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COMMENTARY/POSITION PAPER

# Cancer care coordination: opportunities for healthcare delivery research

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## Abstract

In this commentary, we discuss opportunities to explore issues related to care coordination at three points on the cancer care continuum: (1) screening, particularly coordinating follow-up for abnormal findings, (2) active treatment, particularly challenges for patients with multiple chronic conditions, and (3) survivorship, particularly issues related to facilitating shared care between oncology and primary care. For each point on the continuum, we briefly summarize some of the important coordination issues and discuss potential avenues for future research in the context of existing evidence.

## Keywords

Cancer, Care delivery, Coordination

## INTRODUCTION

Care coordination is an important issue for people being screened for cancer, for those who are or have been treated for cancer and their loved ones, and for the clinicians and health system leaders working to provide high-quality cancer care. Achieving the aim of high-quality care that includes appropriate screening, timely follow-up, multimodality treatment, supportive care, and survivorship care requires well-coordinated approaches to care delivery [1, 2]. Coordination means synthesizing care goals and decisions across the multiple groups involved in patient care, as well as mutually aligning, timing, and adapting key care tasks among different care teams or team members over time [3–6]. Although progress has been made, recent data underscore that these are not easy tasks in an inherently complex healthcare delivery system. For example, studies continue to highlight opportunities to improve follow-up for abnormal screening results, particularly for abnormal fecal occult blood tests and cervical cancer screenings [7, 8]. Studies of care delivery processes and patient experiences also indicate that patients, caregivers, and clinicians are doing significant "invisible work" to coordinate care [9–13]. This includes time spent working around system barriers (e.g., noninteroperable medical record systems, lack of decision support, suboptimal communication systems, and increasing panel sizes) that hinder coordination among the network of health systems, clinicians, patients, and caregivers that collectively coordinate care. The costs and benefits of this invisible work on quality of life, productivity, and other outcomes for patients, clinicians, and health systems are not well quantified, but likely unsustainable.

Health care delivery research, including several articles in this special issue, demonstrates the complexity of coordinating care for people with cancer and propose some promising interventions. However, much remains to be learned. Recent reviews of care coordination interventions point to limited conceptual and measurement coherence across the existing body of evidence [14, 15]. This situation inhibits comparisons across studies and results in variable, sometimes contradictory, estimates of coordination intervention effectiveness. One path toward conceptual and measurement coherence is to more clearly differentiate coordination mechanisms (i.e., tools and strategies used to time, align, and integrate information, decisions, and actions) from coordinated activity (i.e., behaviors involved in carrying out coordinated actions), the emergent conditions, or cognitive states that facilitate coordination (i.e., shared accountability, shared mental models, and trust), and "well-coordinated care" as an outcome [16].

With this simple framework in mind, the articles in this special issue collectively underscore three key areas that healthcare delivery research is well poised to address:

(i) Identifying coordination demands across the cancer care continuum, as well as mechanisms that facilitate or hinder effective coordination over time in different practice environments for different patient populations.
(ii) Developing and testing interventions that facilitate coordination and help patients, caregivers, clinicians, and health system leaders to manage the complexity of care delivery, including understanding how, when, and where to implement and disseminate such interventions.
(iii) Developing valid and reliable metrics useful for understanding the mechanisms underlying care coordination problems and for evaluating the impact of interventions designed to improve them.

In this commentary, we discuss opportunities to explore these issues at three points on the cancer care continuum: (a) screening, particularly coordinating follow-up for abnormal findings, (b) active treatment, particularly challenges for patients with multiple chronic conditions, and (c) survivorship, particularly issues related to facilitating shared care between oncology and primary care. For each point on the continuum, we briefly summarize some of the important coordination issues and discuss potential avenues for future research in the context of existing evidence.

## SCREENING: COORDINATING FOLLOW-UP TO ABNORMAL FINDINGS

Early detection is an important tool in the effort to reduce the burden of cancer both in the USA and globally. Evidence-based screening practices implemented among appropriate populations is associated with decreased mortality for colorectal, breast, lung, and cervical cancers and endorsed by the U.S. Preventive Services Task Force [17]. Screening is a process not a singular event, however, that requires coordination, communication, and cooperation across multiple clinicians, patients, caregivers, and payers [18, 19]. Breakdowns in this process can inhibit or delay follow-up, may result in duplicative or unnecessary testing, and create needless distress for patients and their loved ones [20–22]. Lack of follow-up can also perpetuate disparities in receipt of timely, high-quality care, as well as disparities in cancer-related mortality among minority and underserved populations [20, 23, 24]. In their 2013 report on the cancer care delivery system [6], the Institute of Medicine (now the National Academies) identified the need to effectively bridge transitions in care, including transitions from screening to diagnosis, as one of the several critical improvement opportunities.

Identifying effective approaches to address the barriers to timely, appropriate screening follow-up is not straightforward. There is no single or primary root cause underlying lack of follow-up and the contributing factors vary widely across cases. Existing data continually point to multiple factors at the patient-, provider-, and health system-levels that interact to result in lack of follow-up or significant delays [21, 22]. For example, patients may have to cancel follow-up appointments due to work or other responsibilities, and it may be difficult to reschedule during available appointment hours. Large panel sizes also compress follow-up appointment availability [25]. Additionally, the healthcare delivery infrastructure within a patient's local neighborhood, their insurance coverage (or lack thereof) and care options afforded by the associated provider networks, transportation limitations, and other factors may limit access to specialist follow-up services and increase the burden associated with seeking follow-up care.

These multilevel challenges require multilevel interventions that address the combination of factors contributing to gaps in follow-up for abnormal cancer screening. Designing such interventions requires first identifying the coordination demands (i.e., interdependencies) among the key players involved in the provision of follow-up care, as well as determining who and how these interdependencies will be navigated. For many patients, follow-up care involves first making the decision to seek follow-up testing, obtaining a referral from a primary care provider, checking insurance coverage if applicable or considering financial resources to cover testing, then scheduling testing with a specialist, imaging provider, or lab that, often, is not located in the same office as the primary care provider. Schedule, transportation, and other arrangements must be made to complete the appointment. The samples or images must be read and interpreted by relevant specialists and reports appropriately shared. Finally, many patients may then return to their primary care providers to learn results and discuss options, if necessary. For many patients and the clinicians involved in their care, the interdependencies involved in navigating the space in between screening and completion of follow-up are not necessarily immediately apparent. Additionally, the nuances of who they need to connect with, as well as how and when they need to do so, to complete these steps are not always clear.

Patient and community education programs, reminder interventions, screening-oriented navigator programs, and integrated care models offering on-site testing are promising approaches for addressing some of the individual, social, and health system barriers to follow-up [26, 27]. However, we still know relatively little about if, how, and for whom it is best to combine these types of interventions (or others) in order to effectively deliver guideline appropriate, high-quality follow-up care. We also know little about how these interventions affect the interactions among clinical care team members and their communications with patients or caregivers, or how these interventions affect care team, organizational, and population-level outcomes. Conversely, evidence examining how care team, organizational, or policy factors affect the effectiveness and efficiency of interventions designed to improve coordination during the transition from screening to diagnosis is also needed. Identifying the moderating and mediating mechanisms that influence the effectiveness of multilevel screening interventions is vital for identifying what approaches to abnormal screening follow-up work best, for whom, and under what circumstances. For example, two articles in this special issue draw attention to insurance deductibles and copays as likely partial mediators of decisions about if, when, and where to pursue follow-up among insured patients [28, 29].

Although addressing gaps in appropriate follow-up to abnormal screening is an important issue, conversely, we also must understand how to best address the issues of overscreening and inappropriate follow-up care, particularly among older populations [30]. This is an opportunity to think of care coordination issues at a broader population health level and to ask questions about how changes to clinical guidelines and practice norms—especially changes involving deimplementation of a given clinical practice—spread across clinical teams, practices, health systems, and disciplines [31, 32].

## TREATMENT: COORDINATING CARE FOR PATIENTS UNDERGOING ACTIVE TREATMENT

Poor care coordination during cancer treatment is associated with medical errors and sentinel events, poor symptom control, less-comprehensive supportive care, and increased utilization and costs [33–39]. Coordinating comprehensive cancer treatment is increasingly complex as the range of specialists involved expands and recommendations to provide timely supportive care increase. The Institute of Medicine points out that 18 or more different clinical disciplines or roles may be involved in comprehensive cancer care [6]. The study of patients with newly diagnosed diffuse large B-cell lymphoma included in this special issue, for example, found that these patients were more likely to visit cardiologists, endocrinologists, pulmonologists, and their primary care providers during the period of treatment compared with noncancer patients [28]. For many patients, treatment involves coordination across inpatient, outpatient, home care, and community pharmacy sites. For some, it also includes coordination across multiple health systems (e.g., women veterans with gynecologic malignancies receiving care through both Veterans Affairs and community providers) [40, 41].

For 4 out of 10 cancer patients, care coordination during treatment also requires consideration of one or more comorbid chronic diseases [42]. This number is likely to rise with the aging of the population, as well as an earlier onset of diabetes and other conditions among some populations of adolescents and young adults. Among people with confirmed cancer diagnoses, comorbidity is associated with lower odds of receiving curative treatment [43, 44], poorer survival [45], adverse events [46], hospitalization [47], and higher costs [48].

Comorbidities introduce additional complexity in treatment planning, as well as the coordination of curative and supportive care. Patients with comorbid conditions may require more vigilant monitoring, coordination among a wider range of providers, and more frequent adjustments in care plans or goals. Medication management and reconciliation, as well as barriers to information sharing among multiple providers, may require additional supervision. Shared mental models about who is managing what aspects of care and how these different components of care will be integrated may take more mindful effort to initially establish or to adapt as treatment plans or patient goals change.

Evidence about how to best plan and coordinate comprehensive cancer care for people with comorbid conditions is lacking. This is particularly true for patients who may be seeking care in rural or medically underserved locations. As Sarfati and colleagues point out in a recent review examining cancer care for patients with comorbidities, consensus about how to "record, interpret, or manage" comorbidities is limited [49, 50]. Given that these patients are often not eligible for traditional treatment trials, their situation also highlights the few cancer treatment guidelines that explicitly consider interactions with comorbidities, or the implications of different treatment approaches on the short- and long-term management of noncancer conditions. Many oncology clinicians do not feel well-equipped to manage comorbidities and referrals to primary care or other specialists are unlikely to solve the care fragmentation problem that many of these patients already encounter.

One important question is: what interventions or care models are most effective for coordinating comprehensive care during cancer treatment, particularly for patients with other chronic conditions? Recent reviews of cancer care coordination interventions, including one in this special issue [41], find that patient navigation, designated care coordinators, and collaborative care models are some of the more common approaches evaluated to date [14, 16]. However, heterogeneity among intervention components and outcomes limits conclusions about what approaches work best for which patients, how to best sustain these interventions over time, or how to most effectively adapt such interventions for specific patient needs. Additionally, these reviews demonstrate that few studies to date explicitly examine the impact of care coordination interventions among patients with comorbidities.

There are models we can learn from. For example, chronic care models and related interventions in other domains, including geriatrics, renal, cardiovascular, and behavioral health, may provide a foundation for testing similar approaches in cancer [31, 51]. Efforts to integrate comprehensive geriatric assessments into the care of older cancer patients are one such example. The evidence to date suggests that implementing these assessments can inform treatment decision making and comorbidity management, which may help reduce treatment modifications and facilitate treatment completion [52]. Cancer treatment models that integrate endocrinologists and diabetes educators directly into treatment planning and monitoring for cancer patients with diabetes [53] and strategies designed to facilitate early integration of supportive care are other promising examples [54].

As the range of clinical disciplines and specialties engaged in patient care during cancer treatment grows, research that helps identify the models and interventions that optimize efficient coordination among them continues to be needed. Identifying promising interventions is not enough. Again, the science must help us understand why particular approaches work, for whom, and within what contexts they work best. For example, studies testing mediation and moderation hypotheses grounded in behavioral frameworks of teamwork processes [55, 56] are useful for understanding what intervention features influence how care team members work together and, in turn, how teaming behaviors and cognitive states (e.g., communication and shared mental models) affect patient outcomes. Similarly, studies examining the role that patients and caregivers play as boundary spanners between different specialties, providers, and payers will inform our understanding of the full range of interdependencies involved in coordinating cancer care. This type of work is particularly needed to understand how coordination demands during treatment vary by population (e.g., among rural and underserved populations) and by patient characteristics (e.g., type and number of comorbidities, social support, health, and care goals).

## SURVIVORSHIP: COORDINATION AND SHARED CARE POSTTREATMENT

The number of people living with a cancer diagnosis continues to grow and is expected to reach 20 million in the USA by 2026 [57]. Several factors are contributing to these growing numbers including the aging of the population, implementation of cancer screening and surveillance programs, and advances in the treatment of selected cancers. Although all individuals living with a cancer diagnosis can be considered cancer survivors, the field of cancer survivorship has a primary focus on a subset of survivors who are completing or have completed active cancer treatment (e.g., surgery, chemotherapy, radiotherapy, immunotherapy, and/or stem cell transplantation) [58].

A key event in the early development of the field of cancer survivorship was the publication in 2006 of an Institute of Medicine report entitled, “From Cancer Patient to Cancer Survivor” [59]. Among the report’s major conclusions was that cancer, and its treatment, can have serious long-term effects on health and well-being, and that the transition from active treatment to posttreatment care is critical to the long-term health of cancer survivors. The report also concluded that many patients do not receive the follow-up care they should. As reflected in the report’s subtitle, it described these patients as being “Lost in Transition.”

The report offered several recommendations designed to address the needs of patients in the posttreatment period. Among the most prominent was a recommendation that patients completing active treatment be provided with a comprehensive care summary and survivorship care plan that addresses as follows: surveillance for recurrence and new cancers; assessment and treatment or referral for persistent effects (e.g., pain and employment issues); evaluation of risk and prevention of late effects (e.g., cardiac problems); health promotion (e.g., diet and physical activity); and coordination of care (e.g., identification of providers of follow-up care).

The idea of providing patients with a survivorship care plan was subsequently embraced by a number of professional organizations [60] and accrediting bodies [61]. To date, however, the extent of implementation has been limited [62, 63]. Barriers to implementation include the time and resources required to prepare a survivorship care plan and the difficulty of capturing critical information [64, 65]. The limited evidence from randomized studies that providing patients and other health care providers with a survivorship care plan improves health outcomes [66] has also impeded adoption.

In retrospect, the likelihood that preparing and providing a document to patients and providers would result in improved outcomes many months or years later and successfully address complicated care coordination issues seems unrealistic. Rather than studying the impact of survivorship care plans, there is growing recognition that the focus should be on studying models of survivorship care, of which survivorship care plans are just one component [67]. From a care delivery perspective, the key issues to address are as follows: what should be delivered as part of survivorship care, who should deliver it, and where should it be delivered.

The involvement of primary care providers is now regarded as a central issue in survivorship care given the growing demand for acute cancer treatment services that is taxing existing resources, the rising prevalence of comorbid conditions among cancer survivors, and the increased emphasis on value in U.S. medical care reimbursement policies [68]. Along these lines, an article in this special issue examines the potential for patient-centered medical homes to provide some aspects of cancer survivorship care [69]. There is considerable interest in a shared-care approach that has been developed to treat other chronic diseases. In this model, care is shared among specialists and generalist providers, roles are clearly delineated, and ongoing communication is established [70]. It should be noted, however, that studies of this approach in chronic illness have, to date, yielded limited evidence of clinical benefit [71]. One refinement of this existing approach for cancer is the concept of risk-stratification, with the timing and extent of shared care tailored to the needs of individual patients based on factors such as the intensity of previous treatment, the risk of recurrence, and the extent of existing treatment-related toxicity [70]. Accordingly, survivors at low risk would have aspects of their medical care transitioned sooner and to a greater extent to a primary care provider, whereas patients at moderate or high risk would have their care transitioned later and to a lesser extent to primary care.

Despite the importance of evaluating different models of survivorship care delivery, there has been relatively little research, to date, on this topic [67]. Although trials are ultimately needed that compare the impact of different care models on health outcomes and health care utilization, there is much preliminary work that need to be done, especially for the evaluation of shared care. Critical background work includes as follows: defining the provider behaviors that reflect shared care of cancer survivors (e.g., delineation and completion of tasks), specifying the processes and mechanisms that oncology specialist and primary care providers should use to facilitate shared care (e.g., verbal and written communications), and identifying the cognitive states (e.g., shared goals) and interpersonal factors (e.g., trust) that facilitate effective sharing of care. Completion of this work would set the stage for comparative trials of care models that are likely to be more meaningful and yield more definitive results about the potential benefits of shared care of cancer survivors than current evidence provides.

## CONCLUSIONS

Numerous opportunities for future research are highlighted in the articles in this special issue and the broader care coordination landscape. We discussed just a few examples of these opportunities here. Funding organizations with interest in this area include the NCI's Healthcare Delivery Research Program (HDRP). HDRP's mission is to advance innovative research to improve the delivery of cancer-related care [72]. To this end, HDRP is interested in science that advances understanding about the care coordination burden, interventions, and care delivery strategies that improve coordination and effective teaming across the care continuum, and understanding the methods and metrics best suited to studying care coordination issues and interventions.

There are several existing NIH funding opportunities that focus on understanding and addressing care coordination challenges during screening, treatment, and survivorship (see the NIH Guide for PAR-17-146, PA-17-109/110, PAR-16-391/392, PA-16-012/011 as examples). Additionally, NCI supports several relevant research consortia. For example, the Population-based Research to Optimize the Screening Process (PROSPR) consortium has focused on evaluating and improving the screening process for cervical, colorectal, and breast cancers [73]. Cancer care delivery research is also conducted within the NCI Community Oncology Research Program (NCORP), a network comprised of seven research bases and 46 community sites across the USA [74].

Overall, this special issue underscores that significant attention and research has focused on coordination issues since several seminal reports highlighted problematic fragmentation in the delivery of cancer care. As summarized above, numerous opportunities still exist for reducing care fragmentation and enhancing coordination of care during cancer screening, treatment, and survivorship. Addressing these issues will require observational, interventional, and metric development research that leverages the expertise of scientists and clinicians across multiple disciplines. By pursuing this research agenda, it should be possible to develop novel approaches that more effectively coordinate the increasingly complex nature of cancer care and thereby improve health outcomes for all people affected by cancer.

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