TWO VIEWS OF AGENCY IN
PATIENT ADVOCATES' PROBLEM-HANDLING WORK:
STORYTELLING AND RULE USE

by

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Abstract

Patient advocates are hospital employees who handle the non-medical problems and complaints that patients and their families experience while receiving care in hospitals. Using qualitative data from interviews and shadowing at teaching and Veterans Health Administration (VA) hospitals, this dissertation develops two accounts of agency in patient advocates' problem-handling work. First, my analyses suggest that patient advocates are organizational storytellers who construct accounts that enlist the participation of others to resolve patient and family members' problems. I identify several relational practices that patient advocates use to accomplish their problem-handling work. Second, the analyses also suggest that patient advocates draw on organizational rules to construct legitimate paths of action for patients, families and staff in hospitals. Four patterns of rule use emerged, but in different frequencies across teaching and VA hospitals. The different institutional logics in the two hospital types help explain the variation in rule use practices, in that they supply guidelines for the kinds of rule use patient advocates may creatively employ within an organizational setting. This portrait of work is fundamentally relational, in the sense that storytelling and rule use occur primarily through interaction with others. Through these relational practices, patient advocates are able to effect small changes within their respective hospitals. In addressing the work of patient advocates in this way, the dissertation contributes to research on work, problem-handling roles, and agency.

Chapter 1

Introduction

"It's important to understand the technicalities of the work because it's like we have a credibility gap. It's like a dance. We're not PhDs, we're not doctors, we're not nurses, we're not administrators, we're staff. Once they understand that we are here to help, usually they come around. But we don't want to escalate the patients, and we don't want to alienate the staff. It's like a dance - sometimes we're dancing on hot coals. And some days the patient will hang up on you, and the so-called health care professional does the same thing, and then we're really the monkey in the middle."
Patient Advocate, Heartland Teaching Hospital

"Tom just called me. He wants to see me. He has a whole new slew of problems. He's really mad about the mental health consult. You know, I really don't know what to do. I don't know what I'm going to say."
Patient Advocate, Reveille VA Hospital

"If you hurt your feelings, come to us; if you hurt your body, go to Risk [Management]."
Manager, Heartland Teaching Hospital Patient Advocate Office

Patient advocates are hospital employees who handle problems related to care and service that patients and families experience while in the hospital. Their specialty is not medical mistakes, a topic of increasing scholarly and popular interest (Gibson & Singh, 2003; Kohn, Corrigan, & Donaldson 2000; Ramanujam & Rousseau, 2006). Instead, patient advocates specialize in handling the feelings, concerns, challenges, complaints, grievances, and, I argue, the dignity of patients, families and hospital staff who populate the complex organizational world of hospitals today.

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The quotations that open this chapter point toward a number of themes that I will develop in the dissertation – the work of problem-handling, a sense of ambiguity and "in-between-ness" coupled with a need to act, and the centrality of social interactions. Each of these themes builds on a corresponding set of literature that I review in this introductory chapter. Overall, this dissertation draws on these bodies of research to elaborate a theory of individual agency at work through a focus on the problem-handling role of patient advocates.

More broadly, this dissertation relies on the assumption that understanding peoples' everyday work lives is important and valuable. It is of theoretical import because our understanding of the concrete activities and interactions that comprise our everyday work lives are the building blocks on which theories of organizations and organizing are built (Barley & Kunda, 2001). It is valuable according to an epistemological assumption that posits that understanding a person's thoughts, feelings and behaviors situated in social context can provide insight into how we simultaneously create and are created by our social worlds. Thus, this dissertation has drawn inspiration, knowledge and approaches from several sources, including: phenomenological studies of work (Benner, Tanner, & Chesla 1996; Zuboff, 1988); organizational researchers and sociologists who study the experience of work (Hochschild 1983; Hodson, 2001; Perlow, Gittell, & Katz 2004; Rafaeli, Dutton, Harquail, & Mackie-Lewis, 1997); new institutional theorists' focus on how individuals work within the constraints and opportunities provided by organizations (DiMaggio & Powell 1991; Fine 1996; Heimer, 1999), and especially the recent efforts within this community of scholars to understand the role individuals play in institutional change (Barley & Tolbert 1997; Dacin,

Goodstein, & Scott 2002; Fligstein, 2001; Reay, Golden-Biddle, & Germann, 2006; Seo & Creed 2002).

The outline of the dissertation is as follows. In the first chapter, I offer a general introduction to the literatures that I engage in this dissertation – work, problem-handling roles, and agency. I then introduce the research question that guides the dissertation as a whole, and provide a brief overview of the dissertation. In the second chapter, I provide a detailed description of the case study research design and methods that organized my data collection. I also provide an overview of the data analysis.

Next, I present detailed accounts of patient advocates' work in three chapters. In Chapter 3, I address the role's historical and professional development, its place within the larger structure of hospitals, its occupants, and the kinds of problems the patient advocates in my study handle. This chapter sets the stage for the two chapters that follow. In Chapter 4, I develop a theoretical account of patient advocates' problem-handling work as a process of organizational storytelling. I suggest that the current ways we have of understanding problem-handling work, including boundary spanning, emotional labor, impression management and institutional theory, are limited because they cannot account for the ambiguity in which patient advocates work. In Chapter 5, I compare how patient advocates' work differs across two organizational contexts, teaching and Veterans Health Administration (VA) hospitals. In both types of hospitals, I find that patient advocates draw on rules to handle problems. However, the two kinds of hospitals have distinct institutional logics that shape how rules are used. Both Chapters 4 and 5 are based on the same set of data, but they are meant to be free-standing empirical contributions.

In the final chapter, I look across the dissertation and draw general conclusions about what this dissertation can offer us about the work of problem-handling roles and individual agency at work. I also suggest limitations of the dissertation and directions for future research. In the next section, I describe the research question that motivates the dissertation.

Research Question

My main interest in studying patient advocates is to answer the question: *How do patient advocates, whose work, role, profession and interactions are often ambiguous, exercise agency in handing problems in hospitals?*

One of the characteristics of patient advocates' work is that it is steeped in multiple forms of ambiguity. I define ambiguity as a lack of clarity, which may arise from "general diffuseness, abstractness or fuzziness in understanding, or it may derive from a multiplicity of understandings" (Meyerson, 1994:632). Research suggests individuals are particularly likely to be agentic in ambiguous contexts (Griffin, Neal, & Parker 2007) because they feel less pressure to act in a prescribed manner and because individuals have a motive to reduce uncertainty (Grant & Ashford, 2008). There are several characteristics of patient advocates' work that make it ambiguous.

First, patient advocates are employed by hospitals, which are a type of caregiving organization (Kahn, 2005). As caregivers, patient advocates' core task of *taking in* a patient or their family members' needs is steeped in ambiguity. As Kahn (2005:15) describes, "Patients may know that they need specific operations or medication but not that their fears might disable them from following courses of treatment…The range of such needs, many of which exist beneath the surface of awareness, are crucial to

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understand if the caregiving relationship is to be effective as the core technology of the work." Thus patient advocates' everyday interactions require working through and making sense of the ambiguous needs and problems of people seeking care from the organization and its members. Acting in spite of a problem's ambiguity is a requirement of their role.

Second, patient advocates' experience of ambiguity may be heightened by the professional status (or lack thereof) of the patient advocate role. Members of a profession receive extensive training in a profession's rules through training, apprenticeship, and ongoing education (DiMaggio & Powell 1991; Van Maanen & Barley, 1984). This training includes learning an abstract body of knowledge that members skillfully apply to specific cases (Abbott, 1988). Members follow these rules, in part because they acquire legitimacy by adhering to the conventions of the profession (Meyerson, 1994). However, as I describe in Chapter 3, patient advocates lack a strong professional identity. Job titles vary across hospitals, indicating ambiguity in how the role is designed across hospitals. They are not widely known outside of medical contexts, and sometimes even within the hospitals that employ them. Because patient advocates lack a well-developed professional role, they have not been socialized to adhere to a set of rules or to strive for a particular set of expectations associated with successful role performance.

Third, patient advocates' interactions with others, including both fellow hospital employees and patients and their family members, can be equivocal. It is not unusual that patients and their families do not know whether they can trust the patient advocate because they are employees of the hospital. At the same time, fellow employees assume patient advocates are "out to get them." As one patient advocate vividly described, staff

members "scatter like roaches" when he arrive on units. Indeed, studies report that patient advocates experience a conflict of interest between their obligations to protect the interests of their employing organization and to help patients and families (Charters, 1993; Martin, Heyworth, O'Brien, & Tipton 2006). This conflict of interest means that ambiguity infuses many of their interactions with others.

General Introduction to the Literatures

This dissertation is built on a foundation of three interrelated literatures, the study of work, problem-handling roles and individual-level agency. There is a vast amount of literature on each of these topics across a number of disciplines. Instead of providing a comprehensive review, the purpose of this section is to highlight some of the current questions and tensions within each of these literatures and sketch how a study of patient advocates can be used to contribute to these literatures.

Contemporary Research on Work

In recent years, there has been a renewed interest in the concrete activities and interactions that comprise work lives, in part because of the profound changes in organizations and the economy as a whole (Kalleberg, 2000; Smith, 1997). Connecting these macro-level changes to the detailed study of work is important for both theoretical and practical reasons. Theoretically, the changes challenge existing theories of how work is accomplished (Barley & Kunda 2001; Morrill 1991; Perlow 1998; Powell 1990; Yan & Louis, 1999; Zuboff 1988) and how organizing processes occur (Brown & Duguid 1991; Kellogg, Orlikowski, & Yates 2006; Orlikowski 2002). Moreover, research on work can help people understand their rapidly changing worlds of work.

While there are many different ways that research on work has developed, I focus on two themes. First, with organizations no longer offering lifetime employment, researchers have studied the new ways in which individuals are bound to organizations (Bartel & Dutton, 2001; Blatt & Camden, 2007; Rousseau, 1998) and examined how individuals structure their work in temporary organizations or when they are self-employed (Ashford, George, & Blatt 2007; Kellogg, Orlikowski, & Yates 2006). The greater ambiguity in the relationship between worker and organization has provided the impetus for new research directions. This dissertation complements the existing research of how work is accomplished under conditions of ambiguity, but with a study of role that is firmly planted within a large, complex organization.

A second theme in this literature has been an increased focus on workplace relationships. One reason for the growing interest in this topic is the increase in the number of jobs in the service sector, in which interactions between organizational employees and customers are a central focus (Hochschild 1983; Kahn, 2005; Leidner, 1993) At the same time, organizations are increasingly structuring their work around teams (e.g., Ancona & Caldwell, 1992; Ancona & Isaacs, 2007) and networks (e.g., Hansen, 2002; Powell, 1990), and organizations are placing an increased emphasis on employee involvement and empowerment (Hodson, 2001), all of which point towards growing interest in coworker relationships and interactions.

This dissertation builds on both the themes of ambiguity and workplace relationships, and also takes them in a new direction. While patient advocates roles have similarities to a number of boundary spanning roles whose work has been well studied, such as customer service representatives (Leidner 1993; Rafaeli 1989), bill collectors

(Sutton & Rafaeli 1989), flight attendants (Hochschild, 1983), these roles tend to be ones in which the employee is portrayed as representing the organization. The customer, or person experiencing the problem, and the problem itself are not a theoretical concern. This research expands what we know about roles along the boundaries of organizations, in which the individual is neither simply following the organization's goals, nor resisting the control of the organization, as this literature typically implies. Instead, patient advocates are an example of a role in which the employee is meant to take criticism of the organization seriously. We know very little about this work, though it is becoming increasingly important for organizations to learn from their mistakes (Edmondson, 2004).

A study of patient advocates can also help us understand an increase in consumer rights. In some sectors, consumers have achieved greater rights and secured forms of legal recourse in the use and/or consumption of products and services. Evidence of this includes nonprofit consumer watchdog groups (Rao, 1998), patient rights' groups in healthcare (Archibald, 2008; Faden & Beauchamp, 1986), parent groups in education (Binder, 2004), activist shareholder groups in large corporations (Davis & Thompson, 1994). How have organizations responded to increased consumer rights? Most of our scholarly answers to this question are at an organizational, professional or institutional level of analysis. For example, researchers who draw on new institutional theory have examined how organizations and professions have adopted to equal employment opportunity legislation (Dobbin, Edelman, Meyer, & Swidler, 1988), or how certain practices have diffused across networks of organizations (Strang & Soule, 1998). The focus in much of this research assumes and sometimes shows that organizations find various ways to repel or diffuse consumers' attempts at organizational change.

This research has, for the most part, not included studies of the work of organizational members charged with dealing with consumers' rights groups, instead focusing on a higher (organizational or institutional) level of analysis. Patient advocates represent patients who have rights under local, state and federal law, so they cannot simply do the bidding of the organization. If patients are not satisfied with the resolution of their complaint or concern, they can contact local and state agencies, which can trigger regulatory investigations. As such, patient advocates provide valuable insight into how employees negotiate competing interests of organization and consumer.

Healthcare is a particularly appropriate industry in which to examine this kind of work. There has been a growing acknowledgment that healthcare organizations must become better at systemically finding error (Gibson & Singh, 2003; Kohn, Corrigan, & Donaldson, 2000), resulting in entire hospital departments whose goal is to surface and fix consumers' complaints about the organization. These are typically called Quality Improvement departments. This means that healthcare workers are being asked to "speak up" about mistakes and potentially criticize their colleagues and the organizations for which they work (Edmondson, 2004).

In addition, patients have undergone a sea change in their relationship to hospitals. Patients have gone from being passive to active consumers of healthcare. Originating with the "patient right's movement" that developed to protect the rights of mental health patients (Brown, 1982), patients have achieved legal rights. Medicine has been demystified as medical information has become more widely available and doctors' authority has decreased. The result is patients are increasingly encouraged to take charge of their own health, and have legal rights to fair and safe treatment. By studying patient

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advocates, I hope to shed light on how work is accomplished in the context of changing employee and consumer relationships to organizations.

Agency

This dissertation also engages with theoretical questions of agency. There are many different ways that agency can be conceptualized and defined. The purpose of the review is to familiarize and sensitize the reader to this broad intellectual landscape. By agency, I mean an *individual's purposeful action within a social context*, whether that context is a relationship, an organization, an institution or society writ large. This leaves out those definitions that focus on agency as an individual difference (e.g., Bandura, 2001; Frese, Fay, Hilburger, Leng, Tag, 1997) as well as that literature which has developed specifically around the agency of organizations, professions, or institutions (Brint & Karabel, 1991; DiMaggio, 1988).

Agency is addressed by a number of different interrelated literatures, including organizational behavior (e.g., proactive behaviors, as reviewed by Crant, 2000, or Grant & Ashford, 2008), organizational theory (Creed & Scully, 2000; Meyerson, 2001), sociology (Coleman, 1990; Emirbayer & Mische, 1998) and psychology (Bandura, 2001). Instead of presenting a review of each theory of agency by discipline, I provide a broad overview of some of the major areas for development within agency-related research as a way to preview the contributions of my dissertation. To do this, I review how agency-related literatures discuss assumptions about the psychology and motives of action, the complexity and form of social structure in which agency takes place, and the role of an actor's relationships with others.

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Agency-related theories make a variety of assumptions about the psychology, decision-making and motives of individual actors. These assumptions are important because they provide starting points for understanding and in some cases predicting how and why individuals act. They range from explicit assumptions that individuals are self-interested and pursue goals that will maximize their own benefit (Baker & Faulkner, 1991; Coleman, 1990), to those that assume that individuals are other-oriented and have goals that shift and change over time (Fligstein, 2001). Others theorize that individuals evaluate the chances of success as the result of some potential action (Morrison & Phelps, 1999).

Critics have suggested that we still do not know very much about the interpretive processes that individual actors undertake when deciding how to act (Emirbayer & Mische, 1998; Zilber, 2002). This dissertation aims to shed light on the interpretive processes through which individuals decide how to act through an in-depth analysis of patient advocates work of problem-handling. Specifically, I describe patient advocates' problem-handling work as *organizational storytellers,* for whom interpreting and constructing meaning from bits and pieces of information is a critical part of their work. Patient advocates' agency comes in their ability to construct a story that will makes sense within the organizational context.

Agency-related theories also vary in how they theorize about structure. Structure is important in theories of agency because it is only in relation to social structure that we can see intentional or purposeful action. Scholars have conceptualized structure in a variety of ways. In organizational research, structure is most often conceptualized as a role or role system, position relative to authority or network. For example, many

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organizational behavior researchers assume that the role provides a set of expectations about how to act, and therefore, they can "see" agency when the individual does something above and beyond what is expected (Morrison & Phelps, 1999; Organ, Podsakoff, & MacKenzie 2006; Van Maanen & Schein 1979). Some scholars hypothesize that particular kinds of structural contexts provide settings in which we are more likely to see agency. For example, street-level bureaucrats have discretion, a form of agency, because their role requires them to implement and enforce rules and regulations far away from where the rules are made, so they are left to interpret and implement rules on their own (Lipsky, 1980). Others see contexts that are fragmented or unsettled as opportunities for agency (Abzug & Mezias, 1993; Swidler, 1986). While some research sees agents and structures as distinct, others examine the mutual constitution of agency and structure (Giddens, 1984; Orlikowski, 2000).

My dissertation considers the influence of multiple kinds of social structures, including the role, organization and institution. While many agency-related studies focus on just one context, I vary the organizational context in my research design, which allows me to contrast how the individuals in similar roles exercise agency in two different organizational contexts. In both empirical chapters, I assume – and in chapter 5 show – how individual action and structure are constitutive of one other.

Finally, theories of agency vary in how they theorize about the relationship between actors. Some agency-related theories focus on individuals while others attend to relationships. For example, rational actor theory focuses on the relationship between agent and principal, and how their conflicting motives influence their actions (Kiser, 1999). Relational practice is the study of how individuals engage in interactions in ways

that will promote the growth and development others (Fletcher, 1999). Some theorists attend to not just one relationship, but sets of relationships or interactions over time. For example, Baker and Faulkner (1991) look at how individuals use their roles as a way of accessing people and resources. Meyerson (2001) examines how individuals develop networks that allow them to make incremental changes over time (see also Reay et al., 2006; Morrison, 2002).

Across each of these studies, relationships have a variety of different functions, as a means of achieving some goal (learning information), a source of growth and development, or an audience whose relationship to the actor shapes the performance of a role (Goffman, 1959). My dissertation builds on this prior research and shows how individual actors draw on a unique set of relationships and interactions to resolve problems. These relationships and interactions are resources for individual action, in that they provide access to information and different perspectives on a problem.

In sum, this research will contribute to ongoing conversations in the study of individual-level agency in organizations. With a multi-method qualitative research design, this study will help us understand the interpretive processes with which patient advocates make sense of their problem-handling work. This study will provide both an in-depth look at how agents act in complex structural environments and a comparison of how work practice varies across two types of hospitals. Finally, relationships are of central importance to patient advocates' work. This study provides an in-depth look at the role of relationships in problem-handling work.

Summary and Transition

The purpose of this chapter has been to introduce the reader to patient advocates, the major literatures in which the dissertation is situated, and the research question that motivates the dissertation. In the next chapter, I will describe the research design and methods I used to answer this question. This sets the stage for the following three chapters in which I describe the work of patient advocates in some detail and provide two separate answers to the research question.

Chapter 2

Research Design and Methods

In this chapter, I describe the design of my study. The study used a comparative case study design, relying on qualitative methods to understand patient advocates' problem-handling work in two organizational contexts. I begin by describing my selection of the patient advocate role and the case study research strategy that guided data collection. Next, I describe the goals and methods of the two data collection phases. I follow this with a general description of the data analysis strategies I used. Finally, I discuss the validity of my research design. I leave more specific description of the analysis and the validity of my findings for the two empirical chapters that follow.

Selection of the Patient Advocate Role

I selected the role of hospital-employed patient advocates because patient advocates' work seemed to be an "extreme case" of individual agency in organizations, in the sense that the process I was interested in would be "transparently observable" (Eisenhardt, 1989 citing Pettigrew, 1988). The patient advocates I studied are specialists. It is their full-time job to handle the problems of patients and their families. They do not simultaneously have other responsibilities, as do other roles that include some problem-handling capacity, such as managers (Mintzberg, 1973), nurses (Foley, Minick, & Kee, 2002), social workers (Meyerson, 1994) or peer-support providers (Bacharach, Bamberger, & McKinney 2000), nor are they doing this work informally, as a toxic

handler (Frost, 2003) might. As "experts" at problem handling, patient advocates may be especially likely to be able to *talk about* their work practice because they have had ample opportunity to practice the skill and sometimes coach others how to handle problems.

Several characteristics of their role also bode well for a researcher's ability to *observe* their problem-handling work. Patient advocates receive multiple calls, letters, or walk-ins about problems every day, and work on multiple cases over time, each of which is at a different stage. Patient advocates also have to "resolve" complaints in a relatively short amount of time. They are subject to external regulations and institutional norms that require them to communicate to the patient or family within a specific number of days about how the problem is being handled and whether the investigation is ongoing. The role's primary focus on problem handling suggested that I would be able to observe patient advocates handling multiple cases. Further, because patient advocates' problem handling is time-bound, I could observe, and thus collect data, on all parts of the process. In contrast, the other roles I considered studying, including ombuds, mediators, coaches, labor organizers and negotiators, work on problems that unfold over longer periods of time and over which there is less external pressure to resolve problems.

Research Strategy

Case studies are an appropriate research strategy when one is interested in understanding a phenomenon embedded in its "real life," and therefore often complex, context (Yin, 2003). Case studies frequently include more than one form of data to provide for a stronger base of evidence from which to make inferences (Eisenhardt, 1989; Yin, 2003). A case study research strategy was appropriate for my goal of developing an in-depth understanding of patient advocates' problem-handling work as an example of

embedded or situated agency. I developed two case studies of patient advocates'

problem-handling work by comparing their work in two organizational contexts, teaching

hospitals and VA hospitals.

Data collection proceeded in two phases over a sixteen month period from

November 2005 to February 2007, as summarized in **Appendix 1**. In the first phase, I

developed an understanding of the patient advocate role itself, including its history,

culture, its position in hospitals. I was a relative stranger to the patient advocate role,

having only heard stories about a childhood friend's work as a patient advocate.

Therefore, it was important that I gather this information so that I could be informed

during the second phase of data collection, in which my success was dependent, in part,

on patient advocates' accepting me into their everyday work (Fletcher, personal

communication; Padgett, 1998). As is appropriate for qualitative case studies (Stake,

2005), I refined my initial data collection methods and site selection based on what I

learned in the first phase of data collection. In the second phase, I sought to understand

the patient advocates' work practice, or the patterned ways in which they accomplish

their work. I collected data that would allow me to capture both first-person accounts as

well as observations. I describe each phase in detail below.

Phase 1: Understanding the Patient Advocate Role

I used three data sources to develop an understanding of the patient advocate role:

publicly-available documents, informant interviews, and participant-observation at

patient advocate professional conferences. I deliberately sought divergent sources and

perspectives so that I could develop a broad but relatively complete understanding of the

hospital-employed patient advocate and its environs (e.g., hospital, professional

association, similar roles within hospitals). The following questions guided my inquiry during this phase: What are patient advocates' typical tasks and responsibilities? With whom do they interact? What are the challenges and rewards of patient advocacy? How do patient advocates typically get involved in problems? What is the culture of patient advocate role? Is patient advocacy a profession? How are patient advocates viewed by others in hospitals? What regulations shape patient advocates' work and how do these regulations affect them? How are VA and non-VA patient advocates similar or different from one another?

Interviews with Informants

I interviewed eighteen informants between November 2005 and April 2006. They were informants in the sense that they were "native speakers" to the worlds in which patient advocates reside, and many were in positions that suggested they would be willing to teach me about and speak about various aspects of the role (Rubin & Rubin, 1995; Spradley, 1979). I developed the sample through a combination of purposive and snowball, or opportunistic, sampling (Padgett, 1998). I contacted managers and administrators of patient advocate departments and educational programs whose contact information was listed on websites. They, in turn, suggested additional informants.

I sought a diversity of viewpoints in order to provide me with a variety of perspectives on the patient advocate role (Rubin & Rubin, 1995). The sample consisted of six officers of the national professional association; five hospital administrators; four educators of patient advocates; one vendor; and one "VIP" patient advocate who was assigned exclusively to hospital donors. They included informants who had experience working as patient advocates and those who worked with them; were promoters of the

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hospital-based patient advocate role and those who were suspicious of it; worked in teaching, VA, and community-based hospitals as well as educational settings; for all patients or select populations (e.g., hospital VIPs). (See **Appendix 2** for a description of the background interviewees.)

I was conscious of constructing my role and clarifying my interests in patient advocacy when I initially contacted informants. This is an important step in developing a relationship with an informant and setting the tone of the interview (Fontana & Frey, 2005; Rubin & Rubin, 1995). When I contacted informants and explained that I was interested in studying the patient advocate role, they were often surprised and intrigued that someone would want to write their dissertation on patient advocates. They were curious about how I knew about the role. I made it clear that I learned about the role through a close friend who worked as a patient advocate and that I was impressed by the relational skill the role required. I thought it was important to convey a sense of respect for patient advocates and their work, especially because they are in a role which is not always recognized. The professional association officers seemed particularly enthusiastic and helpful in my study. As the vendor I interviewed pointed out, they were probably hoping that my study would benefit them by providing some legitimacy and visibility to their work, issues with which the professional association was struggling.

During the interviews, I asked informants questions about their perspective on patient advocacy, the challenges and rewards of the work, how the role had changed over times, its importance and relevance in healthcare, typical career paths of patient advocates, the regulations relevant to patient advocacy, and other questions tailored to reveal their perspective on the role. (See **Appendix 3** for examples of questions used in

background interviews.) The majority (thirteen) of the interviews took place over the phone, while five took place in person, which was possible either because they worked near my home base or I interviewed informants I met while attending a conference. I took notes during all of the interviews, and with one exception, recorded all of the interviews.

Conferences

I attended three patient advocate conferences in April and May 2006: a two-day national VA patient advocacy conference, a four-day national professional association conference, a one-day state professional association conference. At each conference, I attended sessions, spoke to conference attendees and collected documents. I wrote extensive field notes about my experiences and observations at each conference, and wrote analytic memos summarizing and organizing what I learned.

Publicly-available documents

Beginning in November 2005, I gathered approximately 1,000 pages of documents from three sources. I gathered material from the websites of the national professional association, educational programs offered at the graduate and certificate levels, and from hospitals. I collected documents from both the informants I interviewed and from the patient advocate conferences I attended. These documents were valuable in illustrating how patient advocates presented themselves and how hospitals presented patient advocates to patients and families, the issues patient advocates discussed in newsletters, conferences and other forums (such as conference programs), the history and important issues to the professional association and hospitals.

Conclusion of Phase 1 Data Collection

This phase of data collection gradually drew to a close as the three forms of data collection contributed to a sense of *completeness* (Rubin & Rubin, 1995), or until I had an overall sense of the hospital-employed patient advocate role. One marker of completeness was my ability to answer the questions I entered the field with, described at the beginning of this section. A second marker was my ability, based on what I had learned, to articulate a refined logic for the site selection and data collection strategies for the second phase of data collection, which I describe below.

Phase 2: Patient Advocates' Work Practice

The second phase of data collection was geared toward understanding patient advocates' work practice. By work practice, I mean recurrent, materially mediated, and situated social activity (Schatzki, Knorr-Centina, Savigny, 2001, cited in Kellogg et al., 2006). This perspective posits that people's everyday activities are done knowledgeably and skillfully, and thus both actors' own accounts and observations by outsiders of everyday work behaviors are worthwhile and important sources of data (Giddens, 1984; Orlokowski, 2002). I used two data collection methods to generate complementary sources of data on patient advocates' work practice. I conducted interviews with patient advocates, which provided me with accounts (Orbuch, 1997) of their own work. I also shadowed members of two hospital's patient advocate offices, which allowed me to collect data on (1) patient advocates' own moment-by-moment interpretations and reflections on their work experiences, (2) to personally observe patient advocates' daily work life and (3) to have ongoing dialogue with patient advocates about their work

practice. Before describing each of these data sources, I review the site selection for this second phase of data collection.

Site Selection

I refined the site selection for the second phase from all hospital-employed patient advocates to those employed by VA and non-VA teaching hospitals based on what I learned during the first data collection phase. This was a form of theoretical sampling, in the sense of controlling similarities and differences between groups to further theory development (Glaser & Strauss, 1967). Specifically, I considered the clarity of the patient advocate role as it is most commonly described in three common types of hospitals (teaching, community and VA hospitals) and what that clarity suggested about the patient advocates' ability to act agentically.

One key learning from the first stage of data collection is that there is variety in how the role is structured and enacted across hospital types. My informants suggested that there was greatest consistency in the patient advocate role within VA and teaching hospitals, while there was the least consistency at community hospitals. In both VA and teaching hospitals, the patient advocate job is typically designed as a full-time job for one or more people. Patient advocates tended to work out of centralized office as opposed to being assigned to a specific unit or department (e.g., Emergency Department) and report to Quality Improvement offices. In contrast, the patient advocate role in community hospitals is more likely to be a part-time responsibility, in combination with other roles such as recipient rights, nursing or interpreter services. Patient advocates at community hospitals reported to a wider variety of offices, from customer service to risk

management to guest relations to marketing and appeared to have less training and sources of support.

Based on these comparisons, it appeared that patient advocates at VA and teaching hospitals were most likely to have the resources, including time, peer support, and supportive reporting relationships, that would allow them to advocate on behalf of a patient and their family and perhaps make small changes in the organization. Because patient advocates at community hospitals sometimes acted as "jack of all trades," the patient advocate role in some community hospitals seemed to be under-resourced to the point of stripping the patient advocate of power. I therefore decided to focus on patient advocates at teaching and VA hospitals. Specifically, I studied individuals employed as full-time patient advocates by tertiary hospitals with medical residents in urban centers in four Midwestern states. Within the VA hospitals, I studied only those patient advocates who worked in Medical Centers, instead of the smaller Community-Based Outpatient Clinics (CBOCs).

While the patient advocate role at Teaching and VA hospitals are relatively similar, they also differ in ways that indicated useful theoretical contrasts. For example, the two kinds of hospitals vary in their patient populations. The VA patient population is comprised of veterans and a small percentage of veterans' family members, resulting in a stable and predictable patient population. The VA patient population tends to be older, predominantly male and have lower incomes compared to the general population (Agha, Lofgren, VanRuiswyk, & Layde, 2000). They also share common health issues based on their experience in the military service, such as PTSD or Gulf War Syndrome (Sartin, 2000; Subcommittee on Posttraumatic Stress Disorder of the Committee on Gulf War and

Health: Physiologic, 2006; Wessely, 2001) and the life experience of participating in the military. In contrast, patients at teaching hospitals tend not to be concentrated around gender or age, and they have a wide variety of health issues and do not necessarily have similar life experiences to one another. Patient advocates in teaching and VA hospitals therefore vary in the familiarity they have with the patients and their health issues.

Patient advocates in these two hospital types are also subject to different regulatory environments. While both the VA and Teaching hospitals record all of their interactions in database systems, the VA is not bound by Center for Medicaid and Medicare (CMS) regulations, while teaching hospitals are. This affects the tasks that patient advocates are required to fulfill. CMS requires that patient advocates write follow-up letters for most interactions they have with patients, providing a written record of the complaint and its resolution, and directing them to state agencies where they can report their complaint if they are satisfied with the resolution they receive from the hospital. While VA patient advocates keep similarly extensive records of interactions and complaints, they are free from the letter-writing task. Patient advocates in teaching and VA hospitals, therefore, vary in the media through which they communicate with patients. VA patient advocates experience primarily face-to-face and telephone communication, while teaching hospital patient advocates correspond with patients via written letters to meet CMS requirements.

Below I describe the data sources I used to generate data about patient advocates' work practice at teaching and VA hospitals.

Patient Advocate Interviews

I conducted 31 one-on-one semistructured interviews with patient advocates at 17 hospitals from June through August 2006. I interviewed 20 patient advocates who worked at 10 teaching hospitals, and 11 patient advocates employed by 7 VA hospitals. The sample consisted of 16 white women, 8 black women and 7 white men. All invitations to participate in the study were accepted, with the exception of two black men who worked at VA hospitals who declined to be interviewed because they were too busy. (For a full description of the sample, see **Appendix 4**.) All interviews were recorded, with the exception of two black women who declined to be recorded and one interview in which the recording device malfunctioned. When I did not record the interviews, I took extensive written notes, immediately made a voice recording of my thoughts after the interview, and typed up my written notes. All recorded interviews were transcribed.

Interviews provide an opportunity to learn about how people perceive and interpret their work lives (Spradley, 1979; Weiss, 1994). I structured the opening of the interview to portray myself as a conversational partner in the interview (Rubin & Rubin, 1995), one who was aware of the sensitivity and confidentiality of the stories I was asking them to share with me. The interview protocol consisted of a series of "warm-up" questions, intended to gather information about their path to their current job and the hospital in which they work. These questions provided me with some standard information about the respondents, and gave them a chance to begin the interview on a topic they were certain to be able to answer well. In this way, it was a deliberate opportunity to construct the interviewee as a knowledgeable participant in the interview.

I then asked a "grand tour" question about a typical day (Spradley, 1979), providing the interviewee with an opportunity to start with a familiar topic and provide me with a sense of the contours of their lives at the particular hospital where they work, the people they interact with, the pace of work, and other topics that were important to them. Often, this would lead naturally into the next set of "example questions" (Spradley, 1979), in which I asked them to tell me stories about specific cases they handled. Specifically, I asked them to tell me about cases in which they felt they were successful, challenged by, and ones in which the situation was ambiguous. I used a variety of descriptive questions to help respondents develop concrete information (Spradley, 1979; Weiss, 1994). (See **Appendix 5** for the interview protocol.) The final set of question addressed their awareness of and use of their own body during their work. These questions were based on body-related themes that had emerged from first phase of data collection.

Interviews lasted an average of ninety minutes, with a range of 45 minutes to three hours. The first 26 interviews took place in the informant's offices, which provided me with the opportunity to talk informally with patient advocates' peers or supervisors, eat meals with the patient advocates, and sometimes have tours of the facility (See **Appendix 6** for more information about the interactions that occurred during the visit.) I conducted the final five interviews over the phone. At that point, I was nearing informational saturation, in that I was learning relatively little from each additional interview (Padgett, 1998). In addition, I had interviewed nearly all of the patient advocates who met my sampling criteria that were located within a day's drive. The time and distance required to continue interviewing patient advocates in person (at least a full

day trip and for some, an overnight trip would be required) did not seem worth the time and money, given the "diminishing returns" (i.e., new information) of each interview. For these reasons, I concluded this collection of interview data.

After each interview, I made oral and/or written field notes (Lofland, Snow, Anderson, & Lofland, 2006; Spradley, 1979) about the interview itself (e.g., the relationship between myself and the interviewee, how and why the interview conversation developed as it did, topics the patient seemed most and least interested in talking about), the informant's office space and its location in the hospital, my impressions of the hospital, and other topics that seemed relevant. I gave each informant a small gift (e.g., a box of chocolates) at the conclusion of the interview as a token of appreciation.

Shadowing

Shadowing is a research technique that involves a researcher closely following a member of an organization over some period of time (McDonald, 2005). The researcher takes extensive notes on the activities of the shadowee. The shadowee explains her actions, reasoning and any other relevant information either during the shadowing period (e.g., Benner, 1984), or in a debriefing interview that occurs soon after the shadowing period (e.g., Fletcher, 1999, interviewed participants the day after shadowing them). Shadowing differs from the more general category of ethnographic observation in that it involves collecting detailed person-centered field notes, as opposed to data collection on a larger unit of analysis (e.g., a department or unit); and that it involves the shadowee interpreting their own actions for the researcher. Shadowing as a technique has been used by a small number of organizational researchers (Bonazzi, 1998; Fletcher, 1999; Jacques,

1992; Mintzberg, 1973; Perlow, 1998; Walker, Guest, & Turner, 1956). Relatively little

has been written about shadowing as a methodology (McDonald, 2005).

Shadowing is especially appropriate to study aspects of organizational life that are

difficult to articulate (McDonald, 2005), including forms of knowledge and competence

that are outside of most definitions of how work is accomplished. For example, Benner's

(1984) work shows caring and collaboration as integral parts of nursing practice, while

Fletcher's (1999) research makes visible relational work as a form of competence, and

explains how it "gets disappeared" in dominant modes of work. Given my interest in the

role of the body at work, this was an especially appropriate data collection method. Prior

to entering the field, I surveyed the specific aspects of the body that other researchers had

used in their research (see **Appendix 7**) and practiced observing how people use their

body at work by observing three University of Michigan instructors and sharing my

observations with two of them. In this way, I prepared myself to enter the field and be

attuned to the body's role in work practice.

Sample I shadowed the members of two patient advocate offices, one at a

teaching hospital and the other at a VA hospital, for which I use the pseudonyms

Heartland Teaching Hospital and Reveille VA Hospital, respectively. Shadowing patient

advocates required a set of permissions in addition to the Institutional Review Board

permission I had secured from my own university, because patient advocates everyday

work entails frequent interaction patients and their medical records, which are protected

by HIPAA Privacy Rule (Health Insurance Portability and Accountability Act of 1996),

which is designed to safeguard the security and confidentiality of health information

(U.S. Department of Health and Human Services, 2007). As a result, I became certified

through two separate sets of training, one at each hospital, to handle HIPAA-protected patient data.

Both patient advocate offices are highly regarded by other hospitals in their regional communities, and are part of award-winning hospitals. At both hospitals, the patient advocate offices are part of the Quality Improvement Departments, whose purpose as guided by Title XI of the Social Security Act is "to improve the effectiveness, efficiency, economy and quality of services delivered to Medicare beneficiaries" (CMS, 2005). One important difference is that the two hospitals are located in different states.

I spent a total of 75 hours shadowing at the Heartland Teaching Hospital patient advocate office during October 2006 through January 2007. The office consisted of five patient advocates and one administrative assistant. The manager of the office, though technically full-time, did not have office space with the patient advocates and in practice spent very little time on his patient advocate responsibilities, instead spending the majority of the time on special assignments elsewhere in his department. I interviewed the manager three times, the prior manager twice and each of the patient advocates and the administrative assistant once. In addition, I attended staff meetings and ate lunch with them as a group during the majority of my observation days. The actual shadowing, or structured observation of the patient advocates, began after I obtained their formal permission to conduct the research and after I interviewed all members of the office. I observed each of the patient advocates for two periods of either a half or a full day.

The patient advocate office at the Reveille VA hospital included three patient advocates and one administrative assistant. One of the patient advocates was also the lead patient advocate for the region (or in VA terms, the Veterans Integrated Service Network

or VISN), so although not the department manager, this patient advocate was a regional leader in the VA and also had a formal role in Society for Healthcare Consumer Advocacy (SHCA), the national professional association. Their manager was the head of the Quality Improvement Department, and patient advocacy was one of several departments that reported to her. Her office was located in a different part of the hospital, and she was not involved in the day-to-day operations of the department. My initial contact at this VA hospital was the lead patient advocate for the region, whom I interviewed once prior to beginning my research. I made one site visit prior to shadowing while I waited for formal permission to shadow. I observed each of the patient advocates for two or three periods, either a half or a full day. I spent a total of 45 hours collecting data from this patient advocate office, during site visits during November 2006 and February 2007.

Data Collection Process At both Heartland Teaching Hospital and Reveille VA Hospital, I began data collection with forms of data collection that provided an opportunity for the members of the patient advocate office and I to become comfortable around one another, which is an important step in shadowing research (Fletcher, personal communication). At Heartland, I interviewed every person who worked in the patient advocate office, including the administrative assistant and manager, as a way of gathering basic information and learning about their work practice. I also attended staff meetings and committee meetings as a way of learning about the larger context of the work. At Reveille, I interviewed the lead patient advocate and did a site visit, in which I met all of the members of the department and took a tour of the facility. In the process of negotiating my relationship with the Reveille VA, I was not able to individually interview

the other two patient advocates, though I had time while shadowing them to ask some of the interview questions (e.g., job histories).

Shadowing aims to record the micro events, interactions and behaviors of the person being shadowed. Prior shadowing studies vary in the degree to which the categories to be observed are developed *a priori*. Some researchers developed different logs to enter shadowing data in (e.g. Mintzberg, 1973, used a chronology record, mail record and contact record), while remaining open to emerging categories. However, sometimes researchers find that when they develop *a priori* categories, it is impossible to use them in practice because it is difficult to simultaneously observe and categorize at the same time (Fletcher, personal communication).

My general focus while shadowing was on how patient advocates handled problems, with the specific interest in how patient advocates used their bodies during this process. I developed a list of body-related categories that other researchers have used in observational research (see **Appendix 2**) to increase my ability to "see" the body and to have valid measurement typologies with which I could compare my own observations. In addition, I familiarized myself with the other categories researchers typically observe. Denzin (1989, cited in Adler and Adler, 1998) suggested that all observational notational records should contain explicit reference to participants, interactions, routines, rituals, temporal elements, interpretations and social organization.

These *a priori* categories functioned as a sort of conditioning for the shadowing process, in the sense they prepared me for potential note-taking categories. However, as is appropriate in theory-building research, I remained open to what I observed in the field. For example, over time I realized that patient advocates' interactions with

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technology played an important role in how they handled problems, so I began to pay more attention to how they used various modes of communication and complaint tracking software. I was also careful to note my own reactions to situations, which I found especially useful when my own personal reaction was different than the reaction of the patient advocate who I was shadowing (e.g., to someone getting really angry). In this sense, my own reactions, including bodily and emotional reactions, were part of the data collection process (Kvale, 1996).

My next step was to observe each patient advocate for two time periods of either a half or full day. I did not know ahead of time I would focus on patient advocates or their cases. I quickly learned that patient advocates handle problems over long periods of time, and the problems themselves are unpredictable. For example, when a patient walked into the office or first phoned the office, there was no predicting how long the patient advocate would be interacting with that person or the kind of problem they might have. In addition, a patient's problem sometimes would appear to be resolved, then it would reappear weeks or months later. Because I was not present at the shadowing sites every day and because I shadowed different patient advocates on consecutive days, the focus of my shadowing was the patient advocate, not the problems they handled.

I rotated who I observed and when I observed them so as not to create bias in the shadowing data. One of the key components of shadowing is to not only observe what people are doing, but ask them about why they are doing it, how they are feeling, etc. Some researchers have this debriefing interview after the shadowing period is complete (e.g., Fletcher, 1999), while other researchers ask questions while observing (e.g., Benner, Tanner, Chesla, 1996). When I entered the field, I was not sure which process

would be more appropriate. It quickly became clear that debriefing during the day would be more appropriate, first, because there was ample opportunity during patient advocates' "downtime." Second, the patient advocates that I studied talked to each other about what was going on during the day. They told each other stories about the people they were interacting with, compared notes, and questioned each other, etc., so there was already a form of ongoing debriefing that occurred naturally. My questions about their work fit into patient advocates' continuous debriefing of their work with their colleagues. Over time, they came to ask me what I thought of a particular interaction or situation, in essence, inviting me into and asking me to contribute to their community of practice (Brown & Duguid, 1991).

Important differences about the sites, and hence my data collection, emerged because of the distinct ways in which patient advocates took in complaints. At Reveille VA Hospital, the patient advocates worked in three individual offices situated at a minor intersection in the hospital. Their doors were typically open, signs clearly directed people to "customer service," and the patient advocate function is mandatory and widely known within VA culture, so veterans and their families generally know about the patient advocate role and how they can help. Because of these three factors, a substantial proportion of their interactions occur in person. During these in-person interactions, I put my notebook away and jotted down notes after they left.

In contrast, at Heartland Teaching Hospital, the patient advocates each occupied individual offices surrounding a small reception area; any foot traffic that entered the office passed by the administrative assistant. The door to the reception area was always closed, and while there were some signs directing people to the office, it was not easy to

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find. I had the impression that the patient advocate function was not widely understood by either the staff of the hospital or the patients and their families. For example, staff would occasionally bring patients or family members into the office, saying, "I don't know if this is the right place, but is this where they can get help with their billing issue?" (The answer is no.) In short, there appeared to be relatively more ambiguity about the patient advocate office even among hospital employees. Perhaps not surprisingly, much of the case handling work occurred over the phone. For the purposes of shadowing, this meant that after receiving permission from the caller, the patient advocate put the call on speakerphone so that I could hear both sides of the conversation. One benefit of this situation was that I could keep my notebook out to write during the interaction, and therefore relied less on my memory.

Researchers who use shadowing as a source of data typically address their effect on the environment as a way of addressing the validity of the shadowing research. In other words, how was the phenomenon under observation (e.g., a person, process, or organization) influenced by the researcher's presence? The goal of these statements, either implicitly or explicitly, is to make the case that the researcher did not in fact influence the normal, everyday activity of the people being shadowed. I took a different stance. At no point did I think of myself or expect to be invisible to the members of the patient advocate office or to the patients and families who I observed, nor did I think of myself as particularly unobtrusive. The work of patient advocacy almost always occurs alone or in interactions among small groups of people and it frequently involves intimate concerns and confidential information. Rather than approaching this situation as one in which I needed to create some kind of cloak of invisibility, I sought to establish myself as

playing a role that would be meaningful to the people with whom I was I interacting, as is frequently advised in writing on interviewing (e.g., Rubin and Rubin, 1995) and fieldwork (Van Maanen & Kolb, 1985). My goal was to try to not interfere with the flow of work by establishing myself in a role that would make sense in the context. In that way, I do not claim to have been invisible and without impact, but rather comprehensible within the social scene, and therefore to have decreased my impact on the ongoing activity in which I observed and participated.

At both sites, I was conscious of needing to develop ways of explaining my presence to both the employees of the patient advocate offices and the patients, family members, and hospital staff with whom we interacted. This is important because access to information depends in part on the extent to which the researcher can be made sense in terms of categories that are meaningful to people in the field (Harrington, 2003). I believe the patient advocates, administrative assistants and patient advocate managers I interacted with most frequently viewed me primarily as a *student*, a role they are familiar with because teaching hospitals are filled with students who shadow practitioners in apprentice-like style. Only rarely did people question my presence (e.g., "who is she?"), and when they did, they often did not wait to hear the full explanation, but rather seemed to stop paying attention as soon as they heard that I was a student.

The patient advocates I shadowed also had some experience with being shadowed by students of various kinds. At Reveille VA Hospital, "shadowing" patient advocates had recently become a required part of their leadership development program, as a way of gaining insight into patients' experiences at the hospital. At Heartland Teaching Hospital, newly hired patient advocates "shadowed" experienced ones as a way of learning the job.

In both hospitals, therefore, patient advocates had some experience with being shadowed by students, although not by a doctoral candidate nor for such long periods of time.

One might expect, as I did, that patients and their families would be particularly sensitive to having a stranger in their midst when experiencing problems in a hospital. However, I found that I fit into another common role in the two hospitals, that of the hospital "stranger." The hospitals I studied are large, complex organizations, and people frequently interacted with others they did not know. This was especially true of patients and their families, who were asked to tell their stories over and over again in front of individuals, small groups and rooms full of people they had never met before (Frank, 1995; Kleinman, 1988). In those situations, I was always introduced as a "student studying patient advocates." However, I think it is likely that to the patients and their families, I blended into the larger social scene of "strangers who work at the hospital."

When I had completed the shadowing data collection, I provided tokens of appreciation to the patient advocates I shadowed and administrative assistants of the respective offices, in the form of flower arrangements and handwritten thank-you letters. Because of its proximity, I was able to hand deliver the flowers and present an overview of my initial impressions of data collection at the teaching hospital. This led to an opportunity to formally present the findings at a department meeting. During both the meeting with the patient advocates and the department meeting, I received both affirmation and feedback on my analyses.

Data Analysis

While some data analysis occurred during the data collection period (e.g., the refinement of the site selection), the majority of analysis occurred once I concluded the

shadowing data collection, my final phase in the field. I describe my overall analysis strategy here followed by more detailed description in the empirical chapters that follow.

Using the data collected in Phase 1, I wrote Chapter 3, called "The Patient Advocate Role." This chapter provides a historical perspective on the patient advocate role as well as a contemporary view of patient advocates, the problems they handle, the regulations shaping their work. This chapter lays the groundwork for subsequent chapters.

The analyses for Chapters 4 and 5 are centered on answering two broad questions: What is patient advocates' work and how can it be understood theoretically? What difference does the organizational context (Teaching versus VA hospitals) make in how patient advocates handle problems? Both questions could be answered with a number of possible answers. Chapter Four presents one answer to the first question, and Chapter Five describes one answer to the second question. I followed similar broad analytic strategies for both chapters. For instance, I began by analyzing a portion of the data on work practice (either interviews or shadowing data). I developed initial answers to my questions based on analysis of a limited set of data, then refined these answers by working "out" from it, first to the remaining work practice data and then to the Phase One data on the patient advocate role. In this way, the emerging theory was developed in one set of data and then expanded to others. This was a beneficial strategy in two ways. First, it provided me with a manageable way of handling the large amounts of data I had generated. Second, this process provided one way of evaluating the validity of the theory that I was developing, as I was evaluating the "fit" of the model across various types of data.

I used Atlas.ti (Muhr, 2004) to organize the work practice data and for some analyses. I uploaded all of the work practice data, including the fractured interview data, into Atlas.ti, making it easy to retrieve information. I also used Atlas.ti to for some analyses, and found it most helpful when I was elaborating a model I had already developed through lower-tech means. At the start of answering each question, I found it more helpful to work with the physical artifacts of the data that I could physically touch and mark with pencil or colored post-it notes.

One important analytic step was extracting the stories patient advocates' told about problem handling from the transcripts of the Phase 2 patient advocate interviews. This helped to fracture the data, or see the data in new ways apart from my experience of collecting it (Locke, 2001) and led to focused coding (Charmaz, 2001). It also helped to explore patient advocates' problem handling in depth. These stories became a distinct source of data that allowed me to focus on their problem-handling work.

Stories have three basic elements, (1) a situation involving a predicament, conflict or struggle; (2) a protagonist, and (3) a plot (Carter, 1993). I read through all of the patient advocate interviews and selected all stories they told me. I found 163 stories in the 31 interviews, with an average of 5 stories person, with a range of zero to 18 stories (**Appendix 5** notes the number of stories generated from each interview). I excluded those interview passages in which patient advocates spoke in general terms. An example of something that would not count as a story is this response to my question about a situation in which they felt challenged:

> Probably the...the most challenging for me again, would be, not meeting the person's expectation. And pain management is a big issue, because a lot of time,

it is just that. They...they don't fair...feel the medications are...are managing their pain. They may want narcotics. And to be quite frank, there is nothing I can do.

Because this person did not tell me about a specific instance about "not meeting the person's expectation" or "pain management," I did not consider this a story. I removed each story from its context in the interview and created a new set of story documents, each with their own identifying numbers. I printed copies of all of the stories and put them in a booklet for further analysis. I also created a one-sentence-description of the story. The primary purpose of this list was to provide an index or table of contents of the stories that I could glance at to look across all the studies or locate a particular story. These stories became an important source of data that helped to focus on patient advocates' problem-handling work.

I engaged in various forms of writing and feedback-seeking (e.g., formal and informal presentations, discussions with people familiar and unfamiliar with the setting) as a way of moving between my ongoing analyses and the theory that seemed best suited to explain the patterns I saw (Lofland, Snow, Anderson, and Lofland, 2006; Richardson, 2005). Both provided forms of finding more about what I did and did not know, and provided me with helpful information about the direction I should push the next iteration of analyses.

Validity Issues

Validity issues are important in qualitative research. Discussions of validity help to answer the question, "Are these findings sufficiently authentic (isomorphic to some reality, trustworthy, related to the way others construct their social worlds) that I may trust myself in acting on their implications?" (Guba & Lincoln, 2005:205) It is important to address validity as it applies to both the method and interpretation (Guba & Lincoln,

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2005). Taken together, this provides insight into the credibility of both the means of collecting data and the process of interpreting it (Maxwell, 1996). To discuss the validity of this study, I turned to Maxwell's (1992) discussion of validity in qualitative research.

Maxwell (1992) suggested four types of validity are relevant for the research design and data collecting phase of the process: descriptive validity, interpretive validity, and generalizability, and theoretical validity. In the following sections, I describe how I addressed these four types of validity.

Descriptive validity is defined as factual accuracy of the recorded observations. This can refer to errors of omission as well as commission. In the interviews with informants and patient advocates, I aimed to enhance the descriptive validity by recording the interviews and taking extensive notes during the interview. I avoided leading questions. I also recorded my reactions to the interview after its conclusion to track my own experience of the interview (Lofland, Snow, Anderson, & Lofland, 2006; Spradley, 1979), in part to keep a record of how those experiences might influence my interpretation of the data later on (Miles & Huberman, 1994). During the observations at conferences and shadowing, I took extensive notes and was careful to ask clarifying questions when I did not understand something or was not sure if my interpretation was accurate (McDonald, 2005), a form of continuous "member checking" (Lincoln & Guba, 1985). In my notes, I developed ways of noting my own interpretations, reactions and thoughts, from the more purely descriptive accounts of the goings-on around me. In the shadowing field notes, I also remarked on topics that patient advocates did not want to discuss with me (typically, having to do with organizational politics) as a way of keeping track of what patient advocates seemed to be keeping from me. Finally, I practiced

observing prior to shadowing the patient advocates. For researchers who use observation as a methodology, it is very common for them to note that practice helps to increase the accuracy of their record (e.g., Liebow, 1993).

Interpretive validity focuses on the participants' perspective, the meaning of the objects, events and behaviors to the people engaged in them. Interpretive validity can apply to conscious and unconscious intentions, beliefs, concepts and values of participants. Because I was interested in patient advocates' experiences, this kind of validity is particularly important. I believe the validity was enhanced by the overall structure of the research design, in which I learned about patient advocates' context through relatively unobtrusive forms of data collection that gave me a sense of the context in which patient advocates work, before I embarked on the more intensive and intrusive forms of data collection. By the time I embarked on the interviews and shadowing, I was relatively educated about the jargon and concerns of patient advocates and could be an informed conversational partner and observer. Interpretive validity was also significantly enhanced by the shadowing data, in which I had continuous opportunities to ask patient advocates about their experience through what Fletcher calls, "contextualizing data" (Fletcher, 1999: 43). This data is elicited by asking open-ended questions, such as "what was this about?," "what was going on here?" and asking for greater detail about observations of particular interest, with questions like, "I noticed that you touched the patient's mother when she was on her way out the door; can you tell me about that?"

Internal generalizability refers to the extent to which the times and places observed may differ from those that were not observed, either because of sampling or

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because of the effect of the observation itself. The main way in which I accounted for the generalizability of the data comes from using multiple methods in both phases of data collection, while at the same time limiting the data collection to patient advocates at two types of hospitals. Triangulating sources of data helps to ensure that meaning is created from multiple perspectives on the phenomenon of interest and verifying that an observation or interpretation is reliable (Maxwell, 1996; Stake, 2005). Within the shadowing data, I rotated who and when I observed so that I would not introduce bias into my data.

Theoretical validity refers to the validity of the concepts and relationships among concepts that I develop to explain patterns in the data. It is relevant during the interpretation and analyses of data. I addressed theoretical validity in several ways. First, I developed my analysis by working across different sources of data and two comparable cases. I deliberately sought to understand inconsistencies between my interpretations and data (Rubin & Rubin, 1995). This provided an opportunity to elaborate and refine my ideas across different types of data, strengthening confidence in my interpretations.

Second, I moved iteratively between the data and theoretical frameworks. When I began to develop the theory, I tested my emergent patterns of data against a variety of different literatures (Ragin, 2001). One indication that a theoretical interpretation was valid was that when a given interpretation generated additional questions, I would be able to return to my data and answer the question. This increased my confidence in my interpretations. For example, in Chapter 4, I arrived at an interpretation of patient advocates' problem-handling work as storytelling. This interpretation suggested further questions, such as "are there aspects of the environment that encouraged this form of

storytelling?" Being able to find answers to these questions supported the likelihood that this was a valid interpretation of the data.

Summary and Transition

This chapter introduced readers to the research design, methods and analysis on which the rest of the dissertation is based. In the two main empirical chapters, Chapters 4 and 5, I will provide more specific detail about how I drew on these data and the analysis used to generate the theoretical accounts of patient advocates' work. Before embarking on these two theoretical interpretations of the data, I describe the patient advocate role in the next chapter.

Appendix 1: Data Collection and Analysis

Type of Data	Amount of Data	Time of Collection	Use in Analysis and Theory Development
Phase 1: Understanding the Patient Advocate Role			
Informant Interviews Interviews with professional association officers, hospital administrators, educators, vendor.	18 interviews	November 2005 – April 2006	- Site selection for Phase 2 data collection. - Basis for Chapter 3. - Read for evidence to elaborate Chapters 4 and 5.
Conference Participant-Observation	3 conferences: 1 national SHCA conference, 1 state SHCA conference, 1 national VA conference	April 2006 – May 2006	- Site selection for Phase 2 data collection. - Basis for Chapter 3. - Read for evidence to elaborate Chapters 4 and 5.
Documents Publicly available documents from websites, educational programs, conferences	Approximately 1000 pages	November 2005 - present	- Site selection for Phase 2 data collection. - Basis for Chapter 3. - Read for evidence to elaborate Chapters 4 and 5.
Phase II: Work Practice			
Patient Advocate Interviews	31 semistructured interviews	June 2006 – August 2006	- Accounts of work practice. - Initial data analyzed for Chapter 4. - Read for evidence to elaborate Chapter 5.
Shadowing 75 hours at Heartland Teaching Hospital's patient advocate office; 45 Hours at Reveille VA Hospital's patient advocate office.	149 pages of fieldnotes from the VA; 163 pages of fieldnotes from Teaching Hospital	October 2006 – February 2007	- Patient advocates' interpretation of own work practice in the moment. - Author's observation of work practice. - Initial data analyzed for Chapter 5. - Read for evidence to elaborate Chapter 4.

Appendix 2: Sample of Background Interview Participants

Role	Type of Employing Organization	Sequence of Interview
Patient Advocate and Professional Association Officer	Community Hospital A	7
Patient Advocate and Professional Association Officer	Community Hospital B	11
Patient Advocate and Professional Association Officer	Community Hospital C	14
Administrator of Patient Advocacy Educational Program	Educational Institution 1	3
Administrator of Patient Advocacy Educational Program	Educational Institution 2	4
Professor in Patient Advocacy Educational Program	Educational Institution 2	5
Professor in Patient Advocacy Educational Program	Educational Program 2	15
Director of VA Patient Advocacy Program	National VA Office	6
Manager of Patient Advocacy Department	Teaching Hospital D	1
Manager of Patient Advocate Office (replaced original manager)	Teaching Hospital D	18
Retired Hospital Executive; Past President of National Healthcare Organization; Professor	Teaching Hospital E	2
Chief Operating Officer	Teaching Hospital E	8
Patient Advocate for Benefactors	Teaching Hospital E	9
Chief Nursing Officer	Teaching Hospital E	10
Director of Community Relations; Former Patient Advocate; Professional Association Officer	Teaching Hospital F	12
Manager of Patient Advocate Office and associated offices; Professional Association Officer; Former Patient Advocate	Teaching Hospital G	17
Patient Advocate and Professional Association Officer	VA Hospital	13
Vendor to Patient Advocate Offices	Vendor Organization	16

Appendix 3: Selected Interview Questions and Topics for Background Interviews

Questions about you
- What are your responsibilities as [title]?
- What was your path to this position?

Careers and Training
- What is the career path for patient advocates?
- How long do they typically stay in their jobs?
- What kind of training and educational programs does the VHA offer Patient Advocates and Service-level Advocates?
- What is their content? Are they designed around specific problems?
- Do you have any training on communication or relationship-building?

Everyday Work
- What kinds of problems do patient advocates and service-level most often deal with?
- What are some examples of problems that are out of their scope?
- What do you think are the most difficult aspects of patient advocate work?
- What are the most engaging aspects of patient advocate work?

Questions about the history/origins of SHCA
- When was SHCA founded?
- Why was it founded?
- Why was SHCA part of AHA and not part of other professional organizations such as social work or nursing?
- How has SHCA changed over the years?
- How have the patient advocate role itself and the profession changed over time?
- How do you see SHCA fitting in within the field of patient advocacy?
- Who are the "heroes/heroines" and "experts" in patient advocacy?

Recent SHCA Initiatives
- What was the impetus for the CSU Patient Advocacy Certificate Program?
- Is SHCA undertaking other initiatives like this to accomplish similar goals? Is so, what are they?
- I've read about the Role Delineation Committee on the SHCA website, and would like to learn about their work as a way of understanding the patient advocate role myself. Can you tell me about their work?
- In what areas/contexts does SHCA have the strongest presence? (e.g., areas of the country, kinds of hospitals, direct v. indirect forms of patient advocacy)
- Where does it have the lowest presence?
- In your experience and exposure with patient advocates, what do you think that people in patient advocate roles enjoy the most about their work?
- What do you think they struggle with the most?

Appendix 4: Description of sample of patient advocates
Because they were semistructured interviews, not every background question was covered in every interview. Therefore, some cells are blank.

Teaching/VA	Title	Reports to *(reporting level only to preserve confidentiality)*	Patient Advocate Coworkers	Years as Patient Advocate	Total Years Experience in Healthcare	Highest Degree Obtained	Educational Background	FTE Personnel/Hospital Bed Size
Teaching	Patient Representative	Chief	No	2	12	College	Nursing (RN)	6/1
Teaching	Ombudsman	Manager	Yes	1	25		Licensed Social Worker	15/1
Teaching	Manager of Customer Service	Director	Yes	22	<22	BA	Business	5/1
Teaching	Patient Representative	Manager	Yes	7 months	11	College graduate		8/1
Teaching	Patient Relations Advocate	Manager	No	1	6	College graduate	Medical technology	4/1
Teaching	Director of Patient Representative Program	Director	Yes	3	8	Masters	Pubic Administration	6/1
Teaching	Manager of Patient Relations	Director	No	5 months	15		Social Work	8/1
Teaching	Patient Representative	Manager	Yes	1.5 years	27	Masters	Licensed ordained minister and therapist	5/1
Teaching	Patient Representative	Director	Yes			Bachelors	Nursing	8/1
Teaching	Patient Representative	Director	Yes	14	>34		Radiographer	6/1
Teaching	Ombudsman	Manager	Yes	22	>41	Some college		15/1
Teaching	Patient Representative	Manager	Yes	12	21	Associates degree	Sciences	6/1
Teaching	Patient Advocate	Manager	No	1.5	"a number of years"		Social work	5/1

Teaching/VA	Title	Reports to (reporting level only to preserve confidentiality)	Patient Advocate Coworkers	Years as Patient Advocate	Total Years Experience in Healthcare	Highest Degree Obtained	Educational Background	FTE Personnel/Hospital Bed Size
Teaching	Patient Representative	Director	Yes	2	2	Bachelors	Psychology	8/1
Teaching	Patient Coordinator	Manager	Yes	6	6	Masters	Counseling	14/1
Teaching	Patient Coordinator	Manager	Yes	12	12	Bachelors	Social Work	14/1
Teaching	Patient Coordinator	Manager	Yes	10	16	Bachelors	Science and Social Work	14/1
Teaching	Patient Coordinator	Manager	Yes	20	33	College	Education	14/1
Teaching	Patient Coordinator	Manager	Yes	6.5	14	Some college	Elementary Education	14/1
Teaching	Patient Advocate	Manager	Yes	17	34	College		8/1
VA	Patient Advocate	Chief	Yes	3 or 4	25	Some college		9/1
VA	Assistant Patient Rep	Manager	Yes	8	18			2/1
VA	Patient Advocate	Director	No	3.5	14.5			5/1
VA	Patient Advocate	Associate Director	Yes	11	>30	Some college		13/1
VA	Patient Relations Specialist/informally Patient Advocate or Patient Representative	Manager	No	2	10	Bachelors		11/1
VA	Patient Relations Specialist/informally Patient Advocate or Patient Representative	Manager	Yes	8	26	Some college		7/1
VA	Customer Service Coordinator	Associate Director	Yes	17	34	Two years of College		2/1
VA	Patient Contact Representative	Manager	Yes	7	30			5.5/1
VA	Patient Advocate	Manager	Yes	2	>20	College		5.5/1
VA	Patient Representative	Manager	Yes		15			5.5/1
VA	Patient Advocate	Director	Yes	2	15	Masters		9/1

Appendix 5: Interview Questions for Phase II Patient Advocate Interviews

Introduction:
I am interested in learning about your work as a patient advocate.

Warm-up questions.
1. What was your path to your current job?
2. Please tell me about the hospital where you work.
3. I would like to learn about a typical day in your life as a patient advocate. Can you walk me through a day-in-your-life, to help me understand what you do?

Key questions
4. Please tell me a story about a time when you felt like you handled a case really well.
5. Please tell me a story about a time when you had a really difficult time with a case.
6. Please tell me about a time when you had a patient or family member who wasn't sure what they wanted or needed help with.

Questions about the emotional and bodily content of the work
8. As you work with people in these emotionally-charged situations, do you even touch patient or their family members when you are helping them? Do you have a personal philosophy about when and if it is a good idea to touch someone you are working with?
9. Do you ever interact with people who are crying? Can you tell me about a time when you interacted with someone who was crying?
10. Do you ever cry about something you've experienced at work?
11. When you are interacting with patients, family and staff, do you ever rely on bodily cues? By bodily cues, I mean your bodily responses or felt intuitions. These can include crying, but can also include feeling sleepy or energetic, your heart racing, your throat getting constricted, or blushing.
12. Do you ever feel like your body is helpful in accomplishing your work? Do you ever feel like it gets in the way?

Renewal and stress
13. What do you do to sustain and renew yourself in your work?
14. Do you ever feel stressed or burned out from your work?
   - How do you manage the stress that goes along with this work?
15. What keeps you in this job as long as you have been?

Rules and regulations/Institutional change
16. Can you tell me about the CMS (Center for Medicaid and Medicare Services) rules and regulations for handling complaints? Can you tell me about these rules and regulations and whether they have affected your work?

17. Before we end the interview, I wanted to just ask you a few quick questions.
   a. How long have you been in your current position?
   b. Are there other patient advocates at your facility?
   c. What kind of patient complaints and issues do you most often deal with?

d. Does your hospital have particular specialties?
e. Is your job title "patient advocate" or something else?
f. Who do you report to?

Appendix 6: Summary of Data Collected During Phase II Interviews

PD#	Teaching/ VA	Sources of Data in Addition to Interview	Number of Stories Told During Interview
1	Teaching	Site visit; field note	7
2	Teaching	Site visit; field note; lunch with manager; tour	6
6	Teaching	Site visit; field note	7
9	Teaching	Site visit; field note	8
10	Teaching	Site visit; field note	4
11	Teaching	Site visit; field note; interview with manager	5
12	Teaching	Site visit; interview with manager	8
13	Teaching	Site visit; field note; interview with manager	3
16	Teaching	Phone interview; notes	3
18	Teaching	Site visit; field note; interview with manager	7
24	Teaching	Site visit; field note; lunch with manager; tour	11
25	Teaching	Site visit; field note; interview with manager	0
26	Teaching	Phone interview; notes	2
27	Teaching	Shadowing site	3
28	Teaching	Shadowing site	5
29	Teaching	Shadowing site	4
30	Teaching	Shadowing site	3
31, 32	Teaching	Shadowing site	2
33	Teaching	Shadowing site	6
34	Teaching	Site visit; field note	10
3	VA	Site visit	6
7	VA	Site visit; field note	18
8	VA	Notes	1
14	VA	Site visit; field note	3
15	VA	Site visit; field note	6
17	VA	Notes	7
19	VA	Field note	2
20	VA	Talk with manager; tour; field note	4
21	VA	Talk with manager; tour; field note	1
22	VA	Talk with manager; tour; field note	5
23	VA	Site visit	4

Appendix 7: Body-related categories for shadowing observation

Citation	Theoretical Focus	Methods	Body categories
Mehrabian (1972)	Positiveness, potency or status, and responsiveness in nonverbal or implicit communication	Laboratory experiments	eye contact; distance (proximity); forward lean; body orientation (shoulders and legs turned in the direction of or away from the other); open/closed arm
Martin (1995)	the social construction of gender in preschools	8 month observations of a pre-school	body movements, use of space and physical contact among and between kids and teachers
Kahn (1992)	psychological presence at work, (the psychological state accompanying engaging behaviors)	Inductive study	Indicators of psychological presence: physical presence (standing solidly, not wavering or moving around); steady eye contact; fullness of speech
Bartel and Saavedra (2000)	Observation of work group mood	Observation of 70 work groups	Facial, vocal and postural indicators for 8 points on circumplex model of mood

Chapter 3

The Patient Advocate Role

The purpose of this chapter is to familiarize the reader with the common but little-known patient advocate role. While the next two chapters are in-depth theoretical accounts of patient advocates' work practice, this chapter focuses on information that will help to familiarize readers with the patient advocate role. While such a chapter would be important in many dissertations, it seems particularly appropriate for patient advocates. While most hospitals employ one or more patient advocates, or at the very least assign someone the task of "handling complaints," I have found that most people never knew such a role existed unless they have had occasion to spend a lot of time in hospitals, either as an employee, patient, or family member or friend of a patient. Others within the profession seem to have noted this lack of visibility. Indeed one of the professional association's central topics at the 2006 nation conference was how to "elevate the profession."

Chapter 3 is divided into two sections. In the first section, I provide a historic view, starting with the emergence of the patient advocate role in the late 1960s and a professional association in the early 1970s. I also discuss the patient advocate position in the context of other hospital roles and its historic vulnerability to the financial health of hospitals. In the second section, I provide a contemporary view, starting with a profile of patient advocates. Next, I present an analysis of the kinds of problems handle, based on an analysis of interview data, which sets the stage for Chapter 4. Finally, I describe some

of the key differences between the patient advocacy job at Teaching and VA hospitals, which provides background information for Chapter 5.

A Historic View

Emergence of the Patient Advocate Role

Hospitals began to hire people into newly created patient advocate positions in the 1960s and 1970s in response to criticisms that disadvantaged patients, specifically the poor, mentally ill, and children, were not receiving fair access to medical care (Hogan, 1980). Over the next decade, patient representatives were described as the fastest growing service in hospital settings (Mailick, 1982). Scholars attribute the development of the patient advocate role to a number of historic changes.

First, after World War II, there was growing concern about fair access to health care in the United States (Rehr, 1981). During this era, medical care was provided through two sets of organizations: nonprofit health systems serving the majority of Americans, and local public systems for the poor and indigent (Scott et al., 2000, citing Boychuk, 1994). Health care costs were paid either out-of-pocket, or people without means relied on healthcare provided by local philanthropic organizations. This changed dramatically with the passage of the Medicare/Medicaid Act of 1965, which provided federal government funding for the elderly and poor, respectively. Scott and colleagues (2000) describe one of the primary institutional logics of this period as *equity of access to healthcare services*, in which health care was increasingly viewed as a right of all citizens.

While Medicare/Medicaid established the federal government as the major purchaser of healthcare, the public call for equitable healthcare access continued. The

powerful Joint Commission on Accreditation of Hospitals came under public criticism in

1969 when its newly revised policy statement failed to mention patients' concerns or

problems (Faden & Beauchamp, 1986). Many consumer groups, led by the National

Welfare Rights Organization, drafted a statement for the rights of patients and called on

the American Hospital Association's (AHA) Committee on Health Care for the

Disadvantaged because it included no representatives of the poor (Hogan, 1980). Over

the next two years, the AHA reacted by increasing the representation of patients on the

Committee and developing the first Patient's Bill of Rights (Hogan, 1980). The Bill of

Rights was adopted by hospitals across the US, and by 1980, the Joint Commission on

Accreditation of Healthcare Organizations (JCAHO) included concerns about patient

rights in its accreditation manual (Hogan, 1980).

Second, in 1971, patient grievance and complaint systems were a component of a

national conversation about medical malpractice, a discourse which started because of an

increase in the number of malpractice lawsuits and the resulting increase in insurance

costs for physicians (Faden & Beauchamp 1986; Kersh, 2006). To address this issue,

President Nixon ordered the Secretary of Health, Education and Welfare to appoint a

commission on medical malpractice, which included the charge "to locate, classify, an

analyze patient grievance mechanisms already in place in hospitals and other health-care

organizations in the United States…and to recommend ways to implement systems for

handling patient complaints and grievances" (Hogan, 1980:31). The report concluded

with several recommendations to increase the use of patient grievance mechanisms,

including patient advocate programs. The patient advocate role was seen, and promoted,

as one way for hospitals to become more accessible to patients (Mailick & Rehr, 1981).

The Hospital Context

Historically, patient advocates have had an ambiguous relationship to other hospital roles (Mailick, 1981; 1982). For example, at the same time that the patient advocate role was established, nurses began to see themselves as patient advocates. While nurses today sometimes claim that they were the original patient advocates, in fact, nurses' professional claim of patient advocacy developed in the late 1970s (Mallik & Rafferty, 2000). Some early writing on the patient advocate role addressed the similarities and differences between patient advocates and social work departments in hospitals, and suggested ways that patient advocacy could claim a unique role in hospitals (Mailick, 1982). Specifically, Mailick suggested that patient advocates' unique functions could be "gathering and channeling of data on patient care problems and the resolution of problems for which existing procedures are not working effectively. The domain of the patient representative would be interdepartmental in nature, and would allow for problem identification and resolution that would be more difficult for members of the staff who are assigned to a specific service." (Mailick, 1982:50)

The overlap of the patient advocate role with others in the hospital has perhaps contributed to its vulnerability to the financial woes and fortunes of hospitals and CEOs' priorities (Mailick, 1982). According to my interview informants who had been employed as patient advocates for a number of years, their own departments had been cut from several full-time employees to one full-time employee as their employing hospital went through difficult financial transitions in the 1990s.[1]

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[1] I found only two studies that addressed the size of patient advocate departments. In one, Mailick (1982) reports on a 1975-1976 study that found that three-quarters of patient representative programs have two or less employees. In a second, Charters (1993) reports on a 1990 study that found 47% of hospitals had 1 patient representative; 33% had 2-4; 13% employed 5-9; 7% employed ten or more. In comparison, the

Founding of a Patient Advocate Association

In 1970, representatives from twenty New York City area hospitals met at a

workshop on effective patient relations. This meeting proved to the catalyst for

organizing a professional association. Prior to the workshop, patient advocates worked at

their own hospitals, in isolation from any kind of professional community. By March

1971, the group had organized the first meeting of the newly formed Association of

Patient Services Representatives. One hundred forty people from 55 institutions in nine

states attended (Hogan, 1980). In the Association's first year, they identified four major

patient representative functions (Rehr, 1981, page 135):

> *Outreach* – to seek out those individuals who need services, link the
> individuals to services, link the services within the institutions and help facilitate
> communication among components of the system
> *Advocate* – to identify the obstacles to service, investigate the source of
> difficulty – to identify the obstacles to service, investigate the source of difficulty,
> determine an appropriate course of action, and document and communicate
> findings to administration or that service which can effect change
> *Educator-Mobilizer* – to participate in activities both within the institution
> and in the community which will personalize and humanize delivery of service to
> patients
> *Data Manager* – to provide appropriate hospital departments with specific
> information relating to the delivery of services.

This initial definition of the patient advocacy role has served as an enduring blueprint for

the role.

Decisions about Professional Status

In its early years, the Association made a number of decisions about whether it

would try to seek professional status. For example, the Society's 1973 Committee on

Career Definition submitted, and the membership approved, recommendations about the

education level and prior experience suggested for patient representatives at different

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patient advocates I interview in the second phase of data collection, 19% were the only patient advocate;
55% worked in offices of 2-4 patient advocates, while 26% worked in offices of 5-8.

levels – director, assistant director, entry level, etc. However, at the 1974 meetings, objections were raised about these recommendations. On the one hand, some thought that having too much education might create a social gap between the patient advocate and poor and disadvantaged patients who they served. Those patient advocates with advanced degrees argued that high levels of education would not necessarily impede them from relating to uneducated patient groups (Ravich, 1981).

During this same period, the Association considered whether there was a need for a systematic body of knowledge or theory on which to base their profession. In these discussions, members expressed that they did not want to exclude individuals who may be able to perform the work, but lacked the formal credentials. In 1978, the Association's Board decided not to participate in any formal educational curriculum, but instead to continue offering educational workshops at Association meetings (Ravich, 1981). With this decision made, some leading members, led by Ruth Ravich of Mt. Sinai Hospital, who had been integral in developing patient advocacy and founding the Society, decided to initiate a masters-level program in health advocacy at Sarah Lawrence College. The program was founded in 1980 and continues today (Hurst, n.d.).[2]

Overall, the professional association appears to have deliberately chosen not to seek the markers of a professional group, such as a specific body of knowledge or restrictions about who could enter the profession. On the contrary, the pursued a strategy of openness, as evident in the following passage written in a history of the professional association by one of its founders, Ruth Ravich (1981:143):

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[2] According to my informants, very few of today's graduates of the Sarah Lawrence Masters Program in Health Advocacy work in the hospital-based patient advocate roles that are the focus of this study. Instead, they work in a variety of the different kinds of health-related organizations, including a variety of healthcare organizations (e.g., nursing homes to HMOs), external advocacy groups, and coordinating programs at hospitals (e.g., clinical research programs).

Two of the role models on which patient representation is based are the Ombudsman concept, which is totally professional, and the Citizens Advice Bureau, wholly nonprofessional. It is essential that patient representatives keep these two divergent roles in balance, staying close to patients, humanizing and individualizing health care, as well as advocating for change. The Society does not have "professionalism" of the field as a stated goal at present. Some members feel that becoming "professional" would create a barrier between them and those they serve. They agree with Dr. Paul Cornely who warned that the Society "should shy away from the models of medicine, nursing, and hospital administration." He stated that entry should be an open one in which degrees and paper qualifications would not be the role standard." Other members refer to themselves as professionals. The better educated and more sophisticated members the Society is now attracting may be interested in pushing toward professionalization. The government may also contribute to this move if educational and other job qualifications are established for staff of mandated patient grievance mechanisms. If it becomes advantageous to establish the field as a "profession," some of the necessary steps have already been taken.

The ambiguous stance towards the patient advocate role continued (Waters & Al-Assaf, 1993), until 2000, when the Society for Healthcare Consumer Advocacy (or SHCA – the current name of the professional association) organized a subcommittee to define patient advocates' core competencies, whose work which was completed in 2003. The committee outlined nine core competencies: complaint management, mediation, negotiation, communication skills, data management, measuring patient satisfaction, patient's rights, customer service, management in healthcare (Society for Healthcare Consumer Advocacy, 2003).

SHCA has since worked with Cleveland State University to organize a distance-learning certification program, in which interested students could sign up to take a 5-week virtual course on each of the core competency areas. According to my interview with informants, the certification program was designed to establish credibility and develop a way in which patient advocates could demonstrate expertise and competence in the core competencies designated by SHCA. The program has been very popular, with all

classes being filled with substantial waiting lists. At the time of my interviews, it was too early to tell whether offering these programs was benefiting SHCA in any enduring way.

A Contemporary View

In this section, I introduce descriptive information about patient advocates today. I start with a basic description of patient advocates' demography. Next, I report on the answers to two questions about their work: Who brings patient advocates problems? What kinds of problems are they presented with? The descriptive answer here anticipates the theoretical account of problem-handling work I develop in Chapter 4. Finally, I describe some key differences between teaching and VA hospitals, which anticipate the themes presented in Chapter 5.

Profile of Patient Advocacy

The majority of patient advocates are women (typically approximately 80% in surveys). Seventy percent of the respondents of the 2005 SHCA survey were between the ages of 41 and 60, and salaries ranged from less than $30,000 per year to over $85,000, with fifty-four percent earning between $35,000 and $55,000.

Patient advocates have always hailed from a wide variety of educational backgrounds. Surveys patient advocates consistently report that they have a wide variety of education levels, from high school to masters' degrees, and that they have a wide variety of disciplinary background, including nursing, social work, business, medical technician and education, to name a few (Charters, 1993; Martin, Heyworth, O'Brien, & Tipton, 2006). A number of my informants argued that knowledge of the hospital system and great interpersonal skills are more important than a particular degree or level of educational achievement.

Just as there is variety in the educational backgrounds of patient advocates, patient advocates are known by many different job titles. A recent survey found that patient advocates' job titles included community relations, customer relations, director, guest services, manager, patient advocate, patient representative, patient relations, and staff (SHCA 2005 Compensation Survey). The patient advocates I interviewed or observed add some additional names – patient coordinator and ombuds. There are typically very few (one to three) patient advocates at a hospital, with many working by themselves, and they report to many different departments, including Quality Improvement, Risk Management, Security, Business Office, and their position in the organization often changes over time as different CEOs or Medical Directors enact their vision for how the role should be used.

Change in the Role Over Time: From Reactive to Proactive

My interviews with background informants suggested that the nature of the role had changed over time, from a reactive towards a proactive role, or more specifically, from one in which patient advocates reported problems and made demands on behalf of the patient and their families, to a more interpretive task in which they tried to determine what the underlying problem was and work from within the hospital to resolve the problem. One of my background informants, a long-time vendor to patient advocates, described it this way:

> In the older environments from years ago, the patient advocate was in a difficult situation, because they were viewed as an employee who was advocating on the part of someone who was anti-organization. So it put them in an adversarial role with the very people they need to work with to effect change, so they are in this quandary. But that's an old mentality. The new mentality now is that as a patient advocate, how can I muster, how can I somehow get my organization to work on behalf of this customer, that's what it's all about.

According to my informants, this more proactive enactment of the patient advocate role has been accompanied by simultaneous changes in the educational and professional backgrounds of individuals hired into patient advocate roles. My interviews with hospital administrators, who are in positions to hire patient advocates, suggest that they are developing a preference for people who have a background relevant to healthcare, especially nursing or social work. People with these backgrounds were reportedly seen as having a greater understanding of the hospital context, such that they could, as one of my informants said, "hit the ground running."

The Problems Patient Advocates Handle

The purpose of this section is to provide an overview of the kinds of problems that patient advocates handle. I base this section on an analysis of the stories patient advocates told me about specific cases during the Phase 2 interviews with patient advocates. I coded the stories in two ways. First, I categorized the stories based on who brought the problem to the patient advocates' attention to provide data about who initiated contact with patient advocates.

Second, I sorted the stories according to the "presenting problem," or the concern or complaint that patient, family, staff member or other person brings to the patient advocate. The term presenting problem comes from clinical diagnoses, and captures the idea that the problem the patient (or whomever) presents to the caregiver may not reflect the underlying problem. This was a common occurrence in patient advocates' work. The following passage provides a relatively simple example of the presenting problem being different from the ultimate diagnosis.

> A doctor called me up and said, 'This patient is just not understanding anything. She doesn't want to go home.' And so I went in to talk to her. And then I went

back to the doctor, and I said, 'Did you ask her why she didn't want to go home?'
'No.' 'Well, she's homeless, so she can't go home. She is right.' And he was sort
of speechless. And I said, 'Patients can get intimidated of doctors, so they won't
just tell doctors things.'

In this example, the patient advocate is told by the doctor that the problem is that patient
does not want to go home because she cannot understand him. The patient advocate
learns from the talking to the patient that she cannot go home – she has no place to go.
The work of figuring out what the problem really is previews a theme in the next chapter.
For now, though, I use this as an illustration of what I am and am not coding. The
following section reports on coding of what the problem first appears to be, not what it is
at the end of the process.

Who brings problems to patient advocates? The analyses, summarized in
Table 3.1, revealed that patients most frequently bring problems to patient advocates,
followed by family members. It is interesting to note that patients but not families were
the primary complainants at the VA hospitals, while they were more evenly distributed at
the teaching hospitals. One reason why this may be the case is that families typically
brought complaints to patient advocates either because their family members were too
sick to complain themselves, or because the patient was a child. Because VA hospitals do
not treat children and have a larger percentage of outpatients, patients may be more likely
to be able to have the physical capacity to advocate for themselves.

Several other categories are important to note. When staff brought problems to
patient advocates' attention, it could be because they were forewarning the patient
advocate about a patient who was likely to complain. These could also be instances in
which the patient was causing significant disruption at the hospital (e.g., threatening staff
members), and thus they were requesting the patient advocate's help. On occasion,

patient advocates would be asked to intervene in a crisis situation, such as when a patient has been shot and their family needs support or the hospital cannot handle the large number of people who have come to keep a vigil.

In only two cases, the patient advocates noticed situations in which they might be able to help. This does not necessarily mean that the patient advocates were not proactive; rather it indicates that patient advocates' offices were not in locations in which they might notice problems they could solve in which they could help. As noted in the previous chapter, the patient advocates I studied worked in centralized offices, often with an administrative assistant working as a gatekeeper. Very few of them actively roamed the halls seeking problems to solve.

What problems do they present? As is evident from **Table 3.2**, patient advocates handle a wide variety of problems, but with particular emphasis on medical care. Current and past medical care was the most common reason for seeking patient advocates' help. These cases involved patients trying to access medical resources, such as appointments, surgery, or pain medication. Most often, a patient or family member had tried to access some kind of medical resource and had been turned down or could not seem to access the right person (e.g., to make an appointment). It also included working with psychiatric patients who had what seemed to be irrational fears or anger about their treatment at the hospital (e.g., fear that the staff is trying to cut off their toes). At the VA, this also involved trying to persuade resistant veterans to come into the hospital to get care (e.g., a patient advocate helped persuade a homeless veteran to have part of his necrotic foot removed).

Patient advocates help was sought on a variety of what I call "process" issues, typically involving coordination between departments (e.g., patients waiting for hours to get lab results), slow or inefficient processes (e.g., wait time, surgery cancellations), or explaining complex hospital processes to patients and families (e.g., how they protect patient data).

The next two most frequent presenting problems were reported by patient advocates primarily at teaching hospitals. First, a variety of issues involving end-of-life or grief issues fell into patient advocates' domain. These cases involved the experience of patient and family members near the end-of-life (e.g., crowds of mourners overwhelming the hospital), problems that occur in the hospital around the passing of the patient (e.g., family members upset because staff had not clearly communicating that the patient was brain dead), and grief issues that occur after the patient has passed away, but the family members continue to have issues or questions about the death. Second, patient advocates were presented with problems that involved patient and family's interactions with staff. Most commonly, the patient or family member felt that the employee was rude, failed to listen, or mistreated them. But in a few instances, the staff complained to the patient advocates about the patients or families because they felt threatened, or they had a difficult time working with other staff members (e.g., a staff member faced resistance from a doctor unwilling to sign a needed form).

Another kind of problem involved access to non-medical resources. At the VA, this often meant assisting patients with reimbursements, cashing check or travel pay. Patient advocates at teaching hospitals told stories about planning weddings and other

special events for patients who had been in the hospital for a long time and were facing stays of unknown length.

Patient advocates also were presented with problems about behavior that seemed clearly inappropriate, such as patient or family bringing a pet dog to the hospital because they did not want to leave it alone at their house or in their car, or a patient having sex or doing illegal drugs while also a patient. As mentioned above, they were sometimes asked to help in medical crises that taxed the normal routines of the hospital. On occasion, they also intervened in difficult patient and family situations, such as when estranged family members suddenly had to make importance decisions about the care of a patient. Several patient advocates also described working on lost items (e.g., dentures or cell phones that were lost while a patient was receiving care at the hospital), or instances in which their own behavior or the behavior of their colleagues elicited a complaint.

Summary This section is intended to provide a sense of the kinds and variety of problems patient advocates handle. Patient advocates interact with a variety of people on a variety of problems. This suggests that their standard diet of complaints require that they help people navigate a complicated organizational system, difficult interpersonal interactions, and unusual or atypical organizational situations. Because this analysis is based only on the data from the interviews, it may be weighted toward those cases that are particularly vivid or memorable to the patient advocates, and thus overemphasize the dramatic for the mundane.

Patient Advocates at Teaching and VA Hospitals

As I described in the previous chapter, my dissertation focuses on patient advocates in two types of hospitals, teaching hospitals and VA hospitals. The two types

of hospitals share many similarities, but also have important some differences. One important difference is that patient advocates at teaching hospitals work at independent hospitals while those at VA hospitals are part of a federal network. Specifically, patient advocates at teaching hospitals typically work by themselves or with a small number of other patient advocates. The hospitals that they work in are private, non-profit, or not-for-profit hospitals. The patient advocate role at each of these hospitals has its own history.

The patient advocate role at VA Hospitals is quite different. VA Hospitals are run by the U.S. federal government. The Secretary of Veterans Affairs, one of fifteen Cabinet level positions, functions essentially as the CEO of the Veterans' Administration, which is responsible for overseeing and distributing federal benefits to veterans, their family members and survivors. The health system is the best known and largest portion of the VA. In recent years, it has achieved recognition as a leading and cutting-edge provider of health care services, overcoming a decades-long reputation as a second-rate healthcare provider (Longman, 2007).

Patient advocates in VA Hospitals are a federally mandated position – VA hospitals are required to have patient advocates - to support veterans' access to healthcare. According to the VHA Handbook on Patient Advocacy (2005:2):

> The Patient Advocacy Program was established to ensure that all veterans and their families, who are served in VHA facilities and clinics, have their complaints addressed in a convenient and timely manner. The Patient Advocacy Program operates under the broader philosophy of Service Recovery, whereby patient complaints are identified, resolved, classified, and utilized to improve overall service to veterans. The Patient Advocacy Program is an important aspect of patient satisfaction and contributes proactively to VHA initiatives to provide world-class customer service.

According to my informants, the patient advocate position is promoted within the VA as an important resource. Veterans and their families are typically aware of the patient advocate position, and at many of the VA Hospitals I visited, their names and photos were posted around the hospital. The VA also provides support and training to patient advocates. There is a National Patient Advocacy Office that provides resources, such as an annual conference and monthly conference calls, for patient advocates to support patient advocates in their work.

Regulations Teaching and VA Hospitals are also subject to different kinds of regulations.

Joint Commission on Accreditation of Healthcare Organizations (JCAHO) There are several regulations that have shaped the patient advocate role in recent years, both involving institutions that are powerful regulators of healthcare organizations. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is the industry accreditation agency. Healthcare organizations voluntarily submit to both scheduled and unscheduled inspections of every element of the healthcare organization. After every inspection, the healthcare organization has a matter of days to address and correct all of the elements, and then the hospital will be re-inspected on those issues. Failure to correct the problem issues results in the JCAHO removing its seal of approval, which has vast repercussions. Insurance agencies and the Center for Medicaid and Medicare Services (CMS) use JCAHO accreditation as a sign of the quality of the hospital and whether they will pay for medical care at those healthcare institutions. Thus, JCAHO exerts powerful regulatory pressures on all healthcare organizations.

In 1990, JCAHO's accreditation standards called for the establishment of patient grievance procedures and notification of patients who issue complaints (Charters, 1993). This meant that how grievances were handled became an area on which hospitals were examined. Exactly how hospitals handled patient complaints was not mandated, but according to my informants, patient advocates became one role that could respond to this regulatory requirement.

Center for Medicaid and Medicare Services (CMS) The Center for Medicaid and Medicare Services (CMS) also has significant power over healthcare organizations and hospitals in particular. CMS oversees disbursement of Medicaid and Medicare funds to all healthcare organizations. CMS sets a number of criteria that healthcare organizations must meet in order to receive reimbursement from the government. It is one way that the federal government influences non-VA healthcare organizations.

In 2004, CMS outlined new standards for how hospitals handled patient complaints. When SHCA leadership saw the proposed new regulations, they thought that they did not take into account the realities of their work, so for the first time, SHCA got involved in providing feedback to the legislation that would affect them. These regulations had significant effects on non-VA hospitals. Most importantly, patient advocates are now required to write letters to every patient who had a grievance within seven days to either tell them about the complaint's resolution or to let them know that they received the complaint and are working on it. They are then required to resolve the complaint within 30 days, and write a "30-day letter" telling them how the complaint was resolved, and telling them who they can contact (typically at the state level) if they are not satisfied with the resolution. As one of my informants explained:

I think that as the profile and emphasis on patient rights was elevated, so too has the profession been elevated, because they're so closely intertwined. You can no longer say that a hospital must have a process in place for addressing patient grievances and not feel like your patient advocates are the people responsible for that, that they aren't extremely important to the organization. It's made them feel really much more integral to the whole process, rather than feeling that they were sort of out there.

CMS standards were a major topic of conversation at the SHCA conference that I attended, although they did not affect all patient advocates in the same way. All patient advocates had database systems that helped them to track in detail how each case had been handled. However, not all patient advocates wrote letters to patients. At some hospitals, routine 7-day letters were written by administrative assistants, while in other departments, letter-writing was handled elsewhere. The majority of patient advocates at teaching hospitals, however, have begin to spend a significant portion of their time writing letters to patients who had made complaints in order to comply with CMS standards.

Congress and Office of the General Inspector

As a health system that is part of a federal agency, the VA's funding is entirely dependent upon Congress. They are inspected by JCAHO as a form of accreditation, but they are not interdependent with CMS because they receive no Medicare or Medicaid funding. VA Hospitals are regulated by the Office of the Inspector General.

Conclusion

The purpose of this chapter was to familiarize the reader with the history of the patient advocate role. I have assembled information that shows the historical moment in which the patient advocate role was born and some of the early choices the professional association made that ensured both a desire for openness and connection to the

community but also left the role open to the changing whims and worries of each passing

decade. This history of the patient advocate roles helps to make sense of the lack of

professional authority that patient advocates can bring to bear on their work, and at the

same time illustrates a decades-long history of living with ambiguity. In the next chapter,

I ask, the question, what is patient advocates work and how can it be understood

theoretically?

Table 3.1: Stories Told by Patient Advocates in Interviews, Categorized by Who Brought the Case to Them

	VA	Teaching	Subtotal
Patient	34	40	74
Family	5	32	37
Staff	5	12	17
Crisis (alerted by someone in hospital)	1	4	5
Family and Patient	2	3	5
Patient Advocate	1	1	2
State Inspector	-	2	2
Outside Advocate	1	-	1
Volunteer	-	1	1
Unclear	10	9	19
Subtotal	59	103	
		Total	*163*

Table 3.2: Stories Told by Patient Advocates in Interviews, Categorized by Presenting Problem

	VA	Teaching	Subtotal
Current or Past Medical Care	15	25	40
Process Issue	8	14	22
Grief/End of Life	1	20	21
Staff	2	17	19
Access to Non-Medical Resources	10	4	14
Inappropriate Patient/Family Behavior	1	6	7
Help Staff in Difficult Situation	3	3	6
Crisis	3	2	5
Family Issue	1	2	3
Lost Item	1	2	3
Patient Advocate's Behavior	2	-	2
Other	10	11	21
		Total	163

Chapter 4

**Storytelling as a Means of Organizational Problem Handling:
The Work of Patient Advocates**

Organizations hire employees to handle the real and imagined mistakes, problems and conflicts that customers, clients and patients experience while using the organization's products and services. They are given such job titles as complaint handler, customer service representative, ombuds, troubleshooter and community liaison. I refer to these as problem-handling roles. Research on boundary spanning, emotional labor, impression management, and institutional theory all address problem-handling work.

It has long been argued that problem handlers occupy an important place in organizations because they are on the front lines of the critical organizational task of ensuring that the core technologies and processes of organizations continue to function, uninterrupted (Thompson, 1967). They are boundary spanners, representing organizations to the external environment and processing external information on the organization's behalf (Adams, 1976; Aldrich & Herker, 1977). A number of literatures, including emotional labor and impression management, describe the tactics problem handlers use to problem-solve. The emotional labor literature tells us about how customer service agents (Rafaeli, 1989), flight attendants (Hochschild, 1983), and bill collectors (Rafaeli & Sutton, 1989) use their emotions while interacting with consumers to control interruptions caused by cranky customers, panicky airline passengers, and delinquent bill payers. Likewise, the impression management literature informs us of how hospital

billing agents (Elsbach, 1994; Elsbach, Sutton, & Principe 1998) and others try to influence external audiences' perceptions of the organization, particularly in light of an image-threatening event. A major theme in these literatures is problem handlers' efforts to control and eliminate problems so that the organizational status quo can be maintained.

Institutional theorists posit a second reason that problem-handling roles are important to organization's pursuit of legitimacy from key regulators. Problem handlers, such as EEO/AA officers, are important organizational symbols of organizational compliance to institutional demands (Dobbin, Edelman, Meyer, Scott, & Swidler, 1988; Edelman, 1992; Edelman, Uggen, & Erlanger, 1999). These researchers have traced the emergence of such roles over time with the pursuit of organizational legitimacy, but they tell us less about how problem handlers actually conduct their work (for an exception, see Heimer & Stevens, 1997).

These two approaches inform us about problem handlers' role in maintaining the status quo and of their importance for creating organizational legitimacy. They also suggest strategies that patient advocates use to enact their roles as problem handlers. However, we know less about how problem handlers work on problems that might require an organization or its members to change or adjust. Yet problem handlers, or employees who hear from customers, consumers, patients, about problems and mistakes they experience, may be an important source of learning and change for organizations. Indeed, a growing literature suggests that front-line workers can help organizations learn from problems and that this might contribute to adaptive organizational change (Edmondson, 2004; Tax & Brown, 1998; Tucker, Edmondson, & Spear 2002). However, these studies have revealed the individual and group characteristics that *prevent* front-line

workers from being able to glean organizational improvements from problems and mistakes. In other words, while there is a greater acknowledgement that problems and mistakes can be a source of organizational learning and change, we are still far from understanding how problem handlers work on problems that might require the organization and its members to change and adjust.

The purpose of this chapter is to fill that gap by examining how problem handlers enact their role when the problems they face may require the organization or its members to change. As such, it builds on a growing literature on the "paradox" of embedded agency, which focuses on how individuals, who are part of institutions which shape cognitions, define interests and provide identities, are able to introduce or envision new practices and influence others to adopt them (Garud, Hardy, & Maguire, 2007). One stream of this research locates agency in the ways individuals enact their roles and look at how this approach to their role creates incremental change over time. Specifically, it points towards how interactions with others (Creed & Scully, 2000; Fligstein, 2001), use of organizational and institutional structures, such as routines, procedures, and technology (Feldman, 2004; Feldman & Pentland, 2003; Orlikowski, 2000; Orlikowski, Yates, Okamura, & Fujimoto, 1995), and knowledge of and experience in the organization can help them promote change (Dacin, Ventresca, & Beal, 1999; Dutton, Ashford, O'Neill, & Lawrence, 2001; Lawrence, Hardy, & Phillips, 2002; Reay, Golden-Biddle, & Germann, 2006). In general, this perspective suggests a process approach to studying how work is accomplished to capture actor's agency.

In this paper, I report on a study of patient advocates, or full-time hospital employees whose role is to handle patient and family members' complaints and concerns

about the care and service the patients' receive in the hospital. The patient advocacy

professional association, the Society for Healthcare Consumer Advocacy, describes them

in the following way: "The advocate operates within an ethical construct, which seeks to

promote the interest of the patient first and foremost, and then seeks to promote

relationships between staff and patients" (SHCA, The Advocate's Role Defined, p.1).

Thus, patient advocates, while employed by the hospital, are expected to act on behalf of

patients.

Healthcare is an industry that is particularly motivated to try to learn from

mistakes. The patient rights' movement (Hogan, 1980), the well-publicized concern with

medical mistakes (Gibson & Singh, 2003; Kohn, Corrigan, & Donaldson, 2000), in

addition to the potential for life-and-death outcomes, have forced hospitals to take patient

complaints seriously. Thus, patient advocates' work is regulated by industry and

government agencies resulting in external pressure and oversight that encourages

problem handlers to attend not only to the organizations' view of the problem, but the

perspective of the person experiencing the problem. For these reasons, patient advocates

are an appropriate role from which to learn about how problem handlers can act

agentically and influence organizational change. Before describing the study in greater

detail, I will review the literatures on problem-handling roles and their perspectives on

the agency of problem handlers.

<center>**Problem-Handling Roles**</center>

There are a number of literatures which address the work of organizational

problem-handlers, including boundary spanning, emotional labor, impression

management and institutional theory. All share an interest in the work of those people

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who handle organizational outsiders' complaints about the products and services of the organization. They also differ in important ways, as is evident in **Table 4.1**. The boundary spanning literature directs attention to how those members of an organization who interact with individuals and groups outside the organization process information for the benefit of the organization and represent the organization to outsiders. The emotional labor literature focuses on the emotional tactics employees use to handle customer problems, while the impression management literature focuses on the use of verbal and written accounts (e.g., excuses, justifications) to protect the organization from external threats, such as crises or scandals. These three literatures share a focus on employees who are clearly acting as agents on behalf of the organization, and how these agents enact their role. The fourth literature takes a slightly different tack. Institutional theory tends to focus on how organizations, not individuals, use structures and procedures to prevent organizational problems, such as the establishment of EEO/AA offices as a means of handling discrimination complaints (Dobbin, Edelman, Meyer, Scott, & Swidler, 1988). A small body of institutional theory has looked at the work of individuals in problem-handling roles. In the following section, I provide a high level review of each of these literatures.

Boundary Spanners

Boundary spanners are members of a group or organization who have frequent contact with people outside of it (Adams, 1976). They have two organizational functions. One of boundary spanners' primary roles is information processing (Aldrich & Herker, 1977). They scan the environment and make inferences about what information the organization can benefit from and what information can be ignored. When information

needs to be brought within the organization, they translate it, making it understandable to others who may use different language or have different values (Pawlowski & Robey, 2004; Tushman & Katz, 1980). At the same time, boundary spanners are also the public face, or the external representative, of the organization, which may require trying to control the organization's public image (Adams, 1976). When there is a problem or conflict, boundary spanners bring that information into the organization to learn from it and protect the organization's public image.

There are at least two approaches to how boundary spanners accomplish their work. In the "information processing perspective" (Kellogg, Orlikowski, & Yates, 2006) on boundary spanning, information as objective and concrete, boundary spanning work involves translating and transporting information across the boundaries. A recent article on patient advocates took this approach, as evidenced in the following example:

> "…an advocate met with a patient who believed that she was treated rudely while checking into a primary-care clinic. The patient indicated that the clerk was rude for no apparent reason. The advocate in turn met with the employee and discussed the importance of good body language, using an appropriate tone of voice, and attempting to display sincerity while at the same time making a patient feel welcome. The patient advocate stressed the importance of using effective communication and thus creating a more positive first impression for the patient." (Martin & Tipton, 2007, p. 188)

The description of this interaction suggests the advocate simply has to meet with the patient to collect the information, and then convey what he or she heard to the clerk. This account of the work is devoid of any emotion and attention to any relational skills that may be needed to solicit the complaint or convey its import to the clerk.

A second boundary spanning literature considers the political aspects of boundary spanning, in which people may have identities and resources at stake in working through problems across boundaries, which can evoke strong emotions (Kellogg, Orlikowski, &

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Yates, 2006). When conflicts occur, Bechky (2003) found that boundary objects, or artifacts that have some meaning in both social worlds (Star & Griesmer, 1989), can be used to transform conflicting understandings because they prompt conversations that change both groups' understandings of their work.

While this research suggests problem-handling requires interactions between people, the existing boundary spanning research looks at boundary spanners' relationship-building skills among members of the same organization, in which the shared goals and organizational identity often help to override or soften the need to deal with problems or complaints (Bechky 2003; Kellogg, Orlikowski, and Yates 2006). We do not know about the relational skills required for boundary spanners to work with organizational outsiders, such as customers or patients.

Emotional Labor and Impression Management

When emotional labor and impression management research is used to study problem-handlers, they focus on how employees, such as flight attendants (Hochchild, 1983), bill collectors (Rafaeli & Sutton, 1989), and cashiers (Rafaeli, 1989), control customers who experience problems in order to minimize disruptions to the organization. In both literatures, the problem handlers represent the organizations that employ them. They may resist the constraints of the role or experience conflict and stress because of them (Goolsby, 1992; Singh, 1998; Singh, Goolsby, & Rhoads, 1994; Weatherly & Tansik, 1992), but these literatures do not entertain the merit of a customers' problem. To resolve a problem means to control it and mitigate any threat the problem might cause for the organizations' operations or image.

While these two literatures share this view of the problem handlers' position relative to the organization and customer, they differ in the kinds of strategies the problem handlers employ. The emotional labor literature suggests that problem handlers use their own displays of emotions and feelings to influence the customer (Hochschild, 1983; Wharton, 1999). The impression management literature suggests that problem handlers use verbal and written accounts to justify customers' negative experiences (Elsbach, Sutton, Principe, 1998). These literatures gloss over how problem handlers might evaluate the merit of a customer's problem, and how the problem handler might influence the organization to make amends or change as a result of the problem.

Together, these two literatures suggest a variety of ways through which problem solvers might accomplish their work – emotion work, verbal and written accounts. The emotional labor and impression management literatures are less helpful when considering a role such as patient advocacy, in which the employee is supposed to assist the patient and family, which may put them in conflict with some members of the organization.

Institutional Theory

Institutional theorists also write about problem handlers. This literature has focused primarily on the establishment of EEO/AA offices as a symbolic means of organizations gaining legitimacy with external constituents and the adoption of grievance and due process structures (Dobbin et al., 1988; Edelman, 1990), which might employ problem handlers. Less attention has been paid to the people who run and are employed by those offices, but the few studies that do exist suggest that while these offices might have been established for the sake of external legitimacy, once in place they "develop a life of their own" (Edelman, Petterson, Chambliss, and Erlanger, 1991). This research

suggested four ways in which people enact these roles. An *advocate* places women and minority rights above administrative ones; a *player* sees management as main client; a *professional* sees themselves as a neutral authority and emphasizes fairness, while a *technician* retreats from political role; focuses on mundane aspects of role (e.g., data collection). What is important about this study is that it suggests that there are a variety of different ways that problem handlers view their roles and that they suggest that they can influence in the organization. How the problem-handler interprets his or her role and environment is an important influence on how they enact their roles and attempt to have influence within organizations. It is less clear, however, what strategies they use to advocate on behalf of others.

Summary

Looking across these four literatures, we can see that we know relatively little about how problem handlers enact their role when the problems they face may require the organization or its members to change. The current literature suggests that the work could involve emotional work, relational work, and that problem-handlers' interpretations of a problem or situation may be important. However, we still know relatively little about how problem handlers might enact their role and help an organization and its members learn and change from the outsiders' problems. The purpose of this study is to build on the existing literature to investigate how expert problem handlers, hospital-employed patient advocates, express agency, resolve complaints and have influence in their organizations.

Chapter-Specific Research Design and Methodology

The focus of this chapter is the patient advocates' problem-handling work from their own perspective. Thus, my analysis focuses on the interviews with the 31 patient advocates (Phase 2) were the central focus. I developed the initial model of problem-handling based on the stories I extracted from the interviews. Then I compiled evidence from all other sources of data in an iterative process to elaborate and refine the model.

Data Analysis

The data analysis for this chapter began in earnest after I left the field. I followed the general guidelines offered by Glaser and Strauss (1967) and Miles and Huberman (1984) in analyzing the data. The data analysis included four major steps. In the first step, I read through the stories and developed a list of the actions that patient advocates described and the factors described as important resources for accomplishing their work. The categories emerged from the data, informed but not constrained by my prior reading of the literature.

In the second step, I tried to make theoretical sense of the different actions generated in the first phase. To that end, I shifted focus from the particular tactics patient advocates described to trying to see the larger pattern within the stories. To that end, I re-read the stories and grouped them according to their endings, or what the patient advocate accomplished or tried to accomplish in the story. Once I identified the ending of each of the stories, I grouped them into categories and defined and described each of the categories (e.g., listen to patient; help family member of deceased patient through grief process; changing policies).

In trying to understand these story endpoints in conjunction with the actions from the first analytic phase, I worked at "enfolding the literature" (Eisenhardt, 1989). I read literature on boundary spanning (e.g., Tushman & Scanlan, 1981), emotional labor (Hochschild, 1983), and dispute resolution (e.g., Kolb, 1987; Kolb & Bartunek, 1992), as well as different approaches to using qualitative data to understand organizational processes, such as grammars of action (Pentland, 1995, 1999), moves (Goffman, 1981) and structuration theory (Giddens, 1984). While all of these were helpful in capturing one portion of patient advocates' work, I found the storytelling literature (Boje, 1991, 1995; Martin, 1983) particularly helpful. It provided a relatively simple organizing metaphor for understanding patient advocates' work, and compared to the other theories I read it was best able to explain the process (Ragin, 2001).

Using the storytelling literature as a guide, I revisited the categories generated in the first stage of analysis and found that they could fit within a model of organizational storytelling. I then read through all of the data to seek evidence that would help to elaborate and refine the storytelling model. **Table 4.2** presents evidence that grounds the model of organizational storytelling. **Figure 4.1** presents the model developed through the analysis.

As I began to write about and describe the data as organizational storytelling, new questions were raised which required further analysis. In the third pass through the data, I coded and categorized how patient advocates evaluated their own effectiveness. I selected portions of the full interview transcripts, looking for segments in which they talked about what made their work, frustrating, challenging, or rewarding. Patient advocates discussed this topic both when I asked them about cases that were particularly challenging or

rewarding, but also arose when talking about cases in general. I categorized their answers into positive and negative responses, which in turn elaborated my theory of patient advocates as storytellers.

In the fourth step, I looked across all sets of data to understand the organizational role in supporting the model of organizational storytelling. The purpose of this analysis was to identify ways that the hospitals may be encouraging, implicitly or explicitly, patient advocates' use of storytelling. In this final step, I read through all sources of data and looked for evidence of organizational structures or practices that encourage patient advocates to work in this way.

Findings

Overview

My findings are organized around four research questions, which together present a process model of problem handling as organizational storytelling, presented in **Figure 4.1**. First, *What is the work of patient advocates?* My analysis suggests that patient advocates can be understood as organizational storytellers. As storytellers, they go through a process of being a good audience for the complainant, construct the story's problem, and then try to enlist others in the story's resolution. I review evidence for these findings from multiple sources of data. The second research question is, *How do patient advocates' accomplish their work?* My findings suggest that they draw upon a number of relational practices to construct the problem and enlist others in the resolution. To be a good audience, they provide patients with the experience of being heard, treat every concern as important, and attend to their own words and bodies. To construct the problem, they discern and investigate. To enlist others in the resolution, they engage in

perspective-taking and creatively use rules and regulations. Next, I ask, *How do patient advocates evaluate how well they are doing?* I find that patient advocates do not get very much formal feedback, but instead rely on cues gathered from the patients, families and hospital staff with whom they interact. Finally, given my findings suggested that patient advocates engage in organizational storytelling, *Are there ways that the environment, such as the organization or larger institution, encourage or support patient advocates to accomplish their work via organizational storytelling?* I find that there are several ways in which the environment in which patient advocates work support patient advocates working in this way.

The Work of Patient Advocates

I begin by describing the three steps that comprise the storytelling model and the practices patient advocates engage in to accomplish them. I then move to discussing the context of this work. I address both the contextual cues patient advocates receive for their work, and the structures that support a storytelling approach to problem-handling work.

Step 1: Being a good audience for the complainant

When patients and family members reach a patient advocate on the phone or walk through their office doors, it is typically because the organization's normal, routine ways of handling the problem has not worked. By the time a patient or family member reaches a patient advocate, they are often frustrated not only because of the problem itself, but because others in the organization have been unsuccessful or unwilling to help them with the problem. Patient advocates keep the complainants' histories of failed or frustrated complaint resolution in mind when interacting with them. Patient advocates try to counterbalance the experiences they have likely had in the organization. Thus, patient

advocates' first step when interacting with a complainant involves becoming viewed as a credible complaint handler in the eyes of the complainant. To accomplish this, the patient advocate tries to provide patients with the experience of being heard and to demonstrate that their concerns are being taken seriously. They accomplish these goals by paying careful attention to their words and bodies. I describe the goals and means below.

Providing complainants with the experience of being heard According to patient advocates, complainants often feel like they have been ignored or "not heard" by other staff members in the organization. To counterbalance that experience, patient advocates try to give complainants the experience of being heard, by which I mean expressing their experience and point of view and having it acknowledged as a legitimate. Patient advocates often described this when discussing the importance of listening:

> I think listening is the key feature. That's just giving them a minute to listen to them....I may even [be] real clear on what the problem is and what the answer is. But if they don't feel that they've told me the problem then they're not going to hear the answer and they're not going to take a recommendation, or they're not going to be happy with it. They feel dismissed. So I think that's really the bottom line, is listening and letting them get it out, you know, before you start to solve it.

As the patient advocate describes, when patients feel that they have fully expressed their own account of a problem, they are more willing to believe later on that the patient advocate has heard their complaint and is addressing the true issues that they have.

Treating every concern as important A second element of becoming viewed as a good audience is treating every concern as important. This can be a challenge because patient advocates hear a wide range of complaints, from the moving to the mundane to the absurd. Patient advocates are careful to appear to take each and every concern seriously and to consider the complaint or concern from the teller's point of view, as a patient advocate describes:

I had one guy come in, the most obscure complaint I've ever heard. So he came in, and he said that he had a complaint against the cafeteria. Okay. So you're thinking food's not properly prepared, it's too cold, something along those lines. He said that he was eating this hotdog, and his hotdog bun broke. It's bread, you know, what's the problem? He said, "So I called the manager over." And I went, okay, the problem is the manager didn't listen to him. No, the manager did apologize for the bun breaking, gave him a five-dollar coupon for his next meal, apologized for the service that he got, and said hopefully your next meal will be better. So then we go on, "Well, what's the problem?" I mean, at this point, I was kind of lost. And he said, "Well, I think you're serving day-old bread to veterans because that bun was too brittle, and veterans shouldn't be getting day-old bread." We weren't giving them the freshest bread. And I thought, you got to be kidding me. I mean, your bun broke. But he had five-dollar coupons because his bun broke. And he said he lost his appetite, couldn't eat it anymore. You know, I don't know if it's day-old bread, I have no idea. But by God, I eat day-old bread at home, I eat week-old bread at home! And I don't know if it necessarily was the case or maybe the previous person didn't wrap it up. I don't know. But that was probably the silliest complaint that I've ever got. Out of all the stuff that can go wrong in healthcare...a piece of bread breaking is not on the top of my list. But you still have to treat him and his problems like you would somebody that husband had died and think that we were the cause of it, because to them, that is their problem.

This patient advocate explains that he and the patient view the complaint differently, but the patient advocate tries to understand the complaint through the patient's perspective and is careful to convey that he is taking the complaint seriously, even when the complaint seems relatively unimportant and absurd.

Attending to their own words and bodies The ways that patient advocates provide patients with the experience of being heard and demonstrate that every concern is important is through careful attention to their words and bodies during the interaction. In the following example, the patient advocate talks about an early failure that taught her the importance of choosing words that would convey that she takes complaints seriously.

I had a gentleman call on the phone, and he had a complaint about something... what I should have said was, "Sir, is there anything else I can follow up on for you?" Instead…it was the word, "Just." So and I said, "This is just the concern that you'd like me to follow up on?" "What do you mean 'just the concern'? Don't you think this is an issue?" and it was like, "Oops, wrong. I said the wrong

thing." Sorry, rewind, start over. So never use the word "just" because it's like somehow demeans the level of importance of their concern.

Patient advocates also demonstrated their concern and seriousness by conveying neutral attention with their bodies. They neither displayed a great deal of empathy or emotion, nor did they express doubt about what the complainant was saying. This was sometimes a challenge because patient advocates hear a wide range of complaints. Even in the face of such stories, patient advocates work to maintain a neutral kind of attention. In the following quote, the patient advocate talks about maintaining this kind of attention in the face of incredulous stories.

> Some of the things you hear are like amazing. Just to be honest with you, they are incredulous. You look there and you just want to let your jaw drop and your eyes bug out but you can't do that. Just to be neutral in facial expressions and not respond with arm or hand gestures or any movement that indicates one thing or another. I usually sit and speak to them face to face and make eye contact and hear what they have to say. If I need to, I'll ask them to slow down so I can write everything that they say. That's kind of like my standard for interacting with them.

These passages demonstrate that patient advocates carefully deploy their words and bodies to be a good audience to the complainant.

Effects on problem handling When complainants feel like their concerns have not been heard by others in the hospital, sometimes simply being an attentive audience can transform the complaint. In the following passage from my shadowing field notes, Lenora, a patient advocate at Reveille VA Hospital, explains how being a good audience can be transformative to a complainant's experience of their problem:

> I asked Lenora what had happened with the man with the walker [a patient who had come in earlier that day]. She explained that he had all of his papers together, and she had made notes about his story in the complaint system so that there would be a record of it. She said, "It's not my job to figure out if [the social worker] is lying. Do I think that the social worker took money from him? No. I think he [the social worker] is credible, but how am I to know? People steal from

each other all the time. Now [the man's] concerns are documented. [The patient] was a very intelligent man; there was nothing wrong with his mind. He said to me at the end of the conversation that he feels like he can let it go. And I felt good about that. Often people come to us looking for validation, and he can get it from me. Sometimes they need credibility in the system."

As such, being a good audience can provide an immediate sense of resolution for the patient.

My informants suggested that when patient advocates are successful in being viewed credibly, the complainant is more likely to feel later on that the patient advocate has heard their complaint and is addressing their concerns. When patient advocates are not a good audience for the complainant, for example by not respecting the storyteller, the patient or family member may become even more frustrated or upset, or simply walk away. In these cases, the patient advocate has failed to resolve the problem.

Discussion When patient advocates first learn about a concern or complaint from a patient or family member, they work hard to be a good audience for the complainants' accounts. In this context, being a good audience means providing the complainant with the experience of being heard and conveying that their concern is being taken seriously. The means through which patient advocates convey this are through careful attention to their own words and bodies. This affects their ability to work with patients and families to handle complaints.

Step 2: Constructing the story's problem

When a problem is brought to patient advocates' attention, the information is often ambiguous, incomplete, contradictory and complex. People seeking care in human service organizations, such as patients and their families, cannot always clearly articulate their problems because they involve both conscious and unconscious thoughts and

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feelings. As Kahn (2005:15) describes, "Patients may know that they need specific operations or medication but not that their fears might disable them from following courses of treatment." Thus, the initial accounts patient advocates hear from a patient or family member are often ambiguous. The accounts that a patient advocate hears may also be incomplete, so that they are compelled to "fill in the blanks" of the story by seeking additional information from other people who might have insight onto a particular problem (Boje, 1991). The multiple accounts patient advocates hear may contradict each other, and as a result, the patient advocate may have to sort through these conflicting accounts and construct what they believe the problem is. Finally, because patient advocates only handle those disturbances that cannot be resolved through the usual routines, they often involve complex emotions, interpersonal relationships and organizational interdependencies.

The importance of being able to construct the problem was first suggested during my background interviews. For example, a number of my informants suggested that the role had changed in recent years and that newly hired patient advocates were selected in part based on their ability to look beyond surface-level stories to understand underlying needs and wants. A Director of the VA Patient Advocate described it the following way:

> *Has the patient advocate role become more visible in recent years (in the VA)?*
> I think there's an attempt on the part of the VA to get people into the positions who can do more than simply say, "This is what the patient wants, how can I get it for him?," but to be able to say, "This is what the patient wants, but that really isn't the problem. The problem is this." Nobody's bothered to explain to the patient why the doctor's getting all these tests and doing all these things.

Similarly, a communications professor in the graduate school program for patient advocacy suggested that a major goal of her class was to help future patient advocates realize when patients complain, there may be more to the story than first meets the eye:

One of the things that we talk about a lot [in class] is that when you're a patient you don't present things in a rational manner. You could think that you will hear somebody and you will be advocating for the wrong thing because you haven't really heard what the person's issue is. I can give you a perfect example of this. There was a case that somebody brought up [in class] about a male in his 30's who was a quadriplegic and they had changed his urinary catheter and the bag that went with the catheter only could hold 500mls of fluid. The problem was that he had to change that bag every 2 hours because he had a huge amount of fluid. I don't know what his circumstances were but anyway this is what sort of was going on – he had to change the bag every 2 hours. He was really upset about that. When I asked the class, "Okay, think about this. What's really going on with this guy?" All they could think of was well, "The bag is too small." I said, "Think about what happens when the bag is too small. The guy's problem is that he can't sleep. He can't get through the night. Imagine your whole life not being able to sleep for more than 2 hours because you have to change this bag and how painful that would be." That's what I'm talking about. They are not thinking about the broader picture. If you think about if from the standpoint of, well here's a patient that can't sleep for more than 2 hours, that might lead you in a very different direction than if you are just thinking about the size of the bag. I mean it might or it might not but that's sort of the thing that I'm talking about of being able to hear what's really going on with somebody.

As this informant suggests, constructing the problem is critical to their work because problem-definition influences how they will direct their efforts to help the complainant.

How do they construct the problem? My analyses suggest that patient advocates engage in two sets of strategies to construct an account of a problem: discerning practices and investigating practices. I describe each in detail below.

Discerning Practices

Discerning is defined as using one's intellect and senses to perceive or distinguish one thing from another (Oxford English Dictionary, 2nd edition). Discerning practices involve *using one's intellect and senses to work through ambiguous information toward constructing an account of a problem.* Patient advocates use discerning practices when they are in conversations with others. These practices involve relating to others in ways that encourage other people to feel comfortable sharing their story. At the same time,

patient advocates have to clarify and evaluate the credibility of the story. If the story is not credible, then they continue to seek information, either from the complainant themselves through discerning practices or from others through investigating practices. My analyses indicate that they do this through the following five tactics. In trying to construct a problem, a patient advocate may use one or all of these tactics.

Encourage emotional expression When patient advocates first learn about a problem, they do not try to suppress others' emotions, but instead provide an opportunity for them to fully express them. At the same time that the patient advocate is providing an opportunity for the complainant(s) to be heard by a member of the organization, they also use it as an opportunity to understand the emotions complainants may be feeling, information patient advocates can use to tailor their responses. This is exemplified by a patient advocate who described hearing a complaint from the family members of a patient who had just died:

> [When I got there] I let them vent their anger. I can't say that I know how [the patient's family] feel, because I don't; they may be feeling guilt, or like they haven't resolved something; they may be angry. But I let them vent, and that's where they were - I didn't try to get them to do something else. Then I let them talk. Is there someone I need to call? Perhaps you would like some prayer. And they will say, yes, we need that to keep the family together. You have to know how to gauge situations.

In this passage, the patient advocate explains that she let the family members vent their feelings and did not try to control or make those feelings fit into a particular prototypical response of a grieving family. The patient advocate explains that she doesn't know how the family feels. In fact, the patient advocate suggests three *different* emotions the family members may be feeling – guilt, unresolved feelings and anger. By letting the family express their emotions fully and then talk about what they need, the patient advocate

learns information about the family's emotional state that may be useful in understanding

the nature of the problem, and eventually, tailoring her response to their complaint.

Attention to physical space Patient advocates pay careful attention to how the

physical space affects a person's ability to articulate the problem. By physical space, I

mean both the content and arrangement of objects in the room, such as furniture,

decorations and temperature, and the positioning of their own body in relation to others'

bodies. Patient advocates attend to the complainant's emotional and physical cues during

the interaction and try to navigate the physical space in ways that will facilitate good

information from the complainant(s). In the example below, a male patient advocate at a

VA hospital explains how he positioned his body and the physical objects in his office to

create a physical space that would enable a veteran to articulate the problem.

> If it's an intense emotional kind of situation, I'll come out with my chair, so then
> I'm close, but not confrontational, and certainly not hiding behind a desk,
> because...I think that puts people off....And especially with female veterans,
> there's always the risk…that they have been the victim of MST, a military sexual
> trauma [Rape, sexual assault]. It just seems awfully common.
> *Raped by other members…?*
> Someone in the service. Someone who's probably outranked them. And so I want
> to get away from any appearance that I'm outranking them because we want to
> bring that out if...if they have that in their history, and they haven't brought it out
> before, it's, you know, it's going to be eating them up....that needs to come out so
> that we can get it addressed. And so I think that the desk is a barrier that interferes
> with that. But you got to be careful too, not to come and put your arm
> around...someone who's trying to wrestle with this issue, because then...then it
> just...there it goes again. You'll drive it deeper, so...I guess you have to kind of
> finesse the situation.

The patient advocate in this passage is attentive to the physical space and how his own

body and the objects around him can potentially encourage or discourage a patient's

ability to name the reason for her visit.

Inquiry One of the challenges of patient advocates' work is knowing whether the complainant has shared all of the relevant information, or if there may be some additional part of the story that has not yet been told but should be brought forward. Patient advocates have both direct and indirect ways of finding out whether there is more to a story. First, patient advocates ask questions oriented toward clarifying problems, as we can see in the following passage:

> I actually had a complaint from a gentleman who kind of complained about our ER doctor. He phrased his complaint to the extent that he made me think that he was complaining because the doctor said that he would admit him to the hospital. I was like, you're telling me that you were upset that the doctor is trying to help you and he's going to admit you to the hospital? He just wasn't very clear or very good at how he expressed himself…..
> *What do you do in those situations?*
> I try my best to hear what they're saying and then if I think I have an understanding of what it is they are concerned about, I will repeat it to them and say "so your complaint is that the doctor didn't do this or this is what happened or that is what happened."

By getting clarity about the patient's underlying issue, the patient advocate can know how best to act and handle the complaint. Thus, the inquiry associated with discernment helps to uncover the complainant's issue and therefore help the patient advocate know how to resolve the complaint.

Challenging a patient's complaint Another form of discerning is challenging an aspect of the patient's complaint by presenting an alternative perspective, and this in turn reveals a little more information about the patient's complaints and priorities. In the following example, a patient had called, very upset, with the complaint that her "face was on fire" and she needed some help:

> …She also said that she was trying to get in touch with me and she figured she couldn't get in touch with me because of the holiday. The operators know very well how to get in touch with me at 2 in the morning. She said that when she finally got through to a ringing phone, she said it just rang and rang. My phone

never rings and rings….I was basically just telling her it was kind of insulting for her to say I tried to get in touch with you but I couldn't, because I have from day one always made myself available. She ended up saying she didn't know who she was supposed to contact and that she would just wait until after the holiday. Okay, so, I appreciated her being honest and what I took from that was I will e-mail the nurse manager and then the nurse manager would get back with me. In the mean time there's really not much that I can do about it right now.

In this case, challenging the patient's account revealed information that helped the patient advocate know more about how to respond to the complaint. Though she had begun her complaint with a description that might sound alarms (a complaint about patient's "face on fire"), by challenging the patient's account, she learns that the patient was lying, which helps the patient understand that the issue is not as urgent as the patient advocate originally thought.

Attention to own responses There are also indirect ways in which patient advocates sense whether there is more to a story. At the same time that patient advocates intently focus on others, they simultaneously pay attention to themselves – to their own reactions, cognitive, emotional and physical. Patient advocates describe paying attention to their own emotional and physical reactions while listening to a complaint, and use them as a way of evaluating the credibility of the story.

> Sometimes when people lose their loved ones, they'll call with a multitude of concerns. And then, sometime...somehow you just have this gut feeling that there's something else going on. And what ends up coming out at the end, when all is said and done, is that there might have been some unfinished business between this individual and their loved ones. And so now, this individual is [on] this crusade...You know what I mean?

Here the patient advocate talks about her "gut feeling," as a way of paying attention to her own bodily feelings to evaluate the stories she hears.

Patient advocates also imagine themselves as the actor in the story, as a way of comparing how they would act with how the complainant acted. In the following

example, the VA patient advocate is describing a case in which the patient has a

combination of physical and mental health issues*:*

> Now he never would initially, until he was seen here in the Medical Center, admit
> to abusing alcohol. He has never, at all, admitted to abusing drugs, or anything
> else. So hopefully, that is not his problem, but he is definitely abusing alcohol.
> And his logic for the alcohol consumption is back pain. So you and I, as logical
> thinking people, [if we were] veterans, would have gone to the veterans' hospital
> when you first got here...because you had intolerable back pain. His answer for
> that was, "I'll just drink to keep myself kind of numb, and then the back pain
> doesn't hurt me so much." So he has at least a minimal mental condition, just not
> logical thinking.

The patient advocate brings herself and me ("you and I as logical thinking people") into

this story as a way of evaluating his behavior and logic. She uses this to help understand

the patient's story, as someone who has issues with addiction, some ability to reason,

though not logically and not compared to some standard of normality.

Investigating

Once patient advocates have heard an initial complaint and decided that it should

be looked into, they have the authority and autonomy to investigate the complaint. Unlike

discerning, which involves sorting through ambiguous cues, investigating involves

seeking information from other people to more fully understand and resolve a complaint.

They may talk to others to get additional perspectives on a story, check out facts, or learn

about how policies, procedures or regulations are applied in a particular setting.

Investigating is primarily a social activity; it occurs through interacting with other people,

and less often through reading books or looking up facts the internet or the hospital's

intranet.

Patient advocates' responsibility for resolving complaints provide them with both

the time and the authority to contact others about a complaint, which is not true of others

who populate the boundaries of hospitals. Even if hospital staff members are aware of a problem that they think should be addressed, they do not necessarily have the time to step away from their own responsibilities to look into it. Further, they may feel personally vulnerable and hesitate to speak up.

Patients and their families' ability to investigate a problem they experience are hampered in a different way. While they may experience a problem in the hospital, they may not know how to navigate the bureaucracy to resolve it. As I overheard one patient mutter to herself on a crowded hospital elevator, "this place is too much for me." Patient advocates have the advantage of embeddedness in the organization (Reay, Golden-Biddle, and Germann 2006): they are familiar with the context through their years of experience in the hospital or health care more generally, and while they may not know the answer to a given problem, they have knowledge of the organization, networks of contacts and some knowledge of the rules and regulations that govern it such that they can work on the complaint.

A complaint may not require any investigation, or it may involve communication with dozens of people, depending on the complexity of the situation and the validity of a complaint. For example, after a patient's family member called to report that a clerk made racist remarks about an African-American doctor in the clinic in which the clerk worked, the patient advocate reported the incident directly to the clerk's boss (the clinic manager), who decided to address the issue immediately. When the patient advocate reported this to the clinic manager, she did not doubt the validity of the complaint, that the clerk's behavior had violated appropriate procedures, or that the clerk's behavior

should be addressed. Because of the clinic manager's response, no further investigation was necessary.

Other times, a case may require multiple phone calls to try to understand, for example, why a patient failed to receive his medication. In the following example, notice the patient advocate describes getting information from patient, teller nurse, neurology, pharmacy ("pharm clinic"), and the doctor, and how this new information changes the patient advocate's understanding of the complaint.

> This morning, when I got in, there was a call on my phone from a veteran, and he's been…trying to get his medication since last month. He didn't know what the problem is, but now he's out of it. He can't sleep, he hasn't been able to sleep for seven days. He's been trying to get his medication for a month. 'Why won't this VA help [me]? What kind of place is this? And I'm calling my President.' That's how the conversation started. [laughter] And you're within your rights to do that. I mean, no one could stop you from doing that...I can't make you not do that, but how about I try to help you here.
>   What I found out along the way was, yes, he did in fact try to refill his medication, but he went through our 800 number teller nurse, instead of calling the Pharm Clinic where he is a patient, and going through their refill line, which he has done numerous times in the past. But he's old...and obviously, he did not remember that that's the procedure for filling this medication….According to Neurology, they forwarded it to the Pharm Clinic, but the Pharm Clinic says they never received that. They have an established extension to dial for medication refills. They have a nurse that takes all of those messages and then gets the refills to the appropriate doctor so that they can sign off on them, so the medication can be refilled, and we do a pharmacy mail-out. It comes from another state, and it's mailed directly to the patients. So none of this happened because he called the wrong place, the wrong place didn't get the information to the right place....and so his doctor never knew that he needed the refill.

By getting additional information from a number of different people about why the patient had not received his medication, the patient advocate is able to come to her own conclusion about what caused the complaint. With this new information, she is able to decide how to handle this particular complaint.

Discussion To sort through ambiguous, incomplete, contradictory and complex information, my analyses suggest that patient advocates focus on answering the question, "what is the problem in this story?" Discerning and investigating are relational practices patient advocates engage in to understand and articulate for both themselves and others the problem a patient or family member is facing. Discerning involves patient advocates relying on their own and others' physical and emotional cues to construct the problem. Investigating enables the patient advocate to bring new perspectives and information to their understanding of a problem through direct solicitation of additional information.

Patient advocates' understanding of the patient or family members' predicament helps them organize the actions they will take to resolve the complaint. It is important that patient advocates construct the story's problem for two reasons. First, identifying the underlying problem helps them organize their own response. If the patient advocate does not understand the problem, they do not know how to respond to it. Second, when patient advocates construct an account of the problem, they may have to explain the problem to an audience in order to resolve it. As one patient advocate describes, "I am always sort of thinking okay, what are the sound bites of information that I need to bring forward so that we'll be clear about what's happening?" The patient advocate may have to "bring forward" information to three potential audiences. First, patient advocates may need to enlist others to help resolve a problem so they must have a credible and motivating story to enlist others' support and participation. The second potential audience is the complainant themselves. Patient advocates may decide that the problem is illegitimate, and may need to explain to the complainant why they cannot help them. Finally, patient advocates are often key players in hospitals' grievance mechanism in hospitals, so patient

advocates may have to explain how they handled a particular problem to a regulatory agency (JCAHO or in VA hospitals, the Inspector General's Office) if the complainant is not satisfied with the resolution. Thus, when patient advocates are constructing an account of the problem, they do not necessarily know how the story will be resolved, but they do know that they need to construct a credible account of the problem.

Step 3: Enlisting others in the problem's resolution

Once patient advocates construct their version of the story's problem, they are responsible for resolving the complaint. Because patient advocates coordinate responses, resolving a complaint involves the participation of others. For example, they may need to convince others to interact in a less problematic way with staff or patients, contribute resources, admit responsibility (e.g., an apology from a doctor), change a problematic process or procedure, or even drop a complaint. To achieve such changes, a patient advocate needs to be able to convince others to cooperate in the resolution.

There were two means through which patient advocates enlisted others to participate in the problem's resolution. First, they engaged in various forms of perspective-taking or "the process of imagining the world from another's vantage point or imaging oneself in another's shoes" (Galinsky, Ku, and Wang 2005). When explaining a problem, patient advocates told the story so that others could understand the story, and potentially their role in it, in new ways. Second, they used rules and regulations to construct a resolution to a problem. In some cases, they selectively drew on rules and regulations to convince powerful people to perform or grant permission for medical procedures. In others, they worked with other staff members to discipline misbehaving or "noncompliant" patients.

Perspective-taking

Facilitating interactions Patient advocates traffic in sharing the perspectives of others. By explaining different perspectives, patient advocates hoped that a new understanding of the situation would alter the way that one or more characters would view the plot and therefore might be able to interact differently with others. For example, patient advocates sometimes became informal organizational coaches to people having trouble in the hospital. For example, one patient advocate helped a divorced mother understand the nurses' perspective so that she would not undermine her own position on the floor where her daughter was a patient. The mother had already experienced the negative consequences of information being withheld because of tension with her ex-husband's side of the family, and was in danger of being asked to leave the floor:

> Every morning she would come down and talk to me because I told her from the beginning when we met, "Anything that you do on that floor that gives the staff any reason to kick you off the floor or not want to tell you the things they are telling your ex-husband's side of the family, are points against you. I understand that you love your daughter totally and completely and there is no greater love than that, but at the same time she's not at home with you so there are certain things that you have to be mindful of." She's having a hard time like getting information from the nursing staff. I was telling her that's the reason why, because the ex-husband's side of the family has been here for so long.

By explaining the staff's perspective to the mother, the patient advocate hoped the mother would help her understand how to interact with the staff in order to continue getting information about her daughter's health.

Patient advocates also explain multiple perspectives to people who might have difficulty understanding or accepting their perspectives. For example, in one difficult family situation, a dying wife wanted to be taken off life support, but her grieving husband was not ready to let her go. As long as the patient is judged to be fully capable of

making a decision, the hospital legally had to respect the patient's wishes, and it fell to

the patient advocate to help explain to an already grieving husband the patient's wish to

be allowed to die.

> It is a juggling kind of thing because, you know, you have a lot of emotions involved in the situation, especially if you have a younger family involved with smaller children. The husband is scared. What am I going to do? How am I going to take care of this 1-year-old, this 3-year-old, and this 5-year-old? You promised that we would be together forever but now you don't even want to bother to do chemotherapy.
> To try to talk him through – this is the type of cancer she has and this is the expected outcome and this is what she's already done and this is what you can expect to happen. And certainly the physicians are involved and I don't make medical decisions or determinations. I get my feedback from the physicians, but the understanding from the physicians to the patient is what I help clarify.

The patient advocate becomes the link between the physician's medical opinion and

information, the wife's wishes, and the husband's reaction to the wife's wishes. She

delicately intervenes in the situation by communicating to the husband in ways that he

can understand – re-presenting the doctor's and wife's perspectives to the husband.

Perspective-taking to defuse emotions One of patient advocates' articulated

intentions in sharing perspectives was to deflate or de-escalate the emotions of the person

to whom they were talking, at the same time that they hoped that the perspective-taking

would alter their understanding of the situation. By creating a new understanding of

another person's perspective, patient advocates hoped that the others' negative emotions,

such as anger, would dissipate with the new understanding. For example,

> I had a family that I worked on for a week trying to get a very good rapport with. I understand that they felt upset but I tried to explain why the hospital did what they did, but they were very angry.

In this example, the patient advocate failed to change their opinions and the family sued

the hospital.

Other times, a change in emotion via perspective-taking allows them to convince the person to change their behavior. When this involves trying to change a hospital employee's perspective toward a patient, the patient advocate may go ahead and suggest other ways that the clerk could treat the patient:

> An example of that is a patient of a mother of disabled child who has difficulty arriving for appointments on time. The physician's office is very angry, very upset. The staff person I spoke to was very unforgiving. I said, have you ever tried to dress a child in the morning let alone a disabled child and be dependent on public transportation to arrive someplace on time? Well no I haven't. Well until you do, perhaps the best thing to do is to schedule this [appointment] for an end of the day when if there is a delay she hasn't backed up the whole schedule for the whole office. Secondly, if she doesn't show, that time can be used as administrative time for the doctor.

In this one example, she explains the perspective of the patient to the staff member, makes a suggestion about how to schedule this particular mother and child, while taking into account the needs of the physician's office and the physician. She used perspective-taking as a way of persuading others to change their behavior, thus resolving the complaint.

Creating empathetic accounts One of the most common categories of perspective-taking is when patient advocates explained multiple perspectives on an issue without taking sides or attributing blame to any one party. By virtue of telling the stories in this way, they tell *empathetic accounts*, by which I mean that they make sense of events, relationships, actions, events in such a way that denotes understanding and acceptance of others' actions. Use of empathetic accounts has the effect of making multiple, and often conflicting, perspectives on a conflict seem reasonable and understandable to people involved in the complaint. In the following example, the patient advocate shares the perspectives of both the mother and the doctor in this story:

The mom came in with her son, who was about 10 years old, [and had a serious problem with his arm], and they were talking to the doctor, and the mom felt that the doctor was really short with them. The doctor said that there was no option but surgery, and the mom stopped listening and asking questions, because she felt that the doctor wasn't listening to her. I don't think the doctor even realized it.

By creating empathetic accounts of both the mother's and doctor's perspectives on this situation – the mother's experience of the doctor as rude and unreceptive, and the doctor's presumed lack of realization about the mother's experience – the patient advocate portrays both of these actors as worthy of understanding and respect. By being able to approach both parties with respect and empathy, she may be more likely to be able to build a relationship with them and enlist their help in resolving the complaint through voluntary means.

One effect of creating an empathetic account, such as the one below, is that they are able to see each party's perspective in a larger organizational whole. Many individuals within a hospital system have neither the time nor the exposure to understand how systems and processes work, and how patients, their families, or hospital staff may be participating in systems that are larger than themselves. Yet patient advocates' role is structured such that they have the ability to learn, via investigation, how or why a patient may be having an experience or a process may work in a particular way. In the example below, a patient advocate describes being called in to help a patient who had gotten physically aggressive towards a doctor. The patient had lost feeling in his feet due to his years as a Prisoner of War (POW), and the doctor and nurse had been unable to help him get special equipment that would allow him to continue to drive his car. [Perspective-taking on behalf of the doctor is in bold, on behalf of the nurse is in italics.]

[The patient] was swearing, and cussing, and swinging a cane at his doctor. The doctor kicked him out of the office. The nurse came up and said, "Doctor doesn't

want to see you anymore. If you have any problems, go see the patient advocate," because they were tired of it. **The doctors themselves just didn't know how to address the issue properly. It wasn't a medical issue, per se, it was a system issue. How do we get this guy his stuff? How do you we write it up properly? Who does it go to? What forms do you use? What office does it have to go to? So they weren't aware of it, you know...they didn't know how to operate that...well, they did once, and it came back denied, and their opinion is, "Hey, look, we tried it, and we failed. Now, go away, and don't bother us." Because for the doctor, it's like, this isn't what they taught me at medical school. You know, I'm here to heal you. I'm not here to jump through seven bureaucratic rings for you. And they have a dollop of truth on their side. This isn't what doctors are trained to do. You know, this isn't why we educate them, and it's not what we pay them for.** *You know, and the nurses are...they're just like the doctors. They're there to render care, and to set things up, and to smooth the way, and to deliver care. They're not set up...well, they are...pardon me, I shouldn't say that. Nurses really do so much of this in the normal course of the day. The thing of it is, is that under our primary care system, we load our doctors and nurses up so much that they don't have time allotted to stop the machine...to stop the process they're in....and then just deal with a special patient and really take the time.* And it did take time. And I do have the resources. And it took me a lot of time. I couldn't begin to tell you how many phone calls it took me, and emails, and okay, well, where's the law, and okay, who do I talk to? and what office do I have to go to? Oh lord, it was a learning experience for me. I learned a lot. But it took me forever. It took me months.

The patient advocate is able to take the perspective of the doctor and nurse (and in other parts of this story not included here, the patient and his wife) and have some empathy for the position that they are in. The patient advocate is not excusing their behavior, but is able to articulate how they could come to their positions as a result of their medical training and the "loading up" of the medical system as a whole. This is important because of the alternatives ways in which this story could be told. If the patient advocate saw it as the fault of the doctor and nurse, then he might concentrate his efforts on finding a way to punish them. Instead, his empathetic account suggests that this is not the problem, or at least one that he can solve, and instead he focuses on spending time working through the bureaucracy to secure this POW specialty equipment for his car and the training to use it.

Creating absurd accounts At other times, patient advocates re-tell the patient's perspectives in ways that sum up patient's experiences in hospital systems in compelling ways. Patient advocates are able to see how the patients' experiences can be absurd, and use this account of their story as a basis for suggesting changes or selling a process change within the organization. For example, one patient advocate told me about a complaint from a patient undergoing regular infusion treatments for liver cancer. The patient had to wait three hours on each visit for paperwork, which from the patient advocate's perspective could be done in advance. The advocate summed up the patient's perspective by saying:

> Here you have a patient who's, you know, dying of cancer, who doesn't want to spend her last hours sitting and waiting for [paperwork].

By contrasting the exigencies of dying and the mundane-ness of paperwork, this creates a compelling case for the patient, one that can be widely understood because of its appeal to humanity. In this case, the account was retold to her colleagues in the patient advocate office, her boss, and staff in other offices whom she was trying to coordinate a response.

Framing story plots with rules and regulations

Patient advocates also used the language of rules and regulations to enlist other people in complaint resolution. Hospitals are regulated by many levels of government (city, county, state and federal) and are closely watched by both the government and a variety of advocacy organizations to ensure that regulations are followed. In this context, the language of rules and regulations are an important part of enlisting others in a story's resolution. Rules and regulations were most important in convincing powerful parties to perform a medical procedure and in coordinating efforts to discipline patients.

Persuading organization members to provide medical care When patient

advocates were trying to get physicians or high-level administrators to perform or grant

permission for a medical procedure that they had already refused to perform, they framed

the patient's perspective using rules and regulations. The following story involved a

patient advocate called in to help a patient who wanted his catheter out, but the medical

staff resisted, in part because the patient and the staff had gotten in a heated argument

that created "chaos."

> I said to the doctor, he is alert and oriented, he is within his rights to do this, just
> take it out. And finally I convinced him to do it.

The patient advocate knew that framing the patient's wishes in term of patients' rights to

convince the doctor to do the medical procedure he had been resisting.

In the next example, the patient advocate worked for years to help a patient to

obtain VA permission (and hence to pay for) beriatric surgery. She worked for two years

to help this patient get surgery and eventually realizes that if she makes the request for

beriatric surgery through his service connection for diabetes, it will be more successful

than trying to get her request within the VA system, in which access to this surgery was

difficult to come by.

> When they came out with this beriatric surgery, there were very few places within
> the VA system that would do it. I have a gentleman, bless his heart, that needed
> the surgery. Do you not know that I worked for two years, two years! I found out
> when I went researching through the VA, when the patient came in and says I
> heard that the VA does this beriatric surgery. Well, we didn't do it here. I
> researched and there was one of the VA's in [a neighboring state]. Because we
> weren't in their catchment area, they wouldn't take any referrals from [another
> city in the same state]. It was a very well kept secret that [a second city in the
> same state] did it. I'm trying to make referrals to [second city]. We went through
> all types of hoops trying to get referrals to [second city]. Don't use that name.
> Long and the short of it is after it bounced back and forth, I never got one of my
> patients in up there. We got some now but this particular patient I've been
> working with all these years and he knew I did everything I knew to do.

He came in to me and . . . I could see the stress on his wife's face. The bottom line was that this man's heart was so bad that if he didn't get some of the weight off of him within months he was going to die. I prayed about it. There's got to be something we could do. When I found out and it came to me that he was service connected for his diabetes. One of the things you know is that if a person loses weight it can affect their sugar so because his weight was related to his service connected disability, I was able to go to the Chief of Staff and get them to agree to pay for him to have his surgery on the outside.

I also explained to the patient that your diabetes corrects this stuff, which is fine, you may lose your service connection. He said, "I don't care."

"That's fine, I would you wouldn't, but I need to let you know that because losing weight not only would help with his heart issue but it could also help with his diabetes issue which would mean that the VA corrected his issue and they could possible lower his service connection and the VA would no longer have to pay him compensation or not at that percentage." That was the method to my madness. It worked. I did all the paperwork and everything I needed to do and consequently the man had his surgery.

I found that patient advocates used rules and regulations specifically to frame requests for medical care from people who were in positions to perform or grant permission for the medical procedure.

Disciplining patients and family members Patient advocates also use rules and regulations to discipline patients and family members. Patient and family members' behavior is regulated by "Patients Rights and Responsibilities" statements. Most hospitals have statements of patient rights and responsibilities in order to comply with CMS. Such statements outline both the treatment patients should expect from the institution as well as their responsibilities when they are in it (US Department of Health and Human Services, 1999). For patient advocates, they can use the patients' rights and responsibilities to make a case to an authority (e.g., their doctor, the state) that the patient or family member should be disciplined, and in many cases, removed from the hospital. For example, in the example below, a patient advocate describes how she handled a long-term patient who was causing multiple disturbances in the hospital – by having sex in her

hospital room, leaving without permission, losing her temper when confronted with her

mis-behavior:

> Eventually we called her physician and got her out.
> *So did she have a condition that would allow her to leave the hospital?*
> No, but she was not following the rules and regulations, and she was here for a medication but she wasn't following protocols. We told the nurses to document, document, document. The patients have rights, but they also have rules.

In cases of serious disciplining of patients, use of rules and regulations to, for

example, remove a patient from a healthcare system requires a coordinated effort of many

administrative and medical staff people. In the following example, the patient advocate

describes the many parties who were involved in containing the disturbances that this

particular patient created and the system they developed that eventually allowed them to

remove her from the medical system.

> I've had a lot of crazy people over the years that I've had to deal with exclusively, just by the luck of the draw. And the last one was a woman who, we finally have her banned from the entire health system. And we had to go to the state, and petition that she be removed from [Hospital's health plan], and put on straight Medicaid, so she could go somewhere else. And I mean, she's show up in crazy outfits. She was verbally abusive. She'd call [the CEO], she'd call the Director's office, she'd call VP's office, she'd call Risk [Management]. And everybody knew, when that woman called – they all knew her voice – went right to my phone. And I'd just say, "Eh," shut the door, and I'd keep a log...of all my phone calls. She goes, "Well, what am I doing talking to you?" "Well, [laughs] I'm your person [laughter]. "Well, I...I called [the CEO's] office." I said, "Yes, I know you did but I'm the one you're going to have to talk to. Now what is it that I can help you with?"
> When somebody's out of control like that, you need to contain it, because otherwise all your phone systems get tied up, and it upsets your clerical staff, the lowest paid people here. You don't need to tie up either your clerical staff or your nursing staff with a person who has unrealistic expectations, and the demands aren't reasonable, and blah, blah, blah. Rather than wasting everyone's time, they just shipped it to me, and I kept a log, and...We would meet with a Risk Management people and the clinic managers. Our last meeting was with the Director for Ambulatory Care and Clinic Manager, Risk Management people, me, and they head of Risk Management. And we all compared notes. I distributed my log. And the Risk Consultant, took it to the state, and we got rid of her. We got permission to disenroll her and ban her from the [health system]. And nobody

really wanted to do it, you know, but...but she was non-compliant, because we wanted her to be seen by community mental health, to be evaluated, because she was...she was not, you know, she was mentally ill. And she would not do it. So and she just caused these horrible scenes in waiting rooms, and you know she was totally out of co-security was there all the time, and it was lots and lots of man hours.

In this coordinated effort, the patient advocate worked with a number of different people throughout the hospital to help the hospital remove a patient they collectively viewed as disruptive to employees throughout the hospital system.

Discussion Patient advocates enlist others to resolve the problems that come across their desks. Patient advocates are a third party to conflicts, and they have limited resources to resolve complaints or problems themselves. They persuade, motivate and convince others to help them. Patient advocates' primary means of influence is to tell accounts of the problem in a way that others may not have considered before and that may open the way towards obtaining the resources necessary to resolve the complaint. Patient advocates can often see the story from multiple perspectives and try to motivate others to participate through a selective re-telling of the story in a way that changes how people understand the plot in which they are participating. For example, the first quote in this section involved a patient advocate coaching a mother about how to understand the dynamics on the floor and her role on the floor. In this and other examples in this section, patient advocates re-narrate the story's plot so that they themselves and others can participate in new ways. Of course patient advocates are not always successful in re-narrating the story such that people understand the plot differently and actually act differently in the plot. In the next section, I address some of the cues patient advocates use to know how well they are doing their jobs.

How do patient advocates evaluate how well they are doing?

My use of the analytic lens of storytelling to describe the work of storytellers raised new questions: How do they evaluate how well they are doing? Or in the language of storytelling, what makes a good story?

Feedback from patients and family Patient advocates felt affirmed in their role as storytellers when they were thanked by patients or their families. Complainants expressed appreciation both when they liked the response and sometimes even when the problem was not resolved in the way that they wanted. Patient advocates believed that complainants thanked them in these latter situations because complainants felt that the patient advocate understood their problem and truly did their best to resolve it. Thus patients and families affirmed the good intentions of their role as storytellers, often attributing the ultimate lack of success to the situation.

But patients and their families did not always believe that patient advocates could help them resolve their problems. At times, they questioned patient advocates' intentions and abilities, most often because they did not believe that an employee of the hospital would try to help them. This was a common dilemma faced by patient advocates. Sometimes patient advocates are not able to convince patients and their families to trust them or believe that they can be of help. In these cases, they were not successful in being good audiences for patients and families.

Feedback from hospital staff Patient advocates also took cues from hospital staff about their effectiveness. When patient advocates got affirmation from the staff, they spoke of it as an important accomplishment. Because their specialty was complaints, patient advocates were frequently the bearers of bad news, so it was common for hospital

staff to become defensive when approached by the patient advocate about a problem.

Patient advocates worked hard to establish a reputation as someone who can help hospital

staff, which is indicated when staff members ask patient advocates for advice or give

them a heads up about a patient or situation and see them as a resource for problems in

the future. This signaled that the staff member viewed the patient advocate as a resource

who could help them in difficult situations, rather than as a threat to their autonomy or

self-respect as a healthcare provider.

Two examples illustrate this point:

When I first had the job, people acted like I was the police - a clerk saw me and
would announce over the intercom - "Patient relations is on the floor." By us
visiting everyday, we are no longer a threat. They don't automatically think that a
visit is necessarily going to be a problem. We are going to support [the staff]. For
instance, there are some patients who are very needy, who are chronic
complainers – and we are not a five-star hotel. If the staff knows, call us ahead of
time. A lot of times, we are doing inner child therapy! People need attention and
approval.

I have earned staff physician's respect. They don't mind working with me. When
I say earned their respect, they will now call me for assistance. It used to be . . . a
lot of them didn't want to talk to you because they just look at you as coming to
pounce on top of them and you're from the Director's office and you're here to
make demands on what I should do. I don't have that resistance from physicians
that I've worked with for years because I worked hard to have a rapport with them
and they know my approach. That makes a difference.

Permanent fixes not band-aids Constructing a problem and enlisting others to

resolve it often takes significant effort and patient advocates did not want to feel that their

efforts were in vain. The ideal situation is one in which the resolution they constructed

became permanent, and they wouldn't see the problem repeated again. Resolutions would

become permanent when the people involved had new understandings of the problem.

For patients and their families, this might mean that they feel like they have a good

understanding for why they had a particular experience in the hospital. For hospital staff,

it means that they understand and "own" the problem. By understanding a situation differently, staff are able to act differently as well. However, patient advocates view some patients as having unreasonable expectations or as chronic complainers, so the patient can never be satisfied. When a person likes to complain, they either bring a steady stream of problems or consistently find fault with the resolutions.

Structural barriers to resolution Sometimes patient advocates faced structural barriers to resolution. When this happened, the patient advocates were relatively powerless. Below is an example of such a situation:

> This is a patient who has a known cardiac history, multiple surgeries, multiple everything and the family is really wanting to get him to main campus and someone who probably should be here because all of his physicians are here. In explaining to the family that you are in a hospital and he's being cared for and he's being well taken care of and as soon as we could bring him here we will. We have patients here forever.
>
> The family responds: "He's been so sick. Can't you bump somebody else and bring him in?" When it's your family member you have these blinders. "Isn't there somebody else who could wait and we could bring him in since he's an established patient?"
>
> That's when the system is so frustrating and it's not even the system, its circumstances. There's only so many beds. That's the kind of stuff where it gets frustrating.

In those circumstances, patient advocates knew what the problem was and how the organizational process operated, but they had no means of influencing it. They did not try to enlist others in the story's resolution because there was no way they would be able to work around the organization's structural limits, such as limited number of beds. But, these situations could be frustrating and deflating because they were forced to confront the limits of their power.

Does the organizational and institutional environment encourage patient advocates to use storytelling as a means of problem handling?

Considering patient advocates work as organizational storytelling led me to ask if there were organizational structures that encourage storytelling. I found that there were several such structures. First, a relatively recent development in patient advocates' work is the use of databases to track cases. Every patient advocate in my sample kept track of their complaints in databases so that they would have adequate records in case of a regulatory investigation. There are several vendors of such databases and some hospitals use homegrown versions, but they typically include a section in which the patient advocate enters a description of the problem and then labels the problem according to a series of choices, e.g., what is the root problem, department(s) and person(s) involved, etc. The databases require that patient advocates describe the story's problem, and update information, and its resolution. The databases help them keep track of cases, patients and hospital staff over time. The format of the database, which in turn is shaped by regulations, requires them to write problems, update their understanding of the problem and its resolution. How these databases are used may vary across hospitals, and may in fact be an example of "ritual assurance" (Feldman and March, 1981), in which the information is gathered for symbolic or rhetorical purposes (Van Maanen and Pentland 1994). However, the form in which the data is collected and recorded appears to support or perhaps even encourage a storytelling approach to problem handling.

Second, at non-VA hospitals, patient advocates are required by CMS to write letters explaining the outcome of a case investigation to the complainant. Viewed through the storytelling lens, these regulators require them to re-tell the story to the complainants.

These documents, too, are formal records regarding the complaint. They are documents in which patient advocates attempt to convince the complainant that their own complaint handling was appropriate.

Third, I found in my shadowing sites that the patient advocates told each other about the cases they were working on as a routine and social part of their day. There are both instrumental and non-instrumental goals for this storytelling among peers. The instrumental purpose is to enable colleagues to handle each other's cases, in case the patient advocate who took the case is away at a meeting or has the day off when an urgent new development occurs. Cases often develop over time, so a complainant may call back a week or two months later with a follow-up question or additional complaint. Sharing stories about problems with colleagues helped patient advocates have more informed interactions with people.

Conversations with peers provided them with an opportunity to test out, revise and learn about elements of the story. Through these conversations, they develop knowledge about how plot points or character development. Patient advocates discussed such conversations in interviews, and I witnessed many such conversations at the shadowing sites. In the following example from one of my shadowing sites, a patient advocate learns about a typical plotline involving patients asking for reimbursement about lost hearing aids:

> Susan calls Jim for number to call for Loss/Theft issues.
> Jim to Susan: Do you have a new case?
> Susan: Someone wants $2800 for hearing aids.
> Jim: They're all like that at the beginning but they turn out to be $1400.

Patient advocates also share stories as a form of sociability. Sharing stories about working on tough, unusual, or ridiculous cases was enjoyable and a way to relieve the

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emotion of interacting with patients, their families or staff. Conversations among peers have the tone of information-sharing and amusement. For example, after taking a call from an "irate" father of a teenage patient, a patient advocate propped open the door to share with the administrative assistant why he had called, telling the administrative assistant and I what had happened. Soon another patient advocate called out to find out what had happened.

Discussion

This paper set out to understand the work of patient advocates. It is organized around four research questions: What is the work of patient advocates? How do patient advocates accomplish this work? How do patient advocates evaluate how well they are doing? Does the organizational and institutional environment encourage patient advocates to use storytelling as a means of problem handling?

I argue that patient advocates work can best be understood as organizational storytellers, a process which consists of three steps. First, patient advocates try to be a good audience for complainants. This is important because patients and families typically have already tried and failed to resolve the problem through more routine channels, so they come to patient advocates not only with the problem itself, but with frustration at failed attempts to resolve it. Being a good audience means both providing the complainant with the experience of being heard and treating every concern as if it is important. Patient advocates accomplish this through conveying that they are carefully listening to the story through careful choice of words and control of their body.

Second, patient advocates work with bits and pieces of information gathered from multiple sources coupled with knowledge about how the organization typically works to

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construct what they believe the problem is. They gather this information in two ways. During interactions with others, they rely on discerning practices to sort through ambiguous information. They encourage emotional expression, attend to physical space, inquire, challenge the complainant, and attend to their own physical and emotional cues. In addition to these indirect ways, patient advocates also engage in investigating, or direct questioning of others, to help understand and define the problem. Through the combination of these two types of practices, discerning and investigating, patient advocates construct the story's problem.

The constructed problem also leads into the third step, patient advocates' enlistment of others in the problem's resolution. My analyses showed that in telling others about the story's problem, they use both perspective-taking techniques and rules and regulations as framing devices to enlist others' in the process of resolving the complaint. In asking others for help, advice, resources or information, patient advocates told the story in a way that they hoped would enlist others in the resolution of the problem. Both sets of practices allow the patient advocate themselves and other people involved in the complaint to understand the predicament in new ways, often from a perspective which they had not considered or fully appreciated (White and Epston 1990). Thus, a critical means of problem resolution is patient advocates' ability to tell a story that would help them understand the story in a new way.

In both steps one, being a good audience, and step two, constructing the problem, patient advocates exhibit an acute awareness of their own role in the storytelling of the complainant. They monitor their own and others verbal, bodily, and emotional cues to try to accomplish these two steps. Patient advocates' attentiveness to their role as audience

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members echoes the literature on narrative therapy (White & Epston, 1990), in which the therapist is keenly aware of how their own responses to a patient's story as an audience member shape what story the patient tells. This, in turn, helps both the storyteller and the patient advocate to create new meanings about the problem.

Patient advocates' careful attention to themselves as audience members is a relational skill (Fletcher, 1999) in the sense that through these interactions, change occurs in both the teller and the audience. In relational theory (Miller, 1976), growth occurs not through separation and individuation, but through mutual engagement and co-influence. By seeing patient advocates' work as relational skill, it allows us to acknowledge theoretically that both the teller and the audience are changed by their interactions. In this case, what is changed is their understanding and the meaning they make of the problem at hand. This does not mean that the interactions are always free of conflict or uniformly positive. Instead, it draws attention to their *mutual interdependence*. Without the patient advocate to listen their story, the patient or family member might never feel heard and thus become the author of their own story; they may recover neither their agency, their ability to act, nor their dignity, or the feeling of respect and worth in their own beliefs and reflected in their interactions with others (Hodson, 2001). But the patient advocate is dependent on the complainant as well, because their own actions to resolve the problem depend on having accurate and empathic understanding of the story.

Constructing a story's problem is important because it influences what steps patient advocates and others will take to resolve the problem. It helps them make sense of the multiple accounts of a problem they hear and solicit, and to understand how the problem is situated in the social fabric of the organization. By constructing the problem,

they can then *act as if* (Paget, 1988) that is the problem toward which they should direct

their efforts. As they continue to interact with people and gather information about the

problem, they may update their understanding of the problem, which may point them in

another direction. As the person coordinating the response to the problem, the constructed

problem organizes their own action, including who they will ask to help resolve the

problem. Their understanding evolves and is updated over time. While they are

constructing the story's problem, they keep in mind a number of potential audiences for

their construction of the story's problem. Thus these various audiences, from their patient

advocates peers to the patients and their caregivers to the legal environment (Van

Maanen & Pentland, 1994), shape their story construction.

　　　This account of patient advocates' work portrays patients, their families and

hospital staff as storytellers themselves, who may have very different, even conflicting,

stories of a situation. The patient advocates' work becomes working on their own and

others' understanding of the problem and trying to shift others' understandings.

Researchers who have taken a narrative approach to mediation have also suggested that a

narrative approach to conflict focuses on changing peoples' understandings, instead of

meeting underlying needs (Winslade, Monk, & Cotter, 1998). With little formal power

yet an expectation that some action will be taken, patient advocates are rarely in a

position when they can meet the needs of the parties in a conflict. Instead, patient

advocates use a variety of relational practices (discerning, investigating, perspective-

taking and using rules and regulations as framing devices) to both construct their own

understanding and influence others' understandings of a situation. Storytelling is their

main form of influence. Thus, patient advocates' agency in the organization comes from

artfully crafting problems and resolutions based on the patients, families and hospital staffs' accounts of their lived experiences, coupled with their embedded organizational knowledge of how the organization works, how to create a compelling story or who will be a receptive audience member.

Contributions

Problem-Handling Roles as Situated Agents

This study suggests that problem handlers can have influence and make changes in organizations through storytelling. Storytelling requires problem handlers to draw on emotional and relational skills, to make sense of and to interpret their environment, and to work from some basis of organizational knowledge. There is some overlap with prior problem-handling literatures. For example, when patient advocates try to be a good audience to patients and families, their work could be described as emotional labor, in that they are using emotional displays (e.g., control of their bodies) as a way of influencing the storyteller. Likewise, that same step is also similar to impression management, in that the patient advocate is trying to create the impression of being a good listener to a patient or family member. However, for the patient advocate these emotional labor and impression management techniques occur primarily during the initial, "on-stage" moments with the patient or family. They draw on a whole host of other techniques and interaction styles during other stages of storytelling.

The storytelling lens also helps us to see that steps that have not previously been identified in problem-handling work, constructing the problem and enlisting people to participate in a resolution. For patient advocates, the work of constructing the problem is central because it helps them know how to act to resolve the problem. Because what they

do is emergent, constructing the problem becomes a way for patient advocates to organize themselves and enlist others into a sensible resolution of the complaint. As such, this research resembles the work of other kinds of roles in organizations that face ambiguity as a matter of course, such as innovators (Kanter, 1988).

This research also provides us with a close look at the relational and emotional work of patient advocates' problem handling and provides a logic, or rhetorical structure, for why a particular strategy would be used at a particular time. Viewing the work of problem handlers as storytelling suggests a sequencing to the strategies problem handlers use to resolve complaints, goals for each step, and interactions with different sets of people at each stage. Thus, considering problem handling as storytelling provides a theoretical explanation for why problem-handlers' strategies should shift throughout the process of problem resolution.

Storytelling

This research extends the literature on storytelling by understanding how problem handlers use storytelling. Previous research has suggested that storytelling can transmit prized information (Ewick & Silbey 2003; Orr, 1996), and spur organizational change (Boje, 1991; Feldman, 1990; Suchman, 2000). It also suggests that the work is relational (Kleinman, 1995; Winslade, Monk, & Cotter, 1998). This research joins that scholarship, but also provides an account of how patient advocates, as the key storytellers, go through the process of constructing a new story and sharing it in different ways and with different audiences throughout the organization. This research portrays storytellers not as telling old well-worn stories, but as actively trying to understand new stories, reconcile different versions of stories, and shepherd forward a version of the story that will be satisfying to

multiple constituents (e.g., hospital staff, patients and their families, and potentially regulatory agencies). As such, they move between being the audience of stories (e.g., when they first listen to a complaint) to the tellers of stories (e.g., enlisting others), or moving fluidly between both in the same conversation (constructing the story's problem). Like entrepreneurs trying to tell a good story to secure resources (Lounsbury & Glynn, 2001), patient advocates try to tell a good story in order to resolve a complaint.

Practical Implications

Finally, this research has practical implications for people in problem-handling roles and the organizations who house them. Problem-handlers often have relatively little formal power. For problem-handlers who are seeking ways of having influence in organizations, it may be quite useful to see their work as organizational storytelling. The skills required are relational, emotional and require organizational knowledge, all of which can be developed without organizational sanction or permission. Developing one's own storytelling capacity can increase one's own means of being a tempered radical (Meyerson, 2001) and making incremental changes in the organization (Creed and Scully, 2000). However, organization leaders who are interested in supporting the storytelling capacity of problem-handlers can use a number of strategies to build this capacity. Hospitals and other organizations could provide structured opportunities, and in organizations that do not hire people with many years of experience, they could design their socialization and development programs so that these employees would have opportunities to understand the perspectives of stakeholders with whom they will interact.

Limitations and Future Research

There are several limitations of this work that bear mention. Because this research uses data only from patient advocates, I cannot shed light on what hospital employees, patients or families think about what makes them effective or ineffective – the patients, families, and various hospital staff. Because patient advocates' work involves interacting with others, this is an obvious shortcoming of the research.

This chapter builds a general model of patient advocates as organizational storytellers, and does not focus on the differences that may exist. For example, the model does not address storytelling across different types of problems (e.g., a crisis versus a mundane problem). I also do not examine how the stories patient advocates tell vary across different types of organizations. The two types of hospitals I studied, VA and teaching hospitals, vary in the patient population. At VA hospitals, patients are relatively homogeneous and use the hospital for their ongoing health care needs. At teaching hospitals, patients are comparatively diverse and come to the hospital only for relatively extreme health concerns. As a result, at the VA hospitals, patient advocates tend to be familiar with the patients, families, and staff who make up their storytellers and audience, while at teaching hospitals, patient advocates interact with strangers experiencing unpredictable problems. Future research may help to identify how familiarity and predictability affects the effectiveness of problem handlers to use storytelling as a means of resolving problems.

Finally, the patients and families with whom patient advocates interact are experiencing problems of care and service in the context of the illness, thus the action patient advocates take occurs in the context of consequential and moral action. Like

doctors making diagnoses (Paget, 1988; Blatt, Christianson, Sutcliffe, & Rosenthal, 2006), patient advocates' problem-handling work is simultaneously regulated and morally consequential. Indeed, the professional association describes the patient advocate as working within an "ethical construct" of promoting the interests of the patient. This chapter has not considered the particular moral tensions that patient advocates may or may not feel when handling complaints. Future analyses may help shed light on ethical decision-making in organizations.

Conclusion

There is a long tradition of research on the work of problem-handling roles in organizations. This is not surprising, as unexpected events, mistakes, misunderstandings and confusion will probably always occur in organizations, and organizations rely on employees to handler those disturbances. For some, like patient advocates, problem handling is a full-time job, while for others it may be an informal (Frost, 2003) or occasional (Mintzberg, 1973). I have argued these bodies of research are limited because they portray problem handlers as captive to their employing organizations' interests or symbols of organizational compliance. This study of patient advocates suggests that problem handlers are not puppets of the organization, enacting or resisting organizational scripts. Instead they are actively engaged in making sense of the problems they encounter and tailoring resolutions that are appropriate for the particular problem, which may require the organization or one of its members to change their behavior or a process.

Storytelling is both a more accurate description of the specific work of patient advocates than existing accounts of problem handling could provide, but I hope that it also reveals a perspective that allows researchers to see a form of agency in organizations

by people engaged in their everyday work. It also suggests a process through which

individuals can instigate incremental changes that can make a difference to one person

(e.g., an apology from a doctor) or have more systemic effects (e.g., change in process).

Thus, this chapter contributes to our understanding of how individuals embedded in

organizations can influence ongoing organizational processes.

Table 4.1: Comparison of Problem-Handling Literatures

Literature	Problem-handling Role	Interacts with	Orientation to Problem	Problem-handling strategies
Boundary Spanning "information processing perspective"	Organization member	Organization outsider	Seek benefit for own group, perhaps mutual benefit	Transfer and translate information across boundaries
Boundary Spanning "political perspective"	Organization member	Member of a different organizational community	Seek benefit for own group, perhaps mutual benefit	Change understandings via boundary objects
Emotional Labor	Organization member	Organizational outsider	Benefit organization, contain the problem	Emotional expression, feeling and display
Impression Management	Organization member	Organizational outsider	Benefit organization, contain the problem	Verbal and written accounts
Institutional Theory	Organization member	Internal complainant	Depends on interpretation of role	(none)
Organizational Storytelling	Organization member	Organizational insiders and outsiders	Evaluate the problem and act accordingly	Three-part process: Being a good audience; constructing a problem; enlisting others in resolution

Table 4.2: Evidence Supporting Process Model of Problem Handling as Organizational Storytelling
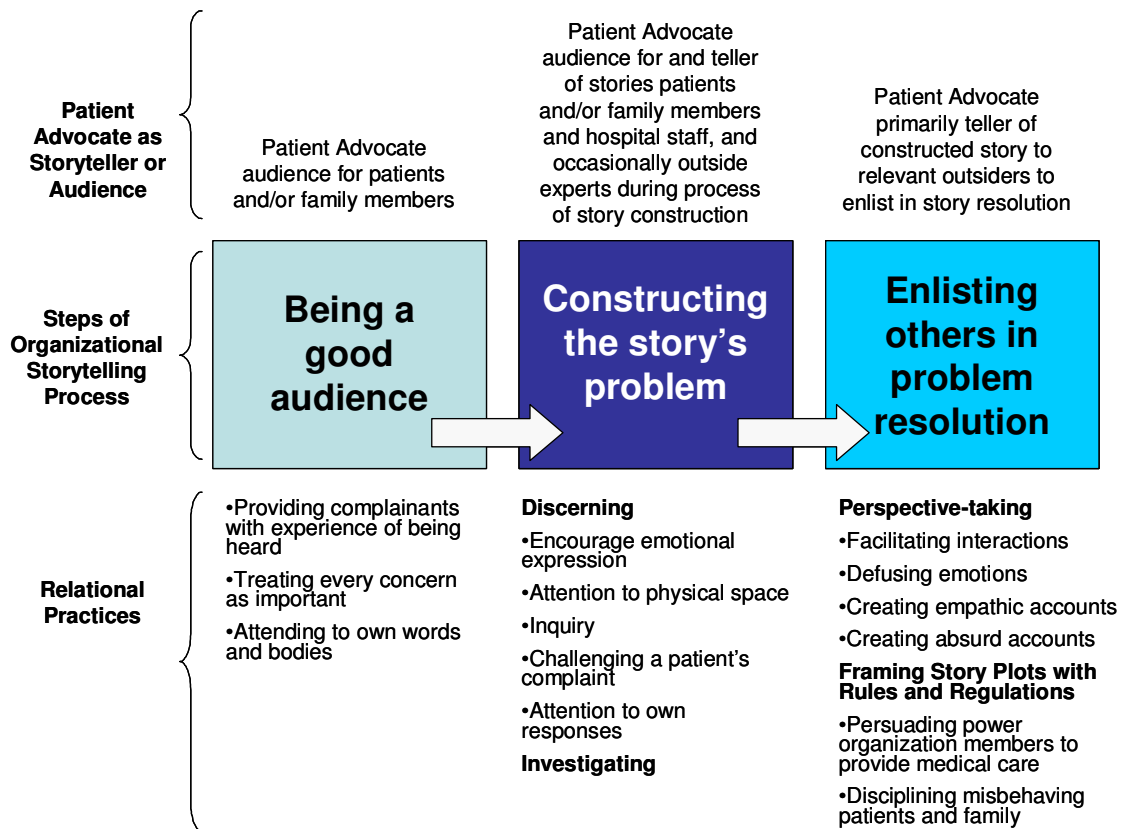
	Exemplars of Step 1: Being a Good Audience for the Complainant	Exemplars of Step 2: Constructing the Problem	Exemplars of Step 3: Enlisting Others in Story's Resolution
Documents	"Ability to demonstrate sincere compassion, sympathy, and understanding for patient's experience and concerns" *The Advocate's Role Defined, SHCA Role Delineation Work Group*	"Questioning Skills. Appropriately uses the following types of questions to learn, clarify, gain understanding and encourage a speaker (open-ended questions, focused questions, closed questions, probing questions)." *Required Competencies for Family Patient Advocate, VHA Handbook, 1003.4*	"Presentation Skills. The ability to effectively communicate thoughts, feelings and/or information to a specified group generally with a purpose of to influence or educate. Platform skills include effective use of body movement, posture, positioning, eye contact, verbal and non-verbal skills, as well as knowledgeable use of any presentation devices (e.g., overhead, projector, PowerPoint)." *Required Competencies for Family Patient Advocate, VHA Handbook, 1003.4*
Background Interviews	"The advocate standpoint is really about representing somebody else and what somebody else thinks is important whether you think it is or you don't think it is." *Instructor of Communication, Health Advocacy Graduate Program*	*Has the patient advocate role become more visible in recent years (in the VA)?* "I think there's an attempt on the part of the VA to get people into the positions who can do more than simply say, "This is what the patient wants, how can I get it for him?," but to be able to say, "This is what the patient wants, but that really isn't the problem. The problem is this. Nobody's bothered to explain to the patient why the doctor's getting all these tests and doing all these things." *Director of VA Patient Advocate Program*	"I would say that overall in our program we are more focused on teaching people the skills that it takes to get things done, and those have to do with being able to understand different perspectives on a problem and really figure out how to communicate with all the people involved to get done what you want to get done. It doesn't mean that at all lose sight of who the population for whom you are advocating, or who may need protection or service in a particular situation. But we do have sort of a holistic, if you will, view of what it takes to do that advocacy and who you need to communicate with to get it done." *Director of Health Advocacy Graduate Program* "In the older environments from years ago, the patient advocate was in a difficult situation, because they were viewed as an employee who was advocating on the part of

	Exemplars of Step 1: Being a Good Audience for the Complainant	Exemplars of Step 2: Constructing the Problem	Exemplars of Step 3: Enlisting Others in Story's Resolution
			someone who was anti-organization. So it put them in an adversarial role with the very people they need to work with to effect change, so they are in this quandary. But that's an old mentality. The new mentality now is that as a patient advocate, how can I muster, how can I somehow get my organization to work on behalf of this customer, that's what it's all about." *Vendor to Patient Advocate and SHCA Member*
			I'm curious about what you think it takes to be effective as a patient advocate? …So you have to be a very good communicator in both verbal and writing. Because you could write a letter that would inflame the situation and make it worse, so, you know, you have to be able to say what you're trying to say and get it across without inflaming the situation, or the person. And sometimes, you know, you just might not be able to do that. And they may come back and still disagree with you and you have to get to the point where you have to say, "Well, you know, I understand what you're saying, and, yes, I understand that you're disagreeing with me, and we have to agree to disagree." You know, you sometimes have to get to that point. Yeah. *SHCA Board Member and Patient Advocate for over 20 years*
Shadowing	[After a attending a tense meeting with a patient and his care team], I asked Matt about his stillness during the meeting; I had noticed that…he was very still when looking at whoever was talking, which was	After we got off the phone [with a patient whose complaint included being seen by a resident in the Emergency Room], Sam said, "When you go to the emergency room, a resident is what you get. I want to	*Shirli talking to Chief of Staff after getting consult about legality of statement from intubated patient:* "Melissa said that the note documented in the chart is not legal; they can fight it out in court…do you want me to notify the

	Exemplars of Step 1: Being a Good Audience for the Complainant	Exemplars of Step 2: Constructing the Problem	Exemplars of Step 3: Enlisting Others in Story's Resolution
	mostly Dr. Samuels. He didn't have variation in his facial expressions. He said that he wasn't conscious of it and that he was just trying to concentrate on what they were saying so that he could write it down later on. And then he's added secondarily that he wanted to try to make them feel heard. *Fieldnote_VA Patient Advocate* [Explaining why she is the main contact with a particular patient] Shirli said that this wife deals with only Shirli and the Assistant Chief of Pharmacy - "it's just easier that way." Shirli said that she has to keep her voice very calm when she talks to this wife, because she gets really upset very easily. *Fieldnote_VA Patient Advocate*	pull up information on this case so we can see our side of the story." *Teaching Hospital Patient Advocate_Sam* At a staff meeting, patient advocates were complaining about the complaint tracking system in which they record all their complaints. Phil used the phrase "slamming in a case," meaning what he does with the case at the end of the day to enter it into the system. Sometimes who you choose to record as the "responsible group" for a complaint changes as the story changes. So someone might be complaining that Environmental Services – they requested Environmental Services five times to clean up the room, but Nursing never called Environmental Services. *Field Notes_ Teaching Hospital Patient Advocate*	Fellow?...I will do that…Got it…I will let them know." Shirli got off the phone, and explained to me: "She [the Chief of Staff] said I can go ahead and call. She's going to put a note in the file to support it. I will call Cara [the nurse] and then the Fellow." Sarcastically, "I'm sure [the medical team] will take that well. Oh he's not going to be happy." I was hoping that [the Chief of Staff] would offer to do it, because I am not sure that the Fellow would like hearing from me that he has to do something, and I wouldn't blame him, but she said I should do it." *Field Notes_VA Patient Advocate* "It's important to understand the technicalities of our work because it's like we have a credibility gap. It's like a dance. We're not PhDs, we're not doctors, we're not nurses, we're not administrators, we're staff. Once they understand that we are here to help, usually they come around. But we don't want to escalate the patients, and we don't want to alienate the staff. It's like a dance - sometimes we're dancing on hot coals. And some days the patient will hang up on you, and the so-called health care professional does the same thing, and then we're really the monkey in the middle." *Teaching Hospital Patient Advocate_Sam*
Interviews	"Sometimes we're completely at fault. Sometimes the patient is way off base but you still have to respond in a manner that their concerns	I've had one guy come in, the most obscure complaint I've ever heard. So he came in, and he said that he had a complaint against the cafeteria. Okay. So you're	You asked me what's rewarding. It's rewarding to have these good relationships with the medical staff, and the administrators, to solve a problem....extremely

	Exemplars of Step 1: Being a Good Audience for the Complainant	Exemplars of Step 2: Constructing the Problem	Exemplars of Step 3: Enlisting Others in Story's Resolution
	are . . . All concerns are valid and need to be treated as valid." [Explaining what the patient advocate did to make a patient's family member feel heard] *Do you have a sense of what you did that made her feel heard or to really actually hear her?* Most of the time when I talk to people and I get that response, they tell me that I listen and that I don't say "Oh, that never happened." I cannot say that. I can never say what has happened or can happen or didn't happen if I wasn't there. If a person is giving an impression that you are automatically defending your staff person or whomever – " oh they would never do that," which I've heard myself, "oh nobody on my staff would ever do that," and then you find out later that somebody on your staff did do that. When I'm talking to them or listening to them and I immediately don't discount what they say or respond in a manner which makes them think I don't believe them, it validates their position."	thinking food's not properly prepared, it's too cold, something along those lines. He said that he was eating this hotdog, and his hotdog bun broke. It's bread, you know, what's the problem. He said, "So I called the manager over." And I went, okay, the problem is the manager didn't listen to him. No, the manager did apologize for the bun breaking, gave him a five-dollar coupon for his next meal. Apologized for the service that he got, and hopefully your next meal will be better. So then we go on, "Well, what's the problem?" I mean, at this point I was kind of lost. And he said, "Well, I think you're serving day-old bread to veterans because that bun was too brittle. And veterans shouldn't be getting day-old bread." We weren't giving them the freshest bread. And I thought, you got to be kidding me. I mean, your bun broke. But he had five-dollar coupons because his bun broke. And he said he lost his appetite, couldn't eat it anymore. You know, I don't know if it's day-old bread, I have no idea….But that was probably the silliest complaint that I've ever got. Out of all the stuff that can go wrong in healthcare...a piece of bread breaking is not on the top of my list. But you still have to treat him and his problems like you would somebody that...husband had died...and think that we were the cause of it, because to them, that is their problem.	rewarding. So I get the reward from the patient, as well as my...what I consider my colleagues... Because...I feel it's not just me solving the problem, it's all these people out here that I have to go to. I have had people ask me, well don't you get your paycheck from the [hospital]? I say yeah I do but the purpose of this office is to lend some degree, to offer a mediating kind of stance as to say let's look at all of these issues. Let me help you understand their side. Let me help them understand what you are going through.

Figure 4.1: Process Model of Organizational Storytelling as Problem Handling

Patient Advocate as Storyteller or Audience	Patient Advocate audience for patients and/or family members	Patient Advocate audience for and teller of stories patients and/or family members and hospital staff, and occasionally outside experts during process of story construction	Patient Advocate primarily teller of constructed story to relevant outsiders to enlist in story resolution
Steps of Organizational Storytelling Process	**Being a good audience**	**Constructing the story's problem**	**Enlisting others in problem resolution**
Relational Practices	•Providing complainants with experience of being heard •Treating every concern as important •Attending to own words and bodies	**Discerning** •Encourage emotional expression •Attention to physical space •Inquiry •Challenging a patient's complaint •Attention to own responses **Investigating**	**Perspective-taking** •Facilitating interactions •Defusing emotions •Creating empathic accounts •Creating absurd accounts **Framing Story Plots with Rules and Regulations** •Persuading power organization members to provide medical care •Disciplining misbehaving patients and family

Chapter 5

Playing with Rules:
Patient Advocates' Rule Use in Two Hospital Types

In the previous chapter, I described patient advocates' problem-handling work as akin to being storytellers in organizations. Viewing their work as storytellers helps to see patient advocates' agency. In this chapter, I focus on how they use elements of their social structure, the rules of the organizations, to act agentically.

There is a long and rich tradition of studying rules in organizations (Mills & Murgatroyd, 1991). Rules are ubiquitous and important, and rules are a legitimate form of authority in modern society (Weber, 1946). In organizations, rules are used to codify expectations about behavior, set standards for how different parts of an organization or the people in them should work together, to ensure the smooth functioning of the organization (Perrow, 1986). Rules can be both explicit and implicit, such as when they are built into forms and documents required by organizations (Preda, 2000; Scott, 2003). To be able to set or create rules, as well as to enforce them, is an important form of power and conferral of legitimacy (Feldman and Levy, 1994; Katz and Kahn, 1978; Scott, 2001). Rules can be set within an organization or unit itself, or can be set by external bodies, such as the state or industry regulators (DiMaggio & Powell, 1991; Fineman, 1998; Sitkin & Bies, 1994). This paper focuses on rule use by individuals.

One literature stream has produced valuable insights into the individuals' use of rules in organizations. These literatures focus on individuals' intentional decisions to

break formal rules and regulations in organizations. Research in this stream has identified a spectrum of reasons why individuals break rules, from self-interested rule violations intended to harm the organization or individuals in it (Vardi & Weitz, 2004) to pro-social rule violation intended to help an organization, customer or coworker (Morrison, 2006). However, this literature is limited it assumes that rules are either followed or violated and that there is clarity about the rule or its application.

There are two important limits to this assumption. First, rules and regulations are sometimes unclear, so that the meaning of the rule requires an individual to interpret its meaning and application to a particular situation (Fineman, 1998; Kolb, 1987; Lipsky, 1980). Second, in some organizational settings, rules can overlap, compete or contradict one another (Friedland & Alford, 1991). This literature would be enriched by explaining what individuals do with rules in these more complex rule environments. Currently, the focus is on either obeying or breaking rules, whereas a more complex rules environment invites ambiguity and perhaps a wider variety of rule-related actions.

Another literature has taken a macro perspective on rules and regulations. Much of this research focuses on the interaction between institutions, such as the medical or legal profession, and organizations (e.g, Dobbin, Edelman, Meyer, Scott, & Swidler, 1988; Edelman, 1990). Organizations comply with institutional rules, they argue, in order to achieve legitimacy in the eyes of important outsiders, such as regulatory bodies (Scott, 1991; Sitkin & Bies, 1994). This literature has overlooked the role of individual actors in organizations and institutions. However, in recent years, there has been a concerted effort to bring individuals into this theoretical perspective (Barley & Tolbert, 1997; Dacin, Goodstein, & Scott, 2002).

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Individuals' use of rules has emerged as one theme in this literature. Two theoretical articles offer relevant ideas. Fuller, Edelman, and Matusik (2000) argue that laws, a form of rules, are symbols that communicate meaning. Individuals interpret these laws based on their own personal history and their organization's previous actions regarding that law. They then act, for example, mobilizing a law to make a complaint of discrimination, based on those interpretations. In a second theoretical article, Fligstein (2001) proposes that rules and resources can become tools for individuals who are trying to create field-level change. These lines of argument are consistent with those who argue that rules provide a form of legitimacy, which in turn can provide a basis for action (Feldman & Levy, 1994). Both of these articles delineate how individual rule use is embedded in their social context and they suggest mechanisms through which individuals use rules to construct their social worlds. For example, both suggest that rules are important because they help people make sense or make meaning of particular situations. However, we still lack empirical evidence about how individuals use rules and how their rule use is enabled or constrained by their environment.

Until now, these two approaches to studying individuals' use of rules have remained separate. This study allows us to integrate two literatures by focusing on individuals who work with rules, but in organizational contexts that have complex rule environments. Hospitals are complex organizations in which medical and legal institutions, among others, coexist in varying strengths (Meyerson, 1994). Sometimes these institutions compete and conflict within a given hospital, and other times they coexist more harmoniously (Heimer, 1999). Thus, this study contributes to individual-level studies of rule use by studying individuals *in situ* who work in complex rules

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environments. The study also contrasts two different kinds of hospitals, teaching and VA hospitals, in which legal and medical institutions have very different powers within each organization. Comparing two cases provides an opportunity to see both similarities and differences that can help build theory about how individuals use rules in complex rule environments.

In this study, I seek to refine and extend theory by describing how patient advocates use rules. Further, I seek to understand how patient advocates' rule use is enabled or constrained by their organizational context. Thus, my research questions are: (1) How do individuals use rules in complex rule environments? (2) How do different organizational environments influence how individuals use rules? My findings suggest that patient advocates in both hospital types engage in four kinds of *rule use practices*, or recurrent situated activities (Orlikowski, 2002). Rules are not simply broken or obeyed, but instead, as Fuller and colleagues (2000) suggested, they are symbols that can be selectively drawn upon, put aside or enacted in new ways to construct ways of handling patient and family problems in hospitals. However, these rule use practices are performed in different ways across the two different hospital types, suggesting that the context can both constrain and enable individual rule use.

My argument proceeds as follows. I begin by asserting that the patient advocate role is particularly appropriate for asking these research questions, and then detail the emergence of rule use in my data collection. Next, I describe my data analysis. I then present my findings in two sections. First, I describe the findings from the shadowing data, and then I elaborate those initial findings with the interview data. Both sections are organized around asking the questions, What rules are used? Who uses the rules? How do

patient advocates use rules? These simple questions help build the answers to my

research questions. I conclude with a discussion of the findings and conclusion.

Chapter-Specific Research Design and Methodology

Appropriateness of Patient Advocate Role

My dissertation research on patient advocates is particularly appropriate for

studying rule use. Countless rules apply to hospitals, including rules generated outside the

organization, such as JCAHO, CMS, HIPAA – all state, federal, or industry rules. They

are also subject to internal (endogenous) rules, such as those set by the hospital or even

different departments or units within the hospital. The intensity of rules in hospitals is

necessitated not only by the administrative functioning of a large organization, but also

because they "deliver" many complex rule-bound services, such as the administration of

FDA-regulated narcotics, which frequently have life or death consequences. Given the

density of rules in hospitals and their many different origins, the people who inhabit them

are likely to become proficient at employing them. This expertise, born of necessity,

suggests that patient advocates are particularly appropriate for developing a more

complex and situated understanding of individual rule use in organizations.

Furthermore, I am contrasting two different kinds of hospitals, VA and teaching

hospitals, which are subject to different sets of rules. Both hospitals are subject to

HIPAA, a set of federal laws governing, among other things, patient confidentiality, and

JCAHO, a regulatory agency set up by the medical profession; for teaching hospitals,

receipt of Medicare and Medicaid benefits as well as insurance reimbursement are

dependent on receiving a passing grade from visiting JCAHO regulators. Teaching

hospitals are also regulated by CMS, because they must satisfy these regulations to

receive Medicare and Medicaid funds. Most salient to patient advocates are a new set of regulations passed in 2001 that were meant to strengthen patient grievance processes. They specifically require that patients who make a grievance receive a series of letters to follow-up on their complaint, whereas prior to this regulation, letters were not required. VA patient advocates, on the other hand, are not subject to CMS regulations because the VA is entirely funded by Congress. Thus, they are subject to extensive government regulations set and regulated by Congress and the Inspector General's Office.

Patients and doctors also have different legal rights and liability in the two kinds of hospitals. In teaching hospitals, patients have the legal right to sue individual caregivers and the hospital. Physicians named in medical malpractice suits can be represented by private practice lawyers. In VA hospitals, medical malpractice suits are handled by the Regional Council, Office of General Council and U.S. District Courts. Physicians named in lawsuits are represented by the VA, not individual legal representation.

Given these differences, any similarities found between the two types of hospitals in how patient advocates use rules would suggest that these rule practices can be found across a broad set of organizational contexts.

Focus on Rule Use during Data Collection

I did not begin this project with a focus on rule use; rather it emerged as a theme over the course of the data collection. I first noted the importance of rule use during the national conferences I attended. In a memo I wrote summarizing the conference, I wrote that patient advocates lived in a "thicket of regulations." This alerted me to rules' potential importance and thus I was conscious of patient advocates' rule use as the data

collection evolved. When I interviewed patient advocates, I did not ask direct questions about rule use but rather probed on their rule use when they brought up the topic (Lofland et al., 2006). The one exception is that during interviews I did ask patient advocates at teaching hospitals about the effects of new CMS regulations that changed the tasks required to do their job because I knew that was a uniform regulation affecting all teaching hospitals. Likewise, when I shadowed patient advocates, I did not direct attention toward rule use but asked about rules when they became an issue. For example, when shadowing at Reveille VA, I observed a patient advocate handling a case that I knew would be classified as a risk case at Heartland Teaching Hospital. The case involved conflicting claims from different groups of estranged family members about who had the right to make a decision about removing (the estranged wife's position) or continuing (the position of the siblings and son – with whom the patient had recently reunited) with medical care for a patient in a coma. I asked the patient advocate if this case would likely go to Risk Management, and she said no, but they might bring in the Ethics Committee to help with the decision – however, she would remain involved in the decision. This helped me to see what rules would be brought to bear on a case, and suggested a difference in the way that Heartland Teaching versus Reveille VA hospitals handled this particular type of case.

The analyses presented in this chapter are based primarily on the shadowing and interview data. The shadowing data provided direct observations of patient advocates at work coupled with their reflections on my observations. This data provided insight into the social aspects of rule use and how interactions with other people and departments shaped the rules they were able to use.

The interview data provide accounts, or ways in which people construct and order relationships between people, events, things in their world (Orbuch, 1997). These accounts shed light on how and why patient advocates use rule practices. They also provide an opportunity to explore a broader set of institutional environments. Individual hospitals can vary substantially in the strength of their institutions (e.g., Meyerson, 1994). While the shadowing data provide detailed snapshots of two quite distinct rule environments, the interviews with patient advocates took place at 17 hospitals (10 Teaching hospitals, 7 VA hospitals) and each hospital is likely to have a unique set of institutional logics present.

Analysis

I arrived at the topic of patient advocates' use of rules in case handling by asking the broad question, How does working in the VA versus teaching Hospital affect how patient advocates' handle problems? Asking broad questions of data after being immersed in the data collection period can aid researchers in the process of removing oneself from the data collection site and seeing the data from new perspectives (Feldman, 1995).

As noted above, patient advocates' rule use emerged as a theme across several sources of data. For example, a number of presentations at the professional conferences I attended focused on educating conference attendees about how to comply with the latest CMS rules and incorporate them into their everyday work practice (e.g., at the State conference, several patient advocates mentioned that the new requirements meant they had to rewrite their entire book of policies and that visiting inspectors had looked at

them). My background informants also talked about the importance of rule use and noted that different rules applied to Veterans' Administration and teaching hospitals.

Coding of three field notes from the shadowing data (28 pages for the VA site, 31 pages for the teaching hospital site) suggested that rules and regulations shaped many different aspects of patient advocates' work. For example, patient advocates used rules when they handled cases. Rules also shaped which cases patient advocates could or could not handle. For example, patient advocates at Heartland Teaching Hospital became annoyed and frustrated when a patient started threatening to call a lawyer, because it meant that they would have to turn the case over to the Risk Management department, which handled lawsuits against the hospital; the patient advocate could no longer be involved in the case. Rules and regulations shaped their physical environment. For example, a poster of Patients' Rights and Responsibilities was posted prominently near the main entrance of Reveille VA Hospital.

I approached the analysis of the shadowing data with a broad analytic question: How do rules and regulations constrain and enable patient advocates in accomplishing their work? In the shadowing data, I noted all mentions of rules and regulations, grouped all of these passages into categories (e.g., handling cases, database systems, physical building), and wrote reflective memos to describe each of the categories, noted any questions the data raised, and identified potential conceptual connections to other categories. When the analysis of the shadowing data was complete, I compared rule use in the VA and teaching sites by asking three questions: What rules are used? Who uses the rules? How do patient advocates use rules?

In the analysis of the interview data, I sought to discern whether rule use practices and institutional logics could be identified and elaborated through the interview data. Institutional logics are "socially constructed, historical patterns of material practices, assumptions, values, beliefs and rules by which individuals produce and reproduce their material subsistence, organize time and space, and provide meaning to their social reality" (Thornton & Ocasio, 1999). They are, in a sense, meta-rules. For each interview, I noted all mentions of the rule use practices and contextual influences. I looked for, but did not find, additional rule use practices or contextual influences over and above what I found in the shadowing data. However, the rule use practices and rule environment categories were revised and elaborated as I made sense of a more varied sample of patient advocates.

Following a strategy of iteration (Locke, 2001), I went back and forth between the data and theory from several literatures addressing rules (Douglas, 1973; Heritage, 1984), law in organizations (Sitkin & Bies, 1994; Edelman & Suchman, 1997), institutions (Goffman, 1961; Powell & DiMaggio, 1991), and perspectives on agency that shed light on agency in the context of complex social contexts (e.g., Feldman, 2004; Fligstein, 2001; Giddens, 1984; Orlikowski, 2002). The literature helped me to refine and structure the categories in a way that both fit and elaborated on prior theory.

My methods involved multiple iterative processes and were consistent with recommendations to establish the credibility of findings (Lincoln & Guba, 1985), including triangulating data from multiple sources and providing extensive quotes from the data.

In the following section, I will describe the evidence from the shadowing data, followed by the interview data. I will organize by talking about what rules are used, who uses them, how patient advocates use rules.

Heartland Teaching Hospital: What Rules are Used?

Hospitals are the site of the multiple institutions (Heimer, 1999). Each of these institutions, in turn, provided an institutional logic (Thornton & Ocasio, 1999). At Heartland Teaching Hospital, several sets of institutional logics shaped patient advocates' work, including: a *medical* institutional logic, which gave primacy to highly complex medical care and the doctors who executed medical expertise; a *legal* institutional logic, which govern the patient's rights to sue the hospital, and hospital employees' rights to prevent and defend themselves against lawsuits; and *human resources* institutional logic, and specifically how it governs the employment relation. As I describe below, each of these three institutional logics shaped how patient advocates at Heartland Teaching Hospital did their work of case handling.

Medical Institutional Logic While we know that the strength of the medical institution varies across hospitals (Heimer, 1999; Meyerson, 1994), at Heartland a medical institutional logic was paramount and appears to be widely shared among many constituents of the hospital. Heartland Teaching Hospital prides itself on providing the best medical care in the region, and in some specialties, the world. In this way, Heartland Teaching Hospital is an example of a hospital in which the profession of medicine is dominant and physicians are granted a prime location at the top of the organizational

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hierarchy and whose authority is rarely questioned (Larson, 1977, cited in Meyerson, 1994).

The widespread acceptance of a medical institutional logic is evident because the staff, patients and their family members frequently made statements that reinforced the preeminence of medical authority in the hospital. For example, when patient advocates relay complaints about long wait times or cancelled appointments, perhaps the most common complaint at Heartland Teaching Hospital, it was not unusual for staff to reply: "They are here for the best; sometimes it takes a long time." In this way, hospital staffs reinforce the idea that high quality medical care is more important than customer convenience and satisfaction.

Patients and families also draw on the logic of medical authority when explaining the problems experienced in the hospital. The following example from my field notes illustrates a patient (the mom) and her families' assertion of respect for a doctor at the same time that they describe why they are very upset about a cancelled surgery.

> The father/husband started talking, then the mom did too. The girls were pretty silent. Pretty soon, the mom and the daughters were silently crying - I was sitting behind the older daughter (who had flown in from [another state]) and I saw a tear drop off her cheek. I felt tears well up behind my eyes as I heard them tell their story – 'we understand the doctor's decision [to cancel the neurosurgery], it was a good decision, it was for safety, it's just the disappointment; we are both [low-paying job], it took us a long time to get the money to fly our daughter home, we have two younger ones at home; she has to go back to [university in another state] tomorrow; we don't want to file a complaint, we really trust the doctor, but we're so disappointed.'

This example illustrates how patients and family members legitimize the doctor's decision-making authority in spite of being in tears about a cancelled surgery and the financial, emotional, and physical impact it would have on the family.

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However, the patient advocates' role of handling patient and family complaints

sometimes put them in a position in which they challenged, or appeared to challenge,

doctor's authority in the hospital. A favorite type of "war story" among patient advocates

was about doctors yelling at them because they think the patient advocate was

challenging their authority. For example, one patient advocate explained to me the careful

way that he approached doctors when he received complaints about physician attitude:

> I learned the hard way never to address an attending physician about his or her attitude. [Laughs] The only way that's going to work out is if their supervisor, their chair, their department head tells them about it. Because it's amazing, you know, although we're just a messenger in many cases, you can get yelled and screamed at, 'How dare you? rar-rar-rar-rar' 'No, no, no. I'm conveying to you what your patient said about you. That's why I'm bringing this to you, because your patient is not happy with something you've done.' But they're yelling at me because I brought it to their attention, or you know, I forced them to go out of their way and do something. Anyway, I just let them yell, or I let them….I don't know. It doesn't bother like it used to.

I also observed doctors get defensive when a patient advocate told a doctor about a

patient's needs or wants. The following example from my field notes describes a

conversation between a patient advocate and a physician after we had visited a patient

who had had a complaint the previous day.

> The attending called back. He had a very quiet voice so that I had to really strain to hear him.
> The patient advocate told the attending that she had gone to see the patient. The attending knew about the patient's conflict with the previous attending physician, but didn't know about the problem with Sam, the Physician's Assistant. The patient advocate reiterated that the patient's main concern was about the blood pressure medication that would help with her very painful blood pressure headaches - she had had 5-6 since she had been in the hospital.
> The doctor asked: "Why did the patient tell you about the blood pressure medication and not me?"
> Patient advocate: "I asked her that and she said that was planning to talk to you today. Is it possible for you to change the Physician's Assistant?"
> Doctor: "Yes."
> Patient advocate: "OK, just wanted to give you a heads up."

The doctor questions why the patient did not tell him about her medical concerns, and the patient advocate reassures him that she had the same question. She is conveying that she respects the doctor's authority and encouraged the patient to respect medical authority as well. Both of these examples demonstrate Heartland Hospital patient advocates' careful handling of doctors, who are the most highly valued practitioners within the institutional logic of medicine.

Patient advocates also *use* medical institutional logic to make sense of and act when handling complaints. For example, one afternoon, a patient advocate was exasperated by a patient who was ordering her own medical care. The patient, who was also an employee of the hospital, described herself as having a "life threatening emergent condition." The patient had paged doctors in ENT [ear, nose and throat], surgery and her own PCP [primary care physician]; taken her own throat cultures and ordered lab tests that she thought were necessary. In discussing this case with me and another patient advocate, the patient advocate said "She needs to be reigned in. She's not a physician, she can't be writing her own labs." Here, the patient advocate uses medical institutional logic – physicians can write lab requests; patients cannot – as a way of classifying this patient's behavior as out of line and worthy of being controlled.

Patient advocates also use medical institutional logic to reinforce how doctors act. Doctors are accustomed to having other professionals and semi-professionals "predigest" and "predefine" problems so that they become the recognizable tasks that they were trained to do (Abbott, 1981, cited in Heimer and Stevens, 1997). Because patient advocates deal with ambiguous complaints and problems – ones that are not easily categorized or solved – patient advocates do get physicians involved in problems when

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the problems remain messy, and such messy problems can leave physicians at a loss about how to act. One such situation involved an adult male patient who had been in the hospital for four months with a sudden and difficult to diagnose illness. The patient had been given a series of diagnoses, which turned out to be incorrect, as the medical team tried to figure out what was wrong. Just a few days prior to my observation, the patient had been given a new diagnosis. The family wanted the patient transferred to another state to be treated by one of two world experts on this rare disease, but the medical team did not think a transfer was warranted at that time. The family was very frustrated that they wouldn't transfer the patient. When the patient advocate discussed the case with the patient's attending physician, the physician said, "Well, what do you want me to do?" The patient advocate explained to me that you sometimes have to remind physicians that "you're in charge" and can make all sorts of things, from a family meeting to a transfer, occur. In these instances, patient advocates encouraged doctors to use their authority.

Overall, at Heartland Teaching Hospital, medical institutional logic had a major presence in patient advocates' work. Patient advocates, patients, their families and other hospital staff all drew upon this logic. Patient advocates reinforced this institutional logic in their interactions with patients and with hospital staff. It helped them make sense of situations and know how to act.

Legal Institutional Logic At Heartland, patients have the legal right to sue hospitals and individuals who work in them (e.g., nurses, doctors) and hospital staff members appear to be aware of the potential of being sued by patients or their family members. At Heartland Teaching Hospital, patient advocates' authority to handle cases changed when the patient or family member threatened to sue the hospital. If a patient or

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family member talks credibly about getting a lawyer to sue the hospital, or the complaint is about what sounds like a serious medical mistake (e.g., "sentinel event" or "near miss"), the patient advocate will alert their contacts in the Risk Management Department. This department, found in most hospitals, protects hospitals against lawsuits. If Risk Management takes the case, any record of it disappears from the patient advocates' database. They do not know the status of the case or how the case was resolved.

Because patient advocates did not have direct access to this information, they sometimes had to call and ask Risk Management for information about "risk" cases. In one such example, the husband of a patient had complained to a patient advocate about a "near miss" – a doctor had been about to give his wife a medication that she was allergic to, but the husband stopped him just prior to giving the medication. The doctor acknowledged to the husband that he had almost made a mistake. While this should be documented as a "near miss," it was not showing up in the patient advocates' documents. The patient advocate called and conferred with her Risk Management contact to find out if there was any documentation about it (there was) and then the Risk Manager coached her on what to say to the husband about the incident.

Hospital employees also were aware when a patient or family member was acting in a way that their behavior warranted classification as a "risk" issue. When patient advocates were trying to get others to help them with a complaint, a risk classification stalled patient advocates' work on behalf of patients or families. For example, a patient advocate took a call early one morning. A mother of toddler-aged special needs twins called to ask if a patient advocate could help get the twins a special kind of flu shot. The mother was frustrated because she had made special efforts to get the shots at a particular

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clinic, but when she and the twins went to the clinic, they claimed they did not have the shots. In working to help this mom, the patient advocate went through a number of steps to get the twins the shots (confirmed that the pharmacy did have them shots in stock and that the pharmacy would release them with a doctor's order; got a doctor's order for both twins). But, the patient advocate's ability to get the twins the shots was permanently halted when a nurse said in a discussion among a number of employees that giving the shot was a "risk issue" – the nurse didn't know the protocol for this shot for a baby who was not "normal"; if something went wrong, she and the hospital could be legally liable. As soon as giving the shot was constructed as a "risk issue," the patient advocate could no longer pursue getting the shots for the twins, much to her disappointment. The patient advocate was left having to explain to the mother that the shots couldn't be administered because it would put the hospital at risk and gave her some coupons (a form of service recovery) for meals and gas for her trouble.

Overall, at Heartland Teaching Hospital, legal institutional logic was a major presence in patient advocates' work. Patient advocates conferred with the Risk Management department about problems and issues, using potential legal liability as a way of deciding which department should handle which cases. But Risk Management and Patient Advocates were not equals. Risk Management had access to information that patient advocates did not. When a case became classified as a "risk issue," patient advocates agency, their ability to work on the complaint, was halted. Therefore, the internal legal authority patient advocates interacted with, Risk Management, appeared to have more power.

Human Resources Institutional Logic At Heartland Teaching Hospital, a Human Resources institutional logic was also relevant for patient advocates' work. The most relevant set of HR rules for patient advocates are those that govern how employees are hired and what causes them to be fired. As was true with the Risk Management Department, if the Human Resources Department conducted an investigation of a case, the case disappeared from the patient advocates' database.

The set of HR rules most salient to patient advocates were those that govern patient confidentiality. Patient confidentiality rules are governed by HIPAA. The HIPAA law regulates who and under what conditions confidential patient health information can be accessed. The Information Technology Department at Heartland can track precise information about which employees have accessed patients' confidential health information and when they accessed it because medical records are kept in electronic form, making surveillance routine.

HIPAA rules governing patients' confidential health information became relevant to patient advocates in two kinds of situations. Patients requested audits of their medical information when they suspected that an employee has accessed their confidential health information inappropriately. Patients typically requested information audits either when the patient suspected an hospital employee who had no reason to know about their mental health diagnosis revealed that they did in fact have such knowledge, or when a patient suspected that a relative, friend, or neighbor had learned about confidential information through an employee (e.g., a patient's suspects her ex-brother-in-law, who works for the hospital, has supplied confidential health information during divorce proceedings).

As employees, patient advocates are also subject to HIPAA rules. Like all employees, patient advocates can be fired for accessing confidential health information inappropriately. This was a salient topic to Heartland patient advocates. During a staff meeting, the manager warned that hospital staff were being fired for inappropriate access to patients' electronic records and urged the patient advocates and administrative assistant to be cautious about their access. In the discussion that followed, the patient advocates disagreed about how much access was appropriate. At one end of the spectrum, one patient advocate thought access to mental health information was helpful when dealing with patients they did not know and who may act unpredictably. At the other end of the spectrum, one patient advocate believed that it was inappropriate to access confidential health information because it could bias them against the patient, instead of paying full attention to the patient in the moment.

Summary Overall, there are several institutional logics relevant to patient advocates at Heartland Hospital. Legal and medical institutional logics each provide a set of rules, values and authority structures that influence what work patient advocates do. As a result, there were clear and hierarchical boundaries between the patient advocates and the Department of Risk Management and clear deference to medical authority, if not every doctor. Patient advocates are also subject to HR rules and they experienced Heartland Hospital as a source of surveillance and control. Patients' rights and responsibilities, while present, were not often mentioned or used by patient advocates at Heartland Teaching Hospital.

Heartland Teaching: Who Uses Rules?

Patient advocates at hospitals interact with other staff members to decide which rules apply to a particular case and occasionally to encourage doctors to use the authority granted the medical institutional logic granted them. Hospital staff members, therefore, co-construct the meaning of a particular complaint and figure out which authority should handle the case with other staff members. The patients and their families are not actively involved in deciding how their case will be handled. They rarely appeared to know the rules, nor would they have an opportunity to learn them. As a result, a case remains with the patient advocates or is channeled to one or more departments to be handled appropriately.

Reveille VA: What Rules are Used?

While Reveille VA Hospital has doctors, a Risk Management Department and is subject to HIPAA just like Heartland Hospital, there are different institutional logics within the two hospitals. At Reveille VA Hospital, patient advocates worked within a *VA institutional logic*. Unlike Heartland Teaching Hospital, in which there are different sets of institutional rules, I found a VA institutional logic, and that patient advocates use, bend and apply rules in a variety of ways, as long as rule use follows the VA institutional logic. I describe the logic below.

First, at Reveille VA, rules should be used or ignored as necessary in order *to provide access to high quality medical care and service to veterans*. This appears to be the highest priority for patient advocates, one that overruled all other rules or authorities. For example, Reveille VA patient advocates handled a number of complaints about patients wanting their physicians changed. One time, a patient called because she was

experiencing symptoms that she thought required urgent care, but her doctor told her that she didn't have any availability prior to her already scheduled appointment. After talking to the patient, the patient advocate called a friend in the scheduling office and learned that the patient's doctor did in fact have appointments available. The patient advocate's side of the conversation suggested that the patient's right to an appointment was more important than the doctor's like or dislike for the patient:

> Oh my goodness! Why can't they give [those appointments] to her? I mean, [the patient's] a pain in the ass. I know her too, but you can't write her off just because she's a pain in the ass…Let's do tomorrow. Where is she coming from? Let's do 10am…I'll call her...

In this case, the patient advocate overrides the doctor's preference not to see the patient prior to her scheduled appointment because of the *patient's* right to be seen. The patient advocate is choosing to follow the patient's right over the doctor's orders.

Rules can also be ignored, as long as they are in service of helping the patients. For example, during a staff meeting, one Reveille VA patient advocate described helping a patient who complained about the lack of city lights near the VA, which he said made it dangerous to get to and from the VA at night via the public bus. The lights were not on VA property, so they were outside of VA jurisdiction and thus the patient advocate did not have to help. However, the patient advocate decided to help the patient and got the city to fix the lights, even though it was out of his jurisdiction because he saw it as his duty to help the patient.

Rules that are not directly applicable to providing high quality patient care may be optional. Two examples follow. One, there is a rule that visitors to the VA must be fingerprinted, given a security badge, and have a background check. However, when I first arrived at Reveille for a one-day site visit, the employee in charge of the process

decided my one-day visit was not worth the $75 it would cost to run a background check. But, when I came back for extended visits, I was brought back to the same administrator, who immediately fingerprinted me and provided me with an identification badge. Another example comes from a story discussed by patient advocates and another staff member. They were complaining about a "super negative" staff member who could be written up and disciplined by her boss, but he chose not to implement the rule because he was afraid of the staff member. These examples suggest when rules do not directly affect patient care, their application is optional.

Second, *veterans, their families and staff should observe the "chain of command."* Following the "chain of command" means going to the appropriate person at the appropriate hierarchical level to register and try to resolve a complaint. If patients do go outside of the chain of command, they should first ask and receive permission for doing so. I suspect that patients, their families and VA staff are socialized into the "chain of command" mindset through their participation in military and VA culture. Many of the VA patient advocates and other staff I met were veterans themselves or had immediate family who were veterans, so they had exposure to military and VA culture in many parts of their lives.[3] There was only one VA patient advocate I shadowed who was neither a veteran nor an immediate family members of a veteran. Nevertheless, even he participated in VA culture as a member of a VA-sponsored bowling team, providing him with social as well as work connections to veteran culture.

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[3] My observation that many VA employees were also veterans is supported by the VA's own data on employees (Office of Public Affairs, 2007). In 2007, approximately 60% of all male employees were veterans, and 14% of their entire workforce are female veterans. Note that these figures do not include employees who are relatives of veterans.

One example of following the chain of command comes from a patient who stopped by the patient advocate's office to complain about several issues, including one chronic problem. The veteran and her partner had recently moved to the area from another VA region (VISN), and neither the veteran nor the patient advocate had been able to get her current VA region to provide the painkiller that worked for her partner's chronic, painful condition. In this passage from my field notes, the patient and patient advocate talk about bringing this problem to their Senator's attention, which would be the next step up the chain of command regarding complaints.

> Susie [a veteran] explained to the patient advocate that she was still working on getting medicine for Linda, her partner. Susie had called a distributor who told her that the 10 milligram capsules of pain medication were available. The person she spoke with said, "I don't know what's going on with your VA down there, but this drug is available within your area."
> Susie: "And the pharmacy told me that it wasn't available. I don't know how many times I have argued with them, and here it was this whole time! I just don't know what to do about this. I am thinking about calling the Senator's office. It is not the right thing to do. I am a marine, and you should work within the system, but this is too much. I am thinking of calling him. I mean, am I crazy?"
> Patient advocate: "No, you're not crazy. You should contact the Senator's office about this. I have done all that I can on this, and I have gotten as far as I can, and I am impressed by how far you have been able to get. You've gotten further than I have."
> Susie: "You think I should call Senator's office? That is not a small step."
> Patient advocate: "I think you should because getting a call from the Senator's office will get you further than I can; I have gotten you as far as I can and he is more powerful so he will get you further."
> Susie: "OK…"

In this discussion, the patient advocate and veteran explicitly discuss the significance and potential impact of going outside the chain of command. In the VA institutional logic, there are also two forms of rule use that are inappropriate. First, the patient advocates, patient and families and other staff members I observed drew a clear line between "inside" and "outside" the VA. *When complaining, patients and their*

families should not embarrass the VA to people on the "outside." For example, one of the

VA patient advocates told me a story about receiving an emergency page to help diffuse

potentially embarrassing situation:

> We had a Congressman coming, and everyone knew about it. And we had a man in a wheelchair in the ER who had a sign that read 'I've been waiting in the ER for 3 hours.' They paged me down in the ER because the Congressman was coming and here was this man with the sign. I prayed, and then I went down there. And we only have 6 ER beds and 1 exam room, and there were people everywhere. [It was extremely busy].
> I went down there, to the nurses station, and I said, "Who is this guy?" No one knew him. But I wanted to know who I was dealing with before I went out there and finally someone told me that he was here for pain.
> I went out there and I apologized. I said, "I am so sorry that you have to wait here. I need something to write on, could I borrow your paper?"
> So he gave the sign to me - the wife told me later that when she saw that, she thought, 'she's good' - and I had a pen, and I wrote some information on the back of it - who his doctor is, etc.
> *The patient advocate pulled out the sign and showed it to me.*
> Now the patient and his wife come back to me all the time - I call him the "sign man." He said, you really helped me that day, and you took the sign. He was in such severe pain, he didn't really notice.
> *What did you do?*
> I apologized, "Let me see if I can help you." So I found a room for him in the pain clinic, and I got him seen in there.

What is particularly notable about this example is not only that the staff in the ER

organized to save themselves from a situation that would embarrass them in front of a

Congressman, but also that the veteran's wife knew that the patient advocate was trying

to save the hospital from embarrassment and was impressed at her ability to disarm them

and get them help.

A second inappropriate use of rules within the VA logic is that *only those people*

with legitimate claims are allowed to criticize VA staff. I observed several instances in

which outsiders – either a patient's family members who had tenuous relationships to the

patient or outside advocates – criticized staff in the process of trying to influence a staff

member. When these outsiders criticized VA hospital staff, their influence attempts were unsuccessful.

Reveille VA Hospital: Who uses rules?

At the VA, everyone – doctors, nurses, administrative staff, patients, their families, and patients – use rules to benefit veterans. It is important to note that these are not distinct groups, but many people are members of more than one group. A large percentage of VA employees are also veterans (Office of Public Affairs, 2007). Likewise, staff members who are not veterans themselves often have family members who are veterans and VA patients. The VA is relatively unique in U.S. healthcare in that once veterans begin care at the VA, they continue receiving care for the rest of their lives. Therefore, they have time to develop long-term relationships with caregivers and learn the hospital's rules. I argue that all of these groups have a relatively similar orientation to rules because of their long-term participation in and socialization into the VA and for many of them, the military.

As co-participants in one institutional logic endogenous to the VA, all patients and staff have access to information about rules and rule use. The rules may be complex, confusing and constantly changing, but they belong to everyone. People from many different groups share information about rules and how that can help in the ultimate goal of providing high quality medical care and service to veterans. I observed many instances of patient advocates talking to other staff members about a patient's need, and the other staff member might remind the patient advocate of how a rule could or would function. For example, a female patient wanted to change doctors. The patient advocate called a scheduler to find out what could be done, and the staff person reminded her that because

she is a "female," the scheduling department could get her right in; the medical residents in that group needed to see a certain number of women so they got faster access to appointments.

Patients also share information about rules, which is facilitated by numerous veterans' services groups, such as the Veterans' of Foreign Wars, AMVets, Blind Veterans of America, among countless others. In these groups, veterans shared information about how to access care and what benefits were available to veterans. When making a request or complaint, veterans commonly raised information that they had learned from their fellow veterans. For example, one patient walked into a patient advocate's office asking to be switched to a particular doctor. When the patient advocate asked why he asked for that particular doctor, he replied: "word of mouth," meaning that the doctor had a good reputation among other veterans.

Comparing the Rule Environments of Heartland Teaching and Reveille VA

In contrast to Heartland, patient advocates at Reveille do not appear to be concerned about legal threats to the hospital. The only time legal rights became important was when the issue involved the next of kin. Patient advocates and other staff I observed knew who claimed to have power of attorney over particular patients and whether that person actually had the legal documents on record to prove it. But the patient advocates, as well as other hospital staff, seem relatively unconcerned about being sued. In fact, patients do *not* sue individuals within the VA (e.g., doctors), but instead sue the federal government.

Medical rules (e.g., doctors' orders) also seem less important compared to Heartland Hospital. They seem subservient to the more general VA rule of providing the

veterans with optimal medical care. This became clear during a meeting in which the medical staff involved in the post-surgical rehabilitation of a veteran. The lead doctor, who had recently joined the VA after many years in the private sector, commented that they were not following rehab protocols for patients as much as they would in the "private world." Instead, the patient was directing his own medical care. In general, the VA appears to have lower boundaries between groups (e.g., legal, medical, and HR authority) within hospital, but strong boundaries between "inside" and "outside" the VA.

Heartland Teaching Hospital: How do patient advocates use rules?

At Heartland Teaching Hospital, I found that patient advocates used rules in two ways. I observed patient advocates *explaining* policies and procedures to patients and families who could not or did not get "good" care at the hospital. For example, patient advocates explained *why* an experience that a patient complained about had happened, essentially helping patients and their families see why the organization works the way it does. They might, for example, explain why information is made visible to medical practitioners. A patient complained because medical staff she consulted about getting beriatric surgery knew that about her psychiatric diagnosis and history. The patient didn't think that it was appropriate for the beriatric surgery team to know about her psychiatric diagnosis and feared that the diagnosis might interfere with her chances of being approved for the surgery. In investigating this complaint, the patient advocate learned that the hospital changed its policy from having a "firewall" about mental health diagnoses and information, to making it visible to medical practitioners because a "disaster" had occurred when ER staff did not have psychiatric information about patient. As a result, the final letter to the patient included the sentence: "This is a decision based

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on the caregivers' need to have access to patient's history in order to provide optimum care." While the patient advocate does not go into detail about the rule, he uses the rule to explain why her psychiatric diagnoses had been visible to the surgeons.

When patient advocates explained rules, occasionally they would also give them either some form of monetary compensation, such as a gift certificate to the cafeteria or a gas card. Explaining was coupled with a resource, such as a gift certificate or an appointment. This is part of what hospitals call "service recovery." Patient advocates sometimes cynically referred to service recovery as "paying them off," but they were all glad to have access to service recovery to make bad situations somewhat better. They were also the only Office in the entire hospital that had access to service recovery.

Patient advocates sometimes used service recovery to reward good behavior. For example, when a patient wrote a letter complaining about her bill, the patient advocate learned that the patient had made one payment towards the bill. To the patient advocate, this signaled that the patient advocate was not trying to get out of paying the bill entirely, so she made a one-time payment to her bill to reward her positive behavior and as a token apology for the trouble in the hospital.

At the same time, patient advocates had to guard against being taken advantage of by patients or families who learned that service recovery could benefit them. For example, a family who had previously received reimbursement for their hotel costs due to canceled surgery requested that the Patient Advocate Office pay for their hotel on a recent visit because of a new complaint. The patient advocate felt that they were trying to take advantage of her, and decided to ignore the hotel request and deal only with the actual complaint.

Another form of resources that patient advocates could provide was access to new appointments. The patient advocates at this hospital spent a lot of time dealing with cancelled appointments. The fault for these cancelled appointments typically lies squarely with the hospital, not the patient. When patient advocates dealt with such complaints, they would often call the clinic and see if the patient could be scheduled earlier. While this was not termed service recovery, it served a similar function of providing the patient with a resource at the same time that they were explaining the reason for the failure.

I also observed Heartland Teaching Hospital patient advocates *documenting* on behalf of patients so that they could access the care and service they want. Many times, this meant documenting the patient or their family in such a way that they will be comprehensible to medical system. For example, an elderly "frequent flyer," or patient who made regular visits to the office complained because she was asked to fill out the same intake forms at all of her frequent appointments. She was frustrated because she knew that every clinic had already this information in their system. The patient advocate explained to me that he knows there is a medical reason for filling out the forms – it tells the clinic how well the patient remembers her personal information (name, address, etc.) and medical history (e.g., dates of surgeries). But, the patient advocate also knew it was a "pain in the patooty" for the patient because she had so many appointments. So, he photocopied a completed version of the forms that she could hand in at every appointment. With these documents, the patient would be comprehensible to the hospital, and she could avoid the annoyance of having to fill out the forms so frequently.

Documenting also involved making the medical system comprehensible to patients and their families. For example, a patient walked into the office wanting some

help with a bill. One of the patient advocates jumped out of his chair to help him. He learned that the patient was trying to understand why two bills for the same type of visit cost two different amounts. The patient had already made at least one call to the hospital and his insurance company, and they had not been able to tell him. So, the patient advocate led him to two different people who worked in the Billing Department in order to understand the discrepancy. The patient left with an explanation of the bill and the documents that the patient would need to fight a different bureaucracy – his insurance company.

In both situations, proper representation of patients in documents is very important to make patients and hospital comprehensible to one another. The result is that the patient and family have an easier time or are better equipped to navigate Heartland Hospital bureaucracy.

Reveille VA Hospital: How do patient advocates use rules?

There are several ways that patient advocates at Reveille VA Hospital used rules when handling cases. Patient advocates *switch between* sets of rules in order to access to medical care. Presumably, I described a patient advocate scheduling an appointment in spite of the doctor's refusal to see the patient. In that case, the patient advocate was switching from the doctor's orders to the patient's rights, in order to get the patient an appointment. Patient advocates also switch between rules to access resources. For example, I observed a patient advocate try to help a patient get an electronic wheelchair. The patient was not eligible for the wheelchair through VA rules, so she asked a doctor to write a recommendation so they can try to get the wheelchair through Social Security.

Patient advocates also ***coach others*** on how to use rules. The following is an example of a patient advocate coaching a patient on how to get the outcome he wants.

> The patient told us that he had asked the doctor in charge of his case if his physical therapist could leave with him to go on a field trip to his local gym, and make recommendations about what physical therapy exercises he could do at the gym once he was discharged. The doctor refused. Upon hearing his story, the patient advocate commented that the physical therapist reported not to the doctor, but to the manager of the physical therapists. The patient advocate suggested that the patient should ask the manager if the physical therapist could accompany him.

The patient advocate is suggesting another avenue which he can try to get a positive answer to his request that his physical therapist accompany him to his local gym. Because of his knowledge of her reporting relationship, the patient advocate suggests that if he asks another person, the patient may get a different answer, and the one that he wants.

Because everyone knows and uses the rules, ***others coach*** patient advocates on how to use the rules. As I described above, a clerk reminded a patient advocate that a female patient could get an immediate appointment because medical residents need to see a certain number of female patients. I also observed patient advocates and other staff members sharing information about rules. Frequently, when a patient advocate referred patients to another office or called another staff member to learn about a rule, the staff members from that office would stop by later to talk about how the rule applied in that particular situation.

Rule use was also a common topic of conversation. For example, on Valentine's Day, a patient advocate, Shirli, received flowers from her beau. This patient advocates' friends and mother, all of whom worked at the VA, stopped by to admire the flowers. While they were chatting, the conversation moved to a case the patient advocate was

dealing with and the rules that were relevant for that situation, as the following passage

from my field notes describes:

> I got back up to the office after a bathroom break, and Shirli was in her office. Grace came by and saying, 'I'm such a packrat.' Grace is going to save this Valentine's paper that came with the flowers that she got from her husband. A friend of Shirli's was also visiting her office. Shirli introduced me. It turns out is the friend that Shirli had gone to Cancun with. She explained that the four women had gone to Cancun and even though it was raining, they had had a really great time. The friend was saying congratulations about the flowers.
> Then Shirli got a call from somebody else who works at the VA. And that person was calling because she had heard from Shirli's mom about Shirli's best friend's husband who has plough contracts with lots of different counties; Shirli's mom thought he would be really willing to plough snow. So that was another sort of indication of the dense social networks of the VA. And then someone else came in, and this woman, it turns out it was Shirli's mom. And then the assistant chief of staff came too. So first Shirli's mom was there, and she had come to check out the roses and admire them. Her mom said, you know, you really have to cut the roses this particular way. And Shirli's replied, "Well, I've never had any problem before."
> And then the conversation moved to the ambulance issue, and Shirli's mom was asking about it, and there were questioning back and forth the way that people so often do – what happened? What was the situation? Da-da-da-da.
> And Shirli's mom told her that the ambulance drivers don't have medical training. They're trained simply for transportation. So they're not supposed to treat people. If some medical emergency happens, then they're supposed to stop and go to the nearest hospital or call a paramedic or something. But they have really basic training. And so Shirli was surprised. She didn't know this. She figured that they had some training.

This passage demonstrates how a social visit at the VA involving people connected

through work, social and family ties turns into a conversation about a case and how rules

apply to it.

VA patient advocates also ***documented*** and ***explained,*** like the patient advocates

at Heartland. An example of explaining occurred during a discussion between a patient

advocate and a patient who was upset that he had been given a psychiatric evaluation.

The patient advocate explained that the entire medical team thought he looked depressed

and that they had an obligation to get a psychiatric consult. Unlike at Heartland, where

explaining was often coupled with service recovery, patient advocates in the VA do not have access to service recovery resources (e.g., meal tickets, gas cards) because of limited funds, although they can provide access to appointments.

Documenting also played an important role in case handling. For example, a speech pathologist stopped by a patient advocate's office to request her help with a patient who was "fixating" on his belief that the social worker was stealing money from his Medicare check. While the speech pathologist had looked into the issue herself and didn't think it was legitimate, she felt like his fixation on the issue was getting in the way of his speech therapy progress and thought that perhaps the patient would feel better if his concerns were documented. The next day, the speech pathologist brought the patient in, and she heard his story and documented his concerns. The patient advocate explained the importance of documenting the patient's concerns:

> It's not my job to figure out if he is lying. Do I think that the social worker took money from him? No. I think he is credible, but how am I to know? People steal from each other all the time. Now his concerns are documented. [The patient] was a very intelligent man, there was nothing wrong with his mind. He said to me at the end of the conversation that he feels like he can let it go. And I felt good about that. Often people come to us looking for validation, and he can get it from me. Sometimes they need credibility in the system.

Summary The shadowing data revealed two distinct rule environments. Heartland Teaching Hospital has multiple institutional logics that shape what cases patient advocates handle and how they handle them. Cases can be classified as outside of a patient advocates' domain, and removed from their jurisdiction by actors in both the legal institutional environment (Risk Management) and HR institutional environment. This has important consequences for patient advocates' ability to work on a case and gain cooperation from others. At Reveille VA Hospital, these institutions had less of a

presence and instead patient advocates worked in a rules environment that more closely resembled a total institution (Goffman, 1961), with its own endogenous set of rules shared widely and relatively evenly throughout the system.

The shadowing data also revealed four sets of rule practices, or patterned ways of working that were evident in both hospitals. Explaining rules involved telling others why something occurred. At Heartland Teaching Hospital, patient advocates could couple explaining with service recovery. The VA did not have the resources to offer service recovery, with the exception of access to appointments.

Documenting involved making patients and their families comprehensible to the medical system. Both hospitals demand extensive paperwork in order for a patient to be processed by the system. As Van Maanen and Pentland (1994:54) explain, "the paperwork associated with the keeping of records mediates the front (public) regions of an organization and the back (private regions)." To those unfamiliar with the inner workings of the hospital, this paperwork could be confusing, seemingly pointless, and difficult to understand. By documenting, patient advocates helped translate between the needs of the individual and the needs of the system. Documentation also appeared to work on an emotional and psychological level for patients, because it made them feel like they were being heard by the system and they knew that being appropriately documented would increase their standing or case.

Patient advocates at Reveille VA Hospital also switched between sets of rules in order to get access to medical care or resources for patients. When one set of rules did not work, they were able to switch to another one in order help the patient. This did not occur at Heartland.

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The fourth rule practice involved coaching others about what rules to use and being coached by others. Again, this occurred only at the VA hospital in my shadowing data. Knowledge about rules was widely dispersed throughout the hospital, making them a topic of conversation among many different VA constituencies that I observed – hospital staff, patients and their families. Patient advocates coached other people in how to use the rules to obtain high quality medical care, but they were also recipients of coaching on how to use the rules to handle complaints.

View 2: Interview Data

In this section, I present my analysis from the interview data. The interview data elaborates the rule practices. The analysis is based on those portions of the interviews in which patient advocates discussed either institutional logics or rule practices.

Rule Environment

Medical Institutional Logic The interview data revealed a broader set of ways in which patient advocates interacted with medical institutional logic, at both teaching and VA hospitals. The interview data revealed evidence of patient advocates challenging medical authority at both types of hospitals. Specifically, patient advocates talked about doctors interacting with patients in ways that did not take into account the emotional state or needs of their patients. While many patient advocates described being fearless about interacting with doctors, others talked about needing to walk a "fine line" between challenging a doctor while respecting his or her authority. One way in which patient advocates talked about challenging medical authority is by countering a doctor's claim with the rights of the patient, as the example below illustrates:

> Sometimes the providers want to label patients as drug seeking. I submit patients have a right to have their pain assessed. I am not telling you what to prescribe

them and I am not telling you to prescribe them something, but I am telling you that you have to assess it.

Patient advocates also drew on medical rules to make sense of patients' behavior, typically about the individuals' ability to make decisions on their own or the state of their mental health. This kind of diagnosis is particularly relevant in healthcare settings because healthcare workers often interact with people whose behavior is not normal for medical reasons (e.g., mental illness, taking powerful medications that alter behavior) or because of the stress of being in a hospital (e.g., a family caregiver under emotional strain because of their loved one's suffering and illness). Being able to use medical labels such as "alert and oriented" or "anti-social" helped patient advocates make sense of and know how to interact with people.

They also used medical diagnoses to intervene in complex social and legal situations, such as when family members argued about who should be making medical decisions on behalf of a patient. In the passage below, the patient advocate uses the terms "thoughtfully," "of sound mind," and "making his own judgments" to refer to an assessment of the patient's decision-making ability.

> There was a patient who came in and was admitted, had shared with the social worker that he did not want to return home. He wanted to live in a skilled nursing facility. He was living with his ex-wife, and the situation at home was a little bit odd. We were able to determine that the patient could make his own decisions and that he was acting, you know, thoughtfully, and he called and canceled his social security, so that the check would not go this ex-wife, and did all these things on his own. The ex-wife found out about this and had an absolute fit because she didn't agree with his placement, didn't think that he was of sound mind, and all of these things. So I had been working on this case the last several days, getting all the information. So my job now, is to write her, and say, you know, "This letter is not in any way meant to belittle what you are doing as a caregiver. However, during our time constraints, as he was a patient, we were able to determine that he was making his own judgments. He requested that you not be present during the decision making process."

As this example suggests, medical diagnoses, especially about one's decision-making power, have important implications.

There were a number of ways in which patient advocates relied on medical authority to get their work done. They often needed a doctor's signature, permission or opinion about how to handle information that bears on the patients' medical care. In the example below, a patient advocate describes contacting a physician in order to get a death certificate changed.

> I paged the physician who signed off on the death certificate. When I told him what the situation was, he said "If you are able to obtain for me another death certificate, I am more than happy to fill one out in its entirety.

In these ways, patient advocates were drawing on and reinforcing medical authority.

One additional way that they relied on medical authority was to work the medical hierarchy in order to influence doctors to act in particular ways. Sometimes doctors did not want to, for example, apologize to a patient or family member if they did not feel like they had done anything wrong.

> So I called Dr. G. I told her about a complaint against her, and I asked her to pass it to her Chair. Now I wouldn't always bring it up that way, it's not a cookie cutter approach. So Dr. H, the chair, said, "Yes, you need to apologize, and you need to recommend a doctor for them to switch to."
> Well, Dr. G didn't want to send the letter. I think that she didn't think that she had done anything wrong. Now I have dealt with her lots of different situations, and usually I can deal with her just fine. Dr. G said that she didn't want to send the letter. So I said, "Dr. G., I am not signing your name." And I was very direct with her, "Are you refusing to sign the letter?" She's fine generally. Dr. G said no.
> I said, "I will make it really easy for you, I'll send the letter down to your secretary, she can print it off, and you can sign it." So she did. Dr. H's involvement was needed in this case because she was taking a strong stand that she hadn't done anything wrong.

In this example, the patient advocate relies on the physician's reporting relationship, to get the physician to act in a way that will resolve a complaint in spite of her resistance to apologizing.

Legal Institutional Logics The interview data revealed a number of different ways in which patient advocates used legal institutional logic. While some ways were shared across the two hospital types, others were specific to teaching or VA hospitals.

Patient advocates at both types of hospitals relied on security and police to help enforce laws. Almost all of the patient advocates interviewed had panic buttons in their offices in case a patient or family member they were interacting with escalated out of control. If they pressed the panic button, the hospital security would immediately come to find out if there was a problem. Though they were only used in extreme situations (e.g., a patient holds a patient advocate or other staff member hostage in their office, or threatens to shoot someone), they were a presence and potential resource in their work lives. Patient advocates also occasionally asked security or police to interact with people who had arrived in their offices with complaints, as the following passage attests:

> Security is my backbone. I love Security. I don't like to have to bring them in first. I try to defuse it first. Then I try to have only one or two in the room, with 6 or 7 waiting in the wings. We have all kinds here. Our hospital takes people without insurance - we get some characters. People get so upset, and sometimes the staff fuels them, but it's not the place for some behavior.

Another form of legal rules present at both types of hospitals includes HIPAA. However, I found differences across hospitals in how reliably this rule was executed. At the teaching hospitals, HIPAA was applied consistently and across many situations. In contrast, at VA hospitals, patient advocates occasionally bent the rule if it got in the way of providing high quality care and service.

I'm not as strict on the rules. I think it's because I feel like, what are they going to do, fire me? I can retire soon, you know. Bad attitude, I know, but I don't worry so much about HIPAA. If Release of Information is giving somebody a hard time...and they come over here to complain...I print off the information they need. Probably shouldn't do that. May get caught someday, but we're here for the veterans. And I don't see giving them this hard time.

Several sets of rules applied to only one type of hospital or another. The legal rules that applied only to the teaching hospital involved a general awareness of legal liability and how a court might treat a particular decision or look at a situation with which they were dealing. Patient advocates reported conferring with their Risk Management departments in order to keep each other abreast of potential problems and get insights into how a case should be handled. The legal rules that applied only to the VA involved Congress. VA patient advocates did not try to challenge Congressional mandates and knew that they and the patients were totally at the mercy of Congressional decisions. One common example of this was "eligibility rules," or rules that determined what conditions veterans had to meet in order to receive particular forms of healthcare.

Human Resources Institutional Logics Only patient advocates at teaching hospitals talked about human resources rules during the interviews. HR rules were present in these patient advocates' work lives in one particular way, namely that hospital personnel decisions are confidential and cannot be shared with patients or their families. This was relevant for patient advocates when patients or their families demanded that a particular caregiver be fired. Patient advocates described telling patients and their families that they had no control over whether someone was fired and that they would not be able to share any information about whether or how a hospital employee had been disciplined. While this was often frustrating to complainants, this was a rule that allowed

patient advocates to draw clear boundaries about what information they could and could

not share with patients and their families.

Rule Use Practices

Explaining

Patient advocates' accounts of case handling revealed several different facets of

explaining. Patient advocates explained rules and regulations to patients, family and staff.

When patient advocates explained rules and regulations to patients and their families,

explaining often had the effect of defusing emotions such as grief experienced when a

family member died in the hospital, or anger about an experience in the hospital. In the

example below, the patient advocate talks about setting up a meeting with the wife of a

patient who died in the hospital two years prior to the interview.

> What happened with this patient was, and he was a very ill man, he had lots of things wrong with him, but in the end [his wife] was actually visiting in the room and she has asthma and got sick herself and so she went down to Emergency and was being treated. He coded while she was in Emergency and, of course, they didn't have time to come down and get her because she was being treated, but she heard the code and the room number so then she ran back up to the room. Her whole thing right now is, she just feels like something is missing. Why didn't someone come and get me when he coded? Well, you were in the emergency room being treated, you know. The meeting is going to be really, I feel, to get her through the grief process. She's dealing with depression. She said her daughter used to work here but now she can't work in nursing any more. I just feel . . . they unfortunately didn't get through the grief process, and that happens.

By explaining why the patient's wife was not brought up from the Emergency Room

when her husband coded, the patient advocates hopes that it will help her through her

grieving process.

According to the patient advocates, explaining rules gave patients and families a

different perspective, which had the effect of decreasing how upset they were or helped

them feel like they had additional options. In the following passage, a patient advocate

talks about how being able to explain to a family member what caused the problem had

enabled them to feel some relief about their doctor.

> A family member came in today and not everything was set up for a
> discharge appointment. She went to a Physical Therapist, and the Physical
> Therapist said, "You should have had a follow up appointment at the Upper
> Extremity Clinic. "So they were mad that the doctor had not told them that they
> should have a follow up appointment. They thought that he had failed. So I looked
> at the discharge note, and I saw that the physician had written a note that they
> should have a follow up, but it hadn't been followed up by the clerk. The problem
> had happened with the discharge clerk. It wasn't until it got to me, two months
> after their first appointment, that they found this out. So it broke down with the
> clerk. They had some sense of relief that the doctor, whom they had put their trust
> and confidence in, hadn't failed them. It was still a problem, but it wasn't the
> doctor's fault. I've arranged an appointment and moved it up a month. They came
> in with the complaint on Friday, I was out yesterday, and it got resolved today.

In the next example, a patient advocate talks about how explaining the hospital's

procedure for handling complaints helps calm patients and family members simply by

giving them the sense that their complaint will be heard.

> No matter how fuming people are, I say, "Hello, I'm [first and last name]…" I
> never say, "I heard you have a problem," I say, "I understand you have some
> concerns" –that way it's not negative right away. "What can I do to resolve it? If
> you don't mind, I'm going to write down your concerns. This is a complaint, and I
> am going to enter this into a web-based complaint system." And that starts to
> bring them down. "When I enter it in, the complaint has to be addressed by the
> manager, and the Clinical manager and the President of the hospital see the
> complaint. If it's a medical error, then it will be seen by our Peer Review Group."
> They start to come down because they know they have options.

Patient advocates also used explaining when they talked to staff. In these

instances, they explained how a problem developed as a result of a problematic rule or

regulation. The purpose of this explaining was to get the staff member to change how a

rule was implemented. In the following example, a patient advocate describes how she

got a rule to be more clearly implemented as a result of a complaint she received.

> One patient called me and said, "You're not supposed to use the phone, but this
> lady got to use the phone, and how come she did and I didn't?" I spoke to the

manager of communications who supervises the operators. She knew that the calls should not have been coming through [to a waiting room]. When I explained the problem, she said, "Oh, well that shouldn't happen." I said, "There are no signs posted to say it shouldn't happen, so the visitors have this expectation that they can." When they put the signs up there, everybody was okay with it.

At the VA, explaining a patient's special circumstances also enabled patient advocates to convince a staff to bend rules in order to provide high quality care for a patient, as the example below illustrates.

What normally would happen is that it would take the pharmacy seven to ten days for this medication to come. Well, this veteran's already been without sleep seven days [because of lack of medication]. So seven to ten days is totally unacceptable. That's not really going to help him. Yes, you did technically take care of what he initially asked you for, but anyone with half a brain could see there's more that needs to be done here. So I contacted the supervisor in the pharmacy. And normally, we don't do this, but she agreed under the circumstances. They mailed the medication out directly from our pharmacy, Federal Express, overnight.

By explaining how the rule about shipping the medication from a central location would negatively impact the patient, this patient advocate was able to convince the head of the pharmacy to bend a rule so as to provide the best care for the patient.

Summary Explaining rules was also a robust category of rule practices in the interview data. The interview data expands our understanding of explaining as a form of rule use in several ways. First, there was no discussion of using service recovery when explaining rules. Service recovery did exist at many of the teaching hospitals, but service recovery was not linked with explaining rules and regulations. Second, the interview data revealed instances of explaining rules and regulations not only to patients and their families, but also to staff. Explaining to staff served the important purpose of convincing staff to bend rules or enact them in atypical ways. Third, the patient advocates illustrated and provided a broader array of reasons for why explaining rules and regulations are

effective, including emotion work and a change in perspective that enables a different understanding and action.

Documenting

Patient advocates talked about documenting in order to remove or control misbehaving patients or family members, a serious action that is highly regulated. Removing a patient or family member typically requires documentation from a variety of different hospital staff members. Patient advocates worked with others to coordinate the process of controlling a misbehaving patient. Examples of why patients would be removed from a hospital included taking illegal drugs in the hospital, inappropriate behavior such as having sex in the hospital, or threatening or behaving violently towards the staff or other patients. Any such behaviors have to be documented multiple times for a patient to be removed from a hospital in order to demonstrate to one or more regulatory bodies that the patient or family member should be removed from the hospital. The following passage demonstrates the intense coordination and documentation required to remove a patient.

> I've had a lot of crazy people over the years that I've had to deal with exclusively, just by the luck of the draw. And the last one was a woman who, we finally have her banned from the entire health system. And we had to go to the state, and petition that she be put on Medicaid so she could go somewhere else. And I mean, she'd show up in crazy outfits. She was verbally abusive. She was nuts. She'd call the President's office, she'd call the Director's office, she'd call the VP's office, she'd call Risk. And everybody knew, when that woman called, they all knew her voice, went right to my phone. And I'd just say, "Eh," shut the door, and I'd keep a log of all my phone calls. You know, she needs to go the Psych ER. And so rather than wasting everyone's time, they just shipped it to me, and I kept a log, and we would meet with the Risk Management people, and the clinic managers. Our last meeting was with the Director for Ambulatory Care, the Clinic Manager, me, and the head of Risk Management. And we all compared notes. I distributed my log. And the Risk Consultant took it to the state, and we got rid of her. We got permission to disenroll her and ban her from the system. And nobody really wanted to do it, you know, but...but she was non-compliant, because we wanted

her to be seen by community mental health to be evaluated. And she would not do it. She wouldn't go. So she was non-compliant. So as long as she's non-compliant, she's out.

Knowing how rules applied, and specifically what documentation was necessary, gave patient advocates authority and confidence to act. In the passage below, a patient advocate describes her interactions with foster parents who were causing problems on the floor where their foster child was being treated. Called down to intervene and help control them, the patient advocates requested their foster parent documentation, which they were not able to produce. This helped to clarify and limit the foster parents' role and ability to influence the situation. As she explained:

> I think having that sort of level of confidence and authority when you go into those situations and knowing you can't just come in and say this. You need to provide documentation. And they could not do that.

In this case, requiring documentation was a way to contain foster parents who were scaring the staff.

Summary While in the shadowing data, documenting supported a process of translating between patients and the employees who make up the hospital system (Heimer & Stevens, 1997; Martin & Tipton, 2007; Van Maanen & Pentland, 1994), the interview data revealed an additional way in which patient advocates used documents. A number of examples showed that documenting was an important means through which patient advocates could control disruptive or problematic patients in the hospital. Documentation both gave them power to build a case towards removing a patient, and could also more quickly defuse behavior when they enforced a rule that required documentation (e.g., the rights of a family member to have a say over a patient's case).

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Switching between Sets of Rules

The interview data provided an elaborated version of patient advocates switching between sets of rules. Patient advocates talked about switching between sets of rules at both VA and teaching hospitals, but the reasons and sets of rules they could move between were different.

At the VA hospitals, switching occurred to obtain additional resources for veterans who don't meet the requirements necessary for certain resources, including access to medical care, treatment resources (e.g., alcoholism) and monetary help (e.g., reimbursement for travel to and from the hospital). Patient advocates knew and expected that the VA would not be able to provide for the resources that veterans need. They may or may not have agreed with the rules, but they rarely broke them. Therefore, they actively solicit, collect and learn information about resources outside of the VA so that they can switch to these outside resources if necessary.

> *So how did you know about all these resources?*
> Well, some of it is because I worked for the VFW [Veterans of Foreign Wars] for so long. And I have a lot of contacts out there. I have a daughter who's an RN, who works for a state program, and she works part time for another program in town. And so she has some sources. I had a mother that had cancer I took care of. So I knew a lot of resources for her. And I just kept in contact. There's a lot of places that I did donations for. There's a place in town that helps set up apartments for not just veterans, but anybody who has a handicap. And alcoholism is considered a handicap. So she takes donated items, like bed sheets and silverware. And so I know that I can send the guys there for some help, not only to get the apartment, but to get some items for their apartment. There's a place in town where it's like a little coffee house in town, and they post jobs. I've donated shoes there, and fruits, and stuff. So I know they can go down there, and I know those people will help. Then if I don't know somebody, I just start calling [laughter].

Being able to switch from one set of rules to another helped them to feel effective in their jobs; being unable to help was a hardship.

What are some situations in which you feel challenged?
Maybe if it's a situation where I don't have anybody to refer him to. A veteran's not eligible for travel, so they come over here. "How am I going to get home?" Well, sometimes our Social Work has a little emergency fund, but quite often, that fund don't have no money in it. So if they live in town, you can refer them to social work to get a bus token, just to get on the bus. That's good. But if there isn't any funds, and they don't live downtown, and they got their car here, and they got to get further than [nearby city], it's like, "What am I going to do?"

　　　Now...and we bend over backwards, trying to figure out a way to get a veteran home. Or you can go to [nearby hospital], and you'll sit in their lobby all night if you ain't got no way to go home. You know? But I find that frustrating, when I can't help. And then, the veterans getting upset, and they're demanding of you, "How am I going to get home?" "I don't know sir. I...I don't know." And you don't want to dip into your pocket and give them money, because veterans talk. And before you know it, you got everybody asking you about money. And so, those kinds of things, I think, when there's absolutely nothing you can do, and no resource to go to, those are hard because then they just stand here in your office, and they just stand there across your desk, staring at you with this glare, like, "What am I going to do?" And I...I don't know what to tell you. So that's been a tough one for me, getting them...home sometimes.

Patient advocates in VA hospitals also switched between internal rules in order to access resources. Tapping into a different set of rules could often net the patient advocate and patient a different outcome to a problem.

> The bottom line was that this man's heart was so bad that if he didn't get some of the weight off of him within months he was going to die. I prayed about it. There's got to be something we could do. It came to me that he was service connected for his diabetes. One of the things you know is that if a person loses weight it can affect their sugar. Because his weight was related to his service connected disability, I was able to go to the Chief of Staff and get him to agree to pay for the patient to have his surgery on the outside.

I found two types of switching between sets of rules at teaching hospitals. At one particular teaching hospital that had organizations for poor patients directly affiliated with the hospital (e.g., housing, inexpensive insurance), patient advocates were able to call on those affiliated organizations in order to get care for patients who needed them. There was only one teaching hospital, though, which had such affiliations. The second instance of switching rules at teaching hospitals involved switching to state rules in order

to get a problematic patient kicked out of the hospital (described above in the documenting category). The patient advocate, in coordination with others in the hospital, had to carefully abide by state rules in order to get a patient removed from the hospital system.

Summary The interview data reveals the creativity and resourcefulness that patient advocates engaged in to cultivate their knowledge about resources and sets of rules so that they could have the capability of switching between sets of rules. This seemed to be a more prevalent finding at the VA hospitals, perhaps because they expected that the VA resources would fall short but at the same time they felt obligated to help as much as possible – to provide high quality care and service in spite of chronic resource constraints. Among the patient advocates at teaching hospitals, there was less evidence of switching between sets of rules. The major alternative set of rules for most teaching hospitals appeared to be the state, which they could rely on for controlling patients. At only one teaching hospital did patient advocates have affiliated organizations that could help patients lacking monetary, insurance, or housing resources.

Coaching

The interview data elaborated on the shadowing data by suggested that patient advocates coach patients, family members and staff. Many patient advocates see their role as helping patients and family to navigate the hospital system themselves.

> I think the goal is always, "What tools or what information can I give you to help negotiate the system yourself?" unless you are just not able to or your family member can negotiate this system, because frequently that is the big issue. It is a lack of communication. You are not trying to do for the patient. What you are doing is saying, "Here are the tools so that you can negotiate the system. You really can."

By coaching patient advocates on how to use rules, they are empowering them to act on

their own. Sometimes this coaching has another purpose, which is to encourage the

patient not to overuse or misuse the patient advocate. In the following passage, a patient

advocate described such a situation:

> He'd be in the airport on his way home from a VA in another city and call me and say they didn't do what they were supposed to do and I'd say that you should have addressed it with them. You can't come back to here and expect us here to address what they should have done in [another VA] for you. He won't tell the provider or ask the provider anything. No matter what VA he is at, he won't question or ask the provider anything. He waits until he leaves the clinic area and goes and talks to the patient advocate and complains.
>
> I did tell him here a couple of weeks ago, I just said 'Mr. So and So, I'm an administrative person. You cannot leave your provider anymore without having the discussion with them. You cannot come to me and complain about it.' It's all things that his provider has to do for him. When he sees his provider, he goes along and agrees with everything that they say and everything is hunky dory and then when he gets out the door he comes to me and complains that they haven't done this or they violated his patient rights. It's just one thing after another.

I also found evidence of patient advocates at teaching hospitals coaching staff

about how to handle dilemmas, including how to use rules. Like the example above,

coaching seemed to be in part about discouraging the staff to use them for problems that

they could likely handle themselves.

> After I've had a couple of cups of coffee, I do a brief walk-through of the units. I touch base with the nurse manager about families that I might know about. I try to get a feel of what's going on. I'm very hands on - I walk around the units a lot, which is both good and bad. It's good because they know who I am. It's bad, because then they're like, "Oh yeah, I was going to call you about something" and then they use for me things that they shouldn't. But the people I've been trained by have been really insistent that 'you have a protocol that you have to follow' because once it comes to me it's in a different situation - and they'll start depending on me if I don't do that. So one of the first things I'll say is, "Have you gone up your chain? Have you talked to the resident nurse? Have you talked to the nurse manager? Has the patient asked for me?" A lot of times I can give them insight and advice over the phone so that they can handle it themselves.

As in the shadowing data, only VA patient advocates appeared to be coached by others about rule use. They learned, for example, how to implement or enforce a rule, as the following example illustrates.

> The patient was cussing, and screaming, and he had jumped up out of the chair, and was just going off about how I'm not doing my job because I can't get the VA to pay for him to go back to Columbus. Well, what ended up happening was, I talked to our VISN, the authority that governs all five of the medical centers. And what they said was, "Follow the rules. Whatever the rules are, follow them to the letter. You can't have done anything wrong, and you will have done all of what is expected." So I did exactly that. I contacted our Patient Care Administration service. They govern our travel policy. I spoke with the chief of that service. He sent me a copy of the travel policy, and then explained to me exactly how things work.

In this example, another staff member coaches the patient advocate on how to implement a set of rules regarding travel reimbursement.

Summary Overall, the interview data shows that when patient advocates coach others about rules use, it is in part as a way of patrolling the boundaries of their own role. They empower others so that they themselves do not get overused by patients or staff. At the same time, patient advocates tried to equip patients and staff with information about how to use rules so that they could navigate the hospital system or a challenging interaction on their own.

<div align="center">Discussion</div>

How do individuals use rules in complex organizational environments?

This study revealed four different *rule use practices*, or recurrent situated activities (Orlikowski, 2002) engaged in by patient advocates in hospitals. These rule use practices enrich our understanding of how individuals use rules to enact their roles. The work of patient advocates points to how these rule use practices can be used to patrol the boundaries of organizations and help maintain the dignity of people who live and work

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along them. Specifically, patient advocates use them to help patients and families who were experiencing problems at the boundaries, as well as to control and remove patients and families who were causing problems for hospital staff and other patients and families. These rule use practices represent a number of ways in which patient advocates drew upon the rules in their organizational environment to enact their roles. These are patterned ways in which patient advocates use rules and rule-following to create a form of legitimate action (Feldman & Levy, 1994). This study builds on Morrison's (2006) findings that rules can used for "prosocial" reasons, such as providing good customer service or helping a coworker. But, while she focused on a simple dichotomy of rule use – broken or obeyed – this study suggests that rules can be selectively enacted, combined and recombined in a variety of ways.

This study has implications for the burgeoning research on situated agency. This body of research aims to understand how individuals embedded in organizations can make organizational change or influence others. Much of this research has at its core the mechanism of identity; acting agentically entails creating a new or common or positive identity that enables individual action (Creed and Scully, 2000; Fligstein, 2001). Another stream of research that takes a practice approach is less focused on identity and more on how actors engage with their environment, such as technology (Orlikowski, 2000) or routines (Feldman & Pentland, 2004), to act. This study takes a practice perspective, but highlights a different element of structure, that of rules. While others have suggested that creative use of rules is an important part of agency (Fligstein, 2001), this study provides empirical evidence of how individual actors use rules to act agentically.

Patient advocates explain rules in order to help patients, family or staff understand why a problem is occurring. Patient advocates described the effect of explaining rules to patients and families as changing their perception or experience of the problem they had in the hospital. At times, patient advocates coupled explaining rules with resources, either monetary resources or some form of access, such as an appointment scheduled at an earlier date. These resources appeared to be a way for the patient advocates, on behalf of the hospital, to offer some form of apology and to improve a negative or problematic situation. When patient advocates also explained rules to staff, they talked about how a problematic situation was the result of an unclear or problematic implementation of a rule. By explaining the problem in terms of the rule, patient advocates were able to convince staff to make changes.

Patient advocates also documented according to the rules. Documenting was critical in making the patients and families comprehensible to the hospital system. In organizations in which there are so many rules, having the proper documents and having them filled out correctly, can be essential to making the organization work in one's favor. Patient advocates helped patients and their families by facilitating proper use of documents, thus helping them to navigate the hospital system. The interview data also revealed that patient advocates, in conjunction with other hospital staff members, used documents to control misbehaving patients. Asking for proper documentation – meaning documentation that was required by rules – was a way of decreasing the influence of different patients and families at least temporarily.

In an environment in which there were many sets of rules emanating from authorities, switching between sets of rules became an important way in which patient

advocates could access resources on behalf of others. Patient advocates at the VA, which

had strict rules and a shortage of resources, were particularly adept at switching between

sets of rules in order to accomplish their organizational goal of providing high quality

care and service to veterans. They solicited and collected information about how various

resources could be accessed, knowing that they might need them at some future date.

Patient advocates at teaching hospitals exhibited and described less of this rule practice. It

was only evident at the specific teaching hospital that had associated resources for poor

patients or in situations in which they were trying to remove a patient from the system,

and thus needed to interact with the state.

Finally, patient advocates coached, and at the VA received coaching, about how

to use rules. Through coaching about rules, patient advocates helped others navigate the

system and achieve their goals. At the VA, rules were a frequent topic of conversation,

and people shared knowledge and made recommendations about how to use rules to

achieve the institutional goal of providing high quality medical care and service for

veterans. Coaching others about rule use was also a way of establishing boundaries

between the patient advocate and others, including patients, families and staff. By

coaching others, patient advocates encouraged others to take on their own problems and

discouraged dependency. This was an important issue for patient advocates because they

often were able to handle difficult interpersonal and emotional situations that most people

would prefer to avoid.

Where is the agency in these rule use practices? We know that procedures within

(e.g., organizational protocols) and outside organizations (e.g., state laws) allow action to

take place because they provide a set of expectations and form of legitimacy to act in a

particular way (Feldman & Levy, 1994). Patient advocates' agency lies in their ability to select and enact (Emirbayer & Mische, 1998) existing rules in a way that will help them to do their job of handling patient complaints. It also lies in their ability to try a different set or combination of rules if an early combination did not acquire the desired result. Knowing how to do this requires understanding what rules exist and how to learn about unfamiliar rules, and then bringing them to bear on the specific situations by sharing their interpretation of the rules with others and convincing them to act on it. While previous research has looked at the "skillful use of rules" of those in positions of power, and particularly how they use those rules to take questionable actions (Sitkin & Bies, 1994a), this research shows how boundary spanners skillfully use rules to handle organizational problems.

In my description of these rule practices, the impact of the different contexts in which they are practiced has already been suggested. Service recovery was a resource at the Heartland Teaching Hospital, but not at Reveille VA. VA patient advocates typically expected to fall short of resources that their patients needed, and actively solicited information about resources to help in future cases. These findings suggest that material or resource environment is an important consideration in understanding how individuals use rules in organizations. In the following section, I examine this issue from the perspective of the institutional logics that set the background values, assumptions and even rules in different hospital types.

How do different organizational environments influence how individuals use rules?

An important contribution of this study is the contrast between two different types of hospitals, that of VA and teaching hospitals. While they are both complex rules

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environments, teaching and VA hospitals are subject to and composed of different sets of rules and institutional logics. The institutional logics shape how patient advocates use rules. At Heartland Teaching Hospital, legal, medical and HR institutional logics each had a powerful, distinct presence. Patient advocates were relatively powerless compared to these institutions. For example, when a case became classified as a "risk issue," patient advocates were relatively helpless to proceed. Their ability to help patients or family members was halted because the problem now fell outside of their job domain. However, they also relied on and reinforced these institutions, particularly the institution of medicine. They could, for example, use the logic of the medical institution to classify, or make sense of, a patient's behavior as problematic, and then act accordingly.

Coupled with these strong institutions, the rule practices associated with teaching hospitals were explaining and documenting, with less emphasis on switching and coaching. Explaining and documenting can be considered a form of *translation*, a classic form of work done by people in boundary spanning roles (Aldrich & Herker, 1977). I argue that patient advocates in teaching hospitals were most likely to use these rule practices because their work can be understood as helping patients and families move among and between the strong, distinct institutional logics. The medical institutional logic dictated the preeminence of doctors and their authority, the legal institutional logic protected the hospital and caregivers against potentially costly lawsuits, while HR both protected employees and surveilled them.

At the VA, in comparison, there was a sense of shared ownership of the rules. All of the same institutions were present – medical, legal, and HR – but cases never disappeared from a patient advocates' domain when one of these institutions became

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involved. Instead, a VA-institutional logic predominated, which is dedicated to providing high quality care and service to veterans. Rules could be followed, broken or bent as long as they were used according to this VA institutional logic.

In this institutional environment, patient advocates displayed a wider variety of rule practices. They explained and documented, but they also switched between sets of rules and engaged in coaching and experienced being coached. This suggests that patient advocates were not only translating between powerful institutions. The VA institutional mandate of providing high quality care and service to veterans meant that they used rules and regulations in broader, more flexible ways. For example, to switch between sets of rules meant, in some cases, cultivating knowledge of rules and resources outside of the VA, suggesting their attention for fulfilling their job was not limited within the hospital walls, but instead ranged outside of it. The coaching practices, too, suggested that the VA constituted a sort of community of practice (Wenger, 1998) of rule use, with continual sharing and learning about rule use occurring. What is particularly notable is that not only did patient advocates coach others about rule use, which did occur occasionally in teaching hospitals, but patients, families, and hospital staff also coached patient advocates about rule use.

The contrast between patient advocates' rule use at two different hospital types builds on and extends prior theory on individual rule use in organizations. Patient advocates interpret rules and mobilize those rules based on those interpretations, consistent with Fuller and colleagues' (2000) theory of legal readings. To work on others' problems, they also try to influence others' interpretations of rules through the selective enactment and interpretation of rules to specific problems (Fligstein, 2001). However, the

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institutional logic(s) provide an important backdrop for individual rule use, because they supply guidelines for what kinds of rule use practices patient advocates consider feasible within a particular setting.

Conclusion

This study suggests that there are four patterned ways in which individuals use rules in organizations, particularly those organizations are densely packed with rules, such as hospitals. Rules are an aspect of individuals' context that can be drawn upon in a variety of ways to handle complaints and help others. The context in which these rule practices occur shapes them in important ways. The context provides different material and resource constraints. Some rule practices, such as explaining at Heartland Teaching Hospital, were coupled with service recovery resources. In contrast, the patient advocates at Reveille VA Hospital expected to be under-resourced so actively collected rule-related knowledge that would help them obtain resources on behalf of veterans when it was needed. The institutional logics of the different hospitals also suggested ways in which patient advocates relied on authority associated with each institutional logic (e.g., Security associated with legal institutional logic) to enforce their rule use practices. Thus, patient advocates drew on rules, material-resource environments and institutional logics to enact their roles.

This chapter contributes to our knowledge of how individuals experience and use rules in their everyday organizational lives. Rules are sometimes a part of patient advocates' toolkit for action (Swidler, 1986), while at others, they are non-negotiable and halt them in their tracks. They consciously treat rules as both constraints and resources. In doing so, it sheds light on literatures that primarily focus on rules as constraints.

Chapter 6

Conclusion

This dissertation has provided a "thick description" (Geertz, 1973) of patient advocates' problem-handling work. Chapters 4 and 5, the two major empirical chapters, have each provided answers to the research question that has motivated the dissertation: How do patient advocates, whose work, role, profession and interactions are often ambiguous, exercise agency in handing problem in hospitals? In Chapter 4, I developed a process model of problem-handling work as organizational storytelling. In Chapter 5, I compare problem-handling work in teaching and VA hospitals, focusing on how rule use varies across the two organizational contexts. Both chapters contribute to the topics of work, problem-handling roles, and agency, introduced at the start of the dissertation.

Work and Problem-Handling Roles

This dissertation provides two theoretical accounts of the work of problem handlers in organizations. They help organizational outsiders (patients and families) and insiders (fellow employees) traverse the organizational boundaries of large, complex hospitals. I have argued that patient advocates can shed new light on this kind of work because they are not only trying to control and contain the problem, nor are they are interesting only as symbols meant to obtain organizational legitimacy. Patient advocates also intervene in dynamic organizational systems to make small changes, whether those changes involve the interaction between a particular patient and physician, intervening in

families undergoing painful end-of-life decisions, accessing resources within the hospital, or working to change a policy. To accomplish these micro-changes, patient advocates work not only with organizational outsiders (customers, patients, etc.) on the problems, but they also work with organizational insiders (doctors, nurses, clerks, administrators) to try to construct solutions.

This approach builds on other recent research on problem-handling roles that emphasizes the relational character of this work. Relationship-building and relational coordination are two strategies to coordinate across internal boundaries within organizations (Boland & Tenkasi, 1995; Gittell, 2002; Kellogg, et al., 2006). Both contribute to transforming the understandings of people on either side of the boundary. This dissertation affirms the relational character of the work, but takes it in a different direction.

This research portrays patient advocates as interacting with a number of different people, both inside and outside of the organization. Patient advocates actively bring together the constellation of people who can help them construct a solution to a particular problem on which they are working. These constellations are not networks or dyads, but flexible and dynamic sets of relationships that patient advocates create to meet the needs of each particular problem. This can be considered a form of "social architecting" (Roberts et al, 2005), or the proactive selection of settings, people, and tasks. This finding extends research that has shown that workers actively craft their interactions with others as part of job crafting (Wrzenewski and Dutton, 2001), socialization (Morrison, 2002) development (Ashford & Tsui, 1991), career change (Ibarra, 2003) and creating incremental change in organizations (Meyerson, 2001).

By expanding the focus of problem-handling work from interactions between dyads (i.e., customer service representative and customer) to broader, dynamic, ad-hoc networks may help us link these boundary spanning roles to processes of organizing. As stated at the beginning of Chapter 4, the two major ways in which organizational theories consider problem-handling roles are as protecting the core of the organization from external problems (Thompson, 1967) and as symbols of legitimacy (Dobbin, Edelman, Meyer, Scott & Swidler, 1988; Edelman, 1990). This research may help contribute to images and theories of organizations as continuously changing (Weick & Quinn, 1999). Patient advocates are an organizational role that, at least in this dissertation, seem relatively responsive to problems and criticisms, and may contribute to revising how we think about dynamism of large organizations.

Agency

In the introduction, I described three different dimensions along which theories of agency differ: the psychology, decision-making and motives of individual actors, how they theorize about structure, and relationships. I revisit each of these here.

The psychology, decision-making and motives of individual actors

In Chapter 4, my analyses focus in some depth on the interpretive processes patient advocates undertake to handle complaints. I found that patient advocates use their own emotional and bodily reactions, reflections and imaginings to try to understand others and to try to create understandings in other people. Thus this provides a relatively holistic account of agency, in which people bring their whole selves into their roles to actively engage in problem handling. This is consistent with some recent theorists of

agency who suggest such a role that, for example, the body might be a source of agency (Joas, 1996).

Structure

Theories of agency occur in front of a backdrop of structure. Both chapters portray patient advocates as working with the elements of social structure surrounding them. Patient advocates, as individual actors, are in the business of constructing legitimate paths of action for themselves and others. To do this required at least two situational resources. First, patient advocates profited from embeddedness in the organization. Their knowledge of the organizations, its cast of characters and its rules provided a rich took kit from which to work. Second, it also required some kind of authority to grant legitimacy, and for patient advocates, these authorities at various times included specific hospital administrators, physicians, staff, and on occasion, state regulators. But they also included different institutions, which provided a set of logics or meta-rules, about the ways in which rules could be applied in particular situations. By looking simultaneously at individual actors embedded in their organizational context, this study contributes to micro-sociological approaches to agency at work.

The studies also build on a foundation of structuration theory (Giddens, 1984), and especially as it has been developing in organizational research (Barley & Tolbert, 1997; Feldman, 2004; Orlikowski, 2000). This perspective focuses on the ways in which structures, such as institutions, are both a product of and a constraint on human action. How individuals *use* structures becomes an important focus for understanding individual agency. Chapter 5 illustrates a variety of patterned ways in which patient advocates put rules into use in order to handle problems. Patient advocates use rules, for example, to

convince powerful people to act and increase patient and family access to hospital resources. The ways in which they use rules is influenced by the institutional logics, which guide acceptable rule use practice. This suggests some benefits of examining the institutional context of rule use. Instead of looking at whether individual people break, bend or follow rules, these analyses suggest that patient advocates' rule use is guided by the institutional logics in the organization.

Relationships

Patient advocates accomplish their work through interactions and relationships with others, as they construct legitimate paths of action for themselves and others in order to handle problems. One way in which they accomplish this is through assembling people who can help handle a problem, as described above. But another important part of their agency is their ability to construct accounts of problems (Chapter 4) or use rules (Chapter 5) that will make sense to others. As such, an important part of the skill of patient advocacy comes from being able to relate to others in such a way that will (1) surface others' accounts and perspectives and (2) influence others through accounts tailored to a particular audience. This resembles what Fligstein (2001) calls social skill, in which actors take the perspective of others to create shared meanings. Patient advocates use storytelling and rules to create shared meanings because of their power to do such things as access resources, motivate behavior, and facilitate interactions.

Overall, this dissertation also contributes to our understanding of situated, embedded agency. This research joins the growth toward understanding individuals' agency in the context of work organizations. Scholars have suggested that individuals actively construct their identities based on existing role models (Ibarra, 1999) and

culturally available occupational rhetorics (Fine, 1996) and use the everyday symbol of dress to execute their work roles and increase their feelings of effectiveness (Rafaeli et al., 1997). Research on the organizational level, including institutional entrepreneurship (Garud et al., 2007), embedded actors (Reay et al., 2006), individuals and collectives with non-dominant identities (Creed & Scully, 2001; Meyerson, 2001) are able to create change in institutions over time.

The analyses presented here portray patient advocates as active participants in organizations, flexibly and creatively perceiving their surroundings and persuading others. They do not have free reign over their environment. Indeed, they are constrained by their context. For example, their ability to handle problems is halted when the hospital's resources are limited (Chapter 4). At the VA, patient advocates worked around a chronic lack of resources by building up stores of knowledge about external rules, which they could then later use to knit together a solution (Chapter 5).

This research on patient advocates is also relevant for understanding dignity at work. Hodson (2001) defines dignity as the ability to establish a sense of self-worth and self-respect, and to experience respect from others. Through a study of ethnographies of work, he found that workers create dignity for themselves occurs through four means: resistance, citizenship, the creation of alternative meaning systems, and coworker relations. This research on patient advocates complements Hodson's research in that it focuses on facilitating the dignity of others. Patient advocates help rehabilitate the dignity of patients, their caregivers, and sometimes even fellow employees who whose agency has been compromised or challenged – their ability to act with purpose, their feelings of self-worth and self-respect have been challenged. This study of patient advocates

suggests that organizational storytelling and rule use practices are two ways in which employees embedded in organizations can assist others in achieving or recovering their dignity.

Limitations

This study is an-depth portrait of patient advocates who work at teaching and VA hospitals in Midwestern states, using a purposive sample. The research design has allowed me to capture their work in detail. This research is well-suited to guiding future research (Yin, 2003) and perhaps a discussion of organization's values (Thacher, 2006), but future research will test its usefulness through whether it inspires further development and refinements of these findings.

As I focused my attention on patient advocates' problem-handling work, some parts of their work were in the spotlight while others fell outside of it. Patient advocates' work is deeply relational. However, I did not collect data about how the patients, families, hospital staff and others who interacted with patient advocates viewed their work, agency or effectiveness. Prior research on boundary spanning roles has demonstrated the usefulness of collecting data of people on both sides of an interaction (Locke, 1996). This data or future studies would benefit from the opinions or evaluations of the people with whom patient advocates.

This study also does not address the question of the impact of patient advocates' work on the organization. This is in fact one of the dilemmas of the job – their impact is hard to measure, perhaps because they work with other peoples' understandings and perspectives. However, the data I collected includes neither their organizational performance evaluations, nor evidence of their work and effectiveness on other people.

This study or future studies could include a focus on a different unit of analysis, that of the complaint or concern. One could select particular complaints, concerns or grievances and develop case studies based on observations of the handling, interviews with all relevant stakeholders, and documentation of the case. Such a design would be better equipped to examine the impact of patient advocates' work on the organization, its members, and patients and families.

Future Research

These analyses raise questions for future research. While this dissertation has provided two detailed accounts of the problem-handling work, it has only superficially addressed the topic of patient advocates as ethical actors. But patient advocates' work has ethical implications because they work on difficult human issues in hospitals, such as who gets to make end of life decisions and who can access the resources of the hospital. While I have described the kinds of decisions patient advocates make, future research could ask, How do patient advocates make decide who, when or how to help?

I started this dissertation project with an interest in the role of the body in individual agency. However, the body has dropped to the background as I have worked with the data. I believe this occurred for two reasons. One, the importance and relevance of the body to patient advocates was ephemeral, appearing during some parts of the data collection (e.g., interviews, especially at the VA), and disappearing at other times (e.g., some parts of the shadowing data). Two, once I had left the field and was then faced with the ambiguity of how to work with such a mass of data, early efforts to ask specific questions about the body and agency seemed difficult when I did not have a baseline understanding of their work or the role of organizational context in their work. I believe

the two main empirical chapters I have developed for this dissertation have helped

provide me with a foundation on which I can base further analyses, including of the role

of the body in patient advocates' work.

A common question in both theoretical literatures about boundary spanning roles

such as patient advocates is the conflict and stress they experience. I found in the second

stage of data collection that patient advocates did not report feeling stress, and enjoyed

and felt proud of their work. How did this happen? It appears that coupled with a genuine

feeling of helping others, they employed one of two strategies to help manage the stress,

either (1) developing strong boundaries between work and home, or (2) merging their

work and personal lives. Future research could examine this topic more closely.

The research also has relevance for understanding the alternatives to professional

power in the organizations. Professions are thought to provide a source of power for their

members (Abbott, 1988). Patient advocates lack a strong professional identity, yet, I was

able to trace the ways in which patient advocates are able to work effectively across

many different groups within hospitals. This contradiction points toward the intriguing

possibility that a lack of a strong professional identity may be strategically useful for

accomplishing certain kinds of work. This question may be particularly useful to consider

for occupational groups, such as the patient advocate group SHCA, who are actively

considering how to promote the role and develop the Association.

Conclusion

In this dissertation, I have provided a rich description of patient advocates' work

and developed two theoretical accounts of their work as organizational problem handlers.

With these accounts, I contribute to our understanding of how individuals embedded in

organizations can draw on their contextual knowledge and relational skills to facilitate small changes in organizations and support the dignity of others. Convincing a doctor to apologize or to listen to a patient's pleas for different pain medication, supporting staff members faced with abusive patients or families, or answering the questions of grieving family members, are just some of the ways that patient advocates intervene in the ongoing social life of organizations. Through organizational storytelling and rule use practices, they try to construct legitimate solutions to the problems others face.

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