Information Work In The Chronic Illness Experience

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Introduction

A proliferation of health information on the Internet and increased pressures for individuals to manage their own healthcare (Eng et al., 1998; D. Lewis, Chang, & Friedman, 2005) have raised health information behavior—individuals' needs, seeking and use of information related to health—as an area of concern for practitioners and researchers. The experience of chronic illness presents a unique and vivid case of health information behavior in that it involves conditions that: can be difficult to diagnose; are often treated through a combination of traditional medical and alternative therapies; and, engage the patient in active management and care over an extended period. The National Institutes of Health has identified both chronic illness management and the ability to "obtain, process, and understand basic health information" as imperative to improving national health outcomes (Young, 2004), highlighting the necessity of understanding information behavior as it relates to ongoing health conditions, and in developing scholarship that can account for a range of health information behavior more theoretically (Baker & Pettigrew, 1999).

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 (e.g., Eysenbach, 2000; D. Lewis, Eysenbach, Kukafka, Stavri, & Jimison, 2005). As a discipline medical science has been oriented around a view of information as expert knowledge delivered in a centralized fashion. As such, it has engendered studies that pathologize lay people's health information seeking, as evidenced by labels such as "cyberchondria" and "an epidemic of misinformation" (T. Lewis, 2006). Critiques of medical science's approach to health information have pointed out that, by and large, that body of research is overly focused on accuracy of information and the potential for its misuse and does not consider information seeking multidimensionally or in the context of people's lives (Dervin, 2005; T. Lewis, 2006).

The field of information behavior provides an alternative lens for consumer health information behavior, offering user-centered and contextually sensitive perspectives to inform an understanding of information needs, seeking and use in the illness experience. Working within an information behavior framework, this research incorporates perspectives from medical sociology that elucidate the lived experience of illness in order to characterize information behavior in the context of chronic illness and the distinctive aspects of the chronic illness experience that shape information needs, seeking and use.

Key Frameworks for Understanding Information Work in the Chronic Illness Experience

Medical conditions that are ongoing and require significant attention not only in medical settings, but also in the daily lives of those who experience them may be especially vulnerable to the shortcomings of a medical informatics paradigm. The persistence and inherent complexity of chronic illness requires research approaches that are attentive to people's subjective

experience of illness in their 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; Corbin & Strauss, 1988; Thorne et al., 2002). The medical sociology literature describing "the illness experience" tells us that the impact of chronic illness is multi-faceted, disrupting not only the body but also sense of identity and daily life (Bury, 1982, 1991; Lawton, 2003; Pierret, 2003).

The chronic illness trajectory model, developed in order to describe illness as a sociological concept rather than a medical categorization (Corbin & Strauss, 1985), goes beyond the medicalized paradigm of "the course" of an illness to comprehend all of the work related to it, its impact on those affected by it and how its management and outcomes are shaped by its context (Corbin & Strauss, 1991). Analytically, the concept shifts attention from the physiological experience of illness to its social context, and carries a strong sense of agency, describing the actions people take to shape their illness trajectories as *illness work* (Corbin & Strauss, 1985). As a type of illness work, information work can play a central role in minimizing and repairing the disruption wrought by illness, and has been identified as a resource for primary activities that have served as focal themes for sociology research on the experience of illness, including: "reducing uncertainty, biographical work, creating medication practices, and developing practical strategies to manage the illness" (Conrad, 1987, p. 14). Health information researchers have also recognized that 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 (Baker, 1996; Hogan & Palmer, 2005).

The field of information behavior, which has long emphasized the user and his needs over a systems orientation (Dervin & Nilan, 1986; Pettigrew, Fidel, & Bruce, 2001; Wilson, 1994), provides an opportunity to more fully understand information in the chronic illness experience by moving away from the information itself and emphasizing the role that it plays in people's lives, why they seek it, and how they understand and use it. Dervin (2005) criticizes top-down, transmission-based 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. In fact, she points out, 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" (Dervin, 2005, p. S79). Information behavior theories that focus on understanding people and their needs in the broader context of their experience offer an implicit alternative to a traditional medical paradigm.

Study Design and Method

The current study is a preliminary analysis of pilot data collected for dissertation research on information behavior in the context of chronic illness. Qualitative interviews were conducted with fifteen people experiencing a wide variety of chronic conditions. Following a purposive sampling approach, participants were recruited based on self-identification of having a chronic illness or condition. Eligibility was confirmed using a definition of chronic illness from nursing as, "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). Illness sampling was kept deliberately broad in order to focus on the common aspects of information behavior across the chronic illness experience.

Recruiting was done in the community at large in order to emphasize a daily life (non-medical) context. Participants were recruited through social and collegial networks, relying on word of mouth and local list-serves. Semi-structured, in-depth interviews lasting from 70-90 minutes were conducted in participants' homes, where the bulk of the chronic illness experience takes place. Elicitation strategies were informed by Dervin's Sense-Making Methodology (Dervin, Foreman-Wernet, & Lauterbach, 2003); the investigator focused on how gaps or problems were overcome in the course of the illness experience. Initial analyses of the interview data used a combination of inductive and deductive approaches (Emerson, Fretz, & Shaw, 1995) to develop salient themes. The preliminary themes reported here emphasize the information intensive work done early on in the course of a chronic illness in order to contextualize the illness into everyday life.

Preliminary Findings: Information Work in the Onset of Chronic Illness

Participants described activities related to managing and coping with their illnesses that can be characterized as information work, including getting a diagnosis or figuring out what is going on with the body; developing an explanation for the illness—what caused this and how did this happen; and establishing an in-depth understanding of how the illness works. These types of work tended to take place in the early stages of illness, but by no means do they happen linearly. Participants described an ongoing process of assembling an understanding of what was happening with their bodies that helped them to repair disconnects in their experience and contextualize the illness into their lives. For the chronic illness sufferer, these processes are highly constructivist and affectively motivated, characterized by a need for making meaning in ways that may be completely unaccounted for in an acute care medical model.

In the course of trying to figure out what was wrong with them or secure a diagnosis, participants frequently sought information to reconcile what they were experiencing and what they were hearing from doctors. Debbie[1], originally diagnosed with pelvic inflammatory disease, could not reconcile the information she had been given about how the causes of the illness with her own experience and her sense of her own body. She recounted the story of a follow-up visit with a nurse practitioner:

> "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' (P07).

After reading about endometriosis and talking to someone else who had it, Debbie had begun to suspect that the painful periods she had had 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.

Establishing a diagnosis was important to participants for expected reasons such as to determine proper treatment or to qualify for clinical trials, but there was also a sense of validation that came with having an official diagnosis. Being able to name the condition provided relief even when it didn't lead to an immediately identifiable treatment. For many participants, a diagnosis was hard to pin down but ultimately legitimated their condition as physiological rather than as a set of imagined or vague complaints. Having a diagnosis also provided a framework to start thinking about the illness and how it would affect their lives, and then finding ways to cope

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[1] **All participants are identified by pseudonyms to protect their confidentiality.**

with and manage symptoms.

The process of achieving diagnosis was frequently 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. Lisa described pushing back on her physician's initial diagnosis 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" (P08).

Having the RA diagnosis gave her a sense of hope regarding her prognosis and a way to start dealing with her condition.

Once they had been diagnosed or had some sense of what condition they have, participants reported engaging in information-intensive work to fully understand the illness and explain how they got it. The need to gain control and mitigate the uncertainty of an ill-defined, uncertain situation such as illness is well documented in the illness experience literature. Participants characterized their information needs in this process with phrases such as "I needed to learn as much as I could," or "I wanted to better understand [illness] on my own terms." Such a base of knowledge seemed to act as a framework for both affective coping and handling the cognitive load of dealing with illness, including making daily life decisions, responding to changes in lifestyle or activities, responding to new symptoms or a progression of the illness, and incorporating the management of additional illnesses.

IMPLICATIONS

The experience of chronic illness is intrusive, immersive and relentless, impinging on just about every aspect of human existence and necessitating coping on multiple levels. Information work in this context plays an essential role in handling its force of impact and seeming intractability, and is shaped by the reality of ongoing coping with a complex and messy problem on a daily basis. The affective states and the need for cognitive flexibility that accompany chronic conditions entail unique processes and considerations for information seeking and use. This research will continue to investigate the way that the chronic illness context shapes information behavior, offering the potential to contribute to a more theory driven understanding of chronic illness information needs, seeking and use, with implications for both information providers and healthcare professionals. A theory of chronic illness information behavior is expected to help information professionals and medical caregivers better understand the world of the chronic illness sufferer and provide information that is relevant and useful. Enabling a better fit between individuals and information could contribute to healthcare professionals' abilities to impact and support treatment, compliance, healthcare decision-making and proactive management of care.

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