

Improving Modern Cancer Care Through Information Technology

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Abstract: The cancer care system is increasingly complex, marked by multiple hand-offs between primary care and specialty providers, inadequate communication among providers, and lack of clarity about a “medical home” (the ideal accountable care provider) for cancer patients. Patients and families often cite such difficulties as information deficits, uncoordinated care, and insufficient psychosocial support. This article presents a review of the challenges of delivering well coordinated, patient-centered cancer care in a complex modern healthcare system. An examination is made of the potential role of information technology (IT) advances to help both providers and patients. Using the published literature as background, a review is provided of selected work that is underway to improve communication, coordination, and quality of care. Also discussed are additional challenges and opportunities to advancing understanding of how patient data, provider and patient involvement, and informatics innovations can support high-quality cancer care.

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Introduction

Modern cancer care is characterized by three important facets. One is state-of-the-art **clinical medicine**, which may include evidence-based and sophisticated therapies targeted to patients’ tumor and biological characteristics. Second, an **approach to care** that is attentive to the spectrum of patients’ needs (i.e., physical, psychosocial, functional, spiritual). Third, the use of **systems solutions**, both human and machine, that support organizations in achieving their clinical medicine and patient-centered care delivery goals. Optimizing these delivery features for a disease as complicated and heterogeneous as cancer often entails complex decision making, multiple handoffs between primary and specialty care providers, and coordination among cancer care team members. Although several IOM reports have described these attributes of care delivery for modern health care generally¹ and for cancer care delivery specifically,² few efforts have been made to describe how to marshal information technology (IT) to effectively measure, monitor, and proactively intervene when necessary across all of these dimensions to continually improve performance and build an effective **system** of cancer care.

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A 2010 presidential commission report on the potential of health information technology (HIT) underscored that IT-enabled health care can reduce fragmentation of information, ensure high-quality, safer care, and aggregate data to enable meaningful use at the point-of-care and population level, leading to a “national health IT ecosystem in which every consumer, doctor, researcher and institution has appropriate access to the information they need”³ These potential benefits of an IT-enabled system are particularly crucial for cancer care given its complexity.

This article examines attributes of high-performing modern cancer care delivery with special attention to opportunities for IT to help cancer organizations achieve a patient-centered delivery approach. As a relatively new area of research, use is made of published literature and in-progress studies on measuring quality of cancer care to address the following questions: How does IT support modern cancer care? What are the challenges in using IT to support patient-centered cancer care? How are technology and performance measurement currently used to help cancer organizations in these transitions? The conclusion proposes approaches for advancing a research and policy agenda for IT-enhanced cancer care.

Role of Information Technology in Supporting Modern Cancer Care

The promise of improved cancer care through IT is eloquently described by Wallace,⁴ who stated, “Health IT can transform—in terms of pace, scale, and scope—the process of answering important cancer-related inquiries. Its poten-

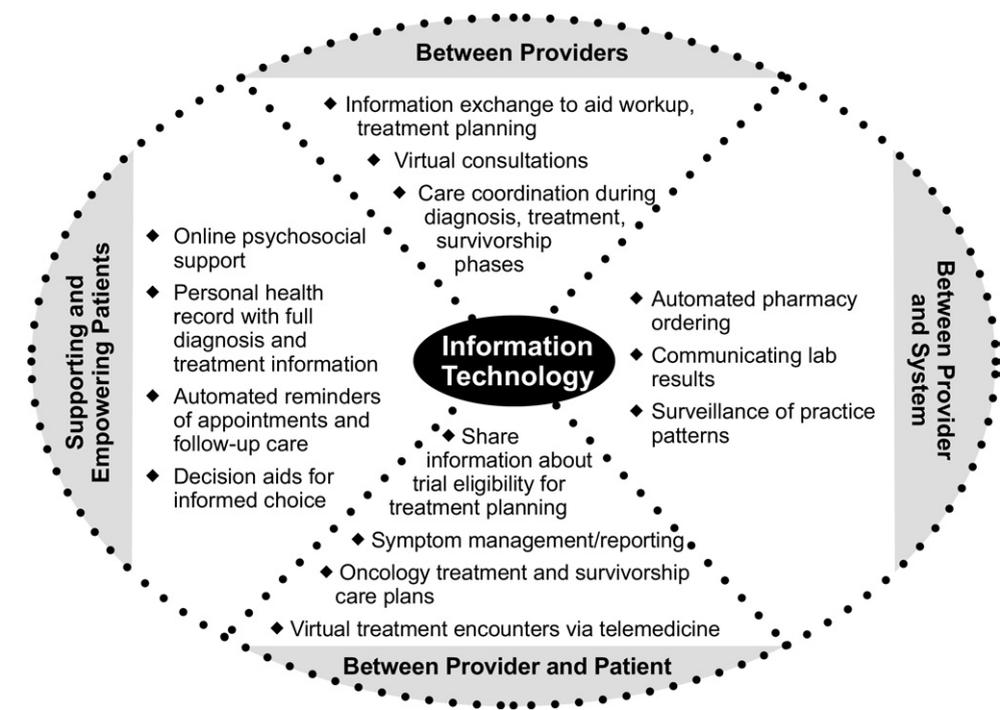


Figure 1. Patient, provider, and system applications of information technology for cancer care

tial to do so lies in its inherent capacity to comprehensively capture rich patient data and to directly support care standardization.” Other recent reports^{5,6} have discussed the potential for IT to improve cancer care from both the patient’s vantage and as part of an overall system-improvement strategy. **Figure 1** summarizes these complex connections and the potential for IT to facilitate care delivery.

A 2010 IOM workshop summary on Rapid Learning Health Systems⁷ for cancer identified several elements that are important for improving care, including electronic registries, a national cancer database, and electronic health record (EHR)–based tools for point-of-care de-

cision support. Although the Office of the National Coordinator for Health Information Technology has formulated a roadmap for an IT-enabled U.S. healthcare system,⁸ we are years away from overcoming the technical, structural, ethical/legal, and cultural barriers to a national health information infrastructure. Nonetheless, the needs of cancer patients demand that these barriers be addressed, and a growing number of IT resources and tools can help pave the way. Some idealized conceptions of how IT could support patient-centered cancer care are spurred by real examples encountered in the current research and presented in **Table 1**.

What Can Information Technology Do for Cancer Care Now?

Sittig⁹ envisioned a cancer care environment in 2015 where technologic innovations from web-enabled mobile devices, integrated patient phenotype and genotype databases for individualized treatment, and real-time decision support, could potentially enhance the

Table 1. Examples of how IT could support patient-centered cancer care

<p>Diagnosis: A patient whose provider suspects cancer orders a diagnostic PET scan. The resulting digital image is captured, annotated, stored, and shared with a provider in a different location for a second opinion, vastly improving the efficiency, effectiveness, and timeliness of care.</p>
<p>Treatment decisions: Any given patient has a range of values, preferences, needs, communication and learning styles, and cultural considerations. For example, a male patient for whom English is a second language, and whose cultural norms encourage passivity, modesty, and deference around physicians, may be unwilling to voice questions about side effects of different prostate cancer treatment options. In this scenario, the ideal IT system could capture and dynamically monitor the patient’s values and preferences, anticipate possible questions and concerns about urological and sexual functioning, and even produce treatment information in another language, or in one of several alternative formats (e.g., print, DVD, podcast).</p>
<p>Symptom management: An optimal IT-enabled system for cancer care could aid providers and patients in handling cancer treatment-related side effects if patients could report problems by accessing a web- or telephone-based symptom reporting system that immediately transfers the symptom data into the patient’s EHR. Depending on intensity and duration of the symptoms, the healthcare team could initiate proactive outreach to the patient by secure e-mail or phone, or at the least, review the symptom trajectory during a subsequent visit. The symptom record would be accessible to all of the patient’s providers (primary care, radiation oncology, medical oncology), irrespective of the provider’s practice setting.</p>

EHR, electronic health record; IT, information technology; PET, positron emission tomography

clinical, organizational and relational aspects of care. Because many individuals are already within a care delivery practice or system at the time of cancer diagnosis, these tools can be useful across the continuum of cancer care to address prevention, diagnosis, treatment, and survivorship.

Recent research focuses on how HIT can empower patients to become more involved in their cancer care. Individuals commonly search the Internet for health information (www.pewinternet.org), and data from a nationally representative survey revealed that nearly half of all Americans have sought cancer-related information on the web.^{10,11} Eysenbach et al.^{12–15} describe evidence suggesting that the Internet may have an impact on cancer patients in four areas: communication (e.g., e-mailing doctors), community (e.g., “virtual support groups”), web-based health information, and e-commerce (e.g., purchasing medications). Depending on needs, web sophistication, and familiarity with the specifics of their cancer, the Internet can help or hinder patients and their caregivers in these areas.

Though several studies^{13–15} note that the Internet has not completely replaced information-seeking from health professionals, family/friends, and print products, it has clearly emerged as an important means of meeting informational needs of cancer patients, particularly for treatment-related information.¹⁶ To help ensure the quality and accuracy of cancer information, a patient-focused Association of Online Cancer Resources (www.acor.org) aims to provide credible Internet-based resources and content for cancer patients.

Beyond information seeking, IT provides resources for social and emotional support of cancer patients and their caregivers. Given the distress and uncertainty that inevitably accompanies a cancer diagnosis, virtual social support groups are a way for patients to find coping strategies and share experiences. The ACOR website has hosted cancer-related Internet mailing lists for both patients and caregivers since 1995. Another example is the Comprehensive Health Enhancement Support System (CHESS), developed nearly two decades ago.¹⁷ CHESS was founded on the principles of “making high-quality information and social support accessible and useful,” and enabling patients to “become . . . actively involved in their treatment and recovery.” CHESS has been instrumental in shaping understanding of how electronic information can help patients with information and support needs.^{18–21} Promising approaches to integrating CHESS into routine care delivery,²² and making it available through the NCI’s Cancer Information System are under way.²³

Improved cancer management through IT has received considerable research attention in shared decision making, symptom management, and treatment adher-

ence literature. Decision aids guide patients (and providers) toward an informed choice in situations where different treatments entail tradeoffs based on preferences and values. IT-enabled decision aids could be individually tailored, highly interactive, and scalable, whereas many treatment decision aids today are a generic comparison of treatment options (e.g., mastectomy vs lumpectomy). Patient-focused interactive decision aids have been developed for breast cancer surgery²⁴ and are under development for prostate cancer treatment. Other emerging tools such as Adjuvant! Online (www.adjuvantonline.com) and the Cancer Profiler Tool provided by LiveSTRONG and NexCURA (www.nexprofiler.nexcura.com) offer personalized treatment options based on patient characteristics.

Treatment adherence may be disrupted if patients experience distress, bothersome side effects, or adverse events. Comprehensive symptom management lends itself to incorporating IT tools. A recent report of an automated system to identify distress among cancer patients described the ability to auto-notify appropriate professionals (e.g., severe pain triaged to physician, nausea triaged to nurse, depression triaged to psychologist), when patients reported treatment-related symptoms. Such a system keeps all relevant providers aware of patients’ evolving medical and psychosocial needs.²⁵

A small feasibility study²⁶ tested instant delivery of tailored advice about chemotherapy symptoms through handheld computers and reported that patients and providers found this strategy feasible and acceptable. Ruland et al²⁷ evaluated a computerized symptom management system in which patients tracked experiences with a tablet computer, and data were incorporated into planning in-person visits with clinicians, allowing the patient’s primary symptom management needs to be addressed in detail. Basch and colleagues²⁸ developed an online platform for patient-reported outcomes related to chemotherapy based on standard criteria for toxicity monitoring, which was well accepted by patients and providers. Existence of this standardized reporting criteria tool has, itself, led to an interesting IT advance—a related smartphone application.

Although the use of smartphones and web-based personal health record (PHR) tools such as HealthVault, Dossia, or the Google Health program to store health information and access it online in partnership with multiple providers is increasing, cancer care seems to lag behind compared with other healthcare applications.^{29,30} Project HealthDesign is studying pragmatic and conceptual aspects of incorporating PHRs into patients’ daily lives and healthcare decisions using mobile phones and other online tools, including an exploratory examination of a customized care planning tool for breast cancer patients.³¹

Challenges and Opportunities for Patient-Focused Information Technology and Cancer Care

Despite growing evidence that IT has great potential to improve care, results are mixed. One randomized trial of a mobile phone–based symptom-reporting system reported benefits to patients in the intervention group,³² but another study³³ noted that their sample of 477 cancer patients preferred more “traditional” means of symptom reporting (e.g., paper, calling a nurse, in-person visit), compared with secure websites, text-messaging, or interactive voice response.

Persistent challenges related to information-seeking include the credibility and trustworthiness of web-based information, and the uneven access to web-based resources among different subpopulations.^{34–36} Consumers’ and patients’ ability to critically evaluate web-based health information is another understudied area that may be only exacerbated by the rapid proliferation of “Web 2.0” technologies (e.g., social media sites, web blogs) of questionable scientific accuracy.³⁷ Helping vulnerable populations navigate online cancer information also is critical,³⁸ as are tools for older adults and the chronically ill who may be less technologically adept.

Security of personal health information is particularly important for cancer patients, who may feel vulnerable or fear discrimination by insurers or employers. Patients may benefit from a portable PHR on a device (e.g., a flash drive) or website, but interoperability and privacy are key concerns, especially as health information is shared across providers or systems. Patients and providers also may not always share perspectives on the use of portable health records. A recent review article³⁹ noted that as patients turn to the Internet to obtain health information, the patient–provider dynamic may shift in various ways—some providers may feel threatened by highly activated patients; others may welcome the opportunity to collaborate with informed patients.

Information Technology Improvements for Providers and Healthcare Systems

Several reports identify decision support, care coordination, and continuity of care as areas where IT could substantially transform and improve cancer care delivery.^{40–42}

Computerized Decision Support at the Point of Care

Galligioni et al.^{43,44} have described their experiences developing and using web-based oncology medical records to support shared patient care. These records were carefully designed to integrate the spectrum of cancer care management tasks, from appointment making and information sharing among providers, to chemotherapy sequencing and toxicity monitoring. Their experience exemplifies how wide EHR adoption could embed oncology care innovations into health systems. EpicCare (www.epic.com), an EHR software system deployed for nearly 200

clients (150,000 physicians), including several large integrated delivery systems, has an optional oncology module with comprehensive decision support, chemotherapy dosing schedules, personalized treatment planning, and support for diagnostic staging. Kaiser Permanente is implementing this oncology module, which will provide an unparalleled opportunity for care coordination and shared treatment decision making, given Kaiser’s large enrollee population. The American Society of Clinical Oncology website (www.asco.org) also provides guidance for practitioners around oncology EHRs, describing ideal functionality, and how to select, implement, and use EHRs in daily practice.

Do embedded electronic guidelines influence treatment selection, prevent errors, or ensure dosing safety for cancer patients? Such guidelines are used routinely in areas other than cancer and have been shown to improve both quality and outcomes of cancer screening. This literature is less well-developed in cancer treatment. A study examining whether computerized reminders could ensure appropriate prescribing of erythropoietin for chemotherapy-induced anemia found better prescribing adherence in the intervention group, which received electronic “triggers” when warranted based on patients’ hemoglobin levels.⁴⁵ Given the numerous decision points throughout a cancer patient’s diagnosis and treatment, opportunities to test and eventually implement other point-of-care decision support strategies appear promising. However, few empirical studies exist specifying optimal design factors to consider when incorporating point-of-care alerts into practice.⁴⁶ Given the challenging treatment considerations in cancer care, it is important to identify the key features, timing, and other aspects of designing and implementing computerized order entry and related decision-support systems, to ensure that tailored clinical solutions do not create new barriers to provider–patient communication.⁴⁷

The clinical trial enterprise offers several opportunities for IT to improve care.⁴⁸ Given the well acknowledged problems of inefficient, incomplete, or slow accrual to trials,^{49–51} a rapid computerized notification system to identify potentially eligible patients is one possible solution. Such a system of embedding in the EHR alerts of clinical trial matches for potentially eligible patients is being tested at Kaiser Permanente. A small study⁵² exploring benefits and barriers to the use of a PDA to provide clinical trial listings highlighted several challenges, including currency of information and nonstandard taxonomy for categorizing trials (e.g., “stage IV” vs “metastatic”). Absence of a widely adopted, technology-driven solution for the trial accrual problem underscores the myriad challenges in this area.

Ensuring Coordination and Continuity of Care

Continuity of care, described as “systematic assurance of uninterrupted, integrated medical and psychosocial care of the [cancer] patient,”⁴² rooted in the provider–cancer patient partnership, is important in cancer care. Haggerty and colleagues⁵³ noted that the main dimensions of continuity of care are informational, relational, and management. These dimensions are closely tied to care coordination. Transitions in care entail extensive information sharing, timely appointments for work-up, and sometimes reconciliation of different recommendations. Patients often serve as their own care coordinators, arranging appointments, being the nexus for information, and navigating the many steps in their care. Even in settings with established cancer care coordinator functions, breakdowns are possible. Incomplete sharing of information between primary and specialty care providers was cited in a recent study, as well as patients “falling through the cracks” when treatment occurs in one or more settings.⁵⁴

The multidisciplinary approach to cancer care is certainly essential to determining the right treatment strategy, but as noted by Nouraei et al.,⁵⁵ ensuring that patients receive appropriate care represents a “formidable organizational challenge in coordinating the input of multiple specialties.” This group implemented a centrally accessible database to reduce delays and furnish information expediently to the many providers responsible for caring for patients with head and neck cancer. Although the database was a relatively simple intervention, it was undertaken with careful attention to process workflow planning, coordination among providers, and information accessibility.

New regulations on meaningful use of EHRs acknowledge the importance of care coordination and emphasize that HIT infrastructure is a means—not an end. Reflecting these ideas, proposed criteria for ensuring that certified EHRs are used meaningfully require that the underlying technology of the EHR supports disease management and transitions between care settings.⁵⁶ One notable caution is that in a shared IT environment, an error or mis-statement in one chart may be inadvertently propagated when shared electronically with another provider or system. Still, an IT-enabled system of care could reduce errors and other breakdowns, automating where it makes sense, but not supplanting the relational aspects of cancer care. EHRs and systems that track and share information among providers about the patient’s experience can reinforce a deeper understanding of patients’ values, preferences, and how health events may interrelate. Development and deployment of oncology treatment summaries is probably the best example of how IT solutions may foster care coordination and enhance continuity of

care between cancer specialists and patients,⁵⁷ and between one cancer specialist and other clinicians.⁵⁸

Measurement Issues in Modern Cancer Care

Successful twenty-first century cancer care organizations will be **learning systems**, able to measure patterns of performance that are critical to patient care and organizational survival.^{1,7,59} Organizational learning—which is used here to describe the capability of a practice or system to acquire new information, modify interdependent processes, and ultimately change (improve) how it works—requires more than IT. It requires availability of appropriate content, structured and standardized in ways that are meaningful to patients, practitioners, and administrative staff, and accessible for monitoring, decision support, and quality improvement. Organizational learning is a function of the **quality** of measurement and the capability of IT to ensure successful acquisition and transmission of this information at the appropriate time and place. Given cancer’s complex presentation in clinical practice, measuring and applying knowledge about optimal care is further considered below.

Improving the Knowledge Base

High-performing modern cancer care organizations are knowledge-based in that they use scientific evidence to guide decision making. In clinical practice, this means pairing evidence-based medicine with evidence-based management directed to improving clinical effectiveness.⁶⁰ This issue is relevant in cancer care as studies find both underuse of guideline-based care^{61,62} and overuse of services.⁶³

Table 2 describes several ongoing measurement initiatives. All of these can be characterized as **passive** quality measurement systems, where performance data are collected after care has been delivered. Feedback lags range from several months, in the case of the Quality Oncology Practice Initiative (QOPI), to almost 2 years for measurement systems that rely on cancer registries as the source of data collection and reporting. The Commission on Cancer (CoC) recently launched a pilot program to test near real-time reporting and tracking of breast and colorectal cancer patients as part of a Rapid Quality Reporting System (RQRS) project.⁷ The RQRS identifies candidate patients soon after surgery and prospectively tracks them throughout their cancer treatment. The system can electronically alert participating facilities to enable them to follow patients and determine whether compliance with guidelines is achieved. This prospective measurement system is still undergoing pilot-testing, but preliminary evidence suggests that test sites improve adherence (M. Johnson, National Cancer Institute, Bethesda MD, personal communication, 2010).

Table 2. Selected national performance measurement systems for cancer diagnosis and treatment indicators, 2010

Sponsor	Date program originated	Data sources	Cancer clinical effectiveness domains	Source of guidelines	Users	Provider quality improvement	National or regional benchmarking	Peer to peer comparison	Public reporting
ACS/(CoC) EQUIP	2007	Cancer registries	Breast cancer Colorectal cancer	NCCN, ASCO, ACS	1460 CoC-accredited cancer centers	Yes	Yes	No	No
ASCO, QOPI	2006	Medical records	Breast cancer Colorectal cancer Non-Hodgkins lymphoma End of life Symptom/toxicity management Non-small cell lung cancer	ASCO, NCCN	238 medical oncologists' and hematologists' practices	Yes	Yes	No	No
NCCN, Outcomes Research Database	1998	Cancer registries, medical records	Multiple tumor types	NCCN	21 comprehensive cancer centers	Yes	Yes	Yes	No
ASTRO, PAAROT	2008	Medical records	Targeted by type of radiation oncology therapy (e.g., brachytherapy) Prostate, breast, and gynecologic cancers	ASTRO, ACR	156 radiation oncologist practices	Yes	Yes	No	No

ACR, American College of Radiology; ACS, American College of Surgeons; ASCO, American Society of Clinical Oncology; ASTRO, American Society of Therapeutic Radiation Oncology; CoC, Commission on Cancer; EQUIP, Electronic Quality Information for the Public; NCCN, National Comprehensive Cancer Network; PAAROT, Performance Assessment for the Advancement of Radiation Oncology Treatment; QOPI, Quality Oncology Practice Initiative

These large-scale initiatives illustrate efforts to develop clinical effectiveness measures in cancer care. Their systems are more prevalent for some cancers (e.g., colorectal and breast) than others, and focus more on initial diagnosis and treatment phase of care, rather than survivorship and end-of-life care. Also, these measures are typically directed at large institutions and cancer specialty physicians, and rarely receive attention in community clinics or primary care settings. Few studies have assessed optimal methods for capturing and reporting the clinical information from medical records necessary to support and sustain these measurement systems in practice-based IT environments.

This knowledge gap is especially relevant for cancer care where many quality measurement systems are still evolving from paper-based chart abstraction to electronic platforms. For example, evidence from the NCI Community Cancer Centers Program (NCCCP) suggests a major barrier to sustained participation in a quality improvement collaborative using QOPI is whether the oncology practice has a functioning EHR.⁶⁴ Nevertheless, recent efforts to develop and deploy these measures show willingness among cancer organizations to regard quality measurement and improvement as a high priority.

Enhancing Patient-Centered Care

Patient-centered cancer care focuses on the preferences, needs, and overall experience of cancer patients, as defined by patients themselves and their families. Interest has grown in incorporating patient perspectives into measurement systems that evaluate cancer care delivery, in terms of either measuring and interpreting the clinical benefit of therapies or the patient care experience. However, to be useful in cancer care delivery, IT infrastructure is needed to capture these measures throughout the entirety of a patient's treatment. Thus, a compelling "business case" is essential for persuading IT vendors to build and deploy applications that support: longitudinal data collection on patient experiences, computer adaptive technology for patient and practitioner reporting and feedback, and organizational studies on incorporating these measures in clinical practice.

Broadly defined, patient-reported outcomes (PROs) comprise information from patients that reflect on the health-related quality of life (HRQOL) that patients experience from a disease and its treatment. As described above, cancer diagnosis and treatment are often associated with high distress and toxicity, resulting in burdensome symptoms, like fatigue and pain, that are best measured by asking the patient directly. Considerable evidence shows that these side effects are often deemphasized in cancer diagnosis and treatment,⁶⁵ and clinicians tend to systematically report fewer symptoms of lower

severity compared with patient reports.⁶⁶ Patients' symptom reports also have been correlated with adverse outcomes, including functional and emotional disability and rehospitalization.⁶⁷

Despite decades of research on cancer HRQOL in clinical trials, research on its application in clinical practice is a newer development.^{68,69} A recent symposium described promising use of HRQOL instruments in clinical practice, especially for their ability to screen for functional problems, improve clinician–patient interactions, and address quality of care from the patient perspective.⁷⁰ Yet, considerable barriers remain, including low acceptance of the clinical utility of these measures by physicians; lack of standardized, IT-enabled measurement and data collection that integrate seamlessly into practice; lack of guidelines on incorporating and using these measures in clinical workflow and decision making; and difficulty adapting these measures and their meaning to the increasingly complex cultural, language, and communication preferences of cancer patients.

Cancer organizations, especially cancer centers, have been engaged in patient satisfaction reporting and tracking of global ratings of care for years. However, fewer cancer organizations have focused measurement on the broader construct of patient experience that includes other attributes of the healthcare encounter considered valuable to patients (e.g., access, patient–physician communication, satisfaction with decision making regarding care planning and treatment). Many qualitative and population-based studies document that patient reports on these attributes are considered the gold standard of care assessment.⁷¹ Yet, because many measurement systems used by cancer organizations are proprietary, little published research is available that directly assesses the utility of these measurement systems for quality management and improvement in care delivery. Most randomized trials in this area focus on patient–clinician communication and decision quality. Few of these studies use proprietary measures of patient experience widely used in cancer organizations as either primary or secondary end points. Beyond communication and decision quality, only a few nonrandomized studies are available to assess relationships between PRO measures and improved patient-centered cancer care in actual care delivery settings.^{72,73}

Efforts are underway by federal agencies to expand the availability of cancer-related patient experience measurement systems for research and practice. NCI and AHRQ are sponsoring development of quality indicators of effective patient–clinician communication in cancer care, and they are collaborating on a cancer module of the Consumer Assessment of Healthcare Plans Survey. Hopefully, development of actionable patient communication quality indicators and measurement systems like these will accelerate

research on their use by diverse cancer care providers across communities and settings.

Enabling Systems-Minded Approaches

Systems-minded cancer care organizations examine the entire care system in a holistic way, intervening—if necessary—to optimize care coordination and continuity. As described earlier, nowhere is that need more evident in modern health care than with the increasing use of multi-specialty cancer care. Design and assessment of multidisciplinary care centers is emerging. These centers view care coordination as a specialty challenge, enhancing teamwork and communication across cancer surgeons, radiation oncologists, and medical oncologists in treatment planning and execution.⁷⁴ More work is needed (especially in community settings) to incorporate the primary care physician as part of the definition and to measure care coordination, especially when considering the ubiquitous interfaces between primary care and specialty care throughout the cancer care continuum.⁷⁵

Measures also are needed that enable patients' assessments of care coordination. Patients cannot be expected to accurately assess the nature and quality of information exchange within their care team, but they can recognize when care coordination is lacking, be it during the hand-offs between physicians (e.g., lack of familiarity of physicians with prior treatment histories), or in the confusion over next steps in care delivery (either by themselves or by other members of their care team).

Conclusion

The importance of IT in supporting and enhancing patient-centered cancer care delivery is compelling in theory, and evidence of tangible progress is growing. Highly integrated systems like Kaiser Permanente and the Veterans Administration Health System have been recognized as pioneers in developing IT-enabled solutions. Multiple studies have documented increased satisfaction of providers and patients in these closed systems, compared to open systems that accept patients from multiple health plans.^{76,77} However, these healthcare systems are the exception, rather than the rule, in cancer care delivery today.

Multiple examples exist of cancer researchers and providers coming together in informal or formal networks to experiment on elements of patient-centered care. Some of the most promising arrangements focus on practice-based research in networks like the Cooperative Trial Groups,⁷⁸ the National Comprehensive Cancer Network,⁷⁹ the Cancer Research Network,⁸⁰ and the NCCCP. These virtual research groups are, albeit slowly, focusing on networkwide research to implement and deliver aspects of patient-centered care that emphasize IT solutions. These networks

strive to improve care by raising awareness of their own performance, sharing performance results with network peers and the broader practice community, and disseminating best practices and tools for quality improvement.

These new developments hold promise for accelerating the use of patient-centered care IT tools and enhancing the evidence base for effectively deploying them in diverse cancer delivery settings. Yet the sustainability of these solutions in our current fragmented system is questionable given that benefits of these programs often do not accrue in the same way to the same stakeholders. Leatherman et al.⁸¹ found that the financial benefit of quality improvement initiatives to reduce unnecessary utilization often did not accrue to the provider in fee-for-service settings even though they were making important changes to implement the intervention. The system simply did not provide the right incentives to make it happen.

Payers and policymakers have been challenged to realign incentives across the healthcare system and have started pilot projects such as the 2006 Medicare “pay for reporting” medical oncology quality demonstration.⁸² A place to start in realigning incentives toward a patient-centered approach to modern cancer care might be to reward cancer organizations that deploy IT solutions that collect the appropriate data and build the required infrastructure for data collection, reporting, and sharing among clinical teams, patient teams, and payers.

Where Do We Go from Here?

This paper has contended that IT is a foundational element for patient-centered care, but IT must be thoughtfully linked with other considerations relevant to the cancer care environment. First, we need the right information and the right measures, both of which are responsive to the needs of organizations, clinicians, and patients. This includes robust measurement of clinical effectiveness, care coordination, patient experience, and other PROs—potentially, a “vital sign” to measure patient-centered cancer care, monitored over time. Second, IT must be deployed in a way that connects providers and patients and facilitates positive communication throughout care systems. Hesse et al. note that IT is not a panacea; user-centered design approaches and attention to the sociotechnical aspects of complex systems are equally critical.⁵

Finally, IT must do more than just inform patients about their cancer care. It must embrace new technologies, adapt to and enhance the changing roles and relationships between formal care teams and the patient team (patients and families), and recognize the interdependency of patient, providers, systems, and technologies in the care delivery process. Patients cannot effectively diagnose or treat their cancer, and care teams cannot provide highest quality care without meaningful patient involvement. Recognizing these

interdependencies will be critical to the effective deployment of IT solutions for patient-centered care.

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