Narrowing the Gap: Chronic Illness Information as Experienced
in Everyday Life and Healthcare Contexts

by

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To my mom, Kathryn Ann Lorenz Serapiglia

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ABSTRACT

This research examines the information experience of people with chronic health conditions in everyday life and as shaped by the healthcare context in order to understand informational aspects of patient-provider disconnects. The study is unique in that it pulls together the perspectives of two distinct contexts, articulating how information use both reflects and plays a role in the disconnects between them. Its patient-centered orientation offers an additional perspective to current consumer health informatics research, which has taken a system-centered perspective, focusing on information and its transmission rather than on how it is experienced by people using it.

Two qualitative studies were conducted which included 14 in-depth interviews with women experiencing a variety of chronic health conditions; observations of 150+ patient encounters in three VA primary care clinics; and interviews with 49 healthcare providers treating patients with diabetes and other chronic conditions. The first study's key finding is that information was used by people with chronic illness in order to manage its impact on their everyday lives, serving emotional as well as cognitive purposes and meeting a host of medical and non-medical needs that were not always sufficiently addressed by providers. The second study found that while allowing chronic illness care coordination over time and among provider teams, the ubiquitous use of the

electronic health record (EHR) in the VA setting also abstracted patient experience,

acting as a representation of the patient in provider interactions. The structure and form

of the EHR reified and privileged certain types of information, i.e., numeric, quantifiable

data, while obscuring more freeform information related to the patient's daily experience,

lowering its priority and making it difficult to track and retrieve from the record.

Considered together, the findings of the two studies indicate that the use of

objective information in healthcare environments may stand in stark contrast to the

subjective ways illness is experienced in everyday life, presenting opportunities for both

disconnect and synergy. The study's findings have implications for recasting the role of

information in individual health literacy, provider-patient communication, and provider

information use related to chronic illness care.

CHAPTER 1

INTRODUCTION

1.1   Information in the Chronic Illness Experience

Living with chronic illnesses, those "requiring medicosocial intervention over an extended interval and affecting many aspects of an individual's life" (Thorne & Paterson, 1998), frequently involves many information-intensive tasks, including choosing doctors, considering treatment options, managing symptoms, and dealing with the emotional and social aspects of the illness (L. M. Baker, 1996; Corbin & Strauss, 1985; J. Corbin & A. Strauss, 1988; Timothy P. Hogan & Palmer, 2005). In this context chronic illness incurs demands for the kind of daily, routine problem solving and decision-making within which information seeking and use play a key role (Rouse & Rouse, 1984). In the experience of illnesses like cancer, individual information seeking has been claimed as "a pivotal force" in patient survival (Johnson, 2003).

The persistence and inherent complexity of chronic illness requires research approaches that are attentive to the subjective experience of illness in people's lives. Chronic illnesses can be difficult to diagnose; are often treated through a combination of traditional medical and alternative therapies; and have significant repercussions physically, emotionally, and socially (Charmaz, 1991; J. Corbin & A. Strauss, 1988;

Thorne, et al., 2002). The medical sociology literature describing "the illness experience"

tells us that chronic illnesses disrupt not only the body but also daily life and sense of

identity (Bury, 1982, 1991; Lawton, 2003; Pierret, 2003). This suggests a holistic and

multi-layered experience of illness and accordingly, of information in that context.

This dissertation examines the information experience of people with chronic

health conditions in both everyday life and healthcare contexts. Significantly, chronic

illnesses are, for the most part, pervasively experienced and perpetually managed within

the context of people's everyday lives. Yet people who have them receive treatment and

information through healthcare environments that were originally designed for acute care,

addressing patient needs in a curative and episodic fashion (Lubkin & Larsen, 2006).

Over time chronic conditions have become the major problem that is dealt with in the

United States healthcare system[1], yet that system has remained entrenched in an acute

care model (*Quality Chasm*, 2001). This situates care in a contextual mismatch that can

leave people with chronic health conditions on their own and disconnected from their

healthcare providers.

1.2 The Need to Narrow the Disconnect

The gap between information and behavior change has long frustrated health

educators and medical practitioners, accustomed to providing what they believe to be the

most necessary and persuasive information. But a biomedical perspective on the type of

information needed to cope with and manage illness has been critiqued as

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[1] Chronic illnesses are currently estimated to affect more than 90 million Americans and account for "more than 75% of the nation's $1.4 trillion medical care costs" (NIH-CDC, 2005). As the U.S. population ages, these numbers will only increase—by 2020, nearly 20% of the US population will be over 65 (He, Sengupta, Velkoff, & DeBarros, 2005 & DeBarros, 2005).

overemphasizing medical expertise and embracing a model of a one-way transfer of "perfect," or complete information that enables rational decisions leading to compliance with treatment (Bury, 1991; Dervin, 2005; T. Lewis, 2006). Some scholars have suggested a need to move away from a compliance-oriented model of information provision toward a "broader conception" that "takes the issue beyond the biomedical, and which is based on a holistic understanding of the patient's lifeworld" (Sligo & Jameson, 2000, p. 860); comprehending the realities of people's lived experience (Dervin, Harpring, & Foreman-Wernet, 1999).

In the current climate of healthcare reform, new models of care are being called for from the medical community which highlight the need to resolve the disconnect for patients with chronic health conditions (Bodenheimer, 2003a, 2003b; Coleman, Austin, Brach, & Wagner, 2009; *Quality Chasm*, 2001; *Improving quality of care: How the VA outpaces other systems in delivering patient care*, 2004; Piette, Richardson, & Valenstein, 2004; Vogeli, et al., 2007). Calls for reform of chronic illness care have surfaced attention to the role of the provider-patient relationship among providers, policymakers, and even in the mainstream media. In 2008 the *New York Times,* one of the world's most respected newspapers, debuted "Doctor and Patient," a column aiming to "bridge the gap between patients and doctors and remedy the disconnect" between them (Chen, 2008a). The author, a doctor herself, interrogates sources of tension in interactions between doctors and their patients. At one point she reflects on her own judgment of patient choices that seem at odds with their best interests and their doctors' efforts: "I am not in their shoes. And as much as I'd like to believe I have tried, I have not even begun

to understand *my* role in *their* choices" (2008b). Her acknowledgement speaks to the complexities of the provider-patient disconnect and the challenges healthcare providers face in stepping around the exam table to more fully understand 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 highlights the importance of this dissertation project. My approach to the problem is two-pronged: first seeking to articulate the everyday life experience of people with chronic health conditions; then examining how that experience is received and supported through information use in a best-practice healthcare environment.

1.3 Narrowing the Gap: Chronic Illness Information as Experienced in Everyday Life and Healthcare Contexts

This dissertation consists of two qualitative studies that address how information is experienced by people with chronic health conditions in two distinct contexts. The first study, *The Everyday Life Experience of Chronic Illness*, uses in-depth interviews with women experiencing a variety of chronic conditions to understand aspects of their daily life experience with illness and the role of information in that experience. The second study, *Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context,* uses data collected in the primary care clinics at three Midwest VA medical centers in order to examine how healthcare providers' use of information in the treatment of patients with diabetes and other chronic health conditions shapes patient experience in that environment. The design of the second study is ethnographically informed, incorporating both observations of provider work and patient

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encounters, and interviews with healthcare providers to provide a rich analysis of chronic illness information use in a healthcare context.

By examining this issue from the vantage points of both everyday life experience and healthcare provider work, this dissertation seeks to articulate how information use both reflects and plays a role in the disconnect between patients and providers. In the following analysis I have addressed the two sets of research questions below.

1.3.1   Study 1: Research Questions for The Everyday Life Experience of Chronic Illness

1.1   How and why do people use information in coping with and managing with chronic conditions in their everyday lives?

- What does information mean in this context?
- What roles does it play—how is it used?
- How does it impact their experiences of illness?

1.2   How does the illness experience manifest in everyday life?

1.3   What aspects or features of the lived experience of chronic illness are relevant to information needs, seeking and use in that context?

1.3.2   Study 2: Research Questions for Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context

2.1   How do aspects of the VA primary care context appear to shape information flows, interaction, and use in the care of patients with chronic health conditions?

- How is care for patients with chronic health conditions organized in the clinics?
- What are the providers' roles and activities in patient care?
- What organizational issues affect providers' roles in chronic illness care?

2.2   How do healthcare providers use information in treating patients with chronic health conditions?

- What information do providers use in their treatment of patients with chronic health conditions?

- For what purposes do they use information in their treatment of patients with chronic health conditions?
- How does information use vary by provider type?

2.3 How is information about the patient, his condition, and his treatment communicated in patient-provider interactions?

- What information do providers convey information to patients during encounters?
- For what purposes do providers convey information to patients during encounters?

2.4 How does the everyday life experience of illness manifest itself in medical encounters?

- How do patients bring their everyday life with illness into medical encounters?
- How do providers respond to patients' everyday life experience?
- What is the nature of mismatches or disconnects between everyday life experience and the medical encounter?

1.4 Significance of the Research

Chronic illness information is particularly useful as a research construct for examining the disconnect between patients and providers in that it is frequently created and provided from a medical context but then used by patients in the context of their lived experience with illness. To date much of the health information and consumer health informatics research has reinforced this disconnect, focusing on questions of type, source, and channel that make information itself the center of investigation. Even in the field of information behavior, known for its user-centered and context-sensitive approaches, research has focused largely on the *seeking* of health information rather than its *actual use* in managing and coping with chronic illness, centering the discussion within information environments and abstracted from daily experience.

This dissertation contributes to addressing this gap in the literature by focusing on the lived experience of people with chronic illness. The research is significant in that it examines this experience through two studies designed to articulate disconnects and potential synergies between the everyday life experience of people with chronic health conditions and their experience in the healthcare environments in which they are treated. The first study offers a rich articulation of firsthand experience with illness and information's role in it, powerfully drawing across a variety of health conditions to extract common themes of everyday life with chronic illness. The second study examines provider practices within the social and organizational contexts of a healthcare setting that is widely recognized as a best-practice environment both in terms of information use and chronic illness care. Its multi-method approach provides a deep understanding of how the contextual forces and information practices of this environment act to shape patient experience.

1.5   Roadmap for this Manuscript

Having laid out the problem and the strength of my approach to it in this introduction, I then proceed in chapter 2 to begin with a review of literature that identifies gaps in the current state of health information research and provides the theoretical framework for my orientation to the problem by drawing on literature from the fields of information behavior and the sociology of the illness experience. Chapter 3 describes the design and methods of the two studies in detail, including a summary of participants for each, and concludes with a discussion of the methodological considerations that inform my analysis. The study findings and analysis are presented in chapters 4-6, with chapter 4 addressing the research questions for study 1, *The Everyday Experience of Chronic*

Illness, and chapters 5 and 6 addressing the research questions for study 2, *Chronic Illness Information Use: Provider Practices and the Patient Experience in VA Primary Care Contexts*, examining contextual forces and information practices respectively. Chapter 7 concludes with a discussion of the implications of the findings, identification of the studies' limitations, and directions for future research in this area.

CHAPTER 2

LITERATURE REVIEW

2.1   Perspectives on Health and Illness Information

Health information studies are receiving recent research attention, spurred in part by the prevalence of health-information seeking on the internet, which has been highlighted in numerous large-scale surveys—a recent Pew study, for instance, found that as many as eight out of ten U.S. Internet users have looked for health-related information online (Fox, 2006). But even more striking than the extent of health information seeking is its potential to impact health management and decision-making. Another study estimates that 24 million Americans deem the Internet to have been "crucial or important" in dealing with a "major illness or health condition" for themselves or someone else (Horrigan & Rainie, 2006). The increasing availability of health information on the Internet and pressures from our healthcare system requiring increasing patient involvement in treatment and care decisions (Eng, et al., 1998; D. Lewis, Chang, & Friedman, 2005) are driving health information seeking and elevating the importance of information in dealing with health problems and conditions. Taken together, "[t]hese trends put increasing responsibility on individuals to become active seekers, rather than passive recipients, of information" (Johnson, 2003, p. 737).

As a medium where the proliferation of health information has been quite visible, the Internet has frequently been a site of study for health information seeking. Vis à vis

health information, the Internet offers the advantages of interactivity, information tailoring and anonymity (Cline & Haynes, 2001). The anonymity of the online context has been found to be particularly appealing in looking for information about stigmatized illnesses such as anxiety, depression, herpes and urinary incontinence (Berger, Wagner, & Baker, 2005 2005). A large body of work, relying on mostly quantitative methods, has focused on understanding the extent to which people use the Internet for health information, and to what effect. Internet health seekers have reported a better understanding of their symptoms and treatment, improved abilities to manage their health, and effects on lifestyle choices such as diet and exercise (L. Baker, Wagner, Singer, & Bundorf, 2003 & Bundorf, 2003; Fox, 2006). Pew studies (Fox, 2006; Fox & Rainie, 2002) have also pointed to the prevalence of online health information seeking, its contribution to illness decision-making, and a host of positive affective impacts, including feeling reassured, confident, relieved, comforted, and eager to share their new-found knowledge with other people. Negative impacts reported in those studies were far outweighed by the positive, but included feeling overwhelmed, frustrated, confused, and frightened.

Many of the advantages of the Internet come from its distributed production and communication model—anyone can post information for anyone else to access, leading to new forms of information transfer based on definitions of relevance that are outside of the medical model. Information that used to be controlled by medical professionals is now more freely available, and people can share information about their illness experience that goes beyond physiological manifestations and medical solutions, and

sometimes beyond mainstream medicine. The accessible and decentralized nature of the Internet draws a sharp contrast to the centralized structures of expertise that determine knowledge in medical contexts, so it is not entirely surprising that much of the research framed within a medical science perspective focuses on concerns with the quality of health information and how people evaluate it. Medical science as a discipline has emphasized issues of accuracy and the potential for misuse of health information by the uninformed consumer, pathologizing health information seeking with terms like "cyberchondria" and "epidemic" references (T. Lewis, 2006). Researchers in this vein have repeatedly concluded that much of the health information available on the Internet is of poor quality and that users don't take the proper steps to ensure the credibility of the health information they find on the Internet (Cline & Haynes, 2001; Eysenbach & Kohler, 2002; Eysenbach, Powell, Kuss, & Sa, 2002). Accuracy is understandably a concern in such an expertise-driven area as medicine, but information behavior theorists have come to understand that accuracy is only one dimension of the usefulness of information (Dervin, 2005). This is a downfall of approaches that consider information outside of the context of the user, who very well might value information's usefulness or fit to his needs and purposes rather than an abstract measure of its accuracy.

The need to understand the actions and implications of health information seeking and use has motivated research in the fields of medicine, public health, health communication, and information science. In its early stages, studies of "consumer health informatics" have coalesced primarily around medical science's need to adapt to the movement of health information beyond the bounds of the patient-physician relationship

and the disruption caused by the emergence of an "engaged" patient, who actively seeks information related to her condition (D. Lewis, Eysenbach, Kukafka, Stavri, & Jimison, 2005). The centrality of this health sciences perspective, however, has engendered research that frequently assumes a systems orientation and conceives of health information behavior in an instrumentalist fashion, with 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; T. Lewis, 2006).

Understanding health information behavior more theoretically would enable us to offer more comprehensive explanations for what motivates and shapes it, explaining differences and irregularities in people's approaches (L. M. Baker & Pettigrew, 1999). For example, normative ideas would assume that information about health is desirable and useful, and that in an expertise-driven area like medicine, high-quality, reliable information would be preferred. In spite of this, there is surprising variance in whether or not people choose to look for information when facing a health situation, and when people do look for information, they look to a wide variety of types and sources, some of which may be perceived by experts to be inaccurate or questionable (L. M. Baker & Pettigrew, 1999). Dervin (2005) points out that this kind of behavior is rarely random and chaotic, but instead patterned in ways emerging from a user's specific needs in a given situation. An increasing distrust in expert and institutional sources coupled with a growing volatility in the information environment have led to a need for continued movement away from top-down transmission approaches to health information, which

often rest on faulty assumptions about the user, ignoring the experiential realities of people's lives and assuming they are ignorant about information (Dervin, 2005). In fact, people often demonstrate recognition of information's pitfalls and are wary and judicious in their use of it. The process by which people conceptualize and strategize their approach to health information is most effectively revealed relative to the context and situation within which their needs arise, "No matter how alarming their inattention to information authority, they mostly care not where the information comes from but whether it is helpful" (p. S79).

The use of information in chronic illness may particularly benefit from a situated and more broadly cast perspective. Research focused on "health" information defined more generally or on seeking and use as confined to the context of a particular medium such as the Internet may not address information's role in navigating the complex, pervasive and ongoing needs that accompany chronic illness. Chronic illness is mostly experienced outside of the boundaries of medical or acute care settings, and incurs demands for the kind of daily, routine problem solving and decision-making within which information seeking and use play a key role (Rouse & Rouse, 1984). Living with chronic illness frequently involves many information-intensive tasks, including choosing doctors, considering treatment options, managing symptoms, and dealing with the emotional and social aspects of the illness (L. M. Baker, 1996; Corbin & Strauss, 1985; J. Corbin & A. Strauss, 1988; Timothy P. Hogan & Palmer, 2005). In the experience of illnesses like cancer, individual information seeking has been claimed as "a pivotal force" in patient survival (Johnson, 2003). A number of studies have been done across

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disciplines which recognize the value of information seeking and use in the sense of the control it imparts to people dealing with illness or health issues, the ability it gives them to play an active role in their treatment decisions and to negotiate the medical system and manage interactions with their healthcare providers (Broom, 2005a, 2005b; Cardillo, 1999).

Studies of the information needs, seeking and use of people with chronic illnesses are relatively recent in information science, and have been limited by their reliance on an "information as transmission" approach that frames the process of seeking and use as linear and discrete, treating information as something to be received or retrieved in an orderly fashion through interaction with a system. A study of cancer information needs and sources, "one of the first to examine systematic differences in the preferences of women for particular types of information from particular information sources" found that doctors were the preferred source of information for every type of cancer-related content, followed by organizations (Johnson & Meischke, 1991, p. 745). The conclusion of that study- that there needed to be increased consumer awareness and education about the availability of such "authoritative" sources of information- served to reinforce the necessity of centralized expertise. An LIS study of the information needs and preferred sources of women with multiple sclerosis indicated that they frequently preferred the physician as an information source, even for non-medical information (L. M. Baker, 1997). Baker (L. M. Baker) hypothesized that this preference could lead to frustration on the part of doctors, who frequently feel too busy and ill-equipped to address non-medical needs, leading to communication breakdowns and friction.

Some of the LIS research on chronic illness information seeking has sought to further more explanatory perspectives by identifying factors influencing preferences and perceptions relative to chronic illness information. Baker's (L. M. Baker, 1996) studies of the information practices and preferences of women with multiple sclerosis explained their information behavior using the psychological framework of monitors, who seek out information to cope with the stress of illness, and blunters, who cope by avoiding information. The application of monitoring and blunting is important in that it applies social sciences concepts in order to understand health information seeking more theoretically. It also contributes a theoretical perspective on the phenomenon of information avoidance, which is fairly common in chronic illness situations, but explains information behavior as driven by a personality type may not account for contextual variability in the experience of illness in daily life.

Studies which focus on the use (or non-use) of information, the role it plays in dealing with chronic illness, or its meaning in that context have made the most headway in situating it within the illness experience, contributing significantly to an understanding of information work in the context. An application of Dervin's Sense-Making methodology in studying women with multiple sclerosis went on to provide a more nuanced examination of information needs and behavior as seen in terms of gaps in knowledge (L. M. Baker, 1998). MS sufferers were found to be negotiating their illness experience with health information; using it to better understand the symptoms they were experiencing, the emotions they felt, and their treatment options and accompanying side effects. The use of Sense-Making in that study allowed for an explication of uses of

information beyond mere question-answering, extending to deepening understanding, anticipating the future, coming to terms with the illness and situating it into their life experience (L. M. Baker, 1998).

Such themes are echoed in various studies in the social science disciplines looking at the experience of illness which identify information as a key component in regaining control in the face of illness or in coping with its physiological, psychological and logistical impacts. The process of seeking, constructing and using information can help people experiencing chronic illness mitigate uncertainty and take control of their experience of the doctor-patient relationship.

A study of women with fibromyalgia and chronic fatigue syndrome, two illnesses with uncertain illness trajectories, showed that used knowledge as a purposeful coping strategy to gain control over their situations and influence interactions with their physicians (Äsbring & Narvanen, 2004). Having enhanced knowledge enabled the women to see themselves as experienced patients who wielded some power in their healthcare situations, capable of assessing their doctors' competence and taking responsibility for their own treatment. This work enumerated the uncertainty-laden aspects of the chronic illness experience that are addressed through knowledge construction and information-seeking, including: clarifying the cause of the problems or symptoms; defining a diagnosis; understanding the condition and its characteristics; determining a treatment plan; and negotiating the healthcare process (Äsbring & Narvanen, 2004). The continual construction and revision of meaning in the face of uncertainty during the chronic illness experience also suggest an ongoing role for

information. Research on the use of the Internet by men with prostate cancer (Broom, 2005b) found that searching for information related to their condition enabled the men to feel in control of their experience and to be less inhibited in their interactions with physicians. Ethnographic research with women participating in breast cancer support groups found that women used information to ease their uncertainty about the illness either by "constructing expertise" of their own or "conferring expertise" on their doctors (Clark, 2005).

An examination of the deeper meanings people with cancer attached to information seeking and use helped to shed light on their avoidance of information about their illness. Patients' decisions not to look for additional information about their cancer were characterized into a typology of three orientations - "faith," "hope" and "charity" (Leydon, et al., 2000). They constrained their information-seeking because they did not want to give up their faith in the abilities of their doctors; because they wanted to hold out hope for a positive outcome and didn't want to know about sub-optimal possibilities; and because they had a sense of not wanting to use up limited resources, such as hotlines, that they perceived as more badly needed by other people. In studying information activities as situated in patients' subjective experience and meaning-making, this research offered insight into how information functions in the context of the illness experience.

As sufferers have been expected and invited to take more of an active role in understanding their illness and treatment options, the concept of the "informed patient" or "expert patient" has emerged in the sociology literature (Hardey, 1999; Kivits, 2004) to convey an engaged information consumer continually evolving his sense of his illness

and treatment in light of his experience and incoming information. Informed patients can be seen as "negotiating agents whose health responsibility is both a matter of increasing knowledge about everyday experience as part of a reflexive project and a matter of locating this project within a broader informational environment" (Kivits, 2004, p. 510), a conceptualization that embodies individual action, context, and process and may be quite useful in characterizing information work in the chronic illness experience.

The phenomenon of the expert patient points to considerations of the role of the "illness narrative" and other forms of experiential information in the context of chronic illness. The Internet, through its interactive and democratic access, offers new opportunities for both the construction and use of the illness narrative, by virtue of its medium easily escaping the bounds of the medical system to provide people with a chance to benefit from the lived experience of others on their own terms (Hardey, 1999). Studies of online health information seekers (Hardey, 2003; Kivits, 2004; Swift & Dieppe, 2005; Ziebland, 2004) confirm the subjective importance of 'experiential knowledge' as well as medical expertise, posing a role for both in sufferers' management and sense-making of their illnesses. In the case of chronic illness, the most valued knowledge gained from experience often focuses on emotional aspects of the disease, identity work, and managing symptoms and treatment regimens on a day-to-day basis, topics typically outside of the purview of medical information.

The use of experiential knowledge and the Internet for health information have also been studied in terms of their impact on the relationship between doctor and patient. By enabling freer access to information that may or may not be sanctioned by the medical

community, the Internet threatens to disrupt a long-held medical model of one-way

transmission of information within the confines of the healthcare setting, controlled by

the healthcare provider. While some physicians welcome the informed and engaged

patient as a needed advance in healthcare and a potential improvement for chronic illness

management particularly, a number of studies (Anderson, Rainey, & Eysenbach, 2003;

Cline & Haynes, 2001; Hart, Henwood, & Wyatt, 2003, 2004) have found that doctors

feel threatened or annoyed by their patients' attempts to locate information outside of the

medical realm, or have concerns about the quality of information or its potential misuse.

Medical science has been criticized for treating online health information seeking

atheoretically and acontextually, without looking at the bigger picture or forces shaping

the phenomenon and its impact (T. Lewis, 2006). Lewis (2006) espouses that the use of

online health information "needs to be contextualized in relation to the changing role of

media in people's lives, new sources of expertise and shifting conceptions of responsible

citizenship in the contemporary West" (p. 523). To be placed in the larger context, she

suggests that online health consumption needs to be seen as a *complex social act* framed

by a '*health habitus.*' Like Savolainen (as discussed in the next chapter), Lewis (2006)

draws from Bourdieu's idea of habitus as an everyday social and cultural frame that

shapes information behavior. The health habitus concept insists on individuals as active

and empowered in their use of information, "while at the same time the kinds of health

material they access, how they perceive that information, and how they make use of it in

their everyday lives is framed by broader dynamics of social identity, such as

socioeconomic status and gender" (p. 536). An important underpinning of the health

habitus framework is that it gives less emphasis to characteristics of the information itself and more emphasis to a person's use of it within the context of his "social identity and the pressures and constraints of everyday life" (T. Lewis).

Within the healthcare delivery system, social aspects of the experience of illness contribute further complexity to managing and communicating health information. The collaborative nature of health information activity, which entails navigating and reconciling the sometimes conflicting information goals of patients, their families and healthcare providers; sociocultural norms that can influence ideas about health information seeking and sharing; and the preponderance of health information that can make information hard to avoid as well as cause confusion and overload have all been identified as contextual factors contributing to the complexity of information management relative to experiencing a serious health condition (Brashers, Goldsmith, & Hsieh, 2002). In the healthcare context, socially constructed worlds and subjective experience collide, offering potential for clashes of perspective with regard to information work.

This review of health information seeking research and the treatment of information in studies of chronic illness experience has revealed a rich area to be plumbed by pulling back to center the study of information behavior within the experience of illness rather than putting information itself at the center. This study proceeds within an interdisciplinary framework that draws on broad, integrated and contextually focused theory from information behavior as a platform for examining

information experience, that is, what information means and how it is used by people experiencing chronic illness, in both their everyday lives and in healthcare contexts.

2.2   Information Behavior Theory for the Chronic Illness Experience

The literature on the experience of chronic illness has revealed it to be a context with a lot of inherent complexity. Sufferers are actively working to manage the illness and its medical aspects, but also to incorporate and account for it in the context of their everyday lives and in terms of its impact on their sense of themselves and their social structures. Studies of the chronic illness experience have suggested a part played by information in meeting the needs of these tasks and in shaping the meanings people ascribe to the experience. The chronic illness experience literature has identified a role for information, but as of yet that role has not been treated significantly or conceived theoretically. The discipline of library and information science (LIS) has the potential to offer a theoretical framework for information within the chronic illness context through its attention, over the last thirty years, to user-centered studies of information behavior. Current trends in information behavior research, particularly the movement to integrative and holistic views of information needs, seeking and use (Choo, 2006; Ingwersen, 1999) position information behavior theory as an excellent starting point from which to incorporate the complexity of the chronic illness experience.

The study of information behavior focuses on "those activities a person may engage in when identifying their own needs for information, searching for such information in any way, and using or transferring that information" (Wilson, 1999, ¶1), and is often described as the study of information needs, seeking and use. Information

behavior studies focused on the needs and seeking of particular user groups have been

around since the 1950s, but began to turn towards a user-centered[2] perspective in the

1970s (Choo, 2006), when researchers began to focus on understanding people and their

needs in the broader context of their experience, not just in relationship to their use of

information systems or resources (Dervin & Nilan, 1986; Wilson, 1994).

> A user orientation... views information as a subjective construction that is
> created internally in the minds of the users. While a document or record
> may be defined and represented as being about something or some topic,
> the user wraps objective content in an interpretive envelope so that the
> information therein becomes meaningful, and it is this combined package
> of content plus interpretation that users find valuable and useable (Choo,
> 2006, p. 32).

User-centered information behavior research is informed by strong sensibilities

about the value of the subjective experience of the user, seeking to understand

information needs, seeking and use in terms of their meanings to those being studied.

Over time, this research has become increasingly theoretical in its conceptualizations of

information behavior, first, as Kuhlthau (2003) acknowledged, from borrowed theory,

and more recently, in theories that have emerged within the field itself (Case, 2002, 2006,

2007; Choo, 2006; Fisher, Erdelez, & McKechnie, 2005).

The development of more theoretical approaches within this user-centered

research paradigm has evolved into more "integrative" approaches to information

behavior, which embrace the entire process, assuming that "the study of information

seeking should extend into an analysis of why information needs arise and how the needs

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[2] Note that actor- or person-centered approaches are commonly referred to in the field as *user-centered*, a
piece of legacy terminology leftover from LIS' historical focus on people in interaction with a collection
or information system.

are perceived, represented, defined, and experienced" (Choo, 2006, p. 32). This orientation has given rise to studies of context in information behavior, which highlight "a user-centered approach to the study of information seeking and use that emphasizes real users with actual information needs prompted by situations arising in daily living" (Kuhlthau & Vakkari, 1999, p. 723). Recent research, particularly that influenced by the Information Seeking in Context (ISIC) conferences, has expanded the development of theoretical frameworks used and has consistently shown that context matters in studying information behavior (Dervin, 1992; Fisher, Durrance, & Hinton, 2004; Kuhlthau, 2003; Pettigrew, 1999; Pettigrew, Fidel, & Bruce, 2001; Talja, Keso, & Pietilainen, 1999; Talja, Tuominen, & Savolainen, 2005; Vakkari, 1997).

The term "context" itself should not be taken lightly, as it is a word frequently used in different senses without explication (Dervin, 1997). Views of context in the field of information behavior have ranged from understanding it as equivalent to the setting or situation in which information needs, seeking and use take place to a much more nuanced understanding of context as a set of meanings constantly created by the user in interaction with his social world (Courtright, 2007; Johnson, 2003). This latter, more subjectively constructed sense of context could prove most useful for theoretically informing studies of chronic illness information work as "everyday life" information behavior, which takes place outside of occupational settings and the bounds of specific information systems and in the midst of the complexities of people's lives.

The development of approaches embracing contextualism, constructivism, everyday life perspectives, and an interdisciplinary sensibility grounded in the social

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sciences make information behavior theory and constructs extremely relevant to the experience of chronic illness. The theoretical framework for the proposed study is grounded in information behavior approaches that comprehend multiple facets of information activity, including needs, seeking and use; look beyond information seeking and use episodes; allow for broad, subjective definitions and uses of information; and conceive of information behavior as a process of iteration, construction and meaning-making. The approaches of several key theorists that incorporate these sensibilities is discussed to exemplify the contributions of an information behavior perspective and map the terrain where this study has situated the experience of information in chronic illness.

2.2.1   *Wilson's Situated and Holistic Models of Information Behavior*

A pioneer in information behavior theory, T.D. Wilson has generated and iterated models of information behavior that conceive of information needs as a driving force for information seeking and that are deliberately broad in order to comprehend everyday information activities. He was one of the first information behavior researchers to point out the difficulty in understanding information needs without comprehending their context and then propose a user-focused model of information behavior that conceptualized information seeking beyond just going to an information system (Wilson, 1981). Like other notable information behavior theorists, Wilson works from a phenomenological perspective, seeing individuals as constantly constructing their social worlds through their interaction with the structure around them and the meanings they give to those structures and interactions. Information needs are often a result of individuals' attempts to make sense of their worlds, and information seeking is "almost always frustrated to some degree because of the division between the meanings

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embedded in information systems and the highly personal meaning of the information-seeker's problem" (Wilson, 1994, p. 32).

Information behavior theorists have often invoked a problem-solving framework to characterize evolutionary search over multiple episodes in a larger context. The problem-solving approach describes a progression from problem recognition to building an understanding of the problem and its possible resolutions (Wilson, 2005), reflecting a social constructivist perspective on information behavior in context. Wilson's early model (1981) articulated a context within which information behavior was initiated that included the person's physiological, affective and cognitive needs, their various roles and performances relative to them, and the local and macro-level environments in which problem-solving takes place. In doing so, he advocated for a "wider, holistic view of the information user" (Wilson, 1981, p. 666). This philosophical thrust emphasizes aspects of information needs, seeking and use relevant to everyday life information behavior. Like other information behavior theorists (c.f. L. M. Baker & Pettigrew, 1999; Bates, 2005; Dervin, 1976; Dervin, 1997; Dervin, Harlock, Atwood, & Garzona, 1980; Fisher, et al., 2005; Pettigrew, et al., 2001; Tuominen & Savolainen, 1997), Wilson has, over the years, characterized information seeking behavior as too complex to be explained by "information concepts" alone, and suggested that the LIS field could draw on other social sciences such as psychology, social psychology and sociology for a more thorough "exploration of the role of information in the user's everyday life" (1981, p. 666).

Wilson's (1997) "General Model of Information Seeking Behavior" expanded on his earlier ideas and proposed a comprehensive framework for information behavior as

triggered by context and situation and facilitated or impeded by characteristics of both the seeker and the information itself. The model included an expanded accounting of the intervening variables that shape the seeking and use of information, addressing psychological, demographic, interpersonal, environmental and source-related characteristics as sources of influence on information behavior, all of which can be seen as especially relevant to any everyday life information behaviors. Described as more "theoretical framework" than actual theory, the General Model incorporates theories from other disciplines that could be particularly useful in "linking theories to action," elucidating the intermediate stages between the "person-in-context" and the actual seeking of information (Wilson, 2005). As such, its role in this study is not to provide a model for information behavior as much as it is to inform a theoretical construct of the relevant forces that may be brought to bear on an understanding of information behavior in a complex context such as the chronic illness experience.

The "General Model of Information-Seeking Behavior" incorporates two stages of *activating mechanisms* that trigger information needs and information actions (or, conversely, inactions) that could be particularly helpful in looking specifically at how complex everyday life contexts can shape information practices (Wilson, 1997). As others have suggested, the concept of "information needs" is particularly difficult for users to relate to, and so, from a phenomenological perspective, may not be a salient or organic construct for the user and "it may prove more helpful to focus upon the proximate causes of information-seeking behaviour," (Wilson, 1997, p. 554) rather than the idea of a defined "information need." A sense of proximate cause can be elicited by

applying stress and coping theory from psychology as an activating mechanism for information needs. In psychology, stress is defined as the threat posed when the needs of a situation exceed a person's available resources and coping as the cognitive and behavioral ways that stress is reduced, mastered or tolerated (Wilson, 1997 [citing Folkman & Lazarus 1984, 1985]). People engage in both 'emotion-focused coping' to deal with the experience of feelings of stress and 'problem-focused coping' to manage the stressful problem itself.

The incorporation of coping theory as an activating mechanism for information seeking and use is particularly salient to considering a role for information in coping with the uncertainty generated by the disruptive experience of illness. In theorizing about activating mechanisms that could trigger information behavior, previous work has suggested a role for information in managing the stress of chronic illness, based on Miller and Mangan's [1983] characterization of monitors and blunters (Wilson, 1997). These typologies translate people's cognitive strategies into behavioral terms related to the role of information in coping: monitors prefer more information, finding it reduces uncertainty arousal in the face of stress, while blunters "prefer less information and suffer more arousal when they have high information input" (Wilson, 1997 citing Miller and Mangan, 1983). As previously discussed, this theory has been used in LIS to study the information behavior of women with multiple sclerosis, finding that monitors wanted more information than blunters about their illness, particularly early on in the illness (L. M. Baker, 1994).

A notable aspect of invoking stress/coping theory is that it highlights a significant role for affect in information behavior. Considering the role of affective as well as cognitive needs in shaping information behavior is intuitively salient in thinking about everyday contexts, especially in health-related where the perceived threat to everyday existence and well-being can be high (Wilson, 1997). Studies of health information frequently call attention to the phenomenon of information avoidance in health situations (e.g., L. M. Baker, 1994; Brashers, et al., 2002; Leydon, et al., 2000; Wilson, 1997), and the very existence of information avoidance acknowledges that the act of information seeking in health contexts is not purely cognitive (Wilson, 1997). In doing cancer-related information seeking, women have sought information to help them deal with the emotional as well as practical aspects of dealing with the disease (Johnson & Meischke, 1991), and other information behavior theorists) e.g., Kuhlthau, discussed below) emphasize the role of affective experiences such as uncertainty and anxiety in shaping information seeking and use.

The second activating mechanism in the General Model of Information-Seeking Behavior intervenes between the acknowledgement of an information need and the decision to actually seek the information, and is also useful for explaining information-avoiding behavior as well. Risk/reward theory, a person's assessment of how much they stand to lose versus how much they could gain by finding the information, could factor into the decision to actively seek and use information (Wilson, 1997). Bandura's social learning theory is also proffered as a way to consider the effects of self-efficacy on information seeking. A person's sense of self-efficacy relates to "personal mastery" and

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has to do with his perception that he can be effective in a particular task or can actually exert influence some influence on an outcome. Bandura links self-efficacy to coping strategies, noting that a person with a low degree of self-efficacy is less likely to even try to cope (as discussed in Wilson, 1997). A person's decision to actually seek information might be related to his confidence in his ability to access and find information. Self-efficacy has been invoked as a key concept for chronic illness self-management (see Jerant, Moore, Lorig, & Franks, 2008) and it has been speculated that the structures of expertise around which medical science is built might raise a self-efficacy barrier even in fairly information literate people (Dervin, 2005). In considering the chronic illness experience specifically, the sense of powerlessness and chaos created by illness might also act to diminish self-efficacy; an individual's determination about the usefulness or futility of information in influencing their outcomes could prompt or impede information seeking and use.

2.2.2   *Kuhlthau's Model of Information Behavior as a Constructive Process*

Kuhlthau's (1991, 2003) model of the information search process (ISP) offers much to a contextual understanding of information behavior that incorporates social, affective and cognitive factors within a constructivist viewpoint. Based on constructivist learning theory, the ISP describes a process wherein the actor is continually assessing and revising his information needs and seeking in response to an evolving understanding of the problem and its solutions and accompanying shifts in his affect and thinking. As such, it incorporates and further delineates many of the salient elements of problem solving, sense-making and information seeking in context. Information seeking is characterized as a process of knowledge construction or "seeking meaning," highlighting the importance

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of recognizing the degree of uncertainty that people feel in the constructive process and how those feelings in turn influence the process itself. "The Uncertainty Principle" takes on a primary role in the constructivist process of information seeking, highlighting its relevance to models for information provision. Recognition of the uncertainty element has been too often overlooked in traditional LIS paradigms that focus on the user's cognitive queries to an information system or collection: "From the user's point of view, information seeking is a holistic experience with thoughts, actions and feeling interweaving in a complex mosaic rather than as separate, distinct entities" (Kuhlthau, 2003, p. 93).

The ISP model outlines six stages in the information search process and depicts the feelings, thoughts, and actions that are characteristic of each. Thinking evolves over the course of the search process, with seekers moving from ambiguity about their information needs to specificity (Kuhlthau, 2003), a progression also expressed in other LIS theories such as the Anomalous State of Knowledge (Belkin, Oddy, & Brooks, 1982) and the concept of question-negotiation (Taylor, 1968). Over the course of an information-seeking project, participants' *feelings* about themselves, the information system, and the task evolved. In the course of deepening their understanding of their topic, students working on research papers went from feeling uncertain and apprehensive to feeling optimistic and then to feeling confused and frustrated, since "the information encountered rarely fits with previously held constructs" (Kuhlthau, 2003, p. 47). Once a focus was formed, their sense of direction and confidence began to steadily grow. The information seekers' initial actions were oriented around seeking generally relevant

information, but as they formed a focus they sought more pertinent information related to their specific need and topic.

The ISP maintains that information seeking is a process of construction- its stages and characteristics parallel constructivist processes described in the education literature (Kuhlthau, 2003). As a complex and iterated process, chronic illness information work might be experienced in similar ways, with a better understanding of what information is needed achieved only as seeking progresses and enough is known to form a more specific question. The variety of cognitive tasks involved in the ISP—contemplation, comprehension, relating to past experience, and consideration of possibilities—can also be useful in understanding the amount and nature of processing that goes into making sense of information in the chronic illness context. The feelings of inadequacy and impatience students experienced when they found themselves bogged down in uncertainty at the beginning of the process also provides a point of connection for understanding the role of affect in information behavior, particularly useful in a situation such as illness where feelings are likely to run high. Kuhlthau (2003) also sees her model as pointing to problems resulting from the mismatch between people's experiences of information seeking and needs and the way the system presents information to them, an insight that could be relevant in articulating implications for understanding chronic illness information work vis à vis the healthcare and information systems.

2.2.3   Information Behavior in Everyday Life

In exploring information needs as they exist outside of systems and as integral to processes of seeking and use, information behavior theorists began to carve out a research

perspective on information behavior as shaped by an individual's total experience rather than defined solely by role, occupation or organizational membership. Placing the user's experience at the center of examination redraws the boundaries of context much like shifting the focal point of a map or a photograph reframes relevant elements within the total picture. In the case of health and illness information, this shift can provide a critical distinction. The consumer movement in healthcare that has forced people to look for information and play a larger role in decision-making, requiring skills they may not have in a situation where they are already overloaded and emotionally taxed, has necessitated a deeper understanding of how everyday life information seeking comes about in order to best support health information seeking (Johnson, 2003). Perspectives on health information seeking that start from a person's interaction with a system such as the Internet or a doctor's office might fail to incorporate key influences and larger forces at play in an individual's experience of health or illness as a daily life problem or challenge.

Everyday life gained prominence as a legitimate and distinct area of study in information behavior in the mid-90s with Savolainen's model of "information seeking in the context of way of life," which he originally referred to as the "everyday life information seeking (ELIS) model" (Savolainen, 1995, 1999, 2002, 2005). The ELIS model was "primarily motivated by the need to elaborate the role of social and cultural factors that affect people's way of preferring and using information sources in everyday settings" (Savolainen, 2005, p. 143). Everyday life information behavior differs from that which takes place for school or work purposes in that it is less likely to be defined by an organizational context or system, less proscribed by a set process or habitual approach,

and has less clear outcomes or expectations (Savolainen, 1995). The ELIS model theorizes more generally about the nature of non-work contexts and how they shape information seeking and use. It expands on earlier conceptualizations of information seeking and use as part of everyday problem solving, theorizing broadly about the cognitive and social influences on information activity that takes place outside of occupational tasks or roles.

The everyday life information-seeking model is helpful in unpacking various elements that may add to the complexity of information's role in the chronic illness experience. Its theoretical base borrows from Bourdieu's concept of habitus, which Savolainen described as a "socially and culturally determined system of thinking, perception and evaluation, internalized by the individual" (Savolainen, 2005, p. 143). Habitus manifests itself as an individual's "way of life"—the enacted ordering and allotment of activities based on their subjective or personal value and objective or external constraints. Personal characteristics and individual values, attitudes, and interests exert a lot of influence over everyday life information seeking; as can the resources of material, social and cognitive/cultural capital available to a person; and aspects of their current situation of life. The concept of habitus helps to theorize about context in everyday life information seeking, describing a framework that can account for the way an individual's actions are shaped by his circumstances, situations and experiences.

The habitus framework suggests that generally, people seek to maintain a sense of coherence among the everyday things constituting their way of life, or "the order of things" (Savolainen, 1995, 2005). Maintaining this sense of coherence is achieved

through the act of "mastery of life." Mastery of life is an active process, associated with pragmatic problem solving, by which people reproduce an order of things that it meaningful to them. It is particularly salient in situations where the order of things has been disrupted or threatened. The goal of mastery of life is to eliminate "a continual dissonance between 'how things are at this moment' and how they should be'" (Savolainen, 2005, p. 144). The experience of disruption and repair is well chronicled in the sociology of illness literature (discussed in more detail in the following chapter), and numerous studies have noted the role of information in coping or maintaining control. Information seeking is integral to the constant reconciliation involved in mastery of life. An important feature of way of life and mastery of life is that they do not determine how a person seeks information in a *specific situation*, but rather suggest source preference criteria or "the tendency to adopt a certain information-seeking strategy in problem-solving situations;" the specific features of the problem situation also need to be considered (Savolainen, 2005). In understanding information seeking and use as shaped by the larger frame of a person's life, preferences and experiences, the ELIS model provides a way to conceptualize information behavior in the context of everyday life, where chronic illness is mainly experienced.

As has been previously discussed, coping is intricately connected to information use in everyday life situations. Everyone needs coping information in some aspect of their lives, and Harris and Dewdney (1994) drew on research from psychology, information seeking and communication to inform a set of basic principles describing the information seeking of "ordinary people." For the ordinary person faced with a

problematic situation, information is "anything that helps people make progress through the situation toward a desired goal" (Harris & Dewdney, 1994, p. 18). In the problem context, information seeking is equated with help-seeking, and can be visualized as a series of expanding spheres of help—personal, informal and formal sources. From their review of the help-seeking and information behavior literature, Harris and Dewdney (1994) distilled six principles of information seeking that allow for the complexity of information behavior as situated in a problematic "everyday life" situation:

- The nature of the information need depends on the helps-seeker's situation,
- The decision to seek help is affected by many factors,
- People seek out the most accessible information,
- People tend to seek help from interpersonal sources they relate to,
- Information seekers expect emotional support, and
- People follow habitual patterns in information seeking.

The theoretically strong models that have been discussed here arguably represent both the mainstay and the evolution of information behavior theory over the last thirty years. Drawing on broad social science perspectives, these theorists have continued to evolve their theories and approaches in order to create information behavior theory that comprehends the everyday experiences of people interacting with information. Even in the face of increasing theoretical richness, Information Behavior as a field still struggles to coalesce around strong theories. One possible explanation for this is the legacy effect of information science models that consistently orient people's information behavior information relative to an information system or collection. The continued invocation of terms such as "user," and even, one could argue, "needs," "seeking" and "use" suggest isolated, discrete activities done in relationship to an objective external entity.

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Understanding how information is experienced within the complexity of lived

experience, as in the case of chronic illness, could yield additional theoretical insight, but

requires informing the conceptual frameworks of the field with new lenses and

perspectives.

2.2.4   Constructionist Paradigms for a Situated, Subjective Perspective

In recent years there has been "an explosion" of information behavior research

that is simultaneously focused on detailing the cognitive processes of information seekers

and users—how they think and feel with regard to information—and with incorporating

social and contextual influences (Case, 2007). Information behavior as a field is evolving

towards multi-faceted frameworks that incorporate both cognitive and social factors:

> A distinct, unifying theoretical body is emerging, that, beyond its strong,
> user-centered core, emphasizes the contextual interplay of cognitive,
> social, cultural, organizational, affective, and linguistic factors and asserts
> that information behavior phenomena are part of the human
> communicative process (Pettigrew, et al., 2001, p. 67).

An important element in the evolution of contextual models for information

behavior is that the meanings associated with context have been increasingly deemed to

be not just individual, but social and cultural constructs as well. Social constructionist

research perspectives have been identified as a way of approaching context interpretively

(Talja, et al., 1999). Constructionism considers people's *experience*—how they think

about their actions and the meanings they attach to them—as the reality shaping their

behavior. In contrast to strictly objectivist frameworks that analyze observable patterns of

behavior to discern meaning, information science models that move away from cognitive

constructivism and embrace social constructivist or constructionist viewpoints can be

useful in fully understanding the individual *in context*, supposing that "the individual

lives in a world that is physically, socially and subjectively constructed" (Talja, et al.,

2005, p. 82).

"Information Practices in Everyday Life" (McKenzie, 2003) is a social

constructionist model of the information practices of women pregnant with twins.

Drawing on social rather than cognitive construction, the term "information practices" is

preferred over "information behavior" because it assumes a social and dialogical

construction of the processes of information seeking and use, rather than a psychology-

driven paradigm "based on the ideas and motives of individual actors" (Tuominen, Talja,

& Savolainen, 2005, p. 328). The "Information Practices" model is decidedly contextual

and subjective, providing "an overview of information practices in the life of the

individual rather than analyzing specific information practices in an individual's

repertoire" (McKenzie, 2003, p. 28). Although not positioned as a model of health

information specifically, the fact that pregnancy is a health-related event ongoing over a

period of time and experienced for the most part in the context of daily life suggest that

aspects of this perspective could be easily translated to the chronic illness experience.

Relative to other information seeking models, McKenzie's (2003) construal of the

women's information practices related to their condition is less directed, more complex,

and entirely fluid, accounting for context-integrated activities such as scanning and non-

directed monitoring as well as purposive seeking. Just the act of living with a health

condition can be seen as dynamically generating an information world or environment in

service to gathering information about the condition. The information practices described

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within the model encompass a variety of activities that could be relevant in chronic illness information work, including identifying potentially helpful sources, serendipitous encounters, being given information without asking for it, planned encounters with potentially helpful sources such as doctors, referrals to potentially helpful sources, making connections to potential sources, proxy searchers who find information on behalf of the women or direct them to sources, and barriers or failures experienced in attempts to connect to sources or get information (McKenzie, 2003).

Those information behavior theorists advocating for social constructionism (e.g., McKenzie, 2003; Savolainen, 2008; Talja, et al., 1999; Talja, et al., 2005; Tuominen & Savolainen, 1997) emphasize a perspective that understands information needs, seeking and use as part of the larger social and cultural fabric, rather than as strictly individual patterns of behavior. Savolainen's recent (2008) conceptualization of "everyday information practices" makes explicit the fit of a social constructionist approach to everyday life information behavior, using the term "practices" to reflect the habitual and extend the original ELIS concept beyond just information seeking. Taking a distinct social phenomenological perspective to move beyond the individualistic cognitive perspective, information practices is defined as "a set of socially and culturally established ways to identify, seek, use and share the information available in various sources," and provides a way to frame information behavior socially and contextually, without having to invoke the concept of a needy individual (Savolainen, 2008).

Social constructionist approaches allow information behavior to be seen through a broader lens, mediated by meanings and values inherent in and attached to the context. In

terms of the chronic illness experience, this might entail understanding information needs

and seeking as driven by more than just situational factors such as illness and life

situation, but also as shaped by people's experiences of cultural norms and values around

illness, the medical system and information itself. Dervin's Sense-Making Methodology,

described at length below, shares many of the sensibilities and philosophical

underpinnings of social constructionism, and is presented in Chapter 5 as one of the main

theoretical veins of the proposed study. Sense-Making and the previously discussed

contributions of evolving information behavior theory offer the potential to examine

chronic illness information activity from the perspective of people experiencing it. But in

order to order to truly move beyond the shortcomings of information behavior paradigms

toward a more nuanced view of the illness *experience* and information's role in it, I turn

next to the sociology of illness literature.

2.3   Sociology of the Illness Experience in Contrast to the "Medical Perspective"

The sociology of chronic illness is characterized by its adoption in the late sixties

of an 'insider' perspective that focuses "directly and explicitly on the subjective

experience of living with and in spite of an illness", as opposed to "outsider" perspectives

based on a medicalized view of the patient (Conrad, 1990, p. 1259). Emerging from the

work of "Chicago School" sociologists in the 1960s, sociology of illness research began

to examine illness from the patient's perspective, providing a counter to the "then

dominant 'sick-role' conception [Parsons 1951] that assumed centrality of the medical

perspective" (Conrad & Bury, 1997, p. 374). Because most of the activity of chronic

illness happens outside of healthcare contexts, at home, inextricably entwined with

people's everyday lives (Corbin & Strauss, 1985; J. Corbin & A. Strauss, 1988), the

medical perspective began to be recognized as limited in terms of what it can provide towards an understanding of the chronic illness experience.

Medicalized views of illness are also limiting in considering information use in the context of illness because they tend to privilege medical expertise and embrace the idea of a one-way transfer of "perfect," or complete, information that enables rational decisions leading to compliance with treatment (Bury, 1991; Dervin, 2005; T. Lewis, 2006). Notions of 'objectivity' inherent in the medical science paradigm run the risk of overlooking the importance of the subjectivity and meaning a person gives to his illness in the context of his everyday life. The sociology of the illness experience has emphasized these meanings and "served to underline the importance of setting and individual biographies in order to understand the complex and often variable ways in which people experience, and 'live with', illness" (Lawton, 2003). Sociologists have pointed to a central role for information as a resource for illness activities such as, "reducing uncertainty, biographical work, creating medication practices, and developing practical strategies to manage the illness" (Conrad, 1987, p. 14).

2.3.1 The Chronic Illness Trajectory

Early sociology of illness work presented an alternative conception of the illness experience with the emergence of the idea of the "illness trajectory" (Glaser & Strauss), which was refined over several decades through application in studies of medical work (Strauss, Fagerhaugh, Suczek, & Wiener, 1985) and the experience of chronic illness (Corbin, 1998; Corbin & Strauss, 1985; J. Corbin & A. Strauss, 1988; Corbin & Strauss, 1991; Strauss, 1987). The term illness trajectory is a conscious effort to describe illness

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as a sociological concept rather than a medical categorization (Corbin & Strauss, 1985). "Illness trajectory" broadens the experience of illness past a medicalized view of the course of disease to comprehend the work related to the total experience of illness, including its impact on those affected by it and how its management and outcomes are shaped by its context (Corbin, 1998; Corbin & Strauss, 1991). Analytically, the concept of illness trajectory shifts attention from the physiological experience of illness to its social context and attendant social relationships (Corbin & Strauss, 1985), a product of its symbolic interactionist grounding. The illness trajectory framework is subjective in its orientation, incorporating a focus on "undergoing and experiencing," as opposed to a traditional sociological analysis of "actions and plans" or a medical view of "treatments and programs" (J. Corbin & A. Strauss, 1988, p. 34; citing Dewey, 1960).

The chronic illness trajectory framework (Corbin & Strauss, 1985; J. Corbin & A. Strauss, 1988) comprehends the activity of illness in terms of the work done by the person experiencing it. The use of the term "work" to describe the actions taken by laypeople in their everyday lives is deliberate and important in that it "highlights the point that sufferers of chronic illness must *do* a great deal … to manage and shape their illness trajectory" (Conrad, 1990, p. 1261). "Information work" is referenced as a type of work shaping the illness trajectory in various ways (J. Corbin & A. Strauss, 1988), but the concept is largely undeveloped. Chapter 5 below elaborates the theoretical framework used to ground the concept of "information work" for this study.

People experiencing chronic illness manage it at home through three primary lines of work: illness work, everyday life work, and biographical work (Corbin & Strauss,

1985; J. Corbin & A. Strauss, 1988). Each line encompasses many other types of work. Illness-related work includes work such as managing treatment regimens, symptoms, and diagnostic work. Everyday life work includes household-related activities such as housekeeping, child-rearing, and everyday activities such as shopping and eating. Biographical work includes coming to terms with the illness, its limitations and possibly, death; reconstituting identity and sense of self in the light of illness and its changes; and recasting biography. Understanding the breadth of activities comprising the constellation of the illness experience is a powerful way to marry its physiological impacts with the entire experience of the person in his or her life. Recognizing the activities undertaken to manage illness and the driving forces motivating those activities can help to contextualize information needs and experience in everyday life and healthcare contexts.

2.3.2 *Disruption and Meaning-Making in Chronic Illness*

Although the conceptual lens of the work of illness is a helpful concept in its emphasis on activity and task, that same emphasis runs the risk of divorcing the experience from other types of meaning, "blind[ing] us to other aspects of the experience" (Conrad, 1990, p. 1261). For instance, an activity such as managing medications may be aptly described as "regimen work," but it would be important not to overlook the other meanings this routine might have for the sufferer, e.g., as a mechanism for control, or an indication of the progression of their disease (Schneider & Conrad, 1983). The experience of illness can also be described as one of interruption, intrusion, and immersion, meanings derived from "the person's bodily feelings, thoughts and sentiments" (Charmaz, 1991, p. 10). The meanings ascribed to illness may not constitute "work" in and of themselves, but "meaning" may be an integral part of the biography

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work that people do to contextualize illness into their lives. Biography work is a way of making meaning as well as a way of responding to the meaning made of the illness experience.

The sociological understanding of the experience of chronic illness recognizes biographical work as a primary concern. The concept of biography "conveys life evolving around a continual stream of experiences that result in a unique—if socially constituted—identity" (J. Corbin & A. Strauss, 1988, p. 50). Biography refers to the way that a person conceptualizes his sense of self and identity in his life and "suggests that meaning and context in illness cannot be easily separated" (Bury, 1991, p. 53). The experience of chronic illness cannot be understood outside of the rest of a person's life: "[participants never] spoke only of the illness. They made it part of their life stories and placed it in a biographical context—what had been going on before, what life was like in the past, what hopes and dreams were interrupted or changed" (J. Corbin & A. Strauss, 1988, p. 51).

Sociologists studying the illness experience have examined the ways in which self and identity are disrupted by chronic illness and the work done to mitigate, accommodate and repair in the face of disruption. The onset of chronic illness constitutes a significant biographical disruption, "where the structures of everyday life and the forms of knowledge that underpin them are disrupted" (Bury, 1982, p. 169). Facing this rift requires the use of cognitive and material resources, generates various forms of explanation for pain and suffering, and highlights doctor-patient disconnects. Taken-for-granted or "commonsense" assumptions are breached, necessitating a reworking of

explanatory systems and the mobilization of resources to cope with the disruption (Bury, 1982). Disruptions in biography occur at multiple levels: in bodily experience; in meaning, as a "shattering of hopes and plans;" and as a disruption of "relationships and material and practical affairs" (Lawton, 2003, p. 25).

Experiences such as pain and suffering that are characteristic of chronic illness but not typically part of everyday life need to be accounted for, and the ways that people make sense of them in the face of incomplete medical knowledge or biographical disconnects (e.g., "I'm too young to have arthritis) may be at odds with how the experience is codified in medical discourse, creating a gap between the experience of the patient and the expectations of the doctor (Bury, 1982). Medical science becomes "both an important resource to people in times of distress and pain and as a constraint in their search for the deeper meaning of experience" (p. 179).

Uncertainty in the ongoing experience of chronic illness can create two types of meaning for the sufferer: the meaning constructed in terms of its consequences, e.g., what kind of disruption to everyday life is caused by particular symptoms or manifestations of illness; and the meaning in terms of its larger significance for biography, which can have a profound impact on how individuals see themselves (Bury, 1988, 1991). By virtue of its ongoing nature, chronic illness creates a state of 'meanings at risk,' in that "individuals constantly test the meanings attached to their altered situation against the reality of everyday experience" (Bury, 1991, p. 454)

A key aspect of biographical disruption is that it occurs in the life of the person experiencing illness and may be completely unrecognized in the healthcare context.

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People with chronic illness can experience a profound loss of self (Charmaz, 1983) resulting in emotional suffering that occurs completely outside of the physical experience of illness, the aspect most recognized by a medical perspective (Lawton, 2003). Chronic illness is an "assault on the self," bringing into doubt the sufferer's sense of self-worth, marked by "former self-images crumbling away without a simultaneous development of equally valued new ones" (Charmaz, 1983, p. 168). Loss of self can result from the restrictions of physical symptoms, treatment regimens or a plethora of medical appointments; the social isolation resulting from the inability to work or participate in regular leisure and social activities; the experience of stigma arising from interaction with others or from not being able to live up to one's own expectations; and becoming a burden due to immobilization or increased dependency (Charmaz, 1983). The loss of self that sufferers experience is clearly connected to a disruption of biography: "chronically ill persons evince a heightened self-concern about the person they see themselves becoming about valued self-images from the past which they have lost, somewhat irretrievably" (p. 190).

In most cases, chronic illness necessitates not only accommodation of the illness, but biographical accommodation, "action aimed at achieving a sense of control and balance over that life, as well as giving it continuity and meaning despite the illness and the changes it brings" (Corbin & Strauss, 1987, p. 251). Biographical processes in the course of the illness trajectory are a way of "putting life back together again" and include contextualizing the illness into one's biography; coming to terms with the illness and its limitations; reconstituting identity and sense of self in the light of illness and its changes;

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and recasting biography (J. Corbin & A. Strauss, 1988, chapter 5). Life course can be interrupted and profoundly changed by illness. The health sociology literature describes illness as a biographical disruption or interruption, and points to the profound sense of immersion in their illnesses that the chronically ill experience (e.g., Bury, 1982; Charmaz, 1991). The task of biographical work is intricately involved in day-to-day living with a chronic illness and almost entirely overlooked in our health system, which has historically revolved around an acute care model of illness, focusing on medical-technical interventions (J. Corbin & A. Strauss, 1988).

2.3.3 *Time, Process, and Change in the Experience of Chronic Illness*

Some of the "sequential aspects of illness experience" began to be captured in early Chicago School work on the sociology of illness (e.g., Goffman, Davis), which laid out the concept of "illness career" (as discussed in Conrad, 1987, p. 9). The illness career concept identified changes over time in people's experiences with illness—the needs, meanings and experiences of the newly diagnosed might be quite different than those of "veteran" sufferers (Conrad, 1987). Time since diagnosis has been shown to affect types of information needed and which sources are considered most useful in dealing with chronic illness (L. M. Baker, 1996). A consideration of illness stage can be somewhat useful for explaining variance in behavior and experience, but the concept may lose some explanatory power in that it assumes a certain linearity of experience, whereas the nature of most chronic illnesses combined with the ongoing effects of aging and changing life circumstances may entail information work that cannot be distinctly characterized in terms of illness stage or time since diagnosis (M. Souden, 2008).

The chronic illness trajectory framework, which invokes the idea of trajectory phasing as opposed to illness stages, is a useful evolution of the illness career concept in that it "encompasses process and change but does not assume linearity or orderliness" (Conrad, 1987, p. 10). Trajectory phases (J. Corbin & A. Strauss, 1988) take into account the physiological course of illness as well as the sufferer's responses, reactions and meanings ascribed to it. In short, phasing can be seen as encompassing the *entire experience* of illness in the context of everyday life at a given point in time. Even though some illnesses have a characteristic overall shape, the amount of variance in how trajectory events unfold makes it more relevant to look at phases rather than the entire shape of a trajectory. Phasing differences harbor tremendous variation in terms of their implications for the work involved (J. Corbin & A. Strauss, 1988). In an acute phase, defined as a physical crisis that needs immediate medical attention or hospitalization to prevent death, the physiology of illness and management of symptoms might be of primary importance. By contrast, the comeback phase that follows it, issues of emotional recovery might emerge, challenged by a sense of uncertainty about the future. Stable phases tend to be marked by an emphasis on return to everyday life and an integration of illness routines, but the degree of unpredictability of an illness can temper the emotional experience of stability. Unstable phases may combine the worst of both worlds, with physical experiences not quite experienced as acute, but still consistently out of control, making everyday life planning and routines difficult. A sufferer in a downward phase may be experiencing a steady descent through stages of incapacity and death, forcing an emphasis on emotional work or reconciliation.

Phases can have sub-phases (e.g., early comeback,) and can be complicated, encompassing paradoxes of physical versus emotional well-being—for example, a patient may be daunted by the work of making a comeback, but simultaneously grateful to be alive and hopeful for the future (J. Corbin & A. Strauss, 1988). Being able to locate information work in a particular phase of an illness could help to identify patterns of critical contextual elements, or account for variation in information behavior. Illness phasing as experienced in a trajectory framework has been used in LIS to better understand the contextual forces that drive patients to certain sources or types of information- in their analysis of survey data regarding the information activities of people living with HIV/AIDS, Hogan and Palmer (2005) suggested that trajectory phasing could account for conflicting ratings of the usefulness and relevance of particular information sources.

2.3.4 Uncertainty in the Chronic Illness Experience

A number of sociologically informed studies have articulated the sufferer's experience of uncertainty at various points in the chronic illness experience and seek to understand the ways people cope with or mitigate uncertainty. Such research has revealed several types of uncertainty experienced by the sufferer—uncertainty of initial perceptions of illness or physical symptoms; medical uncertainty while a diagnosis is being sought or determined; after diagnosis, uncertainty about how the illness will impact their activities and relationships; and uncertainty about the trajectory of the illness, especially in the case of illnesses with unpredictable courses (Conrad, 1987). Uncertainty about the illness and its impact is often accompanied by uncertainty about "appropriate behaviour in the face of its effects" (Bury, 1982, p. 172).

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In the chronic illness trajectory framework, uncertainty and its management are conceptualized through trajectory projections and trajectory schemes (J. Corbin & A. Strauss, 1988). Trajectory projections are the anticipation of the course an illness will take. The answers to questions such as: will it worsen, at what rate, can it be treated or controlled, what is the prognosis, etc., can all be elements of trajectory projections, a construct that can change with additional medical information, new experiences of the illness or its symptoms, and biography or life changes. Doctors, patients and their families all have trajectory projections, which may or may not align. Trajectory schemes are the plans for meeting this projection, or managing the illness. For the doctor, a trajectory scheme looks like a treatment plan, and while not devoid of complexity in its arrangement, it of course does not evoke the degree of biographical work that it does for the patient. The trajectory scheme of the patient is influenced not only by the doctor's scheme, but by his own treatment projections and assessment of how the doctor's trajectory scheme will impact his life and the lives of those around him (J. Corbin & A. Strauss, 1988).

The management of trajectory projections and schemes can be anticipated to entail a considerable amount of information work. For instance, the activity of *shaping* is described as the process of trying to influence someone else's trajectory projection, and can happen between doctor and patient, patient and family or family and patient in order to quell fear, maintain hope, or induce compliance (J. Corbin & A. Strauss, 1988). Shaping typically "occurs through manipulation of the amount and timing of information given and to whom it is given" (p. 39) and may be of highest priority early on in the

experience of a chronic illness, undertaken as the first steps in moving from diagnosis to living with a chronic condition. At this point in illness patients are often facing the limitations of medical knowledge, and may be struggling to construct an explanation for their condition that makes sense to them in the context of imperfect information and their own experience and biography (Bury, 1982).

Understanding the chronic illness experience as actions taken to manage the illness in its intersection with everyday life and sense of self provides a potential lens for understanding the role of information in the process. The impact of information on the physical, emotional and logistical management of illness has been well documented. Relative to information seeking and avoiding in health contexts, research and theory has highlighted information as an "important component of coping with illness and illness-related uncertainty" (Brashers, et al., 2002). A number of studies have been done across disciplines which recognize the value of information seeking and use in the sense of the control it imparts to people dealing with illness or health issues, the ability it gives them to play an active role in their treatment decisions and to negotiate the medical system and manage interactions with their healthcare providers (e.g., Broom, 2005b; Cardillo, 1999; Cline & Haynes, 2001).

Other "social studies" of illness reinforce the idea of information as a means to control or address the uncertainty of illness. Women participating in breast cancer support groups sought information to ease their uncertainty about the illness; their information seeking had a direct relationship to their sense of power and control in managing their illness and treatment (Clark, 2005). Women with fibromyalgia and

chronic fatigue syndrome, conditions characterized by very uncertain illness trajectories, used knowledge as a purposeful coping strategy to gain control over their situations and influence interactions with their physicians (Äsbring & Narvanen, 2004). Some of the uncertainty-laden aspects of the chronic illness experience that are addressed through knowledge construction and information seeking include: clarifying the cause of the problems or symptoms; defining a diagnosis; understanding the condition and its characteristics; determining a treatment plan; and negotiating the healthcare process (Äsbring & Narvanen, 2004)

The continual construction and revision of meaning in the face of uncertainty during the chronic illness experience suggests an ongoing role for information. Uncertainty may trigger information needs, seeking and use; information is recognized as mitigating uncertainty and helping maintain a sense of control in illness. The pervasive uncertainty of chronic illness becomes both backdrop and shaping force for the information work of those experiencing it. The experience of uncertainty and other concepts from the sociology of illness literature help to flesh out essential aspects of the chronic illness context and its complexity by illuminating the meaning and work of illness from the perspective of the person experiencing it. In this way sociology of illness experience also provides a useful framework for considering how the perspective of the person experiencing illness can be at odds or out of alignment with the perspectives of healthcare providers.

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CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 Overview of the Research Studies

This research looked at the how information is experienced in the course of

coping with and managing chronic health conditions. Its two-study design allowed me to

first examine the meaning and use of information in the lived experience of chronic

illness, and then, how aspects of the healthcare context provide a frame for this

experience. In my initial study, *The Everyday Life Experience of Chronic Illness*, I

investigated the experience of illness and information in it from the perspective of the

person living with it. Then I turned to the healthcare context, making opportunistic use of

data I collected from a different vantage point, focused on providers' use of information

in caring for and interacting with patients with diabetes and other chronic conditions.

This second study, *Chronic Illness Information Use: Provider Practices and the Patient*

Experience in the VA Primary Care Context, examined the ways in which provider

practices and the healthcare context act as a frame for the information experiences of

patients with chronic health conditions.

Living with chronic conditions can entail a significant amount of physical and

emotional work that is embedded within the intricate context of daily life and personal

experience. In the healthcare settings where patients and providers come together and

information is gathered, exchanged and sought, the messiness and uncertainty of

everyday experiences of illnesses may stand in contrast to the paradigm of expert

knowledge and clinical evidence that characterizes biomedical approaches. Likewise, the

immersive and relentless aspects of the day-in, day-out experience of chronic illness

might be inadequately addressed by a healthcare system rooted in a model of acute

diagnosis and treatment. Through the two studies described below I examined chronic

illness information in both contexts in order to begin to articulate information's role in

the potential disconnects and synergies between the everyday life experiences of people

with chronic conditions and the healthcare environments in which they are treated.

3.2   Study 1 The Everyday Life Experience of Chronic Illness

3.2.1   *Introduction and Research Questions for Study 1*

My initial study, *The Everyday Life Experience of Chronic Illness* (Everyday Life

study)*,* focused on individuals' experiences of illness from a first-person perspective. I

conducted in-depth interviews with people experiencing chronic health conditions in

order to begin to understand the ways in which they had used information over the course

of their illnesses and the roles it had played in managing and coping with their conditions.

The interviews elicited participants' narrative accounts of their health conditions,

harnessing the power of a qualitative approach to tell a rich story about the complexity of

factors, processes and perceptions related to their experiences of chronic illness.

The aim of the first study was to gain a deeper understanding of the context of

lived experience with chronic illness and to begin to identify the ways in which

information was a part of participants' experiences. The primary research questions

addressed in study 1 are shown in Table 3-1 below. In order to answer these questions I

used a semi-structured approach to elicit retrospective narrative accounts and then analyzed the data inductively to draw out emergent themes that characterized the role and meaning of information in participants' experiences of illness. Findings of the Everyday Life study are presented in chapter 4 and form a rich experiential context for my subsequent study of information use in chronic illness care, where patients' and healthcare providers' information use meet.

Table 3-1 Research Questions for Study 1, *The Everyday Life Experience of Chronic Illness*

1.1	How and why do people use information in coping with and managing chronic conditions in their everyday lives?
1.2	How does the illness experience manifest in everyday life?
1.3	What aspects or features of the lived experience of chronic illness are relevant to information needs, seeking and use in that context?

3.2.2 *Everyday Life Study Methods and Design*

In my initial study, focusing on lived experience from the perspective of people with chronic conditions, I incorporated several methodological and design considerations that reflect the theoretical frameworks discussed in chapter 2 as informing the research. Because the study was aimed at rich description of the ways information was considered, experienced and used in the context of chronic illness, I utilized a convenience sample based on respondent self-selection in order to attract theoretically intense cases of the phenomenon of interest versus striving for a representative or generalizable sample (Patton, 2002). Conducting qualitative interviews focused on the experiences of illness

enabled a narrative that sought to reflect participants' concerns and perspectives more strongly than my own imposed priorities as researcher.

In order to focus on the *experience of illness* rather than the illness itself, I made a conscious decision to be inclusive of a variety of chronic conditions in the study's design. Including a diversity of conditions rejected the idea that biomedical classifications are representative of experience and allowed the study to draw out salient aspects of the illness experience in daily life, such as chronicity, embodiedness, disruption, uncertainty etc. (c.f. Charmaz, 1991; J. Corbin & A. Strauss, 1988) and to examine how those characteristics influenced information's meaning and use. Participants were included based on self-identification of having a chronic health condition which met the definition of "a state of unwellness produced by disability or disease requiring medicosocial intervention over an extended interval and affecting many aspects of an individual's life" (Thorne & Paterson, 1998), which resulted in a diverse sample (details provided in section 3.2.4 below) of chronic conditions across which themes related to the information experience could be drawn.

Addressing the commonalities of illness experience also made practical sense in thinking about the implications of the information experience for healthcare provision. A large and increasing number of chronic illness sufferers have more than one disease— almost a quarter of the 90 million Americans living with chronic conditions actually have three or more illnesses (NIH-CDC, 2005). These co-morbidities, or co-occurring conditions, can create complexity and interactions that can adversely affect chronic illness management (Piette, et al., 2004). Healthcare's current movement toward

providing coordinated, patient-centered care necessitates looking for ways to understand and treat the entire patient rather than just the illness; a study that cut across conditions helped anchor the research questions in the *experience* of illness rather than in the characteristics of the disease.

3.2.3 *Everyday Life Study Data Collection*

I conducted the interviews for *The Everyday Life Experience of Chronic Illness* in April-August 2007, recruiting mainly through local, non health-related list-serves and social and collegial networks. I chose to recruit from the community at large rather than from medical contexts in order to privilege a daily life context and avoid emphasizing information behavior that would be heavily dictated by a particular structure, form, or system, such as online health communities, medical clinics, or support groups. The research sample, design, recruiting tools and data collection instruments were approved by the University of Michigan's Behavioral Science Institutional Review Board (IRB HUM00011929) and participants were consented accordingly. Volunteers were screened to ensure they had a chronic health condition that they had been living with for at least six months. In order to minimize a certain amount of interference and facilitate analysis, respondents whose primary illness was mental were not included in the study.

Once participants had been accepted into the study, interviews were scheduled at a mutually agreed upon time and place. All but one of the interviews were conducted in the participants' homes, my preferred setting for the interview since it is the context where chronic illness is primarily experienced. Recruiting people outside of a medical setting and conducting interviews in their homes more readily enabled an "everyday life"

starting point, as opposed to experience filtered through a medical structure. Participants committed to an interview of about 60 minutes, but no longer than 90 minutes, and were quite willing to tell their stories—none chose to end the interview early, and all of the interviews lasted 70-90 minutes. Most of the participants appeared to enjoy the interview—some even seemed to experience a certain relief or catharsis in telling their stories and a few participants became quite emotional in the course of the interview.

In order to maintain a focus on the entire illness experience and not to impose a particular definition of information on participants, interview questions were not focused specifically on information phenomena, but instead used a semi-structured approach in order to elicit a narrative account of the chronological progression of symptoms, diagnosis, treatment, and experience. Participants were asked to tell the story of their illness, starting with when they first experienced symptoms, how they were diagnosed and what the process was like, then moving through the progression of symptoms and treatment, exploring what their life with the disease is like currently, what they do to manage it, and what they see for their future with the illness (see **APPENDIX A** Interview Guide for Study 1 (Everyday Life) for a more comprehensive list of interview topics, example questions, and probes.)

The interviews were loosely structured, but being primed via the information behavior and the sociology of the illness experience literature reviewed in chapter 2, I paid particular attention to how and why people used information to deal with problematic or uncertain aspects of chronic illness coping and management. Following Dervin's Sense-Making Methodology (Dervin, Foreman-Wernet, & Lauterbach, 2003), I

probed on gaps, disconnects and problems that were brought up in participants'

narratives, seeking to understand how they were overcome in the course of the illness

experience, focusing on the feelings, thoughts and reactions of participants as well as

actions taken and outcomes achieved. In addition to taking field notes on my impressions,

the interviews were recorded for later transcription and analysis.

3.2.4   *Everyday Life Study Sample: Women with Chronic Health Conditions*

In total, 14 interviews were used for the analysis of *The Everyday Life Experience*

of Chronic Illness. Even though no gender specification was made during recruiting, the

vast majority of volunteers were female and the entire final sample used for analysis is all

women. Of the two men who responded, one was excluded since his primary condition

was mental, not physical, and the other never followed up for interview scheduling. This

gender imbalance is not entirely surprising, since the literature indicates that women are

more likely to seek out health information (Hibbard, Greenlick, Jimison, Kunkel, &

Tusler, 1999), and are more likely than men to seek out health information and find it

useful (Pálsdóttir, 2003). The resulting homogeneity of the sample served to cut down on

some analytical noise and provide a view of what I believe are fairly intense

representations of information use in chronic illness, providing rich descriptions of

experience (Patton, 2002) that were particularly useful in this exploratory study.

The study participants ranged from 24 to 67 years old, with a mean age of 38.4

and a median age of 37. Other socio-demographic information was not collected since the

sample was not intended to be stratified or classified, but the majority of participants

revealed themselves to be relatively well educated, at the college level or beyond.

Possible limitations of the data related to characteristics of the participants will be addressed in chapter 7.

Table 3-2 Interview Participants—*The Everyday Life Experience of Chronic Illness*

P#	PRIMARY ILLNESS	TIME SINCE DIAGNOSIS
P01	Crohn's disease	7-8 months
P02	Long-Chain 3 Hydroxyacyl CoA Dehydrogense (LCHAD)	1.5 years
P03	Celiac disease	2 years
P04	Rheumatoid Arthritis	3 years
P05	Rosacea	3-4 years
P06	Idiopathic Thrombocytopenic Purpura (ITP)	4-5 years
P07	Endometriosis	7 years
P08	Migraines	8+ years
P09	Systemic mastocytosis	11 years
P10	Cushing's Disease	13 years
P11	Thrombocytopenia	14 years
P12	Chronic back pain	19 years
P13	Fibromyalgia	20 years
P14	Multiple Sclerosis	40+ years

As seen in Table 3-2 above, participants were living with wide-ranging chronic conditions, including multiple sclerosis, fibromyalgia, celiac disease, migraines, rosacea, chronic back pain, rheumatoid arthritis, Cushing's syndrome, endometriosis, and Crohn's

disease as well as a few relatively rare conditions. The diversity of the conditions allowed the analysis to focus on the experience of illness beyond a biomedical categorization. Simultaneously, an awareness of the nature and physical manifestations of the specific conditions required additional discernment in the analysis of the findings. Participants had been living with their conditions for 8 months to 40+ years, around 10.5 years on average (median 7.5). In chapter 4, I present these participants and their experiences in more detail, along with my analysis of the meaning and role of information in those experiences.

3.3 Study 2 Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context

3.3.1 *Introduction to Study 2*

The articulation of patient experiences of information in chronic illness I had developed from the exploratory study inspired me to look more closely at providers' contributions to that experience. I designed *Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context* (VA Study) to make use of data I had been collecting through my involvement in a study at three Veteran's Health Administration (VA) Medical Centers that looked at healthcare providers' work practices and information use in diabetic patient care. The central aim of the VA Study was to identify opportunities, barriers and considerations for introducing aggregated patient information into primary care in the form of a diabetes database. As such the study was primarily concerned with not only provider work practices and information use, but also factors influencing patient management and decision-making. The VA data collection, consisting of observations of and interviews with healthcare

providers in three different primary care clinics, focused on providers' reports of their use of information in the treatment of patients with diabetes and our observations of their use of information with patients and each other throughout the clinic day in the course of caring for patients with diabetes and other chronic health conditions. This study focused on patients with Type 2 diabetes as a serious chronic illness with life-threatening consequences and potential complications requiring a high degree of ongoing treatment and self-management to control.

The widespread use of the Computerized Patient Record System known as CPRS in the VA context provided ample opportunity to observe provider information use through an information object that represents the patient throughout a coordinated system of care. CPRS 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 ubiquity and comprehensiveness of the electronic health record in the VA environment, where its use is well-established, provides a unique opportunity to look at a timely issue in the current drive for healthcare reform—specifically, the role of information in chronic illness care. From the vantage point of many hours in the field and becoming intimately involved in data analysis, it became clear to me that there were aspects of the primary care context, information practices, and interactions between providers and patients that were captured in the data but were not key concerns for the VA Study, which focused mainly on aspects of providers' experiences that could affect aggregated data use and population management. The research questions I have addressed here attend to aspects of the

primary care environment that frame information use more specifically within the realm of the provider-patient relationship, including its use and role in provider work practices regarding the care of patients with diabetes and in interactions with chronically ill patients.

3.3.2 The VA as a Research Context

The Veteran's Health Administration (VA) is the largest integrated healthcare system in the country, serving 5.3 million veterans annually (Kupersmith, et al., 2007). The VA health system operates as a staff-model health management organization (Richmond), offering comprehensive care to qualifying veterans via nearly 1,400 facilities, including hospitals, nursing homes, outpatient clinics (Kupersmith, et al., 2007). VA Medical Centers provide access to long-term and inpatient care as well as outpatient services at the primary (general practitioner), secondary (specialist) and tertiary (specialized consultation) levels (Kizer & Dudley, 2009).

VA primary care patients are primarily men (97%) who were in the US military and who 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 disease such as heart attack or stroke and the disease is also associated with blindness and end-stage renal disease (VA Office of Research and Development, 2010). For the VA, minimizing these consequences 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 ("About HSR&D," 2010).

VA primary care centers provide an excellent opportunity to study the use of information in chronic illness care due to: the prevalence of chronic health conditions within them; their innovations in chronic illness care; and widespread use of an electronic health record (EHR) in patient care. Almost 20% of veterans in the VA Health System have Type 2 diabetes; 97% of them are men, and most have multiple co-morbid conditions (Pogach, 2005; VA Office of Research and Development, 2010). 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; *Improving quality of care: How the VA outpaces other systems in delivering patient care*, 2004). VA primary care clinics have incorporated aspects of the chronic care model into their care of patients with diabetes and other chronic health conditions, including multidisciplinary teams, coordinated care, decision support and an electronic medical record (Coleman, et al., 2009; Kizer & Dudley, 2009; Longman, 2007; Steven, Elizabeth, Mary, Rodney, & et al., 2004).

VA Medical Centers are also innovators in their use of information systems and the EHR in clinical practice. The VA Health System adopted a computerized health care

information system in the late 1970s, well ahead of the private sector, and by 1997 had launched its Computerized Patient Record System (CPRS) with enterprise-wide communication integration, a computer-based patient record, clinical reminders, computerized provider order entry, and disease management features (Kizer & Dudley, 2009).

3.3.3   VA Study Research Questions

This study, *Chronic Illness Information Use: Provider Practices and Patient Experience in the VA Primary Care Context,* examined how the VA primary care environment and healthcare providers' activities provide a frame for patients' experiences of information. The study was approached through the lens of the primary care clinic context and providers' use of information in the care of patients with diabetes and other chronic health conditions, drawing on data from clinic observations and provider interviews that attended to their work practices, use of information throughout the workday, and routine encounters with patients. My analysis of the findings addressed four main research questions that examine the ways in which the organization of care and providers' actions in this healthcare environment contributed to patients' information experiences relative to their everyday life experience with chronic illness. These questions appear in Table 3-3 below and formed the basis of my analysis of the VA Study data that is presented in chapters 5 and 6.

Table 3-3 Research Questions for Study 2, *Chronic Illness Information Use: Provider Practices and Patient Experience in the VA Primary Care Context*

2.1	How do aspects of the VA primary care context appear to shape information flows, interaction, and use in the care of patients with chronic health conditions?
2.2	How do healthcare providers use information in treating patients with chronic health conditions?
2.3	How is information about the patient, his condition, and his treatment communicated in patient-provider interactions?
2.4	How does the everyday life experience of illness manifest itself in medical encounters?

3.3.4 VA Study Background

In my role as program specialist for the Ann Arbor VA's Health Services Research and Development Service (HSR&D) I was responsible, along with another doctoral student working in the area of health management and policy, for all aspects of project coordination, management, fielding, data collection and analysis. Working from an approved research proposal funded by the VA through HSR&D's Diabetes Mellitus Quality Enhancement Research Initiative (DM-QUERI), the two of us collaborated with the project PI and an academic consultant to finalize the study design, develop sampling and recruitment strategies, and create fielding protocols. My colleague and I collected all of the data, which includes 144 hours of observation in three VA primary care clinics and 49 semi-structured interviews with healthcare providers in those clinics (specifics of the research design and sample are discussed below.)

The data collection emphasized how information was dealt with in the primary care environment (observations) and the use of both aggregated information and individual patient data in the care and management of diabetic patients (interviews). Our analysis of the data for the VA (Lowery, Keith, & Souden, 2010) was drawn primarily from the interview data and focused on: the factors anticipated to influence the use of aggregated data in the primary care clinics; the role of aggregated data in clinician decision-making; and identifying potential barriers and opportunities for the introduction of a diabetes patient registry into the clinics for population management.

3.3.5 VA Study Research Design

The data for the VA Study were collected between September 2008 and May 2009 in the primary care clinics at three different VA Medical Center locations in the Midwestern United States. The study was qualitative and exploratory in nature; we took an ethnographic approach, using both observations and interviews in order to more fully understand: actual clinician work practices; their use of information in the treatment and management of patients with diabetes; and the VA primary care context.

We collected data in two phases, starting with observations of providers at work in the three clinics, focusing on their use of information during administrative and prep time, patient encounters, and in collaboration with other providers. In the second phase of the study, we conducted semi-structured telephone and face-to-face interviews with healthcare providers in those clinics in order to ask more directly about their use of information in the care and management of patients with diabetes; their approaches to

patient management and decision-making; and their experiences with and perceptions of aggregated data use.

The three Midwestern United States VA medical centers where the study was fielded were identified based on the support and interest of the primary care directors at each clinic. The sites reflected a range of institutional factors and characteristics in terms of their size, geographic location, populations served, academic affiliation, and intensity of research activity. This research focused on themes regarding provider information use and the patient experience across the sites rather than analyzing the sites as distinct cases, but differences in their missions, scope, size, and staff composition are more fully discussed in my findings regarding the VA context in chapter 5. Ways in which those differences affected patient care and information use are attended to in the chapter 6 findings when they were salient to the analysis.

3.3.6 *VA Study Sample: Healthcare Providers in VA Primary Care Clinics*

This study included healthcare providers in the three VA primary care clinics who routinely had clinical contact with diabetes patients. The initial phase involved observation of 31 providers; interviews were later conducted with 24 of the observed providers, as well as an additional 25 providers, for a total of 49 interview participants. Altogether, the data represent 56 unique providers across seven different provider types.

The study design for *Chronic Illness Information Use: Provider Practices and Patient Experience in the VA Primary Care Context* included providers working in a variety of professional roles in order to understand overall clinic processes and workflows, and to be able to examine how information use and perceptions varied by

provider type. All of the healthcare providers who routinely had clinical contact with

diabetic patients in the three primary care clinics were included in the sampling:

physicians (Egan, Remde, Landauer, Lochbaum, & Gomez), medical residents, physician

assistants (PA), nurse practitioners (Cronin & Davenport), clinical pharmacists (who have

a PharmD degree, and are abbreviated here as PD), registered nurses (RN), and licensed

practical nurses (LPN). The breakdown of participant types for each phase of the data

collection is shown in Table 3-4 below.

Table 3-4 VA Study Participants

	OBSERVED	INTERVIEWED	# UNIQUE PARTICIPANTS
Physicians (Egan, et al.)	9	11	13
Residents	0	6	6
Physician Assistants (PA)	2	2	2
Nurse Practitioners (Cronin & Davenport)	5	5	6
Clinical Pharmacists (Boeije, Duijnstee, Grypdonck, & Pool)	5	6	8
Registered Nurses (RN)	7	12	14
License Practical Nurses (LPN)	3	7	7
TOTALS	31	49	56

Sampling was deliberately stratified across provider types in order to represent a

range of orientations to chronic illness and patient care. The distribution of providers

across types was roughly proportionate to the overall staff composition at each facility,

which varied across the sites, e.g., while all three clinics had physicians and RNs, only

one site made use of physician assistants, and one site had no LPNs or residents.

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Differences in staff composition as related to diabetic patient care and information use are discussed in more detail in chapter 5. Resident physicians, who are in training and see patients under the supervision of attending physicians, were not intentionally observed in the initial phase, but their work is included in the observations of the providers who mentor them. They were subsequently incorporated into the interview phase as providers of diabetic primary care and information users in their own right.

The included provider types were derived from VA institutional classifications and the labels tend to reflect disciplinary training (e.g., medicine vs. nursing) and level of education or training (e.g., doctor vs. resident, nurse practitioner vs. registered nurse.) As such, the categories speak to some aspects of the providers' roles in the clinic, but not all of them. In chapters 5 and 6 I have discussed in more detail how provider roles are enacted with respect to diabetic patient care and information use.

3.3.7   VA Study Data Collection—Provider Observations

The clinic observations were the first phase of the VA Study; altogether, 34 observation sessions were conducted at the three clinics. Observation sessions consisted of one or two researchers shadowing the provider through a half- or full day of work, including patient encounters, administrative and paperwork, phone calls, and interactions with other clinicians. In addition to patient encounters in the clinic and over the telephone, and routine consultations and mentoring interactions between clinicians, during the course of shadowing providers we also observed a diabetes education class, a shared medical appointment for patients with diabetes, and primary care staff meetings at

two of the study sites. Artifacts representing various aspects of information use were also collected throughout fielding.

The appropriate VA Institutional Review Board (IRB) for each location approved the research design, data collection plan and instruments, and IRB protocols were closely followed to make sure participant rights were adequately protected and confidentiality maintained. My colleague and I recruited providers via several rounds of email invitations and worked with them to arrange observation sessions at a time convenient to them, ideally on a day when they anticipated seeing some diabetic patients, although this was not always predictable. Observations were typically scheduled either for an entire work shift or to include the beginning or end of the shift in order to be able to capture a full range of clinician activity. Once an agreeable date and time had been set, we met the providers in the clinic, usually in an exam room, occasionally in a provider's office. Upon arrival we reviewed the consent document, obtained participant signatures, and explained our intent to be as unobtrusive as possible, simply shadowing the provider throughout the day.

We attempted to shadow providers as much as possible throughout the day—following them when they left the room to go get a patient or consult with another clinician, with the goal of getting a full picture of work practices and information exchanges. As we walked back to the exam room with the provider and the patient, the provider would introduce us and we delivered an oral consent script that informed the patient that we were there to observe the provider at work and would not be capturing their personal information, could leave the room upon request, etc. Over all of the patient

encounters we observed, only 1 or 2 patients even slightly objected to the presence of an observer, and in a couple of cases we were asked to leave the room during physical exams that were particularly personal in nature. Otherwise, we observed each encounter for the duration of the time the clinician was with the patient in the exam room.

As an observer, the goal of being unobtrusive was not always achievable due to the tight quarters of the exam rooms. We strived for chair positioning that excluded us from the interaction, but this was not always possible given the arrangement of the room—we frequently had to drag in an extra chair to use for the observation. As a result several patients made comments directly to the observers, explaining aspects of their conditions or providing evaluative feedback about the provider or their VA experience. We received these side comments neutrally, providing reassurances that we were not evaluating the provider or the patient as necessary. Providers varied in their reactions to being observed. Most appeared comfortable with this model, particularly at teaching sites, and acknowledged our presence primarily in between patients by providing explanations of or elaborations on what had occurred during the encounter. Occasionally providers offered up commentary or clarification that was clearly for our benefit during the course of the patient encounter. Although we were charged with observing clinicians' work practices both during encounters and between visits and during administrative or "down" time, we did take advantage of those opportunities to ask questions or get clarification about what had taken place in a previous encounter.

Detailed fieldnotes were taken which primarily attended to clinicians' daily work activities and how information was accessed, used and exchanged in the course of their

practice. Additionally, environmental and contextual factors that could potentially

influence information use and work practices were documented. Particular interest was

paid to the use of information from the electronic health record (CPRS), 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. Fieldnotes were transcribed shortly after leaving the field to ensure

temporal integrity and were used throughout the analysis as vignettes of clinic action as

described by the observer.

3.3.8   VA Study Data Collection—Provider Interviews

Once all of the observations had been completed, providers were recruited for in-

depth structured interviews in order to more fully understand their practices and

perceptions regarding information, their use of information and data in the clinical

setting, and their treatment of patients with diabetes. Insights from the observational

phase guided the development of the interview protocol, which is shown in Appendix B.

In addition to questions regarding information use in patient care, the interview guide

focused on the ways in which various kinds of information are used in patient

management and decision-making, addressing a series of concepts salient to population

management, a public health driven practice which emphasizes making patient decisions

based on risk/benefit evaluations for specific patient sub-groups.

Providers were recruited from the entire clinician population at each site—about

half of the interviews were conducted with providers who had been observed, and new

participants were recruited, in order to increase the number of unique providers in the

study sample. It should be noted that the original study design called only for selected "high-information intensity" provider types to be included in the interview phase based on their level of engagement with information and patient decision-making. However, it became apparent during the first phase data collection that the centrality of the patient record in clinic interactions meant that providers at all levels of autonomy and ranges of functionality were actively using, eliciting and providing information to patients, so all of the original categories of clinicians were included. An additional provider type, medical residents, was incorporated into the interview phase in order to be able to identify potential generational factors influencing information use and/or population management approaches. The distribution of completed interviews across the various provider types is indicated in Table 3-4 above.

Participants were recruited via email, and an agreeable time was arranged for the interview. Due to geographic proximity, 20 interviews were conducted face-to-face in clinician offices or exam rooms, and the other 29 were conducted over the telephone. Participants were all consented via the procedure specified by the VA IRB, and received a $50 amazon.com gift card as a token of appreciation for their time. The interviews entailed a structured set of questions with a fair amount of probing in order to obtain the clearest, most detailed, and specific responses possible. They 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.

Since the purpose of the interview was to inform implementation of a new database for population management in the primary care clinics, the interview questions (see Appendix B) focused on issues hypothesized to be salient to facilitating the integration and use of such a database. Topics covered included participants' overall roles, responsibilities and work practices in the clinics; use of patient data and information in treating and managing diabetic patients; experiences with and perceptions of concepts related to population management and the use of clinical guidelines and aggregated data in making treatment decisions and setting patient goals.

3.4   Methodological Considerations and Data Analysis for Both Studies

The methodological sensibilities of user-centeredness and subjectivity, which privilege the individual's experience and his interpretation of it offer powerful potential to illuminate how behavior is shaped and triggered in context. By drawing on strong theoretical frameworks from the social sciences and a clear set of assumptions, this kind of research helps to evolve a theoretical understanding of phenomena that offers the potential to illuminate differences vis à vis context and experience. The incorporation of action and interaction, the social and the individual, the mind, body, and soul, and a broad view of everyday life context offer potential explanatory power for the complexity and nuance of individual experience. The methodological perspectives embraced by the sociology of the illness experience and information behavior speak to both a set of methods that can address research questions in a philosophically congruent way and a set of issues that could be fruitfully explored from this perspective.

The specific methods used to address these issues follow largely from their theoretical propositions and the values espoused by the methodological perspective, warranting a general discussion of appropriate methods for understanding information behavior in the context of experiences with chronic illness and also within the context of chronic illness healthcare. The seminal work in both the information behavior and sociology of illness literatures relies on qualitative methods to get at underlying concerns and driving forces. Interviewing provides a subjective perspective and recounting through the "eyes of" participants, while ethnographic observation situates the researcher into the context of examination and illuminates both participant perspectives and aspects of the environment participants may overlook or take for granted.

Qualitative research, often noted as being useful for studies looking at the "how" and "why" of a situation, harbors the power to tell a rich story about the complexity of factors, processes and perceptions that influence the phenomenon under investigation. It is particularly useful for research questions such as the ones investigated here, that seek to understand the *meaning* of events, situations and actions from the *participants' point of view*; understand the *context* within which participants act and how it influences their actions; understand the *processes* by which events and actions take place; develop *causal explanations*; and to identify unanticipated influences and *generate theory* about them (Maxwell, 1998, p. 75, *emphasis* mine).

There has been much discussion in the qualitative research literature about how to evaluate qualitative studies. Leading qualitative researchers Lincoln and Guba developed a parallel concept of "trustworthiness" to replace the concepts of validity and reliability

that were the hallmarks of quantitative studies, comprehending four aspects: credibility, transferability, and confirmability (Lincoln, 1995). Trustworthiness can be viewed as the conceptual equivalent of rigor for qualitative work, entailing specific methodological strategies such as the audit trail, member checks, negative case analysis, structural corroboration, and adequate referential material (Charmaz, 2000; Lincoln, 1995; Morse, Barrett, Mayan, Olson, & Spiers, 2002). The fielding of the ethnographic portion of this study was rapid and intensely implemented, but trustworthiness was established in the data through confirmation of informant members, analysis of discrepant cases to understand variations in findings, and review of artifacts and guiding VA documents for structural corroboration. Additional verification strategies were undertaken in the course of fielding and analysis to "actively attain" reliable data and conclusions, including appropriate and saturated sampling, thinking theoretically, simultaneously analyzing and collecting data, and moving between micro- and macro-perspectives (Morse et al., 2002).

To further ensure the validity of findings for this research, I used triangulation via the use of multiple qualitative methods to provide additional support for observed patterns and greater depth of engagement (Maxwell, 1998). Incorporating multiple data collection methods within the VA Study helped to provide confirmatory data from additional perspectives and strengthen the post hoc validity of findings by enabling me to present participant actions in a very rich way. The inclusion of sample breadth in terms of provider type and institutional characteristics allowed comparisons between participants also enhances believability and validity by allowing me to look at discrepant practices among providers (Maxwell, 1998, p. 93). While not a textbook instantiation of

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triangulation, the ability to use the findings regarding chronic illness experience from the first study as a backdrop for my analysis of the observations in the VA helped to provide some conceptual validity and further my ability to draw some conclusions across the two contexts.

All of the interviews were audio-recorded and transcribed for analysis, along with interviewer impressions. Detailed fieldnotes were taken during observation sessions and later transcribed along with observer comments and reflections. The observation fieldnotes and interview transcripts were managed and analyzed using NVivo 8.0 qualitative data analysis software. My procedural and analytical approach to the data was strongly influenced by grounded theory techniques, which have arguably evolved into a series of basic methodological premises and strategies for qualitative analysis more generally. Grounded theory has frequently been used in qualitative health research studies in service to subjective research on the experience of illness and has been developed and elaborated on over time by key medical sociology researchers such as Corbin & Strauss and Kathy Charmaz. It emphasizes inductive development of theory from the "ground up," emerging from the accounts of those interviewed and the meanings they assign to their experiences.

Several additional methodological considerations were useful in approaching my analysis of the data as it was collected for the VA study. In a sense I was repurposing data I had collected for a different original purpose, so I found it helpful to look to the qualitative analysis literature to facilitate my approach to analysis. In analyzing the observation fieldnotes I adopted an incident by incident approach as opposed to a strict

line by line analysis as suggested by Charmaz (2006) in order to avoid over-atomizing the data and focusing on too mundane a level of activity. Since I was using the interview responses to glean cues about how information was perceived and used in the environment, the notion of theoretical comparisons as discussed in Corbin and Strauss (2008) was particularly helpful. The analytical nuance enabled by comparing concepts expressed in the interviews rather than strictly literal data was useful in examining clinician thinking about information in relationship to patient interactions and care through their responses to questions about their own use and perceptions of information and data.

Taking a grounded theory interpretive approach (Charmaz, 2006; Corbin & Strauss, 2008) with all three datasets, I conducted initial coding to develop categories that were both deductively informed by the priming literature from information behavior and the sociology of the illness experience discussed in chapter 2 and that emerged inductively from the data. Using a combination of inductive and deductive approaches (Emerson, Fretz, & Shaw, 1995) allowed me to draw from the information behavior, medical sociology and healthcare literature to identify categories salient to the research questions while also allowing themes and patterns to emerge from the data. The initial coding was fairly open and impressionistic, informed by the literature and the study's themes of interest, but kept loose enough to be aware of unanticipated themes or novel conceptions from the data that illuminated the research questions.

I then used iterative rounds of coding and memo writing to consolidate impressions, refine categories and facilitate comparisons across sources and provider

types, moving from initial concepts of interest in the data toward a more complex

appreciation of concepts and theoretical constructs to deepen and intensify analysis

(Corbin & Strauss, 2008). Focused coding helped to further categorical development and

consolidation of themes of interest. Eventually I moved toward more theoretical coding

in order to code higher-level concepts or more complex themes emerged through the

earlier coding rounds and understand participant differences in light of their roles and

functions in the clinics.

CHAPTER 4

CHRONIC ILLNESS INFORMATION IN EVERYDAY LIFE EXPERIENCE

(STUDY 1 FINDINGS)

4.1 Introduction and Research Questions for *The Everyday Life Experience of Chronic Illness*

My initial study, *The Everyday Life Experience of Chronic Illness* (Everyday Life study), examined how chronic health conditions were experienced in everyday life and how information played a role in that experience. My objective for this study was to examine the information aspects of chronic illness as experienced in people's everyday experience; set apart from the concerns of the healthcare settings where they are treated and the information systems in which health information is searched. The Everyday Life study was grounded in information behavior research that constructs context as dynamically evolving and models information needs, seeking, and use as a continuous, constructive process, and informed by research from the sociology of the illness experience that portrays chronic illness as experienced beyond its physiological manifestations. This study examined the lived experience of illness from a first person perspective; how information shows up within it; and what information behavior looks like in this context.

The findings in this chapter are based on analysis of in-depth interviews I conducted with women experiencing a variety of chronic health conditions, ranging from

rosacea to multiple sclerosis to idiopathic thrombocytopenia (see Table 3-2 for a complete list of participants and their conditions). The interviews were semi-structured, taking a narrative approach to elicit participants' experiences with their illnesses, what their daily lives were like, and how they used information in the course of navigating and living with their conditions.

The aims of the Everyday Life study were to gain a deeper understanding of the context of lived experience with chronic illness and to begin to identify the ways in which information was a part of participants' experiences. As such, it addressed these research questions:

1.1 How and why do people use information in coping with and managing with chronic conditions in their everyday lives?
   o What does information mean in this context?
   o What roles does it play—how is it used?
   o How does it impact their experiences of illness?

1.2 How does the illness experience manifest in everyday life?

1.3 What aspects or features of the lived experience of chronic illness are relevant to information needs, seeking and use in that context?

The analysis was primed by themes from the sociology of the illness experience literature, particularly those which emphasize the immersive, holistic, and multi-faceted aspects of chronic illness as experienced in daily life and shaped by the work of the person living with it. The data were analyzed within these perspectives while allowing for emergent themes that helped to further characterize the role and meaning of information in participants' experiences of illness. Supporting data is presented in this chapter in the

form of direct quotes from interviews as well as sketches from participant's illness narratives. The methodological perspective of the study calls for a deep dive into first-person experience, and within cross-cutting themes I have chosen depth over breadth in the findings; including specific details of individual situations in order to convey the richness of that experience and its implications for information behavior. The resulting findings present a vivid experiential context for my subsequent study of chronic illness information use in a healthcare setting, where people with chronic conditions bring their everyday life experience into a medical context.

4.2   Information Behavior and the Chronic Illness Experience

Corbin and Strauss' (1988) analysis of the work required in living with chronic illness provided a way to conceptualize the comprehensiveness of the illness context and to think about information behavior as dynamic, evolving and multidimensional. The concept of work done in the illness trajectory highlights that the experience of chronic illness extends beyond the medical, comprehending not only dealing with symptoms and treatment, but also integrating illness management into everyday life and adjusting aspects of identity and biography to cope with its impact. This study looks at information behavior as a key element in coping with chronic illness, taking an approach which moves beyond "a view of information as a resource" (Timothy P. Hogan & Palmer, 2005), to account for its changing and dynamic nature in context, and visualize its role as bridger of gaps and disconnects in everyday experience, essential in their resolution.

Participants described their use of information throughout their illness as clearly shaping the course of the condition or their experience of it. While they described a

concentration of information seeking and use in navigating the early stages of illness, their stories revealed that they continued to acquire and use information as they lived with their illnesses. The control afforded them by information allowed them to negotiate numerous aspects of their lives with illness, including treating their symptoms, living with their symptoms and treatment, and coping with the illness' emotional impact and disruptions.

All of the participants reported receiving information from their healthcare providers, but described routinely augmenting that in their daily lives with information from other sources, particularly those that added an element of trust or contextualizing, such as the experiences of others who had the same condition or the advice of people close to them who had some kind of expertise. The information participants used was sometimes sought out purposefully but also encountered casually; they found it themselves and they got it from others; they encountered it in the course of their daily life interactions as well as through their treatment activities. Sometimes the information was medical, sometimes practical, and its seeking could be prompted by either necessity or curiosity. But they always made sense of it in terms of their ongoing efforts to manage or cope with their conditions in daily life; the roles of information and its attendant meanings in that process is the focus of this analysis.

4.2.1   *Information Aspects of the Diagnostic Quest*

The process of diagnosis often marked the beginning of information seeking and use for participants, frequently taking the form of the diagnostic quest as the "search for the meaning of symptoms" (J. M. Corbin & A. L. Strauss, 1988, p. 24). The diagnostic

quest as described in the sociology literature goes beyond just labeling or defining symptoms, extending to trying to gain an understanding of the meanings that both the symptoms and the diagnosis have in terms of a person's psychological, social and biographical experience. The diagnostic quest cuts a wide swath, potentially comprised of a prediagnostic phase where symptoms are being experienced but have not yet been labeled; an announcement phase, where the physician makes and/or confirms a diagnosis; and a postdiagnostic, or "filling-in" phase, where the ill person makes personal meaning of the diagnosis (Corbin and Strauss, 1988). Work done in the diagnostic quest enables coping and management of illness during a time that can be emotionally charged, marked by grief and uncertainty in facing a life course that will certainly change, but the nature and the extent of the changes are yet unknown.

The work that study participants did in the process of seeking and achieving a diagnosis and then coming to terms with its meaning was often emotionally charged and affectively motivated. The information they struggled with in the diagnostic phases helped participants to feel more in control and to reconcile disconnects between what they experienced in their bodies and what their healthcare providers told them. In seeking to understand—and accept or reject—a diagnosis, participants drew on information from a variety of sources to establish their own sense of what was wrong with them, to advocate for that sense with their healthcare providers, and ultimately to find their way forward, figuring out what the diagnosis meant for them and their future. They drew on multiple sources to inform this work, including medical information; other people's experience; information from their bodies; and their own memories and experiences.

Some participants used information from other sources to challenge their doctors, suggest alternatives, and advocate for themselves, while others used it more personally to come to terms with what the condition would mean in their lives.

4.2.2 *Influence of the Affective on Information Behavior Early in Chronic Illness*

Participants in this study described their use of information in ways that went beyond simply apprehending the facts about their illnesses or treatment, associating its acquisition and use with affective outcomes that enabled them to come to terms with or negotiate various aspects of their illness experience. For instance, participants commonly associated their information seeking goals early on in illness with a need for comprehensiveness, making statements like, *"to inform myself as much as possible,"* and "I spent a lot of time on the Web, *learning as much as I could."* The intensity of this early information seeking suggests not just education but a sense of mastery that could be achieved through acquiring information.

Early information seeking served to assist with some of the emotional work that has been identified as taking place at the onset of chronic illness. One participant directly acknowledged it as a way of handling her emotional reaction to the illness, "Our way of dealing with it was to try to find out as much as possible about it and deal with it in the best way possible." Similarly, when asked about what she was trying to learn by "read[ing] everything about it [her illness]," another participant framed it as a way of coming to terms with her illness: "Figure out why me? How had this happened to me?" For another, reading biographies of other people with her illness helped her to "get an idea of what to expect" after she was diagnosed.

Having access to a lot of information early was not always a positive experience for participants. On a number of occasions their initial information seeking provided the opposite effect, creating enough anxiety about their future that they chose to avoid actively pursuing information. As one participant explained:

> I probably really did a lot of research for like a week and then I was like, "I'm just done. I don't want to hear about it anymore, I don't want to think about it anymore. I just need to focus on getting healthy."

It was not at all unusual for participants to identify themselves as more distinctly seeking information early on in their illness and then tapering off for various reasons. Another participant with a more volatile and unpredictable illness made a similar choice to move on after doing some research on her condition:

> I think it was also just overwhelming and scary to think about having an illness that could eventually turn into something that's fatal. And so I just didn't want to know what the statistics were for that or what the signs were for that. I just sort of wanted to proceed forth.

The decisions made by these women not to pursue information because of its emotional impact highlight its power to influence attitudes and perspectives. In this study, participants' choices to avoid information appeared to be highly situational—related to particular aspects or time periods in their illness experience. They talked about eschewing information that related to a particular topic, came from certain sources, or during a specific phase of their illnesses; but significantly, every participant in this study who mentioned avoiding information at some point in her experience also spoke of other instances where she sought and used it.

4.2.3   *Using Information to Negotiate a Diagnosis*

The process of achieving diagnosis was often negotiated using information to help

validate participants' own sense of their problem, especially when it didn't match up with

a healthcare provider's opinion. Having additional information helped sufferers to act on

information they were getting from their bodies and their experiences with their

healthcare providers. The four stories abstracted below provide powerful illustrations of

how participants used information from outside of the healthcare system to challenge

their doctors, suggest alternatives, and advocate for themselves.

One participant, originally diagnosed with pelvic inflammatory disease, could not

reconcile the information her doctor had provided her about the causes of the illness with

her medical history, her own experience, and her sense of her body. In a follow-up visit

with a nurse practitioner she raised her concern about the original provider's diagnosis:

> I said "I don't think I have pelvic inflammatory disease." And she said the
> same thing – "it's very mysterious, people don't know what causes it" and
> I was like, "well, I just don't think I do. I feel a little better but there's
> something there. I feel like there's something there that shouldn't be there,
> like weight."

After reading about endometriosis and talking to someone else who had it, this participant

had begun to suspect that the painful menstrual cycles periods she had experienced all her

life were not normal and she made a connection to her current suffering through

information from her body that was at odds with the diagnosis she had been given. By

challenging the provider she was able to get an additional diagnostic test and a correct

diagnosis.

Another participant also described pushing back on her physician's initial assessment of her condition based on information she had sought on her own:

> He tried to diagnose me with chronic fatigue syndrome and fibromyalgia and I didn't want those diagnoses because you can't really treat them very well. You can't treat them as well as RA [rheumatoid arthritis], and also I thought the symptoms, from what I read online, were more consistent with RA because I had the swelling in both joints.

From her perspective, her doctor's initial diagnosis was both unacceptable and inaccurate. Armed with an alternative hypothesis from the information she had found online, she was able to push for the test that diagnosed her correctly.

For a third participant, suffering from a rare metabolic disorder, the process of getting a diagnosis and identifying an effective treatment had been part detective work and part self-experiment. After going through a series of specialists for her various symptoms she finally came across some likely candidate diagnoses for an underlying cause through doing her own research in medical journals. Along the way a specialist suggested she had chronic fatigue syndrome, a diagnosis that she felt wasn't right based on her understanding of her lab results (as someone with an advanced science degree) and the information she was reading in the literature:

> I was frustrated, because I'm looking through the results myself and I know what they mean and I'm seeing a problem within two that are really indicative of that we need to do more work on the fatty acid stuff.

After she identified what she felt was a more appropriate candidate diagnosis, she continued to engage extensively with information from the medical literature and an online community for these types of illnesses in order to identify treatments. As she tried out various alternative remedies gleaned from clinical trials she had read or heard about,

she drew her own conclusions based on what helped and what didn't, a process she described as, "fixing myself by experimenting on myself." Although at the time of the interview she had not yet received a specific official diagnosis, her own detective work and ability to advocate for herself using information allowed her to get to doctors who were familiar with these types of disorders, helping her obtain the right tests and appropriate treatment.

Another participant had a similar experience in challenging the doctors' interpretations of her celiac tests. They were read as inconclusive, but her certainty of the fit of her symptoms and experience with other family members who had the illness led her to do more research about the testing process. Through her searching she discovered information that indicated that the interpreting these particular test results could be quite nuanced and that many doctors may not have the experience to do so accurately. Understanding little-known intricacies of the disease helped her to advocate wither doctors and pursue treatment even though she didn't have an official diagnosis:

> It's a disease where you really have to inform yourself and know a lot
> about it because your doctor won't necessarily. The things the doctors
> have told us have been so contradictory and incorrect and if I hadn't done
> the reading myself I would be so confused and uninformed and probably
> all of us would still be eating gluten and harming our bodies with it.

As in the previous examples, this participant married information from several sources in order to get a diagnosis that made sense within her experience.

4.2.4   Making Treatment Decisions or Evaluating Options

When it came to evaluating their options for or making decisions about treatment, participants also noted drawing on information beyond that which was supplied by their

physician. Additional information came into play when sufferers were faced with a

treatment option that they perceived as risky or extreme, and almost always took the form

of seeking information from others who had experience with the illness or the treatment.

When one participant had reached the point where she had explored all of the "low-

commitment" options for dealing with her skin condition, her doctors suggested she

consider laser treatment. The need to make this decision had motivated her most recent

information seeking related to her illness, as she tried to sort out the treatment's potential

risks and costs versus its benefits. She asked her doctor questions but also visited an

online forum to find out, as she out it, "what *really* are the potential problems" from

people who'd been there. She ended up deciding not to go through with the treatment

based on the sharing of a forum participant who had taken a very long time to heal after

the treatment, staying red for six months. Even though the doctor had assured her that

particular side effect was rare, the story of what happened to him was enough to make her

consider the treatment differently:

> Whereas before the decision would have been really been, can I afford
> this, can I not afford this, with a little bit of, okay this is a laser on my
> face,' but not like, oh my god, this is a laser on my face. Hearing [that
> story] has made it… it has made me much more wary.

In making a decision to go off her steroids because of their side effects, another

participant was given two alternative options by her doctor, but not much in the way of

information to help make that decision. She looked up information about the two drugs

online, to see "if people had better luck with one or the other," focusing her attention on

medical websites that provided information like "what the drug is, what it does, this is

what you can expect." She found out that one drug was newer, more experimental, and

derived from rats, but might have been willing to take a chance on it since it had be

shown to be effective, when a guy with whom she had been receiving treatment died

from a reaction to it. This news "terrified" her, and, weighed in with the rest of the

information she had gathered, resulted in her choosing the other drug.

Another woman told the story about her doctor recommending a splenectomy as a

potential way to control her ITP symptoms, but he also told her it was effective in only

50% of cases. Given the large financial and time costs the operation would necessitate,

she explained that she had felt the need for a sounding board beyond what her doctor

could provide in making the decision:

> There were things I do not know…I do not know anyone else who has this
> disease so I had no one to refer to, to say, "hey what do you think?" My
> doctor, he is a very brief man. If I go for my routine check-up every
> month or every three months or so I only see him 10 minutes and he's out
> of there and there's no opportunity for me to ask more so there's no one
> for me to refer to so I usually go online.

She visited an online forum for other ITP sufferers and found that reading about what the

operation was like for others gave her a sense of what she could expect and decide not to

make the investment in the operation.

4.2.5   *The Role of Information in Coordination*

The need to coordinate treatment and care across multiple providers or specialists;

consider a variety of symptoms or conditions in concert; make connections across

disparate health events and keep track of their illnesses over time required a considerable

amount of information work. The chronic illnesses experienced by participants typically

manifested in multiple ways, affecting more than one of the body's systems. Most of the

participants were seeing a number of specialists and taking medications for several sets of

symptoms. One participant had an illness that had manifested first as migraines, then

seizures, and then neurological symptoms. She initially received three individual

diagnoses for those symptoms, and a different specialist treated each. She might not have

even gotten close to a correct diagnosis if she hadn't done her own information seeking to

figure out how her symptoms could be related.

The chronic or ongoing nature of a condition may dictate coordination over time,

engendering information needs that do not necessarily subside after an initial diagnosis

and treatment planning. A participant who experienced a variety of chronic conditions

stemming from overactive hormone production as a result of Cushing's disease had

learned over time to prepare for her doctor visits by doing her own research first to see if

a new health condition or symptom being addressed might be related to another condition

she had or a prior health event:

> I will research beforehand on seeing if anything I have had could relate to
> what has happened. So that I can bring that to their attention – "okay this
> happened back then – this could do this and this – could that have
> anything to do with this?" Because when these doctors aren't familiar
> with me, they don't know all the past history and how atypical I've been
> with a lot of my things, my lab tests sometimes will really come out weird.
> So I have to really kind of be prepared to get them up to that point or make
> that connection for them because it's not going to be right there fresh in
> their minds.

Another woman with multiple conditions described having to constantly adjust

her medications, so that even after almost 20 years with her illness she still frequently

sought information about medication side effects and interactions. She found interaction

information in particular hard to come by from the specialists who were only treating a

specific aspect of her conditions, and did a lot of her own research on the drugs she was prescribed. A participant coordinating care across numerous doctors had taken to keeping her own copies of all of her medical records, lab tests and chart notes and carrying them with her in a tote bag to her appointments in order to make sure that the necessary information was available in that context. In most of the cases, the women felt that they were the only ones keeping track of medical records over time and systems, responsible for bringing knowledge together from across a range of physical effects and over the course of their illness in order to get the care they needed.

4.2.6   The Role of Information in Illness Monitoring

The ongoing physical aspects of the illness experience are interesting from an information standpoint because they entail a specific type of information activity—the work of monitoring, which participants described as relying not only on lab tests but also on their bodies themselves as a source of information. For most of the participants, experiencing pain, reduced functioning, or uncomfortable physical symptoms was a routine occurrence. The ongoing management of the illness, then, involved controlling or anticipating symptoms and their impact on daily life. Participants gathered and used information in the context of keeping tabs on their symptoms and figuring out how to tweak their regimens or their lifestyles accordingly.

Participants frequently described actively tracking how their bodies were feeling and functioning at any given time. They regularly compared these observations with past experience and what they knew about the illness to watch for something out of ordinary or be on the lookout for symptoms they knew to be characteristic of downturns or an

adverse reaction. In learning how to live with her extreme physical reactions to overheating, one woman described monitoring her reactions to various temperatures, lengths of exposure, types of clothing, and levels of activity. Developing a sense of the boundaries and limits of her disease was critical in knowing how to control it. Another kept tabs on her physical self around symptoms that would signal a drop in platelets, such as fatigue, easy bruising or heavy bleeding. Her doctor had arranged a standing lab requisition so that she could go for a blood draw whenever her symptoms indicated.

Illness monitoring as an information activity necessitated the use of information broadly defined, not just as understanding, but also as physical sensation relative to cognitive knowledge and experience and/or memory. The need to monitor the physical through lab work also manifested as a self-efficacy issue. Participants noted that lab reports can be daunting, and those felt very comfortable interpreting them had scientific training, whereas several of the others had taught themselves or relied on online primers to understand the specifics.

Another participant explored her limits with regard to pain; by keeping track of her pain level and duration, she could judge what would be the right time to take pain medication so that it would be effective while not stretching out the length of time she was ingesting it, risking physical reaction to the medication. Over the longer term, she also tracked how well various therapies were controlling her symptoms, since she had come to realize that they "needed to be changed up every now and again" in order to stay effective.

Monitoring also helped participants control the unpredictability of an illness. Even though she had originally been diagnosed about fifteen years ago, one participant had found that changes in her platelet count and in how the condition manifests were somewhat unpredictable, so she found herself constantly monitoring her physical symptoms and lab data in order to manage the impact of the illness. At the time of the interview she was trying mostly to treat and manage other illnesses and factors that contribute to or interact with her condition. Much of her information work involved keeping track of her physical body and comparing the data to what she knew to expect from the thrombocytopenia; seeking additional information when things were "out of the ordinary," or unexpected symptoms or issues came up.

Another participant's body tracking had given her clues about the nature of her illness and what was required to manage it: "it seemed like I was getting sicker when I was eating more fats. So I cut my fats way back, because I've always approached things diet first, and then that helped." When asked what led her to associate her illness with metabolizing fats in the first place, she explained, "it was a combination of learning about the diseases, seeing some could be an issue with fat, and then noticing at the same time that I seemed to be having some problem with that." By continually integrating information from her body with what she was doing, she was able to successfully treat some of her symptoms.

4.2.7   Coping with Illness in Everyday Life and Staying Healthy

Participants described using information in an ongoing way to cope with everyday life aspects of their illnesses; figuring out how to maintain their regular activities or do

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what they wanted to do in spite of illness. In the same vein, they also sought and used

information to stay as healthy as they could in the face of their illnesses. Doctors did not

necessarily address either of these areas, and sufferers sought and used information from

other sources to fill in the gaps.

One participant talked about needing information about products and devices that

could help compensate for the losses in functioning she has experienced over time as a

result of her multiple sclerosis. A pole that could support her in the bathroom and special

sheets that reduce friction were products that she has gotten information about from the

Internet, where she has found she can track down information about products she

described as "out of the mainstream." Another got to a point where she needed an

assistive device, and got a lot of support and advice about getting a wheelchair from

people in the online community she regularly frequents. Through their advice she

realized that she had to make sure to get a prescription from her doctor specifying a "fully

adjustable model" that would support her in reclining anywhere, enabling her to once

again enjoy parties or attend her sons' concerts. Another participant had received

information about practical devices from her fellow sufferers as well—reading a forum

post by someone else with her condition helped her realize that purchasing a Medic-Alert

bracelet was essential in order to make sure her condition was recognized in the case of

an emergency.

Participants also used information to figure out how to stay as healthy as possible

in the face of their illnesses. In some cases, this involved alternative remedies or

supplements, about which they found they couldn't get information from their physicians,

who, in the words of one participant, "push the drugs on you...they're not real

encouraging of alternative therapies." One participant described how medical journal

articles found for her by a professor helped to point her to supplements and lifestyle

changes that could support her overall health with her chronic condition:

> She found an article in the Lancet about Omega 3 supplements that had
> actually been tested. When I told my doctors about it they always never
> had any problem with it. They weren't real supportive, but I do attribute a
> lot of why I'm healthy now to that and to taking vitamins because
> rheumatoid arthritis can also cause anemia ... so I think the supplements
> have been very helpful in just keeping my energy level up.

For a number of the participants, maintaining optimal health through diet, exercise and

supplements became a high priority as they realized how their daily experience of illness

could infringe on their regular activities.

The range of uses of information in the context of illness and the roles it plays in

coping with and managing chronic conditions described in this section suggest that the

fact that it is situated within everyday life is non-trivial from an information behavior

perspective. Information needs, seeking, and use arise not only from the needs of the

illness itself but from the need to recast a sense of self within it and incorporate it into

daily life experience. The next section looks more broadly at how chronic illness

manifests in everyday life in order to consider its impact on information behavior.

4.3   The Interplay of Illness and Everyday Life

This section examines just how chronic health conditions manifest themselves in

everyday life experience and the impact they have. As participants recounted their illness

stories, the ways that chronic health conditions had altered and shaped their everyday

activities and sense of themselves came up over and over again. These impacts can be important in the consideration of information use in the context of daily experience, where illness is ongoing, pervasive, and embedded in multiple facets of existence, aspects which distinguish it from medical or healthcare contexts. The previous discussion has helped illuminate the role of information in the illness experience; this analysis of how illness manifests in everyday life experience provides additional context for what information can mean in that experience. Everyday life experience is broken out in the following sections, which examine illness' impact on daily activities and broader issues of identity respectively, but through the participants' words it becomes clear that these aspects of everyday life are intertwined in many ways as they relate to the experience of chronic health conditions.

4.3.1   Chronic Illness and Daily Life Activities

Just about all of participants in this study talked about the physical aspects of their illnesses as constraining their energy and/or mobility for everyday activities. This impact often resulted in the need to make such life choices as changing jobs or choosing activities which accommodate the illness rather than their own preferences, e.g., going on disability or doing part-time, temporary or "under the table" work with the potential for flexibility and requiring low commitment. One participant talked about how the physical aspects of her illness had made some routine activities difficult, and the resulting drain on her energy resources contributed to her decision to retire from her job:

> I need to use a scooter or wheelchair to get around, my legs really won't work. And there are other things that are hard—getting in and out of bed I can do, but I need silky sheets because I need to prevent friction. Getting on and off the toilet is a challenge, but I've got some equipment that

makes it possible for me to do that. So I couldn't work right now, it would be much too much of a stress right now, so I'm glad I retired. 'Cause it takes a long time to do everything when you're handicapped.

In fact, for her, one of the signals that it was time to retire was the increasing difficulty of daily life tasks, which she described as bleeding over into her work life:

I would take my shoes and my stockings and go into work. I would go in early. The first person I saw I would say, "Can you help me put my shoes on?" And they would do it. But you can only do that for a few months. I thought that was a good clue.

Another participant described a more dramatic escalation of conditions that led her to give up her job:

…the seizures started breaking through the anti-seizure drugs, and I wasn't sleeping very well anymore, and then, shortly after that it got so bad I started having daily migraines and was really groggy and just sort of staggering around and couldn't really think clearly anymore or remember anything. And then the muscle cramping was constant. And I started having more and more neurological problems, so at that point I went off on disability.

One woman dealing with several interacting conditions felt like the uncertainty of her symptoms on any given day had forced her to take sporadic "under the table" jobs that required a minimal investment. Another had reached a similar conclusion, turning in her career track position for a more routine hourly job in order to accommodate the time spent dealing with her health concerns and the low energy levels associated with her condition. Even working a scaled back job left her with diminished energy for other aspects of her life: "Yep, I would need to come home from work and have a nap… it left me pretty much unable to do much except for go to work."

Not only does the experience of illness impact everyday life activities, but the need to maintain particular activities, in turn, influences the experience of illness. Several participants talked about not being willing to make certain changes that could help manage their conditions because of their desire to maintain a certain lifestyle. The participant with rosacea, for instance, was aware of the fact that there were known triggers for the flushing, but didn't view modifying these behaviors as negotiable within her life:

> … it's like anything that you would want to do with your life could cause a flare-up… exercise, spicy foods, cold weather, hot weather, sex, anything that would increase your body temperature, or caffeine or anything. And when I kind of thought about that, I was like, I'm not doing this … for me it's not bad enough that I'm going to cut out any of those things. So I sort of was like, well, alright, I'm not going to change my behavior, because I can't avoid cold weather, I can't avoid hot weather, I'm not going to avoid sex, I'm not going to avoid caffeine at this point. I can't avoid exercise, although that would be really nice [laughs].

Her assessment of taking a behavior modification approach to her condition involved weighing the impacts of both her condition and the options for managing it on her everyday life, and she assessed the changes to not be worth it. Another participant expressed a similar stance towards modifying her diet, only exacerbated by the number of conditions she's dealing with at once:

> … if I were to follow the heart diet, the diabetes diet and the fibromyalgia diet I would absolutely not be able to eat anything because I can't have none of the Splenda, no pop, with the fibro—no Splenda, no caffeine, with diabetes I can't have no sugar, the heart I can't have no fat…I would be down to eating apples and carrots and lettuce and no meat. What can I…I've gotta give one up and it's going to be the fibro one I give up because I can't go without my diet pop. I guess I'll suffer more in that area.

Her quote illustrates not only the difficulty in making choices that align with her life, but also reconciling a plan from among a lot of recommendations and choices.

4.3.2   *The Impact of Illness on Biography and Identity*

Living with illness impacted not only daily activity, but also resulted in some fairly major life changes or adjustments. Participants talked about their illnesses as affecting their lives significantly in terms of their family relationships and the financial burden wrought by medical expenses and reduced household income. One woman was in the process of separating from her husband and moving out, an event she attributed in part to the impact of her illnesses. Her anxiety and uncertainty about the divorce process was exacerbated by the prospect of losing the health insurance that had covered some $16,000 in medications for her last year, and, as she went on to describe, "then I'll lose all my doctors that I have, that I've had for years. It's going to be a big loss *[clearly emotional]*. I won't have the care that I have." Other life decisions brought about in response to illness were evident. One interview was conducted as the participant's husband readied their house for sale; they were downsizing to a less expensive and lower maintenance place in response to the changes brought about by her illness. Another participant with a three-year old daughter talked about her decision not have another child because of the lack of energy and financial resources engendered by her illness.

In some cases, the illness experience influenced daily activities in ways that required participants to make adjustments to their life plans, identities, or sense of themselves. Diminished energy and physical ability, combined with the energy and planning required to manage illness and its symptoms sometimes made spontaneous

activity or out-of-routine activities, such as travel, challenging, if not prohibitive, as one

participant described:

> I was always a real active, spur of the moment type person – "oh let's go to this!" and you know, I can't do that anymore. I cannot just get up and go. I have to think about my meds, I have to look ahead and see… if I have enough to last. … I have to pack my c-pap and make sure wherever I'm going is going to have the right kind of plug, an extension cord, sometimes I have to have distilled water. So when I go to [another city] and spend the night with [my daughter and granddaughter], I have to take so much stuff it's a real pain in the ass to even go anywhere. I can't even imagine trying to travel on a plane or going internationally somewhere with all my crap and the medications and stuff.

Her example shows how having to limit everyday activities can, in effect, mean limiting a

part of oneself. Another participant, confined to a wheelchair, had always imagined she

would be a literacy volunteer in retirement, "but that means getting on a bus and going

someplace. And literacy people are notorious for not showing up." She had to recalibrate

and find another fulfilling volunteer opportunity closer to home.

Other kinds of identity shifts came about as a result of living with illness. The

woman with rosacea, a condition characterized by uncontrollable blushing or flushing,

described having had to incorporate her symptoms into her sense of herself due to their

visibility:

> I've definitely thought about it. So, [my partner] and I joke about it, well I joke about it, I call it "my condition." So, you know, we're at a bar, and alcohol causes flare-ups for me, which is pretty common. So if I drink a beer I can get very red-faced, or red-cheeked at least. So we're at a bar, or whatever, and I'm like, "oh, my condition's acting up." So it is sort of like this thing that I kind of carry around with me, I mean it's definitely there, like I think about it…

Another participant noted the way her illness experience had positively influenced an aspect of her identity. She had found an opportunity to re-examine and redefine her ideas about god and spirituality as she tried to make meaning of her numerous trials with the array of illnesses her condition had caused.

4.4   Discussion: Information and Everyday Life Experience in the Chronic Illness Context

These findings have identified, across the diverse variety of health conditions included in this study, a number of roles for information in the context of the chronic illness experience. Participants described a myriad of ways that the use of information throughout the course of their illnesses helped them to cope with and manage their conditions on multiple levels. At the time of diagnosis, information was depicted as a powerful force in comprehending and coming to terms with the meaning of illness and its symptoms as well as in collaborating with healthcare providers. Information continued to play a role in evaluating options and making treatment decisions. Participants reported using information on an ongoing basis to coordinate aspects of illness management across time, providers, and diverse symptoms; to monitor their conditions and adjust treatment; and to cope with and manage illness in daily life. Information in the context of the chronic illness experience had multiple meanings, serving both cognitive and affective needs, and providing participants with relief, reassurance, and practical support.

Chronic illness manifested in everyday life in the course of all three types of work identified by Corbin and Strauss as comprising the illness experience: managing illness, negotiating daily activities, and the psychological work of recasting identity and biography (Corbin, 1998; Corbin & Strauss, 1985, 1987; 1988; Strauss, 1987). In the

sketches of participants' use of information in their illness experience information is shown as supporting not just the management of illness, but the identity and daily life aspects of experience as well. Significantly in these examples, information use often assisted participants in reconciling gaps or disconnects resulting from friction between any two of those aspects. Much of the information work of people with chronic health conditions was driven by its situation in the everyday life context.

The findings of this chapter highlight certain aspects of the lived experience of illness that influence information behavior within it. By definition, chronic illness is ongoing, and its experience can be characterized by varying amounts of uncertainty, complexity, and physicality, all of which have been indicated in the previous sections as impacting information needs, seeking, and use in the context. The findings here also call attention to potential disconnects between everyday experience of illness and its experience in healthcare contexts. Participants frequently sought and used information to fill a gap or reconcile a disconnect between their perspective and their provider's. The ways and purposes for which they use information are broader than and situated outside of the purview of a biomedical approach. The potential for friction and synergy when everyday experience walks into the healthcare setting sets the stage for study 2.

CHAPTER 5

THE VA PRIMARY CARE CLINICS AS CONTEXT FOR CHRONIC ILLNESS CARE

AND INFORMATION USE (STUDY 2, FINDINGS I)

5.1 Introduction to Chapters 5 and 6

This is the first of two chapters presenting findings from the second study, *Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context*, which looks at chronic illness information use and exchange within the context of a healthcare environment. Healthcare providers are at the nexus of information provision for most people with chronic health conditions. Providers are a primary source of information about the illness (diagnosis), its treatment and management, and what to expect in the future (prognosis). They provide authoritative, expertise-backed information about disease and how to treat it. Yet my first study, *The Everyday Life Experience of Chronic Illness*, showed that people with chronic conditions frequently noted that the information they received from their healthcare providers fell short of their needs or conflicted with their lived experience of illness, requiring them to seek and use additional information to supplement or reconcile with what was provided to them. Participants felt that the information they received did not always fit their own

experience of illness; was incomplete in terms of what they thought they needed to know; or seemed fragmented across disparate providers.

My curiosity about information's role in these perceived disconnects between the lived experience of chronic illness and its reception in the healthcare setting motivated my second study, *Chronic Illness Information Use: Provider Practices and the Patient Experience in the VA Primary Care Context.* This study looks at the healthcare environment as a setting for patient experience, examining how elements of the context; providers' work practices; and their use of information provide a frame for patients' experiences of information. From an analysis of data collected by observing and interviewing healthcare providers engaged in care for diabetes and other chronic conditions in a primary care setting, these two chapters posit that: how care is organized and enacted in the healthcare context (current chapter); and how providers use and communicate information in their care of patients with chronic conditions (chapter 6), both act to frame patients' experiences of information related to their chronic health conditions. This frame provides opportunities for both disjuncture and synergy at this critical point where the lived experience of illness meets its treatment in medical contexts.

To investigate information experiences in a healthcare context, I collected data via a cross-sectional qualitative study of information use in provider work and patient encounters in three VA primary care clinics, implemented as described in chapter 3. The VA Study focused on the use of information in the treatment and management of diabetes, a chronic health condition that is disproportionately prevalent among its

patients. Effectively treating diabetes is confounded by a high incidence of co morbid, or

co-occurring, conditions and numerous self-management challenges for patients. As

discussed in chapter 3, the VA Healthcare System has been cited as an early adopter of

innovative chronic illness care strategies enabled by the use of a centralized electronic

health record to coordinate care, making it a particularly rich environment in which to

study chronic illness information use and experience in a healthcare setting.

The findings presented here draw on my own experiences of fielding in the clinics

and a close analysis of observation fieldnotes and interview transcripts, and are supported

throughout with both quotes from participant interviews and excerpts from observation

fieldnotes that provide vignettes of clinic activity. Because the information activities of

interest to me took place within the work of chronic illness care and the environment of

the primary care clinic, an understanding of the context in which this care is organized

and enacted provides an essential backdrop to more fully investigating questions of

information use and experience in chapter 6. This chapter addresses my first VA Study

research question and its sub-parts:

2.1 What aspects of the VA primary care context appear to shape information flows,
     interaction, and use in the care of patients with chronic health conditions?
     - How is care for patients with chronic health conditions organized in the
       clinics?
     - What are the providers' roles and activities in patient care?
     - What organizational issues affect providers' roles in chronic illness care?

The following analysis works through a number of themes that are salient to fully

understanding information activity in context in the clinics: how information is situated

relative to patients and their care via the electronic health record (EHR); the arrangement

of care for the patient with chronic health conditions; the activity of providers as relates to patients' primary care visits; differences in how care is framed and enacted at each clinic site; and organizational issues affecting the roles of providers vis à vis the care of patients with chronic health conditions. The elaboration of these aspects of the context presented here lays the groundwork for examining information use, interactions, and experience more specifically in the following chapter.

5.2   The Role of the Electronic Health Record in the Primary Care Clinics

A notable feature of the primary care environment as observed in the study was the centrality of the VA's Computerized Patient Record System, commonly referred to in the clinics as CPRS. In the course of our observations it was rare for a patient to be seen or his care discussed without his electronic health record being open for his provider(s) to review and reference. Patient-provider encounters in the primary care clinic routinely began with the opening of the patient's CPRS record, described by some providers as an electronic version of the traditional paper chart and referred to in this manuscript as the electronic health record, or EHR. During the visit, as examined in more detail in chapter 6, CPRS was used 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 to record patient data and information obtained.

When we observed providers discussing a patient's situation, his EHR was typically a shared referent, in essence acting as a proxy for the patient during consultations when the patient was not present; such conversations invariably opened

with the patient's "name and last 4" so that his CPRS record could be pulled up for reference. A patient's EHR was also frequently 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 note in order to trigger an alert in the system that would bring some aspect of the patient's care to another provider's attention for notification or follow-up.

In the VA primary care environment, the patient's electronic health record clearly played a central role in coordinating care across an interdisciplinary and distributed team of providers and in keeping track of the patient's health conditions and medical care over time. The upcoming descriptions of how care is organized illustrate just how salient these roles are relative to the care of patients with chronic health conditions specifically. In this way CPRS and the patient's EHR acted as a substantial shaping force in the primary care context, serving to reify a particular representation of the person with chronic illness and his experience through those aspects of him that are captured in the record and used by the provider team as the basis for ongoing medical care.

5.3 The Patient with Chronic Illness in VA Primary Care Clinics

Although we observed providers interacting with and treating patients with a range of acute issues and chronic conditions, this study was primarily focused on diabetes care and 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."

It became apparent in the course of fielding that 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. In the Diabetes Education Class and encounters with Certified Diabetes Educators (Wenger, McDermott, Snyder, & NetLibrary) we observed, this triad of health markers was introduced to patients 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. We observed specific disease management approaches and strategies being used in the clinics to target patients with diabetes, hypertension (high blood pressure) and hyperlipidemia (high cholesterol).

It was not unusual for the patients we observed to have multiple chronic conditions, and/or ongoing mental health issues such as depression or PTSD. Patients with chronic health conditions were in a variety of stages and situations relevant to their disease and treatment, ranging from the newly diagnosed to the chronically out-of-control to those with well-managed conditions. When they come to the primary care clinics, patients may be coming for treatment, management or monitoring of their diabetes or another chronic condition; for an acute issue such as an injury, influenza or follow-up on a specific medical event; or for ongoing health maintenance and prevention. We observed a wide range of patient encounter types, for example: patient receiving care primarily from an outside (non-VA) provider but coming to the VA for prescription refills; patient recently suffered a heart attack and seeing his PCP post-hospitalization; patient experiencing a dramatic change in chronic condition symptoms or level of control; or patient hesitant to go on insulin even though it has been recommended by a healthcare provider for control of his diabetes.

Studying providers' care with respect to patients with diabetes and associated conditions such as hyperlipidemia and hypertension presented an excellent opportunity to look at how information is obtained, communicated, provided, and used by clinicians in the support of managing an ongoing chronic illness. Diabetes requires continuous self-management from patients: they must adhere to medication regimens consisting of oral agents or insulin therapies, and are encouraged to help control their blood sugar by making behavioral changes related to eating and exercise. In our observations of patient encounters it was clear that 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 use of information in these interactions will be further examined in chapter 6, but patients' struggles to manage their conditions and carry out treatment like their providers expect was recognized and considered somewhat a given in the context of chronic illness care.

5.4 The Organization of Care in the VA Primary Care Clinics

5.4.1 Patient Visit Flow and Introduction to the Providers
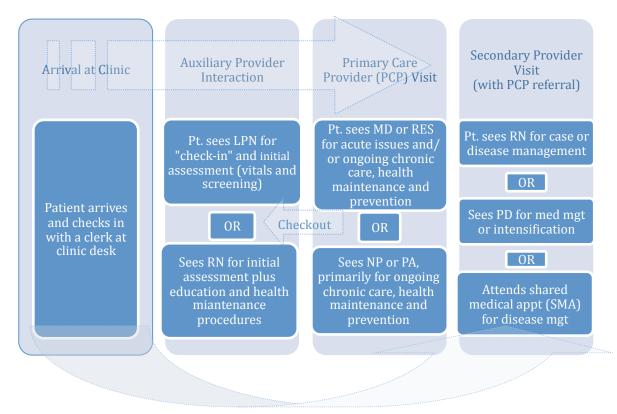
Understanding how primary care is organized at the three study sites helps to situate the providers' roles vis à vis patient information and communication. The VA primary care clinics follow an integrated health management model wherein patients are assigned to a Primary Care Provider (PCP) who is responsible for their ongoing healthcare and management. That provider acts as a gatekeeper for the patient's healthcare, and works on a multidisciplinary provider team that provides a comprehensive array of services in the primary care clinic. The study included providers within three broad functional categories that are useful in understanding their roles in the care of patients with chronic health conditions:

- **Primary care providers (PCPs)**, who in the VA Primary Care clinics can be physicians (MDs), residents practicing under a physician's supervision, physician assistants (Spasser), or nurse practitioners (NPs). The PCPs we observed saw patients for a range of health issues, including acute illnesses and follow-up care; chronic condition treatment and management; preventive care; and ongoing health maintenance.

- **Auxiliary providers,** who saw patients in conjunction with a PCP visit. At the study sites these providers, who were licensed practical nurses (LPNs) or registered nurses (Murray, Burns, Tai, Lai, & Nazareth), conducted screening, assessment, patient education, and certain types of medical procedures to support and augment PCP services. Study data collection focused on the work of auxiliary providers just before their PCP visit, but in some situations they saw patients for post-visit follow-up as well.

- **Secondary providers,** who in the primary care clinic worked with patients with chronic health conditions such as diabetes mellitus (diabetes), hypertension (high blood pressure) and hyperlipidemia (high cholesterol) on referral from their PCPs in order to help them manage their diseases and meet clinical targets. Secondary providers included in this study are registered nurses (Murray, et al.) with specialized responsibilities for case management, disease management, or patient education; and clinical pharmacists (PDs) who saw patients for medication management or intensification, or in the context of shared medical appointments (SMA).

Provider functions with regard to patient care in the context of a primary care visit are summarized in Figure 5-1 below, which shows how the patients we observed typically moved through a primary care clinic visit and the types of providers they interacted with at each step.

Figure 5-1 Patient Movement through a Primary Care Clinic Appointment and Providers Encountered at Each Stage

The figure above illustrates two paths through a primary care visit relevant to this study: one for a PCP appointment, which started with a pre-visit assessment by an auxiliary provider; and the other for an appointment with a secondary provider for disease management, in which all of the assessment was taken care of solely by the RN or PD whom the patient is scheduled to see. The vertical columns indicate the types of providers that patients were seeing at a given stage in the visit, specifics of which varied locally according to how care was organized at each clinic and the details of individual patients' situations. The following sections describe what takes place for the patient

within each provider encounter in order to begin to illuminate the places where information is generated, populated into the record, and used during the course of a visit.

5.4.2   Auxiliary Provider Interaction

When a patient arrived in the clinic for his appointment with a primary care provider (PCP), his first interaction with a clinician was typically with a category of provider I am characterizing here as "auxiliary." Patients did not typically make appointments with these auxiliary providers; rather, they saw them solely in conjunction with their PCP visit. A typical auxiliary provider as we observed them was a licensed practical nurse (LPN) or a registered nurse (RN), depending on the structure of the particular clinic, and responsible for conducting what was commonly referred to in the clinics as a "check-in." This encounter served as an initial assessment of the patient's health status and identification of issues to be addressed during the PCP visit, and as a venue for health maintenance activity such as immunizations. In the course of these interactions, providers were obtaining information from and about the patient, populating it into the electronic health record, and communicating it to the PCP.

During the check-in auxiliary providers collected and recorded patient vitals, including weight, blood pressure, and pulse; and administered certain clinical reminders as directed by the CPRS system, including foot checks for diabetic patients, pain screening, depression or PTSD screening, and health maintenance such as immunizations. During the check-in these providers entered patient data and responses to screening questions into his electronic health record, and in many cases, noted them on

the paper routing sheet as well. In these ways potentially problematic vitals, symptoms, or situations with regard to the patient's health were brought to the attention of the PCP.

In addition to seeing them before their PCP visits, in some cases auxiliary providers also met with patients afterwards for follow-up, sometimes referred to as the "checkout." At this point the auxiliary provider was responsible for taking care of any minor health maintenance, procedures, or education at the direction of the PCP. In the course of our observations, we noticed the LPN "checkout nurses" administering diabetic foot checks, immunizations, or other basic medical procedures such as earwax removal. In the clinic where RNs were responsible for checkouts, the interaction was considerably more elaborate; they followed up on the PCP's assessment and reinforced his treatment recommendations by providing education regarding medications or self-management behaviors such as exercise or healthy eating.

5.4.3   *Primary Care Provider (PCP) Visit*

After the check-in was completed, a patient's next encounter was usually with the primary care provider (PCP) he was scheduled to see that day. For the most part, PCPs acted as the key decision-makers regarding patient assessment, diagnosis, and treatment in the primary care clinics and were the gatekeepers for referral to specialty and secondary care. The majority of PCPs included in the study were MDs or residents practicing under the supervision of MDs, but there was some variation—one clinic was also using a number of nurse practitioners (NPs) in that role, particularly for chronic disease patients, and another utilized a few NPs and PAs as "mid-level" PCPs, where

they frequently functioned as "floats," mostly filling in for absent PCPs or taking on overflow patients.

Depending on the set-up of the clinic, the PCP would either enter the exam room once check-in was completed and the RN left the room, or would come to the patient waiting area to call a checked-in patient back to the exam room. Typically, PCPs had a designated exam room for the day, but did not always have their own permanently assigned room or office, meaning they were often sharing space, equipment, and reference materials located in the room. Most of the exam rooms at the three sites were fairly small, often providing seating for the provider and the patient in addition to an exam table, a sink, and necessary medical equipment. Some providers routinely made sure that a chair was available in case the patient came in with a caregiver or support person and one PCP who worked closely with the VA's physical activity program explained to us that she had arranged to have a small couch as her patient chair in order to more comfortably accommodate the many obese patients she sees.

The purpose of a PCP visit was usually to address acute and/or ongoing health conditions—these appointments appeared to have either been scheduled as a follow-up to the patient's last PCP visit or to address new health issues that had arisen since. The PCP encounters we observed usually consisted of a patient interview wherein information was elicited from the patient; a physical examination; an assessment of the patient's condition; presentation of a treatment plan or recommendation; and identification of next steps. Throughout these encounters, PCPs were almost always actively engaged with

CPRS, both accessing information from the patient's EHR and entering information into it, and in most instances, providing information to the patient as well.

5.4.4   Secondary Provider Visit

If a patient was coming to the clinic specifically for follow-up regarding his chronic condition, he might not be coming to see his PCP at all, but instead, a secondary provider for a specialized disease management intervention. These providers were integrated into the primary care clinic environment and saw patients for stand-alone appointments independent of their PCP visits; I am designating them as secondary providers in that they see patients for specific issues on referral from their PCPs rather than for ongoing, broad-spectrum care.

In the study, the secondary providers were registered nurses (Murray, et al.) and clinical pharmacists (PDs) who we observed participating in several types of clinical activities aimed at helping patients manage their chronic conditions, or in clinic parlance, bring them "under control." Patients who were not meeting certain thresholds in terms of A1c—the standard lab indicator for diabetes management; lipid (cholesterol) levels; or blood pressure measurement were referred by their PCPs to these secondary providers, indicated in the fourth column of Figure 5-1 above. In the case of these visits, the patient followed the alternate path indicated by the arrow at the bottom of the figure—he did not get checked in by an auxiliary provider, but instead went directly to his scheduled appointment with either a PD or RN, or to the shared medical appointment. In these scenarios the assessment or check-in activities typically conducted by an auxiliary provider before a PCP encounter were folded into the secondary provider visit.

Three types of disease management activities were observed in the course of the study: one-on-one appointments with an RN trained in case management or as a certified diabetes educator (Wenger, et al.); one-on-one appointments with clinical pharmacists (PDs) that focused on medication-related strategies for managing chronic conditions; and shared medical appointments (SMAs)—group sessions run by an interdisciplinary team of medical and behavioral health providers. Each is described in more detail below, and each involved using information from the electronic health record, contributing information back to it, and, perhaps more notably than with the other types of encounters described here, providing a considerable amount of information to patients.

5.4.4.1 Disease Management with RNs

In the clinics we saw patients with chronic conditions such as diabetes, high blood pressure and high cholesterol referred by their PCPs to RNs for disease management services, which in these settings consisted of problem solving, disease education, and self-management strategizing. In this role the RNs appeared to provide focused services to patients for enough visits to adjust and monitor their medications and self-management regimens, with the goal of bringing health indicators such as A1c, blood pressure and cholesterol levels under control. In the two clinics where RNs acted as secondary providers for disease management they were either designated as Case Managers or participated in a disease management-focused rotation as RN staff. In these cases, they saw patients independently, outside of their regular PCP visits. Disease management visits typically occurred in the clinic, but the RNs in the study also followed up with patients by phone as the situation required.

5.4.4.2 Medication Management with Clinical Pharmacists

Patients with uncontrolled chronic conditions were sometimes referred by their PCPs to clinical pharmacists, often identified as PharmDs (PDs) in the clinics in reference to their doctor of pharmacy status, for medication intensification and disease management that focused on medication adherence. PharmDs were deployed in two of the VA primary care clinics in the study as secondary providers for chronic disease management. In this role, PDs were seeing patients on a short-term or occasional basis to review their medications relative to their blood sugar, blood pressure and cholesterol levels; provide some patient education with regard to disease management and medication adherence; and adjust medications and treatment accordingly. The PD visits were notably different from the RN disease management visits in an assumed focus on medication as a starting point for illness management; they tended to emphasize medication adherence, intensification if needed, and insulin starts for diabetic patients, all with a goal of gaining better control over their chronic conditions.

5.4.4.3 Shared Medical Appointments for Management of Chronic Conditions

Another secondary provider alternative for patients with chronic conditions was the shared medical appointment (SMA), which was run at one of the study clinics as an approach to helping patients manage certain chronic conditions. In the course of shadowing an RN who was a certified diabetes educator (Wenger, et al.) in the clinic, we had the opportunity to observe a portion of an SMA in which she participated. This group session for patients with diabetes was led by PDs and involved a multidisciplinary provider team, including the CDE, a nutritionist, and a health behavior specialist focusing on self-management of chronic health conditions. The half-day visit included education

about the disease, treatment, and medications, and self-management strategies,

emphasizing the importance of controlling blood glucose levels and other relevant health

indicators such as blood pressure and cholesterol by focusing on adherence to treatment,

acceptance of insulin therapies, self-management barriers and strategies, and lifestyle

choices.

While the didactic content of the SMA was similar to a more traditional Diabetes

Education class we had observed an RN-CDE conducting at another site, the SMA also

encouraged patient participation and interactive discussion among patients in the group.

Patients were encouraged to share their experiences with controlling their diabetes or

changing their eating habits in a facilitated discussion. They were also given information

about home monitoring options such as glucometers and the clinic's Telebuddy program,

which enables patients to provide regular feedback to clinic RNs using a specialized

device and a telephone line. Telebuddy was presented as a way for patients to get

additional help with their diabetes management and regular provider input between visits

to the clinic. In addition to the group session, the SMA also included medical treatment—

participants were also seen one-on-one by a resident, PD, or RN for individual

monitoring, medication adjustment and problem-solving regarding diabetes management.

5.5   The Practice Environment: Arrangement of Care at the Three Study Sites

The three sites included in the study were all in the Midwest United States, and

reflect a diversity of institutional characteristics and populations served. The VA

structure allowed for the specifics of services and provider practice in primary care

clinics to be determined at the local level, and each of the three sites had a slightly

different organization of care and mix of provider types. Institutional characteristics, features of the practice environment, and the way care is organized and work distributed at each site have bearing on providers' roles and practices with regard to patient care and information use. The three study sites are presented here as observed during fielding in order to provide a more complete picture of each clinic environment and a sense of the range within the sample.

5.5.1   Site A

The Site A clinic is located within a mid-size VA Medical Center providing specialized consultative (tertiary) care in addition to its primary and secondary care services. It is co-located with an HSR&D Center of Excellence, affiliated with a large university medical school, and has a significant research and teaching mission. Perhaps because of the overall academic focus of the site, providers were generally much more receptive to participating in the study, and volunteered more readily in response to our requests for participation. The primacy of research at this site was reinforced at the primary care clinic level—we noticed that clinicians made more references to current literature both in our interviews and patient consultations, and patients were more likely to be participating in research studies.

The practice environment at site A was distinguished by the orientation of the physical layout around several mentor rooms, large common spaces located throughout the clinic in between hallways, accessible from either side, and shared by two primary care teams. The mentor rooms, originally established as a space where residents could consult with attending physicians on cases, appeared to facilitate a number of interactions

between clinicians. The mentor rooms were a home base for coordination of work among LPNs, who picked up patient router sheets generated by a printer there and used them to determine which patient to call back next for check-in. The room also functioned as a space for consultation between providers, particularly those where a clinician with a more limited scope of practice, such as an RN, needed to get feedback or approval on a patient assessment or treatment plan from an MD. Clinical pharmacists, who in the VA have the unique ability to actually write prescriptions, were also assigned to the mentor rooms to sign off on medication orders and provide ad hoc consultation and advice to providers of all types.

The mentor rooms clearly functioned as a community collaboration and communication center for the clinic, providing space for clinical discussions and mentoring as well as featuring numerous bulletin boards promoting various health topics and practice reminders, a white board with the daily schedule, and provider room assignments. The presence and prominence of the computers in the room was notable; they lined the walls of the room and much of the interaction between clinicians involved focusing on the patient's electronic health record in CPRS while they discussed his case.

In addition to standard primary care services, site A had RN Case Managers in place as secondary providers (column 4 in Figure 5-1 above) for the management of diabetes and other chronic conditions such as hypertension (high blood pressure) and hyperlipidemia (elevated cholesterol). Case Manager RNs took on a fairly specific and focused role in chronic disease management and care, responsible for patient education and close follow-up between PCP visits, and practicing with a degree of autonomy in

terms of treatment planning and decision-making. Although RNs don't typically prescribe medication, in this clinic they reported being able to place orders electronically for certain diabetes medications and to adjust insulin dosages, a process referred to as "titration," provided a clinical pharmacist signed off on the order.

All of the RNs at site A were designated as Case Managers, while the LPNs performed auxiliary provider functions such as check-ins and checkouts. In observations, one-on-one case management was the most prominent activity of the RNs, and it was typically the primary responsibility they cited in interviews. But they also made reference to being called upon to do support activities for MDs, referred to as "care management," for example, administering clinical procedures such as EKGs or immunizations, or providing triage for or returning patient phone calls on behalf of the MDs.

Clinical pharmacists (PDs) played an active role in the site A clinic, both as secondary providers working with patients directly at the referral of their PCP, and in a consultative role advising other providers on medication-related issues. At site A we observed PDs seeing patients for individual medication and disease management appointments; working in the "mentor rooms" as described above; and also reviewing clinic records, off-formulary requests and prescribing patterns to promote cost containment and pharmacological efficacy and safety. In our observations of other providers, it became clear that the PDs also tended to be involved in numerous research studies that included primary care patients, giving them a high visibility among patients and other providers.

5.5.2   Site B

The site B clinic is located within a smaller more rurally situated referring facility not associated with a medical training program or significant research activity. Providers here were much more reticent to volunteer for the study via email, although we were able to do a fair amount of recruiting for the observation phase "on the spot" while at the clinic. MDs in particular were challenging to recruit, and as a result, are not proportionately represented in the interview phase of the study, for which no onsite recruiting took place.

A predominant characteristic of site B was its large population of psychiatric patients, likely because it was collocated with a VA psychiatric facility. We observed numerous encounters with patients with mental conditions in addition to their physical issues, some of whom were receiving inpatient psychiatric treatment also. Providers consistently attributed a general lack of medication adherence and treatment compliance to the prevalence of serious mental illnesses among the patient population. While we were in the clinic physicians in particular made more negative comments to this effect, and frequently seemed frustrated with their patients' non-compliance.

Site B appeared to be the oldest physical facility of the three sites, and the clinic was comprised of narrow terminating hallways with the exam rooms off of them, which created some issues with congestion and a cramped feeling in the hallway. There was no common workspace for providers in the clinic and much of the coordination of auxiliary work among RNs and communication between RNs and MDs happened in the hallways. Because the visit structure was slightly different here—after the check-in the patient

stayed in the exam room while the RN left and sent the PCP in, there was more opportunity in this environment for the auxiliary provider to speak with the PCP about the patient during the hand-off. We frequently observed RNs giving MDs or PAs a summary of patient needs and issues that had emerged during her encounter in the hallway as they transitioned.

There did not appear to be as much of an emphasis on specific disease management approaches in the primary care setting at site B; patients with diabetes were often referred to the endocrinology clinic when specialized management was needed. Unlike the other sites, clinical pharmacists and RN case managers were not integrated into primary care, although we did interview one case manager working from a satellite clinic that conducted case review and initiated troubleshooting with patients with chronic conditions, and a clinical pharmacist who performed medication oversight in primary care via clinic records. We attended a diabetes education class conducted by an RN at this site that appeared to be the only intervention directed specifically at chronic disease management. Alternatively, chronic illness management and education was generally covered by the RNs, who did so in addition to auxiliary functions such as completing health maintenance reminders and doing the initial intake and assessment before the patient's PCP visit. We observed RNs covering a broad range of issues addressing chronic illness management and overall health with patients, including nutrition and exercise, healthy lifestyles, smoking cessation, and alcohol use.

5.5.3   Site C

Site C was a tertiary care center located in a higher density urban area with a larger patient population and a greater prevalence of diabetes. This site was associated with a fair amount of research and teaching activity but not co-located with a dedicated VA Health Services Research & Development service. This clinic appeared to have more particularly researcher-oriented providers on staff, which seemed conducive to implementing "action research" projects resulting in innovative chronic disease interventions. For instance, an RN at this site had spearheaded an intervention utilizing information from local databases of patients with particular chronic conditions such as diabetes or hyperlipidemia in order to track patients in need of attention or treatment, direct them to appropriate treatment resources, and better manage their care.

While this site did not have an active, central mentor room like the first one, a fair amount of collaborative activity and mentoring between clinicians, and accessing of patient records did take place in a couple of conference rooms located in the back of the clinic. The conference rooms featured just a few computers and we didn't notice nearly as many resident and attending pairs working there, although we did shadow a couple of providers who were in the exam room with residents during encounters, providing feedback to them in between patients. Relative to the other sites also witnessed more group meetings and didactic sessions for residents taking place in a large conference room within the clinic.

Since the common areas were less central at site C, auxiliary provider work was not coordinated there, but instead within a small cluster of cubicles assigned to the LPNs

at the front of the clinic, right behind the clerks' desk where patients initially arrive. At site C, we observed that the PCPs appeared to have permanent offices/exam rooms, which seemed to support being able to access patient handouts, reference materials, and needed supplies during an encounter. RNs and PDs were assigned exam rooms for a day—an index of who was practicing where was prominently displayed on a whiteboard near the LPN area.

Site C appeared to be implementing a number of concerted efforts to address diabetes control, including the SMAs described above, RN visits focused on diabetes and hypertension management, PD appointments for medication management, and heavy promotion of home monitoring through patient use of glucometers and the Telebuddy system. Like site A, the RN responsibilities at site C included both PCP support and autonomous patient care, but their time was divided differently. RNs described their jobs as rotating through one-week stints in several roles: as resource nurse, performing auxiliary functions for PCPs; phone nurse, responding to patient calls that came in for what one RN described as the "45-60 providers working in the clinic"; and as block nurse, seeing patients autonomously for disease management. The RNs described their chronic condition management as being heavily oriented toward hypertension and diabetes; one RN from this site was a CDE, widely referenced as "our diabetes educator" by the other providers, and another mentioned working toward that certification. The CDE had a prominent role in the SMA and in that context was actively precepted, or mentored, by the PDs. Site C also relied heavily on nurse practitioners (NPs) to act as PCPs in the clinic, to a greater extent than the other sites. Nurse practitioners are RNs by

training, but also have advanced education that qualifies them to diagnose and treat independently. In interviews they were more apt to highlight chronic condition management as their focus and described a relatively limited scope with regard to acute issues, whereas MDs tended to describe their responsibilities as relating to overall patient care or primary care more generally.

5.6   Issues Affecting Providers' Roles in the Care of Patients with Chronic Health Conditions

The preceding sections described the overall arrangement of care and provider functions experienced by patients in the VA primary care clinics. In the course of fielding it became clear that to some degree, disciplinary orientation and organizational issues related to clinic structure and perhaps, culture, affected how chronic illness care was actually enacted and shaped the way that providers used or provided information in the context of their roles in the clinic. In interviews providers were asked to describe their roles and responsibilities in the clinic, as well as to talk about what they did in the course of a routine clinic day. Their responses, in combination with our observations of clinic activity and patient encounters; providers' explanations related to their work; exchanges between providers; and providers' comments about other roles in the clinic, revealed several issues related to provider roles and modes of practice that shape how chronic illness care and information is provided.

5.6.1   Chronic Illness Orientation

The various provider types tended to have somewhat different views about their role in chronic illness care. These differences may originate in the orientation of their various disciplines and training or from the way job functions are proscribed in the

individual clinics; of significance here is their potential to influence the ways information is used, provided, and recorded. In interviews, MDs tended to describe their responsibilities in the clinic more as "primary care," or "patient care," a seemingly generalist and comprehensive perspective that only sometimes included references to specific chronic illness management activities. Nurse practitioners, even though they were also designated as PCPs in the clinics, tended to describe their responsibilities more in terms of chronic condition management, with less of a scope for acute issues; in the clinics they appeared to have a more focused practice in that respect.

RNs across the board, whether acting as secondary providers or in an auxiliary fashion, cited patient education as primary among their job responsibilities, and the RN Case Managers clearly understood their roles as related to chronic disease management specifically. Patient education among the RNs tended to focus on behavioral change and addressing barriers to self-management. RNs managing chronic conditions were generally doing problem solving and education during patient encounters, focusing on the patient's current health status and progress, the physiology of disease processes, the impact of uncontrolled illness, directions for managing medication or treatment, and strategies for self-management and lifestyle changes. In interviews, several of the case manager RNs indicated that had had considerable healthcare experience prior to being hired into those positions in the primary care clinic, several in critical care or community health settings where they had to do a lot of independent decision-making, what one participant referred to as "autonomous experience." The RNs who were doing disease

management rotations also came across as extremely knowledgeable in patient interactions; one was a CDE and another referenced studying for that certification.

Not surprisingly, clinical pharmacists (PDs), who were also in disease management roles, tended to describe their practices in terms of medication, and in patient encounters focused on pharmacological approaches to control over behavioral ones. Issues related to diabetes medications can be complex, and MDs cited turning to pharmacists for guidance on medication decisions. PDs also emphasized issues of non-adherence to medications in individual patient encounters and worked with patients to titrate their insulin dosages in response to their daily blood sugar readings, incorporate additional medications, problem-solve around remembering to take their medications, or address barriers to starting insulin.

The ability to refer patients with chronic conditions to secondary providers was clearly valued by MDs, who made reference to relying on the specific expertise of RNs and PDs with regard to the treatment and management of patients with diabetes, recognizing that they might, for instance, know more about the complexities of insulin titration or efficacy of particular oral agents for patients with diabetes. Several MDs cited the PDs as providing additional input in a highly specialized area that they didn't necessarily have expertise in. One marveled at the effectiveness of the PDs when it came to getting patients started on insulin, noting that the pharmacists often succeeded where she had failed to convince. When considering more targeted approaches to improving diabetes management in the clinics, MDs frequently commented that information to support such strategies would be best used by the RNs who are focusing on chronic

condition care. PCPs tended to view this option as an effective way to focus more specifically on chronic condition management and behaviors associated with it and to get patients necessary follow-up between visits so that they don't fall through the cracks.

5.6.2   Hierarchical Structure

Generally MDs were considered the lead decision-makers regarding patient treatment and care. Although RNs practiced with a degree of autonomy as secondary providers in terms of how they worked with chronically ill patients, they tended to report following the PCP's care plan in their encounters, and when asked about decision-making in interviews, a number of them made it clear that they "don't make any decisions." Likewise, when RNs working in auxiliary positions re-entered the room to wrap up the patient's visit with additional health maintenance, medication instruction, or self-management education, we frequently observed them acting at this point in the visit to reinforce an MD's point or even to interpret or explicate something the doctor had told the patient. These RNs tended to work paired with a particular MD; the MDs even referred to them as "my nurse," emphasizing the auxiliary nature of the partnership.

NPs, who are educated as nurses and emphasized some of the same disease management and educational approaches with patients, were designated as PCPs and appeared to practice fairly autonomously in that role as far as patient decision-making. They tended to be referred to by other providers as nurse practitioners, rather than nurses or RNs, highlighting their level of education and consequently, degree of patient responsibility in that environment. The PDs, although practicing as secondary providers

in a role similar to the case manager RNs, seemed to make patient decisions without

deference to the PCP's plan.

5.6.3 Role Confusion

At sites where the RNs had more autonomy as secondary providers, they were

still called on to do auxiliary work for MDs such as returning patient phone calls,

performing minor medical or health procedures, or as one RN described,

> …anything the doctors want us to do—alerts, 'contact this patient about
> X, Y, Z' and then basically everything miscellaneous in between.

In that setting, where RNs are simultaneously functioning in both roles, there appeared to

be some tension around balancing their case management work with auxiliary work, with

pressure to put case management, in the words of one RN, "unfortunately at the bottom

of the list." MD expectations appeared to influence this, as another RN explained,

> …some of the physicians also see the *care management* part to be a
> priority and so I know, personally, I kind of struggle to juggle both those
> roles.

The tension between various dimensions of an RN's role with regards to

autonomy versus MD support was also an issue in the clinic where RNs served as the

auxiliary providers to the PCPs. Even though they were performing a number of auxiliary

functions, described by the LPNs as assessment activities, they still saw themselves as

primarily responsible for patient education and viewed these two aspects of their roles as

competing for their attention in the small amount of time they got to spend with patients.

One RN attributed this directly to the ways roles were structured—she felt that in other,

clinics where case management was in place and LPNs "did a lot of the assembly line

type nursing," that RNs were probably doing their jobs more effectively. She was particularly articulate about the fact that she had more to offer patients with diabetes than she was able to, and would have enjoyed the autonomy of being able to take a case management approach. A PCP at this site echoed this sentiment, adding that she felt that the use of the term "team" was really speaking more to a division of functions, i.e., "oh we're going to have this doc and we're [NPs and PAs] mid-level, and these nurses work on this," rather than to a true interdisciplinary effort aimed at patient management, which might entail RNs and MDs stepping back to collaborate on problem-solving regarding patients with diabetes, rather than just seeing them sequentially during a visit.

5.7   Discussion: VA Primary Care Context as a Context for Chronic Illness Information and Care

This chapter addressed research question 2.1 by examining aspects of the VA primary care context that shape information flows, interaction, and use in the care of patients with chronic health conditions. In examining how information is situated relative to patients and their care through the use of the electronic health record (EHR); the arrangement of care for patients with chronic conditions; providers' roles and activities; and other aspects of the practice environment, this chapter sets the scene for the investigation of information practices and experience in the context of chronic illness care that is addressed in the upcoming chapter 6.

The findings of the current chapter revealed two interconnected forces as significantly influencing chronic illness practice in the VA primary care context: 1) the ubiquity and prominence of the EHR in patient care and treatment, and 2) the multidisciplinary provider teams organized to provide chronic illness care in the clinics.

As discussed in chapter 3, the VA Health System has been considered a pioneer both in its widespread use and integration of the EHR into clinical practice and in its adoption of innovative approaches to chronic illness care. As other healthcare organizations have struggled to find their footing in terms of establishing health information technology systems, the VA is running an integrated patient record and communication system that has been in use in its facilities nationwide for the past 10 years. And as other US providers are just beginning to consider new models for chronic illness care in the larger context of healthcare reform, the VA is well ahead of the curve, with elements of the Chronic Care Model and the Patient-Centered Medical Home already in place in its primary care clinics.

It is no accident that these two aspects of VA primary care practice coexist in close proximity. The ongoing and distributed nature of chronic illness care at the study sites was found to be heavily supported by CPRS. The patient's record served as a robust tool for coordinating patients' chronic illness care over time as well as for collaboration among provider teams. All of the providers included in the study used the EHR in conjunction with their treatment of patients with diabetes and other chronic health conditions. In the course of their daily work practices they used CPRS to support many aspects of care by populating information into the EHR; accessing current and historical patient information; placing real-time medication and referral orders; and sharing information or trigger follow-up action for other team members and specialists. As a comprehensive and accessible source of patient information, the EHR was used as a shared representation of the patient and his condition in the context of mentoring,

training, and curbside consultation with other providers. As we will see in the upcoming analysis, the centrality of the EHR in provider work both supports and constrains the care of patients with chronic health conditions.

The multidisciplinary provider teams in place to provide chronic illness care in the clinics offer opportunities for patients to receive both broad-spectrum primary care and health management and specialized support for chronic condition treatment and self-management. The pivotal role of PDs and RNs in chronic illness care was apparent throughout fielding. RNs in particular were employed in non-traditional case-management focused roles in which they functioned with greater autonomy in patient care and decision-making; their focus on patient education and problem-solving was a key element in how chronic illness care was supported in the clinic. Even within these three arguably "best-practice" environments, these care innovations were not entirely smooth; the changing nature of RN practice clashed at times with the traditionally defined roles and hierarchical structures of authority that have long been characteristic of medical environments. The study found that RNs tended to defer to MDs' plans and goals for patient care and some felt that they were underutilized or that the daily operationalization of their clinic roles required them to subordinate their own practice to MD support needs.

This discussion has illuminated significant forces within the primary care context shaping provider practice, information use, and ultimately, patient experience. The impact of the ubiquitous use of the EHR and the multidisciplinary approach to chronic

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illness care are further articulated in chapter 6 as supports and constraints to provider

information use and patient experience in this context.

CHAPTER 6

INFORMATION IN THE PRIMARY CARE CONTEXT: PROVIDER

PRACTICES AND

PATIENT EXPERIENCE (STUDY 2, FINDINGS II)

6.1   Introduction

Chapter 5 presented the first set of findings for study 2, *Chronic Illness Information Use: Provider Practices and Patient Experience in the VA Primary Care Context*. It laid the groundwork for the current chapter, investigating the primary care environment as a context for chronic illness care, examining how patient care is arranged and how patients are situated relative to information and provider practice in that environment. This chapter turns specifically to provider information practices, examining how information is used, incorporated, and exchanged within the primary care context where patients and providers come together to treat and manage chronic health conditions. The findings from the *Everyday Life* study, detailed in chapter 4, demonstrated that chronic illness as experienced in everyday life may be at odds with daily activities and lifestyle choices; peppered with the uncertainty of unanswered questions; and necessitating psychological work in the course of coping. The healthcare context, by contrast, was shown in chapter 5 to be a more structured and role-driven environment in which the patient, his illness, and his experience were represented as information in the electronic health record (EHR).

This portion of the analysis approaches the data with a primary objective of understanding how chronic illness information practices in the clinic context and in the interactions between clinicians and patients act as a frame for patients' experiences of information. The chapter 5 findings showed that substantial forces drive and shape provider practice in the clinics, including: the use and form of the electronic health record (EHR); chronically ill patients and their health conditions; the organization of care; institutional and organizational factors; and provider roles and modes of practice. This chapter examines information activities specifically, focusing on how information was used, exchanged, and viewed in this environment. The themes of interest were primed by findings from the first study about the everyday life experience of chronic illness and theoretical approaches drawn from the sociology of the illness experience and information behavior literatures, but within these larger conceptual areas, themes and patterns have been emerged inductively from the interview and observation data.

In the VA primary care clinics, the patient with chronic illness, along with the representations of him and his conditions contained in the EHR, interacted with various healthcare providers. In the course of doing their work, these providers engaged in a range of information activities: information was obtained, analyzed, communicated, provided, discussed, created, given to patients, and entered into the record. In this chapter, in order to more fully understand the ways that these informational aspects of provider practice can frame the experience of chronic illness care, it was valuable to focus on provider information activity from two perspectives:

- Through the use of patient data and information in the course of providers' work related to chronic illness care in the clinics, which speaks to the role of information in the environment and in shaping providers' views of the patient.

- Through interactions with patients with chronic health conditions, which embody communicative aspects of information use, emphasizing how it is provided, shared, and received in the patient-provider encounter.

The research questions guiding my analysis of information activity in this chapter address information use both in provider's work to treat patients and within provider-patient interactions:

2.2 How do healthcare providers use information in treating patients with chronic health conditions? (addressed in sections 6.2-6.3)

- What information do providers use in their treatment of patients with chronic health conditions?
- For what purposes do they use information in their treatment of patients with chronic health conditions?
- How does information use vary by provider type?

2.3 How is information about the patient, his condition, and his treatment communicated in patient-provider interactions? (section 6.4)

- What information do providers convey information to patients during encounters?
- For what purposes do providers convey information to patients during encounters?

2.4 How does the everyday life experience of illness manifest itself in medical encounters? (section 6.5)

- How do patients bring their everyday life with illness into medical encounters?
- How do providers respond to patients' everyday life experience?
- What is the nature of mismatches or disconnects between everyday life experience and the medical encounter?

6.2   The Electronic Health Record as an Information Use Medium

The VA's Computerized Patient Record System, CPRS, is the primary way that patient information is used in provider practice. In our observations, every provider

interacted with CPRS and the patient's electronic health record EHR in conjunction with their provision of care to him. When asked in interviews about their use of information in treating patients with diabetes, providers consistently cited CPRS as their main source of patient information; the only other information source brought up with such regularity was the patient himself. The EHR captures key information about the patient and his condition and represents the patient across time and providers in the VA environment. 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 record and how it used in patient care both informs and reflects providers' approaches to chronic illness management and patients.

Chronic illness management was clearly information-intensive in the clinics. The ongoing nature of chronicity and the degree of problem-solving providers needed to do to manage or control illness highlighted the importance of a persistent record of the patient's health situation over time. Providers relied on historical information from CPRS to understand how a patient had gotten to his current state and determine where to go with treatment. The clinics' team-based approach to chronic illness management was also facilitated by the use of the record to communicate information and coordinate care. The EHR's centrality to chronic illness care particularly suggests that it is an essential force in shaping the experience of those patients. The role of CPRS and the EHR are further examined in the context of specific provider information practices in the following sections

6.3   Providers' Use of Information in Treating Patients with Diabetes and Other Chronic Health Conditions

Understanding how clinicians routinely make use of information relative to treating patients with chronic health conditions offers insight into clinician priorities and concerns; how and when information is used to support care and decision-making; and clinicians' perceptions of the key issues in chronic illness care. This study focused primarily on diabetes care, described in chapter 5 as providing an intensive example for looking at provider information use in that it is: a chronic condition that is challenging to control; and requires ongoing management by both the provider and the patient. In interviews, providers were asked to discuss their information use related to diabetes care specifically. Notably, providers also frequently referred to information as used in their treatment of hyperlipidemia, hypertension, and cardiovascular disease, chronic conditions co-occurring with diabetes. In the field we observed encounters with patients with these and other chronic illnesses in addition to those with diabetes, and quite frequently, with multiple chronic conditions. These aspects of data collection contribute to an understanding of provider practice regarding diabetes specifically, but often to chronic conditions more broadly as well.

As mentioned earlier, the patient's CPRS record, or EHR, was the unanimous source of patient information that clinicians cited and were observed using in conjunction with patient care. The most commonly reported information elements from the EHR used in the care of patients with diabetes included:

- Indicators of disease "control," the common clinical term for meeting recommended target levels. For diabetes these included the patient's lab A1c level and other key health indicators related to diabetes, i.e., blood pressure and lipid levels. Indicators of control are the most frequently mentioned and usually the first-mentioned patient information used.

- Encounter notes: written by providers in order to document each visit, including their subjective and objective observations, assessment of the patient's health, and plan for treatment. The "note," as clinicians typically referred to it, often served to aggregate patient information, provide a template for the visit, and carry information over from one visit to the next. It was also a highly cited and valued information source.

- Indicators of disease progression or overall health, including vital sign readings recorded during check-in and key medical tests that assess the degree of damage resulting from disease or medication usage.

- Medication lists and pharmacy records: it was not unusual for patients with diabetes to be on numerous medications to control blood sugar, cholesterol and blood pressure. Refill patterns helped providers get a sense of medication adherence.

- Reminders: notifications automatically generated by CPRS in response to certain pieces of patient information. A reminder might tell a provider that the patient needs a diabetic foot check, eye exam, or other kinds of health maintenance procedures

The kinds of patient information that providers reported and were observed using in conjunction with their encounters with patients with diabetes supported their care activities relative to that visit. Indicators of disease control, patient health or disease progression are all quantifiable assessments, and along with the medication list, represent objective information regarding the patient and his condition. Reminders are generated by CPRS algorithmically in response to certain variables in the record (e.g., diabetes diagnosis + no foot screen in the last year) and serve to direct provider actions. The encounter note may contain any of these elements, but also includes subjective

information regarding provider impressions or assessment and information provided by the patient himself.

The following sections examine provider information use in the treatment of patients with diabetes and other chronic health conditions, drawing on observation data and findings from interviews in which providers were asked to describe their use of patient data and information before, during, and after an encounter patient with diabetes; the information they considered most important in treating patients with diabetes; and additional information they would like to have access to in treating patients with diabetes (see Interview Guide, Appendix B for specific questions). Supporting data is presented throughout as quotes from provider interview transcripts or brief excerpts from the fieldnotes. Of particular interest in this analysis were uses of information that appeared to shape the provider's perception of patients, approach to care, or communication with patients.

As seen in chapter 5, the various provider types included in the study had different roles and functions in terms of their care of patients with chronic health conditions. Accordingly, their use of information varied as well—providers were found to be using information in the ways that best supported the emphasis and objectives of their positions. Role differences are highlighted throughout this analysis where they are particularly notable in terms of treatment perspective or salient to providers' use of information.

6.3.1   *Use of Information by LPNs*

The LPNs included in the study had a notably different intensity of information use than the other provider types. They accessed patient information only as needed to fulfill their functions of updating it in the record or otherwise passing it along to the patient's PCP. The scope of their role relative to patient encounters was limited to checking in patients and doing some initial assessment; consequently they did not report very much use of information in seeing patients with diabetes. They are included in this analysis because of their role in obtaining information from patients and populating it into the EHR, but bracketed from the rest of the discussion of provider information use in order to focus on primary and secondary providers who were actively using information in direct patient care.

For LPNs, using patient information prior to an encounter was not generally considered necessary or feasible. The clinic workflow resulted in them only knowing which patients they would be seeing once the patient arrived and they were about to check him in. The scope of their practice meant they were not typically doing any problem solving or treatment planning, and consequently, most did not feel the need to look at the patient's EHR at all before they checked him in. When they did, it was usually for a quick overview in order to determine what they would need to do during check-in, for example: "to see if he's diabetic and if he needs a foot exam." The information LPNs most often used from the patient record were the reminders that CPRS generates to signal a patient action needs to be taken; they attended to the nursing reminders, which could direct them to ask patients to rate their pain level, record their answers to depression screening questions, or in the case of patients with diabetes, conduct a foot exam.

The LPNs tended to see themselves as conduits of information for the PCPs, and frequently described their role in the clinic as patient assessment. One LPN described her role as that of "patient advocate," because it was her responsibility to bring an understanding of the patient's condition to the attention of his PCP. Most of the LPNs viewed their assessment of a patient's current state of health and potential health needs as a defining aspect of their role in patient care or their contribution to work of the provider team.

6.3.2   Use of Information to Prepare for a Patient Encounter

Primary and secondary care providers generally accessed patient information either immediately before or actually during the first few minutes of a patient visit in order to perform what is still sometimes referred to in terms of its paper analog, a "chart review," scanning the patient's CPRS record for the information they thought they would need going into the encounter. If providers didn't do much preparation prior to a patient's arrival, they might take the first few minutes of the visit to scan the CPRS record for information relevant to treatment.

Generally, the time that was available to providers for preparation was minimal—most providers reviewed information for only a few minutes immediately 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 has checked in and they know he is in the clinic, as described by this provider:

> So I mean I won't sit in the morning and go through all my charts before my clinic starts, because there's one or two patients that don't show up, so yeah, before the patient walks in the [exam room] door, I will have reviewed everything.

Providers' main objectives in conducting this review varied by their role and the patient's situation, but generally appeared to be to: determine the patient's current state of health and/or illness; get up to date on any intervening medical events since they last saw the patient; and get some idea of what they were going to try to accomplish during the visit. Providers tended to consider 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 report out to someone else. Some of the RNs or residents who were being precepted, or mentored, in the clinics, described accessing more patient information ahead of time in order to be able to make their own paper notes that they could carry to the MD or the PD 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. Those kinds of things. Their labs, I have them all written out so I can staff them quickly.

In that same vein, some providers indicated that they did less preparation or information review now than they used to, citing the progression of their own skill or their degree of confidence.

The information of most interest to 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 as the ones they used to determine the patient's current degree of control of his illness, the starting point for making decisions about treatment approaches. Then providers typically proceeded to what they described as "looking at my last note" in order to get their bearings for the day's visit. Their encounter note from 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 here or what needed to be done during the visit today. If the patient had received any intervening medical attention in the time since his last visit, providers would review those encounter notes in order to get current on his health situation. Even when other providers had seen the patient more recently, many providers often expressed a preference for going back to their own notes because of the ease and convenience of a familiar format.

> I'll usually look back at previous notes, whether it's 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.

6.3.2.1   Preparation of Primary vs. Secondary Care Providers

For PCPs, who are seeing patients for a wide variety of acute and chronic conditions, the need to establish why the patient was coming in that day was paramount since it directed what they would be doing during the encounter. This was an issue for MDs and residents in particular since they tended to be responsible for more generalist patient care and their patient visits could address acute issues, chronic conditions, and/or

health maintenance. During observations several providers remarked that although a "reason for visit" field appeared on their computer-generated schedule, it had often been entered by a scheduling clerk or the call center and was less than informative, e.g., a cryptic comment such as "follow-up."

Overall, PCPs tended to think that they knew their patients well enough to recall their general situation, but didn't always know enough about why they were coming in to be able to anticipate what they would need to focus on during the visit. The particular issues they would need to respond to might not be evident until the patient began to express his concerns during the visit itself. Some PCPs responded to this difficulty in anticipating by *not* using much patient information ahead of time. PCPs who did prepare ahead of time sometimes found information in the record helpful to anticipate specific things they needed to cover, in effect laying out an agenda for the encounter:

> I'll see, alright, they're up to date on this, these are the things I definitely need to address, so on and so forth and I will create like a mini-note already—just put dash marks and points that I want to hit to discuss with the patient whether it's medication adherence or they need to have their immunizations re-upped … I'll create a skeleton of things that absolutely must be covered.

The approach described by that provider was fairly typical; it was not unusual for providers to start their note before the encounter, populating it with relevant patient information and a general outline of things they wanted to cover during the visit. The note then served to structure the visit and as a place for them to generate their assessment and conclusions.

PCPs, who saw a regular panel of patients, frequently mentioned "knowing" their

patients, and appeared to draw on this information from their memory or experience to

prepare for a visit, only accessing the EHR to make sure their information was current, as

this MD described:

> Most of my patients I know pretty well because I've been following them
> for some period of time, some of them for up to 10 years. … after I look
> over the list and if I have time, I look at any kind of issues that I may give
> myself a heads up on.

This was borne out in observation as well; it was not unusual at the beginning of an

observation session for an MD to scan his schedule for the day and immediately pick out

the patients with diabetes for us, or to review the list with us while providing a general

summary of each patient's situation. MDs and residents consistently described having

less need to access information before the visit because of their degree of familiarity with

their patients.

> When I first started here, I was probably doing it like the day before or
> something, the night before, looking up the patients and stuff but now that
> I kind of know my patients … I can just kind of do it for a couple minutes
> before I call the patient.

Secondary providers such as RNs or clinical pharmacists, who see patients on

referral for specialized services for chronic disease and medication management,

sometimes spent more time on up-front preparation, accessing patient information in

more detail ahead of the actual encounter. Since they saw patients on a referral basis, they

needed to be able to acquaint themselves with the specifics of a patient's disease

management and make sure they were aware of the PCP's treatment agenda. This was

particularly true for the RNs, who tended to view themselves as carrying out the PCP's

agenda, whereas the PDs were more likely to consider their work as an extension of the PCP's.

The narrower scope of practice in which secondary providers worked (focused on chronic illness management) also allowed them to have more certainty about what the patient was coming in for and to start assessing the patient's situation and potential treatment strategies ahead of the visit. Because they were, by definition, starting with patients who were experiencing problems, secondary providers had a fair sense of the task they were facing ahead of the visit. After assessing the patient's A1c or other indicators of control, RN case managers or block nurses reported going back to their previous notes and the PCP's notes to try and figure out why the patient's diabetes was not controlled, what had been tried, and what treatment plan was currently in place. They were typically charged with problem-solving patients' lack of control of their diabetes, blood pressure or lipid levels and would sometimes conduct a much more thorough review of available information to facilitate that process, digging through a record for overlooked patterns, or taking more of a historical view of a patient's experience, as is evident in these excerpts from two different RN interviews:

> I really review their chart very carefully. I'll go back about a year and look at who did they see, what consults did they have, I look at everything from mental health to foot care to an x-ray for this or that and then I go through labs for the last year.

I want to know what they're taking, how much they're taking, when they're taking it, previous readings if I can get it, the hemoglobin A1C is pretty important, the lipids, whether their blood pressure's controlled … I want to know what their creatinine is, I monitor for their potassium, I want to see their glucose values…previous diagnosis, their A1C—is it stable, is it rising, is it declining, when was the last one before that one, that sort of thing. I basically want to know just about everything about their diabetes I can find. And I don't care how many years I have to go back to get it.

The PDs had a similar problem-solving focus, and in addition to trying to understand the patient's disease management history in general they tended to focus their pre-visit information use on medications, looking at what had been prescribed for the patient, their medication adherence as indicated by their refill history, and lab indicators of medication side effects and degree of control.

6.3.3 Use of Information for Assessment, Problem-Solving and Treatment Planning During Patient Encounters

When providers were asked during interviews to move from information they used *before* the visit to information they used *during* it, their initial response was frequently "the same information." Providers reported continuing to use indicators of control and disease progression, encounter notes, and reminders in order to assess patient health and address the needs of the visit. During an encounter, providers used information to assess the patient's state of health or disease; solve a specific problem or address patient concerns; develop a treatment plan; and educate patients regarding chronic conditions, their treatment, and how to manage them.

The CPRS record was the primary source of information used in caring for patients with chronic health conditions, but during a patient encounter that information was integrated with information from patients' verbal accounts and logs they kept at

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home, and sometimes, with information gleaned from other providers during consults or mentoring. Less frequently, providers used other tangible information sources such as printed and online reference materials, or patient education handouts. Sources of information that were less tangible and not as easily observed or often mentioned by providers, but present nonetheless, included information from memory based on their historical involvement with the patient; information based on their experiences with other patients; and their own medical knowledge and training.

The use of information during a patient encounter appeared quite complex; providers were 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 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. One provider revealed that she had become aware of the challenge of using the EHR during the patient encounter and had developed her own ad hoc preparation and note-taking strategies in order to not have to use the computer as much and mitigate its perceived effect on the patient interaction.

Once the encounter started, health information from the EHR was revisited or used in new ways in the course of trying to solve a health problem or respond to a patient complaint. Most 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 what was happening with the patient by going back to the record as he provided information during the visit. What was a fairly static assessment prior to the patient encounter became a more dynamic, interactive process of eliciting information and returning to the record for more information or a different view, as patient health issues were revealed or illuminated and the provider tried to determine a course of action. During encounters with patients with chronic health conditions, providers used objective health indicators from the EHR, information from the patient's at-home monitoring, and the patient's account of his experience to assess where patients were in regards to the progression of the disease, its complications, and their level of control or management.

6.3.3.1 The Nature of Primary vs. Secondary Care Provider Information Use During Patient Encounters

PCPs tended to rely on a basic structure of eliciting overall information about patient health and concerns first; then reviewing the EHR to update themselves and the patient; conducting a physical exam as appropriate to the situation; and finally, concluding the visit with some kind of assessment, plan, or recommendation, often provided with some sort of education and explanation to the patient about the illness, the treatment, and what needed to happen next. But these steps rarely happened linearly or neatly. Providers were often observed moving back and forth between the tasks as the visit unfolded, in response to new information and the dynamics of interaction. As one provider commented, it was not unusual for it to take until the end of the visit for the patient "come out with what was really on his mind." Her experience was that by then enough information has been raised and a level of comfort attained that enabled the patient to get to deeper questions or concerns regarding his condition.

PCP visits in particular tended to be complex in that providers were actively juggling treatment of a number of acute and/or chronic issues and negotiating between patient concerns raised during the visit and their own agenda for the encounter. Appointments were booked at half-hour intervals, and it was not unusual for them to take the entire 30 minutes or longer, depending on the patient's needs and the clinic schedule. Seemingly as a result of the challenges of prioritizing a number of health issues and responding to patient needs ad hoc in the course of a single encounter, we observed and heard from PCPs about doing lot of on-the-fly work to determine the purpose of the visit, anticipate and respond to emerging patient concerns, and work through issues in a way that accommodated both the patient's needs and their goals for his care.

Secondary provider visits were by nature noticeably more focused or directed than the PCP encounters. RNs managing chronic conditions were generally using information for problem solving and education during patient encounters, focusing on the patient's current health status and progress, the physiology of disease processes, the impact of uncontrolled illness, directions for managing medication or treatment, and strategies for self-management and lifestyle changes. For PDs, their referrals were generally patients whose medications might need adjusting or who needed to be encouraged to start on insulin. They tended to approach visits with the goal of figuring out what might be the next changes they could make in a patient's medication regimen. In the context of direct patient care, both PCPs and secondary providers used the same kinds of information from the record, but in the course of observations it became clear that they had different types of interactions with the record. Specifically, secondary providers

seemed to spend more time obtaining information from the record and the patient for use in problem-solving, while the PCPs spent more time searching in the record and creating their encounter note, which appeared to serve both to document their assessment and impressions as well as structure the visit.

6.3.3.2   Information as an Input to Problem-Solving During Patient Encounters

Following assessment, providers usually progressed to developing some kind of plan for the patient's treatment, or modifying the current plan in some way. In problem-solving patient control, providers also continued to incorporate their previous assessment and notes, the patient's history, treatment plans and goals set by other providers, recent medical events, intervening visit notes, and CPRS reminders which provided information about necessary health maintenance and disease-specific screenings. Providers also mentioned retrospective information from the EHR as helpful in identifying self-management patterns or life events affecting control. By looking at lab results over time, providers could put together a picture of the patient's progression of disease, associating it with life events or trends in its 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. The review of the medication list frequently 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 this list was simply out of date in CPRS. The VA requires reconciliation of the patient's medication list during each visit and was a commonly observed activity

during provider encounters with patients with chronic illness. For patients who were not meeting targets for particular health indicators such as A1c level or blood pressure measurement, a review of the medication list often revealed prescriptions that hadn't been refilled recently or medications that patients weren't taking, information providers found useful in determining next steps in their treatment plans.

During the visit, providers stressed that information from patients themselves also became critical in problem-solving issues of control and self-management. Even though the A1c provided a reliable indicator of average blood sugar for a period of time, providers still needed to look at patients' home readings as taken from their glucometers or logs in order to determine what was happening with their blood sugar throughout the day in response to their eating patterns, activity levels and insulin usage. Providers also referred to eliciting and relying on patient accounts of their illness and its management for problem-solving during the course of the encounter. In interviews they cited using information from patients about their current life situation and lifestyle behaviors in order to come up with treatment plans or strategies for managing chronic conditions. Secondary providers in particular were often concerned with this type of patient-provided information that helped them to illuminate barriers to successful control and identify potential solutions in self-management.

When providers were asked about what kind of additional information they would like to have access to in treating patients with diabetes, the most often mentioned information across all types of providers was that related to problem-solving the management of a patient's condition. Some providers mentioned wanting more

information about what diabetes education and information patients had previously

received, or psychosocial aspects of their lives that would impact their ability to self-

manage. Most notably, providers consistently wanted additional information that would

provide them with a better understanding of patients' control, barriers to control, and self-

management behaviors, all frequently characterized as indicating a patient's

"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 related to patients' diet and exercise behaviors at home.

In observations we noticed that when available, information from the patient's

glucometer was frequently used by providers to pinpoint patient highs and lows for

problem-solving related to daily behaviors. In interviews providers cited technological

challenges in obtaining and using this information—it was not well integrated into CPRS

and sometimes couldn't even be printed out from the machine itself. The other challenge

often mentioned was considered a compliance issue itself—patients routinely forgot to

bring their glucometers with them to their appointments; without those daily

measurements problem-solving the cause of a patient's out of control A1c level could be

impossible, and in some cases, had to be deferred until the next visit.

> I mean I think 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 CPRS necessarily. We are, we have some
> technology now where it's linking that information and downloading it but
> 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.

In addition to wanting more regular or reliable blood sugar readings, providers also

wanted more details about patients' diet and exercise habits, or even whether or not they

were actually taking their medication. Some of the patient-provider interactions observed during encounters, discussed further in section 6.4 below, suggested that providers did not always see patients as a reliable source of information about their own behavior, and the desire for certainty about what a patient was doing to manage his illness at home seemed to motivate these responses.

6.3.4 Use of Information for Documentation or Follow-Up After the Visit

Providers' use of patient information after the encounter is significant in that it addresses how information about the patient and his condition is kept up-to-date in the EHR, continuing to represent him and his condition accurately for ongoing care. Providers indicated in interviews that they used patient information after the encounter in order to complete their documentation of the visit and follow up on lab results. Information from the record or from the provider's own handwritten notes was used after the patient visit to complete the encounter note, update the patient's problem list, and make sure all of the providers' medication and consult orders are entered into CPRS. In observations we noticed that although providers did a lot of this during the encounter, there was almost always some housekeeping to wrap up after the visit. Most secondary providers attended to this right away, while the PCPs often described taking it home with them to complete in the evening, or putting it off all of their "charting" until their scheduled administrative time during the week.

Providers also mentioned that they used information from labwork or other tests after the visit, triggered by an alert notification issued to them through CPRS. PCPs often ordered patient labs during the visit, once they knew what they needed to addressed, and

thus did not necessarily have the most current A1c or cholesterol levels during the visit. In those cases, if the labs were out of line with the provider's assessment and treatment, they needed to follow up with the patient or have an RN follow up with him to make necessary adjustments. By contrast, secondary providers' focus on disease management allowed them to be more current with indicator labs that they typically relied on, such as A1c.

6.3.5   *Most Important Information in Treating Patients with Diabetes*

When providers were asked what information was most important in treating patients with diabetes, A1c levels and blood pressure measurements, used in the clinics as measures of disease control, were almost universally cited first. Notably, however, their responses were not typically limited to a single piece of information, but more likely to be an array of information needed to assess control, evaluate the patient's health, and develop a treatment plan, including other lab tests, medication lists, and risk indicators. Many providers indicated that in addition to aiding their own assessment and planning, this information was most important because they could use it to educate patients regarding the severity of their illness or the need to control their diabetes, as examined further in section 6.4 below regarding information in provider-patient interactions. RNs also cited the patient's plan of care as important information because it enabled them, as secondary or auxiliary providers, to work toward the plan of treatment or health indicator goals established by the PCP.

Along with the relatively de-contextualized information from the EHR, providers also noted that information from the patient that aided in problem-solving control or self-

management was essential. Typically this information was characterized as reports related to compliance—information about the patient's behavior regarding medication, diet or exercise, but some providers also saw 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, I really feel strongly that education is a really important part of it, because you can give people all these medications and whatever but if they don't understand the importance, they won't take them. And also there are a lot of misconceptions about diabetes and a lot of people blow it off.

RNs in particular, who above all other providers tended to view patient education as a primary responsibility, felt like information about factors related to a patient's ability to understand the information presented to him was also of high importance:

> I mean you have to look also; you have to look at the patient, where the patient is, where they are as far as their health care literacy is concerned and their cognitive level because a lot of the patients we see here have a history of substance abuse, you know, poly substance abuse and everything. So I have to evaluate their level, their readiness to learn, how much information that they can retain.

6.4   Information Communicated in Patient-Provider Encounters

Having explored how providers use information in their own work of patient care, this next question looks specifically at how information is conveyed to patients during the course of a clinical encounter. This analysis draws primarily on approximately 125 direct patient encounters observed during fielding. During encounters, the most common types of information providers communicated to patients included health status information such as lab data, vitals, or diagnostic results; education information such as explanations of disease, treatment, and management; and specific instructions for patient follow-up

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after the visit. An examination of how these types of information are shared in patient interactions provides insight into characteristics of the information experience that is being created for the patient.

6.4.1   Use of Health Indicators to Influence Behavior and Self Management

By far the most prevalent type of information shared with patients during the course of a clinical encounter was that which indicated the patient's health or disease status, usually lab results or vitals' measurements that signaled control or lack thereof. For diabetic patients, hemoglobin A1c, blood pressure, and cholesterol levels, sometimes described as "the ABCs" were considered key indicators of control and disease management. Informing patients of the 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 typically conveyed as a reason for patients to maintain or change their health behavior or approaches to self-management. In this context the presentation of such an abstracted representation of the patient's condition appears strikingly discordant with chronic illness as experienced of in the midst of everyday life. Notably, many providers presented this information by bringing the EHR itself into the interaction, which appeared to reinforce and privilege these de-contextualized representations of the patient's condition.

When a patient's health indicators were at the desired target levels, this information was often provided to them along with an exhortation to maintain the behavior that providers' perceived as contributing to it. Providers often shared this

information as relative to a target level, or desired health outcome, as indicated in the

vignette below.

> MD reviews labs and says they all look good. He tells the patient his A1c
> is 6.8 and "we want it under 7, so that's good, your diabetes is under
> control." Says his cholesterol is wonderful- it's 124, the good cholesterol
> is 38, and "most importantly," the LDL is low: "We want it under 100, or
> for a diabetic, under 70, yours is 69, that's wonderful. 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 presented good indicators in the context of patient

improvement, or relative to where they'd been. In these instances providers often

presented trended data or graphs directly from CPRS to reinforce positive health

behaviors, as in this excerpt from fieldnotes: *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 attributed authority of the computer-generated representation is underscored

in the following vignette, where the provider used the CPRS graph to emphasize a

correlation between his weight and his eating that the patient appeared to downplay:

> They go back to talking about his weight— NP pulls up the graph to show
> him his weight loss. They talk about eating habits and weight loss. He
> reiterates that he is a "farm boy" and will always "eat hearty." She shows
> him on the CPRS chart how his BMI has changed and that it is in the
> normal range now.

Likewise, this provider presented the patient's LDL level as evidence that he should

continue to take his medications:

> Doc turns back to CPRS, pointing to the screen. "When you started, your
> LDL was 160, now it's 73," he's pointing to the screen as he tells the
> patient how his LDL has changed. He notes that the patient's cholesterol

levels over time are much improved, he has responded well to meds, and would like to keep him there.

In cases where patients were not achieving target levels, providers tended to present their health indicators as an incentive to change what they were doing to manage their illness. In this vignette the provider issued a strong warning to the patient that he needed to take his medications in order to prevent the consequences of the disease, and then invokes the numbers and information from the EHR to back it up:

> MD says to the patient, "So let's back up. Here are your issues: you have diabetes and it's not going to go away, even if you lose weight… …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 to the patient, "Let me share some numbers with you," as he turns the computer screen towards the patient, "looking at your notes from your last visit… "

In another encounter, a PD, in the course of making some adjustments to a patient's blood pressure medications, shows him that his A1c has also increased from its previous acceptable level, indicating a need for him to attend to his behavior more closely:

> …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.

Providers often presented A1c levels to patients as representing "your average sugars over a three-month period," which only served to stress the measure's abstraction from lived experience. Blood sugar records from patient logs or glucometers, by contrast, are by nature associated with a specific point in time and appeared more closely relatable to a specific experience. In the vignette below, a provider who was reviewing a patient's blood sugar log pointed out his high readings, and the patient instantly responded to the information as a sign of her disapproval of his behavior.

In turn, the provider recruited both the information and his reaction to enlist his cooperation to improve the numbers.

> PD 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 the PD says no and tells him, "I just want your help getting them down."

6.4.2 Use of Information or the EHR to Assert Control or Authority with the Patient

In addition to using CPRS or information from it to influence a patient's health behavior, providers also invoked the EHR in various ways as a higher authority, bringing in information from the record to keep the encounter on track or direct the agenda for the visit. In the vignette below, the patient talked for quite a long time about his experience with his health and what was going on with him at the moment. The provider gave him a moment to talk, and then directed his gaze to the EHR, turning the conversation to the patient's health as defined by the system, in terms of his "issues."

> Continuing on with the narrative on how he is doing, patient tells MD that it was really hard for him to believe that he was having a heart attack. MD listens and turns the computer monitor towards patient as patient goes on to tell him that he experiences vertigo when he gets up or lays down. … After giving the patient time to tell him how he is doing, the MD says "okay," looking at CPRS, "let's go through your issues."

Other times information in the record was used to refute a patient's sense of a problem. Typically this looked like the patient introducing a concern or perception related to his health and treatment, and the provider summoning a more objective piece of information from the EHR such as lab values or vitals measurements. In this vignette the patient had made a decision to go off his cholesterol medication and the provider brings in the computer screen to demonstrate the need for him to continue to take it:

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... it's a cholesterol med and [pt] 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 screen with her to look at his cholesterol numbers.

6.4.3 *Communicating Information for Transparency*

A number of providers expressed or demonstrated strategies that incorporated the EHR and its information into the interaction. For some this was a deliberate attempt to acknowledge the record and create a sense of trust or being on the same page. This RN described how she started every encounter with a review of the information she had just used to prepare, in order to make sure he not only knew his health status, but knew what aspects she was paying attention to:

> I get it off of CPRS. I look at it ahead of time and then when the patient comes in, I walk through their chart with them a little bit. I want them to know you know, like what kinds of things we keep track of and why they're important and I'll say, "Oh look at this? Look at your A1C a year ago? Let's see what it was 6 months ago, let's see what it is now"

Another provider used a similar approach to facilitate between his patients and the CPRS record. As he entered information in the EHR during the patient encounter, he read aloud what he was writing, almost so low as to be talking to himself, but perceptible. When asked about this practice, he indicated that it was deliberate, so that the patient knows what he's typing and what is in his record; that "there are no secrets." Providers did, as discussed previously, bring information into encounters to make a point or assert authority of their perspective, but it is notable that many did this in a way that concretely incorporated the computer screen itself. We witnessed numerous providers appearing to open up the EHR to patients by turning the computer screen toward them, or motioning toward it as they were discussing the patient's health situation.

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The EHR itself was also frequently referenced in patient encounters in the context of referring to the patient's interactions with other providers. In this way providers conveyed a team-based approach to the patient's care and a sense of continuity. One provider explained to us that she included some specific details about the patient's situation in her encounter note "because it builds trust for future encounters," stressing that then the patient feels heard and continuity is ensured when a different provider sees the patient. In another case the RN lets the patient know she is carrying out his PCP's requests:

> She then says, "Let's see what Kent wants." And she reviews the 'Active Orders' in CPRS. She tells the patient she needs to get his labs and a urine sample. She then clicks on Burt's note and reviews it.

6.4.4 *The Impact of Familiarity and Rapport on Communication and Information*

Most of the PCPs, particularly MDs, described seeing a regular panel of patients, and the MDs with more administrative or teaching responsibilities spent fewer hours on direct patient care in the clinics and were less likely to be seeing new or unfamiliar patients. As previously discussed, PCPs often mentioned drawing on their own recall for patient information and history before an encounter. This quote from a resident is telling in that it indicated how his history and relationship with patients impacted his treatment of them:

> And it's good because as you go on in residency, these are patients that you then begin to know over the course of time. So a patient I saw in my first clinic as an intern, that I see, now, like I've developed a rapport with them, I know their history, I know what's appropriate, what's not, what's done for them, like a lot of other things like that.

Providers were observed to have a rapport with their regular patients that demonstrated a sense of continuity of the relationship itself. On several occasions we observed patients bringing in mementos from their latest vacation, small gifts, or holiday cards for their PCPs. This patient had clearly developed a relationship with his PCP and felt free to bring out his vacation photos to show her and the observer:

> He tells NP about his recent trip to California, and they chat for while about that. NP asks about his wife's health, who she knows is bipolar. …
> Then he brings out pictures from his California trip to show us.

The potential benefits of a relational approach to communication in the case of chronic conditions in particular were apparent in this MD's interview remarks about the impact of provider availability on diabetes management:

> I've had some patients make great progress and I think you can probably correlate it to their ability to be in touch with these diabetes nurses, to be in touch with me. The more they see that we care about them and that we're available to them, I think that's why the VA does a better job than most places because most places will have this, you know, therapeutic inertia where they see you every three months and that's it. Whereas here, they get to call us back and there's a nurse every day on the phone if they need it and that I've seen tremendous progress from that.

6.5   The Everyday Life Experience of Illness as Manifested in Medical Encounters

The sociology of illness experience literature reviewed in chapter 2 and the first study findings presented in chapter 4 offered some insight into the lived experience of chronic illness. As experienced in daily life, managing chronic health conditions usually involves managing the illness while simultaneously managing its impact on everyday life activities and identity or psychological health. Participants in the first study were found to use information to resolve disconnects between these aspects of their experience, to address both cognitive and affective needs in their experience of illness, and to use

information from a variety of sources to manage their conditions and treatments. Because the chronic illness experience is immersive, relentless, and ongoing, patients may experience its treatment in healthcare contexts as decontextualized from their daily life and less relevant to their experience. This section investigates how the everyday life experience of illness manifested in provider-patient encounters, examining how patients present their everyday life experience with illness in encounters; how providers respond to, elicit, and connect to patients' everyday life experiences; and the nature of mismatches that occur at the intersection of the everyday life and healthcare contexts.

6.5.1 *Patients' Presentations of Everyday Life in Provider Encounters*

During the course of their encounters with providers, patients with chronic illness often illustrated their current health status or degree of affliction by citing how it affected their everyday life. While providers used a numerical representation such as an A1c level to tell a patient how sick he was, patients tended to characterize illness' impact in terms of what it interfered with in their lived experience, as in this exchange between a provider and a patient with diabetes:

> MD asks patient "how are you feeling?" Patient says that he is feeling mentally fine and physically terrible, saying "I couldn't even put up a gate" as an example of his physical condition.

A similar tension between situated experience and clinical indicators showed up was in patient's experiences of symptoms or medication side effects. Providers' sense of what was tolerable was not always in synch with patient perceptions based on how physical symptoms showed up in their daily experience. In one encounter a provider insisted that a patient's vertigo was harmless since he could find no medical cause, while the patient

continued to lament its impact on his everyday life: "I can't even change my wife's oil

anymore." Another patient was seen illustrating the degree of her symptom by how it

manifested in her everyday experience:

> The patient goes on to explain that sometimes she is so out of it she can't
> remember how to get home from work. She says that she has to call her
> daughter to help her get home.

> Patients also introduced their everyday life experiences or situations into an

encounter as an explanation for their health status or degree of control. Patients attributed

poor health to various to various aspects of their everyday lives that were outside of their

control, as in the case with this patient who was seeing his PCP for diabetes management:

> The patient tells the NP he is unemployed and didn't get a job he applied
> for at the VA. … he says he is not doing well because he is unemployed
> and is therefore sitting around all day. [After she shows him where his
> BMI falls on a chart] the patient responds that he is obese because he is
> unemployed and sits around all day.

Aspects of everyday life were also invoked by patients to hypothesize about why they

were not able to bring their diabetes under control:

> The NP then asks, "What are your numbers like?" and the patient
> responds, "They're up to the 300s. I've been working all summer." … The
> patient goes on to tell her how he wanted to get back to work and he was
> taking his medications at the same time, but he thinks it's the work that
> has got him all out of whack, because he is going up and down steps all
> day for 8 hours.

In this case the NP followed up on the patient's assessment, asking some additional

questions about his routine, and eventually affirmed that there may indeed be a lifestyle

component to his self-management that was altered by his new position:

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> She then tells the patient that his last A1c was 7.5, "That's high. I'm
> concerned this one will be higher." She then goes on to say, "If you're
> working afternoons and putting another meal in there, that could be part of
> the problem."

In their interactions with providers, patients connected their everyday life experience to

their health outcomes by citing erratic or inconvenient schedules imposed on them by

some aspect of their lives, usually their jobs or their spouses. Patients consistently cited

spouses as controlling their meals in some way, giving them less control over or ability to

change their eating habits.

> The patient wants to know if his wife could come [to nutrition class]. He
> complains that because of her schedule they eat dinner late, and since he
> goes to bed early, he is then eating right before bed.

Patients introduced other aspects of everyday life experience as impeding their ability to

change aspects of their behavior that would affect their health as well. They described

circumstances that prevented them from fully taking care of their health or engaging in

optimal management, as in this vignette:

> MD then says to the patient, "I'm telling you to quit smoking." The patient
> tells her his lifestyle doesn't allow him to think about quitting smoking.
> He says he doesn't have a lot of energy.

Other times life circumstances were introduced as a reason for non-compliance with

something the provider has asked the patient to do. In response to a provider asking him

if he was counting his "carbs," the patient reported: "No. I used to, but I'm employed

now." Another noted that she knew that her job as a heavy equipment mechanic wasn't

good for her health conditions. In the scenario below, the patient illustrated how a

competing priority in his everyday life interfered with his self-care for chronic pain:

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The patient says that he went to the pain clinic for his neck. He admits that he's been lifting when he shouldn't. He tells MD that he's been helping his mom get out of the tub.

Patients also brought aspects of everyday life into their provider encounters as motivations or incentives for managing their illness or adhering to certain behaviors. They expressed wanting to be able to do certain things or be around for their loved ones, as in this vignette:

The patient says "at this point I'm willing to do anything," because he can't participate or do anything, he "can't get off the couch," except for when he has his grandchild. "I want to get back in the game, be there for my 10 grandkids."

Other times everyday life experience shows up as patient's experiences with seeing what the disease had done to others:

The patient explains that he probably checks his blood sugar too often and goes on to explain how he lost a number of family members to diabetes….The patient explains that he is very careful with monitoring his diabetes and watching what he puts in his body. He says that no one in his family has lived past 63. PA turns to me and says, "He's 62."

6.5.1.1 Emotional or Psychological Aspects of Managing Illness in Everyday Life

Patients also presented aspects of their illness as being intractable or unbearable because of how they perceived themselves in daily life. This often came up in discussing self-management and lifestyle behaviors such as eating and exercise. A patient's Creole heritage or farm-boy upbringing was invoked as a reason for eating a lot of carbohydrates. In the following example, the patient claimed his current eating habits as part of his identity, even in the face of the consequences of his disease:

Doc looks again at the blood pressure and blood sugar history in CPRS, and determines both are erratic. He looks at the med list, confirms with

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patient what he's taking and says he doesn't really want to increase them. Patient mentions he tries to be good, but "I'm an eater."

Similarly, another patient described how his multiple sclerosis had affected his ability to exercise, suggesting some accompanying frustration or sense of loss at not being the person he was before it:

> The patient then goes on to tell PA2 that he can't run with his MS. He feels that has the body of a runner even though he can no longer run.

Diabetes management can call on patients to make many changes in health behaviors, and in this vignette a patient was seen holding onto a bad habit as an affectively motivated decision, even a way to defend his identity

> Doc discusses the problems with smoking, asking patient "If you had a broken foot, would you kick a wall with it?" Patient says he "probably would," adding, "the smoking is all I got left."

> In other cases, everyday life was evoked by patients as a constellation of

situations and accompanying emotions that impact their illness and management of it. Mental health diagnoses are not uncommon among veterans, and VA patients generally have low income levels, both of which can interfere with getting necessary resources for self-management and healthcare. The intricate ways that emotional health and patients' life situations can be connected to their health conditions are illustrated in the vignettes below.

> Patient indicates he has stressors: "the shit's bumming me out pretty bad." Doc asks what he means by stressors, and patient indicates that it's memories. Doc asks about his sleeping, patient indicates he is waking up in night. Looking at CPRS, doc asks if he's had formal counseling; patient says he can't afford it and that he wanted to see a PTSD expert [outside VA]. Doc offers: "I could hook you up with our PTSD doc here, that's

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what they do" [indicates they are also experts here.] Patient asks: "Will they help me with my medical bills?"

The patient has depressive symptoms, lost 30 pounds, uncontrolled diabetes, and doesn't take medications regularly. The resident says that he asked the patient about his medications and the patient said that he doesn't have any insulin or blood pressure medications that he takes. The resident goes on to explain that the patient has trouble getting to appointments and is experiencing a lot of financial issues.

6.5.2 *Providers' Use of Patients' Everyday Life Experiences*

Despite the prominence of the EHR and seemingly more objective information in the clinic environment, providers recognized the need to understand patients' subjective experiences of illness in order to help them manage it. As discussed in section 6.1, providers described routinely using information from patients in problem-solving diabetes control. The types of information they described valuing from patients tended to relate to their everyday experience of illness, as one provider put it: "any life stressors, anything that might be prompting diet changes, things like that." Sometimes patient information related to daily life experiences of illness was elicited through the presentation of indicator information such as A1c history. By keying off of specific points in time, providers were able to encourage patients to connect their health situation to their daily activities, thinking about changes in life factors that might be influencing their ability to manage their diabetes:

> So then I can say, you know, "back in 2002, your A1C was fine. You're fine, fine, fine, fine, until this fall and they'll say "Oh yeah, because I went through a divorce or you know, my mother's dying" or whatever and "I was eating bad" or "My wife died, nobody was cooking for me", you know… you can say, "Your A1C was great, all of a sudden you picked up 30 pounds, now your A1c's high. So it just helps them figure out, or I'll say, "What were you doing last summer that things were well and now in the fall, it's not". So you kind of pin down some stuff to know what's going on.

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6.5.2.1   The Glucometer as a Link to Everyday Life

Patients' blood sugar measurements were also used to connect to their everyday

life during encounters. As discussed in section 6.3.3.2 above, patients' blood sugar

readings as tracked through their use of a glucometer were a desired piece of information

in treating patients with diabetes, and frequently used by PDs and RNs during an

encounter to problem-solve self- management. When information from a glucometer or

patient blood sugar log was available, providers were frequently observed using them to

look at patterns in patients' sugar levels. In reviewing a blood sugar log with patients,

providers could pinpoint certain behaviors associated with highs and low levels:

> Then PD says she wants to go through his schedule with him for his
> insulin- when does he check his sugar and what does he do? The patient
> says that if his insulin is low, meaning under 140, he eats a bedtime snack.
> The PD looks at his sugars on the glucometer and says that they are all
> around 160-ish, so he shouldn't ever be having a bedtime snack.

As in the previously mentioned A1c graphs, providers used high and low points on the

glucometer printout to elicit patient accounts of everyday life behaviors associated with

diabetes management.

> The PD asks the patient about this morning's reading, which was high-
> does he know why? He doesn't know why. The PD asks him what he ate
> last night. They talk about food for a minute; trying to sort out what it
> could have been, discuss the kinds of food that could cause his blood sugar
> to increase.

Glucometer logs were also used to understand patients' experience of their illness at

points in time outside of the medical encounter, as in this example:

> PD looks at the printout of his glucometer readings attached to the check-
> in sheet. She asks him about one reading that is a 79 – how did he feel? He
> says he was sweaty, fatigued, confused. She asks him what he did and he

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says he ate something, adding that it wasn't so bad that he had to eat a
sugar tab.

The glucometer's ability to connect to a patient's health or health behaviors at a specific

point in his life outside of the clinic was a clearly useful way of bringing patients'

everyday experience into the healthcare context.

6.5.2.2 Providers' Responses to Everyday Life Information

Providers varied in how adeptly they could respond to everyday life information

as presented by the patient in the encounter, or as gleaned from the patient's EHR. One

area where providers consistently reported taking patient's circumstances and lived

experience into account was in their consideration of their goals for the patient, or their

target health outcomes. This excerpt from an observation note illustrates how information

helped the provider scale her goals for the visit to what the patient could do given his

circumstances:

> The doc explains to me that she likes to think about her goals for the
> patients before they get there. She starts preparing for her first diabetic of
> the day. She opens his CPRS record and tells me that he's diabetic and a
> paranoid schizophrenic. She comments that, "it's like being doomed,"
> because the patient has such a "hard time coping with the basics in life."

Another provider talked about not pushing a patient for greater control based on input

from his family about his life situation, his age and consideration of his resulting quality

of life:

> The one guy, actually the other day, his hemoglobin A1C is 8.9 and so he
> can't take Metformin because of renal deficiency, he's already on
> Glypizide so I talked to him and his family about insulin and they said
> there's no way, he won't give it himself, which he had told me too but his
> family agreed that he won't give it himself and his wife won't do it and so
> it's just, don't go there. So, if he was 60 years old, I would push harder.

Since he's 85, I'm going to say okay, at least they don't want to make your life miserable.

Recognition of and sensitivity to patient's everyday life situation was also incorporated into providers' sense of what information a patient would be receptive to, as this RN explained in an interview:

Well you know, some patients, maybe too much information is too much information and maybe taking one little thing at a time is just as important, you know, "let's just work on lowering your blood pressure right now," and not worry about all the other things. "Get this taken care of first" and then move on. I think some people can get too obsessed with worrying about, "Oh they said I had 10% chance of having a heart attack" So I don't, you know, again, I think some people might get more use out of that [information] than others.

It was not always readily apparent how the everyday life experiences of patients were met or not met by providers during the course of an encounter. The structure of provider work practices, the EHR, and the clinical visit did not necessarily allow for everyday life information to emerge, nor did providers always have the opportunity within that context to respond appropriately when patients introduced it. For a provider to respond to everyday life experience would, in some cases, require an exchange that was not purely medical, as is the case when this MD addressed the patient's stated barriers to managing his health:

MD looks at the patient's dose again to see why he might be tired. Patient says it's his lifestyle—he's not working and he's living with his mother. He explains that he drinks coffee with her which then causes him to have a cigarette. MD offers that the patient can come to the VA where they have a lot of volunteer opportunities if he needs something to do.

In other encounters a mismatch or a disconnect was apparent, usually arising when providers responded to patients' everyday life information with a medical solution

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or medical information. These kind of disconnects were often observed during encounters in discussion of patient eating habits. In the course of conversation, a patient might reveal some aspect of his daily life that was influencing his ability to eat healthily, but providers routinely recommended a trip to the nutritionist as a solution, or focused on the food itself rather than the patient's life around it. In this vignette the patient suggested that his difficulties in eating healthy were related to his wife's death, yet the MD treats the problem medically, offering a referral to a dietician:

> MD asks him what he is eating. He says sausage and eggs for breakfast. She says "that's the worst thing you could do." She asks him about seeing a dietitian- she wants to refer him to one-he should be eating oatmeal or cereal in the morning. He doesn't want to see a dietitian; he can change on his own. He says the problem is that he has been picking these prepared meals since his wife passed away earlier this year … Patient mentions that he is a retired chef, but that he just hasn't had much appetite since she died. MD encourages him again to see the dietitian, but he doesn't want to.

Instances where patients offered up insight into their everyday life were sometimes missed by providers, perhaps because of their focus on clinical outcomes, medications, and other information highlighted by the EHR. The vignette below shows the NP focused on the EHR's view of the patient rather than addressing the everyday life barrier to managing his diet that he presents in the course of the encounter.

> The NP then questions him, "you are following a strict diabetic diet?" And the patient responds, "I'm disciplined, but it is not realistic that I wouldn't go off the diet, but I do like to have a healthy dinner once in a while." … [Then he asks]"What can I eat so I don't get cranky?" and without looking at him the NP responds, "It is a fact of life that you must be on a strict diabetic diet or you will continue to have problems." Continuing to look at the computer screen and not the patient, she goes on to explain that he is already on insulin of 60 two times per day, which she tells him is a lot, she then continues, "Diabetes takes a lot of dedication and it sucks, but if you don't do it, it affects your heart."

Given how much of chronic illness is experienced in the context of everyday life, the potential to connect to patients' experiences there provides an opportunity for healthcare providers to more effectively share appropriate information; likewise, missed opportunities can be seen as reinforcing the disconnect between the two contexts.

6.6   Discussion: Provider Practices and Patient Experience in Chronic Illness Information Use

This chapter addressed three major research questions (questions 2.2., 2.3, and 2.4), which are summarized here: how healthcare providers use information in treating patients with chronic health conditions; how information about the patient, his condition and his treatment is communicated in patient-provider interactions; and how the everyday life experience of illness is manifested in medical encounters.

The findings presented in this chapter illustrate that VA primary care clinic providers relied on objective information in the form of health indicators such as A1c or blood pressure measurement in their work of caring for patients with diabetes and other chronic health conditions. The EHR was the primary source of this information, with clinicians using it to assess a patient's status and develop their own priorities for an encounter. During the course of a visit, the provider updated his original assessment and agenda based on information provided from the patient's home health tracking and narrative accounts of his experience during the clinical interview. Assessment, problem-solving and treatment planning during the visit were all information-intensive activities undertaken by the provider in treating patients with chronic conditions; all of them required ongoing negotiation both within the patient's CPRS record and between the EHR and the patient.

In turn, providers presented the same objective information regarding health indicators to patients during encounters, frequently framed as reasons to maintain or initiate desired health and self-management behaviors or to change undesirable behaviors. Providers were also observed to be using information and the EHR itself with patients in order to direct or control the course of a visit or as a way of invoking or reinforcing the authority of that information. Additionally, they used the EHR and information from it with patients in order to convey a sense of transparency, continuity, and coordination over time and across provider teams. Aspects of familiarity and rapport evident in providers' ongoing relationships with patients appeared to facilitate effective elicitation and use of information within the visit.

In the course of visits, patients frequently shared information with providers that provided insight into their everyday life experience of their conditions. Everyday life was invoked in patient discourse as a way of emphasizing the impacts of their illnesses, accounting for changes in their health status, and explaining their non-adherence to medications or recommended self-management behaviors. Patients' everyday life narratives often incorporated affective aspects of their experience with illness or expressed their feelings about managing their conditions. Providers acknowledged to some degree the value of everyday life experience and were observed eliciting patients' accounts of everyday life with illness and connecting it to their health outcomes and self-management behaviors. They also felt that not enough of this information was available to them in the EHR or was poorly tracked and organized there. Their responses to everyday life information provided by patients appeared constrained by their designated

practices and the clinic environment within which they worked. A patient's invocation of everyday life experience was during the encounter occasionally, but not always, met as presented, engendering some bridges, but also disconnects, between providers and patients.

These findings illuminate a number of themes relative to chronic illness-related information use in the VA primary care environment that can be seen as shaping patient experiences in that context:

- A pervasive focus on de-contextualized information to represent health and illness as compared to the situated experience of illness in everyday life.
- The central influence of the EHR in highlighting, privileging, and facilitating medicalized and de-contextualized information and the opportunities it presents to promote coordination, communication, and transparency in patient care.
- The emphasis on patient compliance as a one-way and top-down positioning of health behavior and goals relative to everyday life experience.
- The limitations of meeting everyday life experience with a medicalized response during a patient encounter and the contextual challenges of responding to everyday life information appropriately and opportunistically
- Differences in the nature of information use and activity between provider types which suggest that RNs and other secondary providers may have greater opportunities to incorporate and account for patients' everyday life experience into their care and treatment.

The articulation of these issues throughout this analysis illuminates both the origin of provider-patient disconnects and the opportunities for reconciling these disconnects in the experience of illness in medical settings through information use that fosters synergy and mutually beneficial outcomes.

CHAPTER 7

CONCLUSIONS AND IMPLICATIONS

The purpose of this dissertation was to study the role of information in the disconnect between patients with chronic illness and the healthcare providers who treat them. The research took a two-pronged approach to this problem: first investigating the everyday life experience of people with chronic illness and the role of information in that experience; and then turning to the healthcare context to examine how that experience is met by the information practices of healthcare providers and aspects of the environment within which they work. Using qualitative methods in order to gain a deep understanding of experience and information use in each context, 14 in-depth interviews were conducted with women experiencing a variety of chronic health conditions in the first study, and in the second study, 56 healthcare providers at three VA primary care clinics were observed and/or interviewed. In considering the implications of this research, it is useful to look not only at what each study reveals, but what we can learn from considering them together. After a brief review of the key findings of each study, this chapter discusses the implications of these findings as they reflect on the patient-provider disconnect, the limitations and strengths of the research, and the directions for future research that all of these suggest.

The first study, *The Everyday Life Experience of Chronic Illness,* illustrated the pervasive nature of chronic health conditions in everyday life, and showed participants as actively working to maintain their daily activities and sense of themselves while managing their treatment and coping with the psychological impact of their conditions. As Hogan (2007) pointed out, Corbin & Strauss's model of work in the illness trajectory still very much bears out based on the experience of these participants—there is much active management of illness, on multiple levels of experience. Participants with chronic health conditions regularly engaged in sense-making to bridge disconnects engendered by the friction between the various aspects of their lives with illness—managing daily activities; medication and treatment management; and reconciling shifts in identity or biography. Information played a role at all stages of the illness experience, and served not only to inform or educate, but also to provide support and reassurance; enable participants to look ahead; and gave them a sense of control or meaning in their experience. In short, information fulfilled a host of roles that were non-medical in nature.

The persistence of illness, its physicality, and its complexity all influenced information needs, seeking and use in the everyday life context of the first study. Information use in the daily experience of chronic illness was typically intricately entwined with the everyday activities and concerns; drawing on medical and interpersonal sources as well as the sufferer's own experience and the experiences of others with the disease. The use of information in everyday life was affectively as well as cognitively motivated. In addition to gaining a sense of control and power around their illness, from a medical standpoint participants used information to help get a diagnosis; to

make decisions regarding treatment and management of their conditions, to monitor their bodies and adjust treatment; to respond to changes in their conditions; and to coordinate between providers and across time. Notably, even these medical needs were not always very straightforward or anticipated by providers. In fact, participants often used other information sources to fill gaps left by their provider's information, or even to challenge or refute what a provider had told them.

In the second study, *Chronic Illness Information Use: Provider Practices and the Patient Experience in Three VA Primary Care Clinics*, healthcare providers' information use in the primary care context and how care happens there were examined in order to understand how they appear to frame patient experience. That study found chronic illness care and information use in the environment to be largely driven by the EHR and a multidisciplinary provider approach. In the primary care context, the EHR was a ubiquitous information medium that represented the patient and his condition for providers' individual and collaborative work. In treating patients with chronic conditions, providers relied primarily on objectively measured health indicators from the EHR, both in their own work of patient problem solving and treatment planning, and in exchanges with patients, to encourage or influence treatment adherence and compliance with proscribed health behaviors.

Within the study, there was ample evidence from the provider side that information that could serve to contextualize patient health indicators, connecting their numbers to patients' everyday life experience, was desirable and useful. Providers talked in interviews about the importance of eliciting information from patients about their

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health and their experience with managing it, and used these types of self-reports along

with information from home logs, such as the glucometer, in order to problem-solve

effective self-management and control of diabetes. This kind of daily life information

was often what providers talked about wanting more of in the EHR, yet it became

apparent in observations that it was sometimes difficult to find or track. Patient-reported

and subjective information was usually captured in the encounter notes, which were

relatively freeform or idiosyncratically structured, making it challenging for providers to

use each other's notes. Patients were observed bringing their everyday life experience

with illness into the primary care environment, usually as a way to describe the impact of

their condition, account for health changes, or justify a lack of adherence to medications

or other self-management behaviors. Disconnects were most apparent when an everyday

life situation was met with a biomedical solution during the encounter, or not responded

to at all.

7.1 Conceptual Contributions and Implications of the Research

7.1.1 Nature of the Disconnect

A significant difference between information as used in everyday experience

versus in the healthcare context is in the emphasis in the latter on abstracted information

in the form of lab values and vitals measurements. Healthcare providers in study 2 relied

heavily on objective, quantifiable indicators to convey patients' health, illness, and

degree of control of their condition. While these indicators are completely appropriate

and necessary in clinical assessment, they appeared as a contrast to the ways people

experiencing illness tended to express its impact on their lives. Study 1 participants and

patients observed in study 2 often expressed their experience of illness more qualitatively

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and as situated within their lives, in terms of how it impacted their functioning or everyday life activities, disrupted their sense of themselves or their life plans, or influenced their emotional well-being. Even the idea of "control" in everyday life was much more about a sense of mastery or level of knowledge, versus its representation in the healthcare environment as a particular number or measurement. In light of this contrast, health indicators such as lab test results or blood pressure readings have the potential to be experienced by patients as abstract or de-contextualized from their daily experience.

This kind of disconnect between perspectives may be a driver in the seeking of illness-related information that can be more easily contextualized. Participants in study 1 frequently sought advice or information from others who I am characterizing here as "close experts," those within their immediate social networks who had some expertise in what they needed to know about, e.g., my friend the physical therapist, or my mom the disability lawyer, where the interpersonal relationship could conceivably add context, relevance, and trust to the information provided. The value of this additional context has implications for the kinds of sources that are sought by people seeking information to cope with or manage chronic health conditions. A recent Pew study on the use of online health information found that almost 40% of adults in the U.S. accessed health information that was "user-generated," found in blogs or online communities rather than strictly medical sites (Fox & Jones, 2009). The report, *The Social Life of Health Information* refers to this as "searching for a 'just-in-time someone-like-me'" (Fox & Jones, 2009, p. 3) This was borne out in the current study as well; when participants

sought more information in response to a perceived gap in their provider's knowledge, they frequently went to peers with the same condition, such as in an online community or forum. Veinot (2010a) elucidated the value people living with HIV/AIDS (PLWHA) gained through peer-based information: similar to participants in the current study, PLWHA revealed that it provided a way to interpret their own stories and meet various emotional needs in coping with their conditions (Veinot, 2010a). The increasing availability and popularity of peer-based information suggests that it is meeting needs for context-aware information that are unmet or overlooked within the medical environment.

Another way information becomes situated or contextualized is for the appropriation of medical indicators into personal experience of illness. Some of the study 1 participants reported tracking their lab values or other clinical information in order to monitor their illness and track its changes and progression, as well as to determine the effectiveness of treatment regimens. Other studies have indicated as well that clinical indicators can be co-opted by patients for personal use (Carey, 2003; Veinot, 2010b). This gives credence to the value of being able to put potentially abstract data to use within the personal experiences of illness, and suggests that the disconnect is more about how information is anchored and contextualized rather than a strict dichotomy between information types. Thus we see Internet sites such as *Patients Like Me* or *Cure-Together*, which provide both a forum for sharing experience and a means aggregating and quantifying clinical data regarding symptoms and treatment), providing a way for a patient to place even the most medical aspects of his experience of illness and its treatment relative to other sufferers.

7.1.2   What Constitutes Information? What Constitutes Use?

As the previous section alludes to, one way the healthcare-everyday life disconnect is reflected is in the very idea of what actually constitutes information in dealing with a chronic health condition. Social studies in medicine scholars have been converging on the idea that the definition of information in this context needs to be broadened, and this research adds to that evidence. The experience of the participants in study 1 suggests that information used in their sense-making can be seen through a fairly broad lens; participants used not only medical information, but also experiential information from peers and friends, sensations from their bodies, and information from their own experience and memory in order to address living with and managing their chronic conditions. In the primary care interactions in study 2, most of these types of information were not elicited or addressed by providers. Medical information was given prominence through the EHR and sometimes even positioned as a higher authority than patient experience, situating the encounter in a disconnect.

For information behavior theorists, this research supports a more nuanced perspective of its component parts: needs, seeking, and use. Information behavior research can appear to make a hard-lined distinction the three areas, a tautology that seems entirely appropriate in looking at behavior in the context of an information system, where we imagine the user approaches with a specific question or need, searches for an answer, and takes the information back to apply to the task at hand. But the experience of study 1 participants illustrated that coping with chronic illness is more of an experience

than a task, and in the context of an ongoing issue embedded in everyday life, information needs are much less apt to be cut and dried. Participants in study 1 talked about information needs that were so pervasive or so interwoven with their experience that they probably would have been hard-pressed to identify them as *information* needs at all if they had been asked that way. Information use in this context is equally elusive in that it suggests some visible and evaluable outcome or application of information.

The use of information presents an interesting parallel to health-related disciplines, where compliance and control are continually reinforced as the desired outcomes of patient information and education. Healthcare providers have historically assumed patients are *using* information if they are getting the desired results. In fact, patients might actually be using it in a much different way than the provider intended. They might have different goals for their health, they may see their providers' goals for them as irreconcilable with their own, or they might experience unarticulated blocks to effective self-management in their daily lives. The participants in study 1 were not using information in isolation or uncritically—they were marrying it to their experience, to what they gleaned from other sources and to what providers were telling them, toward an ultimate judgment about its truth for them in the context of their own situation. Clearly certain measures of physiological control are important in managing chronic health conditions, but providers and researchers might do well to acknowledge the value of supporting patients' other priorities and goals as well.

7.2 Practice Contributions and Implications

7.2.1 The Role of the EHR in the Disconnect

The EHR was revealed in the study as an important contributor in managing chronic conditions across a primary care team and over time. Clinicians used the record to achieve continuity, access the opinions and insights of others, and easily identify patient health trends and changes. However, the EHR can also be problematic in that it tends to reify a certain type of information and impose its own constraints. Objective or quantifiable information is much more easily stored in and retrieved from the record for provider use and sharing, as compared to more subjective, variable, or nuanced information. The latter type of information tends to be located in the EHR within encounter notes, which can be less structured and more varied across providers, its retrieval can be challenging; in fact providers often referenced using their own notes most regularly. Patient-provided information also relies on the individual provider to elicit it and record it, additional challenges within an environment where providers are already pressed for time and may not have the training or guidance to decide how to record seemingly subjective or idiosyncratic information.

The constraints of the EHR raise the question of how it can continue to be made more useful in chronic illness management and in reconciling disconnects between patients and providers. Diabetes management may be well-suited to the format of the EHR in that it involves a number of health indicators that are easily captured and tracked by the system, but even then, as has been shown here, there are shortcomings in the system's ability to track potentially useful and relevant information. For chronic conditions that rely even more on information from patient self-reports, the implications

of relying on the EHR for their management are even greater. Illnesses such as fibromyalgia or chronic fatigue syndrome that typically have more uncertainty regarding diagnostics, prognosis, and appearance of symptoms may present a greater need for self-management and information in order to control the experience (Äsbring & Narvanen, 2004). Medically unexplained disorders with subjective symptoms and no means of objective diagnosis tend to not do well in the typical medical model (Malterud, 2000; Milliken & Northcott, 1996). In the VA system particularly, Gulf War Syndrome might fall into this category; with a less demarcated presentation and fewer lab-driven indicators, this type of chronic condition might present even more conflict with regard to information type, form, and perspective in the EHR.

Similarly, it is important to consider the influence of the EHR on provider thinking and practice. Other studies addressing the sociotechnical aspects of EHR use in the medical setting have noted the complex co-evolution of provider practice and technology use (Reddy). Aspects of the record shape how providers think about their practice, and providers use the EHR in unintended ways to support practice. In this study, providers revealed that they clearly considered their own practice as an art, and one that allowed them to bring a considerable amount of their own judgment and experience to bear on a patient's situation. In the clinic environment, however, he EHR looms large. Since it accompanies every patient discussion or interaction, the computer is always there as a silent authority, not only for patients, but also for providers. In addition to introducing the computer to challenge a patient's idea of their health, providers also responded to its presence and usage in the encounter. Providers were observed adopting

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the language of the system, as in "let's review your problem list." Continual reinforcement of particular kinds of information as most important could create a disconnect for them in their own practice, speaking to the need for healthcare organizations to consider not just the technical, but also the social ramifications of the systems they implement.

7.2.2 *Everyday Life Information in Contrast to Biomedical Information*

The issues that participants talked about trying to resolve about in study 1 had little overlap with the content of the healthcare provider interactions in study 2. This is likely an artifact of the influence of the context; the constraints of the environment are not conducive to eliciting that kind of information, a norm that both healthcare providers and patients adhere to. The information related to experience outside of the medical setting that was dispensed by primary care providers was likely to focus on more biomedical aspects of living with illness, such as medication instruction, the rationale for proper self-management, and the potential side effects of medications. This medical perspective on the type of information needed to manage illness may overemphasize medical expertise and downplay the realities of living with illness, leaving its recipients with unresolved questions, problems, and needs.

The disconnect was not purely the result of missed provider opportunities; patients often did not even raise during encounters the issues they might be struggling with in everyday life. This schism was most apparent in study 2 in the discussions about self-management behaviors such as dietary modification. Patients were decidedly unrevealing about their home eating habits, leaving providers to default to standard kinds

of information about what to eat and what not to eat, information to which patients tended to respond to be indicating that they *know* what to do. What patients often brought to conversations about eating is a sense that they are being "bad" or "good." In this way they can be seen as already having framed their everyday experience within the language of a compliance-driven environment.

In many ways, information provision and exchange presents an opportunity to bring the contexts of everyday life and healthcare together. McKenzie's (2003) study of interactions between patients and midwives found that providers and patients used positioning in their discourse in order to defend, clarify, or make a connection to information being shared. Communication and information literacy skills that enable both providers and patients to more easily apprehend the other's perspective and relate it to their own experience could enable more common ground, allowing information to provide a cohering function, furthering connection rather than disconnect.

7.2.3 *Provider Roles and Functions*

There is evidence from study 2 that how provider roles are oriented or defined contributes to opportunities to connect to everyday life experience of patients. As secondary providers, the RNs and the PDs focused on self-management problem-solving, which was often directly connected to everyday life behavior, exposing opportunities to bridge to the patient's experience outside of the clinic. The versatility of a provider who is acting as secondary to the PCP and coming from a different disciplinary perspective reinforces the value of a team-based approach to chronic illness care. Nursing has a long tradition of imparting information through health education (Bella, Harris, Chavez, Fear,

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& Gill, 2008); in interviews the VA RNs often defined their role not as *treating* patients, but were more likely to describe their primary function as *educating* patients. This role may offer more opportunity for two-way communication than a strictly top-down model, but it may also fall into the "compliance trap" described earlier—previous research has assessed healthcare definitions of patient education as inherently attached to an outcome, rather than providing information for the patient to use as he needs to (Bella, et al., 2008). Additional challenges in crafting new roles and new models of care were revealed in the study 2 findings and indicated that changing job descriptions or adding new roles might not be enough; such innovations need to be consider as embedded within the structural, social, and cultural aspects of the environment.

7.3   Limitations of the Research

This research used qualitative methods in order to understand a phenomenon that had not been well studied previously at a deep level. The desire to get beyond a mechanistic view of information and focus on subjective experience dictated this approach. The outcome is a rich description of experience that allows for an interpretive approach. Of course, as qualitative studies, they are subject to limitations. The findings are not generalizable; their applicability to a larger sample cannot be determined.

In both studies, the samples represented what Patton (2002) refers to as "intense cases." The study 1 participants were fairly young for people with chronic conditions, they had above-average education levels, they were all women, and all appeared to be routinely and somewhat facilely using information resources. This provided an excellent chance to look deeply at how the phenomenon unfolded in daily experience, but it is not

clear that the findings related to outside or traditional information sources would hold true for participants of different socioeconomic status, education, age, or gender. Study 2 presented an opportunity to observe chronic illness patients of a very different demographic profile—older, predominantly male, and not as well-educated. Their presentation of everyday life in medical encounters suggested some commonality of illness experience across the two demographic segments, but without opportunity to interview VA patients directly it was hard to gauge just how participants perceived this experience or how it manifested in *their* everyday lives outside of the healthcare setting.

As a healthcare environment, the VA can also be seen as a relatively intense case of information use, given its "best-practice" status in both chronic illness and information management. This offered ample opportunities to witness provider chronic illness information use and get an understanding of how that was shaped by the environment, but in keeping with this type of study, it was limited to a few sites, which limits its generalizability.

The qualities engendering this research's limitations also, in turn, speak to its strengths. The rich instantiations of information use provided by the data in each context have allowed a number of complexities about the lived experience of illness and the dynamics of its interaction in the healthcare environment. By examining information use in two contexts, the analysis sets the stage for considering them in concert, viewing chronic illness information as experienced multidimensionally. This analysis present a rich and provocative set of findings that can be further explored, challenged, and built upon in future research in a number of domains, as described in the following section.

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7.4 Future Work

This research suggests directions for continued investigation that could build on and broaden these findings, addressing the issue of chronic illness information experience and provider-patient disconnect as played out in a number of areas.

7.4.1 Substantiating and Broadening the Current Findings

The everyday life sample was relatively homogenous, presenting an opportunity to broaden the findings regarding individuals' use of information in their everyday lives. Research with other socio-demographic groups could help determine if the findings from study 1 regarding the everyday life experience with chronic illness and the role of information in it bear out in diverse populations and the ways in which particular contextual differences contribute to experience. Additional in-depth interview studies of the everyday life experience of illness could be conducted drawing sample from other populations, e.g., males, older, poorer, less well-educated. Because the samples from the two studies are somewhat disparate to use together, an extension of the research that involved interviewing VA patients directly experience about their would also serve to strengthen common themes.

7.4.2 Revisioning the Construct of Health Literacy

The findings of this study point to a need to potentially recast the idea of what it means to be health literate, and what the role is for information in supporting health literacy. Health literacy constructs traditionally focus on individual capacities for processing information, such as reading level and prior knowledge, and the characteristics of the information itself, such as readability and "living room" language

(Maria Souden, et al., 2010). Within this context *health information literacy* has emerged as a set of professional practices that consider and ameliorate these factors, prescribing a role for information professionals as intermediaries charged with connecting people to *authoritative* information sources (MLA, 2010). The current study, along with others focused on the information use of people with chronic health conditions (e.g., Genuis, 2010; Veinot, under review), found that some of the most commonly used information comes from sources typically considered non-authoritative, including friends, family, and fellow sufferers. Other non-traditional information sources, such as the body and past experience, were also used. Understanding how people make sense of and negotiate this range of sources in their illness experience has the potential to reposition health literacy as a set of skills and actions that go beyond cognitive apprehension.

7.4.3 Enhancing Patient-Provider Communication

The findings of the current study have suggested that the patient-provider disconnect can be addressed communicatively and in the context of ongoing provider relationships and rapport. Looking at information as lens for characterizing the nature of the disconnect could contribute to our understanding of dissatisfaction and frustration on both sides of the provider-patient relationship. Further research to understand the interactions between providers' communication patterns, patient perceptions, and information experience may yield additional actionable insights toward addressing information as a joint construction between provider and patient. And since chronic conditions are ongoing, research that assesses the role of time and ongoing relationship in facilitating communication and overcoming disconnect. Accounting for time and the ongoing context of the patient-provider relationship would aid in fully comprehending

information's role over an illness' trajectory and how it accrues, accumulates, or changes for both parties over time.

7.4.4   The Role and Impact of the EHR on Chronic Illness Experience

Findings from the current study have indicated that the EHR exerts considerable shaping force in the healthcare environment, and that this force affects not only provider work, but patient experience as well. This issue can be expected to become increasingly prevalent as mandated health information technologies (HIT) are put into place in healthcare settings more broadly. This research suggests that the EHR might both contribute to a disconnect between provider and patient *and* provide opportunities to reach across the gap and ameliorate that disconnect. HIT field implementations and research, then, would benefit from taking a socio-technical perspective, considering how the EHR and its use actually act to shape provider practice and patient experience. Taking such a perspective can be useful in anticipating and addressing challenges and barriers raised by the use of the EHR in chronic illness care, and alternatively, help organizations identify and harness opportunities to use the EHR in actually narrowing the patient-provider gap.

APPENDICES

APPENDIX A

Interview Guide for Study 1 (Everyday Life)

Opening thank-you and introduction to the study via review of informed consent.

I'm interested in people's experience with long-term or chronic health conditions, so I'm going to ask you to tell me the story of your experience with *condition*, including as much as you can remember about how you felt and what you did at different points. Mostly I will let you talk, but I will interject questions from time to time to ask specifically about particular situations or experiences.

Guiding questions for story elicitation
- Tell me about the events surrounding your diagnosis.
- How did you determine treatment options to pursue?
- How has your illness or condition progressed over time?
- How has your course of treatment changed over time?
- What have been the biggest challenges in managing your condition?
- What has changed in your life since you've had *(condition)*?

Sense-making probes (used to understand how participant navigated gaps, expressed as points of uncertainty, conflict or confusion)
- What did you know abut that already?
- What questions did you have? What was confusing or uncertain?
- What things did you do?
- What were you hoping to accomplish?
- How hard or easy was it to move forward or do what you wanted to do?
- Who else was involved, and in what ways?
- What helped you/What wasn't helpful?
- What feelings did you experience?
- What else did you do?

Information-related probes
- What did you want to know in that situation?
- Where did you look for that information?
- How did you determine if the information was useful to you?
- What information was helpful/What information didn't help?
- How did you know you had the information you needed?
- How did you end up using the information you received?

Demographic items
- Age
- Occupation, employment status
- Married/single/kids-household composition

Interview Guide for Study 2 (VA Study)

SECTION 1: OPENING

1. [*If applicable, briefly refer to your experience observing the interviewee.*]

2. [*Introducing the Study*] Thanks for your continuing support in this study. As you may know, our objective is to understand your work practices in treating patients with diabetes. Down the road what we learn here will help us provide you and your colleagues with better resources. This interview will take approximately 45 minutes to an hour. Your participation and your responses will be treated confidentially and all of our findings will be reported anonymously. We will greatly appreciate a recording of this interview for analysis, and your consent for conducting and publishing the aggregated results.

3. [*Hand out the Informed Consent, if applicable.*]

SECTION 2: BACKGROUND QUESTIONS (Warm up questions to gather general facts about the interviewee and the work environment.)

[*I'd like to start with some questions about your position here and your general work setting.*]

☐ **Q1. How long have you been working as a _____?**
[Probing]
  1. How long have you been working at the VA?
  2. How long have you been working in this clinic?
  3. What is your work experience prior to joining VA?

☐ **Q2. What is your role in the clinic?**
[Probing]
  1. What's your job title?
  2. What are your main responsibilities and locations?
  3. What is the time allocation across responsibilities and locations?
  4. What is your general work schedule?
  5. Do you work in other settings [*e.g., physicians at the Ann Arbor site may also practice in the university system*]?

🗋 **Q3. Can you briefly describe a typical day of your work?**
[Probing: Make sure the interviewee describes her/his day of work in a chronological order.]
1. How do you prepare in the beginning of the day?
2. What is your typical patient load, how many patients do you see?
3. What do you do to wrap up your day?

🗋 **Q4. Outside of patient visits, can you describe other activities that you engage in regularly that you did not describe as part of your typical day?**

SECTION 3: CURRENT PATIENT DATA OR INFORMATION USE

🗋 **Q1. When you see a diabetic patient, what patient data or information do you access <u>before</u> the visit?**

🗋 **Q2. When you see a diabetic patient, what patient data or information do you access <u>during</u> the visit?**

🗋 **Q3. When you see a diabetic patient, what patient data or information do you access <u>after</u> the visit?**
[Probing for 3.1-3.3]
1. What information do you need?
2. Where do you get this information?
3. How do you use it?

🗋 **Q4. Considering the patient data and information you just described, what information do you find most important when treating a diabetic patient?**
[Probing for location, context, systems where the information is retrieved, who prepares it, etc]
1. What information?
2. Where do you use the information?
3. When do you need the information?
4. Where do you get the information?
5. Why is this information most useful and how is it used?

🗋 **Q5. What additional patient data or information would you like access to in caring for diabetic patients?**

🗋 **Q6. Thinking about how diabetic patient information is organized and presented in CPRS, what do you like?**
1. What do you dislike about how diabetic patient data is organized and presented in CPRS?

SECTION 4: POPULATION-MGT RELATED

☐ **Q1. When you are treating or managing diabetic patients, what (factors) do you consider in determining appropriate targets or goals?**

☐ **Q2. When managing diabetic patients, do you use the VA's clinical practice guidelines?**

☐ **Q3. What does the concept of risk stratification mean to you?**
[Probing]
    1. Do you use risk stratification in your practice?
    2. How do you use it? (at what point in process, with what tools/support, etc.)
    3. What do you think of it?

☐ **Q4. Are you aware of any patient registries being used at the VA?**

    +++If no+++

    1. Do you think patient registries are useful?
    2. Why or why not?

    +++If yes+++

    1. Can you tell me more about that?
    2. Do you use them yourself? (or use information from them)
    3. Do you think they patient registries are useful?
    4. Do you think the patient registries are easy to use?

☐ **Q5. Do you receive any kind of regular feedback on clinical performance measures or patient outcomes for your patients?**
[Probing]
    1. What kind of feedback do you receive? Based on clinical guidelines or standard quality indicators such as HEDIS?
    2. How is feedback given? [Try to obtain more details about the feedback.] What type of reports, how often, are you benchmarked with other providers, how is feedback distributed?
    3. Who produces the feedback?
    4. What do you think of the feedback?

+++If "Yes" to Q5 (receive feedback) +++

☐ **Q6. How do you use the feedback you get?**
[Probing]
    1. Is the feedback useful to you in your practice?

⬜ **Q7. Do you receive performance feedback regarding diabetic care specifically?**

      +++If yes+++
         1. In what ways do you think the current performance feedback on diabetic care could be improved?

      +++If no+++
         1. If you were receiving feedback reports on performance measures for diabetic patients, what would be useful for you to see?
         2. How would it influence the care you provide to patients?
         3. Do you want to see your performance on managing diabetic patients, potentially benchmarked with your colleagues here or even across the entire VA system?
         4. How would you like to receive the feedback, how would you like it presented to you? In what format and how often?

⬜ **Q9. Now I'm going to tell you a little bit about the VA's Diabetes Cube and describe its contents and then ask you some questions about it.**

The VA's Diabetes Cube is a national database of diabetic and pre-diabetic or "at risk" patients that aggregates over 50 data dimensions, including demographics, vitals, lab results, co-morbidities and medications. The goal of the Cube is to provide clinicians with tools to improve care by identifying populations of patients at a higher risk who may require additional follow-up and to evaluate patterns of care delivery. The Cube includes the ability to look at population differences and costs associated with care delivery and severity of illness, and can help with early detection and intervention as well as treatment assessment.
         1. Do you think it would be useful to you to have access to the Diabetes Cube as described? Why/why not?
         2. How would you see yourself using the Cube?
         3. What aspects of the Cube are particularly appealing to you?
         4. What other kinds of data, information or capabilities would you like to see the Cube provide for clinicians?

SECTION 5: OPEN-ENDED WRAP UP

⬜ **Q1. Is there anything else that you think would improve diabetes care in your clinic?**
[Probing]
         1. Do you think this improvement would be feasible? Why or why not?

⬜ **Q2. Is there anything else you'd like to tell us, or anything you haven't covered?**
Thank you very much for taking the time to participate in the study. We appreciate your help.

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