Assessing Patients’ Perceptions of Cancer Care Coordination in a Community-Based Setting

Izumi Okado, PhD; Kevin Cassel, DrPh; Ian Pagano, PhD; and Randall F. Holcombe, MD, MBA

QUESTION ASKED: What are patient and practice characteristics associated with patients’ perceptions of cancer care coordination in a community-based setting?

SUMMARY ANSWER: The presence of a family caregiver and the diagnosis of hematologic cancer were associated with positive reports of care coordination. Poorer perceptions of care coordination were correlated with a head and neck cancer diagnosis and the absence of a family caregiver.

WHAT WE DID: Using a cross-sectional study design, we assessed patients’ perceptions of care coordination using a Care Coordination Instrument (CCI) for 200 patients with cancer who received community-based care. The CCI assesses perceptions of care coordination overall and across three care coordination domains: communication, navigation, and operational.

WHAT WE FOUND: In multivariable analysis, the presence or absence of a family caregiver and type of cancer had the strongest associations with patients’ perceptions of cancer care coordination. The effects of disease stage and the presence of a patient navigator were not statistically significant, with benefits of having a patient navigator eclipsed by the presence of a family caregiver.

BIAS, CONFOUNDING FACTORS: We conducted this study at multiple community-based sites but within a single location in the country. The sample was racially diverse but with a preponderance of patients with breast cancer. Additional research will be required to confirm that results are generalizable to other populations.

REAL-LIFE IMPLICATIONS: Improving cancer care coordination is a priority to facilitate high-quality care delivery. Use and integration of the CCI into clinical practice will provide important information regarding current care coordination approaches and identify potential areas to target for improvement. Family caregiver inclusion in the care coordination process may be a key strategy to optimizing patient-centered cancer care delivery.

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abstract

PURPOSE Effective care coordination (CC) is a hallmark of a high-quality cancer care. However, efforts to improve cancer care delivery are limited by the lack of a clinically useful tool to assess CC. In this study, we examined patients’ perceptions of cancer CC using a novel tool, the Care Coordination Instrument (CCI), and evaluated the quality of the CCI.

METHODS The CCI is a 29-item patient questionnaire that assesses CC across varied practice settings and patient populations overall and for three critical domains of CC: communication, navigation, and operational. We conducted univariable and multivariable regression analyses to identify patient clinical and practice characteristics associated with optimal versus suboptimal CC.

RESULTS Two hundred patients with cancer completed the CCI questionnaire between October 2018 and January 2019, of whom 189 were used for the analysis. The presence of a family caregiver and a diagnosis of a blood cancer were correlated with overall positive reports of CC (P < .001 and P < .05, respectively). Poorer perceptions of CC were associated with having a head and neck cancer and the absence of family caregiver support. The effects of cancer disease stage and having access to a patient navigator on CC were not statistically significant.

CONCLUSION Integrating a patient-centered tool to assess cancer CC can be a strategy to optimize cancer care delivery. Understanding factors associated with effective and ineffective CC can help inform efforts to improve overall quality of care and care delivery.

JCO Oncol Pract 16:e726-e733. © 2020 by American Society of Clinical Oncology

INTRODUCTION

Care coordination (CC) during cancer treatment is a critical component of patient-centered care. The Agency for Healthcare Research and Quality defines CC as “deliberate organization of patient care activities between 2 or more participants, including the patient, involved in a patient’s care to facilitate the appropriate delivery of health care services.” Oncology CC is complex, and it is particularly challenging for patients because they must navigate a series of outpatient visits that often involve multidisciplinary interventions, numerous health care providers, and varied health care entities. A hallmark of high-quality care is a coordinated, patient-centered approach; however, many patients with cancer continue to receive poor and fragmented care. Poorly coordinated care can result in medical errors, adverse patient outcomes, and spiraling health care costs due to test duplication, overuse of emergency services, and unplanned hospital admissions. Given the increasing complexity of anticancer interventions and rapid expansion of multimodal treatments requiring greater coordination of care, it is important to gain understanding of current CC approaches and develop evidence-based, innovative approaches to improve the efficiency and effectiveness of care delivery.

Multiple barriers to improve cancer care delivery exist. One major gap is the paucity of CC research focused on patients. Much of prior research has relied on health care systems or providers’ perspectives of CC. Although limited prior work has shown that some patient characteristics are associated with poor patient reports of CC, we know relatively little about specific factors that distinguish optimal versus suboptimal CC. Lack of adequate measurement instruments has also been identified as a barrier to
improving cancer care delivery. Some measures have been developed; however, these measures were generally developed for use at large institutions and with cancer specialty physicians, leaving the optimal methods to assess CC in community-based practices and hospitals relatively unknown. Given that patients with cancer are frequently treated by medical providers working in different care settings, a patient-centered approach to evaluate CC that encompasses a variety of practice settings and providers is needed to understand the current CC landscape. To address this knowledge gap, our prior research focused on developing and refining a Care Coordination Instrument (CCI), a self-report questionnaire designed to assess the perceptions of CC among patients with cancer. The CCI measures patients’ perceptions of CC overall and across three domains (communication, navigation, and operational) that are conceptualized as critical components of CC. Although our prior work has established reliability and face and content validity of the instrument, the utility of the revised CCI in a broad population of patients with cancer has not yet been evaluated.

The aims of our study were to evaluate patients’ perception of CC in community-based samples across varied care settings (hospital vs private practice), examine the utility of the CCI, and conduct psychometric evaluation of the CCI. To identify potential factors contributing to optimal versus suboptimal CC, we also examined associations between patient reports of CC and patient clinical and practice characteristics. A better understanding of patients’ perceptions of CC can inform ways to improve cancer care delivery, and such information may benefit providers, hospital administrators, policymakers, and patients as we work toward developing effective and efficient care delivery models.

METHODS

Setting and Study Population

In this cross-sectional study, 200 patients (age ≥ 18 years) who received active therapy for any cancer were enrolled. Active treatment was defined as having a minimum of three outpatient therapy or cancer care visits within a preceding 6-month period based on patient self-report. Participants were recruited between October 2018 and January 2019. We conducted this study at the University of Hawaii Cancer Center, a National Cancer Institute–designated cancer center, in collaboration with private oncology practices, hospital-based outpatient clinics, and community-based support groups. Participants completed the CCI survey and a demographic questionnaire (age, gender, race/ethnicity, cancer type, disease stage, and provider type) in paper format at the University of Hawaii Cancer Center or at the collaborating clinics/hospitals. The study was approved as exempt research by the Institutional Review Board at the University of Hawaii at Manoa.

CC Measure

The CCI, a 29-item, multiple-choice survey questionnaire, was used to assess patients’ perceptions of cancer CC. Instrument development, field testing, and initial psychometric properties of the CCI were described in our prior study. If the respondents had multiple oncology providers or received more than one intervention, they were asked to base their responses on what most commonly applied to them. This instrument assesses patients’ perceptions of CC overall and three domains of CC: communication, navigation, and operational. Briefly, the communication domain assesses information about the quality of communication among the health care team(s) and between providers and patients. The navigation domain evaluates global aspects of care beyond the physician’s office or practice site, such as information about financial resources and emotional support. The operational domain, a unique domain in this CCI, probes for information regarding access to care and efficiency of care delivery. The CCI items are rated on a four-point Likert scale, from “strongly agree” to “strongly disagree, and these scores were converted into a numeric scale prior to analysis. An overall composite score for patients’ perceptions of CC (CCI: Total) was computed by summing the values for all items, with higher scores corresponding to better perceptions of CC by patients.

Analytic Approach

Standard descriptive statistics were used to describe the patient and practice characteristics. We used Cronbach’s $\alpha$ and exploratory factor analysis to determine reliability of the CCI and validity of its three-domain structure. Prior to analysis, missing data were examined, and surveys that were missing responses to 20% or more questions were excluded from the final analysis.

To examine the associations between patients’ perceptions of CC and patient and practice characteristics, we analyzed the CCI scores for the total and the three domains using univariable and multivariable linear regression models. We examined the following patient and provider characteristics as independent variables: cancer type, cancer disease stage, practice setting (private vs hospital-based ambulatory), having access to a patient navigator, provider type (medical oncology, radiation oncology, surgeon, other), and having family/friend/relative caregiver support (family caregiver). In the multivariable models, to determine the strengths of the effects of each predictor on CC, all independent variables were entered simultaneously. $P$ values reported in this study are 2-sided and considered statistically significant at $\alpha = .05$.

RESULTS

Sample Characteristics

A total of 200 participants completed the survey. Eleven surveys were missing responses to 20% or more questions;
thus, these surveys were removed, and 189 surveys were included in the final analysis. Table 1 lists the demographic and clinical characteristics of the study sample. Patients were primarily female (56.6%) and Asian (42.0%), with a mean age of 63.4 (standard deviation, 12.3) years. The highest proportion of patients presented with breast cancer (31.2%), and the stages of the disease (I-IV) were fairly evenly distributed. The majority of the patients received hospital-based ambulatory care (58.2%), were seen by a medical oncologist (78.8%), and did not have a patient navigator (60.3%). Among respondents, 64.6% indicated having a family member, relative, or friend who helped coordinate their care.

### TABLE 1. Study Participant Characteristics (N = 189)

| Characteristic                  | %   |
|--------------------------------|-----|
| Female                         | 56.6|
| Mean age, years (SD)           | 63.4 (12.3) |
| Race                           |     |
| White                          | 17.0|
| Asian                          | 42.0|
| Native Hawaiian                | 14.8|
| 2 or more                      | 25.4|
| Major cancer types             |     |
| Breast                         | 31.2|
| GI                             | 22.8|
| Lung                           | 10.6|
| Head and neck                  | 6.9 |
| Lymphoma                       | 6.3 |
| Prostate                       | 5.8 |
| Blood                          | 5.3 |
| Other cancers                  | 17.5|
| Cancer stage                   |     |
| 0                              | 2.1 |
| I                              | 15.9|
| II                             | 14.3|
| III                            | 16.9|
| IV                             | 22.2|
| Unsure/unknown                 | 28.6|
| Practice setting               |     |
| Private                        | 41.8|
| Hospital based                 | 58.2|
| Oncology provider type         |     |
| Medical oncology               | 78.8|
| Radiation oncology             | 8.5 |
| Surgeon                        | 8.5 |
| Other                          | 3.2 |
| Patient navigator              |     |
| Yes                            | 39.2|
| No                             | 60.3|
| Family caregiver               |     |
| Yes                            | 64.6|
| No                             | 35.4|

NOTE. All data are % unless otherwise indicated. Cancer types < 3% were aggregated into “Other”; this category included brain, urinary tract, gynecologic, skin/bones/muscle, and unknown. Abbreviation: SD, standard deviation.

Reliability and Validity of the CCI

Cronbach’s α was .917, demonstrating a high degree of internal consistency reliability of the CCI items. Exploratory factor analysis extracted 3 factors, supporting the three-domain structure of the CCI. Evaluation of factor loadings indicated that a question, “I have a family member, a close relative, or a friend who helped coordinate my cancer care,” did not load onto any specific domain(s). Given that the role of the family caregiver for patients with cancer is well established, this item was deemed as a potential patient characteristic associated with CC and thus was examined as an independent variable.

Univariable and Multivariable Analysis

As shown in Table 2, in univariable analysis, cancer type and having a family caregiver were associated with overall perception of CC (P < .05 and P < .001, respectively). Specifically, having a blood cancer was associated with better overall perception of CC, whereas a diagnosis of a head and neck cancer was associated with poorer perception of CC (P < .05). Cancer type and availability of a family caregiver were also correlated with the communication and operational domains (P < .05 and P < .001, respectively). Only the presence of a family caregiver was statistically significantly correlated with the navigation domain (P < .001). Neither practice setting (private v hospital ambulatory), oncology provider type, nor the presence of a patient navigator were statistically correlated with overall CC or any of the specific domains.

In multivariable analysis, patients’ overall perceptions of CC were associated with cancer type, type of provider seen, and the presence/absence of a family caregiver (Table 2). Post hoc analysis indicated that patients with blood cancer reported higher CC scores than those with other cancer types, and patients with head and neck cancer reported the lowest overall CC scores (P < .01). Regarding type of provider seen, the lowest scores were found for surgical oncology (P < .05). The presence of a family caregiver was associated with higher overall CC scores, whereas the absence of a family caregiver was associated with lower CC scores (P < .001).

Similar patterns were found for the communication domain. For the navigation domain, practice setting (hospital-based ambulatory care receiving higher scores) and provider type (radiation oncology receiving lower scores) significantly
TABLE 2. Results of Univariable and Multivariable Regression Analysis for CCI Total and Three Domains

| Measure of CC (DV) | Independent Variable | Univariable Analysis P | Multivariable Analysis P |
|-------------------|----------------------|------------------------|-------------------------|
| CCI: total        | Cancer type          | .046*                  | .003**                  |
|                   | Cancer stage         | .926                   | .857                    |
|                   | Practice setting     | .552                   | .066                    |
|                   | Provider type        | .299                   | .033*                   |
|                   | Patient navigator    | .090                   | .081                    |
|                   | Family caregiver     | < .001***              | < .001***               |
| Communication     | Cancer type          | .041*                  | .004**                  |
|                   | Cancer stage         | .841                   | .707                    |
|                   | Practice setting     | .518                   | .094                    |
|                   | Provider type        | .224                   | .049*                   |
|                   | Patient navigator    | .170                   | .143                    |
|                   | Family caregiver     | < .001***              | < .001***               |
| Navigation        | Cancer type          | .184                   | .016*                   |
|                   | Cancer stage         | .936                   | .838                    |
|                   | Practice setting     | .615                   | .045*                   |
|                   | Provider type        | .285                   | .016*                   |
|                   | Patient navigator    | .145                   | .208                    |
|                   | Family caregiver     | < .001***              | < .001***               |
| Operational       | Cancer type          | .046*                  | .005**                  |
|                   | Cancer stage         | .642                   | .696                    |
|                   | Practice setting     | .707                   | .113                    |
|                   | Provider type        | .374                   | .164                    |
|                   | Patient navigator    | .177                   | .133                    |
|                   | Family caregiver     | < .001***              | < .001***               |

Abbreviations: CC, care coordination; CCI, Care Coordination Instrument; DV, dependent variable.
*P < .05.
**P < .01.
***P < .001.

Influenced patients’ perceptions of CC for this domain (both P < .05). Finally, having a blood cancer and the presence of a family caregiver were associated with higher scores in the operational domain, whereas having a head and neck cancer and the absence of a family caregiver predicted lower operational scores (P < .01 and P < .001, respectively). The effects of cancer disease stage and the presence/absence of a patient navigator were not statistically significant overall or for any of the specific domains. Statistically significant results from multivariable analysis are presented in Figure 1.

**DISCUSSION**

Improving cancer CC is a priority to facilitate high-quality care delivery. Our study highlights the utility of a validated, patient-centered tool to assess CC and demonstrates how it can bring new insight into understanding specific areas underlying optimal and poorly coordinated care. A patient-centered tool provides a significant opportunity for clinicians, providers, and oncology practices to gain understanding of current CC approaches and inform areas needing intervention.

We observed significant effects on CC for cancer type, type of provider seen, and practice setting. Patients with hematologic malignancies reported superior CC. These patients require highly intensive treatment and are monitored frequently throughout the course of therapy by a limited number of providers. Thus, patients with hematologic cancer may receive more active disease management with frequent interactions with fewer clinicians and providers, enhancing opportunities for CC. Regarding type of provider seen, although it was statistically significant, given that nearly 79% of patients were seen by a medical oncologist, we were unable to determine whether specific provider type influenced patients’ perceptions of CC. Additionally, patients who received care in a hospital-based ambulatory setting reported better navigation. It is possible that these findings are in part due to the greater availability of patient navigators in hospital-based treatment centers. In our study sample, approximately half of the patients who received hospital-based ambulatory care indicated having a patient navigator (53%), whereas only 21% of those who received private practice care had a patient navigator. The presence or absence of a patient navigator was not independently verified; thus, it is possible that some patients were assigned a patient navigator but did not recall the availability of a patient navigator. That said, our results indicated that the effects of a patient navigator were not statistically significant, suggesting that other factors, such as type of intervention, availability of other support staff, and frequency of clinic/office visits, may partially explain variations in practice settings.

Our study demonstrates the strong positive effects of a family caregiver on patients’ perceptions of CC. As health care systems shift to greater use of outpatient care, family caregivers are increasingly being relied on to assume informal caregiving duties and responsibilities. Given that informal family caregivers often provide critical assistance to patients and manage their health care needs, it is possible that many CC-related tasks fall on the family rather than the patient, relieving patients from active involvement in CC.

A diagnosis of a head and neck cancer, the lack of family/friend/relative support, and provider type were associated with poorer patient perceptions of CC. The finding regarding poorer CC in patients with head and neck cancer is...
consistent with a prior study; head and neck cancers are complex and often require multimodal treatment and multispecialty care, and these patients may require greater CC. Regarding the absence of a family caregiver, poorer perception of CC may be in part due to a lack of social and emotional support. The lack of instrumental support, such as assistance with transportation, has been associated with poorer survival and adverse outcomes, and it is possible that social isolation contributes to poorer perception of CC. As noted previously, additional replication with a larger sample is needed to validate observations regarding provider type.

In contrast to prior work, our study found that the clinical stage of cancer did not affect patients’ perceptions of CC. Given that nearly a third of the patients in our study indicated their stage of cancer as “Unknown” or “Not sure,” we were not able to sufficiently determine any potential effects of disease stage on CC. Alternatively, the lack of patients’ understanding of their disease stage may suggest that there is inadequate documentation of a treatment plan or unclear communication between clinicians and patients. Notably, in our analyses, the benefits of having a patient navigator were eclipsed by the presence of a family caregiver. This finding is surprising, given that the patient navigation services are geared to facilitating and improving CC efforts. It may be that patient navigation services are effective primarily for patients who are at greater risk for treatment-related toxicities or reside in rural or underserved areas.

Alternatively, it is possible that the current limited availability of patient navigators creates increased workload for navigators, potentially affecting the effectiveness of CC.
services provided by the navigators. Moreover, with increasing complexities of cancer treatment, many patients may require more intense CC activities beyond the current scope of services provided by the patient navigation programs. Additional research is needed to identify aspects of patient navigator programs that may require improvement and intervention.

Findings should be interpreted in the context of the study limitations. Because our study aimed to examine the applicability of the CCI across varied care settings and populations of patients with cancer, a broad sample of patients with cancer was used in the study. Our sample represented a diverse group of patients with cancer, with higher proportions of female and Asian patients and those with breast cancer; thus, it is possible that reported findings are in part due to variations in patient characteristics. Furthermore, it is possible that the number of providers and involvement of multiple treatment modalities, length of treatment, and the frequency of office visits may influence patients’ perceptions of CC. Finally, beyond patients’ perceptions we did not assess any objective measures of CC that could include compliance with therapy, untimed emergency department usage, unplanned hospital admissions, and timeliness of care.

Subsequent studies informed by our findings include replication using a larger sample derived from multiple institutions and validation of patient reports including the presence or absence of a patient navigator. Furthermore, our study encourages additional investigation of the effects of intervention, phase of treatment, provider type, number of providers, team-based care, and disease type/stage on patient reports of CC. Future research should examine associations between objective measures (eg, compliance with therapy, unplanned hospital admissions, timeliness of care) and patient reports of CC. Examining correlations of patient satisfaction with CC will expand the scope of the current study and provide additional information regarding patient reports of the quality of care delivery.

Implications

From a policy perspective, improving CC has emerged as a key strategy for enhancing the quality and value of health care. As clinicians and policymakers search for ways to transform our cancer care delivery system, incorporating patients’ perspectives is critical to ensure that the efforts to improve CC are informed by patients and their needs. To that end, a timely assessment of patients’ perceptions of their CC experiences can be an important first step in informing the effectiveness of current CC approaches and identifying potential areas that need improvement.

In the context of outpatient oncology care, our findings suggest that having a family caregiver is an important component of well-coordinated care. This information can inform current efforts to improve health care delivery by taking into account the critical roles informal caregivers play in coordination of care. Clinicians and providers can actively engage family caregivers and provide resources to them. Moreover, the gaps in CC may be more pronounced for patients without family caregiver support. We suggest that developing innovative ways to provide CC support for patients with limited family support, such as a targeted patient navigation intervention, might be useful.

Our findings highlight an important gap between recommended CC approaches and actual care. Patient navigator services are being widely implemented and may be particularly useful for addressing cancer health disparities in specific populations. However, with increased complexity of cancer treatment, the patient navigation services may outweigh available resources. It may be that if family/relative support is available, a formal patient navigator is less crucial, at least for the majority of patients.

For practices to provide high-quality, high-value care, understanding and integrating patients’ perspectives are important steps to optimizing cancer care delivery. As health systems increasingly emphasize patient-centered approaches to treat individuals, rather than diseases, integrating assessment and routine monitoring of patients’ CC experiences into existing clinic workflows and patient portals are recommended to inform efforts to improve cancer care delivery. To improve the quality of care delivery, the integration of a patient-centered CCI into oncology care may identify areas of potential interventions for CC improvement and lead to a better quality of care.

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PRIOR PRESENTATION

Portions of this article were presented at the American Society of Clinical Oncology Annual Meeting, Chicago, IL, May 31-June 4, 2019, and the American Society of Clinical Oncology Quality Care Symposium, San Diego, CA, September 6-7, 2019.

SUPPORT

This study was supported in part by Grant No. P30CA071789 and the University of Hawaii Cancer Center.

AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

Disclosures provided by the authors and data availability statement (if applicable) are available with this article at DOI https://doi.org/10.1200/JOP.19.00509.
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Conception and design: Izumi Okado, Kevin Cassel, Randall F. Holcombe
Financial support: Randall F. Holcombe
Administrative support: Izumi Okado, Kevin Cassel, Randall F. Holcombe
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Manuscript writing: All authors
Final approval of manuscript: All authors
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ACKNOWLEDGMENT
We gratefully acknowledge the following individuals for their contributions to this study: Erin Fukaya (University of Hawaii Cancer Center), Timothy Kelleher (Queen’s Health System), and Tracey Hewitt (Hawaii Pacific Health Cancer Center).

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AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

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Other Relationship: Merck

No other potential conflicts of interest were reported.