Providing Care for Cancer Survivors in Integrated Health Care Delivery Systems: Practices, Challenges, and Research Opportunities

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Abstract

Purpose: Optimal approaches to cancer survivorship care are needed. This study sought to identify practices, barriers, and research opportunities in meeting the care needs of cancer survivors in integrated health care delivery systems.

Methods: This study was conducted at 10 sites within the Cancer Research Network, a National Cancer Institute–funded consortium of integrated health care delivery systems providing care for nearly 11 million enrollees. We identified 48 clinical leaders, administrators, and providers in oncology, primary care, nursing administration, and specialty care. Forty (83%) completed semi-structured, audio-recorded, transcribed telephone interviews, which we analyzed using an immersion-crystallization approach.

Results: Respondents were aware of the needs of cancer survivors and the difficulties they face in transitioning from treat-

ment to follow-up care. Respondents from all sites reported that oncology and primary care are jointly responsible for the care of cancer survivors, often through the use of electronic medical records. Many respondents were not familiar with standardized survivorship care plans. Only two sites had formal cancer survivorship programs in place, and two were developing such programs. Respondents at sites with and without programs acknowledged existing gaps in evidence on the effectiveness of formal survivorship care and expressed a desire for additional research.

Conclusion: Our exploratory study suggests an awareness of cancer survivorship care in integrated health care delivery systems, although approaches to providing such care vary across systems. These settings may offer a unique opportunity to develop, test, and implement innovative models of care, which can be systematically evaluated to inform and enhance cancer survivorship care in diverse health care settings.

Introduction

Improvements in cancer screening and treatment have decreased cancer mortality¹ and improved survival rates for patients with many common cancers.² Overall population growth has also contributed to increased numbers of cancer survivors. Of the nearly 12 million cancer survivors in the United States, more than half have survived at least 5 years, and more than 1 million have survived at least 20 years.² This growing population of cancer survivors requires follow-up to detect recurrences and new primary tumors, diagnose and treat late effects of cancer treatments,^{3,4} maintain appropriate self-care for residual impairments of cancer treatments,⁴ foster self-management,⁵ address non-cancer-related health problems, and promote healthy behaviors, especially those that reduce cancer risks.⁶⁻¹¹ In addition, in its report *From Cancer Patient to Cancer Survivor: Lost in Transition*, the Institute of Medicine (IOM) recognized the importance of researching and optimizing the delivery of care to cancer survivors, particularly the coordination of care between specialists and primary care providers.¹²

Current approaches to cancer survivorship care include: shared care among primary care and specialty providers,¹³ disease-specific programs,^{13,14} and formal comprehensive survivor programs.^{13,14} Evidence about the comparative and cost effectiveness of these approaches is lacking.^{12,15} Furthermore, much of the research on cancer survivorship care has focused on care provided at academic and community-based cancer centers.^{13,16} Studying survivorship care practices across health care systems is essential. There is growing interest from the National Institutes of Health in conducting comparative effectiveness research within integrated health care delivery systems, which offer comprehensive utilization data and electronic medical records (EMRs).¹⁷ These attributes are conducive to developing, testing, and implementing innovative approaches to cancer survivorship care that may be translated into other community-based clinical practices. The aims of this qualitative study were to describe integrated health care leadership perspectives on: one, the needs of cancer survivors; two, current practices in cancer survivorship care; three, barriers to providing care for cancer survivors; and four, areas for future research aimed at improving cancer survivorship care. We chose to focus on the

perspectives of administrators and clinicians with leadership responsibilities because they are in the position to make decisions about the structure, policies, and processes of care within their organizations. Their perspectives about organizational priorities and future directions are likely to yield insights that will shape efforts to optimize survivorship care and inform survivorship research.

Methods

Setting and Participants

This study was conducted within the Cancer Research Network (CRN).^{18,19} Funded by the National Cancer Institute, the CRN consists of research programs, enrolled populations, care delivery systems, and data systems of 14 integrated health care delivery systems across the United States. The CRN studies cancer prevention, early detection, treatment, long-term care, surveillance, survivorship, palliative care, end-of-life care, cancer communication and dissemination, and translation and implementation. All CRN sites were approached for participation, and 10 sites participated: Geisinger Health Plan (Pennsylvania), Group Health (Washington), Harvard Pilgrim Health Care Institute/Harvard Vanguard Medical Associates (Massachusetts), HealthPartners (Minnesota), Henry Ford Health System (Michigan), Kaiser Permanente Colorado, Kaiser Permanente Hawaii, Kaiser Permanente Northwest (Oregon and Washington), LCF Research (New Mexico), and Marshfield Clinic (Wisconsin). Each participating CRN site considered its local institutional review board (IRB) processes and CRN infrastructure IRB approval. When required or not covered by the CRN infrastructure IRB approval, local IRBs reviewed the study. Approvals were either obtained or waived.

The principal investigator (PI) of each site identified three to six key informants to invite for in-depth interviews. PIs were asked to identify department chiefs, department managers, and other leaders and clinicians in oncology, specialty care, primary care, and nursing administration. Cancer survivorship program leaders were approached if site PIs identified programs at their sites. In certain circumstances, other key informants were identified either by the site PIs or by the invited participants. As a result, key informants included a range of administrative leaders, clinical leaders, and individuals with leadership roles in the design and implementation of cancer care.

Key Informant Interviews

The semi-structured interview guide was developed by a CRN-wide cancer survivorship scientific interest group and was pilot tested with two informants who were not included in the study sample. The final guide consisted of 16 questions with probes to encourage in-depth exploration of each issue (Appendix, online only). Topics included: processes of cancer survivorship care, opinions about formalizing cancer survivorship programs, challenges in providing survivorship care, cancer survivors' unmet needs, and future research opportunities. When introducing the study to participants, we defined a cancer survivor as a person who had completed primary cancer treatment, identi-

fied by the IOM as the phase of care requiring special attention.^{12,20} We defined a formal program as one with dedicated staff and specialized services.

Three investigators (J.C., L.T., C.H.) conducted telephone interviews with 40 key informants between June and October 2009. Interviews lasted from 30 minutes to 1 hour and were audio recorded with respondents' permission. Two research assistants familiar with medical terminology transcribed the interviews verbatim. Interviewers reviewed their transcripts for accuracy and filled in inaudible passages.

Qualitative Analysis

We analyzed interview transcripts using the immersion-crystallization approach, which included the following steps.²¹ Transcripts were first coded using the broad concepts embedded in the interview guide. Three authors (J.C., L.T., C.H.) then read through the transcripts and proposed a more detailed set of codes and discussed these codes to ensure a shared understanding of the definitions. The primary coder (L.T.) coded all of the interviews using this detailed code list. To ensure coding was consistent, two other coders (J.C., C.H.) coded five interview transcripts each, which the primary coder then compared and reconciled with her coding. Comparing and resolving coding discrepancies with these 10 transcripts provided assurance that team members agreed on the definition of codes and their application to the text. The primary coder finished coding the transcripts without further comparison. Our coding was inductive and iterative, identifying many themes. In coding memorandums, we summarized findings according to salient themes across all interviews with supporting quotes. In this report, we present the most prominent themes to highlight those that cut across sites and respondents. We chose not to compare site-by-site or interviewee role-by-role themes, because the aim of this study was to provide a summary of the care practices and research needs about survivorship care across integrated delivery systems. Atlas.ti Version 5.0 software was used for data management and coding (Berlin, Germany).

Results

Forty (83%) of the 48 potential informants personally invited by researchers in their respective health care systems agreed to participate in this study. Nonrespondents were more likely to work in oncology departments than in primary care. Respondents represented 10 of 14 CRN sites serving geographically diverse parts of the country and employing clinicians with training in diverse disciplines and working in varied practice settings (Table 1). The median number of respondents per site was four (range, two to six).

Needs of Cancer Survivors

All but one respondent identified unmet needs of cancer survivors. Many (n = 24) seemed to understand the difficulties for patients transitioning from active cancer treatment to follow-up care as they become cancer survivors.

Table 1. Professional Characteristics of Participants Interviewed About the Organization of Cancer Survivorship Care in Integrated Health Care Delivery Systems (N = 40)

Characteristic	No.	%
Training		
Physician	24	60.0
Nurse	11	27.5
Other (eg, physician assistant, social work)	5	12.5
Department affiliation		
Oncology	22	55.0
Primary care	9	22.5
Other (eg, surgery, administration)	9	22.5
Administrative or leadership role		
Yes	31	77.5
No	9	22.5
Member of survivorship committee/program		
Yes	6	15.0
No	34	85.0

“Some [patients] describe even more anxiety than when they were first diagnosed, that they are suddenly set loose . . . They’re used to the frequent contact with their care providers and with people in their lives who have been supporting them and suddenly, once treatment ends, people assume they’re back to normal and they really aren’t. They’re still adjusting.”

Sixteen respondents suggested that current care for cancer survivors does not adequately help survivors understand how to manage and coordinate their follow-up care.

“We don’t do a good job right now of making sure that patients actually know what’s next and who they should be seeing and why.”

Respondents reported that care for cancer survivors should address fear of recurrence, provide information about long-term effects of treatment, offer nutritional and exercise guidance, and provide additional psychosocial support (Table 2).

Organization of Cancer Survivorship Care

Of the 10 participating sites, two had formal cancer survivorship programs in place (one nurse-led program and one physician assistant–led consultative service). Both had dedicated funding and a provider that championed the program. Two other sites had programs under development.

Shared Care and Transitions Between Oncology and Primary Care

At all sites, participants stated that oncology and primary care shared provision of care for cancer survivors. Despite lack of standard approaches to sharing care between oncology and primary care, many respondents (n = 36) expressed that they transition patients between oncology and primary care settings once they complete cancer treatment.

“Our care presumes that there is a primary care provider involved in every patient’s care and cancer patients are not seen as different in that regard . . . Cancer providers at some point

make a hand-off to primary care, perhaps making some recommendations for ongoing surveillance or follow-ups and then it’s back in my hands for . . . subsequent visits.”

Some respondents (n = 25) mentioned that transitions, or hand-offs, between departments or care teams tended to be informally coordinated.

“It’s an expectation that when there is a hand-off it’s communicated and there’s a plan documented in the chart so that their primary care physician knows what the medical plan is for the patient. I’m not too sure if it’s formally written anywhere.”

Some respondents (n = 26) reported that EMRs were critical in coordinating and sharing care for cancer survivors. All but one of the 10 participating sites used EMRs.

Survivorship Care Plans

The IOM has recommended that all patients transitioning out of cancer treatment have a formal survivorship care plan consisting of a cancer treatment summary and follow-up care plan including a review of short- and long-term effects of therapy, surveillance for recurrence, recommendations for preventive lifestyle behaviors, resources for psychosocial services, and identification of clinicians responsible for follow-up care.²² Some respondents (n = 10) were not familiar with these plans, whether their organization had them, or the distinction between treatment summaries and summaries of individual office visits. Five of the 40 respondents reported that their sites used survivorship care plans, either in paper form or via patient Web portals, some of which were based on published guidelines or templates (eg, National Comprehensive Cancer Network, City of Hope, Dana-Farber Cancer Institute). However, some respondents voiced reservations about using care plans specific to cancer survivorship.

“There’s a lot of controversy around the use of survivorship care plans because they’re not real standardized and follow-up isn’t standardized.”

Management Tools Used by Providers

Some respondents (n = 10; six sites) reported that most of the tools used to manage survivorship care were for general prevention, screening, and treatment. Both oncology and primary care providers reported that EMRs helped them track the care their patients received and communicate with one another. Some respondents (n = 16; eight sites) reported relying on published guidelines available online from professional organizations, such as the American Society of Clinical Oncology and National Comprehensive Cancer Network for information about surveillance, medication and symptom management, and best care practices.

Approaches to Support Patients

Most of the patient tools mentioned were not specific to survivorship care. Respondents reported that their institution supported survivors by: providing health education or cancer care materials (eg, booklets, videos; n = 14; seven sites); hosting celebratory events for survivors finishing treatment (n = 13; six sites); hosting educational seminars on topics such as exercise,

Table 2. Representative Participant Quotes on Care Needs of Cancer Survivors (N = 40)

Need	Quote
Addressing fear of recurrence (n = 14)	<p>"A lot of people that have had cancer want to come in and see the doctor more frequently just to make sure that they're not having some other kind of cancer or a recurrence. Sometimes that's a false sense of security 'cause we don't do extensive imaging . . . but they do seem to want and need more contact and more reassurance . . . which is understandable."</p> <p>"Even though they may have been treated there's always the possibility . . . that it's under control but not really gone. So I think there's this issue of continued care for these folks in terms of screening, monitoring, and oversight."</p>
Information on long-term effects of treatment (n = 16)	"My experience is the patient will leave and then a year or 2 or 3 down the road something will start to show up that's a long term effect of treatment and they haven't really been well educated on the possibility or where to go or who to talk to."
Support with nutrition and exercise (n = 11)	"We could do better with that and I think nutrition and exercise are things that people really want to make alterations [in] their lifestyle following cancer treatment that we don't yet do well with."
Psychosocial support (n = 25)	<p>"The other thing that I think is needed is more education on psychosexual issues, on medical sexual issues, because people who go through treatment experience all kinds of stuff in that area . . . Very often it's an area that people don't want to talk about."</p> <p>"There's this uncertainty and unpredictability that surrounds leaving treatment. They've attached and built these relationships for over a 6-plus month period of time and then all of a sudden it's their last chemo day and . . . patients are expected to go and live their life and reintegrate as if it's a simple easy transition off of active therapy. And so I think . . . the survivor feels this unpredictability, this uncertainty about next steps . . . There are the emotional pieces, what did I just experience and what just happened to me and my life isn't the same . . . In the survivorship role, you hear about this new normal; they're learning to develop a new normal in life."</p>

bone health, and long-term effects of chemotherapy (n = 2; two sites); and referring patients to internal health system and general cancer support groups (eg, Gilda's Club, American Cancer Society, Lance Armstrong Foundation; n = 26; ten sites).

Challenges to Providing Care for Cancer Survivors

Some respondents were concerned that survivorship-specific care might not add to what is already provided in oncology and/or primary care settings (n = 9). Furthermore, several were concerned about formal survivorship care programs giving rise to care silos and undermining the unique value of integrated delivery systems in coordinating care for multiple patients with multiple chronic diseases (n = 7).

"I think there are risks in pulling services out of our current care delivery model which is primarily organized around our primary care teams and . . . carv[ing] those services up, for lack of a better term . . . developing programmatic approaches that don't integrate well with the way our teams [are] currently organized."

Although many respondents reported that primary care and oncology shared management of cancer survivors, transition back to primary care could be challenging (n = 12; Table 3).

"[A challenge is] training our primary care physicians to feel comfortable following these patients long-term as opposed to the specialists in oncology and then creating plans of care that are dynamic enough and fluid enough to go back and forth between the primary care and the oncologist."

Respondents identified time and staffing as challenges that often limited the availability of oncologists to follow up with cancer survivors and treat newly diagnosed patients. Resources to serve cancer survivors, particularly in specialized clinics, were also lacking. Patient financial concerns and insurance reimbursement were also noted as challenges (Table 3).

Evidence Gaps and Opportunities for Research

Respondents identified gaps in empirical evidence regarding: long-term treatment effects (n = 8); effectiveness of different approaches to surveillance (n = 9); and value, effectiveness, and cost effectiveness of different care models (n = 14). Respondents wanted information on whether existing programs and/or tools had been evaluated and how the evidence could be translated into different settings (n = 18). They also sought general evidence regarding the financial costs and benefits of formalizing survivorship care, including whether these services could be reimbursed if part of a formal program (n = 12).

Some respondents suggested that researchers investigate the potential advantages of using different models of care, group visits, and self-management programs developed for other chronic conditions to meet the needs of cancer survivors (n = 16). Some respondents mentioned that integrated delivery systems provided an advantageous setting for research seeking to develop improved survivorship care models, because many of the challenges for cancer survivors pertained to care coordination issues (n = 15).

Discussion

Consistent with the IOM report,¹² clinicians and leaders in our study reported that cancer survivors need health care that addresses a broad range of medical and psychologic concerns. Although there seems to be an awareness of how cancer survivorship care is provided across integrated health care delivery systems, there are few formalized programs, and these have not been rigorously evaluated.

Reports have called for research into what constitutes optimal care for cancer survivors.^{15,23-25} Findings from this exploratory study suggest there is attention to the importance of survivorship care yet uncertainty about the best models of care. Most interviewees reinforced the need for future research evaluating the comparative and cost effectiveness of different ap-

Table 3. Representative Participant Quotes on Challenges of Providing Cancer Survivorship Care (N = 40)

Challenge	Quote
System level	
Lack of guidelines on survivorship care (n = 8)	"We don't have systematic ways to follow-up. We all do follow-up very differently since there's no written guidelines. [For example,] this person's finished breast cancer therapy, [so] basically what should be done at these intervals? There's a lot of variability in that."
Informal and unstructured transitions between oncology and primary care (n = 12)	"There is nothing formal . . . [We're trying] to develop something formally so that we could hand it back to a primary care provider and say, 'Okay, these are your guidelines, make sure in year 1 that this is done, this is done.' Then we have a group of providers, of oncologists, who tend to hold on to patients and act like a primary care physician 'cause they're fearful that these patients will be lost to follow-up."
Lack of time and staffing (n = 9)	"The only possible problem would be that when you saturate an oncologist's practice with cancer survivors, it leaves less room for the active cancer patient." "There are budget concerns. We don't have enough counselors available. We'd like to be able to have more on site."
Patient level	
Financial and insurance concerns (n = 11)	"With the current economic climate, with people faced with the potential of job loss if not already having lost jobs and therefore potential for losing health insurance, they may or may not qualify for government assisted programs."
Uncertainty about follow-up care and self-care (n = 10)	"It's been my experience . . . that they experience their cancer care in isolation and once they're through with their chemotherapy they just basically see oncologists and then follow-up with their primary care physician, but don't get any real treatment associated with their post-cancer diagnosis." "You want them to be self-directed, you want them to . . . participate in self-care. I guess that would be what we [would] want: [a] formal program to help them guide them[selves] back."

proaches to cancer survivorship care. Clearer evidence could support clinicians' understanding of and confidence in providing effective care to cancer survivors. The way cancer survivorship care is organized within delivery systems may shape future research on the effectiveness of different models of care in diverse clinical settings. In particular, EMRs used in integrated delivery systems may facilitate coordination of care among providers, sharing of information with patients, and use of survivorship care plans, if shown to be effective.^{13,26,27}

If research demonstrates that formal survivorship programs are more effective than informal shared care or usual care, integrated delivery systems and other community-based practices will need to address several barriers, including funding and leadership support. Respondents in our study described challenges in adequately staffing and financing formalized survivorship care. These issues are especially important to consider given the anticipated shortage of medical oncologists and primary care providers in relation to demand.^{28,29} Additionally, we found that formal survivorship programs existed only at those sites that identified funding support for the survivorship care services and where a member of the care team had championed the effort.

We used a qualitative approach to generate ideas and insights to guide future research efforts. The data collected are inductive and hypothesis generating. They may not be generalizable to other organizations or to all individuals in the organizations we studied. To our knowledge, this is the first survivorship study to interview leaders within integrated health care delivery systems about the delivery of cancer survivorship care. Most research on cancer survivorship care to date has been conducted in academic institutions and comprehensive cancer centers. Because the majority of patients with cancer (85%) will not receive care in these settings (unpublished data), it is important to understand how care is organized in the community, including in integrated health care delivery systems, which have

approximately 40 million enrollees nationwide.³⁰ Our study explored cancer survivorship care practices, barriers, and opportunities in integrated delivery systems across the United States in both urban and rural areas. Another strength of this study is its focus on administrators and clinical leaders within the organizations who are likely to be responsible for shaping practice at their sites and who may ultimately be in the position to shape future efforts and optimize survivorship care.

Our study also has limitations. The respondents were leaders from integrated health care delivery sites; thus, their reported experiences and opinions may differ from those of administrators and leaders of fee-for-service practices or other settings. Furthermore, the participants' views may not be generalizable to other leaders in the organization. However, because the vast majority of the respondents in our study were not associated with cancer survivorship programs, they were likely to describe the practices of and unbiased views regarding their organizations. Although the fact that many community-based practices do not currently use EMRs—which our participants emphasized as a facilitator of communication and care coordination—may be viewed as a limitation of our study, our findings will be informative for other settings, because numerous initiatives encourage the use of EMRs.^{31,32}

Our study provides insight into pertinent issues about the organization of cancer survivorship care outside of specialized cancer centers. We found that integrated health care delivery system leaders and clinicians were aware of cancer survivorship care and the challenges faced by cancer survivors in transitioning from treatment to follow-up, although approaches to providing survivorship care varied. Few formalized care programs have been established, but whether such programs may enhance the quality of care for survivors has not been evaluated. Comparing the effectiveness of health care interventions in health maintenance organizations is of growing interest.¹⁷ These community-based settings offer a unique opportunity to develop,

test, and implement innovative models of care, which may be used to inform and enhance cancer survivorship care in diverse health care settings.

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