scale=4) and never being given contradictory information – odds ratio (OR): 2.22; 95% confidence interval (CI): 1.73-2.86; p-value: <0.001					
ER for Cancer Problems					
How often did you go to an Emergency Room or Urgent Care for problems related to your cancer or cancer treatment? * (n=883)	6.68 (59)	2.72 (24)	26.39 (233)	64.21 (567)	1.52 (0.84)
Association between optimum care coordination (scale=4) and never going to the emergency room – OR: 1.12; 95% CI: 0.87-1.44; p-value: 0.385					
Symptoms Between Visits					
How often did you experience symptoms or problems between visits? * (n=904)	4.54 (41)	6.86 (62)	41.92 (379)	46.68 (422)	1.69 (0.79)
Association between optimum care coordination (scale=4) and never experiencing symptoms between visits – OR: 1.48; 95% CI: 1.12-1.95; p-value: 0.005					
Symptoms Help Between Visits					

Items In Care Coordination Scale					
	Always % of those that responded (n)	Usually % of those that responded (n)	Sometimes % of those that responded (n)	Never % of those that responded (n)	Mean Score for each Question (SD)^{**}
How often did you get the help you needed for symptoms or problems between visits? (n=856)	54.09 (463)	17.99 (154)	9.23 (79)	18.69 (160)	3.07 (1.17)
Association between optimum care coordination (scale=4) and always getting needed help between visits – OR: 5.53; 95% CI: 4.04-7.56; p-value: <0.001					

* Indicates that survey item was inverse coded in regression analysis. This recoding ensures that a higher number (i.e. Always=4, Usually=3, Sometimes=2, Never=1, Missing=.) consistently indicates better coordination of cancer care.

** For each individual question, the last column reports the mean score and standard deviation (SD) for the question. For the care coordination scale, the column reports the mean and SD of the scale score.