



Survey Instrument Says: Patients Care About Cancer Care Delivery

Healthcare delivery systems are rapidly evolving, and research on cancer care delivery expanded with the National Cancer Institute's emerging field, cancer care delivery research (CCDR). CCDR focuses on improving clinical outcomes and patient well-being by developing new and generalizable knowledge on patient, clinician, and organizational factors that influence care delivery. Patient-centered research is an important attribute of CCDR, and patient-centered care is highlighted as a hallmark of high-quality cancer care delivery. In this article, we describe patients' perspectives on participation in CCDR studies based on feedback and comments received from patients during our research. Insights reveal the importance and enthusiasm for CCDR studies expressed by patients, and their perspectives on these studies will inform future research and clinical practice toward high-quality, patient-centered care delivery.

Research on how we deliver healthcare has rapidly expanded in recent years. With nearly 1.7 million individuals diagnosed with cancer each year in the United States and the rising costs of care, cancer programs face considerable challenges to providing high-quality care for patients with cancer.^{1,2} Healthcare delivery for these patients is complex, because anticancer treatment often involves multimodal interventions, numerous providers, different care settings, and multiple transitions in care.³⁻⁵ Projected oncology workforce shortages also hamper efforts to improve cancer healthcare delivery.⁶ In response to evolving cancer health services research, the National Cancer Institute Community Oncology Research Program (NCORP) developed CCDR as “a multidisciplinary science that seeks to improve clinical outcomes and patient well-being by intervening on patient, clinician, and

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organizational factors that influence care delivery.”⁷ Importantly, CCDR focuses on developing new and generalizable knowledge about the effectiveness, acceptability, cost, optimal delivery mode, active ingredients, and causal mechanisms that influence outcomes and affect the value of cancer care across diverse settings and populations.⁴ As described in a recent commentary by Geiger et al.,⁸ under NCORP, CCDR has evolved to address a diverse range of research topics, study designs, patient populations, and outcomes.

Patient-Centered CCDR

As stated above, patient-centered research is recognized as an important attribute of CCDR. According to a review article by Kent et al.,⁴ CCDR studies are most likely to have the greatest impact on practice change if they encompass patient-centered attributes, including saliency of problems to patients and clinicians, incorporation of diverse patient populations and settings, and implementation into real-world practice. Consistent with this perspective, at a 2019 National Cancer Policy Forum workshop, attendees identified augmentation of the patient voice in routine

cancer care delivery as a potential strategy to improve the efficiency and overall quality of care delivery.⁹ Many CCDR studies include patient-reported outcomes; patient-reported outcomes address patient-reported symptoms, quality of care, and functional assessment, and they are increasingly integrated into routine clinical care and research.¹⁰ Other examples of patient-centered CCDR include studies focused on financial hardship and financial toxicity, patient navigation, cancer screening and prevention, and survivorship.¹¹⁻¹³

Another important area in CCDR is care coordination. Despite rapid advances in anticancer therapies and declining cancer mortality,² prior research indicates that many patients with cancer receive poorly coordinated care.¹⁴ Given the complexity of care coordination involved with cancer treatment, it is not surprising that lack of care coordination is identified as one of the challenges patients and families experience during their cancer care journey.

Patients' Perspectives on CCDR Participation

Though patient input is recognized as important to derive meaningful practice changes through CCDR, few studies have examined patients' perspectives regarding participation in CCDR studies. A better understanding of patients' experiences with CCDR participation provides important insights to inform the development of future CCDR studies. To that end, this commentary provides a broad view of patients' motivations for participation, benefits gained from participation, and suggestions for future research derived from our studies on cancer care coordination.

Our Methods

Since 2018 we have conducted investigator-initiated CCDR studies at University of Hawaii Cancer Center, a National Cancer Institute-designated cancer center. This cancer center is also an NCORP Minority and Underserved Community Site. In the course of these studies, we have developed, validated, and refined a Care Coordination Instrument for patients with cancer (Figure 1, right)^{15,16} and created and tested a parallel instrument for family caregivers (Figure 2, page 55).¹⁷ Nearly 400 patients on active therapy have participated in our studies, which, in addition to survey administration, included both focus group discussions and interviews. Throughout, we have gained an understanding about patients' perspectives on care coordination, as well as their thoughts on participation in CCDR studies. Because this article is a commentary, we did not obtain institutional review board approval. The research studies referenced in this commentary are approved by our institution's institutional review board.

To summarize patients' perspectives of CCDR participation, we first reviewed all transcripts of focus group discussions from our prior research,¹⁵ email communications, and responses to open-ended questions incorporated in the survey. Next, we identified patients' comments that specifically addressed CCDR participation and organized their comments into major themes.

Our Results

Four major themes emerged from our content analysis: (1) CCDR participation: motivation, (2) CCDR participation: benefits, (3)

Figure 1. Patient Care Coordination Instrument

For each of the questions, respondents are asked to check the box for the response that best applies to their experiences with care coordination. Response options range from *strongly agree* to *strongly disagree*. Two representative questions from each of the three domains are listed below:

Domain 1. Communication

- My oncologist explains different treatment options to me.
- I know which of my doctors to call if I have questions or any complications from my treatments.

Domain 2. Navigation

- I have a family member, a close relative, or a friend who helped coordinate my cancer care.
- I was provided information or received assistance for any emotional, financial, or social issues that might be of concern to me.

Domain 3. Operational

- It was easy to schedule visits with my primary oncologist.
- When I call my oncologist, I receive a return call in a timely fashion.

Editor's Note: The full patient care coordination instrument is available upon request from the authors: iokado@cc.hawaii.edu.

reflections, and (4) future directions. These themes are described below, with examples of patients' comments illustrating each.

CCDR Participation: Motivation

Consistent with UK-based research findings regarding altruistic motivation among research participants with cancer,¹⁸ many patients described their motivation to participate in CCDR studies as wishing to help other patients with cancer in the future. For some patients, CCDR participation also served as an indirect means to communicate their experiences to inform clinical practice.

"I am interested in joining your discussion group and participating in the cancer care improvement study. Anything to help us going forward and those in the future in need of care."

"I think it's really good you're doing this survey because I hope doctors learn from it. ...If this information ever gets out to them of what patients really need. It's not just the medical, I'm taking care of your cancer. There's so much more. And that just having a good oncologist isn't enough."

Figure 2. Caregiver Care Coordination Instrument

For each of the questions, respondents are asked to check the box for the response that best applies to their experiences with care coordination. Response options range from *strongly agree* to *strongly disagree*. The 27 items in this instrument are parallel to those in the patient instrument. Two representative questions from each of the three domains are listed below:

Domain 1. Communication

- The role of doctors from different specialties is clearly explained to my family member and/or friend.
- The oncologist always reviews past and current medical history with my family member and/or friend.

Domain 2. Navigation

- My family member and/or friend was informed of financial aspects of cancer care.
- I feel like the oncologist thinks about my family member's/friend's living situation when planning treatments.

Domain 3. Operational

- I have trouble scheduling an appointment at the time and date that is good for my family member/friend.
- The oncologist had all of the information he or she needed, such as test results, to make decisions about my family member's/friend's treatment.

Editor's Note: The full caregiver care coordination instrument is available upon request from the authors: iokado@cc.hawaii.edu.

Reflections

Participation in CCDR focus groups provided opportunities for some participants to reflect on their cancer care experiences. An advantage of focus groups is that they can serve as an opportunity for participants to learn about others' experiences and diverse opinions,¹⁹ because these discussions served to bring new insights on their care experiences:

"The questions and group discussion made me more aware and appreciate the good care I received while undergoing cancer treatment."

"I think there's a lot to be desired in how they [providers] are doing things. There's a lot of good, but there's a lot to be desired."

Future Directions

In our CCDR studies, most patients expressed interest in participating in future studies. Of all of the participants, more than 95 percent requested future updates and communication from the research team, and many patients have periodically contacted the research team after conclusion of these CCDR studies to inquire about opportunities to participate in additional projects:

"I consider this program extremely valuable, thus, important to write to you. If you still need volunteers to talk story, complete a survey, or whatever you might need, please let me know. I am available to you."

"I am happy to support those whose mission is to improve cancer care. Please contact me in the future if you need anything more."

Additionally, a major theme on patient navigation emerged regarding suggestions for future research. In our CCDR studies, many patients indicated that they have not heard of a patient navigator or of patient navigation services. For those participants, upon learning about patient navigation services from other focus group participants, this was identified as a gap and need for future studies:

"[We need] something that addresses this navigator that everybody says exists, but [who] hides in a closet."

Our Limitations

There are limitations with this commentary. Patients with cancer in our CCDR studies were derived from community-based oncology practices and hospital outpatient treatment clinics; thus, generalization could be limited to patients receiving inpatient services or those seen in academic settings. Participation in CCDR studies may not be feasible for some patients who require intensive therapy and/or hospitalization, and those who participate in interventional studies may have varied experiences with research participation. Further, our CCDR projects were primarily observational and included focus groups and survey administration. It may be that because the time and effort required from participants were minimal, patients with cancer in our prior CCDR studies were more willing to participate in future studies.

CCDR Participation: Benefits

In contrast to clinical intervention trials where patients may receive new therapy, participation in CCDR studies, particularly those that are observational, often provides minimal direct benefit to patients. That said, many patients in our CCDR studies provided extensive positive feedback, indicating that they enjoyed and perceived benefits from participation. Focus groups provided an opportunity for patients to not only participate in the research process (refining the Care Coordination Instrument) but also describe their care coordination experiences, as well as discuss and share their thoughts with other focus group participants:

"I wanted to let you know how much I enjoyed the focus group last evening."


"This is very good and informative."

"Thank you for the opportunity to join this study."

Discussion

This commentary summarizes major themes regarding how patients with cancer view participation in CDDR. Overall, patients perceived many positive aspects of CDDR participation and expressed enthusiasm about participating in these studies. Participation in CDDR studies provided benefits to participants, including opportunities to contribute to research for altruistic motivations; to reflect on their care experiences; to learn new information, such as patient navigation services; and to discuss and receive support regarding their concerns about care delivery among focus group participants. Importantly, patients recognize the value and need for CDDR studies, and they are willing to contribute to efforts to improve the quality of cancer care delivery.

As we focus on enhancing patient-centered care, future healthcare delivery studies focused on cancer care should incorporate patients' perspectives and explore strategies to improve patients' experiences with care delivery. Integrating patients' needs and preferences with respect to cancer care delivery will lead to improved quality and value of care—something our patients clearly desire.

Potential implications of this commentary include increased role and participation of cancer patients in healthcare delivery research, improved cancer care quality, greater focus on a patient-centered care model of delivery, and greater patient satisfaction. Future research incorporating patients' perspectives of cancer care coordination is warranted to improve the value and quality of healthcare delivery for oncology patients. 

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References

- Mariotto AB, Yabroff KR, Shao Y, et al. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst.* 2011;103(2):117-128.
- Siegel RL, Miller KD, Jemal A. Cancer statistics, 2020. *CA Cancer J Clin.* 2020;70(1):7-30.
- Balogh EP, Ganz PA, Murphy SB, et al. Patient-centered cancer treatment planning: improving the quality of oncology care. Summary of an Institute of Medicine workshop. *Oncologist.* 2011;16(12):1800-1805.
- Kent EE, Mitchell SA, Castro KM, et al. Cancer care delivery research: building the evidence base to support practice change in community oncology. *J Clin Oncol.* 2015;33(24):2705-2711.
- Nekhlyudov L, Levit L, Hurria A, Ganz PA. Patient-centered, evidence-based, and cost-conscious cancer care across the continuum: translating the Institute of Medicine report into clinical practice. *CA Cancer J Clin.* 2014;64(6):408-421.
- Ganz PA, Hassett MJ, Miller DC. Challenges and opportunities in delivering high-quality cancer care: a 2016 update. *Am Soc Clin Oncol Educ Book.* 2016;35:e294-e300.
- National Cancer Institute. NCI Community Oncology Research Program (NCORP) Cancer Care Delivery Research (CDDR). Available online at: <https://healthcaredelivery.cancer.gov/ccdr/>. Last accessed April 28, 2020.
- Geiger AM, O'Mara AM, McCaskill-Stevens WJ, et al. Evolution of cancer care delivery research in the NCI community oncology research program. *J Natl Cancer Inst.* 2020;112(6):557-561.
- Takvorian SU, Balogh E, Nass S, et al. Developing and sustaining an effective and resilient oncology careforce: opportunities for action. *J Natl Cancer Inst.* 2020;112(7):663-670.
- Basch E, Snyder C, McNiff K, et al. Patient-reported outcome performance measures in oncology. *J Oncol Pract.* 2014;10(3):209-211.
- Stankowski-Drengler TJ, Neuman HB. Cancer care delivery research: a path to improving the quality of oncologic surgical care. *Surg Oncol Clin N Am.* 2018;27(4):653-663.
- Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. *J Clin Oncol.* 2016;34(3):259-267.
- Freund KM, Battaglia TA, Calhoun E, et al. Impact of patient navigation on timely cancer care: the patient navigation research program. *J Natl Cancer Inst.* 2014;106(6):dju115.
- Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, Board on Health Care Services, Institute of Medicine. *Delivering high-quality cancer care: charting a new course for a system in crisis.* Washington, DC: National Academies Press; 2013.
- Okado I, Cassel K, Pagano I, Holcombe RF. Development and psychometric evaluation of a questionnaire to measure cancer patients' perception of care coordination. *BMC Health Serv Res.* 2020;20(52):1-11.
- Okado I, Cassel K, Pagano I, Holcombe RF. Assessing patients' perceptions of cancer care coordination in a community-based setting. *J Oncol Pract.* 2020;16(8):e726-e733.
- Okado I, Pagano I, Cassel K, Holcombe RF. Perceptions of care coordination in cancer patient-family caregiver dyads. *Support Care Cancer.* 2020;Sep 24. doi: 10.1007/s00520-020-05764-8. Epub ahead of print. PMID: 32970231.
- McGrath-Lone L, Ward H, Schoenborn C, Day S. The effects of cancer research participation on patient experience: a mixed-methods analysis. *Eur J Cancer Care (Engl).* 2016;25(6):1056-1064.
- Frazier LM, Miller VA, Horbelt DV, et al. Comparison of focus groups on cancer and employment conducted face to face or by telephone. *Qual Health Res.* 2010;20(5):617-627.