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The Diagnosis Narratives & The Healing Ritual

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THE DIAGNOSIS NARRATIVES & THE HEALING RITUAL

by

JAMES PETER MEZA

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

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2013

MAJOR: ANTHROPOLOGY

Approved by:

Advisor Date

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DEDICATION

Dedicated to K.C., who was there at the very beginning of my journey of understanding.

ACKNOWLEDGEMENTS

I would like to acknowledge my dissertation committee members: Andrea Sankar, Ph.D., Mark Luborsky, Ph.D., Stephen Chrisomalis, Ph.D., and Kurt Stange, M.D., Ph.D. Each of them should see themselves reflected in this work.

Dr. Sankar served both as my advisor and committee chair. She guided me through the transformative process of becoming an anthropologist. She is responsible for teaching me the importance of theory to ask questions, design research, and analyze data.

Dr. Luborsky took me on a wild exploration of theory related to social narratives. We agreed to a collaborative project, not knowing the outcome. I'm glad we were adventurous. I understand narrative more fully.

Dr. Chrisomalis opened the world of cognitive anthropology for me. He helped me understand one of my longstanding scholarly interests—examining the relationship between the self and society.

Dr. Stange served as my mentor, my muse, and my confidant. He introduced me to the concept that scholars can scientifically study healing. He is not only a scientist but also a healer.

I would also like to acknowledge the American Academy of Family Physicians Foundation—Joint Grant Awards Program that provided funding during this research (G0907).

The participants in this research were very generous of their time and attention. As an anthropologist, I cannot make value-laden comments without risking ethnocentricity; as a doctor, I can say that I have never seen a finer group of doctors and people they work with—the best of the best.

Thank you to my family who sacrificed to give me this opportunity.

PREFACE

One of my early academic mentors stressed the need for a consistent and progressive line of inquiry as a prerequisite for becoming recognized as a legitimate research scientist worthy of funding. At one point, he screamed at me, "Get out of my office. Don't come back until you can tell me what you're willing to spend the rest of your career studying." I surveyed my entire career – past, present, and future. When I returned to his office, I said that I was going to study healing. I audaciously believed that I could study healing scientifically. I believe it now more than ever.

This current research is part of the middle of that line of inquiry. Will Miller and Kurt Stange proposed that healing changed health outcomes, and they outlined a research paradigm (Miller, et al. 2003), one that was proposed but not able to be executed because of lack of healing measures. Because measures require a domain analysis, I read everything I could find with the word "healing." When I started, I asked "an expert" for a reading list and was told I needed to find my own. A few examples from those years included *Healing the Soul in the Age of the Brain* (Frattaroli 2001); *The Healing Tradition: reviving the soul of Western medicine* (Greaves 2004); *The Lost Art of Healing* (Lown 1996); *The Psychodynamics of Medical Practice* (Stein 1985); *Healing the Child Within* (Whitfield 1989); *Trauma and Recovery* (Herman 1992); *The Undiscovered Self* (Jung 2006 [1957]); *Toward a Psychology of Being* (Maslow 1999); *The Doctor, His Patient and the Illness* (Balint 1957 [2000]); and *The Healer's Power* (Brody 1992), among others too numerous to mention. I also read every journal article I could find that mentioned the doctor as healer; I include a sampling of citations. (Beach and Inui 2006; Beckman and Frankel 1984; Brock and Salinsky 1993; Brody 1994; Cassell 1976; Egnew 2005; Elwyn and Gwyn 1999; Engel 1996; Hsu, et al. 2008; Loxterkamp 2001; Scott, et al. 2008) This is but a

glimpse of the starting point of my anthropological education. I knew from personal experience as a doctor that healing was real, not a reified construct. I even tried to measure it. (Meza and Fahoom 2008) I was not the only one interested in the topic, but healing was always considered “the step-child of medicine,” an exercise in the humanities, not science. Rita Charon probably did the most to advocate the interdependency of narrative and [scientific] evidence in *Narrative Medicine* (2006) and her subsequent work. (Goyal et al. 2008) In hindsight, all of this reflective and scholarly work was only the emic perspective, and as such, I knew that something was missing. Much of the work was grounded in the humanities or psychological perspectives based on psychoanalysis, which prevented scientific inquiry.

I could not answer the question, “What is healing?” It was at that point that I literally and metaphorically “crossed the bridge” onto the campus of Wayne State University and embarked on my anthropological career. I still remember the day I walked out of my office and into the department of anthropology at Wayne State University, asking to enroll in qualitative research methods class. The answer then, as now, was, “Take a class on theory.” What follows is from the perspective of where I found myself after crossing that bridge. Stories have a beginning, middle, and end. This document is part of the middle. I have a clear idea of what my next research project will be when this one is complete.

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SECTION 1: INTRODUCTION

Chapter 1: Introduction to the Research Project

Both the Institute of Medicine and The Future of Family Medicine Report emphasize the importance of "continuous healing relationships" to improving quality of care in the future of our health care system. (Donaldson et al. 1996; Institute of Medicine 2001; Martin et al. 2007) Likewise, the NIH has called for research that explores the interaction of behavioral and social factors and their effect on health outcomes. Despite the recognized importance of healing as a construct, its domain analysis is woefully inadequate, limiting scientific advances. Anthropological investigation is well suited to address this need, as there is a rich body of extant literature on the subject and methodologically can describe "healing practices" as social phenomena rather than attempt to define healing itself, which is a conflated construct not amenable to scientific study. This research hopes to advance the study of healing practices in the context of American medicine. The IOM and the NIH state the underlying hypothesis: Healing relationships improve quality of care and outcomes.

This research examines the relationship of narrative to ritual in medical encounters. After an introductory review of a few fundamental texts related to narrative, I explore Cheryl Mattingly's work *Healing dramas and clinical plots: the narrative structure of experience*. Mattingly effectively develops the argument that narrative structure, experience, and ritual converge to produce healing dramas.

Mattingly's work approaches my own understanding of healing practices most closely. She recognizes the contribution of cognitive anthropology to narrative, acknowledges that narrative exists prior to experience, discusses time in narrative as well as ritual time, and argues for therapeutic emplotment as a model of healing practice. She also invokes Turner: "Narratives

become one medium through which the healer tries to connect a person's individual experience to an ideal or preferred narrative, and healing itself is equated with the rhetorical task of persuading the patient to see her experience in a certain way (Turner 1992). Stories which are located in ritual actions may take on special therapeutic powers; indeed, certain kinds of stories may have their special place as an integral part of a healing ritual" (Mattingly 1998:14). She acknowledges the transformative properties of healing, and challenges the dominant assumption that the primary purpose of narrative is to give the self a sense of coherence.

Mattingly suggests that the necessary precursor to therapeutic emplotment is "locating desire" in a social drama and arises by the work of the therapist in creating multiple possible imagined endings to the narrative drama. I contend that W.H.R. Rivers was correct and the existential threat of disease and death creates the "universal desire" to enter into healing rituals with doctors. I use the descriptions of ritual by W.H.R. Rivers, E.E.Evans- Pritchard, Victor Turner, and Meyer Fortes to organize the presentation of my data. By showing a high congruence between my observations and the ritual structure outlined by these anthropologists, I claim clinical encounters in Western biomedicine form a healing ritual. I highlight the similarities and the differences between my observations and others who have described Western biomedicine as a healing ritual.

The theoretical frame for this research was cognitive theory as it related to narrative theory. I will argue that both share the common denominator of experience and connect the self to the cultural body. Unexpectedly, the relationship of narrative to ritual emerged within this research project. Again, I will argue that ritual is about experience and condenses multiple perspectives of narrative that allows the transformative process to occur.

Using this anthropological model, I then focus on contextualizing my anthropological data into the lexicon of prior scholarship related to “healing.” Arthur Kleinman asserts that exploring the illness narrative promotes healing and finds fault with biomedical specialists to the point that he states medicine needs to be “re-conceptualized.” Mattingly joins Kleinman and other anthropologists with dismissive comments about doctors and the biomedical paradigm as something that is “anti-narrative” and extinguishes the illness narrative, a common theme among anthropologists writing about narrative and healing. For both Kleinman and Mattingly, something the healer does or should do results in healing. Both recognize that biomedical practitioners don’t do what they suggest, which I believe results in their critique of biomedical practitioners. I claim that the healing relationship results in healing—not a particular social behavior of the healer. I assert that the social practice of doctors performing the healing ritual – including a diagnosis narrative--creates a healing relationship. Joint attention is the paramount social practice that results in a healing relationship by connecting the person in distress to a larger social and cultural framework.

With this understanding, Kleinman’s ethnographic work demonstrates how psychiatrists and patients focus joint attention on illness narratives, Mattingly’s ethnographic work demonstrates how occupational therapists and their clients focus joint attention on the desire of an imagined future, and I describe how doctors focus joint attention on a diagnosis narrative. Although Kleinman and Mattingly accurately describe healing within the setting of their respective field sites, I challenge their assertions that the biomedical practitioner is anti-narrative or lacks healing relationships.

I argue that biomedicine and the diagnosis narrative is a healing ritual and fosters the expression of individuality and self-expression within the doctor–patient relationship, allowing

for full participation in the cultural domain. The anthropologic enterprise is advanced by illustrating an under-examined and under-reported aspect of medical anthropology, the cultural practices of doctors in relationship to patients. This project illustrates the far more common and harder to illustrate normative practices of going to the doctor. Perhaps this will encourage others to gain a more balanced perspective for future research.

Goal and Specific Aims of the Research

The goal of the proposed research was to explore and describe the social experiences of patients and clinicians and identify the discursive maneuvers used by each within the context of clinical encounters to achieve a narrative with the socially acceptable explanation of sickness expressed as diagnosis.

The specific aims of the research were (1) to identify and describe the salient social practices within clinical encounters between urologists and patients engaged in addressing sickness, primarily cancer diagnoses, and (2) to describe the scholarly context within which the above encounters occur.

To accomplish these aims, I worked in a urology office and all of the clinical sites associated with this practice, including the hospitals, other clinics, and associated clinical disciplines. My data included interviews, but I relied most heavily on participant observation as a data source. Because I was interested in what actually happened during a clinical encounter, I refrained from gathering patient narratives, recognizing that this would add an added layer of individualized meaning-making that could prevent me from my goal. I selected several aspects of the practice because of methodological strengths, which I describe later. There is limited the ability to generalize the findings to primary care.

My analysis and subsequent claims are:

1. Experience is narratively structured.
2. A diagnosis is a narrative constructed by the doctor.
3. Ritual is a shared experience in which doctors and patients attend to shared cultural understandings.
4. The shared experience creates a social relationship—the healing relationship.

Chapter 2: The Narrating Self

Theory of the Mind

In *The Cultural Origins of Human Cognition*, Michael Tomasello (1999) summarizes his argument based on his prior works. He claims the cognitive phenomena he describes form the basis for all future cultural development in human beings. Specifically, Tomasello reviews three types of learning: imitative learning, instructed learning, and collaborative learning. He then states, "These three types of cultural learning are made possible by a single very special form of social cognition, namely, the ability of the individual organisms to understand conspecifics as beings like themselves who have intentional and mental life like their own." (Tomasello 1999: 5) His argument proceeds that natural selection is unable to explain the rapid cultural developments of *Homo sapiens* because there is simply not enough time for the myriad of evolutionary changes to take place. Based on this simple cognitive argument listed above, he describes the ratchet effect:

The process of cumulative cultural evolution requires not only creative invention but also, and just as importantly, faithful social transmission that can work as a ratchet to prevent slippage backward – so that the newly invented artifact or practice preserves its new and improved form at least somewhat faithfully until a further modification or improvement comes along. [Tomasello 1999:5]

He goes on to state, "Multiple individuals create something together that no one individual could have created on its own. These special powers come directly from the fact that as one human being is learning 'through' another, she identifies with that person and his intentional and sometimes mental states" (Tomasello 1999:6). Tomasello's argument is that cultural development and the genesis of culture itself is based on the premise described, broadly acknowledged in other disciplines as "the theory of the mind."

Tomasello describes individual human growth and development in the mental cognitive domain, stating:

The child comes to experience herself as an intentional agent – that is, a being whose behavioral and attentional strategies are organized by goals – and so she automatically sees other beings with whom she identifies in the same terms. Later in ontogeny, the child comes to experience herself as a mental agent – that is a being with thoughts and beliefs that may differ from those of other people as well as from reality – and so from that time on she will seek conspecifics in these new terms. [Tomasello 1999:14-15]

Tomasello describes accumulated history as “processes of cultural learning and internalization by which developing individuals learn to use and then internalized aspects of the collaborative products created by conspecifics.” (Tomasello 1999:15) Tomasello thus describes anthropological self as mental agent with thoughts and beliefs, derived from conspecifics, but are nonetheless unique, evidenced by the fact that the individual mental agent evaluates self from other with an understanding of the other. When I use the term *self*, I refer to this definition.

Tomasello later recapitulates:

This is the uniqueness from which all else flows, as it enables infants to exploit a novel source of information about other persons: the analogy to the self. At around nine months of age, analogizing self and other persons enables infants to attribute to other persons the same kinds of intentionality in which they themselves are just beginning to engage (and they may also analogize to the self, somewhat inappropriately, in their causal reasoning about why inanimate objects behave as they do).” [Tomasello 1999:213]

This goal-oriented and causal reasoning allows for the development of shared narrative – in the context of this research a shared diagnosis narrative. It also allows for a shared narrative conveying intentionality, a necessary precursor of transformative powers.

The second major concept outlined by Tomasello is the emergence of joint attention. By careful and detailed exposition, Tomasello explains normal human development, beginning at approximately 9 to 12 months of age, when “a new set of behaviors emerge that are not dyadic, ... but are triadic in the sense that they involve the coordination of their interaction with objects

and people, resulting in a referential triangle of child, adult, and the object or event to which they share attention” (Tomasello 1999:62). This joint attention is a uniquely human communicative behavior. While joint attention is required for cultural learning, I will examine a very narrow focus of cultural learning described as communicating the diagnosis narrative by joint attention to a specific object, the three-dimensional computer image of a diseased organ. This triadic attention will later re-surface as persuasion of the diagnosis narrative. For now, it is important to understand that basic human cognitions described by Tomasello are essential to the healing ritual enacted during clinical encounters. Expanding the argument, Tomasello elaborates:

Narratives add more complexity still, as they string together simple events in ways that invite causal and intentional analysis, and indeed explicitly symbolized causal and intentional marking, to make them coherent. And extended discourse and other kinds of social interactions with adults lead children into even more esoteric cognitive spaces, as they enable them to understand conflicting perspectives on things that must be reconciled in some way. [Tomasello 1999:214]

This research study depends on the ability of the doctor to construct a diagnosis narrative and convey that cognition to the patient, to persuade the patient to accept the diagnosis narrative despite potential conflicting explanations, and to subsequently act on the diagnosis with a therapeutic maneuver. This shared activity demonstrates “learning through the other” and creates a shared narrative between the doctor and the patient.

Theoretically, I find the anthropological literature related to narratives based on these cognitive foundations. Throughout the literature, the contested role of self as it relates to culture cannot stray too far from those attributes of humans that make culture possible. Culture would not exist in the absence of a human self; likewise, the human self would not survive without culture.

Personal Experience and Narrative

William Labov's sociolinguistic observations of natural speech provide one of the basic definitions of narrative. His work is highly consonant with the findings of Tomasello. He states, "[Human] communication may draw upon the fundamental capacity to transfer experience from one person to another through oral narratives of personal experience" (1997). This is one-half of the ratchet effect referred to by Tomasello. In the preceding quote, it is important to note that narrative, as defined by Labov, is preceded by experience and subsequently "told" to a conspecific. His contribution is to elaborate the fundamental structure of narrative (as opposed to the cognitive attributes allowing narrative). Labov states, "Narrative structure is established by the existence of a temporal juncture between two independent clauses." (1997) Labov points out that the second major function of the narrative is to establish an evaluative connection between Event A and Event B. Labov states, "Most adult narratives are more than a simple reporting of events. A variety of evaluative devices are used to establish the evaluative point of the story." (1997) Notice that this definition of narrative structure echoes Tomasello's theory of the mind because it includes the causal and intentional relationship between Event A and Event B. Labov's linguistic performance is supported by the cognitive abilities of humans as described by Tomasello. Both Labov and Tomasello emphasize the ability to convey experience to another human, a form of argument or persuasion that is an essential component of a diagnosis narrative that is embedded in the healing ritual.

Labov further expounds on the structure of narrative, indicating the first clause usually includes the orientation, which identifies the participants in the action, the time, the place, etc. Labov expands the definition of narrative by saying the evaluative function reports the "So what?" portion of a communication, something that "provides justification for the narrative's

claim on a greater portion of conversational time...,” (1997) another way of saying that narrative may be of mutual interest to conspecifics, one of the fundamental building blocks of cultural meaning. Labov describes this as "reportability or tellability" of an event. The ‘So what?’ or reportability is what connects both the teller and the listener. To further develop that concept Labov says, “Narratives include a protagonist, antagonist and third party witnesses,” indicating the “self as original author of the narrative and its immediate animator.” (1997) Again, this is consistent with how Tomasello details these actions resulting from natural human growth and development beginning at an early age.

Embedded within this definitional structure of narrative is the concept of self; similar to Tomasello it creates evidence the self exists, the self narrates. Labov collected data about the interactions between two individual selves, the narrator and the listener.

The two structural functions of narrative are (1) referential and (2) evaluative. The temporal sequence of the narrative, one of the important defining properties, proceeds from the referential function which allows a recapitulation of experience. The second necessary requirement in the structure of narrative is the evaluative component. In summary, both Tomasello and Labov report extremely concordant results from two data sets that are very divergent. Tomasello uses primate interactions and observations of primates while Labov uses observations of linguistic encounters. Together they form the basis for narrative as I explore its cultural dimensions. It is important to note that both Tomasello and Labov acknowledge the presence of both polarization or integration of participants within the narrative structure. This dichotomy of polarization and integration will echo throughout the theoretical framework for this research and resurface at the very end of this paper in the form of alienation and healing relationships.

Narrative, Schema, and Self

Roy D'Andrade gives a history of the development of cognitive anthropology and is closely associated with describing schema theory (1995). He notes that "the schema is an organized framework of objects and relations which has yet to be filled in with concrete details" (D'Andrade 1995:124). He also notes that simpler schemas can be embedded in more complex schemas and that the complexity of human thought can thus be explained with this concept. (1995:124) Using the basic cognitive building blocks of Tomasello and the structure of narrative by Labov, it seems a natural extension that the causal and intentional understanding of human behavior and the description of experience with evaluative function can be combined and expanded into narrative schema. Cognitive schemas are based on experience. This is consistent with Tomasello's description of human growth and development at a very early age.

D'Andrade has a small section on consciousness and a discussion of the self:

The conscious, perceiving center of awareness and agency is the self.... It is composed of both the conscious, aware perceiver of the thing that is perceived as doing the perceiving. William James called the perceiver the "I," and the entity perceived the "me." The perceiving self not only observes things in the world, it also perceives that it is perceiving – that is, it is conscious. The perceiving self has a continuing identity through time; it knows that it is the same perceiving self that it was aware of across previous observations – it observes that is the same observer that was observing before. [1995:163]

He goes on to cite evidence that while non-Western models of the mind are not identical to the Western model, there are many commonalities. He quotes Wierzbecka:

Findings of cross linguistic semantic investigation show that much the [Western] folk model ... corresponds in fact to the folk model operating in any other culture of the world: despite the very considerable difference between different folk psychologies that have been described in the literature, the idea of a "person" who "thinks," "wants," "feels," and "knows" (as well as "says" and "does" various things) appears to be universal. The fact that all languages appeared to have words

for all of these concepts (though not for "believe" or "desire," as distinct from "think" and "want") provides evidence for the universality of this model. [D'Andrade 1995:166]

Relating this to narrative theory, I recognize consensus among these anthropologists that narrative reflects experience of the narrator and that the ability to tell a narrative arises from the interaction of the individual with the cultural environment. Early childhood growth and development provide the basic cognitive framework to engage with human experience, indicating that the biological human being is receptive to developing into a unique individual self. An interactive cycle between being, experience as perceived by the individual of both interior and external environments, generation of narratives related to prior experience, communicating to a conspecific, which then becomes a repeating cycle, has been described. As I mentioned earlier, the individual self and culture are co-constituent of each other.

The Self in Culture

Clifford Geertz summarizes the relationship of self to culture as follows: "Becoming human is becoming individual, and we become individual under the guidance of cultural patterns, historically created systems of meaning in terms of which we give form, order, point and direction to our lives." (1973:52)

The cognitive psychologist Jerome Bruner argues that narrative forms experience, but later provides an example where a "perceiving self" developmentally predates the ability to construct a narrative. He gives two powerful examples, highlighting these contrasting views. The first is the exodus from Nazi-dominated Europe after the outbreak of World War II and his observations of

heartbroken people on the boat – families separating for safety, and merchants leaving their businesses behind, refugees fleeing the Nazis – I couldn't help being

amused by the ever-ready impulse to see life as imitating art. And I, too, was using the narrative in conceiving that journey: the Shawnee's voyage as yet another enactment of the biblical book of Exodus! [Bruner 2002:7]

In that example, Bruner understands his personal experience through a pre-existing narrative, structuring, filtering, and organizing his experience to fit a recognizable story.

Later he talks about audio recordings of an infant while she was alone in bed before she fell asleep:

She seemed drawn to the unexpected, to things that had surprised her or caught her unprepared. These little surprises would start her off on comments about how she had coped with their likes in the past or would cope with them tomorrow. So intent was she on getting her stories right that we came to believe her progress in acquiring language was driven by some sort of narrative energy. In some way, Emmy seemed to know what a story required for its telling even before she had the grammar needed to tell it right. It was as if a narrative sensibility were guiding her search for the right syntactic forms." [Bruner 2002:32]

In retelling the story of Emmy, although not directly referential to the work of Tomasello, his description is perfectly consistent with the theory of the mind as expounded by Tomasello. How Emmy "would cope with them tomorrow" is an example of an intentional and causal self. The goal direction described by Tomasello is the "narrative energy" to overcome the unexpected.

He goes on to say:

Self making is a narrative art, though it is more constrained by memory than fiction is, it is uneasily constrained, a matter to which we shall come presently. Self making, anomalously, is from both inside and the outside. The inside of it we like to see in our Cartesian way, is memory, feelings, ideas, beliefs, subjectivity. Part of this insidedness is almost certainly innate and species specific, like our irresistible sense of continuity over time and place in our pastoral sense of ourselves. But much of self making is from outside in – based on the apparent esteem of others and on the myriad expectations that we early, even mindlessly pick up from culture in which we are immersed.

Besides, narrative acts of self making are usually guided by unspoken, implicit cultural models of what selfhood should be, might be – and, of course what shouldn't be... Telling others about oneself is, then no simple matter. It depends on what we think they think we ought to be like – or what selves in general ought to be like. [Bruner 2002:65-66]

In that passage, Bruner acknowledges the “innate and species-specific” attribute of self with characteristics the human capacity to narrate. Additionally, he outlines the cultural influences on that same self:

None of this seems to discourage us. We go on, constructing ourselves through narrative. Why is narrative so essential, why do we need it for self definition? The narrative gift seems to be our natural way of using language for characterizing those deviations from the expected state of things that characterize living in human culture. None of us knows the just so evolutionary story of its rise and survival. But what we do know is that it is irresistible as a way of making sense of human interaction. [Bruner 2002:85]

Based on the foundational aspects of narrative reviewed so far, it is my opinion that the intentional self as described by Tomasello is part of the biological, neurological form of a human. I agree with Geertz when he says, “We are, in sum, incomplete or unfinished animals who complete or finish ourselves through culture – and not to culture in general but through highly particular forms.” (1973:49) In this way there is bidirectional cultural flow between the individual and the cultural body. Although I can accept in part the constructivist perspective of the self, I reject the extreme that there is nothing beyond that. As Tomasello points out, innovation (by a self) is required for participatory learning and the ratchet effect. Each human is in the process of living and experiencing, creating a unique self.

Quoting Strawson in *The Self in Health and Illness*, edited by Frances Rapport Paul Wainwright, the editors recount:

By “self-experience,” then, I mean the experience that people have of themselves as being, specifically, a mental presence; a mental someone; a single mental something or other. Such self-experience comes to every normal human being, in some form, in early childhood. The realization of the fact that one's thoughts are unobservable by others, the experience of the sense in which one is alone in one's head or mind, the mere awareness of oneself as thinking: these are among the very deepest facts about the character of human life. [Rapport and Wainwright 2006:3]

Again, Strawson describes experience as self-experience in relationship with the social environment. The role of self to narrative is definitional.

The Self, the Unexpected, and the Narrative

Bruner introduced the element of the unexpected experience, managed by the telling of a narrative. (2002:32) This unexpected experience foreshadows an essential aspect of what I will later describe in a clinical encounter. What if Bruner's unexpected is a disease that poses an existential threat? That existential threat calls for a narrative of why it occurred and how to cope with it. Like Emmy, we are self-making creatures, but when the perceiving self is caught in a story of self-unmaking, a story of disease and death, it must cope narratively. No one individual can cope with that alone, so as Tomasello phrases it, we learn through the other. I suggest that when confronted with such a circumstance, the narrating self engages cultural resources of the doctor who draws upon other complex narratives of causal explanations of disease called "diagnosis" to incorporate into one's own self story. Using this theoretical frame, I believe my data show the collaborative interaction of self with culture to deal with the unexpectedness of disease. The existential threat of disease and death is actually a threat to the narrating self.

Chapter 3: Narrative Engagement in a Social World

Narrative and Emotions

The discussion of emotion in anthropology is extensive; I will highlight only certain aspects that further the theoretical argument of this research. Alexander Hinton in his introduction to *Biocultural Approaches to the Emotions* (1999) gives one of the first and important reasons to include emotion in the study of narrative. He states, “Emotions are cognitive appraisals that are made and acted upon within an interpersonal social context and on the basis of a culturally relative set of beliefs and values” (Hinton 1999:8). It is the appraisal or evaluative component of the emotions that is fundamental to Labov’s definition of narrative. Hinton widens Labov’s evaluation of the relationship between two experiences in the past to evaluating the self in relationship to the world. This draws on themes of self-creation through interaction with experiences of living in the world. Hinton is merely stating that emotions are powerful social tools to accomplish that evaluation.

Carol Worthman, in *Emotions: You can feel the difference* (1999), presents material that is concordant with Bruner. Bruner pointed out that there is an iterative cycle between an individual telling a narrative and a narrative informing the individual’s experience and retelling of that experience. This conceptual framework supports the understanding that the individual self and culture are mutually interactive, echoing Geertz’s statement. Worthman states:

Emotions are particularly thorny for anthropologists because they require integration of the individual and cultural levels of explanation, but they are interesting for just that reason. Emotions involve relational – evaluative stances of the individual to situation. Moreover, they effect a crucial link in embodiment of the experiential self by entraining physical states with both individual experience and behavior. [1999:53]

This statement highlights the evaluative nature of emotions while recognizing the bi-directionality of an emotion between an individual and the cultural body. She draws on other theorists in making this argument, stating:

Contemporary culture theory increasingly employs the notion of embodiment, a concept initially advanced by Merleau-Ponty (1962) to indicate this situated – projective relationship of subject to object in perception, and by Bourdieu (1977) to denote the “socially informed body.” Conceptions of embodiment address the persistent conceptual gaps between mind and body, individual and society in both social and cognitive theory. [Worthman 1999:51]

Restating that argument after diagramming the bidirectional nature of emotions, Worthman says, “Emotions are central to reciprocal processes of bringing forward physical states into personal experience and social behavior, as well as transducing individual social experience into physical states. This dual embodiment instantiates the relationship of individual to culture” (1999:63). Again, the intent is not to have a detailed explanation of emotions and anthropology but to understand the relationship of emotions to narrative. The following statement sets up this argument: “Finally, emotions participate, often crucially and definitively, in meaning making” (Worthman 1999:49). I contend that the clinical encounter, with all its narrative and emotional overtones is a process of meaning making, a cultural performance designed to avert alienation.

Daniel Fessler, (1999) in his chapter, *Toward an understanding of the universality of second order emotions*, integrates the Malay emotion *malu* as a socially engaged emotion. *Malu* is described as: (1) averted gaze, (2) face turned down and away from others, (3) stooped shoulders, (4) shrinking posture, (5) bent-knee, shuffling gait, (6) reddening of the face and neck, and (7) attempts to avoid being seen, culminating in flight. (1999:84) *Malu* approximates shame in Western culture. These observations occurred in the Malay population. The importance of that

is that Fessler directly supports Tomasello's theory of the mind by placing *malu* in the following social structure:

- If (1) Ego can recall emotions that she experienced in the past,
- And (2) Ego is sufficiently aware of her own actions to make a connection between her emotion displays and the emotion displays of others,
- And (3) Ego is aware that others have minds like our own,
- Then (4) Ego is likely to recognize emotion displays not simply as threatening or rewarding stimuli in the environment, but rather as clues to the internal state of the Other. The clues which displays provide are interpreted on the basis of empathy, the formation of an association between the Other's display and Ego's memory of the subjective experience of the corresponding emotion. [Fessler 1999:91]

This bridges the understanding of emotion away from something experienced internally by individual humans to a socially engaged cognition. Fessler details the shared cognition of emotions and broadens our understanding of the Theory of the Mind. Emotions not only help serve in the evaluative function of telling a narrative, but also contribute to the social learning necessary for the “ratchet effect” described by Tomasello.

The Emotion of an Existential Threat

It is the culturally engaged self that experiences meaning. As I incorporate discussion of the existential threat of disease and death, there is an unarticulated emotion associated with that experience. This discussion on emotions in narrative should all be condensed into the term *existential threat*, an emotionally laden term used by Kleinman (1988:153), and alluded to by Rivers (2001 [1924]:54) and Jerome and Julia Frank (1991:5), all of whose writings I reference in the argument I present. In this way, I use existential threat not only to refer to disease that threatens to end a life, but also the narration that ends a self. I see healing as a broader context

than terminal disease—or rather I see each self afflicted with a terminal existence manifested with death of the body–self. I suggest that humans use a diagnosis narrative learned through the other (the doctor) and incorporated into the schema of the story of the self to navigate the unexpected in life, reclaiming the ability to self-narrate. It is the self, connected to culture through shared narratives, that creates the meaning for the individual, a self which is also recognizable to others.

Emotions and Ritual Healing

In *Affecting experience: Toward a biocultural model of human emotion*, Keith McNeal continues the conversation on emotion and offers the following comment: “The human perceptual apparatus continually evaluates the status of the organism in its socio-ecological niche, so affective feeling states are implicated in the overall orientational processes of maintaining the organism’s well-being in relation to its milieu” (1999:216). He goes through detailed analysis of neuro-anatomy and neurophysiology, constructing a biological model of emotional appraisal. I included his comments in this theoretical discussion because one of his examples closely approximates the thesis of this research. He says:

Consider further the importance of interpretation for the processes of ritual healing and contemporary psychotherapy (Kleinman 1988; Frank 1991 [1961]; Csordas 1994). Kleinman has highlighted the process of evaluative transformation, indicating that successful healing therapies – of whatever sort – are often predicated upon effecting deep changes in the way one knows, and therefore perceives, the world. To a certain extent, this process is one of interpretive reformulation; the problem (anxiety, neurosis, etc.) leading to the healing process can largely emerge as a result of the ways the subject interprets his/ her status in the world and then acts upon it. Effective therapy requires a thorough reworking of the patient’s problematic, habituated ways of knowing, including reinterpretations of past experience (Locke 1987). [1999:241]

I explore this discussion of Kleinman's "re-education" or persuasion later, not strictly within the context of emotions, but within the context of narrative reinterpretation, acknowledging that narratives include emotions as evaluative components in their basic narrative structure. McNeal discusses emotions and the mutually interactive way in which the self and culture interact. He also emphasizes the transformative properties of healing rituals. Narratives are also imbued with societal norms, an essential component for meaning making.

An emotion-laden, societal norm saturated in meaning is the healing relationship. One of the major discoveries of this research is the relationship of healing rituals to healing relationships. Drawing on Kleinman and ritual, McNeal emphasizes the transformative powers of healing rituals as a re-working of the ways of knowing and of experiences. In this way, a narrating self is a transforming self; in a simplistic way, it is a form of lifelong growth and development.

The Self as Narrator of Self-Transformation

Naomi Quinn reinforces the concept of a narrating self as a transforming self and the idea that new ways of knowing change the way we experience our lives. She discusses how cultural schemas are incorporated into the narrating self and "self-understandings" and the relationship to the self as having existential concerns is a critical concept in understanding the data I present.

Quinn states:

If "self-understandings" are more than a semantic gloss for "general goal schemas," then the substitution must hold some new implication. I believe that it does. We are now led to ask, what is it about self-understanding that is so compelling to us that it defines our most general goals? The answer lies in the way we come to understand ourselves. The process by which cultural schemas are incorporated into a sense of "self," thereby entering into the definition of an individual's existential concerns and life ambitions, is lifelong and causally complex. Most of us would agree that crucial stages of this process of self-

definition is occurring in childhood and adolescence; however, dramatic or otherwise compelling experiences at any age can inspire redefinition of the self or elaboration of prior self-understandings. [1992:91]

Quinn's description is much more consonant with the work of Tomasello. It acknowledges the uniqueness of a self as distinguished from the other while allowing for the evaluative process of experiences and interactions between the two. Tomasello acknowledged that conflicting or differing understandings of the self from attributions of others are possible and it is the interaction of the individual human being with the environment, including the social environment, where the bootstrapping process of creating a self-narrative begins.

Quinn's description is also consistent with the model of ritual healing and healing relationships presented in this research. She outlines an anthropology of the self that is entirely consistent with McNeal and is a model that I highly endorse. This particular passage is almost an anthropological description of psychotherapy. Because of the metonymic use of "existential concerns" and "self-understandings," I connect her work with what I will later describe as the appropriate setting of Kleinman's illness narratives. My major argument is that such existential concerns of the self are not part of routine clinical encounters but, more appropriately, a reworking of past events that occurs in the setting of a failed healing ritual and a secondary cultural form of healing called psychotherapy. Cognitive anthropology is the basis of her description of self-understanding, and she incorporates the concept of self-transformation brought about by existential concerns. I will make this same argument when discussing clinical encounters as narratively structured rituals.

Conflated anthropological taxonomies

In the above discussion, I have chosen anthropological theorists that are consistent with my own beliefs. I have also read the work of other anthropologists whose work have gained wide acceptance but whose work lack face validity from my perspective. For the purposes of disclosure, I present their work to indicate why I do not find their work practical or useful.

Robert Hahn, in his book, *Sickness and Healing: an anthropological perspective*, claims to widen anthropological perspective. He states, "Broadly speaking, the essence of 'sickness' is an unwanted condition in one's person or self – one's mind, body, soul, or connection to the world." (1995:5) He goes on to state:

It is not commonly recognized in the West that ideas about what a "person" and "self" are and should be differ greatly from one cultural setting to another. Indeed, the individual weighted person, separate from the rest of society in the universe, is a distinctly Western notion (Dumont 1965; Lutz 1980 5B); in many non-Western societies, persons are regarded as essentially an inextricably linked with other beings, human and nonhuman. Autonomy and independence are also largely Western values about desirable connection with others. [Hahn 1995:5]

This statement echoes that more famous reference by Geertz:

But at least some conception of what human individual is, as opposed to a rock, and animal, a rainstorm, or a god, is, as far as I can see, universal. Yet at the same time, as these offhand examples suggest, the actual conceptions involved vary from one group to the next, and often quite sharply. The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment, and action organized into a distinctive whole and set contrastively both against other such wholes and against its social and natural background, is, however incorrigible it may seem to us, a rather peculiar idea within the context of world cultures. [1984:126]

Up to this point, I have used the terms *individual* and *self*, avoiding the term *person*. The question immediately becomes, What is the anthropological relationship between person and self? Reviewing Hahn's definition of sickness, he conflates person and self and lists attributes of that entity as mind, body, soul, or connection to the world. (1995:5) I believe these are conflated

terms leading to false dichotomies and not helpful for this research. Within the context of this research, person is a cultural construction and, as such, a cultural actor responsive to external expectations of socially appropriate behavior. Self is a cognitive component of an individual, unique in the sense that Tomasello points out, who may choose to incorporate what it perceives in the cultural environment or choose to reject it.

My simplistic formulation of distinguishing self from person and using self as the context of this research avoids the philosophical and scholarly debates regarding the object of healing. This surprises even me, as I had previously differentiated “curing disease” with “healing the person.” I now believe that the person, as a cultural construction, is not universally the same in all cultures; the self, however, is a universal. I contend that the enduring and transforming self is the object of healing and the self is the anthropological entity that defines a healing relationship. I define *illness narratives* as stories told by persons acting as social actors. I define *healing relationships* as shared experience between two selves. Although others may criticize my nomenclature as overly simplistic, I use it as a corrective response to anthropological literature that is conflated and less helpful for this research project because it expands the scope of the argument to the point that it is no longer manageable.

If I were to put the controversies into context, I would say Geertz and Hahn have “hypo-cognitived” the self in the sense that Levy describes certain emotions in certain cultures as hypo-cognitived (1984:219). Just because they're hard to observe or may not be expressed by members of the culture is not the equivalent to nonexistence. I mention this here to caution the reader about conflated terms. As I present data, results, and analysis, I will emphasize the words *individual self*, *illness*, and *disease*, as they lend themselves to a more parsimonious argument.

Scheper-Hughes and Lock used the term “individual body-self,” a term much closer to the theoretical underpinnings of this research study. (1987:1)

Person or Self?

Arthur Kleinman and Cheryl Mattingly both have a corpus of anthropological work directly related to narrative and culture; both of them conflate person and self, at times using them interchangeably. Yet both acknowledge the clinical encounter as a healing ritual. In this research, I discuss both healing rituals and healing relationships. I intend to show that healing rituals allow the development of healing relationships. For the purposes of clarity in argument, I will define someone who participates in a ritual as a *person* and define someone who is part of a healing relationship as a *self*, a self that has incorporated the *other* into a self-narrative. Clarifying this ambiguity is essential to sorting through all the conflicting literature on the topic of healing.

Illness Narratives

For my entire professional career, I was taught that listening to the illness narrative was the way to create a healing relationship with the patient. My mentors presented that cause-and-effect relationship simply as “the given wisdom,” and it is incorporated into the clinical medicine syllabus at Wayne State University School of Medicine. It is also institutionalized in the Accreditation Council of Graduate Medical Education for Family Medicine that requires a behavioral scientist on faculty in Family Medicine residency programs. With the benefit of having completed this research project, I now realize that this is a misrepresentation, in large part based on Kleinman’s landmark book, *The Illness Narratives: suffering, healing and the human*

condition. (1988) The misrepresentation I refer to is that illness narratives are not part of the Western biomedical healing ritual in the way that Kleinman suggests, and those who critique Western biomedicine for not including it do not fully understand how Western biomedicine functions in society. For me, this was a shocking re-education. With hindsight, I shouldn't have been so surprised. I had been listening attentively to illness narratives for over 25 years, yet I still could not answer the question, What is healing?

I now recognize two basic forms of Illness Narratives: (1) I love my doctor—she is such a good diagnostician, and (2) I hate my doctor—she didn't listen to me. I contend that the first illness narrative completed the full healing ritual, which allowed a healing relationship to develop. The second illness narrative resulted from a narrative failure of the diagnosis narrative. The good news is that healing relationships flourish between doctors and patients. I witnessed countless examples of it during this research. Later in this paper, I will argue that anthropologists have studied the second illness narrative (“I hate my doctor—she didn't listen to me”) and mistakenly represented it as the norm of Western biomedicine when, in fact, it derives from misdiagnosis and failure of the healing ritual.

While I have no doubt that illness narratives exist, I contend they simply are not causally related to the development of healing relationships. Illness narratives are also not necessarily part of the healing ritual, as Kleinman suggests. I will return to this later in the discussion of my data.

Illness Narratives in Medical Anthropology

Arthur Frank writes in the genre of the wounded storyteller, firmly grounded in the world of medicine as a subculture. He describes his book as theoretical but also bases it on his own personal story of undergoing cancer treatment, supplemented with stories from others. He points

out, rather dramatically, “Sooner or later, everyone is a wounded storyteller.” (Frank 1995:xiii)
All of us must at some time face disease or death.

Consistent with the development of narrative in the above theoretical considerations, he states, “These embodied stories have two sides, one personal and the other social” (Frank 1995:2). “The ill body’s articulation in stories is a personal task, but the stories told by the ill are also social. The obvious social aspect of stories is that they are told to someone, whether that person is immediately present or not” (Frank 1995:3). He describes exactly how a schema for storytelling occurs, stating:

The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a nonprescription remedy, or he was instructed to ‘tell the doctor what hurts’ and had to figure out what counted as a story that the doctor wanted to hear. [Frank 1995:3]

He goes on to say that illness stories become a circulation of stories and recounts how he told his personal illness story multiple different times to different people in the course of one day. He does go on to say however, “The story of illness that trumps all others in the modern period is the medical narrative. The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not” (Frank 1995:5). When people accept this authorized medical story, Frank refers to it as “narrative surrender” (1995:6). This narrative surrender takes on huge proportion as he goes on to describe its ultimate effect as “medical colonization.” In this way, he is describing the control of the body and equating it with control of the story.

The self can compare and accept or reject a self-narrative, as noted by Tomasello. (1999:52) Frank also echoes Tomasello’s sentiments: “The self is understood as coming to be human in relation to others, and the self can only continue to be human by living for the Other”

(1995: 15). Frank acknowledges “the storyteller” and the narrative development of the self. His focus seems to be on who controls the narrative. Although underemphasized in his writing, he acknowledges:

These modernist roots remain the basis of professional practice even on this side of the postmodern divide, and popular demand for that practice increases. The prospect of economic necessity requiring explicit rationing of healthcare provokes fear in many people.... The same people one moment are fearful that their healthcare will be rationed away, in the next moment attend a pro-choice meeting on the euthanasia and speak to their fear of "dying on the machine." (Frank 1995: 16)

My critique of Arthur Frank is that he got it wrong when he chooses ‘narrative surrender’ as the hallmark of a clinical encounter in Western biomedicine; he artificially creates winners and losers, and he portrays the doctor as the antagonist rather than a witness to the narrating self in a struggle with disease and death. Later, I describe narrative surrender as *Homo sacer*, but I believe such cases are rare. Purely on the basis of theoretic musings, I believe that professionals — doctors — can give power to individuals without diminishing their own power through ritual, which seems to me to be a deeply embedded social narrative. I realize this is a discursive maneuver, curtailing discussions of power by redirecting such discussions into the framework of “learning through the other” and narrative transformation. I share musings simply to generate questions as I explore how theorists inform my research.

Frank discusses the work of Arthur and Joan Kleinman in his discussion of the body in medical anthropology. (1998:27-28) He uses their term of the "body-self," echoing Scheper-Hughes and Lock’s “individual body-self” (Scheper-Hughes and Lock 1987), stating, "The Kleinmans provide one of the most sophisticated analysis of the interweaving of bodies, cultures, and lives, and the limitations of their efforts to hear the body speaking reveal the dilemma that every such attempt, including my own, must struggle with" (Frank 1995:28). This body–self is

actually one side of the triangulated terminology of narrative embodiment, narrative self, and body–self. Working with a related term called “self-stories,” Frank aggregates all of these terms into “body–self–story” (1995:57). I’m not sure how much more helpful this is other than to point out the metonymic importance of each component.

Claiming that illness is a call for stories, “Stories have to repair the damage that illness is done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations” (Frank 1995:53). Again, I caution about the conflation of terminology that I believe has left this area of inquiry dense. I hope to demonstrate that it is not illness but disease that forms the call for stories. Additionally, it is the self — not the person — that must self-narrate the story. Here again I differentiate the duality of illness/person as contrasted to disease/self as vital concepts to understand healing rituals as social practice and healing relationships as two selves recognizing each other as being like the other and being capable of entering into an authentic relationship.

Frank quotes Schafer:

In telling the self-stories to others we may, for most purposes, be said to be performing straightforward narrative actions. In saying that we also tell them to ourselves, however, we are enclosing one story within another. This is a story that there is a self to tell something to, a someone else serving as audience who is oneself or one's self... On this view, the self is a telling. [1995:55-56]

The process of telling a story reaffirms both the relationships with others and the self.

Elaborating further he says,

We need to tell someone else a story that describes our experience because the process of creating a story also creates the memory structure that will contain the gist of the story for the rest of our lives. Talking is remembering. Memory is not only restored in the illness story; more significantly, memory is created. If the story being told... something to live up to, then a future is also being created, and that future carries a distinct responsibility. [Frank 1995:61]

When Frank reverts to the self as narrator, I concur with his description.

Notice the congruence with D'Andrade's term "narrative schema" and the description above. The 'future' is the relationship between objects that are expected, given the particular narrative schema deployed. Tomasello would describe it as intentionality.

Throughout the rest of the book Frank outlines a taxonomy for three different illness story schemas: the restitution narrative, the chaos narrative, and the quest narrative. He characterizes the restitution narrative as "surrendering one's body to the medical world ...the high-tech medical world remains a perpetual source of the hope that keeps restitution stories going" (1995:174). Frank's word choice of "surrender" reveals a judgmental perspective. "Surrendering to the restitution narrative" (losing the preferred self) is somehow construed as the unmarked category, the norm. This research will challenge that perspective.

Although Arthur Frank's work was theoretical, Andrew Sparkes and Brett Smith provide ethnographic data in their article, *When narratives matter: men, sport, and spinal cord injuries* (2006). They use Frank's taxonomy of illness stories (restitution, chaos, and quest narratives), but provide actual examples from patients with spinal cord injury. The authors sort their ethnographic data using this taxonomy, giving credence to Frank's theoretical musings. (Sparkes and Smith 2006:56) Their work is interesting in that they describe the same patient population that Cheryl Mattingly studied. It is Mattingly's work, not Arthur Frank's, that I will use as an embarkation for this research.

Narrative Theory in Medical Anthropology

In a substantial review of narrative and anthropology, Cheryl Mattingly and Linda Garro organize chapters originating from the Harvard Friday Morning Seminar in medical anthropology, resulting in *Narrative and the Cultural Construction of Illness and Healing*.

(2000) The introduction begins, “Narrative is a fundamental human way of giving meaning to experience” (Mattingly and Garro 2000:1). They quote Rosaldo, “Telling stories allows narrators to communicate what is significant in their lives, how things matter to them. Narratives offer a powerful way to shape conduct because they have something to say about what gives life meaning, what is inspiring in our lives, and what is dangerous and worth taking risks for” (Mattingly and Garro 2000:11). They refer to Carrithers and his discussion of plot as it refers to an inner notion of what will happen as well as an outer sense of ‘landscape’ (Mattingly and Garro 2000:3). Narrative connects storyteller and audience, is a powerful method of socialization, and mediates emergent constructions of reality. “Stories also concern events as experienced and suffered through by quite specific actors. They allow us (the audience) to infer something about what it feels like to be in that story world, that is, they give form to feeling. Telling the story is a ‘relational act’ that necessarily implies the audience” (Mattingly and Garro 2000:11). Mattingly and Garro also acknowledge the alternate side of the power equation, quoting Ochs and Capps, “Narrative practices, including who is entitled to tell a story and when it can be told, ‘reflect an established power relations in a wide-ranging domestic and community institutions’” (2000:18). Mattingly and Garro summarize these themes as represented in the body of work in anthropology and other disciplines engaged in the study of narrative.

Byron Good and Mary Jo DelVecchio Good discuss narrative in the medical setting. The following statement will be important later for further interpretation of my data; they repeat a common critique of Western biomedicine:

In spite of the ubiquity of storytelling in medical settings or in research with healthcare practitioners, one prominent form of critique of medical care has been based on physicians’ failure to recognize the narrative dimensions of the illness experience, to attend to the stories the patients tell. Physicians constitute ‘disease’ as disordered physiological structure and function, set within abstract, medicalized time, or as ‘dehistorized objects-in-themselves.’ Thus while

patients experience 'sickness' in the context of life narratives, the lived body, and diverse forms of social relations and power structures, medicine constructs the objects of therapeutic attention as ahistorical, atemporal, and nonsocial dimensions of the medicalized body. [Good and Delvecchio Good 2000:51]

This type of statement sets the general frame of medical anthropology as a critique of biomedicine. Here, the Goods are repeating Arthur Kleinman's critique of Western medicine, demonstrating the generalized acceptance of this perspective within the corpus of work in narrative and healing. I will contest this perspective as incomplete after my discussion of clinical encounter as a healing ritual. Healing rituals are very engaged with self-stories, are set in a temporal context of a lifespan, and are extremely social performances, all attributes contradictory to the statement by Good and DelVechhio Good; I will demonstrate that illness narratives are told to others but not to the doctor.

Further emphasizing their point, Good and Delvechhio Good go on to repeat the metaphor of the colonized dimension of the medical lifeworld. They state:

Stories such as these [reflective stories] complement the formalized medical stories of the wards, revealing aspects of the inner life of medicine and serving in a modest way to protest against dehumanizing aspects of ward culture. Seldom, however, do they lead to serious efforts to change the structure of clinical life. Even more seldom do they lead to any serious questioning of the basic structure the narrative practices through which disease is constituted as the object of medical attention. [Good and DelVechhio Good 2000:65]

In a rather damning commentary, they label this dichotomy as a moral failure. I will argue the opposing position as I explore the narrative experience of the self in relationship to the cultural body.

In Lawrence Kirmayer's chapter on "broken narratives," he states:

Patient and clinician are actors engaged in conversation; although they need each other to tell and enact their stories, at the same time they wrestle with each other to see whose version of the story will be lived. This wrestling itself may become part of the final version of the story, or it may be suppressed to construct an authorizing genealogy. Once authorized and accepted, the story is retold and so persists, becomes stabilized, and influences future stories. [Kirmayer 2000:156]

It is important at this point to recognize this as a struggle characterized by the word "wrestle," and that there are differing versions of the story competing to become the realized and the reality. He later says, "These situations of conflict and contestation can reveal structural problems and ideological conflicts in medical care; at the same time, they provide important opportunities for the creation of new meaning" (Kirmayer 2000:157). I contend that the creation of new meaning is equivalent to healing.

In the final chapter, "Emergent Narratives," Mattingly asks, "What has any of this to do with healing? What can we see about healing if we discover narrative moments, times when healing and recovery take on all the compelling power of the well-told story? It may bring us closer to the perspective of the sufferer" (2000:206). The perspective of the sufferer is metonymically correlated with healing. She summarizes by saying, "This evangelical bent, this need to act as transformative agents and not as mere technicians of the body, drives even some Western healers to engage in the creation of healing dramas in their efforts to assist clients in transforming their lives" (Mattingly 2000:207). Note the persistent critique of biomedicine as "mere technicians" and the implied minority of Western healers that engage in healing. I contend that Mattingly overlooked the biggest healing drama of all—the diagnosis narrative.

In the introduction to *The Illness Narratives*, Arthur Kleinman (1988) repeats the dominant viewpoint:

For members of Western societies the body is a discrete entity, a thing, an "it," machine-like and objective, separate from thought and emotion. For members of many non-Western societies, the body is an open system linking social relations to the self, a vital balance between the interrelated elements in the holistic cosmos. Emotion and cognition are integrated into bodily processes. The body—self is not a secularized private domain of the individual person but an organic part of the sacred, socio-centric world, a communicative system involving exchanges with others (including the divine). [1988:11]

Instead of using the term *individual self* he uses the term “individual person” and thereby conflates the theoretical narrator with the cultural construction of the person. Personhood is a fascinating and valid pursuit of anthropological inquiry; it just is not part of this research project.

Kleinman continues:

For the practitioner, the patient's complaints (symptoms of illness) must be translated into the signs of disease.... That tale of complaints becomes the text that is to be decoded by the practitioner cum diagnostician. Practitioners, however, are not trained to be self-reflective interpreters of distinctive systems of meaning. They are turned out of medical schools as naïve realists,... who are led to believe that symptoms are clues to disease, evidence of a “natural” process, a physical entity to be discovered or uncovered.... Illness experience is not legitimated by the biomedical specialist, for whom it obscures the traces of morbid physiologic change; yet for the care giver of the chronically ill, who would be an effective healer, is the very stuff of care, “a symbol that stands for itself.” Legitimizing the patient's illness experience – authorizing that experience, auditing it empathetically – is the key task of the care the chronically ill, but one that is particularly difficult to do with the regularity and consistency and sheer perseverance that chronicity necessitates. [Kleinman 1988:16,17]

Here, the default definition of healing requires legitimating the individual illness experience. Again, I will portray the heretofore not illustrated alternative perspective of Western biomedicine later when I present my data. When Western medicine is viewed as a healing ritual, the importance of the illness narrative needs to be carefully re-examined. I suggest the illness narrative is real but not a prerequisite of a healing relationship. An illness narrative may in fact emanate from a healing relationship.

Kleinman is consistent with other anthropologists in pointing out that Western civilization emphasizes the individual more than non-Western societies, but he then critiques biomedicine for not legitimating that same individual's illness experience. That is inherently contradictory. One aspect of Kleinman's statement will trump all others. An “authentic relationship” is the marker of a healing relationship. The method by which patients and doctors arrive at an “authentic relationship” will emerge in this research and I will definitionally label a

healing relationship as an authentic relationship, a sharing between two intentional selves, each with mental lives.

Kleinman gives us the explanatory model of healing stating: (1) the first step is the elicitation of the patient's (and family's) models; (2) the second step of the explanatory model technique is the presentation of the practitioner's explanatory model. He points out that no doctor is taught how to explain the biomedical account to patients; (3) the third step in the process is an explicit comparison between the lay model and the professional biomedical model, identifying gaps, and (4) the final dimension of the explanatory model paradigm is the opportunity it presents the clinician for self-reflective interpretation of the interests, biases, and emotions that underlie his own model. (1988:239-243) I will return and critically reanalyze this model, incorporating my data, and suggest a re-organization of the component parts of healing later in this paper.

He summarizes by saying, "I see medical psychotherapy, then, as a collaborative relationship within which the techniques for exploring illness meanings encourage catharsis, persuasion, tactical problem solving, and other of the mechanisms of psychotherapeutic change" (1988:246) Kleinman essentially equates the practice of medicine with psychotherapy, saying, "When the tasks of support, attention to emotional needs, and negotiation of an authentic relationship are accomplished in a caring fashion the question of how to do medical psychotherapy vanishes. That is the psychotherapy" (1988:246) This statement, rather than being an anthropological explanation, is part of the "critique of biomedicine" mentioned by so many others and closely approximates the lay model of healing. The fact that the lay model of healing seems to be consistently absent from the practice of medicine was, of course, the motivating factor for this entire research project.

Cheryl Mattingly and Healing Rituals

In *Healing dramas and clinical plots: The narrative structure of experience*, Cheryl Mattingly (1998) effectively reviews the theoretical work outlined above, incorporates ethnographic data, and pushes the limits on the theory of narrative as it relates to human experience and healing. She is familiar with and gives credit to the group from Harvard: Mary Jo Delvecchio Good, Byron Good, Michael Carrithers, Arthur Kleinman, Linda Garro, Linda Hunt, and others. It was on this foundation that she undertook that work. She starts by stating, “The need to narrate the strange experience of illness is part of the very human need to be understood by others, to be in communication if even from the margins” (Mattingly 1998:1). She then quotes Jerome Bruner saying, “If narrative is based on a ‘breach’ of the commonplace, then profound physical and mental suffering constitutes one breach that seems to demand a narrative shape. It is one liminal place within the human condition that calls for sense-making and this often takes narrative form” (Mattingly 1998:1). The term *breach*, used by Bruner, is synonymous with the terms *disruption*, *unexpected*, and, I will argue, synonymous with the term *existential threat* that I use in presenting my data. A narrator tries to make sense of the inchoate and get to the other side of liminality through a narrative endeavor. Mattingly argues that narrative serves as an aesthetic and moral form underlying clinical action and that therapists and patients not only tell stories but also create storylike structures through their interactions. Her terminology for this interaction is “therapeutic emplotment,” which she claims is integral to healing power of this clinical practice. (Mattingly 1998:2) Throughout the book Mattingly mentions “self” and “healing” at least 25 times each and often relates them to narrative power. Although not stated, I

understand this as the power to transform one's self narrative. I comment on this power in my final discussion.

Mattingly states, regarding her work at the World Bank project in Calcutta:

I recognized that stories were not just told after experience but were constructed while people were still very much in the midst of action. This active storytelling played a critical role in team strategizing about how to turn project implementation into more desirable directions. Thus I began to examine narrative as an aesthetic form with rhetorical powers, one which could become a persuasive tool for convincing others to see the world in a certain way. [Mattingly 1998:5]

Mattingly openly equates narrative with persuasion, a key element of the healing ritual as presented in my data. This statement is entirely consonant with theorists listed above. She goes on to state, "They were telling very personal stories about very social events which would have extensive political consequences. These personal stories were then woven into collective story to be later used in arguments to country officials were presented with an oral history which opened along the lines of 10 years ago, when this project was first conceived" (Mattingly 1998:5). It is important to note that Mattingly acknowledges that personal stories affected politics—her definition of narrative power, another interpretation of narrative power, contrast the power to transform oneself with the power to transform politics. In this paper, I will focus on the former.

Mattingly's book, published in 1998, describes a rapidly growing conversation among medical anthropologists, sociolinguistics, psychologists, and a host of other students about narrative and healing practices (1998:6). Mattingly stands shoulder to shoulder with Arthur Kleinman in terms of advancing narrative methodologies in anthropological studies. She understands it is a social act: "What draws these studies together is a focus on the meaning making aspects of illness and healing ... the meaning centered paradigm of medical anthropology.... Meaning is not given but something actors struggle to discover" (Mattingly 1998:9-10).

Mattingly explores the relationship of narrative to experience within the context of the healing ritual. These rituals give an opportunity to rework experience; she's using narrative and the narrative structure of experience as the basis for healing activities. Again her term is "therapeutic emplotment," a term that conjures up both narrative and experience:

That is, therapists and patients not only tell stories, sometimes they create story-like structures through their interactions. Furthermore, this effort at story-making, which I will refer to as therapeutic emplotment, is integral to the healing power of this practice. Thus, this book considers the narrative structure of action and experience. (1998:2)

The basic argument of this book, elaborated in the context of occupational therapy, is that narratives are not just about experiences. Experiences are, in a sense, about narratives. That is, narratives are not primarily after-the-fact imitation of the experiences they recount. Rather, the intimate connection between story and experience results from the structure of action itself. Many kinds of social actions (including many therapeutic interactions) are organized and shaped by actors so that they take on narrative form. Thus narrative and experience are bound in a homologous relationship, not merely a referential one. [Mattingly 1998:19]

This summary by Mattingly gives reprise to the argument of Bruner, that narratives exist before experience and help give structure to experience.

Mattingly has an entire chapter named "The self in narrative suspense: therapeutic plots and life stories" (1988:104-128). She contrasts the meaning of life with uncertainty of life and indicates how life plots and therapeutic plots are irrevocably intertwined.

She reviews the history of the self in anthropology, citing Mauss, Carrithers, Csordas, and others. Admitting that this is beyond the scope of her book, she summarizes the difficulties anthropologists have had with the concept of self, "the internal private self and a culturally constructed, socially governed public persona" (Mattingly 1998:105). Unfortunately, she confounds the term *self* with *person*, and discusses the perplexity of the topic, perhaps reflective of the confusion within the discipline of anthropology itself:

And a dualistic self is provided narrative with confused and even paradoxical place in anthropological thought. Sometimes narrative is linked to publicly knowable self, a cultural of scripted person who could be distinguished from a private, inaccessible inner self. But scholars have also recently turned personal narrative to explore informants sense of self as this relates to, or contrasts with culturally shared meanings. Anthropologists have been drawn to the study of the self as characterized by emotions, personal histories, unique experiences, private ruminations, tacit knowledge, even the unsaid. Here, narrative emerges as a vehicle for exploring just that inner experienced self Geertz (and many others) have declared out of bounds to the anthropologist. [Mattingly 1998:105]

Unfortunately, Mattingly repeats the mistake of confounding “self” with “person,” as demonstrated by her word choice. Again, for the purposes of this research I assert they are theoretically different. For the purposes of clarity, I contend that it is the *person* who participates in a ritual, but it is the *self* that is healed.

Mattingly writes:

On the one hand narrative is elevated to the very thing which guarantees us the ability to have a self, at least in the sense of something we perceived as a unified and whole. On the other, it turns out to be a kind of trickster, a rhetorical ploy by which we disguise the genuine nature of ourselves – as splintered and discontinuous. [1998:105-106]

She goes on to state:

For if narrative helps make an inner phenomenological self coherent, this suggests that there exists a pre-narrated self which is, in its primal state not coherent. This inner self as something experienced is very often depicted as fractured,... The coherent self emerges conceptually as an “illusion,” a “fiction” which is part of our Western ideology but is not borne out in the individual experience. [Mattingly 1998:106]

I find a logical flaw in this statement. Previous theorists have portrayed the self as emergent, making the pre-narrated self latent, not inchoate. Mattingly reviews all the previous arguments and eventually resorts to philosophy. She summarizes by saying that narrative is often perceived as the prime strategy by which the meaning of life-altering ailment – in the meaning of a life – is created. She acknowledges that narrative deals with breaches of cultural convention,

(another example of disruption, which I refer to as the existential threat to the self by disease and death). She goes on to state:

Throughout this book, I have tried to complicate or challenge anthropological assumptions which turn on a strict dichotomy between experience as narrated and experience as lived. I have also suggested that coherence is not, perhaps, the most significant thing narrative offers to the afflicted or their healers. In my studies of clinical work, *I have found that the drive to create a compelling therapeutic plot has less to do with need to find continuity or coherence than with a need to locate desire.*[Mattingly 1998:107, emphasis added]

The location of desire as discussed when I reviewed emotions as socially engaged cognitions becomes an even more important portion of the narrative schema in light of this statement by Mattingly. By very different intellectual paths, narrative, experience, self and desire are all part of healing. Mattingly summarizes:

Looking for the motive does not mean climbing into someone's head so much as scanning the scene to see what the actor could possibly have been up to in doing what he did. Put differently, the search for motive required just to name an action demands more than a simple assessment of individual intentions; it requires placing what others do in a plausible narrative frame. Intentions are only intelligible within the situational cultural context, that is the narrative context. To understand and act in its motivational fullness, one must have some hints about the situation which concerned in which it occurred. [Mattingly 1998:109]

This summary by Mattingly could have been authored by Tomasello, as it contains exactly the same argument. Mattingly argues strongly for narrative as experienced and therapeutic emplotment as experience (1998:119). Mattingly states, “The ability to connect events through narrative plot allows the self to be revealed not only in terms of sameness, but in terms of discontinuity, instability and the like” (1998:119)

Mattingly finishes one of her analyses with the following: “The action which the stories recount express an exploration of self, provisionally answers the question ‘Who am I?’ among a limited range of historical possibilities” (1998:128).

In conclusion, Mattingly talks about therapeutic plots. She emphasizes the development of desire; drama is heightened when what happens really matters. She talks about imagined endings as necessary to practical action. Essentially she's negotiating the future:

In narrative theory, this unexpectedness allows for the essential element of plot, the reversal. More often than not, the moral of the story concerns things turning out differently than the characters intuited. The 'sense of an ending' which guides the telling of the tale (and its reception) is powerful because it reveals experience as a struggle toward an ending which evades us, or which turns out to hold a different meaning than we had originally cast. Collision between expectations and experience (what, as it turned out, happened) gives narrative course its drama. In narrative terms, I have thought of this as a collision between a prospective story and the story that actually unfolds. If narrative provides a homology to lived experience, it is only because the structure of narrative, like life itself, is built on suspense. [Mattingly 1998:157]

In one of her more powerful statements, Mattingly says, "Rather than seeing occupational therapy as in 'applied science,' it is perhaps better understood as a kind of healing ritual.... Like other healing rituals, therapeutic success depends on the kind of efficacious performance" (1998:161). From a theoretical perspective, I wholeheartedly concur. She then goes on to discuss ritual time as different from narrative time, life as lived, and the association of ritual to transformation, "transformation not only of the body but of the whole self" (Mattingly 1998:161).

Summary of Mattingly's Arguments

To summarize Mattingly's argument, I repeat the following key elements that represent healing rituals as narrative experiences:

- (1) Mattingly says, "The need to narrate the strange experience of illness is part of the derives very human need to be understood by others" (1998:1). I agree and describe the convergence of narratives in ritual as the as the antidote to alienation.

- (2) Mattingly invokes Bruner's term "breach" of the commonplace and acknowledges the resultant liminality that invokes the need to narrate (1988:1). I give more emphasis to this disruption by emphasizing the relationship of disease and death as the ultimate form of alienation.
- (3) Mattingly says, "Therapists and patients not only tell stories, but also create story like structures through their interactions" (1998:2). Although Mattingly refers to this as "therapeutic emplotment," it is an equally good description of what she and I refer to as "ritual."
- (4) Mattingly says, "Narrative has rhetorical powers...a powerful tool for convincing others, one which could become a persuasive tool for convincing others to see the world in a certain way" (1998:5). I highlight persuasion as a component of healing rituals.
- (5) Mattingly highlights the relationship of narrative to experience, a theme that spans all of the theoretical background reviewed (1998:19). I contend that a ritual is experienced, opening the possibility for narration. It is important to recognize from the outset that I deploy "ritual" in the sense that it is a shared experience; I am not emphasizing the condensation of symbolic meaning that ritual studies typically evoke.

Ritual Healing—the model for presenting this research

Although her entire ethnography is based on an exploration of narrative theory, Mattingly portrays the therapist–client interaction as a healing ritual. It is this portrayal of narrative as ritual that becomes foundational to my research. Mattingly joins other anthropologists in understanding the transformative powers of ritual and ritual narrative:

Healers may draw upon narrative to encourage powerful reframings of illness that actively change the sufferer's perception of his own body and personal

experience. In studies of healing rituals, narratives (often cultural myths) are treated as one among a range of multi-media poetic forms that give ritual its perlocutionary power (Tambiah 1985; Leach 1976). Narratives become one medium through which the healer tries to connect a person's individual experience to an ideal or preferred narrative, and healing itself is equated with the rhetorical task of persuading the patient to see her experience in a certain way (Turner 1992). Stories which are located in ritual actions may take on special therapeutic powers; indeed, certain kinds of stories may have their special place as an integral part of a healing ritual. [1998:14]

I use this text to frame my entire argument for my research. Mattingly recognizes and describes such a narratively informed ritual, complete with narrative persuasion to a preferred narrative to produce the therapeutic transformation. This is why I say that Mattingly most closely approximates my model of healing. She incorporates ritual, persuasion to a preferred narrative, and reframing or transformations of the self-story. Her data and interpretation do not emphasize the illness narrative in any substantial way. As we both focus on ritual aspects of healing, the historical illness narrative is not the experience that creates a healing narrative; it is the narrative structure of the therapeutic experience (ritual) on which both Mattingly and I focus our analysis.

She and I differ in a minor area. Mattingly claims, "In my studies of clinical work, *I have found that the drive to create a compelling therapeutic plot has less to do with need to find continuity or coherence than with a need to locate desire*" (1998:107, emphasis added). Mattingly finds that desire as a choice among potential futures, in part a choice generated by the work of the therapist. In my study of clinical work, I locate the desire in the need for a self to avoid disease and death, a premise given us by Rivers (2001 [1924]). With this minor revision, I will present the healing ritual in Western biomedicine.

Of particular interest to me is how this ritual allows the formation of a healing relationship. I contend that the healing relationship is the important outcome, sidestepping the repeated and forceful critique of biomedicine as inattentive to the illness narrative. The premise

of this critique is that attention to the illness narrative is the prerequisite to a healing relationship. My data show otherwise. Throughout the entire theoretical survey, the term *healing relationship* does not appear. The closest approximations are Kleinman's "medical psychotherapy" and Mattingly's "therapeutic emplotments" and "therapeutic interactions." There is much about "social actors," but that references the *person*, not the *self*. It is the relationship of one individual self to another self, as like beings, that forms an authentic relationship (using Kleinman's term). This authentic relationship is the ultimate defense against alienation and, as Tomasello would phrase it, the foundation of culture. I argue that healing rituals foster healing relationships not by attentiveness to the illness narrative but through an experience that has both an antecedent narrative structure and results in an emergent healing narrative. The patient's illness narrative becomes a subplot in the overarching healing narrative.

SECTION 2: METHODOLOGY

Chapter 4: Fieldwork and Data Analysis

This research was an exploration of the clinical encounter using narrative theory as a filter for observation. As discussed in Section 1, narratives involve a self, or selves, interacting with its cultural environment. The goal of the proposed research is to explore and describe the experiences of patients and clinicians and to identify the discursive maneuvers used by each within the context of clinical encounters to achieve a narrative with the socially acceptable explanation of sickness expressed as diagnosis. For this goal I needed a method that would allow me to collect data about doctors and patients interacting in a setting where a story was being created. It is for this reason that the data collection method used most often was participant observation.

The narrative thread was somewhat like a tangled ball of yarn. Upon entering the field, I grabbed the thread and had to follow it along until large sections of the narrative became recognizable. The reporting of data starts with this initial episode of fieldwork. Consistent with the theoretical discussion above, I was surprised by the veritable absence of an illness narrative in the clinical encounter, as I had assumed this would anchor my observations. From that point onward, I had to both understand what the story was about and follow the narrative thread.

Because I was studying discursive maneuvers by both the patient and the doctor, I spent most of my time doing participant observation. During these times, it was easy to insert informal questions or ad hoc questions based on what I had seen. I used interviews primarily for triangulation and validity.

Fieldwork site

I chose the fieldwork site deliberately, based on the study design. The attributes of the setting itself contributed to the observation of data. The discipline of urology has tremendous conflict, diversity of opinion, passionate debate, and a standard of care that is fluctuating. The current practice of urology is not a stable social system, and the areas of disagreement highlight and bring forth key cultural facts in a readily accessible manner. I am referring to the controversy regarding PSA as well as radical robotic prostatectomy, etc.; thus, I expected much discursive work to be done, a rich sampling frame based on my research question.

Another attribute of the fieldwork site was that it involved a postgraduate medical training program and in that way was an example of rapid cycle cultural replication. The first-year resident (postgraduate, year two) enters as the neophyte and through the course of the program emerges as an independent practitioner. From the participant observer's point of view, "training" is a process of socialization into the cultural norms of the practice of urology. The rapid replication of culture in a setting of conflicting standards of practice amplifies the ability to observe cultural facts in the field setting.

Field notes

Because I was observing clinical encounters, it was vital that I not disrupt the actual work of the doctor or interfere with the encounter from the patient's perspective. Learning to collect field notes occurred prior to entry into the field, in methodology classwork, I learned about the process of observation as well as collecting field notes, including use of scratch notes. One of the methodological concerns stressed included detailed descriptions, with the example of *Let us Now Praise Famous Men* by James Agee (Agee and Evans 2001[1939]) as the level of detail to which

I was to aspire. Other standard textbooks provided the didactic background and introduction into the process of collecting field notes (Bernard 2002; Emerson et al. 1995).

I had four extensive opportunities to practice the skills of generating field notes as described below:

While attending Boy Scouts of America summer camp I observed the social interactions of adolescent males both within the context of their own scout troop, which is analogous to a small tribe, and within the context of multiple scout troops interacting in organized activities, such as waterfront races, other competitions, etc. The setting provided a rich opportunity to observe social behaviors at multiple different levels of social organization. I carried a small notebook throughout the day and made scratch notes, which I dictated in private each night I was at the camp. In total, this represented approximately a hundred pages of entextualized double spaced typewritten notes. This exercise was not research, but an educational exercise to learn research methodology.

The second opportunity for an extended period of collecting field notes was at an exclusive luxury community on the shores of Lake Superior. This was a closed community with a fixed number of individuals, approximately one hundred. They had daily meetings for meals, individualized activities throughout the day, and children's activities, and they organized all-community events themed on water recreation. In addition to the members, there was an equal number of hired support staff that did all the cooking, cleaning, baking, mechanical repairs, medical care, activities planning, children's programming, etc. The interaction between these two very distinct but co-existing social groups also provided opportunities for rich field notes. Again, the social dynamics built into the setting was a good learning exercise in which to practice the process of generating field notes.

In both of the above instances, my dissertation advisor reviewed the notes, commented on the style and content, and provided feedback on how to produce quality field notes.

The third opportunity occurred during two separate trips to Israel-Palestine. Again, I collected detailed scratch notes throughout the day as well as extensively took photographs documenting spatial relationships and demarcations that were both physical and social. I collected scratch notes throughout the day, and every single evening I dictated from those scratch notes in a manner similar to that described above. These were travelogues, a precursor to anthropological methodology.

The fourth opportunity to practice collecting field notes was during methodology class, within the context of an ethnographic research project, with a research question and required IRB approval. This class assignment was for Anthropology 7100. The field setting for that project was the similar to the current research project in that it was a hospital setting and I was observing social processes related to my own professional experience. Those field notes were extensively coded with Atlas ti v6.2 and, together with interviews, were analyzed based on midrange theory forming a completed a research project.

Because I had the previous experience and practice writing field notes, that skill set was in place as I entered the field for this research project. For making scratch notes, I used Moleskin[®] notebooks that were 3.5 x 5.5 inches with 64 plain pages per notebook. The size allowed me to keep it comfortably in the palm of my hand while observing, as well as to store the notebook in almost any pocket. This was more optimal than obvious data collection tools (such as an iPad[®]) that would stick out as foreign to the field setting.

For every observation session, I dictated the scratch notes almost immediately after the observation, most often in the parking lot nearest to the field site; this provided privacy and

freedom from interruption and allowed me to capture the experience in almost real time. Dictating immediately after observation also allowed short-term memory to augment the scratch notes while contextualizing the observations. I used an Olympus Digital voice recorder (DM-420) for dictating. I was careful to dictate field notes that were observational in nature with as much detail as possible as indicated above. I recorded dialogue and verbal quotations to the extent possible. Once dictated, the observations were preserved and eventually transcribed by Dragon NaturallySpeaking 11[®]. Using the transcription software there were minor errors, but they did not interfere with understanding because they were all phonetic in nature; I was able to reconstitute the words with ease.

Occasionally, I observed something, that I as the ethnographer had an opinion about what that event meant. I was diligent to segregate my opinions in the notes with the heading "observer's reflection" so that the actual observations were not conflated with my internal thoughts that occurred during the period of observation. On rare occasions when I had a strong emotional reaction, that was also recorded in the segregated notation.

When beginning this research, I met monthly with my advisor for advice, feedback, and progress review. During these mentoring sessions, I received what seemed to be contradictory advice of "Record specific details, or a year or two from now you won't have anything worthy of being analyzed" and "Just try to get the big picture about what is going on." Dealing with this confusion is part of the ethnographic process. In one attempt to record specific details, I recorded an Agee-esque description of the contents of a garbage can, thinking that a midden must certainly contain cultural information; the description of the midden turned out to be completely irrelevant information. The answer came through: "Get the big picture." Although I was recording detailed descriptions in my field notes, the descriptions were repeatedly of the same

thing: I was looking at computers here and there and people interacting with computers, etc. Computers were omnipresent in the field site. This led to the ethnographic lens of looking more closely at questions like “Who was looking at the computers?” and “What were they doing when looking at the computers?” and “What part of patient care was the computer necessary for?” Originally, I focused on how providers recorded the patients’ narrative in the computer, but soon recognized there was so much more data that I began to use “the computer” as an ethnographic lens and followed that perception as a line of inquiry throughout the study. Harry Wolcott describes that process as follows: “In the very act of constructing data out of experience, the qualitative researcher singles out some things as worthy of note and relegates other to the background” (1994:13). Like re-discovering the wheel, I learned how to merge the contradiction of “detail” and “big picture.” What followed was a cycle of details and bigger pictures that repeated itself throughout the study.

Recording conversational data

Because I was trying to identify the discursive maneuvers in a clinical encounter, my scratch notes recorded the speaker sequence, the word choice, and the conversational content by rapidly beginning each speaker with only the opening quotation marks and skipping to the next line when a new speaker started or indicating the speaker with one initial of their codename. As mentioned above, I dictated these conversations almost immediately when I still had an intact short-term memory of the conversation, allowing me to include most of the detail. I occasionally missed a portion of a conversation, but incomplete notations were not included in the results. In this way, I was able to reconstruct large segments of conversation without being overly intrusive and using an audio recording device. Because the observational data is dialogue of natural

speech by the participants, it contains a fair amount of medical jargon. I provide footnotes to translate Medicaese into discipline-specific English. Because language reflects cultural categories, I needed to mentally code-switch as I looked for the data that would answer my research question.

Brian's story

I first observed "Brian" during an office visit in the urology clinic. Later I conducted two ethnographic interviews--one shortly after the visit and again three months later. (Kvale 1996; Spradley 1979). "Brian's story" is a seamless melding of two informants to achieve a ten-year perspective. Both informants were engineers, both related their experiences in a nearly identical way, and neither added substantially to what the other said. One emphasized early experiences, and the other contributed reflective comments ten years after initial presentation. Because the research data was collected within a two-year time frame, the stories were combined to portray personal experiences over the full spectrum of a decade. I chose these two informants because of the nearly identical presentation of data. Together, they can be considered the illness story to accompany my predominantly observational data set. Other ethnographic interviews with patients related stories of kidney cancer or were sparse and unrevealing regarding the totality of personal experience. Combining two informants is obviously a narrative device to create coherence in reporting the results. During the ethnographic interviews, the opening utterances were written as a list on a piece of paper and sequentially I asked for clarification of each item on the list, resulting in a virtual monologue. The transcription was verbatim. I chose to retain the sentence fragments, incomplete thoughts, repetitions, and meandering nature of the spoken word as it was entextualized.

I deployed “Brian’s story” in segments to introduce the structure of the observational data from a first person retrospective re-telling of an illness narrative that happens to validate my completely different type of data collected observationally and contemporaneously during the clinical encounter. To clarify this contrast for the reader, I segmented “Brian’s story” into shaded text boxes later in this paper.

Timeline for fieldwork

Although the intellectual basis for the research spanned years, the artificial timeframe, truncated by being “in the field,” occurred from February 22, 2011 until August 31, 2012. As part of collecting field notes, there was the concurrent experience of reflection and pondering both what I observed and what the meaning of what I observed was. Typically, I would take a two-mile walk, lasting about 90 minutes, and simply let my thoughts flow over the experiences of fieldwork. Sometimes I could not help myself: the excitement and adrenaline rush of the experience was exhilarating. This dedicated reflection time occurred in equal measure to the time I actually spent at the field sites. It was during these times that I would formulate the ongoing hypotheses that I would then go back and trace the detail trail or the narrative thread that started with the big picture, or frame of the study.

The fieldwork site and the metaphor of “the village”

As mentioned above, I met monthly with my dissertation advisor to plan and monitor my fieldwork. We quickly established a metaphor of “the village” as the fieldwork site. I was encouraged to stay in one clinical setting, an office-based practice, until I had a clear grasp of the research setting and structure of the observational data. The rest of “the village” was easily

identified because it was a renowned cancer institution with excellent branding, color-coding, and multiple alternative sites for the doctors at the clinical practice at which I started.

Using the metaphor of “the village,” I was fortunate that the index site (Maple Grove Clinic—an outpatient urology office) incorporated the workplace of both the “chief” and the “medicine man”; namely, the chairperson of the department of urology and the residency program director both used the index site as part of their clinical practice.

The methodological purpose of spending enough time at the index site was to form hypotheses so that subsequently, when I went to other portions of “the village,” I could try to confirm observations made earlier. This confirmation of the same ethnographic data in a different location with other people was a form of validity for this study. I was able to confirm the observations in every other site of “the village.” The process of taking field notes described above included enough detail that I was able to not only confirm observations going forward in time, but I was also able to look back at earlier field notes and confirm observations retrospectively that were not appreciated at the time of data collection. Again, the process of understanding the cultural information was cumulative, and I confirmed observations in both an ante-grade fashion and a retrograde fashion, a marker of validity. Other areas in “the village” included:

- (1) Maplewood Hospital, the community hospital where the index practice group operated and the residency physicians trained, which was across the street from the index site,
- (2) The operating room in the large urban university hospital where the Connaught Cancer Institute rented operating room space,
- (3) A remodeled floor of the nearby hospital specifically designed for the Connaught Cancer Institute where I made rounds with the urology team and the oncology team,

- (4) The uro-gynecology clinic at the main clinic at Connaught Cancer Institute,
- (5) The auditorium and administrative building where the multidisciplinary care conference (MCC) met,
- (6) The central offices for the urology residency downtown,
- (7) The radiation oncology center in the hospital complex downtown,
- (8) The chemotherapy suites connected to the uro-gynecological oncology clinic,
- (9) The radiation oncology center which was at a satellite clinic of Connaught Cancer Institute,
- (10) The once yearly national endowed memorial conference sponsored by the urology department, and
- (11) A urology office in the nearby academic practice building.

After starting at the index site, I sequentially added these new sites while maintaining contact with the index site and concluding by completing some of the final observations at the index site itself. It was a complete urological experience from multiple different perspectives. At each site, I had to ask permission and gain access. In terms of "exploring the village," I reached saturation having visited every place on multiple occasions.

Visits to the fieldwork site occurred approximately twice-weekly, every week, or every other week. There was never an extended gap or lack of contact with the fieldwork site. If I was away for an extended period of time, I would stop in and say hello, just to let the people I was working with know that I was still thinking about them. Likewise, if I changed locations, I notified participants where I was and when I would return. The amount of time spent at a site was typically four hours or one-half of a workday, although many observations were from 12 to

14 hours, particularly when the fieldwork site was in the hospital. Fieldwork site and data description is provided in Table 1.

Table 1. Date, location / person, and type of data collected

Date	location / person	type of data
March 4, 2011	administrator	ethnographic interview
March 4, 2011	Worthy Clinic lobby	participant observation
April 15, 2011	administrator	ethnographic interview
May 18, 2011	urology outpatient clinic	participant observation
May 23, 2011	urology outpatient clinic	participant observation
June 1, 2011	administrator	ethnographic interview
June 1, 2012	Maplewood pre-op	participant observation
June 15, 2011	Maplewood inpatient surgical floor	participant observation
June 15, 2011	Maplewood intensive care unit consultation	participant observation
June 15, 2011	urology outpatient clinic	participant observation
June 16, 2011	Maplewood inpatient surgical floor	participant observation
June 16, 2011	Maplewood operating room	participant observation
July 1, 2011	administrator	ethnographic interview
July 20, 2011	urology outpatient clinic	participant observation
July 29, 2011	University residency office	participant observation
August 3, 2011	urology outpatient clinic	participant observation
August 15, 2011	Connaught inpatient-urology	participant observation
August 16, 2011	Connaught inpatient-urology	participant observation
August 16, 2011	University cafeteria with urology residents	participant observation
August 16, 2011	University operating room	participant observation
August 18, 2011	University main campus	participant observation
August 18, 2011	Connaught inpatient – kidney cancer patient	ethnographic interview
September 14, 2011	urology outpatient clinic	participant observation
September 14, 2011	University residency office	participant observation
September 14, 2011	patient – seen for abnormal PSA	ethnographic interview
September 30, 2011	patient – normal prostate biopsy	ethnographic interview
October 14, 2011	national urology conference	participant observation
October 26, 2011	urology outpatient clinic	participant observation
November 17, 2011	urology outpatient clinic	participant observation
December 16, 2011	multi-disciplinary care conference	participant observation
December 16, 2011	Connaught inpatient-urology	participant observation
December 16, 2011	breakfast diner with urology residents	participant observation
December 16, 2011	University urology clinic`	participant observation
December 19, 2011	Connaught inpatient-urology	participant observation
December 19, 2011	DaVinci robotic operating suite	participant observation
December 20, 2011	Connaught inpatient-urology	participant observation

December 20, 2011	University cafeteria with urology residents	participant observation
December 20, 2011	DaVinci robotic operating suite	participant observation
February 20, 2012	urology outpatient clinic	participant observation
February 29, 2012	urology outpatient clinic	participant observation
March 1, 2012	Connaught inpatient-oncology	participant observation
March 6, 2012	family member of patient	intercept interview
March 13, 2012	Connaught research offices	participant observation
March 14, 2012	Maplewood	participant observation
March 15, 2012	humanism in medicine lecture	participant observation
March 16, 2012	prostate cancer epidemiologist	ethnographic interview
May 2, 2012	multi-disciplinary care conference	participant observation
May 2, 2012	Worthy oncology clinic	participant observation
May 3, 2012	Worthy oncology clinic	participant observation
May 5, 2012	urology outpatient clinic	participant observation
May 16, 2012	University campus – radiation oncology	participant observation
May 23, 2012	prostate cancer patient	ethnographic interview
May 27, 2012	Principal Investigator PLCO	ethnographic interview
May 31, 2012	Connaught satellite clinic – radiation oncology	participant observation
May 31, 2012	prostate biopsy patient	ethnographic interview
June 5, 2012	Connaught satellite clinic – radiation oncology	participant observation
June 5, 2012	lung cancer patient – radiation oncology	ethnographic interview
June 6, 2012	Connaught	participant observation
June 6, 2012	two physicians, one administrator	intercept interview
June 27, 2012	urology outpatient clinic	participant observation
July 18, 2012	prostate cancer patient – radiation treatment	ethnographic interview

Anonymity and Confidentiality

Scratch notes recorded only codenames. Site locations were not recorded other than by memory. The only risk of breach of confidentiality was signatures on informed consents, which were kept locked and separated physically from work or fieldwork sites. Pseudonyms are used throughout the research manuscript for people and places.

List of codenamed participants

- Albert Stein, M.D., Chair of the department of urology, specializing in uro-oncology surgery

- Thomas Jeffries, M.D., Urology Residency program Director, specializing in robotic surgery
- Jarinder Patel, M.D., faculty specializing in urological plastic surgery
- George Stephens, M.D., new faculty, just finished robotic fellowship
- Carmen Rodriguez, C.M.A., works primarily at the Maplegrove office with Dr. Jeffries
- Marsha Miller, C.M.A, works primarily with Drs. Stein and Patel at Maplegrove office
- Barbara (Barb) Pawlaski, C.M.A, works primarily with scheduling at Maplegrove office
- Suzanne Vermalapalli, M.D., uro-gynecology, works at Worthy Clinic downtown, always referred to simply as “Dr. V”
- Heather Spangler, M.D., uro-gynonology, works at Worthy Clinic downtown
- Kenneth Q. Powers, M.D., professor of urology, works at University settings
- John O. Bridge, M.D., professor of urology, works at University settings
- Amber Sparks, C.M.A, medical assistant to Dr. Spangler
- Jane Awesome, R.N., works with Dr. Spangler
- Jason Rivers, M.D., radiation oncologist, works at Worthy Clinic as well as at a satellite clinic equipped for radiation oncology
- Andrew Fields, M.D., first year urology resident
- Charles Williamson, M.D., first year urology resident
- Seth Smith, M.D., senior urology resident
- Petyr Solski, M.D., junior urology resident
- John P. Wright, M.D., senior urology resident
- Rajiv Pinder, M.D. chief resident, urology
- Cheryl Johnson, M.D., chief resident, urology

Anthropologist as measurement device

This fieldwork experience highlighted the issue of positionality. As described below, I became aware of it as problematic in the fieldwork site on a specific day. However, looking back, it was present from before I even entered the field site and I had discussed it with my advisor before entering the field. While trying to gain access to the field I had spoken to Dr. Jeffries. He agreed to write a letter introducing me to the department of urology. He asked me to draft the letter and he would put it on letterhead and send it out. While writing the draft letter I took great pains to avoid mention of my medical credentials and to have it only introduce me as an anthropologist. When comparing my draft to what he wrote it became readily apparent to me that he changed what I had written and that he was introducing me as a physician in order for me to gain entrance to the field. (Figure 1 and Figure 2) Only near the end of my fieldwork did Dr. Stein tell me that the only reason he agreed to allow me to observe his clinical encounters was because Dr. Jeffries asked him to by sending out that letter.

Figure 1. Draft letter I wrote for entry to the field

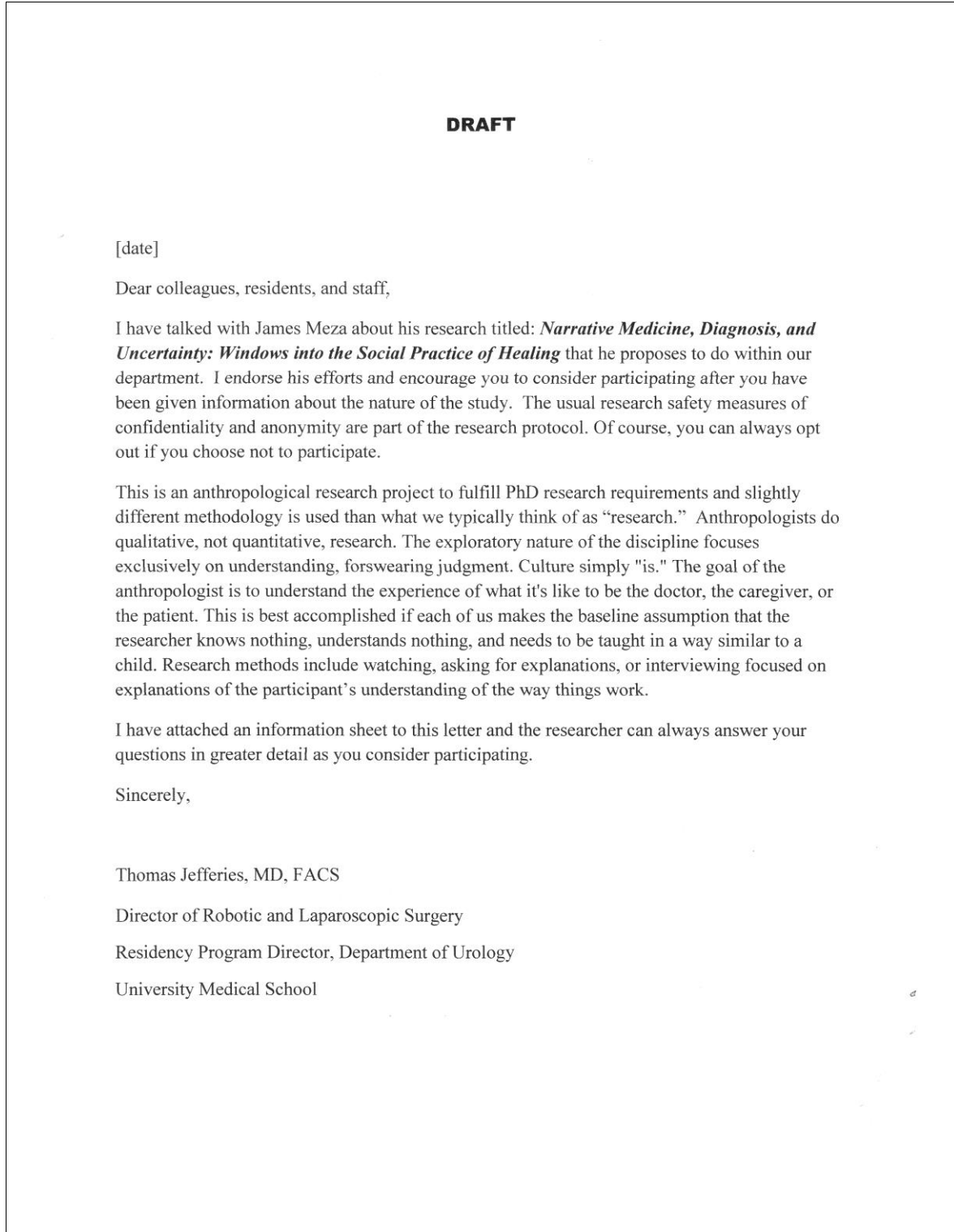



Figure 2. Letter that was sent for entry to the field



Department of Urology
 University Center, 3 C
 5632 St. Anthony
 Somewhere, XI, 550
 Phone: (555) 567-5555
 Fax: (555) 567-5555

January 13, 2011

Faculty

Albert I. Stein, M.D.
*Professor and Chair
 Thankful Patrons
 Endowed Professor
 of Urology*

Darinder Navi, M.D.
Assistant Professor

John O. Bridge, M.D.
Professor

Kenneth Q. Powers, M.D.
Professor

George Reinhardt, M.D.
Professor (Full-time Affiliate)

Jarinda Patel, M.D.
Associate Professor

Thomas Jeffries, M.D.
Assistant Professor

Administration

Jennifer Goest, M.H.A.
Sr. Practice Administrator

Research Faculty

Beebe Simmer,
 M.P.H., Ph.D.
Assistant Professor

Barbara Katz, Ph.D.
Assistant Professor

Bonnie Sikkle, Ph.D.
Associate Professor

Serena Chamomile, Ph.D.
Assistant Professor


Dear colleagues, residents, and staff,

James Meza, Assistant Professor, Deptmt of Family Medicine and Public Health has proposed doing a research project within our department titled: *Narrative Medicine, Diagnosis, and Uncertainty: Windows into the Social Practice of Healing.*

This is an anthropological research project to fulfill PhD research requirements and slightly different methodology is used than what we typically think of as "research." Anthropologists do qualitative, not quantitative, research. The exploratory nature of the discipline focuses exclusively on understanding. Culture simply "is." The goal of the anthropologist is to understand the experience of what it's like to be the doctor, the caregiver, or the patient. This is best accomplished if each of us makes the baseline assumption that the researcher knows nothing, understands nothing, and needs to be taught in a way similar to a child. Research methods include watching, asking for explanations, or interviewing focused on explanations of the participant's understanding of the way things work.

I endorse his efforts and encourage you to consider participating after you have been given information about the nature of the study. The usual research safety measures of confidentiality and anonymity are part of the research protocol. I have attached an information sheet to this letter and the researcher can always answer your questions in greater detail as you consider participating.

Sincerely,



Thomas Jeffries, MD, FACS
 Director of Robotic and Laparoscopic Surgery
 Residency Program Director, Department of Urology
 University School of Medicine

Throughout the course of the fieldwork, I became more and more vigilant regarding my position as a social actor and how that affected the research. As I worked with my informants in the fieldwork site, I was also working with my own positionality and the lens through which I was observing. There are many references to the researcher as measurement instrument in qualitative textbooks. In my case, both my theoretical perspective and my social position as they related to the fieldwork site affected collecting data and interpreting observations. Again, this was an ongoing process.

All anthropologists have to deal with the issue of objectivity in observations, being highly aware of the frame of reference with which they collected data. The ultimate protection for validity of the observations is for the ethnographer to be self-aware and highly self-reflective during the process of data collection. It is more difficult to function as an anthropologist in “one's own culture.” It is much easier to compare the *other* to the culture of origin while studying an unfamiliar culture. Prior to fieldwork, I spent several years studying theoretical perspectives. I learned that theory determines the type of questions that can be asked, the method for collecting the data specific to answer those questions, as well as guiding analysis of the data. Filtering observations through a theoretical lens keeps the observations focused on the research question, limiting personal filters.

My first fieldwork experience made me highly aware of how much positionality influenced the performative aspects of the participants. My informants treated me as a medical student, a family medicine physician learning urology, a Ph.D. student, an interloper or voyeur, a pet, an uninitiated observer, or the object of teasing. For the purposes of validity, I was constantly mindful of situations when I was in a position of having assumed knowledge. Fortunately, this was rare. I was usually ignored, remediated, teased, taught, or given gifts of

insight. I was diligent about reinforcing the non-evaluative nature of anthropology as a social science. I am thankful for the participants allowing me access and establishing rapport sufficient to acquire the data. Rarely was I excluded; the only two occasions I recall were a VIP patient and a matter of litigation. I helped in the daily tasks consistent with my novice level of experience. (On one occasion, I drove around town to retrieve a cell phone so that the clinic could stay on schedule.)

The medical assistants were extremely diligent about giving the patient information sheets and asking permission for me to observe. They struggled with my various different roles as student, student doctor, observer, researcher or learner, as well as physician. They would often say, "He is a doctor but that's not why he's here." Other methods of identification, including how I was labeled with badges I wore, the business card in a translucent pocket identifying me as a Ph.D. candidate from the department of anthropology, the visible Connaught identification badge, as well as a Maplewood identification badge at certain times when appropriate. The information sheet was always available to the patient prior to meeting me and sometimes the patients would comment or direct my activities when I was in the exam room. At one point, I was in an exam room with a resident physician and the patient asked if we were doctors in training. Knowing how difficult it would be to explain everyone's specific role, I merely said, "Yes, but we're training to be different types of doctors." At other times, patients would be saying and doing things directly for my benefit and interacting with me. For the most part I remained silent and in the corner trying as much as possible to be a wallflower and allowing the clinical visit to proceed as if I wasn't there.

When in social areas not directly related to patient care, the medical assistants were extremely friendly and we all engaged in chitchat. At certain intervals, I would provide lunch

simply to give an opportunity to socialize. This allowed for data collection in a very informal manner because we were essentially breaking bread together. When I was with the resident physicians, I was at about the level of the medical student in terms of hierarchy. There were many times the residents were not directly supervised by someone higher in the hierarchy, and at those times I felt a strong degree of affinity towards them, a sense of belonging. This also extended to the urology outpatient office. When I was absent more than a couple of weeks, I would miss being there and would make a point to stop by simply to say hello. These episodes occurred when I was in the other field site locations. In the presence of attending physicians, I was treated like they treated the residents, tolerated and guided as a learner. Throughout the entire data collection, I maintained contact with that initial site.

All of the medical personnel and support staff were highly aware that I was there and often used the word “spying” or say “He’s writing this down.” At the time I was probably overly sensitive but said or did nothing about it, and in retrospect I now realize that it was simply a way to incorporate me as part of the team, as I had no other specified role. When they persisted, I would respond that it was simply data, my standard response when I felt the need to reassure the participants.

Consider the following vignette regarding my positionality:

We were talking in the hallway and I was thanking him for his participation and he pointed and touched my Connaught badge and asked me if that was a joke that I was an M.D. I said, “No. I’m a family medicine physician.”

He then said, “I’m sorry,” and went on to apologize for I don’t know what, but I imagined not giving me respect or whatever it in front of the patients. He then continued to joke and tease me, saying, “Between me and the nurse, we have a sociology degree and a psychology degree, so you can’t fool us – We’re a tough crowd.”

Language best illustrates the issue of positionality. Usually an anthropologist learns a language to learn the cultural categories that are relevant in that culture. In this case I was fluent in Medicaese, but when I tried to explain the research project to Dr. Stein he would shoo me away saying he didn't understand anything I was saying. I told him I didn't know how to translate AnthroSpeak into Medicaese. I recorded scratch notes directly from speech events I observed. Only on one occasion did I take scratch notes with code-switching because I could not keep up with direct quotations.

Practicing self-reflection, I frequently reviewed how the experience of gathering data was changing me. On one occasion, I realize that I changed my own clinical practice with regard to conversations I had with patients when I was in the role of physician. This specifically went along the lines, "In prior years I would caution patients against getting a PSA, however if you feel strongly, I now know of a group of urologists I trust not to overreact to a single number."

In general I was very disciplined in both my behavior and my thinking, recording the data and reflecting on what I was seeing, taking care to identify which theoretical lens I was using at any given time. Only at one point did I somewhat break character:

I told Dr. Jeffries, "I shouldn't do this, but even without seeing the patient and only listening to you, I can almost diagnose her using the DSM-IV R. [psychiatric manual]. From a doctor to another doctor, you need to set boundaries, limit the patient's time, and if she's offended she'll go somewhere else and just consider you to be a jerk. She probably has an Axis II diagnosis,"¹ and he agreed to that. After this brief interlude I said, "I'm going to have to try and go back and be a scientist now," signaling that I was going back into observation mode.

As evidence that I was able to achieve the multiple perspectives of both the doctor and the anthropologist, consider the following experience. I had been in the field for a year and began sharing the initial findings with the funding agency, members in my field site, colleagues, friends

¹ Axis II is part of a formal psychiatric diagnosis. It is not a disorder of the emotions and not a disorder of thinking—it is a personality disorder.

and described details about how Michel Foucault's "clinical gaze" is a three-dimensional cognition. I explained this all as if it was a profound discovery. For me it was extremely exciting finding of my fieldwork as an anthropologist. It was not until almost the conclusion of fieldwork, and at least six to nine months after I had sufficient data to begin sharing this concept with others, that I had my "Aha!" moment and realized I had discovered in my field site that which I myself have done hundreds of times in clinical practice. I also used computer or CT² scan images and MRIs³ in the same manner that I described in my fieldwork with my own patients in the office. The fact that I was unable to see it in my own behavior until after I had stepped out of the medical culture in which I function and look at it from an anthropological perspective demonstrates how I was unable to see my own culture of origin but able to see the culture being studied. This is consistent with my experience from fieldwork done in Anthropology coursework. In both situations, I embody both the emic and etic perspectives, both of which are part of the anthropological enterprise. In this particular case, I needed to explain myself to myself instead of explaining an exotic culture to my own cultural milieu. The methodological importance of being able to recognize this helps with the validity of the study. This will become important as I later discuss Arthur Kleinman's "Illness Narratives."

One advantage I had was life experience with positionality. I have a master's degree in (Healthcare) Administration. I had to learn how to perceive identical medical episodes through the lens of an accountant, a lawyer, a human services manager, a systems analyst, and a business

² An acronym for Computed Tomography. A tomogram is a slice, in this case, a slice of the body as reconstituted with a computer using X-Ray data. Synonymous with CAT scan, computer axial tomography.

³ An acronym for Magnetic Resonance Imaging. This uses the electrical valence of electrons in the body and disrupts them with an extremely powerful magnet. When the magnet is disengaged, the electrons snap back into place and generate small amounts of radiation that "resonates" and therefore measurable. This also generates a tomographic image, generally of higher quality than the CT.

researcher. I vividly recall the same wonderment upon initial realization of how others view the world. The same was true of anthropology for me.

Analysis

The field notes and interviews resulted in a large body of textual data. All documents were included in the hermeneutic unit of Atlas ti v6.2. I sorted and explored textual data using Atlas ti v6.2. The utility of doing this was to reduce the data set. The illustrations of each code include at least one example used later in the results section, but I sometimes included multiple examples to give a sense of the size of the original dataset from which this analysis was derived.

I learned to put the key variables of the research proposal in the title. The title of the American Academy of Family Physicians Foundation grant was “Narrative Medicine, Diagnosis, and Uncertainty: Windows into the Social Practice of Healing.” It is therefore natural that parsing the title of the AAFP-F grant resulted in the first group of codes, as the variables and coding scheme share a direct relationship. The only alteration was substituting “Narrative Schema” for “Narrative Medicine.” Narrative Medicine has a wide readership in medicine, but based on the theoretical outline I converted it to “Narrative Schema” to situate it more solidly within the anthropological framework. The other codes are used verbatim.

Narrative Schema (N=97) — Source of story components; from whom or from where. Also the construction of the story, including antecedent cultural categories used to create a narrative for the self, cultural, or social “body.”

Dr. Spangler was dictating while she was looking at the previous notes so she was reading the notes and dictating relevant sections back into the computer. She was using this primarily to get the history right and then flipped to the vital signs sheet which was recorded on paper that was generated during office visit and then flipped to the labs and began reading the labs from

computerized lab displayed back into her office visit note for that particular day.

Diagnosis (N=175) – A mutually agreed upon label for explanation of distressing symptoms; an explanatory category.

The wife and the eldest daughter both had legal pads and were taking notes. Throughout the entire interview the patient spoke initially giving the details of dates and a diagnostic studies and scans. He actually had a parallel record typewritten in the folder that said Connaught on the cover. He was able to pull dates, results of tests out and specific treatments throughout the entire interview.

Uncertainty (N=65) — Unknown, not quantifiable.

I don't want him to have to, have to sit here and tell me all kind of jokes. No, that's what I want from you, I just want you to sit down and explain everything very, very logically. Not logically; very, very easily, so I understand all these words you're using. Because if you're using some words I don't know- I can remember when my son was studying for his, one of his tests, and I was asking him questions, but I don't know what I was asking him. You know, so that's what I'm talking about. I want somebody to tell me, so I know what I'm talking about.

In addition to coordinating care, this venue is a place where doctors can share their uncertainty, the uncertainty that is never part of the pronounced diagnosis.

Social Practice (N=186) — The cultural body; descriptions of who, what, where, when, and why of observed behaviors.

Most of the medical personnel labeled with badges indicating their specialty, hospital affiliation, medical school affiliation, etc. the entire labeling system for personnel is quite complex.

If a patient was to have a biopsy during clinic hours, Carmen and Dr. Jeffries could complete an entire biopsy routine wordlessly. Each anticipated the movements of the other and they coordinated the many different sequences flawlessly and efficiently. Carmen and Dr. Jeffries worked silently, not even looking in the same direction at the same time, but each completing what the other was doing. Dr. Jeffries would point to the ultrasound screen, and Carmen would move the rollerball, making exact measurements of the size of

the prostate. During the punch biopsy, the tissue specimens were collected and labeled efficiently.⁴ Both gave instructions to the patient at different times without any duplication of effort.

Healing (N=80) — A hypothesis code; an exploratory code to identify social practices related to the topic of interest.

The patient was very pleased. Dr. Rivers gave him a very positive prognosis and told him based on the first 10 months of follow-up he doesn't expect to have any problems and he thinks will be just fine. They ended the visit with a very firm handshake and smiles all around the room. The patient left.

I had written in my scratch notes next to Dr. Smith's name: "tender caring bedside manner." I showed him what I had written and he replied, "That extra 30 seconds to a minute makes a big difference, even if you just listen. Sometimes it works, and sometimes it doesn't. You can tell the patients like it. Like the patient with the small bowel obstruction. Sometimes I go up there in the afternoon when I have nothing to do and spend five minutes just talking, but not necessarily about his medical condition. I think it helps the patient to talk to the doctor about things other than what's going on; otherwise, you don't know anything about him and nothing about the context of the patient's illness. I think it makes it better."

Codes derived from mid-range theory described in SECTION I or derived from other anthropological texts on narrative:

Disruption (N=91) — Deviation from a cultural lifecourse at any level or of any type resulting in distress. I derived this code from anthropological exploration of social narratives, which were included in the data collection. I use the heuristic of ritual to organize the manuscript, which explains why all the data seems to relate to ritual. From that perspective, I selected *disruption* as a proxy for existential threats in the presentation of the data.

I was mostly concerned with ending up with a diaper. I've seen too many men my age at my complex who are either having to wear a diaper or they're dribbling or one problem after another. And I just was really concerned with that. Dr. Rivers said, "Well, what about your sex life?" I said, "At 77 years of age, I don't have a sex life." And that is hardly a thing that is important to me. What is important is the quality of life not having to wear a diaper. So I went

⁴ A punch biopsy uses a hollow needle which is thrust into the organ to yield a core of tissue that is removed for microscopic examination.

through the procedures there; I can't remember whether it was 29 or 32 days of radiation every day.

Dr. Jeffries referred to the genital area as “dog meat” when he was showing the residents the extent of the injury. The anatomy is not even recognizable to the surgeon and the “repair” required to address the existential threat was to create an alternative urinary system with the suprapubic catheter and urine collection bag that replaced the urethra and bladder during this time of bodily disruption.

Emotion (N=106) — A socially engaged cognition. Used in the way described by Keith McNeal.

I did tell Dr. Stein that he no longer scares me and Marsha said yes Dr. Stein can be quite intimidating when you first meet him. He then said something and Marsha turned around and looked at me and said, “There's hierarchy in action.”

Dr. Jeffries did return and talk a little bit more about scheduling. Dr. Jeffries brought up the issue of scheduling and said, “There is no rush for surgery. You won't have any more difficulty functioning than you are now, actually less because the two weeks more of healing time.” The issue of billing came up again and Dr. Jeffries reassured him again, at which time the patient became tearful.

Space (N=66) — Cognitive apprehensions of the world; Kantian argument of reality. This is consistent with Tomasello who states, “All mammals live in basically the same sensory-motor world of permanent objects arrayed in a representational space” (1999:16).

There's a window to the radiation room that could be seen on the computers in the control room. There's also an intercom and double video screens you can watch the patient from two different angles and talk to the patient. In the control room, as I said, up in the top left were double videos so you can always watch was going on inside. Then there were five flat-panel computer screens all lined up. The one on the far left had three fields displayed. The middle one was ticking as the dose was administered. The next one had the outline of the perimeter plan.

Dr. Stein said to the patient, “We looked at the CT scan. The kidney is this big,” he indicated by showing the size with his hands. “We can show you [on the computer screen].” But then he started drawing it and said, “This is the

shape of your kidney, and down here there's a solid mass. Usually this is kidney cancer, and the treatment is surgical removal. If there's no spread, you can consider this a cure.”

Persuasion (N=59) — Rhetorical powers, as defined by Mattingly. (1988:5)

Also during that visit Dr. Priest said specifically, “Here's the story. We checked with the emergency department and they took the sample out of the bag,” indicating the bag attached to this suprapubic.⁵ He said, “That's always contaminated. They might as well take it and swab the floor and then send that for culture.” He did this entire thing, demonstrated by putting his index finger in his mouth, dragging his index finger just above the floor surface, and making the motion of putting it into a container and sending off. He said, “If any doctors or primary contact care doctors wanted to bitch, then just drop my name and tell them they should contact me.” The patient's daughter said thank you.

Dr. Stein then asked the patient to come out from the exam room and brought them over the computer and pointed to the kidney stone on the CT scan and said to the patient, “This is where the kidney stone is, right between the bladder and prostate.

Clinical Gaze—As defined by Foucault (1973; 1994).

Dr. Fields then said that he has had the experience of poor quality CT scans with Hopewell hospital. The presenter said that when he was there they were using a four head CT scanner and of course now they're using a 64 head CT scanner for most things and sometimes a 128 head. They agreed that if there was a question to simply repeat the CT scan with a higher resolution.

Dr. Stein then resumed clinical work by reviewing a CT scan image. He addressed the medical student, “The CT is easiest for me because I have more familiarity with it.” He did look at the cyst on the kidney and said, “That looks benign.^{6,7} It is eccentric⁸ on the left.” As he was changing the slices on the CT image using the rollerball on the mouse, he pointed to and touched the screen, saying, “That is the kidney. There is a stone ... another stone.”

⁵ Shorthand for suprapubic catheter—a tube placed through the skin above the pubic bone and inserted directly into the bladder to drain urine.

⁶ A cyst is a mass that is filled with fluid as opposed to solid; the significance is that cysts are very rarely malignant.

⁷ Benign means not malignant—cancer is only one type of malignancy.

⁸ This word means that the mass is growing outward from the contour of the kidney.

I derived some codes from prior research in similar settings. The prior research was an anthropological research project in a similar setting, involving a teaching medical service in a tertiary care hospital. The following codes were expected components of the fieldwork site and were therefore included in the data collection and analysis.

Computers (N=163) — An essential tool used by health care personnel.

Scanned into the computer were radiation oncology records from China, all written in Chinese. Nobody knew how to read Chinese. Dr. Rivers said they were able to tell what dose to what area, which is the only information they needed. When I looked back, Dr. Rivers was sitting looking at flat panel computer screen with his head leaning in towards the screen so the center of gravity of his head was in front of the center of gravity of his body and his hand was on the mouse. This is a typical stance of any teenager who does gaming, and I've seen it multiple times in my fieldwork. He then went on to e-mail, and is very astute with keyboard, but they were e-mailing back and forth about next steps in planning radiation therapy, etc.

On a different occasion, I walked into the clinic and it was immediately apparent that Carmen and Dr. Jeffries were having trouble accessing clinical data. Dr. Jeffries asked Carmen, "Have we asked if they could print it and fax it, because we can't do a thing until I get them?" The Administrator was talking to someone downtown in administration, simultaneously, in recognition that the difficulty accessing the information would disrupt the entire clinic schedule and cause patient dissatisfaction.

Hierarchy (N=164) — Necessary for functionality; has the potential for abuse of power.

At one point Dr. Jeffries said that that's why he's so smart. He understands all the statistical data. Dr. Stein also pointed out that this particular trial was drug A versus drug B and that there was no placebo arm, so the size effect would be larger if there was. He said in general we believe the study. Dr. Jeffries commented about him being smart. "That's why he's speaking in [foreign country] in front of (the prime minister) of [foreign country]."

Once we were outside the room and back the hallway, Dr. Fields said to Dr. Pinder, "This is the first time in my entire residency that I've been late; it's been 14 months and this is the first time. You showed up two minutes before I did." Dr. Pinder said, "It doesn't matter what time I show up." Dr. Fields replied, "I was hoping you wouldn't chew me out on rounds."

During preparation for fieldwork, my advisor and I decided the following “emergent” codes were methodologically relevant. I discussed positionality separately in the methods, as it is a major threat to validity that I monitored throughout the entire project. The “manuscript” code was applied when the data in the scratch notes used to prepare the fieldwork notes indicated that I recognized seeing an instantiated example of the theoretical framework for the research project and that I was aware that the observation was important enough to be included in the manuscript.

Positionality (N=101) — Recognition of the duality of anthropologist–doctor and its effect on data collection.

I asked what type of patients they saw and Marsha said incontinence, cancer, bladder, renal, kidney, erectile dysfunction, BPH. She then went and gave me a list of diagnoses and highlighted the diagnoses on the billing sheet. Observer’s reflection: I asked the types of patients – it could’ve been little old ladies, kids, or guys with prostate problems, but instead she gave me a list of diagnoses. This is now a recurrent finding: the medical assistants think of the patient’s as diagnoses, the patient’s pick up the language and use the language of diagnoses, and the doctors are using medical diagnoses.

I told Dr. Jeffries, “I shouldn’t do this, but even without seeing the patient and only listening to you, I can almost diagnose her using the DSM-IV R. [psychiatric manual]. From a doctor to another doctor, you need to set boundaries, limit the patient’s time, and if she’s offended she’ll go somewhere else and just consider you to be a jerk. She probably has an Axis II diagnosis,”⁹ and he agreed to that. After this brief interlude I said, “I’m going to have to try and go back and be a scientist now,” signaling that I was going back into observation mode.

Manuscript (N=53) — Moments during fieldwork when event was of such important that it would be included in the dissertation manuscript as significant result.

The patient said directly to Dr. Rivers, “I’d come for you... You know that.” She then turned, looking at me, and said, “I’m speaking for his benefit.” She was referring to me.... There was some talk about our different roles, etc., and then after Dr. Rivers left. She asked me why I wanted to interview her, and I said, “It’s because of that comment you made about him,” how important it was to point out that she would do anything for Dr. Rivers. I said that’s what I

⁹ Axis II is part of a formal psychiatric diagnosis. It is not a disorder of the emotions and not a disorder of thinking—it is a personality disorder.

was interested in and then she said, "He relaxes me. I wasn't relaxed this morning, but now I am. Observer's reflection: Again I'm going to call this the "hug equivalent," because this closeness occurred after all the radiation planning, after the counseling, after the treatment, and the simple follow-up exam. There's obvious affection between the two of them, and the hug equivalent is because I heard it with Dr. Jeffries and I heard it with Dr. Spangler.

Dr. Stein then asked the patient to come out from the exam room and brought them over the computer and pointed to the kidney stone on the CT scan and said to the patient, "This is where the kidney stone is, right between the bladder and prostate.

Analysis Strategy

Each fieldwork experience resulted in a primary document that was included in a single hermeneutic unit in Atlas ti v6.2. I coded the entire hermeneutic unit using the codes described above; I added occasional comments and all future reports included both the original text and comments. Initial review of the data started with generating reports of individual codes to understand the range of content in the data set. I then generated crosstabs queries of paired codes. I reviewed these crosstabs query reports and related data elements were selected from the entire report by using scissors and tape after geographic pile sorting on a large flat surface, 12-by-15-feet. I used Atlas ti v6.2 to organize and manage the large data set; the analysis itself came from reflection throughout the entire fieldwork timeframe and re-filtering the themes through my theoretical perspective to create the argument represented in the results section. The first step of analysis replicated the fieldwork process chronologically and by site visited (location), I sorted the data using the codes described above. The pile sorting of the queries resulted in the key analytic insights presented in Table 2. After re-reading the theoretical framework described in Section I, I chose "ritual" as the organizing structure to convert analytic insights into anthropological insights.

Table 2: Findings after initial sorting of data set

1	The illness narrative is not a component of the diagnosis.
2	The components of a diagnosis narrative are dispersed in time and place.
3	The doctor is actually a team of clinicians and support personnel that manipulate multiple social institutions for the benefit of the patient.
4	The record of the diagnostic narrative resides in the computer network.
5	A cancer diagnosis is a three-dimensional cognition of the doctor.
6	The doctor creates the diagnosis from narrative components and proclaims the presence or absence of disease.
7	Doctors attempt to persuade patients to accept the proclaimed diagnosis.
8	Doctors use their own body to communicate the three-dimensional cognition of a diagnosis.
9	The healing relationship is the result of a shared diagnosis and treatment—not an antecedent.
10	There is a connection between hierarchy—experience—and competence among doctors.
11	Patients are socialized to live within the world of the medical diagnosis and use that social reality to deal with ongoing disruptions in their lives.
12	Patients and doctors hope for a cure with the diagnosis narrative, but even when that is not possible, patients find a need to be in relationship with a doctor.
13	Patients experience disease, or the potential to have disease as an existential threat.
14	The social narrative related to prostate cancer care (as a subset of general healthcare in the United States) has an internal conflict.

I reassembled the spliced textual data into a single digital document using the above themes as the organizing framework. While working with these themes, I recognized the pattern “ritual” that I had not previously appreciated. I then re-read Kleinman’s “Illness Narratives” and Mattingly’s “Healing dramas and clinical plots: the narrative structure of experience.” Unrecognized by me prior to that point, they both recognized the clinical encounter as ritual. This led to my re-examination of the foundational literature on healing rituals. (Fortes 1987; Pritchard 1976; Rivers 2001 [1924]; Turner 1969)

I re-examined my original theoretical grounding for this research project. I wanted to understand the clinical encounter in the way Mattingly described, “the narrative structure of action and experience” (1988:2). Most anthropological literature on healing rituals has a dominant symbolic interpretation. I merged these theoretical concepts as an adaptation of Mattingly, and argue that the clinical encounter is the narrative structure of ritual experience. This has the parsimony of argument that joint attention (to the ritual experience) is a narrative cultural production that both Mattingly and Tomasello could endorse. I use ritual healing merely as a heuristic to present data about narrative and healing. I found support for the foundational descriptions of the healing ritual in the works of others (Dow 1986; Frank and Frank 1991; Milne and Howard 2000; Moerman 1979)

I re-sorted the data using this heuristic and used this reduced dataset to identify illustrations most closely related to the analytic framework of a ritual process. Using Microsoft Word[®] files labeled “drafting table” and “chopping block,” I re-ordered and selected examples to use in the final document, and added commentary to develop the results and analysis. As mentioned earlier, reflection on the data and the meaning of the data occurred simultaneously

with collection of the data, with close attention to theoretical considerations. I considered the data reduction using Atlas ti v6.2 as merely a mechanism to interrogate the dataset for theoretically important illustrations. The textual data presented is a small fraction of the data collected.

Limitations of the Research

I centered my fieldwork on a urologic, surgical practice. The data are limited to that setting and cannot be generalized to primary care. There is a valid critique that the practice incorporated a high volume of cancer care, which would over-emphasize the existential threat aspect of the healing ritual. Although I have no evidence my data can be generalized, my expanded definition of *existential threat* to include diseases that can kill the body or a threat to the narrative body–self in some way anticipate future research in other settings. In some way, my theoretical approach defines healing rituals, which begin when a patient seeks the assistance of a healer. Again, this would require further research to extend my data to other settings. My analysis and discussion needs to be viewed within this limited framework. I speculate on these issues in the last section of the research report.

SECTION III: RESULTS

Overview to Section III

The theoretical lens I will use to present data includes cognitive anthropology and narrative in all of its forms. I begin where Mattingly left off, the consideration of narrative as ritual and her discussion of locating desire. (1988:137) Although she thought it required the active participation of the client and demonstration of motivation to participate, I believe this is a relatively rare occurrence. Using the same basic concept of narrative as ritual, structured by motivation, I will use Rivers' declaration of the universal motivation to enter into healing rituals—fear of disease and death (2001 [1924]:53-54). In this way, I substitute the infrequent, motivated patient in an inpatient spinal cord rehabilitation ward for the commonplace experience of “sickness” and the clinical encounter. I hope to further develop the concepts introduced by Mattingly (1988). I cite Rivers to provide the explanation for “desire” or “motivation” (2001 [1924]), Evans-Pritchard for his detailed description of the oracle as diagnostic tool (1976), Fortes' description of divination in healing rituals (1987), and Turner's description of the healing ritual for the affliction of “*Isoma*” as validation of the components of a healing ritual (1969). There are commonalities in the description of healing rituals, but I give priority to Rivers', because he directly links healing rituals throughout time and around the world directly with Western biomedicine in the form that it is practiced today, as exemplified in the Flexner report on medical education (Flexner 1910). Each chapter will begin with definition of a component of the healing ritual as described by the above anthropologists.

As mentioned earlier, I am using healing ritual because it is observable in action, as it must be performed, not for the symbolic condensation aspect of ritual. I also continue the line of investigation started by Mattingly that healing can be described by the narrative structure of

experience—rituals are experienced. (Mattingly 1988:2) My research does not emphasize the symbolic manipulation embedded in rituals. I focus on ritual as a universally recognized anthropological construct within the boundaries just explained. Others speak to the universality of ritual in human life. Moerman says, “The idea that one person can heal another is widespread, perhaps universal. It is an anthropological commonplace that shamanism, not prostitution, is the first profession.” (1979:59)

James Dow also recognizes the universality of ritual healing, but he is concerned with the common structure that can describe and explain the organization of all forms of symbolic healing regardless of the culture in which healing occurs. He gives us the following:

- (1) The experiences of healers and healed are generalized with culture-specific symbols in cultural myth.
- (2) A suffering patient comes to a healer who persuades the patient that the problem can be defined in terms of the myth.
- (3) The healer attaches the patient’s emotions to transactional symbols particularized from the general myth.
- (4) The healer manipulates the transactional symbols to help the patient transact his or her own emotions. (Dow 1986:56)

For my discussion of biomedicine, the generalized myth is medical science, the definition of the problem is a diagnosis, the healer persuades the sufferer to accept the diagnosis, and the healer manipulates the symbols by attaching a therapeutic plan to the diagnosis. In this way, Dow’s work on the common structure of the healing ritual validates ritual components that I provide to introduce each chapter (1986).

Jerome D. Frank did cross-cultural work and outlined the following prerequisites of a healing ritual:

- (1) A healing agent, typically a person trained in a socially sanctioned method of healing believed to be effective by the sufferer and at least some members of his or her social group.
- (2) A sufferer who seeks relief from the healer
- (3) A healing relationship—that is, a circumscribed, more or less structured series of contacts between the healer and the sufferer (1991[1961]:2)

He goes on to describe the structure of the healing ritual:

- (1) An emotionally charged, confiding relationship with a helping person
- (2) A healing setting
- (3) A rationale, conceptual scheme, or myth that provides a plausible explanation for the patient's symptoms and prescribes a ritual or procedure for resolving them
- (4) A ritual or procedure that requires the active participation of both patient and therapist and that is believed by both to be the means of restoring the patient's health. (1991[1961]:40-44)

Salient components of the ritual discussed in my data are a socially sanctioned agent (the doctor), an emotionally charged relationship (the existential threat), a plausible explanation (the diagnosis), and a ritual procedure requiring participation (experienced by both) (Frank and Frank 1991). Brian's monologue provides a patient's perspective of the components of the healing ritual. The rest of each chapter presents data from my research that portrays Western biomedicine as fulfilling the criteria for the healing ritual that is universal and timeless. This will fulfill Specific Aim 1 of this research project.

After describing the clinical encounter as a healing ritual, I contextualize this data by revisiting the patient explanatory model proposed by Arthur Kleinman (1988) and propose a critical rethinking, aligning the concepts he described as a healing ritual with the framework and data in this research project, pointing out the marked similarities and notable differences.

I will conclude the discussion of my data by commenting on the anthropological canon and missing portions of the medical anthropological research endeavor. By highlighting the sampling frame created by anthropological notions of Western biomedicine, I discuss how this systematic error introduces bias. I suggest that anthropologists have focused on the marked category of Western medicine — all the easily observable adverse effects — and failed to adequately describe the unmarked category of how clinical encounters in Western biomedicine address both the individual and societal imperatives to deal with disease and death, fulfilling Specific Aim 2 of this research.

Medicine, disease, and doctors: The Healing Ritual Then and Now

The advancement of science depends on building scientific models. Healing rituals have a long and illustrious career in the discipline of anthropology and at this point contrasting and comparing them with my results will provide part of the analysis of my data. I argue that the healing ritual in Western biomedicine is structurally and functionally the same as healing rituals in many other diverse cultures throughout the globe.

W.H.R. Rivers, in his book *Medicine, Magic and Religion* (2001[1924]) provides a global perspective on a multitude of different cultures and describes the basic elements of each. Most of the societies he surveyed were small-scale societies. After brief discussion of magic and religion he turns to medicine stating:

Medicine, on the other hand, is a term for a set of social practices by which man seeks to direct and control a specific group of natural phenomenon – viz. those especially affecting man himself, which so influences behavior as to unfit him for the normal accomplishment of his physical and social functions – phenomenon which lower his vitality and tend towards death. By a process of generalization, society has come to classify these phenomenon together, and has distinguished them from other groups of natural phenomena under the name of disease. [Rivers 2001[1924]:4]

This pairing of medicine and disease is portrayed as universal. Notice the absence of *illness* in this model. When discussing the various linguistic nomenclature for practitioners of the healing art, Rivers chooses the term "leech" when speaking of a member of society whose special function it is to deal with the cure of disease (Rivers 2001[1924]:5). Others use the words *medicine man, shaman, or diviner*.

Victor Turner summarizes the components of the healing ritual, which I will explicate in the following discussion, examining the components in more detail. In *The Ritual Process*, Turner is more concerned about the symbolism of the ritual process, but he describes the following components of the healing ritual, known as *Isoma*. In this symbolic system, "a person is believed to have been 'caught,' as Ndembu say, by a shade and afflicted with misfortune thought to be appropriate to his sex and social role" (Turner 1969:11). In this instance, a "shade" is the equivalent of a disease. He continues:

A woman suffers from gynecological disorders; then either her husband or a matrikinsman seeks out a diviner, who denominates the precise mode of affliction in which the shade, as Ndembu say, has "come out of the graves to catch her." Dependent upon that mode the husband or kinsman employs a doctor (*chimbuki*), who "knows the medicines" and the correct ritual procedures for appeasing the afflicting shade to act as master of ceremonies for the coming performance. [Turner 1969:13]

Here, the "shade" is identified as the disease and a diviner "denominates the precise mode of this affliction." This diviner has the equivalent social function of a doctor--making a diagnosis; the doctor is the one that performs the actual ceremony (Turner 1969:13).

As with all Ndembu rites, the pattern of procedure in each specific case is set by the diviner originally consulted about the patient's affliction. He is the one who establishes the woman has lost a succession of children by miscarriage or death in infancy – misfortunes summarized in the term *lufwisha*. It is he who decrees that the rites must begin at the hole or burrow, either of a giant rat (*chituba*) or of an ant-bear (*mfuji*). [Turner 1969: 20]

Again, the diagnosis is an integral part of the cure or therapeutics, described as “The Curative Process.” (1969:33)

Through the work of these anthropologists, I will identify the following components of healing rituals:

- (1) Patients experience disease as an existential threat
- (2) Explicating the cause of disease—the diagnosis
- (3) Persuasion
- (4) Relationship of diagnosis to therapy
- (5) Qualifications of a “leech” (the doctor)

I begin each chapter by describing the above ritual components and then I provide data that explicates the modern equivalents in biomedicine for each. I argue that the modern Western clinical encounter is a healing ritual based on this strong concordance.

Chapter 5: Patients experience disease as an existential threat

Disease and Death

One of the reasons why medicine, magic, and religion are worldwide is that “disease and death are so closely connected that, even if the earth had been divided up into independent and self-contained apartments, we should have expected much similarity in the reaction of different groups of mankind towards them” (Rivers 2001[1924]:54). It is important to note that the potential threat of a disease—not an illness—invokes the healing ritual. I maintain that a disease is a social construction and, as such, a shared cognition between an individual self and the cultural body, as described in Section I. To give voice to the individual self throughout this discussion, I will quote from a monologue by Brian, someone who participated in all aspects of this ritual. Again, I use Brian’s illness narrative to introduce my observational data. Although Brian narrated the entire story without interruption and in the sequence portrayed, I will segment his story into the components of the healing ritual. In this first section, Brian uses his own words to describe an existential threat:

I have a great internist ... I love my family doctor. I had an annual physical and had a whole gamut of tests ... One of them – one of them is what is called the PSA test, and it came in at five. The test was a routine now that I was 50. That this was something we should start screening for. So I was now 50, and so it was something that should be, we should be screening for. And I remember being a little perturbed because I went back the year before and just looked up my blood tests and it wasn't run. So it occurred because I'd hit a magical age of 50 and I was a little taken aback, I guess, because I'm thinking, Well, I hit 50, and they did the first test and it was positive. So shouldn't we have been screening at some time before now to be sure we caught it?

These introductory remarks describe a life lived as usual or typical. The narrative component illustrated is the setting, as described by Labov. This portion is important because it highlights or contrasts with the existential threat as experienced.

And my doctor was like, “Okay, this is unusual.” We laughed about it. She said, “Come in and we’re going to do the PSA test again.” So I went in a second time and it went from... it was at 6.3. So then she said, “Okay, now this is serious.” She gave me a whole bunch of antibiotics in case I had an infection. “Take these for 21 days and get it tested again.”

I said, “So what? Are we going to do the best of three?”

And she said, “Yes, something like that.” I did that just before Labor Day and it was 6.4. At that point, she called me and said, “You know what, I’m just an internist and I did what I could and, I’m not the specialist. It’s time for you to start seeing ... the professional.”

“Okay, now this is serious...it’s time for you to start seeing...the specialist,” are utterances by the doctor to initiate the concern. Although not overtly stated, these actions are display emotions, evaluating the social situation. I point it out here to help the reader understand the performative nature of emotions in a ritual re-enactment. If the doctor thinks it is serious, what is the patient supposed to think?

Oh, you know, I checked it out on the internet. Thank God for new technology. Well, I knew what PSA was, I knew what the PSA test was. It's like – it's kind of like something that leads to whether or not you have prostate cancer. It's a trigger. Yeah it's, what you call it – I don't know. It was – You could be there for hours and you investigate what PSA is and what it means, and then you start reading about prostate cancer and this other stuff and you say, “Okay. This is this could be serious.” It doesn't mean anything, doesn't mean anything. But if A equals B, then possibly B equals C.

The patient repeats the doctor’s utterances – “whether or not you have prostate cancer... you starting reading about prostate cancer and this other stuff and you say, ‘Okay. This is this could be serious’” – confirming the potentially serious nature of the circumstances. Yet the rationality of the potential that it “doesn’t mean anything” and the irrationality of “B equals C” co-exist in the cognitions of Brian’s self.

So my PSA test was slightly elevated, above normal, at least. It wasn't real high, but it was above something that warranted follow-up, so she referred me to a specialist. I think I met with him once and then came back for the exploratory biopsy, which was interesting. Well, okay, now, so to be honest with you, the appointment was – was one of five in my calendar. And to a very large degree that's the way the whole week went. I spent Monday and Tuesday, I was in Toronto on business, um, I did talk to a – I had a friend in from Tokyo. He was in for business, so his family was still in Tokyo. I spent a lot of time with him and we talked about it, um, because I e-mailed them about it. We talked about it a little bit, but the gravity of it, the gravity of the whole situation, it still – Even then it still didn't hit me. It's like I'll go see what this doctor has to say and we'll go from there type thing.

After talking about “the gravity of it” with his friend, Brian decides to “go see what this doctor has to say and we'll go from there type thing.” In the language of narrative, this is all foreshadowing, building of suspense before the plot becomes apparent. The next section confirms the basic premise of the healing ritual — an existential threat.

I'll be honest with you. It wasn't until – it wasn't until I left the office and I was already down in the elevator, I was in the lobby of the building where – I wouldn't say I had a mini breakdown, but, holy shit, that's when the whole gravity of the potential – kind – It kind of flooded on me. That's when it hit me. That was the mini breakdown when I finally got down into the lobby, yes. Up until then, you know, I am a – I'm an automotive engineer.

Brian acknowledges that he had a mini-breakdown—the existential threat—because up until then he was an automotive engineer. Brian's choice of words is important: is he no longer an automotive engineer? Clearly, he is trying to indicate merely the threat of disease (this all occurred prior to biopsy) disrupted his self-narrative as he was able to previously recognize it. He has entered the arena of the unknown. Brian's introductory portion of his narrative demonstrates Rivers' claim that disease as the harbinger of death is experienced as an existential threat to the individual self. At this point, Brian has only consulted the doctor-leech and confirmed the gravity of his situation. This is a necessary part of propelling both the patient and the doctor to the next phase of the ritual.

Disease and death as existential threat versus disruption of the narrated self

Disease is the natural cause of death and is experienced as an existential threat to the body in the form of the death of the body. In the next scenario, I would like to expand *existential threat* to include an existential threat to the body–self, the individual self-narration. This scenario relates a story of a patient who sustained a motorcycle accident with significant physical injuries, an event that is assumed to carry the risk of death. After that near-death experience, the patient is left with multiple disruptions in the body, self, and social domains. It is these disruptions that once again initiate the healing ritual.

Dr. Williamson said to Dr. Johnson, “Did you hear about that patient who had a traumatic urethral disruption?”¹⁰ He described the injury in detail, “Dr. Fields got to scrub in. He told me that the patient was riding a motorcycle and he hit a pole, flying forward, striking his groin against something hard, and disrupting the urethra.” Dr. Williamson then shrugged his shoulders and made a face as he walked away. Later in the clinic session it became apparent he had not yet seen the patient but he had already heard about the case from the other residents.

Carmen brought the patient back to an exam room. The patient was holding a urine bag out in the open and the wife was walking behind him texting on her phone, looking at the phone and not looking at where she was walking. The door was open and Carmen did ask permission if I could observe the interview. She took his blood pressure and said, “It is 129/100. That’s good.”

“I’ve had a stressful day.”

“You’re allergic to IVP¹¹ dye, right?”

“Yeah.”

After seeing the patient, Dr. Williamson was standing around the documentation counter, chatting. Dr. Jeffries interrupted and asked, “How far out?”

Dr. Williamson said, “Two weeks. He’s comfortable with meds, he’s had a bowel movement, he still continues to have perineal¹² swelling...”

Dr. Jeffries interrupted saying, “What do you want to do for him?” As they reviewed the chart Dr. Jeffries said, “He’s really three weeks out...” He then described a butterfly hematoma¹³ and indicated that the patient had surgery on July 1, at which point he took his Smartphone out and showed the trauma case

¹⁰ Urethra is the tubelike structure in the penis through which urine flows.

¹¹ IVP—an acronym for Intravenous Pyelogram (dye), a way to improve the x-ray image of the kidney and the urinary collecting system.

¹² The anatomical area surrounding the anus, scrotum and penis.

¹³ The word “butterfly” describes the shape of the hematoma which resulted from the mechanism of injury.

photos to the residents, “There was significant peritoneal as well as perineal hematoma.”¹⁴

Dr. Williamson said, “So what you want to do?”

Dr. Jeffries replied, “I would do an antegrade and cystoscopy¹⁵ through the suprapubic tube trying to thread a catheter from the bladder through the penis. The tissue during the initial operation was dog meat.” He indicated that the catheter would provide a lattice for healing and decrease the possibility of requiring a post repair urethroplasty.¹⁶ He summarized by saying, “I don't want to do anything. If we do something it will cause increased incontinence, increased impotence. I would only intervene after the first suprapubic catheter change. That's the miracle of embryology: those cells will seek to find each other and essentially close the traumatic laceration naturally.”

At that point, we all went into the room. Dr. Jeffries interviewed the patient a little bit. He then asked to examine the patient. “Don't worry. It's what we do.”

After the interview and exam, the patient replied, “I've had multiples previous surgeries under Medicaid. Now I'm self-employed, and for some reason my Medicaid lapsed.”

Dr. Jeffries said, “Don't worry. We work for University Hospital. They will have someone assist you with insurance. You won't see one red cent of the bill.” Almost imperceptibly, I observed a small tear welling up in the patient's eyes as Dr. Jeffries made this commonplace reassurance.

Dr. Jeffries then asked the patient, “This is a little bit of a personal question, but have you had an erection since the accident?”

The patient said, “Last Thursday I woke up with an erection. It scared the hell out of me. I thought everything was going to explode. I was terrified.”

Dr. Jeffries smiled and said, “I've been a urologist for 17 years and nobody died of an erection. The cavernosal artery fills it with blood.¹⁷ Having an erection is a very good sign.”

The patient said, “It scared the hell out of me.”

Dr. Jeffries asked, “Was it uncomfortable?”

“No.”

The conversation then went on to scheduling. Dr. Jeffries said, “I would prefer to do it August 1, giving at least a month before touching anything. I'm going to go out to schedule it.”

The wife left the room asking if she could go to the bathroom. She did go into the bathroom and come out. Dr. Jeffries was doing other things, but before he could go see the next patient, she pulled him aside and said, “Could I have a minute of your time before you go back in the room? I'm planning to go up north to visit my parents. I go every year. I don't want to go if he is going to have a problem. Also, he's concerned about missing work for financial reasons.” She had Dr. Jeffries cornered in an empty exam room for a fairly extensive time and then

¹⁴ A hematoma is a collection of blood that displaces the tissue and normal anatomy.

¹⁵ Direct visualization of the inside of the bladder cavity.

¹⁶ Surgical repair of the urethra—the tube through which urine exits the body.

¹⁷ This refer to the artery that fills the penis with blood.

said, "Give me a few minutes to get back in the room. I don't want him to know that we talked." She then went back into the exam room with her husband.

Dr. Jeffries did return and talk a little bit more about scheduling. Dr. Jeffries brought up the issue of scheduling and said, "There is no rush for surgery. You won't have any more difficulty functioning than you are now, actually less because the two weeks more of healing time." The issue of billing came up again and Dr. Jeffries reassured him again, at which time the patient became tearful.

The wife then introduced the concept of getting back to work, scheduling the exam, and being comfortable going up north during the next procedure. Dr. Jeffries agreed, "That wouldn't be a problem." The patient then left the room and talked to Barbara, the surgical scheduler.

As Dr. Williamson left the room, he was visibly shaken (emotionally), his color was ashen gray, and he was very quiet, which was unusual, as he usually displayed an overall upbeat, positive, helpful demeanor. The silence was notable.

Dr. Jeffries talked to Dr. Williamson about doing the history and physical, "Some of it is on paper. Make sure all the documentation is ready in terms of scheduling operative time. Do you want to see the CT that was done during the recent hospitalization?" While the patient was scheduling the procedure, the residents and Dr. Jeffries reviewed the CT images in detail. Dr. Jeffries said, "I would like to see the coronal views."¹⁸ They looked at everything with particular interest on where the catheter was placed. Dr. Jeffries said multiple times, "It's in the bladder right? It's not in the bowel?" They reviewed the film three times to try to make that determination.

One of the residents asked, "Do you wait six weeks after the injury to do the surgery?"

Dr. Jeffries turned and said, "I personally always wait at least 8 to 10 weeks.

The reason that such a junior resident (Dr. Fields) was able to scrub in and assist on such a major case was that the patient presented to the emergency room of a nearby hospital. The very nature of an emergency room is to stabilize the patient to prevent death. In this case, re-establishing a basic bodily function, eliminating urine, was an existential threat, because unless that bodily repair was accomplished in the emergency setting, it is probable that the patient would have died. Evidence for this is the surgery and the surgical photos displayed on the Smartphone detailing the injuries. Dr. Jeffries referred to the genital area as "dog meat" when he was showing the residents the extent of the injury. The anatomy is not even recognizable to the

¹⁸ Coronal views is one of the three axes that planar images of three dimensional objects can be displayed on the computer.

surgeon and the “repair” required to address the existential threat was to create an alternative urinary system with the suprapubic catheter and urine collection bag that replaced the urethra and bladder during this time of bodily disruption. The intent in this chapter is to establish the initiation to the healing ritual, which I argue is self-evident, given the nature of the clinical case.

I present this scenario to highlight other existential threats to the self, or narrated body-self, as described in Section I. Although the patient isn’t narrating his illness story, he does provide display emotions that are social communications about his experience. Notably, the tear and tearfulness related to the financial disruption of losing Medicaid and not having insurance is a direct threat to initiating and maintaining the healing ritual. Not all doctors are willing to see patients without insurance or even patients with inadequate insurance. The relative importance of this interaction between the patient and Dr. Jeffries was under-emphasized in the context of the healing ritual of the office visit, but I attribute this to the narrative structure of healing rituals. Dr. Jeffries simply did not perceive it as important to his job of presiding over the ritual; he would rather look at the CT scan, verify that he placed the catheter anatomically correctly, and plan further medical-surgical management.

Likewise, there is a discrepancy of perception related to the patient’s erection. The patient was “terrified it was going to explode” and said “It scared the hell out of me,” something I claim is a statement of an existential threat, while Dr. Jeffries was happy the cavernosal artery was patent or intact. Dr. Williamson was a newlywed with a young infant. Simply observing the “dog meat” of another man’s procreative organs after a motor vehicle accident affected him, despite his training to maintain the role of the objective observer. Again, this is not enacted as part of the healing ritual.

The existential threat was also demonstrated when the wife asked if the patient was going to be all right if she travelled, the underlying assumption being that the patient could not care for himself after the next surgery. If there is no one to care for you when you need to be cared for, the potential for physiologic decline, or “decreased vitality,” to use Rivers’ words, could lead to death.

Through the lens of healing narrative as healing ritual, this scenario highlights the transformative nature of the process. It is a before-and-after situation. Labov might say the first declarative clause was, “The patient had a motor vehicle accident.” The second declarative clause was, “The patient’s bodily functions were disrupted.” Frank would say the restitution narrative is a dominant metaphor in clinical stories. I would add that the healing ritual in Western biomedicine is the same as other places and other times—the existential threat of disease (physical trauma) and death brings the patient and the doctor together and initiates the healing ritual.

Patient cognitive models versus doctor’s cognitive models

Again, the following brief scenario demonstrates that the patient and the doctor may disagree about the cause of the existential threat, but they both acknowledge one exists. Even that is enough to initiate the healing ritual.

Dr. Stein said to the patient, “We looked at the CT scan. The kidney is this big,” he indicated by showing the size with his hands. “We can show you [on the computer screen].” But then he started drawing it and said, “This is the shape of your kidney, and down here there’s a solid mass. Usually this is kidney cancer, and the treatment is surgical removal. If there’s no spread, you can consider this a cure.”

The patient replied, “My husband died four years ago from renal failure, so when you mention ‘kidney,’ I become uneasy. My primary care physician told me that the lymph nodes were small and that was a good thing because it meant that it probably not spread. I would like it done as soon as possible.”

The patient is concerned about death from kidney failure, based on her experience with her husband. There is a high chance she attributes loss of part of her kidney with decreased kidney function — her existential threat. For Dr. Stein, the existential threat would be the spread of the kidney cancer. Although never clarified, the healing ritual proceeded without interruption or clarification. The patient scheduled the surgery.

When research conflicts with cultural models

The word *cancer* itself provokes a cultural model of disease and death. I interviewed one of the principal investigators for the PLCO study¹⁹, which was a multicenter, randomized, prospective controlled trial of screening for four different kinds of cancer, including prostate cancer. This trial is only one of two in existence of this type. It showed no survival benefit for screening for prostate cancer. This doctor told me that even his own urology colleagues continue to screen despite the evidence of no benefit with defined risk of harm. Additionally, he speculated on the patient perspective:

I think for many patients the notion that you have a cancer and that you want to do nothing about it and sit tight is anathema. I don't know the data on this, it probably drives an awful lot of the decision-making afterwards, because people are just not comfortable that they can live with cancer and not die from the cancer or suffer greatly from the cancer.

I believe this clinician-scientist was referring to the cultural model of existential threat of disease and death associated with the word *cancer* when he made that statement. Despite evidence to the contrary, the potential to have prostate cancer is still enough to initiate the healing ritual. In the clinical encounter, the cultural model that cancer causes disease and death trumps the research evidence. Consider the following:

¹⁹ Prostate, Lung, Chest, Ovarian cancer screening trial

The patient said, "I came to you for surgery because you are highly recommended. I did some online investigating about prostate cancer and read a lot about it and the different types of treatment options that were available. I have a lot of cancer in my family, and I think I want surgery. I want to get rid of it before it spreads." Dr. Stein provided extensive counseling comparing radical prostatectomy versus active surveillance, explaining both have demonstrated equal outcomes. After twenty minutes of explanation of the research, the patient turned to Dr. Stein and said, "Let's do it. Let's go ahead and schedule the appointment. I just want it taken care of."

I believe this clinical encounter supports the clinician-scientist's perceptions that patients cannot tolerate the possibility that they have a potentially life-threatening disease despite what scientific evidence demonstrates. Rivers best describes this motivation, the attempt to locate desire, this drive for self-understanding that underlies healing narratives as the threat of disease and death.

The patient's explanation of existential threat

This next quotation occurred after one of the patients I interviewed asked me if I had ever had cancer. I told her I hadn't. Her next words were:

"Well then, when you're told that you have cancer, it terrifies you. It surprises you, you're totally confused. You don't know what's going on. So when you meet a doctor who's saying no you're not going to have side effects, no, we caught this early. That gives you reassurance and also makes you look at him like hey, he's going to help me. And that's very important when you see a doctor. I was seeing another doctor who didn't even call to tell me that the results showed I had cancer and that irritated me. I was thinking that this isn't because I have a pimple on my face. This is my life and this is life-threatening."

That last sentence, "This is my life and this is life-threatening," was reason enough to engage in a healing ritual.

Chapter 5: Summary

Rivers identifies disease and death as the reason healing rituals exist. I agree with him, and this is the one theoretical disagreement I had with Cheryl Mattingly, who seemed to focus on narrating the bodily disruption. I prefer Rivers's explanation because I believe the disruption that requires healing is the narrating self and that the body is the proxy that keeps the narrating self anchored in this world and not lost to oblivion. To summarize, it is a threat to the narrating self that forms the existential threat. I assert that this threat is necessary to initiate the healing ritual. People without problems don't go to the doctor. The evaluative function of the narrative ritual puts death as "something worth a claim on conversational time." (Labov 1997)

Chapter 6: Causation of disease and diagnosis

The structure of a diagnosis narrative is embedded in the healing ritual

In this section, I use the same anthropologists discussed in Chapter 7 to describe the next segment of the healing ritual. Again, following their descriptions, I present data that support that Western biomedicine has the same healing ritual components and, in summary, the same healing ritual structure as those described in the anthropological canon.

Rivers states, “Mankind has theories of the causation of disease, carries out proceedings which correspond with those we call diagnosis and prognosis, and finally has modes of treatment which, even if they have little in common with our own remedies, nevertheless may be regarded as making up a definite system of therapeutics. (2001[1924]:6) He re-emphasizes the point saying:

One element of the concept of disease, and perhaps the most important, is that it includes within its scope the factor of causation. There are usually clear-cut ideas concerning the immediate conditions, which lead to the appearance of disease. One happy result of this fact is that we are able to approach our subject by way of the etiology, and are thus led to deal with the medicine of the savage peoples from the same standpoint as that of modern medicine, which rests, or should rest, entirely upon the foundation of etiology." [Rivers 2001[1924]:7]

Identifying the etiology of disease is otherwise known as diagnosis. In his world survey, Rivers indicates that the causation falls into categories:

If we examine the beliefs of mankind in general concerning the causation of disease, we find that the causes may be grouped into three chief classes: (one) human agency, in which it's believed that disease is directly due to the action on the part of some human being; (two) the action of some spiritual or supernatural being or, more exactly the action of some agent was not human, but is yet more or less definitely personified; and (three) what we ordinarily call natural causes. [Rivers 2001[1924]:7]

Notice the frequency of the term “cause,” taking us back to Michael Tomasello, the very first cognitive anthropologist discussed, who described human experience as organized intentional

beings who understand the world in terms of causal events, allowing the development of culture. Western medicine fits perfectly within Rivers' global survey of explanations for disease under the category of disease as a result of natural causes (biomedicine). Rivers points out that it is the "leech" (doctor) that "carries out proceedings which correspond with those we call diagnosis" by the practice of "leechcraft." I will demonstrate that, indeed, in current medical practice it is the doctor that pronounces the diagnosis and the patient is informed, or is the recipient of the naming of the disease.

Bringing us close to contemporary medicine, Rivers says:

The emergence of medicine from its intimate associations with religion and magic is closely connected with the gradual substitution of the concept of physical causation for the spiritual list of agencies of the animism which formed the early attitude towards nature. The growth of medicine is closely bound up with the development of the concept of the natural world as opposed to world we now regard is supernatural. [2001[1924]:110]

He continues:

For the worms and snakes of savage medicine have been substituted from microscopic and ultra-microscopic organisms of the germ theory of disease, while the place of the old humours has been taken by the alteration in the proper proportion of internal secretions which is now coming to be recognized as an immediate cause of so many morbid states. [Rivers 2001[1924]:111]

The reason for this substitution takes us back to the cognitions of causation: "Every physical event has its physical antecedent, without the presence of which it would not itself have come into existence. The progress of physical science depends largely on the robustness of the faith in this law of causation" (Rivers 200[1924]:116). The theory of the mind is the common denominator between healing rituals described in prior anthropological literature and that which I describe in the results of this research.

In Section I, I developed a line of thought that began with the theory of the mind and tried to demonstrate how it forms the basis of narrative thought. It is for this reason that the

causal structure of “leechcraft” described by Rivers is described by me as a *diagnosis narrative*. The construction of a narrative requires a series of events, evaluative statements, and further events building a cause and effect structure known as a *diagnosis*. It is by collecting these narrative components and assembling them into a narrative structure that the doctor is allowed to proclaim the diagnosis; hence the term *diagnosis narrative*.

Evans-Pritchard, in his ethnography, *Witchcraft, Oracles, and Magic Among the Azande* (1976) provides even greater detail on the diagnostic process. When a man’s health is threatened, there is a highly elaborated process for finding out the etiology or cause, in this case a result of witchcraft from some other person in the society. The process of diagnosis is described”

They take a chicken to the name of one person and pour poison down its throat, and ask the poison oracle whether this man is the witch or not. If the Oracle says that this particular person has nothing to do with the health of the inquirer then they take another chicken to the name of the second person and repeat the test. When the oracle kills a fowl to a man's name, i.e., says that it is he who will cause the inquirer sickness among the coming month, they then ask it whether this is the only witch who threatens his welfare or whether there also others in the offing. If the oracle says that there are others, then they must seek them out till the oracle says that there is no need to inquire further since he now possessed the name of all the witches will cause the Inquirer ill health. [Pritchard 1976:38]

Pritchard details the sequence of asking questions and confirming the answers from the oracle. The questions are asked both in the positive and in the negative and need to concur. In essence, this becomes a process of diagnosing the cause of the illness or disease (caused by witchcraft).

Meyer Fortes also describes diagnosis as divination. In keeping with the theme of undifferentiated roles of religion and medicine, Fortes discusses ritual in his book *Religion, morality and the person: Essays on Tallensi religion* (1987). He has an entire paragraph on divination, stating, “I return now to divination. In the most general terms where divination is a central feature of the system of religion or magic, it is a ritual instrument by means of which choice is made, from among the total ritual resources of the community, of the right ritual

measures for particular occasions and with regard to individual circumstances” (Fortes 1987:7).

Fortes presents a series of photographic plates, the titles of which are extremely important. They are in sequence:

- Figure 1. Tallensi divination: a collection of code objects. [bones, sticks, gourds, and other natural instruments.]
- Figures 2 a,b,c. Tallensi divination: a divining session.
- Figure 2a. First episode: the diviner summons his divining ancestors.
- Figure 2b. Second episode: the diviner and consultor work out the diagnosis of the situation.
- Figure 2c. Third episode: the consultor works over the diagnosis to confirm it. (1987:8-9)

The diviner provides a diagnosis and the consultor confirms it prior to adoption for action.

However, Fortes goes on to say:

The conceptual curtain between knowledge of the occult and knowledge of the patent must be kept in place.... Hence divinatory verdicts are tested by posing the same questions in alternative forms, and by the well-tried method of seeking a second and a third independent opinion and by ordeals which use the logic of chance.... One of the most important functions of divination lies in the authority it carries. A confirmed divinatory verdict is an authorization, a sanction emanating from the ultimate source of authority in matters that concern the occult, the occult agencies themselves, for the ritual action proposed. [1987:11-12]

This reinforces how important a correct diagnosis is: It governs the ritual action. The specialized knowledge of the doctor keeps “the conceptual curtain between knowledge of the occult and knowledge of the patent” in place. Although power is often discussed—and maligned—in anthropological literature (Hahn 1995), it is necessary for a healing ritual. Rivers framed healing rituals as controlling disease and death, not controlling persons. Again, in these examples of ritual healing, both the “leech” and the patient are part of the cultural body. It would seem logical to analyze both the doctor and the patient as being the object controlled by the body politic.

With this background, I begin my presentation of the diagnosis narrative as observed in my fieldwork. I will be discussing diagnostic narrative schemas, the role of the doctor to

pronounce the diagnosis, and the specific diagnostic methods currently used by urologists. This last topic, the fact that a cancer diagnosis is a three-dimensional cognition, brings us back to the foundational understanding of human cognition.

A narrative is a series of clauses connected by evaluative statements, forming a cause-and-effect cycle that progresses through time – in this case, through narrative time. My first major assertion is that a diagnosis is just such a narrative. The diagnosis is the conclusion of a narrative, the story of an etiology of disease. From this point onward, I will use the term *diagnosis narrative* to identify this one narrative component of healing rituals. Later, I will highlight other narrative components based on reporting the experience of participating in the ritual. But first, the structure of the diagnosis narrative.

Brian's perspective on the process of assigning causation

Again, I start this section by picking up Brian's story where he left off. This provides a patient's perspective on what I will demonstrate is an activity reserved for the doctor according to the healing ritual model.

I worked on the premise of data. And without data – you know, we have a saying in the engineering world: Without data you're just another idiot with an opinion. And when I walked in the specialist's office I had no data. So, it's like there's nothing to worry about here. There's nothing to – we're here to gather data and I addressed it, I addressed it. Like I said, it was one meeting on my calendar out of five today, and I addressed it the same way I addressed the other four. And it wasn't – ah, what word am I looking for – It wasn't a release mechanism, a cover-up mechanism, you know. It wasn't like I was trying to – what word am I looking for? I don't know. So I'm so scared about this – that I'm then treated like an engineering assignment. I wasn't trying to do that. I just did it. You know the way I attack – attack things.

You know, I got a little bit more data, but I still don't have the, “Well, okay, let's take the next step.” When he [the urologist] said, “You want to take the next step?” It's like, of course, I want to take the next step. You know when he said, “Let's do the biopsy,” he said, “Do you want to do it?” I didn't get it. You want me to say no? I didn't get that. Of course, I want to take the next step. We

gotta get data, data, data. We gotta do this. If he would've said, "We have an opening tomorrow," I would have said, "Put me in coach." I'm like, let's keep going, let's keep going. I'm not – I'm not as much – where I am right now. I'm like, "Let's keep going." I'm not – I'm not as much – I was past the breakdown stage and I'm into let's keep going, let's figure this thing out, let's go coach.

I didn't know what to expect. I made the appointment, the doctor's office called me to confirm it, and I said, "What do I need to bring?" "Nothing." "Okay how do I prepare? Do I need to not eat or anything?" "Nope, none of that." The biopsy was all very innocuous and how it was approached. "We're just going to insert this little thing in here, just kind of look around and if I see something I don't really like, then I may just take a little nip of it." Well, it was the first little nip of it that was truly a nip of my prostate, which was painful. And the first time I went to the bathroom after the biopsy there was blood and stuff.

Brian acknowledges he is scared and his response is that his problem should be treated like an engineering assignment. He is interested in data, but this is not engineering data, this is diagnostic data. He is eager to proceed but has no idea what to expect. The suggestion that he has a choice whether or not to proceed with biopsy makes no sense to him. After all, his life is at stake. He asks questions about what he should do, and surprising to him, the answer is "Nothing"—just show up. Brian makes the same mistake many anthropologists make when describing biomedicine—he assumes he has a role in making the diagnosis. As the introduction to this chapter indicated, however, making the diagnosis in the healing ritual is the role of the doctor. Eventually, I will present how the patient is re-integrated into a *healing narrative*, but for now, rituals have a sequence, order, and timeframe all their own. In the sections that follow, I will spend a lot of time reporting data on what is arguably the most important part of the healing ritual.

Prostate biopsy as data to address the existential threat

This part of the healing ritual concerns the formulation of a diagnosis narrative, a causal explanation of the perceived existential threat. I emphasize data gathering, and Brian focusses on

data to form this portion of the healing ritual. As a corollary to Brian's self-reported experience of having a prostate biopsy, I start by reporting an observed prostate biopsy and the follow-up office visit. I present this now because this vignette ends by re-enforcing the prior discussion of existential threat and its relationship to diagnosis while the doctor gathers data for the diagnosis.

If a patient was to have a biopsy during clinic hours, Carmen and Dr. Jeffries could complete an entire biopsy routine wordlessly. Each anticipated the movements of the other and they coordinated the many different sequences flawlessly and efficiently. Carmen and Dr. Jeffries worked silently, not even looking in the same direction at the same time, but each completing what the other was doing. Dr. Jeffries would point to the ultrasound screen, and Carmen would move the rollerball, making exact measurements of the size of the prostate. During the punch biopsy, the tissue specimens were collected and labeled efficiently.²⁰ Both gave instructions to the patient at different times without any duplication of effort. Consider the following action:

Carmen said to Dr. Jeffries, "Your biopsy is ready."

"I'll be right there." Dr. Jeffries was sitting at the computer documenting his second-to-last patient of the day. He sat there typing with his index fingers. I noticed that he typically uses the computer farthest to the left at the doctors' charting station with high stools and countertop. Carmen went to give the patient the informed consent.²¹

He continued typing. Eventually Dr. Jeffries said, "Are you ready, Carmen?" Shortly thereafter, Dr. Jeffries got out of the chair/stool, and they both went into the procedure room. Dr. Jeffries told the patient, "Just sit back and let us drive the machine. We're ready to roll." He spent a significant amount of time positioning the patient, "Sit on the edge and then lie down... Roll on your left side... Scoot your hips to the edge of the table... Move your shoulders here, and then roll your shoulders towards the opposite end over there." This took a lot of verbal direction and working with the patient. Dr. Jeffries then sat on a stool next to the ultrasound machine, which was on his left. The patient was on his right. Carmen had a procedure setup table covered with a blue drape over the top. They both had blue gloves on. She took the drape off, revealing six small bottles filled with fluid. There was also a trigger-activated biopsy gun with an incredibly long needle, approximately 8 to 10 inches. Carmen stood behind Dr. Jeffries, and Dr. Jeffries spent half the time looking at the ultrasound machine screen and half the time looking at the patient. Dr. Jeffries warned the patient that there can be a pressure sensation and told him to "Breathe out." The ultrasound probe had a portal to insert the trigger-activated biopsy needle. The probe was plastic, approximately fourteen inches long, including the grip handle. The handle and the

²⁰ A punch biopsy uses a hollow needle which is thrust into the organ to yield a core of tissue that is removed for microscopic examination.

²¹ Informed Consent refers to a signed document that signifies the patient understands the procedure and accepts the risks of the procedure.

tip looked extremely phallic—almost the exact shape of a penis. Dr. Jeffries inserted it and the patient expressed some discomfort with mumbled utterances but no verbalizations. Dr. Jeffries said, “Dr. Stein said he doesn't like this one. It can't scan.

“Why can't it read?” Carmen wondered aloud. “I'm not going to question things.”

Carmen and Dr. Jeffries were working silently but in a highly coordinated way. At times Dr. Jeffries would point to the ultrasound screen. Carmen would move the rollerball and pushed the button in different areas and different times. Dr. Jeffries said, “Here you can see the seminal vesicles. That's prostate tissue. the bladder is quite empty, which is good.” He then said to the patient, “I would like to rotate the probe,” and made a comment that he didn't like this [referring to the position]... “It's hard to [insert the syringe and/or loaded punch biopsy syringe].”

As Dr. Jeffries rotated the ultrasound probe intra-rectally, the patient had a grimace on his face.

Dr. Jeffries said, “This is not hurting me a bit. [Pause] Is it hurting you?”

As Dr. Jeffries was pointing to the screen and Carmen was pushing the button. She said, “Apex, right?” There was again more nonverbal communication.

After taking measurements, [dimensions of the right and left lobe], Dr. Jeffries said, “There is going to be some poking and some stinging,” then inserted a syringe with very long needle through the sheath and injected clear fluid. The patient winced with discomfort. He did it twice more, removed the syringe, and inserted the next instrument. It was a hollow tube with a hollow needle, cocked like a gun. It made a loud click as Dr. Jeffries pushed the button. When it was inserted and the trigger was pulled, I could see the needle stab into the prostate on the ultrasound machine displaying live video, demonstrating the hollow core needle penetrating through the prostate. During the process, Dr. Jeffries explained they were going to take 12 of those core biopsies, six on each side. Throughout the procedure, the patient essentially had his eyes closed.

After that phase of the procedure, Dr. Jeffries asked the patient, “Do you have children?”

“A son, and my daughter is a nurse. How many more?” He repeated this exact same question again having not gotten a response the first time.

After the patient asked the second time, Dr. Jeffries replied, “Does it hurt?”

The patient asked [for the third time] “How many more?”

“Two. It's normal to have blood in the urine and blood in the poop.” Dr. Jeffries turned his attention from the patient back to the ultrasound machine saying, “We never printed the dimensions.”

Carmen replied, “Yes. I'm on the ball.” After that, Dr. Jeffries removed the probe. It was covered in blood.

After completing the procedure, Dr. Jeffries told Carmen that the ultrasound images with the measurements needed to be scanned into the medical record. Overall, it was an impressive demonstration of teamwork.

Three weeks later, the patient and his wife returned to get the results of the biopsy. Before we entered the exam room, the two of them were speaking in a foreign language. Her English was much better than his. When Dr. Jeffries entered the room, she immediately asked, “What was the result of the biopsy?”

“There's some good news and some bad news. I brought this copy of the report for you to keep.” He then went over the results, explaining that there was some “pre-cancer,” continuing, “The bad news is the cells were abnormal, and it would require a repeat prostate biopsy to know for sure. The good news was there was no definitive prostate cancer.” After he explained this to the patient and the wife, Dr. Jeffries asked, “Is that something you'd be willing to do?”

Without asking her husband, she replied, “Of course. We want to know the answer. We want to catch it in time.”

Dr. Jeffries replied, “Yep.” They went on to schedule it on October 5. Dr. Jeffries left the room and typed detailed notes in the computer.

This vignette illustrates the dichotomy of experiences between the doctor and the patient, best illustrated by the statement, “This is not hurting me a bit. [Pause]. Is it hurting you?” Despite this seeming divergence of experience, the need to “catch it early” creates the motivation to complete the rest of the ritual. This section deals with the formulation of a diagnostic narrative as a component of the larger healing ritual.

Observing the diagnostic process – an outpatient urology office

I started fieldwork by trying to find the story, the narrative thread. From my prior work in anthropology, I believed the illness narratives perspective and assumed the best place and time to start would be when the patient presents to the doctor's office. My earliest observations started with one of the medical assistants,²² Marsha, calling the patient out of the waiting room and bringing them back into an exam room in the clinic. Marsha was very consistent regarding the informed consent process, personally asking the patients if they agreed to have an observer

²² A Medical Assistant is a trained individual and has a certification to perform tasks in medical settings involving patient care and routine clerical jobs.

present prior to acknowledging my presence. Not a single patient declined participation during this phase of data collection.

The physical setup of the exam rooms has the exam table underneath the window on the opposite side from the door. The chair for the patient is against the wall between the exam table and the countertop with the sink and the computer. I observed Marsha typing the vital signs into the computer and asking questions facing the computer with her back turned to the patient. This means she asked the questions and, hearing the patient's voice from behind her, and directly entered the information into the computer program. There was minimal to no eye contact. She would bring the patient into an exam room, have them sit, and then ask the same standard opening questions. I witnessed this scene repeatedly. Marsha asked, "Have there been any changes in your medications, your pharmacy, or any changes in allergies? Why are you here today? Are you doing well?" Without sitting down, she typed each response into the computerized medical record using the keyboard of the computer standing on the countertop in the exam room. Sometimes, while eliciting the complaint she started verbally administering the American Urological Association Symptom Score.²³ If it was a new patient, she gathered information on the past medical, family, and social history in the same manner, always using triple- or quadruple-barreled questions, sometimes double-triple-barreled questions. "Do your mother-father's siblings have diabetes hypertension or cancer?"

My overwhelming first impression was that I was observing a more rigorous form of a structured medical interview similar that described by Elliot Mischler (1986:56). In this case, however, it was even more overt—the only allowable responses were those that fit into the database structure of the computerized medical record.

²³ The American Urologic Association Symptom Score (AUASS) is a validated, standardized psychometric exam measuring obstruction to urine flow as experienced by the patient.

The patient didn't seem to find this unusual or unexpected. In fact, the following example illustrates an extreme case. The patient was new to the clinic, a young African-American I estimated to be in his twenties. As mentioned before, the patient sat in the chair next to the exam table after being brought into the room. This particular patient had an iPhone in his left hand and a regular phone in his right hand. Throughout the entire intake interview by Marsha, the patient was surfing the web, checking pictures, and interacting with his iPhone® while Marsha was asking him questions and entering the data into the computer. Both Marsha and the patient focused on a digital device, but this time both were looking away from the other. The patient was actually multitasking, answering medical history questions while surfing the internet with his phone. The presenting complaint was frequent urination, which he had for years, and the patient reported that he had an Interstim²⁴ procedure done at Harvey Frank Hospital. The patient characterized it as needles going in his back. I thought he said something about getting the evaluation but never actually having the procedure. Marsha repeated back to him that he had had the procedure done and entered it into the computer as if that were true.

Right from the beginning of fieldwork, I recognized the pattern of interaction was not what I had expected. I then began watching for similar examples and tried to understand the social practice of taking a medical history. The senior staff replicated the same process. Upon entering the room on one occasion, Dr. Jeffries almost immediately started asking a pointed series of questions that was a verbal form of the American Urological Association Symptom Score. He ended with the question, "Does this bother you enough to take a medicine?" Both the patient and the patient's wife were sitting there, and after a pause the patient indicated that he might be interested in it. Dr. Jeffries said, "Your cancer is up to snuff, so now we're focusing on

²⁴ Interstim is a Medtronic device that modulates the nerve stimulation to the bladder, often used to control an overactive bladder, a condition that sometimes leads to leaking of urine.

quality-of-life issues.” The next section of the interview was the review of systems. Dr. Jeffries turned his back to the patient and his wife, and asked questions directly off the computer screen and entered the answers in the computer as the patient was answering. Both the patient and his wife were observing the back of the Dr. Jeffries's head during this interaction. Again, similar to my earlier comment about Mischler’s analysis of the medical interview, it seemed as though the computer was asking the questions instead of the doctor. In these examples, the tightly structured interview was a reflection of the software program of the electronic medical record.

Diagnosis as narrative schema

The next scenario demonstrates the diagnostic narrative schema and its powerful effect on the healing ritual. The ritual cannot proceed without attaching the specific instantiated details to the general outline structure of the diagnostic narrative schema. The patient was Chinese and came with a family member as interpreter. The exact relationship between the patient and his translator was never determined. Marsha put them both in the room then had him go to the bathroom and immediately did the urinalysis. Since this was a new patient, she attempted to take a complete history, but he did not know the name of this medicine and he did not know his pharmacy, at which point Marsha had to turn around and face the patient to try to get information. The patient spoke very few English words, and the interpreter translated most of the interaction.

Marsha asked, “Why are you here?”

“I don’t know.”

She checked the electronic medical record and asked him, “Do you have a headache or dizziness?”

“Yes.”

Marsha said, “Those are neurologic problems, not urologic problems.” At this point, Marsha appeared frustrated because she could not determine the reason why his primary care doctor sent him here for consultation. Having acquired no

information of value, she left the exam room and started checking the computer on her desktop, saying to herself, “It must be an elevated PSA²⁵ or voiding problems.” It was at this point that she called the primary care doctor’s office and scanned through the electronic medical record.

When Marsha went back into the exam room the caregiver for the patient said, “Did you ask if he had it or they said he had it?” The interpreter was referring to a CAT scan.

Marsha said, “He must've had an elevated PSA, and they're checking his prostate level.”

The caregiver asked, “Does he have an infection?”

Marsha replied, “It looks like you had an ultrasound, but I don't see a PSA. But based on the size of his prostate, it may be elevated.” Marsha continued typing an electronic health record and then asked, “Is he having trouble voiding, stopping, starting, nighttime voiding, or anything like that?”

An extensive conversation followed, all in Chinese, lasting several minutes. At the conclusion of the conversation, the caregiver turned to Marsha and said, “No.” At that point in the conversation, the caregiver asked, “What's the prostate?”

Marsha replied, “It’s an organ only men have.” Marsha then proceeded to ask about past medical history, family history, cigarette consumption, etc.

When Dr. Patel entered the room, he asked the patient, “What's the problem?”

The caregiver replied, “We have no idea. He had an ultrasound, but we don't know the results.”

Dr. Patel had spent perhaps less than a minute to ascertain that they did not know why the patient was there. He tried to find the referring physician and then he left the room, saying to Marsha, “He doesn't know why he's here. I wonder if it's an increased PSA? It must be a PSA problem.”

Marsha replied, “There are 13 pages of medical information in the electronic health record filed under outside records.”

At that point, Dr. Patel returned to the exam room and again engaged with the medical record, reading all 13 pages, which included a CT scan and ultrasound, etc. There was dead silence in the room for an extended time while Dr. Patel was reading off the computer screen (with his back turned to the patient and interpreter). Dr. Patel finally broke the silence by saying, “He's here because of microscopic hematuria and an enlarged prostate.” Dr. Patel made this pronouncement by indicating that he read through the previous medical records.

The caregiver then referred to the microscopic hematuria and said, “I tried to find what that was.”

Dr. Patel replied, “I found the problem. He needs a test. It's like a telescopic check of the bladder. We're going to check for cancer cells.” He then turned to the computer without any further explanation, questions, or examination and started to type into the computer using his two index fingers. He types hunt-and-peck style. During this prolonged interaction with the computer, he answered

²⁵ Prostatic Specific Antigen (PSA) is a blood test for a specific protein used to screen for prostate cancer or monitor the management of prostate cancer.

a telephone call on his iPhone but continued typing. When he was done typing he told the patient to come out into the hallway. Dr. Patel told Marsha the explanation of why the patient was there and said, “Marsha, book him for a cystoscopy on June 1 at 11:30 a.m.”

The caregiver asked if the procedure could be done on the Monday instead of a Wednesday and she was told, “No, the schedule won't allow it.” Marsha then gave very careful instructions about having to go back to the primary care physician, getting a referral with an authorization number²⁶ and procedure code²⁷ on it, and bring that back with them. “If you don't get that referral code, the procedure will be canceled and rescheduled. There should be enough time to get the paperwork completed.”

After the office visit, I asked Marsha about her perception of the patient's encounter. She said, “It was hard because getting the patient's personal information was hard work with a translator. I called the primary care doctor's office and got told that there was only one person working there and he didn't have the time to find the ultrasound or provide information about the referral. That slowed down patient flow here.”

Carmen interrupted, saying, “I was dumbfounded that a patient would show up without knowing why they were at the doctor's office. The referral process in the healthcare system should be much more careful about having the information available.” Carmen expressed this same sentiment several times on other occasions. “This is frustrating. He [the patient] doesn't speak a lick of English. I've looked online for labs and his renal ultrasound – who knows? We call ourselves Sherlock Holmes here; we're always investigating why they're here. I've tried calling the primary care office, and all I got was a message and a phone recording. There's no referral. There's no procedure code. The referral's been cancelled and he's going off on me. Dr. Jeffries already yelled at me.”

From these initial interactions, I concluded that the illness narrative was not a part of the *diagnosis*, as I believed throughout my medical and anthropological studies. When analyzing these interactions through a narrative lens, I quickly realized that I was observing a “Diagnosis Narrative,” an enacted experiential performance of how the doctor assembles relevant information to pronounce the diagnosis. The computer program and the AUASS provides the templates—the schemas—to construct the narrative. Although I continued to

²⁶ A n authorization number is an indication of pre-authorization from the health insurance company. This allows the insurance company to review the clinical case before authorizing payment.

²⁷ Current Procedural Terminology (CPT code) is a standardized nomenclature of medical procedures, again allowing authorization for billing of services provided. It is a necessary part of obtaining a referral code.

observe for behaviors of the patient that contributed to this overall narrative, my subsequent observations remained consistent with my experiences that first day of fieldwork. My next question and objective of observations was to locate and identify where the narrative was located and who the *narrator* was. I recognized how important this process was, as illustrated by the following vignette:

Dr. Jeffries told the patient, “I can’t get a copy of your MRI to figure out if the stone is still present. I wouldn’t be doing you any favors if I took the stent out if the stone was still there. That’s why this information is essential.” Dr. Jeffries left the exam room and asked Carmen, “They are supposed to be sending it, aren’t they?”

“Yes.”

Dr. Jeffries said, “If we need to call again, I will call Regent’s Hospital. If I call, I’ll make people jump.”

Carmen went into the exam room and came back out saying, “I got the phone number.”

Dr. Jeffries repeated, “I don’t have a CT scan, but we need the results so we can take out his stent today.”

I had timed the entire process of tracing the CT or MRI data, recording over an hour delay for Carmen, Dr. Jeffries, and the patient. To use Carmen’s words, this type of investigation, Sherlock Holmes-style, was a frustration. I called this balance of identifying what data the doctor needed and how to acquire it “collecting the narrative elements.” At this point, I had no idea what the story was about, but I recognized the importance of the process to the experience for all involved. I was beginning to get the sense that the narrative schema called for the doctor to be the narrator of the diagnosis—counterintuitive, but complementary to the assumption that the patient was the narrator of the illness. This also became a consistent theme throughout the research.

More Examples of Narrative Schemas—Assembling the Diagnosis Narrative

At this point, I was still observing to locate the narrative. My methodological instructions were to continue observing until I was actually seeing what was happening from a cultural perspective. The following example confirms the diagnosis is a narrative schema and one of the roles of the doctor is to collect narrative components to pronounce the diagnosis.

When doctors work together, the process becomes slightly easier to observe, as they have to confirm verbally with each other the cognitive components of the diagnosis narrative. Because the doctors engage in a shared social practice, it was observable by me. Consider the following clinical encounter and note that filling in the narrative schema takes precedence over the actual experience of the patient, again confirming that the illness narrative is not a component of the diagnosis narrative, even though the patient may be the source of part of the data.

Dr. Stein gave Dr. Williamson specific instructions to make sure he read the self-administered history and physical questionnaire before going in to see the patient. When entering the room, Dr. Williamson asked only one open-ended question, which began, “Can you tell me about...”

The patient used English as a second language, and his expressive ability was limited. He said, “I am not going through my urine—not strong. I’m worried that there might be something wrong.” Later in the interview, the patient asked, “Did a kidney stone get into my prostate and that’s what is causing the problem?”

Dr. Williamson was nodding and occasionally said, “Sure.” Without a transition, Dr. Williamson started asking standardized questions, “How long have you had these symptoms? When did you have the stone? Is there any burning when you urinate? Do you wake up in the night to urinate? The patient apologized because his English wasn’t very good. Dr. Williamson said, “You left out a couple of answers here [on the self-administered form]. Dr. Williamson brought the rolling seat (a stool) closer to the patient and directed the patient’s attention to the paper.

The patient said, “I didn’t understand the question.”

Dr. Williamson rephrased some of the questions (going over the AUASS) and after talking to the patient without being able to ascertain the patient’s answer, said, “We will just say less than one in five.”

At that point, the patient said, “I can hold my urine but it is painful to do it.” At that point, I noticed that Dr. Williamson checked the lowest score for that item on the AUASS.

Dr. Williamson went out of the exam room to present the case to Dr. Stein, who asked about the PSA. Dr. Williamson just said, “The patient said his doctor checked it and it was okay.”

Interjecting, Dr. Jeffries leaned over and said, “Did you check here?” indicating the computer.

Dr. Williamson went on presenting the case to Dr. Stein and said, “The prostate is 30 grams with a good medial sulcus.²⁸ The patient scored six on the AUASS, but he was not satisfied.”

Dr. Stein said, "Did you give him all the adjectives?"

“Yes, I did.”

Dr. Stein said, “Happy, not happy....,” and proceeded to list five or six more possible adjectives.

Dr. Williamson said, “He's not pleased.”

Dr. Stein said, “Google it [AUASS] and you can get it in two seconds-- I'm old, you're young.” It seemed at the time that Dr. Stein wanted a thorough, accurate, and complete American Urological Association Symptom Score recorded in the chart.

This vignette is similar to the earlier one in that there was a language barrier; the patient was not the source of the necessary narrative elements. Doctors will fill in a medical history template, even if they have to interpolate or guess at the answers. Important at this point in the investigation, I became aware of from how many different sources the narrative elements were derived. I also recognized how important collecting such data was.

In my data, the doctor is heavily dependent upon a team of personnel to collect the data. Remember Brian’s need for data. In these scenarios, the data are the narrative components. Not only are ancillary personnel necessary for the doctor to function, but the data collection starts and ends by inputting and extracting data from the computer. In this manner, computer networks are the keepers of the diagnosis narrative as it is being constructed. Doctors, like engineers, rely on data to function in their job role. Current practice requires a complete dataset to be acquired, stored, interpreted, and re-stored, awaiting the “diagnostic pronouncement” by the doctor. I present several examples to illustrate this point.

²⁸ Medial sulcus is a slight depression between two lobes of the prostate gland.

On a different occasion, I walked into the clinic and it was immediately apparent that Carmen and Dr. Jeffries were having trouble accessing clinical data. Dr. Jeffries asked Carmen, "Have we asked if they could print it and fax it, because we can't do a thing until I get them?" The Administrator was talking to someone downtown in administration, simultaneously, in recognition that the difficulty accessing the information would disrupt the entire clinic schedule and cause patient dissatisfaction.

Carmen called the IT (Information Technology) help desk and said, "My boss was talking to someone downtown, and they're going to print it and fax it over to us." By saying this, she was acknowledging that the computer system downtown was unable to make the electronic records available at the Maplegrove clinic. On similar occasions, I recorded the time that Carmen spent doing this type of work, and it occasionally took her over an hour to get a specific report or piece of clinical data.

"I can't do a thing until we get them," is a revealing statement. Here Dr. Jeffries is saying that he cannot function in the basic role of the doctor unless he can access the data that is ordinarily stored in the computer. As I continued to observe, I paid particular attention to what type of data was stored in the computer and how the doctor used that data. The following demonstrates this same point:

Dr. Jeffries's last patient of the day had kidney stones, and he told me she declined any type of metabolic work-up. As we entered the room, he confirmed that was her decision. The patient said, "I doesn't want to take pills."

Dr. Jeffries then proceeded to give a long list of precautions, such as drinking copious amounts of water to keep the urine dilute, avoiding certain food, etc. The patient listened patiently and then replied, "I'm already doing all those things. What was the composition of the stones? That's why I'm here." She repeated that statement multiple times.

Dr. Jeffries said, "It often takes six to eight weeks, and they send them to Texas, so I can't answer that question right now." The patient left the office while Dr. Jeffries said, "If we can be of any further service just contact us." Dr. Jeffries then went over to Carmen and said, "May I ask where the stone analysis was?"

Carmen said, "It will take me ten minutes to get into the old chart."

Dr. Jeffries told her, "Ten minutes is all you get." He then mumbled under his breath. "She was pissed off, she waited that long, and she's being passive aggressive."

Dr. Jeffries, similar to all the doctors I observed, always tried extremely hard to meet the patients' needs. In this case, there was no diagnosis, and both the doctor and the patient were dissatisfied. By this time, I had realized that each of the CMAs takes primary responsibility and has a one-on-one working relationship with one of the faculty members.

Not only did the medical assistants assist in retrieving data required for a diagnosis narrative, they also assisted in generating such data. For this task, they often interacted with multiple different bureaucratic and social institutions:

Marsha then embarked on an extended task of trying to get prior authorization for a CT scan for the next day. It was with [a patient's insurance company]. She said, "I am calling for Dr. Patel," using his name. Next, she was placed on hold for an extended time before being transferred to someone else. When she didn't get the satisfaction of obtaining an authorization number, she hung up the phone and said to herself and to the phone that was hung up, "You can't even help me." She then made another phone call. "I was put on hold forever. I never heard of that number. Dr. Patel's NPI number²⁹ is 5845669328." She had a habit of asking for the person's name that she was speaking to and kept notes in her stenographer's pad. On the computer screen in front of her there was a scanned image of the [medical insurance] card displayed larger than actual size, approximately 7" x 11". She was reading the numbers from it. This became an extended episode of not only talking about a prior authorization for a CT scan but also for bone scan. Once she was on hold so long she simply hung up. She made a comment about trying to do this now because she knew that she would be too busy for the rest the afternoon. Marsha was talking to someone and said, "Hopefully, I'm not calling them back. I wrote her name down and I just want to double-check with you [that the authorization number was valid]. The other person I talked to didn't seem very helpful. It's crunch time. The surgery scheduling at Hopewell won't let them do it without prior authorization. This is for a prostate biopsy." All types of clinical information was requested and Marsha said, "The patient had a PSA, then a biopsy, and the biopsy was positive for cancer, so there were no symptoms." The person she was talking to kept asking for symptoms and Marsha kept saying, "There are no symptoms." Marsha then had to provide more information about the biopsy that had been performed on October 25. Marsha conversed with two or three different people; she kept writing their names down on the stenographer's pad. When she finally did get the

²⁹ NPI number, or National Provider Identifier, is a standard unique identifier for health care providers. And is a way to track physician activity. It was mandated by the *Health Insurance Portability and Accountability Act of 1996 (HIPAA)*

authorization number, she said, “Can I repeat that number for you? I just want to know your name.” She then had to call surgical scheduling and convey the authorization number to prepare for the surgery the next day. After she hung up, she realized she had been on the phone for approximate 35 minutes trying to get this preauthorization. Marsha indicated that that was usual. She concluded by saying, “Their attitude makes me mad and then it's my ‘snitty’ attitude myself which I don't like.”

I recognized that this was a lot of work, but I still could not recognize the story of the narrative. I merely understood that what I was seeing was the work of assembling vast amounts of data used to proceed with the cultural practices at my field site. Eventually, I came to understand that the diagnosis itself was a summary of the causative sequence and that pronouncing the diagnosis was the work of the doctor. I gained an appreciation for how important the computers were to do this work. The next excerpt is specific to the software used for the electronic health record.

Dr. Stein went over to Carmen and said, “Do I have to send her a task or can I tell you?”

Carmen asked, “What do you want?”

“I want to get a CT scan of the chest. Put on the requisition ‘renal mass, rule out metastases.’ I prefer that he have it done at Maplewood so I can look at the film myself.”

“I'll take care of it for him.” In this way, Carmen circumvented the computer software and simply focused on getting the job done.

Similarly, Dr. Jeffries referred to the software architecture while working at the documentation countertop:

“I can't believe this. I just had a complex discussion with the patient about elevated PSA. I took extra effort to do shared decision-making. There's no template in this electronic medical record for an increased PSA.”

Marsha replied, “Why don't you ask the electronic medical record team to generate one for you. Their job is to make your job easier.”

Dr. Jeffries said, “Yeah, the electronic medical record team is all about helping out the doctors,” very sarcastically.

“Dr. Jeffries, I think you should try yoga. That's what I recommend.”

Continuing with the concept of template medical records, Dr. Jeffries was working with Dr. Williamson, saying, “There are templates for this diagnosis that are comprehensive and fulfill all the criteria for Level 4 billing.”³⁰

Dr. Jeffries was distracted by a phone call, and Dr. Williamson was using the electronic medical record, choosing different radio buttons to click pre-defined choices in the database that would eventually be assembled into a clinical progress note. He said to me, “I object to progress notes written with electronic health records because it’s too much. I like to type with free text.”

While Dr. Williamson was working, Dr. Jeffries was on the phone but leaned over and said to Dr. Williamson, “If you’re going to document, you do it my way.” Dr. Jeffries then showed Dr. Williamson how to use the software and walked him through how to use the template in the software. “It’s not kidney pain, dude.” Dr. Jeffries demonstrated how to navigate through the medical record using only mouse clicks—click, click, click – the two of them standing side by side as they completed the progress note together.

The electronic medical record has become such an integral part of providing care that Marsha used the initialism EMR as a verb. Marcia was putting a patient in the room and she gave the patient a very cheery greeting. She was all smiles and in an extremely good mood. She was working with Dr. Stein and turned to him and asked, “Dr. Stein, do you want me to set up the procedure room or do you want me to EMR the patient in Room Two?”

Gathering diagnostic narrative components requires teamwork

On another occasion, there was a computer malfunction, and Dr. Jeffries asked Carmen about the next patient. Carmen was able to give a detailed medical history using medical terminology, correctly sequenced, and summarized the patient’s history of the present illness. She knew the names, doses, and frequency of the patient’s medication as well as his urinary volumes from when the patient had a Foley catheter placed in the emergency department of the

³⁰ Level 4 indicates a higher reimbursement amount for this visit—achievable only if you have all the components of the medical history included in the electronic medical record.

hospital.³¹ Observing this interaction I had the distinct sense that she was performing better than most resident physicians. Most importantly, Dr. Jeffries trusted the information and was able to complete the office visit.

This level of detail was not a unique experience. The next day, Dr. Jeffries said, “Carmen, how is Mr. Schmidt doing today?” Again Carmen provided a complete medical history. This type of accuracy and reliability was a result of Carmen reading each consultation and reviewing the medical records before scanning them into the chart. On one occasion, Carmen was eating lunch and opening mail. One of the pieces of mail was a three-page consultation letter from someone at the state university. Carmen read the report carefully and thoroughly before filing it.

The previous section documented the amount of work it took to assemble a complete set of data to provide patient care, but these observations made me realize the amount of personal responsibility the medical assistants took to involve themselves in this process. Not only did they know what information was needed to provide patient care, but they also understood the content and were able to provide it when the doctor requested it.

On one occasion, Dr. Jeffries stepped out of an exam room to ask Carmen, “What dose does Toviaz come in?”³²

Carmen said, “4 mg and 8 mg but she is already taking 8 mg.”

On another occasion, Dr. Jeffries started asking a question but Carmen stopped him mid-question and said, “It’s printing out the stuff right now.”

Dr. Jeffries asked, “Carmen, how do I manage signing all these attestations? I end up doing it all twice.” He was referring to how the electronic medical record forced redundancy in order to clear out his inbox.

Carmen said, “I’ll do it. Just go see the next patient.” She did his repetitive computer work so he could see another patient.

On another occasion, Dr. Jeffries asked Carmen, “What are these [papers]?”

³¹ This type of phrasing is typical in a medical environment, often filled with euphemisms—“placing” a Foley catheter is uncomfortable for the patient.

³² A medication for Benign Prostatic Hypertrophy (BPH) that helps increase urine flow.

Carmen replied, "I'll figure it out. Just sign them."

Again, she was doing the tedious paperwork so he could do the work appropriate to his level of training.

The medical assistants also worked as a team and cross-covered for each other effortlessly, frequently asking, "You need anything?"

Carmen said to Marsha, "I have to send that out for cytology."

Marsha said, "Okay."

Carmen responded, "You're the best."

Later, Carmen asked Barb, "Hey Barb, can you print me an insurance paper?"

Barb replied, "It's on the counter," indicating that she had anticipated Carmen's need and supplied the insurance information before Carmen actually asked for it.

Marsha had to "unlock" one of the electronic medical records and asked Carmen for help. Carmen said, "I'll do it for you because I love you."

Marsha replied, "You're the best."

Carmen followed that with, "You always help me when I'm in a jam."

After a busy day, Barb said, "We survived it."

Marsha said, "We are good at what we do. We run like a well-oiled machine."

Indeed, the office does "run like a well-oiled machine." These people truly have affection for one another. I use these observations to support my impression that the *doctor* is actually a group of people working in a highly coordinated fashion toward a unified goal: patient care. In order for a ritual to be efficacious, it must be performed correctly.

Clinical time and narrative time

In this section, I demonstrated the compression of time into a clinical encounter by retrieving past narrative components, procuring future narrative elements, and assembling data related to a schema for a diagnosis narrative. As discussed in Section I, the element of time is fundamental to narrative—it is what relates episode one to episode two. In order for the doctor to

create a diagnostic narrative, he has to fill in the blanks of the diagnostic narrative schema. It is in this way that I view the social practices described in this section. This diagnostic narrative is only one part of a larger healing ritual experience, but it is one of the more important. It is the basis for the one of the two functions of the healer, diagnosis and therapeutics. As I continued my research, I discovered yet another critically important component of the diagnosis narrative. There was something more than words or stories residing in the computers, something I take up in the next section.

To conclude this section about assembling narrative components for a diagnosis narrative, I provide one more vignette demonstrating the complexity of working with multiple computers simultaneously and sorting through multiple access points into various computer systems simultaneously in the context of completing a single clinical encounter. From the standpoint of ritual, I am still attempting to portray how doctors practicing Western biomedicine achieve a diagnosis.

Dr. Stein came out of the exam room and began documentation at the podium with the barstool-type chairs. He was actually using three separate computers and looking at paper reports simultaneously. On the left-hand computer, he was looking up lab test results in one software program on the right-hand computer he was documenting an electronic health record associated with the University. He was also incorporating data from the paper reports. The middle desktop computer he used to log onto Maplewood system to look at diagnostic images. Periodically through the session he was checking his email on his laptop. Dr. Stein was creating his documentation in the same electronic health record used by the others. I did notice that he was the first physician to all ten fingers to type (The others used different versions of hunt and peck.). Interestingly enough, he would open the same templates but only filled them in partially and then went to the preview of the consultation letter and edited heavily in the actual letter as opposed to entering the data in the database format of the electronic health record. He was meticulously writing a document. He asked Marsha, "Could you call a telephone number?"

Marsha scribbled the telephone number on a paper towel and said, "I need patient information to do that." Dr. Stein gave her the billing sheet that had the patient's demographic information printed on it and then Marsha called to get the

results of the scrotal ultrasound. She later reported to Dr. Stein, “Dr. Moss did the ultrasound himself and there is no report, but there were some labs.”

After Dr. Stein finished his consultation letter in the electronic health record, he took the papers to the large square formica box with the slit for disposing of protected health information and discarded the papers. I personally have seen them in four different offices and they are emptied by a standardized shredding service. There is a life cycle of paper in this office. Whenever paper documents are received, they are scanned into the electronic medical record. As the medical assistants prepare the patients for the office visit, they print the relevant scanned images of previous paper records so that they are available to the doctor. As indicated above, when the doctor has incorporated whatever he deems relevant into the note and is finished with the paper documents, they are shredded.

Embedded in this vignette is a clue to one of the key findings of this research. Included in the process of assembling data, Dr. Stein has one of his computers open to the Maplewood server where he can view the CT scan directly himself instead of relying on a printed report of the CT scan from a radiologist. In the next segment, I emphasize the relative importance of this type of data compared to all other types of data.

Figure 3. The documentation countertop used by the doctors

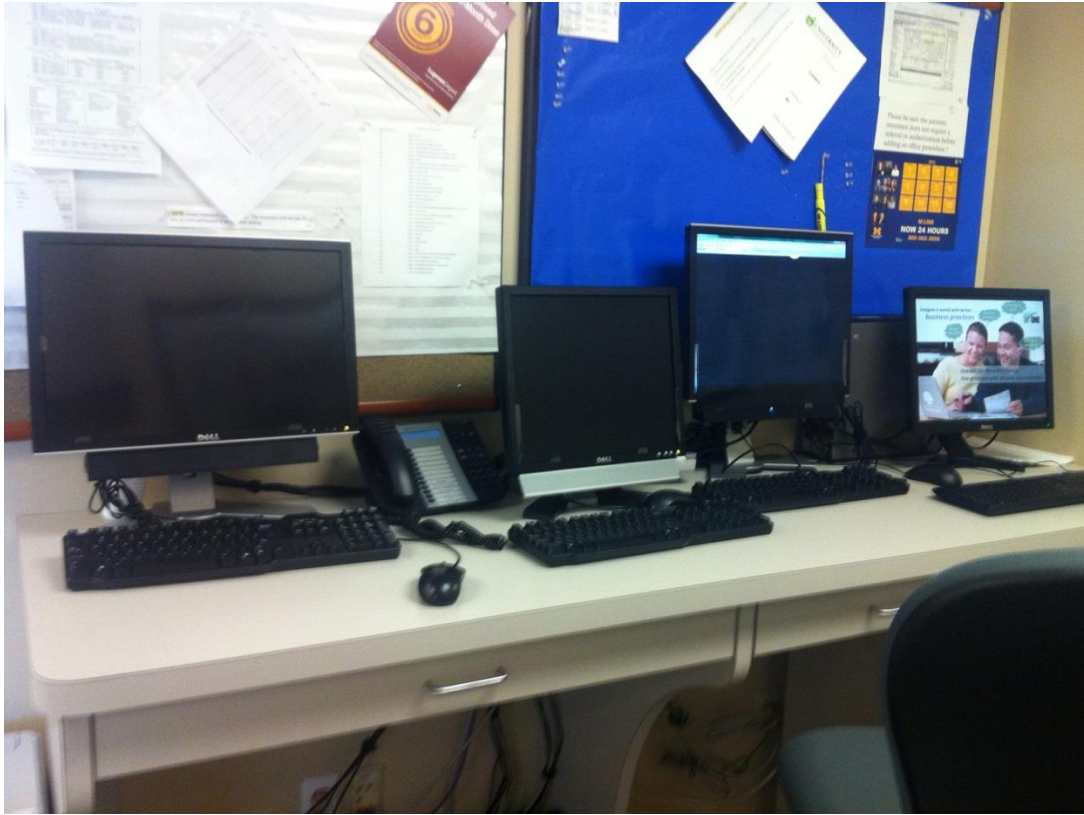


Figure 4. The CPUs for the computers on the documentation counter used by doctors



A cancer diagnosis is a three-dimensional cognition of the doctor

As an introduction to this discussion, I am going to refer back to Michael Tomasello who characterized our sensory-motor world in terms of spatial relations. He states:

All mammals live in basically the same sensory-motor world of permanent objects arrayed in a representational space; primate, including humans, have no special skills in this regard. Moreover, many mammalian species and basically all primates cognitively represent the categorical and quantitative relations among objects as well. These cognitive skills are evidenced by their ability to do such things as:

- Remember “what” is “where” in their local environments, e.g., which fruits are in which trees (at what times);
- Take novel detours and shortcuts in navigating through space;

- Follow the visible and invisible movements of objects (i.e., pass rigorously controlled Piagetian object permanence tests—some stage 6;
- Categorize objects on the basis of perceptual similarities;
- Understand and thus match small numerosities of objects;
- Use insight in problem-solving. [Tomasello 1999:16]

Ritual has an element of re-enactment, and this re-enactment occurs in a social space that is simultaneously a physical space. These basic cognitive skills allow multiple social actors to have joint attention to the ritual re-enactment. In Western biomedicine, the body becomes the physical location of the ritual. In this research, it is the body in the physical and temporal surroundings of a clinical encounter. While the prior section detailed gathering clinical data throughout time to record it in narrative and ritual time, this section highlights the nature of space as an essential component of the diagnosis narrative. Both space and time are important attributes for ritual and ritual healing.

As I mentioned earlier, the medical assistants and doctors assembled the information required to conduct an office consultation prior to the doctor walking in to greet the patient. In this section, I want to focus on a very specific but vitally important subset of that process: reviewing the imaging tests. The following vignette demonstrates the importance of viewing images to the work of the doctor. It is important because Dr. Stein attaches such a high importance to it.

Dr. Stein then resumed clinical work by reviewing a CT scan image. He addressed the medical student, “The CT is easiest for me because I have more familiarity with it.” He did look at the cyst on the kidney and said, “That looks benign.^{33, 34} It is eccentric³⁵ on the left.” As he was changing the slices on the CT image using the rollerball on the mouse, he pointed to and touched the screen,

³³ A cyst is a mass that is filled with fluid as opposed to solid; the significance is that cysts are very rarely malignant.

³⁴ Benign means not malignant—cancer is only one type of malignancy.

³⁵ This word means that the mass is growing outward from the contour of the kidney.

saying, “That is the kidney. There is a stone ... another stone.” He then commented, “This is so slow.” As he was continuing to review the CT scan he said, “This is so small.” Dr. Stein finalized his review of the CT scan by saying, “I don't think it's worth an operation for that little thing.” He then walked around the corner into the administrator's office. Coming back with administrator and pointing to the computer, he said, “There's the hourglass of death.” He was referring to the time it took to download the image. He asked the administrator, “What has been done about it?”

She said, “I contacted the people at the hospital. I asked the director and they told me the only other option was to drop a cable to improve data transfer [from the hospital across the street].”

Dr. Stein said, "How do we know they're doing anything about it?"

The administrator replied, “We purchased new computers. You approved the expense. It's not the computer. It's the data transfer that is preventing more rapid opening of the images.”

At that point, Dr. Stein repeated himself, “How do we know it hasn't just been dropped and forgotten about?”

The administrator replied, “It's been on our list. The only thing we can do is keep reminding them that we want something done. They work on their own time schedule and are not responsive to the response time we were hoping for. It will continue to be slow until they drop the new cable.”

Dr. Stein replied, “You have not calmed me down.”

The administrator replied, “Apparently that's not something I can do.”

After the exchange with the administrator, Dr. Stein came back to the computer and, looking at the computer with a medical student, said, “So I would not operate. I don't even want to try the MRI because it's going to drive me nuts.”³⁶

This vignette is important because Dr. Stein made a diagnosis, “I don't think it's worth an operation for that little thing,” simply by reviewing the CT scan image. The diagnostic narrative components were all contained in the reconstructed three-dimensional image. This is in contrast with the work involved in acquiring the other aspects of the diagnostic narrative mentioned in the previous section. The relationship between the two activities is that all the office work that led up to obtaining this CT image preceded the event of Dr. Stein reviewing this CT image. A similar experience when Marsha worked with the insurance company to get a pre-authorization to

³⁶ There is a much higher data load burden for an MRI compared to a CT scan

perform a diagnostic imaging test. In most cases, imaging exams were key diagnostic narrative components:

Dr. Stein asked Dr. Jeffries to look at images on the computer screen, saying, “There was a CT scan in 2007, 2009, and 2011.” He had all three scans open simultaneously. Dr. Stein said, “This area was present in 2007 and 2009, but looks cystic and non-worrisome. But on this 2011 scan it looks markedly different,” as he was scrolling through the mass with the rollerball of the mouse.

Dr. Jeffries said, “Sounds like you need to do a biopsy, or surgery.”

A few minutes later, Dr. Jeffries's came walking down the hall and said, “What did you decide to do?”

Dr. Stein replied, “Get more information with an ultrasound.” Although Dr. Stein said this with an absolute deadpan voice, never taking his eyes off the computer screen, it is vital to understand that this response was complete sarcasm: he said the exact opposite of what he meant to say. After consulting with his most trusted colleague and staring at the images repeatedly, he needed to make a decision; he needed to make a diagnosis.

I will return to this case in the next section, but at this point is vital to understand the role of three-dimensional cognition as part of the diagnosis narrative within a healing ritual. Indeed, I will present several other identical cases and relate how the doctors deployed the images in the ongoing ritual. It is only important to note that this was a daily activity, not something rare. The next vignette combines the concept of the three-dimensional cognition and the computer as repository of the diagnostic narrative components of scanned images.

A multidisciplinary care conference (MCC) is a type of tumor board where doctors from multiple disciplines review difficult diagnoses. The presenter solicits multiple opinions about diagnosis and management. At one session, a radiologist was reviewing images. He said, “This case shows a very large tumor on the kidney. I’m going to show the coronal images,³⁷ just to get a different vantage point. With the MRI of the abdomen, we can see the renal vein [pointing, speaking, and flipping through the MRI slices simultaneously]. We can track this all the way back. This is the renal vein and it is normal, not affected by tumor.”

Another case at MCC, the presenter was demonstrating the effect of chemotherapy by comparing two images simultaneously, “This mass is almost the size of the entire liver and after chemotherapy, it shrank to this—the size of a marble. But as we move down here [using the rollerball on the mouse], you can

³⁷ Coronal, the last of the three axes to create the three dimensionality slices the images of the body starting at the belly button and proceeds toward the spine.

see that the bladder wall is still thickened [indicating the source of the primary tumor].”

Dr. Stein presented a case at MCC, and toward the end he showed a PET³⁸ scan of the patient. This is different because it was in color, not in the black, white, and grey of the CT scan or MRI. The PET scan displayed coronal images, and Dr. Stein scrolled the wheel on the mouse, moving the images toward the front and back through different slices. He said, “Try to get a sense of the size and shape of the tumor.” As he was doing this, the computer screen was freezing, causing a delay in the presentation of the images, fragmenting the three-dimensional perspective. The computer’s central processing unit froze and an error message came up on the screen that indicated there wasn’t enough memory. This was followed by another error message that read “low memory detected.” Part of the problem was that he had left all the previous scans opened, but minimized—there were four or five of them. When the computer froze again, Dr. Stein stopped, saying, “I just wanted to show that PET-CT scan because it’s so clear.”

I will return to the three-dimensionality of cognitive processes as I present more data, but at this point I was convinced that the diagnosis was something the doctor arrived at by reconstructing the anatomy and pathology, using the various imaging techniques. My overwhelming impression at this point as an anthropologist was that I was observing the new and improved version of what Michel Foucault called “the clinical gaze.” I also recognized that my earlier observations of collecting diagnostic information to fill in the diagnostic schema during the office visit included collecting the CT, MRI, and other films for the doctor to review. Sometimes they were stored in the computer system downtown, sometimes they were stored in the computer system at Maplewood, and sometimes patients brought them in on a CD.

The practice of using the computer mouse and the rollerball on the mouse to flip through slices of the CT or MRI was ubiquitous. Every urologist did it during every clinic session. Other specialists, the oncologist and the radiation therapist, also practiced the same visualization technique. The following is an observation during oncology inpatient rounds:

³⁸ PET scan, or Positron Emission Tomography. This image is generated by a radionuclide (radioactive) particle injected as part of glucose (sugar). The images demonstrate physiology instead of anatomy.

The resident was presenting a follow-up case, and Dr. Spangler asked, “What about the EGD [esophagogastroduodenoscopy]?”³⁹

The resident said, “You want to look at the pictures? He got the chart off the rack and showed Dr. Spangler the printed digital images that were taken during the EGD.

Dr. Spangler said, “That is nasty and makes me want to puke.”

The resident said, “There were three liters of fluid that were taken out.”

As Dr. Spangler was looking at the printed digital picture she said, “Oh, my God! Oh ,my God, that is disgusting!” One of the residents commented, “It’s odd that a doctor is making a statement like that.”

Dr. Spangler said, “No, we’re sympathizing with her [the patient]. She wants to know where the necrosis in the stomach was, where the obstruction was. Oh, crap.”

The resident said, “We should strongly consider hospice.”

Dr. Spangler came back asking, “Where’s the pressure causing the necrosis coming from? Look at the last [CT] scan. Anatomically I can’t see it.” The stomach was necrotic,⁴⁰ even though it was pancreatic cancer. “There must be some compression, potentially of an artery or vascular structure causing the necrosis in the stomach,” Dr. Spangler continued, “She’s a walking skeleton.” At that point, everyone stopped what they were doing and Dr. Atlas pulled up the image of the CT scan and scrolled through the slices demonstrating the tumor, scrolling up and down until they could anatomically connect the pancreatic cancer to the area of the stomach that was black on the printed digital images from the EGD.⁴¹

Oncologists typically reviewed films during the multidisciplinary conferences in conjunction with urologists, radiation oncologist, and radiologists. To a lesser extent they reviewed them on an as-needed basis, as in the above example. In contrast to the urologists, who reviewed every single scan every single time, the oncologist would consider the radiologist’s opinion as sufficient evidence to make diagnostic decisions. The radiologist’s report, of course, required the radiologist to perform the same cognitive reconstruction of a three-dimensional image by reviewing different planes (cross-sectional, sagittal, and coronal) and flip through the sliced images to mentally create the holographic image. This is based on the mammalian and primate

³⁹ A combination of a fiberoptic light and tube to directly visualize the esophagus, stomach and first part of the small intestine.

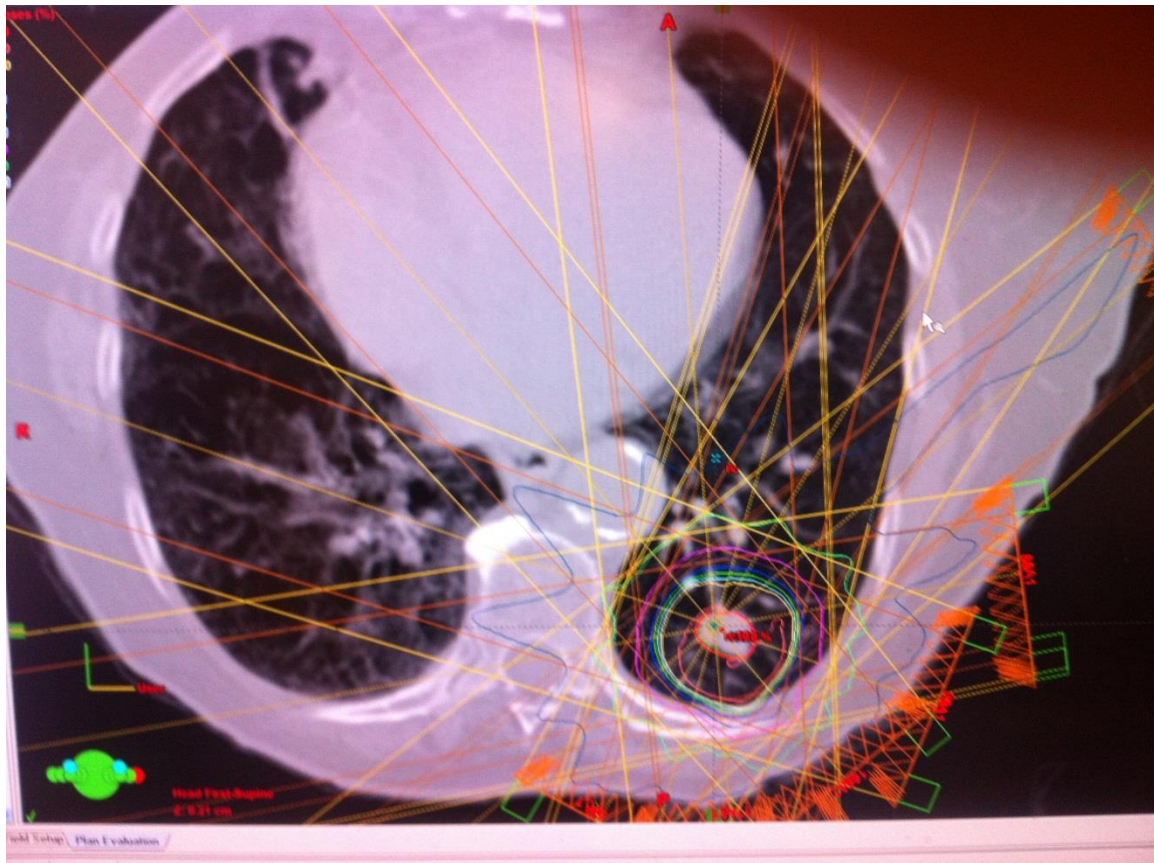
⁴⁰ Necrotic refers to dead tissue.

⁴¹ EGD—an acronym for esophagogastroduodenoscopy, a direct visualization of the esophagus, stomach, and the beginning of the small intestine.

cognitive abilities described by Tomasello and recorded earlier in this segment. The natural extension and progress in technology is to allow the computer to construct the hologram. This next vignette demonstrates exactly that:

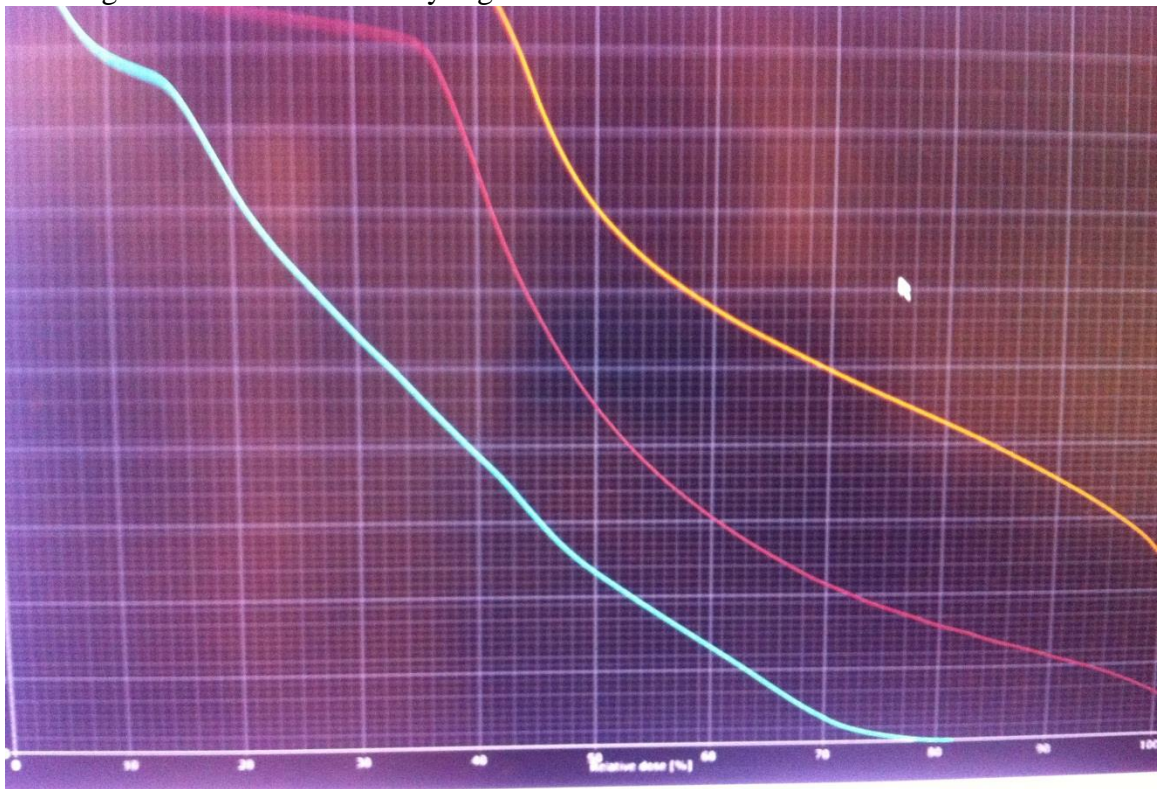
Dr. Rivers started explaining the entire process to me. He said, “I use the CT scan in the room next door and that is aided by MRI if necessary. It's my job to outline the prostate and specifically the contour of the prostate. I'm also responsible for indicating the area in which the radiation field can occur.” He used a computer system with software very similar to commercially available Adobe Photoshop, outlining the anatomical structures on the CT image itself. “Here I'm outlining the lymphatic bed. It's my job to actually read the film and identify the structures. When I'm done, I turn it over to the person who works on designing the angles and the dose. There is anywhere from two to five different angles. The object is to maximize the dose on the organ that needs to be treated. There are official standards of tolerances for dose irradiation for non-affected organs and this view represents those numbers in a dose volume histogram. The CT images of specific organs are reconstructed on the computer.”

Figure 5. Anatomical structures outlined on CT with dosimeter plan overlay.



Dr. Rivers referred to the building manager and said, “He is the best planner.” He then qualified, “One of the five best planners,” because apparently there are five individuals that do that particular task. He showed me a case of prostate cancer. “So on the X axis is the relative dose percent with the far right being 100 percent. The y-axis is the ratio of total structure volume with the highest point being 100 percent. On this particular radiation plan the prostate stays near the top of the graph, indicating that the entire organ structure received maximal dose for the entire therapy. The bladder dose falls quickly. These other lines are for each anatomic structure. For every line other than the area under treatment, it would be best to minimize the area under the curve... and conceptualizing how to do that is the job of the planner.

Figure 6. Histogram of radiation doses by organ.



Dr. Rivers is using the computer and the CT scan image in the same manner as Dr. Jeffries and Dr. Stein, identifying pathologic organs and outlining them anatomically. Again, this diagnosis is for treatment planning. The treatment planner cannot make the diagnosis; his job is merely to calculate angles and doses to fit into the standardized tolerances. Because the connection of diagnosis to therapy is so closely linked, it is difficult to isolate them. I will

explore therapy further in Chapter 10. For now, I want to demonstrate how all physicians use the rollerball on the mouse while interacting with computer images and to illustrate the next logical formulation that is fairly represented in current medical practice, the hologram.

When he was looking at the CT scan, he was using the rollerball on the mouse coming back and forth using slices to re-create and identify structures in the same way that I saw Dr. Stein and Dr. Jeffries do hundreds of times. He said, “In radiation oncology we use stereotactic body radiation therapy. We are able to use a 4D CT, meaning the CT scan monitors the maximal excursion of the organ being treated during respiration. That way we can limit the amount of radiation to that tightly defined boundary. The only other alternative is to extend the boundary to make sure we treat the entire diseased organ.”

Figure 7. Computer-rendered three-dimensional avatar

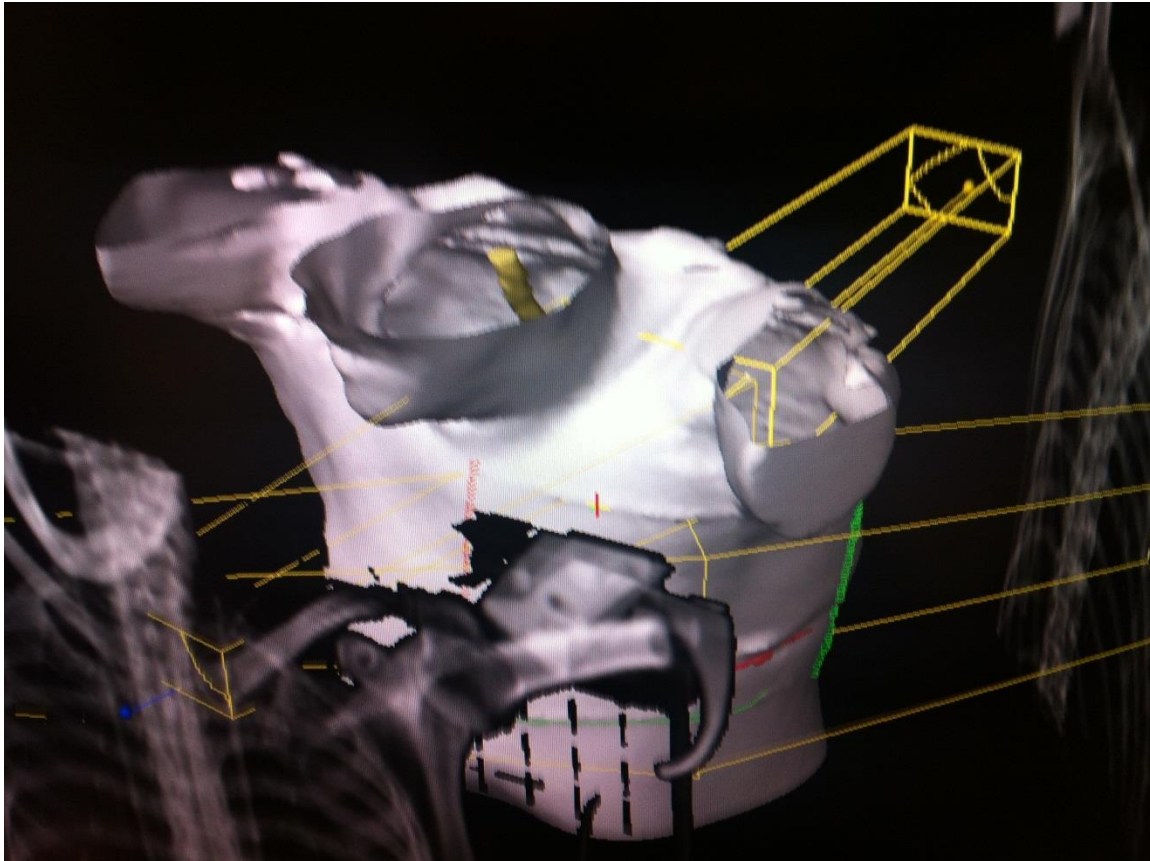
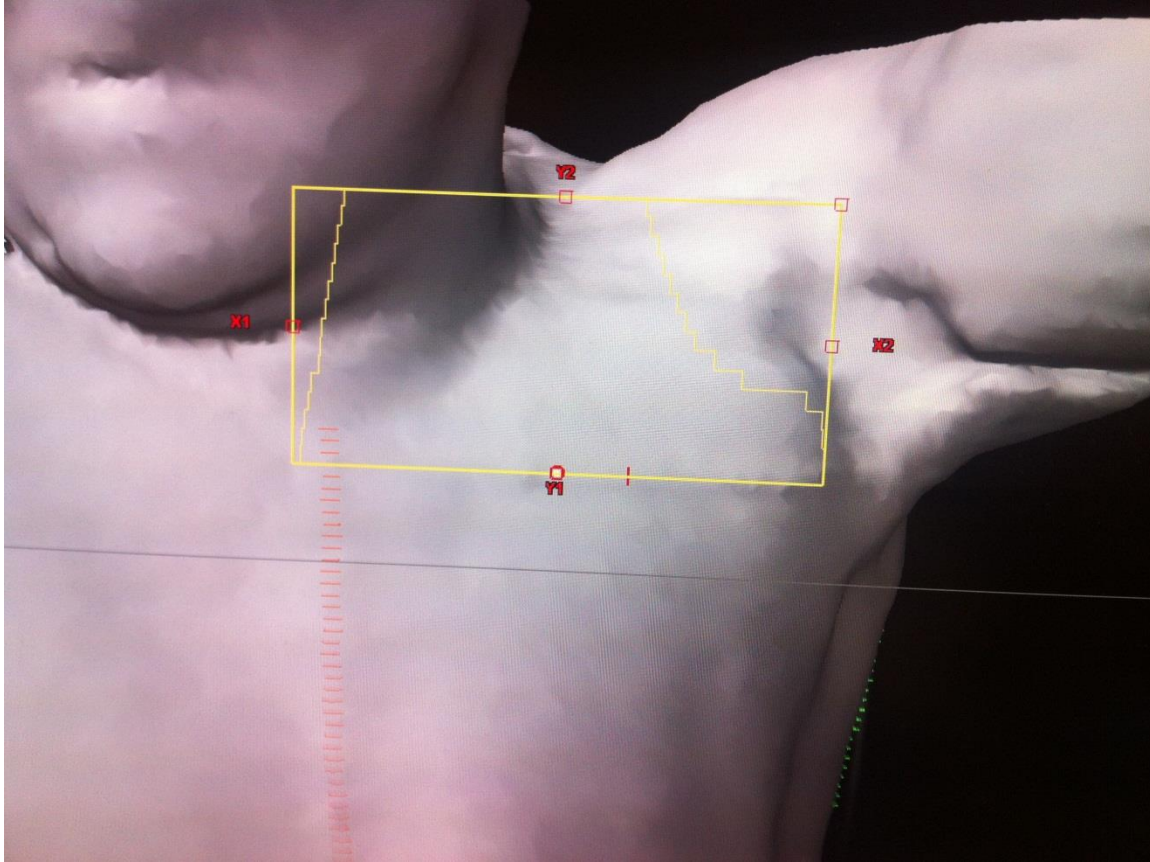


Figure 8. Another rendering of an avatar whose images can be manipulated in space



At this point, I have demonstrated that a cancer diagnosis is a three dimensional cognition of the doctor. During fieldwork, I witnessed hundreds of such examples from multiple specialties coordinating with the urology team that constituted the sampling frame for this research. At the time I was amazed and thought that I had discovered something fascinating. I began sharing my discovery with people and presented preliminary findings at a national professional convention of researchers. I had been working on the research project for almost two years, all the while believing that I had discovered something unique. As mentioned in Section II, self-reflection is part of objectivity. It was a brutal shock to me on the day when I realized I personally had been doing the same thing in my own clinical practice for years. This highlights the difficulty in

observing one's own culture when immersed in it and the advantages of taking an anthropological stance and viewing cultural practices as an outsider. After that self-realization, I told myself that my experience accounted for "face validity" of the findings.

Diagnosis is critical to the healing ritual. At times, it is called divination, listening to the oracle, proceedings, leechcraft, clinical gaze, or some other term. Yet, diagnosis is essential to the healing ritual. Using the diagnosis narrative schema to achieve a three-dimensional cognition of diseased organs is the Western biomedical equivalent of leechcraft.

The doctor creates the diagnosis from narrative components and proclaims the presence or absence of disease.

In this segment, I describe the sequential next step in the ritual process. Because it is the role of the doctor to ascertain the diagnosis in a healing ritual, it is normative to portray this portion of the ritual as an activity of the doctor, not as an activity of the patient. This is in contrast to other anthropological literature that portrays assigning a diagnosis as a misuse of power over the patient. It also explains why the illness narrative has not yet entered into the healing ritual. Rather than stigmatize doctors as powerful and patients as victims, I suggest that both are participating in a socially sanctioned ritual, each with their own part to play. Later I will portray the reciprocal balance of power, but at this point the doctor has achieved a diagnostic cognition prior to entering the consultation room where he shares the diagnosis with the patient. It comes in the form of a pronouncement that is resilient to change.

As mentioned above, every office visit began by collecting all the relevant clinical information and reviewing the imaging studies. After preparation, the doctor went into the room

prepared to convey a decision he made prior to ever greeting the patient. Consider the following examples:

Dr. Jeffries explained to me, “The next patient has a seven-millimeter renal mass and it doesn’t meet criteria for biopsy. The patient is complicated because she’s on warfarin.” He went into the room, which was the first time he ever met the patient, and the patient was sitting there with who appeared to be her mother. He opened by saying, “I know you know why you’re here. I’m just going to say it anyway. There’s a lesion on your kidney or a mass or tumor. Those words are all bad because they have negative connotations. What you really have is just a small bump on your kidney. I can’t promise you that it’s not a malignancy, but by imaging criteria and size criterion I’m not thinking of doing surgery. I’m sure you have a lot of anxiety and your doctor has a lot a lot of anxiety.”

The patient said, “That’s true.”

Dr. Jeffries resumed, “I have a suggestion that may resolve all the problems. I recommend a biopsy with the interventional radiologist at Connaught Cancer Institute. They will not only evaluate the seven-millimeter lesion to determine whether it needs to be biopsied and if necessary also do a biopsy of the kidney for the nephrologist because she is considering lupus nephritis.”

Dr. Jeffries and left the room first, and then the mom and the patient started laughing aloud. While laughing, the patient smacked the mom on the back with a magazine and said, “I told you there’s nothing to worry about.” As they were leaving, the patient said, “Goodbye. Thank you.”

This was a very short visit with a new patient. The patient was pleased simply to hear good news, that she didn’t have cancer. There was no long explanation; the patient and the patient’s mother simply accepted the diagnosis at face value. I witnessed this same social dynamic many times, and I labeled it the *diagnostic pronouncement*. The important thing is that the doctor always made the decision before seeing the patient. In the next vignette, Dr. Stein introduces himself and discursively steers the patient to his pre-formulated diagnosis:

Dr. Stein was also seeing a patient in consultation, so he approached the patient as if he never saw him before. He reviewed all of the medical records prior to entering the room. Upon entering the room, he said to the patient, “I reviewed all of your scans before coming in, and I think I know why you’re here, but I’d like to have you tell me why you think you’re here.”

“I’ve had many biopsies—at least eight or nine—because my PSA is 19.”

Then Dr. Stein told the patient, “My partner sent you to me for a different type of biopsy.”

“Is it going to hurt?”

Dr. Stein said, “We’re going to do it in the operating room and so they will give you something so it won’t hurt, but you won’t be totally asleep.” He took a plastic model of a prostate off the windowsill and said, “This is the direction the needle usually goes to do a prostate biopsy, but Dr. Patel wants a different type of biopsy so we can check a different part of the prostate. The needles will go through the skin. They go in at a different angle,” and then using his index finger demonstrated the direction and area of the prostate he was going to biopsy. “Everybody is worried about a cancer that hasn’t been diagnosed. It’s mysterious why your PSA is high, because your prostate is not that big.” Dr. Stein leaned back and said to the patient, “So do you want to do this biopsy?”

“Yes.” At that point, the patient went out to the appointment counter.

Dr. Stein said to Barbara, “Schedule him for a saturation prostate biopsy and if they ask they can set up the operating room similar to brachytherapy.”⁴²

Again, there was a pronounced diagnosis: “I’ve reviewed all your scans before coming in.” He already has in mind what he is willing to offer the patient. The patient can accept or decline, but the diagnosis doesn’t change. Even when patients think they know the story and convey clinical data, it is the prior review of the diagnostic narrative schema, including review of the images by the doctor, that creates a component of the ritual process. The following vignette demonstrates this point:

For the next patient, Dr. Stein was looking at the CT scan and again said, “There it is. I can’t memorize T1, T2, but blood is white,” pointing to the screen and then said, “No, I’m sorry. That’s the gallbladder. These images are loaded backwards. They are labeled ‘R’ on the left side of the screen which is standard, but as I take progressive slices lower, the liver becomes more prominent on the right side of the screen.” He pointed out that discrepancy to the medical student. After standing in the hallway reviewing all the images, Dr. Stein went in to talk to the patient. He sat down on the stool looked straight at her and said an introductory hello.

The patient said, “Let me help you out. I had proteinuria,⁴³ so I was sent to a nephrologist initially, had an ultrasound and the CT scan, and then the MRI. I saw Dr. Patel who asked for the second opinion by you.”

Dr. Stein allowed the patient to complete the entire chronology and only then said, “We just spent 20 minutes reviewing the different scans. I think the probability is that the cyst is benign. It’s a very low probability that it’s cancer.”

⁴² Brachytherapy is the placement of small “seeds” into the prostate that emit high dose, localized radiation therapy as a treatment for prostate cancer.

⁴³ A word that means protein in the urine—normally there is not supposed to be any detected, but if it is, it is considered abnormal.

While Dr. Stein was in the room, he only made direct eye contact with the patient. “I recommend you come back in six months to have a checkup with the CT scan.

We left the room, and as she was leaving the room passing the podium she said, “Thanks for the reassurance.”

As indicated above, most patients don’t challenge the diagnosis or management. The following example was one of the few exceptions I observed. In this example, the patient’s challenge did not change the diagnosis or the recommended management:

Dr. Stein said to the medical student, “I’m done but I have a CT scan of a patient I saw last week here on this CD.” He then inserted the CD into one of the computers at which point he turned to the fourth-year student saying, “This one loads quickly because all the data is on the CD and we don’t have to wait for data transfer.” Dr. Stein then went over with the medical student a detailed analysis of the CT scan saying, “The tumor is in the top location.”

Dr. Jeffries was finishing his clinic session and said, “Is that for a partial?”

Dr. Stein said, “I haven’t done an open partial in the longest time but this would be a crazy partial. This was an incidental finding. After I looked at it, there are difficulties in doing this laparoscopically.⁴⁴ It’s behind, not anteriorly. It’s too big. Eventually I need to call the patient and tell him ‘I think you need surgery.’”

Dr. Stein then called the patient saying, “I got your discs. This is a sizable tumor. My preferred approach is to do an open surgery.... I agree with you but it’s not in a good position. It’s too big to attempt it laparoscopically. I am doing a lot of surgery laparoscopically, but in my judgment this one would be too difficult.” He then used his index fingers to count space on the countertop before saying to the patient, “It’s about 6 to 7 inches in diameter.... I’m looking at the CT scan while I’m talking to you.... You would be laying on your side.... The incision would be under the ribs. We could use stitches or staples whatever you prefer.... We can put stitches in if you would like.” There was a short pause and then Dr. Stein said to the patient on the phone, “I’m trying to do as many cases laparoscopically as I can, but this one is in the wrong place, is too big, and the tumor itself will be difficult to resect⁴⁵.... You’re also going to need a CT of the chest to make sure it hasn’t spread. A lot of urologists would simply do the easier surgery which is the total nephrectomy but it’s always better to do a partial nephrectomy, even if you can’t do it laparoscopically. I’m pretty aggressive laparoscopically and I have a lot of confidence.... I don’t want to do this one laparoscopically. I don’t know what [another surgeon] would do.” After getting off the phone, he turned to Dr. Jeffries, saying, “It’s oblong, exophytic as well as

⁴⁴ Laparoscopically means surgery done through a metal tube the diameter of about a finger—all the cutting, clamping, and visualization instruments are inserted through this tube inserted into a one inch incision. Other instruments are sometimes also inserted through other small incisions simultaneously.

⁴⁵ Resect means to cut out of the body.

endophytic, deep in the retro peritoneum and asked Dr. Jeffries for a second opinion.⁴⁶

The vignette has rich detail of multiple different aspects of the healing ritual and anticipates both Chapter 7 (Persuasion) and Chapter 8 (Relationship of Diagnosis to Therapy). Here, I want to point out that like every diagnosis, the culmination of gathering narrative diagnosis elements results in the review of the three-dimensional mental image of the cancer in relationship to location in the body, surgical access points, and technical considerations in acting on the diagnosis. When Dr. Stein pronounced this more complex diagnosis, he refused to change his opinion, despite multiple challenges from the patient. Dr. Stein dismissed newer and more sophisticated technology based on the three-dimensionality of his diagnosis. He also defended his diagnosis against the cultural model of newer technology always being better. As I mentioned, the ritual components flow seamlessly, and I will move to those considerations in the next two chapters.

The diagnostic pronouncement

The concept that the doctor makes the diagnosis and pronounces it to the patient without benefit of input from the patient seems harsh, yet it was a consistent finding throughout the research. Others argue that this finding demonstrates that Western biomedicine is detached from the social reality of the patient. I argue that it is merely a component of an ongoing ritual that defends against alienation, alienation of the self to life and the self to society. I provide one more example of the pronouncement of a diagnosis. This time it occurred on the inpatient oncology service:

⁴⁶ Exophytic means growing outward, endophytic means growing inward.

The resident was presenting another patient who had metastatic prostate cancer. “He is a patient of Dr. V. He is on a Phase I drug versus placebo trial⁴⁷ and scheduled to receive radiation therapy but was admitted with nausea and vomiting. They gave him the Zofran this morning.⁴⁸ Apparently, the patient also tripped and fell.”

Dr. Spangler summarized the management by saying, “Get physical therapy and occupational therapy on board.”

A resident was reading one of the reports and the report had a big word in it. He said, “I’m not even sure what that means. The previous CT scan was done in January.”

Dr. Spangler replied, “That’s probably just fatty liver.”

The oncology fellow then turned to check the labs on the computer, “The PSA was 260.” He showed a graph of the PSA, and although it looked like a stock market graph, the end of it went straight up.

Dr. Spangler asked, “What was the calcium level? So why is he puking?”

One of the residents guessed, “Hepatitis.”

Dr. Spangler asked, “How much narcotics is he getting today? We still haven’t solved the issue of why he’s puking.”

“Could it be the radiation...or brain mets?”⁴⁹

Dr. Spangler said, “I’ll be a monkey’s uncle if it’s brain mets.” She thought about it, “I guess I can’t be an uncle but I’ll be a monkey and aunt,” then used it as a contraction, “a *m’aunt*.” She was referring to the fact that prostate cancer rarely metastasizes to the brain, unlike lung cancer in the previous patient. “We need to talk to him about goals. We’re pretty much done. We need to send him back to his primary care physician. He is living off half of a lung. He needs to finish out the course of radiation therapy, get occupational therapy and physical therapy.” She then pulled out her iPhone to look at the calendar, calculate how much longer the radiation therapy would continue, and made the statement, “He has two or three weeks more to go [with radiation therapy]. “We’ve maxed out what we can.... It’s a hard discussion. Social work needs to find out what he needs at home. This is going to be a hard discussion, because he just lost his daughter and his mom. He’s dying and is only 55 years old.”

The diagnosis was “He’s dying.” Dr. Spangler reached this conclusion while sitting around a table in the hospital reviewing CT scan reports, the medical record, laboratory data, and other diagnostic narrative material. It was not an inconsequential diagnosis. It was also not the

⁴⁷ Phase 1 trial is the first time a new pharmaceutical or chemotherapeutic agent is used in humans. The research is designed only to determine if it is safe. There is no intent to even determine if it is useful or not. It is like experimenting on human guinea pigs.

⁴⁸ Zofran is a drug used to treat vomiting, especially in patients receiving chemotherapy.

⁴⁹ Met or mets is shortened slang for metastasis, or spread of the cancer to distant organs.

conclusion to the healing ritual. There was more doctoring to be done. After all, the healing ritual addresses existential threats.

Summary of Chapter 6

Establishing a diagnosis is essential to the healing ritual. It identifies the existential threat, naming a disease. When doctors proclaim the diagnosis, they are really telling a story of how the diagnosis was established. This diagnosis story or diagnosis narrative has temporal and spatial components. The importance of this diagnosis narrative forms the foundation for the entire ritual. I demonstrated that making the diagnosis is the work of the doctor, as predicted by the healing ritual model at the beginning of the chapter. Conspicuously absent is the illness narrative, which has no ability to establish the name of the existential threat. The diagnosis narrative has a narrative schema specific to a story about a diagnosis, and that schema is the specialty of the doctor. The patient is expected to provide data to fill in this schema, and the doctor solicits exactly what type of data is needed. In this case, the imaging data is critically important to tell the story of the diagnosis, and doctors and medical personnel spend tremendous effort to retrieve and interpret these data. Once the diagnosis narrative is formulated, it is pronounced; again, highlighting the specific role of the doctor, the pronouncement is also a sharing of the storyteller with the listener, setting up the next component of the healing ritual, persuasion to the preferred narrative, the biomedical diagnosis narrative.

Chapter 7: Re-education and persuasion

W.H.R. Rivers describes medicine as a set of social practices that “seek to direct and control” disease (2001 [1924]:4). The imperative to control disease derives from “[disease lowers] vitality and tend toward death” (Rivers 2001 [1924]:4). Although subtle, Rivers identifies the object controlled as the disease, not the person or the body, as portrayed by Foucauldian thought. This allows for shared participation in a cultural practice, as both patient and leech agree with the basic intent of their shared activity, control of disease. If there was no disease or death, there would be no need for leeches (doctors) or leechcraft (medicine). Rivers locates the healing ritual within the cultural body, not the body politic.

Rivers continues his formulation with multiple references to causation, “One element of the concept of disease, and perhaps the most important, is that it includes within its scope the factor of causation” (2001 [1924]:6). Tomasello reminds us that humans understand the world in causal terms (1999:18-19). Shared cognitions of causal understanding create culture and, in this case, the subculture of Western medicine. Again, in order for medicine to be sustained as a cultural practice, it must be a shared understanding, and in this case a shared understanding between doctor and patient. Rivers says:

In the case of one process, the attainment of self-knowledge as a means of treatment, the resemblance with the social process of normal health is so obvious that the physician has come to use a term derived therefrom. The process by which a faulty trend of feeling, thought, or conduct is diverted into a more healthy channel is generally known as re-education. [2001[1924]:127]

Re-education is part of Kleinman’s explanatory model. He says, “No doctor is taught how to explain the biomedical account to patients. Yet this is an essential task in the work of doctoring” (1988:240). Similarly, Fortes indicates, the diviner provides a diagnosis and the consultor confirms it prior to adoption for action (1987:9).

In the case of the healing ritual, Rivers refers to the “re-education” of the patient into the belief system of the leech after the proper diagnosis has been ascertained (2001 [1924]:127). If the fundamental structure of the healing ritual results in the re-education into the natural causes of the disease, this bears a marked resemblance to the endeavor of Western biomedicine. I use Rivers’s term “re-education” and *persuasion* interchangeably. It is imperative to acknowledge that the patient is persuaded to recognize in themselves part of a culture that they implicitly share with the doctor—biomedical science. This is not a form of aggression by the doctor on the patient.

Patients are socialized to live within the world of the medical diagnosis and to use that social reality to deal with ongoing disruptions in their lives. Thus, the disease and how it is “removed” becomes a part of the self-narrative, allowing for the ongoing self-narrative to continue through a transformative process that is socially recognized, supported, and sanctioned. The process of re-education creates a change in the patients’ self–stories, a second major component of narrative within the healing ritual. The self-stories converge with the diagnosis narrative and become a shared *diagnosis–illness narrative*.

When observing the healing rituals, Evans-Pritchard gives the following insight, “If one witch doctor fails to cure Azande he goes to another in the same way as we go to another doctor if we're dissatisfied with the treatment of the first one we've consulted” (1976:108). In the data presented I described several patients seeking second opinions. They are following a pattern described by Evans-Pritchard. If there is a failure to agree upon the diagnosis, the healing ritual becomes a narrative failure and the individual becomes suspended in unnamed disease or disputed disease, unable to complete the ritual and the desired transformation it provides. I will present examples from my data and from the anthropological literature to illustrate this point.

Persuading Brian to the best treatment plan

Brian’s story continues. He uses the word “consensus” in a somewhat abstract way, as if he is not part of that decision. Although nonsurgical options are mentioned, they are discounted. Brian is seemingly effortlessly propelled to the “logical” therapy, radical prostatectomy.

It was a follow-up office visit, that once I'd gone in and then he had done the biopsy and then when I came back I think I got a phone call to come in and sit down and go through the results. Well, you're always thinking – Well, I'm – you're back and forth. It's not gonna be me. Or, yeah, well, maybe it is. And then what's it gonna – you know. Then my entire life is gonna change. So you're back and forth, I was back and forth between, okay, I'm gonna deny that this is happening or I'm gonna accept it and get all wigged out and that's going to be too difficult to handle.-- So I'm gonna go back here and say, you know, statistically, I'm sure this is not me. And so we just move on. And I don't remember how long it was. I don't recall it as being an extended period of time. It was within a few days, I think.

Once the biopsy came back and he said, “Yeah, you do have cancer.” You go, “Hmm.” That was kind of a wakeup call. I was pretty young and certainly – and I had no symptoms, none, nothing to – no blood, no large prostate, no problems going to the toilet, no nothing. So it was pretty much out of the blue that there was even anything recognized, that there was anything wrong. So that was a little bit of a setback or at least a concern. The biopsy came back positive. I think it was four of seven samples were positive for cancer and it was deemed to be a fairly aggressive form of it at the time. And as it turned out it was just in time. I had a discussion with the surgeon afterwards about how long I had before it got beyond the prostate because it was all contained within the prostate, which was one of the things I attribute to a good outcome and everything. Okay, well, how long did I have? “Certainly six months. Maybe a year.” But it was a fairly aggressive growing, growing form of cancer.

From all he could tell it was contained within the prostate. So I think I met again with the – a doctor to go over treatment options and that type of thing, and the basic consensus was for someone of my age, which was 51 at the time, that I should think about surgery as the option rather than radiation or some other passive wait-and-see type of treatment. So we discussed that, my wife and I, and thought a second opinion was something that we should at least pursue at that point. But his characterization of it was, it's a Gleason, so I think it was seven, and that was on the higher end of the aggressive scale it wasn't the most aggressive.⁵⁰

⁵⁰ Gleason score is a combination of two numbers from two samples of the biopsy when added together are a measure of how aggressive the cancer is. This affects prognosis.

But it was getting towards that point which meant it was – what it meant to me was it was a fairly fast-growing thing that isn't something you would sit there and do nothing with because it's – something else is gonna kill you first. It was something that should be treated was the message I was getting because of my age, that I had a great lifespan left and the cancer was fairly aggressive, and so the two were not compatible. So something needed to be done about it. It was – I don't remember his exact words, but it was laid out within the context of I'm a relatively young man. I'm 51, at my age he would recommend the surgery as the best form of treatment, because I have a long life yet to live and some of these other things are not – Don't get rid of it and could lead to more things down the road if radiation, for example, doesn't quite do it or there's some complications with radiation. And there was also certainly complications with – potential complications with the surgery, but it was the goal of getting rid of it. Fixing it.

Brian said, “I met again with the doctor to go over treatment options...the basic consensus was for someone of my age, which was 51 at the time, that I should think about surgery as the option rather than radiation or some other passive wait-and-see type of treatment.” The consensus he was referring to was a consensus among doctors, and, almost imperceptibly, he joins that consensus by consenting to the surgery. He was talking about the portion of the healing ritual that is the topic for this chapter, re-education and persuasion.

Seeing is believing

It was common, but not universally practiced, to re-demonstrate the CT scan review with the patient as a method of explanation of the diagnosis. Consider the next observation.

Dr. Stein was talking to the medical student at the documentation countertop, pointing to a CT scan, saying, “Look at that renal mass.”⁵¹ He was flipping through the CT scan slices as I had seen him do innumerable times. He said, “This is the nephrogram phase and this is the collecting system phase.”⁵² You check the non-contrast images to check for kidney stones,” and then he motioned Dr. Jeffries to join them, “Look at this scan.” Dr. Jeffries, Dr. Stein, and the medical student were all staring at the CT scan. Because I was just standing there, I

⁵¹ Renal is another word for kidney.

⁵² During CT scans or MRIs a contrast dye is injected into the vein. First it is collected in the tissue of the kidney and second it concentrates into the collecting system (the plumbing), making it easier to identify anatomical structures.

naturally drifted over to view the scan as well. All four of us wound up staring at the CT scan. Dr. Stein said, “Here’s the kidney.” He used his finger to point to the image of kidney on the CT scan as he reviewed the various slices of the CT image from the top to the bottom and back, finding the optimum slice to demonstrate what he wanted to demonstrate to the rest of us. Finding the optimum slice, he used the arrow location on the screen, controlled by the mouse, making circular motions with the arrow to point out the abnormality on the kidney that was suggestive for a renal mass. Dr. Stein said to Dr. Jeffries, “This would be difficult to do robotically.” Dr. Stein then used the rollerball incessantly and when I looked over to see what he was doing, I saw him scrolling through the sagittal⁵³ slices of the CT scan instead of the cross-sectional images.⁵⁴ Dr. Jeffries and I saw another patient and when we came out of the room from that office visit, Dr. Stein was still looking at the exact same films of the patient with the renal mass. Dr. Stein said to Dr. Jeffries, “Take a look at this. Do you agree this is a stone?”

“Yes.”

“They completely missed it when they read this CT.” Dr. Stein then asked the patient to come out from the exam room and brought them over the computer and pointed to the kidney stone on the CT scan and said to the patient, “This is where the kidney stone is, right between the bladder and prostate.

The patient asked, “Is my prostate large?”

Dr. Stein said, “Yes, and I’m surprised you’re not having symptoms.”

Dr. Stein asked Dr. Jeffries, “Will you do the ureteroscopy and take care of the stone, and I’ll take care of the renal mass later? I’m going to get a CT-guided biopsy of the renal mass.” They agreed to schedule it at Maplewood. All these scans were on a CD that Dr. Stein had put in his computer. Dr. Stein said, “Maybe the patient should keep the disc.”

Dr. Jeffries said, “I wish we had a way to upload those images to our computer.”

Dr. Stein then put the CD in an envelope and told the patient, “You need to bring the disc to the operating room so that they could look at it when you get there.”

There are multiple key practices revealed in the above example. The first is using the rollerball on the mouse to flip through the slices of the CT scan. This is similar to a pack of cards that you flip through to create the image of a figure in motion (replicating an old-fashion silent movie.) The doctors did this without exception for every imaging test that they had not previously reviewed.

⁵³ Images created by taking slices at a ninety-degree angle for the entire length of the body—starting at the side of the body and moving toward the middle.

⁵⁴ Most common angle of slices—through the body as if it were a sausage.

There are three levels of persuasion in this vignette: first Dr. Stein persuades himself that he has made the correct diagnosis; then he persuades Dr. Jeffries his own diagnosis is more correct than the one in the written report by the radiologist; and finally he brings the patient out of the exam room and points out exactly where on the image demonstrates his rationale for treatment. In this case, he suggests treatments, one by Dr. Jeffries for the kidney stone and the definitive cancer treatment subsequently scheduled with him.

Again, a similar observation demonstrates the same format:

Dr. Jeffries walked down the hallway to an exam room, saying to the people in the room, "I want to show you on x-ray – would it be possible for you guys to come down here?" referring to the documentation desk with the computers to view the CT scan images. There was an older woman who didn't speak English, a younger woman who translated from Spanish, and a five-year-old little boy who was running up and down the hallway. I played with the little boy a bit so the others could concentrate. Dr. Jeffries said, "This is the CD [with the CT scan on it] you brought me." Then standing in front of the computer screen he turned around and faced the patient and the interpreter.⁵⁵ He did a demonstration on his own body saying, "This is like a special telescope, so this is the right side and you're looking in this way." He then turned back to the computer and used the computer mouse rollerball, scrolling through the CT slices, saying, "We're moving inward here from the belly button."

The younger woman was translating everything he said. At one point, she said, "Can you put them back side-by-side?" She was referring to the two kidneys. Dr. Jeffries adjusted the slice image on the CT scan and there was a prolonged time of interpretation directed at the patient by the interpreter. The interpreter was pointing at the computer screen, comparing the normal kidney to the one with the abnormal mass. Then the patient asked about the pain in the leg.

Dr. Jeffries said, "I can't explain the pain in the leg. Perhaps the tumor is growing inside the blood vessel, and it's partially obstructed, and that's giving you discomfort in the legs. In order to find that out I want to get an MRI," saying each letter of MRI very slowly with long pauses in between, "to make sure there isn't any blockage. This needs surgery as soon as possible. I'm going to have Carmen arrange the MRI."

The issue of insurance coverage came up. By this time, Dr. Jeffries was standing behind the appointment counter and said, "Tell her you don't have to worry about that." He then interacted with Carmen and asked, "Should I talk to an administrator?" He decided that that he would take care of it. He repeated his admonition, "You don't need to worry about that. We're from University Medical

⁵⁵ Compact Disc

School.” The interpreter asked about the pain and Dr. Jeffries recommended Tylenol. He specifically said, “She can't take aspirin or Motrin or anything else like that because it will interfere with her ability to have surgery. Put your feet up on the pillow when you get home from work and take Tylenol.”

These type of interactions demonstrate joint attention: the doctor and the patient are both attending to the CT image and there is verbal dialogue and visual input that results in a shared cognition, that cancer is the diagnosis. It seems that the side-by-side comparison of the normal kidney with the diseased kidney was essential to understanding as she asked to have that image re-demonstrated. This allowed a comparison: there is a general bodily conception that the right side of our bodies should be similar to the left, if inverted. The important part of this vignette is that with a language barrier, the “language” used is allowing patients to see the three-dimensional images for themselves.

The next vignette was introduced in Chapter 8, demonstrating that the diagnosis was a three-dimensional cognition of the doctor. Here, I extend the vignette to demonstrate the next step in the healing ritual, persuading the patient of the diagnosis.

Dr. Stein asked Dr. Jeffries to look at images on the computer screen, saying, “There was a CT scan in 2007, 2009, and 2011.” He had all three scans open simultaneously. Dr. Stein said, “This area was present in 2007 and 2009 but looks cystic and non-worrisome. But on this 2011 scan it looks markedly different,” as he was scrolling through the mass with the rollerball of the mouse.

Dr. Jeffries said, “Sounds like you need to do a biopsy, or surgery.” A few minutes later, Dr. Jeffries's came walking down the hall and said, “What did you decide to do?”

Dr. Stein replied, “Get more information with an ultrasound.” Although Dr. Stein said this with an absolute deadpan voice, never taking his eyes off the computer screen, it is vital to understand that this response was complete sarcasm; he said the exact opposite of what he meant to say. After consulting with his most trusted colleague and staring at the images repeatedly, he needed to make a decision, he needed to make a diagnosis.

Quite a bit later Dr. Stein brought an elderly gentleman and two other people, one male, one female, out to the same computer screen and showed them the images. He then said, “The problem is they log you out. It's torture getting logged out. I'm trying to see patients, and it continually logs me out.” He then

asked them to step back in the exam room to see if they could use the computer there. Approximate five minutes later he had re-opened all the images again on the computer screen. He informed them, “The first CT scan was in 2007, the second one was 2009, and this is the CT scan in 2011. It looks a little more solid. I’ve been studying all of these [referring to the images], and on MRI things look slightly different. This [pointing to the image on the screen] is what I’m worried about. We can do a needle biopsy into this area. The surgery would be coming in like this [indicating on his own body the direction of the incision and how to reach the mass demonstrated on the CT image].”

“What if it’s cancer?” the patient wondered out loud.

“I would only take this part of the kidney out. You only have one kidney. I would not take the whole kidney out. You think about it and let me know what you want to do.”

The patient replied, “I’ll think about it.”

Dr. Stein then said, “I apologize for the very long visit. This was very complicated and difficult to figure it out.” At that point, the family group left the office.

Again, there are multiple levels of persuasion. When making a major diagnosis, Dr. Stein asks Dr. Jeffries to confirm his three-dimensional interpretation of the CT scan image. Here the argument includes a change over four years. Instead of left should be similar to right, the argument is that there should be constancy over time. Change is a marker for growing cancer. Dr. Stein is again quite careful, and, instead of merely relying on a verbal description, he shows the images to the patient to persuade them of the cancer diagnosis. In many other examples, he simply uses the rhetorical argument, “I’ve reviewed your CT scan images carefully,” before ever attempting to pronounce a diagnosis to a patient.

These three examples show how the doctors use visual images to explain their recommendations for treatment to patients. Again, in an attempt to “see” what is really going on at the field site, I explored and confirmed the diagnosis is three-dimensional, a cognitive hologram constructed cognitively that replicates diseased anatomical structures. These examples also demonstrate one form of “rhetorical persuasion,” sharing the image with the patient, using joint attention to achieve persuasion to the proclaimed diagnosis.

The next vignette occurred in an inpatient setting. The urologist couldn't take the computer into the patient's room, so he printed an image from the CT scan and took it with him to pronounce the diagnosis.

Immediately after he came out of the room, I went in to see the patient and she said, "Here is the kidney cancer. He told me that, based on the size, he would be able to take all of it out and I will be cured. See, here is the cancer [the patient points to the CT image]."

Figure 9. Patient using a CT image to explain to the researcher the diagnosis



Persuasion Bluntly stated

On multiple occasions, I attempted to explain anthropology and cognitive anthropology to Dr. Stein. He told me one time, “I don’t understand what anthropologists do. When I was in school I took a minimum of social science because I didn't understand it at all”

I showed him the back cover blurb from Edwin Hutchins’ book *Into the Wild*, which had a succinct description of the combination of anthropology and navigation. I told him, “I'm combining anthropology and medicine.”

After reading the book blurb about cognition, Dr. Stein's response was, “We want them to think like us.” By “them” he meant the patient. Again, Dr. Stein was being candid. For this reason, he was always a valuable source of data.

On another occasion, one of the medical assistants told me Dr. Stein wasn't feeling well that afternoon, and so I told him that I would not attempt shadowing him today. He then asked me if it was anthropologically acceptable to open his shirt collar. He was teasing me or testing me. I replied with results from a research study done with a standardized physician image dressed three distinct ways: the first dress code was a very upscale casual; the second dress code was with the white coat, shirt, and tie; and the third dress code was business professional. With only viewing the images, patients were asked pick which one of the three doctors was most intelligent; it was the exact same person dressed three different ways. The patients responded that the doctor dressed in a white coat was more intelligent. I said that I wanted to be more intelligent for my patients, so I tried it, and my patient satisfaction scores, that had been rock solid in the high 90s for years, plummeted. I shared with Dr. Stein that my interpretation was that my patients knew me extremely well, and they perceived the white coat as a barrier to the intimacy that I had developed with them. Dr. Stein replied, “I prefer to wear a white coat because

I want to be in a position of authority. I'm going to operate on them." Dr. Stein's comment revealed how he uses the hierarchy of the doctor–patient relationship.

Dr. Stein started joking around a little bit, specifically in regard to patient-centered outcomes research. Dr. Stein said, referring to the patients, "I just tell them they are supposed to listen to me."

The administrator commented, "That's not a very patient-centered approach."

Dr. Stein continued, saying, "What do you mean my patients don't understand? I don't care if they understand as long as they do as I say." At this point he was joking about the patient-centered outcomes research, but the joke wasn't funny, because his statement was consistent with what I'd observed about the doctor making the diagnosis and deciding what is appropriate treatment prior to entering the exam room. Although he was contradicting political correctness, I eventually realized that he was correct with regard to the interpretation of my results and the healing ritual. These statements just described contrast with Drs. Stein's and Jeffries's statements below.

There was a quiet moment and Dr. Stein sat down, eating lunch. He was talking about me and I shared with him my prior work related to hierarchy in medical education. He seemed very interested in that and then said, "There are people higher than me." I commented that as chair of his department there weren't too many. He responded to my comment, "The patients are the boss." This becomes important in Chapter 12 when I discuss my data in comparison to Arthur Kleinman's model.

Later that same day, Dr. Jeffries said, "He is the most important person," and nodded in the direction of the patient he just saw.

Marsha looked at me and said, "There, you've heard it out of both of the horses' mouths."

When the diagnosis doesn't imply the treatment

The purpose of diagnosis in the healing ritual is to know what therapy to apply, what offending agent to remove. Many patients will require a combination of treatment modalities, so doctors from different disciplines discuss cases at multidisciplinary care conferences once a week. In addition to coordinating care, this venue is a place where doctors can share their uncertainty, the uncertainty that is never part of the pronounced diagnosis:

Multidisciplinary care conference was held at the main Connaught building, and, as the name implies, physicians from different disciplines discuss cases and solicit input from others. The auditorium seats about a hundred people. The room is, oddly enough, shaped like a kidney, with curving, convex outer walls and drooping ceiling, with a feeling of theater in the semi-round, focused on the screen where CT and MRI images are displayed.

At about seven o'clock, there was a rush of people into the room, and Dr. V (the doctor that had to sign my initial Connaught protocol) started presenting a case. She gave a very short presentation that had the following structure: (1) chief complaint, (2) diagnosis of bladder cancer, (3) CT showed lymph nodes, (4) biopsy and biopsy results, (5) chemotherapy summary.⁵⁶ It was an extremely abbreviated clinical presentation, and then she presented the following, "The patient has reached the limits of chemotherapy and I'm presenting her to see if there is something else that can be offered. At that time, the co-presenter (who was probably a resident) pulled up the CT scan images on the screen. Dr. V demonstrated the original mass in the liver which was massive (approximately a third the size of the liver) and post-chemotherapy images demonstrating that the mass had had shrunk to approximately marble size. The resident used the rollerball on the mouse and slowly scrolled downward, through multiple image slices, to the bladder, showing a thickened bladder wall.

At that point, Dr. Stein spoke and said, "That's all? No lung mass?"

Dr. V said, "I'm conflicted. I can't imagine putting her through surgery given the fact that she's had liver mets."

Dr. Wright said, "She's only 40 years old."

Dr. V continued, "At a minimum she can get cryo⁵⁷ to the bladder, and someone can look in the bladder."

Dr. Rivers, the radiation oncologist, added, "I don't think surgery is warranted."

⁵⁶ There is a rigid organizational schema for case presentations common to any clinical setting, typically called a "history and physical," although it is used in many settings. Dr. Jeffries usually always provided me with such a summary when I was seeing patients with him.

⁵⁷ "Cryo" is short for cryotherapy, a type of tissue destruction caused by extreme cold temperatures.

Dr. Stein said, “The patient has liver mets and the bladder looks terrible, but she's not about to die from her cancer. Just do a quick cystectomy. The literature supports surgery.”

Dr. V seemed surprised and with an upward tonal inflection of her voice asked, “She's not [about to die from her cancer]?”

Dr. Stein said, “The cystectomy could be considered palliative with potential for survival benefit.”

At that point, Dr. Rivers said, “There isn't any support for that in the literature.” His statement sparked a very robust discussion among multiple participants. The urology residents participated freely despite their junior status amongst a mixed group of faculty physicians with residents.

They reviewed the CT scan again and Dr. Stein said, “We do lots of things we don't have level I evidence in the literature.”⁵⁸

Dr. Rivers said, “I don't think that's reasonable.”

Dr. V asked, “Can you cryo the lymph nodes?”

Dr. Rivers said, “Not this one. It's too close to the femoral nerve,” and pointed directly to the CT scan on the screen.

Dr. V said, “So you're both willing to offer cystectomy with an informed discussion?”

Dr. Stein said, “Are you going to talk to the patient with a frown on your face?”

Dr. V replied, “I think it's crazy...they [other cancer centers] could call us crazy.”

“I completely disagree with that statement,” responded Dr. Stein.

Dr. Wright said, “She's got one met and she's young and healthy.”

Dr. Stein continued, “I don't agree with what you said.”

Dr. V responded, “If you can find a couple of experts to say that, it's going to need a lot of informed discussion.”

Dr. Stein then said, “Maybe the discussion should be with someone who does surgery.”

Dr. V said, “You'll get your chance.”

The conversation then drifted to the quality of life and Dr. Stein said, “When the patient leaves the hospital, she will be on an oral diet, have an ileal loop, and within six weeks will be back to a normal lifestyle.”⁵⁹

Dr. Rivers said, “What happens while she's off chemotherapies for six weeks for surgery? Don't you risk rapid recurrence of her disease?”

Dr. V and Dr. Stein continued presenting opposing viewpoints. Dr. V said, “The time issue is important. We have to present it as if we don't know if it's going to blow up with metastatic disease. There is other disease there. We're just not seeing it. I can talk to the patient whether or not she should have surgery, but with metastatic disease her long-term chances of survival are 5 percent. This would be a big lifestyle change.”

⁵⁸ There are multiple grading systems in evidence-based medicine to describe the quality and believability of the research.

⁵⁹ Ileal loop is a surgery where the bladder is removed and part of the small bowel is brought to the abdominal wall for use in draining urine out of the body and into a bag.

“Where'd you get this 5 percent?”

“Clinical reports and patient studies.”

“Is she like those other patients in the study?”

“Do you want to see her first so I don't pollute her mind?”

Dr. Stephens said, “I can see her later today and review it with her.”

This is an unusual case, illustrating the edge between the known and the unknown. The fact that the medical opinions are so disparate is important. Also, note the “consent” comments. There is very little confidence in a consensus of what the patient will be “consenting” to undergo. This vignette highlights the importance of persuasion in the healing ritual, but the case is notable because the doctors are having difficulty recommending a treatment because they cannot persuade even themselves.

Patients are socialized to live within the world of the medical diagnosis

Early in the ritual, the patient has to be convinced the diagnosis is correct and agree to the treatment. Later, patients begin to use medical jargon and present themselves—their illness story—using the diagnosis narrative as at least part of the story. This was a rather consistent finding. My data demonstrate that, in the setting of the clinical encounter, patients acknowledge the audience (doctors and nurses) and contribute to a shared narrative using the lexicon of biomedicine. At this point, there is a shared culture as the doctor and the patient speak the same language. Consider the following examples.

Dr. Atlas had seen the second opinion patient from Harvey Frank Hospital and when he came back to the charting room he presented the case to Dr. Spangler. “This the 57-year-old man with a family history of prostate cancer in both the uncle and questionably the father. Diagnosis was made in 2008, PSA was 6.5. Ultrasound guided biopsy showed Gleason eight high-grade lesion, PSA at that time was 10. After surgery the PSA was undetectable and then became 0.3, 0.4 which was a rise and at that time patient was put on Lupron in March of 2009. It was stopped approximately year ago and last month PSA rose to 0.3 with the increase in the back pain. The patient sought second opinion.”

Dr. Spangler pointed out that the only imaging that was done was five years ago. “They needed a bone scan.” She then explicitly told Dr. Atlas, “What patients need from a second opinion: number one, they need to know whether something’s been done right or wrong in the previous care the patient received, and, number two, they need to know what to do next. She then specifically went over the details of the case with Dr. Atlas and pointed to the pathology report, saying, “It’s right there – two positive lymph nodes – which means that it was locally metastatic at the time of surgery. One could argue that he should have been treated with androgen deprivation therapy right at that time,” and referred to a journal article in *New England Journal of Medicine*. “We are going to have to couch that very gently if we tell him about it. She talked about whether the patient should have had radiation oncology treatment at that time. “Does it change things in the big picture? No, not really. The guy’s on hormones and he should stay on hormones. There’s been no imaging and it’s been four years later. He still can be considered castrate because it takes a long time for the testosterone level to rise and she said if you do reimage, there’s a good chance you might find something.

Dr. Spangler went into the room to talk with the patient. Dr. Spangler asked him, “Since this is a second opinion, it is very important for me to know what you are expecting.”

The patient said, “They weren’t aggressive enough. They haven’t done any scan since my diagnosis.” The patient talked about getting the robotic prostatectomy and then being put on Lupron. He said, “I’m having back pain and that worries me. I use the word worried; I could use the word concerned...” He then pointed to a lump in the back. The patient described his case with a lot of technical jargon. When Dr. Atlas initially talked to him, the patient said, “My PSA was drawn on a regular basis and it was seven after surgery. It was undetectable after that.” He listed the specific dates that the PSA was undetectable and said, “I’m fighting it.” Dr. Atlas was looking for the most recent PSA which he didn’t have. The patient said, “I’m sure it is in the folder [the folder the patient brought with him].” He went through the papers, found the lab letter with the result on it and gave it to Dr. Atlas.

Dr. Atlas examined this lump on the back and he said, “It is a lipoma—a fat tumor under the skin.”

Again, the patient used all medical jargon. He used words like “undetectable,” “radical prostatectomy,” “Lupron,” he knew the date of every specific PSA level and the PSA value result. He presented the data in chronological order. He knew every scan that he had and the result of the scan. In summary, he actually told Dr. Spangler, “I know this is stage IV... I just decided I should find out if we should be doing something else.”

Dr. Spangler asked, “What was your previous response to Lupron?”

“Shortness of breath.”

“That isn’t a known side effect of the medication.”

“I had to go to the emergency room twice. It was a very stressful time...we had to move in with my son.”

Dr. Spangler informed him, “You need to go back on the hormones. You need a complete evaluation, including a CT scan of the thorax, a CT scan of the

abdomen, a CT scan of the pelvis, a bone scan and a dexta scan for bone density. We need to check for pathologic fractures from osteoporosis --a side effect of prolonged hormonal therapy.” After Dr. Spangler told him of the extensive workup, she turned to Dr. Atlas and added blood tests to his workup. “Are you going to follow up here at Connaught?”

The wife asked, “Are all the scans were going to be done at Connaught?”

“Yes, Connaught has its own CT scan and its own MRI. We work very closely with the radiologist. We will sometimes look at the films with the radiologist together. We get along very well.”

At the end of the interview the patient said, "That's exactly what I wanted."

The wife said, “When he started getting back pain, it started messing with him psychologically and it was bothering him. He was wondering about what was going on.”

Both the patient and his wife seemed extremely happy as Dr. Spangler told Dr. Atlas in front of them—he literally filled out the note with a long list of things and tests to get done before coming back in two weeks.

When Dr. Spangler got back into the charting room she said, “Nobody read the freaking paper. I go off road all the time, but you have to know why you're going off.” She then made some comments about the urologist who is treating the patient at Harvey Frank Hospital that was the only physician that they had seen – just a urologist, never the oncologist, never anyone else from radiation oncology. Again, she was referring to the fact that the patient did not get immediate hormonal therapy in the clinical setting of localized metastatic prostate cancer.

There are several important points illustrated by this vignette. First, the patient can tell the diagnosis narrative as well as anyone else. He knew the missing laboratory value, knew where to find it in his file of records that he kept, and knew how it related to the rest of his care. He “diagnosed” himself as “Stage IV.” The medical system and the doctor socialized the patient into the life world of the diagnosis ritual. This is a type of persuasion to the social myth or belief system of scientific medicine. The patient knows his role and knows how the ritual proceeds. The patient said, “I’m having back pain and that worries me. I use the word ‘worried’; I could use the word ‘concerned.’” He then pointed to a lump in the back. The wife referred to the fact that it was bothering him “psychologically.” I interpret those comments by the patient and the wife as another existential threat requiring an interim diagnosis. The patient was seeking the

second opinion specifically because “they weren't aggressive enough. They haven't done any scan since my diagnosis.” The issue of CT scans and re-imaging as a form of interim diagnosis is absent from the care he received and the patient understands that without the doctor telling him. Likewise, when Dr. Spangler lists all of the CT scans and imaging studies he needs and how the radiologists work closely with the oncologists, the patient summarizes, “That's exactly what I wanted.” At this point, the patient is a full participant in the healing ritual.

The next vignette demonstrates the exact same thing—the patient and family are conversant in medical jargon and the language of the healing ritual.

The next patient was an elderly gentleman; his wife accompanied him. The wife gave the entire history and was totally in control. She complained, “He's been moody for the last three months. His PSA was 2.0 at the beginning of April. He was due to get Lupron at the end of April and his prior PSA before that was 2.3 and the one before that was even higher. He's been on Lupron since July of 2011.” The wife also said, “He had a negative CT scan on April 12. He sees a cancer doctor in Florida at Moffett clinic. They put him on Casodex,⁶⁰ I forgot to tell that girl. We go back to Kentucky in September and visit some friends, and then go visit my daughter in Tampa, and then go to our place in Florida where we winter.” The wife actually reported the results of the CT scan done at Moffett Clinic in Florida and knew exact date of the exam.

Outside in the charting area, Dr. Spangler was at the computer and she said to nobody in particular, “Yeah, he got a bone scan... If he's having more pain he may need radiation.” She then went in to see the patient.

Dr. Spangler asked the patient, “How about pain?”

The wife interrupted and said, “He is the pain.” The wife was reading newspapers. She said, “I was reading in the newspapers that prostate cancer is a slow growing cancer.”

Dr. Spangler then said, “Yes that was a big deal up there on Capitol Hill ...there is a lot of controversy about unnecessary treatment. But you talk to do two different people and one person will say it saved my life and the other person may say that's totally crazy. Some primary care doctors don't think we should be screening with PSA, but you have a lymph node on your CT scan.”

The wife interrupted, saying, “The CT scan in Florida was negative.”

Dr. Spangler continued saying, “There was all that mess about mammograms, but we got that fixed: women are better advocates. I don't agree with that PSA fear. We have it. We might as well use it.” Dr. Spangler made a derogatory comment about primary care doctors and their reluctance to use PSA

⁶⁰ Casodex is the brand name for bicalutamide, a medication that binds to the androgen receptor, blocking the effect of testosterone; a treatment for prostate cancer.

screening. Dr. Spangler pointed out to the patient's wife, "He's been living with prostate cancer for years and that some people with pancreatic cancer or lung cancer die within a year. This seems like the reverse, but I'm going to stop the Casodex. Sometimes by stopping the medicine, it has the effect we want." She acknowledged multiple times that this was counterintuitive but then advised the patient, "Don't think about it to look much." Dr. Spangler alluded to the fact that if this doesn't work that they would have to get "more aggressive."

The patient asked, "What is my PSA?"

Dr. Spangler checked, "0.7"

"So, it's higher."

Dr. Spangler replied, "At least it's less than 1.0. Everything is done by monitoring the PSA. That's very important."

"The Lupron gives me mood swings, hot flashes, and muscle aches."

Dr. Spangler acknowledged, "You have every single side effect of the therapy. It's just too bad – Do it anyway. Are you buying this argument?"

The patient replied bluntly, "No."

"You have to do it anyway."

Later when we were in the charting room one of the nurses brought the issue up again and Dr. Spangler said, "His other option was an orchiectomy."

In this case, the patient's wife forgot to tell the nurse that the patient was on a new hormonally active medication (Casodex), but she knew the name of the medication and when it was prescribed. She also knew the results of the CT scan. Dr. Spangler said, "You have a lymph node on your CT scan..." and the wife corrected her saying, "The CT scan in Florida was negative." The patient himself is asking for an update by using the words, "What is my PSA?" He understands this number is a reflection of his disease progression – the amount of pain he is experiencing represents something else. Again, the persuasion is so complete that the patient and the doctor understand the existential threat in the same way.

This last example demonstrates how the patient tries to exist in the world of the doctor, but seems to be his own worst enemy. His multiple concerns result in confusion in testing, diagnosis, and treatment. He confuses a symptom with a diagnosis. The middle of the interview with the nurse practitioner demonstrates multiple miscommunications and evidence where the conversation has major disconnects, such as when the patient confuses the bronchoscope with the

gastroduodenoscopy, both abridged to “scope.” The nurse practitioner doesn’t pick up on this, but the son does and interrupts the conversation, asking for Dr. Spangler. Yet, the patient and his family are very well socialized into the world of prostate cancer therapy and the relationship to following the PSA as a marker of disease.

Dr. Spangler and Jane were chatting about the very last patient of the morning, even though it was 12:30 in the afternoon. Dr. Spangler picked up the chart and started going over labs in the computer. She looked at the flowsheet and printed reports. The nurse practitioner picked up the chart, looked at the labs, and printed papers and reports, and then the nurse practitioner went into see the patient. The first thing the patient wanted to know, of course, was his lab results. The nurse practitioner said it was 0.1 and instantaneously the patient, patient’s son, and the patient’s wife all broke into very broad smiles, relaxed, and were extremely happy. The son said, “That’s good, because it was 0.3 last time. Of course we wanted to be <0.02.”

The nurse practitioner said, “It takes time.”

The patient probably had been waiting for three hours. Everyone seemed exhausted. The nurse practitioner asked him, “When was your colonoscopy? The gastroenterologist ordered a CT scan of the abdomen but you haven’t had it yet. You should get an upper endoscopy to screen for cancer – I mean, ulcers.”

The patient said, “So ulcers?”

The nurse practitioner said, “Yes, ulcers... or reflux”

The patient asked, “Does the lung doctor do the scope?”

The nurse practitioner said, “No, the lung doctor does PFTs, the G.I. doctor does the scope.”⁶¹

At that point, the son said, “Are you going to bring Dr. Spangler now?”

I was standing there in the documentation room. Dr. Spangler came in and said, “Okay let’s get rid of that last patient. He doesn’t have that many questions right?”

The nurse practitioner said, “He’s got a lot of questions.”

Amber came in and said, “He’s chomping at the bit.”

Dr. Spangler went in and apologized for being late. The patient, the patient’s son, and the patient’s wife were absolutely delighted and smiling to see Dr. Spangler. Very shortly, they started talking and laughing again. They repeated, “We want the PSA to be zero.” The patient kept throwing out concerns and symptoms, none of which seemed to be addressed during this office visit. He again mentioned bloating and nausea. He said, “I’m losing weight because I don’t want to eat.”

Dr. Spangler said, “Your sodium is 131. Maybe that’s because you aren’t eating. Thank goodness you have a primary care doctor. He can go try and sort all these things out.”

⁶¹ PFTs means pulmonary (lung) function tests.

“My gastroenterologist questions the diagnosis of Crohn's disease.”

Dr. Spangler said, “Maybe the nausea is from the Crohn's disease.”

The son said, “No, he was not suspecting Crohn's disease as a possible explanation for his gastrointestinal symptoms.”

Dr. Spangler replied, “Wait a minute, he can't take back a diagnosis. I think you should have an upper endoscopy. I can call the gastroenterologist so that they know what's going on.”

The patient asked, “Is the nausea not related to the cancer?”

“It's not related to cancer,” and once again big smiles all the way around the room. They were all very happy with that.

Again, “It's not related to the cancer,” brings out smiles all around. The healing ritual is all about the existential threat. As in the previous example, the patient, the doctor and the patient's family are all using a common language related to the healing ritual and the diagnosis. This is the “re-education” W.H.R. Rivers referred to and the persuasion component of the healing ritual I am describing.

Summary of Chapter 7

The diagnosis narrative is only effective in the healing ritual if the patient can recognize the diagnosis story as the story of the disease affecting themselves – the cause of the existential threat. Persuasion is a key component of the narrative because it is necessary to move from diagnosis to therapy or treatment. If the patient is not persuaded – a narrative failure – then the ritual ends without benefit. Once the persuasion occurs and therapy is performed, the patient is fully integrated into the ritual experience and based on that experience can begin to use the diagnosis to narrate the story of their own disease. To do this, the patient learns the language of the diagnosis and medical jargon. Metaphorically, the doctor and the patient “are on the same page” of the story. The distinction between the diagnosis narrative and the illness narrative blurs as the story becomes shared between the doctor and the patient. Mattingly and others describe this as the “preferred narrative,” the one with social power. This story is the one that can lay

claim on society's resources. The ritual is an experience and in a way, the story both precedes the experience (a diagnostic schema) and the experience of the ritual can be a narrated (the diagnosis narrative), just as Jerome Bruner, Mattingly, and others described.

Chapter 8: Relationship of Diagnosis to Therapy

W.H.R. Rivers says, “The practices of these people in relation to disease are not a medley of disconnected and meaningless customs, but are inspired by definite ideas concerning the causation of disease. Their modes of treatment follow directly from their ideas concerning etiology and pathology” and “The treatment follows directly from etiology, the aim being to extract the object or essence from the body, and thus remove the cause of disease” (Rivers 2001[1924]:13) Rivers could easily have been describing a DaVinci robotic radical prostatectomy for prostate cancer when he wrote those words. I conclude this chapter with an abridged version of this part of the healing ritual. Rivers describes the foundation of the cultural model: “Cancer – cut it out.” Again, noting the proximity of diagnosis to therapeutics, Rivers states, “Mankind has theories of the causation of disease, carries out proceedings which correspond with those we call diagnosis and prognosis, and finally has modes of treatment which, even if they have little in common with our own remedies, nevertheless may be regarded as making up a definite system of therapeutics” (2001[1924]:6). In this chapter the focus is on how the diagnosis narrative determines the treatment, both in the societies described by Rivers and in Western medicine. Rivers states:

This lesson is the rationality of the leechcraft of such peoples as the Papuan and the Melanesian. The practices of these peoples in relation to disease are not a medley of disconnected and meaningless customs, but are inspired by definite ideas concerning the causation of disease. Their modes of treatment follow directly from their ideas concerning etiology and pathology. [Rivers 2001[1924]:48]

Importantly Evans-Pritchard also delineates the social roles that correspond to diagnosis and therapeutics: “The Azande witch doctor is both diviner and magician. As diviner he exposes witches; as magician he thwarts them” (Evans-Pritchard 1976:66). Evans-Pritchard reinforces Rivers’s link between the “diagnosis” and the treatment. Azande divining is analogous to the

diagnosis narrative. Urologists used the oracle of the CT scan image and reconstituted it into a three-dimensional representation of the “health of the individual” and confirmed it with the MRI to divine that disease was present before thwarting the prostate cancer with a DaVinci robotic prostatectomy. The Azande also have a cause-and-effect cognitive structure to the diagnostic and therapeutic process: a witch causes disease, using witchcraft; the magician thwarts witchcraft, using magic.

Brian’s story continued

Brian’s monologue picks up after he has received the diagnosis of prostate cancer and is awaiting the therapy for that specific disease. He discusses the social dimensions of having a disease but contextualizes it within the healing ritual. His best summary statement illustrating the theme of this chapter is, “Well I’m gonna be on the prayer list because I have cancer and I have surgery on Monday.” Two weeks later he finds out the therapy was successful: “And the confirmation [that the cancer was completely removed] was that two weeks later my PSA was less than 0.1, or less than whatever the detection limit was, and it has remained there since.” With these statements, Brian confirms the basic structure of the healing ritual: diagnosis, followed by modes of treatment based on ideas concerning etiology and pathology.

<p>I had told the head of my company, local head of the company, and the people in the office all knew. My boss in Detroit came to visit me just as I was leaving the next day. And I told – The people at church knew. It was, it was very difficult to tell people I have cancer. It was probably I guess now in thinking about it was one of the most traumatic parts about the whole thing was to tell people I had cancer and that I was gonna have surgery. We would go – kinda made the rounds to our good friends and, you know, I think – Well, somehow in the course of conversation we’ll – we’ll work it into the conversation. Well, it isn’t something that comes up in conversation. So we would go over to somebody’s house and we’d be there all night and we hadn’t said it and I hadn’t said anything and I was</p>
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kinda – [My wife] was trying to help me a little bit, and I was kinda waiting for her to, well, “I’ve got something to tell ya,” or something –to say, “Well, by the way, I have prostate cancer.” And I was viewing that as a – that was a really difficult thing to tell people that I had cancer and I don’t quite know why. It was a flaw in me or something. I don’t know. It was—I didn’t want to burden them with my problems. I’m not sure I ever really understood that. I mean, I remember we had – I had told the pastor. We had gone to sit down with him and let him know, and then the Sunday before the surgery I was on the prayer chain – uh, on the prayer list – that I was gonna be having surgery. And I remember, you know, I had to run up and tell the guys in the choir, “Well I’m gonna be on the prayer list because I have cancer and I have surgery on Monday.” And I had put it off that much, and so it was something I felt I needed tell people, but it was really hard to say, “I’ve got cancer.”

Afterwards he felt that the outer wall of it had not been penetrated by any cancer cells, and then that was confirmed – at least that’s what was portrayed to me. And the confirmation was that two weeks later my PSA was less than 0.1, or less than whatever the detection limit was and it has remained there since.

Brian is an observer of the healing ritual as he participates in it. Although earlier he described the existential threat as “mini-breakdown,” in this section he also describes a sense of social alienation when trying to share his situation with friends. Although not formally articulated in prior anthropological work, I surmise the social alienation described by Brian is the reason that healing rituals exist: disease and existential threat of death alienates not only the individual from their own self–story, but also alienates the individual from other significant social relationships. Although my dataset doesn’t address this directly, I will comment on it theoretically in Section IV.

From diagnosis to therapy and diagnosis within therapy

This next vignette illustrates the relationship of diagnosis to therapy when Dr. Jeffries says, “I need a couple of days so I can get an operative plan in my head and counsel him appropriately.... How about Friday afternoon?... That’s when we were thinking about doing surgery.” Dr. Jeffries is describing aloud the cognitive process of taking a three-dimensional

diagnosis and converting it into action, converting it into surgical therapy. Another fascinating aspect of this vignette occurs when he reverts to looking at the CT scan images despite having his hands inside the patient's body and visualizing the surgical field through a laparoscope. He depends on his cognitive hologram of the diagnosis narrative to the extent that it overrides his perceptual senses of touch, feel, and vision. The vignette starts in the office reviewing the CT scan and proceeds to the operating room in what turned out to be one of the more difficult surgeries during my fieldwork.

Dr. Jeffries was reviewing a CT scan and looking at hepatic veins. I knew that because he was talking to himself and he said it aloud to himself. He then turned to Dr. Stein and said, "What you think about this?" Dr. Jeffries was sitting at the bar stool on the far left computer with his screen and Dr. Stein leaned over, put his arm on the back of the chair and the two of them were simultaneously looking at the CAT scan. They reviewed the entire scan again looking at a tumor in the kidney and then some shadowing hepatic veins. Dr. Jeffries said, "Here. Here's the coronals....This is why I am concerned."

Dr. Stein said, "That looks like CT contrast." His opinion was the shadow that Dr. Jeffries was looking at was contrast and he took his hand away from Dr. Jeffries's chair saying, "You might be right." He was referring to possible growth of the tumor into the hepatic veins.

Dr. Jeffries said, "Would you get an MRI?"

Dr. Stein replied, "Hell, yeah. You want to know that before you get in there." The morning drifted into the afternoon clinic session. Dr. Stein said to Dr. Jeffries something about the free lunch from the pharmaceutical representative and then in a discrete voice said, "You're in charge of reading the CT. It doesn't matter what the radiologist said."

Continuing the discussion, Dr. Jeffries said, "The cardiologist will not allow the patient to come off aspirin because he has a bare metal stent [in his coronary artery]. This will be my first freaking nephrectomy with 325 of aspirin."⁶²

Dr. Stein inquired, "Are you going to do it laparoscopically?"

"Yes."

Later in the day, Dr. Jeffries was on the phone and said, "I need a couple of days so I can get an operative plan in my head and counsel him appropriately.... How about Friday afternoon?... That's when we were thinking about doing surgery."

⁶² A stent is a wire mesh that keeps the coronary artery open, or patent. In this case, the stent is not coated with a drug to prevent clots, which means the aspirin is necessary to prevent clots.

The case transitions from the outpatient clinic to the operating room. This surgery was a “partial open laparoscopic⁶³ surgery,” which meant that they made a six-inch curvilinear incision in the lower abdomen, just large enough to insert a hand and arm into the patient’s abdomen. Just prior to the surgery, the residents were anticipating the procedure and said, “He’s on aspirin.”

One of the medical students asked, “Why use a scope? What’s the advantage?” Dr. Wright said, “The incision is smaller and easier. Dr. Jeffries does a lot of hand-assist surgery. An open surgery is much larger incision. And the patient is obese. It’s really tough because it’s so deep down in there,” acknowledging that an obese patient would be difficult to do with hand-assist surgery anyway.

When we got to the operating room, this all became clear. The circulating nurse said in a very loud voice, “I don’t know him.” She was referring to me. She had a brief conversation with the residents and then she said in a very loud voice, “If these guys vouch for you you’re okay.” That was the end of my introduction. There was a laparoscope inserted higher in the abdomen. A gloved right hand was visible on the flat-panel monitor hanging from the ceiling. The gloved hand was that of Dr. Pinder, the resident who started the case. He was also holding the laparoscope in his left hand and it displayed the image on the flat-panel monitor. On the flat-panel monitor, you could see Dr. Pinder’s fingers grasping, pulling, and he was using the cautery attached to the laparoscope to snip tissue. Dr. Pinder could actually see his own right hand displayed about eight feet away from where his actual hand was located. He could also see the image of the laparoscope that he was manipulating with his left hand. He used this virtual image to perform the surgery. They did the entire procedure this way; there was no direct visualization of the operating field. Dr. Jeffries was talking about some part of the procedure and pointing at the screen with his index finger trying to coach and guide Dr. Pinder. Dr. Jeffries then told Dr. Pinder, “Lift things up with your hand, right up there in the corner.” They were working simultaneously with forceps, cautery,⁶⁴ and feeling tissue with their fingertips. I looked up. I could see Dr. Pinder’s entire hand on the screen, meaning his entire hand was inside the patient’s abdomen. It soon became obvious that this was going to be a difficult surgery, so Dr. Jeffries took over from Dr. Pinder and called for help.

Dr. Jeffries announced, “We’re going to use up a load of staples on this guy. We can’t have him bleeding.”

“There are seven staples in each stapler, and there are only two available.”

Dr. Jeffries said, “Nice. Thanks guys.” (He said this with a lot of sarcasm.) At this point, they had a cloth sponge in the abdominal cavity trying to stop some of the bleeding.

At one point in the procedure, Dr. Jeffries was feeling between his thumb and his index finger, compressing the tissue and then there was an episode where Dr. Pinder was cutting tissue between Dr. Jeffries’s fingers. At a certain point, Dr.

⁶³ A laparoscope is a tube, about a half inch in diameter inserted through a small incision that allows visualization of the surgical area as well as insertion of small instruments to do the actual surgery.

⁶⁴ Cautery is burning to prevent bleeding from small blood vessels such as capillaries. In this case the burn is caused by an electrical current. At other times, it is a chemical burn, etc. Electrical cautery is also referred to as a “bovie.”

Bridge entered the room. He helped identify the anatomy displayed on the monitor screens throughout the operating room. These screens were the only way anyone, including the surgeon, could see anything because the incisions were only large enough to put an instrument or a hand into the patient's body. The case was tedious and obviously risky. Dr. Jeffries was using the cautery and said, "I haven't found my ureter yet."

There was country music playing in the operating room. Dr. Bridge said, "The problem you have is the music. You should have classical music. This music is getting everyone excited."

Dr. Jeffries said, "You can change it or turn it off; it doesn't bother me. Put on some [then he named a musical artist]. Your heart's not going 120 beats per minute."

Dr. Bridge said, "I think you're in the right plane Jeffries.⁶⁵ Absolutely that's the right plane," and then he pointed to the screen with his index finger all the way across the room – approximately 15 to 20 feet. He cupped his hands and swung his arm indicating that Dr. Jeffries should dissect the tissue with his hands that were in the patient. Because this gesture was non-verbal and everyone in the room was fixated on the video monitors, no one other than me saw him do this.

Dr. Stephens entered the room. Dr. Jeffries said to Dr. Stephens, "This is a nightmare – I thought it would be easier, but it's harder."

"Is the aspirin a problem?" Dr. Stephens inquired.

Dr. Jeffries said, "Not so far. You should have a stapler prepared." Simply observing, I was feeling and sensing the danger in the room. Dr. Jeffries was struggling.

There were eight doctors staring at the screen. They seem mesmerized by the flat-panel monitor video images. Dr. Jeffries said, "This stuff is rock-hard. It's stuck to this flipping kidney. It doesn't look like anything other than straightforward on the CT."

The tall medical student, Dr. Bridge, Dr. Stephens, and the short medical student were all looking at a laptop computer screen of the CT images as well as the monitor on the ceiling, comparing the CT images to the video images intra-operatively. Aware of them, Dr. Jeffries said, "What are the Illuminati saying in the back of the room there?" Jeffries went on to say, "I have the whole kidney here in my hand – not the whole kidney the lower pole."

Dr. Stephens said, "Can you feel the vessels there?"

Dr. Jeffries said, "Is the CT still up? Bring it up because I want to see where the hilum⁶⁶ is."

Dr. Stephens said, "Lateral to your middle finger is okay."

Dr. Jeffries said, "Am I going to cause ischemia?" Dr. Jeffries and Dr. Stephens were discussing the case. Dr. Fields walked into the room and now all eight members of the urology team were in this one single operating room. Dr.

⁶⁵ Dr. Bridge is an emeritus professor with lots of experience. Although Dr. Bridge is still surgically active, Dr. Jeffries is the busy, active surgeon using the latest techniques.

⁶⁶ The hilum is the only place the kidney is connected to the rest of the body. It contains vital anatomical structures, such as the renal artery, renal vein, etc.

Jeffries then said, “It gets all stuck like this. I don't want to de-vascularize the kidney.”

Dr. Wright was looking at the CT, saying, “It almost seems as if those are the renal veins.” Dr. Stephens and Dr. Wright were looking at the CT images displayed on the laptop computer, comparing them to the video images of the surgery.

Dr. Jeffries had scrubbed in and was in a sterile gown so he held his hands up in the air, leaving the operating table, and walked over to the laptop to look at the CT scan on the computer. Dr. Stephens said, “There are two arteries.”

Dr. Stephens was showing the CT scan to Dr. Jeffries who was studying the CT scan, “Where's the second artery? Behind both veins? I think this is the two veins.” He then went back to the operating room table. Looking from screen to screen Dr. Jeffries said, “[referring to an anatomical structure] – he's the issue. How do I deal with this guy? I'm open to suggestions. How do I preserve that? Something bad is all I think about.”

Dr. Stephens said, “It looks like you had your fingers on the aorta.”

This vignette demonstrates how important this three-dimensional cognition is to both diagnosis, but also to actual patient care. Having the surgeon's fingers on the aorta implies that the wall of the aorta can tear – a lethal consequence. The residents all sensed that their leader was engaged in a high-risk surgery. Having multiple senior attending surgeons all giving opinions about what to do is not typical, but I believe it reflects the inherent dangers associated with this case. The drama, according to Mattingly, occurs when something really matters. The drama is communicated by the display emotions during the surgery. Although the field notes may not convey a sense of the palpable emotions in the operating room, the “high anxiety” was unmistakable; anthropologically, I could have written the field notes as a series of display emotions. To the extent that the reader could recognize the tension and danger in the above story, the emotion became part of the narrative of this patient's surgery. I was interested in the perspectives of various participants in this drama, so about a week later, I asked Dr. Jeffries about his experience. He said, “I was sweating bullets. That still gives me nightmares.” I asked Dr. Stephens about his experience during this surgery. He said, “It was sort of hard, being the new attending and trying to help the well-established expert. I eventually took over the case, and

we were able to complete the surgery. It was sort of weird.” The day after the surgery, I visited the patient while he was recovering in the hospital. Although I tried desperately to get an illness narrative from him, his only comment was, “[Dr. Jeffries] told me he got all the cancer. If he did, that’s good. If he didn’t, well, then that’s the end of me.” That was an existential comment if I ever heard one.

3-D diagnosis, 3-D therapy in radiation oncology

Earlier I described how Dr. Rivers was responsible for outlining the diseased organs on the CT scan before the “planner” could design a treatment plan specifically related to the three-dimensional diagnosis. The topic in this chapter is how the diagnosis determines therapy. This is just as true in radiation oncology as it is in urology. The radiation machine itself has a mini CT scan built into it. It is not a high resolution CT for diagnosis but actually takes a CT scan of the patient's position on the table to compare to the CT scan used for treatment planning. Dr. Rivers said:

Sometimes have to make 3 mm or 4 mm adjustments. This screen shows both the positioning CT scan and the diagnostic CT scan layered over each other. On a left to right basis we can match up the patient’s position on the table to make sure that the contours match up perfectly with the planning that was done on the diagnostic CT. We match the position of the patient for each treatment with the planning CT. Sometimes there are markers placed in the organs themselves. That is another way to line up the CT images with radiation machine. Here’s a gold marker for a prostate cancer case. Dr. Stein put the markers in the prostate in the biopsy suite for this case.

The next vignette highlights the spatial relationships in therapy:

I then wandered into the control room and the technologist running the radiation therapy said, “We line the patient up and check very closely the distance from the skin to the machine. We use laser beams to match the patient’s tattoos.” This was in addition to the CT image that Dr. Rivers had shown me earlier. There were two helpers in the room positioning the patient, and after the patient was

positioned correctly, the control room could move the machine, rotating in multiple different planes from different angles. Again, in the design and treatment planning there is a window of radiation that could be seen on the computers in the control room. There is also an intercom and double video screens you can watch the patient from two different angles and talk to the patient. The control room also had five flat-panel computer screens all lined up on the countertop. The one on the far left had three fields displayed, the middle one was ticking as the dose was administered, the next one had the outline of the perimeter plan, the next one after that had radiologic views – again, three-dimensional radiologic views of the treatment plan – and the far right had an Excel[®] spreadsheet with lots of numbers.

Underneath the countertop there were four large boxes (larger than a typical CPU). The person running the control room said, “These computers allow us to run all the machines.”

The second patient for treatment was apparently a no-show and I was just standing there. The physicist came by and asked, “Have you seen the room yet?”

“No.”

He took me into the treatment room and drew several diagrams. The table in which the patient lays is underneath the curved arm of the radiation machine. On one side of the machine is the positioning CT where they can do in ultra-quick CT of the patient to help line up with the diagnostic CT. The machine itself had a circle for where the radiation came out that could turn 360°. The arm that's arched could turn 360°. The table that was sitting on the floor could spin 360°, and so the combinations and positioning options seemed endless. The physicists showed me a stack of tungsten slabs similar to what a tool and die maker would use to trace shapes. Those all moved in and out to replicate the shape of the radiation field that is designed on the computer. “Everything is done by coordinates and turns on the four-way laser. The laser can line up all of the positioning on the radiation delivery machine, the CT scan, and the person receiving treatment. That's the iso-center image of the distance that can be projected onto the table and the patient, so this is a shadow, almost like a slide, and it's this scale, depending on where the crosshairs align, that can measure the distance from the skin to the point where the radiation is generated. This is a newer machine. It's three-dimensional alignment. It's a very cool machine.” He went on to characterize his job as calibrating everything to make sure it's accurate, including the laser, the dose, and all of that. “I'm also responsible for safety of every individual in the building, monitoring how much exposure to radiation they get. I also have to check the treatment plan and sometimes test one just to make sure that the treatment plan as designed is feasible, using the equipment. Occasionally the computers do something weird – maybe one percent of the time.” Then the physicist said something fascinating, “All of these computers talk to each other. The computers in the radiation oncology suite, and all of the computers in the control room, and the computers where they design and generate the treatment plan, and the computers in the CT scan on the arm of the radiation machine. The computers pass information one to the other to the other. The CT has to give information about the patient to the dosimetry computer and that computer has to give it to the

planning computer and the planning computer has to transfer to the control room system operating room and that interfaces with those five computers and the radiation machine itself. All of this is automatic and I have to verify the system is working correctly. There's lots of computers, and everything is controlled by computer.”

Figure 10. The radiation treatment room.



Figure 11. The researcher, showing the laser beams and scale to determine depth projected onto my body.



In Chapter 6 I emphasized the role of a three-dimensional cognition in making a diagnosis. In this chapter I highlight the necessity of using this three-dimensional cognition to plan surgery. Three-dimensional printing for prototypes is becoming common. Specifically, three-dimensional industrial printers “use CT scans to construct translucent models made with variations of acrylic resin, enabling surgeons to understand the internal structure of the liver” and plan surgical approaches” and “a more realistic-looking model, made partly of polyvinyl alcohol, assimilates the wetness and texture of a real human liver, making it more suitable to cut with a surgical knife” (Osawa: 2013:B5). Although this technology is still in development, the doctors

use the three-dimensional images or cognitive reconstructions for exactly the same purpose: surgical planning.

Extracting the essence or object from the body

“Extracting the essence or object from the body” is the wording used by W.H.R. Rivers when he describes therapy. Consider the similarity of Quesalid’s scrap of bloody feather from Claude Levi-Strauss’s *The Sorcerer and His Magic* (1963). Symbolically, the bloody feather is proof that the offending agent, the disease, has been removed from the body. In the introduction to this chapter, I alluded to the striking similarity of Rivers’ description to the DaVinci robotic prostatectomy. Although this is a highly abridged version, notice the omnipresent spatial relationships of the therapy in the operating room in the verbal and visual representation. This extended excerpt is rich with correlation of the three-dimensional diagnosis and the three-dimensional therapeutics. This vignette is also included because of the importance of the DaVinci robotic surgery to the entire practice and all the doctors at every stage of expertise. This is the pinnacle of biomedical competence:

We were in the operating room. Dr. Johnson was helping reposition the patient’s arm off the armrest and putting it next to the patient’s body. She continued assisting with draping the patient. The patient was naked lying on the surgical table. Dr. Williamson shaved his abdomen and then made a comment, “Just because we’re urologists, most people think that we’re not interested in anything above the pelvis.”

Dr. Johnson said, “Call Dr. Stein.” They kept prepping the patient. She then said, “He does use towels across the chest. Call him and ask what kind of prep he wants.”

Dr. Williamson then shaved the belly and one of the nurses walked up to me and asked what I did. I explained it to her. She was exceptionally friendly and took good care of me for the rest of the morning and into the afternoon.

I was standing by the wall I noticed that the DaVinci robot was draped in plastic. It was not close to the surgical table. They were taking egg crate foam and taping it across the patient’s chest. Dr. Stein was back in the room and when he walked in the noise level and talking decreased. Dr. Stein gave instructions on

how to position the arms of the patient's side. Both Dr. Stein and Dr. Johnson were assisting positioning the arm and the double-taped egg crate across the patient's chest. They created a cocoon-like wrapping for the patient. Dr. Williamson had scrubbed in and was air-drying his hands Dr. Stein was positioning the surgical table and asked, "Can we put this in Trendelenburg?"⁶⁷

Dr. Stein was working with the monitor equipment. Initially the monitors were faced towards the head of the table where the anesthesiologist sat. Dr. Stein went to the back of the DaVinci robot, and the nurse said, "You need help back there?"

Dr. Stein then said to the nurse anesthetist, "You know how I like the fluids. Give him a liter and a half and then I keep them on the drip." Dr. Stein returned to his laptop and was looking at the electronic chart.

The RN said, "What did you just plug in?"

Dr. Stein said, "The video recorder. Go ahead and make the incision. I'll be back in ten minutes." They did the timeout. They put the massive drapes over the entire the surgical table and patient on top of the preliminary drapes. They cut a small area inserted the Foley in patient's penis and re-draped it around that. Dr. Johnson was using a permanent ink marker to mark the incisions.

Dr. Stein then went to the console which was in the corner of the room. The console is connected to the robot with two large cords. Dr. Williamson was sitting on the right side near the patient's shoulder with the scrub nurse next to him and the nurse anesthetist on the other side of the drape. Dr. Williamson held a large trocar with the camera head attached to it throughout the entire procedure. He also used clips and instruments through one of the ports for this same trocar. Dr. Stein started, ensuring the micro-instruments worked properly. The scissors on the right side had an electrical current. Dr. Stein was in the console; his voice was amplified as if it was on an overhead announcer. I noticed that he was sitting and had propped the chair up so that he was looking through the double-screened slanted or angled view box. This had the appearance of old-fashioned cardboard eyeglasses from 3-D movies where one side was red and the other side was blue. These lenses were attached the console itself. His arms were inserted underneath that, and there were foot pedals. Dr. Stein had his clogs off and he was in his sock feet. Dr. Stein verbally identified the spermatic cord and small bowel, as well as other anatomical landmarks. His voice was projected by the intercom, his eyes were looking into the console, he was controlling the robotic "arms" and using them to point to and identify the organs inside the patient's body, and multiple participants watched on multiple flat-panel monitors throughout the room. Dr. Stein and Dr. Johnson traded turns, performing different parts of the procedure. Throughout the entire time, constant verbal interactions guided the surgical dissection as the procedure progressed.

The trocars were attached to the robot that had four sliding cassettes that could go up and down; there were other parts on the robot arms that could move in space, with at least eight joints, the third one from the body of the machine was able to rotate. There were multiple instances where three or four arms were all

⁶⁷ A term referring to positioning of the body with the head down and the legs elevated. In this case, the patient's legs were also in stirrups, spread apart similar to a female pelvic exam.

moving in an anthropomorphic fashion making it look like a spider with multiple joints all moving at the same time. The arms on the robot were draped in plastic and they were all moving simultaneously. There were four incisions and the pneumoperitoneum insufflation created an open visual field, viewable on the flat-panel monitors throughout the operating room and, of course, in the console.⁶⁸ I noticed that the right-hand was a curved scissors, and is also electrified, and often they would touch it with the outside portion of the scissors on the convex side and simply use the bovie⁶⁹ to cut away adipose tissue.

I watched the entire procedure. There was a reason patients sought out Dr. Stein; even as a novice I could tell his expert skill. I noticed that the “hands” were interacting in terms of pulling something up grasping it transferring it from left-hand to right-hand. Crossing the midline like this is a very sophisticated neurologic phenomenon and is a significant milestone in the growth and development for children. I noticed that they were able to do it here using the robot itself.

The trocars were operated by the DaVinci robot for multi-functional surgical techniques. They could rotate they could flip up and down for they could open they could close and obviously the entire trocar could change directions. Watching the arms on the robot move was like watching a spider; there are multiple joints all moving simultaneously. Dr. Stein instructed Dr. Williamson, “Down like this but not straight like that.” He was indicating angles and Dr. Williamson inserted and clamped with a plastic clamp twice. They were essentially collaborating to proceed with the surgery. After the prostate was completely dissected, Dr. Stein used one of the trocars to grab it with both cut sections of the vas deferens⁷⁰ and hold it up into the open space inside the abdominal cavity. These were essentially embedded in the prostate.

There was a double needle on one wire suture. They started stitching. Dr. Stein went back and forth suturing the distal urethra to the bladder neck. At this point it was like shoelaces and everything was loose. He put of four stitches in the distal urethra and the bladder neck, then said that will be enough where it won't back out, and he started tightening the suture like tightening shoelaces, and the back wall of the distal urethra approximated the bladder perfectly. I thought the surgical technique was astonishing.

Dr. Stein instructed Dr. Williamson, “Cut this one,” and the needle was then passed from forceps to forceps and taken out of the abdominal cavity through the plastic trocar exit. Dr. Stein started doing surgical knots, square knots, tying it the metallic suture with one needle on and the other end of bare suture.⁷¹ The knots were perfectly tied. Dr. Stein came over and sat back down next to me and started typing on his laptop. I had previously tried to explain my thinking about space, time, and three-dimensionality, and he always acted as if he didn't

⁶⁸ Pneumoperitonewum is air in the abdominal cavity. Insufflation means to inflate a cavity, similar to inflatable lawn entertainment systems.

⁶⁹ An instrument to cauterize blood vessels to stop bleeding during surgery.

⁷⁰ The vas deferens are the tubular structures that carry sperm from the testicles, through the scrotum and penetrate the prostate before emptying into the prostatic urethra, the channel where urine comes out of the bladder.

⁷¹ Suture is a fancy word for string, often made of very special materials for different surgical purposes.

understand. In this case, he told me to go over to the console and take a peek through the 3-D glasses, which I did. The others were putting the surgical drains in, and I went over to the console where I could see the three-dimensionality of the surgical field as if I had binocular vision in an open incision. AMAZING! I did look down at the hand controls. There were actually small bands for the thumb and forefinger as you grasped the bar with again multiple joints on the arms in the console.

Figure 12. The draped, jointed arms of the robot over the draped body of the patient.



Figure 13 Similar image, but also shows IVs, flat-panel monitor, and multiple robot arms.



Figure 14. Video image of surgical field, as displayed on flat-panel monitor.

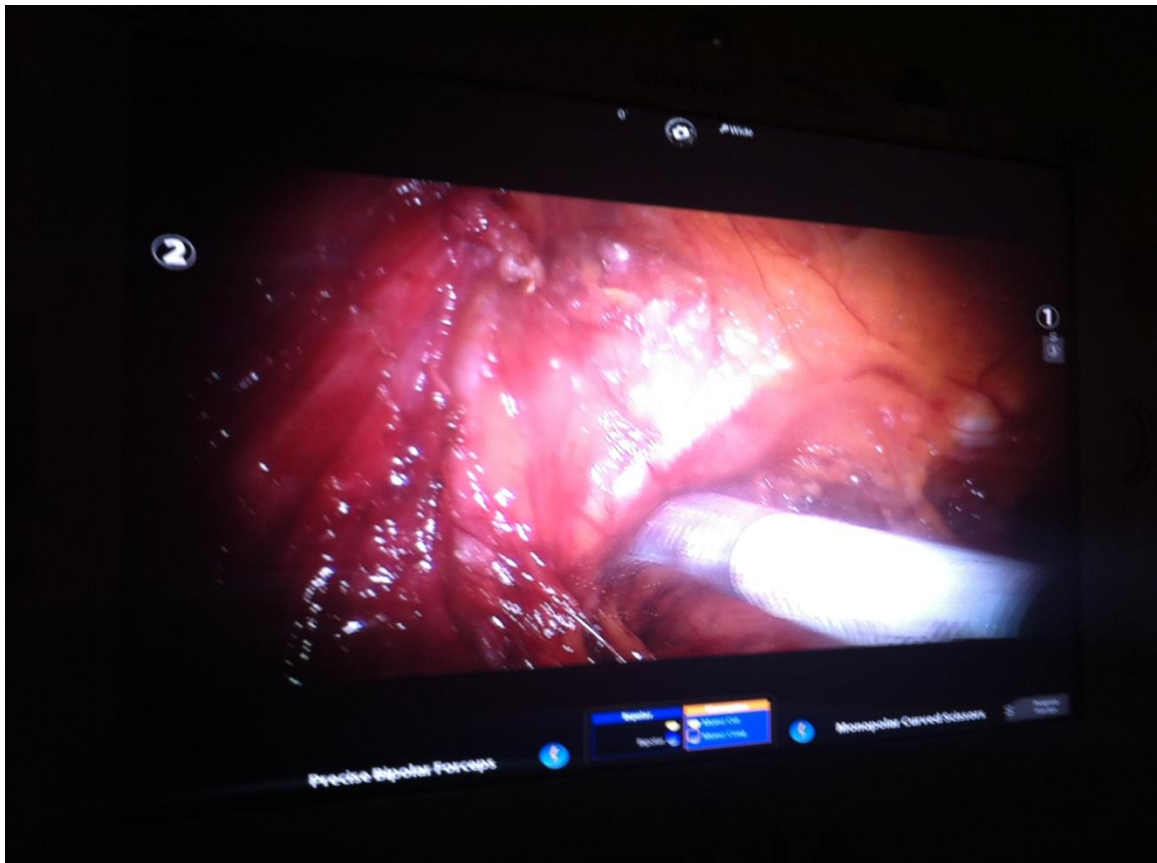


Figure 15. The console that operates the robot.



Figure 16. Both the robot and the console after the surgery (not draped).



Figure 17. One of the micro-instruments inserted through the trocars, showing multiple joints and swivels on the “hand.”



Figure 18. The researcher, self-portrait in the locker room of the operating room.



The three-dimensional diagnosis and chemotherapy

One could argue that the emphasis on spatial relationships and three-dimensional imaging is an artifact of my data being from surgically-oriented specialties. Oncology is a specialty of internal medicine, which typically is conceptualized as heavily dependent on laboratory data. My fieldwork data showed that there was always a residual emphasis on CT imaging as the final arbiter of “removal of the disease.”

Dr. Spangler said, “Are you doing a CT scan? When was the last one?”

One of the residents replied, “One million years ago.”

Dr. Spangler asked, “We didn't do one this admission?”

They decided they needed to do one. But they needed a reason to order it, not just because it's been a long time.

The resident said, “You could say we're looking for obstruction.”

Again Dr. Spangler said, “When was the last one? He needs a CT scan of the chest before he goes.”

One of the residents pointed out that the patient's creatinine was up. “We want to avoid giving IV contrast and extend the hospitalization.”

Dr. Spangler said, “Just get a non-contrast CT because we need to get the big picture in order to treat his cancer.”

Even though chemotherapy is a medication and not a surgery, a three-dimensional image is required to provide the therapy.

Summary of Chapter 8

The diagnostic narrative determines the etiology of the disease. That same narrative determines the correct therapy. The healing ritual proceeds by removing the diseased organ from the body. This process is closely connected to the diagnosis, which guides the doctor through the therapeutic phase of the healing ritual.

Chapter 9: Qualifications of a “leech”

Rivers (and others) describe another aspect of medicine that is consistent with a biomedical healing ritual. Speaking further about the qualifications for a leech, Rivers says:

The most complete instruction in any branch of medical magical or medical religious art is of no avail to the people unless money has passed from himself to his instructor. This instruction and purchase, however, nearly always include both the production and cure of disease, where disease is ascribed to human agency in the power and knowledge to perform rights other than those of the curative nature where medicine is allied with religion. [2001[1924]:41]

Although he's talking about healing rituals in Melanesia, that same statement is a fairly accurate description of postgraduate medical education in the United States. Consider that Dr. Fields has \$240,000.00 of educational debt. I will provide further aspects of training a leech later.

Repeating what Rivers said, Evans-Pritchard states:

Magic must be bought like any other property, and the really significant part of initiation is the slow transference of knowledge about plants from teacher to pupil in exchange for a long string of fees. A teacher may show them casually to his pupil at any time when they were both out in the bush together, as on a hunting trip, or he may specially take him out for the purpose. Unless the medicines are bought with adequate fees there's a danger that they will lose their potency for the recipient during the transference, since their owner is dissatisfied and bears the purchaser ill will. [Pritchard 1976:97]

The modern-day version of that is a medical-surgical residency. There is a connection between hierarchy, experience, and competence among doctors.

Meyer Fortes also talks about training and its vital role in generating a healing ritual. “But I have in mind more the fact that divination is often a specialized technique. The diviner may have to undergo training to become expert in it, or he may be selected for it by virtue of his talents for his psychological makeup. The diviner must be properly accredited, often by a public initiation after evidence of his acceptance by the occult agencies” (Fortes 1987:10).

Those passages describe the initiation and transfer of the systems of meaning that comprise diagnosis and therapeutics. This is as much a part of the healing ritual as any other. If Western biomedicine is a healing ritual, then my data should contain observations to verify this. After all, society confers the privilege of pronouncing a diagnosis narrative to only those whose qualifications and credentials are recognized by others. This training not only qualifies the practitioner to proclaim a diagnosis but also is a vital aspect of the persuasion component of the healing ritual. Although a supportive function, it is a necessary function and intimately connected to the other narrative components of the ritual. It identifies an authoritative narrator.

Brian assesses the qualifications of his doctor

Brian intuitively understands that there is a connection between hierarchy, experience, and competence. This portion of his monologue highlights that concordance and affects how he navigates the healing ritual.

Well, I knew enough about what was going on to know that prostate surgery included urinary incontinence and sexual problems and things. I'm imagining I'm gonna run around with a diaper for the rest of my life and my sex life is just gone completely and is gonna stop from here on, and I'm gonna to be rendered pretty much unable to do any of that. I mean, that's – You jump to the extreme of what you've heard and know about.

Knowing that I was probably not thinking totally clearly, as the one who is trying to assimilate all of this. I know at one point I asked him, "Okay, how many surgeries of these do you do," because I was – and I don't remember at what point we heard from this friend of ours, and it was probably at the point we knew we had it, but before we had decided where we were gonna go about this. So I know there were some questions about, "Okay, how many of these do you do?" And it was something like well 20 or 25 a year. And then we were comparing that with Dr. Stein, who did 30 a week or something like that. It was drastically different the number of these things that people did. And so that was also part of the discussion of where we were gonna have this done and how we were gonna do it.

The husband of a colleague of hers had been through similar things more advanced and more serious than what I was dealing with, and he had a very

positive experience at Connaught and referred me there. So I contacted Dr. Stein, who was the surgeon who had done the other guy's surgery and for seeking at least a second opinion and potentially to do the surgery. Well, he was very busy, and it was going to be very difficult to get in to see him. I think he was the head of the oncology department over there, and so getting to Dr. Stein was supposed to be rather difficult, and the first contact was, "Well, you know, would you be interested in having one of his students or one of his colleagues do that?"

And I said, "I really would like to have Dr. Stein do this," and subsequently I was accepted as a patient of Dr. Stein and met with him at least once to go over that and then ultimately the surgery was scheduled.

My thinking at the time and the reason for going to Dr. Stein was he had – at least I had become aware, and some of it was from the reference that got me there. And other sources, I don't recall. He had lots of surgical experience with the robotic surgery. He went out of his way to not just hack away at it and take whatever was left. His specialty was leaving as many of the nerves as possible and being very exact in how this was done, and he has developed a reputation for that and with some very good results. His whole focus was "We're gonna do this and leave you in absolutely the best shape we can to live a normal life from here on." And so that aspect of it, of the outcomes, was pretty high in my looking for, you know – I wanted it to be a successful surgery, but my mission was I want it to be successful. And I want my full function of my body when I'm all done, and so the whole emphasis on – the whole reason for going to Dr. Stein was the – I'll say "reputation," but it was the focus of a lot of his research, and his practice was doing this surgery in as least harmful way as possible.

Embedded in this passage is the contemplation of incontinence and diapers, impotence, and a sex life that is just gone. Brian's response is to seek out the best practitioner of the healing arts, the one that leaves as many of the nerves as possible and is very exact in doing it with the DaVinci robotic surgery technique.

Transference of knowledge from teacher to pupil

The inpatient urology rounding team consists of a chief resident, senior residents, the intern, and finally the medical students. A strict hierarchy is enforced, with the chief resident acting as proxy for the attending physicians for clinical management of the patients, supervising

the more junior residents. The chief resident also decides who gets to scrub in on what surgery. The chief himself claims the difficult cases and the robotic cases; the others have to wait until they become senior enough or chief to have this opportunity. On the other extreme is the intern who does the repetitive, routine surgical cases, such as retrograde urograms and cystoscopies. In the following vignette, notice how strictly the hierarchy is enforced. The slight infraction is punished by comments about getting experience in the operating room and the ultimate insult to a resident, offering the first assistant position to a medical student.

Connaught Cancer Institute rents renovated floor space on the fifth floor of Hopewell Hospital. The accreditation for the urology residency is through Connaught, so they see most of their patients on this floor. However, they also see consultations on other floors of the interconnected hospitals. Rounds start at 6:30 a.m., so I tried to arrive slightly earlier. The medical students were already there and collecting data from the various computers as well as a perfunctory interview with each patient. Shortly after I arrived, Dr. Wright showed up and immediately went to the computer and started jotting down labs. The tall medical student was doing the identical procedure with a different computer, jotting down labs, both of them copying them onto a computer printout with the patients' names. After Dr. Pinder arrived, he started whispering with Dr. Wright. Shortly thereafter Dr. Wright says, "What we have here?" The medical student started presenting patient after patient to Dr. Pinder. He reported symptoms, lab results, temperature and vital signs,⁷² including input and output.⁷³

At 6:48 a.m., Dr. Fields joined the group. Dr. Pinder said, "Dr. Fields just wants to show up and operate while I take care of patients. At least he wants to go to OR now, so that's a little bit of progress." Rounds continued without comment. Dr. Fields took one of the portable computers on the small tabletop and pushed it around down the hallway and into each individual patient room. He was constantly staring at the computer and typing throughout the walk, the discussion, and the patient interviews. I was able to get a very close look at the computer that Dr. Fields was using. I was able to ascertain that it was actually progress notes that he was generating directly onto the computer program.

While in a room with a patient, Dr. Pinder asked, "Are you passing any gas?"

The patient replied, "Why do you say that?" There was no response from Dr. Pinder. Dr. Pinder put gloves on and examined one patient's wound while asking "Any nausea or vomiting?" after finding out the patient had not yet passed gas. Instead, Dr. Pinder started examining the incision and asked, "Any pain?"

⁷² Vital signs include blood pressure, pulse or heart rate, temperature, respiratory or breathing rate, and "pain".

⁷³ Measures of fluids going into the body and fluids coming out of the body, recorded in the nursing notes section of the chart.

The only response was “Arrghr-rrghh!” Even while the patient was moaning, Dr. Pinder said, “Incision looks good. We started TPN yesterday.”⁷⁴

The patient asked, “Can the drain come out?”

Dr. Pinder said, “Yeah, there's not a lot draining. The incisions look good. Your urine looks good too [even though it was bloody red]. You have a low-grade fever,” which seemed to surprise the patient. Dr. Pinder continued, “The most important thing is to use this device,” referring to the incentives spirometer. “You should get up and walk around, and perhaps you can get the urinary catheter out today and maybe even possibly go home.” As everyone left the room, Dr. Fields pushed the computer on wheels outside the room.

⁷⁴ TPN is Total Parenteral Nutrition—all nutrition provided through an IV and not the gastrointestinal system.

Figure 19. Computer on wheels—almost ubiquitous in inpatient settings.



Once we were outside the room and back the hallway, Dr. Fields said to Dr. Pinder, “This is the first time in my entire residency that I've been late; it's been 14 months and this is the first time. You showed up two minutes before I did.”

Dr. Pinder said, “It doesn't matter what time I show up.”

Dr. Fields replied, “I was hoping you wouldn't chew me out on rounds.”

The conversation drifted to “What’s the case today?” Then someone said, “There are four cases tomorrow.” Dr. Wright turned toward the medical students saying, “You might be the first assistant on one of the surgeries.” The entire time the residents were discussing surgeries and surgical techniques. One of the senior residents used hand gestures in three-dimensional space to demonstrate anatomy and surgical techniques. He did this multiple times. Once, when they were arguing about a specific procedure, one of the residents demonstrated a reported technique from the literature and performed the entire operation in three-dimensional space with his hands to show the others.

The constant conversation and gesturing about surgical techniques was always part of the daily discourse in the life of a resident. They are learning their craft – surgical skills. They also have to learn cognitive skills. On Friday mornings, there is a conference at the residency office attended by a couple of attending physicians and the residents, followed by an unstructured learning session for residents led by the chief resident. The typical format for this would be to review board questions from a board exam preparation book.

The pretense for the meeting was to study. They asked questions from a textbook. They would intersperse clinical case discussions with test questions and socializing:

In contrast to the admiration and banter with their own faculty, they discussed the strengths and weaknesses of private attending physicians with an almost mocking perspective. They said things like, “He went crazy on me” Or “That was when I was the most uncomfortable, when we went in to see a guy dying from cancer and [this particular attending physician] said, ‘Hey you’re dying of cancer. How’s life, huh, big guy?’” or “He’s the best one to be on call with. He’s an Iron Curtain.”

They were also joking about the attending, and one of the residents had asked a particular community attending, “How do you do a hydrocoele?”⁷⁵

The attending replied, “I open the scrotum. I take it out.” The resident was aghast that he didn't have any particular procedure and was unfamiliar with a

⁷⁵ Hydrocele is a cyst on the spermatic cord,; when very large it can cause discomfort, the reason tor surgically remove it.

particular named procedure that Dr. Patel uses. When the resident questioned the community attending, he reportedly said, “I don't know what you're talking about.”

In addition to sharing surgical techniques and medical management knowledge, the topic discussed the most was the amount of surgical experience each of them had, and how they could get more experience. A junior resident said, “I beat him by an hour [arriving at the hospital], so I did the surgery and I was actually leaving by the time the senior resident got there.” Another resident pointed out, “The next senior should get there late, because I want a chance to have opportunities [to do such big surgery] myself.”

Another resident said, “I saw an autotransplant. It was a sweet case. It failed miserably.” This willingness to gain experience without benefit to the patient was echoed by another resident's comment, “We have to do a stat prostatectomy before they diagnose the lung cancer.”⁷⁶ The residents talked about a retroperitoneal varicocele⁷⁷ repair and the senior residents said, “What's the plan for that case? I plan on scrubbing, but if one of you guys wanted to do it, I'll walk you through it.”

“He let you do on those?”

The senior resident said, “Those guys [at an affiliated hospital] are open surgeons, so they are more comfortable letting you do things that are open, because they know that they can get you out of trouble. They are less comfortable letting us use the robot. That's totally different with Dr. Jeffries.” They talked about the different robotic surgeries each resident had done and the senior resident said, “The Cowboys are in town, and that's never going to happen again.” He was referring to the episode where one of the junior residents did more robotic surgeries than one of the senior residents. “That was selfish of them. You're still third in line. Just remember that.”

This desire for surgical experience is understandable. It is the only way to achieve competence. On a different occasion, I overheard Dr. Jeffries telling the residents that he would be happy to confront the private attending physicians if they weren't allowing the residents to get enough experience. Because robotic surgery is relatively new, patients seek experienced surgeons. This measure of experience both creates the hierarchy and the hierarchy ensures that each resident is trained properly. Consider the socialization process of the more junior residents:

⁷⁶ STAT refers to immediate; prostatectomy is surgical removal of the prostate gland. In this case, the residents were joking about how to get more surgical experience. If lung cancer was diagnosed, the patient would not be eligible for a prostatectomy.

⁷⁷ Retroperitoneal refers to anatomical structures behind, “retro” the abdominal cavity, which is covered with a membrane called the peritoneum. Varicocele refers to “varicose veins” or engorged veins in the scrotum.

Dr. Fields was one of the least experienced residents, still in his first year. During the morning “education” session described above, the conversation drifted to a clinical discussion of the patient who had a PSA of 10.6 without any rectal manipulation. He said there were some pulmonary findings. Someone asked Dr. Fields, “How big was the prostate?”

He replied, “It was hard to feel. This is a problem: How are you supposed to know how big it is, because there is no frame of reference?”

Another resident said, “People want a number. Just do the exam and then guesstimate.”

Dr. Fields mentioned, “After the beginning of the New Year, there will be a general surgery resident on the urology service, and then there will finally be someone lower on the totem pole than me. I’m looking forward to them carrying the pager because it’s very annoying trying to answer the pager while being scrubbed in and answering questions through the nurse. I had to do two internships, one general surgery internship and one urology internship, and during both I’m the lowest person on the totem pole.”

As if to add insult to injury, Dr. Fields said, “I have \$240,000.00 in educational debt. I lost my deferment, so now they take the money right out of my debit account every month.”

Dr. Solski walked over to Dr. Fields and slapped him on the back hugging his shoulders, reassuring him it will be okay.

While undergoing the uncertainty of acquiring new skills, Dr. Fields comments about his educational debt. This is validation of the apprentice role in the healing ritual described by Rivers in the introductory paragraph of this chapter. Not only do senior residents teach junior residents, attending doctors teach residents. Consider the following interaction during inpatient oncology rounds:

Dr. Spangler asked, “Why doesn't he sleep?”

One resident answered, “He told me because of his headache.”

Another resident said, “Because he's restless.”

Dr. Spangler said, “It's not because he's having a heart attack, is it?” At that point, they listed all the different causes of mental status change, including infection, myocardial infarction,⁷⁸ stroke, etc.

One of the residents said, “We didn't get an MRI.”

Then Dr. Spangler said, “What else?”

The presenting resident suggested, “Psychiatry problems or medication.”

Dr. Spangler said, “What would give you mental status changes with gait changes?”

⁷⁸ Heart attack

“Normal pressure hydrocephalus.”⁷⁹

Then Dr. Spangler said, “What else?”

The resident guessed, “HIV.”

Dr. Spangler said, “No!” quite emphatically and repeated “No!” slapping the table. “What about a sleeper?” (She was referring to a hypnotic medicine.) “We need to think about it like a good internist.”

The resident said, “He seems a little odd [referring to the patient].”

Dr. Spangler then interrupted and went back to her previous line of thought, “We missing one more. There's one more.” There was relative silence, and Dr. Spangler continued, “I must've tortured you at least once this month about this.” None of the residents could come up with the answer, and so Dr. Spangler told them “Thyroid problems.” Her conclusion on this case was, “We don't know what's going on. Let's wait for the scan.”

Dr. Spangler was doing some more teaching, “Where does lung cancer metastasizes to? It's a really tiny gland.”

The presenting residents guessed, “The pituitary.”

Dr. Spangler laughed, bending down and putting her forehead on the table while laughing. When she rose back up, Dr. Spangler said, “The gland I'm looking for is close to the liver.” The post call resident couldn't figure it out and finally Dr. Spangler said, “It's the adrenal gland.”

The post call resident replied, “Which is also close to the liver.” This was a deadpan joke because the pituitary is in the skull and not close to liver.

Dr. Spangler used this teaching technique a lot. This next section demonstrates the relationship of a CT scan to nausea, followed by teaching about causes of nausea:

The next patient was a transferred from Harvey Frank Hospital. There was no notification to the resident prior to the patient arriving on the floor, to which Dr. Spangler expressed her displeasure. The patient had just gotten his first dose of cisplatin⁸⁰ and he started vomiting, so his mom called and took him back to the hospital. In the emergency room at Harvey Frank Hospital, they did an x-ray and a CT scan determining there was no obstruction, so he was sent back to Connaught. The discussion continued about multiple reasons why they couldn't start chemotherapy. Dr. Atlas went to the computer and looked at the CT scan. Dr. Spangler replied, “He never had puke problems before,” and then went over four different reasons for nausea. “The first one is anticipatory nausea. That's when the patient is approaching the chemotherapy suite and starts to get nauseated. That's the right answer on the test. The second type is acute nausea. That's with the initiation of the chemotherapy right at the moment of chemotherapy infusion. Chemotherapy-related nausea, which is the third type, which is after the patient's had the treatment.”

⁷⁹ This type of social interaction in medical education is called “pimping” after a famous article in JAMA 1980. She is asking them what she is thinking as a method for them to recognize diseases, syndromes, or diagnoses.

⁸⁰ A toxic cancer chemotherapeutic drug.

Dr. Atlas piped in, “Non-chemo-related nausea.”

Dr. Spangler asked, “What’s the next kind?” Nobody could provide an answer. “The fourth type is chronic nausea, which means it’s there all the time despite chemo or the disease. No one can find the reason.”

This type of Socratic teaching occurred in all types of settings whenever doctors of different hierarchical status worked together. At one point, the emeritus urology professor, Dr. Bridges, was supervising a operating room case when Dr. Stein stopped by to watch Dr. Wright and Dr. Fields perform a retrograde uroscopy and cystoscopy and biopsy. Dr. Stein asked a trick question about how to locate the source of malignant cells in a complex clinical situation. They all discussed the case. Even the medical student joined in the mind-teaser, and despite the input of the chief resident, the senior resident, and all the others, no one could figure out the answer to the question. This type of cognitive practice occurred abstractly or related to the clinical case at the time.

In addition to all the learning described above, residents reviewed CT scans and MRI images as part of daily activities. Whenever a resident was in clinic, the attending always reviewed the images (remember the instance when there were four of us all staring at the same image.). During each of these encounters, the resident always reviewed the images together with the attending physician as part of the clinical encounter. Residents reviewed images in clinic, at Multidisciplinary Care Conference, in the operating room, and on rounds in the hospital. Residents reviewed images as often as attending physicians, which was practically on every case.

Summary of Chapter 9

The healing ritual is a cultural production, and in order for it to survive, there must be cultural replication. This is accomplished through the specialized training required to perform healing rituals. Without this specialized knowledge, the ritual would not be effective. With the

comment about the three-dimensional printing of internal organs to facilitate surgical planning, we see the “ratchet effect” described by Tomasello. In fact, the DaVinci robotic operating system itself is the result of such “ratchet effect.” In multiple settings during fieldwork, I observed residents working closely with senior faculty, reviewing computer images, answering Socratic questions, and practicing motor skills in the hallways and in the operating room. The residents “pay” for the specialized healing skills that create the expertise to claim socially recognized power by long work hours, studying, apprenticeship-like workdays, and the all-important surgical experience. This learning process is all implicit. At no time were the “qualifications of a leech” described overtly as learning how to make a diagnosis narrative or even the more remote concept of healing. These last two concepts are anthropological insights that arise from observing daily routines.

Chapter 10: Critical Re-Appraisal of Illness Narratives and Healing Relationships

Introduction to Chapter 10

Throughout my analysis, I have noted the absence of illness narratives in healing rituals and attempted to describe the importance of diagnosis narratives. Yet, Kleinman and I both claim to describe “healing.” Kleinman claims, “What is important is to lay out the anatomy of successful healing so that it can be understood, taught, acquired, and more routinely practiced” (Kleinman 1988). In this chapter, I will attempt to explain how we came to different conclusions. First, I will provide a comparative review of methodologies that I believe explain our different perspectives. Second, I will describe what I believe to be evidence of healing relationships in my data. Third, I will review the last three steps of Kleinman’s Patient Explanatory Model and attempt to show how they are consistent with my data.

Brian’s explanatory model

Throughout Brian’s monologue, there was never a discussion about how Dr. Stein explored what having abnormal PSA meant to him or what socially symbolic meanings were associated with a cancer diagnosis. Brian’s story contradicts Arthur Kleinman because his illness wasn’t made into a disease that changed Brian from a person into an object. According to Kleinman, “Physicians’ overriding interest in disease and disregard of illness is, regrettably, commonplace.” Yet in the last segment, Brian gives his perspectives on life, on having had cancer, having had “a scare,” the fear of the unknown, and being welcomed into the club of having the teddy bear.

Now, most of the time I don't think about it much. A lot of the time I, I felt like I came through it really, really well to the point where I live my life virtually completely normally since. I've had the thought that I really, you know, that people will talk about being cancer survivors, and I – My image of cancer survivors are people who have been through hell and back and still have pain or have some pretty devastating things that they are dealing with on a regular basis, and I don't have any of that. And so I don't feel like a cancer survivor. I'm not a real one, at least. Mine was – Yeah, it was a scare. And it wasn't particularly pleasant to have it, the surgery and everything. I wouldn't choose to go through it again, but once I was done with the – I was pretty well done with it and have continued to – Like I say, I lead a quite normal life.

I was out of work three weeks. I was in the hospital a couple of days. I think I went back to work part-time, I think, the third week after. And there were a couple of days there that – “Okay, it's noon and I'm going home.” So I think I was off two weeks, and then the next week I was kind of part-time, and then after that I was back to work pretty normally. I mean the first five or six days I have the catheter, and so I want to get that out, and that was a step. And there was – oh, I don't know, it was probably a couple of months I was still wearing diapers to just make sure I was gradually gaining urinary control again, and so I would say six months I was pretty much over the whole thing.

It's much easier now because it's all behind me, and it's all worked out really well. I can look back on it. Again I think you – It was an unknown. It was the fear of the unknown. I don't know what's gonna happen. I don't know how this is gonna turn out. After the fact when it's turned out really well, it's much easier to relate and say, “You know, I had a very positive experience with this after the fact.” There were a couple of highlights in there but it was – and, you know, I – There've been several people that have welcomed me to the club of guys who have had prostate cancer, and there were several at church that – “Well, welcome to the club!” And I got a little teddy bear, or something, from one of our friends, and – and pastor. Now there was a teddy bear, and then there was another little stuffed toy that was a good luck thing, so I've passed it on, and it's actually been passed on several times now. I passed it on to Tom, who had also had his surgery with Dr. Stein, and then another friend of his, and so he passed it on, and I don't know where it is now. But it was just something that we can kinda did – “Well, okay. I've got a friend who's gonna go through this” and so I'm gonna give him the – It was just a good luck thing, so it was – That was kinda fun.

Brian's experience is entirely consistent with the clinical encounters I witnessed. What Brian's story demonstrates is that there is not a missing component to the healing ritual as practiced around the world, throughout time, and here and now in Western biomedicine. This chapter is a re-examination of the healing relationship from an anthropological perspective.

Comparative review of methodologies and research questions

Both Arthur Kleinman and I agree on the basic premise that enhancing healing in medical practice will improve the healthcare system and patient outcomes. However, we used vastly different methodologies and approached the topic on completely different levels of analysis. I believe the difference in methodology and level of analysis explains why our findings diverge. Comparing methodologies facilitates an understanding how illness narratives and diagnosis narratives exist simultaneously in different places and social contexts. Kleinman set out to study the relationship between medicine, psychiatry, and culture. In *Patients and Healers in the Context of Culture—An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*, Kleinman writes, “The reader will find this book contains a dialectical tension between two reciprocally related orientations: it is both a cross-cultural (largely anthropological) perspective on the essential components of clinical care and a clinical perspective on anthropological studies of medicine and psychiatry. That dialectic is embodied in my own academic training and professional life, so that this book is a personal statement.” (1980:ix) This work relies almost exclusively on cross-cultural ethnographic data collected in Taiwan and incorporates multiple different ethnomedicine perspectives. Upon closer examination of his ethnographic data, he studied patients with psychiatric distress presenting to psychiatric clinics. He argues (successfully) that illness experiences and broader culture are related. It is in this book that he presents most of his primary ethnographic data. In his *Illness Narratives* (1988) he repeats the argument for a broader audience, using his American clinical practice, and presenting a case series to make the same argument. Within this context, I agree with Kleinman that exploring illness narratives is an appropriate clinical management for *psychiatric patients* that typically do not fit a classical biomedical model. Using my own positionality of being a primary

care doctor, I see both psychiatric patients and biomedical patients within the same clinical office setting. I find it imperative to distinguish what the patient needs the most—joint attention to an illness narrative as a reflection of psychosocial distress or joint attention to a biomedical diagnosis narrative of disease. Of course, it is never all of one and none of the other, but some of the most dissatisfied patients result from a missed biomedical diagnosis. Often, as represented in the data of this study the process is sequential—the “illness narratives” or intimate personal sharing between the doctor and the patient begin to emerge after successful completion of a biomedical healing ritual.

In contrast to Kleinman, I was fastidious about positionality because I was not studying “the other” but rather, a subculture in which I participate as a clinician. Kleinman’s wiliness to merge the domains of anthropology, medicine, and psychiatry compared to my need to maintain a rigourously anthropological approach “at home” meant that we had different perspectives as part of our respective methodologies. For example, in the *Illness Narratives* Kleinman states,

From a psychiatric standpoint Alice Alcott was deeply distressed and depressed in response to her chronic illness, but although she was desperate, her state did not warrant the clinical diagnosis of major depressive disorder or any other serious psychiatric syndrome...Early in psychotherapy, our sessions centered on grief for her multiple losses. But as her spirits lifted, she returned to her characteristic denial. The last few times we met, she would discuss her children’s problems, her parents’ problems, anything but her own. [1988:38]

In addition to assuming his diagnosis was correct, Kleinman presents his cases in the third person and follows each case with a section labeled “interpretation.” It is in his psychiatric interpretation that he attempts to provide the cultural context and “meaning.” Whether he presents these interpretations as anthropologist or as psychiatrist is not clear. Because he is trying to argue that they are co-constituent of each other, it probably doesn’t matter to him. I understand why and how he is trying to put forth his argument, but I also recognize that he opens himself to threats to

validity of his analysis by taking this approach. He is clear that he is willing to accept this limitation when he says, “That dialectic is embodied in my own academic training and professional life, so that this book is a personal statement.” I find it ironic that in trying to illustrate his point, he subordinates the “voice” of the patient by presenting the data using his role as psychiatrist. He chose this tradeoff to make his larger point about the connection of illness narratives and culture. Psychiatry reviews experiences in the patient’s past to offer clues into current behavior. An illness narrative is a method of creating a joint attention to past experiences.

Arthur Kleinman acknowledges that healing rituals are part of Western medicine but considers them flawed by lack of attention to the illness narrative. To consider his frame of reference:

From an anthropological point of view, recording the case is an example of a secular ritual: it formally replicates a social reality in standardized format to a central problem in the human condition. Like religious rituals, secular rituals express and manipulate key symbols that connect a shared set of values and beliefs to practical action. By observing in this light the writing of a case into the medical record, we should be able to see more clearly the influence of professional values (and the professional’s personal preferences) in the care of the chronically ill. To accomplish this end, I will first provide a transcript of a doctor-patient interview and then describe the wording of the physician’s formal write-up in the patient’s record. I don’t contend that the following example is representative; indeed I believe that the degree of professional insensitivity it depicts is unusual. But I do think that the physician’s overriding interest in disease and disregard of illness is, regrettably, commonplace. (Kleinman 1988:131)

The lack of attention to the illness narrative in the healing ritual is *regrettable* for Kleinman. He concludes that if biomedicine is to become a healing social practice, it must pay more attention to illness narratives. Kleinman says, “This alternative approach [to biomedical practice] originates in the reconceptualization of medical care as (1) empathic witnessing of the existential experience of suffering” (Kleinman 1988:226). Note that these quotes from Kleinman acknowledge both ritual and “existential” aspects of chronic illness. My critique of Kleinman is

that he overreached in his conclusion. He is saying that to improve “healing,” doctors have to incorporate patients’ illness narratives into biomedical practice. To improve healing, we need to improve medical practice. This is the identical argument made by Rita Charon. (2006) In both cases, the “power to heal” resides with the doctor. As stated in Chapter 1, I reject this formulation, preferring to believe that healing emanates from a relationship with a socially authorized healer that connect the distressed person to the broader culture.

In contrast to Kleinman’s broad, synthesizing approach, I studied the very narrow confines of the Western biomedical clinical encounter in a urology practice. I was looking for “the narrator,” and how the story was constructed. That is where I discovered an overlooked “narrative,” the diagnosis narrative. The healing ritual involves the construction of the diagnosis narrative as well as “persuasion” of the patient that the diagnosis is correct. This persuasion is not a form of aggression, as so commonly presented, because the biomedical model is a shared cultural category by both patient and doctor. “Persuasion” as used within the ritual is helping the patients recognize something about themselves that they already agree with—biomedical science. Based on my theoretical review, I am describing the narrative structure of **shared experience** during a healing ritual, expanding on Mattingly’s observations of narrative structure of experience. This shared experience is a form of “the ratchet effect” described by Tomasello. I further argue that shared experience creates healing relationships. In contrast to Kleinman and Charon, I believe that to improve healing we do not need to improve medicine or doctors; we need to improve healing relationships. I argue that healing is a product of the relationship created by the shared experience of the healing ritual. We all agree, however, that more healing in medical practice is a desired goal.

I am not saying that illness narratives don't exist—they do, and they have social significance, just not within the context of medical-surgical clinical encounters. Illness narratives are the stories you tell your neighbor, your friends, your relatives, (an anthropologist), or psychiatrist, etc., to explain your life experiences in a culturally appropriate way. In this way, they help maintain a social network. My data simply show that they are not universally present in clinical settings, yet healing relationships develop anyway.

Upon reviewing each of Kleinman's cases – Alice Scott, Howard Harris, Rudolph Kristiva, Antigone Paget, William Steele, Patrick Esposito, Paul Sensabaugh, etc. – I find that Kleinman picked “narrative failures,” instead of the success stories of biomedicine (such as Brian's). In both *Patients and Healers in the Context of Culture* (1980) and in *The Illness Narratives* (1988) Kleinman uses cases that present to psychiatric clinics. I suggest that there is an inherent selection bias in studying only this population. From each of these cases, he recorded an illness narrative and, based on his psychiatric interpretation, suggested a “healing narrative.” He explains this:

I see medical psychotherapy, then, as a collaborative relationship within which the techniques for exploring illness meanings encourage catharsis, persuasion, practical problem solving, and other of the mechanisms of psychotherapeutic change.... When the tasks of support, attention to emotional needs, the negotiation of an authentic relationship are accomplished in a caring fashion the question of how to do medial psychotherapy vanishes. That is the psychotherapy. [Kleinman 1988:246]

Kleinman's mistake was to generalize the narrative failures of the diagnosis narrative (somatization) to all clinical encounters. I contrast illness narratives, as told by a person in a Labovian recall of past experience with healing relationships, as experienced by a self, a self completed by interaction with culture, the culture of a medical encounter.

Kleinman's influence on narrative and healing in anthropology

There are many examples in medical anthropology where the doctor is described doing clinical work that portrays the doctor without this implied criticism, and the results are balanced and informative (Inhorn 2003; Kaufman 2005; Pool 2000); however, within the narrow scope of narrative and healing, Kleinman seems to have had a dominate legacy. According to Labov, "Narratives include a protagonist, antagonist and third party witnesses" (1997). Illness narratives commonly portray the doctor as the antagonist, such as Arthur Frank's (1995) "biomedical colonization," a work that relies heavily on the work of Kleinman and the Harvard Friday Morning Seminar in medical anthropology. Rather than an antagonist, I ask my anthropological colleagues, where in the ethnographic record of narrative and healing is the doctor portrayed as protagonist or witness? Kleinman (and others, including Mattingly) bemoan the fact that doctors don't explore the illness narrative, yet even Cheryl Mattingly, when she summarizes the anthropological canon, says:

Narrative studies of patient/doctor communication have addressed power through examination of a subordinate (patient) voice which is in contest with a prevailing and powerful medical voice. Analysis of interchanges between doctors and their patients often show patient narratives as neglected or reorganized through the doctor's "medicalizing" discussion.... 'Doctor talk' often emerges as a kind of anti-narrative speech act, a 'literary rhetoric,' which gains its perlocutionary power precisely through a set of discursive moves which suppress personal narrative, such as adoption of the passive voice and consequent elimination of agency. [Mattingly 1998:12]

In this characterization, Mattingly reinforces the concept that doctors medicalize and therefore subordinate patient voice in an anti-narrative rhetoric, which implies an abuse of power. I demonstrated how doctors use that same power to benefit the patient.

Again, Mattingly acknowledges anthropology's critique of biomedicine and then almost immediately finds a new way to relegate biomedical practitioners to the role of "bad guy":

We [anthropologists] have documented the miscommunications which so often characterize patients' discussions with doctors and other healers of Western medicine. We have also criticized the culture of biomedicine for being insufficiently mindful of personal, familial, institutional and cultural factors that influence how a disabling condition is experienced and handled by the person who is ill. We have been less attentive to how the illness experience is addressed in clinical practice, especially among lower-status health professionals who spend sustained time with patients. A hospital world operates in two time spaces. One is the time paradigmatically expressed by the doctor—fast and efficient. Doctors cannot afford to linger too long in any one spot. The other is the time of the lesser health professional: therapists, aides, sometimes nurse. Things move more slowly here. These professionals may spend an hour or more a day with a patient, and some of this may be quite informal. [1998:12]

Mattingly presents no data whatsoever of how doctors interact with patients but relegates them to “fast time,” implying insufficient time to address real concerns. My data show that doctors often spend an hour and a half talking with patients and families in the office setting, hours interacting with multiple institutions, to be able to perform surgeries that often take two to four hours to perform. That is not “fast time.” Mattingly then sets up the false dichotomy of the doctors versus “the lesser health professionals,” valorizing their sacrifice of time and effort. This dichotomy belies an attitude that prevents anthropologists from observing what really happens between a doctor and a patient. I will present my explanation for that and its significance for anthropology, but first I will demonstrate how pervasive these attitudes are. She continues:

Because there's almost no language within biomedical discourse recognizing and examining exchanges which address the illness experience and because this is not a “reimbursable” part of treatment, the phenomenological aspects of treatment are quite neglected, carried out almost furtively. These attentions to the illness experience constitute an “underground practice” in occupational therapy and doubtless many other health professions. Taking careful note of the narrative structure of clinical interventions reveals “hidden values” within biomedical practice which run counter to the dominant metaphor of body is machine that holds such persuasive force in Western medicine. Put differently, it reveals how some health professionals, some of the time, recognize a physiologic body which is inextricable from the imagined and lived body, the body which carries a person through social space and time. [1998:22]

Mattingly repeats the criticism that biomedicine is insufficiently mindful of how a disabling condition is experienced and handled by the person who is ill. Again, the premise is that exploring the illness narrative and the patient's experience is the only way to establish healing relationships. This position has other adherents in the writings of Byron J. Good and Mary-Jo Delvecchio Good (2000). I believe this attitude prevents further investigation into healing relationships. If anthropologists uniformly expect to see abuse of power, then the observation bias created by this analytical lens cripples the ability of anthropologists to see other aspects of the clinical encounter between patients and doctors, an example of inattentional blindness. (Simmons and Chabris 1999). This is particularly important for a discipline that relies so heavily on participant observation and in an area of research that has gotten so little attention—actual ethnographic data of Western biomedical clinical encounters with doctors.

Mattingly's ethnography of healing dramas has hardly any illness narratives in her data, very much like my data. No one comments on its absence, but I believe that the reason for her lack of attention to illness stories is the same as the reason my dataset lacks illness stories; we were both looking at ritual as narratively structured experience. She and I both focus on activities the practitioner and patient do together using observational methods. This fact contradicts Kleinman's claim that illness narratives are a necessary part of healing or healing rituals. Mattingly defines narrative in a way that also offers a privileged perspective on the lived experiences of patients, not one told to an anthropologist but one experienced in the presence of the anthropologist. She gives the "experience-near" account that anthropologists strive for, the emic experience:

To summarize, three features of narrative form make it especially appropriate for addressing illness and healing experiences. One, *narratives are event-centered*. They concern action, more specifically human action, even more specifically, human interaction. They concern social doings. Two, *narratives are experience-centered*. They

do not merely describe what someone does in the world but what the world does to that someone. They allow us to infer something about what it feels like to be in that story world. Narratives also recount those events that happen unwilled, unpredicted, and often unwished for by the actors, even if those very actors set the events in motion in the first place. Narratives, one could say, are about the unintended consequences of action (Arendt 1958). Three, *narratives do not merely refer to past experience but create experiences for their audience.* Narratives mean to be provocative. They request a different response from the audience than denotative prose. Narrative offers meaning through evocation, image, the mystery of the unsaid. It persuades by seducing the listener into the world it portrays, unfolding events in a suspense-laden time in which one wonders what will happen next. [Mattingly 1998:9, emphasis added]

Mattingly contrasts her experiential narrative (narrative as ritual) and highlights the difference between narrative as experience versus narrative as denotative prose (illness narratives). Kleinman, I, and Mattingly respectively describe joint attention to experiences in the past, present, and future—healing relationships – and I was interested in how healing relationships come into being through social practices. It is for this reason that I centered my research project at the point where Mattingly left off.

The critique of biomedicine that it does not attend to the illness experience, I argue, is a misplaced critique. I believe Mattingly accurately described healing encounters between occupational therapists and clients based on shared attention to locating desire of an imagined future. The shared attention to the larger cultural context creates the healing encounter. Occupational therapists do not make diagnoses.

Doctors don't always explore illness narratives. It simply is not the domain of biomedicine to perform this function. The corollary is also underemphasized. Doctors do establish healing relationships with their patients, despite their inattention to the illness narrative. The healing relationship occurs naturally as a result of learning through each other and creating a transformed self-narrative. The healing ritual transforms the doctor–patient relationship, which in turn transforms self-narratives.. In fact, I am quite encouraged by the richness of healing relationships within biomedicine, a topic I turn to next.

Healing relationships

My data are uniformly consistent in documenting that doctors do not explore the illness experience as part of a routine clinical encounter, yet I observed ample evidence of healing relationships between doctors and patients. The healing ritual facilitates a healing relationship, and the healing relationship generates intimacy that subsequently allows doctors to explore and become part of the patients' experiences, including illness experiences. I suggest that the person who is ill experiences an existential threat to life, and that is what biomedicine is mindful of addressing in a very culturally defined way. Sequence matters. Biomedicine and healing relationships are not mutually exclusive, as portrayed by many anthropologists. I argue that healing relationships result from completion of the healing ritual. Healing relationships are not an antecedent to a shared diagnosis and treatment. They result from a shared diagnosis and treatment.

First, I will present data that describe authentic relationships between patients and doctors. These relationships are characterized by the classic definition of healing relationships as "knowing the whole person." I present observations that indicate such relationships are commonplace in the context of a biomedical clinical encounter. I will then discuss Kleinman's Patient Explanatory Model in light of my data on healing rituals.

Some anthropologists portray Western biomedicine as devoid of meaningful interpersonal relationships between doctors and patients. Yet I observed the opposite: Patients loved their doctors. My first clue as to how this attachment formed occurred on inpatient rounds with Dr. Smith:

I arrived at Connaught inpatient unit early, approximately 6:15 in the morning. Dr. Williamson walked in and looked somewhat non-communicative, not smiling, and there was no specific greeting for me. Shortly after that, Dr. Johnson walked

in, and they were side by side on computers both retrieving lab work in preparation for rounds. Dr. Smith showed up while Dr. Johnson and Dr. Williamson were still working, looking up labs and x-rays. There were apparently only three patients on the service and Dr. Williamson said, “One of them should go home. He looks pretty good numbers-wise.”

While still in front of the computers, reviewing an abdominal x-ray, Dr. Smith said, “Who is it we consulted for G.I?⁸¹ I forget - it's been so long. Maybe we should think about a cardiologist.”

Dr. Johnson said, “It's just sinus tachy.⁸² It's probably not his heart. We just have an ECG.”⁸³

“I like to rule everything out,” Dr. Smith replied.

The first patient we saw referred to that discussion and he engaged in an extensive negotiation about an NG tube. The patient said, “It causes severe pain, and I want it out as soon as possible.” The residents had previously looked at this x-ray when they were making sit-down rounds in front of the computers. He had multiple air fluid levels⁸⁴ since surgery (which is why they had consulted gastroenterology). Dr. Smith acknowledged his perspective, acknowledged his pain, and explained why it was necessary to keep the NG tube in.⁸⁵

The patient questioned, “How much later?”

“We'll check back later in the day.”

“I can't wait until you finished in the operating room.”

Both Dr. Smith and Dr. Johnson asked his cooperation and finally they came to a compromise solution, “If you leave it in a couple more hours we could have the nurse page us.”

Next patient was talkative and comfortable. Dr. Smith said, “You did well.” In this case, Dr. Smith did most of the interacting with the patient. I had the sense that Dr. Smith had participated in the surgery because there was a natural rapport between the two of them.

Dr. Smith asked him, “How did this all start?”

The patient said, “Ten days ago there wasn't anything wrong with me, this was simply something they found. I heard of Connaught, and that's why I came here.” The patient had a large, well-healed nephrectomy scar but had severe tape burns with open ulcerations.

Dr. Smith examined him and said, “No more silk tape for him...[to the other residents] Is the Norco⁸⁶ helping with the pain? [to the patient]”

The patient asked about his prescription for narcotics when he went home. “Right now I need it every four hours, because if it goes to the fifth hour it starts hurting severely. When it heals, I won't need it anymore, and I'll cut back.”

⁸¹ GI—an acronym for gastrointestinal, or gastroenterology; a medical specialty dealing with the digestive system.

⁸² Fast heartbeat.

⁸³ ECG—Electrocardiogram, a tracing of the electrical activity in the heart as measured by transducers placed at specific locations on the skin of the chest.

⁸⁴ A finding on X-Ray indicating the bowels weren't working; there is no propulsion downstream.

⁸⁵ NG tube—nasogastric tube, placed through the nose and inserted into the stomach; an extremely noxious procedure when left in any length of time.

⁸⁶ Narcotic pain medication—a brand name.

While leaving the room, Dr. Smith said, "I cannot argue with you because you carry a gun." After getting out of the room Dr. Smith said, "The security officer came up to visit the patient and told me to take good care of him because the patient was a police officer."

When dictating the field notes of those interactions, I noticed that the conversation was a lot more personal than typical for morning rounds. I couldn't help but think that Dr. Smith had been the resident to operate on the policeman. The next day, I asked Dr. Smith if that was true and he said, "Yes." I had written in my scratch notes next to Dr. Smith's name: "tender caring bedside manner." I showed him what I had written and he replied, "That extra 30 seconds to a minute makes a big difference, even if you just listen. Sometimes it works, and sometimes it doesn't. You can tell the patients like it. Like the patient with the small bowel obstruction. Sometimes I go up there in the afternoon when I have nothing to do and spend five minutes just talking, but not necessarily about his medical condition. I think it helps the patient to talk to the doctor about things other than what's going on; otherwise, you don't know anything about him and nothing about the context of the patient's illness. I think it makes it better." He then indicated that he had done the surgery for the patient with the bowel obstruction and NG tube as well. I told him how impressed I was about what he said, and he continued, "If you don't do that stuff, you're just wasting your time. Anybody can learn the science."

The next day, Dr. Smith emailed me his personal statement that he was submitting for his fellowship applications. Although it was personal, he wrote about the same topic of knowing the patient intimately. This was very revealing data.

Dr. Smith actually used the word "illness," one of the only times I heard the word used during my entire fieldwork. He contrasted "science" and "knowing about the patient." His caring bedside manner was everything Arthur Kleinman could wish for as a compassionate physician caring for patients. The important observation was that these behaviors occurred only with the patients he personally operated on and only after he had operated on them. This episode caused me to re-evaluate all of my data, searching to see if this pattern was consistent. Going through my field notes I was able to confirm this both ante-grade and retrograde. In all sites and for each doctor, with patients being evaluated for surgery or treatment, there was a respect and attentiveness to the patient and the patient's needs. For follow-up visits, there was laughter,

fondness, open displays of affection, and a different level of sharing, often on a personal level, which was totally absent prior to surgery or therapy.

I recorded a clinical encounter in the outpatient clinic when Dr. Jeffries was running almost two hours behind schedule. None of the patients complained or showed any irritation when he finally entered the exam room. For one patient, the visit was a totally routine follow-up. Dr. Jeffries merely ordered trivial labs during a very brief visit. When Dr. Jeffries apologized for the long wait, the patient said, “It’s no problem. I gave up three previous urologists for you. For you I would do anything.” This statement by the patient demonstrates an allegiance and tolerance beyond what could be expected without a healing relationship. As we were leaving the exam room, Dr. Jeffries told me that he had resected a renal cancer for her nine years ago. Again, in a manner similar to Dr. Smith, there was an understanding and healing relationship forged by surviving the existential threat together as a doctor–patient team. Enacting a healing ritual (resection of the kidney cancer) allowed me to observe a different type of the interpersonal relationship between the doctor and the patient.

The same is true for Dr. Stein:

Dr. Stein said, “Every single year Rabbi Levine sends me a message on Rosh Hashanah. Rosh Hashanah begins tonight and is a time when you’re supposed to contemplate life, what your life is all about, the fact that you’re alive and not dead. Rabbi Levine sends me a thank-you note every year for being alive because I performed his surgery. He’s still alive. There were all these men with black hats and black coats [Dr. Stein took his hand and made swirling motions of the side of his face indicating the Hasidic curls]. At the time of the surgery, he had people praying at the Western Wall to guide my hands during surgery. In his annual thank-you note he mentions that he’s thankful that my hands performed the surgery well.

Both Dr. Jeffries patient and Dr. Stein’s story confirm what I learned from Dr. Smith. I noticed a change in the doctor–patient relationship before the diagnosis and treatment compared to after

the diagnosis and treatment. I concluded that the intimacy and personal knowledge of the “whole person” by the doctor is a consequence, not a pre-requisite, for a healing relationship.

There are multiple other examples. The urologists were not treating a decontextualized “body organ.” During office visits with patients, while simply following up for cancer surveillance (post-surgical), Dr. Jeffries talked with his patients about all types of social aspects of their life. He talked about NASCAR with his patient who was a NASCAR fan; he talked about local politics with his patient who habitually wrote letters to the editor of a small town newspaper; he knew all the patients’ family members and asked about them when they didn’t show up. He listened to their concerns about money, their travel plans, their worries, and their hopes for the future. He advocated and guided them about how to manipulate the healthcare system to get catheters or dressing changes, etc. When a patient talked about getting readmitted to the hospital, Dr. Jeffries joked, “You should get in-store-credit—every seventh admission is free.” When patient complained about hospital food or bad coffee, he replied, “That’s how they plan to get people out of the hospital.” The patients also knew details of his personal life. When asked what type of car he drove, Dr. Jeffries was quick to respond, “An F150.”

After this point in the fieldwork, I started to look more closely to verify this finding because it was the exact opposite of my pre-conceptions of the temporal sequence of healing relationships based on Kleinman’s model. After reviewing all of my data, there was not a single episode of this type of banter and intimacy during the formulation of a diagnostic narrative and treatment plan. Those visits were always respectful and attentive in a polite way, but there was no sharing of any personal information as I describe above. Sharing personal information with patients is a form of intimacy, a hallmark of a healing relationship. Self-disclosure is just that: a narrating self disclosing information about the self. The act of disclosing is evidence of a self

recognizing the other as a like being with a mental life similar to one's own. The turning point or transformation in the doctor–patient relationship, with regard to intimacy, candor, and allegiance, was always after the ritual of diagnosis and treatment. I suggest these examples demonstrate that a transformation occurs in the doctor–patient relationship that results in the doctor knowing “the whole person,” the definition of the illness narrative. Hence, the illness narrative is not missing or not attended to by biomedical practitioners; in fact, it is the exact opposite. Kleinman, Hahn and, others simply looked in the wrong place.

Perhaps the best data, and certainly the most convincing observations to verify this assertion regarding the transformation of the doctor patient relationship, occurred with Dr. Spangler. I observed her on inpatient oncology rounds prior to observing her in the outpatient clinic. She was not the attending physician of record for the patients in the hospital. She was merely supervising their care when they were in the hospital. The vast majority of the time at the inpatient site she spent teaching and reviewing cases, hardly spending any time at all in the room with the patients. The few minutes she did spend with them, her demeanor was cut and dry, merely informing them of management decisions that had been made when discussing their cases earlier. This was consistent over the approximately forty patients I observed on the inpatient service.

In contrast, for patients that she saw in the outpatient clinic, she was the attending physician and directly participated in the oncology diagnosis and oncology treatment plan. Her behavior was instantly changed. In the outpatient clinic, she hugged nearly every patient, greeted them with enthusiasm, teased them about their foibles, fussed over their difficulties. Her naturally bubbly personality was openly displayed with the patients and they reciprocated. She knew the life story of every patient. Again, these patients had experienced the existential threat

of the healing ritual together with her, the authentic relationships where total honesty and open discussions about things medical and things meaningful were on full display.

We then went back into the room and Dr. Spangler gave the patient a large hug.

The patient asked, “Could I have a B 12 shot for energy?”

Dr. Spangler said, “Sure,” and then told Dr. Atlas to make arrangements for it.

Dr. Atlas appeared uncomfortable and then told the patient, “You are taking all kinds of supplements for energy and you don’t need B12 because you’re taking a multiple vitamin tablet that has B 12 in it.”

Dr. Spangler told the patient, “You can have it,” and then Dr. Spangler started teasing Dr. Atlas in the exam room. Dr. Spangler self-disclosed that she herself was vitamin D deficient.

Eventually Dr. Atlas said, “I don’t think a B12 shot is necessary.”

Dr. Spangler told the patient, “It’s his fault.” Continuing, she asked, “Did the radiation oncologist do a rectal exam?”

The patient said, “Yep, and I asked him if he should have both hands on my shoulders during the rectal exam.” This comment was ignored. Then the patient said, “I’d like to see Dr. Bridges.”

Dr. Spangler said, “He’s in his vineyard, and he spends half the year in Brazil, only coming back to Michigan for the summer. He has a vineyard here as well.”

The conversation drifted to the initial treating urologist at a community Hospital and the patient said, “If I saw that guy in the parking lot I would run him over.” The office visit concluded, and Dr. Spangler left after giving the patient a hug and then went immediately to her computer.

This interaction is typical. It began with Dr. Spangler hugging her patient, and ended with Dr. Spangler hugging her patient. During the interview, she indulged his request for a B 12 shot knowing that it was purely for placebo reasons; the less experienced Dr. Atlas, who didn’t have a healing relationship with the patient, wasn’t as comfortable. Dr. Spangler tolerated the patient’s off-color joke, despite the gender difference between the two of them. Similar to Dr. Jeffries and his patients, Dr. Spangler was perfectly comfortable disclosing her personal health information, that she is Vitamin D deficient. This speaks to a level of intimacy and comfort that is remarkable.

The before-and-after aspect of these observations was very apparent when Dr. Spangler was seeing a patient or family for a second opinion. In those instances, she focused purely on the

diagnosis narrative. It would be totally inappropriate for her to hug such a patient. I believe this is explained again by the change in relationship that occurs by completing the healing ritual.

Near the beginning of this chapter, I quoted Kleinman and his characterization of the medical record, “I will first provide a transcript of a doctor-patient interview and then describe the wording of the physician’s formal write-up in the patient’s record. I don’t contend that the following example is representative; indeed I believe that the degree of professional insensitivity it depicts is unusual” (1988:131). The following observation indicates how Kleinman misinterpreted that data:

Dr. Spangler uses a lot of banter with the patients, a lot of joking. She seems to know the life story of each patient extremely well. When she was dictating it was almost a Dr. Jekyll and Mr. Hyde phenomenon because she reverted to strict biomedical language with history and physical formatting. The juxtaposition of the two styles was dramatic. Verbally she said the patient was just a ‘worry wart’ about his sinuses. The patient said that he ordered his own CT scan. Dr. Spangler diagnosed postnasal drip, told him to use saline nasal spray and to not worry about it. When she was dictating the progress note, she said she examined the sinus, there were no lymph nodes, reading all the available labs, and it was the biomedical version of a viral illness and sinus problems.⁸⁷ Dr. Spangler is usually very effervescent, poignant, joking with the patients, but when she's dictating she uses a rapid monotone devoid of emotion, a stark contrast to the experience I just observed in the exam room.

As with every other clinical encounter I observed – at the urology clinic, the oncology clinic, or the radiation oncology clinic – the healing relationship in the exam room was never recorded in the medical record—because it is not a part of the diagnosis narrative; the medical record is only to record diagnosis and therapy. The medical record was never intended to record attributes of the healing relationship. The purpose of the medical record is to support the diagnosis narrative. It is an analytic error to conclude that the personal relationship of knowing the patient as a whole

⁸⁷ Dr. Spangler wrote the note in a way that precluded recurrent cancer as an explanation for the sinus symptoms.

person is absent because there is no documentation of it in the medical record. The purpose of the medical record is to record the diagnosis narrative—not reflect the healing relationship.

Kleinman’s model begins with empathetic understanding. My observations demonstrated empathetic understanding after the completion of the healing ritual:

We then returned to Dr. Spangler's cubicle. Dr. Spangler said, “I got that e-mail. It was so sad. I called to tell him about his metastatic brain disease. There were three mets on CT of the brain, and I thought I heard the patient crying on the phone. He was actually devastated because his business was bankrupt because an employee of 30 years had embezzled everything. He declined evaluation. The embezzler took everything.”

Was this patient quietly crying about the end of his life’s work resulting from the betrayal, because he had yet another existential threat, or both? The doctor was empathetic enough to appreciate the sadness. Dr. Spangler utilized those healing relationships as therapeutic maneuvers:

I was following Dr. Spangler into the next room and she said, “We're going to stick together for a good long time. You can't get rid of me. Do you want to start today?”

He said, “Next office visit.”

She said, “That’s what you said last time. It’s been two years since you’ve had it, but you steadfastly refuse.” The entire office visit was essentially banter. Dr. Spangler asked, “How’s your friend?”

The patient said, “He is avoiding you. He actually brought me to clinic today.”

The friend was also a patient of Dr. Spangler's but he failed follow-up. She said, “Come on, I need to go hassle him,” and the patient went out into the lobby. Dr. Spangler followed him and I followed Dr. Spangler. We went out through the doors, and Dr. Spangler walked right into the lobby and sat down next to the gentleman. There were probably 35 people in the waiting room, and she was out there talking to the patient, “You need to follow up.”

Dr. Spangler then told me, “I needed to track them down. They're both drinkers.”

There is a difference between Dr. Atlas, who hasn’t gone through the healing ritual with the patients, and Dr. Spangler, who has:

I went with Dr. Atlas to see the next patient. Dr. Atlas said, “You are going to have to decide whether or not you are going to accept treatment, or no treatment, because the chemotherapy you are currently on wasn't working. Your PSA level is rising.”

The patient said, “My great-grandson is three years old, and he announced to everybody that somebody's going to die and then I won't see them anymore. Two days later my son-in-law in Kansas died of heart problems.”

Dr. Atlas went over all of his history of chemotherapy including the entire documentation of the recent rise in the PSA. He did then say, “There are good new experimental drugs that can treat your cancer despite the treatment failure of the current chemotherapy, and so that good therapy still available.”

“I've never had any symptoms at all despite my obviously very long history being treated for prostate cancer.”

Dr. Spangler went into the room and the patient repeated the entire story to Dr. Spangler. Dr. Spangler hugged the patient on the way in and hugged the patient on the way out again. She did say to the patient, “I am considering no treatment, but I don't want the prostate cancer to get away from us. There's really good treatment. As soon as I get my hands on it, it will be available for you, but in the meanwhile, I want to go ahead with the experimental protocol.” Multiple times when she was in the exam room, the patient referred to records from a different doctor, and she kept turning to say, “We need to get those records.... We need to get those records.” Dr. Spangler did seem to provide more empathetic statement saying, “I'm sorry for your loss,” referring to his son-in-law.

In this example, Dr. Atlas performed a history and physical. The physical exam requires touching the patient in very stylized ways, considered acceptable only in the setting of going to the doctor. This type of touching occurs between strangers in the doctor's office. Dr. Atlas had never met the patient before. Contrast Dr. Atlas's stylized physical exam (the same style Dr. Spangler used at the inpatient setting when she didn't personally know the patients) with Dr. Spangler's abundant use of hugging between herself and patients she treated personally. I contend that “hugging” is a marker for the healing relationship, something that only occurs after performing the healing ritual. In fact, later in my data collection, I was able to discern other doctors say such tender things that I referred to them as “hug equivalents,” comparing them to Dr. Spangler's style. Dr. Spangler was able to treat the threat of the son-in-law's death because of her healing relationship with the patient. The contrast between Dr. Atlas and Dr. Spangler in

responding to the news of the death in the family was very different. I don't think it was a coincidence: empathy and condolences are socially acceptable. I believe the ability to incorporate it into the clinical encounter is facilitated by having a healing relationship.

Sometimes the healing ritual is cyclical, as with patients who have chronic disease.

Consider the following case:

Amber told me the next patient had a PSA of 6000 and was very weak. He tried to go to one of his children's graduations, but he wasn't able to make it.

Dr. Spangler came in and said the patient whose PSA was 6000 wasn't taking any pain medicines. "I am going to force him to be treated today because if I let him go he won't come back. I took a look and he's two liters behind." I followed her into the room. His family member was there and Dr. Spangler said emphatically, "You're weak, you're tired, you're getting it treated with chemotherapy." The family member was nodding agreement. Although silent throughout the entire time, the patient was extremely weak. He could barely lift his arm. He was brought in in a transportation chair. Dr. Spangler looked in his mouth; he did appear to be dehydrated. Dr. Spangler then said, "It's a good thing I know you well; I can yell at you." After we left the room, she said she had known him for four years. She had initially met him when he had cord compression and he was severely ill. "When he gets better, he will become noncompliant, and then he comes back when he gets into trouble."

Knowing the patient well enough to be able to yell at them for their own good is a marker of the quality of the relationship.

Even when there is no cure, patients seem to need to be in a relationship with a doctor. This next example demonstrates how Dr. Stein embarked on a healing relationship with a new patient. Although Dr. Stein offered no cure, the patient was instructed to follow up. Because this was the first time Dr. Stein met the patient, the clinical encounter was devoid of Dr. Stein's dry wit, yet at the end of the visit the patient thanks the doctor. Bearing witness to suffering and diagnosing a condition that has no therapy is still part of the healing ritual:

Dr. Stein signaled to begin the next presentation, "Okay.""

Dr. Williamson said, "This is a tough one." They reviewed all of the documents together. Dr. Williamson said, "He had a robotic cysto-prostatectomy.

The patient was initially scheduled for a prostate sparing surgery, but on frozen section in the operating room there was a positive margin of bladder cancer in the prostate. The patient is upset; now he has incontinence and is wearing a condom catheter at night and has erectile dysfunction.” It was extremely complex history. They reviewed the paper chart from Harvey Frank Hospital as well as University of Elsewhere.

Dr Stein said, “I don't understand why he came here.”

“He left Harvey Frank Hospital, and Dr. Kilpatrick and went to University of Elsewhere where they offered him a sling, but he had two episodes of sepsis and has been followed-up by urologists. He was treated with two weeks of ceftriaxone. He's just not happy with everything.”

“He had outcome expectations,” said Dr. Jeffries.

“He keeps asking why.”

“He had irrational expectations.”

Dr. Stein said, “He needs to go to a place where they know how to do robotic surgery – not Harvey Frank Hospital.”

Dr. Williamson said, “The final pathology didn't show any cancer in the prostate, but they did have the frozen section.”

When we went in the room, the patient was obviously quite tense. Dr. Stein concentrated fully on the patient, making good eye contact, and he asked very specific questions about how much incontinence he is having and how much erectile dysfunction he's having. Dr. Stein then said, “Urology is a small specialty. Everybody knows everyone else. I've worked with all your previous doctors. I know the doctors at Harvey Frank Hospital and I know the doctors at University of Elsewhere.”

The patient said, “I just want to get on with life as usual. It is so frustrating.” The frustration he mentioned was having to wear a diaper, having to do the self-catheterization. There was a long discussion about using a 16 French catheter versus 14 French catheter, trying to flush out the mucus. One doctor told him he didn't have to do it; the other doctor and Dr. Stein said that he needs to flush out the mucus so he doesn't get a mucous plug that causes the incontinence at night. “I'm tired of wetting the bed and having to clean sheets, and during the day sometimes I wear two pairs of underwear.” They had an extensive discussion regarding erectile dysfunction. “I've tried everything – Viagra, Cialis, vacuum pump, different formulations of penile injections – one injection caused pain. Right now, I'm getting a special pharmacy to the mix my injections. It's frustrating for me to hear that I have to cath myself every four hours. I'm only 51 years old, and it's frustrating.”

Dr. Stein asked, “Do you want a penile implant? The penile implant might actually help with the incontinence because it causes a little bit of compression on the urethra.”

The patient said, “That's what my original doctor told me, but one of the subsequent urologists told me it wasn't true.”

“So two of three doctors told you that?” Dr. Stein offered suppressive antibiotics multiple times during the interview but each time said, “I don't recommend it, but it is available. I would lean against it.” There was an implied

non-recommendation for it. Dr. Stein summarized what was different but possible that he could do. “You need to see the doctor from the University or me, but [you] don't need both.”

The patient said, “I live and work on the east side of town. I'll schedule follow-up with you.” This was relatively long discussion. Both Dr. Stein and the patient were highly educated about dealing with these complications – the patient from his vast experience and Dr. Stein from working with these patients. They covered a lot of ground quickly.

There was also a discussion of the neo-bladder, how the attached ureter failed and he had to have repeat surgery. The patient asked, “What about an artificial sphincter?”

“That's more invasive than the sling.” The problem with the sling was that he would certainly have to cath himself.

One of the more interesting things was after the office visit both Dr. Stein and the patient were standing at the appointment counter and the patient said, “Thanks. It helped.”

It was such an intense feeling being in the room, I actually skipped the next patient. Dr. Stein saw the next patient without me. I asked Dr. Williamson, who did not go in with next patient either, what he thought about the patient. He said, “The patient was depressed. It was hard that he went from doctor to doctor and now is with us. We just have to take care of it. The most important part is to be honest. You don't want to lead him down that path,” referring to the path of hope that it might get better, because it might not get better.

Kleinman's Patient Explanatory Model reconsidered

So far, I've challenged Kleinman's assertion that the doctor has to explore the illness narrative to achieve a healing relationship in medical-surgical clinical encounters. I contend that the doctor has to perform the healing ritual, and the natural consequence of doing that is the doctor and the patient achieve trust and intimacy, the antidote to alienation. Kleinman claims:

This alternative approach originates in the reconceptualization of medical care as (1) empathic witnessing of the existential experience of suffering and (2) practical coping with the major psychosocial crises that constitute the menacing chronicity of that experience. The work of the practitioner includes the sensitive solicitation of the patient's and the family's stories of the illness, the assembling of a mini-ethnography of the changing contexts of chronicity, informed negotiation with alternative lay perspectives on care, and what amounts to a brief medical psychotherapy for multiple, ongoing threats and losses that make chronic illness so profoundly disruptive. [1988:10]

I claim that no reconceptualization of medical care is needed: The healing ritual has withstood the test of time and meets the needs of the patient. Now I would like to consider the remaining portions of Kleinman's Patient Explanatory Model. After exploring the illness, Kleinman gives the following outline:

- Step 2: The second step in the explanatory model technique is the presentation of the practitioner's explanatory model. No doctor is taught how to explain the biomedical account to patients. Yet that is an essential task in the work of doctoring...
- Step 3: He must encourage the patient and family members to respond to his model...
- Step 4: The clinician engages in self-reflective interpretation of the interests, biases, and emotions that underlie his own model. [Kleinman 1988:240-243]

Step 2 and Step 3 correlate well with diagnosis and persuasion, both elements of the healing ritual. In fact, the similarity to the healing ritual is striking. If I were to map Kleinman's Patient Explanatory Model onto the healing ritual, I would say that his observations would concur with my own if he were to re-order them as Step 2, Step 3, Step 1, Step 4. Step 4 is where the moral overtones to medical practice predominate. It was best described when both Dr. Stein and Dr. Jeffries verbalized that the patient is their "boss." The drive to provide better care, the best care possible, occurs in the context of doctors who truly care about their patients. It doesn't mean that they have to abandon the basic tenets of medical practice. It does mean that they re-evaluate experiences of the difficult partial nephrectomy of the patient who was taking aspirin. It does mean figuring out how to offer active surveillance for prostate cancer when there is no easy way to do it.

There is the the previously reported interaction to reconsider:

As Dr. Jeffries was leaving the clinic, I asked him about a comment he made earlier in the afternoon, to no one in particular, while approaching the exam room,

“This will be like pounding my head against the wall.” I asked him what he meant by that. He said, “The patient comes in every six months with an elevated PSA in the range of 10 to 16. He is a very high-risk patient, being African-American and elderly. Every six months we go over the rationale for doing a biopsy. I believe it is my due diligence to recommend a prostate biopsy to this patient. I do that every six months only to have the patient tell me, ‘I don't want to know.’ Despite my offer to biopsy his prostate every single time I see him, he tells me the same thing, but in the end, I work for him.”

The combination of “banging his head against a wall,” a painful experience, striving for “due diligence,” and recognizing he works for the patient, I suggest, is the equivalent of the clinician engaging in self-reflective interpretation of the interests, biases, and emotions that underlie his own model. I found confirmatory evidence for this in comments from the epidemiologist researcher–clinician who works with Dr. Jeffries:

He thinks active surveillance is the right thing to do for certain patients. He is a surgeon and, yes, he loves to do surgery. But he also doesn't want to create harm where there isn't any need to, and he does a good job of following people. Another thing that's come up in our discussions that's given as a reason for not recommending active surveillance is the concern that people won't follow up in time. Again, getting to the medical–legal aspects, you know if they don't [surgically remove the prostate], in every three, four, six months or whatever you decide is the time they need to follow up for their PSA or they won't have their next biopsy in 12, 18 months... Are you then liable? Because he didn't take it [the prostate gland] out right when you had the chance?

Dr. Jeffries said, “Yeah that is a concern.”

Active surveillance has no standard of care, yet the standard of care is the legal definition of malpractice. Yet Dr. Jeffries wants to do the right thing. Not being able to quickly identify the right thing is what Kleinman refers to in Step 4 of his Patient Explanatory Model. The re-evaluation of “doing the right thing,” where “right thing” is synonymous with “moral overtones,” occurs when doctors struggle to determine what is the “right thing” for that patient. Multidisciplinary care conference (MCC) is where doctors debate alternative treatment plans. Although doctors pronounce the diagnosis with certainty with patients, they share the ambiguity, the uncertainty, and the conflicting demands of difficult cases at MCC. Continuing the rhetorical

re-formulation of prostate cancer management, one need only consider the tongue-in-cheek conclusion to the following case. Again, I assert that these rhetorical devices are how doctors fulfill Step 4 of Kleinman's model:

Dr. V presented the second case. "This case is a patient with a PSA greater than 10, Gleason score 3+3, stage II.⁸⁸ The patient didn't want treatment but was offered hormonal treatment. He then went to the Voter's Hospital and heard about 'seeds'⁸⁹ but eventually chose no treatment. When he was reevaluated for his cancer at the Voter's Hospital, they repeated the biopsy and it showed no cancer. So this patient actually went from biopsy proven disease, an interlude where he declined treatment, followed by a biopsy that was negative for cancer, and he never received treatment from 1997 until now. Throughout that entire time, he refused to have a PSA, but he's being presented at tumor board because his primary care physician did a PSA by mistake and the PSA turned out to be 250. The patient has arthritis and the Voter's Hospital did a bone scan, which couldn't exclude mets. The patient had some obstructive symptoms, controlled with Flomax."⁹⁰ The assistant for the presentation was scrolling throughout the bone scan, again using the roller on the mouse.

No one responded throughout this entire time until Dr. Stein said, "You can use finasteride⁹¹ to improve voiding symptoms. You can say he made the right decision at the time." The group then discussed what the standard of care was in 1997. Dr. Stein continued, "The patient had peri-neural invasion with prostate cancer, and the second biopsy that was negative was false assurance that the cancer was gone; this patient's been living with his cancer for the entire time.

Dr. V said, "There are multiple cores."

Dr. Stein said, "He put himself on watchful waiting 15 years ago, and this is just his 15-year follow-up."

At that point Dr. Rivers said, "It depends what you presented to him, a smile or frown."

The doctor offered this patient treatment and the patient declined. The moral re-evaluation occurred when Dr. Stein totally reframed the case from one of non-compliance to "He put

⁸⁸ The Gleason grade tells you how fast the cancer might spread. It grades tumors on a scale of 1 - 5. You may have different grades of cancer in one biopsy sample. The two main grades are added together. This gives you the Gleason score. The higher your Gleason score, the more likely the cancer is to have spread past the prostate: Scores 2 - 5: Low-grade prostate cancer, Scores 6 - 7: Intermediate- (or in the middle-) grade cancer. Most prostate cancers fall into this group, Scores 8 - 10: High-grade cancer. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001418/>

⁸⁹ "Seeds" refers to radioactive pellets inserted into the prostate gland tissue as a form of treatment.

⁹⁰ Trade name for Tamsulosin, a drug that relaxes muscles near the bottom of the bladder, making it easier to get urine out.

⁹¹ A drug that inhibits an enzyme that changes testosterone into a more potent form of testosterone; this means that it is an anti-androgen, or male hormone medication.

himself on watchful waiting 15 years ago, and this is just his 15-year follow-up.” Using his deadpan humor, Dr. Stein presents the paradox of the treatment not directly related to the diagnosis and an implied re-evaluation of how to present the diagnosis to the patient. Dr. Rivers quickly re-iterated the moral dilemma, saying, “It depends on what you present to him, a smile or frown.” Here in the arena of uncertainty of the MCC, doctors are re-evaluating the moral dimensions of pronouncing a diagnosis.

Summary to Chapter 10

My observations confirm each step of Kleinman’s Patient Explanatory Model individually, but Kleinman’s causal sequence for performing the ritual is not supported by my findings. I attribute this discrepancy to Kleinman conflating non-biomedical psychiatric patients with medical-surgical patients. I believe my data support that close, intimate, meaningful relationships are formed through the process of performing a healing ritual. The illness narrative is not something that is part of the healing ritual. I assert that the nature of the illness narrative is drastically different if a healing ritual is successfully completed compared to an illness narrative where the healing ritual was not completed successfully through misdiagnosis or failure to persuade. I explore this further in Chapter 13. I contend healing relationships develop naturally through the shared experiences of doctors and patients who survived an existential threat together. Although other anthropologists have described other perspectives on this topic, what we do agree upon is that healing relationships do exist and they are important. Clarity of nomenclature allows both interpretations of healing rituals to be correct, but I believe the major misunderstanding is the temporal sequence. Illness narratives tell stories of experiences that occurred in the past, and healing in that setting involves psychotherapy. Healing rituals occur in

the medical-surgical clinical encounter, and the story is a lived, narratively structured experience shared by the doctor and patient.

Chapter 11: When the healing ritual fails

Introduction

In order for a ritual to be efficacious, the leech must be performing the ritual correctly. Any deviation is a cause for failure. In this chapter, I describe one clinical encounter and one case report in the published anthropological literature on this topic.

Conflict between the illness narrative and the diagnosis narrative

The doctor's role in the healing ritual is to assign a diagnosis. From the perspective of the healing ritual, it is normative to portray this as an activity of the doctor – not an activity of the patient. I saw hundreds of clinical encounters where the doctor proclaimed the diagnosis and the patient accepted the diagnosis as a basis for beginning therapeutics. This contrasts with other anthropological literature that portrays assigning a diagnosis as a misuse of power over the patient that somehow makes the patient into a disease and changes the person into an object. It also explains why the illness narrative has not yet entered into my dataset. This final vignette is the exception to the rule. In this vignette, the illness narrative disrupts the healing ritual by preventing the doctor in proclaiming a diagnosis. Although the vignette is somewhat long, it is important to count the number of diagnoses offered and the rebuttal by the patient for each diagnosis. The patient is “self-diagnosing” with some regularity.

Dr. Jeffries described the patient to me as a real problem and said, “The patient came for a second opinion after being treated at State University for many years. The patient is a 54-year-old woman with scoliosis and multiple urologic surgeries. She is a Jehovah's Witness, and that could be a problem. She's had recurrent urinary tract infections, complaining of incontinence around the stoma as well. She has previously had a bladder augmentation and a sling for the incontinence and eventually wound up with a right hydronephrosis requiring removal of the kidney. She had an ileal loop and her BMI was greater than 40 [morbidly obese]. She has multiple chronic medical problems including restrictive lung disease requiring oxygen at home, coronary artery disease, COPD, and she is coming to

me for a third opinion. The last time I met her I had a 'two-hour cyclical conversation.' She brought up her urologic problems, and I explained all of that to her. She brought up her bacterial problems, and I explained all that to her. She brought up multiple other problems, and I explained all that, too. At the end of it I felt bad because every single other patient for the rest of the day I had to apologize because I was so late. After all this discussion, the patient refused ultrasound, refused any blood draw, but did agree to go for urodynamic study, which she had downtown. That did not demonstrate any leaking which was inconsistent with her story. The only surgery would be an ileovesicostomy, but again I'm very concerned about the surgical risk."

Dr. Jeffries told me, "You will see how painful this patient is." Carmen had been trying to put this patient in the room for 25 minutes, and I could overhear the patient talking incessantly. Dr. Jeffries characterized it as cartoon characters where the two of them are fighting and there's a whirlwind and other people get sucked into it. We were sitting there waiting over thirty minutes prior to going to see this patient.

I asked Dr. Jeffries about one of the statements when he said he wanted to help the patient and he replied, "I do want to help her, but I don't want her to die on the [surgical] table. I can't get her to change any of her medicines." He then went on to say, "It's not going to be pleasant." He said, "I'm going to try to put the patient at ease."

Dr. Jeffries said, "I want to see the look on Carmen's face when she walks out of that room."

Indeed Carmen contracted all her facial muscles as she turned the corner when she finally got out of the room. She muttered under her breath, "For the love of God..." She then walked over to Dr. Jeffries gave him a back rub, put her elbow on the charting table, and pushed her face very close to his and expressed some words of encouragement.

I asked Dr. Jeffries, "How many patients are scheduled for today?" because it was such a late start.

"I do not want to check the schedule because it would only make me frustrated. I want a clear head and get in my Zen mode when I walk in the exam room with the patient." Dr. Jeffries said, "I'm going to take control of the power in this interview. Unfortunately, this is going to be like Jurassic Park. There are raptors on the island; at night all the other dinosaurs get docile, but the raptors probe defenses for weakness. Watch for when the patient wrestles control of the interview from me." All of this occurred before we even walked in the room.

When we walked in the room the patient was in a wheelchair facing from the curtains towards the two chairs on the opposite wall. The patient instructed Dr. Jeffries, "Empty my belongings off one of the chairs."

"No, I'll sit right next to it." Dr. Jeffries started by saying, "I'm going to give you a copy of your urodynamic study because I know you keep notebooks with all kinds of data." Dr. Jeffries then turned to the keyboard, sitting there until the end of the interview.

The patient was silent for a short period of time but then interrupted him to say, "It does leak," despite the fact that Dr. Jeffries reported there was no leakage

on urodynamic studies. The patient went on to say, “It leaks when I cough or move. It happens four to six times a day.”

Dr. Jeffries said, “Your bladder has shrunk to 250 mL.”

“When I had those urodynamic studies, I started hollering and screaming because the pain intensity was so severe. The other doctor reported the comfortable volume limit of my bladder when he did previous urodynamic studies.” The patient talked about the pain for a while.

Dr. Jeffries became quiet, and she was doing all the talking, “My bladder looks like an alien. I’ve seen pictures of my bladder.” Dr. Jeffries continued sitting in the chair with his legs crossed. He listened for about twenty minutes and then interjected, “And that brings us to what can be done.”

The patient replied, “I reflect, pray, reflect, pray.”

Dr. Jeffries went on to explain, “High pressure in the bladder can damage the kidneys, and high pressure-causing reflux can also damage the kidneys. You told me you were worried about dialysis.”

The patient changed the subject back to meds, “Previous doctors told me, ‘This will work.’ Nothing ever worked,” and at that point she had her hands folded as Jesus is typically portrayed in the garden of Gethsemane. When I glanced over, I noticed that Dr. Jeffries had his hands in identical, mirroring position held closely together in front of his mouth. Following that, Dr. Jeffries put his fist on his chin in the thinker position and all this time the patient was producing large amount words describing mostly bladder spasms. At one point, the patient took her fist and smashed it into the other hand creating a forceful impact, trying to describe the pain associated with the spasm.

Dr. Jeffries was trying to work with her but she interrupted, saying, “I have constipation and diverticulitis, and I had impacted bowel. The pain is so bad. I do a lot of research.” She repeated this phrase about doing a lot of research about ten times in the course of the interview. She followed that statement with, “What I’m thinking is, I’m not a doctor. I am a *me*. I don’t think surgery would be helpful.”

Dr. Jeffries tried to describe the ileovesicostomy and said, “Of course it could never be a guarantee.”

She interrupted and said, “I’ve got leak.”

He said, “The goal is to increase the bladder capacity and decrease the pressure in the bladder and that will help to decrease the leakage. There’s a trade-off between medications...,” and then gave a verbal physiologic explanation.

The patient responded by saying, “My experience is I know what I’m doing.” She went on to explain, “Because of the scoliosis I take a lot of fiber and oats. I’m a lab experiment in trying to avoid medication.”

Dr. Jeffries tried to acknowledge her concerns, “I appreciate the fact that the scoliosis causes some of the constipation.”

She immediately came back, “There are many learned men, but I know my body and I know the research. I’m not a surgical candidate.”

Dr. Jeffries said, “Surgery would be challenging, but the thing that scares me the most is the heart problems and lung problems. Those would be risky options. I could just revise your stoma.”

The patient jumped on him verbally saying, “I just had that done.” He tried to explain what it was, and she said, “I just had it done at University of Elsewhere.”

He said, “Usually they don't use a catheter through that type of stoma.”

“I do it anyway. My first problem started after becoming sexually active at 17 years old. I have three different sources of back pain. The onset of the issues began after my children were born. Then the onset of my issues was after I had the sling. I do research and talk to people who are a lot smarter than me, but I'm way up there.” She then embarked on a monologue about, “...what I'm thinking...” and then she threw out there, “No one's talking to me...what is my renal function?”

Dr. Jeffries said, “I don't have any lab data. You refused to get worked up last time.”

She replied, “I want to know how close I am to dialysis.”

“You would need to see a nephrologist.”

“I've already seen two of them, and I'm not a candidate for dialysis because my veins aren't good enough.”

Dr. Jeffries recommended a medication for now, “because it would take the bladder neck and relax the body of the bladder, decrease the pressures, but it does run the risk of constipation.”

The patient replied, “I do thorough research. Write the name of the medicine and give it to me and I'll look it up. The last time they tried to use medication I had a racing heartbeat to the point where I felt like I might stroke out. I've got some anxiety that I'm not a candidate for dialysis.” The patient then said, “I haven't shared this with you, but I'm an ordained minister. I don't get blown out of shape by bad news. I want to know how close to dialysis I am,” going into an extensive discussion, talking about the television show *House*,⁹² and how she was watching the television show. “No one has given me a diagnosis and so I kept checking the symptoms off and, even though it's a fictitious show,” implying she was making her own diagnosis, “my urine is light brown.”

Dr. Jeffries said, “You lost a kidney.”

“Where did it go?” and “I don't have much of an appetite—I lost weight.”

“You're starving and didn't know it.”

“I lost 41 pounds.”

Dr. Jeffries was sitting with his arms crossed and his legs doubly crossed, not saying much. “When did you last see a nephrologist?”

“What's the difference between a nephrologist and a urologist?” When he explained that to her, she said, “You told me something I didn't know.” The conversation proceeded and the patient said, “The nephrologist told me to get rid of the bacteria.”

“That's not possible with a catheter in place. There is an important difference between infections and colonization, and he would prefer to be free of infection.”

⁹² A television show about an irritable and irritating doctor that solves medical mysteries.

“I’m not to take any more antibiotics. When you take antibiotics you’re selecting for resistant bacteria. I know. My previous urologist told me, since I’m not a candidate for dialysis, I need to flush my kidneys, so I drink a lot of water. My kidney is only about 40 percent functioning. Nobody listens to me anyway.”

Dr. Jeffries told her she can put the papers in her file, and she verbally confronted him saying, “Don’t generalize me.”

Then Dr. Jeffries said, “The nephrologist was passionate, but he also wants to be realistic. It is like trying to get bacteria out of the garbage can,” and then tried to backpedal the garbage can metaphor. Dr. Jeffries was paged and so he tried to wind up the interview. He was standing up, pushing the pager button every time the pager went beep. They had another extended discussion regarding antibiotics where the patient essentially wouldn’t let him leave the room. He suggested an infectious disease specialist.

“We had those people.” She talked about not having a functioning kidney, kept using the word, “no,” then “No” in a louder tone of voice, and then said to Dr. Jeffries, “You guys are eggheads. My research shows that is all I need to do is concern myself with – I don’t want any more medications. I don’t want to discuss antibiotics. I don’t want to discuss surgery. I know my body is ravaged by surgery. The reason I am here is to find out the level of kidney failure I have.”

“Urodynamic studies aren’t able to tell that.”

She replied, “Well that’s what I signed the papers for.”

Dr. Jeffries said out loud, “No, no, no.”

The patient echoed back, “No, no, no.”

“Do you need help getting out of the room?”

I glanced at the clock. Dr. Jeffries spent an hour in the room with this patient. Carmen had to go back in the room and she got stuck in there another 15 minutes. Dr. Jeffries wanted to see his next patient, but he said to me, “I don’t go by that route again.” He essentially ran past the open door trying to get to his computer to find information to see next patient.

Arthur Frank, in the *Wounded Storyteller*, insists that the body narrates itself and describes medical practice as “biomedical colonization.” Although there is a pejorative tone to his nomenclature, this last vignette demonstrates how the illness narrative derails the healing ritual by not allowing the doctor to create the diagnosis narrative. To use Frank’s own nomenclature, this patient is caught in a “chaos narrative,” unable to be healed because she is preventing performance of the healing ritual. Dr. Jeffries anticipated this clinical encounter would be “painful.” For me, it was painful to watch. There was none of the typical intimacy, trust, sharing, and shared goals I was used to seeing as part of daily life in the clinic.

“Under the Medical Gaze”

The second case study I use to illustrate when the healing ritual fails by Susan Greenhalgh, *Under the Medical Gaze: facts and fictions of chronic pain* (2001). Very similar to the clinical vignette described above, the author–patient in her auto-ethnography begins by describing the tasks of the clinician within clinical encounters in a section called “How medicine Works”:

The clinician’s first task is to turn the person who comes into his office into an object of medical scrutiny: a patient.

Second, the clinician must translate the disorganized details of the patient’s suffering body into the ‘scientific facts’ of the case—the diagnosis, prognosis, and treatment plan—and weave them together into a compelling story about what is wrong and what must be done to right it.

Third, the doctor must convince the patient that the story is true, objective, and efficacious. That is, he must persuade the patient that the story is complete and error-free, unaffected by his values and interests, and will work to ease her pain.

Fourth and finally, he must put the prescribed treatment into effect to improve on the suffering body by alleviating the symptoms of the illness he has diagnosed (which may or may not be what ails the patient).

These four phases might be called those of patient construction, storytelling, persuasion, and treatment. [Greenhalgh 2001:26-27]

This contemporary summary of the healing ritual is identical to the ritual portrayed in my research. Greenhalgh goes on to illustrate a firsthand account of how this ritual fails. Although she interprets her data in a different way, I will use her data to support the argument in my research.

After multiple attempts at finding “Doctor Right” and failing, “S” met “Dr. K,” who was empathetic and caring as well as attending to the diagnostic investigation. The diagnosis proclaimed was “psoriatic arthritis.” Eventually, “S” rejects this diagnosis, setting up the case identical to the first vignette. Following that, “S” moves to the West Coast and consults a

renowned doctor, Dr. D, who does an elaborate clinical encounter and proclaims five diagnoses: psoriatic arthritis, osteoarthritis, degenerative joint disease, fibromyalgia, and scoliosis. What ensues is a dramatic farce masquerading for medical care. “S” insists on tracking her own symptoms and reporting them as “data,” which Dr. D discounts, upsetting “S” because she believes Dr. D doesn’t respect her intellect (Ph.D. in anthropology, a “doctor”). Instead, he collects his own “data” and begins prescribing medications with toxic side effects based on the diagnosis of fibromyalgia. The relationship is bumpy and the drama escalates, eventually ending with fury directed to the doctor for all the damage he did. This case illustrates the second major cause of failure of the healing ritual: misdiagnosis. Borrowing from my positionality, Dr. D is a quack – unprofessional and dangerous because of his blind faith in his own ability to diagnose fibromyalgia. After tremendous suffering, “S” returns to Dr. K who treats her for psoriatic arthritis. “S” also enters psychotherapy and avails herself of a Kleinmanesque “re-storying” of past events. (Greenhalgh 2001)

This case illustrates both the healing ritual as practiced in the clinical encounter of biomedicine, what prevents the ritual from being enacted efficaciously, and the appropriate role for the healing described by Kleinman. This case is useful to highlight that Kleinman and I disagree about what happens during a clinical encounter, except for the value of Kleinman’s Patient Explanatory Model for existential threats that occurred in the past or distant past. I believe that this is what Naomi Quinn (1992) was referring to when she talked about existential concerns related to childhood or adolescence. I find this analysis useful to help differentiate my claims from those of Kleinman. I don’t perceive one to be right or wrong—we have a different perspective on narrative in clinical encounters, as illustrated by Labov versus Mattingly. The value is to discern between the two when the patient enters the consultation room.

SECTION IV: DISCUSSION

Chapter 12: Healing relationships in medicineOpening new perspectives

In this research I have portrayed the medical-surgical clinical encounter as a ritual, ritual as a form of experience, and experience as narratively structured. This framework is the starting point of my analysis, as I mentioned my agreement with Cheryl Mattingly's work in narrative theory in which she took the same perspective. I also explicated how Michael Tomasello's concept of joint attention was a vital component of confirming diagnoses and persuading patients by pointing to CT and MRI images with other doctors, residents and most importantly, patients. This joint attention creates a **shared experience**. The next frontier in narrative theory is to explore the narrative structure of shared experiences. These shared experiences create social relationships—the one portrayed here is the healing relationship. This theoretical perspective of the narrative structure of shared experience (the ratchet effect) and how social relationships are created by this process is a framework that I believe extends beyond my exploration of biomedical clinical encounters.

Although Arthur Kleinman and I agree that healing needs to become a greater part of clinical medical practice, we differ on the circumstances and how that is accomplished. He suggests reconceptualizing the practice of medicine. I focus on ways to make the healing ritual more efficacious by attending to clear statements of diagnosis and verifying that the patient recognizes and accepts the diagnosis as something they can recognize as relevant to themselves within the context of the shared cultural category of biomedicine. Unexpectedly, I realized the

dangers of inaccurate diagnoses that arise from the cognitive framework of medical education. That is, however, a future research topic that arises from this current work.

This research was an exploration of healing relationships and the social practices that support the development of those relationships. In order to accomplish this goal, I answered for myself one of my enduring questions in anthropology—the relationship of the self to society. There are multiple, conflicting, and confusing accounts in the anthropological literature, but I presented the one that I found believable and useful, a bonus for me in terms of my learning and professional development as an anthropologist. I endorse Kleinman and Mattingly to the extent that they also describe therapeutic encounters that result in a shared attention. For Kleinman, it is a shared attention to a psychiatric illness narrative that occurred in the past and for Mattingly it is shared attention to a therapeutic encounter that attempts to locate desire to an imagined future. Both of these settings connect the distressed person with a powerful individual that represents a broader cultural context. The connection of the person to the cultural context dispels the alienation underlying the distress. What this analysis and my research adds to the anthropological canon is that biomedicine also serves this same underlying function and is a healing practice. Rather than seeing the work of Kleinman, Mattingly and my own as mutually exclusive, I understand them to share strong social practices, but are manifest in different social spaces and times.

The healing ritual in perspective

All research, including anthropological research, has to address two fundamental questions: So what? and Who cares? This final section consists of reflections on some of the possible answers to those questions.

The healing ritual merely provides a story of how to live with or survive disease and death. Out of necessity, I presented my data as a consistent ritual process to elucidate the actual structure of the ritual. I do that knowing that ritual performance allows for wide variations in actual content. There are as many types of clinical encounters as there are doctors and patients. All I can portray is the cultural dimensions of such occurrences. Western biomedicine is merely a cultural performance, and should be viewed through that perspective. It is however a particularly enduring and resilient cultural performance. From that perspective, I ask why is it so resilient? I believe that through the ritual, the patient is culturally sanctioned to enter into the healing relationship, and the healing relationship has benefit to society and the individual. For the individual, I agree with Mattingly and the vast majority of anthropologists that narrative or narrative ritual is a transformative experience. Transformative from what to what is the question. I suggest that disease and the existential threat of death create an alienation from the rest of society, based on the potential to interrupt cultural reproduction. The potential loss of the creative potential of the individual threatens the integrity of society. For the individual, the death of the body creates a separation of the narrating self from the cultural milieu. Death therefore is a social and individual concern because *meaning* is how individuals measure their personal experiences against cultural norms and motivates behavior within a cultural model. Culture is an interactive system. The transformation for the individual is from alienation to participation. This is instantiated in the healing relationship. Embedded in the term *existential threat* are the unmanageable emotions associated with annihilation, ceasing existence. Ritual functions to manage those otherwise unmanageable emotions. If left unattended, they would cause social disruption.

I believe that the healing relationship is an iterative process, where deeper meaning is cultivated with prolonged exposure. In fact, prolonged exposure in a healing setting can generate a healing relationship (Mainous et al. 2004). Again, this is not simply “just because,” but the healing relationship, once formed, can itself be used to address deeper existential questions. Kleinman (1988) gives examples: Why me? What is the meaning of suffering? It is through the intimacy and trust that results from the healing relationship that this next layer of existential questions can be expressed and shared. I give one such example in the next section.

“Continuous healing relationships”

When the Institute of Medicine (IOM) declared that the future of healthcare in the United States should be based on “continuous healing relationships,” I had no idea what they were talking about. As stated in the beginning of the research paper, I could not answer the question, “What is healing?” After completing this project, I can answer what a healing ritual is and how cultures create a form of social interaction known as a healing relationship. But why would the IOM be interested in that aspect of healthcare? I will attempt an answer using only one possible example. As mentioned in the above paragraph, I believe healing relationships are iterative in nature and that increasing amounts of trust and intimacy results in an authentic relationship, one free of cultural performance and allowing one *self* to interact directly with another *self*, the ultimate antidote to alienation.

The healing ritual and the diagnosis of futility

Approximately one third of Medicare expenditures occur in the final year of life and much of that is concentrated in the last month of life, mostly for life-sustaining care. Americans

are now spending 17 percent of gross domestic product on healthcare. The healing ritual is a process where individuals engage healers to deal with death or the potential of death. Yet everyone must die. The healing ritual depends on an accurate diagnosis, yet there is a well-established diagnosis within biomedicine that is almost never used: futility. The diagnosis implies the treatment. The appropriate treatment for futility is to stop treatment. There is no moral obligation for physicians to provide health care that is futile. Yet it is an extremely difficult diagnosis to make, knowing that persuasion is also a component of diagnosis. Persuasion within a healing relationship is completely different than persuasion for a patient without an established healing relationship. The diagnosis of “the process of dying” is far simpler when the patient has already trusted the doctor in situations where disease and death defined the scope of the social relationship. Like all diagnoses, an incorrect diagnosis is a catastrophe but an accurate diagnosis provides a necessary social function. It might be that healing relationships, the consequence of the healing ritual, are a necessary but beleaguered cultural component of our healthcare system. This research project is an invitation to my fellow anthropologists to study Western biomedicine as the unmarked category, the cultural performance where for the most part things go well, not the easily observable disasters. Even though the IOM never explained what a continuous healing relationship actually was, they recognized its importance. Describing the social practices that constitute continuous healing relationships is a task for anthropologists.

Culture and biology

Humans need both culture and biology to survive as a species. Thus, the existential threat to an individual is a threat to all. That is true both on a biological level as well as a social level.

Although this research centered on the healing ritual and the production of the healing relationship, it is informative to consider the social ramifications of the opposite of healing – *homo sacer*: he who can be killed but not sacrificed. *Homo sacer* is a description of humans when culture and biology are divorced from each other. I contend that the healing ritual creates narrative existence and meaning for the individual–body–self and society.

Narrative Existence

In *Homo Sacer: Sovereign Power and Bare Life*, Agamben discusses sovereign power and bare life. It is a complex argument, but Agamben states:

Thus it is as if the emperor had in himself not two bodies but rather two lives inside one single body: a natural life and the sacred life. The latter, regardless of the regular funeral right, survives the former and can only ascend to the heavens and be deified after the *funus imaginarium*. What unites the surviving devotee, Sacer, and the sovereign in one single paradigm is that in each case we find ourselves confronted with bare life that has been separated from its context in that, so to speak surviving its death, is for this very reason incompatible with the human world.... For Homo Sacer, finally, we are confronted with the residual and irreducible bare life, which must be excluded and exposed to death that no rite and no sacrifice can redeem." [1998[1995]:100]

In that passage we see that sacred life is connected to a political function and bare life is outside of the body politic. *Homo sacer* is thus defined as life that may be killed but not sacrificed. That phrase I will take to mean that the biological function has no potential to be associated with meaning as understood in the broader context of culture. Although this argument seems extreme, it is demonstrated with a modern example, the concentration camps of the Third Reich. Indeed, Agamben also mentions Rwanda and other extreme cases of genocide. This theoretical outlook explains why normal cultural values and behaviors are tolerated by society and humans become de-humanized – that is, separated from meaning as members of a society. The existential threat that initiates the healing ritual is the apprehension of the same annihilation

– a death without meaning, an alienation from culture and society. This extreme case is the underlying purpose of the healing ritual – prevention of alienation. Prevention of alienation is healing. This function occurs within the context of a healing relationship – two individual selves connected by shared experience. Even in the shadow of death, this relationship endures. Consider that all of Dr. Spangler’s patients had recurrent prostate cancer, yet most all were fully alive. That is evidence that the healing relationship thrives in the face of chronic disease as well as acute disease.

Additionally, Agamben is essentially describing an existential threat to the self, the anthropological self. It is in this context that, divorced from culture and society, a narrating self ceases to exist. Narrative requires the self to find meaning by measuring one’s personal experiences against cultural norms, and motivates behavior within a cultural model. This is the other half of the existential threat to the body or, as so many anthropologists describe, the body–self. Healing rituals address the existential threats to both the body and the existential threat to the self by ensuring a culturally mediated relationship that functions in what would otherwise be a world of alienation, one so extreme that it might approach *homo sacer*.

In high contrast to Agamben, we have Viktor Frankl's book, *Man's Search for Meaning*. (1959[1992]). In this case Viktor Frankl himself was an example of *homo sacer*. He was in a Nazi concentration camp and therefore, according to Agamben, his life had no meaning. Although this is a first-person narrative and there was only an imagined audience, Frankl, a psychiatrist, essentially performed a healing ritual on himself. Against all odds Frankel survived without biological death, but more to the point he survived and was able to claim purpose and meaning in life. That is what makes his narrative so powerful. It is set in high contrast to Agamben and brings us back to the voice of the narrator, the self, the self embodied, able to

produce a narrative out of the void of *homo sacer*. Although most anthropological work of this study was done within the frame of a healing ritual, even that frame is contextualized by something more extreme, which is perhaps beyond the anthropological scope of practice. Nonetheless, the context helps understand the range of questions able to be asked within the discipline. What questions should be asked about the healing ritual as exemplified by Western biomedicine?

In the first chapter, I challenged Arthur Frank's portrayal of the biomedical clinical encounter as "narrative surrender," because he argues, as many others have argued, that the biomedical paradigm is the antagonist to the narrative self. I argue that both the narrative self and the doctor performing the healing ritual both participate in the same culture. "Healing Power" is not inherent in the doctor or biomedicine but in our culture; our culture has power over all participants because it is what defines reality as we know it. The doctor and patient can perform a healing ritual repeatedly, sharing power, because power is a form of cultural replication. Cultural replication in the form of a healing ritual is the antidote to alienation, the alienation that arises from the fear of disease and death. It is the narrative in the healing ritual that re-infuses meaning to all social actors.

Implications of this research

In the methods section, I acknowledged the limitations of this study. From an anthropological perspective, I hope my critical reappraisal of Kleinman's model and the legacy he left in medical anthropology and, specifically, of the narrative healing investigators encourages anthropologists to look more closely at medical-surgical clinical encounters involving doctors and patients participating in healing relationships in a more complete

perspective. I believe that the clinical encounter has something to tell us about wider issues within our culture. Personally, my next research project will be the interaction between the profession of medicine and the healthcare industrial complex. I fear the external pressures of a commodity-driven healthcare system might prevent doctors from an efficacious performance of the healing ritual. When I have a perceived serious illness, I want a doctor, not an administrator. The current push for value-based reimbursement for population health needs to be designed in a way that is consistent with the healing ritual.

I can make no claim based on my data about “trivial” diagnoses made in the primary care physician’s office. Using the positionality of having a clinical practice in just such a setting, I am able to report personal experiences of such clinical encounters. Through my enhanced understanding of what actually happens in a clinical encounter, I have routinely used the word *diagnosis* in clinical encounters. When I said, “My diagnosis today is a sprain,” a patient responded, “So you don’t think I have a sarcoma?” Another time when I said, “I think your symptoms are consistent with a diagnosis of heartburn,” the patient started crying and said, “Then I’m not having a heart attack?” And another time when I said, “My diagnosis is a viral infection of the throat,” the patient said, “Thank you. That is helpful.” The diagnoses seem trivial only to doctors; patients may have some unexpressed worry that brought them to the doctor’s office, and simply by saying the word “diagnosis” the patients’ behaviors change. I think this is another iteration of the healing ritual, and I believe it is worth exploring that hypothesis with empirical studies.

Nationally, the healthcare industry measures quality care with the HCAHPS score. This has massive financial implications and includes the following two questions:

1. How often did doctors listen carefully to you?

2. How often did doctors explain things to you in a way you could understand?

The diagnosis narrative is a cultural communication that might convert those questions into:

1. Did the doctor listen carefully enough to make an accurate diagnosis?
2. Did the doctor persuade you that the diagnosis was correct?

Besides the anthropological implications, I was always interested in knowledge that could make me a better doctor. I enjoy healing relationships with my patients.

Epilogue

The oldest recorded narrative in the entire world, Gilgamesh, recounts how a proud and powerful king found and subsequently lost “a marvelous plant, the antidote to the fear of death.” Until something better comes along, we still have the diagnosis narratives and the healing ritual to help us live life.

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ABSTRACT**THE DIAGNOSIS NARRATIVES & THE HEALING RITUAL**

by

JAMES PETER MEZA**December 2013****Advisor:** Dr. Andrea Sankar**Major:** Anthropology (medical)**Degree:** Doctor of Philosophy

The goal of this dissertation was to describe healing practices in the setting of clinical encounters between patients and doctors. The theoretical background for this research began with the theory of the mind and using concepts from cognitive anthropology described the anthropological self as distinguished from person or identity. Additionally, the conceptual framework of cognitive anthropology was used to describe narrative theory. Narrative theory in the form of the narrative structure of experience, particularly the experience of ritual, formed the basis for investigation.

The fieldwork setting was a urological practice and all of the clinical sites associated with this practice, including two hospitals, satellite clinics, related disciplines of urogynecologic oncology and radiation oncology. The majority of the data was obtained using participant observation. Analysis was accomplished by sorting the data using Atlas ti v6.2 and generating themes by codes. These themes were then re-examined using the theoretical framework.

The major finding was that diagnosis narratives were an essential part of the healing ritual. This was in contrast to current anthropological emphasis on illness narratives. Diagnosis narratives contributed to the healing ritual and successful completion of the ritual resulted in healing relationships. The theoretical and practical aspects of these findings were discussed in the results.

This research has implication for future anthropological research using narrative theory for investigating narrative components of healing rituals in Western biomedicine. Additionally, it has applications for cultural communication in clinical practice.

AUTOBIOGRAPHICAL STATEMENT

James P. Meza, M.D., M.S.A. received his bachelor's degree in biomedical sciences from the University of Michigan, followed by his Doctorate in Medical Arts and Sciences from the University of Michigan Medical School. He completed his internship and family practice residency at University Hospital in Ann Arbor, Michigan, where he was socialized into the concept of George Engel's biopsychosocial model of medical care. After several years in practice, he realized that the process of care was limiting the quality of care and subsequently received his Master of Science in Administration, Health Services Administration from Central Michigan University. He worked as a health education administrator for a decade. During that time he became a credentialed Balint Leader and explored the psychoanalytic aspects of patient care. Also during that time that he met Kurt Stange, M.D., Ph.D., who suggested writing a grant on "healing." Thus began an enduring line of inquiry that eventually brought him to Wayne State University, Department of Anthropology.

Dr. Meza currently serves as the Associate Residency Program Director and Director of Research at Oakwood Annapolis Hospital Family Medicine residency.

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