

Information Use in Chronic Illness Care: The Role of the Electronic Health Record in Bridging Patient Experience and Healthcare Contexts

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ABSTRACT

Chronic health conditions typically manifest as pervasive and ongoing in daily life, in contrast to their curative and episodic mode of treatment in most healthcare settings. A growing sense of provider-patient disconnect and calls for healthcare reform have emerged new chronic care models that advocate for a team approach to care that is heavily supported through the use of an electronic health record (EHR). This interdisciplinary research examines the use of the EHR in chronic illness care within a best-practice environment to understand how provider practices frame patient experience. Drawing on data from 144 hours of observation and 49 interviews with healthcare providers at three VA primary care clinics, we examined information use in provider work and patient care. Findings indicate the EHR as a de facto representation of the patient and a ubiquitous force in shaping provider work and patient care. The organizational context and provider work practices as reified in the EHR privileged and elevated objective indicators of the patient's level of "control" while obscuring subjective information and patient narrative that could be useful in problem-solving disease management. The pervasive use of objective information in patient care and communication framed patient experience in the healthcare context in ways that seemed abstracted from their lived experience with illness, contributing to provider-patient disconnects. Providers were stymied by not having enough information to support effective self-management or a more complete picture of patients' everyday life experiences, but there was no clear pathway for capturing, retrieving, and using such information in patient care. We suggest that EHR design for chronic illness care should make patients' experiential information more readily available and enable patient input and patient-provider co-construction of information. More work is needed to further

understand how everyday life experience is presented and received in patient encounters.

Keywords

Information behavior, health information, chronic illness, healthcare work, health information technology, electronic health record (EHR).

INTRODUCTION

Over time chronic conditions have become the major problem that is dealt with in the United States healthcare system, yet that system has largely remained entrenched in an acute care model (*Quality Chasm*, 2001) that addresses patient needs in a curative and episodic fashion (Lubkin & Larsen, 2006). By contrast, chronic illnesses are, for the most part, pervasively experienced and perpetually managed within the context of people's everyday lives. In recent years this contextual mismatch has increasingly been played out with regard to health and illness information: patients may feel they are not getting adequate information from their healthcare providers (Souden, 2008), while providers remain frustrated by gaps between health information and behavior change (Shumaker, Ockene, & Riekert, 2009).

In the current climate of healthcare reform, new models of care are being called for which highlight the need to resolve the disconnect for patients with chronic health conditions (Bodenheimer, 2003b; Coleman, Austin, Brach, & Wagner, 2009; *Quality Chasm*, 2001; Piette, Richardson, & Valenstein, 2004; Vogeli, et al., 2007). Calls for a re-visioning of chronic illness care have surfaced attention to the role of the provider-patient relationship among healthcare providers, policymakers, and in the mainstream media. For the last three years, the *New York Times* has run a regular column written by a medical doctor with the goal to "bridge the gap between patients and doctors and remedy the disconnect." (Chen, 2008). The author interrogates sources of tension in interactions between doctors and their patients, and reflects on her own difficulty in stepping around to the other side of the exam table in order to better understand patient choices. Her acknowledgement speaks

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to the complexities of the provider-patient disconnect and the challenges providers face in more fully grasping patients' perspectives and their own roles in those relationships.

The challenge in bridging between the lived experience of patients and the medical contexts in which they are treated is exacerbated in health informatics research that starts from the perspective of the information or healthcare system and assumes a transmission-based approach to information use, placing the information itself as the locus of concern. Critiques of medical science's approach to health information point out that, by and large, that body of research fails to consider information behavior multidimensionally or in the context of people's lives (Dervin, 2005; Lewis, 2006). Information science, as a discipline, offers an orientation that allows it to step back from a focus on medical accuracy and expertise as embodied in the information itself, and instead address questions of its physical, social, and design aspects (Bates, 1999) within another domain.

This study is interdisciplinarily informed. Its sensibilities are grounded in the sociology of the illness experience literature that views the person with chronic illness as actively working to manage and make meaning of that experience not only within the context of his symptoms and treatment, but also in light of a shifting sense of self and the challenges of maintaining everyday life (e.g., Bury, 1982; Charmaz, 1991; Conrad, 1987; Corbin & Strauss, 1988). The analytical lens invoked here draws on constructionist, contextually sensitive, and process-oriented frameworks from information behavior theory (e.g., Dervin, 1992; Kuhlthau, 2003; Savolainen, 1995; Wilson, 1999) in order to examine information as experienced by patients with chronic illness within the social and organizational contexts of a primary care setting.

The research examines the information elements of healthcare provider practices and patient encounters within the context of Veteran's Administration (VA) primary care clinics, a healthcare setting that is widely recognized as a best-practice environment both in terms of information use and chronic illness care. These two elements are brought together powerfully in this context through the ubiquitous use of the electronic health record (EHR), presenting a unique opportunity to examine the interaction of health information use and chronic illness care.

Questions of how to support effective EHR adoption and use have been and will continue to be increasingly salient in the face of U.S. government mandated and funded healthcare reform initiatives. However, research focusing on the impact of the EHR on the patient-provider relationship is still nascent. Previous work from this study has looked at providers' appropriations of the EHR in their clinical care work (Veinot, Souden, Zheng, Keith, & Lowery, 2010). This paper extends that research to examine the power of EHR use in shaping patient experiences of

chronic illness care through its impact on provider information use and provider-patient interaction.

STUDY CONTEXT

The Veteran's Health Administration (VA) is the largest integrated healthcare system in the United States, serving 5.3 million veterans annually (Kupersmith, et al., 2007). The VA health system operates as a staff-model health management organization, offering comprehensive care to qualifying veterans via nearly 1,400 facilities (Kupersmith, et al., 2007). VA Medical Centers provide access to outpatient services at the primary (general practitioner), secondary (specialist) and tertiary (specialized consultation) levels (Kizer & Dudley, 2009). Numerous studies of service delivery and patient outcomes have continually re-affirmed the VA Health Care System as a provider of what author Philip Longman (2007, 2010) has pronounced as "The Best Care Anywhere."

VA primary care patients are predominantly men (97%) who served in the US military and are eligible for services due to service-connected health issues and income qualifications. Generally, VA patients are older, sicker and poorer than the general population (Kupersmith, et al., 2007). The VA has identified uncontrolled Type 2 diabetes as a leading cause of amputation and increased risk of macrovascular diseases such as heart attack or stroke, and the disease is also associated with blindness and end-stage renal disease (*VA OR&D Website*, 2010). Almost 20% of veterans in the VA Health System have Type 2 diabetes, and most have multiple co-morbid conditions (Kupersmith, et al., 2007), so minimizing complications through improved diabetes care is a key concern. The VA's Health Services Research and Development Service (HSR&D) Diabetes Mellitus Quality Research Enhancement Initiative (DM-QUERI), which funded this study, is a central component in the VA's efforts to improve evidence-based care for veterans with diabetes.

The VA Health System is forward-thinking in its approach to chronic conditions, having adopted aspects of the Chronic Care Model, an emerging paradigm for primary care of patients with chronic health conditions that incorporates essential features such as self-management support; social aspects of chronic illness; and coordinated care across a multidisciplinary team (Bodenheimer, 2003a; Coleman, et al., 2009). In its care of patients with diabetes and other chronic health conditions, the VA has implemented multidisciplinary teams, coordinated care, decision support, and a robust electronic medical record (Asch, McGlynn, Hogan, Hayward, & al., 2004; Coleman, et al., 2009; Kizer & Dudley, 2009; Longman, 2007).

VA Medical Centers are innovators in their use of information systems and the EHR in clinical practice. The VA adopted a computerized health care information system in the late 1970s, well ahead of the private sector, and by 1997 had launched its own EHR with enterprise-wide communication integration, a computer-based patient

record, clinical reminders, computerized provider order entry, and disease management features (Kizer & Dudley, 2009). The EHR supports practice on multiple levels of the VA environment, including provider-patient interactions; provider-provider collaboration; overall clinic management and quality improvement; and external reporting and oversight. The widespread use of the EHR in the VA context provided ample opportunity to observe provider information use within a persistent medium that represented the patient throughout a coordinated system of care.

RESEARCH DESIGN AND METHODS

Study data were collected between September 2008 and May 2009 in the primary care clinics at three socio-demographically diverse VA Medical Center locations in the Midwestern United States as part of a larger study undertaken to identify opportunities and barriers to introducing additional information about patients with diabetes into clinical care. The study was qualitative and exploratory in nature and took an ethnographic approach in order to more fully understand: the VA primary care context; actual clinician work practices; and their use of information in the treatment and management of patients with diabetes. Data collection, conducted by the first author and a VA colleague, consisted of two phases: 1) 144 hours of field observation of 31 providers across the three locations; and 2) 49 semi-structured interviews with both observation participants and additional providers recruited from the clinics.

As indicated in Table 1, providers working in a variety of professional roles were included in the study in order to be able to examine patients' entire information experience in the context of team-based care. Altogether, the data represent 56 unique providers across seven different provider types and capture over 200 provider-patient encounters.

	Obsvd	Intvd	# Unique Participants
Physicians	9	11	13
Residents	0	6	6
Physician Assistants	2	2	2
Nurse Practitioners	5	5	6
Clinical Pharmacists	5	6	8
Registered Nurses (RN)	7	12	14
Licensed Practical Nurses (LPN)	3	7	7
Totals	31	49	56

Table 1. Study participants

During observation sessions, detailed fieldnotes were taken which attended to clinicians' daily work activities and how information was accessed, used and exchanged in the course of their practice. Key elements of interest in the observation were: the use of information from the EHR; information exchanged between the clinician and patient; information created or recorded by the clinician; and information exchanged between clinicians in the course of clinical consults or care coordination.

The second phase of data collection consisted of in-person and telephone interviews in which providers were asked to discuss their daily work practices and their use of information in caring for patients with diabetes. Interviews ranged from 45 to 70 minutes in length, and typically took just under an hour. In addition to interviewer notes, all of the interviews were audio recorded and transcribed by a VA transcriptionist for use in analysis.

The observation fieldnotes and interview transcripts were managed and analyzed using NVivo 8.0 qualitative data analysis software. The procedural and analytical approach to the data was strongly influenced by grounded theory techniques. Analysis of the observation fieldnotes utilized an incident-by-incident approach as suggested by Charmaz (Charmaz) in order to avoid over-atomizing the data. The notion of theoretical comparisons as discussed in Corbin and Strauss (Corbin & Strauss) facilitated a conceptual analysis of the interview data regarding clinician perceptions and use of information in relationship to patient interactions and care.

Iterative rounds of coding and memo writing served to consolidate initial impressions, refine categories, and facilitate comparisons across data sources and provider types, moving from initial themes of interest in the data toward a more complex appreciation of concepts and theoretical constructs used to deepen and intensify analysis (Corbin & Strauss, 2008). Further categorical and thematic development was enabled through additional rounds of focused and theoretical coding.

FINDINGS

Patients in the VA Primary Care Clinics

The VA Clinics provided an excellent opportunity for the researchers to look at how information is obtained, communicated, provided, and used by clinicians in the course of managing ongoing chronic illness. Although providers were observed interacting with and treating patients with a range of acute issues and chronic conditions, the study was primarily focused on the care of patients with Type 2 diabetes, a metabolic disorder related to how the body processes sugar for fuel. In order to minimize complications and prevent the progression of the disease, patients with diabetes must control their blood sugar level through behavioral or lifestyle modification such as diet and exercise and/or through the use of oral agents and insulin therapies. Per VA practice guidelines and general medical standards for diabetes care, providers tended to

assess patients with diabetes as “in control” or “out of control” based on their hemoglobin A1c level, a lab value commonly referred to in patient interactions as “your A1c” and often described to patients as representing their “average blood sugar over a three-month period.”

Patients with diabetes were also actively encouraged to monitor and manage other biomarkers considered essential to managing the disease and its progression, including blood pressure readings and lipid (cholesterol) levels. This triad of health markers was introduced to patients in the VA clinics as the “ABC’s of Diabetes,” referring to A1c, Blood pressure, and Cholesterol. Body mass index (BMI) was also emphasized as a contributor to diabetic risk factors, and patients were encouraged to manage their weight in relationship to their diabetes or other chronic health conditions. High blood pressure, elevated cholesterol levels and metabolic issues such as obesity were chronic health conditions frequently addressed in the clinic not only in relationship to diabetes, but also in terms of their contributions to other chronic illnesses such as cardiovascular disease and chronic kidney disease and as ongoing chronic health concerns in their own right.

Diabetes requires continuous self-management from patients: they are often asked to adhere to medication regimens and encouraged to help control their blood sugar by making behavioral changes related to eating and exercise. The intensity of this ongoing management required providers to continuously convey information to their patients regarding their health status; the progression of their illness; the nature of the disease and its severity, the purpose and importance of medications; and approaches to self-management.

The Role of the EHR in the Primary Care Clinics

Chronic illness management in the clinics was an information-intensive endeavor. The EHR was observed and described as the primary source of information used by providers in treating patients with diabetes; the only other information source brought up with as much regularity was the patient himself. In the course of observations it was rare for a patient to be seen or his care discussed without his EHR being open for his provider(s) to review and reference. The EHR's centrality to chronic illness care suggests that it is an essential force in shaping the experience of these patients; ultimately the information in the EHR comes to represent the patient in the course of care.

Patient-provider encounters in the clinics routinely began with the opening of the patient’s EHR, which was used throughout the encounter to access the patient’s health information and medical history; view results from lab work and diagnostic tests; place orders for medications and consultations; review and update patient prescriptions; and update patient information and health status. The prominent role of the EHR in the clinics places information as central to provider’s work; its structure, form and content are

salient to information use at every juncture of care. What is captured in the EHR and how it used in patient care both informs and reflects providers’ approaches to patients and chronic illness management.

The ongoing nature of chronic conditions and the degree of problem-solving required to control them highlighted the importance of the EHR as a robust record of the patient’s health situation and clinical interactions over time. Providers relied on historical information from the EHR to understand how a patient had gotten to his current condition and determine how to move forward with treatment.

The clinics’ team-based approach to chronic illness management was facilitated by the use of the record to communicate information and coordinate care. When two or more providers discussed a patient’s situation, such conversations invariably opened with the patient’s “name and last 4” so that his EHR could be pulled up as a shared referent; in essence acting as a proxy for the patient during consultations when he was not present. Similarly, a patient’s EHR was routinely used in providers’ work as a mechanism for collaboration and coordination of care in the primary care clinics: providers placed referral orders through the system, read each other’s notes, and deliberately added each other as signers to their encounter for the purpose of sharing information.

Use of the EHR in the Care of Patients with Diabetes

Commonly Used Information Elements from the EHR

The kinds of patient information that providers used in conjunction with their encounters with patients with diabetes were those seen as informing patient’s level of control, complication, and disease progression. The information elements most frequently accessed in the EHR; referred to in discussing information use in treatment; shared with other providers during consultations; and communicated with patients during encounters tended to be quantifiable, numeric indicators of patient health or disease status. Table 2 indicates common information elements accessed in the EHR and how providers used them in treating patients with diabetes and other chronic health conditions.

Biomarkers which indicate disease control, such as hemoglobin A1c, blood pressure, cholesterol levels, and other lab tests and vital signs, were the most commonly used type of information in treating patients with diabetes. The encounter note, as a clinician-generated, free-text field, was significant in that it served to aggregate information from other parts of the EHR, but also included an accounting of provider impressions and assessment as well as information considered subjective—that provided by the patient at the time of the visit. Medication list review provided a way to troubleshoot out-of-control indicators and medication adherence. Reminders generated by the system algorithmically in response to certain variables in the record (e.g., diabetes diagnosis + no foot screen in the

Element	Description	Ways used
Biomarkers	<ul style="list-style-type: none"> Hemoglobin A1c, cholesterol, kidney function & other lab tests Vital signs such as blood pressure & weight 	<ul style="list-style-type: none"> Indicators of disease “control,” progression, or severity Measure of complications resulting from disease progression
Encounter note	<ul style="list-style-type: none"> Free-text field created by clinician documenting patient encounter 	<ul style="list-style-type: none"> Aggregates patient information Template for current visit Carries information over from previous visit
Medication lists and pharmacy records	<ul style="list-style-type: none"> Numerous medications to control blood sugar, cholesterol, and blood pressure 	<ul style="list-style-type: none"> Reconciliation to correct record and patient confusion Refill patterns provide a sense of medication adherence
Reminders	<ul style="list-style-type: none"> Notifications automatically generated with EHR in response to certain patient information 	<ul style="list-style-type: none"> Inform provider that the patient needs a diabetic foot check, eye exam, or other health maintenance procedures

Table 2. Commonly accessed information elements of the EHR

last year) served to direct provider health maintenance and preventive actions as well as providing decision support for treatment.

The following sections detail how providers used these information elements of the EHR in their treatment of patients with diabetes.

Use of Information to Prepare for a Patient Encounter

Providers generally accessed the patient’s EHR either immediately before a patient visit or actually during its first few minutes of in order to perform what is still sometimes referred to in terms of its paper analog, the “chart review,” scanning the EHR for the information expected to be needed during the encounter. Generally, the time that was available to providers for preparation was minimal—most reviewed information for only a few minutes just before bringing the patient into the room. Providers reported tightly scheduled clinic shifts, with patient visits frequently running long due to the difficulty in dealing with a complexity of health issues. One MD remarked that it was not unusual for him to need to cover 12-13 “issues” with a patient during a visit. Providers also expressed some reluctance to invest in advance preparation based on previous experiences with no-shows. Many reviewed the EHR “just in time,” only after the patient had checked in with the front desk clerk and they knew he was in the clinic.

Providers’ use of information in preparing for an encounter varied according to their role in the clinic and the specifics of the patient’s situation, but generally appeared to be to: determine the patient’s current state of health and/or illness; become aware of any intervening medical events since they last saw the patient; and establish an agenda for the visit itself. Providers considered this preparatory use of information as kind of a clinical “heads-up,” or as one commented, “so I know what I’m getting into.” Sometimes the preparation done before a patient encounter was associated with a providers’ need to convey information to

another clinician. Registered nurses or residents who were being precepted, or mentored, in the clinics, often accessed more patient information ahead of time in order to create a set of paper notes that they could actually bring to the attending clinician with whom they were working and better present the patient’s case:

I just make myself a little outline so that when I go to present to a staff person, I have all their meds listed, I have their vital signs, I have what reminders are due, what their last set of vital signs were, their last weights, I have something to compare.

The information considered most important by providers in preparing for an encounter with a patient with diabetes was objective data that was used to assess the patient’s current health or disease state. Providers consistently cited A1c, blood pressure, lipids, vitals, and other indicators used to determine the patient’s current degree of control of his illness as the starting point for making decisions about treatment approaches.

Providers then typically proceeded to what they often described as “looking at my last note” in order to get their bearings for the day’s visit. The encounter note generated during their last visit with the patient was used to remind themselves of the details of his situation, their treatment plan, and determine why the patient was coming in and what needed to be accomplished during the current visit. If the patient had received intervening medical attention since his last visit, providers would review those encounter notes in order to become current vis à vis his health situation. But even when other providers had seen the patient more recently, providers expressed a preference for going back to their own notes specifically:

I’ll usually look back at previous notes, whether [they’re] mine or another provider’s. My notes obviously, you know, everybody has their own style, way of making things make sense so I generally try to look for mine, especially if it is my patient.

As mentioned earlier, the encounter note is notably different from other commonly accessed information elements in the EHR in that its content goes beyond objective data and medical information. In incorporating subjective, contextual, and patient-provided information, the encounter note reflects not just the patient and his condition, but significantly, the provider's *interaction* with the patient; from the provider perspective this note is a key component of the EHR.

Use of EHR Information During Patient Encounters

Over the course of an encounter, providers continued to use information from the EHR to update their initial assessment of the patient's state of health or disease; solve emergent problems or address patient concerns; develop a treatment plan; and educate patients regarding their condition, treatment, and management. During encounters existing information from the EHR was integrated with information gleaned from patients' verbal accounts and logs they kept at home, and sometimes, with information received from other providers during consultations or mentoring.

The use of information during a patient encounter could be quite complex; providers were frequently observed navigating through numerous screens or sections of the EHR, picking out information that they needed, while also eliciting information from patient; responding to issues raised by the patient; informing the patient about his health, developing a treatment plan and presenting that to the patient; and documenting all of these aspects of the visit. Providers varied as to how well or smoothly they could achieve all of these, and while some appeared to fluidly incorporate the EHR into the encounter, for others its use seemed to eclipse patient interaction. Some providers adapted to the challenges of using the computer during patient encounters by developing ad hoc paper preparation and note-taking strategies that allowed them to minimize EHR interaction during the visit.

Information from the EHR was frequently revisited during an encounter in the course of trying to solve a health problem or respond to a patient complaint. Providers cited their patients as a significant source of information during the course of an encounter, and they often appeared to be updating their own sense of the patient's health situation by going back to the EHR in response to patient-provided information. What was a fairly static assessment early in the encounter became a more dynamic, interactive process of eliciting information and then returning to the EHR for more information as physical symptoms or contextual issues were illuminated and the provider tried to determine a course of action.

Information as an Input to Problem-Solving "Control"

Following their assessment of the patient's situation, providers usually progressed to developing or modifying what is referred to in clinic parlance as his "treatment plan." In problem-solving patient control, providers continued to incorporate their impressions from previous

encounter notes; the patient's medical history; treatment plans and goals set by other providers; recent medical events; intervening visit notes; and system reminders. Additionally, providers utilized retrospective information from the EHR in order to identify self-management patterns or life events affecting disease control. By looking at lab results over time, providers could put together a picture of the progression of disease, associating it with patient's life events or changes in self-management.

Problem-solving also incorporated the use of the patient's medication list from the EHR in order to establish what the patient was currently taking to control his illness and in what dosages. Reconciling the medication list involved eliciting information from the patient in order to establish what he was actually taking; patients often were confused about their medications, had stopped taking them for one reason or another, or the list was simply out of date in the system. For patients who were not meeting targets for particular health indicators such as A1c or blood pressure measurement, a review of the medication list and pharmacy records often revealed prescriptions that hadn't been refilled recently or medications they weren't taking, information that providers found useful in determining their next steps.

Along with the relatively de-contextualized information from the EHR, providers also indicated that information from the patient that aided in problem-solving control or self-management was essential. Even though the A1c lab test provided a reliable indicator of average blood sugar over a period of time, providers still needed to look at patients' home readings as taken from their glucometers or logs in order to troubleshoot variations in blood sugar throughout the day in response to eating patterns, activity levels and insulin usage. Providers elicited patient accounts of their illness and its management to aid in problem-solving, along with information about their current life situation and behaviors in order to prescribe treatment plans or strategies for managing chronic conditions.

The importance of real-time, patient-provided information was underscored by providers' desire to be able to access more of this kind of information in treating patients with diabetes. When asked what additional information they would like from the EHR, the most common responses were related to problem-solving conditions seen as impacting the management of a patient's illness, including what education the patient had previously been given about diabetes and patient details that could impact his ability to self-manage, such as undiagnosed depression or PTSD; extreme poverty, or living alone.

Providers consistently wanted additional information that would provide them with a better understanding of patients' control, barriers to control, and self-management behaviors, frequently characterized as indicators of patient "compliance." The most desired additional compliance indicators were information from the glucometers that

patients used to measure their blood sugar at home and reliable information that would speak to patients' diet and exercise behaviors at home. When available, information from the patient's glucometer was frequently used by providers to pinpoint patient highs and lows for problem-solving control related to daily behaviors. Clinicians identified technological challenges in obtaining and using this information since it was not well integrated into the EHR. Patients also routinely forgot to bring their glucometers with them to their appointments, a lapse that some providers considered a compliance issue.

One of the main things is... seeing their home readings and knowing what their patterns are. I think that's really important and that's something that you can't see in [the EHR] necessarily. ... if the patient forgets their meter, you know, sometimes our hands are tied as far as what you can do safely with adjusting their regimen.

Some of the patient-provider interactions observed during fielding suggested that providers did not always see patients as a reliable source of information about their own behavior, which may have manifested as a desire for more certainty about what a patient was doing to manage his illness at home. In this vein providers expressed wanting to see other details in the EHR about patients' daily life, including diet and exercise habits or even whether or not they were actually taking their medication.

In addition to better understanding compliance, providers also identified eliciting the patient's "take" on their illness as important:

I think the most important thing out of all these things is getting a read on what is their understanding of their disease. How do they see this and making sure that they get the education that they [need].

RNs in particular, who above all other providers tended to view patient education as a primary responsibility, reported that information about factors related to a patient's ability to understand the information presented to him was of high importance in problem-solving patient control.

You have to look at the patient, where the patient is, where they are as far as their health care literacy is concerned... I have to evaluate their level, their readiness to learn, how much information they can retain.

Use of Information to Maintain the EHR

Providers' use of patient information after an encounter is significant in that it addresses how information about the patient's condition is kept up-to-date in the EHR, which is maintained as a representation of the patient for ongoing care. Providers used patient information after the visit in order to finish their documentation of the encounter. Information from the record or from the provider's own handwritten notes was used to complete the encounter note, update the patient's "problem list," in the EHR, and make sure all medication and consult orders were entered into the system. Although providers did a lot of this while they were seeing patients, there was almost always some work

in the EHR that took place either immediately after the visit or later on in the week during clinicians' administrative time.

Providers' Use of the EHR in Patient Communication

In addition to using patient information from the EHR to inform their own work of patient care, providers also shared the information with patients during the course of a clinical encounter. The most commonly shared information elements of the EHR were those that conveyed health status information, such as lab data, vitals, or diagnostic results. An examination of how the EHR is invoked and its information communicated in patient interactions provides further insight into its role in shaping the patient's information experience.

Use of Biomarkers to Influence Self-Management

By far the most prevalent type of EHR information shared with patients during the course of a clinical encounter was that which indicated his health or disease status, usually lab results or vital signs that signaled control or lack thereof, such as hemoglobin A1c, blood pressure, and cholesterol levels. Informing patients of test results or diagnostic measurements could be considered a routine part of medical care, but in encounters with patients with chronic health conditions they were frequently conveyed as a reason for patients to maintain or change their health behavior or approaches to self-management.

When a patient's health indicators were at the desired target levels, this information was often communicated as a reinforcement of behaviors contributing to them. Providers often framed this information relative to a target level, or desired health outcome, as seen in this excerpt from the observation fieldnotes.

MD tells the patient his A1c is 6.8 and "we want it under 7, so that's good, your diabetes is under control." ... You're doing everything right. I wish all my patients had labwork like you." Patient says that he exercises and tries to be good. Doctor affirms this, says "that's great."

At other times, providers framed on-target biomarker information in the context of patient improvement, or relative to where they'd been. In these instances providers often presented trended data or graphs generated within the EHR to reinforce positive health behaviors:

The patient says he's been working out and the NP says 'it shows.' She turns the screen toward him and shows him the graph of his weight.

The authority conferred on a computer-generated representation of illness is apparent during encounters where providers present information from the EHR in order to counter a patient's perception of his health situation. This commonly occurred when patients wanted to discontinue a medication that they saw no need for; providers used their trended improvement to demonstrate why they should continue to adhere to their medication regimen.

Patient indicates he has discontinued his cholesterol medication. Doc turns back to the EHR, pointing to the screen: "When you started, your LDL was 160, now it's 73." He tells the patient how his cholesterol levels over time are much improved, he has responded well to the meds, and that he would like to keep him there.

In cases where patients were not achieving target levels, providers presented biomarker information as an incentive to change what they were doing to manage their illness. In interviews providers indicated that they considered sharing A1c levels with patients as an important means of educating them about their illness and the need to control it. The authority of out-of-range numbers and the EHR's documentation of them were frequently recruited by providers to back up their treatment plan—as a reason to take medication, eat healthier, or change their lifestyle.

Provider tells the patient, "You are a young guy and if we don't get this under control, your problems will spread to your kidneys and eyes."... He then says, "Let me share some numbers with you," as he turns the computer screen towards the patient, "looking at your notes from your last visit..."

Clinicians often used the A1c level or other indicators from the EHR to demonstrate a decline in control over time, again, to support the importance of improving medication adherence or self-management behaviors.

...she says to the patient that the other thing she wanted to tell him is that his A1c is 8.9, up from 7.1, so his control has gotten worse. She points to the graph of A1c levels on the screen and explains to him that he should watch his insulin and his food and diet.

Patients, on the other hand, tended to present their experiences of illness in terms of its impact on their life, as in "it's gotten so bad I can't even change my wife's oil," or "I want to be able to get on the floor and play with my grandkids." Such concrete expressions of illness contextualized within daily life experience stand in stark contrast to its abstracted representation in the EHR as a numeric lab value. Providers often described A1c levels to patients as representing "your average sugars over a three-month period," an explanation which could be viewed as emphasizing the measure's abstraction from daily lived experience. Blood sugar records from patient logs or glucometers, by contrast, are by their very nature associated with a specific point in time and appeared more closely relatable to everyday life behavior.

The pharmacist counts the readings on the log and tells him that only 2 out of 18 of his evening sugars are in range. She makes notes on the log as she tells him. The patient asks if she's going to fire him and she says no and tells him, "I just want your help getting them down."

In this example the provider utilized the reality of the information and the patient's reaction in order to enlist his cooperation in improving his control.

Using the EHR to Assert Control or Authority

In addition to using information from the EHR to influence a patient's specific health behaviors, providers also invoked it in various ways as a higher authority, using the EHR to assert their own agenda for the visit. The physical presence of the computer monitor with the patient's EHR open on it was observed to provide an opportunity for a very literal redirect of the conversation. In one example, a provider rejoined a patient's extended response to the question of how he was doing by turning his gaze from the patient to the computer screen and saying "okay, let's go through your issues."

At other times the EHR information was used to refute a patient's interpretation of a problem. These situations typically consisted of the patient introducing a particular perception related to his health and treatment, and the provider responding by summoning a more objective piece of information from the EHR.

... it's a cholesterol med and the patient hasn't been taking it. He seems unsure that he needs it because he feels his cholesterol levels are good. ... MD explains to him that as a diabetic they want him under 100 for his "bad cholesterol" and has him look at the EHR with her to see his cholesterol numbers.

Using the EHR to Convey Transparency

A number of providers expressed or demonstrated strategies that incorporated the EHR and its information into the patient interaction. For some this was a deliberate attempt to acknowledge the record and create a sense of trust or of being on the same page as the patient. One provider explained that she started every encounter with a review of the EHR information she had just used to prepare herself, in order to make sure the patient knew not only his health status, but also the aspects of his health she was paying attention to: "I want them to know, you know, like what kinds of things we keep track of and why they're important."

Another provider used a similar approach to facilitate his patients' acceptance of the EHR. As he entered information into the record during an encounter, he read aloud what he was writing, almost so low as to be talking to himself, but still perceptible. When asked about this practice, the provider indicated that it was a deliberate effort to make sure the patient "knows what I'm typing" and what is in his record, and that "there are no secrets." Providers did, as discussed previously, bring information into encounters to make a point or assert the authority of their perspective, and it is notable that many did this in a way that incorporated the physicality of the EHR. A number of providers were observed "opening up" the EHR to patients by turning the computer screen to them or gesturing toward it in the course of discussing their health situation.

Another way the EHR was used to create transparency was by referencing previous encounter notes to engage the patient regarding his interactions with other providers. In this way providers tangibly conveyed a team-based

approach to patient care and a sense of continuity. One provider explained that she was including some very specific details about what the patient was doing to quit smoking in her encounter note, *“because it builds trust for future encounters.”* For her this was a way of *“making sure the patient feels heard”* when a different provider sees him.

Likewise, secondary providers seeing patients on referral often considered the “plan of care” as a key piece of information from the EHR because it enabled them to carry out the treatment goals established by the patient’s primary care provider. Occasionally these providers interacted with the EHR so as to signal their attention to his PCP’s requests.

She then says, “Let’s see what Kent wants.” And she reviews the ‘Active Orders’ in [the EHR]. She tells the patient she needs to get his labs and a urine sample, then clicks on Kent’s note and reviews it.

DISCUSSION

The EHR’s integration at all points of care and levels of VA administration positions it as a powerful contributor to the shape of both provider work and patient care. As a primary information and communication medium for chronic illness care, the EHR plays a substantial role in situating information relative to patients. Through its ubiquitous use in patient encounters and provider decision-making, the EHR becomes a de facto representation of the patient with chronic illness in the primary care context.

While allowing crucial care coordination over time and across provider teams, the prevalent use of the EHR can also be seen as abstracting patient experience by emphasizing objective, de-contextualized information.

In treating patients with chronic health conditions, VA primary care providers relied first and foremost on biomarker information from the EHR such as A1c, cholesterol, and blood pressure. These measures were used by providers to set their agenda and expectations prior to a patient encounter and then to educate, motivate, and encourage desired health behaviors during the interaction. In healthcare settings, where top-down, expertise-driven information is the norm, an out-of-range biomarker might make a convincing case for the severity of illness and risk of complication. However, since self-management of chronic illness takes place largely outside of this context, it is likely that the pervasive use of numerical data to represent illness and its consequences may be too much of an abstraction from patients’ daily life experience to instigate lasting behavior change.

As a ubiquitous presence in the clinic, the EHR is easily incorporated into patient interactions as a higher authority or to refute patient assertions. These interactions may result in privileging objective and abstract representations of the patient’s illness. The structure and form of the EHR, along with the priorities of the organizational context, acted to reify and elevate delimited and seemingly definitive

indicators of illness. Unstructured, narrative information related to the patient’s personal experience of illness tended to be more obscured in the EHR, effectively downplaying its importance and making it difficult to track and retrieve from the record.

Although objective, quantifiable data was important to providers and a key input into chronic illness care, most of them considered subjective information from the patient to be nearly as important in problem-solving elevated biomarkers. In order to develop a treatment strategy for bringing the patient “under control,” providers needed to update their original EHR-based assessment with real-time patient accounts. This kind of subjective information was considered valuable in that it could serve to contextualize patient health indicators, connecting their biomarkers to everyday behaviors and their lived experience of illness. Those connections helped patients and providers identify barriers and strategies for self-management behaviors.

Providers were consistently stymied by not having enough information to support effective patient control and at-home management of chronic illness, but there was no clear pathway for capturing, retrieving, and using such information in patient care. Information related to patients’ subjective experience and life outside of the clinic was often what providers wanted more of from the EHR, but its relegation to the relatively freeform and idiosyncratically structured encounter notes was a barrier to use. When patients were able to provide more objectively measured and structured information, such as blood sugar readings from a glucometer or home blood pressure logs, providers readily used them to troubleshoot issues of control in terms of everyday life behaviors, but this information was frequently not available during the interaction.

IMPLICATIONS

The EHR’s ability to support multidisciplinary collaboration and maintain a persistent record over time position it as a lynchpin element in advancing new models of chronic illness care such as the Patient Centered Medical Home. The innovations observed here in providers’ use of the EHR as a platform for patient education, communication, and trust suggest that it has the potential to be perceived and adopted as a useful tool in managing chronic illness. Previous research has concluded that aligning the EHR structure more closely with providers’ use of it could facilitate its adoption (Veinot, et al., 2010). The findings of this study suggest that EHR effectiveness may also benefit from a closer alignment with patients’ everyday life experience of chronic illness.

EHR design and implementation for chronic illness care could incorporate structures and interfaces that make experiential and subjective information more readily accessible and actionable for providers. If the EHR is to represent the patient in the healthcare environment, it needs to be able to reflect the whole of his experience.

Information behavior theories such as Dervin's sense-making and Kuhlthau's information search process suggest that the EHR's effectiveness as an information medium may be improved through further integration into the provider-patient interaction as a collaboratively and co-constructed record of health and illness. Allowing patients to access and contribute to their EHR from home, where they are actively coping with and managing illness on a daily basis, might lead to a more complete and useful capture of patient experience.

This research has identified the potential mismatch of the EHR to the everyday life experience of chronic illness. More work is needed to fully examine how everyday life is presented and responded to in the context of patient-provider encounters. A further understanding of this gap could suggest additional ways to support provider-patient communication and interaction.

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