

Primary Care and Communication in Shared Cancer Care: A Qualitative Study

Yvonne H. Sada, MD; Richard L. Street Jr, PhD; Hardeep Singh, MD, MPH;
Rachel E. Shada, MHR; and Aanand D. Naik, MD

The incidence of cancer is increasing in patients older than 50 years,¹ who often have multiple chronic conditions.^{2,3} Because patients having cancer with comorbidities experience worse disease-free and overall survival,^{4,9} this presents challenges for effective cancer care. Better integration of primary care physicians (PCPs) into the cancer care team may be an important strategy to alleviate the burden of comorbidities during cancer treatment.

Shared cancer care, in which clinicians from different specialties jointly manage a patient, includes the cancer survivorship continuum from diagnosis to posttreatment surveillance.¹⁰ One shared cancer care model proposes that PCPs manage chronic diseases, referrals, and physical and emotional health, while oncologists manage cancer treatment and communicate with PCPs about survivorship care.¹⁰ Responsibilities are proportionally divided between PCPs and oncologists based on the cancer survivorship phase in this model. Another model describes fluctuating oncologist and PCP participation depending on whether a patient has active, remission, or relapsed cancer.¹¹ Both models interpret shared care as alternation of primary responsibility between oncologists and PCPs based on the survivorship phase, the success of which depends on the quality of handoffs between clinicians. However, PCPs are often disconnected from the cancer team because of ineffective communication and poor integration of treatment plans between physicians.^{12,13} Despite the key role of the PCP, the concept of effective integration and communication between clinicians is not well understood.

In this study, we interviewed patients having cancer with additional comorbidities, PCPs, and oncologists to describe clinicians' roles and patterns of communication in shared cancer care. We examined these issues within 3 integrated health systems that colocate PCPs with oncologists and use electronic health records (EHRs), which can facilitate communication and potentially enhance the process of care coordination.^{14,15}

METHODS

Between April and August 2009, we approached 26 patients receiving primary care and colorectal cancer treat-

Objective: To explore perceptions of primary care physicians' (PCPs') and oncologists' roles, responsibilities, and patterns of communication related to shared cancer care in 3 integrated health systems that used electronic health records.

Study Design: Qualitative study.

Methods: We conducted semistructured interviews with 10 patients having early-stage colorectal cancer and with 14 oncologists and PCPs. Sample sizes were determined by thematic saturation. Dominant themes and codes were identified and subsequently applied to all transcripts.

Results: Physicians reported that electronic health records improved communication within integrated systems but that communication with physicians outside of their system was still difficult. Primary care physicians expressed uncertainty about their role during cancer care, although medical oncologists emphasized the importance of comorbidity control during cancer treatment. Patients and physicians described additional roles for PCPs, including psychological distress support and behavior modification counseling.

Conclusions: Integrated systems that use electronic health records likely facilitate shared cancer care through improved PCP-oncologist communication. However, strategies to promote a more active role for PCPs in managing comorbidities, psychological distress, and behavior modification, as well as to overcome communication challenges between physicians not practicing within the same integrated system, are still needed to improve shared cancer care.

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Take-Away Points

The following themes on primary care for patients having cancer with comorbidities were observed:

- The electronic health record facilitates communication between physicians within integrated health systems; however, novel technologies are still needed to communicate with physicians from disparate medical systems, and further coordination is needed for shared cancer care within integrated health systems.
- All participants described the following 3 roles for primary care physicians in shared active cancer care: comorbidity management, psychological distress support, and behavior modification counseling.
- The emphasis and mechanisms for primary care involvement are unclear among different physicians.

ment at a Veterans Affairs (VA) health system. During the same period, we approached 23 PCPs and oncologists (including medical oncology, surgical oncology, and radiation oncology) practicing in 1 of the following 3 settings: VA hospital, a county health system, or a local comprehensive cancer center. Clinical sites used an EHR and were integrated health systems located within the same geographic area. Ten patients and 14 physicians were enrolled for in-depth individual interviews.¹⁶

Patients having nonmetastatic colorectal cancer diagnosed within 2 years before enrollment were recruited from a local VA cancer registry. We first reviewed medical records to identify patients who received primary care at the same VA health system for a comorbid medical illness known to affect colorectal cancer outcomes (ie, chronic obstructive pulmonary disease, cardiovascular disease, or diabetes mellitus).⁴ Patients with early-stage colorectal cancer were then chosen for interviews because of their favorable prognosis.¹⁷ To address perceptions that VA practice patterns are distinctly different, we purposively sampled PCPs and oncologists from VA and non-VA settings to assess if responses were thematically different.¹⁸ Patients were recruited until thematic saturation was achieved, defined a priori as when the final 3 patient interviews yielded no new information. Thematic saturation for clinician interviews occurred when ongoing data analysis yielded no new information or redundancy of theme categories across all sites and specialties.¹⁶

Three in-depth semistructured interview guides¹⁸ were developed for patients, PCPs, and oncologists to assess their perceptions of communication and care coordination for patients having cancer with comorbidities. Patient interviews asked about the effect of cancer on their life, comorbidity-related symptoms, and treatment goal communication with physicians. Primary care physicians were asked to envision cases of patients having cancer with comorbidities and to describe their roles and communication with patients and oncologists for comorbidity management and overall medi-

cal care. Oncologists described treatment planning for complex patients with cancer, their perception of PCP roles in cancer care, and communication with patients and PCPs. Structured interview probes asked participants about the effect of EHRs on communication and delivery of integrated care. Informed consent was obtained before each interview. Interviews were conducted in person for approximately 20 to 45 minutes, audiotape recorded, and professionally transcribed. Patients received a \$15 cafeteria voucher. The study was approved by the local institutional review board.

The research team included an oncologist (YHS), PCP with expertise in chronic disease epidemiology (ADN, HS), a project coordinator with qualitative research experience (RES), and an expert in physician-patient communication and qualitative research (RLS). At least 2 investigators identified emerging themes and coded meaningful sections of each transcript. All investigators reviewed transcripts independently to improve reliability. The group discussed dominant themes and codes until consensus was reached. The final codes were applied to all transcripts.¹⁶

RESULTS

Eight of 14 physicians (57%) were oncology specialists. Patient characteristics are summarized in **Table 1**, and physician characteristics are summarized in **Table 2**, stratified by primary care and oncology categories. Qualitative analysis identified the following 3 dominant themes pertaining to shared cancer care: (1) communication among physicians was partially facilitated by the EHR, (2) lack of clarity persisted about the prioritization and responsibility for comorbidity management, and (3) participants described 2 additional shared cancer care roles for PCPs.

EHR Connection Among Physicians in Integrated Health Systems

Physicians believed that the EHR improved communication and efficiency within their hospital system.

Here everything is electronic.... I think that's the way to communicate.... We e-mail sometimes. (medical oncologist 4)

Sometimes I'll put [a question] in my progress note and identify [PCP] as a co-signer so they can see my thinking and address any [chronic disease] issue.... (medical oncologist 5)

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■ **Table 1.** Demographic Characteristics of 10 Interviewed Patients With Early-Stage Colon Cancer

Patient Characteristic	No. (%)
Age, y	
40-60	3 (30)
60-80	5 (50)
>80	2 (20)
Sex	
Male	10 (100)
Female	0
Race/ethnicity	
White	6 (60)
Black	3 (30)
Hispanic	1 (10)
Time since cancer treatment began, mo	
3-6	2 (20)
>6 to 12	5 (50)
>12 to 24	3 (30)
Education completed	
Primary or secondary school	4 (40)
Some college or trade school	6 (60)

■ **Table 2.** Demographic Characteristics of 14 Interviewed Physicians

Physician Characteristic	No. (%)	
	Primary Care (n = 6)	Oncology (n = 8)
Sex		
Female	4 (67)	2 (25)
Male	2 (33)	6 (75)
Race/ethnicity		
White	2 (33)	5 (63)
Black	1 (17)	0
Hispanic	0	2 (25)
Asian or Pacific Islander	3 (50)	1 (13)
Practice setting		
Veterans Affairs hospital	1 (17)	6 (75)
Comprehensive cancer center	2 (33)	2 (25)
County health system	3 (50)	0
Oncology specialty		
Medical	—	3 (38)
Surgical	—	3 (38)
Radiation	—	2 (25)

I don't have to contact [oncologists] too much about basic things.... [Electronic notes] are all accessible. (PCP 11)

We are totally on EMR.... We [can] reference results and then e-mail somebody [through the EMR]. (PCP 13)

The perceived value of the EHR in an integrated health care system was also reflected in physicians' reported difficulty in communicating with physicians from outside hospitals.

Communication can definitely become a barrier, especially people not inside your same system...trying to figure out what the other one's doing. (medical oncologist 6)

The [electronic] note...is easily accessible by every other physician...on the same system.... It's obviously not as easy [with external physicians]. (PCP 8)

However, when describing communication outside of one's integrated system, physicians reported problems with sending letters and believed that patients were becoming the messengers.

Some patients [say] I just talked to your surgeon about my case. Why do I have to talk to you again [about] the whole thing? (medical oncologist 4)

Sometimes the patients convey messages...between specialists but can develop conflict if the patient has a different agenda. (PCP 11)

[With the EHR] the flow of information is pretty good.... [Getting outside records] can be hugely inefficient. (radiation oncologist 17)

Despite the EHR and other advantages of an integrated system, physicians within the same system still used direct communication via phone calls or e-mail to communicate when specific urgent problems arose.

I don't have to contact [oncologists] too much about basic things.... [EHR notes are] all accessible...when I'm contacting them...usually e-mail, occasionally paging...if urgent...to clarify something that isn't in the note or a major discrepancy between the patient and the oncologist. (PCP 11)

We have a once-a-week tumor board...to get good communication with [other physicians]. (radiation oncologist 15)

Specific probes asked physicians about the use of EHRs and care coordination. However, there were no substantive responses from participants describing the use of EHRs to develop shared cancer care models.

Prioritization and Responsibility in the Role of Comorbidity Management

All participants acknowledged the primacy of cancer treatment compared with comorbidity control. Patients, PCPs, and oncologists reported some uncertainty about the role of PCPs and the priority of comorbidity management during acute cancer treatment.

The cancer has really been the forefront..., but when I feel better..., the breathing problem [will be] back to the front. (patient 6)

Other illnesses take an immediate backseat [to cancer].... (surgical oncologist 3)

To further emphasize this point, several PCPs perceived themselves in marginal roles.

[Patients'] most important concern is getting [their cancer] treated.... As their cancer gets treated...and prognosis [improves], then you might go back to treating more intensively the chronic illness. (PCP 9)

[Cancer] diminishes the role of primary care.... It interrupts [a patient's] regular routine...(PCP 11)

In contrast, medical oncologists described which adverse effects of cancer treatment can affect comorbidity control and how uncontrolled comorbidities limit cancer treatment options.

If they have long-term survival, then their comorbid illnesses have to be managed much more carefully.... If the patient has very severe comorbid illnesses, sometimes you're not able to treat the cancer as aggressively. (medical oncologist 5)

In fact, oncologists advocated active PCP involvement during acute cancer care.

Some of our treatment...may aggravate [comorbidities], so we need closer collaboration with primary care. (medical oncologist 4)

In addition, 2 PCPs discussed the need to assume more assertive roles in treating the chronic illnesses of patients with cancer.

I really took a backseat...had to actively initiate contact with the oncologist. (PCP 13)

Didn't want to lose focus on hypertension...make sure that cancer doesn't end up being a distracter. (PCP 11)

The theme of role uncertainty was crystallized by conflicting views of medical oncologists about who provides

primary care during cancer treatment. One medical oncology view was that oncologists orchestrate all aspects of care during cancer management but use PCPs as a comorbidity consultant.

It's the difference between principal care and primary care...not their primary care, but who will...have a grasp of the whole picture of cancer treatment.... (medical oncologist 4)

I encourage patients to continue the management of [chronic illness] with their PCP.... I'm so subspecialized now that I don't really feel comfortable managing. (medical oncologist 6)

The other medical oncology view was to let the oncologist assume responsibility for both cancer and comorbidities to facilitate patient convenience.

...[I]n most cases, I take on a primary care role...because they're coming in very frequently for oncology care..., and [patients] don't feel well enough to go to multiple physicians, so I...take care of any problem that might arise. (medical oncologist 5)

Surgical oncologists and radiation oncologists were clear about only managing cancer-related issues.

We don't control the diabetes.... We focus only on the cancer. (radiation oncologist 15)

Additional PCP Roles of Managing Psychological Distress and Behavior Modification

Patients, PCPs, and oncologists identified 2 additional roles for PCPs during active cancer care. The first PCP role that emerged involved support for psychological distress from cancer diagnosis and treatment.

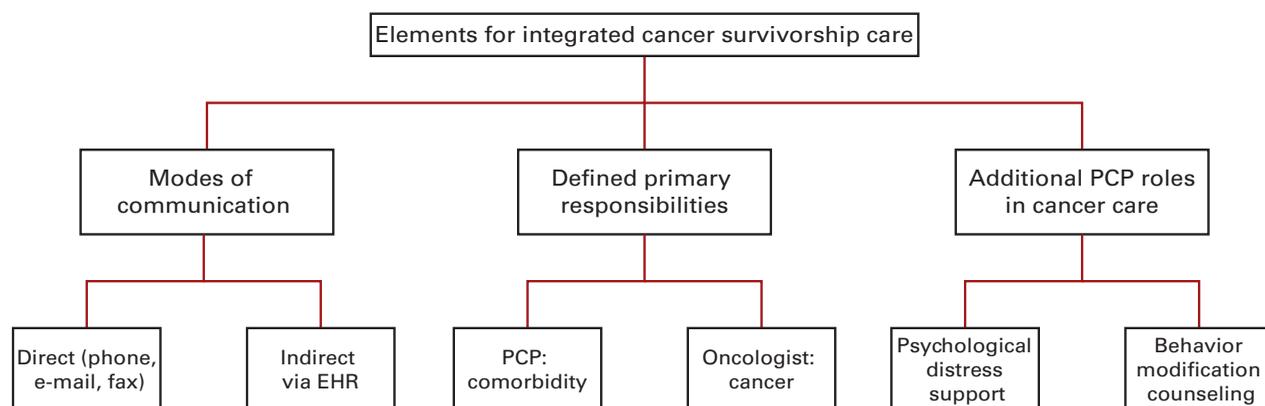
I find that patients...often use their primary care appointments during their cancer treatment almost as adjunct therapy sessions.... I have patients with very early-stage disease that...are cured but still have trouble refocusing on their chronic conditions because they're so traumatized. (PCP 11)

My PCP is good about listening to my concerns and problems.... The cancer clinic needs to listen closer. (patient 6)

Oncologists noted that their role in psychological support involves promoting hope rather than exploring psychological distress.

I try to always give some kind of optimistic perception...hope but with that specific patient's reality. (surgical oncologist 1)

■ **Figure.** Patient Flow Diagram



In addition to the psychological effect of cancer, physicians described the cancer experience as an impetus for patients to consider healthy behavior changes.

Patients...say OK, I'm not going to go through [cancer treatment]...just to get lung cancer because I'm still smoking, so...[they] make themselves quit. (medical oncologist 10)

The vigilance regarding the cancer gets translated to vigilance about other diseases. (PCP 11)

Although patients often improve their weight or smoking habits because of cancer and treatment, maintenance in the cancer surveillance phase is difficult.

Patients get cancer and they lose weight...their [comorbidities] become in excellent control.... I try to encourage the patients...not to gain back..., [but] sometimes they gain it back. (medical oncologist 5)

Therefore, the second PCP role that emerged involved support for maintenance of healthy behavior modification and goal setting.

The treatment goal is...to understand there's a [diabetes] target to reach, and we are going to just work with each other to reach that target. Some [patients] have trouble understanding..., but...I explain this is the target and they have to reach it. (PCP 7)

Despite being ready for behavioral change, patients often do not get the behavior modification support they require during cancer treatment. The need for increased PCP involvement was best articulated by a patient who described minimal support from oncologists for behavioral modification.

[Cancer doctors] didn't really get deep into [health goals]. It was just to let me be aware.... They gave me books and stuff. (patient 10)

DISCUSSION

Our study revealed insights into 3 major themes for clinicians' roles and communication in shared cancer care within integrated health systems (Figure). First, EHRs facilitated communication within an integrated system, but communication with outside systems remained difficult. Second, PCPs were uncertain about comorbidity prioritization during cancer care, but oncologists highlighted the importance of comorbidity management by PCPs during cancer treatment. Third, participants described 2 additional roles for PCPs during chronic cancer care, namely, support for psychological distress and for behavior modification.

Primary care physicians and oncologists in integrated systems used the EHR to answer management questions, communicate decisions, and review medical records, whereas external physician communication required phone calls, letters, or the use of patients as messengers. While physicians within integrated systems used direct verbal or e-mail communication for specific questions, the EHR enabled asynchronous communication for information exchange and care coordination between PCPs and oncologists.¹⁴ Participants did not cite any electronic communication strategies that could facilitate communication outside of one's system.

A possible method to improve integration of physicians from different health systems is the use of Web portals whereby patients or physicians can access medical information electronically via an encrypted Web site.^{19,20} Web portal technologies could potentially enable a PCP to access a patient's

cancer history and to communicate with the oncology team electronically. Telemedicine, such as videoconferences for virtual tumor boards or treatment planning sessions,^{21,22} might also help overcome communication barriers to shared care.

The Figure shows significant PCP roles in cancer survivorship care for comorbidity management, psychological support, and behavior modification counseling. Previous shared care models advocated for handoffs between PCPs and oncologists in the primary responsibility for patient care during and following cancer treatment. Our data suggest that active coordination between physicians with clear delineation of roles throughout cancer care is needed to manage complex patients with cancer. Integrated health systems using EHRs not only identify areas of potential improvement but also highlight how shared cancer care and coordination may evolve in the future.²³

Participants were in agreement that PCPs should manage comorbidity in patients with cancer and that oncologists should focus on cancer treatment. However, all respondents expressed uncertainty about the prioritization of comorbidity management. Patients and PCPs stated that cancer treatment became the main priority, while comorbidity management took a backseat and was readdressed if cancer treatment was successful. Conversely, medical oncologists highlighted the importance of PCPs in acute cancer care relative to the effect of a comorbidity on cancer treatment options (eg, corticosteroid-induced hyperglycemia or uncontrolled hypertension from bevacizumab). Medical oncologists had mixed views on their role in comorbidity management. Most believed that they coordinated cancer care but that specific comorbidity management was the role of PCPs. A few medical oncologists managed comorbidities and cancer for patient convenience. Surgical oncologists and radiation oncologists consistently thought that comorbidity control was within the purview of PCPs. Evidence suggests that patients, PCPs, and oncologists agree on minimal involvement of oncologists with comorbidity management.²⁴

Another theme that emerged was recognition by PCPs of psychological distress and behavior modification needs (Figure). Many PCPs described their role in helping patients cope with distress, while both medical oncologists and surgical oncologists described framing discussions to maintain hope. Although cancer survivors can continue to have anxiety after cancer treatment,²⁵ no guidelines address the integration of psychosocial support for survivors.^{26,27} Studies^{28,29} demonstrate that PCPs can contribute to the quality of life and psychological state of patients with cancer by providing coping support and mental health referrals when needed, while oncologists can focus on balancing hope with honest disclosure.³⁰

Cancer diagnosis and treatment completion are teachable moments for behavior modification³¹ whereby PCPs can

provide tools for healthy lifestyle changes. Given the time constraints that PCPs face, greater clarification and support are needed for their role in behavior modification counseling during cancer survivorship.³² Once psychosocial needs are identified, PCPs may refer patients to ancillary services, such as support groups, psychologists, and nutritionists, if they are unable to directly address these issues.³³ Certain integrated health settings, such as the VA, have effectively implemented behavioral psychologists as part of the primary care team to assist patients in coping or behavior modification strategies, and other systems teach PCPs techniques that briefly integrate these strategies into routine clinic visits.^{33,34}

Our study has several limitations. The small sample size and study design could not provide quantitative estimates of observed patterns and themes. By design, qualitative research is hypothesis generating and develops novel conceptual models rather than testing specific causal relationships of an a priori model. Qualitative studies can lead to the development of surveys that validate our findings or interventions to improve processes of shared care and communication. Generalizability is limited by the inclusion herein of only male veterans and physicians from 1 geographic area. Consistent with qualitative methods, the study used purposive sampling to identify a broad representation of specialists involved in shared care across 3 integrated health systems.

Given the effect of comorbidities on cancer survival outcomes, PCPs skilled in chronic disease management are necessary throughout cancer survivorship. The findings of our study suggest a more active role for PCPs in managing comorbidities, psychological distress, and behavior modification in shared cancer care. Novel strategies are needed to clarify responsibilities at the PCP-oncologist interface and to enhance PCP engagement in acute cancer care. Although EHRs may improve communication between PCPs and oncologists within integrated systems,¹⁴ innovative information technology-based interventions are needed to overcome challenges to achieve shared cancer care between physicians from different systems.

Author Affiliations: From Houston Health Services Research and Development Center of Excellence (YHS, RLS, HS, RES, ADN), Michael E. DeBakey Veterans Affairs Medical Center, Houston, TX; Division of Hematology and Oncology (YHS), Department of Medicine, Baylor College of Medicine, Houston, TX; Division of Health Services Research (RLS, HS, ADN), Department of Medicine, Baylor College of Medicine, Houston, TX; and Department of Communication (RLS), Texas A&M University, College Station, TX.

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Address correspondence to: Yvonne H. Sada, MD, Houston Health Services Research and Development Center of Excellence, Michael E. DeBakey Veterans Affairs Medical Center (No. 152), 2002 Holcombe Blvd, Houston, TX 77030. E-mail: yhlam@bcm.edu.

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