Cognition of Shared Decision Making: The Case of Multiple Sclerosis

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COGNITION OF SHARED DECISION MAKING: THE CASE OF MULTIPLE SCLEROSIS

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

By

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Abstract


The increasing emphasis in the medical community on shared decision making and patient centered care suggests that patients play a role in their care, but research on clinical reasoning almost exclusively addresses practitioner cognition. As patient involvement increases, it is important to understand the effect patients have on clinical cognition. This necessitates moving beyond a model that equates clinical cognition with practitioner cognition to incorporate the influence of patient cognition and dyadic patient-practitioner cognition. In this dissertation, I suggest that patient-practitioner interactions constitute a distributed cognitive system. As a result patient cognition and the nature of the interaction inherently contribute to clinical cognition. By analyzing different aspects of clinical interactions involved in managing Multiple Sclerosis (MS), I provide an exploratory observational study of how patient-practitioner dyads engage in clinical cognition that may serve as a guide to more conventional future hypothesis testing.

To assess clinical interactions, I observed twenty-three patients interacting with three medical practitioners at a clinic specializing in the chronic disease of Multiple Sclerosis. Consistent with Institutional Review Board review, patients agreed to observations of their clinical session including audio recording and/or taking field notes.
and participated in follow-up phone interviews. Analysis employed techniques from grounded theory, task analysis, and discourse analysis.

The results comprise four separate analyses focusing on different aspects of patient-practitioner cognition outlining the core functions of MS management, the fundamental role of the patient in the reconceptualization of management as a distributed task, the effect of patient expertise on clinical reasoning and the role of narrative in facilitating the exchange of information.

Specifically, in the first analysis, I decompose the interactions involved in MS management into a series of core functions each of which depends upon different cognitive elements. I analyze the contributions of patients and practitioners to each of these tasks showing that patients and practitioners engage in distributed cognition during all major tasks except interpretation of technical test results. Across the clinical session, practitioners and patients collaborate to create a common trajectory that guides clinical reasoning.

The second analysis focuses specifically on the patterns of patient and practitioner responsibility during decision making. To execute the range of decision making tasks, participants navigate through a decision space that includes situational understanding (the state space) and possible actions (the action space). While making decisions, practitioners and patients can each exert control over different constituent tasks, creating four patterns for distributed decision making: practitioner dominated, practitioner defined-patient made, patient defined-practitioner made, and patient dominated. The specific pattern used in a given decision depends upon the access patients and
practitioners have to different portions of the decision space. As practitioners and patients navigate through the decision space, they negotiate shared decisions as inflection points in the process of creating a common trajectory for clinical cognition and care.

The third analysis examines the effect of patient expertise in MS self-management on distributed clinical cognition. I first demonstrate that patients vary in their level of medical expertise in the management of a chronic disease such as MS. Experienced patients actively constructed representations of clinically relevant experience and presented initial evaluations for the practitioner to refine and validate. By contrast, conversations between newly diagnosed patients and practitioners demonstrated the practitioner’s working to establish a common understanding of the problem space and acceptable interventions. Because of this difference in patient expertise, practitioners must adapt their clinical cognition and mode of interacting. The existence of this adaptation supports my argument that the conceptualization of clinical cognition is fundamentally distributed.

The fourth analysis looks at the role of linguistic representation, especially narrative representation, as fundamental to the exchange of information in distributed clinical cognition. Narratives support cognition through attention, memory, and reasoning processes during practitioner-patient interactions. Narrative representations extended access to clinically relevant information by providing specific information about circumstances, subjective experiences, functional capacities of the patient, and prior decision processes. In addition, the hermeneutic nature of narrative supported reasoning, allowing collaborative hypothesis testing.
Results across all four analyses supported an interpretation of clinical cognition as an integrated, ongoing process, distributed among patients and practitioners and supported by linguistic representation. Instead of isolated sequential choice points, analyses indicated that the major tasks involved in clinical reasoning are non-sequential and mutually determining, reflecting standard issues in cognition such as problem detection, representation, categorization and causal reasoning. Practitioners and patients each contribute to this trajectory of clinical cognition. Because patients and practitioners inherently have widely different perspectives distributed clinical cognition depends upon the actors’ abilities to represent and integrate divergent conceptualizations of the clinical problem space. As such, language provides an essential medium for distributed clinical cognition.
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Chapter 1: Introduction

Public policy and medical ethics increasingly emphasize the importance of moving from a practitioner-centered to a patient-centered model of health care (Coulter, 2012; Barry & Edgeman-Levitan, 2012). Shared decision making, involving patients in making decisions about their care, is one of the touchstones of patient-centered care. Shared decision making represents a change in social values, clinical processes and medical advancements that have converted once-fatal diagnoses to manageable diseases. Whereas traditionally practitioners made decisions autonomously, now patients and practitioners collaborate to execute clinical, cognitive functions. Supporting clinical cognition under a patient-centered model will require supporting the cognition involved in patient-practitioner collaboration. Yet, research on cognitive aspects of practitioner-patient interactions is limited. As a whole, this study focuses on beginning to address the question:

Research Question: As a cognitive process, how are medical decisions shared?

Much of the existing literature conceptualizes shared decision making in terms of communications, social interactions and power dynamics. By contrast, I examine shared decision making as a cognitive process. Investigating this process is necessary to understand shifts in medical practice resulting from the patient-centered care movement and to design supportive training, and technical systems. Given the lack of research on the cognition of shared decision making, I felt that the first step to addressing this question was an open-ended, qualitative study that could produce a detailed picture of
shared decision making and develop an initial theory of underlying constructs. This work could then provide direction for future hypothesis-driven research.

This study focuses on interactions surrounding Multiple Sclerosis (MS) management as an initial test case for examining shared decision making processes. As is typical of hypothesis generation work (Charmaz, 2006), I begin with a first level, wide angle analysis of the target phenomenon by examining cognition across the entire clinical session. My second level analysis builds on the first level with a focused analysis of the nature of shared decision making and the factors affecting how decisions are shared. Finally, I present a third layer of analysis focused on specific issues that emerged as significant in the prior analyses: how patient cognition affects practitioner and dyadic cognition and the role of language as a tool for facilitating effective patient-practitioner collaboration. These analyses are mutually supporting. The first level of analysis provides a theoretical basis for the second and third, each of which in turn adds depth and support to the earlier analyses. Taken together all of the analyses allow for the development of a theory of the cognition involved in shared decision making. Chapter 3 provides a more complete description of the evolution of these layers.

Because the individual analyses address different aspects of shared decision making, I have split them across four chapters, generally corresponding to different publishable articles. Each chapter includes specific introductory material and conclusions directly linked to the focal analysis. The introduction below provides background information that is pertinent across the analyses. I begin by reviewing the literature on medical cognition by practitioners, patients, and practitioner-patient dyads. I
introduce the role that representations, especially language, play in facilitating the collaboration between practitioner and patient. Finally, I provide some basic information about MS and the tasks involved in MS management.

Medical Cognition

Increasingly, health policies, researchers and medical professionals all emphasize the importance of patient engagement in the healthcare system (Coulter, 2012; Barry & Edgeman-Levitan, 2012). As patients become more active in the healthcare system, how they think about illness and their interactions with health professions may influence clinical cognition. Below, I review the literature concerning how practitioners and patients think about illness separately, as well as the limited literature on how their interactions affect cognition.

Practitioner Reasoning

A great deal of work has focused on practitioners’ clinical cognition (Croskerry, 2002; Elstein & Schwarz, 2002). These studies suggest that clinical cognition follows a dual processing model (Kahneman, 2011; Norman, 2009; Pelaccia et al., 2011) including both intuitive, recognition-based reasoning and deliberation. Persisting debate concerns the integration and utility of these two modes of reasoning. Some researchers have embraced intuitive clinical cognition, admiring expert practitioners’ abilities to form judgments by rapidly synthesizing large quantities of information, including contextual information (Bogner, 1997; Hogarth, 2001). These researchers have emphasized the utility of pattern recognition skills and parsimonious heuristics for making timely decisions, especially in emergency situations (Gigerenzer & Gaissmaier, 2011). Other
researchers warn against the tendency for intuitive, recognition based processing to introduce biases into clinical reasoning (Crosskerry, 2012). By emphasizing errors in intuitive reasoning, these researchers have given primacy to the deliberative mode of clinical cognition. Deliberative clinical reasoning uses a hypothetical-deductive model to analyze evidence, generate hypotheses and test potential diagnoses (Kassirer, 1989; Schwarz & Elstein, 2009). The deliberative mode of medical cognition involves logical and probabilistic analysis and is often the basis for medical informatics systems (Patel, Kaufman, & Arocha, 2002). Researchers often present the two modes of medical cognition as dichotomous or opposing, but practitioners utilize both forms of reasoning (Custers, 2013).

Studies of clinical cognition based on a dual processing model typically consider practitioners as isolated thinkers, but practitioners are part of a larger environment that influences cognition. Research that moves beyond the individual practitioner to examine medical care more holistically as a system including multiple actors and technical artifacts has examined these contextual and interactive factors (Engeström, Engeström & Kerousou, 2003; Maseide, 2007; Pimmer, Pachler, & Genewein, 2013). These studies emphasize the fact that medical reasoning relies on interactions with multiple professionals as well as upon records and test results that are often produced by others. On a systems level, clinical reasoning increasingly reflects interaction with the computer systems responsible for maintaining electronic medical records (EMRs) (Zhang & Patel, 2006; Patel, Aroch, & Kushniruk, 2002).
**Patient Reasoning**

Surprisingly, even system level analyses rarely include patients as cognitive actors within the medical system. The limited work on patient cognition usually focuses on socio-emotional coping with illness (Leventhal & Diefenbach, 1991), the consumption of health information (Galarce, Ramanadhan, & Viswanath, 2011), or adherence (Berglund, Lysty, & Westerling, 2013; Leventhal, Diefenbach, & Leventhal, 1992). The premise seems to be that patients are peripheral to the medical system. Even when patients make decisions about their care, these decisions are apparently isolated from other forms of clinical reasoning. Accordingly, discussions of patient decisions exclusively concern resources provided by medical professionals (e.g. patient educational materials, verbal descriptions of efficacy) requiring a minimum of specific knowledge (e.g. treatment success rates, lists of side effects) without substantial patient understanding of his disease (Stacey et al., 2012). Research that examines how patients understand illness is nearly always anthropological in nature and focused on how particular cultural groups interpret illness (Garro, 2000; Good, 1994).

The lack of research on patient medical cognition is especially unfortunate in understanding chronic diseases. Patients have critical information and the powers to act upon that information, but they often do not have the training to use their resources effectively. Accordingly, patients vary considerably in the skill they bring to clinical interactions. Some patients have little understanding of their disease processes and may struggle to engage in appropriate self-care. When researchers have examined ways to increase adherence with medical treatment, they often focus on those patients requiring the most intervention (Bernabeo & Holmboe 2013; Viswanathan et al., 2012). On the
other end of the skill spectrum, some patients have a sophisticated understanding of their illness. These patients can identify, understand the significance of, and respond to illness events. They may or may not have substantial knowledge of the physiology of disease or how their illness functions generally, but they have extensive knowledge of their body and how it functions under diverse circumstances. They can compare their current phenomenological experiences to a range of previously experienced illness episodes and hence can interpret the significance of current symptoms. In addition, they have the ability to apply their understanding in a way that enables effective self-care (Lippa, Klein, & Shalin, 2008).

Thus, patients lack the domain expertise of medical professionals, but they do have the situation-specific expertise of their own illness. In my previous work, I studied how this situation-specific expertise functions in terms of patients’ self-care (Lippa, Klein & Shalin, 2008). Patients’ level of situation-specific expertise has implications for understanding patient-practitioner cognition as well. Patients’ ability to understand and act effectively with regard to their illness inherently will influence how they discuss illness events with practitioners as well as their ability to engage effectively in clinical functions such as treatment decision making.

*Reasoning in Practitioner-Patient Interactions*

The limited existing evidence suggests that how patients discuss their symptoms influences diagnostic reasoning (Ainsley-Vaughn, 2003) and treatment decisions (Stivers, 2002). Because the way in which patients represent their illness presumably reflects the way they think about their illness, these studies suggest that patient cognition affects
physician’s clinical cognition. As patients become more involved in caring for their chronic conditions, their influence on clinical cognition may gain prominence.

Shared decision making is one of the most widely discussed forms of patient involvement (Barry & Edgman-Levitan, 2012). As the name implies, the shared decision making paradigm welcomes patient influence on, at least, the decision making portion of clinical reasoning. The shared decision making paradigm challenges the view that the practitioner, by virtue of his expert knowledge, should decide the best interests of the patient. This paradigm assumes that patients have a right to be informed of and understand their treatment options and to exert control over decisions about their health (Elwyn et al., 2012). The translation of this general ethical stance into clinical care is debatable. Various authors have proposed guidelines for shared decision making ranging from practitioners eliciting and considering patient goals/values to having patients carry the primary responsibility for decision making with practitioners taking the role of expert advisor (Moumjid et al., 2007). Nearly all of these definitions share the common premise that power to decide is what makes a decision shared.

Logically, sharing decision making, under any of a range of definitions, will affect the thought processes involved in medical decision making. However, the enormous literature on shared decision making focuses on communications, social interactions and power dynamics with little discussion of clinical cognition. Nevertheless, when patients and practitioners engage in shared decision making, they not only share the power to make a final decision but the reasoning necessary for decision making to occur. In sharing a medical decision, patients and practitioners face challenges
involving cognitive elements\(^1\) such as memory, attention, and reasoning. Patients and practitioners must remember information about the patient’s case history. They must work together to identify and direct attention to relevant symptoms and surrounding circumstances. Moreover, they may have to construct causal explanations for observed symptoms or medication effects. Understanding the cognition involved in shared decision making will inform models of clinical reasoning and further efforts to support effective shared decision making.

A few researchers have begun to acknowledge that the shared decision making paradigm must integrate patient cognition into the medical system (Epstein, 2013; Rapley, 2008). Epstein (2013) in particular offered the term ‘shared mind’ to describe situations in which mental processes of two or more individuals intersect “sometimes to the point that none of the individuals can fully ‘own’ the resulting perspective, preference, or choice.” This construct implies that shared decision making constitutes an interactive decision making processes regardless of who ‘makes’ the final decision.

\textit{Distributed Clinical Cognition}

This study elaborates Epstein’s (2013) contention that shared decision making involves a sharing of thought rather than simply a sharing of decision making power. In

\(^1\) Throughout this study the term ‘cognitive element’ is used to refer to any aspect of cognition that is typically studied as a context independent, fundamental capacity such as attention, memory, and decision making. Larger contextualized tasks that are dependent upon these elements are called ‘cognitive functions.’
particular, I explore the idea that clinical cognition, especially in chronic disease management, is a distributed cognitive system that incorporates both practitioner and patient cognition. Fundamentally, the paradigm of distributed cognition simply acknowledges that cognition occurs in the world and hence is enmeshed with the events, people, and physical characteristics of the environment. Whereas laboratory studies of cognition are pervasive, the very things that make that setting desirable such as the ability to isolate a problem and the level of control achievable are aberrations from the normal environment in which thought occurs. Laboratory research is an appropriate research strategy when the isolated cognitive elements do not interact with the richer context.

However, outside the lab the physical background, people who form the social environment, and objects available for manipulation all can influence cognition, calling into question the proper unit of analysis. The significance of the environment suggests that cognition is not a process that occurs locked in one individual’s mind but rather a distributed process involving people and their environment on multiple levels (Hutchins, 1995; Zhang & Norman, 1994; Zhang & Patel, 2006). The study of distributed cognition concerns how thought processes are distributed across individuals and groups, humans and technical artifacts, and space and time. This view of cognition changes the conceptualization of basic cognitive elements such as attention and memory. Distributed cognition transforms these from isolated processes dependent upon the capacities of a single individual into distributed processes spanning multiple cognitive actors or actors and environmental elements.
In the medical domain\textsuperscript{2}, work on distributed cognition acknowledges that patients with chronic or complex illness require services from multiple providers. Providing adequate care depends upon coordination among multiple professionals (Engeström, Engeström, & Kerosou, 2003; Hazlehurst, McMullen, & Gorman, 2007; Tariq, Georgiou, & Westbrook, 2013). Similarly, during inpatient care, multiple providers work with the same patient throughout the day (Abraham, Kannampallil, & Patel, 2011).

I suggest that just as multiple professionals must coordinate their efforts, patients have a critical and often complex, but unacknowledged, role in their care. Before seeing a practitioner, they make decisions about how to respond to illness/injury and when to seek medical assistance. After they leave the clinic, they self-administer medications, carry out medical procedures, or practice therapeutic exercises. To the extent that such functions are recognized, they fall under “adherence,” on the assumption that another authority dictates the task. When illnesses are complex, chronic or co-morbid, patients often become their case workers, bearing responsibility for ensuring that they receive necessary services and that multiple providers are aware of each other’s efforts. Therefore, patients participate as substantial intentional agents, alongside practitioners, within the distributed medical care system.

\textsuperscript{2} Appendix A provides a discussion of Human Factors in the medical domain.
Researchers examining distributed cognition amongst medical professionals have emphasized the importance of representations and technical artifacts as boundary objects to facilitate efficient, ongoing coordination (Engeström, Engeström, & Kerosou, 2003; Hutchins, 1995; Star, 1989). In patient-practitioner distributed cognition, there is a similar need to coordinate information about past procedures, current status and projected future actions. However, patients and practitioners share few tangible representations. Typically patients enter the clinical encounter empty handed and left with only a prescription or occasionally an educational pamphlet. During the clinical encounter patients may fill in forms providing basic information (such as a symptom inventory) but as representations of symptoms, these tend to be both generic and sparse providing relatively little detail about the patient’s status. Similarly, during an appointment, the practitioner may share medical imaging with the patient, but these images require specialized training to interpret and thus convey limited information to the patient. In the absence of physical representations, patients and practitioners primarily use speech to represent information and coordinate action.

Unlike tangible representations that may be static or highly constrained, speech is fluid and fundamentally interactive. This fluidity allows it to act as a medium for distributed cognition as patients and practitioners co-construct verbal representations. Because they are co-constructed in real time, the interactive process involved in creating

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3 In this study, the term representation refers to physical representations, including intangible representations such as speech, rather than mental representations.
linguistic representations is both a product and reflection of the processes of distributed
cognition. Throughout this study, I analyze the speech of patients and practitioners as a
way of accessing distributed cognition in the clinical encounter.

Clinical Cognition in Multiple Sclerosis Management

Multiple Sclerosis provides the context for this research. Multiple Sclerosis is a
chronic disease of unknown etiology wherein the immune system attacks the central
nervous system causing lesions in the brain and spine. Lesions can lead to a wide variety
of sensory symptoms (e.g. pain, tingling, numbness) and functional deficits (e.g. motor
deficits, profound fatigue). MS occurs in three major forms. In the most common form
(relapsing remitting MS) patients experience periodic exacerbations of symptoms that
diminish over time. Occasionally, patients with relapsing-remitting MS stabilize at a
point where they have minimal disability and few, if any, relapses. Practitioners refer to
this as ‘benign MS’ (Pittock et al., 2004). In secondary progressive MS, patients begin
with begin with a relapsing-remitting disease course but at some point the symptoms they
experience fail to diminish leading to a progressive loss of functioning. Finally, in
primary progressive MS patients never experience a reduction in symptoms so that their
degree of disability progressively increases from the onset of the disease. No test can
determine which disease course a patient will follow, so patients with relapsing-remitting
MS must live with the possibility that their disease will become progressive.

Managing MS requires a complex set of judgments and decisions. Diagnosing
MS is not easy. A period of uncertainty including one or more misdiagnoses often
precedes the diagnosis of MS. Once a clinician diagnoses MS, practitioners and patients
must make ongoing judgments about whether various symptoms that the patient experiences are due to MS or a comorbid condition and whether MS symptoms are indicative of new disease activity. The stochastic relationship between neurological damage and symptoms complicates judgments of relevance to MS. In some cases, environmental factors (e.g. heat, overexertion, stress) may lead to an exacerbation of symptoms without new neural lesions whereas at other times lesions may form without giving rise to any symptoms. Practitioners use a combination of patients’ reports of symptoms, clinical neurological assessments and magnetic resonance imaging to track disease processes and functional status. Practitioners and patients must use their assessment of the patients’ state to make two major categories of treatment decisions: if and how to take action to deter disease progression and how to manage symptoms and disabilities as they arise.

As a domain, MS management has certain advantages for studying practitioner-patient cognition. Because the disorder is chronic, practitioners and patients have time to develop an ongoing relationship and patients have an opportunity and incentive to learn about their disease and actively engage in their care. Because a wide variety of symptoms can occur, MS presents an opportunity for analyzing discussions that include many different medical problems necessitating a broad range of demands on diagnostic reasoning and treatment decision making. Finally, the need to incorporate both highly subjective information about symptoms and highly technical information regarding MRIs means that practitioners and patients need to communicate with each other and are more likely to articulate their thought processes (e.g., classification, causal reasoning). Overall, MS presents a domain in which practitioners and patients have an opportunity to
develop ongoing relationships involving verbal collaboration to achieve a wide variety of clinical reasoning tasks.

**Overview**

This study approaches the cognition of shared decision making from several different angles. The exposition begins with philosophical and methodological concerns that were used throughout the study and then goes on to address the specific analyses. The next chapter locates the study in relation to salient philosophical and methodological issues. Chapter 3 includes methodological detail that is common to all the studies including issues involved in data collection. Chapter 4, *Creating a Common Trajectory*, traces the distribution of cognition between practitioners and patients during the major cognitive functions that occur in a typical MS management visit. Subsequent chapters adopt a distributed cognitive paradigm to examine more specific aspects of patient-practitioner interactions affect clinical cognition. Chapter 5, *Navigating the Decision Space*, examines patterns of shared decision making and the factors affecting the roles patient and practitioners play in shared decision making. Chapter 6, *Lay-Professional Collaboration*, analyzes how the range of patient’s clinical and cognitive skills affect how the practitioner and patient work together on clinical tasks. And Chapter 7, *Medical Narratives as an Aide to Clinical Cognition*, examines the use of language, especially narrative speech, as a tool for exchanging information to facilitate distributed clinical cognition. The final chapter incorporates results from all of the component analyses into a set of common conclusions.
Chapter 2: A Note on Theory and Methods

There are many valid ways to approach most complex questions. Different research disciplines have different philosophical perspectives and methodological toolboxes that offers a unique and valuable opportunities for insight but come with inherent limitations. Some problems are well suited to exploration by a particular discipline, whereas others require a hybrid approach. This study deals with the cognition associated with practitioner-patient interactions. Exploring this area has required that I draw on several research traditions: psychology (esp. human factors and cognitive psychology), anthropology (esp. ethnography) and linguistics (esp. discourse analysis).

Several scholars have combined some or all of these disciplines. Cultural psychology (Bruner, 1990), cognitive anthropology (D’Andrade, 1995), ethnographic discourse analysis (Ainsworth-Vaughn, 2003), and linguistic anthropology (Duranti, 1997) are all efforts to combine some or all of these different research perspectives. Among these many attempts at synthesis, this study most closely follows Cole and Scribner’s (1975) call for the creation of “ethnography of a specific cognitive activity.”

As with any interdisciplinary effort, I have necessarily adopted some of the methodological and theoretical positions of each discipline and abandoned others. In this section, I attempt to locate the current study as it relates to larger theoretical and methodological debates between and within disciplines.

Qualitative and Quantitative Research

Most psychologists use quantitative methods, whereas researchers in anthropology and (to a large extent) linguistics tend to use qualitative methods. The
The present study is primarily qualitative. Qualitative research differs significantly from quantitative research in several ways. Qualitative research tends to focus on theory building or elaboration (Snow, Morrill, & Anderson, 2003) whereas quantitative studies typically begin with a theory and test associated hypotheses. This study focuses on the initial development of a theory to begin to understand the cognitive aspects of the interaction between practitioners and patients when managing chronic disease. It is essentially an exercise in grounded theory (Charmaz, 2006; Glaser & Strauss, 1967), characteristic of scholarly research in anthropology and linguistics. A more thorough treatment of my qualitative methods with respect to other such methods appears in Chapter 3. Here I focus on the rationale for qualitative research methods, of which grounded theory is an example.

Grounded theory focuses on the inductive development of social science theories through close, iterative analysis of data. The resulting theories are ‘grounded’ in real world data as opposed to methods of theory construction that focus on logical deductions or a priori speculation. In addition to the obvious desirability of having theory and reality align, creating theory grounded in data from natural environments has three advantages. First, a holistic approach allows for more flexibility about where to partition issues. Laboratory studies segment portions of a particular phenomenon a priori to permit controlled study. This approach is very successful in the presence of a substantial, coherent theoretical foundation. However, in the absence of a well-developed theory that yields clear hypotheses, the flexibility to parse issues in ways dictated by the ongoing progression of the research can be very valuable. In addition, holistic analysis of a domain has the potential to uncover ways in which processes that are conventionally
segmented for research purposes are integrated during in vivo applications. Such integration provides a multi-dimensional depth that complements laboratory research. Second, because the theory comes from a data set various components easily can be operationalized and tested through analysis of additional data. Third, because the theory comes from real-world domains, the theoretical constructs created are usually easily comprehensible to practitioners in the target domain. This is a great advantage for studies such as this one that have both academic and applied components.

The description above hints at several other substantial differences between qualitative and quantitative research. The first disparity involves the setting in which the research takes place and the roles of the various participants. Whereas quantitative research typically requires a controlled setting, qualitative research tends to occur in natural environments. Inherently to an inductive approach necessitates observation of the phenomena of interest as they would normally occur, including its typical socio-cultural environment. In qualitative studies, the context in which events occur can be as significant as the events themselves. In this study, the natural setting has two key advantages. First, it allows us to examine how participants develop the problem space that becomes the context for subsequent problem solving and decision making. In a laboratory study, participants are usually given a predefined task along with a structured set of information to use in arriving at the solution. This makes sense when the scope of the task and accompanying information has an independent foundation, typically a well-developed theory. A complex task such as distributed medical cognition lacks an underlying theory to guide the parsing into predefined tasks. Using a natural setting allows for fluid examination of emerging issues such as how patients determine the
nature of a problem or realize the need for a decision. Second, when theory leads to
to changes in practice, the success of the application itself can serve as a test of the
generalizability of the theory.

Working in a natural setting necessarily changes the role of the participants and
the researcher. Just as most quantitative studies attempt to decontextualize the
phenomena of interest they try to depersonalize the results. Researchers posit that similar
results would occur with any set of participants from a similar population in any context.
Qualitative research in general and ethnography, in particular, maintains a tension
between etic⁴ and emic⁵ analysis (Pike, 1967). The researchers balance etic and emic
perspectives in different ways from entirely etic to purely emic. This study maintains an
intermediate approach aimed to represent the participants’ perspective while creating
theories that can generalize beyond the specific setting of the study (Geertz, 1977; Weis
& Fine, 2000). Often this means that the final presentation of the work focuses on a
detailed analysis of data from a small subset of participants. Similarly, quantitative
studies typically assume that the personal characteristics of the researcher are
unimportant. Certainly, this assumption has been challenged by critics of the notion of
ture objectivity (Kuhn, 1977). However, qualitative studies assume that the
characteristics of the researcher are a relevant part of the context in which the research

⁴ Research that adopts an etic approach prioritizes the perspective of the outsider in
building a domain general theory.

⁵ Research using an emic approach prioritizes the perspective of the insider to capture,
describe, and elucidate the meaningful experiences of the participants.
occurs and must be acknowledged (Shah & Corley, 2006). Appendix B includes information about my personal perspective and its impact on the study.

Quantitative and qualitative research efforts have different goals, settings and methods and consequently require fundamentally different criteria for judging the quality of a study and the validity of its findings. In most quantitative studies, the core standards for judging the validity of results are reproducibility and statistical significance. These standards are not appropriate for judging qualitative work. Qualitative studies are not replicable because they occur in real world settings at particular moments in time. Even when two researchers examine the same pre-extant data set, they are not expected to arrive at identical conclusions because characteristics of the researcher are expected to affect the analysis. Does this mean that results are arbitrary and completely ungrounded? No. It simply means that by including the full environmental context the data set becomes too rich to be encapsulated fully by any one theory or description and different researchers will tend to focus on different elements and relationships. A well-executed study resulting in a properly grounded theory presents something that is true albeit inherently incomplete. This is akin to asking several people to describe the events that occurred during a party. Even if all the descriptions are completely accurate, one would expect every description to be slightly different from all the others but with large areas of overlap.

Similarly, statistical significance is not an appropriate standard for judging qualitative work. This is obviously the case because it requires quantitative data, but is true on a theoretical level as well. Statistics are designed to verify broad generalizations
which inherently erase the individual and contextual factors that are core to most qualitative research. In fact, one of the major criteria for judging the quality of many forms of qualitative work, including ethnographic studies (Fetterman, 1998; O’Reilly, 2012), is that the resulting analysis retains a sense of the phenomenological experiences of the participants, which are inherently individual. The reader of the study should have a clear sense of the experience of the participants and how that experience connects to the theory presented. In this study, extensive presentation of examples, along with accompanying analysis, provide the thick description need to support a strong theoretical argument.

Research tied to individuals and circumstances begs the question of how results generated from such specific data have bearing beyond the specific reference case. Researchers infer generalizability by finding that elements of a theory that hold true in one case are true in others despite variability in specifics. In particular, qualitative researchers consider triangulation (finding similar phenomena across multiple cases) strong evidence for supporting a conclusion (Moran-Ellis et al., 2006). The evidence can come from similar findings across studies or by comparing different settings or individuals within the study.

In this study, the specific points made in each of the results chapters applied to multiple participants. In addition, the major theoretical points are supported by findings from the separate analyses presented in the results chapters, which constitute a means of triangulation via convergent measures. Finally, certain key points are connected to similar conclusions I reached in working with people who have diabetes (Lippa, Klein &
Shalin, 2009) or confirmed by comparison with data collected by Markus Feufel (Lippa et al., 2016). These studies are not directly addressed but are cited for comparison.

**Major Philosophical Issues**

Implicit in the different methods and standards for judging validity described above are some substantial philosophical issues. Similarly, there are philosophical issues within each of the disciplines I draw on that have an impact the choice of methods and interpretation of results. I have not designed this study to support directly any philosophical perspective. However, this study touches upon larger philosophical debates, concerning basic ontology, the nature of language, and the nature of cognition. Therefore, the discussion below briefly locates the philosophy undergirding the analysis.

**Basic Ontology**

Questions of ontology, what exists in the world and is appropriate to study, undergird all scientific endeavors. In psychology, major ontological questions include defining constructions such as thought, behavior, perception, social interaction, symbols, meaning, etc. Scholarly traditions define each of these constructs in different ways, so that behaviorist, cognitive psychologists, psychoanalysts and neuropsychologists all have different ontological perspectives. The research tradition includes certain ontological assumptions that inform the resulting work. Because this study does not descend directly from a single discipline, I take this opportunity to define my basic ontological perspective within the realm of social science philosophies.

Broadly speaking, this study adopts the framework of symbolic interactionism (Blumer, 1986). This framework suggests that people actively construct symbolic
representations of reality through language in the form of internal dialogues and social interactions. These representations, rather than an external objective reality, form the basis for human action, and they can be revised continuously based on their pragmatic value in the current situation. Most studies that adopt symbolic interactionism look at the social construction of individual or group identities or social structures. However, Engeström and Middleton (1996) have brought together work looking at a wide range of applied domains, including transportation, production facilities, and scientific investigation, that, broadly speaking, fall under a symbolic interactionist framework. This study is of that ilk with the primary focus of social constructions of reality being diagnoses and illness states rather than more personal forms of social identity.

In looking at the specific social construction of medical representations, I have found two more specific ontological arguments to be valuable: Habermas’ (1984) theory of communicative action and Dennett’s (1987) concept of intentionality. Habermas suggests that rationality is an inherent property of linguistic interaction, especially argumentative interactions, in which participants actively engage and try to create a mutual understanding by presenting and critiquing the validity of each other’s claims. Habermas’ discussion of the multiple forms of argumentation and their bearing on the social construction of understanding and social judgments has informed the analysis here of the dialectical processes involved in practitioner-patient interactions. Similarly, Dennett’s (1987) formulation of intentionality as being both an object subject to manipulation and an explanatory proposition informs the analyses how of patients and practitioners use verbal representation in causal reasoning and the concept of a socially defined problem space, suggested in the analysis of decision making.
Linguistic Concerns

The properties of language as a representational medium: This study focuses on clinical decision making but uses entirely linguistic data. Although human factors tends to emphasize more technologically intense forms of representation, language is a rich multi-faceted representational medium (Clark, 2006). As a form of representation, the properties of language fall into three dimensions: syntax, semantics, and pragmatics.

Syntax refers to the organizational properties of language, such as grammar, that structure language without providing any inherent meaning. In this study, syntax is significant because syntactic rules govern how participants connect concepts and in some cases the choice of syntax has pragmatic significance. For example, even though questions as a syntactic form are neutral, in a particular context asking a question may imply doubt.

Semantics refers to the meaning associated with language including both the referential meaning (the object(s) to which a word is linked) and the intentional meaning (what the speaker wishes to convey with the word). In patient-practitioner interactions, the lay-professional gap causes unique semantic challenges, because practitioners use a technical lexicon that may be incompatible with patients’ colloquial approach to discussing illness. The ways patients and practitioners establish (or fail to establish) the shared points of reference necessary to engage in effective clinical cognition are an ongoing concern throughout the analysis.

Pragmatics refers to the context-dependent properties of an utterance. The pragmatic elements discussed in this study largely refer to the functional significance of statements in a particular context. Even when participants use the same language, the
functional significance of statements may vary depending on the context. In this study, utterances are discussed in terms of their pragmatic significance for accomplishing cognitive functions. For example, the question fragment “Any weakness?” might be a routine question about recent symptoms, serve to test a diagnostic hypothesis, or be used to verify the efficacy of treatment.

*Language as a measure of cognition.* In approaching the relationship between language and cognition, I focus on how verbalization fulfills the cognitive demands involved in clinical reasoning. I discuss language as functioning in relation to the external environment and ongoing interaction (Searle, 1995; Steffensen, 2013) rather than as it relates to mental correlates of linguistic forms (Chomsky, 1957; Fodor, 1975). In particular, I describe language as active (Austin, 1962; Searle, 1969; Searle, 1995), meaningfully constructed (Grice, 1991) and situationally bound (Barwise & Perry, 1983). I take as a premise that language not only conveys information but that speaking itself constitutes action in the world. I follow Austin’s (1962) assertion that speech may be directly performative (e.g. a legal proclamation) and/or illocutive, but action is limited to the direct interaction. In the latter case, Searle’s (1969) extension of this notion to include illocutionary force, the idea that how something is said can be as significant for the action involved as the content of the utterance, becomes especially relevant for certain analyses.

Similarly, I accept Grice’s (1991) argument that language is produced and interpreted not only in light of the lexical content of the utterance but the speaker’s intended meaning and the listeners understanding of the speaker’s intent. As an
outgrowth of this philosophical argument, I follow Cicourel’s (2006) position that just as language comprehension requires some understanding of the speaker’s meaning, analyzing language can provide a tool to assess speaker cognition. This use of language bears certain similarities to protocol analysis (Ericsson & Simon, 1993) in that both suggest that language reflects underlying cognition. However, there are certain key differences. Protocol analysis assumes that verbalization is a relatively direct, cognitively neutral process that does not significantly impact underlying cognition. I adopt the position that verbalization reflects cognition because it is integrated into distributed cognitive functions (Cicourel, 2006; Steffensen, 2013). Similarly, in protocol analysis, verbalization is divorced from the task and supposedly excludes any social or interactive context, whereas I discuss language as an integral part of the task and embedded in the specific context of the interaction.

Finally, I assume that understanding the nature of the interactions requires understanding the context in which they occur (Cowley, 2011; Gee, 2010) this includes local context for the interaction, the larger sociocultural context, and the participant’s backgrounds. This view of language has a couple of key implications. First, it means that analysis focuses more on language use in relation to particular pragmatic, interpersonal, or cognitive goals rather than on the specific semantic and syntactic structures employed. This focus is especially evident in the discussions of narrative in chapter 7 and definition of decision parameters in chapter 5. And second, it requires that the analysis extends beyond the most localized assessment of particular utterances to include context from the interaction taken as a whole and to some extent contextual factors beyond the particular interaction.
Nature of Cognition

Just as a particular understanding of language affects the scope of analysis, this study employs particular ideas about the nature of cognition. In this respect, I adopt the notion of distributed cognition from psychology as a paradigm. Fundamentally, distributed cognition proposes that thought occurs not just within individual minds but as an emergent property of interactions among individuals and elements of their social and physical environment (Clark, 1998; Hutchins, 1996). In many ways, this perspective corresponds to symbolic interactionism’s premise that meaning is negotiate by individuals interacting in a formative socio-cultural environment (Blumer, 1986), but it extends these claims by suggesting that not only are meanings contextually derived but that processes of mind can be said to occur in a similar way. There has been some debate about where the mind can be said to exist within the framework of distributed cognition (Sutton, 2006). In this work, I assume that mind, or at least cognition, can be said to be both individual and a product of a distributed system. I assume that the localization of cognition is not a dichotomy (i.e., individual versus distributed) but rather a continuum, ranging from primarily individual to highly distributed processes. Also, I suggest that cognition can occur simultaneously at both an individual and a distributed level and that the appropriate level of analysis depends on the nature of the focal issue. As such, at different times, I speak of both individual cognition and distributed cognitive systems.

Similarly, I discuss cognition as functioning on a variety of levels. Many activities occur at different levels of decomposition. For example, if I write the letter ‘a’ on paper I am writing in the sense that I have physically formed an alphabetic symbol. If I write a simple sentence like ‘The girl jumped,’ I can still say I am writing, but now the
term ‘writing’ incorporates an additional level of complexity involving issues of phonology, semantics and grammar. Finally, if I compose an essay, I am ‘writing’ in a way that incorporates prosody and exposition. Similarly, I discuss cognition on a variety of levels. At the most basic, I refer to cognitive elements such as attention and memory (Medin, Ross, & Markman, 2005). In the clinical context, these elements are leveraged and combined to execute ‘cognitive functions’ that constitute the mental work necessary for clinical tasks. Finally, I refer to ‘clinical cognition’ as a general term when discussing issues that span multiple cognitive elements and/or functions; this usage aligns with other research in this domain (Crosskerry, 2009).
Chapter 3: Methods

The following chapter provides detailed information on the methods of data collection and analysis that apply to the entire study. Subsequent chapters provide additional information regarding methods of analysis pertaining to specific findings.

Methodological Perspective

This study uses a hybrid approach combining elements of ethnography, grounded theory and discourse analysis. Understanding medical decision making in context is important for the design of medical systems. Developing such an understanding requires a combination of medical practice knowledge and a strong theoretical conceptualization of medical cognition. A single method does not address both practice and cognitive theory development. Accordingly, I chose to use ethnographic methods for data collection in the field and to analyze the data using tools and principals from grounded theory and discourse analysis. I used grounded theory to generate a more comprehensive theoretical approach to the cognition involved in medical decision making through iterative, conceptual coding and the creation of multiple levels of supporting analysis. Because the data were primarily in the form of dialogue, I used discourse analysis as a tool for analyzing the conversations. Table 1 summarizes my general methodological approach in comparison to the primary methods used. In Table 1, the primary methods I used are presented in columns with my approach on the far right. The rows list various aspects of the practice of qualitative research with brief descriptions of how each method approaches them. In general, relative to an experiment, unobtrusive observation provides data along with interviews. Grounded theory and my use of it is relatively more focused on particular research questions. For a more detailed point by point comparison of the
methods in this study see Appendix C. A more detailed explanation of “my approach” appears later in this chapter.

**Table 1. Comparison of methods**

<table>
<thead>
<tr>
<th>Approach</th>
<th>Ethnography</th>
<th>Grounded Theory</th>
<th>Discourse Analysis</th>
<th>My Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Based on O’Reilly (2012)</td>
<td>Adapted from Starks &amp; Trinidad (2007)</td>
<td>Adapted from Starks &amp; Trinidad (2007)</td>
<td></td>
</tr>
<tr>
<td>Original Discipline</td>
<td>(Cultural) Anthropology</td>
<td>Sociology</td>
<td>Linguistics</td>
<td>Cognitive Ergonomics</td>
</tr>
<tr>
<td>Philosophy</td>
<td>Social life is the outcome of interactions of agency and structure in daily life and can best be understood by immersion in group practice.</td>
<td>Theory is discovered by examining concepts grounded in data</td>
<td>Knowledge and meaning are produced through interaction with multiple discourses</td>
<td>Applied and basic research are mutually informing. Cognitive science theory can be discovered by relating concepts grounded in field data to fundamental cognitive processes.</td>
</tr>
<tr>
<td>Goal</td>
<td>Holistic understanding of social groups</td>
<td>Develop an explanatory theory of basic social processes</td>
<td>Understand how people use language to create and enact identities, activities and relationships</td>
<td>Develop an explanatory theory of cognition in natural environments; support design and execution of critical cognitive tasks</td>
</tr>
<tr>
<td>Basic Question</td>
<td>What is the experience and practice of a focal social group?</td>
<td>How does a given basic social process happen in a specific context?</td>
<td>What discourses are used and how do they shape focal issues?</td>
<td>How does a particular cognitive task occur in the relevant work environment?</td>
</tr>
<tr>
<td>Sampling</td>
<td>Those within the focal community</td>
<td>Those who have experienced the phenomenon under various conditions</td>
<td>Those situated in the discourse(s) of interest.</td>
<td>Those engaged in the focal task purposively sampled to capture a range of experience</td>
</tr>
<tr>
<td>Observational Techniques</td>
<td>Extended participant observation</td>
<td>Observe participants where social processes occur.</td>
<td>Observe participants in conversation in their natural environment</td>
<td>Brief participant observation in the task environment</td>
</tr>
<tr>
<td>Interview Techniques</td>
<td>Variable</td>
<td>Both engage in dialogue; interviewer probes for intertextual</td>
<td>Participant describes experience; interviewer probes</td>
<td>Participant describes task performance and critical incidents; interviewer probes</td>
</tr>
</tbody>
</table>
### Analytic Methods

**Variable**

- Iterative coding, concept development and theory construction based on integrating concepts into core categories & relations
- Analysis and data collection occur simultaneously or in iterative cycles

**meaning**

- Close examination of language focusing on how specific linguistic elements construct meaningful identities, activities and relationships

**for detail, clarity**

1. Iterative coding and concept development
2. Examine concepts across properties and dimensions to develop an explanatory framework
3. Reinforce explanatory framework through quantitative and/or discourse analysis

### Role of Researcher

**Reflexive understanding of personal perspective and influence**

**Bracket views**

- Examine own place in discourse

**Bracket Views**

### Product

**Thick description that is holistic and includes, at least, some emic perspective**

**Theory generated from the range of participants’ experiences**

**Description of language in use and how it is related to socially constructed meaning**

**Thick description of task performance; theory of cognitive functions supporting task; some degree of theoretical reflection on basic cognition**

### Common Quality Criteria

- Holistic description
- Resonance with participants
- Reflexivity (Fetterman, 1998)

**Credibility (from triangulation, saturation, and coherence)**

**Reflexivity**

**Convergence**

**Attention to linguistic detail**

**Resonance with participants**

**Originality** (for domain and development of cognitive science)

**Usefulness**

- Credibility (from triangulation, saturation, and coherence)
- Originality (for domain and development of cognitive science)
- Usefulness

### Development of Research Questions

This research began with the general question:

**Research Question 1:** As a cognitive process, how are medical decisions shared?
Preliminary analysis of the data showed an interplay between how practitioners and patients conceived of problems and approached decisions. Capturing the cognitive significance of these exchanges seemed like the first step to understanding shared decision making. Background reading suggested that distributed cognition provided a conceptual framework for understanding how this intersection could translate into a shared cognitive process. When I conducted a more targeted literature search, I found that Epstein (2013) had offered a similar speculation but had not developed it empirically. This line of reasoning led me to adopt the notion that shared decision making is a form of distributed cognition in which practitioners and patients are the primary cognitive agents.

During data collection, I observed that the vast majority of the interaction between practitioners and patients occurred through dialogue. The back and forth interplay of this dialogue seemed like the interface between patient and practitioner cognition. This led to me to adopt the idea that shared decision making occurs, at least to a large degree, through discourse. This allowed discourse to serve as the measure of distributed cognition.

Because of the lack of definition of the target phenomenon, I began the research process with a very broad question designed to capture the target phenomenon and as much of its context as possible and to test my initial conceptualization of the practitioner-patient interaction.

Research Question 1a: Do practitioners and patients engage in distributed cognition? If so, how does that manifest in their discourse?
I address these questions through the task analysis found in chapter 4. Results supported my basic conceptualization of practitioner-patient dyadic cognition. In addition, this analysis showed interrelationships between different clinical, cognitive tasks and considerable variability in task distribution. This prompted exploration of the following more focused questions:

**Research Question 1b**: How is decision making positioned within the flow of distributed clinical cognition?

**Research Question 1c**: What determines the distribution of cognitive processes during shared decision making?

Chapter 5 addresses these questions. The results of these analyses suggested that at least during decision making, patients and practitioners cognitive processes were inherently interdependent and that coordination required verbal representations. Fully exploring these issues would be a monumental task. Accordingly, one specific component of each was selected for further examination. Namely:

**Research Question 1d**: How does patient expertise affect distributed clinical cognition and practitioner reasoning?

**Research Question 1e**: How do patients and practitioners use narrative as a representational component of a distributed cognitive system?

Chapter 6 addresses research question 1d. Although this research question only addresses one specific patient characteristic, it supports the fundamental inference that how patients think about illness affects dyadic and practitioner cognition. Chapter 7
addresses research question 1e. This question is limited in scope but answering it supports the importance of verbal representations in shared decision making. It also provides a vehicle to explore some of the functional significance of these representations.

In summary, I have addressed the broad question of distributed cognition associated shared medical decision making with little prior supporting research. Accordingly, rather than beginning with a well-defined theory and testing it, I began with a broad conceptualization of the domain (RQs 1a). This first analysis yielded results that allowed for the more theoretically driven secondary (RQs 1b & 1c) and tertiary (RQs 1d & 1e) analyses, each of which elaborated on and supported the earlier analyses. Taken together all of the analyses address the basic research question and allow for the development of a theory of the cognition involved in shared decision making. Future work can use this theoretical framework to construct more specific testable hypotheses.

Site and Participants

Site

I collected data for this study through a center specializing in Multiple Sclerosis attached to a clinic for neurological disorders and neurosurgery. The entire clinic is part of a large, Midwestern medical school. The MS center is committed to providing an exceptionally high standard of care to their patients. In addition to their consultations with practitioners specializing in MS, patients receive help coordinating other care services such as diagnostic testing, physical therapy, social service assistance and care by other specialists directed at specific symptoms (e.g. pain or urinary problems).
Initial appointments last 1-1.5 hours and include a neurological assessment to confirm an MS diagnosis, education about MS, and formulation of a treatment plan. For routine appointments, patients alternate between hour-long sessions with a nurse practitioner and 20-30 minute appointments with a neurologist. Typically patients will see the same neurologist for as long as they receive care at the center. However, at the time that data were collected for this study, one of the neurologists had recently left so several of the patients participating were switching between practitioners within the center.

Routinely, most patients are seen 2 to 4 times a year, depending on the severity of their case. Additional appointments are scheduled as needed. Between appointments, patients can contact the clinic by phone for assistance with medication management and support during mild to moderate flare-ups.

Participants

Three practitioners and twenty-three patients participated in the study. Two of the three practitioners were doctors specializing in M.S. Both physicians had completed residencies and fellowships in neurology and were board certified in psychiatry and neurology. In addition, to clinical practice, they both conducted research on MS and related conditions. The third practitioner was a nurse practitioner who was certified in family medicine and had worked for two years primarily with MS patients.

Of the twenty-three patients, nineteen were female and four were male. Patient participants ranged in age from 18 to 76 (mean = 43) years. Twenty-one of the patient participants were white and two were African American. Three participants had a high
school education or less, seventeen had taken some college credits or completed college, and three had post-graduate degrees. This demographic profile closely matches population estimates for MS in the United States (Avasarala et al., 2007) except for being more educated than average.

Patient participants ranged in time since diagnoses from those newly diagnosed to those having lived with MS for more than 30 years. The uncertainty associated with the process of diagnosing MS meant that several participants were unsure about how long they had MS, so it was not possible to obtain a reliable mean time since diagnosis. Fourteen of the participants had relapsing-remitting MS, two participants had primary progressive MS, two had secondary progressive MS, two had benign MS, and three did not have a clearly diagnosed disease course. Of this last group, two were newly diagnosed and it was considered too early to tell the likely course of the disease. The last participant had an ambiguous diagnosis such that it was unclear if she had MS or some alternative disorder. Participants experienced functional difficulties associated with MS that ranged from 1 to 5 on the Kurtzke Expanded Disability Status Scale (Kurtzke, 1983). Ten of the participants scored a 1 on the scale indicating minimal symptoms and no significant functional limitations associated with MS; five participants scored a 5 on the scale indicating substantial disability in several systems or an inability to work or an inability to walk. The remaining participants exhibited minor to moderate disability in one or more functional systems. Although several participants reported lapses in working memory, the practitioners reported that any cognitive decline was age appropriate.
**Procedures**

**Observations**

I spent approximately 65 hours making ethnographic observations at the clinic. During this time, I observed twenty-nine clinical sessions; patients from four of these sessions either withdrew (2 participants) or were dropped from the study because they were diagnosed with something other than multiple sclerosis (2 participants). One patient participant was observed during two appointments, leaving the final sample of twenty-three participants. In addition to clinical sessions, I observed daily operations including administrative work, social conversations amongst the staff and consultations between practitioners.

Practitioners gave consent to participate at a clinic staff meeting. Patients were approached by the researcher and asked to participate either in the waiting room of the clinic or an exam room just before their appointments. Patients who agreed to participate provided their phone number and a convenient to time to call for a follow-up interview. All participants, patients and practitioners, signed HIPAA-compliant consent forms that had been approved by the Wright State University Institutional Review Board and the Institutional Review Board for the data collection site.

If patients agreed to participate, the researcher remained in the room observing during the appointment. During the first four days of observations, I recorded the conversations between practitioner and patient and took field notes regarding particularly interesting or unusual incidents and record non-verbal behaviors. For the last four days, the audio recording was suspended at the request of the practitioner participants and
instead I took detailed notes during the sessions focused on documenting the content of the dialogue, speakers, and, where possible, the vocabulary of the conversation. Between the first four days of observation and the last four, there was a gap of two months while I revised the method of data collection to compensate for the elimination of the audio recorder. Notes of non-verbal behaviors and incidents were taken on a form (Appendix D) as soon after the session as possible.

Interviews

I conducted follow-up interviews with patients within fourteen days, the majority within ten days, of the observations. If I could not contact a participant within fourteen days, the follow-up interview was omitted. I failed to contact four participants; the study includes observational data from these participants even though I did not interview them. Interviews occurred over the phone at a time that was convenient for the participants. Interviews lasted between 15 minutes and an hour and 10 minutes, with the majority of interviews lasting between a half hour and an hour. During two interviews, the participant had to hang up the phone, and complete the interview during a second call.

At the beginning of each interview, the researcher reintroduced herself and verified that the participant was still willing to talk about his appointment and that it was a good time for him to talk. Then a series of semi-structured questions was asked. These questions followed a standard interview guide (Appendix E). However, the specific order and wording of the questions varied so as to maintain a natural a flow of conversation. Standard questions probed the participant’s history with MS, past and current experiences living with MS, and current understanding of MS. For example: “Could you tell me
about the events that led up to your diagnosis?” “What is it like for you right now living with MS?” and “How would you explain MS to someone who didn’t know anything about it?” In addition, participants answered customized questions about symptoms and incidents described during the clinical session and decisions made during the clinical session. For example, I asked a participant who reported “playing with” (independently changing) his medications because he felt they were ineffective: “when you started playing with the Mirapex and the Stalevo, was there something that made you decide that it’s time to test out and see whether this is working?” Another participant was asked: “I think you mentioned having problems with fatigue? Could you tell me about that?”

Interviews included discussion of any additional issues that arose during the session. At the end of the interview, the participant provided any demographic information not obtained during observations. The most common missing demographic information concerned the participant’s educational level.

Transcription

The taped clinical sessions and interviews were transcribed using a literary transcription approach designed to capture the meaningful content of the interviews (Kowal & O’Connell, 2004). Transcripts recorded all the words participants used in their original phrasing, content free utterances such as ‘uh,’ ‘mm,’ and laughter. Transcription did not include a provision for recording pauses or intonation.

As soon after collection as possible, I typed an elaborated the field notes. Elaboration involved expanding notations to full sentences and filling in context as appropriate. The unelaborated notes were retained for comparison as necessary.
Coding Procedures

I began the analysis with a period of open coding and memoing (Charmaz, 2006; Strauss & Corbin, 2008). This analysis was unmotivated. Apart from a general interest in decision making, I focused on inductively parsing the data collected. I used Atlas.ti to assign codes to segments of dialogue (Silver & Fielding, 2007) some of these codes were descriptive (e.g., ‘discussion of MRI’) while others were conceptual (e.g., ‘persuasion’ or ‘explanation’). During this coding process, I wrote memos regarding the significance of particular pieces of data, emerging patterns, relationships between elements within the data and nascent theories (Birks, Chapman, & Francis, 2008). At the end of this process, I had a good sense of what the data looked like and some of the issues and themes that Recurred throughout the data set. I then used the constant comparative method (Glaser, 1965) to refine the coding by removing codes that were tangential to the issues I wished to focus on, collapsing overlapping codes and developing conceptual relationships between individual codes (e.g., causal explanations, diagnosis, and explanation were logically and functionally connected). This phase of coding did not directly generate any of the analyses, but it provided the preliminary steps for more focused exploration of particular issues.

In some cases, the open coding was followed by focused inductive coding (Charmaz, 2006). This phase of coding focused on a particular issue identified in earlier analysis and was designed to identify one or more core categories with the power to explain the target phenomenon (Glaser & Holton, 2004). For example, to begin the decision making analysis I began with a focused coding of just the segments of dialogue in which decisions were made and with a specific interest in the process of decision
making and the roles participants adopted. This type of coding was still heavily inductive. It was data driven and if a particular category proved unfruitful, the analysis was modified or abandoned. For example, at one point I tried coding around the issue of mental models. However, because the idiosyncratic course of the disease and stochastic disease symptom relationships in MS, I found that framing the patients’ understanding of MS in terms of mental models was not productive and abandoned this concept as a focus of analysis.

After the focused coding, in each of the analyses I used some form of selective coding (Strauss & Corbin, 2008; Glaser & Holton, 2004). This involved systematic, top down application of codes that were either developed inductively or derived from background research. For example, focused inductive coding on decision making identified ‘decision parameters’ as a key concept, so I selectively coded all the decision for this concept. This level of coding identified clear, consistent patterns in the data and allowed me to compare quickly different instantiations of target phenomena. In some cases, I chose to have a second coder apply the selective codes as well to get reliability data either so that I could make quantitative claims about the data or to verify the validity of a developing construct.

The focused and selective coding along with ongoing memoing allowed for the creation of theoretically motivated connections – conceptual links between codes, coded segments or elements of the data that allow for the construction of a theory surrounding the focal phenomenon. For example, to derive the distribution of cognitive functions in chapter 4 a major part of the analysis involved memos about the utility of specific
statements for clinical reasoning. How theoretical connections were drawn varied depending upon the analytic focus. Although I used software for the open coding, I did most of the focused coding, selective coding and theory building by hand.

*Discourse Analysis*

I used discourse analysis (Gee, 2011; Willig, 2008) in two ways. In some of the analyses, I used discourse analysis as an inductive tool during the focused coding phase or as a means for uncovering semiotic relationships during the theory construction phase. By looking closely at the dialogue in terms of the multiple layers of meaning and context involved in discourse, I became more aware of the issues involved, how they were enacted and their functional and conceptual significance (Willig, 2000). In addition, I used discourse analysis (or in the narrative a similar hermeneutic analysis) as a way to provide a thick description of the patterns, concepts and connections uncovered during coding.

*Privacy Protections*

Ethical concerns and legal constraints require that patients’ health information remain private (Department of Health and Human Services, 2004). However, qualitative research methods depend on rich data and advocate maintaining a sense of the phenomenological experiences of the participants. This creates a tension between the need to depersonalize data to protect participants’ privacy and the need to retain the richness and context necessary for high-quality research. To balance these concerns, I have generalized a strategy that HIPAA guidelines recommend for documenting participants ages (Department of Health and Human Services, 2004). Rather than
providing specific ages, when possible, researchers are encouraged to group participants into age brackets. Accordingly whenever I provide a quotation from a patient, the patients’ characteristics are described in terms of four general categories: age bracket (by decade), approximate time since diagnosis (1-2, 3-5, or 5+ years), level of disability (minimal, moderate, or severe), and level of education (high school, college, or graduate). This level of background about participants should be sufficient to understand the context of the interaction without individual identification.

Similarly, providing large numbers of lengthy examples could support the generality of the findings. However, to protect patient privacy, I have tried to limit the amount of verbal data reproduced for each participant. Because only ten of the clinical sessions were audio recorded, I occasionally either use the same passage twice in relation to different topics or use data from interview and session notes rather than the more direct support provided by transcripts.
Chapter 4: Creating a Common Trajectory: Share decision making and Distributed Cognition in Medical Consultations

Do practitioners and patients engage in distributed cognition? If so, how does that manifest in their discourse?

Introduction

A man develops congestion and sinus pressure. After a few days, he thinks he might have an infection and goes to see a practitioner. The practitioner takes a medical history, conducts a physical exam, diagnoses a sinus infection, and prescribes an antibiotic. This common scenario raises a complex question. Who makes diagnostic and treatment decisions? Patients who decide to seek care often with possible explanations for their symptoms? Practitioners who record diagnoses and write prescriptions? Practitioner-patient dyads that exchange information through the clinical encounter? All of these elements contribute to clinical reasoning. Medical diagnosis and treatment emerge from a complex process that includes multiple actors thinking and interacting with the physical world and with one another.

In this chapter, I explore the idea that the multiple elements involved in clinical cognition constitute a distributed cognitive system centered on practitioner-patient interactions and examine how this system functions during clinical sessions focused on Multiple Sclerosis (MS) management. In the remainder of this introduction, I briefly

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6 This chapter presents a slightly modified version of a paper by the same name submitted to the journal Patient Experience.
overview trends toward increasing patient involvement, background on the nature of distributed cognition, current work on medical discourse and the nature of MS. I then use a combination of task analysis and discourse analysis to trace the distribution of cognitive functions between practitioners and patients during the clinical interactions involved in MS management. Finally, I discuss the implications of this analysis for the conceptualization of shared decision making.

**Integrating Patients into Medical Cognition**

Traditionally, practitioners bore full responsibility for diagnosis and treatment decisions. Patients were expected simply to comply with these decisions (Gerhardt, 1990). Recently, medical culture has shifted from this practitioner-centered model to a more patient-centered approach (Thille & Russell, 2010), emphasizing shared decision making and patient perspectives (Elwyn, Frosch, & Thomson, 2012; Epstein, 2013). The exploration of ideas about patient engagement and activation has begun to extend the role of patients beyond localized decisions to greater integration through many aspects of clinical care (Bernabeo & Holmboe, 2013; Elwyn et al., 2014).

In addition to social and ethical concerns, patient-centered care allows for a greater integration of practitioners’ and patients’ contributions to clinical reasoning. Practitioners and patients inherently have access to different information about the patient’s status and different repertoires of action. Patients have details about their phenomenological experience and case history whereas practitioners have abstract biomedical knowledge. Similarly, patients engage in direct self-care, but practitioners have the authorization to provide access to various treatments. Epstein (2013) suggested
the distribution of clinical cognition during shared decision making and it is implicit in models of patient activation (Hibbard & Greene, 2013). However, little empirical work has been done on patient cognition or on how practitioners and patients collaborate during clinical cognition. This chapter draws on two research paradigms (distributed cognition and medical discourse analysis) to show that practitioners and patients engage in distributed cognition throughout the clinical interaction with both actors contributing to the majority of clinical reasoning tasks.

**Distributed Cognition**

Most thought is highly contextualized. It is influenced by the setting in which it occurs, the people who are in the social environment and the objects that are available for manipulation to simplify cognitive functions. This reality has prompted researchers to adopt a notion that in some, maybe even most, cases cognition in the world is not a process that occurs locked in one individual’s mind but rather one that is distributed between a person and his social and physical environment (Hazlehurst, 2011; Hutchins, 1995). The paradigm of distributed cognition concerns how thought processes are distributed across individual and groups, humans and technical artifacts and space and time.

Studies of medical cognition have typically analyzed practitioner reasoning as isolated from the social context in which it occurs (Monteiro et al., 2015; Sherbino et al., 2014). However, many diagnostic processes and treatment decisions involve interaction between practitioners and patients. The paradigm of distributed cognition provides a framework for assessing the impact of this interaction on clinical reasoning.
In the medical domain, research has captured interactions amongst health care providers and between providers and technical artifacts as distributed cognitive systems (Engeström, Engeström, & Kerosuo, 2003; Pimmer, Pachler, & Genewein, 2013). These studies point to the fact that medical reasoning does not occur in isolation but relies on interactions with multiple professionals. However, researchers have failed to consider the contributions of patients to clinical reasoning.

Nevertheless, patients are key actors in the medical system, especially in caring for chronic diseases. Patients with complex medical conditions are often responsible for substantial self-management and making real-time judgments/decisions about their care when unusual events or novel symptoms occur. To engage in self-care, patients necessarily must develop some understanding of the disorder and their bodies in the context of the disorder. The specifics of this understanding can affect patient decisions about disease management (Lippa, Klein, & Shalin, 2008; Thorne, Paterson, & Russell, 2003).

*Medical Discourse*

Dialogue is a crucial part of medical consultations. Analysis of practitioner-patient interactions reveals a standard structure to medical consultations, including an opening to the visit, a case history, a physical exam, an education/counseling phase and a closing to the visit (Roter & Hall, 2006). Research examining conversations between practitioners and patients has not generally focused on cognition, but certain findings suggest patients’ speech impacts practitioners’ understanding of symptoms and selection of treatments (Cordella, 2004; Stivers, 2002). Understanding this discourse is critical
because words are a medium of collaborative reasoning. I suggest that as patients and practitioners interact across the clinical interview, with each turn they contribute information and reasoning to a mutually constructed trajectory of clinical cognition. From the perspective of assessing dyadic practitioner-patient reasoning, this means that dialogue effectively acts as a natural think aloud protocol providing access to distributed clinical cognition. In the analysis below, I use dialogue to track the distribution of cognition between practitioners and patients throughout clinical encounters focused on Multiple Sclerosis (MS) management.

*The Case of Multiple Sclerosis*

MS is a chronic disease of the central nervous system requiring complex judgments and decisions. Because of the stochastic relationship between symptoms and disease processes, interpreting the significance of illness episodes requires judgments about relevance and causality. Treatment decisions involve how to 1) deter disease progression and 2) manage symptoms. These judgments and decisions require at least a neurologist and a patient and may involve family and additional medical specialists.

To analyze the distribution of cognitive functions in MS management, I begin by decomposing the cognitive work done during a typical MS management consultation into a series of clinical tasks. I then use discourse analysis to examine the distribution of cognition that occur during segments of dialogue surrounding the key tasks. This analysis challenges the assumption that patients have little, if any, role in clinical cognition by illustrating the numerous ways in which patients participate in clinical
reasoning. Finally, I discuss the implications of these findings for understanding distributed cognition, medical discourse and the shared decision making paradigm.

Analytic Methods

The analysis began with open coding and memoing for the entire data set (Strauss & Corbin, 2008; Charmaz, 2006). The coding process focused on inductive identification of concepts and categories including topics of discussion, interaction styles, discourse elements, and indications of cognitive processes. The memos were used to note comparisons, impressions and potential theories for later development (Birks, Chapman, & Francis, 2008). From this initial coding it was clear that a) the clinical sessions varied considerably in terms of how tasks were accomplished and the ways in which participants interacted and b) that tasks that are typically described as distinct (e.g., diagnosis and treatment) were intermingled.

Unlike regimented domains, such as aviation (Hutchins, ), MS management does not have an institutionally imposed task structure. Therefore, examining the cognition involved in MS management requires first deriving a general organizational structure for the domain. To provide this structure, I created a cognitively oriented work analysis (Schraagen, Chipman, & Shalin, 2000; Vincente, 2009) that represented the tasks involved in a consultation for MS on a general level. I began the analysis by conducting a second inductive analysis in which I coded each interaction line by line according to the topic (e.g., MR images) and purpose of the utterance (e.g., diagnosis). This provides a detailed process trace for each interaction. I used Banxia Decision Explorer to create visual maps using the codes to trace the progression of the interaction and the
connections between topics (e.g., from reviewing test results to assessing the patients status). I aggregated and pruned the visual maps to create a representation of common nodes and connections. I then developed concepts surrounding the nodes. In this process, I eliminated nodes that occurred in isolation and aggregated nodes that were functionally equivalent into higher level concepts (e.g. use of narcotics, over the counter pain reducers, acupuncture and referral to a pain clinic were all subsumed under the concept ‘pain management’) (Strauss & Corbin, 2008). These concepts in turn were grouped into categories (e.g. the concepts involving treatment for specific symptoms were categorized as instances of ‘symptom management’). Some categories subsumed a large number of concepts (e.g. ‘symptom management’) and others included few concepts (e.g. ‘physical exam’). In parallel, with concept and category development I traced the connections between the evolving concepts/categories. In the earliest representations, the connections largely were derived from the temporal flow of individual interviews. During aggregation these connections became more conceptual based upon which concepts/categories provided informational input or pre-requisite judgments/decisions for other concepts/categories. The composite diagram began as a plan-goal graph, but the plan/goal distinction did not seem well suited to the data so the final version represents a set of connected cognitive functions that formed a trajectory. Finally, I drew connections between my representation of the cognition involved in MS management and core constructs from cognitive science and a common stage model representation of the clinical interaction (Roter & Hall, 2006).

I then used discourse analysis methods to explore how these tasks were achieved through dialogue (Cicourel, 2006; Gee, 2011; Willig, 2008), focusing especially on the
contributions of each actor. Because each interaction was unique, the specific
distribution of cognitive functions varied considerably from interaction to interaction. I
selected the examples and accompanying analyses because they represented modes of
interaction that occurred in multiple patient-practitioner interactions and clearly
illustrated how the patient’s cognition was a substantial factor in clinical reasoning. The
analysis was intended to demonstrate the existence of and to explore the opportunities for
practitioner-patient distributed cognition rather than to represent all clinical interactions.
Given the exclusive focus on practitioner reasoning in research on clinical cognition,
evidence for the distribution of clinical cognition between practitioners and patients is
relevant even in the absence of a quantifiable estimate of the frequency of specific
interaction types.

Results

Task analysis preserved a distinction between two inter-related sets of clinical
cognitive functions in each session; one focused on the progression of the disease and the
other on symptom management. Monitoring the physiological progression of the disease

7 Chapters 5 and 6 include discussions of the factors affecting which interactions were
practitioner dominated versus patient driven.

8 Neurologists consider MS treatments in terms of three categories: disease modifying
agents, symptom management and the treatment of acute exacerbations (Cook, 2001). My
analysis reflects the disease progression versus symptom management distinction but
does not include acute exacerbations since none of the patients were currently
experiencing a crisis.
was achieved through a combination of magnetic resonance images (MRIs), neurological exams, and monitoring symptoms. Treatment followed two parallel paths, treatment of disease processes and treatment of symptoms.

Figure 1 depicts the basic task structure for MS management. The figure decomposes MS management interviews into a series of specific cognitive functions. Individual clinical sessions involved some or all of these functions depending on the particular circumstances of the patient. For example, if a patient had not had a recent MRI, there might not be a need to ‘evaluate MRI’ images. The history taking and physical exam sections are combined because the cognition involved is functionally interrelated. The labels on the right side of the figure associate the accepted stages of a clinical interview (Roter & Hall, 2006) with general cognitive elements.
As practitioners and patients proceed through the clinical session different cognitive elements (labeled on the left side of the figure) become prominent. In the initial tasks - evaluating MRIs, discussing case history, and physical examination, cognition relied on memory and selective attention. Participants had to remember relevant information from the patient’s case history and select experiences from the case history, physiological information from the MRIs and clinical observations from the physical exam meriting attention. Participants then combined the selected information into meaningful representations of disease progression and current symptoms. Participants then worked to understand the implications of these representations for...
disease status via categorization (e.g. relapse versus pseudo-relapse) and causal reasoning (e.g. visual symptoms from optic neuritis versus from migraines). Finally, participants used their understanding of the patient’s status, in terms of physiology and symptomatology, to select actions to manage disease progress and symptoms. This counters the claim that shared decision making is exclusively an issue of information exchange, communication or power.

A second point concerning Figure 1 is that cognitive elements are not localized to a discrete decision making task. Moreover, these tasks build upon each other so that as practitioners and patients progress through the clinical session they are not engaged in a series of discrete processes but an ongoing trajectory of clinical reasoning. The following results follow the flow of a clinical interview, examining each of the major tasks and analyzing the ways patients and practitioners contribute to clinical reasoning.

Case History

During the case history portion of the visit, researchers and clinicians typically have assumed that a patient presents an initial concern and the practitioner then takes control of the dialogue eliciting additional information as necessary to reach a diagnosis (Marvel et al., 1999). Interactions in this data set followed this structure superficially, but analysis showed that patients played a substantial role in defining the direction of clinical reasoning.

Discussions of case history depended on patients’ memories of past events. How patients presented remembered events influenced which aspects of the event received attention. Sometimes the patient carefully constructed a symptom presentation and/or
responded to questions so as to constrain certain paths of reasoning and promote others. The following example illustrates how a superficially neutral problem presentation may function to frame and therefore constrain the diagnostic environment.

Patient\(^9\): I guess an episode is what you’d call it. Um, where I had a visual problem. I had kind of a backwards c shape blurry spot, you know in my vision, and it lasted about ten minutes. I called is it \{assistant’s name\} and told her about it and um… And as I sat there I thought you know is it the right or the left, so {ok}\(^10\) then I you know closed my right and checked and then closed my left and checked and it seemed like it was in both, so it didn’t seem like it was in one or the other in particular. And so then I closed both eyes and you could still like when you sit down and stare at a light bulb \{uh, huh\} you still got that kind of greenish. \{yeah\} Well it was still there. I hadn’t been like staring at a light or anything.

Practitioner: Um, hum. That’s unusual.

This patient constructs his presentation to facilitate certain ways of thinking about his symptoms and constrain others. Before he even describes the specific symptom he frames it in two ways, as an ‘episode’ and as a ‘visual problem,’ each of which places constraints on the problem space. The word ‘episode’ suggests that the incident was discrete in time, neither the worsening of a known chronic problem nor the onset of something persistent that the practitioner could assess directly. The phrase ‘visual

\(^9\) Patient characteristics: 30s, college level education, 1-2 with MS, minimally disabled

\(^{10}\) {} Indicate continuing comments by the listener.
problem’ constrains the problem space to the visual system and discounting the possibility that it is an artifact of some other condition, like fatigue. Whereas the word choices may initially seem arbitrary, they are salient to diagnosing the problem, are discussed multiple times and the practitioner eventually challenges the patient’s judgment on both points. He concludes by saying that he called the clinic about the symptom when it occurred. This suggests the patient believes that the visual loss might fall within the neurologist’s expertise. Without ever saying the word ‘neurological,’ he constructs an argument favoring a neurological etiology, describing a kind of layman’s eye exam to prove that it was not localized in either eye and making a comparison to an after image, which is a neurological phenomenon. The patient had already seen an optometrist and wanted an explanation for his symptoms despite the fact that they had dissipated; he actively desired the practitioner’s engagement in this explanatory process.

In this case, the patient carefully shaped his presentation to focus practitioner attention on certain diagnostic categories and limit others. He identified critical elements of his experience (i.e., qualitative descriptions and duration), framed key parameters in his initial presentation (i.e., persistence in both eyes) and constructed his description in a way that suggested a broad diagnostic category (i.e., a neurologically based vision problem). Without challenging the culturally endorsed prerogative of the practitioner to provide diagnosis, the patient shaped the diagnostic process. Effectively, the patients’ presentation of their case histories provides the starting point and initial trajectory for clinical reasoning.
**Physical Exam**

Practitioners are typically considered to be the sole cognitive actors during a physical exam with the patient simply complying with instructions. Patients’ minimizing speech during a physical exam supports this view (Roter & Hall, 2006). When the exam was routine without motivating symptoms, conversations in this study followed the expected pattern. However, even when the practitioner was doing most of the active work with little contribution from the patient, the speech that did occur could be significant as illustrated below. Interactions with patients guided the practitioners’ attention to specific areas of concern. Similarly, when practitioners asked questions they prompted patients to attend to specific aspects of their experience and create more nuanced descriptive accounts (representations) of their symptoms. These descriptions guided further examination.

In the case below, the patient reported a non-specific sensory symptom earlier in the clinical session but could not clearly identify or describe the sensation referring to pain, numbness and lack of sensation successively. This description, although vague, pointed to an area of concern. As a result, during the physical exam, the practitioner supplemented a routine exam with more careful attention to the potential problem area.

**Practitioner:** This is on this side right?

**Patient**\(^{11}\): Yeah

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\(^{11}\) Patient characteristics: 30s, graduate level education, 1-2 years with MS, minimally disabled
Practitioner: Is that painful?

Patient: Um

Practitioner: Oh this is it. This must be tender

Patient: Yeah

Practitioner: Sometimes the muscle can kind of get clenched up like that; it’s not, I don’t think it’s MS.

The practitioner’s comments help to define the scope and nature of a symptom that the patient could not clearly define as pain not lack of sensation. The patient accedes to this definition saying ‘yeah,’ which paves the way for the practitioner to categorize the symptom as musculoskeletal rather than neurological and ultimately refer the patient for treatment at a pain clinic. The relevance categorization with respect to disciplinary responsibility is a key aspect of clinical work, and with few exceptions (e.g., Feufel, 2009) rarely recognized.

This is an interesting example of distributed cognition also because the initial complaint was prompted by the Electronic Medical Record technology. This technology changed how the practitioner and patient interacted verbally and physically. The interaction, in turn, allowed the patient and practitioner to collaborate in defining the phenomenology and physiology of a symptom that was not fully accessible to either actor alone. The role of the EMR in this instance was atypical, but practitioner-patient dyads routinely used the physical exam as a coordinating mechanism to focus attention on an area of concern and combine information about the phenomenology and physiology of symptoms. Crucially, feedback from the patient, confirming the practitioner’s
representation of the experience, permits the practitioner to categorize the symptom as relevant or not to MS.

*Evaluate MRIs*

Because interpreting MR images is a highly trained professional skill, only the practitioners have access to this information. Patient participation in this portion of the clinical sessions was largely passive with only an occasional interjected question. However, MRIs did serve to facilitate distributed cognition as an anchor for sharing reasoning and contingency planning. For example:

Practitioner: We have to repeat the MRI again and see if there are any new lesions. On Copaxone we don’t want, if there will be new lesions what we will have to do is switch the medication…

Here, the practitioner is describing the MRIs to give the patient a sense of her current disease status and then defining a decision criterion for a possible future change in medication. This type of foreshadowing based on MRI scans was fairly common. By anticipating possible future changes, the patient will be more prepared for and less resistant to altering medications. MRIs thus served as a summary of the outcome of prior decisions and a way of anticipating and communicating criteria for future alterations in the patient’s clinical trajectory. In addition, practitioners used MRIs for patient education, especially with newly diagnosed patients, as an aide in explaining the physiology of MS. For example, the patient below was recently diagnosed and had only been on medication for a few months.
Practitioner: There’s probably new ones here in the corpus callosum. It connects both hemispheres part of the brain, and you see a little bit changes here. Minimal symptoms though. We need the contrast cause the reason we need that is to check how old the spots are in the brain. Because if they’re new they pick up the contrast and they look bright not like this... We have to make sure though that the medication that you take helps prevent the new lesions.

As the practitioner evaluated her MR images, she provided basic information about the physiology of MS, the information available from MRIs and the function of disease modifying medications. As above, this reveals practitioner reasoning and anticipates the possibility of adjustments in medication.

Assess Disease Progress

Assessing a patient’s disease progress involved integrating two types of information unique to each participant into a single representation: physiological information and functional information. The practitioners assessed physiology based on information from MR images and observations during the physical exam. Patients contributed functional information about symptoms attributed to MS and background from their case history. The example below shows the parallel contributions of patients and practitioners to a shared representation.
Patient\textsuperscript{12}: I started to get some like weird pains and aches and things that kind of scared me. So…

Practitioner: Yeah. Because I see for you, you have here new spots \{on the MRI\}. So, new areas of \{yeah\} demyelination basically in hypothalamus area.

In this example, the patient first provides information about her symptoms that suggests a possible progression of the disease. Her statement “that kind of scared me” suggests that she was aware of the possible significance of the symptoms. She invites the practitioner to comment on the implications with the open-ended “so.” The practitioner provides corresponding physiological information that the MR images suggested new disease activity. Because of the stochastic relationship between physiological processes and symptoms in MS, neither the patient nor the practitioner can assess disease progression alone. The dialogue involved sharing information to create a mutual representation of the disease as progressing. This representation serves as common ground in further clinical interactions and provides a basis for assessing the patient’s status and evaluating treatment needs.

Assess Current Symptoms

Whereas assessing disease progress created a mutual representation of disease processes, assessing current symptoms created a mutual representation of the patient’s current phenomenological experience distilled from the case history and physical exam.

\textsuperscript{12} Patient characteristics: 20s, college level education, 1-2 years with MS, minimally disabled
Because of the wide variety and occasionally non-specific nature of MS symptoms, patients sometimes had difficulty making the judgments involved in creating representations of their symptoms. In the example below, the patient is uncertain about how to define and represent her symptoms, only doing so slowly through the course of the interaction.

Practitioner: Do you have any symptoms?

Patient\textsuperscript{13}: I, I don’t think so, I think they are still pretty much the same. If I have symptoms, the same.

Practitioner: What symptoms do you have?

Patient: Um, right now I could feel… In the very, very beginning I had a tight band from about here \{rib cage across torso to lower belly\}. If I looked down I’d have tingling in my spine

Practitioner: [Lermit’s sign]

Patient: What was that?

Practitioner: We call it Lermit’s sign

Patient: Lermit’s?

Practitioner: [yah, yah]

\textsuperscript{13} Patient characteristics: 30s, graduate level education, 1-2 years with MS, minimally disabled
Patient: [I didn’t know it had a name but…

Practitioner: [So you had that

Patient: and sometime I get tingling in my fingertips and lose a bit of sensation in my fingers {ok} my pinkies in both hands. Um, mainly there [points to pinkie finger and area extending from finger down into palm]. I don’t if the muscle pain I’ve been feeling in my shoulder, in like my shoulder blade area on my back. {um} Always the right side. I don’t know if that has anything to do with other than…

Practitioner: Remind me of that during the physical exam. I’ll try to palpitate it and see if it’s musculoskeletal or from MS; we’ll try to figure it out.

In this example, the practitioner asks the patient to assess her symptoms. The patient is experiencing certain sensations but is not certain whether they qualify as symptoms in this context. She begins by hesitantly denying having symptoms and then quickly revising her assessment to suggest she does have symptoms but that they are stable and hence non-problematic in this context. The practitioner presses her for more details, prompting a longer phenomenological description. Interestingly in the middle of this exposition, the practitioner interjects by labeling one of the patient’s symptoms. Although this interjection disrupts the flow of conversation, it signals to the patient that her information is pertinent. Whereas initially the patient was not sure what she had to contribute was relevant, in labeling one of the symptoms the practitioner signals that it is appropriate to this type of interaction and is sufficiently important to have a specific name. The patient apparently remains uncertain, concluding her description by
questioning whether the symptom is neurologically related and hence appropriate to the specific clinical context. The practitioner validates her concern agreeing to complete the assessment of the symptom during the physical exam.

The process of symptom assessment is important to clinical cognition as a representation that provides joint access phenomenological information. Practitioners have no direct access to many symptoms (e.g. sensory symptoms, functional difficulties experienced outside the clinic), so they depend upon patients’ representations. Assessment of current symptoms provides a starting point for identifying clinically relevant problems and the raw data for classifying their provenance and judging their relevance. By representing an experience as a symptom in the context of a neurological consultation, patients suggested that an experience was both potentially problematic and possibly neurologically based. This then opens a trajectory for clinical reasoning that moves into categorizing the symptom and defining the problematic.

Judge Symptom Relevance to MS

When a patient with Multiple Sclerosis presents a symptom it raises two questions: is the symptom MS related and, if so, is it the result of existing lesions or new lesion activity. These questions require patients and practitioners to categorize symptoms into diagnostic categories (e.g. relevant neurological pain versus irrelevant musculoskeletal pain) and to make inferences about the cause of symptoms (e.g. lesion formation versus fatigue). The example below shows how patients participated in evaluating whether new lesion activity is causing these symptoms.
Patient\textsuperscript{14}: Yeah, yeah, yeah, Monday I was up here on Monday. Well when I had my cardiac. Well, uh uh I was walking a little bit in downtown [omitted] to a lunch meeting and uh … my left leg started to tingle really bad and that that usually is … is a uh they it’s been called … they call it I want to say false flare up but that, that’s not correct but …

Practitioner: Pseudo relapse is what we call that.

Patient: or it could be a relapse. This is usually a sign. But as I relaxed you know I stopped what I was doing I went and I lay down didn’t do anything it has seemingly dissipated. I believe it was just the amount of walking I was doing.

Practitioner: Ok how long did it last in total?

Patient: Probably about 4 hours, 5 hours

Practitioner: so we wouldn’t classify it as an attack, because it lasted such a short time. It \{right\} would last more than that.

Here, the patient introduces the episode and provides a brief description. Then he immediately provides his judgment about the cause of the symptom (“the amount of walking”) and associated assessment of relevance for MS. He even tries to come up with the technical term, which the practitioner supplies for him. The practitioner asks a question to check whether the episode fits the diagnostic criteria for an MS attack, and eventually validates the patient’s self-assessment.

\textsuperscript{14}Patient characteristics: 40s, college level education, 3-5 years with MS, severely disabled
With repetition, this kind of dialogue allows patients to internalize the parameters for symptom assessment. Parameters included both the attributes for categorizing symptoms as diagnostic (e.g. a symptom lasting less than 24 is not categorized as an MS attack) and the potential causes for symptoms (e.g. motor problems can be the result of new lesion activity or fatigue/heat). As they learn these parameters over time, patients, like the one in this example, can argue for symptom relevance in ways that practitioners can evaluate. This participation was especially characteristic of patients like this one who had MS for a long time, a phenomenon that I will pursue further in chapter 6.

*Judge Patient Status*

In almost every session, the practitioner provided an overall judgment about the patient’s status. During this task, participants used the representation created in assessing disease progress to categorize the patient’s illness trajectory as stable, deteriorating, or improving. Sometimes this assessment was simple: ‘our exam looks great, so uh, I am not concerned. You have no new symptoms, so looks good.’ At other times, the status summary was more complex and involved both practitioner and patient participation. In the example below, the patient has recently changed medications and experienced a dramatic improvement in mobility.

Patient: I know this right leg I could barely feel anything and now

Practitioner\(^\text{15}\): I can’t believe it

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\(^{15}\) Patient characteristics: 40s, level education, 3-5 years with MS, moderately disabled.
Patient: I know, I can’t either. This is like the closest I’ve been to like my old self, you know?

Practitioner: You got lucky. I’m so happy.…

Practitioner: oh my god. I want to see you walking. Man I remember you were dragging this leg. Like you’re cured.

Patient: maybe I am cured. I’ll just leave it at that, I’ll just think I am.

In the first part of the interchange, the patient initiates a status summary by contrasting her current level of sensation to her prior one and then judging that this makes her feel ‘like my old self, you know?’ The query at the end of this statement (you know?) is partly rhetorical, but it creates a conversational context that invites the practitioner to validate her judgment. The practitioner does so twice. First, the practitioner expresses emotional gratification (I’m so happy). Later, after directly assessing the improvement, she echoes the structure of the patient’s status summary that she is ‘like my old self’ by saying it is ‘like you’re cured.’ The patient then picks up this validation and elaborates on the idea that she is ‘cured.’ She assertively ends the status discussion saying ‘I’ll just leave it at that.’ Note that the patient initiates the status summary, defines the parameters for the assessment and terminates the interaction. However, the practitioner plays the crucial role of validating the patient’s subjective sense. Of course, both practitioner and patient know that her MS is not really ‘cured,’ but the conversation marks a qualitative shift in her status from physiologically deteriorating and significantly disabled to physiologically stable and minimally disabled. By making an overall judgment about the patient’s status together the dyad established an understanding of the current situation and expectations regarding the current trajectory of the illness (i.e., stable, improving, or
deteriorating). This judgment defined the trajectory for subsequent reasoning by defining the scope of the problem to address and the requirements for selecting subsequent actions (i.e., minor decisions involving maintenance therapy versus major decisions about revising the course of treatment).

Select Actions to Modify the Course of Disease

Shalin and Bertram (1996) noted the absence of attention to the cognition of treatment selection, other than the problem of biases in the conceptualization of risk. However, the selection of treatment options involves a variety of issues outside efficacy and risk. Selecting a disease modifying agent is a multi-dimensional decision process. In some cases, the patient’s physiological status dictates a particular treatment method but in others, there are a variety of alternative actions available. In these cases, the patient’s preferences (e.g. frequency of administration, side effects, and desire for more or less aggressive treatment) can be a major factor in medication selection. Below, the patient says very little but nevertheless affects the decision making process.

Practitioner: There is like you know what there is a drug named Copaxone which does not go {uh, huh} through the liver, does not cause flu-like symptoms and that might be a good choice for you.

Patient: When I was here you told me about Betaseron, when you said that that just came out {yeah} with new studies.

16 Patient characteristics: 20s, college level education, 1-2 years with MS, minimally disabled
Practitioner: With new studies and in the studies Copaxone was with the Betaseron as well. {ok} They were comparing the two kinds when it comes to the results, the frequency of attacks, they both decrease the frequency of attacks about 60%. The Betaseron was slightly better{um} when it comes to the MRI outcomes. With the Copaxone it was a little bit {ok} worse when it comes to new enhancing lesion. But you don’t have any new enhancing lesions. And because I remember you saying that you decided not to do and you were saying that you were thinking more about natural medicine. Copaxone is more like a mixture of amino acids and so its mild {ok} than Betaseron. Betaseron is like interferon. {yes} That’s why it’s a strong, little bit more synthetic I would say…..

Practitioner: So, you comfortable with the Copaxone or you prefer the Betaseron medication?

Patient: um, I read both and the Copaxone actually sounded like in the stuff that I read sounded like something I’d rather do because it seemed more simple and it didn’t have the flu like {yeah} symptoms I was worried about…

This patient was newly diagnosed and seeing the practitioner for the second time. On her first visit, she refused to begin a disease modifying therapy and instead used alternative medicine. Now, she has had new lesions form and the practitioner wishes to convince her to accept treatment. The practitioner begins by introducing the medication and some of its advantages. The patient very briefly challenges the practitioner by pointing out that her current recommendation is not consistent with the one she provided previously. The practitioner responds by going through her reasoning first by arguing that both medications might be equally effective and then by suggesting that the chemical
structure of the medication is more compatible with the patient’s norms. Ultimately, she presents the patient with a direct choice. The patient echoes the practitioner’s arguments, accepting both the greater alignment with her norms and the desirability of lower side effects. By refusing initial treatment, the patient has altered the dyads’ trajectory of clinical reasoning. This refusal requires the dyad to change from a relatively straightforward decision process based on efficacy into a more complex, multi-dimensional one that requires the practitioner to redefine the medications in a way that incorporated these new dimensions. By the end of the session, they have developed a mutual definition of the drugs that includes both efficacy and ‘naturalness.’ This was the only case where the chemistry of the medication was a key parameter. However, in other cases, the patient’s goals (such as treatment schedules that accommodated specific constraints or the desire to become pregnant) and preferences (such as method of administration or side effect profile) changed the trajectory of clinical reasoning, altering the course of the decision making process. The importance of integrating these preferences into the selection process underlines the fact that the patient plays a substantial role in directing the physician’s argument.

*Select Actions to Manage Symptoms*

Because symptom management is more about comfort than managing a disease process, the patient’s understanding of his/her symptoms and medication preferences (e.g. tolerance of side effects) are a crucial part of the selection of actions to manage symptoms. Often the practitioner would simply provide support for the patient to make decisions about how to control symptoms. This support could include providing
information about treatment options and allowing the patient to access treatment options that required referrals or prescriptions. For example:

Practitioner: Would you like to take medication every day to prevent the headache?

Patient: On top of the Copaxone? I don’t know what is it is it a pill?

Practitioner: It’s a pill, a prophylaxis to make the headaches happen less often.

Patient: I mean can I just try it and if I decide I don’t want to do it.

Practitioner: Oh yeah no problem, no problem.

In this case, the practitioner provides information about and the prescription necessary to access a possible treatment, but the patient ultimately chooses whether to take any action. Here the patient chooses about whether to take medication at all but has no choice about which medication to take. In other cases, the practitioner settles the need for treatment but provides the patient with a choice of medications or with samples of multiple medications and a range of possible dosages. In the latter case, patients took samples home to try out what ‘works’ for them, allowing a final decision to emerge through direct experimentation. This type of dialogue involves defining a trajectory for decision making rather than making an actual selection. Even though no decision is taken in the clinic, the patient and practitioner have agreed on the nature of the problem, the range of possible solutions and means by which the patient with make the final

\[17\] Patient characteristics: 20s, college level education, 1-2 years with MS, minimally disabled
decision. The next chapter discusses the process of making treatment decisions and the distribution of cognition during decision making extensively.

Create Plan for Care

The plan for care is usually the least cognitively involved part of the session. During this task, practitioners primarily restated decisions made during the session and discussed the logistics of obtaining medications, prescriptions, testing, etc. The following example is typical.

Practitioner: So what I’m gonna do, I am gonna give you a brain, MRI. And I’m gonna see if anything comes up. I just want to be sure how the MRI looks and then think about switch medication.

Here the practitioner simply summarizes the plan for care. In some cases, the patient participated by asking questions or requesting particular pragmatic services like prescriptions renewals. This portion of the clinical session essential involved converting the cognitive trajectory created during the clinical interaction into an actionable trajectory for clinical care.

Conclusions

Patients and practitioners engage in distributed clinical reasoning as they complete the major tasks involved in Multiple Sclerosis management. Except for interpreting MRIs, patients contributed significant cognitive elements to all the major tasks in the clinical sessions. The decisions and judgments that emerged in this way were not entirely constructed either by the practitioner or the patient.
As patients and practitioners spoke to one another, they accomplished the cognitive work necessary to complete core clinical tasks. I add a new construct, *common cognitive trajectory*, to capture the resulting process. Borrowing from the notion of common ground (i.e., mutual knowledge and beliefs) in communication, (Clark & Brennan, 1991) a common cognitive trajectory reflects the shared understanding that develops over the session. Patients and practitioners contributed to the initial representation of clinical information, subsequently building off of these representations as a means for collaborative categorization, reasoning and decision making. Patients presented symptoms in a way that facilitated particular paths of reasoning or conclusions, and practitioners incorporated patients’ values/preferences and ensured that they were aware of their current status and prepared for future decision points. Negotiation of a common trajectory was a key element in the distribution of clinical cognition.

This study suggests that patients are more involved in the cognitive work of medicine than has generally been acknowledged. The typical notions of shared decision making and self-management are too narrow. Shared decision making is not just a sharing of power, information, or prioritization of values (Barry & Edgman-Levitan, 2012; Lagare & Wittman, 2013). Finally, this analysis of shared decision making also challenges the prevailing notion of the independent physician decision-maker, with implications for the conceptualization of medical expertise.

Efforts to increase and improve shared decision making should target tools and skills training that can increase the efficiency of distributed cognition from the perspective of both practitioner and patient. Interventions of this type have been used
effectively in a variety of professional fields including aviation and collaboration among medical professionals. Notions of patient support have been fairly narrowly focused on the enactment of practitioner instructions. Effort to understand the patient contribution to medicine may support the development of tools and/or training to facilitate patient cognition.

**Subsequent Analyses**

Shared decision making is a complex distributed cognitive function that is not fully understood. This chapter has established the practitioner-patient dyad as the appropriate unit of analysis to account for the cognition of clinical care and has raised issues that are worth exploring in greater detail. The following chapters analyze how specific elements of distributed clinical cognition function. Chapter 5 specifically addresses the decision making process in the context of the common cognitive trajectory that develops through clinic interactions. In particular, it focuses on the roles that practitioners and patients can assume during decision making. Chapter 6 explores how patients’ skills with respect to clinical cognition alter the process of clinical reasoning including practitioner reasoning. And, chapter 7 uses narrative speech to explore the role of representation and language as a medium for distributed clinical cognition.
Chapter 5: Navigating the decision space: Patterns of task distribution in shared medical decision making

How is decision making positioned within the flow of distributed clinical cognition?

What determines the distribution of cognitive processes during shared decision making?

Introduction

Research increasingly emphasizes shared decision making (Hibbard & Greene, 2013; Thille & Russell, 2010). However, models of shared decision making merely reflect the incorporation of patient preferences at isolated choice points and discussion of factors that facilitate or hinder shared decision making (Bernabeo & Holmboe, 2013; Légaré & Witteman, 2013). The available research provides little analysis of shared cognition or of the factors that shape the distribution of clinical cognition among patients and health professionals.

Part of the difficulty in analyzing the cognition of shared decision making stems from the intermingling of tasks that involve medical decision making with other clinical cognitive functions. The previous chapter demonstrated that patients and practitioners

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18 Portions of this chapter are included in “Navigating the decision space: A study of medical decision making as distributed cognition,” which is being revised and resubmitted for publication in Qualitative Health Research.
collaborate throughout their interaction to accomplish clinical cognitive functions. This ongoing collaboration creates a trajectory for clinical cognition\textsuperscript{19} that integrates a variety of cognitive elements including the direction of attention, representation, categorization, causal reasoning, etc. Medical decisions, the topic of this chapter, occur as embedded inflection points along this trajectory where practitioners and patients must share information and coordinate action (Elwyn et al., 2014; Epstein, 2013).

To illuminate how practitioners and patients distribute decision making tasks, I conceive of shared decision making as navigation through a Decision Space (Lippa et al., in review) that combines the state of the world in which the decision is made (state space) and the possibilities for action (action space). I use ethnographic data from decision making in MS management to show how the distribution of resources among actors creates a corresponding distribution of decision making processes. These findings have theoretical and applied implications for shared medical decision and understanding the nature of medical decisions.

\textit{Toward an Understanding of Shared Medical Decision Making}

The majority of research on medical decision making bifurcates along artificial methodological lines. Most laboratory studies analyze how people process medical information to make decisions with predefined problems and solution/evaluation criteria (Croskerry, 2009; Marewski & Gigerenzer, 2012). Similarly, research focused on shared

\textsuperscript{19}The clinical cognitive trajectory occurs in parallel with the physical, organizational and institutional work that Strauss and his colleagues (1997) define as an illness trajectory.
medical decision making typically focuses on a small number of factors (e.g. health literacy, diagnosis, intervention programs) in relation to specific outcomes (e.g. satisfaction with care, accurate risk assessment disease status) (Ghane et al., 2014; Hibbard & Greene, 2013). By contrast, qualitative studies mainly examine the sociocultural dynamics involved in decision making (Corbin, 1998; Roter & Hall, 2006), but attend less to information flow and associated cognition.

In *medias res*, decision making is a part of an ongoing cognitive trajectory complicated by fluctuating preferences, contextual constraints, and incoherent task requirements (Broadstock & Michie, 2000). These contextual factors form a socio-cognitive landscape that is as inextricably linked to decision making processes and outcomes as topography is to nautical navigation (Hutchins, 1995). Many medical decisions that are of concern to public health (e.g. misdiagnoses and non-compliance) may be better understood when socio-cultural and cognitive factors are considered as a whole (Barber, 2002; Cameron, Leventhal, & Leventhal, 1993).

Distributed cognition captures this complexity by combining multi-dimensional constraints to form a system in which cognition is not solely located in the minds of individual actors but distributed across agents, technical systems, time and space (Cowley & Tourangeau, 2013; Hutchins, 1995). This paradigm provides a basis for developing a conceptual model that integrates the major aspects of shared decision making into a single decision space.
Resources for Information and Action in Lay-Professional Interactions

Although patients are a core part of the medical system, their role in clinical care and the nature of their interaction with practitioners are unique. Patients are laymen without any formal training interacting with highly trained professionals. Therefore, patients and practitioners enter the interaction with very different resources of information and action. Although all of the chapters touch on the distribution of resources among participants, this is a particular focus of the present chapter.

Knowledge resources. Medical reasoning relies on a variety of informational resources including semantic and episodic knowledge (Norman, Monteiro, & Sherbino, 2013) as well as access to additional information through reference sources. Practitioners and patients each have access to a subset of informational resources. Medical practitioners bring an array of obvious resources to the clinical interaction. They are highly trained professionals often with years of expertise. The combination of explicit biomedical information (semantic knowledge) and experiential expertise (episodic knowledge) drives clinical cognition. In addition, practitioners can access additional informational resources, such as reference manuals, research studies, and discussions with colleagues to bolster their knowledge of a particular case.

Patients lack the extensive semantic knowledge available to practitioners, but they possess critical episodic knowledge. Patients know their personal course of illness and phenomenological experiences including the circumstance surrounding illness events, what symptoms feel like and how their current experiences compare to past events. Like practitioners, patients access information beyond their knowledge by reading educational
materials, using internet resources and talking to others. These informational resources can directly influence critical cognition, as when a patient requests a treatment he read about or that a friend found effective. In addition, information resources influence clinical cognition indirectly as patients turn to outside resources to understand their experiences and then interpret their situation accordingly. Effective clinical cognition may depend upon combining practitioners’ and patients’ separate knowledge.

*Action resources.* Similarly, practitioners and patients have separate, but interdependent, resource for action. Practitioners have broad powers to act within the clinic. They may order tests, conduct exams, perform procedures, and prescribe treatment, but they have limited ability to affect action outside of the clinic. In addition, outside constraints can limit practitioners’ ability to act. For example, a patient may refuse a procedure or a particular test may not be covered by insurance.

Patients engage in many actions outside the clinic including making decisions about seeking care, self-administering home based treatments and coordinating multiple service providers. However, much of this care cannot be conducted entirely independently, as many forms of treatment require a practitioner’s prescription. The distribution of action resources between practitioners and patients necessitates collaboration for many forms of care to be successful.

*The Decision Space*

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20 *The Decision Space Model was developed from the intersection of earlier work by Markus Feufel (2009) and the data in this study. The model as used in this study was a*
This study uses the concept of a Decision Space to parse the resources that cognitive actors have available for decision making. The Decision Space incorporates the physical, psychological and social influences that shape decision making (Lippa et al., 2016). This model treats the actors involved in distributed decision making as integrated into a single decision framework (see Fig.2). As such, the model incorporates the collaborative effort between Markus Feufel, Eric Robinson, Valerie Shalin and myself. It is discussed in further detail in Lippa et al. (in review).
cognitive elements, environmental constraints and opportunities for action of both actors as integrally related components of the distributed decision making process.

Throughout decision making, clinical reasoning occurs in a decision space that represents the intersection of environmental circumstances and action. Consistent with the literature on problem-solving, the state space consists of the properties of the task environment (Simon & Newell, 1971). It includes both the actors’ assessment of desirable states, some of which may be unobtainable, and the range of possible states. The action space describes how agents convert undesirable states into preferred outcomes. It includes information about which actions are both viable based on acceptability relative to personal and societal values and possible given available resources.

Critically, in shared decision making, individual actors conceptualize the state and action spaces differently. Practitioners and patients are working on the same problem, but their understanding of the parameters and constraints involved in decision making differ. Nevertheless, practitioner and patient clinical cognition are interdependent and, ideally, cooperative (see chapter 4)\textsuperscript{21}. In the state space, practitioner reasoning depends

\textsuperscript{21}The combination of potentially disparate perspectives into a single mutually acceptable decision requires language. Each actor must verbally represent critical information from his understanding of the state space. In addition, actors may have to articulate their reasoning processes to create a shared trajectory for clinical reasoning and ensure that the
upon patient-provided information. Similarly, the patient depends upon the practitioner for technical information, such as symptom-disease contingencies. In the action space, the practitioner depends on the patient to comply with treatment, while the patient needs the practitioner to provide access to treatments that require medical expertise or authority. Satisfactory decision making must draw on the perspectives of both parties. Figure 2 illustrates this interaction.

As patients and practitioners interact to understand the state space, develop options and negotiate acceptable solutions they engage in an extended decision making process. Laboratory research on practitioner decision making often uses predefined problems and limited, explicit decision parameters. In medias res decisions do not simply appear (Zsambok & Klein, 1996). Medical decision making is often an ill-defined task where the need for a decision, information used in making the decision and/or parameters for deciding may be context specific and ambiguous. This suggests that medical decision making is less an a priori fixed choice point than an inflection point on a trajectory of clinical cognition (see Fig 3).

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final decision is mutually acceptable. Chapters 6 and 7 provide more specific analysis of this process.
As seen in chapter 4, decisions begin with a *representation of the current clinical situation* that practitioners and patients build by combining their respective semantic and experiential knowledge into a shared assessment of disease progress and/or symptoms. They then judge this representation to determine the patient’s status and/or the significance of specific symptoms for MS. If the dyad’s judgment includes indications of a situation that includes both a problem (an undesirable feature of the state space) and actions available to address the problem, a *decision point is realized*.

Once a decision point is activated, actors have to select a course of treatment. This function includes parameter definition and evaluation. *Defining the parameters of the decision* requires developing a set of options and criteria for selection. In medicine parameters will consist of those actions that are contemplated to address the decision point, such as a range of medications and associated attributes that the actors consider in making the decision including clinical indications and patient values, such as willingness to tolerate side effects. Once defined, the *parameters are evaluated* yielding a decision. This process is what has traditionally been defined as decision making. It involves comparing the attributes of each option and making judgments about an appropriate and desirable course of action. In medicine, the evaluation stage involves weighing the costs and benefits of various courses of action with respect to pragmatic constraints (e.g. insurance coverage), the medical situation (e.g. efficacy) and the patient’s goals and preferences (e.g. willingness to self-administer daily injections).

However, even after making a choice, the decision is only preliminary until someone *implements* it. Planning (or agreeing) to act is not the same thing as acting. In
medicine, this final step is non-trivial because patients reverse many decisions made in the clinic by failing to implement them (Dunbar-Jacob, Schlenk, & McCall, 2012).

Although all five of these steps are vital to the decision making process, this study focuses on the middle three: the realization of a decision point, parameter definition, and parameter evaluation. Chapters 6 & 7 discuss representation extensively; so, here I limit the discussion to its use in specific instances. Implementation is largely beyond the scope of this study because it typically occurs outside the clinic.

As Figure 3 shows, while navigating the decision space, practitioners and patients have access to different portions of the decision space. This suggests that the distribution of clinical cognition involved in completing each portion of the decision making process depends on who has access to relevant information about the state space and possibilities for action. Traditional work on medical decision making implicitly assumes that practitioners are the primary or sole actor controlling the entire decision process (Elstein & Schwarz, 2002). Table 2 includes these decisions as physician dominated. Even the literature on shared decision making tends to assume that practitioners control the process, if not the outcome of decision making. Proposals range from practitioners incorporating patient contributions, a version of practitioner dominated decision making, to practitioners enumerating parameters for patients to make decisions, practitioner defined-patient made decisions (Moumjid et al., 2007). However, these are not the only possibilities. In a truly distributed system, two other patterns are logically possible that place the patient in control of the decision making process: patient defined – practitioner
made decisions and patient dominated decisions. The literature on medical decision making had not addressed these patient oriented patterns.

Table 2. Possible patterns of distribution for decision making processes.

<table>
<thead>
<tr>
<th>Identification of Decision Point</th>
<th>Definition of Parameters</th>
<th>Final Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioner Dominated</td>
<td>Practitioner responsibility</td>
<td>Practitioner responsibility</td>
</tr>
<tr>
<td>Practitioner Defined- Patient Made</td>
<td>Either actor may be responsible</td>
<td>Practitioner responsibility</td>
</tr>
<tr>
<td>Patient Defined – Practitioner Made</td>
<td>Either actor may be responsible</td>
<td>Patient responsibility</td>
</tr>
<tr>
<td>Patient Dominated</td>
<td>Patient responsibility</td>
<td>Patient responsibility</td>
</tr>
</tbody>
</table>

The remainder of this paper identifies decisions in the MS data set that follow all four distribution patterns. I provide an existence proof for each and include discussion of each decision pattern in terms of access to elements in the decision space. The discussion focuses on examples of how these patterns occur in particular instances.

Methods

Analytic Methods

Data were analyzed based on the principles of grounded theory (Charmaz, 2006; Willig, 2001). Initial, open coding identified decision making as a core category. All the data involving decisions was microanalyzed for indications of underlying decision making processes. This analysis involved axial coding (Strauss & Corbin, 2008) to identifying conceptual elements relating to decision making as a category. Concepts
identified included what information was present and how it was used, factors affecting the ultimate decision, and roles adopted by physicians and patients. Comparisons between decisions suggested a common, multi-stage process of decision making (Glaser & Strauss, 1967). Selective coding of a subset of identified decisions found these stages productively described most of the decisions. However, some decisions excluded one of the stages or altered the ordering of the stages. Connections between the identified concepts and the stages of decision making revealed four common patterns of decision making depending on the distribution of information, action, and cognitive activities across patient and physician. Comparative analysis of decisions from each pattern helped to refine the conceptualization of the decision patterns.

A final analysis focused on close examination of decision making and discourse in illustrative examples. I selected individual decisions to illustrate the decision making patterns identified based on the degree to which the dialogue surrounding the decision clearly articulated cognitive, discursive, interpersonal, and environmental characteristics that were common to decisions of a particular pattern. For each decision pattern, one example from the transcripts illustrates the interactive decision making process. Patients’ descriptions of past decisions during their follow-up interviews provided additional support. The examples are representative in that they include common processes, but often contain higher than average ambiguity or conflict in the decision parameters prompting direct articulation of decision making efforts. The use of problematic cases as a way to explore underlying cognition parallels the use of critical decisions in naturalistic decision making research (Klein, Calderwood, & MacGregor, 1989) and self-explanations in educational research (Chi et al., 1989).
Results

Practitioners’ and patients’ verbalization suggest differential access to relevant portions of the state and action spaces. Resulting decision patterns varied from being primarily individual to being completely distributed, depending upon the distribution of information about the state space and available actions. The characterization of cognitive control depended on who took responsibility for various parts of the decision making process: the identification of a decision need, elaboration of relevant parameters, and final choice. Table 3 revisits the decision making patterns posited in the introduction and suggests the situations in which each may occur22. Practitioners and patients each dominated some decisions, taking responsibility for all aspects of the decision making process with varying degrees of consideration for the other. In other cases, the practitioner and patient split responsibility for decision making tasks. In the split patterns, one actor identified the need for a decision and established decision-relevant parameters, whereas the other actor made the final choice. The analysis below begins with practitioner-dominated decisions then progresses to examine practitioner-defined decisions made by the patient and patient-defined decisions made by the practitioner and concludes by assessing patient dominated decisions.

<table>
<thead>
<tr>
<th>Identification of Decision Point</th>
<th>Definition of Parameters</th>
<th>Final Decision</th>
<th>Situations in which the pattern occurs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioner</td>
<td>Practitioner</td>
<td>Practitioner</td>
<td>Decision is highly technical</td>
</tr>
</tbody>
</table>

22 For supporting evidence regarding the validity of these decision patterns in acute care see Lippa, et al. (in review).
<table>
<thead>
<tr>
<th>Dominated responsibility</th>
<th>responsibility</th>
<th>responsibility</th>
<th>and/or urgent and requires minimal patient action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioner Defined - Practitioner Made</td>
<td>Either actor may be responsible</td>
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<tr>
<td>Patient Dominated</td>
<td>Patient responsibility</td>
<td>Patient responsibility</td>
<td>Patient responsibility</td>
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</table>

Table 3. Patterns of distributed medical decision making.

*Practitioner dominated decisions*

Practitioner dominated decisions occurred when the decision need and process depended on specialized biomedical knowledge of disease states and the practitioners’ action space. Some practitioner-dominated decisions were completely unilateral with no provision to inform or include the patient in the decision. In MS management, decisions made by practitioners alone appear at the end of the clinical encounter concerning the formulation of a plan for care (Roter & Hall, 2006). As part of this conclusion, practitioners made unilateral decisions about highly technical topics. This was clearly true when practitioners ordered tests (e.g., blood work), prescribed medications or followed discipline-prescribed routine protocols with no complicating factors (e.g., patients should have annual MRIs). Practitioners made these decisions alone, drawing on elements of the decision space under the practitioner’s control. Practitioner control appears as a simple statement of what will happen without questions or discussion of why for example, “I am gonna give you [an] MRI.”
However, in some practitioner dominated decisions complicating factors required consideration of elements of the decision space primarily accessible to the patient or involved patient actions. In these cases, practitioners engaged in a more deliberative decision processes, in some instances verbalizing their reasoning. By articulating the decision process, the practitioner helped the patient understand and potentially garnered her support for decisions affecting her care. The following example illustrates the enactment of this process.

Practitioner: I am just debating. Should we repeat the MRI - see where you’re at? Or just not do anything and wait? Like I said, it’s a little bit difficult to proceed. Because if we were going to know that you can get pregnant in the next two three months there is no reason to even do the MRI. And then again if you are going to be trying to get pregnant we’re not going to start your medication anyway. The only thing would be like if the MRI were tremendously bad, what I don’t expect, and then we could consider starting you on medication, wait? Otherwise, we’re going to try you again to get pregnant after you go off the medication. That’s the only thing I am debating right now. But I think that we’ll probably just wait to see, you know, how it goes.

Here, routine procedures within the action space indicate an MRI, but the practitioner identifies circumstances in the patient’s personal life (i.e., the desired pregnancy) that limit the utility of an MRI for evaluating medications contraindicated for pregnancy. This conflict creates a context-specific, idiosyncratic inflection point that might not otherwise occur, prompting the practitioner to explore other parameters within the state space (probability of pregnancy and disease status) and their implications for
possible actions. Only after exploring these parameters does the practitioner make a final decision.

The exclusivity of the practitioner’s decision making process here is understandable. Only she has the technical knowledge of the state space to evaluate most of the parameters and weigh whether an MRI is medically indicated and appropriate to the patient’s situation. Moreover, even though the practitioner does all of the cognitive work, in this case, she frequently uses the first person plural. That is, she understands that she is in charge of the decision process (“I am debating”). Nevertheless, she includes the patient when sampling options from her action space (e.g. “Otherwise we’re going to try you again to get pregnant when you go off the medication”). This shift indicates that this practitioner considers the decision as part of the common care trajectory that requires patient involvement.

In summary, despite a biomedical rationale for a particular choice, practitioner dominated decisions sometimes require coordination with patients’ personal circumstances. These contextual elements, as part of the state space, created inflection points and became one of the parameters that constrained the range of appropriate actions. Thus even in the case of practitioner-dominated decisions, the need to create a common trajectory of care may require the practitioner to incorporate the patient’s perspective. The articulation of the practitioner’s clinical cognition including elements of the patient’s perspective allows the patient to understand the rationale and implications for the decision. Cases like this one highlight the importance of searching the decision
space for patient-provided contextual information and negotiating a mutually accepted trajectory even when making decisions about routine procedures.

**Practitioner-Defined, Patient-Made Decisions**

In practitioner-defined decisions, either actor may identify the need for a decision, but the practitioner elaborates relevant parameters. This may involve the practitioner presenting information about a limited set of options so that the patient can make an informed choice about the final decision. This decision pattern appears in the literature on shared decision making as a process wherein practitioners guide patients to make informed, well-reasoned decisions in line with their preferences and the available evidence (Elwyn et al., 2012). Decisions of this type occur when the practitioner’s essential understanding of the physical aspects of the state space (e.g., pathophysiology) and properties of the action space (e.g., action efficacy, side effects, and pharmacology) determine option, but the patient enacts the decision (e.g. taking the medication) and incurs the majority of consequences (e.g. side effects, costs). This decision pattern captures the interaction of the practitioner’s privileged access to biomedical information from the state space and the patient’s capacity for self-care as part of the action space.

A clear circumstance favoring this pattern involves the selection of a course of treatment or use of complementary treatments (i.e., physical therapy). These technical decisions require practitioner knowledge, but involve substantial action by the patient. The distributed dynamic this creates is especially clear when the patient’s perspective conflicts with the practitioner’s analysis of the state space. For example, the patient in
the dialogue below initially refused conventional treatment in favor of alternative medicine. To resolve this conflict, the practitioner redefines the decision parameters.

Practitioner: There is like you know what there is a drug named Copaxone which does not go {uh, huh} through the liver, does not cause flu-like symptoms and that might be a good choice for you… I remember you saying that you decided not to do and you were saying that you were thinking more about natural medicine. Copaxone is more like a mixture of amino acids and so it’s milder than Betaseron. Betaseron is like Interferon. That’s why it’s a strong, little bit more synthetic I would say.

Patient\textsuperscript{23}: OK.

Practitioner: Copaxone would be more natural. That’s the reason I was just, I was changing my mind. [...] So you’re comfortable with the Copaxone or you prefer the Betaseron medication?

Patient: Um, I read both and the Copaxone actually sounded like, in the stuff that I read, sounded like something I’d rather do because it seemed more simple and it didn’t have the flu like {yeah} symptoms I was worried about.

The practitioner begins to set up possibilities and –decision parameters by introducing a new medication and contrasting it with a medication she had previously discussed with the patient. She represents the chemical structure of the new medication

\textsuperscript{23} Patient characteristics: 20s, college level education, 1-2 years with MS, minimally disabled
as more compatible with the patient’s construction of the decision space (e.g., preferences for natural medicine) and presents the patient with an explicit choice of medication. The patient’s selection echoes the vocabulary the practitioner used to define the decision parameters, accepting the greater alignment with her desire for natural medicine and concern about side effects. By refusing a course of action proposed by the practitioner the patient has expanded the set of usual decision parameters, requiring the practitioner to present a new alternative and reinterpret the decision space in a way that more closely aligns with the patient’s norms. This indicates the inherent interdependence between the patient’s action choices and the practitioner’s clinical reasoning.

In the case above, the practitioner’s reasoning had to accommodate the patient’s preferences in the state space to create a mutually acceptable trajectory. Physical concerns present in the patient’s understanding of the state space, but not in the practitioner’s, occasionally emerged during the definition of decision parameters. In the example below drawn from session notes, the patient has indicated that fatigue is a major issue for her.

From session notes

Practitioner: [Describes medication for treating M.S. related fatigue.] One medication that’s available is Amantadine; this is a well-established drug. It was developed for Parkinson’s disease but is no longer used for that. [Then he describes the dosage, the success rate, which is relatively high. Potential side effects and recommends trying this drug first.] Another option is high dose Aspirin, there’s one study at the Mayo Clinic that suggests that this may help with
M.S. related fatigue, but it has possible side effects. Another option is Provigil which was designed for Narcolepsy and is a fairly classic stimulant. There are three trials with M.S. of the use of Provigil. With two of these there was a clearly positive result and with one there was an ambiguous result. Provigil is not yet approved for M.S. related fatigue treatment which means that it may be difficult for the insurance to pay for it. I would suggest that you try the Amantadine and if that doesn’t work we can go onto other options. The final option is classic stimulants, such as Ritalin or Adderall, but these have problems because they’re amphetamines and are controlled substances, which makes it more difficult to obtain them.

Patient\textsuperscript{24}: [Expresses concern about the use of stimulants because she’s had Epilepsy.]

Practitioner: [Says that we now know that stimulants are less likely than previously thought, to cause seizures.] Are you on seizure medication?

Patient: No. [The last seizure was seven years ago maybe, and then describes the seizure.]

Practitioner: I would recommend Amantadine because it’s not a classic stimulant.

Patient: [accepts recommendation]

\textsuperscript{24} Patient characteristics: 50s, high school education, 1-2 years with MS, moderately disabled
In this case, the practitioner provides a generic overview of the action space for treating fatigue, providing information applicable to MS patients generally without reference to this patient’s particular case. In response, the patient raises concerns about her history of seizures. This issue, which appeared in the chart but was outside the practitioner’s initial active consideration of the state space, causes the dyad to shift focus from a multifaceted set of decision parameters to focus on this issue. This parameter overrides other considerations making the final decision fairly straightforward. Here the existence of an inflection point and even the options considered did not change in response to patient input, the justification of the choice did.

For both preference driven (natural treatments) and physically driven (seizure risk) reasoning examples, the practitioner directs the dyad’s attention to specific physical properties and associated potential actions, essentially mapping possible trajectories of care. The practitioner then interprets and discusses the desirability of these trajectories in light of the patient’s construction of the decision space. The patient uses the information and analysis from the practitioner to make a final decision. The challenge is turning a distributed cognitive problem into a shared trajectory for reasoning about care. The practitioner’s efficacy depends on representing the decision in terms of the patient’s understanding of the decision space.

Patient-Defined, Practitioner-Made Decisions

Patient-defined decisions, although not discussed in the literature on medical decision making, did occur in this data set. In these decisions, the patient guides the trajectory for clinical cognition and creates inflection points. These decisions occurred
when the patient held privileged knowledge of the state space (e.g. phenomenology, case history) and the practitioner held powers of action (e.g. to write prescriptions or order tests). In these cases, the patients used their knowledge to define the parameters of the decision either generally or as a fixed choice within a limited set of actions. The practitioner correlated the range of possible treatment options, biomedical aspects of the state space and associated decision parameters outlined by the patient to make a final and informed choice. In many cases, some or all of the considered options required action by the practitioner, at least in the form of a prescription. This structure places practitioners in a gatekeeper role, requiring them to make the final decision; a patient may prefer a particular option and set up a choice set in the state space but cannot enact it without practitioner participation.

Relative to Figure 1 in chapter 4, Patient-defined decisions arise in the treatment of symptoms that the patient introduces. The patient obviously understands phenomenological aspects of the state space better than the practitioner and hence can create decision points and define relevant parameters in this area. Similarly, treating symptoms involves judgments about comfort and functionality rather than medical necessity, so the patient’s desires play a larger role. The practitioner helps match the patient-defined parameters with available medical actions and provides access to those options she deems appropriate. The example below incorporates all of these elements.
Patient: I want my Ultram back. Tylenol arthritis just ain’t cutting it.

Practitioner: It worked for a little while {high protesting voice}. Hahaha.

Patient: It’s not anymore…

Practitioner: There’s a potential interaction between those two [Ultram and Nortryptaline, which the patient also takes]. But you wouldn’t be taking them necessarily at the same time…

Patient: So do you think we should change the Ultram to something else that wouldn’t contradict it?

Practitioner: Then I think we get in… I don’t want to go into narcotics because that’s really… I’m gonna go ahead and give you one [prescription] for the Ultram. Try not to take it on a daily basis though if you don’t need it.

This patient has had MS for a long time and suffers from chronic neurological pain. She feels her current over-the-counter medication is inadequate and asks for a prescription she has used successfully in the past. Thus, she initiates the decision process by fronting the desired action. This defines the decision parameters for the practitioner narrowly as a choice between two options rather than a broader decision about pain management. Based on this narrow construction, the interaction addresses the state space (the patient’s case history and pharmacology) and constraints from the action space (timing of the medicine and norms regarding narcotics) to negotiate a satisfactory decision for both parties involved in the encounter. The dialogue reflects the specific

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25 Patient characteristics: 20s, college level education, 5+ years with MS, severely disabled
information and action profile that each participant has available and can contribute to
negotiating an acceptable trajectory of care. Based on expert knowledge about her every-
day experience, the patient is in charge of representing her phenomenological experience
and administering self-care, including decisions about when to take the medication. As
the medical expert, the practitioner is responsible for identifying biomedical elements
(such as drug interactions) from the state space concerning the advisability of particular
actions.

As inflection points, decisions are a means to alter the trajectory of clinical
cognition. The example above reflects a case where the patient took control of the
decision making process to try to achieve an articulated, specific outcome. In other
instances, patients took control for less specific reasons. Sometimes patients defined
decision parameters when they felt the current trajectory of clinical cognition was not in
accord with their understanding of the state space. Patients sometimes activated decision
points and defined decision parameters to modify the practitioner’s clinical reasoning. In
the example below taken from a follow-up interview, the patient and practitioner were
working to identify the etiology of her first MS symptoms. The practitioner had ordered
a brain MRI and peripheral nerve test. However, the patient believed the primary
problem was in her spine and wanted the practitioner to investigate this hypothesis.

Patient26: Originally the next day after I woke up, it was my feet but it was also in
my spine when I bent a certain way. I felt, you know just felt odd. {okay} That’s

26 Patient characteristics: 40s, graduate education, 2-3 years with MS, minimally disabled
what it was and that’s why I was just thinking it was something like I had a pinched nerve or something was not right about that. Uh, yeah. And so you know they had done a test on that as well to see and I actually insisted that they do an M.R.I. on my spine cause I was convinced that it was something that the chiropractor did. … I went there to see-uh Doctor ------, when she did the nerve test I said, “You know I think it’s something on my spine and aren’t they gonna do that?” And then she ordered it.

This patient directly questioned the practitioner, thereby creating a narrowly defined inflection point. By saying “You know I think it’s something on my spine and aren’t they gonna do that?” she forces the practitioner to consider a portion of the state space she had not addressed and to decide whether additional testing specifically focused on the spine is indicated. By activating a decision point, the patient created the possibility that the clinical cognitive trajectory would move away from a trajectory she sees as flawed and by defining the decision parameters narrowly she ensured that the practitioner would at least consider moving in a direction she preferred.

In both of the cases discussed above, the participants split the decision because of the distribution of information about the state space and the ability across actors. The patient has the information to identify the inflection point but cannot or does not know how to translate this into action, whereas the practitioner has the knowledge of the physical constraints that allows her to judge the advisability of a given action and societal authorization to implement it. This distribution of differential access to information about the state space and action yields a distribution of cognition. The patient directs the
focus of attention and provides initial judgments about appropriate decision parameters; the practitioner refines/revises these judgments and makes the decision.

**Patient Dominated Decisions**

Patient dominated decisions occur when the patient can act independently of the practitioner. Patients independently made two major types of medical decisions: to seek care and to discontinue care. Discussions of medical decision making rarely include care seeking because it takes place before entering the clinic. Whereas many appointments in chronic care are routine, during acute episodes seeking care can become a complex decision. MS patients experiencing exacerbated symptoms make judgments about the urgency of care (from an ED or through a clinical visit) and the proper provider (a primary care physician, neurologist, or another specialist).

Because clinical cognition and care inherently differ between practitioner specialties, when a patient chooses a provider, they initiate a specific trajectory for both care and clinical cognition. If the patient is dissatisfied with the trajectory of care and/or cognition, he may choose to change providers as a method for altering his trajectory. The example below, drawn from a follow-up interview, illustrates this type of decision process. In this case, the patient was dissatisfied with the trajectory for care created by his original physician. This dissatisfaction had two components, one medical and the other interpersonal. On the medical side, the patient disagreed with the practitioner’s construction of the state space in terms of diagnosis and treatment response. The practitioner’s lack of communication skills compounded this dissatisfaction, because he
could not articulate his reasoning processes and negotiate a mutually acceptable trajectory for cognition and care.

Patient 27, 28: Consequently I-I decided that we were gonna go to the Cleveland Clinic [unintelligible], I really wasn’t happy with him either because he had me on [unintelligible] and he still was maintaining the Paroxysmal Dyskinesia diagnosis despite the fact that the Levodopa was helping the situation. Uh, and he’s not a very strong communicator sound thinker-uh but he’s-but he’s not a strong communicator and uh consequently I-uh I started around for yet again another physician that…So I, as you said I went out found a-a-a physician who turned out to be a-uh…a-uh oncologist and…what do you call the people who do…a rheumatologist. Uh, but (s)he had a-an excellent reputation in a diagnostician and somebody who was a problem solver and wouldn’t give up until she had reached the a-a-a diagnosis for whatever was going on… I wanted her diagnostic skills, but I did have bad knees so I used that as a-as a friendly pretext of going to see her and ask her about the swelling… Uh, and when I explained what

<table>
<thead>
<tr>
<th>Practitioner</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis of Paroxysmal Dyskinesia</td>
<td>Decision to change practitioners because he feels diagnosis is contradicted by response to medication</td>
</tr>
<tr>
<td>Decision to see a practitioner with another specialty because he believes she is generally a better diagnostician</td>
<td></td>
</tr>
<tr>
<td>Patient attributes the acceptance to her personal style</td>
<td></td>
</tr>
<tr>
<td>Practitioner accepts working outside her</td>
<td></td>
</tr>
</tbody>
</table>

27 This is an excerpt from the middle of a longer narrative. The rest of the narrative includes similar content focused on the reasoning of a number of physicians and the patient’s opinions about their reasoning.

28 Patient characteristics: 60s, graduate level education, 5+ years with MS, moderately disabled
I wanted her to do or I wanted her to try to help me to do-uh, she took it was a challenge which is also a very good thing. She had a-she had a communications [unintelligible] uh, she would do everything exhaustively. Uh, and-uh wanted to know everything-uh my history and was very interpersonal in terms of her her style…she put me back through a whole bunch of tests-uh, once again she wanted to go down the path that the other folks had decided not to go down, when they made a decision that you know, “It’s one of these, it’s close to one of those.” Kind of thing…She wanted to go down the-the opposite path each time.

When patients decide to change practitioners as a method for altering their clinical trajectory, their behavior is typically rejected as a negative outcome, ‘doctor shopping.’ However, this type of transfer of care can be a reasoned decision, especially when, as in the case above, the patient and practitioner fail to negotiate a mutually acceptable understanding of the decision space.

Similarly, another major type of patient dominated decision does not appear as medical decision making in the literature. When patients choose to stop acting in accordance with prior decisions (e.g., canceling a routine appointment, discontinuing a medication or delay treatment) their decisions are typically written off as ‘non-adherence.’ Most patients understand that taking action independently from the practitioner violates cultural norms. As such, these decisions entered the conversation indirectly as reports of past behavior that influenced the current decision space. For example:
Patient: No, I don’t take Provigil anymore.

Practitioner: Oh, just the Ritalin. How were you feeling when you were taking both?

Patient: I never took both.

Practitioner: Oh, I thought that it was in the notes.

Patient: Oh no, no, no. As soon as I started taking - as he put me on the Ritalin, I stopped taking Provigil because I was scared to take them together.

This decision appears at the beginning of the dialogue as information to include in the current state space, rather than at the end as a product of a process of reasoning. After reporting the decision, the patient works backward to explore issues that prompted (and justified) taking a deliberate action. MS patient dominated decisions, as above, often could be classified as non-adherence, but the patients were engaging in self-care according to their analysis of the decision space. These instances represented failures to develop a shared trajectory for clinical reasoning during an inherently distributed task.

Conclusions

Decision making occurred at context-dependent inflection points during an ongoing trajectory of clinical cognition. As such, decision making was a multi-stage process embedded in ongoing clinical reasoning and distributed between practitioners and patients. The results populated the four patterns for the distribution of decision making

29 Patient characteristics: 30s, high school level education, 3-5 years with MS, severely disabled
processes between practitioner and patients. These result from the different distribution of information and possibilities for action between practitioners and patients.

One pattern of decision making was practitioner dominated but, even in these situations, some instances required knowledge, or at least consideration, of the patient’s interpretation of the decision space for the decision to be integrated into a mutually accepted trajectory for clinical cognition and care. Other observed patterns included split-decisions, where one party specified the parameters of the decision and the other party made a final decision. Split decisions occurred when the information required to make the decision and the ability to enact it were distributed among patients and practitioners. Finally, patients alone made some decisions that needed to be understood as part of ongoing clinical reasoning. Thus, the participation of both practitioners and patients in decision making processes is not just socially desirable, as suggested by the shared decision making paradigm, but inevitable, because of the division of knowledge of the state space and the ability to act in a given clinical context.

This study suggests that shared decision making is not a discrete step, as many researchers have characterized it (Elstein & Schwarz, 2002; Gigerenzer & Gaissmaier, 2011), but rather a number of unfolding interrelated processes involving representing the decision environment, identifying decision needs, searching for relevant decision parameters, evaluating the identified parameters and enacting decisions. The practitioner or the patient may lead each of these processes. The distribution in a given case depends on the understanding each actor has of the state space and his available range of actions. In addition to taking responsibility for various stages in the decision making process,
sharing decision making involves patients and practitioners consideration for each other’s perspectives in terms of understanding the others’ perception of the decision space. Effectively, the personal values, functional status, capacity, and representation of the decision space of each actor become a constraint on the state space of the other actor.

These findings lead to two substantive conclusions with implications for both theoretical and clinically oriented work. First, both practitioners and patients can potentially assume responsibility for any part of the decision process. The intersection of the requirements for the specific condition and the participants’ ability to access relevant portions of the decision space determine the distribution of decision making tasks. Second, shared decision making is a multi-stage context-sensitive process in which inflection points emerge in an ongoing trajectory of clinical cognition.

**Distribution of Decision Processes**

The four patterns for decision making identified highlight the fundamentally interactive nature of medical decision making. A focus on the division of available information about the state space and action opportunities between actors illuminated the distribution of cognition at these stages. Decisions in this study reflected the inherent structure of the particular decision task, and who had the informational resources and capacities for action undergirding the decision. When neither party had both the necessary information and the capacity to independently enact a decision, the process of decision making was necessarily shared between actors. These inherent structural constraints highlighted the importance of patient contributions to decision making and the interdependent quality of patient and practitioner cognition.
The patient’s role in the decision patterns described here, including two patterns of decision making that are patient-led, illustrate the core contributions that patients make to clinical cognition. Moreover, this recognition clarifies the source of failures. When practitioners and patients split key cognitive tasks and associated actions, failure to create a shared cognitive trajectory may increase the likelihood of clinical errors and non-adherence. Error may arise from an undeveloped decision space missing patient-provided parameters. These findings suggest that studying patients’ reasoning processes – including those that occur before entering the health care system – is important to understand better the inherently ‘shared’ nature of medical decisions. When researchers limit their discussion of medical decision making in the practitioner’s office, they risk reinforcing a limited paternalistic model.

The four decision patterns reinforce the conclusions of chapter 4, that practitioner reasoning is broadly dependent upon patient reasoning. This is readily apparent in patient defined decisions, where the patient’s construction of decision parameters directly shapes the practitioner’s decision process. Patient cognition also influenced practitioner dominated and practitioner defined decisions but more subtly. In these cases, the practitioner presented elements of the decision space in ways that incorporated the patient’s understanding and/or values and norms (e.g. desired pregnancy and preference for natural medicine).

The interdependence of practitioner and patient cognition implies that the applied goal should not be to instruct practitioners to engage deliberately in shared decision making – a change in attitudes – but to understand and improve upon the ways both
practitioners and patients already adapt their performance of cognitive functions to accommodate differences in the resources available for distributing cognition. Training should focus on helping practitioners identify critical components of the patient’s decision space and vice versa, communicate about these elements effectively, and efficiently coordinate associated cognitive functions.

**Shared decision making as a Multistage Process**

First, patient-practitioner decision making is a multi-stage decision process that occurs in the context of ongoing clinical cognition. Decision making includes identifying decision points and refining decision parameters in addition to the recognized problem of selecting a final decision. The identification of decision points occurred when one or both participants suspected the inadequacy of the current trajectory for clinical reasoning and/or care. Many factors could prompt this realization including circumstances (as with the patient who did not receive a routine MRI because she wished to become pregnant), dissatisfaction with clinical outcomes (as with the patient who felt her pain medication was inadequate), or dissatisfaction with the direction of clinical reasoning (as with the patient who requested spinal imaging).

Given a realized decision point, practitioners and patients defined the relevant parameters for making the decision. This step could be critical to the final outcome. Defining parameters required participants to make judgments about which aspects of the decision space to attend and to draw connections between elements in the state and action spaces. The definition of decision parameters was sometimes a complex process of negotiating the norms and perspectives of the participants (as with the patient who
preferred natural medicine). Once participants identified clear parameters, the final
decision sometimes required little further consideration (as with the woman who needed
an anti-fatigue treatment that would not decrease her seizure threshold). On a theoretical
level, the salience of activating decision points and defining parameters suggests that
decision making research needs to be sensitive to more than just final decisions. When
researchers study decision making using standardized scenarios and probabilistic
comparisons (Croskerry, 2009; Marewski & Gigerenzer, 2012), they fail to include
critical initial steps involving identifying the need for a decision, searching the decision
space and correlating assessments of states and actions.

Subsequent Analyses

The analysis presented above raises several issues, further addressed in chapters 6
and 7. The critical involvement of both actors implies that clinical cognition depends
upon the skills that both the patient and the practitioner bring to the interaction. Chapter
6 explores this issue by examining the effect that the patients’ level of expertise has on
the dyads ability to carry clinical cognitive functions.

As part of an ongoing trajectory for clinical cognition, decision making processes
depend on the creation of linguistic representations and naturally extend into action. As
the actors worked through the decision process together, they used language to represent
their understanding of the state space and the implications of this understanding for
action. This process of representation was an intrinsic part of split decision processes, as
one participant presented decision parameters to the other (e.g. the practitioner
enumerating treatments for fatigue). Representation served a supporting function in
decisions dominated by a single actor, creating a mutual understanding and acceptance of the decision (e.g. the patient who worked backward to justify her decision to discontinue a medication without medical advice). On a theoretical level, the processes of representation and negotiation seen in these decisions suggest that understanding how patients and practitioners discuss and represent illness is an integral part of understanding shared decision making. Chapter 7 focuses on the use of language to represent and reason about illness.
Chapter 6: Lay-Professional Collaboration: The Effect of Patient Expertise on Distributed Clinical Cognition

How does patient expertise affect distributed clinical cognition and practitioner reasoning?

Introduction

Most studies of distributed cognition have been concerned either with technical systems (Patel, Arocha, & Kushniruk, 2002) or the interactions among professionals (Hutchins, 1995). But not all complex distributed cognition occurs solely between trained professionals. Many domains (e.g. medicine, financial services, real estate) involve professionals with extensive knowledge and experience working with laymen in a joint cognitive task.

This chapter examines professionals and laymen engaged in one such cognitive task, namely practitioners and patients engaged in managing Multiple Sclerosis (MS). In the previous chapter, I conceptualized medical cognition in terms of a practitioner-patient dyad that jointly identifies the problematic and determines the design and acceptance of...
an intervention. Here I illustrate mutual dependence by contrasting the coordination between the practitioner and the “expert” layman with the extended effort required of both the practitioner and “novice” layman in the identification of the problem and the acceptance of a resolution. In doing so, I address the mischaracterization of medical expertise as exclusively medical, in as much as it must adapt to patient understanding. To understand the issues the lay-professional division creates in patient-practitioner reasoning; it is important to delineate clearly the differing perspectives each actor brings to the interaction and the nature of patient expertise. The remainder of the introduction lays this groundwork.

Practitioner and Patient Approaches to Illness

Patients and practitioners each fulfill a distinct role. As discussed in chapter 5, each of these roles is associated with different kinds of information and abilities to act. However, the patient-practitioner distinction is more fundamental than role dependent access to the decision space. Patients and practitioners have qualitatively different ontological constructions of and epistemological approaches to understanding illness. Similarly, the processes patients and practitioners not only have the capacity to take different actions; they have fundamentally different experiences regarding what constitutes action. Some of these discrepancies are inherent in the nature of lay versus professional domain constructions generally, but others are unique to medicine. Below, I lay a foundation for discussing how patients’ lay expertise affects practitioners’ professional reasoning by systematically outlining the differences in perspective as well as the nature of patient expertise.
The Practitioner’s Perspective

Practitioners approach the clinical interaction with a predefined ontology for medical issues generally and specific diagnostic categories. Portions of this ontology are formally defined and instructed such as biochemical relationships learned in medical school and the formally identified symptoms used in diagnostic manuals. In addition, observationally oriented studies of medical expertise have identified a culturally defined normative ontology for medicine, including less formal ontological categories such as the acceptable definition of problems (Shalin & Bertram, 1996). The professionally defined ontology practitioners use complements a similarly constructed epistemology for transforming clinical data into medical knowledge. As is discussed in the introduction, the literature on diagnostic reasoning characterizes this epistemology as the combination of logic and intuition.

The practitioner’s role incorporates actions that have certain distinctive characteristics. First, practitioners’ actions are professionally defined. By virtue of their specific training, practitioners are empowered to enact a certain set of actions and only that set of actions. Thus, a neurologists, orthopedist, and physical therapist may all address the same symptom, but the diagnostic and treatment procedures each uses will differ. Second, practitioners’ actions typically occur in dedicated environments that are specifically designed to facilitate an action or category of actions. Hospital parlance highlights this tendency by naming spaces after the procedures they are designed to facilitate (e.g. operating room, x-ray lab, phlebotomy room, etc.). Finally, certain types of practitioners, notably physicians, often direct rather than execute actions (e.g. prescribing medications, ordering procedures enacted by technicians).
The technical language that practitioners use during clinical work reflects the shared ontological, epistemological and process orientations that are inherent in professional medicine (Sheehan, Robertson, & Ormond, 2007). These commonalities regarding ontology, language and work processes provide practitioners with a core common ground to facilitate collaboration among professionals (Bangerter & Clark, 2003), but they are often discordant with a patient’s construction of illness.

**The Patient’s Perspective**

Patients fall outside the professional medical culture. Although they participate in the interaction, as demonstrated in the previous chapters, the patient contribution is typically characterized as non-medical. To some extent, this may result from the fact that patients think about illness and engage in clinical care in different ways than practitioners. The patient’s ontological construction of illness begins with his experience: the symptoms they experience and any perceived relationships between symptoms or between symptoms and contextual elements. This initial understanding may then be elaborated both through cumulative experiences and by exposure to abstract biomedical concepts from practitioners or other sources (Lippa, Klein, & Shalin, 2008). Patients’ epistemology reflects a combination of experience and biomedical sources matched to personal experience. They developed knowledge of their illness both inductively through experience and by accepting authoritative statements from medical practitioners (see Appendix F).

Patients’ processes of action are different from practitioners. Whereas practitioners are performing actions that are within their training in settings adapted to the
procedures, patients perform actions for which they receive little, if any training, in a wide variety of environments. For example, one woman in this study described the logistics of self-administering injections on a trip to Australia.

Because of these differences in ontology patients necessarily talk about illness differently than practitioners. They may not have technical language to describe symptoms or procedures. Their conception of illness in based on their experiences and their practice of medical self-care occurs in settings dictated by a variety of life circumstances, these factors mean that patients tend to discuss illness in ways that are phenomenological and situated. Many studies of medical interactions portray practitioner and patient conflict, with the patient attempting to speak through a holistic ‘voice of the life world,’ whereas the practitioner uses a ‘voice of medicine’ and in so doing exerts power over the patient (Ainsworth-Vaughn, 2003; Mishler, 1984). I suggest that the conflict these studies identify is not a power conflict but the result of divergent notions of ontology and epistemology that patients and practitioners both must attempt to integrate.

As I discussed in chapter 5, patients and practitioners both have access to knowledge about different aspects of the clinical situation and can take different types of action to facilitate care. Because the practitioner depends upon patients to represent their phenomenological experiences and requires patient compliance in the out-patient setting, I show that practitioner effort must complement a patient’s ability to participate, thereby supporting the claim that the patient mutually determines the nature of the exchange and part of practitioner expertise accommodating patient expertise.
Patients think about illness and engage in medical care differently than practitioners. However, at least in chronic illnesses, patients develop expertise concerning their illness and how it manifests in their bodies (Lippa, Klein, & Shalin, 2008). They learn how specific environmental stimuli interact with their illness and what different illness states feel like phenomenologically. This helps them develop mental models of how their illness functions that can facilitate the clinical reasoning involved in self-care. Thus, patient expertise combines semantic knowledge about their illness with experiential knowledge, linking abstract understanding with to identifiable phenomenological experiences. If differences in patient expertise affect their self-care activities, presumably the same differences will impact their collaboration with practitioners and practitioners must accommodate these differences.

In the previous chapter, I suggested that the patient-practitioner dyad constitutes the central portion of a distributed cognitive system. However, practitioners and patients form a distributed cognitive system that in some ways is qualitatively different from the systems created by professional teams (Cole & Engeström, 1993; Pimmer, Pachler, & Genewein, 2013). Patients are laymen and as such their interactions with professionals are different from the interactions among professionals. As described above, the lay-professional distinction in medicine involves divergent ontologies, epistemologies and processes of action this means that actors’ conceptions of the domain and the problematic within it may vary. Lexical differences may mean that they have different words for the same idea, whereas words in common may correspond to different ideas, e.g., “black-out.” In order, for this system to function, practitioners and patients must overcome the gap between laymen and professionals. I suggest that this requires that participants create
a shared problem space. How this occurs will vary in accord with the patient’s illness expertise. To explore this process, I analyze segments of dialogue from clinical encounters concerned with MS management (Cicourel, 2006).

**Analytic Methods**

Chapter 4 identified the core cognitive functions that occurred during clinical reasoning. Analytic comparisons (Glaser, 1965; Strauss & Corbin, 2008) of dialogue segments surrounding these cognitive functions identified considerable variability in how dyads approached and accomplished these tasks. Even in cases where different patients were discussing similar issues with the same physician, the language used (Willig, 2000), management of the task through turn taking and discourse markers (Bangerter & Clark, 2003), and distribution of clinical reasoning could vary considerably. This variability implied that characteristics of the patient could affect the way cognitive functions were accomplished through dialogue and by extension dyadic clinical cognition (Cicourel, 2006). In order to identify a core category (Strauss & Corbin, 2008) that could account for some of this variability, I conducted a focused analysis of dialogue segments in which the focus of discussion was similar but the discourse patterns were disparate. This analysis suggested that dialogues involving patients who had been managing MS for longer periods of time and were more engaged in self-care varied qualitatively from dialogues with less experienced and/or more passive patients. Theoretically, these patient attributes were comparable to the characteristics that distinguished expert versus novice patients in my prior research (Lippa, Klein, & Shalin, 2008). Accordingly, patient expertise was adopted as a core category for subsequent analysis.
To examine how varying expertise affected how dyads accomplished clinical cognitive tasks, I macroanalyzed and compared matched segments of dialogue (Strauss & Corbin, 2008). I chose dialogue segments in which the same physician spoke with two different patients (one an expert patient who had actively engage in managing MS for several years and the other a newly diagnosed, novice) about a common symptom or similar clinical problem. In order to illustrate the effect of patient expertise on the process of dialogue and the reasoning involved in carrying out clinical cognitive functions, below I present a close, comparative analysis of discourse during for segments of dialogue. Two segments focus on understanding symptoms, in terms of assessing current symptoms and judging their relevance to MS, and two segments concern disease modifying agents. Because assessment of current symptoms and judging symptoms relevance to MS are related tasks, these are discussed together.

Results

Assessing Current Symptoms and Judging Relevance for MS

As identified in chapter 4, figure 1, one of the core tasks in MS management involves assessing current symptoms. This process begins when participants identify a symptom. Then, the practitioner and patient work to create a common representation of the symptom. This involves a qualitative description of the symptom, identification of the relevant context, and definition of the time course of the symptom (i.e., onset & duration), though occasionally conversations only included 2 of these 3 elements. The practitioner and patient then decide on a diagnosis (categorization) for the symptom and to come to a conclusion about what relevance, if any, the symptom has for MS. Although the process for evaluating symptoms may appear highly consistent on the surface, closer
analysis showed variability in how it was enacted particularly in the distribution of cognitive tasks between the practitioner and patient. This distribution in part depended upon patient expertise. Table 4 aligns the tasks of assessing symptoms and judging relevance for expert and novice patients.
Table 4: Evaluating Symptoms

<table>
<thead>
<tr>
<th>Process</th>
<th>Expert Patient</th>
<th>Novice Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem Identification</td>
<td>Pr: Any new <em>symptoms</em> since I’ve seen you?</td>
<td>Pr: Any other <em>complaints</em>?</td>
</tr>
<tr>
<td></td>
<td>Pt: Yeah, yeah, yeah. Monday,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I was up here on Monday. Well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>when I had my cardiac. Well, uh uh I was walking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a little bit in downtown Cincinnati to a lunch</td>
<td></td>
</tr>
<tr>
<td></td>
<td>meeting and uh … my left leg started to <em>tingle</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>really bad and that that usually is… is a uh they</td>
<td></td>
</tr>
<tr>
<td></td>
<td>it’s been called… they call it I want to say</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>false flare up</em> but that, that’s not correct but…</td>
<td></td>
</tr>
<tr>
<td>Symptom representation</td>
<td>Pt: My <em>headaches</em>. That’s the only thing. I get</td>
<td></td>
</tr>
<tr>
<td></td>
<td>headaches <em>all the time</em>.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pr: Are you on any medications for the headache?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pt: Just ibuprofen that’s the only thing I take.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pr: How often do you get them?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pt: Not every day, every other day. A lot of times</td>
<td></td>
</tr>
<tr>
<td></td>
<td>its mild and it’s not too bad. Like, I have {uh,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>huh} one right now. But it’s…</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pr: How does it hurt? The top of your head?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pt: It hurts like right here right through my</td>
<td></td>
</tr>
<tr>
<td></td>
<td>{temples}, but I get these weird, weird pains</td>
<td></td>
</tr>
<tr>
<td></td>
<td>like in the back of my head. {huh} And then I</td>
<td></td>
</tr>
<tr>
<td></td>
<td>have to just literally just stop for a second</td>
<td></td>
</tr>
<tr>
<td></td>
<td>because it’s a pressure like something’s squeezing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>the back of my head at times and it just makes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>my whole head throb. I don’t know what is.</td>
<td></td>
</tr>
</tbody>
</table>

31 Pr stands for practitioner and Pt stands for patient. Italics indicate words that are especially significant for the analysis.

32 Patient characteristics: 40s, college level education, 3-5 years with MS, severely disabled

33 Patient characteristics: 20s, college level education, 1-2 years with MS, minimally disabled
Problem Identification

Both discussions begin with a move to identify a problem and establish it as a joint focus of attention. Patients have knowledge about illness events and phenomenological experiences that are inaccessible to the practitioner. To judge what response, if any, is appropriate the practitioner asks an open-ended question that invites the patient to share elements from her experiential knowledge that she believes are problematic. This process entails the establishment of mutually comprehensible language...
to ground the exchange. With the expert patient, the practitioner uses the term ‘symptom,’ suggesting this patient can distinguish medically relevant symptoms from other forms of discomfort. For the novice patient, the practitioner chooses the broader term ‘complaints’ to elicit the patient’s symptoms. This elicits a wide variety of issues; the physician must then distinguish which issues are clinically significant.

*Symptom Representation*

Patients and practitioners inherently understand symptoms differently. The patient has more episodic knowledge of illness events. However, the practitioner has greater semantic medical knowledge. To effectively discuss symptoms, the participants must construct a joint representation of the symptom by sharing pertinent knowledge.

The expert patient had the ability to parse his episodic knowledge in a way that was medically relevant and then integrate that episodic and semantic information into a coherent, medically oriented representation. He created a detailed initial representation including both a qualitative description and relevant context. Moreover, he suggested a partial solution to the diagnostic problem, reaching for a medical term to use as coordinating language. His introduction of this term with ‘they call it,’ implies that he did not think of his symptoms using these terms. In so doing, he conforms to one of the social control components operating in the clinical setting that medical personnel have privileged access to technical terms. “That’s not correct” prompts the practitioner’s turn, to validate or refute his symptom representation. Thus, he creates a preliminary integrated representation and interpretation of the symptom but defers to the practitioner for a definitive interpretation.
By contrast, the novice patient does not construct her contribution in a way that is immediately compatible with a medical understanding. In the beginning, it is still not clear if her ‘complaint’ is even a medically relevant ‘symptom.’ However, she asserts that the frequency of her headaches makes them medically relevant. The practitioner follows up on this implication by checking, i.e., the responsibility of another medical professional. Having determined that the headaches may require her to act, the practitioner attempts to gain access to enough of the patient’s experiential knowledge to construct a representation of the patient’s symptom that is compatible with medical interpretation. The practitioner does this by asking the patient very focused questions, prompting her to elaborate on medically relevant aspects of her experience. The patient here has the essential subjective experience (episodic knowledge) but lacks the semantic medical knowledge to understand what aspects of her experiences are clinically relevant, whereas the practitioner has the necessary semantic knowledge but depends on the patient to provide specifics for her episode. The interplay between them comprises an effort to create a sufficiently shared understanding of the symptom to support a diagnosis. The patient concludes by saying she does not ‘know what it is’ with the implicit question “do you?” to prompt the practitioner’s turn.

*Causal Attribution and Categorization*

After the practitioner provides the expert patient with the relevant biomedical term, the patient chooses a related term to provide an alternative hypothesis to his initial self-diagnosis. He then revisits his initial diagnosis, by saying it matches a familiar pattern (it’s ‘usually a sign’), and that it ended quickly. He completes his turn asserting his belief in his last explanation (walking a lot). This assertion provides an opportunity
for the practitioner to either validate or object to the patient’s self-assessment. The practitioner questions the time course of the incident; this clinically defines an MS attack and validates the patient’s self-assessment. The patient presents the symptom and provides the initial analysis, but together they decide on an account that renders the symptom non-problematic. Had the patient not considered the symptom potentially problematic, he would have provided a diagnosis by omission. After introducing a symptom, judgment cannot have the status of a diagnosis without the practitioner’s contribution.

In contrast, the classification phase with the novice patient illustrates a broader knowledge disparity between practitioner and patient. In diagnosing the patient as having ‘migraines,’ the practitioner introduces a medical term. However, the patient lacks the knowledge to associate this term with her subjective symptoms. The practitioner and patient must work together to test the migraine theory. During this testing process, the practitioner asks specific questions whereas the patient must infer the clinical characteristics of a migraine from those questions and try to match them with her experiences. As the practitioner’s questions become more leading, the patient’s answers flag caution, using limiting language like ‘not too much’ and a ‘little worse,’ and making sure the practitioner doesn’t over-interpret her responses by asserting that light ‘doesn’t cause’ the headaches.

**Judgment of Relevance to MS**

The physician’s evaluation of significance is not a question of simple medical significance, but significance as a problem for this specialist to address. The expert patient provides his assessment. However, the novice lacks the knowledge to understand
the significance of her symptoms and poses the question to the practitioner. The practitioner already has dismissed the headaches as unrelated, but his role is not complete. The patient has not agreed on this conclusion. Far from being inert, the novice patient raises concerns and influences turn taking, directing the practitioner to provide a medical overlay.

To summarize, in both dialogues, the patient’s choice of which experiential elements to represent in the conversation constrained the practitioner’s reasoning whereas the patient’s level of semantic knowledge about MS constrained their reasoning. Differences in the sophistication of the language used and patterns of turn-taking illustrated the variance between expert and novice interactions. The expert patient was able to combine episodic and semantic knowledge into a fully developed representation. This was apparent in the sophisticated language used and a pattern of patient presentation of symptoms and proposed diagnosis followed by a practitioner response. Whereas, the novice patient lacked semantic knowledge and had trouble representing episodic knowledge in a way that was compatible with the practitioner’s understanding. Therefore, the dialogue had a basic vocabulary and required many more question-answer sequences to ensure the availability of relevant information and accuracy of the diagnosis.

*Selecting Actions to Modify Course of Disease*

Many clinical sessions included discussions focused on evaluating the efficacy and/or side effects of particular treatments, either currently being used or being considered for use. Whereas the medical community typically discusses action selection in terms of evaluation functions that match clinical characteristics to treatment options
(Woolf, 1992), in this study action selection was a more complex process that involved pragmatic as well as clinical considerations. These assessments used multiple criteria including side effects, clinical outcomes, MRI outcomes, and pragmatic considerations. Each party was responsible for a subset of the evaluation criteria. The patient was the only one to have subjective knowledge about the acceptability of symptoms and side effects, and the physician was the only one who could assess efficacy with respect to MRI outcomes. Both participants could evaluate clinical outcomes. The multi-attribute evaluation required input from both perspectives and interaction concerning multiple issues. Table 5 includes dialogue from two patients (an expert and a novice) who have recently begun new treatments. The structure of the table and accompanying discussion focus on the criteria being assessed delineated in the central column and drawing comparisons between the discussions of particular criteria in each dialogue shown on each side.

Initial Evaluation

In both discussions, the practitioner initiates the evaluation of treatment alternatives by asking a question. The expert patient, who has had MS for several years and been treated unsuccessfully with a number of medications, immediately responds in a medically relevant fashion. Even though the practitioner’s introduction is very vague, she understands that this visit is part of routine care for monitoring patients using the medication she has recently started, Tysabri. Accordingly, she interprets the general question as a reference to this issue. By contrast, the dialogue with the novice patient illustrates an initial struggle to establish common ground. The practitioner asks for an assessment of the treatment in medical terms; in fact, she phrases her inquiry narrowly.
couching it explicitly in terms of the medication. However, the patient interprets the question more broadly describing her emotional response.

Assessing side effects. The expert patient begins with her assessment of the medication’s side effects. In doing so she uses medically oriented, but not explicitly technical, language (e.g. ‘muscle tightness,’ ‘joint pain’). As with the expert patients’ assessment of symptoms, she links her subjective experiences to her abstract knowledge about the nature of side effects for this medication and further supports her interpretation by relating the opinion of the nurse. The practitioner responds directly to the patient’s contributions and shows acceptance of her evaluation. By contrast, the novice patient does not spontaneously volunteer information about side effects. She leads her evaluation with her emotional experience. This apparently signals to the practitioner that she failed to understand the intent of the practitioner’s question, prompting her to ask a much more specific question to repair the conversation. By asking about ‘injection site reactions,’ rather than side effects the practitioner not only narrows the conversation solely to focus on physiology but defines criteria for assessing how she is ‘doing on Copaxone.’ The patient’s response is purely descriptive ‘a little lump’ without any attending judgment about whether her experience is an injection site reaction. She simply provides information leaving the interpretation to the practitioner.
D: So, tell me how it is.

P: It’s good, it’s very good. I had the first. Um, the first two were no side effects. The third one I had some muscle like tightness like sore in my wrists, kind of like joint pain. And {uh, uh} then after that dose the one time and I had read that that was a side effect and I talked {um, hum} to the person that infuses it and they had said also you know that it was. And I didn’t {oh, ok} have any side effects then this last time.

D: So just one time.

P: Just the joint pain but that was it.

D: So a little bit of muscle tightness in the area but that was it.

P: Yeah, yeah but I mean physically I feel so much better.

D: Do you?…

P: Yeah, I’m like back to normal. I mean even the numbness is not what it was. I mean I have a little in my toes but like what you can live with you know.

D: Oh, hahaha. Me too. How was walking?

P: Great. I mean it’s, we adopted our little girl and we were in Guatemala.

D: No way, no way, no way.

P: I mean that’s what I mean I was down there we were in the airports and holding the baby. It was fine, I just made it. I wasn’t tired. …

---

Table 5: Evaluating Treatment

<table>
<thead>
<tr>
<th>Expert Patient³⁴</th>
<th>Criteria Assessed</th>
<th>Novice Patient³⁵</th>
</tr>
</thead>
<tbody>
<tr>
<td>D: How are you doing on Copaxone?</td>
<td>Side effects</td>
<td>P: First I didn’t want to do the shot cause {I} wasn’t too fond of needles. I was afraid of them, because I had a bad experience with needles.</td>
</tr>
<tr>
<td></td>
<td>Pragmatics</td>
<td>Dr: Oh.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P: I got used to it.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dr: You’re not getting any injection site reactions?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P: It turns red and there’s a little lump sometimes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dr: And they’re frequent to like every day you have to do that {injection}. …</td>
</tr>
</tbody>
</table>

³⁴ Patient characteristics: 40s, college education, 5+ years with MS, moderately disabled

³⁵ Patient characteristics: Late teens, high school education, 1-2 years with MS, minimally disabled
Assessing clinical outcomes. The expert patient readily assesses the clinical effect of her treatment by moving immediately from her judgment regarding side effects to a discussion of the efficacy of the medication. The patient then focuses on the treatment’s benefits, providing both abstract assessments and a functional description of specific circumstances where the improvement was especially evident. The practitioner supports this process with her assessment of the patient’s improved gait. The patient does much of the active assessment whereas the physician validates to her judgments. The husband prompts further physician validation by asking how the patient’s experiences compare to others. The practitioner provides this final validation by relating her professional experience. The discussion with the novice patient does not assess clinical outcomes because the medication this patient was using is a prophylactic that is not expected to create an immediate effect.

Pragmatic Considerations. The discussion with the expert patient does not include any pragmatic concerns regarding the medication. The novice patient raises a pragmatic issue, the need to self-administer injections, obliquely at the beginning of the discussion as part of her assessment of the emotional impact of the medication. The practitioner initially ignores the patient’s emotional concerns steering the conversation...
toward side effects. But then, she returns to the pragmatic aspects of the patient’s concern in a disjointed manner later in the conversation when she mentions the frequency of the injections. This dialogue includes two distinct threads: a physician-led discussion of side effects and a patient-led discussion of the emotional impact and pragmatics of the medication.

**MRI results.** Both discussions end by relating the medications efficacy to MRI outcomes. With the expert patient, the practitioner responds to the husband’s question about whether the patient’s experience is typical partly by describing the physiological profile and associated MRI results that indicate medication efficacy. Even though she never mentions this patient’s specific images, all of the participants in the conversation are familiar enough with the technical aspects of the patient’s case history to understand that she fits this profile. By contrast, in the discussion with the novice patient, the practitioner describes the implications of the patient’s MRIs, which she brings up to show the patient. The practitioner uses the images to assess the efficacy of the medication directly and elaborates on the implications for treatment. The patient does not participate at all in the discussion of this factor, lacking the technical knowledge and language to contribute.

In summary, the contrast between expert and novice discussions is striking. The expert patient both defines the problem space and provides the basic evaluation. However, the practitioner provides the validation and extension that transforms the patient’s personal assessment into a verified medical outcome. By contrast, the novice patient and physician evaluate the medication on three dimensions. However, each participant assesses one dimension, with minimal contributions from the other. The
novice patient relates her subjective experience, which is not a category of concern to the practitioner. Whereas, the practitioner considers medical outcomes that the patient cannot interpret meaningfully. There are no co-constructed conclusions.

Conclusions

In this study, I have examined the interactions between practitioners and patients with varying degrees of skill in Multiple Sclerosis management. I revealed the impact of patient experience of practitioner reasoning, using a classic expert-novice contrast to identify otherwise hidden features of patient expertise. I used the physician response to demonstrate that this difference impacts medical cognition.

Practitioner reasoning depends upon information that is only directly accessible to the patient. This requires parsing the patient’s experiences in a way that is medically relevant. The expert patients in this study could make effective judgments about what information was clinically relevant. Moreover, they had the experience and medical language to understand what information the practitioner was asking for and to represent that information effectively. But, novice patients did not have the sense of relevance or access to language that facilitated dialogue with expert patients. Therefore, it became the practitioner’s responsibility to elicit a relevant contribution.

In addition to representing their experiences more effectively, expert patients had enough experience with MS and semantic knowledge of the disorder to be able to fit their experiences into medically relevant. Therefore, their discussions included judgments as well as informational components. The practitioners’ reasoning had to adapt to take these initial interpretations as a starting point. To respond appropriately, they had to
understand the patients’ reasoning and then build off that understanding. This included the practitioner checking and validating or refuting the patients’ conclusions, and extending the conclusions by relating them to broader medical constructs. With novices, the practitioner was solely responsible for the interpretation of illness events. However, their reasoning was constrained by what the patient contributed to the dialogue and the patient’s acceptance of hypotheses.

This chapter illustrated the variability of patients and the responsiveness of the physician, in so doing it contributes to the more general claim of medical reasoning as a function of the dyad, articulated in the previous chapter. Because practitioner cognition must adapt to fit the patient’s clinical skills, even when the patient is not able to engage in substantial clinical reasoning, the practitioner’s ability to adapt to the patient’s limitations becomes a major factor in determining the course of clinical reasoning. With expert patients, the distribution of clinical cognition is even more apparent as patients assert control of the initial representation and interpretation of illness events thereby setting a trajectory for clinical cognition.

Subsequent Analysis

In this chapter, the patients ability to represent their experiences and the use of mutually (in)comprehensible language directly affected clinical cognition. Chapter 7 builds on these findings exploring the role that verbal representation plays in distributed clinical cognition.
Chapter 7: Medical Narratives as an Aide to Clinical Cognition

How do patients and practitioners use narrative as a representational component of a distributed cognitive system?

Introduction

Narrative occupies a unique position in medicine. It is pervasive and well integrated into clinical practice, but its cognitive and functional significance are largely overlooked. Practitioner training using case history narratives and practice exploits narratives to collaborate and share information (Morgan-Witte, 2005). Patients share narratives with practitioners as they recount acute episodes and elements of their medical history (Haidet & Paterniti, 2003). However, despite the acknowledged role of narrative in medical practice (Charon 2001), researchers studying clinical cognition typically do not consider narrative elements. Instead, they focus on analytic reasoning by practitioners, emphasizing the information used in clinical cognition with little consideration for the nature of the interaction used to obtain information. Indeed, the previous chapter adopted this perspective, focusing particularly on identifying and representing the parameters that participate in decision making.

36 A shortened version of this paper will be presented as a poster and appear in the proceedings of CogSci 2016 under the title “Distributed Cognition in the Past Progressive: Narratives as Representational Tools for Clinical Reasoning”.

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Throughout this dissertation, I have demonstrated that the practitioner-centric model of analytical clinical cognition is inadequate because it fails to consider patients’ substantial contributions to clinical reasoning. I relied on language as the form of evidence for distributed clinical cognition using language. In making this argument, I have relied on the contents of dialogue. This chapter shifts emphasis to focus on the form a dialogue takes. I suggest that how participants construct a clinical dialogue has cognitive significance, and, in particular, that narrative as a distinct and pervasive mode of speech serves specific functions for clinical cognition.

The introduction to this chapter begins by briefly addressing the nature of narrative as a means of representation. It then shifts to review the literature on the role of narrative in medicine and the relationship between narrative and cognition. From this basis, I examine how narrative completes specific clinical tasks involved in MS management. Because narrative is inherently hermeneutic, this analysis has a substantial interpretive as well as analytic orientation. Finally, I address the implications of this analysis for understanding clinical cognition and the relationship between narrative and cognition more broadly.

**Narrative as Representation**

To collaborate effectively, patients and practitioners need to create a shared focus of attention. The practitioner-patient interaction provides a coordinating mechanism to establish and maintain joint attention to specific situational elements. In many cases, lack of mutual access to pertinent information complicates this process (Lippa et al., 2016). When actor-specific access to information challenges the maintenance of joint attention
(Moore & Durham, 2014), participants must create mutually accessible representations to allow for more effective interaction.

Narratives provide uniquely rich, mutually meaningful representations of alternative times/realities. As a form of representation during clinical interactions narrative has two aspects. Narrative is both a process, the act of narrating/listening to narrative, and a product, the resulting story. These two aspects of narrative are interrelated but non-identical. Each is likely to facilitate clinical cognition in different ways. As a process, narratives are powerful. In Niles’ (2010) term narratives are cosmoplastic; they have the ability to create elaborate worlds endowed with characters, sensations and events, each of which has an attendant meaning. When patients use narratives to describe their illness experiences, they are recreating essential aspects of their world experience in the clinical context. By narrating illness events, patients increase the practitioner’s ability to access episodes outside the clinic. This capacity of narrative can extend the interaction space available to practitioners and patients. As a product, narratives serve as a record of illness related events comparable to a formal medical record.

*Narratives in Medicine*

Narrative is an integral part of clinical care (Charon, 2001; Greenhalgh, 2006). Patients share narratives with practitioners as they recount acute episodes and elements of their medical history. Practitioner questions may disrupt or curtail patient’s narratives (Haidet & Paterniti, 2003). The nature of these interruptions (endorsement or redirection) conveys information about the significance of specific narrative elements (Lippa &
Practitioner response may lead to elaboration, modification, or (re)interpretation of the narrative. After the appointment, the practitioner may record elements of the narrative in the patient’s chart. Charts may serve as a repository for the recording of patients’ stories about specific instances and practitioners’ stories about patients (Atkinson, 1995). The chart as a whole functions as a narrative of the patient’s clinical history (Hunter, 1991).

If the case is particularly interesting or the patient sees other practitioners, some form of the narrative may be retold by the practitioner to other medical practitioners. Practitioners share narratives formally via the patients’ charts and informally as stories they tell one another about their work experiences. Informal narratives allow practitioners to share information they consider relevant that does not fit into the formal communication structure (Morgan-Witte, 2005). Narratives of this type include stories illustrating aspects of the patient’s personality or communicating critical contextual information, as for example when a patient is engaged in an ongoing conflict with a family member about some element of treatment (Cassell, 2004). When practitioners are struggling with a difficult case, they tell one another stories about similar instances as a way of increasing their understanding of the current situation (Hunter, 1991). Similarly, when the case ends in an undesirable outcome, such as iatrogenic injury or death, practitioners may retell the story of the incident seeking places where acting differently might have prevented the negative outcome (Morgan-Witte, 2005).

On the patient’s side, the narrative persists beyond the clinical encounter. When patients leave the clinic, they take away an altered narrative that includes the
interpretations, results, and implications from the clinical session. In cases of chronic illness, the narratives recounted in a given clinical session will only be part of a larger narrative encompassing the illness as a whole. Extensive research has focused on analyzing the significance of such narratives, for identity formation (Crossley, 2000; Frank, 1995) and the cultural construction of illness (Garro, 2000; Good et al., 1994), see Appendix G. However, researchers have not devoted much attention to how narratives are related to patient cognition. Research has demonstrated that narratives about others can affect patients’ assessment of risk (Wong & King, 2008), but has not addressed how patients’ construction of their illness narratives affects the breadth of cognitive functions considered here (e.g., assessing symptoms and judging their relevance). The frequent and varied uses of narrative in medicine suggest that this form may complement the challenges of clinical cognition. However, discussions of medical narratives have either not addressed cognitive issues or have treated the reasoning associated with medical narratives as separate from the diagnostic (Cassell, 2004; Garro, 2000) and decision making functions typically defined as clinical cognition (Hunter, 1991).

Narratives and Cognition

Studies analyzing narrative and cognition have also tended to separate narrative from classical cognitive functions. Whereas a few studies have examined ways in which narrative facilitates cognition, especially memory (Black & Bower, 1979; Bower & Clark, 1969; Mullen & Yi, 1995), most psychological studies of narrative have followed Jerome Bruner’s conception of narrative cognition (Bruner, 1986, 1990, 2002). Bruner (1991) has argued that human knowledge and reasoning abilities are inherently domain specific. The cognitive tools used to understand one subject do not necessarily connect
with or translate into abilities in another area. Bruner (1986, 1990) has suggested that there are two basic forms of thought: the paradigmatic and the narrative. He associates paradigmatic thought with scientific reasoning and logical processes and narrative thought with social reasoning. Thus, people understand why when two balls are dropped they fall together by paradigmatic reasoning about physical relations but understand why Galileo decided to drop two balls off the bell tower in Pisa by using narrative reasoning to consider human relations. This distinction mirrors research in the medical domain that analyzes biomedical reasoning as clinical cognition whereas narrative studies look at humanistic aspects of medicine. Effectively, researchers have classified how people understand disease as a paradigmatic problem, but their experience of illness calls for narrative cognition.

However, as I have demonstrated in the previous chapters both are critical. The fusion of the biomedical and personal components of medicine suggests that in clinical cognition, narrative and paradigmatic thought may be complementary or synergistic rather than dichotomous or opposing. Close examination of the properties that Bruner attributes to narrative supports this idea. In conjunction with other scholars’ discussion of similar narrative properties, a detailed assessment suggests that Bruner’s definitions of narrative cognition may actually facilitate classical cognitive functions.

Bruner’s conception of narrative cognition includes ten core properties, See Table 6.
Table 6. Bruner’s Properties of Narrative Cognition.

<table>
<thead>
<tr>
<th>Property</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narrative Diachronicity</td>
<td>Narrative is inherently temporal as events occur across time.</td>
</tr>
<tr>
<td>Genericness</td>
<td>Narratives fall into genres that involve both stylistic conventions and prototypical plot elements</td>
</tr>
<tr>
<td>Canonicity and Breach</td>
<td>Narratives tend to focus on a disruption in the normal flow of events</td>
</tr>
<tr>
<td>Normativeness</td>
<td>Narratives contain implicit norms</td>
</tr>
<tr>
<td>Particularity</td>
<td>Narratives are highly specific.</td>
</tr>
<tr>
<td>Intentional State</td>
<td>Narratives incorporate the phenomenological and psychological experiences of the characters</td>
</tr>
<tr>
<td>Hermeneutic Composability</td>
<td>Both creating and understanding narrative are interpretive activities</td>
</tr>
<tr>
<td>Context Sensitivity</td>
<td>Where, how, and to whom the narrative is told all affect its meaning</td>
</tr>
<tr>
<td>Referentiality</td>
<td>Audiences judge a narrative’s validity on verisimilitude rather than verifiability</td>
</tr>
<tr>
<td>Narrative Accrual</td>
<td>Narratives tend to aggregate to form larger narrative traditions</td>
</tr>
</tbody>
</table>

From a cognitive perspective, the narrative form provides a number of advantages. To begin with, narratives provide an organizational structure for information. Narratives are diachronic, with an inherently temporal component (Labov, 1997; Ricoeur, 1988). The temporal nature of narratives scaffolds the organization of complex events by chunking information into episodes. Moreover, narratives are typically constructed to follow a particular genre that provides a schematic organization (Barthes, 1975). The genre conventions guide the inclusion, structuring and presentation of particular narrative elements (e.g. a superhero story requires a positively cast
superhero and a negatively cast villain acting in opposition to one another). Possibly because of these organizational advantages, narrative aids both semantic and autobiographical memory (Black & Bower, 1979; Bower & Clark, 1969; Mullen & Yi, 1995).

Narratives not only offer a structure to aid in reconstructing events but facilitate reasoning about them. A common, and according to some theorists defining, characteristic of narrative is canonicity and breach (Bruner, 1991; Labov, 1972). Normal life is disrupted and the narrative centers on evaluating, making sense of, and ameliorating this disruption (Riessman, 2008). A core part of the reasoning involved in narrative composition is the development of causal arguments. The temporal nature of narrative facilitates abductive reasoning. Some theorists have even gone so far as to advocate that all narratives are in some sense causal arguments employing post hoc ergo propter hoc logic (Robinson & Hawpe, 1986; Singer & Bluck, 2001). These causal arguments augment cognition by improving recall and judgments regarding the relevance and importance of events (Trabasso & van den Broek, 1985). Theoretically, narratives may facilitate inductive reasoning. The combination of particularity and genre conventions may allow narrative to facilitate theory generation by filtering noisy data in recognizable patterns. Dubba et al. (2012) showed this effect in an AI system for modeling airport logistics by interleaving inductive and abductive processes through the

37 Although abduction and induction are formally closely related (Flach & Kakas, 2000), here they are discussed separately because the temporal aspect of abduction makes its relationship to narrative distinct from other forms of induction.
creation of spatiotemporal narratives. Their work suggests that it is at least theoretically possible to come to understand a dynamic domain by combining inductive processing of sensory information with abduction-based hypothesis testing through a narrative framework.

A single individual may perform these intermingled processes of reasoning and narrative composition or they may emerge as part of a social dynamic as two or more actors co-construct a narrative (Ochs, Smith, and Taylor, 1989). When narratives are co-created or simply told by one person to another, narrative becomes a social activity that involves the creation of shared meaning. The audition and composition of narrative are inherently hermeneutic activities that require a person to understand all of the components of the narrative as constituent elements in a meaningful whole (Bruner, 1991). On the surface, this aspect of narrative directly opposes any form of paradigmatic thought. However, it may facilitate distributed cognition. When reasoning together, each person brings a unique perspective to the interaction. This variance in perspective may be minor or involve substantial ontological differences. Because narratives are hermeneutic, they can overcome basic differences in perspective as each participant has access to a common representation, open to discussion but meaningful under a variety of interpretations. At least two different interpretations applied to each of the narratives in this study. The practitioner understood the meaning of the narrative by relating components of the story to definitions, physiology, biochemistry, and prior experiences. The patient understood the narrative as meaningful in terms of his personal experiences, functional capacities, and understanding of MS. In writing this paper, I am adding a third layer of interpretation to the narratives, relating story elements to one another in terms of
their cognitive and pragmatic relationships. The existence of multiple interpretations of a narrative does not indicate that the narrative is purely subjective and thus meaningless in terms of an objective notion of reality. Rather it reflects the multifaceted nature of reality and humans’ limited capacity to comprehend fully or represent it.

**Narratives in MS Management**

As was discussed in chapter 4, managing Multiple Sclerosis is a complex process, so clinic sessions typically include multiple tasks involving a variety of forms of information, making reasoned judgments, and engaging in decision making processes (see Figure 1). During most of these tasks, both the practitioner and the patient can make substantial cognitive contributions. When patients make contributions based on their personal experience, they are likely to use narrative speech. In the analysis below, I examine which tasks involved narrative. I then analyze the role that the narrative form plays in the clinical cognition involved in executing each of these tasks. Finally, I contrast the narrative interactions discussed with a few non-narrative interactions to highlight the functional qualities of narrative in clinical reasoning.
Methods of Analysis

I analyzed transcripts and notes using grounded theory methods to examine narratives as a cognitive construct. The initial analysis was unmotivated, using inductive coding to identify salient features of the data set (Charmaz, 2006). The issues identified inductively, including the prevalence of narrative, helped to create a defined coding set that I applied systematically to the entire data set. During this analysis, I coded segments to indicate the presence or absence of narrative in each turn of speech. I defined a narrative as speech describing one or more particular events and including temporal, evaluative and contextual components (Ricoeur, 1988). To verify the reliability of the narratives identified, five years later approximately 25% of the corpus (3 transcripts from
clinical sessions, 3 sets of session notes, and 5 interviews) was recoded in an analysis focused only on identifying narratives. A comparison between the two codings indicated a high level of reliability for the identification of narratives, kappa = .8179 (CI .7753-.8605; max possible: .8451). The vast majority of disagreement between the two sets of narratives occurred in the form of addition narratives identified during the second coding. Relative to the second coding, the precision of the first coding was 97% and the recall rate was 74%. To ensure the integrity of the narratives identified subsequent analyses focused on the 88 narratives originally identified.

I examined all the narratives repeatedly in successive rounds of detailed analysis. The first round of analysis selectively coded narrative passages based on the elements of narrative as defined by Bruner (1991). This analysis verified that Bruner’s conceptualization of narrative applied in this setting, but failed to provide insight into the role narratives play in clinical cognition. Therefore, the next round of analysis returned to inductive coding and analytic comparisons focused on identifying patterns concerning the cognitive and pragmatic utility of these narratives in the clinical context (Strauss & Corbin, 2008). This analysis identified a variety of concepts related to the utility of narrative as a representational tool including as a boundary object (Star, 1988), record keeping system, hypothesis testing mechanism, persuasive device, means for virtually recreating external environments, etc. All of these uses were integrated into the core category of narrative use as a psycholinguistic tool. Then, I sorted the narratives according to their clinical cognitive function, as identified in chapter 4, and compared narratives used for similar and disparate cognitive functions. This analysis suggested the importance of narratives in causal reasoning and as a way to convey functional
descriptions. In order to quantify the frequency of these functions, I recoded the narratives using a focused coding scheme specifically to identify causal reasoning and functional descriptions. A second rater coded a subset of narratives (approximately 25%) independently. Reliability between the raters was high (Kappa=.63 [CI .41-.85]).

Finally, I selected exemplars of narratives used in performing different clinical cognitive functions for hermeneutic analysis (Ezzy, 2002). This analysis focused on identifying the meaning the narratives conveyed and how they informed the practice of clinical cognition. The narratives analyzed below were selected as illustrative examples to provide a thick description to complement and enrich the theory of narratives as representational tools (Wilson & Hutchinson, 1991). Hermeneutic analysis was selected, as opposed to the discourse analysis used in other chapters, because 1) some of the narratives were primarily created by a single individual rather than in dialogue and 2) interpretation is an inherent part of narrative.

Results

Both clinical interactions and interview data included substantial narrative components; 88 in all. Each clinical transcript and interview contained one or more narratives. Only three sets of session notes contained clearly identifiable narratives. This probably reflects the limitations of the note taking system, because there is no a priori reason to suppose that the first 10 clinical sessions observed differed from the subsequent 14 in this respect.

Seven of the nine major clinical tasks identified in chapter 4 involved narrative speech to some degree. Narrative speech was prominent in discussions of case histories;
every audio recorded clinical session included one or more narratives during this portion of the interaction. As shown below, the narratives created while discussing case histories served as key representations supporting the processes of assessing disease progress and assessing current symptoms. Discussions about the relevance of symptoms for MS and selection of actions to control the course of disease or symptoms had a substantial narrative component as well. In addition, participants told narratives during physical examinations, but these narratives were less central to the conversation. The discussion below traces how narratives facilitated cognition during each of these tasks. Certain tasks used narratives in ways that were either highly integrated (discussing case histories in relation to assessment tasks) or similar (selection of actions) so I discuss these tasks together.

**Discussing Case Histories**

Narratives pervaded the case history discussions. Discussions of case history, by definition, require reasoning about external events. These events may be completely past or ongoing – originating outside the clinic and extending into the present. In either case, the discussion invokes memory to recall events and associated details and attention to select focal elements of an event. Narrative addresses the more general challenge noted earlier, to render external patient experience accessible to the practitioner.

As an especially immersive form of representation (Bruner, 1991; Niles, 2010), narratives are well adapted to creating joint access to external events. Participants drew upon narratives from the case history discussion during subsequent assessment functions. Accordingly, in this section, I briefly describe the kinds of narratives told and leave
detailed discussion of their structure and cognitive utility for later sections focusing on the assessments they support.

The narratives created during discussions of case history provided the basic information for two different clinical cognitive functions: assessing disease progress and assessing current symptoms. Different types of narrative furthered each of these goals, mirroring the scope of the cognitive function: anamnestic\textsuperscript{38} narratives and episodic narratives. These narrative types varied based on the time course described and the nature of the particulars included. Participants used anamnestic histories in discussions assessing disease progression. They featured brief reports of multiple events occurring across an extended time and included few sensory or contextual details about any given episode. By contrast, participants used episodic narratives to assess current symptoms. They covered short periods of time and included substantial details about timing, context and sensations. Each sub-genre incorporated features, discussed in detail below, which supported the cognitive functions involved in and clinical goals for the discussion.

\textit{Assessing Disease Progress}

Understanding the evolution of a patient’s disease status is a challenging cognitive task. Patients and practitioners need to integrate information about events, treatments, multiple practitioners and symptoms as they occur across time. They may need to recall information from weeks, months or even years previously and organize this

\textsuperscript{38} Anamnestic in this context refer to the use of narrative as an aide to recall events. For a similar use see Little and Schneidman (1959).
information in a way that facilitates judgments about evolving disease processes.

Narratives could incorporate all of the relevant clinical and circumstantial information.

In some cases, narratives incorporated metacognitive reflections (Flavell, 1979), consideration of prior or ongoing clinical cognitive functions including representations of clinical status, causal inferences, and decisions. Participants used metacognition to evaluate changes in their understanding of the disease across time and monitor the justification for and outcomes from prior decisions. In examples 1 and 2, all of these processes are evident.

Table 7. Anamnestic narratives

<table>
<thead>
<tr>
<th>Examples</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example 1</strong></td>
<td>Initial temporal grounding</td>
</tr>
<tr>
<td>Patient: I went to the hospital <strong>on Christmas day</strong>, because I was, just, I was feeling just like this</td>
<td>Event 1: emergency room visit</td>
</tr>
<tr>
<td>Practitioner: [were you still on the medication for pain then, at that time?] Patient: No, no, I had stopped, I had stopped at the beginning of that week unfortunately been a day, a day or two, I went the hospital. They gave me, he wrote a script for me. Ay, ay, I took the medicine as soon as could. And sure you know within 4 hours, or actually, within 20 minutes I <strong>started to feel better</strong>. Within an hour, my quality of life just improved dramatically... dramatically. {um uh} Um, then I knew I wasn’t going to be able to see you until today. Then I’ve been trying to get into any pain place. But then Um, the places that I’m trying to get into. Anyone you want to get into they all require from you, from your office as far as you know my background and all those other things, which is understandable. Um, but, unfortunately, I haven’t been able to get in to see them. So I had to go to the hospital again last week and um</td>
<td>Assessment of medication efficacy</td>
</tr>
<tr>
<td>Event 2: attempting to get an appointment with a pain clinic</td>
<td>Metacognitive</td>
</tr>
</tbody>
</table>

39 Patient characteristics: 40s, college education, 3-5 years with MS, severely disabled
they wrote me another script. He wrote me another script for about a week of pain medicine.

Practitioner: [what kind of medication were you on?]

Patient: hydrocodone (um, um) uh scratch that out. Actually, it’s about two weeks ago I went. He wrote it for a week, but I knew I wouldn’t see you until today. So I had to stretch it out as far as possible. And last night was the end, the very end. I think I took it about four o’clock yesterday evening and um, my body right now is…

Example 2:

Patient: I’ve had a lot of stuff going on. Um, I went to the hospital in the beginning of January because I had such bad muscular pain. It was just like I slept for 3 days and I had taken those muscle relaxers they didn’t help so I went to the hospital and they gave me um like a really high dose inflammation shot and what was it zermetrol? Or something some kind of pain shot.

Practitioner: Darvocet?

Patient: something else that they gave me in the hospital.

Practitioner: Demerol?

Patient: no and then they gave me like adragenal or something they said I need to relax. And then I went to the doctor at (garbled word) colleges and he said I had the fibromyalgia.

And um so I just anytime I get the least bit of sick or I had this sinus infection and I felt like I was dying or something. I trusted my doctor and he said it was a muscular skeleton inflammation from having MS. I have been suffering a lot this winter, seriously I’ve been in a lot of pain. They want to say it’s MS, they want to say it’s the fibromyalgia. It’s hard to distinguish between the two.

Practitioner: So, mainly what you have since the optic neuritis is you have the pain.

---

40 Patient characteristics: 30s, high school level education, 5+ years with MS, severely disabled

---

Patient: [reflection on his own decision making bridging events 2 & 3]

Event 3: second emergency room visit

Metacognitive reflection on his own decision making

Assessment of current status

---

Initial temporal grounding

Metacognitive reflection on her own behavior-based decision making

Event 1: emergency room visit

---

Event 2: specialist visit

Assessment of current status

Integrating the judgments of multiple practitioners

---
In some ways, these two narratives seem very different. The first is much more detailed, well organized, and articulate than the second, probably reflecting the difference in education between the two participants. However, despite differences in sophistication, each of these descriptions utilizes properties of narrative to further the process of assessing disease progression.

The patients in examples 1 and 2 both suffered from poorly controlled pain. In recounting these narratives, the patients focused on recalling events over the last several months as they inform his/her current status. Both patients used the temporal nature of narrative to facilitate this process, beginning by explicitly situating the events in their temporal context (“on Christmas day,” “in the beginning of January”). They then recall events leading up to the present. In this sense, the recounted events essentially become semantically meaningful chunks. The temporal flow of the narrative allows disparate information about events occurring at different times and places to be organized into a coherent, and presumably easily remembered, story.

Where greater detail is needed, specific events are described forming small narrative sequences within the larger composition. Example 1 includes three narrated events (2 emergency room visits and an attempt to been seen by a pain clinic) and example 2 includes two events (an emergency room visit and a specialist visit). The recounting of each event becomes a mini-narrative that incorporates its characters, recounted symptoms, and specific clinical information. For each of these narratives, the details included are similar including multiple practitioners, various forms and degrees of pain and information about the pain medications provided. The narrative form integrates
all of this information into a single composition. Moreover, as participants recount events, they articulate the relationships among them, as per example 1 where the patient emphasizes the fluctuations in his level of pain as mirroring his access to pain medication.

In addition to recounting factual information about events, narratives incorporated intentional elements tracing participants’ understanding of and reactions to events. In each narrative the participants included assessments of the efficacy of medication, positively for example 1 “I started to feel better,” and negatively for example 2 “they didn’t help.” In example 1 the narrative documents the patient’s decision process “I knew I wouldn’t see you until today. So I had to stretch it out as far as possible.” While in example 2 it incorporates elements of the practitioners’ reasoning “They want to say it's MS, they want to say it’s the fibromyalgia. It’s hard to distinguish between the two.” The integration of intentional information into the narrative form allows participants to mark the evolving understanding of disease status, which includes their own understanding and practitioners’ judgments.

Overall, the narratives for assessing disease progress had utility as a means of integrating information and as an aid to memory. The temporal structure of the narrative and its ability to link information about individual events into a broad, meaningful whole provides an organizational structure for patients to recall large amounts of complex information. In addition, the capacity of narrative to incorporate particulars concerning a variety of topics (i.e., actions taken, medication use, and symptoms) allowed patients to integrate all of the relevant information into a single representation. Finally, the
intentional components of narrative meant that patients combined both information about events and meta-cognitive information including discussions about their assessments, their decision making, and the judgments of their practitioners.

Assessing Current Symptoms

Table 8: Episodic narratives

<table>
<thead>
<tr>
<th>Example 3</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioner: Ok. Difficulty walking? Difficulty with balance?</td>
<td>Temporal grounding</td>
</tr>
<tr>
<td>Patient\textsuperscript{41}: There was an episode that I had when I lived with my grandma. She has \textit{carpet floors} and I got up for school. This was when I was still in school. I got up for school that morning in my bedroom to get dressed. And \textit{when I got up I felt fine, but when I started to walk I fell and I hit the carpet with my head}.</td>
<td>Contextual information</td>
</tr>
<tr>
<td>Practitioner: Ok, oh really, wow, so you had a fall.</td>
<td>Functional anchoring</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Example 4</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practitioner: Did you have \textit{optic neuritis} before in that eye? {Uh} Like did you lose vision before? Or have blurry vision for</td>
<td>Hypothesis 1: optic neuritis</td>
</tr>
<tr>
<td>Patient\textsuperscript{42}: Um, two weeks ago I had a um, um I guess an episode is what you’d call it. Um where I had a \textit{visual problem. I had kind of a backwards c shape blurry spot, you know in my vision, and it lasted about ten minutes…}</td>
<td>Temporal grounding</td>
</tr>
<tr>
<td></td>
<td>Problem Detection</td>
</tr>
<tr>
<td></td>
<td>Initial description</td>
</tr>
</tbody>
</table>

\textsuperscript{41} Patient characteristics: late teens, high school education, 1-2 years with MS, minimally disabled

\textsuperscript{42} Patient characteristics: 40s, college education, 1-2 years with MS, minimally disabled
some time before in that eye?

Patient: Um, I’ve had a what people have told me it’s called a like floater in my eye for a long {uh huh} time. Since like 93, 94. I have like uh like uh I haven’t experienced that kind of loss of field in my eye before. And as I sat there I thought you know is it the right or the left, so {ok} then I you know closed my right and checked and then closed my left and checked and it seemed like it was in both, so it didn’t seem like it was in one or the other in particular. And so then I closed both eyes and you could still like when you sit down and stare at a light bulb you still got that kind of greenish. Well it was still there…

Practitioner: How big was it?

Patient: Um, it was fairly large. I mean um I guess it was kind of like a field in my vision and I guess if I was looking at my computer there were certain portions where I was looking where I wouldn’t be able to see what I was typing, because it would be obscured by the blurriness.

Practitioner: [Do you get migraines?]

Patient: No, I do have headaches but I’ve never experienced what people told me is a migraine…

Patient’s Wife: He had me drive home it scared him that much…

Practitioner: But it lasted only half an hour right?

Patient: I don’t even think it lasted that long? I know on Friday it only lasted 10 minutes because when it started I thought ‘well this is unusual’ and I looked at my watch and I wrote down in my notebook…

Practitioner: Cause usually like MS attack would last it has to last more than 24 hours right, so we wouldn’t consider it MS attack. What you describe to me is not really what sound like {but} MS related problem.
Whereas, assessing disease progression involves integrating multiple events across time, assessing current symptoms involves considering the details of a specific event. Clinical reasoning depends upon a great deal of information that the practitioner cannot directly access including phenomenological details. Events outside the clinic complicate this process. Practitioners require an understanding of the qualitative nature of symptoms and the context, sequence and timing of episodes for diagnostic purposes (see chapters 4 & 6). The patient bears responsibility for bringing these subjective and environmentally distributed elements into the clinic (see chapter 5). To meet these challenges, participants composed detailed, highly-focused narratives; see examples 3 and 4.

Although they are very different, examples 3 and 4 share some common features that may facilitate assessment of current symptoms. They both focus on identifying and defining the nature of a problem. They both use details to direct the patient and practitioner’s joint attention to potentially relevant aspects of the episode. Moreover, they each employ functional descriptions to help establish a common understanding of the focal symptoms.

As noted in chapter 4, one of the key concerns in assessing current symptoms involves whether an experience should be considered a clinically relevant problem. Narratives may act as a vehicle to help define whether and to what extent the central events constituted an MS related problem. Example 3 serves this function. Here, the
practitioner asks a question and rather than answering the patient tells a brief story. The patient may be uncertain whether the events described constitute the type of symptom the practitioner is asking about. Rather than making her own assessment, she describes her experience allowing the practitioner to judge its significance. Example 4 also involves understanding the nature of a problem, but in this case, the patient has concluded that the events described are problematic prior to beginning the narrative. That the patient had immediately identified the event as problematic is clear from the fact that he wrote down the exact time of onset. The narrative focuses on defining the nature and parameters of a problem, not on whether a problem has occurred.

Both narratives incorporate a variety of details to help define the nature and scope of symptoms. Each narrative begins by situating events in their temporal context. This is important because, unlike acute care, clinically relevant symptoms in chronic illness management may have begun and resolved weeks or months prior to the clinical session. The patient then provides details about the focal event. In example 3, the patient composes the narrative by using details that are broadly contextual, including her setting (“carpet floors” “in my bedroom”), activities (getting up in the morning), and previous state (“I felt fine”). Her presentation is factual and neutral, simply providing information allowing the practitioner to select elements meriting attention.

Example 4 includes more complex details with both participants actually engaged in selecting focal details. The patient and practitioner co-constructed this narrative; for a similar effect in psychotherapeutic settings see Sluzki (1992). The patient began the narrative with an initial, brief description of his symptoms. Then, the practitioner’s
questions directed the patient toward MS relevant aspects of his experience. The practitioner asks about any previous history with similar problems, the specifics of the symptom ("How big was it?") and the time course ("But it lasted only half an hour right?"). The patient could have chosen to respond to each question with a brief statement, but instead he responded with extensive descriptions. The practitioner’s questions showed which aspects of the narrative she was attending to and to direct the patient’s attention to elements worth elaborating. In addition, in his responses the patient reiterated salient parameters of the problem by providing detailed descriptions of the nature and extent of the experience (e.g. “And so then I closed both eyes and you could still like when you sit down and stare at a light bulb you still got that kind of greenish”). The resulting narrative was a collaboration incorporating elements both participants judged to be significant.

Whereas the details provided in the narratives were useful in creating mutually accessible representations of events, they were often ambiguous (e.g. I had kind of a backward c shape blurry spot, you know in my vision; I felt fine). Patients bolstered their purely phenomenological descriptions with functional descriptions of how symptoms affected their ability to perform specific tasks. By providing a mutually understood anchor, functional descriptions reduced ambiguity and conveyed a more specific meaning. In some cases, participants used functional descriptions to give greater detail about the nature of the experience. In example 3, the patient situates her description in terms of the actions she was taking “And when I got up I felt fine, but when I started to walk I fell.” By linking the episode to actions with familiar demands, she clarifies her degree of instability. In example 4, the patient addresses one of the practitioner’s
questions about the characteristics of the symptom by providing details concerning how the symptom affected his work at the computer. In other cases, functional descriptions convey a sense of magnitude. In example 4, the patient’s wife emphasizes the seriousness of the episode by saying “he had me drive him home. It scared him that much.” Because functional descriptions related symptoms to tasks with culturally grounded demands they provided a more fine-tuned understanding of the nature and severity of the symptom.

In summary, assessing current symptoms often requires practitioners and patients to consider events and symptoms that began or occurred solely outside the clinic. Because practitioners have no way of directly accessing these events, patients use narrative to create mutually accessible representations that facilitate clinical cognition. Narrative reports of symptom episodes provided a rich representational medium allowing both actors to consider the pertinence of situational elements and to direct attention in the conversation to those elements. In doing so, the narrative form allowed for the integration of multiple types of information including context, phenomenological experience, medical history, and metacognitive assessments about ongoing events. The use of functional anchors in particular enriched narratives and provided a clear description of the nature and magnitude of symptoms.

Judging Relevance for MS

Judging the relevance of symptoms for MS depends on understanding the nature of the symptoms, the details of the symptom episode and the contextual factors that may have caused a flare up without new disease activity. Accordingly, these judgments relied
on the same episodic narratives involved in assessing symptoms. Once an episodic narrative was complete, creating a fully detailed mutually accessible understanding of the events, participants could judge the relevance of the events to MS relatively easily. Thus, many of these narratives ended with a diagnostic judgment (see example 4). In example 4, participants used the process of composing the narrative to facilitate reasoning about possible causes of the symptoms described. Sometimes the practitioner would present a possible diagnosis during the course of the narrative and ask the patient questions to see if information either from the narrative or from past experience supported her hypothesis. In example 4, the practitioner proposes two possible diagnoses during the narrative (i.e., optic neuritis and migraines) and asks the patient questions that might provide information to support one or the other. The practitioner’s questions and the patient’s responses allowed them to test possible assignments of meaning to key events while co-constructing a narrative. The hermeneutic properties of narrative support hypothesis testing because effectively each hypothesis serves as an interpretive frame for understanding the symptom.

Table 9. Reasoning through Narrative

<table>
<thead>
<tr>
<th>Example</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 5</td>
<td>Hypothesis 1: irritation from salt supported by</td>
</tr>
<tr>
<td>Practitioner: No signs of any adverse reactions, no rashes or itching after you get it? Patient: I have a rash here [hand/wrist] but that’s probably because I was using salt outside and I used my bare hand to get it</td>
<td></td>
</tr>
</tbody>
</table>

43 Patient characteristics: 40s, education not stated, time since diagnosis uncertain, minimally disabled
out of the barrel and
Practitioner: [it wasn’t immediately after] your
Patient: [no, no]
Practitioner: [Ok, it wasn’t like at the IV site or anything]
Patient: [no]
Practitioner: [Ok]
Patient: Is that what the rash would be like at the IV site?
Practitioner: No, if it was just like a local one if it was like an
irritation then it would be. Um, most of the time it’s just gonna be
a generalized one all over your body.

Example 4 is exceptional in that the conversation exploring the possible causes of
and relevance to MS of the symptom lasted through most of the session, with both
participants directing the narrative to encompass multiple types of information.
However, similar processes of hypothesis testing and co-construction occurred elsewhere
in a more abbreviated form. Example 5 shows one way in which this process occurred in
a briefer interaction. This case is simpler because the symptom is visible and can be
directly assessed by the practitioner; the narrative simply provides context. In addition,
because the patient already has a hypothesis about the cause that renders the symptom
irrelevant the conversation need only verify this conclusion. However, as with example
4, the participants use the narrative here to assess the cause of a symptom and establish
whether it should be considered an MS related problem. In doing so, two competing
hypotheses are tested. First, the patient uses the narrative to create a simple deductive
argument that irritation from salt caused the symptom:

If salt exposure then skin irritation.
Salt exposure.

Therefore, the salt caused the rash (on my hands).

The practitioner checks the counter hypothesis that the rash is a medication reaction by asking questions, essentially creating a competing deductive argument.

If medication administered, temporally proximal adverse reactions occur.

If medication injected, spatially proximal reactions occur.

Adverse reaction (rash) is not temporally proximal

Adverse reaction (rash) is not spatially proximal.

Therefore, the rash is not medication related.

‘Interestingly, in this case by using her questions to direct the patient’s attention to details not included in the initial presentation of the narrative the practitioner ends up both testing the relevance of the symptom to MS management and instructing the patient in how to interpret future symptoms. The fact that the patient ends the interaction by confirming that she understands the implications of the practitioner’s questions for identifying injection site reactions makes this clear. This suggests that co-constructed narratives, even brief ones, can serve to facilitate clinical reasoning and to develop the patient’s capacity to distinguish problematic events and relevant symptom parameters.

*Physical Exam*

Narratives were not a prominent feature during physical exams. However, they did occur to corroborate or extend the practitioner’s direct observations. Example 6 shows this type of brief narrative.
Table 10. Narrative during a Physical Exam

<table>
<thead>
<tr>
<th>Example</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 6</td>
<td></td>
</tr>
</tbody>
</table>
Practitioner: How was walking? I see much better.
Patient: Great. I mean it’s, we adopted our little girl and we were in Guatemala.
Practitioner: No way, no way, no way.
Patient: I mean that’s what I mean I was down there we **were in the airports and holding the baby. It was fine, I just made it. I wasn’t tired.**
Practitioner: That’s wonderful.

Direct observation

Functionally anchored narrative to corroborate observation

This narrative uses a functionally anchored task to confirm and extend the practitioner’s observation that her gait has improved. By describing her ability to perform a relatively difficult physical task (carrying a baby through an airport), she confirms that the limited observations seen in a setting with minimal demands and no fatigue extend to a more demanding context. This type of narrative is similar to those that support the assessment of current symptoms in that it effectively provides access to events from outside the clinic.

*Selecting Actions to Modify Disease Course or Symptoms*

Participants used narratives in similar ways to help select actions to respond to both symptoms and disease processes. In discussions of both types of treatment, narratives supplemented the information available in medical records by providing richer details than a typically written record, incorporating metacognitive reflections on prior judgments and decisions, and including information about interactions with other medical

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44 Patient characteristics: 40s, college education, 5+ years with MS, moderately disabled
professionals. Therefore, this discussion applies to treatment selection generally without differentiating based on the nature of the medication. The examples referred to include a discussion of a disease modify agent in example 7 and a discussion of symptom management medications in example 8.

The fact that a medical record includes specific pieces of information does not guarantee that practitioners will attend to or remember them. Even with the aid of an electronic medical record, the practitioners in this study were not always aware of relevant details about medication use. Narratives in treatment selection helped to ensure mutual awareness of basic medical information; this is evident in both examples 7 and 8. In example 7, the narrative begins with the patient referring to her decision to discontinue a disease modifying agent. She uses a simple past tense to refer to her use of the medication, implying that she no longer uses it. The practitioner asks a question to check that this implication is correct prompting the larger narrative. Even though the practitioner had immediate access to the patient’s medical record, which included information about dates of medication use, she had not attended to the fact the patient no longer used disease modifying agents. The patient’s narrative fills in the information that the practitioner missed. Similarly, in example 8, the patient had a very complex pain management history. Even though his records included the medications he had used, the narrative ensured that the practitioner was aware of and attending to salient information including what medications he had taken, their efficacy and even the dosing information for his most recent medication. All of this information was in his medical record, but the narrative allowed immediate mutual access and joint attention to relevant information without having to search through the record.
### Table 11. Narrative Aids to Treatment Decision Making

<table>
<thead>
<tr>
<th>Examples</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example 7</strong></td>
<td></td>
</tr>
<tr>
<td>Patient(^{45}): <em>I was</em> on Rebif. <em>I was pretty much on it from</em> December of 2006.</td>
<td>Providing detail</td>
</tr>
<tr>
<td>Practitioner: <em>You’re not on it right now?</em></td>
<td>Patient’s decision</td>
</tr>
<tr>
<td>Patient: <em>No. I went off of that when we decided</em> to try and to have another child. <em>Cause we were told</em> wait a month, {ok} go off the meds and wait a month before trying to conceive.</td>
<td>Recalling prior practitioner reasoning</td>
</tr>
<tr>
<td><strong>Example 8</strong></td>
<td></td>
</tr>
<tr>
<td>Practitioner: <em>Which medication helps you the best? Pain medication?</em></td>
<td>Supplemented Records</td>
</tr>
<tr>
<td>Patient(^{46}): <em>Hydrocodone, the Methadone, the Methadone seemed to help a lot…But then</em> when I started to taper, <em>because I didn’t want to take it so much…</em> it was the worst thing that’s ever happened to me.</td>
<td>patient’s decision</td>
</tr>
<tr>
<td>Practitioner: <em>what happened?</em></td>
<td>Providing details</td>
</tr>
<tr>
<td>Patient: <em>um, my body went into the worst type of shock. Just withdrawal and shock. Uh,uh,uh. I never want to take anything that my body becomes that reliant on.</em> { yeah} I mean it hurt. It hurt so bad I would lay in home in bed. The sweats were so bad and I was freezing cold. I had clothes on, a down comforter on, I had a heater blowing on my body, and I could not get warm and I am just shaking so bad. I was seeing things, got a bad headache. <em>When I go to the restroom it was terrible. Didn’t eat, dropped probably about 15 pounds in a week because I didn’t eat any food.</em> I was sweating, I mean I was dripping in sweat but it was cold sweat. And I, uh, I never want to take that again. I mean that is the worst.</td>
<td>preferences</td>
</tr>
</tbody>
</table>

\(^{45}\) Patient characteristics: 30s, graduate education, 1-2 years with MS, minimally disabled

\(^{46}\) Patient characteristics: 40s, college education, 3-5 years with MS, severely disabled
Unfortunately, because from what I understand, from that {wow} doctor, not doctor[name], but another physician that I did before because we were, **I went from fentanyl which I didn’t like either because it was really bad.** And he said you know they’re doing some really good things with methadone as far as for chronic pain treatment and uh we checked those things out. And it uh, it uh, **it worked. You know 40mg/day. One 10mg tablet four times a day.**

In addition to facilitating joint attention to medical information, narratives included metacognitive reflections on the reasons for prior decisions that official records typically did not include. These narratives documented on-going reasoning processes and associated treatment decisions. In examples 7 and 8, one of the functions of the narrative is to rationalize past decision making. In example 7, the patient justifies discontinuing her medication by explaining that her medical decision was linked to a personal decision to have a baby and instructions she had received from another practitioner. Similarly, example 8, includes cursory information about the motivation to discontinue two separate medications (not wanting “to take so much” Methadone and Fentanyl because “it was really bad”). In each case, the narrative includes details to support these brief judgments. The decision to discontinue Methadone incorporates phenomenological descriptions of the patient’s withdrawal reaction that had many of the same vivid features as the narratives used to assess current symptoms, including the use of functional anchors to emphasize the severity of the symptoms. The severity of the reaction supports the patients’ judgment that he was over-medicating. As in example 7, the patient in example 8 supports his decision to discontinue Fentanyl by referring to the reasoning of a prior practitioner. The intentional components of narratives used in making treatment decisions suggest that narratives may facilitate clinical decision making by maintaining a
record of not only prior decision outcomes, as in a typical medical record but the supporting reasoning. By interleaving the patients’ judgments and decisions with those of practitioners these narratives integrate the medical information driving decision making, the preferences and life choices of the patients, and reflections on prior clinical decisions. This provides a complete picture of the decision process, as opposed to simply the decision outcome than would be captured in a formal record.

Non-narrative Discourse

This section illustrates the utility of narrative by comparison with interactions that do not have fully developed narratives. In some cases, non-narrative discourse included brief narrative elements, *micro-narratives*, which fulfilled some of the same functions as the longer narratives. The existence of narrative inclusions in non-narrative speech emphasizes the utility of narrative. In other cases, interactions did not have any narrative components. These interchanges could be stilted and/or incoherent when the topic of discussion was not mutually accessible. Such incoherence underscores the role of narrative as a medium for creating shared representations.

*Micro-narratives* One of the clearest findings in attempting to identify non-narrative interactions was the pervasiveness of narrative qualities. Even in speeches that did not include fully developed narratives contained narrative elements. These speeches included a subset of the definitional properties of narrative but were much shorter, limited to a couple of sentences or less, and served a specific function. The bold section in example 9 shows this type of micro-narrative. In this example, the main interaction is not focused on narrative. The patient describes her pain by analogy, not through an episode, and the practitioner does not ask for any narrative detail. Nevertheless, the patient briefly
inserts a short narrative to introduce a possible causal explanation, which the practitioner
then addresses. The pervasiveness of micro-narratives like this one and their use in
addressing similar, if more limited, cognitive challenges supports the utility of narrative
as a psycholinguistic tool in this context.

Table 12. Micro-narrative embedded in an otherwise non-narrative interaction

<table>
<thead>
<tr>
<th>Example</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 9</td>
<td>Micro-narrative</td>
</tr>
</tbody>
</table>

Practitioner: How was the pain?
Patient: It feels like I’m gonna sprout wings and just fly.
Practitioner: Here?
Patient: Yeah, right there. It’s real tender and stuff and [I] went to have a massage and they said I have a lot of knots.
Practitioner: Yeah there is there is like a lot of hard spots. Maybe you should go for massages. Cause the MRIs are good, so it’s probably musculoskeletal and not coming from the MS or disks or anything like that.

Non-narrative interactions Multi-turn discussions that essentially had no narrative components could be incoherent and inconclusive. Such segments of dialogue are somewhat vague and include multiple issues that remained unresolved as the dialogue shifts focus. In example 10, the practitioner initially doesn’t understand the patient’s description and does not directly address any of the patient’s theories. The conversation ends without a resolution on the significance of the pain. Example 10 demonstrates the flow of the dialogue in the strained non-narrative discussions found throughout the data set. It addresses a symptom that occurred outside the clinic and that has a substantial

47 Patient characteristics: 30s, high school education, 3-5 years with MS, severely disabled
phenomenological component. The practitioner cannot directly access the patient’s pain. Without the contextual and functional information included in a narrative, she cannot arrive at an understanding and resolution of the problem. The vague nature of MS invites consideration of such issues, which may be part of why so many conversations included narratives.

Table 13. Non-narrative interactions

<table>
<thead>
<tr>
<th>Example</th>
<th>Commentary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 10</td>
<td>Disjointed symptom presentation</td>
</tr>
<tr>
<td>Patient⁴⁸: I get my legs just ache so bad. Lately, they’ve been aching not even on, not even when I’m my period, sometimes all the time. It’s only in one leg really. Practitioner: ok, so they aren’t aching or they are? Patient: they’re aching, but it’s not to the point where I can’t function with it. You know what I mean. Sometimes I don’t know if it’s just a natural pain, cause you know like your body always has natural pains and stuff. Practitioner: right Patient: so I never know… Practitioner: [So that’s new right.</td>
<td></td>
</tr>
<tr>
<td>Example 11</td>
<td>No diagnosis or interpretation of symptoms results from discussion</td>
</tr>
<tr>
<td>Patient⁴⁹: I don’t if the muscle pain I’ve been feeling in my shoulder, in like my shoulder blade area on my back? {um} Always the right side. I don’t know if that has anything to do with other than? Practitioner: Refresh my memory. When I examine you I going to palpitate it and see if it’s musculoskeletal or from MS; we’ll try to figure it out.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptom is described with clear physiological references Question about relevance to MS Relevance can be assessed through direct observation</td>
</tr>
</tbody>
</table>

⁴⁸ Patient characteristics: 20s, college education, 1-2 years with MS, minimally disabled

⁴⁹ Patient characteristics: 30s, college education, 1-2 years with MS, minimally disabled
In a few cases, practitioners could more directly access information about the symptoms and experiences under discussion through other means. The few cases of clear, effective dialogue without narrative address more directly accessible symptoms. For instance, in example 11 the patient describes a symptom very similar to that in example 9 without any narrative but with the same basic null result. The few coherent non-narrative interchanges in this data set suggest that the use of narrative as a psycholinguistic tool is situationally specific and could be less common in addressing medical problems where patients’ subjective experiences are less central to diagnosis and treatment.

Conclusion

Overview

From the beginning of the clinical encounter until making a final decision about medication patients told or co-composed with practitioners a variety of narratives. Narratives facilitated cognition during the majority of clinical tasks identified in Chapter 4, addressing a variety of cognitive challenges. When assessing the progress of their disease, patients used anamnestic narratives to facilitate memory and to organize critical information. When assessing current symptoms, participants used the cosmoplastic qualities of narrative to provide practitioners with access to events outside the clinic. In doing so, they composed narratives that directed joint attention to relevant particulars and employed functional descriptions to anchor the phenomenological nature of symptom presentation. During judgments about the significance of specific symptoms for MS, the participants used the narratives to reason about symptoms, including exploring alternative, hypothetical explanations for symptoms. Though rare during physical exams,
patients used narratives to confirm and extend the practitioners physical assessment. And finally, during the selection of treatments, participants use the details and intentional information available in narrative accounts to supplement medical records. The frequent and varied uses of narrative within this data set suggest that narrative is integral to clinical cognition, both as a means of representing external events and as an interactive process of narrative construction to use in making sense of illness related events.

**Narrative Cognition**

The research literature has typically discussed narrative cognition as divorced from other forms of cognition especially cognition involved in problem solving, logical reasoning and hypothesis testing (Bruner, 1986). However, the narratives in this study were integrated with ongoing cognitive functions including those involving analytic reasoning. In fact, many of the properties of narrative that Bruner presented as definitional and distinct from paradigmatic reasoning served to facilitate key cognitive elements, see Table 14.

<table>
<thead>
<tr>
<th>Property</th>
<th>Description</th>
<th>Cognitive Functions</th>
<th>Use in Clinical Cognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narrative Diachronicity</td>
<td>Narrative is inherently temporal as events occur across time.</td>
<td>Memory &amp; Reasoning</td>
<td>Maintain understanding of case history</td>
</tr>
<tr>
<td>Genericness</td>
<td>Narratives fall into genres that involve both stylistic conventions and prototypical plot elements</td>
<td>Attention &amp; Memory</td>
<td>Combination of episode based and anamnestic narratives to remember clinically relevant information</td>
</tr>
</tbody>
</table>
This suggests that paradigmatic and narrative cognition are not dichotomous or opposing. Rather, they can be, and, in this context, often are productively intermingled. In this study, the properties of narrative served critical functions in distributed practitioner-patient cognition by providing a vehicle for patients to create representations of key elements of the clinical problem space that would not otherwise be accessible to practitioners. In this data set, narrative was not opposed to paradigmatic reasoning, but rather was a tool that facilitated clinical reasoning, including causal reasoning and hypothesis testing. Further research should analyze how narrative usage in other clinical
settings and whether other forms of linguistic composition are involved in medical reasoning.

**Implications for the Medical Domain**

The extensive use of narratives in clinical interactions suggests that language is an elemental part of distributed clinical cognition. In this study patients and practitioners use the (co-)composition of narratives to make sense of and describe clinically relevant elements of the environment. The emergent narratives were neither epiphenomenal nor peripheral to ongoing clinical cognition. Participants constructed narratives during core clinical cognitive functions. These narratives acted as informational resources to represent external and/or prior events, support metacognition, coordinate care between medical practitioners, and provide detailed, functional accounts of symptom episodes. In addition, the interpretive aspects of narrative facilitated hypothesis testing and causal reasoning. Medical education could include instruction on narrative, not just as a socio-emotional concern but as a cognitive resource that can be used more or less efficiently.

Similarly, the use of narrative could be integrated into the technical systems that support clinical cognition. Narratives in this study addressed some of the challenges MS management creates in terms of attention, memory, causal reasoning and metacognition. For patient-practitioner interactions, acknowledged tools (i.e., rating scales and record keeping systems) are available to help manage challenges such as judging the impact of subjective symptoms and the difficulty of keeping track of clinical details over the course of long-term illness. Narratives provided utility beyond these formal systems, by incorporating more situational details and functional descriptors. Some of these functions
could be incorporated into technical systems to increase their utility. Similarly, patients used narratives to understand their illness experiences, incorporating different types of information including physical sensations, functional effects of symptoms, understanding of disease processes and treatment implications into a single composition. At the moment, education materials for MS patients typically include symptom lists and treatment options as separate entities (Mayo Clinic, 2015). Many of these materials use biomedical terms that are abstract and do not connect well with patient experiences. Incorporating narratives that integrate specific instances of sensation and action into educational materials might improve their utility (Clark & Rossiter, 2008).

**Narrative Beyond Medicine**

Narrative is a fundamental human capacity (Niles, 2010). Around the world, throughout history, from early childhood to old age, at work and home people tell stories. This study has examined the use of narrative in medical cognition, but narratives are prominent in other work domains as well. Human Factors and Industrial Organizational Psychology are aware of the ubiquity of narrative. These areas have noted the prevalence of narrative amongst professionals (Dekker, 2011; Snowden & Kurtz, 2003) and incorporated narrative components into their research methods (Hoffman, Crandall, & Shadbolt, 1998; Klein, Calderwood & MacGregor, 1989). However, they have not explored the cognitive and functional utility of narrative. This study has shown that narrative, both as a process and as a representational form, has utility for distributed cognition in medicine. Narratives used in other work domains may serve substantive cognitive functions that are an integral part of work processes (Nersessian, 2008).
In this study, narrative was especially effective for representing external events, integrating factual and metacognitive components, and reasoning about events. Other domains share these requirements and may benefit from narrative cognition. For example, disaster response and strategic planning both require access to external events and any type of diagnostic reasoning may use the narrative affordances of integrating factual and intentional content and facilitating hypothesis testing. Finally, work should focus on how to integrate the representational capacities of narrative more systematically and effective into professional tools – including training materials and systems to support collaboration.
Chapter 8: Conclusions

As a cognitive process, how are medical decisions shared?

The individual analyses in this dissertation address specific questions. But, they are mutually informing and supportive. Below, I review the conclusions from individual chapters and describe how they combine to answer the primary research question. The study began with a broad characterization of the domain (in chapter 4). This analysis indicated that patients and practitioners engage in distributed clinical cognition, by using their dialogue to collaborate on a set of interrelated cognitive functions. A secondary focused analysis (in chapter 5) located decision making as an integrated part of these functions. It suggested that clinical cognitive functions act together as an integrated trajectory of clinical cognition. This analysis also provided insight into the distribution of cognition between patients and practitioners by showing that the roles participants adopt in the decision make process depend on their access to information and possibilities for action. Tertiary analyses (in chapters 6 and 7) elaborated upon and supported the conclusions of earlier analyses by demonstrating that patient cognition affect practitioner and dyadic reasoning and that participants actively used language as a representational medium to support distribute clinical cognition. Combining these specific conclusions provides the following answer to the primary research question: as a cognitive process, how are medical decisions shared?

Shared medical decisions are part of an integrated trajectory for clinical cognition in which cognitive functions are mutually determining and non-sequential. This cognitive trajectory is inherently distributed between patients and practitioners.
because, in many cases, neither party has both all the knowledge required to make and the power to enact a decision. Therefore, patients and practitioners necessarily share medical decisions because they both participate in the reasoning that enables decision making. Patient-practitioner dyads make shared decisions via language since language provides the medium supporting distributed clinical cognition.

The discussion below addresses each of these aspects of shared decision making its distributed nature, integration into ongoing clinical cognition and reliance on language in separate sections. I begin each section by enumerating how specific results throughout the study support my conclusions about shared decision making. Then, I broaden the discussion by examining the main theoretical constructs that support each aspect of shared decision making, describing how these constructs build on or alter conclusions from prior research, and elaborating how they developed through and are grounded in the results of the study. Finally, I suggest associated hypotheses and directions for future research.

*Shared Decision Making as Part of Integrated Cognition*

Shared decisions are not isolated choices. They are integrated into ongoing clinical cognition. The idea that decisions are part of integrated clinical cognition originated in chapter 4 with the conclusion that patients and practitioners make decisions through an interactive process involving multiple cognitive functions across the course of the clinical interview. Chapter 5 supported the integration of decision making with other cognitive functions by demonstrating that decisions begin with situation representation, the realization of a need for a decision, and the definition of decision parameters before
any choice is possible. These early processes in turn depend on other cognitive functions involving issues such as assessing disease progress and judging the relevance of symptoms. The discussion below develops the notion of integrated cognition for shared decision making and discusses the broader implications of this idea for cognitive science.

**Relationship to Prior Research**

Cognitive research and theory have conceived of cognition as a sequence of discrete processes unfolding in a linear, or occasionally parallel, fashion (Simon, 1979). Researchers tend to treat each process as largely independent (Simon, 1962; Sperber, 2005). A treatment decision, for example, begins with a defined set of parameters and leads to a choice of actions to implement (Austin et al., 2015). Accordingly, decision making can be studied with minimal reference to the cognitive functions that proceed or follow it.

This approach informs the understanding of cognition as the aggregation of basic building blocks (Cosmides & Tooby, 1994). However, considering cognitive elements as inherently linear and discrete hides important processes. The current research supports an integrated view of cognition by demonstrating that cognitive functions are highly interactive so that the way in which each function occurs influences the nature of functions that both preceded and followed it. Thus, shared decision making requires not just selection among pre-specified choices but includes the realization of a need to act and definition of selection parameters.
Naturally, antecedent functions affect subsequent ones. Chapters 4 and 7 included instances where earlier processes, such as the memory and attentional processes, directed later ones, such as the classification and causal attribution of symptoms. This was particularly interesting in cases where earlier processes either simplified or eliminated the need for later ones. For example, in the split decision patterns described in chapter 5, the manner in which the two parties conveyed clinically relevant information to each other shaped how the diagnostic problem was defined. In some cases, the process of defining decision parameters constrained the choice of solutions to a relatively restricted set of options (as when a practitioner only offered a patient a choice of two treatments) or entirely eliminated available alternatives (as when the patient reminded her practitioner that she had a history of seizures thereby converting a complex decision into an obvious course of action). Consequently, large components of decision making took place before explicitly engaging in the selection task. Because both the realization of a decision point and the definition of the options reflect prior cognitive functions, understanding the final decision requires understanding the integration of a trajectory of reasoning.

Subsequent influences on antecedent functions. Functions apparently occurring towards the end of a sequence may affect earlier presumably prerequisite functions. Sometimes these temporally inverted relationships were intentional. For example, functions involving representation (i.e., assessing symptoms) and causal attribution (i.e., judging relevance to MS) temporally precede functions involving decision making (i.e., selecting treatments). So, the functions earlier in the sequence are typically judged pre-
requisite for the later. However in this study, patients sometimes entered the clinical encounter hoping that the practitioner would select a particular treatment (e.g., the patients in chapters 6 and 7 who wanted specific pain medications). These patients carefully constructed representations and causal arguments to structure the practitioner’s decision making in a way that would produce the desired action.

In other cases, the temporally subsequent functions influenced early functions because of the nature of the decision space. For example, current cognitive models see representation and decision making as pre-requisites for action (Newell, Lagnado, & Shanks, 2007). But, as in Shalin & Bertram (1996) in the current study, functions involving those cognitive elements reflected the range of available possibilities for action. For example, the availability of a straightforward treatment for migraines may prompt practitioners and patients to attend to this issue, whereas a similarly pervasive problem, such as numbness, might be ignored because it is difficult to treat. Similarly, whether a problem became the focus of cognitive activity to some extent depended upon the specific action repertoire of the actors. For example, in instances of truncated problem discussion when the practitioner felt an issue best matched another provider’s expertise (as in the recommendation for massage) or the patient was unwilling to consider any of the projected options (as in the patient who initially rejected conventional treatment in favor of natural medicine). Understanding the nature of decision making in these cases requires considering the influence of available options for later action. These effects are evident in the role the action space plays during decision making (see discussion in chapter 5).
The integrated nature of cognition through time suggests that cognitive functions and their constituent elements are not simply a series of serial, independent processes. Instead, these functions appear as ongoing, iterative, and mutually influential. For example, the extended narrative regarding pain medication use in chapter 7 did not simply precede, but rather altered, the decision making involved in selecting treatments. In calling attention to specific episodes from his case history, the patient evaluated the efficacy of past decisions and defined parameters of what he would consider an acceptable treatment in terms of efficacy, side effects and risk of dependence. Moreover, through his exposition, he provided information to justify the practitioner’s decision to prescribe a narcotic. These types of mutual influence suggest conceptualizing cognitive functions as a spiral, where cognitive elements including attention, representation, decision making and planning action occur iteratively through time, rather than a sequence. This expands on models that suggest an important temporal dimension for cognition (Hazelhurst, 2011; Hutchins, 1995) but confine that dimension to a linear notion of temporal sequence. The linear view may seem correct because thought often produces a linear set of visible actions. However, the linear structure of observable action does not reflect the integrated nature of cognitive functions, each of which reflect both past and future functions.

**Future Research on Integrated Cognition**

Studies in other domains could help develop a deeper understanding of the integrated cognition found in this study. Field studies in other domains could help to identify the factors involved in problem identification, where prospective and retrospective functions may influence current reasoning and the complex relationships
between action and cognition. In addition, laboratory work could test specific hypotheses derived from a notion of integrated cognition. The following example hypotheses follow from this study.

1. This study has suggested that projected action affects prior cognition. Hypothetically, the coupling between an aspect of the environment and action will be related to that the likelihood that people will attend to and create detailed representations of it.

2. Similarly, this study has suggested that representation of the environment impacts the realization of decision points and definition of decision parameters. Hypothetically, presenting people with the same information but different representations, in terms of attributes such as ordering, detail, emphasis and temporally implied causality, should change how likely they are to believe that a decision to act is necessary, the options they choose to consider and the factors they emphasize in selection.

The Distributed Nature of Shared Decision Making

Practitioners and patients necessarily share medical decisions because they share the reasoning process that supports decision making. Chapter 4 introduced the idea that shared decisions result from sharing a process (distributed clinical cognition) rather than sharing power by demonstrating that patients’ reasoning makes a substantial contribution to the majority of clinical cognitive functions. Conclusions in chapter 5 that clinical cognitive functions are split between patients and practitioners further supported the idea
of practitioner-patient distributed cognition as did the conclusion, in chapter 6, that patient cognition affects practitioner and dyadic cognition.

Beyond supporting the conceptualization of shared decision making as a distributed cognitive process, these findings suggest a need to move from practitioner-oriented models of clinical medical cognition to models that accommodate both practitioner and patient cognition. The discussion below, explores the general issues of patient-practitioner distributed cognition and related conclusions regarding patient expertise that support the inclusion of patient cognition in discussions of medical cognition.

**Relationship to Prior Research**

Clinical cognition is frequently viewed as an exclusively professional activity (Crosskerry, 2009; Engeström, Engeström, & Kerosuo, 2003), whereas discussions of patient cognition focus on social and emotional concerns (Leventhal & Diefenbach, 1991). Even discussions of shared decision making assume the practitioner controls the process of clinical cognition but shares some of the power to select actions with the patient (Elwyn et al., 2014).

The interrelationships among cognitive functions demand an understanding of clinical cognition as distributed. As discussed throughout the results, the knowledge and action abilities involved in the entire trajectory for cognition and care are rarely (if ever) solely under the purview of a single actor. Because the cognitive functions involved in clinical reasoning are interrelated, the cognition of actors contributing to various
functions is similarly enmeshed. This suggests that clinical cognition is distributed between practitioners and patients rather than localized in one or the other.

**Patient-Practitioner Distributed Cognition**

All of the analyses in this study demonstrated that patients and practitioners engage in distributed clinical reasoning. Clinical reasoning is necessarily collaborative because many tasks require access to information and capacities for judgment that are split between actors; see chapters 5 and 7. Figure 4, discussed below, illustrates this necessity for the reasoning tasks associated with assessing symptoms each of which emerges from the intersection of the practitioner’s medical knowledge and patient’s experiential understanding.

![Assessing Symptoms Diagram](image)

**Figure 4.** Patient contributions (shown in green) combine with practitioner contributions (shown in blue) to carry out core clinical cognitive functions.

While assessing symptoms, patients analyze their experiences and make judgments about the necessity of and appropriate outlet for care. Patients introduce
symptoms they feel are problematic and potentially relevant to the practitioner. Similarly, practitioners focus on those presented experiences that they consider problematic and within their scope of practice, dismissing others as irrelevant or requiring a referral to a different practitioner. It is only when both patient and practitioner consider a symptom as a relevant medical problem that it merits further attention. Evidence for this is particularly salient in the event of disagreement. For example, a disagreement occurred in the discussion of blurred vision in chapter 7. In that case, the patient argued that it was distinctly problematic, whereas the practitioner tried to define it as not medically significant for the particular encounter.

Patients and practitioners have different access to illness experiences and background knowledge so they may judge symptoms differently. Patients judge their symptoms in terms of their typical functioning and prior illness experiences. Patients’ understanding of their health status affects what information they present and how they structure it. Sometimes, patients intentionally structure their presentation to persuade the practitioner that certain interpretations or outcomes are appropriate. Practitioners interpret the information that the patient provides in the light of their understanding of physiology and disease processes to judge the significance of the symptoms for the course of the disease. Despite the differing perspectives, the practitioner’s diagnostic judgment depends upon the phenomenological representation provided by the patient. For example, in chapter 7 when a patient and practitioner discuss the significance of the patient’s frequent headaches, the conversation requires an extended sequence of questions as the practitioner tries to obtain medically relevant information from the patient’s description.
Practitioners by virtue of their knowledge of treatment options and prescription authority define the range of potential treatments. However, patient attitudes influence which options are feasible and acceptable. This interaction was evident in a variety of ways. In some cases, it involved collaboration about the personal and clinical implications of using a medicine. For example, consider the partially excerpted discussion in chapter 5, where a practitioner and patient discuss the appropriateness of medication given that the patient wished to become pregnant. In other cases, participants disagreed and had to negotiate the relevance and relative weight of parameters for treatment. This form of interaction appears in another example from chapter 4 that involved a practitioner who had to use her professional knowledge to redefine treatment options in a way that was compatible with the patient’s preferences for natural medicines.

All of these examples illustrate how pervasive distributed cognition is clinical cognition. Every part of the clinical visit, from the earliest presentation of symptoms to the final choice of treatment, involved iterative interaction between patient and practitioner in which the contribution of one influenced the cognition of the other.

Patient Expertise. This study contributed to the notion of patient expertise in chronic illness, which supports the characterization of medical cognition as distributed problem solving. Patient expertise also reveals the adaptive skills of the practitioner. As shown in Chapter 6, the degree to which patients and practitioners were able to align their reasoning processes varied. When managing a chronic illness such as MS patient expertise increases over time, as they develop clinical skills through interactions with practitioners. As patients gain experience, they become more attuned to the significance
of particular symptoms and develop the ability to parse more effectively their phenomenological experience. This allows them to participate in the clinical process more effectively. Expert patients provide the practitioner with a full and clear description of their symptoms. For example, one expert patient discussed in chapter 6 was able to describe his sensory symptoms in a way that presented all of the relevant diagnostic parameters, along with a proposed evaluation of their significance.

The effect patient expertise has on clinical interactions underlines the degree to which bridging the lay-professional gap that separates patient and practitioner is a critical aspect of clinical cognition. Practitioners, as well as patients, must work to bridge this gap. The extended question sequences in the novice dialogues in chapter 6 underline the skills practitioners need to bring to the clinical interaction. Effective clinical reasoning depended on the practitioner’s ability to gauge and respond to the patient’s level of expertise and to adapt his reasoning processes to accommodate the patient’s skill level. Whereas the medical community acknowledges that non-medical skills (i.e., ‘bedside manner’) are a part of clinical care (Weissmann et al., 2006), these skills are primarily discussed in humanistic terms. The need for practitioners to adapt their cognition to patient expertise suggests these interpersonal skills may affect clinical cognition in addition to social and emotional aspects of medicine.

Future Research on Distributed Cognition and Expertise

This study has recast the shared decision making paradigm in terms of patient-practitioner distributed cognition. However, it is limited by the use of a single setting and the small number of audio recorded clinical sessions. Future work should expand and
refine the conceptual framework proposed here. Additional qualitative research is needed to study how patients understand different forms of disease, parse illness experiences into clinically relevant information, and make decisions about their care. Also, research is need examining how practitioners and patients distribute cognitive functions in other types of medical practice including acute care and inpatient settings, for their own sake as well as to better highlight the unique properties of chronic care. (Prevalence of patterns should be assessed.)

Certain conclusions from this study lend themselves to specific hypotheses. For example:

1. This study has suggested that medical cognition is inherently distributed and that the enactment of clinical cognitive functions depends on the distribution of experiential and semantic knowledge and abilities to act. But, this suggestion is based on correlational logic (albeit small n). The effect of distributed information and action could be tested experimentally. An experiment could ask two participants with predictably different knowledge bases and skill sets (e.g., a student studying ecology and a student studying computer science) to solve problems or make decisions skewed to involve one participants knowledge but requiring the other’s skills (e.g., writing a program to track migration patterns). Hypothetically, the participant with a greater knowledge of the issue at hand would be more likely to specify options and criteria whereas the participant with the skills to act would be more likely to select actions.
2. This study has suggested that over time patients develop expertise in parsing clinically relevant information and representing it in a medically compatible form. Hypothetically then, if given disease scenarios, patients with greater expertise should attend to and remember more clinically relevant information and be more likely to categorize information according to diagnostic categories than novices.

3. This study has suggested that practitioner reasoning is affected by patient expertise. Hypothetically then, there should be a correlation between patient expertise and variables associated with practitioner cognition such as the number of pieces of clinically relevant information considered, the consideration of multiple treatment options, and most important the probability of arriving at a correct diagnosis (correlation of process with outcome). These relationships could be tested either through analysis of recorded clinical conversations or by having medical practitioners interact with standardized patients instructed to replicate an expert presentation (coherent, clinically relevant and including judgments) or a novice presentation (disorganized and largely occurring only in direct response to questioning).

Language as a Medium for Shared Decision Making

Language provides the medium for shared decision making. In this study, patients and practitioners used language to create a shared linguistic environment that supported their performance of clinical cognitive functions. In chapter 4, language allowed participants to coordinate their efforts and direct attention. The ways participants used language to develop a shared understanding of the decision space in chapter 5, the
importance of shared language for effective dyadic reasoning in chapter 6, and the use of language to provide access to external events in chapter 7 further supported the role of language in creating a shared environment of distributed clinical cognition.

In addition, language served cognitive pragmatic functions in which the use of language enacted or facilitated cognitive functions. The effect that labeling had on judging symptom relevance in chapter 6 and the role on narrative in causal reason in chapter 7 illustrate this type of pragmatics.

Since many domains include substantial verbal components, the role of language in supporting cognition has implications beyond shared decision making. The discussion below draws overall conclusions regarding the role of language in this study and elaborates the associated constructs regarding language as creating linguistic environments and cognitive pragmatics.

*Relationship to Prior Research*

Researchers interested in distributed cognition routinely examine the language used during distributed cognitive processes (Hazelhurst, McMullan, & Gorman, 2007; Hutchins & Palen, 1997). However, these studies examine language use by participants with shared access to the task environment and tend to focus on the informational content of utterances. In the present study, language was more than a means of communication about the environment. It was a critical way to create shared access to elements of the environment that were not shared. Effectively, the language was not a way to coordinate action in a shared physical environment (Hazelhurst, McMullan & Gorman, 2007) it was
a way to create a shared virtual environment, transcending space and time to allow for collaborative functioning.

Similarly, other studies typically talk about language in terms of the information it conveys for use in distributed cognition. However, in this study the interactions themselves constituted part of the thought process. The idea that language can shape and facilitate thought is not new. Studies have demonstrated that language can facilitate basic cognitive processes such as memory and categorization (Bloom & Keil, 2001; Fulkerson & Waxman, 2007; Gelman & Markman, 1986) as well as facilitating more complex conceptual understanding (Chi, 2000; Chi et al., 1989). However, these studies are largely decontextualized studies of individuals that suggest that labeling increases the ease or sophistication of symbol-ground mapping. By contrast, this study addresses language use during interactive dialogues that occurred in a natural context. Results suggest that situated language use both serves as a medium for coordinating cognition in action and has pragmatic functions that facilitate cognition.

Language as a Medium for Distributed Clinical Cognition

The integration of diverse cognitive functions and actors requires a medium to bring disparate elements into relationship with one another. In some domains, a shared physical environment provides a medium for coordinating cognition and action (Hutchins, 1995). However, in chronic care, different actors perform the cognitive functions at different times, in different settings without boundary objects to help coordinate their efforts (Star, 1989). Linguistic representations (Ty’len et al., 2010)
compensate for the absence of a shared, mutable environment or tangible boundary objects.

In addition to providing an environment that allows for distributed cognition, language can have pragmatic cognitive functions. Language is inherently integrated into thought itself. In this study, language served such a pragmatic function\(^{50}\), as a means for participants to engage directly in distributed clinical cognition. In some cases, cognitive pragmatics were performative; as a part of the clinical interaction language itself accomplished the cognitive functions, e.g., deduction. Whereas in other cases, the hermeneutic\(^{51}\) and discursive properties of language had pragmatic cognitive functions as a means to construct collaboratively and negotiate a trajectory for clinical cognition.

*The effective linguistic environment.* One of the recurring points throughout this study is that patients and practitioners each have unique information and abilities that are essential for effective clinical cognition and care. However, many of these resources are not mutually accessible. As a result, as was discussed extensively in chapters 6 and 7, practitioners and patients must use language to create a mutually accessible

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\(^{50}\) Pragmatics refers to the context specific use of language. For example, saying ‘hello’ is a greeting and may also indirectly be a way of getting as getting a person’s attention. Cognitive pragmatics therefore is the way in which language in a particular context enacts, alters or facilitates cognitive functions.

\(^{51}\) Hermeneutics refers to the interpretive functions of language.
representation of the clinical situation. In essence, language creates a virtual environment for supporting distributed cognition.

Just as participants in other distributed systems may have differential access to the physical task environment, e.g. use of different displays and trained competencies, (Hazlehurst, McMullan, & Gorman, 2007; Hutchins, 1995), patients and practitioners have differential access to the linguistic environment. Each participant approaches the clinical encounter with a specific set of linguistic resources that includes a corpus of previously generated or internalized linguistic constructs. The latter category may include linguistic units ranging from very small texts, such as traditional metaphors, to extensive texts associated with narrative and rhetoric. Individuals have access to these linguistic tools on two different levels: the sociolinguistic and the personal. Figure 5 illustrates this idea for two different participants.

![Diagram showing the relationship between sociolinguistic corpus, personal corpus, and effective linguistic environment.](image)

**Figure 5. Individually and mutually accessible linguistic resources.**

The sociolinguistic level includes those language-based resources available to people by virtue of the communities in which they live. These resources include basic
language elements, vocabulary and syntax, and complex linguistic constructs, expository, analogical and narrative texts, which form a part of the cultural domain and are readily accessible (Cowley, 2011). In this study, for example, medical practitioners had socioculturally determined access to basic linguistic resources, such as technical vocabulary, as well as more complex ones like the reports from imaging studies.

The personal level contains the resources that an individual has internalized and can access directly. This includes the subset of socioculturally available resources that the individual has personally mastered. For example, in chapter 6 one of the differences between expert and novice patients was the medical vocabulary they had assimilated. The personally defined linguistic tools include internalized and self-generated texts, which reflect the distillation of someone’s experience and understanding. For example, the narratives discussed in chapter 7 were self-generated linguistic resources. Because of differences in sociocultural status and personal experiences, people have access to different linguistic tools.

During an interaction, only a subset of the linguistic resources available to the separate individuals is mutually accessible. The area of overlap defines the effective linguistic environment for a dyad; it contains shared access to basic language and complex texts. To execute distributed clinical cognitive functions and avoid miscommunications, participants must maintain their interaction within the effective linguistic environment.

The scope of the effective linguistic environment affects the efficacy and quality of communication. A large area supports deep and complex discussions. A limited area
imposes significant constraints on communication. The smaller the effective linguistic environment, the more limited the resources available for the creation of common ground (Clark & Brennan. 1991). One of the major benefits of patient expertise was that it expanded the effective linguistic environment allowing for more efficient communication. As patients gained expertise, they expanded their personal corpus to encompass a larger percentage of the sociocultural corpus, thereby developing the ability to represent their experiences in ways that were immediately compatible with biomedical representations of disease processes. For example, as was discussed in chapter 6, expert patients were often able to self-label symptoms using medically relevant terminology and clinically significant semantic categories.

I suggest that to the extent that the actors engaged in distributed cognitive activities share common linguistic tools, their collaboration has the potential to be more efficient and reach more satisfactory outcomes. To the extent that they lack a common set of tools, the collaboration is likely to miss critical paths or options. In this study, experienced patients had access to a larger effective linguistic environment enabling them to participate more fully in the diagnostic and treatment process. Similarly, when practitioners understood and incorporated the linguistic tools of their patients, they could more effectively create a shared understanding of disease status and a mutually acceptable trajectory for thinking about treatment.

Cognitive pragmatics. Language not only provides an environment that allows for distributed cognition, as was discussed above, but articulation itself can be a cognitive act. In certain situations, cognitive functions are not only expressed in language but may
be accomplished through language. These pragmatic cognitive functions could be either
directly performative or facilitative depending upon the context and specific use of
language. The discussion below begins by looking at directly performative cognitive
pragmatic functions and then at the indirect utility of language through hermeneutics and
the process of discourse.

The way that participants in this study used language for collaborative clinical
cognition suggests that, as a behavior, language may function to take cognitive actions in
ways that are analogous to its use for social action. Linguists generally accept the idea
that in social situations language can be used directly to perform certain actions. For
example, greeting, betting at cards, and blessing someone are all accomplished through
speech (Austin, 1962). Similarly, in this study, language operated pragmatically as a
means to enact directly clinical cognitive functions. This was obviously the case for the
discussion of symptoms as a representational process, but it occurred at other points in
the clinical interactions. For example, the assessment of symptoms began when the
patient, either independently or in collaboration with the practitioner, identified a
problem by verbally labeling a phenomenological experience as a symptom, designating
the status of this as a problem. Symptoms labeled as problems remained part of the
diagnostic process whereas those without that label were excluded. Similarly, judgments
of a symptom’s relevance to MS were directly enacted through language. These
judgments were effectively classification tasks that involved mapping a verbal
representation of a symptom onto a clinical designation; see for example the expert
patient discussed in chapter 6.
The speech involved in performing these processes was not simply a declaration of a prior mental process by a single individual; it was an interactive process that emerged from multiple spoken turns. This was seen most clearly in the extended interactions with novice patients that practitioners used to convert the patients’ phenomenological experiences into medically relevant semantic categories.

Hermeneutics. In addition to performative aspects, in this study, the hermeneutic aspects of language (see chapter 7) had pragmatic value. A large portion of clinical cognition is fundamentally hermeneutic (Greenhalgh, 2006). Before a decision point or problem emerges, elements of attention, representation and causal attribution shape a chaotic environment in meaningful ways. The language participants use to describe and assess the clinical situation implicitly incorporates hermeneutic elements. The value of this for causal attribution was discussed directly in chapter 7.

The hermeneutic process was a constant factor in bridging the perspectives of patients and practitioners. Biomedical language incorporates a hermeneutic framework that facilitates certain forms of interpretation and constrains others. For example, western health practitioners favor physiological explanations over those that involved in psychosocial or spiritual concerns. Patients are neither trained to utilize this framework nor are they culturally required to do so. To the extent that patients either lack a coherent framework for interpretation or use an alternative framework, their representations lacked connection to the biomedical frame. This was seen, for example, with the novice patient discussed with respect to evaluating treatment in chapter 6. This patient had an
emotionally focused frame that led her to interpret the practitioner’s questions in ways that were not intended.

Participants were able to use hermeneutic processes to create decision parameters that were meaningful for the person they were interacting with, thereby facilitating the selection of desired actions. From the practitioner’s side, this was most clearly evident in the dialogue in chapter 4 where the practitioner reinterpreted various treatment options in terms that were meaningful to the patient changing the decision parameters from a focus on efficacy to incorporate the patient’s requirement for naturalness. From the patient’s side, a comparable interaction appeared chapter 7 with the patient who created a narrative about intense experiences with chronic pain using a biomedical frame. This patient interpreted his personal experiences in ways that presented addressed decision parameters relating to efficacy and addiction risks thereby justifying the patient’s preferred treatment options.

In this study, the interactive nature of discourse had pragmatic cognitive value. For thousands of years, people have suggested discussion can facilitate reasoning by drawing relationships and exposing insufficiencies and fallacies in reasoning (Shields, 2015). Cross-cultural psychologists have even suggested that the ways in which this process occurs in different societies can account for significant differences in cognition (Nisbett, Peng, Choi, & Norenzayan, 2001). In this study, participants used the properties of discourse to facilitate clinical reasoning. Two of the places where this occurred were in the assessment of symptoms and the definition of decision parameters.
While assessing symptoms, participants co-constructed representations of the nature and details of the symptom. This meant that while they created representations both parties had an opportunity to contribute key information and to challenge assertions that were not consonant with their understanding. For example, chapter 7 discusses how participants used the co-construction of narratives to create and test causal arguments. The extended narrative about blurred vision illustrates this particularly well. During this dialogue the patient and practitioner both repeatedly made contributions that supported their assertions about the nature and cause of the symptom and challenged perceived fallacies in their partner’s assertions.

Similarly, participants used the interactive nature of discourse to justify and challenge particular decision parameters. This was evident, for example, in the split decision processes described in chapter 5 when patients interjected challenges (one about her history of seizures and the other about conducting a spinal MRI) that altered the practitioner’s construction of the decision space.

The pragmatic cognitive functions enumerated above demonstrate that language plays a role greater than simply expressing ideas. Language helps parse and categorize experience; it helps define the problematic, structure the parameters of clinical reasoning, and allow for the discursive and interpretive processes necessary to negotiate a common trajectory for clinical cognition. In distributed cognition, language further determines the interactive space for cognitive collaboration. Language is at the very core of distributed clinical reasoning, having the power to expand or contract the efficacy of interactive clinical cognitive functions.
Future Research on the Role of Language

The functions of language found in this study are likely to occur elsewhere. The use of language to create a virtual, shared environment and the issues associated with doing so given the differential resources may be prevalent in other domains where actors lack shared access to a physical environment and/or have disparate training. I would be interested in examining language use in areas like automotive sales or personal finance where laymen depend upon the expertise of professionals to make high-stakes decisions. Similarly, language may serve pragmatic cognitive functions in other domains. This study has delineated a few such functions, but qualitative work in other settings could help enumerate a wider range of pragmatic cognitive functions and develop a theory regarding how they are structured and implemented.

I would like to test a few more specific hypotheses regarding the use of language. For example:

1. This study has suggested that practitioners and patients operate in a shared linguistic environment and that the size of this environment impacts cognitive functioning during clinical interactions. Hypothetically then, interventions to increase patients’ functional clinical vocabulary should increase the coherence of their symptom presentations and their participation in medical decision making.

2. This study has suggested that narrative facilitates causal reasoning. Hypothetically then, people should be more likely to identify causal factors in descriptions of events using a narrative rather than an expository format.
Limitations

This study does not address questions of prevalence or saturation. It does not include any way to measure the prevalence of the target phenomena either in terms of quantification or generalization. As a descriptive study aimed at theory generation, this work does not quantify the majority of the concepts presented. Therefore the analyses do not speak the prevalence of specific findings within the study. Similarly, this study focuses on a very narrow domain. Although, there are logical reasons to believe that the findings from this study are generalizable. For example, certain findings (e.g. the four decision patterns presented and the use of functional descriptions in narrative) stem from structural features of the clinical interaction that characterize other medical encounters. The study does not include any empirical support for such extensions.

Saturation refers to the practice of iteratively collecting data to ensure that the study captures all the relevant variation in a theoretical construct (Strauss & Corbin, 2008). In this study, all the data were collected before the majority of the analysis. Therefore, I did not have an opportunity to collect data in a motivated fashion to confirm the developing theory or to verify theoretical saturation. However, the convergence of findings from the various analyses suggests that the data were sufficient to support the conclusions presented, even if they may not include all possible variations.

Contributions

The fundamental contribution of this study is to bring elements of clinical cognition that are marginalized or ignored into focus. On the cognitive level, I have highlighted how the context and composition of thought shape the processes of cognition.
In the laboratory, one mark of a well-designed study is its ability to control or statistically eliminate contextual variables. This implies an assumption that in the absence of experimental control cognition is modified by idiosyncratic contextual elements. Yet, the current work shows that these idiosyncratic contextual elements affect the elements of cognition and the functions they perform. Understanding cognition thus requires an integration of elements captured in experimental studies with the variations that experimental procedures necessarily exclude. By adopting an ethnographic approach, I have identified several ways in which variation and context are core components of clinical cognition. First, cognition is personal. The personal traits of the actors shape the ways in which cognitive functions. When multiple actors are involved, the cognition of each is affected by the personal attributes of the others. Second, cognitive elements and functions are highly interconnected; past thoughts and actions, as well as projected future thought and action, affect current cognition.

On a clinical level, I have argued that patients necessarily play a role in clinical cognition, that their contributions affect practitioner cognition, and that many patients directly engage in portions of the clinical reasoning involved in MS management. Patients are typically considered only on a social and emotional level, suggesting an underlying assumption that they lack the knowledge, skills, or authority to serve as cognitive actors. This study showed that whereas patients lacked technical expertise, many developed some degree of personal expertise regarding their illness that influenced clinical cognition. Moreover, even when patients were not engaging in deliberate clinical cognition, the distribution of knowledge and resources for action between practitioners and patients meant that the patient’s contribution or lack thereof shaped clinical
Studies that define clinical cognition as practitioner cognition have overlooked the importance of patient cognition. Whereas laboratory paradigms that replace the patient with standardized clinical descriptions or simulations completely mask the affect patients have on practitioner reasoning. The results of this study emphasized the need to reintegrate patients into theories of clinical cognition.

Finally, I have argued that language is a medium for distributed clinical cognition on multiple levels: on a representational level it allows actors to function in a shared linguistic environment and on a pragmatic level, it allows actors to accomplish collaboratively cognitive functions. Each of these findings provides opportunities for future research to explore and refine the interplay of cognitive elements with the particulars that control cognition in medias res.
References


*Qualitative Health Research, 14,* 663-674.


Appendix A: Human Factors in Medicine

Medicine is a complex, safety critical domain. Human factors professionals have worked extensively to reduce medical errors and improve safety (Carayon, 2012). Human factors researchers have studied many aspects of medicine including the origins and means to prevent error (Reason, 1991), teamwork (Patel et al., 2014), functioning of health care as a system (Carayon et al., 2014), and the use and usability of medical technology (Kortum & Peres, 2015). Most of these studies focused exclusively on the performance of medical professionals. A few human factors studies have addressed the role of patients primarily in terms of improving medical compliance (Klein & Meininger, 2004) or examining home health technology (Rogers, Mykityshyn, Campbell, & Fisk, 2001).

But patients play a role in medical care that extends beyond compliance. As Carayon and his colleagues (2014) have suggested, patients are a part of the medical system. As such, they are responsible for performing specific tasks and are influenced by physical, organizational, and technological aspects of the medical system. To ensure quality work processes, it is important to understand how patients function within the medical system both as individual cognitive actors and in conjunction with others. In my previous work, I demonstrated that patient cognition has a substantial impact on clinical outcomes (Lippa, Klein, & Shalin, 2008). This research extends the notion that patient cognition is clinically significant by examining patient-practitioner collaboration. This is an area that human factors has failed to address and which may suggest ways that health systems can be designed to improve joint patient-practitioner cognition. In addition,
patient-practitioner interactions provide an opportunity to address how laymen function in conjunction with a highly complex and professionally oriented socio-technical system.
## Appendix B: Methodological Comparison

<table>
<thead>
<tr>
<th>Procedure</th>
<th>This Study</th>
<th>Comparison</th>
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<tbody>
<tr>
<td><strong>Design</strong></td>
<td>Open design guided by general questions that are adapted throughout the study</td>
<td>Flexible design is common in many qualitative traditions. Grounded theory and ethnography are both especially known for emphasizing flexible design that adapts to ongoing data collection and analysis. This study is closer to ethnography in that it had more specific guiding questions than are classically included in grounded theory studies.</td>
</tr>
<tr>
<td><strong>Selection of setting</strong></td>
<td>The setting for this study was selected specifically for several reasons: 1. The highly specialized nature of the clinic meant that data saturation was likely in a relatively brief period. 2. I considered the chronic and complex nature of MS conducive to patient engagement and the development practitioner-patient relationships. 3. One of the goals of the study was to understand disability. And, MS is closely linked to a variety of disabilities.</td>
<td>1. The concern with data saturation is a key part of grounded theory. The assumption being that developing a theory requires a comprehensive view of the target phenomenon. 2. Ethnography often selects specific situations that are 'natural experiments' exposing a particular phenomenon of interest. 3. This concern was based on the goals of the LWD-IGERT program.</td>
</tr>
<tr>
<td><strong>Selection of participants</strong></td>
<td>This study used a convenience sample comprised of the patients available at the times the clinic allowed data collection. As it happens, the convenience sample included patients that closely match to general characteristics for the MS population. The practitioners were exceptionally specialized and may not reflect the practice of internists or neurologists in general practice who manage MS</td>
<td>Most qualitative methods encourage purposive sampling to ensure that a full range of experience is captured. However, in practice, many studies use convenience samples simply because they are available.</td>
</tr>
<tr>
<td><strong>Observational techniques</strong></td>
<td>Brief participant observation recorded through field notes and transcription of dialogue.</td>
<td>The use of participant observation and field notes are hallmarks of ethnography, but classic ethnographic methods include many more field hours than this study. Transcribed dialogue is typical of discourse analysis. Grounded theory may use either of these methods but interviews or focus groups without field observation are more typical.</td>
</tr>
<tr>
<td><strong>Interview techniques</strong></td>
<td>Semi-structured interviews especially emphasizing critical incidents</td>
<td>Grounded theory studies often use comparable semi-structured interview protocols.</td>
</tr>
<tr>
<td><strong>Transcription techniques</strong></td>
<td>Literary transcription</td>
<td>This method is occasionally used routinely in ethnography and grounded theory. It is much less comprehensive than is typical of discourse analysis.</td>
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<tr>
<td><strong>Analytic</strong></td>
<td>Multi-method hybrid approach</td>
<td>Hybrid analysis is increasingly common in</td>
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| Chapter 4: Task Analysis | 1. The task decomposition was derived inductively through multiple rounds of coding beginning with open coding to identify concepts followed by selective coding and aggregation by mapping the interaction for individual interactions and then pruning them to common nodes.  
2. How tasks are completed in a shared manner is documented using close analysis of language in specific examples. | 1. The underlying assumptions that tasks can be decomposed and represented in a general format and the motivation to do so came from cognitive task analysis. The method for identifying task components and relating them to one another and to cognitive elements came from grounded theory.  
2. The analysis of task completion used a discourse analytic approach based on studying how language is used and meaning is created in the context of interaction. |
| Chapter 5: Decision Making | 1. Decision related segments were identified during open coding and then selectively coded for indications of underlying decision making processes. Coding included identifying concepts relating to what information was present, how it was analyzed, factors affecting the ultimate decision, and roles adopted by physicians and patients. Connections between these concepts identified common patterns for the distribution of information, action and cognitive activities during decision making.  
2. Close analysis of language is used to support and exemplify the decision patterns. | 1. The coding procedures were derived from grounded theory.  
2. The examples are analyzed using discourse analysis. |
| Chapter 6: Expertise | The expertise work was conducted in conjunction with the task analysis and used the same basic coding and grounded conceptual development complemented by language analysis. But it focused on creating a theory to understand the variation in the data as opposed to the commonalities in chapter 4. | Combination of grounded theory and discourse analysis as in chapter 4. |
| Chapter 7: Narrative | 1. The narrative analysis began with the identification of narratives during open coding. I then reviewed and compared the narratives first with a particular concern for the manifestation of Bruner’s concepts of narrative cognition and then a second time with a particular concern for the representational functions of the narratives in the dialogue. I finished | 1. The coding procedures came from grounded theory. The interpretive phase used hermeneutic analysis techniques especially the intertextual comparisons that are common in comparative literature.  
2. The examples are analyzed using hermeneutic techniques, which focus on the significance of the |
with a selective coding for a few of the issues identified that seemed conducive to quantification.

2. The analysis is supported by close analysis of specific narratives.

<table>
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<th>narrative as a whole, and discourse analysis, which focuses on the interactive composition of the narrative.</th>
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Appendix C: Role of the Researcher

Many qualitative methods assume that researcher is a participant in the research with a unique set of perspectives that influence the design, conduct and analysis of the work. In order to judge the effect of the researcher’s perspective authors are encouraged to provide information acknowledging their own role. Accordingly, I present the following statements as bearing on how this study was formulated. They are presented in order of my perception of their influence on the study.

1. While analyzing the data for this study, I managed a series of medical problem in my family including: neurological dysfunctions, cardiac problems, autism, and acute psychiatric illness. These issues meant that I spent a great deal of time in healthcare settings including: inpatient facilities (psychiatric hospitals, heart hospitals, general medicine, and children’s hospital), emergency departments, rehabilitation centers (including physical, occupational, behavioral, and speech therapy), specialty care clinics (cardiac, urology, neurosurgery, psychiatric, interdisciplinary), and primary care. Overall, the total number of hours spent in medical settings greatly exceeded (by 7-10x) the number of hours spent collecting data and some of the analysis and writing in the final document took place while in hospitals/waiting rooms. Although none of these experiences are directly addressed here, the interactions with practitioners, observations of practitioners interacting with patients and discussions I had with other families in these settings influenced how I understood the interactions I was analyzing. Overall, I think this influence served to strengthen the study as an additional resource for testing my theories. When the ideas I was using in my analysis seemed to apply well and enlighten the interactions around me, I was more confident in my analysis. Whereas, when my
analysis seemed discordant or irrelevant in relation to other interactions I was more likely to be critical of my efforts.

2. The data for this study were collected 5-6 years before the majority of the analysis. When the data was conducted I tended to assume that the disconnect in practitioner-patient communication was due to a combination of patients’ inability to understand biomedical language/reasoning and practitioners’ inability to speak to patients’ perspectives and level of comprehension. Just before I restarted work, my daughter suffered serious post-surgical complications that clearly involved miscommunication, but had nothing to do with discordance between biomedical and folk understanding. Trying to make sense of that incident forced me to reconsider the nature of practitioner-patient interaction in ways that looked more at issues such as how practitioners and patients parse information from the environment and the functional roles of each party.

3. My earlier work examined patient cognition in conjunction with diabetes self-management. This work convinced me that patients’ understanding of their own disease affected their self-care, interactions with the medical system, and health outcomes. It also suggested to me that the ways patients and practitioners think about and discuss disease were often incongruent.

4. My undergraduate work was heavily centered on languages and interpretation. The understanding I have of the semiotic properties of language from this work provided tools for the analysis here and influenced the discussion of hermeneutics in the chapter on narrative.
Appendix D: Qualitative Note Taking Form

- Patient characteristics
  - Age
  - gender
  - ethnicity
  - education
  - relationship with practitioner (1st time appt, has seen on several occasions, or has seen over several years)
  - overall level of disability (simplified from Kurtzke Expanded Disability Status Scale modifications have been made to allow assessment based on general observations and interaction and to incorporate disability categories that do not involve ambulation)
    - [1] No disability, minimal signs in one or more functional systems (FS)
    - [2] Minimal to Mild disability in one FS or minimal disability in two FS
    - [3] Moderate disability in one FS, or mild disability in several FS.
    - Fully ambulatory
      - [4] A major disability in one FS (blind) or assistance (cane, crutch, brace) required to walk
      - [5] Major disability in several FS or is unable to work or unable to walk
      - [6] Severely disabled, unable to perform several basic activities of daily living independently

- Major Topics/Actions in the Session
  (Each event here should be addressed in the interview, except standard procedures like EMR and physical. Ask for patient to recount the event and as appropriate ask him to explain why the event occurred and his understanding of it.)
  - What was the purpose of the interview?
    - Purpose of visit (checkup, medication management, symptom management, diagnosis):
      - Dr’s Goal (if evident):
      - Pt’s Goal (verify in subsequent interviews):
  - What happened during the appointment?

- Conversational roles
  - Who directed the conversation? If dominance shifted through out the session, where was each partner dominant? (markers of dominance: initiating topic, substantive interruptions, curtailing topic, directing topic onto a tangent)
  - What information did each partner provide?
  - What questions did each partner ask?
• Critical incidents reported
  o  What happened?
  o  How was it described?
    ▪  Narrative elements included [events, characters and settings]?
    ▪  Causal theories included?
  o  How was it responded to?
    ▪  Where did the partner interrupt?
    ▪  What purpose did interruptions serve (clarification, increased
detail, directing discussion into a specific area, change topic)?
  o  What conclusions if any were taken from the incident?

• Explanations
  o  What was explained?
  o  Who gave the explanation?
  o  What was the purpose of the explanation?
  o  How was the explanation received?
  o  What does the explanation indicate about the speakers underlying
conception of MS?

• Disability Issues (Any issue that is raised regarding the patient's functional status
including ability to work, need for assistive technology, need for personal care, or
requirements to handle functional problems such as fatigue & pain)
  o  What was the issue?
  o  How was it raised (as a side issue, while describing symptoms, as request
for some intervention by doctor)?
  o  What were patient’s and doctor’s concerns about disability?
  o  How was the issue addressed?
    ▪  What was the resolution?
    ▪  Who was involved in generating a solution?

• Decision points
  o  What was decided?
  o  Who was involved in the decision?
  o  What were their concerns?
  o  How were these concerns addressed in the decision?
<table>
<thead>
<tr>
<th>Topic</th>
<th>Covered</th>
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<tbody>
<tr>
<td>Current Experiences</td>
<td></td>
</tr>
<tr>
<td>• Understanding of any critical events described during appt</td>
<td></td>
</tr>
<tr>
<td>- understanding of specific symptoms</td>
<td></td>
</tr>
<tr>
<td>- causes</td>
<td></td>
</tr>
<tr>
<td>- assessment of interaction with doctor</td>
<td></td>
</tr>
<tr>
<td>• Assessment of current condition, including:</td>
<td></td>
</tr>
<tr>
<td>Standard probe: Could you describe what it is like to live with MS?</td>
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<td>- changes from past experience</td>
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<td>- impact of disorder on daily living</td>
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<td>Standard probe: How would you explain MS to someone who didn’t know anything about it?</td>
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<td>- treatment/management</td>
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<td>Initial Experiences</td>
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<td>• Story of diagnosis</td>
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<tr>
<td>• How they learned about MS: sources of information, motivations/determinants of information search</td>
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<tr>
<td>• Initial response to diagnosis</td>
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</table>
- emotional aspects
- cognitive aspects
- behavioral aspects

Other Experiences

- Medications: interpretation of side effects, decision to change medication
- Flare ups: descriptions of, interpretation of symptoms & determining cause

Standard probe: Could you tell me about the last time your MS flared up?

Could you explain what caused it?

- Adjustment: methods for coping with permanent damage, methods of coping with fatigue
- Plans for the future and possible disability
- Interaction between MS and other medical conditions
Appendix F: Explanations in MS

The conversation about health care in this country is a complicated one. It involves pain and restoration, money and politics, vast bureaucracies and intimate choices, cutting edge technologies and ancient dilemmas. And too often it seems to involve taking sides. In the biopsychosocial literature on healthcare there is a pull between those who criticize patients for failing to adequately take responsibility for their own health burdening the medical system unnecessarily and making doctors’ jobs harder and those who champion the patients’ perspectives and criticize the medical system for being too impersonal and failing to account for the human aspects of healing. I would like to suggest an alternative perspective that rather than being antagonists health professionals and patients struggle valiantly to come to common solutions to health problems. But that too often these negotiations fail because the parties involved start from vastly different perspectives and fail establish the common ground needed for a successful solution.

Illness explanations provide a window into the perspectives of patients and practitioners including clues about why their reasoning is not always compatible. This chapter explores the functioning of explanations in health care by focusing on the use of explanations involving Multiple Sclerosis (MS). The chapter begins with a discussion of what we know about the characterization and cognition of explanations in general and the utility of explanations for medical care in particular. Then the focus shifts to describing MS as an explanation rich domain. I then present data on how patients and practitioners create, support and utilize explanations during MS management. Finally, I discuss the
implications of these findings for a theoretical understand of explanations and for medical practice.

Explanation and Cognition

The term explanation refers to a number of different kinds of processes. People explain how to perform specific tasks as when a nurse explains how a patient should use a medication. They explain the meaning of terms as when a doctor defines a diagnosis for a patient. They also explain motivations such as why a person chooses to go the doctor. All these forms of explanation are interesting and function within the medical context, but they are not the focus of this chapter. Here we look at explanations that focus on why some observed phenomenon occurred. Issues addressed by this type of explanation include why a symptom appears or disappears, why people get a disease, or why a medication is effective.

These types of explanation are the folk equivalent of the scientific explanations that have been the subject of philosophical and methodological inquiry for centuries (Salmon, 1984). Like scientific explanations, answers to the why questions examined in this chapter are externally focused and based on some form of objective reality. Answers to these questions should help patients understand the complex environment in which they live and how it relates to their bodies and functioning. And, the apparently objective nature of such explanations provides a shared basis for practitioners and patients to construct a mutually acceptable interpretation of the patient’s illness.

What Makes a Good Explanation?
Unfortunately, there is little consensus on what makes an explanation acceptable. We all know what an explanation is and have criteria for judging the truth and acceptability for explanations when presented. There is a recognizable feeling of increased understanding and insight into the world when a satisfying explanation is presented (Trout, 2002). But the criteria that allow for this reaction are elusive.

A variety of epistemological criteria have been suggested for evaluating explanations. One school of thought prefers explanations in which a phenomenon is explained in terms of causal mechanism(s) (Salmon, 1998). Causal explanations can be created in a formal, syntactic way by demonstrating the logical necessity of the phenomenon to be explained given the laws of nature and certain starting conditions (Hempel-Oppenheim, 1948). Alternatively causality can be demonstrated through a pragmatic, iterative process dependent upon inference across cases and judgments regarding the credibility of alternative explanations (Harmon, 1965). The primacy of causality in explanation has been canonized within scientific circles in the experimental paradigm and the requirements for experimental control (Thagard, 1978). The primacies of causal explanations and resulting methodological developments have propagated from science to medicine and are evident in the prominent use of randomized clinical trials in testing treatments.

An alternative approach suggests that the criterion for an explanation is its ability to unify diverse phenomena under a single explanatory framework (Friedman, 1974). Many of the explanations under this rubric are causal but it also encompasses purely logical explanations such as geometric proofs. There is some evidence that unification
based explanations may be functioning in medical diagnosis. In a study on the prevalence of diversity effects in categorization, Kim and Keil (2003) found that undergraduate participants preferred to assign diagnostic labels that unified as much of the presented data as possible.

Epistemological criteria are useful for a formal understanding of explanations but they do not capture many of the ‘sloppier’ explanations used in the real world, clinical contexts. In the clinical context people are not exploring an entire class of phenomena. Explanations are highly focused on specific individuals in particular contexts. There have been a few attempts by psychologists to bridge the gap between philosophical criteria for explanations and the functioning of real world explanations. Medical explanations are not alone in these differences; they are characteristic of a whole class of daily explanations.

*The Limits of Explanation and How People Cope with Them*

In real world settings, there are inherent limits to how people construct and utilize explanations. The properties of the phenomena being explained may not be fully known. A woman who notices pain in her leg is unlikely to know the detailed anatomical structure of her leg let alone the chemical and physical properties that control the leg’s functioning. If knowing the phenomenon to be explained is hard, defining contextual and historical factors that may play a role is nearly impossible given the sheer magnitude of variables involved. Beyond increased complexity, in real world settings people do not have access the perfect knowledge assumed in many theories of explanation. There is no
way to experimentally determine how a particular person at a particular time became ill or injured.

How do people deal with these constraints on real-world explanations? One answer is that people have an illusion of explanatory depth, they believe that their explanations are less limited than is justified (Keil, 2003). These skeletal frameworks give us enough comprehension to feel like we understand the world around us and, where necessary, they can be elaborated based on the observed patterns, relations, and relevant functions in a particular situation. Another option is to actively try to fill in explanatory gaps by looking for more information. For example, people who have been newly diagnosed with a chronic condition often ask others with the same condition what it is like or look things up on the internet. Finally, in some cases, people cede the need to explain to an authority (Cole & Engeström, 1993). This type of explanatory delegation can be functionally adaptive and even critical in cases of interdisciplinary collaboration. In the case of medicine, culturally endorsed roles for doctors and patients encourage the patient to feel comfortable with yielding his need for detailed explanations to the doctor greater expertise (Leigh & Reiser, 1992). This last strategy is likely to be particularly significant in medical contexts, like MS, where explanations are complex and the patient may not have the prior knowledge and tools to understand full biomedical explanations of disease and treatment.

 Why Explanations Matter

Cognition.
Explanations serve a number of important cognitive functions. Notably providing explanations sharpens a person’s ability to effectively parse and decipher the world around us, improves learning outcomes, and is integral to communication. Keil and Wilson (2000) described one function of explanations as serving “to buttress our overall conceptual frameworks for interpreting and making sense of the world.” Through explaining particular phenomena we become acquainted with the constraints, variables and social norms governing the environment as a whole. In addition to using explanations to learn about the environment in a global sense, developing explanations can also help students learn specific material (Chi, 2000; De Leeuw & Chi, 2003).

Explaining complex material to oneself allows for, amongst other things, the correction and elaboration of mental models, clarification of ambiguities, and relation of material to be learned to outside knowledge. The increased understanding provided by explanations in turn facilitates prediction. Explanation and prediction have a reciprocal relationship drawing on many of the same cognitive processes (Malle & Tate, 2006). Explanations account for the way in which specific conditions resulted in a particular outcome, whereas prediction is concerned with the outcome that will result given a set of conditions.

**Communication**

Outside of its value for individual cognition, explanations are a critical component of effective communication. One of the essential elements for effective communication is establishing common ground (Clark, 1996). Unless the participants in a conversation can come to a mutual understanding of what is being discussed and the meaning of the
discussion, communication is impossible. Establishing common ground requires that the participants have at least a minimally shared knowledge base on the topic being discussed. In many cases one participant will know vastly more than the other and will have to provide some explanation of the topic before an effective conversation is possible. For example, a doctor may need to explain something about why blood glucose levels are important for diabetes management before the doctor and patient can have a coherent discussion about the patient's test results and possible lifestyle modifications.

Explanations in the Medical System

Explanations are a central aspect of medicine. When a person makes the decision to see a physician they are usually seeking two things: a diagnosis and corresponding treatment. The first of these two tasks is essentially explanatory; a central function of diagnostic labels is to explain why a person is experiencing a particular set of abnormal bodily sensations and functions. The effectiveness of the later task, treatment, is dependent upon the successful completion of the former. There is a substantial research literature on how doctors explain things to patients in clinical practice and the practical consequences attendant upon providing adequate explanations (Whaley, 2000). But we know little about how patients understand doctor’s explanations and explain illness to themselves and others.

Doctor’s Explanations to Patients

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Although this research looks at doctors and nurses as representative of medical practitioners in general, in this section the terms ‘doctor’ and ‘physician’ are used in place of ‘practitioner’ because research in this area has focused on doctors in particular.
Providing patients with information is an important part of medicine. Patients have to have relevant facts about their diagnosis, the purpose of particular treatments and treatment options in order to participate in their own care. But patients’, informational needs extend beyond the type of factual disclosure of information mandated by informed consent procedures. Patients need broader information about the significance of their illness and treatment; and, they need explanations to enable them to understand all the information provided. Partially this is simply because patients want information and are more satisfied with their care when they receive sufficiently clear and detailed explanations (Frederikson, 1995). But explanations also serve a practical function. They allow patients to make sense of what is happening to them, what they can expect will happen in the future, and any actions they may need or want to take in response to the information provided. In chronic illnesses, these informational functions are even more vital as that they provide patients with tools for self-care after leaving the office and the help them manage the uncertainty attendant on living with a chronic condition (Mishel, 1988).

In addition to ethical and humanitarian reasons for providing explanations, there is substantial evidence that provision of adequate explanations has the potential to measurably improve many aspects of health care. Studies have indicated that both institutional goals and patient goals are met better when patients receive sufficient explanations from health care providers. Demonstrated improvements have included reductions in health care costs and malpractice litigation and improvements in medication adherence, medical outcomes, and patient satisfaction (Baird 1996; Beck, Daughtridge, &
Sloane, 2002; Buller & Street, 1991; Clare, 1993; DiMatteo, Reiter, & Gambone, 1994; Frederiksen, 1995; Lieberman, 1992).

Despite evidence that explanations are important, too often physicians fail to adequately explain critical pieces of information (Jackson & Kroenke, 2001; Sanchez-Menegay & Stalder, 1994). Even when legal protections are put in place to try and ensure informed consent, such efforts often do not result in doctors providing patients with substantive explanations regarding the procedures to which the patients are consenting. And instead become a formality where the patient simply signs a form under circumstances of considerable social and institutional pressure and without having received adequate additional information from the physician (DiMatteo, Reiter, & Gambone, 1994). Research suggests that less than 10% of all decisions are completely informed. Moreover the provision of explanations seems to decrease with the complexity of the issue to be explained with complex decisions about medication and medical procedures being much less likely to receive adequate explanations than simpler interventions (Braddock et al., 1999).

**Patients Explanations to Themselves and Their Physicians**

The nature, function and importance of patient generated explanations have gone virtually unexplored. We know next to nothing about how patients account for illness, understand particular symptoms, believe medication functions, or understand diagnostic categories. Nor do we know much about the effects of patients’ self-explanations on health outcomes.
The limited literature that is available on patient explanations largely concerns the understanding of specific populations such as children or patients coming from different cultural backgrounds (Kister & Patterson, 1980; Mercado-Martinez & Ramos-Herrera, 2002; Murdock, 1980; Pelto & Pelto, 1997). The few studies of adult patient’s understanding that are available tend to take one of two approaches. Some studies analyze how patients misunderstand or formulate inaccurate representations of biomedical concepts and treatments as explained by their physicians. Examples of research in this tradition include studies of misrepresentations of diagnostic information such as Blumhagen’s (1980) description of alternative understandings of hypertension diagnoses as indicating that the patient was under excessive stress, ‘hyper tense,’ as opposed that he had abnormal blood pressure. Other studies focus on demonstrating the limitations of patient’s explanations of the functioning of treatment regimens and concomitant problems with appropriate adherence (Mayeaux, Murphy, Arnold, Davis, Jackson, & Sentell, 1996). These studies suggest patients try to internalize the biomedical models presented by the doctors’ but that the transmission of these models from doctor to patient is imperfect resulting in problems with adherence.

The paucity of information about how patients explain illness is not simply an academic problem. It has real consequences for health care. In the current health care environment, shared decision making paradigms are becoming more prominent and the need for patients to participate in their own self-care is growing. As such, the understandings of disease and logic patient’s use in constructing explanations for various elements of their disease can have practical consequences as it affects their participation
in decision making, their ability to confer with their physicians to share decision making responsibility, and their ability to adequately provide self-care.

Explanations in MS

Virtually every aspect of MS is highly uncertain. When most people get sick they want answers to a fairly basic set of questions: What’s wrong with me?, How will this impact my life?, What will I feel in the future?, How can I get better?, etc. For MS most of these questions are difficult to answer and the answers available tend to be highly ambiguous and idiosyncratic. The chronic nature of MS means that most patients have to confront these questions and become comfortable with some way of answering them both when they are first diagnosed and repeatedly thereafter as their symptoms and circumstances change.

Diagnosis and Misdiagnosis

MS is difficult to diagnosis taking weeks to years before a firm diagnosis can be established. During this period the patient and their physicians are largely engaged with the explanatory aspects of medical diagnosis. The extended diagnostic process is due to two features of the definition of MS. First, a diagnosis of Multiple Sclerosis requires evidence of disease activity that is distributed in both time and space (Miller, 2006). There has to be evidence of multiple temporally separate attacks and such attacks have to affect at least two different areas of the central nervous system. This means that diagnosis can be delayed and tentative for patients who upon first seeing the doctor have had only a single attack or whose lesions initially are highly localized. Second, Multiple Sclerosis is a clinical diagnosis of exclusion (Miller, 2006). That means that in order to
diagnose MS the physician has to first rule out any alternative explanation. Often in this process of ruling out alternative diagnoses one such diagnosis will seem to fit the clinical evidence at least for a period of time, so that by the time an MS diagnosis is reached a patient has often already received one or more misdiagnoses. Thus in reaching a final diagnosis patients and physicians often have had to engage in an extended explanatory process fitting their understanding of the situation into multiple, ultimately inadequate explanatory frameworks.

For some patients, the experience of having been misdiagnosed can lead to a feeling that the medical community does not have an adequate explanation for their experiences. They may begin to doubt the competence of their physicians and/or distrust the medical system in general. This can lead to switching doctors multiple times, ‘doctor shopping,’ and/or the use of alternative medicine. It addition it can prompt patients to generate their own explanations for their illness.

Symptoms Attribution

One of the more confusion aspects of MS involves the specific manifestation of symptoms. Because MS lesions can occur virtually anywhere in the central nervous system, they can produce a vast array of symptoms. Symptoms include perceptual, motor, and cognitive dysfunctions and to add to the confusion some brain lesions may produce no symptoms at all. This means that anytime a person with MS is faced with unusual bodily sensations she has to decide how to explain the symptoms: is this MS or is it caused by something completely different? If this is an MS related symptom what does
it mean? Should it be brought to the doctor’s attention? Might it require a change of medication?

**Treatment Decisions**

Finally, treatment decisions require the development of explanations. Doctors have to explain to their patients the nature of the treatment being prescribed and its probable effects. This especially true with MS, where most medications are prophylactic and cause side effects. So, physicians need to be sure their patients understand that the medication will not necessarily make them feel better while still providing a physiological benefit.

**Research Question**

Our understanding of explanations comes predominantly from enclosed environments of experimentation and logic which are assumed to be able to encompass the entire explanatory phenomenon. Models of medical explanations largely co-ops this approach replacing the laboratory with an exam room and assuming the physician embodies received biomedical schemas for explanations. One of the challenges of chronic illness is that by definition it requires an interaction between the clinical encounter and the outside world in which the patient functions. Given the multiplicity of influences operating in a dynamic world how do doctors and patients choose the parameters of an explanation and how do such explanations function in the clinical setting?

**Analyses**
**Issue Identification**

The transcribed clinical sessions, field notes, and interviews were reviewed repeatedly. The initial review was unmotivated and explanations emerged as one of the interesting elements of the data noted at this time. As second review of the data was focused on identifying specifically cognitive elements of interest and particularly for looking what data was available to analyze participants’ mental models and sensemaking processes. Analyses during this review suggested that there was little data regarding participants’ mental models and sensemaking, but that explanations, a related construct, were well captured by the data and seemed to play a significant role in participants’ thinking.

**Segmentation and Coding**

Relevant segments of data were initially identified by using the computer assisted qualitative data analysis tool Atlas.ti to search for passages including the 108 terms used in Pennebaker’s Linguistic Inquiry and Word Count (LIWC) software to denote causality (Pennebaker, Chung, Ireland, Gonzales, & Booth, 2001). Examples of terms used include: because, effect, hence, etc. Of the segments so identified, those segments were retained that explicitly or implicitly included an explanation answering a question about why some phenomenon occurred. Segments which did not contain a qualified explanation were dropped. In these segments the terms of the search were either used in another kind of explanation most often one explaining the psychological motivation behind some action by the speaker or were used in a non-explanatory manner as for example using the phrase “Cause you see…” to continue a speech. The initial
computerized search identified passages that were all one turn long. In some cases a segment of this length was insufficient either to contain the entire explanation or it contained the explanation but not critical context need to make the explanation comprehensible. In these cases, additional content surrounding the targeted segment was added at the discretion of the researcher.

Identified segments were analyzed in three rounds using analysis methods based on grounded theory (Strauss, 1986). During the first round notes were made for each segment regarding the issue to be explained, the basic explanation(s) offered, and other notable features. Emergent codes were also used to track patterns during this round. A review of notes and emergent codes suggested three dimensions along which the explanations varied: explanatory stance used, type of evidence offered, and purpose served. A second round of semi-emergent coding was conducted to elaborate the three dimensions identified. The second round identified the final list of codes, see below for codes and definitions. Some of the concepts that were identified during the emergent coding were similar to those discussed by other authors, notably Daniel Dennett (1971), these parallels are included in the in depth discussions of each code in the results section. Due to variations in the length, sophistication, and complexity of explanations, it proved impossible to code all explanations with exactly one code from each dimension. For example, one explanation might successively draw on a variety of different forms of evidence for support. As a result, some explanations received two codes from the same dimension.
The third round of coding was conducted by two independent coders. After approximately four hours of training during which the definitions of the codes were discussed abstractly and with reference to practice quotations, each coder coded all of the quotations. The separate codings were compared. Cohen’s kappa of reliability as used to calculate the agreement between coders for each dimension. Agreement on the explanatory stances was in the ‘moderate’ range, $K = .56 \ (CI = .45 - .67)$. Agreement on the modes of evidence was in the ‘good’ range, $K = .79 \ (CI = .71 - .87)$. And agreement on the functions was nearly perfect falling in the ‘very good’ range, $K = .90 \ (CI = .84 - .97)$. After reliability had been calculated all instances of disagreement were discussed until a consensus was reached, which was used for analysis.

**Qualitative Analysis**

The qualitative analyses provide a thicker description of how patients and practitioners explain illness and the functions such explanations serve. These descriptions are designed to provide a rich picture of explanations using illustrative quotations to show how trends and significant aberrations in the data. Charts were created to illustrate interactions between explanatory elements. Frequency counts based on the coding are used to track the prevalence of different types of explanations provided by patients and practitioners.

**RESULTS AND DISCUSSION**

A total of 146 segments including explanations were identified. Twenty-seven of the explanations were provided by practitioners without input from the patient. One hundred and six of the explanations were provided by patients by themselves. One
explanation was provided by the wife of a patient, who had accompanied her husband to his appointment. And, twelve explanations were constructed using input from both the practitioner and the patient.

Explanations came from three sources: transcripts of clinical sessions between patients and practitioners, notes taken during clinical sessions between patients and practitioners, and interviews conducted with patients. Eighteen explanations (8 by practitioners alone, 5 by patients alone and 5 involving both patients and practitioners) were identified in the transcripts. Thirty-two explanations (21 by practitioners alone, 6 by patients alone and 5 involving both patients and practitioners) were found in the session notes. Ninety-six explanations (all of which by definition had to come from patients) were found in the interviews.

Model of Explanations in MS

Explanations involved three conceptually independent dimensions: explanatory stance, mode of evidence and function. Despite similarities in topic, the explanations employed several fundamentally different explanatory stances each with a unique ontology. A second dimension, the mode of evidence, concerns the type of information presented to develop and support the plausibility of the explanation. The final dimension concerns the purpose of the explanation in the clinical context. Below, I first will present results regarding the nature and prevalence of each of the dimension of the explanations and then will examine how these dimensions interacted with on another.

53 The term ‘explanatory stance’ is used to refer to differences in ontology, because two of the four categories overlap with concepts that Dennett (1971) called by that name.
Explanatory Stances

Explanations did not all draw upon the same universe of causal structures and potential connections as resources for explanation. For example, the following two excerpts are from interviews with patients who had recently had an increase in symptoms and were asked about why they believed their symptoms had worsened.

...I'll tell you one of the one of the reasons that I had an exacerbation back in October/November is because it was at that time - that's the stress that was on my body. I was stripped off of Methadone and I went through two weeks of hell and I think that's what caused these probably, that was probably exactly what caused me to have the exacerbation.

...my current understanding is that, or my sense is that you know there has been some new activity. New lesion activity and that’s probably manifesting itself in some of these sensory symptoms.

Each of these statements contains a plausible explanation of why symptoms might have worsened, i.e., stress and lesion formation. But the explanatory mechanisms invoked different. In the first explanation, the participant is drawing upon knowledge of events in his life to explain why the symptoms got worse. In the second explanation, the participant invokes biological processes to construct an explanation. These two explanations do not differ either accuracy, on different levels it is likely they are both correct, or the situation they account for, both participants reported increased symptoms. Rather, they differ in terms of underlying explanatory stance.
Participants in this study were found to draw on four different explanatory stances for the construction of explanations. Each stance constituted a complete ontology with its own vocabulary of objects, attributes and relations as resources for explanation. The first two stances were similar to what Dennett (1971) called the physical and design explanatory stances. The other two, which we will call the holistic and entitive stances, have not, to my knowledge, been described before and maybe especially related to the explanatory tasks associated with MS specifically or illness more globally. The remainder of this section presents descriptions and analyses of each ontological stance.

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**Table 15. Distribution of Explanatory Stances.**

*Physical*

The physical stance was the most frequently used by both practitioners (52 % of all practitioner explanations) and patients (35 % of all patient explanations), See Table 15. In the Physical Stance, explanations are predicated on the physical state of the system being explained and the laws of nature. Under this ontological framework accepted objects include physical items and substances (e.g. bodies, blood, neurons) along with their associated measurable attributes (e.g. temperature, ability to conduct
neural impulses, oxidative properties). Accepted relations consist of scientifically accepted laws of physics and biological processes. Explanations in the physical stance tend to resemble explanations in the biomedical literature.

Consider the following explanations in the physical stance:

*Interviewee:* ...and it starts attacking your own nervous system, and ...your nerve is kind of like an electrical wire, and it has insulation on it, and part of the M.S., you know it attacks that insulation and it kind of shorts out that wire. You know and it could...You know most of the effects-uh, you could have spots or-uh fulcra in the spine, or a spinal comb, so it could have varying-uh...you know a wide ranging-uh multitude of symptoms. (male, middle aged, has had MS for 2 years, college education)

*Interviewee:* I did my shot yesterday and I was bad and my shot went [unintelligible] and then my whole body started to hurt.

*Interviewer:* ...Why did you think that that was happening?

*Interviewee:* Because I did it too far down in my arm and I hit a-I hit a nerve...

(female, late teens, recently diagnosed, high school education)

These explanations differ in terms of the demographics of the participant, type of phenomenon being explained, linguistic construction. Nevertheless, both explanations draw on the same ontological world. All of the objects involved are physical items which function according to biological laws and are generic elements of human biology as opposed to particular characteristics of the speaker. The first explanation concerns a nervous system, nerves, and a spine. The second is simpler and involves a body, an arm, and a nerve. The physical objects in each explanation have known observable attributes.
In the first example nerves are presented as being covered by insulation and being like a wire in that it can be ‘shorted out’ and the spine is presented as susceptible to trauma in the form of combs, spotting and fulcra. In the second example the critical attribute is only implied, but it is suggested that the nerve is susceptible to trauma specifically that it can be ‘hit’. Both explanations rely on the accepted biological relationship between nerve trauma and perceptual experiences.

*Design*

The design stance was the least frequently used overall (17% of all explanations), see Table 15. The majority of design explanations were constructed by practitioners (37% of practitioner only explanation), but patients (11% of patient only explanations) and dyads (25% of co-constructed explanations) occasionally used design explanations. The design stance is predicated on the teleological nature of that which is being explained (Dennett, 1971). Any type of object is admissible within this ontology but the only attributes and relations that appertain are those that realize the final cause of the explanandum. While in theory any phenomenon can be explained using this stance, it lends itself particularly well to explaining the behavior of man-made objects. In this sample, the design stance is primarily used to explain medication.

For example practitioner 1 gives patient 9 the following explanations for why a medication works for some patients but not others:

*Practitioner: I would think that they are patients with progressive disease if the disease is not so active with much inflammation going on they are not going to respond*
[to Tysabri] as well as somebody with a lot of inflammatory process going on, cause that's where the medication is the best.

This explanation is somewhat unusual in that it is explaining the likely outcome of a theoretical situation. However its structure provides a paradigmatic example of design explanations. Here the central objects are patients and the medication Tysabri. The critical attribute of the patients is that they have a course of MS which is characterized by little active inflammation; the critical attribute of the medication is that it is designed to decrease inflammation. It is this functional attribute of the drug that explains the probably differential outcome for medication usage by different classes of patients.

Holistic

The holistic stance was used almost exclusively by patients (32% of all patient only explanations); see Table 15. The Holistic Stance is predicated on the state of the surrounding environment, physical, psychological, and social as a whole. The undergirding logic is emergent and relational such that elements in the surrounding environment are seen as having indirect, emergent effects (Heft, 2001). Under this stance admissible objects consist of salient elements of the environment, their experienced attributes and relationship amongst themselves and between them and the explanandum.

Because holistic explanations can include a greater variety of influences and are linked to specific context they are more variable than design or physical explanations. One common type of example centers on a specific far-reaching aspect of the environment. For example:
Interviewee: The Gulf War, and-uh one of the things that we’ve been...my wife and I have been looking at lately-uh and once I had been diagnosed was-uh we found out that...I’m trying to think of the right word for it. Uh, an extraordinary amount of Gulf War vets are being diagnosed with M.S. Or M.S. type symptoms. Uh, so that’s something that we’ve been kind of looking at, and-uh another... environmental issues that are things that I was exposed to, plus there was the...kind of-uh there was a pill that was supposed to be like protective of my...protecting you if you get like attacked by biological agents or whatever.

In the first example, the participant attributes contracting MS to a significant, life-changing event in his personal history. He does this first globally suggesting a connection between having fought in the Gulf War and MS and then goes on to suggest particular aspects of his experiences and environment (i.e., environmental exposure and prophylactics against the biological agents) that might specifically have been related. The critical objects here are the Gulf War along with its attribute of having been conducted in a foreign environment and the anti-biological warfare pills. The critical relationship is that these are dominant elements of his personal history. The pattern of attributing some effect to a particularly significant aspect of environment or personal history first globally and then in terms of suggested specifics is a common form of holistic explanation.

The other common pattern for holistic explanations was for participants to rapidly attribute a particular phenomenon to a whole variety causes taken from different aspects of their lives. For example:
Interviewee: *Yeah, I’ve been really tired. I was last summer also, maybe it was I was just noticing more tired, but this really does seem to vary with work stress too. I think I, I’m sixty six years old, I’m getting tired anyway, and I haven’t… I have dropped my membership to the gym last year.*

Here participant 20 is explaining why she feels unusually fatigued. Within the space of a few seconds she attributes the fatigues to work with it attribute of being stressful, age, and lack of exercise. Each of these is a culturally accepted cause of fatigue that corresponds to some aspect of her current experience. It is notable that none of these explanations is given primacy; rather they are draw together from different aspects of her life and are suggested as acting in concert to explain the phenomenon.

*Entitive*

The entitive stance is the second most commonly used explanatory stance (30% of all explanations); see It was used primarily by patients (30% of all patient only explanations) and in co-constructed explanations (58% of all co-constructed explanations) but was occasionally used by practitioners (15% of all practitioner only explanations). Entitive explanations are predicated on the fact that definitional properties of the elements (e.g. concepts, premises, and terms) in the explanans account for the explanandum. The only ontological elements required for the explanation are the explanandum and explanans as objects, their defined attributes, and the relations between them.

The Entitive Stance is the most limited of the explanatory stances. The explanations generated in this stance are epistemologically unjustified because they have
a circular logical structure and sometimes appear to be more of an exercise in labeling than explanation. Nevertheless, these explanations are extremely common in the data and appear to be both satisfying and sufficient for the participants in the contexts in which they are used.

Most of the entitive explanations are centered on explaining specific symptoms by placing them under the umbrella of a biomedical label. For example:

Patient: ... And then I don’t know if this has to do with the fibromyalgia or what sometimes I feel uncomfortable in my own skin. My skin is so sensitive. Like I’ll just hurt and I’ll be like in the car with my seat belt and I’ll be like what gives. Just pain. Does that go with the fibromyalgia?

Practitioner: It’s hard to say because there are sensory symptoms that are not always very specific in patients with MS.

In this example, the participant is asking the practitioner to explain why she is experiencing unusual tactile sensitivity and pain. Here two explanations are proposed that the pain is the result of having Fibromyalgia or that it is the result of having MS. Because both these disorders are clinical diagnoses which can partially be defined by presence of pain, the explanation is entitive. While there are instances of entitive explanations that are more sophisticated this example is typical.

**Modes of Evidence**

All but two of the explanations in the data set referred to evidence either to describe how the participant developed his explanation or to justify the explanation to
others. Overall, four modes of evidence were used frequently: mechanical, correlational, authoritative, and pattern matching. These modes largely parallel evidence from formal domains but they are substantially less stringent in the criteria for justification and unique aspects that distinguish them from formal modes of evidence. The first two modes of evidence, mechanical and correlational, are similar to evidence presented in the sciences. The third mode, authoritative, is a common type of justification used in legal proceedings. The fourth mode, pattern matching, does not appear to directly parallel evidence from any formal discipline.

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**Table 16. Distribution of modes of evidence.**

**Mechanical**

Mechanical evidence was the most common type of evidence employed by practitioners (67% of practitioner only explanations) and practitioner-patient dyads (50% of co-constructed explanations); see Table 16. However, when explaining things by themselves patients were much less likely to use this type of evidence (20% of patient only explanations). In explanations using mechanical evidence, the person providing the explanation attributes an outcome to a specific causal agent with an explicit or implied process whereby the agent produces the outcome. In many ways this mode of evidence is
parallel to the theoretical models presented by scientists which are supported by experimental evidence. The difference is that in the explanations in this data set the causal model is itself presented as evidence often times without citing any empirical support.

Consider the following example of an explanation supported by describing a mechanism:

Interviewee: ...and the lesions press and rub against the myelin, they wear the myelin away and eventually rub up against the nerves, and as they rub up against the nerves they can either wear the nerve away or they can cause pain or sufferers to feel different things. Basically the electrical impulses that move through those nerves, your brain tells different parts of your body to do different things, they press up against there, they cause a-a problem with the-uh I guess what would be the little electrical transmission.

Here the participant is explaining why people with MS can experience a variety of symptoms. His basic explanation is that lesions cause MS symptoms. In order to support this explanation he describes an elaborate causal model, employing two linked causal agents – diminishing myelin and disrupted electrical signals - that connects the proposed cause (the lesions) with the observed effect (the symptoms).

*Correlational*
Correlational evidence\textsuperscript{54} was the most frequently occurring mode of evidence (40\% of all explanations); see Table 16. Correlations were frequently used by patients (48\% of all patient only explanations occasionally by practitioners (15\% of practitioner only explanations) and dyads (33\% of all co-constructed explanations). Explanations supported by correlations involve two or more events one of which was instrumental in facilitating or causing the other.

Two distinct types of correlations were used as evidence to support explanations: temporal correlations and salient correlations. Temporal correlations either involved sequential events with an assumption that prior events caused subsequent ones or two correlated events that co-occur repeatedly at different points in time. For example:

Interviewee: \textit{Well, the headache, because I had this horrible headache and it was you know it was just so wet outside, very-very wet, it had been raining forever. I really felt that at the time that it probably was sinus...And I guess I just figured that-uh it was all related, you know the-the... numbness and everything. I figured it was all related, because it, you know the numbness went away.}

In this example the participant suggests her symptoms were due to a sinus infection and supports this explanation by pointing to the fact that the symptoms occurred

\textsuperscript{54} Correlational evidence in this data set differed from the scientific use of correlations in two ways. First, in the sciences, correlational research typically involves large samples. In this data set, participants typically use correlational evidence in cases where the correlated events have only occurred once or in a small number of cases. Second, in the sciences, researchers refrain from using solely correlational evidence to make causal claims. Whereas, the participants in this study routinely use correlations to infer causation.
during a period when there was a weather pattern that might have caused sinus problems and that both the symptoms and the weather cleared up simultaneously. The explanation is supported by the temporal contiguity of the events.

Salient correlations involved something in the patient’s life of unique importance that is assumed to be the cause of an illness related event regardless of temporal or recurrent connections. For example:

Interviewee: *I-I don’t really know other than I assume you know, with situations like-uh you know my Bells Palsy or my Migraines that you know those might have something to do with it*

This participant suggests that her MS was related to two other health conditions that had caused her substantial difficulty in the past despite the fact that they did not co-occur. In addition to connecting a variety of health conditions participants also connected MS related events to significant personal events, such as travel abroad or family history.

*Authoritative*

Explanations that appealed to authority were used by practitioners (30% of practitioner only explanations), patients (39% of patient only explanations), and dyads (25% of co-constructed explanations). Explanations support by reference to outside authorities drew on the credibility of an outside informant (e.g. a professional or publication) often with no specific supporting evidence. In some cases these explanations name a particular source (e.g. Dr Smith), while in others they just suggest the presence of an unnamed source (e.g. ‘I’ve read…’ or ‘They say that…’).
Typically the authorities patients refer to are their doctors, patient-education pamphlets, or to information from the internet. For example:

Interviewee: *Uh, I have heard and read that stressful situations can bring it on and-uh when I was having my first real symptoms I was in an extremely stressful situation with my job.*

This participant alludes to a theory that stress is related to the onset of MS citing two vague sources (people she’s heard from and things she’s read) and then connects the theory to circumstances in her own life.

When doctors refer to authorities for support, they usually cite biomedical research. For example, during an appointment that was only recorded using notes, the practitioner explained to the patient that someone with her disease course would not benefit from using disease modifying agents. As part of his explanation he cited several efficacy studies. All three practitioners at various times casually referred to research studies to support the credibility of their explanations.

*Pattern Matching*

Pattern matching was the most infrequently used mode of evidence (21% of all explanations), see Table 16. It was used in only 2 explanations constructed by practitioners alone (7% of practitioner only explanations). However, it was common in co-constructed (58% of co-constructed explanations). Patients by themselves occasionally also used this type of evidence (21% of patient only explanations).
The use of pattern matching as a mode of evidence does not directly correspond to any formal system. Pattern based explanations drew parallels between the target phenomenon and features of a known phenomenon. Pattern matching sometimes involved deliberately weighing similarities and differences between the target phenomenon and known classes. In other cases, pattern matching was more reflexive bearing a resemblance to recognition based reasoning (Klein, 1999; Schmidt, Norman, & Boshuizen, 1990). In addition to these differences in how patterns are identified there are two qualitatively different patterns that are invoked: experiential patterns and categorical patterns.

Experiential pattern matching relates a current event to a previously experienced or described event assuming that the cause of the previous event applied to the current event. For example:

Interviewee: *That’s usually what happens, at times numbness in my fingers but that can fluctuate throughout the day, what that looks like. So I am thinking of it not like that’s a flare up but that’s just part of the damage that’s been done.*

This participant describes her current symptoms as part of a pattern that she has experienced before. She suggests that because it is a known pattern it is probably due to existing damage rather than a flare up, which would indicate new disease activity and new symptoms.

By contrast categorical pattern matching is more abstract. These explanations involve matching an event to defined characteristics for a category with a known cause. Category membership is assumed to be sufficient for explanation. For example:
Interviewee: He was not very good. He-uh...he diagnosed Diabetic Neuropathy...Which-uh usually is a nonsensical diagnosis because... Neuropathies in particular are always-uh; deal with the extremities kinds of things, whatever you might want to call by them.

This participant described a misdiagnosis and why he did not believe it was correct. He supported his assertion by suggesting his symptoms did not fit the pattern described by the diagnostic category. Even though this a negative explanation, it is prototypical of explanations supported by categorization in that its strength depends on the relationship between key category feature (i.e., the clinical definition of diabetic neuropathy) and the features of the phenomenon being explained (i.e., his symptoms).

Functions

Up until now the discussion has focused on general properties of explanations. The third dimension of the explanations involves their purpose within the specific domain. One of the basic tasks facing the patient is deciding how to interpret changes in the way he is feeling and how to respond to these symptoms. This task is inherently explanatory and is unusually complicated in MS where there is a stochastic relationship between symptoms and disease processes.

Four categories of explanatory function were common. Two of these, diagnosis and assessing treatment, have direct implications for health outcomes. The other two, uncovering meaning and providing knowledge, are likely to impact health outcomes indirectly.
TABLE 17. DISTRIBUTION OF EXPLANATORY FUNCTIONS.

Diagnosis

Diagnostic explanations were used to explain an entire set of symptoms in light of the patient’s current experiences, environment, and personal and medical histories. Once a patient received and accepted a diagnostic explanation it not only sheds light on the specific phenomena that led to the explanation but becomes an explanatory framework for constructing future explanations.

There were 26 diagnostic explanations in this sample (18% of all explanations); see Table 17. These explanations were primarily created by patients (23% of patient only explanations). Diagnostic explanations were rare for dyad (8% of all co-constructed explanations) and practitioners (4% of practitioner only explanations). The apparent paucity of physician involvement is less surprising than it might initially appear. Because most of the patient-participants were already diagnosed with MS, there were few cases where the practitioner was called on to make a new diagnosis. It is likely that in a primary care setting, or even a less specialized neurology clinic, that there would be many more diagnostic explanations by practitioners.
Most diagnostic explanations came from patient’s describing their case histories during the interviews. Some patients described their self-diagnoses. For example:

Interviewee: *And-uh I ended up taking antibiotics and-uh. I didn’t know I thought I had a bad reaction to them or something... It didn’t seem right but my tongue started going numb and the entire left side of my face went numb, and-um. So then I had diminished hearing, so I finally had to go to...Cause I went to the practice. I went to my primary care partner.*

This participant is describing the onset of her first MS symptoms, which she initially subscribes to a medication side effect. Only when symptoms developed that did not fit with her self-diagnosis did she go to her primary care physician. Many of the participants developed some type of preliminary self-diagnostic explanation for their first MS symptoms and delayed going to see a physician until these self-diagnoses no longer had sufficient explanatory power. Sometimes, as in the example above, they saw a doctor later into their first episode while other participants used a self-diagnosis to completely explain their initial symptoms only seeking medical care when they had a second or third episode.

Other patients focused on the explanatory efforts of various practitioners. For example:

Interviewee: *Uh, I became unable to really grip anything with my right hand-uh, all that kind of stuff, you know sensory problems on that side, everything. Then I started having trouble with-uh my right leg, it was going numb and then they told me, “Oh you press on your legs too much, stop doing that.” I said, “Okay, whatever.” Everything’s*
occurring on the right side of my body, which was weird [laughs]. And then I switched doctors and-uh everything and they were sending me to a physical therapist. “Maybe you need some physical therapy.” She looked at me and said, “This is neurological, it has nothing to do with what I could do for you.”

In this case the participant recounts a succession of three diagnostic explanations prior to her final MS diagnosis. Like the participant quoted above, the majority of participants were not immediately diagnosed with MS either going through a prolonged period before reaching any diagnosis or being given multiple misdiagnoses. Faced with these differing explanations participants had to judge the acceptability of a succession of possible explanations, revising the explanatory framework with which they viewed their symptoms with each successive diagnosis.

Assessing Treatment

Practitioners (37% of practitioner only explanations) and dyads (42% of co-constructed explanations) frequently used explanations as part of assessing treatment; see Table 17. Patients used this type of explanation less frequently (17% of all patient-only explanations). Explanations were used to assess treatment during discussions of particular medications or therapies that were being used or considered for use.

Explanations in this context usually served one of two specific functions: assessing efficacy and assessing side effects. Some explanations were used to assess the observed and/or probable future efficacy of a particular treatment. For example:
Patient: *medicine takes care of it or if I don’t have pain medicine I’ve got to sit bouncing my legs because when I’m moving my legs although the pain is still there I am thinking more about moving my legs as opposed to the pain.*

Practitioner: *oh I see, I see is that the reason you asked for requip?… Is that helping you?*

Patient: [the requip]

no

Practitioner: *It’s not going to help. The reason being is that you may need restless legs to relieve something. You’re pretty conscious about. With restless legs it’s a little bit different. You have the inner urge to … move the legs to get rid of that inner sensation of to move your*

Patient: [to move your legs] [ok]

Practitioner: legs. *With this this is intentional movement.*

[male, 40s, college educated, 4 years with MS]

In this case the patient and practitioner are discussing the efficacy of a medication the patient hopes will help him with his pain. He had believed that the medication would help because when he is in pain he bounces his leg and this medication is designed to help with excessive leg movement. The medication has not worked and the practitioner explains its failure to help him by distinguishing between the kind of leg motion he experiences and the kind targeted by the medication. Discussions like this regarding the correspondence between characteristics of the patient’s clinical profile and
drug indications were common ways of explaining the efficacy or inefficacy of a medication.

At other times explanations were used to assess experienced and/or anticipated side effects as a first step toward ameliorating them. For example:

Patient: Is it common to have these flu-like side effects?
Practitioner: Yes, that's common. They don't go away, but you should only have them the day after you take the shot.
Patient: That's all it is, but I have to go on with daily life - kids and church.
Practitioner: Avonex because it's a large dose 1x a week, your body doesn't adjust to it.

Unlike the efficacy explanations which typically referenced both patient characteristics and medication characteristics, explanations of side effects often only discussed drug characteristics.

*Uncovering Meaning*

Explanations to uncover meaning were by far the most common form of explanation in the data set (55% of all explanations); see Table 17. Explanations were frequently created for this purpose by all participants: practitioners (44% of all practitioner-only explanations); patients presented (58% of all patient only explanations), and dyads (50% of all co-constructed explanations). Explanations used for uncovering meaning explored the etiology and/or significance of the focal event. Three common
themes pervaded this category: explanations of symptom significance, explanations of the etiology of the disease for particular patients, and explanations of the interactions between multiple health conditions.

Symptom oriented explanations were the most common, with all but 3 participant (the 3 who were not available for interviews and for whom we therefore have less data) constructing at least one explanation to serve this purpose. These explanations tended to concern the significance of currently experienced symptoms as related to the patient’s health generally and MS specifically. For example:

Interviewee: *I was thinking, “Well if it’s in the brain you know, somehow it’s messing up the picture that’s getting to the brain from the eyes. You know then it could affect both”, at least...again what I...So that’s...that’s kind of why started you know closing one eye and...*

In this explanation, Participant 10 is trying to explain why he is having a vision problem and in particular to justify his explanation of the problem as a neurological issue that is MS related rather than a problem with his eyes. Many of the explanation centred on discovering the significance of symptoms were similarly focused on deciding whether symptoms could be explained by the current status of the patient’s MS or if they indicated a new problem.

MS has no known etiology. Nevertheless many patients created etiological explanations. The explanations often began by disavowing any possible explanation and then immediately offering one. For example:
Interviewee: Right-right, but it is, cause that's what I'm wondering. And I don’t know for sure, I don’t know. And then I have thoughts about, “Well, my Dad was in the military [laughs], so I can go all day long you know and tell you about my theories on that, but I don’t know. I mean we lived in foreign countries and, we lived in air force bases and you know they would be something on the base in lakes, and I mean, you know what I mean.

This pattern of first denying then asserting meaning is a particularly poignant indication of the drive of MS patients to create meaning in the fact of incredible uncertainty.

Explanations used to make sense of co-morbid conditions were much less common. Not all patients had to contend with this issue; however, for those patients for whom it was relevant it was a significant challenge. For example:

Interviewee: ... These things are interacting in some way and causing some things to be affected when they shouldn’t be, causing other things to…we think should be affected to not be affected and resulting in difficulties.

Interviewer: Do you have any idea of what some of the variables in that interaction are, or just that there’s some kind of interaction going on?

Interviewee: Well I can’t tell you...I can tell you all the negative ones and that there’s not correlation. Uh, I mean any of the classic drugs we’ve tried for-uh-uh-uh muscle spasms, and any other things that would try to gain full Dyskinesia-uh. The only thing that had been showing any positive effect was the Levodopa, which I’m taking.
While this participant had an unusually complicated and ambiguous set of health problems, the struggle to identify what factors are involved in generating particular symptoms and reacting to particular drug combinations was common to all the patients dealing with interacting health conditions.

_Provision of Knowledge to Others_

Simply providing knowledge was the least common purpose for explanations (see Table 17) with only 12 explanations created for this purpose. However, they were a fairly common kind of explanation for practitioner; practitioner (37% of practitioner-only explanations) and occasionally were collaboratively constructed (17% of co-constructed explanations).

Explanations of this type were usually used for patient education give basic background information to patients who were newly diagnosed or beginning a new form of treatment. For example:

Practitioner: …so normally what happens is the impulse goes from this node to that node to that node to that node and then what happens in MS this Myelin gets destroyed so the impulse cannot jump so easily just starts to disperse you know like you break this wire...with the plastic around it then you know you start to have symptoms and that's how it works. That's the cells from the blood they go to the brain and the spinal cord because that's where it happens and they start to attack and eat away the myelin see and then they as they eat away the myelin the nerve gets destroyed as well so you start to see weakness or pain or get tired and the areas where that happens we see these white spots and sometimes dark on the MRI.
In this segment, the practitioner is explaining to a patient who has recently been diagnosed how lesions form in MS and why they cause symptoms. While explanations that are primarily to provide knowledge may seem unrelated to health behavior or outcomes they are often used to help the patient make good health choices or convince a patient to undergo a particular course of treatment. As a case in point the example above was used to help convince a patient who initially wanted to only use natural medicine that the disease activity indicated on her MRI results suggested the need to use disease modifying medications.

Relationships among Dimensions of Explanation

Theoretically any combination of explanatory stance x mode of evidence x function is possible and in practice most of the possible two-way combinations (explanatory stance x evidence, explanatory stance x function, and evidence x function) occurred\textsuperscript{55}; see Tables 18, 19 and 20. However, certain combinations were far more frequent than others. The explanatory stances adopted seem to have differentially lent themselves to employing different modes of evidence. While, specific explanatory stance by evidence combinations were particularly well suited to different purposes. In this section we look at typical patterns used in constructing explanations.

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\textsuperscript{55} The only two-way combinations that did not occur involved the providing knowledge function which was found in combination with physical, design, mechanical, and authoritative but not with holistic, entitive, correlational, or pattern matching. The absence of certain combinations with this function is probably largely due to infrequency.
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**Table 18. Explanatory Stances and Modes of Evidence.**

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<th>Correlational Salient</th>
<th>Pattern Matching Categorical</th>
<th>Pattern Matching Experiential</th>
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</table>

**Table 19. Explanatory Stances and Functions.**
Figure 6 shows a tree diagram of all the modes of evidence used within the explanatory stance and all purposes of explanations using this explanatory stance and supported by particular modes of evidence. The numbers enclosed in brackets represent the frequency with which explanations were found on a particular branch.

It was common for explanations phrased in the physical stance to be supported by mechanical, correlational or authoritative evidence. Of these the mechanical was the most common. The physical explanatory stance is employed in scientific theory and by extension incorporated into the biomedical perspective. Accordingly, practitioners’ biomedical explanations (whether stated directly or recounted by patients) and patients folk scientific explanations often employed this combination. There was considerable variation in the sophistication of the biomedical model undergirding these explanations. The physical model in the first example below is both complex and sophisticated while the second example has a sparser physical model and more limited articulation of the causal mechanism.

Here it just shows you ...the neuron & the axon of the neuron & there's the myelin covering. So normally what happens is the impulse goes from this node to that ....what happens in MS this Myelin gets destroyed.... [practitioner]
Actually it started with my right leg. It went numb & I thought I had pulled a muscle.

Because the physical stance is privileged in biomedicine, many of these explanations cited sources with credible scientific and/or medical expertise. For the practitioners, and sometimes the patients, this meant supporting a statement by referring to scientific research. For example:

I guess there were studies in Canada that were showing that M.S. patients that...I guess they found a...a commonality between-uh between people with M.S. that their vitamin B levels were low, and-uh...or maybe if they weren’t low that if they elevated them either with taking vitamin B supplements, that it would help

The frequent use of correlations in the physical stance to some extent is probably a base-rate phenomenon; physical is the most common explanatory stance and correlational is the most common mode of evidence. But it may be more than that. The majority of the physical-correlational explanations involved uncovering the meaning of symptoms. Because most symptoms, at the very least, have some physical aspects it would make sense for people to connect them with correlated physical events. For example, one patient observed: “If I don’t get good sleep the next day I will have more M.S. symptoms.”

The intrinsically physical nature of symptoms probably also accounts for the frequent conjunction of the physical stance and the function of uncovering the meaning of symptoms. The other purpose for which the physical stance is most frequently used is to provide knowledge. Explanations of this type usually involve practitioners instructing
patients on some aspect of biomedicine and thus favor employing the same explanatory stance and mode of evidence preferred in biomedicine.
Figure 6. Modes of evidence and functions in the physical stance.
Explanations in the Design Stance

Design was the least frequently used explanatory stance and correspondingly has the most sparsely populated tree; see Figure 7. But, design explanations using the mechanical stance to explain man-made objects occurred frequently. One obvious way to account for the behavior and effects of a man-made object is by explaining how it accomplishes a function and/or how malfunctions in the object can account for undesired outcomes. The following excerpt in which a practitioner explains the differential effects of a medication shows this type of logic.

*If the disease is not so active with much inflammation ...they [patients] are not going to respond as well as somebody with a lot of inflammatory process going on, cause that’s where the medication is the best.*

This explanation addresses the functional success of a man-made object, in terms of the biological mechanisms by which it functions, in other words how the drug accomplishes its purpose.

Given the utility of the design stance for explaining the behavior of man-made objects it is not surprising that it was to assessments of treatment. However, the design stance could be used effectively for other purposes. In particular there was a case, from the session notes, in which the design stance was critical in creating a diagnostic explanation. In this instance, there was a question as to whether the patient had MS or not. The practitioner supported his explanation by reviewing all of the patient’s lab results, explaining how each test works, what the patients result’s were, and what her results suggest about the origin of her current symptoms. This is an interesting example
in that it articulates explicitly the way in which the practitioner uses the function of particular tests to reason about the origins of a condition.
FIGURE 7. MODES OF EVIDENCE AND FUNCTIONS IN THE DESIGN STANCE.
EXPLANATIONS IN THE HOLISTIC STANCE

Figure 8 shows how the holistic stance is used in combination with different forms of evidence and for different purposes. Explanations in the holistic stance most often were supported by correlations. The frequent use of correlations is in line with the relational nature of the holistic stance, which essentially entails drawing connections between disparate aspects of the environment. In addition, correlational evidence may be conducive to the construction of holistic explanations, which are idiosyncratic and tend to employ multiple variables making it difficult to posit specific causal mechanisms.

Authoritative support was used in interesting ways with the holistic stance. Unlike other explanatory stances, holistic explanations supported by authority frequently did not import as whole cloth an explanation from an outside source. Rather they actively connected information provided by an outside source with situation-specific characteristics to construct an explanation. For example the following participant connected external information to her own life circumstance to construct an etiological explanation: “I have heard & read that stressful situations can bring it on &-when I was having my first real symptoms I was in an extremely stressful situation with my job.”

Etiological understanding was the most common function of holistic explanations. To address disease etiology, people drew on a wide variety of factors often creating multiple explanations or extremely complex, multi-dimensional explanations. One pattern that was particularly common was for patients to focus on particularly dramatic and/or unusual incidents in their life, such as having a baby or fighting in war, and then connect these all encompassing events with the development of MS. For example: “I can go all day ... & tell you about my theories on that, but I don’t know. I mean we lived in
foreign countries & we lived in air force bases & you know they would be something on the base in lakes.”

The single holistic explanation constructed wholly by a practitioner is an unusual but notable use of the holistic explanatory stance. In this case, the practitioner explained to a patient what her treatment options were and described patterns of observed utility relative to the patient’s circumstances. What is unusual about this discussion is that in addition to drawing on physical factors for assessing treatment the practitioner also discussed the cost of the medications, how convenient they are to use, and the likelihood of insurance reimbursement. Thus with this explanation the practitioner does an excellent job integrating medical (indications as related to symptoms), adherence (convenience and cost), and bureaucratic (insurance) issues.
Figure 8. Modes of evidence and functions in the holistic stance.
EXPLANATIONS IN THE ENTITIVE STANCE

The tree diagram below, Figure 9, show the modes of evidence used with and purposes served by explanations in the entitive explanatory stance. Explanations in the entitive explanatory stance were most frequently supported by two modes of evidence: authoritative evidence and evidence based on pattern matching. Both these types of evidence are highly compatible with definitional nature of the explanatory stance. Explanations supported by authoritative evidence usually used a definition provided by an authority to explain an object, event, or circumstance that either is a component of the thing being defined or a corollary of the definition. Consider the following example: “He said it could have been fatigue & it could be probably his MS, cause it happened 2 days in a row”. In this explanation a patient explains one of her symptom, pain, by saying that the doctor defined it as part of fibromyalgia. Fibromyalgia is a syndrome of unknown origin characterized by pain, so to say that a disease that is defined by the presence of unusual pain explains why a person is experiencing pain is a tautology.

Entitive explanations supported by pattern matching paired characteristics of the explanandum with definitional properties of a class of phenomena that was either familiar as an abstract category or from personal experience. The target phenomenon could then take on the explanatory framework of the phenomenon type for which it is defined as being an exemplar. For example, during one clinical session, a patient asked about the side effects of a particular medication. The practitioner explained these issues by classifying the specific drug the patient was taking as part of a large category of drugs, which had the property of causing side effects described.
Diagnostic explanations frequently employed the entitive stance. Often times diagnostic explanations were phrased simply as a label defined by a set of symptoms and/or diagnostic test properties that in turn explained the experiences of patients with the symptoms and/or test results incorporated into the diagnosis. Take the following unusually extreme example of this type of explanation:

*He diagnosed the problem as a Dyskinesia, he thought Paroxysmal Dyskinesia.*

*That also I thought was kind of a silly diagnosis... I didn’t doubt the Dyskinesia, but it didn’t seem to me to be Paroxysmal.*

In this case, a patient who has consistently been having spasticity and trouble walking is given a diagnosis of paroxysmal dyskinesia (literally bursts of disrupted movement). He is frustrated because he agrees with the assessment that his movement is disrupted but this disruption is continuous rather than coming in bursts. Thus he sees this diagnostic explanation as largely descriptive (and slightly inaccurate) with little explanatory power. Individual symptoms were often explained using the entitive stance by attributing them to known conditions partially characterized by the presence of such symptoms.
Figure 9. Modes of evidence and functions in the entitive stance.
CONCLUSIONS

1. Overview of results

It was found that both patients and practitioners frequently used explanations in discussing MS. Practitioners were more likely than patients to provide explanations during clinical sessions, but patients did offer some explanations in clinical sessions and provided many more explanations during interviews.

The explanations offered had three distinct dimensions each of which had four levels. Explanations varied in terms of their explanatory stance, the conceptual world within which they were created. The most common explanatory stance was the physical in which explanations were phrased in terms of the physical state of the thing(s) being explained and relationships that are believed to govern the interaction of physical objects. The next most common explanatory stance was the holistic stance in which explanations were phrased in terms of the physical, social, and psychological environment of the thing being explained and experienced relationships within that context. The third most common explanatory stance was the entitive stance in which definitional properties of the elements in the explanation accounted for the thing being explained. The least common stance was the design stance in which explanations were based on the teleological nature of the thing being explained.

Explanations were supported using different modes of evidence. Correlational evidence, in which the explanation assumed a relationship between two or more phenomena, was the most frequently used form of evidence. The correlations suggested could be based either on temporal cues or connections between especially salient phenomena. The second most common form of evidence was authoritative evidence, in
which the explanation was supported by reference to an outside authority. Mechanical evidence, which supports an explanation by suggesting a specific causal agent, was the third most common. The least common form of evidence was pattern matching, in which the explanation was based on parallels between the thing being explained and a known class of phenomena.

The last dimension of the explanations found involved their function in the clinical context. By far the most common function of explanations was to help uncover the meaning of illness events. Explanations serving this function allowed the patient and/or practitioner to interpret the significance of global or specific events relating to MS. The second most common function of explanations was to help assess the efficacy associated with and/or side effects from current treatment or treatments being considered for the future. Diagnostic explanations were the third most common. And explanations purely to provide information were the least common.

Although the basic dimensions of explanations were similar for patients and practitioners, the specifics of how each dimension was used differed. I discuss what these findings suggest about the nature of explanations in chronic illness and especially the functioning of patient explanations along with practical implications for the clinical setting. Finally, I discuss theoretical implications of these finding for understanding of explanatory processes in natural settings.

Differences in Practitioner and Patient Explanations

The relative frequency with which practitioners and patients used each of the explanatory stances, modes of evidence, and functions has already been mentioned in the
results above. But, it is worth looking more extensively at some of the differences in how practitioners and patients explain illness.

*Explanatory Stances*

Patients made ample use of all of the explanatory stances except for the design stance, which they used much less frequently. It is likely this simply reflects limitations in the patient populations understanding of the functioning of medical tools such as medications and diagnostic tests that make it difficult to construct design based explanations. The vast majority (80%) of practitioner constructed explanations were in the physical and design stances. As discussed above, these stances are parallel to those endorsed by science and biomedicine and the practitioners’ use of them is in accord with their training.

Practitioners constructed very few explanations using the entitive stance, but patients created many entitive explanations, which were often supported by authoritative citation of practitioners’ judgments. This may suggest that practitioners are sensitive to the explanatory weakness of this stance and provide more sophisticated explanations. Whereas patients are satisfied with these explanations, because they assume the practitioner has a more sophisticated explanation underlying their judgment and thus that they themselves do not need one.

There was only one explanation by a practitioner in the holistic stance. This suggests a general tendency for practitioners to construct explanations completely in biomedical terms. Patients are more likely to combine biomedical elements with contextual elements to construct explanations. This biomedical versus holistic split may
principally be due to differences in knowledge base. Practitioners know a great deal about biomedicine but little about patient’s lives outside the clinic. Whereas patients know about their life circumstances but have limited technical knowledge.

**Modes of Evidence**

Practitioners supported their explanations primarily by using authoritative and mechanical evidence. As with the explanatory stances this is likely to be because these modes of evidence are privileged in biomedicine. Patients used all four modes of evidence. It is likely they drew more heavily on correlations and pattern matching because these modes of evidence can accommodate holistic elements and disparate experiences while still being useful for making sense of specific events.

**Functions**

Practitioners used explanations for all of the functions identified. Patients used explanations for most functions the exception being that they did not use explanations purely to provide knowledge. This is probably due to the differential between patient and practitioner in technical expertise that is an inherent part of the clinical setting.

Overall, practitioners used those forms of explanation that were most closely aligned with the formal explanatory paradigms endorsed in biomedicine. Sometimes, patients seem to adopt the biomedically endorsed notions of explanation that were used by the practitioners. Patients used this paradigm by repeating explanations from practitioners, accepting tautological explanations and constructing original explanations. In addition to, and sometimes in conjunction with, the physical, mechanistic explanations favored by practitioners, patients also created holistic explanations predicated on their
personal experiences. Whereas, there were many cases where patients adopted explanatory frameworks from practitioners, the practitioners did not move to integrate the holistic elements of patient created explanations. This imbalance points to an ontological disconnect between practitioners’ purely biomedical construction of illness and patients’ movement to understand illness in a combination of biomedical and holistic terms.

Implications for the Medical Domain

The ontological disparities between practitioners and patients have real implications for medical practices. Differences in ontology may complicate communication between practitioners and patients leading to a lack of common ground. Explanations phrased from one ontological perspective may be unsatisfying or even incomprehensible. In this data set there were cases where conflicting explanations led patients to feel dissatisfied with their care sometimes prompting them to find new medical providers. Much of this dissatisfaction may come from cases where holistic elements that are part of the patient’s explanatory framework are not addressed by the practitioner’s more restricted ontology.

Similarly, this study found that patients often either adopted explanatory frameworks from biomedicine, either as provided by practitioners or from patient education materials. In some cases, they simply drew on these explanations as a full explanatory framework either by internalizing them or referring to them in ways that outsourced the need for fully articulated explanations. However, in other cases they actively connected portions of the explanation to holistic elements in their own lives. Practitioners and the authors of educational materials need to be sensitive to the
importance of the connections between biomedical and holistic elements so that they can present information in a way that facilitated productive integration.

Theoretical Issues

The functioning of explanatory stances and the use of evidence in this context have intriguing parallels to and differences from models posited in theoretical and empirical research. These similarities and differences throw light on the relationships between the nature of explanations, cultural influences, and specific contextual factors. To look at these issues, we will start by looking at explanatory stances and then move on to modes of evidence.

Explanatory stances in real-world environments

Theoretically explanatory stances are ontologically complete and coherent; in practice they are often fragmentary and inarticulate. Some explanations especially those by practitioners to provide patients with knowledge of the disease were clear, consistent, and appeared to be based on a fully integrated ontology. Others were scattered drawing on an apparently poorly integrated system or swinging dramatically between multiple explanatory stances. Finally, two of the explanatory stances found in this data that were not part of Dennett’s original proposal and are for different reasons inherently formally problematic. The entitive stance is problematic because it entails circular logic, while the holistic stance is problematic because it is fundamentally subjective. This subjectivity does not necessarily decrease the value or substance of the explanation but it does make the ontological world within which the explanation is phrased inaccessible to an outsider.
So why do people formulate these incoherent explanations? One reason is that in practice human beings have limitations on their knowledge and information processing capacity. For example, the most commonly used explanatory stance in this study was the physical stance, but we know that most people have trouble fully explaining even very simple physical phenomena (CITE something on how people can’t explain why things role down inclined plains). And the kinds of higher level anatomical relations involved in MS are substantially more complicated, posing problems for even those with substantial training (Chi – paper on med students understanding of heart-lung connection). So, even in an explanatory stance that is theoretically well articulated people create inarticulate explanations. One way that these explanations arise probably relates to the illusion of explanatory depth discussed in the introduction, the fact that people think they can explain something in much greater detail than is really the case (Keil, YEAR). In this study, this type of process might well have been functioning in explanations where that began as confident statements and then deteriorated into fragmentary ones.

Another reason for the fragmentary nature of many of the explanations found may be that many of the explanations offered are not supposed to fully account for some phenomenon. Given the social nature of illness, people may not feel a need to have a fully articulated understanding of why something occurred, but they want to know that such an explanation is available should they wish to explore it. In this kind of distributed system skeletal explanations can act as signposts to larger explanations that could be fully explored if desired. The orienting function of explanations can occur either directly, as in many of the authoritative explanations, or indirectly. In the later case, the explanation
may appear ontologically impoverished while using language to allude to culturally available knowledge. For example, a patient may discuss trends in his family health history briefly mentioning that MS may be a ‘genetic thing’ without elaborating any causal mechanism. Even if the patient knows nothing about genetics the use of this vocabulary strengthens the explanation by invoking a body of knowledge, which is assumed to be available to both explainer and listener even if neither has immediate access to it. Similarly, sparse explanations may act as the tip of an iceberg of more sophisticated explanations that the explainer either cannot or does not choose to put into words. These parsimonious explanations may be the product of efforts to articulate or formalize tacit, non-verbal understanding. This kind of cognition has been well documented in experts, and may be a driving force behind poorly constructed practitioner explanations (Klein, 1999). For patients explanations that are fully constructed may remain largely unspoken for fear of censure. The distance between practitioners and patients in terms of power and expertise is vast. Patients may feel it is not their place to suggest an explanation or may worry that their explanations will appear naïve prompting them to suggest explanations in a hesitant, fragmentary fashion. Similarly, patients may feel uncomfortable openly espousing explanations that contradict accepted medical explanations. Many of the patient-participants in this study, for example, prefaced explanations about why they believed they developed MS by saying that no one knows the etiology of MS. Stating that MS was unexplained seems to have served as an apology for distancing the participant from any inadequacies of the subsequent explanation.

Both explanatory outsourcing and the prevalence of fragmentary explanations suggest that in the real world one of the defining characteristics of a good explanation is
not just its breadth or epistemic justification but its fungibility. As participants in this study constructed explanations they drew on a culturally defined pool of explanatory resources. How these resources were used depended upon the participants abilities in terms of accessing appropriate explanatory frameworks and applying them to a particular set of circumstances. When an explanatory framework either could not be access sufficiently to fully match the level of explanation needed or contradicted other culturally prevalent premises (e.g. that MS has no known etiology) the explanation became fragmentary.

Function as a determinant of explanatory adequacy

The adequacy of explanations was also functionally determined. In particular different functions prompted the use of different explanatory stances. In some cases the function of the explanation did not require a formally complete explanation. Notably, diagnostic explanations were often entitive. These explanation were tautological and therefore epistemologically useless. But they were also highly functional in the clinical context. The might not formally explain anything, but they provided a culturally constructed label that brought the explanandum into a known realm and hence created a culturally predefined problem space with an accompanying set of explanatory resources.

Explanations related to treatment decisions also involved placing the explanandum in a known problem space. These explanations were very grounded in specific concrete goals and often utilized a design stance. Treatment decisions focused on matching the utility of a limited set of tools to particular, desirable outcomes. The explanations served to ground an abstract set of teleological properties with a concrete treatment situation.
Explanations involve in sensemaking varied depending upon the specific focus of explanation. When making sense of symptoms participants used a variety of stances often using entitive or physical explanations to match specific symptoms to culturally available explanatory frameworks for MS. But when addressing etiology, patients used holistic explanations. This may be related to the fact that there is no culturally accepted etiology for MS, so patients drew on their personal experiences to create original explanations.

Both the limitations of the explanations constructed and the connection between how explanations are constructed and the functions they serve point to the fact that real world explanations are contextually embedded. The explanations in this study were not created to stand alone as epistemologically justified constructs. Rather, they were constructed to be adequate for a particular situation where actors in culturally constructed roles used the explanations for a particular purpose. Similar constraints probably function in other natural environments such that the quality of the explanation is not the degree to which is formally complete but the degree to which it fulfill the purpose for which it was created.

**Code Definitions**

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<tr>
<th>Code</th>
<th>Definition</th>
<th>Example</th>
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<tr>
<td><strong>Explanatory Stances</strong></td>
<td>Physical Explanations predicated on the physical state of the object or system being explained and the explainer’s understanding/knowledge of the laws of nature</td>
<td><em>..it started with my right leg. It went numb &amp; I thought I had pulled a muscle.</em></td>
</tr>
<tr>
<td>Design</td>
<td>Explanations predicated on <em>Enhancing lesions it means when they use the</em></td>
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</tr>
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<td>Modes of Evidence</td>
<td>Mechanical</td>
<td>Explainations attributing an outcome to a specific causal agent with an explicit or implied process whereby the agent produces the outcome</td>
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</tr>
<tr>
<td>Correlational</td>
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<td>Explainations where the person providing the explanation assumes that two or more events are related to</td>
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<td>Holistic</td>
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<td>The only thing I can think of for me, routine is very important In the summer, I don’t have a routine although they say heat can affect M.S. ...or whether it was the stress from the whole school year &amp; I just kind of hit a wall ...</td>
</tr>
<tr>
<td>Entitive</td>
<td></td>
<td>I had one of my worst attacks ... when I had a sinus infection &amp; bladder infection,... because they took, you know, a lot to get rid. You [have] them Pseudo-Exacerbations when you’re sick.</td>
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<td></td>
<td></td>
<td>If the disease is not so active with much inflammation ...they [patients] are not going to respond as well as somebody with a lot of inflammatory process going on, cause that’s where the medication is the best.</td>
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<td></td>
<td>If I don’t get good sleep the next day I will have more M.S. symptoms….</td>
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<td></td>
<td></td>
<td>the teleological nature of that which is being explained contrast the blood not go to the area which is abnormal where the demyelization is. Because if the contrast goes there it means that the area of demyelization is new... in the studies it shows that the Betaseron were better to decrease the number of these lesions than the Copaxone.</td>
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<td></td>
<td>The only thing I can think [caused the flare up] of for me, routine is very important In the summer, I don’t have a routine although they say heat can affect M.S. ...or whether it was the stress from the whole school year &amp; I just kind of hit a wall ...</td>
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<tr>
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<td></td>
<td>I had one of my worst attacks ... when I had a sinus infection &amp; bladder infection,... because they took, you know, a lot to get rid. You [have] them Pseudo-Exacerbations when you’re sick.</td>
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<td>If the disease is not so active with much inflammation ...they [patients] are not going to respond as well as somebody with a lot of inflammatory process going on, cause that’s where the medication is the best.</td>
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<tr>
<td></td>
<td></td>
<td>If I don’t get good sleep the next day I will have more M.S. symptoms….</td>
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one another and suggests that one of the two events was instrumental in facilitating or causing the other

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<tr>
<th>Authoritative</th>
<th>Explanation that have no specific facts presented as supporting evidence and instead are supported by attribution to an outside informant</th>
<th>I have heard &amp; read that stressful situations can bring it on...</th>
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<tr>
<td>Pattern Matching</td>
<td>Explanations where key features of the target phenomenon are seen as corresponding to features of some known class of phenomenon</td>
<td>I thought it might have been lupus, because I know someone who has lupus, I know 2 people who have lupus and their symptoms were so similar to what I was feeling.</td>
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</table>

<table>
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<tr>
<th>Functions</th>
<th>Diagnosis</th>
<th>Explanations that explain an entire set of symptoms in light of the patient’s current experiences, environment, and personal and medical histories</th>
<th>I had this horrible headache &amp; it was you know it was just so wet outside, very-very wet, it had been raining forever. I really felt that at the time that it probably was sinus.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing Treatment</td>
<td>Explanations furthering the discussion of particular medications or therapies that are currently being used or are being considered for use.</td>
<td>When I first started taking it [Topomax], it was helping &amp; I think my body got immune to it.</td>
<td></td>
</tr>
<tr>
<td>Uncovering Meaning</td>
<td>Explanations used to create orderly meaning out of large questions, such as why this happened to me?, and small questions, such as what usual sensations in the body signify?</td>
<td>I can go all day ... &amp; tell you about my theories on that, but I don’t know. I mean we lived in foreign countries &amp; we lived in air force bases &amp; you know they would be something on the base in lakes...</td>
<td></td>
</tr>
<tr>
<td>Providing</td>
<td>Explanations used to give</td>
<td>Betaseron is based on</td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>basic background information to patients who are relatively newly diagnosed or who are beginning a new treatment</td>
<td>interferons, which are a naturally occurring part of the body. These are just putting more in.</td>
<td></td>
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Appendix G: Illness Narratives

Practitioners

Despite its scientific focus, medicine as practiced is not only an empirical but also an interpretive activity. Practitioners use narrative on a daily basis in the clinic (Mattingly, 1998). Historically, the significance and use of narrative in medicine has been minimized, but recent trends have moved towards a more robust form of narrative medicine (Charon, 2001 & 2006; Mullen & Ficklen, 2006). While this chapter focuses on patients’ narratives, these more practitioner oriented uses of narrative are worth reviewing both as background on the functioning of narrative in the clinical context and as a source of insight into the way illness narratives are generally viewed by academics and medical practitioners.

Narrative in the clinic

An easy way, I find, to think about the functioning of illness narratives in the clinical context is to think of a narrative as having a prototypical life cycle. The narrative enters the clinic in the form of a story told by the patient to a healthcare practitioner during the first portion of the appointment while the practitioner is taking the patient’s medical history. The interaction between the patient and practitioner will lead to elaboration of some aspects of the narrative and the (re)interpretation of others. After the appointment, on the practitioner’s side, the narrative is recorded as part of the notes and the patient’s chart. If the case is particularly interesting or the patient will be seen by other practitioners, some form of the narrative will be retold by the practitioner who saw the patient to other medical professionals. While on the patient’s side the narrative is altered to include the interpretations, results, and implications from the clinical session.
In cases of chronic illness the narratives recounted in a given clinical session will only be part of a larger narrative encompassing the illness as a whole.

Looking more carefully at research concerning each stage of the narrative lifecycle, the first stage of the lifecycle – narrative presentation as part of a medical history – has been the most discussed. Patients’ are inclined to use a narrative format to relay their illness experiences; while practitioners tend to take control of the history taking process by asking questions. This frequently leads to patients’ narratives being disrupted and/or curtailed by new practitioner questions, pushing both the narrative and the contextual issues incorporated in it to the side (Haidet & Paterniti, 2003). Recently this mode of interaction has been changing. There is now greater understanding of the personal value that telling their story has for patients and the potential informational functions of the stories for practitioners (Eggly, 2002). As a result, medical schools are beginning to train their students to exploit rather than disrupt patients’ narratives during history taking. Haidet and Paterniti (2003) provide a good side by side comparison of traditional question focused and newer narrative focused approaches to taking a clinical history.

After the appointment, the practitioner will may retell the patient’s narrative in a formalized written account noted in the patient’s chart. Charts are a repository for the recording of patients stories about specific instances and practitioners’ stories about patients. The chart as a whole comes to serve as a narrative of the patient’s clinical history. Narrative construction in patients’ charts can involve either individual or communal effort (Hunter, 1991). Some charts are the work of a single individual, as for example when a family practitioner is both the primary author and reader of the chart. In
other cases, as in the hospital setting, many different practitioners may be involved in composing and making use of a chart.

While at first glance, a medical chart may not seem like much of a story, in fact charts fit the characteristics of many models of narrative. For example, Atkinson (1995) describes how medical charts correspond to Labov’s (1972) classical model of narrative structure. According to Labov’s model, there are four elements that are essential to narrative and two that are optional. Narratives begin with an optional abstract foreshadowing and summarizing the events of the narrative. In medical terms this corresponds to the initial notation frequently found in charts of the basic classification of the patient’s case (e.g. Mr Jones has type 2 diabetes with vascular complications). The next element is an orientation that describes the story’s essential persons and settings. In the medical context, this is usually a brief discussion of the personal characteristics of the patient and her presenting problem. The narrative then moves on to the element of complication, which involves the basic actions and events of the narrative. In medicine this is usually the most extensive portion of the narrative, including both past medical history and a summary of the patient’s story about their current complaint. Evaluation is the fourth element in Labov’s model, presenting the narrator’s point of view or reason for telling the story. In medical charts, the evaluation may be implicit or explicit. Evaluation can involve a moral judgment of the patient (e.g. persists in high risk behavior) or a prognosis (e.g. appears to be a poor candidate for chemotherapy). Often the evaluation will be combined with the fifth element, results. The results section presents the outcome of the narrative and in medicine usually involves a clinical diagnosis and the presentation of a treatment plan. The last optional element of Labov’s
model, a coda summarizing the narrative, is not usually found in medical charts because these tend to represent ongoing cases for which there is no definitive conclusion. In some cases, a coda may be present in the form of an autopsy report or discharge notation.

One way for narratives to be shared amongst practitioners is via the patients chart. But it is also common for narratives to be shared informally as stories practitioners tell one another about their work experiences. The informal use of anecdotes about patients and other practitioners can serve a variety of functions, notably: sharing information, rehashing treatments gone awry, establishing norms, moral judgment, and emotional expression (Cassell, 2004; Hunter, 1991; Mattingly, 1998; Morgan-Witte, 2005). Informal narratives are often used as a way for practitioners to share information that is considered relevant but does not fit into the formal communication structure (Morgan-Witte, 2005). Narratives of this type include stories illustrating aspects of the patient’s personality or communicating critical contextual information, as for example when a patient is engaged in an ongoing conflict with a family member about some element of treatment (Cassell, 2004). Another informational function of narratives is their use in the discussion of cases that are difficult or which have resulted in a negative outcome. When practitioners are struggling with a difficult case, they tell one another stories about similar instances as a way of increasing their understanding of the current situation (Hunter, 1991). Similarly, when the case ends in an undesirable outcome, such as iatrogenic injury or death, practitioners may retell the story of the incident looking for places were acting differently might have prevented the negative outcome (Morgan-Witte, 2005). Finally, informal narratives are told as a way of coping emotionally with the stress is involved in healthcare (Morgan-Witte, 2005). When narrative is used as a
way to reanalyze difficult cases or increase emotional coping the narrative focus can change. Rather than just being about the patient, the practitioner becomes the protagonist in the narrative. The auditor is asked to adopt the practitioner’s perspective and either see if they would have acted similarly or provide sympathetic support.

At a more general level, specific anecdotes can serve to establish norms for patient and professional behavior (Morgan-Witte, 2005). Stories about unusual or aberrant cases are often used in this fashion, as negative examples to illustrate norms via discussion of instances of deviation. The moral function of narrative is closely related to its use in establishing norms. Often times, narratives illustrating aberration will include an implicit (or explicit) moral condemnation (Cassell, 2004; Mattingly, 1998). For example, Morgan-Witte (2005) describes a narrative that was retold a multiple times in an emergency room setting. A patient had been injured when a tree, which he had been standing under while drinking beer, was hit by lightning. The paramedics that brought the man in called in to tell the hospital about the patient and relayed details of the accident. In this case part of the value of the story was in the unusual circumstances surrounding the injury, but in its retelling the emergency room staff had labeled the patient as a drunk prior to his even entering the hospital. Although the effects of such moral stories have not been documented, it is likely that they affect the type and quality of care provided.

*The Rise of Narrative Medical Training*

Until quite recently, few attempts were made to actively use the power of narrative to improve medical care, but this is now changing (Charon, 2001a; Greenhalgh, 1999; Launer, 2003). Narrative medicine advocates a more holistic approach to patients,
illness, and the practice of health care. As Rita Charon (2001b) defines it, narrative medicine is “medicine practiced with the narrative competence to recognize, interpret, and be moved to action by the predicaments of others.” In essence, narrative medicine advocates adding an empathetic, hermeneutic approach to specific cases of illness to the standard scientific, technical approach to disease. [One thing that narrative does particularly well is emphasize the quality of life consequences of the complaint.

Practically speaking, narrative medicine can refer to a wide variety of activities. One type of narrative medicine involves advocacy of increased attention by practitioners to patient narratives. This may involve approaching clinical encounters in a way that is accepting of and encourages patients’ use of narratives when describing their experiences and symptoms (Eggly, 2002; Greenhalgh & Hurwitz, 1999). Or, it may take the form of increased use of stories and literary works by patients in medical education (Chen, 2008; Swenson & Sims, 2000). Another type of narrative medicine involves the creation of narratives by practitioners to express their own experiences. Such writing may take the form of a self reflective journaling with no intended audience or it may be intended to provide insight into the experience of providing medical care either for the benefit of other practitioners or in popular accounts to inform the public (Charon, 2001a; Frank, 1997; Gawande, 2002; Groopman, 2008). While narrative medicine of all these types has made great progress in adding a more phenomenologically sensitive element to health care there is still little work on narrative as a either a mode of cognition or a tool for use in cognitive problems such as decision making.

Patients
In contrast to the relative scarcity of work on practitioner narratives, a great deal of research has been done on patient narratives, both as a general form and as they are told about specific diseases (Harter, Japp, & Beck, 2005; Hyden, 1997; Murray, 2000). Study in this area has looked at the construction of narratives both as an artifact of cultural contexts and as a personal expression (Crossley, 2000; Frank, 1997; Good, 1990). Culturally focused studies have generally looked at the resources supplied and pressures put on patients as they construct narratives of their own illness (Garro, 1994). Personally focus studies have looked at narrative as an emotional outlet and a tool for identity formation (Ochs & Capps, 1996).

*Illness Narratives in Cultural Context*

From a cultural perspective, individual narratives are instances of larger societal understandings of disease. One way of looking at this is to see cultures as having a type of template for how stories of illness in general and of specific illnesses are supposed to go (Good, 1990). For example, Garro (2000) looked at the narratives Anishanaabe tribe members with diabetes told about their illness. She found that as a community the Anishanaabe believed that a variety of illnesses including diabetes were a result of contact with ‘white men.’ Individual narratives mirrored this wide reaching cultural narrative. In one representative story, a tribeswoman describes being diagnosed with diabetes in a standard medical clinic and being given normal [Western] treatment recommendations involving diet and medication. When following these instructions did not produce an immediate effect she rejected both modern medicine and processed foods switching to a traditional diet and set of explanations for illness.
As the example above illustrates, cultural narratives of illness can not only affect the rhetoric in which illness’ experiences are described but also the patients understanding of the illness itself and choices of treatment. At the most basic level, cultural narratives can affect the legitimacy of a patient’s claim to being ill. This is especially the case for illnesses that are seen as marginal or are hard to define (Garro, 1994). In these cases, how the social narrative about the disease is constructed may determine whether the patient is seen as malingering or suffering legitimately. Even in well understood diseases, cultural narratives about the disease affect how patients understand their condition and the forms of treatment that they see as normative and desirable. For example, Wong and King (2008) have traced how stories told about breast cancer in the United States affect women’s understanding of their own degree of risk and use of treatment if diagnosed.

**Personal Illness Narratives**

Research looking at illness narratives from a personal perspective typically regard illness as a disruptive event within a person’s life history (Hyden, 1997). The challenge is to come to terms with this disruption emotionally and to adapt one’s sense of self in a way that accommodates the disruption (Crossley, 2000; Frank, 1995). Because this project is not focused on emotional aspects of the illness experience and because research in this area is far too expansive to adequately cover, it is simply worth noting that the vast majority of illness narratives incorporate an emotional aspect (Kampainen, Bartels, & Veach, 2007).

One way to think about the relationship between the narrative and identity during a serious illness is to consider how illness presents a challenge to the two aspects of
identity posited by the eminent narrative theorist Paul Ricoeur. Ricoeur (1992) suggest that identity has two components *memete* (Selfhood), which is a person’s individual self definition as distinct from others, and *ipseite* (Sameness), which is a person’s sense of coherent identity over time. In different ways, both of these aspects of identity are challenged by serious illness and can be addressed through narrative.

Selfhood is challenged when an illness causes the patient to be dehumanized in their own eyes and or in the eyes of others. Two of the major ways in which this happens are through prejudice and through statistics. Prejudice often involves a negative culturally pervasive narrative that devalues the personhood of those against whom the prejudice is directed. When an individual joins the group against whom the prejudices are held the cultural narrative may conflict with their own sense of self and require them to create a new narrative to resist the prejudice (Bamberg & Andrews, 2004; Ochs & Capps, 1996). The disability rights movement provides a good example of this sort of narrative resistance. Prior to the disability rights movement, the dominant cultural narrative held that in becoming disabled and a person also became socially valueless (Fleischer, Zames & Zames, 2012). People were not expected to work or maintain normal social relationships. The disability rights movement has strived to replace this narrative with one that argues that people with disabilities are equally valuable and capable of carrying on normal social roles; they simply have a different range of functioning. An extension of this narrative is that changes in the way society structures its institutions is capable of eliminating the barriers to normal activity that people with disabilities face (Fleischer, Zames & Zames, 2012). The pervasive use of statistical procedures in medicine can also pose a challenge to selfhood. Modern medicine is
largely based on studies that established norms that can be generalized across large populations, thereby minimizing the significance of unique characteristics of the individual patient. Many patients have difficulty with this standardization and use narrative as a way to connect the medical perspective with their unique attributes and personal histories (Brody, 2003; Kampainen, Bartels, & Veach, 2007).

The sameness aspect of identity involves the creation of a sense of continuity of personhood across time. As such, it is highly compatible with the narrative format. As was noted in the discussion of the nature of narrative, one of the defining attributes of narrative, according to most theories, is their assumption of a temporal aspect (Polkinghorne, 1988; Ricoeur, 1988). Temporality is critical to the relationship between illness narratives and personal identity (Crossley, 2000). One of the primary uses of personal narratives is to create a coherent sense of self across time and circumstances. As Ochs and Capps (1996) describe it “We use narrative as a tool for probing and forging connections between our unstable, situated selves. Narrative activity places narrators and listeners/readers in the paradoxical position of creating coherence out of lived experience while the same time reckoning with its impossibility.” The experience of serious illness shatters this sense of continuity.

Serious illness and can radically change a patient’s sense of his own abilities, relationships, activities in the world, and expectations for the future (Brody, 2003; Reissman, 2004). This causes a discontinuity between a patient’s understanding of his life history leading up to the illness event and his present experiences and modified expectations for the future. The specific nature of this discontinuity in the type of narrative used for coping with illness can vary. Arthur Frank (1993) has discussed three
kinds of illness narratives involving self change. In some cases, the narrative entails a revision of the patient’s understanding of himself prior to the advent of the illness. In these narratives, the patient describes how the illness has prompted him to discover resources that he already had but of which he was unaware. Alternatively, the patient may accept the disruptive nature of the illness but interpret it as a positive catalyst for change. In these narratives, the patient describes the illness is allowing him to discover the person he may become. Finally, some illness narratives are what Frank has termed “cumulative epiphanies” in which the narrator has been living with the illness for an extended period of time, sometimes from birth. The narrative centers on how the long-term development of the narrator’s identity has been inextricably tied to his illness experiences.