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ACCESS, HEALTH, AND LITERACY: ON BECOMING AN INFORMED
PATIENT

By

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ABSTRACT

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This project is a case study exploring the reading, writing, and learning practices of individual cancer patients and/or their caregivers at a cancer center located in a medium-sized Great Lakes city. The study population consists of two patients and one caregiver. Data also includes interviews with the support group in which one patient and caregiver participated, and with the clinic's social worker. The goal of the study is to provide future researchers with a thick description of why, where and how patients learn to be informed, "health literate" patients. My study, therefore, is intended to help address the gap in voices participating in conversations about health literacy (and related conversations, like decisions about health policy) by making actual patient literacy practices visible in the literature, providing future researchers with a more complete view of health literacy in action, and patients with a source of more accessible and applicable information.

The results of this study show that patients engage in complex inventional practices, often in collaboration with others, and that patients and caregivers must then share that knowledge with other audiences: family members, other patients, and medical professionals. Health literacy is multimodal, contextual, and distributed. Further, invention processes are a significant and ongoing feature of health literacy. My findings are significant for the study of rhetoric because they

show the deeply rhetorical nature of health literacy, a complexity that must be accounted for in the design of patient education materials, in the ways patients are supported, and in the ways doctors and nurses interact with patients and caregivers.

The study utilized a survey, extensive observation of patient/caregiver research, reading, and writing practices (and the collection of documents they consume and create), and a series of related interviews to deeply examine the work of becoming a health/literate and “informed” patient. These interviews were structured in open, emergent ways to enable the researcher to follow the patients’ actual practices.

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DUNDEE CARROLL LACKEY

2009

This work is dedicated to James and Lynn Lackey,
and to the memories of Earl and Ginie Morris, and Pete and Maudie Lee Lackey,
who taught me what it means to be a survivor.

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Chapter One

INTRODUCTION

Background and Motivations for Research

This project is a case study which seeks to explore how cancer patients and/or caregivers develop (before and after diagnosis) and use literacy skills to help them negotiate the new situation(s) they find themselves in, in terms of the information they must locate, interpret and synthesize, as well as in terms of the rhetorical situations they now find themselves writing and/or speaking in. This study is focused on providing thick, contextual descriptions of the skills required of “health literate” individuals, exploring the whys, wheres, and hows in the development, learning, and deployment of such literacies.

I am interested in this project on a personal level because of my life experience: I was diagnosed with Mycosis Fungoides, a form of Cutaneous T-cell Lymphoma, at the age of 28. Despite this personal connection, the project also commands my passion and attention because of my academic interests and personal ethics. My research interests and teaching strategies center, to some extent, on Paulo Freire’s concept of *conscientizacao* or critical consciousness. Because it represents a certain mode of political consciousness and carries with it a sense of personal empowerment and agency allowing one to address contradictions and oppressions, *conscientizacao* is a critical concept to keep in mind when exploring the health and medical situations central to this research. When a person is diagnosed with cancer, there is a feeling of having lost their power and of having the diagnosis and treatment take over at least a portion of

their identity. Further, there is a pronounced need for information, which must be gleaned through the disciplinary veils that separate practitioners from patients.

I used reading to help me gain the knowledge I needed to be powerful in this situation. I used writing not only to help me negotiate the new identity I had, "cancer patient," but also to help me get the treatments I needed to forge another new identity: "cancer survivor." I had to become a health literate, "informed" patient--a patient who has "appropriate information in order to be properly involved in their own care" (Detmer et al 3). In these actions, I am representative of others. This study is located squarely within the transition from patient to health literate patient, and is committed to 1) describing the moments in which we can see health literacy as a set of contextual, enabling practices; 2) describing "literacy" from the perspective of the user of medical discourse; and finally 3) locating the rhetorics through which literacies are learned and used.

Dundee's Story: Diagnosis

After several years the odd skin rash that began on my left breast and continued creeping across my body, while little more than a nuisance, had finally amounted to enough office visits and prescriptions to result in an HMO-approved referral to a specialist. She looked me over, called in three of her colleagues, and commenced to have a "private" conversation--right there in front of me--in which they used a lot of language they thought I wouldn't understand to discuss what surely sounded like cancer, one whose name I couldn't quite catch. They took a

biopsy, and sent me away. Having cared for my grandfather as he died of prostate cancer metastasized to bone cancer, I partially understood, and was too afraid to question them. I tried to convince myself it couldn't be cancer, or they would have shared their suspicions. They were just ruling this out. I waited through almost three weeks for the test results, terrified at the things they'd said to one another, with no one to ask.

On February 12, 1998, I received a phone call informing me that the biopsy was positive for a form of Cutaneous T-Cell Lymphoma (CTCL) called Mycosis Fungoides. It was not a relief to know the rash finally had a name: all I heard was "cancer." Upon my return to her office, Dr. Omniscient-Specialist explained that in many cases the road to a CTCL diagnosis is a slow one because it looks like so many other things. It is often mistaken for psoriasis, eczema, food allergies, and more. She had recognized mine and gone straight to a biopsy because she had recently had another patient with this. She asked me to attend the grand rounds of an upcoming dermatological conference with her so other doctors could see my rashes, which I now learned were more properly called "plaques." Presumably, this would help other patients by training physicians for earlier diagnosis. I wanted to do something proactive, and thought this might help me gain more information about my condition while helping others, so I agreed to participate.

Not long after, naked but wrapped in a brand new robe printed with little rosebuds--our attempt to make the whole thing a bit less clinical--my mother and

I nervously settled into a tiny examination room. Over the next few hours, more than one hundred physicians came in to see me--or my skin, as the case may be. Some looked me in the eyes and spoke with me as if I was their own long-term patient. Others treated me like a laboratory slide (or perhaps animal), and never made eye contact. In a bit of silent rebellion, their demeanor with me eventually determined which spots I was willing to show them. Some were treated to the "first and worst," which required baring my breast to them. Others were left to poke, unguided, around the edges of my robe. It was alternately an interesting and dehumanizing experience.

While I hoped the doctors had learned something, I went home knowing not much more than I had known before. I wanted to do something that would help me feel less powerless when I was in a doctor's office, no matter what that doctor's demeanor. I had always been a writer, a reader, and an avid researcher, so I went to the computer and began looking for information. I terrified myself by reading every remotely relevant medical entry I could find. I did not, however, understand some of what I was reading; I did not have the context to do so. For instance, in the first batch of articles I managed to locate I found one that listed the life expectancy of MF patients as being approximately ten years. I was 28 and terrified, and, since I was trying so hard to be strong for my family who knew even less about this cancer than I did, I had to find another support group.

Dundee's Story: Writing a Letter

I researched some more, and this second batch of results led me to what would become another family: an online support group, sponsored by the Association of Cancer Resources Online (ACOR)¹, which provides via email listservs information, support, and community for persons fighting cancer and related disorders. The MF/CTCL group (which, at the time of this writing, consists of approximately eleven hundred patients and/or caregivers) helped guide me through this experience, sharing their stories/wisdom as well as pointing out resources they had identified (and evaluated). They played, as we will see, a large role in helping me to write the letter I am leading up to by teaching me the tactical, rhetorical positionings required.

As many will know from personal experience, obtaining benefits through an HMO, particularly in the case of unusual illnesses or treatments, often requires much effort, and that was certainly true in my case. We assume that the people "in charge" of making medical decisions for us, which more and more includes our insurance companies, have basic knowledge about the illnesses and treatments we are facing. This is not always the case. Sometimes, these folks simply don't know what they're doing. At other times, their "guidance" is more motivated by the company's financial bottom line than by the patient's needs or the doctor's prescriptions. It was, then, necessary for me to become very well

¹ <http://acor.org/>

educated about my cancer. The only way to win the battles I would face was to have more information than the people I had to convince to help.

Here is the problem that I needed to solve. By May of that year, I had managed to get approval for a form of topical chemotherapy treatment, but for thirty days only. While still appealing the "30 days only" decision, my physician decided to have me use a different mixture of this agent; this meant each prescription would be more costly to the insurance company. Perhaps not surprisingly, they began to come up with new reasons to deny coverage, claiming first that the treatment, since it required an off-label use of nitrogen mustard (also called mustargen, and hereafter referred to as NM), was "experimental" -- despite having been used for many years. Secondly, they claimed that this new form of treatment would require me to dispose of a highly toxic substance, something they "could not allow" despite the fact that many patients are trained by our cancer centers in safe handling so that we can utilize this treatment.

Solving this problem demanded action in the form of a letter. This letter required me to position myself in a number of ways, all of which were challenging, since I'd had less than three months between diagnosis and this battle. I'd spent many hours researching my condition, almost from the moment of diagnosis, but now it felt like I'd had far too little time to learn how to use these foreign discourses to help me argue from a position of strength. I had to demonstrate medical knowledge (both to educate my HMO about required

treatments, and to shoot down their ridiculous objections to coverage), an awareness of my legal rights, and knowledge of the insurance contracts, policies, and state coverage regulations. This letter had a lot of work to do. I was an educated person, but still felt unprepared to meet all these needs.

Because of these broad and demanding requirements, much of what I did was based on lessons I learned from others, primarily fellow members of “my” ACOR list. In attacking the HMO’s judgments’ of NM therapy as both experimental and unsafe, I made use of articles from medical journals, chosen to educate the HMO’s board of directors about CTCL and all possible treatments, and to attack specific reasons for denial. I hoped, by extension, some of this information would reach reviewers in charge of rubberstamping subscribers’ care and make things easier for later patients. Some of the articles chosen were of the “general information” type, and had been posted by list members. Others were focused on the treatment the HMO and I were arguing over; I located these on my own, using indexes, databases, and websites with credible reputations. I learned which were considered credible by examining the documents offered by ACOR, our list sponsor, as well as those that came to me through the CTCL list-serv. I learned research tactics and keywords by reading posts from Peter and Nick², dedicated members of the list who frequently shared the results of their medical research, and whose postings made apparent their care and ethos. I wrote these gentlemen off list, and discussed the medical

² The names of list members have been changed to protect their privacy.

articles I'd selected for inclusion. I debated with my family, and list members, which sections of each article provided the most compelling evidence with regard to the denials (and misinformation) coming from my insurance company. The reading and research skills I developed through my research and conversations with list members also helped me use, rhetorically, information from my HMO coverage agreement, as well as state and federal insurance regulations, positioning myself as one who had legal knowledge. I discussed drafts of this letter with a few members of the list-serv, but mostly they were there to help with the big-picture: information and tactics.

Perhaps most of all, I had to demonstrate tenacity; I had to be willing to argue until I got what I needed. As a Southern female, reared on politeness and respect for authority, this was difficult for me, and took special effort. I was encouraged to do it by stories from other list members, both those who'd given up--people who were now receiving either no care, or much less than they required--and those who had succeeded. List members urged me from the very first, in both personal and list messages, to be pro-active, to make phone calls, to keep a phone log, to use those notes and their research as the basis for my appeal, and, most of all, not to surrender. All of this advice, all of these resources, enabled me to write a brief, well-supported, highly rhetorical letter addressing every objection the insurance company had ever given me, as well as those I--we-- anticipated would come next. As a result, I was approved for NM treatments, and when the doctors decided some months later that I needed,

instead, a costly and lengthy series of injections, and then radiation treatments, I received those too, without further battles. This is a short and successful story, which is nice, but my current study focuses on trying to understand what stories like this mean.

Figure 1 (following page) maps just this one example from my own experiences as a patient--the letter I had to write petitioning for a denied treatment. This map reveals that meeting the needs of this rhetorical situation required skills I gained through other persons and texts. Without truly understanding how and why the activity and learning these images so roughly graph occurs, I see no way to proactively build the "health literate" futures needed; instead, society can only react to problems as best we can, as we realize they exist. I--a single patient--wrote the letter. But as the map reveals, I didn't do it alone. I had input from many sources. It was a communal practice in many ways. My learning, and the work this letter represents, was fed by knowledge and skills possessed by other members of the ACOR community, and the cycle doesn't end with me and that letter. That input helped me develop skills that led to texts, other patients.

In terms of my own literacy practices, my cancer diagnosis became an open doorway instead of a closed one; I began to write again as I hadn't in years, and I began to read, and write, in new ways. I wrote constantly, composing poems, short stories, email updates to friends and family, a treatment

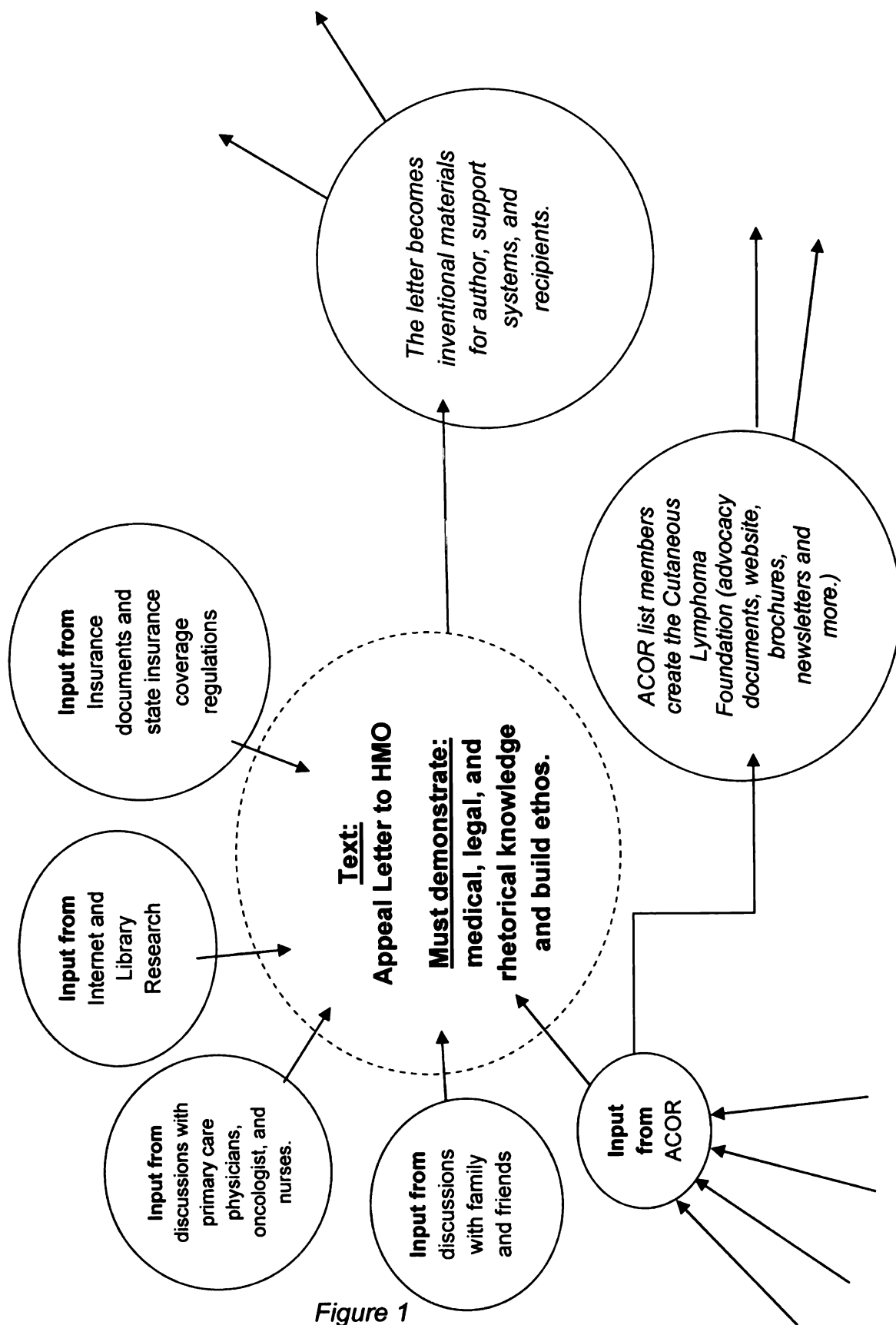


Figure 1
Mapping Dundee's Letter

journal, notes on the endless phone calls requesting this and appealing that, and letters to lawyers, doctors, HMOs and drug companies. Eventually, I began to write for other patients in the form of brochures, newsletters, and list-serv postings guiding those who were in the shoes I had so fearfully occupied not too long before. I wanted to provide my fellow list members with an encouraging example, so I documented my processes through lengthy emails to the list. These messages are now archived there so that other patients might borrow or build on the tactics that helped me win treatment. Ultimately, I wrote documents that helped to establish support groups at several major cancer centers.

This distributed invention process³, then, led to new knowledge for me, the insurance company (who became educated about the treatments available for CTCL/MF), my primary care physicians (with whom I shared and discussed the resources I, their only CTCL patient, found) and at least one of my communities, the ACOR list. Further, individuals from the ACOR MF/CTCL list that helped me do all of this have since, in collaboration with Dr. Stuart Lessin, created the Cutaneous Lymphoma Foundation⁴, a patient advocacy and support group. This foundation has created a web site and a number of other publications that make available to a broader audience materials based, in part, on years of patient conversations held through the ACOR list. Further, the foundation has participated in, and helped organize, conferences and seminars

³ The concept of concept of "distributed invention" is important. This will be addressed in Chapter 4: "What is Health Literacy? Who Becomes Literate?"

⁴ <http://www.clfoundation.org/>

for patients and medical professionals alike, "...call[ing] attention to the needs for education and research in this field" (Cutaneous Lymphoma Foundation). In other words, over time, this community of patients, and their families and caregivers have gradually made material the products of coordinated intentional practices for the purposes of supporting the continued intentional needs and practices of community members.

In my actions, I am therefore representative of many other patients and survivors, and I believe that our experiences can help many fields learn to help other patients with life-threatening (and life-altering) illnesses to reclaim their power, rebuild their identities, and speak in powerful ways. To speak powerfully is both an issue of rhetoric and of literacy. With respect to literacy, this is widely recognized in medicine, as there is a large, rich, and growing body of literature on health literacy. However, as I will demonstrate in this project, while "health literacy" is being studied, the approaches typically would leave invisible the story that I have just told. We need, at this stage, a descriptive, contextual study of health literacy in action. Stories like mine and those made visible in my cases have something to teach us. These stories are also important in broader contexts: American health care is in crisis. The current push for "health care reform" will benefit from a deeper understanding of user experiences in the current system.

Research Context: “America’s Health Care Crisis”

The “National Health Care Crisis”, like our health care system itself, is complex. Both involve intertwining, sometimes conflicting, systems of advertisements, employment and insurance, medical knowledge, money, access and education. Because of the literacies required for successful negotiation of these increasingly complex systems of care and coverage, the more “literacy” any individual (and their family and other support systems) has, the better the patient fares in these systems⁵. The national health care crisis is, then, in part a problem with health literacy and health literacy initiatives.

We seem well aware of this. “Health” seems a topic constantly on the American radar. Very few minutes pass, whether online, or simply near a TV or radio, without hearing/seeing some new health, safety, or medical study on the news, or perhaps a website where we are promised health information that will enable us to solve everything. Frequently, we are told all about a new medication--usually one that sounds worth asking my doctor about, though I couldn’t say precisely what it’s for, or possibly remember all the nasty-sounding, quickly-listed side effects it may cause. Despite all the attention that is paid to

⁵ Estimates on the economic costs of low health literacy are available many places; however, one of the most useful reports I read in the course of this research, “Low Health Literacy: Implications for National Health Policy” estimates low health literacy to cost the nation and the system from \$106 billion to \$238 billion dollars. (Vernon et al 6). The report further reveals this cost “represents an amount equal to the cost of insuring every one of the more than 47 million persons who lacked coverage in the United States in 2006, according to recent Census Bureau estimates” (Vernon et al 9). The authors go on to posit that, “when one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion” (Vernon et al 9).

"health" and health information, we still have a crisis--one that seems to be constantly escalating.

According to the most recent U.S. Census Bureau data, the number of uninsured Americans of all ages, as of 2005, was 46.6 million, or 15.9% of our population ("The Number of Uninsured..." emphasis mine). Perhaps because of the erosion of employer-based insurance, current numbers include "5.4 million more people [who lack] health insurance in 2005 than [did] in the recession year of 2001" ("The Number of Uninsured..." para. 1). In addition to the uninsured, "...millions more [are] underinsured or facing bankruptcy due to medical costs" (Leger para. 3, emphasis mine). The health care crisis" is, accordingly, such a hot-button issue that in March of 2007 a presidential forum was held to provide candidates with a space for focused discussion of their positions/platforms/plans regarding the crisis (Leger). During the 2008 presidential election, "health care" was one of the leading issues identified as important to voters. Accordingly, in President Obama's February 24, 2009 speech to a Joint Session of Congress, health care reform was virtually demanded:

...we must also address the crushing cost of health care. This is a cost that now causes a bankruptcy in America every 30 seconds. By the end of the year, it could cause 1.5 million Americans to lose their homes. In the last eight years, premiums have grown four times faster than wages. And in each of these years, 1 million more Americans have lost their health insurance. It is one of the major reasons why small businesses close their doors and corporations ship jobs overseas. And it's one of the largest and fastest-growing parts of our budget. Given these facts, we can no longer afford to put health care reform on hold. We can't afford to do it. It's time.

As I write this dissertation, the economic situation in America is quite grim,

despite the changes in Presidency and policy we all hope will soon be fruitful. If one follows the discussions on the health care crisis--and it's becoming hard not to--one will shortly encounter discussions of health literacy.

The medical system manifests itself in health literacies as well. Historically, individuals whose work did not make them somehow part of "medical discourse" did not have ready access to medical information; doctors were therefore expected to be patients' source of information, and to make informed decisions on behalf of the patient as necessary. Ethical considerations aside, how doctors involved patients in the decision-making process was largely a matter of personal preference (Hogg; Parsons & Parsons; Segal). Under this paternalistic model, "health literacy" wasn't something that had to be considered. Today, however:

a constellation of changes has complicated the adult's challenge of being healthy: the health care system's shift from a paternalist to a partnership model, with more individual responsibility for prevention, informed decision making, and consent; complex choices about insurance; the need for self-management of chronic conditions...; and responsibility for both children's and elders' health care (Kerta 2).

The explosion of health and medical information available through Internet and media sources has changed physician-patient communication, and has challenged patients to become informed and "health literate." As my case suggests, "health literacy" is a complex set of skills--knowing when and how to locate specialized (often difficult) information, and how to use that information to solve problems. There is therefore a need for a different kind of health literacy study, one that makes the actual practices of users in this system visible.

When I began this work several years ago, it was difficult to find academic work on the subject of health literacy. Treatment of this topic, however, is becoming extensive. Current academic publications on informed patients and/or health literacy involve many disciplines: several different areas of medicine, pharmacology, social work, education, literature, insurance, advertising, rhetoric, and professional and technical communication are now considering “patients,” particularly where we intersect with “information” and technology in ways that affect the doctor-patient relationship (in journals as wide ranging as *Ambulatory Pediatrics* and *Qualitative Research*, *Anthropological Quarterly* and *Open Learning*). There are no fewer than sixty recent dissertations, representing a similar broad swath of disciplines. The difficulty with the interdisciplinarity of a literature such as this is that although most are interested in literacy, few actually study the practice of literacy or are aware of the body of work in literacy studies.

Composition’s focus on developing and assessing literacy skills and Rhetoric’s insistence upon exploring literacies in context (as well as the relationship between literacy and power) ideally suit this study to our fields, and yet we have done little work in this area. While I learned much from thoughtful methods utilized in literacy studies and discourse studies like Shani Orgad’s *Storytelling Online: Talking Breast Cancer on the Internet*, Martha Balshem’s *Cancer in the Community: Class and Medical Authority*, and Ken Hyland’s *Disciplinary Discourses: Social Interactions in Academic Writing*, there are few

studies within language-oriented fields directly addressing health literacy. The few notable exceptions are in technical and professional writing. These include Joelle Kivits "Researching the Informed Patient: The Case of Online Health Information Seekers" and Sarah Nettleton's "Health E-types? An Analysis of the Everyday Use of the Internet for Health." (both published in *Information, Culture and Society*), and Ellen Barton's "Design in Observational Research on the Discourse of Medicine: Toward Disciplined Interdisciplinarity" and "Discourse Methods and Critical Practice in Professional Communication: The Front-Stage and Back-Stage Discourse of Prognosis in Medicine," both published in the *Journal of Business and Technical Communication*⁶.

There have also been some promising studies on patient literacy skills done by other disciplines. Where many studies outside our fields focus on evaluating patient health literacy skills as a means of determining in what forms information should be published for patient consumption, this is not always true. One exception I particularly admire is Gunter Eysenbach's "The Impact of the Internet on Cancer Outcomes," published in *A Cancer Journal for Clinicians*. Eysenbach's study pays more attention to the settings and motives for patient Internet research than seems customary in studies for medical readerships and suggests patients turn to the Internet for information because "...the expectations of Internet patients have changed in a sense that they become more dissatisfied than non-Internet users when they realize how much

⁶ These exceptions, particularly Barton's work, were crucial in developing my methodology and methods, and will come into play again later in this document.

information is out there that they should have received” (Eysenbach 365).

Eysenbach seems well aware this study was a bit of a departure from the norm in his field, as he goes on to state that health literacy researchers have been distracted by debates over the quality of health information on the net, and suggests as future areas for research studies focused on “the relation of different quality criteria to each other (including which markers of a Web site can be used by a consumer to judge whether the site is trustworthy), or the relation between quality criteria or presentation formats on the one hand and outcomes such as knowledge transfer or satisfaction on the other” (368). He suggests, in other words, that researchers instead look at why and how patients locate, process, and use information.

Christine Hogg, author of *Patients, Power & Politics: From Patients to Citizens*, characterizes the situation in this way, “[m]edical research tends to concentrate on narrow science based questions that do not take account of the subjective views of users” (70) , or as I would argue, on what patients actually do to become health literate. My study is an attempt to speak directly to the conversations in medicine and nursing that are interested in health literacy and patient outcomes but fail to actually study literacy itself (and so these studies tend to erase patients as well). We must adjust our practices and make a real space for patients in our research, because “...[t]he research topics of today determine the treatments and services that will be available tomorrow” (Hogg 70). This absence of the patient in current studies also means patients--the users

at the center of health/medical systems--have little effect on future research: ...the analysis of current health issues is based on the experiences of people who are in a position to get their view heard: politicians, clinicians, managers, economists and drug companies. Political debates and decisions on health policy are based on their analyses of the problems and the negotiations, disputes and alliances between them (Hogg 1).

My study, therefore, is intended to help address the gap in voices participating in conversations about health literacy (and related conversations, like decisions about health policy) by making actual patient literacy practices visible in the literature, providing future researchers with a more complete view of health literacy in action. I believe that rhetoric may provide a mediating space for the current conversations taking place through all our disparate research into what constitutes "health literacy": "...rhetorical study--essentially the study of persuasion--is a good means of illuminating and recasting problems in health and medicine" (Segal) in ways that will provide a more workable, full, and realistic conception of "health literacy". This concordance is necessary before our research can move forward in fruitful ways.

Chapter Overviews

This dissertation focuses on the following issues:

In Chapter 2, I survey concepts that will be important in the study, including literacy, the connections between health and literacy, and common definitions and measures of health literacy. I identify problems with basing

studies and assessments on definitions rather than practices, and go on to survey the foreign disciplinary and discourse community, Medicine, in which informed patients endeavor to participate.

Chapter 3 outlines my methodology and study design. I have developed an approach to knowledge/power that is informed by Michel Foucault and Robert Johnson. Foucault's exploration of medical discourse suggests researchers attend to the points of dispersion as ways of exploring the whole: the work of health literate, informed patients marks such a point of dispersion. Johnson's work adds additional support, directing us to allow practices to inform our theories.

Following this, I review relevant theory on the value of narrative to science, and the ways in which rhetorical studies of such texts may add to scientific knowledge. The remainder of this chapter treats the study population and shares instrumentation and data collection and analysis procedures. My data analysis procedures involved the development of a coding schema allowing me to track issues of knowledge, access, practices and agency as they appear in the narratives provided by patients, caregivers, and medical professionals involved in the study; this coding scheme, continually refined throughout the data collection and analysis phases, is an important deliverable from my study.

Chapters 4 and 5 explore individual case studies of patients' and caregivers' practices, highlighting issues of access, invention, and the development of literacy skills. In Chapter 4, I focus on describing health literacy practices observed in the study, and explore the communal nature of many of

these practices. Writing to survive as a patient (or with a patient) in contemporary medical settings is to engage in knowledge work-- complex, knowledge-producing activity requiring advanced information technologies and other elements of infrastructure. Patients and caregivers must interact with complex databases--even create them--work with ill-formed sets of information, and from this material, write persuasively to audiences. In addition, this rhetorical work is also deeply coordinated and sometimes collaborative. That is, unlike the classical rhetorics developed based on (and for) the individual rhetor, rhetorical activity in contemporary communities requires the participation of many people and technologies. I have therefore come to think of health literacy as a communal literacy. Clearly the work of a health literate patient involves the cooperation of multiple individuals. This suggests obvious problems in the ways that Medicine and Public Health currently operationalize and assess health literacy, which interfere with their intentions to support health literacy.

In Chapter 5, I consider issues of power and access observed in the study. The stories participants tell throughout this study underscore the effects that the differential power levels inherent in the doctor-patient relationship may have. Power and Access play crucial roles in the development of patient and caregiver health literacy skills, but not necessarily in a predictable way. Much depends on individual agency and access. I believe, in fact, these skills exist on a continuum, with an individual's development dependent upon their individual contexts.

In Chapter 6, I discuss my conclusions, which are significant for the study of rhetoric because they show the deeply rhetorical nature of health literacy. The results of this study show that patients engage in complex inventional practices, often in collaboration with others, and that patients and caregivers must then share that knowledge with other audiences: family members, other patients, and medical professionals. Because of the fluid nature of the contexts in which health literacy is developed and practiced, and the individual nature of and support systems available to patient and caregivers as they make their way through these contexts, the informed patient exists on a continuum supported and/or bounded by agency, practices, knowledge and power. The sum total of this complex continuum is the true “definition” of/for health literacy. This complexity is what must be accounted for in the design of patient education materials, in the ways patients are supported, and in the ways doctors and nurses interact with patients. In closing, the participants of this study and I offer recommendations for medical practitioners and future researchers.

Chapter 2

REVIEW OF LITERATURE

Health Literacy: Why does it Matter?

Physician-patient communication has changed in recent years. The move from paternalistic models of health care to partnership and consumer models has led to "more individual responsibility for prevention, informed decision making, and consent; complex choices about insurance; the need for self-management of chronic conditions" (Kerta 2000). Further, Americans are increasingly responsible for the health care of extended family. The Caregiving Initiative (a project of Johnson & Johnson) estimated in a May 2006 report that "46 million American adults take care of an ill friend or family members..."; this figure represents approximately 80% of all long-term care provided within our borders (Srikameswaran scr. 1 para. 1). Being an effective caregiver requires information, which can be difficult, for "[a]t each stage in life people have a different attitude to health and want different things from health care" (Hogg 6). To compound this problem, the explosion of computer-mediated communication and the mass media means medical information is now increasingly available--on TV, online, and through specialized journals--to the public at large. Increasingly, patients are expected to be more equal partners in their health, requiring increasing levels of health literacy, among more and more streams of information, at a time when America was already bemoaning its literacy crisis.

As technology continues developing and access becomes more prevalent, more medical information is available to patients (and more on a daily basis, it

seems). This is good in a sense, for the responsibilities of being a patient seem to have changed in this new landscape; however, many of us who can read and write still don't have the skills required to function well in this new health economy. And yet--we must become more health literate so we can be more equal partners in our own care. Low literacy skills affect health care, for patients *and* the system, and many individuals termed "literate" are nevertheless unable to function successfully in situations where health literacy is required.

The conflation of these terms--literacy and health literacy--can be problematic, leading to an incomplete understanding of both the exigencies requiring the skill set, and of the context in which it is developed and used. In this chapter, I briefly consider how to usefully conceptualize health literacy for research purposes. I begin by surveying basic definitions for health literacy, and then recount and reflect on the assessment measures most commonly used. In the next section, I explore how literacy studies understand "literacy", and how reductive definitions can lead to reductive studies on and understandings of literate practices of any kind. Finally, in an attempt to demonstrate the true complexity of this skill set, I consider health literacy from the point of view of patients, the users at the center of complex and often foreign networks of doctors, disciplines, and discourses.

Defining Health Literacy

Definitions of health literacy that begin from the idea of literacy as simply the ability to read and write tend to arrive at models that seem less than

representative of the complex nature of health literacy practices. One of the most common definitions, provided by the AMA Council on Scientific Affairs, positions “functional health literacy” as “the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient” (cited in Center for Health Care Strategies “What is Health Literacy?”, emphasis mine). This definition is extremely reductive, in that it essentially sets the patient up as one who can understand information given to them, and follows instructions. This definition presumes doctor/patient expectations match, which may or may not be the case, and does not, I believe, allow for the critical literacy that might lead an individual to determine more or different information is required (and whether/how to glean this from professional or more personal resources, and how to interpret and apply that information....)

The problem with defining complex skill sets like (health) “literacy” is that our definitions tend to assume a single context for development/deployment of skills--or worse, render them acontextual. Definitions limit us: definitions neutralize, and “...the apparent neutrality of literacy practices disguises their significance for the distribution of power in society and for authority relations: the acquisition, use, and meanings of different literacies have an ideological character that has not been sufficiently recognized until recently” (Street “The New Literacy Studies” 431). Such studies aren’t taking us where I think we need

to go. We need to try something new. Useful literacy studies first conceive of literacy more broadly and contextually.

The National Literacy Act of 1991 discusses literacy in a much richer way. It is not just “the ability to read and write” but instead is treated as a set of skills that enable one within specific contexts: literacy is conceived here as the ability

...to read, write and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and to develop one’s knowledge and potential’ (qtd. in US Dep’t. of Health and Human Services’ “Literacy and Health Outcomes” 1, emphasis mine).

This is a more useful definition of “literacy,” one that demands a consideration of context. We need to do the same thing in considering health literacy. J.L. Lemke adds further support to this notion, suggesting that:

[w]e also need to reconceptualize the relations between literacies and the societies in which they operate, and the role of people in these larger processes... It is no longer sufficient to imagine that societies are made up of isolated human individuals, tentatively linked by voluntary social contacts, with individual and autonomous minds somehow dissociated from the material world. We cannot get by anymore thinking that there is just one thing called literacy or that it is simply what individual minds do when confronted with symbols one at a time” (Lemke 73).

Robert Johnson agrees, arguing that “[u]ser knowledge is always situated” and that situated location shifts...but “there are connections and commonalities among these experiences that help thread them into a visible knowable tapestry” (9). Johnson suggests that our goals (particularly with regard to technology) should be based on understanding this “complex of events,” interrogating the “set of social, technological and knowledge interactions” (Johnson 9).

My experiences suggest to me that the “complex of events” surrounding any act or practice related to health literacy involve an amalgam set of skills, which go beyond the reading and writing implied by “literacy”. Health literacy is complex: it involves knowing when and how to locate complex, specialized information, and how to use that information to solve problems and set/achieve goals. These tasks imply even more skills at work in the background, seemingly developed by patients without the benefit of specialized training.

For example, patients with access to the Internet and/or good libraries now have access to extensive medical information. Some of this is intended for patients, and some for physicians. This kind of research takes “eHealth literacy,” which the designers of eHeals (a testing protocol) define as comprising “the ability to read, use computers, search for information, understand health information, and put it into context” (Norman scr. 1 para. 1). Something our (definitional) studies don’t seem to get at are the hows: HOW do patients learn to do this? Even physicians--highly trained professional researchers--must work to improve their skills locating information in specialized databases. A cursory search revealed three such papers delivered at the Mayo Clinic within a single year’s time (Demaerschalk “Literature-Searching Strategies...”; Ebbert et al “Searching the Medical Literature Using PubMed...”; and Sood et al “Using Advanced Search Tools on PubMed”). “Searching” is only part of “research,” or “inquiry,” let alone “critical research”--and yet, research skills (which I consider comprised of, at least, information and critical literacies) are not something most

definitions of "health literacy" suggest a space for. Despite this, patients are doing research, online as well as in these in these specialized/professional databases that even physicians--who already have at least the content knowledge required--need special training to use well. We need to describe these processes, in order to learn from how patients are accomplishing this work, rather than assuming they cannot, are not, and/or might not desire to--or benefit from--doing so.

In Kerta's review of health literacy studies, she finds that health literacy "...is not identical to general literacy" (Kerta 2), and, in fact, goes far beyond this. Kerta says,

[h]ealth literacy issues that go beyond basic skills include (1) health information communication; (2) literacy and health as cultural and social practices; (3) the relationship among health information, literacy, and behavior; and (4) the impact of the Internet on the use of health information (Kerta 2).

A more useful conception of "literacy" then is Gee's definition of it as "control of secondary uses of language (i.e. uses of language in secondary discourse)," ("What is Literacy?" 8); this definition posits literacy as a skill building on reading and writing, used in specific contexts, for specific purposes. "Health literacy" then becomes the use of reading and writing that enables one to function in health and medical contexts. A study built on such a conception of literacy will consider literacy more broadly and contextually, and be prepared to explore practices, and networks of practice. Thus far, the "health literate" or "informed" patient has been discussed without this level of consideration of

context, leading us to definitions that depict us primarily as outsiders, or interlopers, or perhaps just happy accidents. A study that is attentive to all aspects of the contexts in which participants need, develop, and/or use “health literacies”--including race, culture, gender, class, educational background, geographic location, and more--describing rather than defining--seems the next necessary step. We need to understand the networks in which health literacy is developed and deployed.

Assessing Health Literacy

Significantly, current definitions of health literacy are supported by a large and powerful set of assessments. Because I know that some tests used to measure “literacy”--“mere” reading and writing conflate multiple skill sets without acknowledging they are doing so, and further, often seem blind to a number of obvious factors of import (like...race, age, gender, culture, class, and more), it is important to consider the scales used to measure health literacy, of which there are several.

As Peter Sacks writes in *Standardized Minds*, “[s]tandardized tests generally have questionable ability to predict one’s academic success” (qtd. in “Meritocracy’s Crooked Yardstick”). There are similar problems with assessing health literacy. Standard literacy measures are misleading: because “high literacy levels are no guarantee that a person will respond in a desired way to health education and communication activities” (Nutbeam qtd. in Kerta 4). In order to improve practices in assessing and supporting health literacy work, we need

direct assessment(s) of health literacy, and patients' comprehension of health related materials. Thus far, the measures used do not capture all the information that would be useful.

Perhaps the most basic of these is the SMOG (Simplified Measure of Gobbledygook) readability test ("Smogging").⁷ SMOG and the Flesch-Kinkaid scale (so common it is built into the program in which I am now writing) are used by the United States Veterans Administration Office of Patient Testing for "field testing the readability levels of veteran health and information materials" (Wonch 2); this governmental endorsement carries with it enough power to standardize "health literacy" and testing policy. The SMOG test works by simply "counting the number of polysyllabic words in three chains of ten sentences," supposedly a "simple technique for predicting the reading difficulty of written text" (Wonch 2). This seems a good thing when considered in light of Davey et al's "An Exploratory Study of Cancer Patients' Views on Doctor-Provided and Independent Written Prognostic Information," which demonstrates that patients want information available via pamphlets and on the Internet, and that they prefer "positive, relevant and clear information" expressed in "plain language" (1450). I believe, though, that the difficulty with this test when applied in health

⁷ For a demonstration of how SMOG works, visit <http://www.literacytrust.org.uk/campaign/SMOG.html> and paste any text you'd like into the calculator you'll find there. The paragraph that launched you here, at some point in the life of this draft, had a SMOG grade of 16.96, which indicates an educational level between "university degree" (grade 16; example text: Atlantic Monthly) and "post-graduate studies" (17-18; Harvard Business Review). This is interesting, but, again, limiting when one moves into texts involving specialized vocabularies.

circumstances is that patients are far less likely to be familiar with polysyllabic “medical” terms/jargon than with “everyday” words. Wonch concurs, noting “that readability tests measure only the structural difficulty (e.g., vocabulary, sentence structure and idea density) of written text. They do not measure other factors related to readability, such as conceptual difficulty, organization of material, content, or reader characteristics” (1).

Furthermore, while general health communication is assumed, according to medical literature, to be facilitated through “...simplification, or plain language, and the use of visual aids and pictographs” (Kerta 2), Kerta points to a number of complicating factors, including research that indicates “...simplification can impede learning even for highly literate people if no context for unfamiliar concepts is provided; brevity can lead to the use of narrow, ethnocentric examples and oversimplification of critical information” (McConnell-Imbriotis qtd. in Kerta 3). Kerta’s brief review of literature suggests that “[p]lain language is useful but not the primary solution: written communication should supplement physician-patient conversation (Shohet qtd. in Kerta 3.) Physician-patient conversation permits us to meet one another where we are (rather than where we assume the other is) and work together in more effective partnerships. Conversation allows us to learn from one another⁸.

⁸ “Through the questions and answers and the dialogue with the group members that ensue, medical professionals leave our meetings with a deeper understanding of the “total patient.” (Kaps “The Role of the Support Group” 2193).

The Flesch-Kinkaid test has similar shortcomings. Of interest here is a response to a professional article on assessing how well patients understand informed consent forms, written by Dr. Jessica Ancker, a biostatistician at Columbia University. Ancker explains that, while many studies still use the Flesch-Kinkaid scale and similar, these do not assess relevant factors, like whether information has been presented "in the context of familiar information," which provides an aid to comprehension, or to what extent visual cues did or could have helped communicate complex information, or even the motivations of the "testee." All of these, Dr. Ancker says, clearly affect comprehension and should be taken into account when measuring readability and/or health literacy.

Naturally, then, other tests have been devised. One that addresses a concern I have over the SMOG test is the REALM (Rapid Estimate of Adult Literacy in Medicine) test; this, at least, has the strength of making use of medical terms. The REALM test is a laminated list of:

66 medical terms, arranged in order of complexity by the number of syllables and pronunciation difficulty.... Patients read down the list, pronouncing aloud as many words as they can while the examiner scores the number of words pronounced correctly using standard dictionary pronunciation.... The score assigns health literacy skills into 4 categories of grade-equivalent reading level: 0–18 (\leq 3rd grade), 19–44 (4th to 6th grade), 45–60 (7th to 8th grade) and 61–66 (\geq 9th grade) ("Health Literacy Assessment Tool" scr. 1 para. 4).

While this is a handy test--one that can be performed very quickly by minimally trained personnel ("Health Literacy Assessment Tool") to arrive at a quick, basic measure, I question how much weight is given here to pronunciation, and how little to understanding. Remember: health literacy is more than just being able to

read the words and a mispronunciation does not necessarily mean a lack of understanding the concept.

Another option is the Test of Functional Health Literacy in Adults (TOFHLA). This test, which measures reading comprehension and numerical ability using a series of questions based on actual hospital materials (Parker et al), seems more useful than REALM if only because (presumably) patients are asked to work with words in context rather than just words. This test is said to “provides a more thorough picture of the patient's ability to comprehend health material” but has the shortcomings of being (at 22 minutes) “...more time consuming and less practical” (Safer and Keenan). Another option, from Pfizer, is “The Newest Vital Sign” (a reference to health literacy itself). This test, they say, is validated against the TOFHLA, and is touted as a replacement for it. At three minutes, this test is far less far less time consuming than some other options; however, the premise is questionable, particularly when offered up as a replacement for the TOFHLA. “The Newest Vital Sign,” available in English and Spanish, involves a health care provider giving a patient “a nutrition label from an ice cream container” and asking a series of six questions regarding how patients “would interpret and act on the information contained on the label” (Pfizer). While this may achieve diagnoses as useful as the TOFHLA, this serves only to damage my opinion of the TOFHLA, for it seems obvious that The Newest Vital Sign is unlikely to tell us much about how patients (particularly ESL and EFL patients) may make sense of medical materials--words/textual forms far more

alien than ice cream containers. This test might tell us something about basic literacy--but little to nothing about health literacy, which, as we have seen, involves more than just the ability to read.

One of the most recent (and surprisingly, compelling) options was developed by Educational Testing Service (ETS) researchers, who identified 191 health literacy tasks, such as calculating medicine dosage and "interpret[ing] information from a news article on bicycle safety" (Educational Testing Service 5) and, based on these, developed the Health Activities Literacy Scale (HALS), a 0-500, 5-level scale. Although the HALS scale, being focused on actual and varied health literacy tasks is an improvement over other measures surveyed, I am suspicious of standardized tests that attempt to measure skill-sets which vary so much from one context--one individual with a specific needs--to another, even when they seem, as does this measure, to have actually attempted to account for this. ETS made, for example, a point of noting "adults do not read in a vacuum" and lists multiple contexts/contents to consider: home and family; health and safety; community and citizenship; consumer economics; work; and leisure and recreation (13). They are more focused on what people *do* with information than any other study I have yet encountered. To this end, this study tracks several process/strategies: locating, cycling, integrating and generating information, and formulating/calculating (Educational Testing Service 14). Despite this, at the end of it all these are equated to numbers, there being no space or time in standardized tests to capture the how. We need, alongside such

studies, more narrative- and language-in-use oriented studies--studies that add user explications to our tables and charts, studies that ask users what problems are encountered, and what solutions they have found.

I find further support for this kind of health literacy study in Ancker's suggestion that researchers wishing to "...assess and improve informed consent forms, ... should consider using communication research techniques" such as think-aloud protocol analysis, asking participants to paraphrase documents, and usability testing, working over time with small, successive groups of patients to design more effective forms (Ancker 74). Such methods may prove a useful corollary to assessment measures discussed above, for even the best of these tests still do not provide a way to explore how patients learn--nor do they consider that the "patient" dealing with these materials may, in some sense, be plural. Key to my thinking here is Antonucci et al's study, which revealed that "[k]ey social relationships enabled the health of lower-educated men to parallel that of men with higher education...suggesting that social networks and practices could moderate the effects of low literacy on health" (qtd. in Kerta 3). The patient may not, in a sense, be singular. We have already seen this to be true in my own case.

Despite my fears over standardized tests usefulness in measuring contextual skills, the results of ETS' study are worth considering at some length here, for they uphold other studies that suggest that health literacy has strong correlations to educational level and race/ethnicity (Educational Testing Service

3, 20). ETS finds health literacy to be “strongly related to educational attainment” (Educational Testing Service 5). Study results further suggest that the proficiency of White adults is “significantly higher than the average proficiency of Black, Hispanic, and other adults living in the United States,” and that these differences “reflect the influence of many variables such as education, resources, and/or immigrant status” (Educational Testing Service 3). Wealth status, health status, reading practices, and civic engagement are also said to affect individual health literacy, with those at the “higher” ends of each scale exhibiting higher health literacy (Educational Testing Service 4).

The most interesting and useful aspect of ETS’ study is, perhaps, the civic engagement category, which explores the implications/effects of voting, library use, and reliance on television as a source of information (vs. reliance on a broader range of sources). ETS reports, as well, that the health literacy of older adults is significantly lower than that of younger adults (Educational Testing Service 4). Presumably, the difference lies in technology use. By contrast, however, Ivanitskaya, O’Boyle, and Casey’s study on how well college-aged health information consumers can locate and evaluate health information found that younger adults may well have “better” skills, they are far from completely “health literate”: many students who self-reported possession of good or excellent research skills were found to be “...unable to conduct advanced information searches, judge the trustworthiness of health-related websites and

articles, and differentiate between various information sources” (Ivanitskaya et al, scr. 1, para. 5).

There are many other studies on the use of the Internet for health information. A 2003 Pew Internet & American Life report reveals that women are more likely than men, and older users more likely than younger, to seek out health information online (Madden 2, 3). Some studies show that many of these persons are “generally revealed to be in good health” (Ferguson qtd. in Kivits 513); this suggests that individuals may be seeking preventative health information *or* may be online in their capacity as caregiver. Approximately 93 million Americans looked for health/medical information online during 2003; this represented an increase of 59% from the previous year (Madden 5). It follows, then, that another test--eHEALS, the eHealth Literacy Scale--has been devised solely to measure “consumers’ combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems” (Norman & Skinner scr. 1 para. 1). Because younger users presumably possess more computer literacy this test has (thus far) only been used with that population; this seems unfortunate, for younger users--while more health literate, according to ETS--are less likely, according to Pew reports, to use the Internet for health and/or medical information.

Literacy Studies and Health Literacy Studies: A Critique

While health literacy is something separate and yet intricately entwined with “general alphabetic literacy” (the ability to read and write) and worth

studying in its own contexts, there are obvious connections between the two that must be addressed if we are either to understand fully the idea of health literacy as something built on, yet distinct from, general literacy, or if we are to realize the benefits that health literacy studies might bring. Studies of health literacy, as I understand them, are currently disconnected from the larger literature on literacy.

Though definitions of “literacy” are common, they are not very helpful to a study of health literacy. Despite this, they are relevant to how health literacy is typically understood and assessed. Although literacy is most often defined in simple, common-sensical terms such as “the ability to read and write” (“Literacy”), it is a problematic term, because these definitions do not help us understand the practices of literacy well. There are many instances in which individuals who meet this basic definition nonetheless struggle to be effective in their lives.

Werquin was not overstating the case when he wrote, “[l]iteracy underpins the ability to learn and adapt in this new technological era” (34).

Perhaps it naturally follows, then, that:

[l]iteracy is a slippery notion. Once traditionally limited to communication processes taught in school, literacy has moved beyond the confines of text and into the functional and workplace worlds of information processing, economics, and politics. ... The opportunity to become 'literate' in its many senses can mean the difference between a fully functioning life and one on the margin (Gallego and Hollingsworth 206).

The “slipperiness” of conceptualizing literacy seems to have caused increasing modification of this word to make it more specific, as seen in terms like

computer literacy," "media literacy," and "health literacy." These terms are intended to designate "a person's knowledge of a particular subject or field" ("Literacy"); however, many of these "other" layers of literacy are becoming integral to the ability to fully function in our society. Health literacy is therefore a matter of some importance to individuals, our communities, and our nation(s).

By literacy, we clearly mean more than "the ability to read and write." For example, a "literate graduate" is framed in the Reagan-era document *A Nation at Risk* as one who can

- a) comprehend, interpret, evaluate and use what they read;
- b) write well-organized, effective papers;
- c) listen effectively and discuss ideas intelligently; and
- d) know our literacy heritage and how it enhances imagination and ethical understanding, and how it relates to custom, ideas, and values of today's life and culture (qtd. in Davenport and Jones 53).

The authors of this study seem to be integrating aspects of critical, rhetorical, and cultural literacies but without (apparently) acknowledging that they are doing so.

Another example: A 2004 news report revealed that "40...to 44 million Americans, age 16 and older, have minimal ability to read prose, interpret information on charts and graphs, and manage everyday arithmetic" (Byron 6). This provides another, expanded notion of literacy. Some of these persons, are literate in that they can "read and write"--but clearly that is not all there is to being fully literate. This definition suggests one must be able to glean information--to "read" it--in other forms as well.

This conflation of other aspects of literacy with “reading and writing” is common enough: when we administer standardized tests to measure students’ reading ability (and writing ability, for that matter), we assume a certain measure of information literacy (in that they’ll be able to locate needed information, and assess that information), critical literacy (in that they’ll be able to analyze what they read), and cultural literacy (in that we expect them to possess a certain set of cultural knowledge), at the very least. The definitions and assessment of health literacy treated earlier in this chapter reveal similar complications in health literacy studies. Further, these tests and measures cannot yet account for the complicated nature of health literacy practices, nor account for the acquisition of these skills.

For example, the solution to low health literacy has historically seemed to consist primarily of a push to have medical information “translated” into “plain language” more accessible to laypersons and those with low literacy skills (“CIGNA Foundation...”; *Clear Language Group*) this tactic does not fully recognize the complex nature of “health literacy.” It is therefore unsurprising to find multiple non-profit organizations working on this issue, alone and collectively. One of the most striking (if only because of its sponsors) is the Partnership for Clear Health Communication. This coalition is comprised of “...national organizations... [such as Pfizer Pharmaceuticals and the American Medical Association] working together to promote awareness and solutions around the issue of low health literacy and its effect on health outcomes”

("Partnership..." scr. 1) The organization states that "limited literacy skills are a stronger predictor of an individual's health status than age, income, employment status, education level, and racial or ethnic group" ("Partnership" scr. 1). They also reveal that, "[a]lthough ethnic minority groups are disproportionately affected by low literacy, the majority of those with low literacy skills in the United States are white, native-born Americans" (scr. 1).

Disciplines, Discourses, Doctors and "Informed Patients"

"Doctors may be partly magicians, relying on their craft and status, and partly technicians, relying on their skills and science to help patients" (Hogg 45).

"It is easiest to communicate with people most like ourselves. As many doctors are still white, middle class and male, women, poorer people, black and disabled people may have particular difficulties in communicating their problems to them. Problems in communication may cause distress to patients and their families but also lead to inappropriate treatment" (Hogg 24).

It is important, at this place and time, to consider from the perspective of the patient, how/when/where individuals use reading, writing, and research to cope with illness(es). The patient, after all, is the user at the center of the network of doctors, disciplines, and discourses. This is a confusing and foreign position to occupy. While disciplines "hierarchize individuals in relation to one another" (Foucault *Discipline and Punish* 223), disciplinary discourses may also amount to exigencies that may motivate patients to become more "informed"--more literate and active--in medical situations. In the absence of satisfactory physician-patient interactions, those in need of health care are increasingly seeking solutions from nontraditional sources. This change in practice is fueled in many instances by patients' (i.e., consumers') desire to have better access, rapid response, and more control over their lives coupled with suppliers' desire to

generate profits” (Lanier 979). These exigencies, however, may amount to roadblocks if patients do not possess enough advanced literacy skills (or enough appropriate supports) to develop health literacy and become informed.

At one time, we did not speak of ‘health literacy,’ or “informed patients.” It wasn’t necessary. People who could afford doctors and medicines had them; people who could not, mostly did not, and literacy didn’t enter into it⁹. Paternalism, given the amount of information early physicians had versus the amount available to the average patient, was probably a natural occurrence: a physician’s “...level of knowledge gave them a very powerful role in the doctor-patient relationship” (Parsons and Parsons 6-7). Paternalism is unlikely to meet the needs of modern, consumer-oriented patients, many of whom must take greater responsibility for their own health and information needs due to the limitations placed upon us, and our physicians, which are many.

Physicians have less time to spend with patients (Furst 226), who are more mobile than we used to be, and less likely to know the doctors we grew up with. For that matter, dependent on our insurance, we may not know our doctors all that well. (Take, for example, the case of TAs at this university, who must use whatever physician, is available, where there are relatively high turnover and reassignment rates. We therefore struggle to establish continuity of

⁹ ...or at least on the surface. Literacy is implicated in who had access to medical care and/or the funds for it.... But patients did not have to be “health literate” in the ways I’m focusing on in this study in order to function within the health/medical system. Issues of access glossed over in this statement will, however, be returned to in later work.

care, and a true working partnership with a “family” physician.) And (most of all-
-and here we return again to “time”):

medicine has been ‘monetarized.’ It has come to speak ‘much more the language of business, with cost/benefit analyses, time management, and financial profiles being an important part of any practice.’ ...there is a ‘trade-off between efficiency and deeper personal relationship, between productivity and medicine as art’” (Hilfiker qtd. in Furst 227).

The pressures of time are further complicated by our easy access to information, which, coupled with a lack of health literacy, may lead to “simplified knowledge of diseases” and a failure to “understand the necessity of working with probabilities and uncertainties.” Our doctor, in turn (though he may not disapprove of informed patients in principle) may take the easy way out by “issuing reassurance that the doctor know best” rather than “really...engag[ing] with patients” (Hilfiker qtd. in Furst 226). And yet...though that paternalism seems in the interests of time, we may still find paternalism at work in other ways. There are the obvious cases--the “old fashioned” doctor-who-knows-best, the “old fashioned” patient who doesn’t want to know--and then, occasionally, there’s the disapproving doctor:

John [,a fellow resident,] began telling a story of a teenager who came in with an overdose of drugs. ‘You can give Ipecac to adults who have overdosed to make them throw up a lot, if you want, but it’s just to punish them,’ he explained, angry at the patients who seemingly contributed to their own illness. He knew there were better ways to treat overdoses. It was confusing to me to identify more strongly with the patients in the stories than the doctors, who were my peers (Heymann 101).

In the face of all this, because physicians have so much more knowledge than patients, who come to them (almost by definition) in a weakened state¹⁰, our relationship must be categorized by trust. Even the Hippocratic Oath, a reminder of ethical practice, in fact, can be taken as a ritual that "...binds[s] physicians to a series of limitations on their power" (Furst 217). Perhaps, for this reason, there has been much made over the years of the legal and ethical implications/responsibilities of the doctor-patient relationship. The doctor-patient relationship has been categorized as contractual, a step that forms the basis for physician liability/malpractice (Picard). We have spent untold amounts of time discussing informed consent,¹¹ the very doctrine that should guard against physicians punishing patients, as John did.

Reminders of the Hippocratic Oath, taken as physicians enter practice, may not be enough to overcome the fact that medicine, at its heart, is a ...bureaucracy and a[n] applied science, both of which distance and depersonalize the patient" (MacIntyre qtd. in Furst 225). The discourses we

¹⁰ Merriam-Webster Online defines patient as a noun thusly: "1 a: an individual awaiting or under medical care and treatment; b : the recipient of any of various personal services; 2: one that is acted upon."

¹¹ "Caroline Faulder (1985) has outlined five principles that underlie informed consent:

- Autonomy--the individual's freedom to decide his or her own goals and to act according to those goals. This demands a respect for individuals even if the clinician disagrees with their view or actions.
- Veracity--trust in doctors by patients must be based on truth and honesty.
- Justice--both parties have a duty to treat each other justly, whether the doctor-patient relationship is seen as a contract, covenant or a partnership.
- No harm--the doctor has a duty to do no harm.
- Best interests--the doctor has a duty to act in the best interests of the patient" (qtd. in Hogg 11).

practice on a daily basis shape us and the ways we interact with others, both insiders and outsiders. Physicians speak an insider's language full of specialized knowledge, jargon and sometimes dark humor. Heymann, a physician who entered a period of dire and extended illness just as she graduated medical school, and went on to pen a text that provides the rare experience of watching an insider--a doctor--suddenly become an outsider/patient, explains that:

[p]hysicians use jokes and coarse language to distance themselves from patients, to ease the difficulty of dealing with death, which does not look as clean or pretty in real life as it does on television, and to keep from feeling the pain of witnessing the destruction of the young and the devastation of the old. To make that task easier, the language is purposely dehumanizing. The doctor-patient relationship is an accidental casualty (Heymann 100).

Examples of this kind of jargon include euphemisms (like the "you'll feel a little sting" we're all familiar with) (Heymann) but also what Parsons and Parsons term "buzz talk," some of which--like "shoobuzzard", a terminal patient--might have dire effects on communication with the patient who happened to overhear it. Despite this, this seems for medical professionals a way of releasing stress (Parsons and Parsons 83; 77-8) and one kept carefully for insiders only.

Informed patients have, however, to learn two other aspects of medical discourse: medical terminology, and abbreviations (Parsons and Parsons 77-8). Heymann's experiences upon returning to practice, reveal "... repeated reminders of how medical education and the finances and organization of medical care in the United States affect our doctor-patient relationships and leave patients' voices unheard" (105). Patients must learn some of the language of doctors--at

least the language they're applying to us--with nearly the same facility, and without the extensive support geared specifically towards helping us do that.

Clearly, this is a difficult task. Medical discourse is both conteXt and conteNt--a set of knowledge, and a set epistemology, a communicative practice that holds together a workplace (Sarangi and Roberts qtd. in Schryer and Soepel 251)--that must be learned by patients who hope to be more literate, and more informed. It's a difficult discourse to learn; Popham, in fact, argues that "medical forms represent a commingling of the business, science, and medical professions" (Popham 279). Further, medical discourse isn't exactly welcoming to the patient: scientific work, in terms of both study design and stylistic/surface features of texts, is all about removing the variable, the individual. As students and interns become physicians, the discourse community around them shapes their professional identity, giving them habits of language/habits of the mind (Schryer and Spoel; Heymann): "genres, such as case presentation and policy documents, function as mediating tools...that shape [medical students] sense of themselves as medical practitioners" (Schryer and Spoel 250; see also Freedman and Adam).

All of this, and more, shapes the doctor, and the patient--an individual with an illness, trying to find their way around in a new language. Some patients are content to leave things up to the doctors, and seek out no information on their own, make no decisions on their own-- but our society is making that seem less and less acceptable to us: "...access [to] health information on the Internet

may provide patients with an opportunity to display a particularly modern marker of competence and social fitness" leading to "the emergence of a felt imperative to be (or present oneself as) an expert and critical patient, able to question advice and locate effective treatments for oneself" (Ziebland 1783). Using the Internet to locate health information has become a societal norm.

Further, because "[i]ndividuals with limited health literacy incur medical expenses that are up to four times greater than patients with adequate literacy skills, costing the health care system billions of dollars every year in unnecessary doctor visits and hospital stays" (AMA "Health Literacy" scr. 1 para. 2), our physicians (who may, for various reasons, not wish to serve as "health literacy" sponsors) may feel forced (in an attempt to maximize effective treatment and minimize costs) to serve as (at least) assessors of literacy. This may not work as effectively as we would hope: "... most patients hide their confusion from their doctors because they are too ashamed¹² and intimidated to ask for help" (AMA "Health Literacy" scr. 1 para. 2). And doctors, after all, should not be expected to be literacy scholars any more than we should be diagnosticians.

And yet, patients seem to be working in complex, diverse ways, literally inventing the skills and knowledges required to function as informed patients.

¹² It's interesting to note, given this awareness of "shame", that the AMA links from this page to one selling health literacy tool kits:

Learning objectives for this education program are:

- to understand the full scope of health literacy
- to recognize health system barriers faced by patients with low health literacy
- to improve verbal and written communications to patients
- to create a "**shame-free**" environment for patients" (AMA "Health Literacy").

They are conversing with insiders--medical professionals, who, through extensive training, have learned information, epistemologies, and skills that position them as the most expert users of the system. Considering medical discourse and the affiliated communicative practices of insiders therefore helps us see the nature of the (foreign) context/s in which patients must become, and act as, informed patients.

In his exploration of "medical discourse," Foucault initially explains it as the "rules" for "writing (in/through/about) medicine" including the ways that "texts" adhere to or break with these (*The Archaeology of Knowledge* 33).

Eventually, Foucault realizes that:

...the doctor has gradually ceased to be himself the locus of the registering and interpretation of information, and because, beside him, outside him, there have appeared masses of documentation, instruments of correlation, and techniques of analysis, which, of course, he makes use of, but which modify his position as an observing subject in relation to the patient" (*The Archaeology of Knowledge* 33-4).

Foucault could be describing "the informed patient," the source of a supposed

"loss of authority" on the part of the medical establishment, and the very

phenomena I find such a revealing position on literacy/acquisition. This is the

point of departure for my study of health literacy, a contextually embedded set

of skills that enable successful health and medical communication. In the next

chapter, I explore ideas from Foucault and other theorists that shaped this study,

and walk you through my methodology and methods.

Chapter 3

METHODOLOGY & METHODS

Research Question

In an attempt to fill in the gap in Medicine, Composition, and Rhetoric's disciplinary knowledge on literacy in health and medical situations, my study focused on the actual research, reading, and writing practices of patients and caregivers facing serious or chronic illnesses, providing an insider's view of what patients research, read, and write, with an eye to understanding how patients become health literate, "informed" patients. I believe descriptions of practices will help us navigate the maze of sometime conflicting definitions of health literacy benefiting not only patients, but also future researchers. My research, then, focuses on access and invention: why, where and how do patients learn to be informed, health literate patients?

There are consequences in how literacy is defined and theorized, just as there are consequences for lacking certain literacies. When individuals lack literacy, they lack access. They lack agency. And literacy, therefore, is tied up in power. The same is true of health literacy, and it causes similar difficulties in both practice, and in research. My approach to research is therefore framed by theories helping me account for power, knowledge, and literate practices. In this chapter, I consider relevant theory on power and knowledge, events and practices, before going on to lay out how these theories informed my specific data collection and analysis procedures.

Rhetorical Studies of Medicine

The research done by one interested discipline is not always useful to another. My experiences as a patient and volunteer, as well as a student of Rhetoric, convince me that an interdisciplinary study of use to both Medicine and Composition/Rhetoric must make visible the actual practices--the creations, and inventions, and arrangements, and deliveries--of patients. In beginning a study, however, one must ensure the methodology, resultant data, and methods of analysis will be in forms that can be similarly useful and convincing to all those audiences one hopes to reach.

In "Design in Observational Research on the Discourse of Medicine: Toward Disciplined Interdisciplinarity," Ellen Barton argues that language-based fields (i.e. linguistics, rhetoric and composition, professional communication) are useful in examining the discourse of medicine; however, most such studies "primarily address and answer questions within their home fields" and "develop their analyses primarily for audiences" within the same field (311). This makes sense, of course, because linguists need to address disciplinary questions in order to be taken seriously as linguists. Barton is interested in how language-based researchers can have an impact in medicine. She suggests that observational studies on such topics should be intentionally designed as interdisciplinary, "defined as research that makes an acknowledged contribution to both medicine and language studies" (Barton "Design..." 309). Barton points out that, even when our questions may contribute to both our field(s) and

medicine, our research design(s) often do not meet the needs of other audiences.).

Schryer and Spoel agree, explaining that fruitful interdisciplinary research should be about conversations--listening and talking, learning and communicating--and "as much about constructing common ground as about persuading an audience to accept a conclusion" (273). Segal, who is also interested in encouraging humanities scholars to engage in research useful to those outside our disciplines, explains that whether or not research is truly "useful" when health and the humanities cross should be determined by whether or not it is "instrumental"--applicable (4). Beginning with the idea that "[p]ersuasion is a central element in many medical situations" (1), Segal also builds a careful case for why rhetoric is an appropriate tool for applied, interdisciplinary health research studies. Rhetoric seems to be the common ground through which health and the humanities can collaborate fruitfully. Medicine itself is inherently rhetorical.

Schleifer and Vannatta's "The Logic of Diagnosis" teaches us that a major component of the diagnostic process --the history of present illness--is a narrative, one which physicians learn to "read" abductively to discover the connection between "case" (symptom) and "rule" (cause) (365). The authors argue that "the systematic apprehension of the ways that stories create explanations is [therefore] of the utmost importance to the practice of medicine" (Schleifer and Vannatta, 381). Segal further argues that "[m]edicine is not only

rhetorical as it is reproduced in published texts; it is also rhetorical as a system of norms and values operating discursively in doctor-patient interviews, in conversations in hospital corridors, in public debate on health policy, and in the apparatus of disease classification (3).

Rhetorical criticism, which "...has considerable explanatory power in a world in which we act upon each other by influence," and works by "...identify[ing] the persuasive element in the discourse of health and medicine and ask[ing], 'Who is persuading whom of what/' and 'What are the means of persuasion?'" can therefore provide "... a greater understanding of human action" (Segal "The What, Why, and How..." 1-2), or of human practices.

Describing and exploring the actions individuals take to achieve access (to...information, care, treatments, "health"...) provides access narratives that others can learn from, far more useful amid the current context (in which health care and access have been featured platforms points for all leading presidential candidates) than are definitions. With such an understanding, teachers, writers of health/medical documents, and medical professionals could adjust their practices to account for and accommodate the actual practices of patients. A rhetorical approach to a study of patients' medical practices therefore seems appropriate and useful to multiple disciplines: Composition, Rhetoric, Medicine, Social Work, Public Health, and others.

Power & Knowledge

The roadblocks to clear communication between doctor and patient are many.

One obvious potential blockage, the one most focused on, is disciplinary knowledge. Another potential--and more difficult to navigate--roadblock to real partnership between doctor and patient has to do with power. As Brandt explains, "[a] dominant social group will elevate its brand of literacy to the status of Literacy, marking other versions as deviant or 'restricted' (Brandt 26). This is precisely how many medical professionals view the knowledge work of patients: as a potentially deviant practice. This observation is therefore indicative of the many ways both power and knowledge are crucial and intricately intertwined factors to consider in a study of this nature.

Robert Johnson helps me to understand the dismissive ways medical discourse so often seems to regard the work of "informed patients," explaining that while individuals:

...often act and do as specialists...we are not allowed to claim such knowledge because (in most cases) we were not taught such knowledge in a formal educational environment. ... We learn of know-how and use through practice, so that the practices define the theory of our actions: the actions of know-how and use" (Johnson 6).

Both Medicine and Composition and Rhetoric need a study of health literacy that uncovers how we "learn through doing" (Johnson 134) *and* what we do with it, documenting the "fundamental characteristics of users' situations in order to describe those cunning solutions that users have developed for dealing with" (Johnson 132) the needs of reading/writing as action on/in those specific contexts. Only this can lead to a full understanding of the exigencies that

motivate patients, how we inform ourselves, and the roles supporting players *and* systems play in our learning.

Knowledge, however, is just part of the conversation; power is another crucial aspect to be considered. The body itself, for Foucault, is the site of a power struggle. The “mastery and awareness of one’s own body” is challenged by the teachings of society: “there inevitably emerge the responding claims and affirmations, those of one’s own body against power, of health against the economic system, of pleasure against the moral norms of sexuality, marriage, decency” (Foucault *Power/Knowledge* 56). That body is also a patient, at the center of the increasingly complex systems of health and medicine, further complicated for many by insurance. When patients “take charge” of information, decisions, or tasks previously perceived as “professional”, the claim to knowledge becomes a claim to power. At such moments, patients may be disciplined, or power may be shared.

Foucault explains that medical discourse winds up being defined by the exceptions, and dispersion characterizes the boundaries of it (*The Archaeology of Knowledge* 37-8). Foucault means, in part, that we often positively identify what something is by pointing out what it isn’t: exceptions prove the rule. “Discourse” is, after all, “the dispersion of the points of choice, and...a field of strategic possibilities” (Foucault *The Archaeology of Knowledge* 37). At this point, Foucault’s concept of subjugated knowledges, those “present but disguised”, becomes quite useful (*Power/Knowledge* 83). These subjugated knowledges are

what guide the choices patients make in navigating the discourses of health and medicine. Foucault further posits the “re-appearance of...these disqualified knowledges” as a form of criticism.

Foucault, then, counsels me to:

- consider who is speaking (*The Archaeology of Knowledge* 50).
- “...describe the institutional sites... from which the (x) makes his discourse and from which this discourse derives its legitimate source and point of application” (*The Archaeology of Knowledge* 51).
- locate the positions of the subject (both perceptual: questioning, listening, seeing, observing and institutional/technical/spaces in the information network(s) (*The Archaeology of Knowledge* 52-3).

A description and interrogation that begins with a map of how patients and caregivers--non-professionals, “laypersons”--learn to decode and use the disciplinary discourses of medicine, and includes descriptions and interrogations of actual practices within these contexts is important, for the contexts that patients operate in affects how, and why, they develop and use health literacy skills.

The mapping discussed above may form what Foucault calls a “genealogy ...the union of erudite knowledge and local memories which allows us to establish a historical knowledge of struggles and to make use of this knowledge tactically today” (*Power/Knowledge* 83). This is a rich source of tactics, or know-how, of use in understanding health literacy and developing more effective mechanisms for teaching and supporting these skills. Based on Foucault and Johnson, I track access, power, and knowledge in the data, paying particular attention to several sub-codes within each, as described below.

Events & Practices

In my research, I began by asking patients to help me isolate "literacy events", or "social action going on around a piece of writing in which the writing matters to the way people interact" (Brandt and Clinton 342). Health literacy is not always text-bound; consider, for example, that we receive most of our information from our doctors orally, and that many of us discuss the information we are given (orally or in print) with others for various purposes. What I was looking for then were moments in which locating, understanding, and using health and medical information were crucial. These moments are health literacy events, and so health literacy events formed the boundaries of my analysis.

The literacy event is a significant analytical concept in the literacy literature, and its sister term is "practices," which has been used variously but commonly to designate actions or activity. In order to understand the activity of a literacy event, I also tracked practices within events. Brian Street, for example, defines new literacy studies as providing "...detailed, in-depth accounts of actual practice" and "...bold theoretical models that recognize the central role of power relations in literacy practices" (Street "The New Literacy Studies" 430). New Literacy Studies:

...[focus] not so much on acquisition of skills, as in dominant approaches, but rather on what it means to think of literacy as a social practice (Street, 1985). This entails the recognition of multiple literacies, varying according to time and space, but also contested in relations of power. NLS, then, takes nothing for granted with respect to literacy and the social practices with which it becomes associated, problematizing what counts as literacy at any time and place and asking "whose literacies" are dominant and

whose are marginalized or resistant (Street "What's New in New Literacy Studies..." 77).

This line of questioning--who benefits?--seems particularly relevant in my study, where medical discourse is still fairly consistent in defining patient literacy from a caretaker, rather than partner, perspective; that model of literacy does not serve the interests of the patient. Further, Street directs me to account for the literacy practices of individuals in relation to health, *whether or not* medicine itself regards these as health literate practices. "Practices" can be captured alongside more narrative data, by asking patients to share

- Samples of "required writing"
 - "institutional"--insurance, hospital, etc.
- Samples of "voluntary writing"
 - Emails, listserv postings, blogs, websites, journaling, etc.
- Observation of research/reading/writing practices

An accounting of practices can help us understand how individuals reappropriate the technology that is literacy, and use it as a tool to "break into" and reshape foreign discourse communities. Health literacy is an amalgam set of skills, and it goes beyond the "reading and writing" implied by "literacy": being fully health literate, in all situations, is nearly impossible. Even physicians specialize, and, despite years of education and training, the life of a physician seems one of continual research and learning. From this vantage point, a patient's "health literacy" is clearly a complex set of skills--knowing when and how to locate complex, specialized information, and how to use that information to solve problems and set/achieve goals. These tasks imply even more skills at work in the background, seemingly developed by patients without the benefit of

specialized training. Therefore, in the analysis of my data, I paid particular attention to the complex practices that participants used to become literate.

Research Design

My methodology is informed by the theoretical work that I have just summarized, which showed me a need to be attentive to power relationships (particularly with regard to moments of disciplining and dispersion), but also to events, practices, and contexts. The study design therefore starts and ends with the patients, and is guided, throughout, by the patients' experiences, and their understanding of those experiences. Because this is a descriptive study, in which the phenomenon we need to observe are accessible only through certain methods, I was largely reliant on observations and interviews, as detailed below.

Because of the nature of cancer and the often debilitating treatments involved, patients may not always be the ones doing the health literacy work necessary to understand and manage care. Often, caregivers assume part of this burden. Therefore, the concept of the individual patient as the unit that becomes health literate is something that is not descriptively accurate. The study is a case study of two patients--one a couple called Denise and Michael, the other of an individual called Celia--and focuses on their reading, and writing for personal reasons, advocacy work, or both in the course of dealing with diagnosis, treatment, and maintenance.

Study Population

The study took place at a cancer center in a mid-sized Great Lakes city, Big Waters Cancer Center, at which I distributed calls for participants through physicians, research nurses, the clinic's social worker, and also directly to patients with whom I had developed relationships through my volunteer work and participation in a lymphoma and myeloma support group. My criteria for selecting participants were patients and caregivers dealing with a diagnosis of cancer (which might be in remission or maintenance) who researched, read, and wrote in the course of managing the diagnosis and treatment.

Two patients and one caregiver who use reading and writing for reasons related to the diagnosis chose to participate. I also interviewed a support group to which one patient and caregiver belonged, as well as the social worker who facilitates that group, and found both useful sources of additional information. Because of the nature of the inquiry and data that results from a descriptive case study, these two cases provide adequate data to explore my research question--the goal of case studies is to provide enough information to explore the event and provide data for the researcher's audience to use in formulating their own opinions and use as guides for planning future studies.

Instrumentation and Data Collection Procedures

I relied heavily on emergent and text-based interviews. By "emergent interviews", I mean conversations that began with sets of pre-planned questions from which I could choose (Appendix B). Not all questions were asked of all participants, nor were all questions asked pre-scripted: this left me open to

follow participants' stories, and practices, as they unfolded naturally. The data collection process is illustrated in table 1, below.

Table 1
Three Levels of Methods

| Research Question: Why, where and how do people learn to be informed, health literate patients? | | | |
|--|------------------------------------|---------------------------------------|---|
| Methods | Why | Where | How |
| | an initial survey and an interview | | |
| | | Literacy Diary Follow-up interview | |
| | | | Analysis of specific texts read/written by patients |

Interviews were structured in three levels. Participants began by completing a survey (Appendix A) This survey aimed to gather background information that helped me better understand the context in which each individual participant operates; however, it was also intended to get participants thinking about how and when they've used research, reading, and writing. This was followed up by an initial hour-long interview, in which we discussed participants' survey responses. Questions asked during this interview were focused on eliciting greater levels of detail than are possible in a survey. Participant responses to the survey and subsequent interview were used as a guide for selecting experiences, practices, and texts--essentially "critical incidents" for interpretation.

As participants left the first meeting, they were asked to maintain for a period of one week a diary charting all reading, writing, and/or research activity

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(Appendix C). Participants were asked to note the date, start/end time, activity, purpose, and text title or other identifying information (i.e. web site address) they cared to note. This was the basis for second interview, in which patients were asked questions (Appendix D) geared towards eliciting more details and gaining a better understanding of the motivations for and requirements of the work noted in the diary.

In the next level of inquiry, participants brought in artifacts from “critical incidents” identified through the first two interviews. These included texts consumed and texts created, both required and voluntary. Together we read and discussed these samples, exploring the exigencies surrounding and lessons embodied in/by them.

Data Analysis Procedures

The data that my study yielded was largely oral, but then preserved in textual forms: interviews were transcribed. I also utilized patient artifacts, more text-bound documents consumed or created by them. My analysis, therefore, involved close textual analysis of writing. The transcripts of these observations and conversations were analyzed using techniques of both rhetorical and discourse analyses, in order to see what individuals’ choices as researchers/writers revealed about “institutional discourse” as well as skills transference and collaborative learning.

Ellen Barton, who along with Segal and others helped me see the relevance of rhetoric in exploring medical communication, also provides some

support for discourse analysis as an applicable interdisciplinary tool. In "Discourse Methods and Critical Practice in Professional Communication..." Ellen Barton uses genre theory, genre analysis and discourse analysis to examine the forms medical discourse about prognosis take "front stage" (in conversations between doctor and patient) and "back stage" (in conversations between physicians, or physician and researcher, without the patients' knowledge). She argues that this combination of methodological tools "...can be used to uncover the multiple connections between discourse practices and their underlying concepts and categories within professions" (Barton "Discourse Methods..." 69). Such a positioning seems a natural fit for the questions I am pursuing, and the types of data gathered to explicate the knowledge work of being an "informed" or "health literate" patient/caregiver.

Based on the theories offered me by Foucault, Johnson, Street, Barton and Brandt, I chose codes that assist me in tracking issues of knowledge, power, access, and agency, and tracking practices (see table 2, following page).

Table 2
Codes

| <i>KNOWLEDGE</i> | |
|------------------|---|
| KW-PRA | Knowledge of Practice, User as Practitioner: "User as a tool user": User demonstrates knowledge of a technique, technology or system. |
| KW-PRO | Knowledge, User as Producer: The user has produced or is producing knowledge about a technique, technology, or system. |
| KW-CIT | Knowledge, User as Citizen: The user produces knowledge about a technique, technology or system alone or in cooperation with others. The user is producing a community or encouraging participation. |
| <i>POWER</i> | |
| PW-DS | Power-Discipline: Any act in which knowledge is used to maintain the status quo |
| PW-DP | Power-Dispersion: Any act in which knowledge is used to move another to think or act differently |
| <i>ACCESS</i> | |
| AC | A d-unit in which access to technology, people, institutions, or knowledge is an issue means of entering, communicating with, or making use of. |
| <i>PRACTICES</i> | |
| PR-T | Practice, Oral: The use of oral language. |
| PR-Rd | Practice, Reading: The use of reading. |
| PR-W | Practice, Writing: The use of writing for the purposes of processing or sharing information, or accessing services. |
| PR-R | Practice, Research: The uses of research to investigate medical questions, locate information, and make decisions. |
| <i>AGENTS</i> | |
| AG-P | Agent, Patient: An individual with a diagnosis of cancer who acts or exerts power, which may lead to change. |
| AG-C | Agent, Caregiver: An individual caregiver who acts or exerts power, which may lead to change. |
| AG-D | Agent, Doctor: An individual trained in healing arts who may act with, on, or on behalf of patients. |
| AG-MP | Agent, Medical Professional: A professional advocate and caregiver, who may act with, on, or on behalf of patients. |
| AG-T | Agent, Technology: Technology used to enable growth and/or action. |

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Using a two pass coding system, I first identified "literacy events" in the data, and then isolated "d-units" involving the concepts I needed to track: knowledge, power, access, practices, and agency. A d-unit is defined as "any stretch of continuous text--a whole text, a section, a paragraph, even a small group of related sentences--that functions as a unit and whose parts are more related to each other than to those outside the d-unit" (Colomb and Williams 87). Because of the nature of oral interviews (and the multiple persons who may constitute a single "case"), I could not always isolate a single stretch of speech from a single speaker. Often, the story involved multiple persons. In my data, then, an individual d-unit may be a monologue or "paragraph" on a given topic spoken by a single person, but may also involve an interchange between two or more persons. The theoretical framework of a d-unit allowed for this, and helped me to isolate to the boundaries of each literacy event.

D-units were then imported into an Excel spreadsheet organized by literacy events. I then made a second pass through the data, submitting d-units to a process of discourse analysis, which enabled me to apply the relevant codes. My next steps included: (1) counting of the number of codes across events to identify more and less common features; (2) identifying key patterns in the data (e.g., forms of power and knowledge or types of practices used; and (3) reading the literacy artifacts, using my coding scheme as a rubric. Throughout this process, I continually worked to refine coding categories, such that one deliverable of this project is the coding scheme itself.

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In conclusion, my study methodology is built on a foundation of belief in the applicability of a rhetorical approach to the study of medical situations as well as the necessity of exploring how power may limit or encourage access and skill development. Building on Street and Brandt's ideas about literacy events, I have designed a set of methods that enable me to isolate literacy events in order to be attentive to individual patient and caregiver contexts and practices. Those practices are then unpacked in light of Johnson and Foucault's conceptions of power and knowledge and submitted to a process of rhetorical criticism. The resultant data is shared in Chapter 5, which explores what the data reveals health literacy to be and considers who becomes health literate, and in Chapter 6, an exploration of power and access.

Chapter 4

WHAT IS HEALTH LITERACY? WHO BECOMES HEALTH LITERATE?

Overview

In this chapter, I unpack the data collected in this study in order to explore what health literacy means in the lives of my participants, and to document the practices involved. Their stories reveal health literacy to be a set of flexible practices engaged in by groups to support the process of becoming an informed patient. Those practices entail a large number of practices supported by oral and reading literacies, with use of writing ranking just a bit lower. A significant amount of health literacy communication is oral and takes place in inquiry groups (for example, families and support groups). The research conducted by health literate groups is primarily and understandably focused on understanding medical conditions, but the array of inquiry activities necessary to do this is complex. Following a broad survey of the data collected and the patterns noted therein, I will introduce some of the health literacy artifacts shared by these participants. These will be explicated to uncover and document literacy practices. We will revisit these artifacts in Chapter 6 in order to further consider their roots in issues of power and access, and the ways in which literacy practices connect to, and strengthen, patient agency.

Introduction to Participants

My study followed the health literacy work of a couple called Denise and Michael, and an individual called Celia. Michael is a farmer and former soldier who was awaiting deployment to Iraq at the time of diagnosis; he is now retired and a

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volunteer deputy. Denise, who works for a scientific department in a Tier 1 research university, is his wife. Celia, a former teacher of high school English and French now self-employed as a seamstress, is a breast-cancer survivor. Both cases received their first cancer diagnosis at my study site, Big Waters Oncology Center, Michael in 2004 and Celia in 1994. While Michael and Celia are two very different patients, the stories of each reveal complex and compelling health literacy practices grounded in issues of access, agency, and power.

Denise and Michael were uncomfortable at Big Waters for a number of reasons, foremost among them delays in treatment, but also an extremely negative doctor with whom they had poor communication, issues I will explore in Chapter 5. Their research eventually led to a second opinion at an out-of-state cancer research and treatment center we'll call the Apple Blossom Center. They specialize in myeloma, and Denise and Michael were presented with an array of options--precisely what they had been seeking. They chose to participate in a clinical trial. Today, Michael has local doctors, but his oncological care is still overseen out-of-state at the Apple Blossom Center. Denise and Michael currently participate in a local support group at Big Waters, but they are no longer patients there.

Celia also had some negative experiences at Big Waters, but she chose to be treated for her breast cancer there, supplementing what she thought was missing from her medical treatments--a positive outlook, and attention to the whole patient--with research into alternative and complementary treatments.

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Celia no longer lives in this area and does not return to Big Waters for checkups. She was recently diagnosed with (and had a successful surgical removal of) an unrelated oral cancer.

My data included written surveys and several hours of taped interviews with each of these individuals. I also was fortunate to interview the lymphoma and myeloma support group to which Denise, Michael, and I belong, as well as the social worker, Flora, who facilitates the group. Flora is also the primary life force behind the Big Waters' American Cancer Society-sponsored volunteer program and literacy sponsor of the Patient Resource Room, at which I volunteered for approximately two years.

Additionally, case study participants Denise, Michael and Celia volunteered several artifacts--medical texts consumed or created by them--which they identified as being pivotal to their experiences as patients. Denise and Michael shared a toxicity record she maintained during his clinical trial treatments as well as a clinical trial protocol recently sent them; documents listing questions and tracking medications, symptoms, side effects, and more written in preparation for doctor's visits; a notebook they were given upon intake at the second treatment center; and, finally, the "traveling notebook" this has grown into. Celia shared an unpublished manuscript detailing her cancer journey. These documents were not coded and tabulated in the ways interview data was; however, my coding scheme was used as a heuristic for reading and

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interpretation, and the documents themselves provide another important stream of data that helps me understand the practices recounted in interviews.

As explained in Chapter 3, on the first pass through the interview transcripts I was working to identify literacy events, operationalized as moments in time at which health/literacy practices can be seen in development or use. The literacy events referenced in interviews fell into three basic categories (types): learning and researching; communicating with medical professionals; and dealing with paperwork. Once literacy events were identified, I isolated d-units involving the concepts I needed to track: knowledge, power, access, practices, and agency. These d-units were then sorted into an Excel spreadsheet organized by literacy events. Some d-units contained reference to more than one literacy event, and so were used in both places. Table 3 (following page) lists all literacy events and the total number of d-units gathered in support of each. The most common types of literacy events are 1) asking questions of and communicating with doctors, 109 d-units; 2) connecting with other sources of information (information *not* provided them by the physician), 94 d-units; and 3) dealing with insurance and billing issues, 67 d-units.

Table 3
Literacy Events and Total D-Units

| Learning and Researching | |
|---|------------|
| Learning about support groups | 19 |
| Connecting with other sources of information | 94 |
| Learning about condition and treatments | 62 |
| Choosing a treatment center/a doctor | 30 |
| Getting copies of medical tests/records | 18 |
| Reading medical tests/records | 8 |
| Maintaining personal records | 27 |
| Tracking/making sense of symptoms | 16 |
| Learning about alternatives/complementary therapies | 19 |
| Misc. "non-medical" writing to heal/share | 7 |
| Communicating with medical professionals | |
| Receiving diagnosis | 24 |
| Conflict with Doctors and Medical Professionals | 47 |
| Participants in clinical trials | 11 |
| Learning jargon | 12 |
| Breaking the news to others | 3 |
| Dr's visits: asking questions, communicating | 109 |
| Dr's visits: preparing for | 14 |
| Dealing with (paperwork) | |
| Dealing with insurance/billing (getting referrals, billings, claims, payments, appeals, evaluating insurance plans...) | 67 |

The third and final stage in coding involved analyzing the language in the d-units, which enabled me to apply the codes I used to explore the issues of interest to me in the study. Table 4 (pages 72-3) shows the total counts for each code, within and across literacy events. Perhaps unsurprisingly, the two literacy events with the most supporting d-units also have the most total codes applied; what is interesting is that their positions are reversed. Connecting with other sources of information, with the second highest number of supporting d-units, has 360 codeable moments within those d-units, making it the most "active." Asking questions of and communicating with doctors comes in second, with 351

codes applied. While patients are getting information from their doctors, health literacy clearly also involves the ability to locate and process information “on their own”, through alternative sources. These acts combined contribute to the work documented in d-units addressing “learning about condition and treatments”, in which we see 244 coded moments. “Dealing with insurance and billing issues”, the category of literacy events with the third highest number of supporting d-units (68) is, with 200 coded moments, the fourth most active. Some of the “smaller” literacy events--like reading medical tests and records, directly addressed in only eight d-units--are nonetheless quite significant events once one considers the individual codes at work within that event and the relationships revealed between patients and doctors as mediated by literacy practices (to be explored in this chapter) but also by issues of disciplinary knowledge, access, and agency (to be explored in Chapter 5).

Table 4: Total Counts by Code on pages 72 and 73 reads:

| Table 4: | total d- units | KW: PRA | KW: PRO | KW: CIT | PW: DS | PW: DP | AC: | PR: O | PR: RD | PR: W | PR: R | AG: P | AG: C | AG: D | AG: MP | AG: T | total |
|--|---------------------------|--------------------|--------------------|--------------------|-------------------|-------------------|------------|--------------|---------------|--------------|--------------|--------------|--------------|--------------|---------------|--------------|--------------|
| Learning and Researching | | | | | | | | | | | | | | | | | |
| Learning about support groups | 19 | 7 | 7 | 18 | | 6 | 4 | 5 | 1 | 1 | 4 | 10 | 8 | | | 1 | 72 |
| Connecting with other sources of information (not provided by the physician) | 94 | 22 | 14 | 30 | 7 | 25 | 45 | 40 | 39 | 4 | 39 | 34 | 31 | 4 | 9 | 17 | 360 |
| Learning about condition and treatments | 62 | 19 | 7 | 9 | 8 | 12 | 21 | 11 | 41 | 3 | 36 | 20 | 27 | 2 | 5 | 23 | 244 |
| Choosing a treatment center/a doctor | 30 | 10 | 7 | 1 | 8 | 9 | 7 | 5 | 10 | | 14 | 8 | 17 | 9 | 2 | 7 | 112 |
| Getting copies of medical tests/records | 18 | 3 | 2 | | 9 | 9 | 5 | 4 | 5 | | 9 | 7 | 4 | 5 | 1 | 2 | 65 |
| Reading medical tests/records | 8 | 3 | 5 | | 1 | 3 | 1 | 1 | 5 | | 5 | 4 | 7 | 1 | 1 | | 37 |
| Maintaining personal records | 27 | 18 | 10 | | 3 | 11 | | 8 | 3 | 10 | 7 | 8 | 13 | 2 | 3 | 1 | 97 |
| Tracking/making sense of symptoms | 16 | 6 | 5 | 1 | 5 | 3 | | 9 | 5 | 4 | 4 | 5 | 10 | 3 | | | 60 |
| Learning about alternative and/or complementary therapies | 19 | 1 | 1 | 1 | 7 | 10 | 1 | 2 | 7 | | 7 | 8 | | 8 | | | 53 |
| Misc. "non-medical" writing | 7 | | | | | 2 | | | 3 | 6 | 2 | 5 | 3 | | | | 21 |
| subtotal | 89 | 58 | 60 | 48 | 90 | 84 | 85 | 119 | 28 | 127 | 109 | 120 | 34 | 21 | 52 | | |

Table 4: Total Counts by Code (continued)

| | total d- units | KW: PRA | KW: PRO | KW: CIT | PW: DS | PW: DP | AC: | PR: O | PR: RD | PR: W | PR: R | AG: P | AG: C | AG: D | AG: MP | AG: T | total |
|---|--|------------|------------|------------|-----------|-----------|-----|-------|--------|-------|-------|-------|-------|-------|--------|-------|-------|
| Communicating with Medical Professionals | | | | | | | | | | | | | | | | | |
| Receiving diagnosis | 24 | 5 | 2 | | 8 | | 3 | 1 | 1 | | 1 | 4 | 6 | 12 | 3 | | 46 |
| Conflict with Doctors and Medical Professionals | 27 | 8 | 7 | 6 | 32 | 11 | 15 | 11 | 7 | | 9 | 5 | 10 | 22 | 8 | 1 | 152 |
| Participants in clinical trials | 11 | 1 | 1 | 1 | | 2 | 5 | 4 | 6 | | 2 | 5 | 3 | 1 | | 2 | 33 |
| Learning jargon | 12 | 5 | 5 | 3 | 2 | 1 | 1 | 4 | 7 | | 2 | 2 | 6 | | 3 | | 41 |
| Breaking the news to others | 3 | | 2 | 1 | | | 2 | | | | | 1 | 1 | | 2 | | 9 |
| Dr's visits: asking questions, communicating | 109 | 24 | 20 | 26 | 9 | 7 | 4 | 53 | 20 | 22 | 22 | 44 | 40 | 44 | 14 | 2 | 351 |
| Dr's visits: preparing for | 14 | 8 | 9 | 3 | | | | 9 | 1 | 11 | 3 | 3 | 10 | 1 | 1 | | 59 |
| subtotal | | 51 | 43 | 41 | 52 | 21 | 30 | 82 | 42 | 33 | 39 | 64 | 76 | 80 | 31 | 5 | |
| Dealing with Insurance & Billing | | | | | | | | | | | | | | | | | |
| As above. | 67 | 34 | 26 | 8 | | 7 | 28 | 12 | 16 | 3 | 21 | 15 | 21 | 7 | 2 | | 200 |
| subtotal | | 34 | 26 | 8 | 0 | 7 | 28 | 12 | 16 | 3 | 21 | 15 | 21 | 7 | 2 | | |
| total across literacy events | | | | | | | | | | | | | | | | | |
| K | 174 | 128 | 109 | 100 | 118 | 142 | 142 | 179 | 176 | 64 | 187 | 188 | 217 | 121 | 54 | 57 | |
| E | KW: PRA = Knowledge Work: User as Practitioner | | | | | | | | | | | | | | | | |
| E | KW: PRO = Knowledge Work: User as Producer | | | | | | | | | | | | | | | | |
| E | KW: CIT = Knowledge Work: User as Citizen | | | | | | | | | | | | | | | | |
| Y | PW: DS = Power: Discipline | | | | | | | | | | | | | | | | |
| Y | PW: DP = Power: Dispersion | | | | | | | | | | | | | | | | |
| | AC: Access | | | | | | | | | | | | | | | | |
| | PR: O = Practice: Oral/Aural | | | | | | | | | | | | | | | | |
| | PR:RD = Practice: Reading | | | | | | | | | | | | | | | | |
| | PR:W = Practice: Writing | | | | | | | | | | | | | | | | |
| | PR:R = Practice: Research | | | | | | | | | | | | | | | | |
| | AG:P = Agent: Patient | | | | | | | | | | | | | | | | |
| | AG:C = Agent: Caregiver | | | | | | | | | | | | | | | | |
| | AG:D = Agent: Doctor | | | | | | | | | | | | | | | | |
| | AG:T = Agent: Technology | | | | | | | | | | | | | | | | |

What is Health Literacy?

The coding analysis is useful for revealing what is present in the data, or for shaping the data in terms of the concepts of interest to this study. This study was designed to provide a way of understanding health literacy by documenting the on-the-ground practices of users. I was gratified then, to see that the third highest code is that designating research practices (187 instances)¹³. Access to information is crucial not only to understanding what is happening, but also to being able to participate in making decisions about one's own, or a loved one's, care. Patients and caregivers gather information from a variety of data streams. Research often means going to books or computers to seek information--reading practices are noted in the data 176 times--but research is just as likely to involve more informal, oral practices. Oral practices, mentioned 179 times in the data, include talking to other patients/caregivers and/or support group members, and also supportive doctors, nurses, and other medical personnel. Learning from waiting room chats with other patients is mentioned frequently. Denise explains: "There's a lot of patients talking in every waiting room. So it's like, 'which therapy are you on? Oh, you're on X? I'm on that too. What unit of [chemotherapy agent name] are you doing?' And people will tell you." Michael agrees, adding:

...every waiting room is a support group. In every waiting room, because every patient is dealing with the same disease, then there's conversation that takes place. It's only myeloma patients.... You know that going in. I

¹³ This comes in just behind those designating caregiver (217 instances) and patient agency (188 instances), issues which I will discuss in Chapter 5.

think, though, that culture could possibly exist in another facility [with a greater variety of cancer types present].

These research practices, both textual and oral, often coincide with high levels of knowledge work, rivaling those of literacy events like “asking questions of and communicating with doctors,” an event in which high levels of knowledge production are expected. Because knowledge is intricately bound up in and with power, I will return to this issue in Chapter 5.

Given the preponderance of oral practices documented in interviews, it should come as no surprise that a number of those who participated in the focus group interview expressed a preference in certain situations for non-print, aural materials. Some note attending grand rounds, conferences and seminars. Many have participated in teleconferences. Still another mentions benefitting from these oral lessons when their treatment center loaded mp3 archived teleconferences onto an iPod lent to patients for use during hospitalizations and treatment sessions, an idea the support group facilitator latched onto for Big Waters. Still others--both patients and caregivers--relate using books on tape to gain information when they do not feel well enough, or focused enough, to read.

An aural practice often discussed in group is tape-recording doctor’s visits, a practice that is generally considered complementary to note taking. Denise, Michael, and another group member report this practice is common at their treatment centers, both of which provide not only loaner recorders, but also cassette tapes. Caregiver Denise says, “...you get too sick to really focus. And that’s why I think the tape recorders help.” Denise further comments that these

tapes provide a good way of reviewing information after the fact to verify that you understood and remembered correctly, but also a valuable tool for sharing information with family members and friends unable to be a day-to-day part of direct caregiving. For example, she relates sharing these tapes with Michael's mother, who lives out of state (and who lost her husband to cancer shortly before Michael's diagnosis):

...when they said, before that one Christmas that [Michael] had achieved a progression where they would call it a graded remission--and I had to preface it so that they didn't get like he's cured--but um, they could actually hear the doctor say that and you could tell in his mom's voice it meant a lot to her. It was more than us calling her and saying it; she heard the authority say it.

At other times, aural formats are insufficient. Denise states:

I find that it's nice to be able to listen...but if it's stuff that I'm struggling with either emotionally or physically because I'm too tired and too overwhelmed, the fact that I have it in print and I can go back over it, or I can highlight it, and then come back to the parts I want to reread, is important.

Writing practices (64 instances) occur most frequently in the contexts of note taking, as Denise's comment above and most of the 22 d-units related to writing during doctor's visits would suggest. Note-taking occurs during office visits, but also while reading about medical conditions and treatments, and while participating in group learning experiences, such as teleconferences, support groups, and medical "training sessions" (which include a broad variety of experiences, like chemotherapy classes training patients and caregivers in treatment practices and procedures, or public meetings, like the Leukemia and

Lymphoma Association lecture on clinical trials that many members of this support group attended.)

Difficult material encountered in print is often printed out, highlighted, and written on as the patient and caregiver read and re-read, making new knowledge. For example: when asked how she made sense of the published medical studies she gathered in order to select a treatment center, and choose a treatment plan, Denise said:

sitting there reading them over and over. For me it's easier in print.... I can look at it on the screen, and I can make notes to the side. But you've seen my handwriting; it's awful. I can do that to a point, but then eventually if it really interests me or I think it's important I've got to download it and print it because then when I download and print I have highlighters, I do a lot of sticky things.... So it's repeated engagement, and then I'll cross-reference it and I'll try and see... OK, if they reference an article in *The New Yorker* then I can bring *The New Yorker* up online. If they reference an article in PubMed then I will go to PubMed.

Writing is also used in preparing for doctor's visits to create lists of medications, symptoms, questions, and requests. Additionally, a few patients and caregivers mentioned writing for personal reasons such as maintaining journals or diaries, reflecting on the cancer experience on the anniversary of diagnosis, and even creating visual and/or alphabetic texts to share the experience with others, as in the case of two group members who attended a workshop sponsored by the center to create art and written statements on "The Cancer Journey" for submission to the Lilly Oncology on Canvas competition and exhibition¹⁴. Writing, for the patients and caregivers participating in this study, is

¹⁴ <http://www.lillyoncologyoncanvas.com>

therefore a practice relied upon for gathering, sharing, preserving, and processing information, for both personal and medical purposes.

Technology, like use of the Internet to connect a patient or caregiver to a medical study, support group, or other source of information, was coded with other agents because technology is a practice that enables. Technology in health and medical situations is therefore both practice and agent; as a result, the 56 times technology is specifically mentioned in the data, and the ways technology connects patients to information and helps them build knowledge, are useful to consider here. Denise's comment about cross-referencing reveals the importance of Internet access to being able to read across multiple sources of information. Most members of the support group report pursuing information across multiple forums, as did Denise. They also frequently mention using the Internet to visit websites and chat rooms sponsored by cancer-related publications and organizations, although they comment, too, that on many sites chat rooms are too-often empty, and links are too-often dead. Michael comments:

...those chat rooms and sites really don't have a life of their own. ... If one person's responsible for it and their focus changes or whatever support has been going on in their life changes they're not going to keep perpetuating that, you know, so that's the drawback of a bulletin board or a chat room or anything like that is it's based...you know it's got to be driven by the people that use it and if the use drops off at all then you lose that forward momentum.

At this point, Flora--who as an oncology social worker realizes how fundamental an open and non-judgmental source of information is to enabling and supporting patients' health literacy work--asks:

You know one question I have is in all the survivorship literature that I've read and learned, the largest portion of survivors are 65 and older.... And so many of the things are going to technology, and I wonder--everybody here is talking about the Internet and computers, but I think there's quite a large sector of survivors and active cancer patients that don't, number 1 have a computer, or even to be able to come into here [gestures towards Patient Resource Room] to use it wouldn't have...the background to do that. So then, where does that leave that person as far as getting information?

Most group members stated in reply that a lack of digital access to information would make the knowledge work they do much more difficult. While most group members reveal in conversations and surveys that they did not use the Internet as much before diagnosis, it is now a resource used by nearly all group members, if sometimes cautiously. For example, we had a newly diagnosed couple join us one week. This is always an opportunity for group members with more experience dealing with cancer to make suggestions about how to navigate this life change--one of the many instances of Knowledge Work: Citizenship documented in the study. On this occasion, Denise reports, other group members "were like, 'Don't look at the Internet too much.' And I'm like, 'Well, sometimes that is the fastest way to research!'"

Denise herself reports her use of the Internet and email has changed drastically since Michael's diagnosis. Her use of online resources--even at the early stage of their journey when she was locating clinical trials and comparing physicians and treatment centers--reveals the sophisticated practices developed by most of these group members. After their disappointing experiences at Big Waters, Denise began doing Internet searches looking for:

...second opinions everywhere. I was looking at who is publishing, what was being published, what they were doing. We looked at MD Anderson; we looked at Mayo. I looked at some East Coast hospitals because I'm from the East Coast. I didn't care where they were: I was just looking. Well, if you look, there's a tremendous amount of stuff published on myeloma that comes out of the Apple Blossom Center. And when you look at how much [they are] rewarded in grants, I think one time out of ten NSF grants they had three.

When, the month after the new members were cautioned away from the Internet, I asked group members where they go to seek out medical information, nearly everyone simultaneously stated "Google" and laughed. The Pew Report suggests this is likely true for most individuals with Internet access: "66% of health seekers began their last online health inquiry at a search engine; 27% began at a health-related website" ("Online Health Search 2006" ii). This, in and of itself, is not troubling. What is most bothersome are the results on how critically most of us evaluate our hits: "only 15% of health seekers say they 'always' check the source and date of the health information they find online, while another 10% say they do so 'most of the time'" ("Online Health Search 2006" iii).

While this support group might begin with Google, the evaluation of web-based resources is a matter of consideration for these group members, who suggest several different tactics, including considering the publisher and triangulation, or locating several sources that say the same thing-- preferably, one group member jokes, sources by people who do not seem to know one another. Another group member suggests comparing information gathered through Google against information from more trustworthy sources, such as the

American Cancer Society or the Multiple Myeloma Research Foundation. Upon questioning then, it seems a worry that the newly diagnosed might not have the context to understand how to evaluate information found online may have caused some group members to caution their newest visitors away from use of Internet resources. Nearly every group member has a story of how failing to properly evaluate a source caused him or her a few sleepless nights.

Celia: Diagnosis as Exigency for Reading, Writing and a Return to School

The artifact that Celia volunteered to this study is an unpublished manuscript charting her cancer journey. In it, she details her diagnosis, communication with doctors, and the research she did on caring for herself as a whole patient, a patient constituted of not only a body but also a mind and a spirit. In our interviews, she told me the story of her diagnosis, how it changed her and her literacy practices, and what came out of that: this manuscript.

Celia had more experience with cancer than anyone cares to: her mother fought breast cancer twice, dying of it at age fifty-seven. Given this history in the family, both Celia and her doctors watched her body carefully for changes or signs of cancer: she received a baseline mammogram at age thirty-five and returned annually. Despite this, her tumor went unnoticed for some time, and had metastasized by the time it was discovered: she was at stage three when diagnosed.

The day of Celia's first appointment at Big Waters, she was quite frustrated by the handling she received, a story of power, access, and agency I'll

share more fully in Chapter 5. While a trip to a cancer center to receive a prognosis and plan for treatments is not a day anyone is likely to enjoy, Celia's day went terribly. The nurses and physicians she met with treated her as if she had received a death sentence. Of this day, Celia writes:

Whatever I knew of the subject before, facing cancer gave the concept of survival a whole new meaning. For the first time in my life, I was grateful I'd had plenty of experience with large, stubborn challenges. I was thankful I had experienced the workings of faith, perseverance, and positive thinking as successful methods for dealing with challenging situations. I told them on the day of diagnosis that I was a positive thinker. I could tell immediately by the looks on their face that positive thinking, in their esteemed medical opinions, rated zero on the list for affecting a fast growing, metastasized tumor. On that date, my regard for the medical profession, or the Whitecoats, as I've come to call them, took a huge dive. Sadly I met no Bernie Siegels on the path. A cure was highly unlikely, in fact out of the question. Empirical statistics were against me. Extending hope was not ethical. The one statement of encouragement, and there was only one, came from the surgeon, who after reading the pathology report said ... 'You still have a few good times ahead of you.' He said 'times' not years. I had hope for more. If this was all I could extract from the medical system then I figured I had better marshall all the positive survival skills I'd ever encountered and give it my best tough girl shot.

She did not know how to face the aggressive treatment plans they had for her without both information and support, and she had, she says, no real reason to think she would receive either from these particular doctors. She did not know what to do next, so she did what we all do at moments like this: she fell back on what she knew. Celia used her literacy skills and her general knowledge about health and wellness to help find her build the health literacy skills that would enable her in her new role as breast cancer patient.

Celia was raised on a farm, eating food fresh from the land, by a family that did for themselves and saw doctors only as a last resort. She is a woman of great strength, perseverance, and resourcefulness. She trusted the doctors to do what they must. She writes, "As much as I didn't want to lose a breast, my faith was still saddled with logic. Many years of gardening and preparing fruits and vegetables for canning teaches that pruning the bad spot often saves the whole." But on the way home, Celia says, "...I stopped at the health food store and started getting books right away. You know. I really felt that I was going to be abandoned by those people." Celia, who held two college degrees and was already, by anyone's measure, extremely literate, was not health literate in this situation, not by Deborah Brandt's conception of literacy: "knowing how to write or read is knowing what a text means for things on your end, knowing what it is saying about what you need to be doing, right here, right now" (Brandt 38).

While Brandt is speaking here of more alphabetic literacy, it is one of the finest descriptions of what is required in order to be fully health literate-- knowing what to do now-- that I have encountered. When Celia met with these doctors to discuss her diagnosis, prognosis and options, a text was delivered to her, a text that, for the professionals involved, indicates certain choices to be made in preparation for a finite number of possible re/actions. They understood what their words meant for the actions they would perform to and for her, and additionally, what she should be doing for herself. She did not; not fully. She therefore began researching and reading for two purposes: both to locate

information to help her understand things from the physicians' perspective, but also to help her locate information that was not important to, or addressed by, her physicians.

Notably, Celia's 1994 breast cancer diagnosis just predates widespread availability of the Internet and all the health and medical resources it makes available. When asked where, then, she gathered information, she replies: "a lot of books." Based on use of the Internet by the focus group and Denise and Michael (as well as by individuals frequenting the Patient Resource Room I volunteered in at Big Waters) I anticipate that numbers for the Agent: Technology code would be higher if Celia's first diagnosis of cancer were more recent, particularly given that she does now research other issues online.

In her manuscript, Celia makes reference to some of the many books she consulted during her time as a patient. They include three types of books: mainstream "cancer" books of the type stocked in Big Waters' Patient Resource Room; books on spirituality (including the Bible, *Wheels of Light*, and *The Woman's Book of Healing*); and books on alternative medicine (such as Bernie Siegel's *Love, Medicine and Miracles*, Susan Weed's *Breast Cancer? Breast Health!*, and Marc Ian Barasch's *The Healing Path*). She also read a number of autobiographies written by cancer patients, such as *Recalled by Life*, which tells the story of a man who, in the final stages of cancer, goes on a macrobiotic diet and regains his health. Like Denise and the other patients and caregivers in the support group, Celia reports cross-referencing ideas: when she found something

promising, she pursued it through multiple texts, so that an autobiography of someone who benefitted from a macrobiotic diet led to medical studies on the diet, cookbooks, and more.

Celia's research, while quite broad, was focused along two lines: it helped her understand the medical treatments she was receiving and to make decisions about these, but it also made up for the things the doctors could not (or would not) provide her, including positive thinking and steps she could take on her own. From these books, Celia learned many things she credits with increasing the efficacy of her treatments. Among other things, Celia began walking daily and went a macrobiotic "cancer diet," which she says nearly instantly cleared up skin and digestive problems she'd lived with for years. She meditated, chanted affirmations, and visualized the chemotherapy agents blasting the cancer cells from her body. She even stopped at the hospital library as she left some days, opened books with pictures of cancer cells, and practiced her visualizations there.

Her doctors were less than supportive about these measures, a sort of power clash I will revisit in Chapter 5. Despite this, there is some evidence of a mind-body connection that validates Celia's actions: for example, there are studies on writing to heal that document patients having positive physical affects following focused writing about an emotional event ("Writing to Heal..."). Even improvements to the immune system have been documented ("Writing to Heal..."). Some of Celia's actions can be considered a way of processing the

emotions connected to the diagnosis and treatment of cancer, strengthening her spirit so that her body might follow. Others, like exercise and eating more healthfully, literally strengthened her body, helping her to endure treatments.

Celia also recalls learning from other patients:

... Susan Komen was just starting to get going then, and then there was an organization in Chicago called Why Me. And you could talk to somebody on the phone there that had been through what you were going through.

Like the other patients surveyed in my study, then, Celia, who did not participate in support groups and described herself as being reclusive and focused on self-nurturing during this time period, nevertheless participated in some knowledge-making practices with other patients, largely via telephone conversations with a breast cancer survivor located through Why Me. She also received support from her husband, who dealt with insurance and billing issues for her, a friend who accompanied her to doctor's visits and treatments (and who handled the responsibilities of note taking at these times), and from her mother-in-law, who brought her "a whole bunch of books on cancer...that got [her] going." Health literacy work seldom seems performed solely by the patient.

The manuscript Celia shared began life in the reading notes she took during her time in treatment for breast cancer: Celia explains these notes as a way of making sense of what she was reading (much like Denise's marginal comments and sticky notes on print outs of electronically accessed medical studies). It took manuscript form seven years later when Celia went back to school for a master's degree in comparative religion; as part of this she received

a master's level certification in holistic health. This is further evidence of her use of writing to process information, but also marks the beginning of Celia's writing to share her health literacy work and knowledge with others.

Celia no longer has a television, nor has she spent time reading fiction since her breast cancer experience. On this, she writes, "I had the privilege of spending the first half of my life absorbing information.... In the second half, I will look for ways to give it back." Not only, then, did Celia's diagnosis and her research, reading, and writing practices support purposeful and focused knowledge work during her time as a patient, it affected her health literacy practices and her perceptions of health and medicine in on-going ways. In Chapter 5, we will return to Celia's story to see what it reveals about the impact of power and agency.

Michael, Denise, and the Traveling Notebook

Michael and Denise shared several artifacts with me, but the most fascinating is The Traveling Notebook. The notebook is nearly four inches thick, and (Denise hopes) it contains every medical test, contact, or record a doctor might ever need from them. Many of the other artifacts Denise and Michael shared with me (like the toxicity record maintained during treatment, and the documents listing current medications, symptoms and questions they write in preparation for each visit to the oncologist) were, at some point in their existence, vital items in the notebook. They have now been replaced by information that is more current:

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this notebook is in a constant state of flux, growing and changing as does Michael's condition and treatments, and the needs of the family.

When Denise and Michael first went to the Apple Blossom Center, they were presented with a much smaller notebook, less than an inch thick. They were taught by the intake nurses to use this as an organizing device and a memory aid. The practice has grown from there. The current incarnation of the notebook includes local and out-of-state lab reports; the clinical trial protocol Michael was on; doctor's orders; dictations; the most recent appointment schedule and the upcoming appointment schedule; contact information for all health and medical personnel connected to the family; lists of medications; prescriptions for medicines and even eyeglasses (in case they break while they are visiting the Apple Blossom Center); physical therapy reports; a DVD with all the images taken of Michael by various doctors; powers of attorney; contact information for patient advocates; information on drugs, interactions, and side effects; and more. It is labeled with a red cross, and lives in the car when Denise hopes a friend or emergency worker might notice it were Michael to need help in her absence.

The notebook might seem simply a collection of everything--but it isn't. Each item in this notebook has been chosen for a specific purpose, and is reevaluated as time passes and conditions change. As an example, the inclusion of current lists of medicines may seem obvious to nearly anyone who has been a patient. The manner in which Denise and Michael maintain their notebook,

however, adds layers of extra value to this document as time passes: several months of worth of outdated lists form a new and valuable resource when patient and caregiver move them to another section and add notes on each, detailing what these were prescribed for, with what results, and the reasons for any discontinuations or changes. These actions demonstrate ongoing awareness of and ever deepening knowledge about disciplinary procedures. The “question” documents the family writes together in the days before each scheduled medical appointment provide another illustration of this. These documents provide an overview of Michael’s condition since the last visit, making a simple list of medications, symptoms, and questions more like an addition to the patient’s medical history.

Throughout, Denise’s Traveling Notebook demonstrates an awareness of the practices of Medicine, learned through repeated engagement. The documents in this notebook have been chosen, located, and even created purposefully. The deliberate nature of each document’s inclusion, with each decision focused on what these documents mean to medical professionals, and therefore what they mean to the ways in which Michael will be received, treated, and supported by these professionals, reveals highly developed health literacy practices. These include, at a minimum, highly developed reading skills, but also information literacy skills (such as knowing there is something to look for, where to look for it, and how to get copies of it), archiving skills, and specific disciplinary literacies that help the couple read across and use all this information

for medical, personal, and insurance purposes. This notebook is a clear illustration of the fact that health literacy builds on Brandt's sense of literacy: it is a skill set that requires "knowing what a text means for things on your end" (38) and what it suggest for the next steps. It is also an illustration of the multimodal nature of health literacy. Patients and caregivers must work across different types of texts--including oral, alphabetic, and numeric information--from a variety of sources.

These documents make the patient and caregiver a very active participant in the diagnostic process, and yet there is more to the story. Many items included in the notebook are the result of knowledge made by the patient and caregiver, and therefore they are representative of less visible work that went on in the background, often involving research to answer questions raised by documents as they were obtained. Throughout this study, patients and their families spoke to me of how information needs continually grow and change. A question about a lab report may lead to a variety of other literacy acts, including online searches, conversations with both other patients and medical professionals, and more. Participation in a clinical trial may raise new questions about insurance coverage, leading to more research and reading, and the addition of another section in the notebook. When this collection of documents is read as a whole, they form a complete picture of the patient, one that designed to be meaningful for and useful to multiple audiences. This notebook is, in a sense, an informed patient's paper precursor to the electronic medical record--

perhaps even an extension thereof. The patients and caregivers consulted in this study commented often on how electronic medical records accessible to a very broad set of audiences (including their insurance provider, physicians' offices, hospitals, treatment centers, and billing entities would vastly simplify the work required of patients). This is likely true; however, assembling these records is an important step in the production of health literacy.

Keeping a notebook like this is not unique to Denise and Michael: this is a suggestion made to (and by) many patients and caregivers, and a practice supported by several organizations, including the Lance Armstrong Foundation and the American Cancer Society¹⁵. In fact, in my orientation as an ACS volunteer, we were trained to help patients order from the Society a sort of traveling notebook starter kit. The patient fills out a brief questionnaire (or calls the ACS and goes through their needs orally), and the ACS fills a durable and expandable accordion folder with information appropriate to the needs of this patient and family. There are sections for recording most of the things Denise accounts for in her notebook. I, and nearly every "old timer" patient I have offered this to, have admired the design and organization of the ACS folder. We have wished somebody had trained us in this practice when newly diagnosed, and provided us with this support system.

¹⁵ The Lance Armstrong Foundation (<http://www.livestrong.org/>) offers a number of downloadable worksheets through their website. One can also order the notebook referenced here. Both are good ways to get organized. To get the personalized information kit from the American Cancer Society, simply call 1-800-ACS-2345.

While the literacy practices involved in this act of knowledge work are already quite revealing, there is still more to this story: the notebook itself is Denise's way of dealing with the power differentials involved in making decisions with highly trained medical specialists. It is a way of keeping away the powerless feeling she had during the time of diagnosis, and the dark times at Big Waters. It is both a way of making knowledge and claiming agency. We will explore these aspects of Denise and Michael's practices in Chapter 5.

Who becomes health literate?

As the practices documented thus far should make clear, separating patient and caregiver agency may have proven slightly misleading; there are many occasions in the data where patient/caregiver agency is shared/blurred, others at which the caregiver is acting as proxy for the patient, and still others when the patient or caregiver would, can, and have done precisely the same thing (sometime, in fact, even preparing for a solitary event together). Further, I noted a number of times in interviews and in the focus group that even caregivers refer to themselves as "patients in the waiting room."

The most compelling thing documented in this study is not, then, the practices utilized by patients. Having been a cancer patient myself, I had expectations, and, while I designed this study quite carefully in order to guard against seeing what I expected to see, I see the practices I expected and the issues of power we have all experienced. What is surprising is that when we study the writing consumed and the knowledge produced by patients in the

course of this work, the traces of other hands and other minds come into view. The agents and practices documented in this study clearly show “the patient” may be, and often is, plural.

The individual behind health literacy work does not exist in a vacuum. Health literate patients and caregivers read across multiple data streams, finding and gathering and sorting out information. From these multiple sources, patients and caregivers work to extract the answers sought. I think of finding these answers as finding information; being able to use that information for self-defined purposes is a higher state of development. In other words, there is a difference between having information and being knowledgeable. Part of the process of moving from an informed patient to a truly knowledgeable one requires discussing ideas with others, whether that means patients, caregivers, physicians, or other medical professionals. To demonstrate: the “Knowledge: Practitioner” code occurs in my data 22 times in literacy events related to communicating with doctor’s during visits, and 24 times in events related to learning about the condition through “other” (non-physician) resources. Significantly, in these two literacy event categories we also see the highest incidences of both my other knowledge codes: knowledge production and knowledge: user as citizen. These two contexts for learning--inside the doctor’s office and conversations with others outside the clinical context--produce similar elevations in knowledge production, but through cooperation with very different communities.

Health literacy is a true community literacy in that its component parts can be, and often are, distributed across individual members of several larger communities, who work together as circumstances require. In fact, the 2006 Pew Report on Online Health Searches proves that forty-eight percent of all searches for health information are done on behalf of another person (5). Another eight percent of Internet users surveyed report the information sought was “both for themselves *and* someone else” (5).

My study supports those findings. Several members of the focus group attend with their spouses, who, like Denise, do the majority of the research required. Behind Denise, though, are other helpers, and there are practices that help Denise make use of information from accidental helpers. Her health literacy work also involves, in part, the sister who sends articles and took her turn staying in the hospital with Michael; the journals written by other patients and shared through the Apple Blossom Center; the insurance agent who let a critical concept slip (and all the others Denise questioned about this until she riddled it out); the nurses who staff the training seminars she has attended; the lawyer friends consulted when questions demanded; the patient she talked to in the waiting room last Tuesday; and more. Following the focus group interview, I asked Flora whether she, too, noticed this symbiotic quality to health literacy. She agrees, and went on to say that many families at the center “...if they’re kind of organized which a lot of families are, each of them will take on a little piece” of the work required. The morning of our interview, for example, Flora had met

with a new patient whose “daughter [was] doing the Internet research,” printing off things for her parents to look at.

Of necessity, patient and caregivers--whether that caregiver is a friend, spouse, or family member--share agency. One must likewise consider their health literacy skills shared. As Denise explains it, “...you have to have some basis of knowledge, even if it isn’t you the patient. Somebody in your corner should.” When asked if perhaps she did the bulk of the research required because she wanted to know more than Michael did, Denise reminds us that the patient may be focused on other issues, explaining that she did all the research leading to the second opinion and participation in the clinical trial: “...partly because he was sick, partly because I think at one point Big Waters did its job and he just figured he was going to die and he just had to figure out what he could do.” He was focused on gaining closure on more personal issues while she was focused on finding a way to save his life. Overall, the stories told me throughout this study reveal that the notion of the patient as singular is misleading. The patient’s body is singular. The patient’s literacies are aggregate, multiplied by the available physical and digital support systems.

Our vision of who participates in the health literacy work of an individual patient is further complicated by the fact that the Internet is not the only source of information patients and their helpers consult. Of interest here is a 2004 study published by the American Cancer Society focusing on “the frequency of use of non-electronic media resources” such as information gained from books,

pamphlets or telephone hotlines. Most participants--58% of patients and 68% of companions--in the study had home Internet access. Despite this, the authors find that "print resources were used by 79% of patients and 83% of companions, with telephone resources used by 22% and 23%, respectively" and that "topic areas sought via print and the Internet were similar, with the exception of nutrition-related information...more commonly sought in print" (Basch et al 2476).

Writing to survive as a patient (or with a patient) in contemporary medical settings is to engage in knowledge work--complex, knowledge-producing activity requiring advanced information technologies and other elements of infrastructure. Patients and caregivers must interact with complex databases--even create them--work with ill-formed sets of information, and from this material, write persuasively to audiences. In addition, this rhetorical work is also deeply coordinated and sometimes collaborative. That is, unlike the classical rhetorics developed based on (and for) the individual rhetor, rhetorical activity in contemporary communities requires the participation of many people and technologies. I have therefore come to think of health literacy as a communal literacy. Clearly the work of a health literate patient involves the cooperation of multiple individuals. This suggests obvious problems in the ways that Medicine and Public Health currently operationalize and assess health literacy, which interfere with their intentions to support health literacy, an issue I will return to in Chapter 6.

Chapter 5

POWER= (ACCESS + AGENCY) KNOWLEDGE

Overview

As a doctoral candidate who volunteers in a cancer center and a cancer survivor who still returns each six months for “cancer checkups,” I have occasion to talk to more than a few doctors over the course of each week, and many have asked the topic of my dissertation study. From the head doctor at Big Waters to my own personal physician, most physicians and other medical professionals assumed a dissertation “about patient health literacy” would (naturally) be focused on determining the most appropriate mode or form, and vocabulary or reading level, for publishing educational materials for patients and families. Most non-medical professional--or patients, for we are all patients at some point in our lives--I have mentioned my dissertation topic to assumed my research (naturally) focused on issues of power in the doctor patient relationship, as well as on how patients access information, and why. Nearly every patient went on to share a story of a time she or he felt powerless in a health or medical situation. Further, nearly everyone had some story to tell of how they, a friend, or a family member had used research and writing to help them deal with not only information needs related to diagnosis or treatments, but also with insurance and billing issues connected to their diagnoses and treatments. The reactions from within Medicine and without are both quite revealing: they indicate not only different understandings of health literacy work, but also the roadblocks to clear

communication between doctor and patient--the foundation of successful medical care.

One obvious potential blockage, the one most focused on, is disciplinary knowledge, but in truth there are multiple disciplinary knowledges involved in health literacy, as well as a great deal of agency, and access is not assured, even then. The disciplinary knowledges required include both medical knowledge and knowledge of insurance policies and procedures, with answers in one arena leading to questions in the other in deep and dizzying ways. Denise, in fact, said to me once in a discussion of the ongoing paperwork she manages related to Michael's diagnosis: "The reason nobody wants to say cancer is once you do it never lets go of you." The only way she will ever see the end of the paperwork related to Michael's illness--or the ongoing problem solving and skill building, this paperwork requires--is death. The sheer volume of what must be known is massive. But, again, possession of knowledge is only one of the problems.

Because, as Brandt explains, "[a] dominant social group will elevate its brand of literacy to the status of Literacy, marking other versions as deviant or 'restricted'" (26), another obvious--and more difficult to navigate--roadblock to real partnership between doctor and patient has to do with power.

Communication and partnership are complicated by knowledge and access to knowledge, and by different power levels associated with possession of that knowledge. Because of these differences in power levels, patients and caregivers are sometimes disciplined in a Foucauldian sense, being indoctrinated into the

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expected ways of behavior through an almost constitutive rhetoric¹⁶. There are subtle reminders of power everywhere, once you look, and of the ways in which the disciplines of Medicine expect patients and physicians to behave, alone and together. On top of these almost expected disciplinary actions, patients are sometimes put off by little thoughtless actions, simple human mis-steps in communication that underline other, very real issues of power and “disciplining”. The combination can be devastating to the idea of a working partnership between patient and physician. While conversations with our physicians are not the only times and means through which patients and caregivers create knowledge about health and medicine, these are obviously crucial moments.

As reported in Chapter 4, a large percentage of patients’ and caregivers’ research involves oral practices; further, patients’ research practices outside clinical contexts (as when, for example, they learn from other patients, or from a book, Internet, or other media resource located on their own) coincide with high levels of knowledge work rivaling those of literacy events like “asking questions of and communicating with doctors,” an event in which high levels of knowledge production are expected. Accessing and using knowledge, particularly knowledges previously marked as experts only, are processes intricately bound up in and with power. The reading, writing, and research practices documented in this study and introduced in Chapter 4 are grounded in very real life and death

¹⁶ For more information on constitutive rhetoric, which seeks to motivate action in the ideal audience by addressing them as if they already naturally exist as a single community willing to act in this fashion, see Robert E. Terrill’s *Malcolm X: Inventing Radical Judgment*, pp. 22-23.

contexts, tremendous exigencies for patients and their families to engage in literacy work.

In Chapter 4, I examined practices and knowledge work in order to describe health literacy as operationalized by my research participants. In this chapter, I turn my attention to issues of power in order to see what is revealed about the contexts in which patients and caregivers perform this work. Subsequently, I will share with you two stories--that of Celia's diagnosis, and that of Michael's--in order to explore how these stories of communication between doctor and patient are complicated by issues of power, as well as how conflicts can lead to health literacy work and the creation of the knowledge required to feel, and be, agentic in the situation. Practices become tactics.

The Data says Knowledge Enables

In my analysis, the primary way that I attempted to track issues of power was to pay attention to agencies in terms of who seems to be the agent in a given event and in terms of whether the event can be characterized as disciplining or dispersing in its effects. The top two codes occurring in the data are Agent: Caregiver (217 incidences) and Agent: Patient (188). Doctor agency, the ninth most awarded code of fifteen, was recorded only 121 times in interview data. This is significantly lower than the numbers for patients or caregivers, particularly when one considers that patient and caregiver are generally acting in concert, or to achieve the same goal. Doctor agency can be positive or negative: this occurs 44 times in the category of "doctor's visits" and 22 times under the

event “conflict with doctors and other medical professionals.” In some contexts, some doctors share agency with or enable the patient/caregiver, an event I think of as dispersion, because it indicates a moment at which knowledge is used to move another to think or act differently. Importantly, the agent behind this dispersion can be doctor, patient, caregiver, or other.

Individuals may also, however, through conscious choice or simple habit, instead use agency for the purposes of “disciplining” another, a process of using knowledge to indoctrinate someone into expected ideologies and/or modes of behavior. Disciplining can be seen as a way of maintaining the status quo, and the divisions in knowledge and agency that were previously common between doctor and patient. The participants in this study are well aware that they are patients at a time when the doctor-patient relationship is in a sea change (as discussed elsewhere in this document). As in other cultural shifts, the old paradigm and the new co-exist. Acts of disciplining still occur frequently, although degree and intentionality vary. One example of this is a small thing that likely happens to patients every day: whether a medical professional shares routine information with you. Michael explains this as one thing he’s noticed as a tip off regarding an individual practitioner’s information sharing practices with patients:

...when they do the intake at Apple Blossom, they do the blood pressure...and all that good stuff, and every time they do it they rattle off the readings. But we have an appointment up here and the assistant took my blood pressure, and just took it, rolled up the cuff, and started writing it down. I said, ‘is it a secret?’ And she goes “OH!” and then told me what

it was. ... And then she took my temperature and you would have thought she would have learned... and I said, "Uh, now that's a secret right?"

This seems a small enough thing, but it reveals something deeper: medical information, particularly bits of information gathered in the diagnosis process, is presupposed to be the business of medical professionals. For those of this mindset, there is no real reason to share this information, particularly routine information, with the patient. It is enough that the professionals know. Inquisitive patients in this study report frequently hearing things like "I don't have time to deal with your questions" and "If you don't understand your lab reports, it's not my job to explain them to you. All you need to know is that I know what they mean; you don't need to know what they mean." Further, the fact that Michael (and Denise) now expect to be given this information as a matter of course reveals that their expectations about disciplinary practices have changed. Their asking for the information, repeatedly if necessary, is an act of dispersing, or a pushing back against the status quo. Their practices have become tactics, to be used as necessary.

In this study, medical professionals other than doctors are sometimes noted as having or sharing agency in a situation, but at only 54 instances, this is much less frequent. In some cases, the data reveals patients and caregivers asking questions of or being given information by nurses, social workers and other medical professionals, or attending training sessions staffed by these individuals, all instances of dispersion. Nurses, social workers and other medical Professionals are often the most accessible persons for patients and caregivers to

reach with questions outside of office visits; they are frequently the front line.

Flora, for example, reveals that:

We know that people are tuned in to what's in the media. ...when there's a piece on the news here, we usually get a significant amount of calls from our patients. Like if they highlight something on the 6 o'clock news that there's a new gene test out or a new treatment out? We'll get calls from folks that have that particular type of cancer and say, "Can you ask my doctor if this is something that would benefit me, or that would be applicable?" I've noticed that quite a bit. And I've been pretty impressed with our doctors saying well, this is why or why not. They've been really good about addressing that.

At other times, these interactions are more negative. Occurrences of disciplining sometimes act as catalysts, launching patients and caregivers into actions that enable them to "talk back" or act on their own in ways that counteract or work around disciplinary actions. As an example, consider the discussion that took place when the focus group was asked how their doctors feel about the practice of patients tape recording appointments. A group member said, "If you brought a tape recorder into your doctor's visit and he had a problem with it, I'd find another doctor," a sentiment that other group members heartily agreed with. Denise stated, in fact, that she had experienced doctors who "...actually would refuse to talk to you unless you turned the tape off and put it away" and that she had subsequently simply hidden a digital recorder in her pocket or purse so as not to have to face another conflict with the doctor over this; she was resentful, however, of being placed in that position. The group largely agreed, pointing out that the discussion being taped is, after all, about them. Denise,

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who works in a scientific field for a major research university, also told us a story about how this practice might be represented to doctors:

When I worked in the clinical center, I actually read some stuff one night. ...the insurance companies had been sending propaganda to the doctors and one was about letting your patients tape, and they were against it. They were telling doctors it was going to be used against you and jack up your malpractice insurance. I'm sure it's like everything else. There will be people that use it against them....

For this family, though, tape recording visits, even if it must be done surreptitiously, has been an important practice, one that enables them in terms of the content of the visits but also in terms of the emotional costs of the cancer journey. Denise explains: "...when [the doctors] said that one Christmas that Michael had achieved a progression where they could call it graded remission" the family scattered across several other states "could actually hear the doctor say that, and you could hear in his mom's voice that it meant a lot to her. It was more than us calling her and saying it: she heard the authority say it."

That patients and caregivers find ways of reclaiming agency when necessary also seems visible in the roughly even numbers of Power: Disciplining (100 occurrences) and Power: Dispersion (118). Patient access to information and technology (and information accessed through technology) seem the primary means of dispersion, but it also occurs when one patient/caregiver teaches another something they learned previously, whether that initial lesson came through a medical professional or courtesy of another patient or caregiver. As discussed in Chapter 4, the health literacy work of patients and caregivers involves taking information in from a number of sources and making sense of

these multiple (and sometimes conflicting) data streams as they work through what are often ill-defined problems; this process of moving from a state of having information to a state of being knowledgeable often involves high levels of oral practices. Alongside these, we often see high numbers in the knowledge code categories. This indicates that the process of talking through what has been found is an important step in the production of patients' and caregivers' knowledge.

Unfortunately, another pattern noted in the data indicates that physicians are not always supportive of this practice. At times, physicians don't seem to want to take the time to explain things. Consider this focus group member's comment:

I remember...when I did...I don't know if it was my chemo or my radiation, I wanted to know what exactly it's going to do. I believe it was radiation. I wanted to learn more about it before I did it. And...I...I...sensed the doctor didn't want to go too far. "What is it that you need to know?!" [said very impatiently]. You know something like that. I didn't like the way he reacted.

The patient did not ask again. The group suggests that this kind of reaction occurs mainly because physicians do not have much time to spend with us before having to rush off to the next patient (particularly when one considers how much face time our insurance payments really cover). Michael comments at this point:

You know what's surprising about it though is if you have patients that have some medical literacy it really doesn't take that much time because they already are understanding what you're talking about, so they have some information already. It's not like you're trying to completely educate the patient.

Despite this, when patients bring in information from outside sources, they too often seem met with “disciplining” reactions; nearly every member of the focus group volunteered a story of such a moment. As Michael explains it, “It seems like as if they’re [the doctors] not familiar with it, then...they get defensive. It’s the whole attitude of ‘I don’t want to appear like I don’t have that information.’” Denise agrees, saying, “I do think it’s different if you bring in information that they’re not comfortable with. They’re trained in traditional medicine, so as soon as you broach integrative medicine, holistic medicine, alternative medicine, most of them get downright angry.” Some study participants indicate they have experienced the same reaction when bringing up questions about a published, and seemingly quite credible, medical study. One member suggests:

Don’t you think some of the attitude--and not in just the medical field but in every field...? I mean if you go to a tire store, they want to make sure their butt’s covered, so they don’t get some frivolous lawsuit shoved at them, you know what I mean? I’ve got to think that ... they want to keep things kind of hush hush and in their control, so they’re only going to give you enough information to get a smile on your face and stop there.

To this, Denise replies:

I think there’s some CYA like you’re saying, but I also think the other thing is there was a time when the doctor was the ultimate experts. And now when you bring questions, if he can’t answer them he actually has to step down in his own perception of who he/she is and actually be able to say and still be comfortable in saying “I just don’t know.” When’s the last time you actually had a doctor look at you and say, “I just don’t know.” They look at you and they say, “This is what you should do.” “Don’t look at the Internet.”

It seems obvious that negative reactions can discourage patients and caregivers from sharing their research, their questions, and the thinking behind their decisions in the open and honest ways true partnership would require. When one considers the high levels of knowledge production documented in many physician-patient conversations, and often about information brought in by the patient or caregiver, the impact of this can be more fully understood. Denise confirms this question, saying:

too many doctors act ... actually intimidated or challenged when you question them and sometimes to the point where they don't want to be your doctor. And that can be intimidating to a patient because then you're faced with, well if he tells me that if I keep asking questions he doesn't want me as a patient, then where do I go? Who do I see?

Denise is not alone in this fear. A 2005 study by Davey, Armstrong and Butow finds that cancer patients "need for certainty, trust in their doctor and concerns about the effect of undermining that trust, appear to influence whether [patients] would discuss independent information with their doctor, and how they would deal with conflicting information" (349). The authors suggest that people writing prognostic information, and doctors, must take these concerns into consideration. They advise that medical practitioners be willing to discuss information patients have obtained, to the extent of initiating such discussions in order to encourage patients to discuss such items with them, and that, further, all "independent information should contain an acknowledgement that the information may be different to that provided by a doctor, and that patients should discuss the information with their doctor" (Davey et al 354).

It is perhaps notable here that a few support group members were uncharacteristically quiet throughout the focus group interview. In our follow-up interview, Flora stated:

You know that the folks in the group that I knew were--like lower income, you know, typically on Medicaid for insurance--were the ones that really didn't speak up about the fact that they had researched. And one of them kind of said to the side to me, "Oh I've just, I just go with what the doctor says. I haven't really done any of that...." Again, all patients aren't given all opportunities, or don't have the skills to tap into all...alternatives, opportunities. The same with their pursuing of their health care, same kind of thing? Because the stats show the folks that aren't insured at the time of the diagnosis, their mortality rate is much more significant, so then you wonder, too, again, this is like another barrier.

When asked whether she believes access to health information is mostly, then, linked to class and/or educational background, Flora replied:

yeah, I think so, and being that those opportunities aren't there because of that. The access to how do you use a library, how do you use a computer, and they're kind of focusing on their basic needs, like maybe I've lost my job because of this. And my housing, my food's in jeopardy, so I'm working on those things and I don't have the energy to fight this too.

Flora also commented that limitations in Medicare and Medicaid coverage might cause research into options into second opinions or treatments to be frustrating on another level: by revealing options that aren't options under this level of coverage. Based on her professional experience, Flora believes that overall the "publicly insured" are much less likely to engage in the sorts of research practices other support group members take for granted. While the most recent Pew Report on the use of online health resources reveals that "eight in ten Internet users go online for health information" ("Online Health Search 2006" ii),

placing “health searches at about the same level of popularity ... as paying bills online, reading blogs, or using the Internet to look up a phone number or address”, the report also lends some support to Flora’s assertion:

[t]he percentage of Internet users who search for health information has been stable over the past four years, even as the Internet population has grown and broadband connections at home have become the norm. As in 2002 and 2004, certain groups of Internet users in 2006 are the most likely to have sought health information online: women, Internet users younger than 65, college graduates, those with more online experience, and those with broadband access at home (“Online Health Search 2006” ii).

Access, however, is a complicated issue. Clearly the use of the Internet as a health literacy resource depends on access to technology, and the skills to utilize it, but certain exigencies may drive patients others might not expect to have Internet access, much less be “Internet savvy,” to nevertheless find ways to access this information.

For example, Denise and Michael refer several times to having dial-up access at home, which frustrates accessing digital resources; they work around this by making use of high-speed connections and printers at work to make digitized information available for offline use. Patient Resource Rooms at many cancer centers provide similar workarounds by making available both volunteers to help people use computerized sources of information and printers. Further, as we have already seen, many patients or caregivers may have other “helpers” doing this part of the research for them. Pew’s “Online Health Search 2006” report reveals that an astounding half of all online searches for health information are done on behalf of someone other than the person at the

computer (5). In an article entitled "Internet Access and Empowerment: A Community-Based Initiative" Christopher Masi et al offer further support. They report on a project that provided "in-home Internet access and training...to volunteers" in a 57-block area on the West Side of Chicago (Masi et al 525) who then were expected "to obtain health and safety information for themselves, their families and their neighbors" (526). The project also developed a webpage with links to "general and community-specific health care resources...to support [volunteers] in this role" (Masi et al 526). The study found that "Internet-access to community-specific and general health information can lead to increased empowerment and appreciation of information technology" (Masi et al 525). Clearly patients without personal access to the Internet may make use of this resource through other means. The determining factor in how much health literacy work a patient does appears, then, not to be rooted solely in issues of access to technology; the true access issue here may be that of access to more critical understandings of the doctor-patient relationship.

In Chapter 1, I referenced Paulo Freire's concept of critical consciousness, or *conscientizacao*: because it represents a certain mode of political consciousness and carries with it a sense of personal empowerment and agency allowing one to address contradictions and oppressions, *conscientizacao* is a critical concept to this study. The data makes clear to me that there is a continuum of development to health literacy. Health literacy, in its most basic form, is something akin to alphabetic literacy, a skill set that enables patients

and caregivers to understand and follow simple medical directions. As patients and caregivers continue working on increasingly ill-defined medical problems, however, they build more complex understandings not only of medical information but also of medical institutions, including insurance, developing a health literacy that

...encompass[es] the skills and abilities in these definitions: (1) functional health literacy--basic reading and writing skills to understand and follow simple health messages; (2) interactive health literacy--more advanced literacy, cognitive, and interpersonal skills to manage health in partnership with professionals; and (3) critical health literacy--ability to analyze information critically, increase awareness, and participate in action to address barriers (Nutbeam qtd. in Korta 2.)

Critical health literacy, and true partnership with our physicians, requires breaking through many obstacles including disciplinary knowledges, but also ideologies. This critical health literacy, then, is something like *conscientizacao* in that it involves breaking through existing ideas about the doctor-patient relationship and being willing to take on the work of engaging with medical research as well as analyzing medical procedures and institutions in light of the very real power relations that exist. In order to explore the exigencies--the conflicts of power and disciplinarity--that may help patients develop this high level of health literacy, in the remainder of this chapter I will share with you the diagnosis stories of my participants, Celia, and Denise and Michael. These stories clearly demonstrate that their health literacy work was initially stimulated by issues of power, leading these individuals to the development of a deeply critical health literacy.

Celia: the Balker's Code

As I mentioned earlier, Celia's mother fought breast cancer twice, dying of it at age fifty-seven. She lost other members of the family to other cancers. Given this history, both Celia and her doctors watched her body carefully for changes or signs of cancer, particularly of the breast: she received a baseline mammogram at age thirty-five and returned annually. Despite this, important information slipped through the cracks. Of this, Celia writes:

When I was forty, the radiologist reading that mammogram recommended that a calcification in my left breast be checked again in six months. When my doctor relayed that recommendation to me, he failed to go into detail about what the presence of a calcification could imply. This is a prime example of the presumptuous attitude held by many Whitecoats [doctors]. They somehow think that the patient is truly better off on a strict need to know basis. The expectation is for the client to have complete trust in their degree of education and diagnostic experience. All inquiry and attempts on the part of the client to self educate just muddles up the processing of the patient through standard clinical procedures. I started slipping. I failed to look after my own best interests. I didn't think to search out a specialist.

Celia, in fact, did need to know. Had Celia known what a calcification could mean, she might have been more proactive in her follow-up care. While I am not a doctor, even a cursory exploration of Internet information on calcifications in breast tissue reveals that, while these are common, a questionable calcification should be rechecked in six months, as it could be an early indication of a more serious problem. Celia did not fully understand this. Although both Celia and her husband noticed a lump forming in her breast over the next year, she dismissed it to be fibroid, an assumption she made "...because it was all the doctor ever talked about when [she] went for an examination. [She] had heard from him

over and over again that the texture of [her] breasts was completely dominated by fibroid tissue.” Her next visit to the doctor was nearly eighteen months later, for an overdue annual checkup. She also had another mammogram at this time, much later than the six months later suggested. In other words, partial medical knowledge led to what seemed a minor delay in follow up care. She now feels that the kind of education she received about breast cancer, even given her high-risk status and the early warning signs encountered, was non-existent prior to her diagnosis. The information she could have used then was given to her AFTER her diagnosis, as we will see, when by that point she needed a completely different type of information, a need she says was largely unfulfilled by medical professionals.

Shortly after her overdue checkup, Celia received a phone call saying that there was an elevated count on a liver function test, and they would like to repeat it. This could, and perhaps even should, have been a tip-off. Celia, a woman who watched her mother fight cancer, twice, and who had been through years of tests watching for just such an occurrence, knew what this elevation could mean, and was frightened by the news. She returned to the lab for another blood draw, and then to her doctor’s office for the result. Celia writes:

Without preliminaries, Nurse Uptight said, “Well this obviously has to do with a drinking problem!” She never even asked me if I drank alcohol. ... Then the doctor, Dr. \$200 Casual Slacks, sauntered by. He deigned to show me on the print-out where the normal range for that blood function should be. He prescribed large doses of vitamin B, folic acid. He, too, casually mentioned...that this elevation was affected by the amount of alcohol in the blood stream. He went no further in the discussion. The trace of condescension in his voice set me at odds. I left his office

thinking, "Gee I just paid \$500.00 out of my pocket for this check-up and I've been treated as if I'm a worthless drunk."

Sometime later, Celia's nipple inverted and her breast changed in other drastic ways. It was obvious something was wrong, but, she writes, "I found it impossible to call my 'compassionate' personal physician. I remember how I was offended by his casually presumptuous attitude back in August." While, again, I am not a doctor and there may well be reasons why her physicians assumed the test results were caused by alcohol consumption, their handling of the situation does not precisely encourage a patient to confide in them--particularly when that patient is without medical insurance, bearing the costs of preventative/prophylactic care and tests out of pocket.

The changes in Celia's breast frightened her, but despite this she did not return to the doctor; not yet. Not only was she put off by his behavior, Celia and her husband were newly married, and did not have medical insurance at the time. Eventually, unable to shake her worry, she did call the office to ask for her most recent mammogram result: "...the radiologist's report said everything looked fine. [She] felt relief for about two days and then [she] looked at [her] deforming breast and...knew things weren't fine." She suggested her husband shop for an insurance policy and tried to wait patiently while he did. Celia writes:

Somehow, I knew that even if I let a month go by between the time we purchased the policy and the day I actually found out what was going on, our new insurance company wasn't going to be happy. We were about to spend \$75,000 insurance dollars on medical expenses. I felt that I couldn't see a doctor with my concern until the insurance was bonafide.

When she was able to return to a doctor, she was sent for a needle aspiration biopsy, and following that a surgical biopsy. Celia was at diagnosed at stage 3. Her cancer cells had escaped the margins.

Whether the doctor's and nurse's assumptions about the test were based in previous experiences with Celia or with other patients, they led to a missed warning sign. These actions are one of many I conceive of as "disciplining." While alcohol in the blood stream can cause this elevation in a liver function test, even my cursory reading on the subject suggests it is not the only thing that can, and further that liver function tests are often important in the diagnosis of cancer. Additionally, if Celia had a drinking problem--an addiction with physical side effects, and even, potentially, a physical (i.e. genetic) causation--one would expect a medical professional to find a more helpful way of discussing this with the patient. My feeling is that drinking habits are probably the most common reason for elevated readings on this test; the doctor may therefore have made an assumption based on the status quo. The assumption made by Celia's doctor and his subsequent treatment of her distanced her from her health care providers, leaving her less willing to communicate openly with them during what turned out to be a crucial time. Celia's diagnosis was delayed because she was offended by the assumption that she was a drunk. (She is not.) Her care was then further delayed by a lack of access: without insurance coverage, the costs of the tests required for diagnosis would be prohibitive. And, without insurance

coverage at the time of diagnosis, this would go on Celia's permanent record as a pre-existing condition, causing coverage problems for years to come.

Following her biopsies, Celia had an appointment at Big Waters, one of several cancer centers in the region. As I mentioned in Chapter 4, this visit did not go well. The day began with the screening of an educational film:

Big Waters Cancer Clinic reserves Thursday mornings as the day wherein all the women who've tested positive for breast cancer...are treated to their treatment plan. The patient is encouraged to bring as many family and friends as they like for moral support. There were only two of us that day. I brought [friend, Maya] and [husband, Dan]. The other woman brought five relatives and friends with her. First, we all sit in a conference room and watch a detailed educational film describing in laymen's terms the exponential growth of one little cancer cell and its evolution into a detectable tumor. It describes what happens when the cancer cells escapes the confines of the tumor wall and make their way into the lymph nodes. It spoke also about how different cancers originate in different parts of the breast and have different rates of growth. So far, we only know that we both have cancer. We are kept in suspense for two hours before finding out (though it has been ungraciously hinted at throughout by the physician's assistant) which one of us has the fast growing, metastasized cancer and which one has the contained curable cancer.

In our interview, Celia adds a bit of detail to this account, saying "...the nurse practitioner who was leading it, she goes 'now one of the women here has a really bad case of cancer and the other woman doesn't' and we're sitting there with all those families, and we don't know who's got the bad case and who doesn't." What is particularly upsetting about this treatment is that while the families don't know who had the "bad case" and who might live, Celia knew that her cancer has been confirmed by two kinds of biopsy, and that the surgical biopsy showed it to have escaped its margins. Putting this together with the information she has just been given in the film, she now has just enough

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information to be terrified, and nothing to do with the knowledge, knowledge that might have been useful to her earlier in life:

I remember thinking through the haze of shock that all women should have the opportunity to see this film, to be aware of the details way, way, way before the day of diagnosis.

In our interview, Celia, remembering this moment, comments that the only other information she ever really saw about breast cancer was a poster, located in the dressing room adjacent to the radiation treatment area, reading: "A mammogram caught my cancer at stage 0. Have a mammogram today." Celia says she has often wondered why the information she was given after her diagnosis wasn't shared with her in the preceding years of prophylactic care when it would have been useful to her. Her post-diagnosis research practices, explored in Chapter 4, also make clear that the information she was offered by her medical caregivers following her diagnosis was not appropriate to her needs, or at least did not fulfill her needs. In these observations, Celia demonstrates a kind of critical health literacy that enabled her to function in the medical system, but also that enables her to critique the system.

Following that movie on the first day at Big Waters, patients and their families meet with "a representative physician from each phase of cancer treatment." Celia's account of this is reminiscent of my account of participating in grand rounds at the dermatologist's conference. She writes, "One at a time the physicians enter the room where the patient is sitting in a gown, trying to make brave small talk." There is perhaps no place that a human feels more powerless

than there, in an exam gown, before the gaze of these knowledgeable people we hope will heal us. As revealed in Chapter 4, the news each physician brought Celia was uniformly grim: the cancer was aggressive, the treatment would likewise be so, but “extending hope was unethical.” She had two, perhaps five years to live, even with this aggressive treatment. To add insult to injury, the radiation oncologist even jokes about “there not being really very much breast tissue.” Celia is quite slender and slight in build.

Celia’s feelings are made clear in the names she gives them in her manuscript. They are called: Dr. Hark Unto the Angels, who told her she had “a few good times ahead”; Dr. O Let me Tell You Your Future, who told her she had two to five years, which made Celia feel as if the doctor was playing God; Dr. Negative Nan, who (Celia writes) actually “really tries to be optimistic” when you first meet her; Dr. Going to Move and Leave You (who earned her name later); and Dr. Almost Honest, the plastic surgeon. When Celia writes of doctors in a general or collective sense, she refers to them as The Whitecoats. Her choices in pseudonyms underscore the very real power differentials that exist between doctor and patient, as well as the effects interpersonal communication skills may have.

Celia had learned from her pre-diagnosis experiences. She, and her support network, began to ask questions and to seek answers, but their opportunities to do so were limited at this stage. Celia’s friend Maya, who accompanies her throughout her treatments, asked “point blank whether or not

the radiologist had failed to read the most recent mammogram properly” the doctor reluctantly told them that biopsy showed a “significant change in the calcification that deserved more attention than the two sentence report stating that there were no abnormalities present.” The parade of doctors continued. Following this, Celia writes, they were sent to the waiting room, to wait for:

I don’t know what. The minutes ticked away and I started to lose the frayed edge of my composure. I went out into the hall to cry. ...I really just wanted to go home and voiced this to [Maya], who being the excellent caring friend that she is marched over to the closed door of the conference room, knocked boldly, and demanded of Dr. Hark Unto The Angels that he finish his business with us. ...what they were doing is eating lunch.

As detailed in Chapter 4, Celia drove herself home from that visit, stopping at a health foods store to pick up information on nurturing herself and healing herself. Celia explains that, considering the many ways in which information was withheld throughout her diagnosis experience, not to mention the ways in which Celia and her family was received at Big Waters, she had no reason to feel that all of her needs could or would be met there. She trusted medicine to do what it must, but did not feel she could trust it to do all that was needed to support her body, mind, and spirit as she went through the surgeries, chemotherapy, and radiation that lay ahead.

Celia’s subsequent research, discussed in Chapter 4, focused both on understanding her condition and treatment options, so that she could make decisions about them, but also on complementary therapies and spiritual nurturance. Celia is not alone in seeking these types of support. Many patients

feel the need for spiritual care. The focus group also discussed issues related to this. Denise wanted to make sure, in fact, it was included in this study, stating, "...one thing we haven't mentioned, and one thing I saw especially in the South is that some people, their faith is entirely in God. And the doctor respects those people and where they are religiously."

When physicians appear to tread upon religious beliefs, as Celia felt Dr. O Let Me Tell You Your Future did in telling her how many years she could expect to live with treatment, on the very first day they met and without taking her beliefs or positive, can-do attitude into account, this feels like an unnecessary act of disciplining. According to Mayer and Villaire's *Health Literacy in Primary Care: A Clinician's Guide*, many patients believe their spiritual beliefs are relevant to their medical care, and should be therefore be relevant to their physicians:

Patients in [McCord et al's 2004 study] believed that information concerning their spiritual beliefs would assist their health care providers in encouraging hope (67%), giving medical advice (66%), and changing medical treatment (62%). In addition, King and Bushwick found that 70% of patients would welcome physician inquiry into their religious beliefs, 55% would appreciate silent prayer, and 50% believe their physician should pray with them (112).

The encouragement of hope, which Celia believes helps strengthen the body and therefore impacts treatment, is precisely what she was missing.

While this is understandable--our physicians and medical professionals are, after all, wo/men of Science and not religious or spiritual leaders--when doctors and patients engage in life and death discussions together they are still two humans, each with a body, a spirit, a culture, and a belief system, about

medicine, health, life, and death. The physician, through long practice, has cultivated clinical distance. The patient has not, and to some extent cannot: their life is at stake, and that perhaps naturally brings up issues of religious belief. Because of this, Mayer and Villaire's *Clinician's Guide* reminds physicians that "regardless of the religious or spiritual attitudes of health care providers, religion and spirituality permeate all aspects of life for patients who are devout." (112). Further, our beliefs often affect our medical decisions: "all patients...make decisions about what is medically or morally good according to a specific worldview or thought tradition. When religion and spirituality are part of the patient's tradition, the effect on his or her health care is compounded" (Mayer and Villaire, 112).

Celia shared, at times, the results of her research into medical treatments and complementary treatments with her physicians and other medical professionals. When asked whether she shared her research into complementary therapies with the doctors, Celia says:

they shook their heads and laughed. You know: "I'm on the cancer diet," [met with] like "oh...so what." I mean there was a very, very distinct... attitude on their behalf about helping yourself, other than what they gave you. And they don't give you anything. No personal help whatsoever.

In other words, Celia's research and her attempts to discuss this knowledge work with her medical supports were met with the same sorts of disciplining comments reported by other focus group members who broached the topic of complementary therapies. Celia's research into, and questions about, the medical treatments she was receiving were met with responses varying from

disengagement to outright hostility. She says, "You know, there's such a resistance there. It's like they want you in their hands; they want you to be their... I felt like the sheep being herded through this treatment plan."

Celia's treatment as detailed here and her perceived lack of support for the whole patient throughout her cancer experience perhaps understandably prompted her to do extensive research to supplement her treatment and her understanding, but further led to her return to school for a degree in holistic health, and her manuscript. In many ways, Celia moved from being a passive recipient of medical care to an engaged and proactive participant in her own care. Further, she developed advanced knowledge about health and medicine that enables her to function today as a critical user of the system. This is evidenced throughout her manuscript, which aims to teach future patients how to be agents in a system that does not encourage it, in order to navigate a system that does not--or cannot--support them as whole patients. Where other activists have responded to the power conflicts detailed in Celia's story with a Patient's Bill of Rights, Celia's answer is "The Balker's Code of Behavior," which she has graciously permitted me to reproduce here in full:

1. Remember Balking is Good! It means that you have spirit, that you are unwilling to let the prevailing authority or the hypnotic influence of mass consciousness sweep you up and trash you power.
2. Balk! Refuse to Cooperate if a social worker, anesthetist, technician or chaplain appears at your bedside and beings to interview, question, or prod without your consent or prior arrangement.
3. Balk! Refuse to Cooperate with inconsiderate and unnecessary delays in the return of test results.
4. Balk! Refuse to Cooperate as soon as your doctor begins assuming that he/she has carte blanche for administering your treatment plan. Question

- everything: “do I have to have this blood transfusion? Where does the blood supply come from?” Take a pen, paper, and a stern looking friend.
5. **Balk!** Refuse to Cooperate when you start to feel overwhelmed by the intimidation process that is a built in feature of taking a cancer tour through the hospital jungle. Retreat to a safe place and regain your focus and strength.

The Balker’s Code, a reminder to patients to speak up for themselves, is tangible evidence of the critical health literacy Celia developed as she moved through the medical system. The Balker’s Code, as is much of Celia’s manuscript, is a catalogue of the dispersion techniques she utilized to push back against acts of disciplinization, or maintaining the status quo. Celia hopes to publish this manuscript in order to help other patients help themselves, as she did. These techniques force the doctor and treatment center to remember the patient is an individual, and remind them to share information in ways that help the patient make knowledge and decisions. Each patient lives through this experience only once, and deserves appropriate information and agency in the process. My study suggests that the degree to which this happens does not depend entirely on the patient or caregiver’s health literacy as a body of knowledge about medical treatments, but also on health literacy as a state of critical consciousness--a set of information, resources, and knowledge about access--required to navigate medical practices and institutions in a much more agentic way.

Denise and Michael: Be Prepared

The story Denise and Michael tell of his diagnosis is fraught with both the same kinds of miscommunication, as well as acts of disciplining, as was Celia’s.

Ultimately, the instances of disciplining they experienced prompted their research

and the development of deeply critical health literacy skills--tactics of dispersion they are now using to help both themselves and other patients met in support groups and waiting rooms push back against the status quo. Their participation in this study, in fact, is an act of dispersion. While they are overwhelmed with work, home, family, and the ongoing physical and emotional needs of managing Michael's care, they felt it important to make time to tell their story. They believe it is time for medicine to change, and time for patients and caregivers to become more pro-active, and hope that sharing their diagnosis story and their health literacy practices will help this process.

The first real step towards Michael's diagnosis came when he was in Washington DC on business. While away he had a pancreatic attack and was in such severe pain he had to be checked into the hospital, where, Michael says, "basically they kept saying you know, kept hovering around the fact that I must be an alcoholic. 'You don't get pancreatitis attacks unless you're an alcoholic.'" This is somewhat ironic, given that Celia's doctors made the same assumption about her liver function test, and it seems equally unfounded. While (again) I am not a doctor, several Internet sources from trusted medical authorities state that the causes for pancreatitis are many, including medications, infections, trauma, and metabolic disorders, and, in fact, in ten to fifteen percent of patients, the cause is not known. These physicians made an assumption, likely one based on the most common cause, or the status quo. This was likely exacerbated by the

fact that Michael was out of town, and unknown to these physicians, but not necessarily.

Denise remembers:

...every shift change there was entirely new staff...and they had no idea what had happened in the last ten or twelve hours. They didn't know who had done what test, they didn't know what was going on, they didn't know what he was on, and he had to start all over. We were not important. Lost.

Eventually, sensing no answers would be found there, Denise simply put Michael in a wheelchair, checked him out, and flew him home to follow up with their family physician. It was later discovered that Michael had multiple myeloma, and that the pain he was experiencing was due to a lesion on his pelvis. He was in bad shape, and was in and out of the ICU a number of times, where he felt as helpless as he did in D.C. Denise told me:

When [Michael] originally talked to you about this, he was very interested because one of the frustrating things was for him there were times when he knew he was out of it and he wanted to feel like there was somebody with him, dealing with the doctors, and like especially when he was in intensive care. They kept insisting that I stay out. And I could only go in for very limited times. Well it never failed when it was a visiting time then they'd take him off to some test or something so we didn't even really get our visiting times in ICU. Well he had a really weird phenomenon where his voice would go and people couldn't understand him so he'd get even more frustrated and angry. And so then I tried approaching the resident who was in charge of ICU and he just absolutely refused to let me spend any extra time, they would come in and do rounds and all this and my husband...he got mad at them. Because they would ask him stuff, and they wouldn't understand him because he had hardly any voice. But they would refuse to come get me even if he wrote, "Go get my wife." And he said that whole attitude in the hospital just really...it made him feel helpless and it made him feel like he was really at the mercy of whoever was in charge and he wasn't going to have any say....

In truth, the hospital was likely following procedure on this point; however, it shows a troubling lack of attention to the patient as an individual. It is another instance of disciplining the individual for the benefit of the system.

For personal reasons, Denise and Michael did not immediately share his diagnosis with their parents, siblings, or adult children. The choice of when to share the news was ultimately taken from them. One weekend, their daughter came home for a visit when her father happened to be in the hospital. Before they could tell her anything, a nurse came into the room and, without asking who this person was or whether they wanted her privy to Michael's medical information, the nurse asked: "How long have you had myeloma?" Denise remembers her daughter's eyes going wide with fear. They were forced to make a series of phone calls telling their geographically dispersed family, then and there, no matter how poor the timing for any particular member. Denise said they had no choice, at that point: her daughter needed to be able to talk to whomever she needed to about her feelings, so it wasn't fair to leave her the only one knowing. It also wasn't fair to break the news to the family this way. Denise and Michael accept their share of this, but still resent it: they had not told the family yet because so much of the family lives out of state. They wanted to do this face to face. Perhaps HIPPA, today, would have prevented a nurse making this statement in front of anyone but the patient without permission, but perhaps not. The nurse was likely just making conversation. It was a thoughtless human error of the kind that feels like disciplining, even if it was not intended

that way. Disciplining need not be intentional. It is often ideological, systemic, and nearly invisible even to its agents--but its effects are not.

Soon after, Denise and Michael were referred to an oncologist at Big Waters where they had further conflicts, foremost among them a doctor who was consistently quite negative, and with whom they had poor communication. They were offered no hope and, in fact, no real treatment options. In our interviews, Denise and Michael offered numerous examples of how things went wrong between them, this doctor, and this center. Denise still, years later, questions why physician-patient communication was so ineffective, and even offensive, in this case. She wonders if they did or said something that just caused a poor interpersonal relationship, or if the doctor was just burnt out. She also, however, says that based on her initial research as well as their interactions the cause doesn't matter. They had little faith in this physician, and ever more critical reasons for it:

...she might be a doctor, but the woman is stupid. She's looking at stuff that's fifteen or twenty years back in the books. And she's not offering us, or even willing to talk to us about anything that's out there now. Well and then you couldn't get like mortality rates in this area, you couldn't find mortality rates from any of the doctors or any of the hospitals for myeloma patients.

Denise had begun doing research, as discussed in the last chapter, and tried to engage their doctor:

...in some conversation. And she kept blowing me off and blowing me off, almost to the point of being rude and saying shut up. So then it was like, every week that we went, she still didn't want to talk about treatment options or anything. "Well it's too soon," she'd say. How can it be too soon? "It's too soon."

After several visits, Michael had not yet received any treatment, and Denise had no reason to believe any treatment from this physician would be fruitful. The lack of a treatment plan and the doctor's interpersonal manner were frustrating, and dangerous, and the lack of information sharing practices caused ongoing problems:

She didn't tell us what stage it was at, she never gave us any results from any of the tests.... Typically she'd run a blood test on a Tuesday or Wednesday and then she'd leave a phone message--not on his cell phone, but on the house phone--on Friday when they closed at noon. So that always forced us to the ER for the weekend. The message would say, if you don't get this in time the ER will know what to do. The ER would be looking at you like, who are you and why are you here? And then they wouldn't let you go because they couldn't get her in.

Denise and Michael began seeking a good place to get a second opinion. As Michael explains it, he had no choice: "they were killing me here." They chose the Apple Blossom Center. Denise sold her lambs "shoved the money in [her] pocket and [they] took off," because, she says, "I was really dreading those insurance policies. And we had called the doctor here and I asked him if they would give us a referral and they flat out refused." Michael adds, "Not only did they refuse, but they really blocked us when we tried to get the records from here." The records, supposedly, were lost. Whether this is true, or is an act of disciplining patients is unknown. Because of this problem, Michael and Denise happened to call the lab to see if anything was still there. In the end they were able to take with them only one pathologist's report on the bone marrow, so recent that the paperwork and sample were still in the lab. By the time he got to

the Apple Blossom Center for a three-day series of tests, Michael, who had seen his local doctor only the day before leaving, collapsed. He had been cleared for travel with pneumonia. A copy of the Apple Blossom Center's first dictation from the doctor "basically blasts doctors from Big Waters as unconscionable because the patient wasn't treated and progressed to stage 4."

In addition to the very real physical consequences, the series of events leading to Michaels' diagnosis and treatment left the couple feeling powerless, and hopeless. The health literacy work evident in the traveling notebook they subsequently developed (the contents of which were discussed in Chapter 4) clearly seems prompted by a need to feel empowered and proactive. Denise seems to be comforted and prepared by the notebook and the documents therein for two reasons. First, the notebook is, in a sense, a security blanket. In other words, it lets this family feel prepared that they will be able to produce the requested information and without making an error in, for example, the name of a drug, or its spelling. It contains the information a strange doctor would need to be familiar with Michael's complex medical history. Having access to this information presumably, would help forestall the kind of reception they had at the ER all those night. As I mentioned before, this notebook is, in a sense, an informed patient's paper precursor to the electronic medical record--perhaps even an extension thereof. The patients and caregivers consulted in this study commented often on how electronic medical records accessible to a very broad set of audiences, including their insurance provider, physicians' offices, hospitals,

treatment centers, and billing entities would vastly simplify the work required of patients. This is likely true; however, assembling these records is an important step in the production of health literacy. In any case, it is doubtful that electronic medical records will ever fully serve the needs of patients like these, and therefore alleviate the burden of maintaining a set of personal medical records. Patients involved in this study frequently commented that they doubted the likelihood of all the offices and entities they must deal with choosing one universal system.

Perhaps this is a good thing, in terms of developing health literacy skills, for the notebook is important, and irreplaceable, in a second sense. It is a valuable resource to Michael's physicians, but because of the couple's advanced, critical health literacy, it is also a valuable epistemological resource for them. In learning how, and where, to get copies of the documents in the notebook, Denise and Michael have learned much about medical and insurance systems, information that continues, exponentially, to enable them in navigating these systems. This is not always an easy process. Denise and Michael shared many instructive stories about the difficulties of gathering medical information from the institutions involved in their treatment. For example, she said stated:

I asked my insurance and his insurance to send me in hard print the [policy] manual. Well, they will, except the manual doesn't contain the part for a clinical trial. That's on page 56 and it's a special request and no they won't send it to you individually.

A patient must have this sent to a doctor on their behalf. Unfortunately, the willing participation of the physician and his/her staff in matters of insurance is not always guaranteed. Denise also revealed

we wrote appeals to fight for payments, and some of our appeals were as long as 85 pages. And we had to actually approach different parts of hospitals and people who treated my husband and trying to talk doctors, nurses, or staff people into giving you a statement, even though you and they agree that it's an accurate statement.... But the fact that they know you're going to use it to fight for money from an insurance company. It is very difficult to get them to give statements on paper.

In short, Denise says, the process of gathering support for an appeal involves "browbeat[ing] people to provide the supporting documentation," and worse "nobody tells you exactly what it is they want."

This family has learned specific content knowledge about their illnesses and treatments, but also about the systems of care and delivery, and, by making use of previously identified resources and learning processes, they are now able to read across relevant, self-identified sets of medical and insurance documents and make new knowledge. This enables them to be participants in their own care, and even self-advocates. The stories Denise and Michael shared with me contain many examples of this. One of the most compelling is an instance in which Denise solved a medical mystery. Michael, she said, suffered from severe fatigue following his treatments. To alleviate this side effect, was placed on another medication. Around the same time, his blood work became irregular: he had too many red blood cells. The doctors, and the family, feared a secondary cancer. Testing commenced. Denise continues:

...they were deciding whether they needed to treat it or not treat it, did we want to live with the possibility of him having a stroke or heart attack, could it cause kidney failure yadda yadda yadda. And I'm watching the numbers, trying to talk to [the local oncologist and nurse], and I've got Apple Blossom calling me asking "have you seen the last numbers, are you guys doing anything up there?" And...I saw this article in the newspaper. Actually Michael saw it and it was about testosterone and one of the side effects was causing peoples' blood cells to have a decrease in red blood cells. I cut the article out, called the doctor up, said we're going to have an appointment with you. I notice that he spikes after his treatment down here. Have you guys considered the testosterone? And that was it.

The doctors ran some more tests, administered testosterone, and Michael's blood counts came back to normal. Denise and Michael, who have high levels of information literacy that helps them ask questions and locate answers, and high levels of critical literacy that helps them move through "the system," are now sure to have a very different experience in health and medical settings than is patient whose health literacy skills operate at a more fundamental level, and more fulfilling and comfortable experience than that of the day leading up to, and just after, Michael's diagnosis.

Concluding Remarks

This study was designed in order to enable thick description of the actual reading, writing, and research practices of patients with the intention of understanding both the individual practices used as well as the context in which patients must develop and use these skills. The stories Denise, Michael, Celia, and the focus group members offered underscore throughout this study that the differential power levels inherent in the doctor-patient (or even Medicine-Patient) relationship have negative effects in that disciplining actions may distance

patients from their physicians, but the reverse may also be true. When patients and caregivers feel a lack of agency due to a lack of information, some find this to be an exigency prompting the development of ever more critical health literacy skills. As suspected, the issues of power--with seemingly small conversational difficulties underscoring more intention acts of disciplinization--play a crucial role in the development of patient and caregiver health literacy skills, but not necessarily in a predictable way. Much depends on individual agency and access. I believe, in fact, these skills exist on a continuum, with an individual's development dependent upon their individual contexts. I will explore this continuum and how disciplining and dispersion are linked to very different kinds of informed patients.

Chapter 6

WHO IS THE INFORMED PATIENT?

Overview

This study is intended to help address the gap in voices participating in conversations about health literacy (and related conversations, like decisions about health policy) by making actual patient literacy practices visible in the literature, providing thick descriptions of why, where and how patients learn to be informed, “health literate” patients. I wanted to understand what that term “health literacy” means in, and to, the lives of those central to the systems that are medical and health care. I wanted to describe the moments at which health literacy mattered to specific patients and caregivers, and document the practices embedded in those moments. I wanted, you see, to capture not just literacy, but also learning, and its contexts. In essence, then, this project was a study of both invention and access, and their role in the development and use of a specific avenue of literate practice. By making these contexts and practices visible, it is hoped that literacy researchers and medical professionals alike will gain a better understanding of the very real issues of access and power involved, enabling us to more usefully assess health literacy skills and support their development, an act that should reduce the impact of low health literacy for both individuals and our society.

This is an important matter on several levels. Estimates on the economic costs of low health literacy are available many places; however, one of the most thorough reports I read in this course of this research estimates low health

literacy to cost the nation and the system from \$106 billion to \$238 billion dollars (Vernon et al 6). The report further reveals this cost “represents an amount equal to the cost of insuring every one of the more than 47 million persons who lacked coverage in the United States in 2006, according to recent Census Bureau estimates” (Vernon et al 9). The authors go on to posit that, “when one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion” (Vernon et al 9).

As a participation in MSU’s “Meet Michigan” Traveling Seminar, I had the opportunity to hear many individual--including public health volunteers and officers, elected officials who’d had to cut Medicare funding, and physicians--speak on the state of medical care and health in Michigan. Issues in quality care were almost uniformly identified to be cost, access, and quality. Health literacy, which forms the basis for communication and partnership between patient and provider, is deeply involved in all three issues. The most important thing we can do to support health is to support public health, and public health involves health literacy initiatives. From a disciplinary perspective, then, this is important work for both rhetoricians and literacy researchers to contribute to.

In this chapter, I discuss my conclusions, which I believe are significant for the study of both rhetoric and literacy because of what they show of the deeply rhetorical nature of health literacy in both its acquisition and deployment. Further, however, they should be relevant to medical and social work

professionals interested in supporting health literacy practices and skills development. The results of this study show that patients engage in complex inventional practices, often in collaboration with others, and that patients and caregivers must then share that knowledge with other audiences: family members, other patients, medical professionals, and more. The agents and practices documented in this study clearly show “the patient” may be, and often is, plural. Further, my results indicate that “health literacy” itself is an ongoing and symbiotic act of invention.

Because of the fluid nature of the contexts in which health literacy is developed and practiced, and the individual nature of and support systems available to patient and caregivers as they make their way through these contexts, the informed patient exists on a continuum of development both bounded and driven by agency, practices, knowledge and power. The sum total of possibilities within this complex continuum is the true “definition” of/for health literacy. This complexity is what must be accounted for in the design of patient education materials, in the ways patients are supported, and in the ways doctors and nurses interact with patients. Based on these findings and in closing, the participants of this study and I offer recommendations for medical practitioners and future researchers.

The Informed Patient: A Continuum of Development

When I first met with the chief of staff at the medical center where I volunteered and conducted this research, he suggested to me a text containing a

chapter on the psychological adjustments cancer patients must go through. He suggested that patient and caregiver research practices are often a phase, like denial, bargaining, anger, or depression, and that once patients build trust in the physicians, the research practices stop. Having spent two years now listening to patients' stories of when health literacy mattered and what that work entailed, I think the doctor may be right, but that how much information is "enough" depends on contexts far broader than that of the individual doctor-patient relationship.

Taking Denise and Michael as an example, it seems clear that their health literacy work has not been simply one of the stages required for acceptance of the disease (although that much literacy work may be enough for other patients or their caregivers). Denise and Michael have now arrived at a situation in which they have a true, working partnership with their physicians at the Apple Blossom Center, and yet their research has not stopped. Their research will likely never stop, for it is those research practices, and the problem solving they represent, that equip this family to deal with the ongoing issues of access related to a diagnosis of cancer (or, really, any serious illness), from managing quality of life issues to staying on top of the ever-shifting mountain of paperwork required by tests, participation in clinical trials, billing entities, and insurance companies. While their skills are advanced, Denise and Michael's development as informed, health literate patients will likely remain ongoing. There is never a moment at which one can achieve a state of unchanging acceptance if the situation itself

does not remain static. Denise and Michael, then, represent only one possible informed patient.

At the end of this study, then, I believe there are certain factors that are always involved in discussions about health literacy, but the degree to which any individual develops and uses health literacy skills is simply NOT predictable. Engagement at the deepest levels involves not only health literacy as a body of knowledge about medical treatments--the level at which this doctor assumes research likely stops--but also of health literacy as a stage of critical consciousness--a set of information, resources, and knowledge about access--required to navigate medical practices and institutions in more agentic, even activist, ways.

Clearly, health literacy is complex, as is the process of acquiring skills and developing practices. Definitions therefore prove limiting in understanding health literacy (or, I would argue, other applied literacies, like computer literacy.) In the two cases presented in this study--those of Celia, and Michael and Denise--we see very different kinds of patients, all health literate in their own ways. While their practices teach us valuable lessons about the systems and structures of health, medicine, and health care, these individuals represent only two possibilities. The voices of focus group participants hint at others.

The individual behind health literacy work does not exist in a vacuum. Health literate patients and caregivers set out with questions, and read across multiple data streams, finding and gathering and sorting out information. I think

of finding these answers as finding information; being able to use that information for self-defined purposes as in making decisions, or self advocacy, or activism, are still higher states of development. In other words, there is a difference between having information and being literate. Part of the process of moving from an informed patient to a truly knowledgeable, or literate, one requires input from and discussion of ideas with others, whether that means patients, caregivers, physicians, or other medical professionals. It is this aspect of my work, I think, that makes it most valuable to literacy studies. I believe that invention is a feature of literacy, particularly of health literacy. This skill set truly seems best understood as a set of contextual and flexible practices, which enable patients or caregivers to identify when information is needed, to locate that information, and to make decisions based upon it. Because of the constantly fluctuating nature of health, the questions that must be investigated and the decisions that must be made are also constantly in flux. Because of the complex nature of our systems of health care, coverage, and delivery, health literacy questions further require increasingly complex investigations and negotiations. For all of these reasons, the informed patient--the user of health literacy--is best understood as existing on a continuum of development mapped in figure 2, following page.

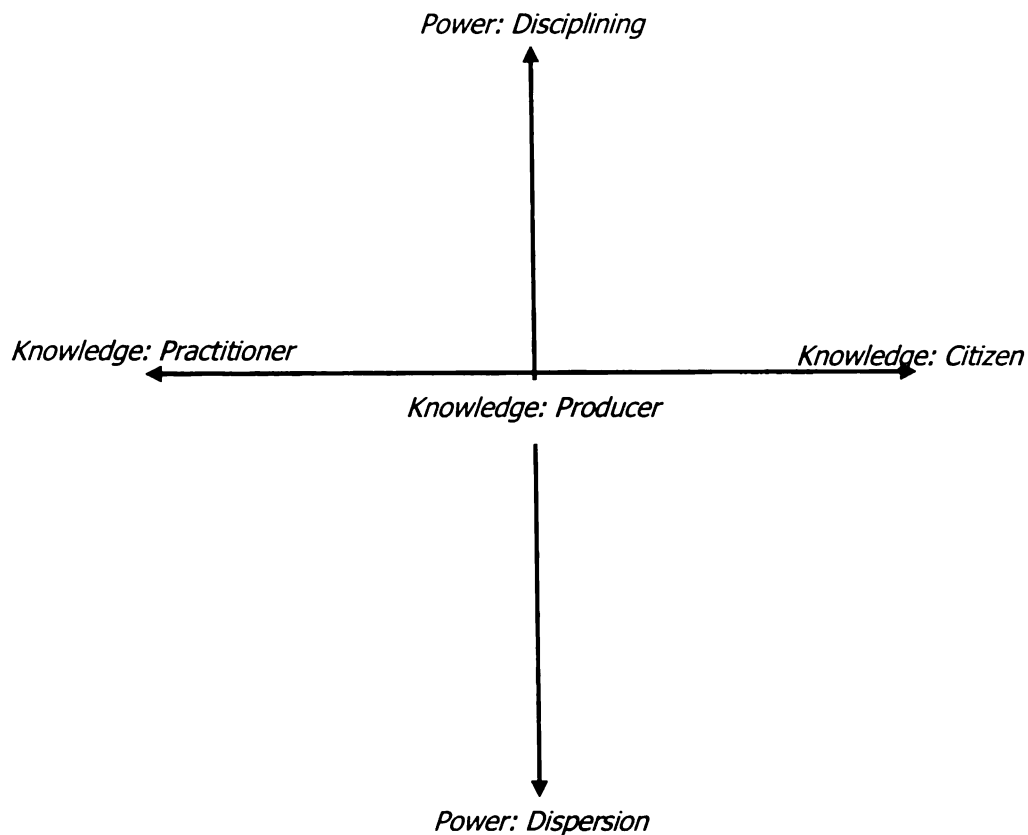


Figure 2
A Continuum of Health Literacy Development

This continuum represents a web of possibilities for disciplining and/or dispersion, embedded in practices and driven by power, access, agency, and knowledge. Along the horizontal axis of the continuum, I gauge disciplinary knowledge, with the left margin representing basic, practitioner-level knowledge, a level of development at which the user demonstrates knowledge of a technique, technology or system. At times, users may move from this stage to that represented by central portion of the map, the producer category: at this stage, the user has the ability to produce knowledge about a technique, technology, or system. The right margin represents the activities tracked in my

Knowledge: Citizenship category, a state of literacy at which the user continues building on their skills and knowledge to produce knowledge about a technique, technology or system, either alone or in cooperation with others, often for the purposes of producing a community or encouraging participation. An informed patient can exist anywhere on this map, but different locations suggest different types of patients, each of whom will have different skills and expectations (and, it is important to remember at this point, access to different systems of information and support.)

To illustrate the possibilities in envisioning health literacy as an enabling and contextual set of skills and practices, I have plotted four theoretical patients (of infinite possible patients) on this continuum (Figure 3, following page). The difference between these patients, horizontally, is the degree to which they and their support systems (caregivers, medical personnel, and more) have invented complex processes that enable their health literacy work. Adding a vertical plot to this enables me to consider the patient's relationship to both knowledge practices, and power practices.

The "traditional patient" is located in the upper left quadrant. This patient is, in many ways, consistent with the official definitions of health literacy: "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient" (American Medical Association qtd. in Center for Health Care Strategies "What is Health Literacy?"). The Institute of Medicine utilizes a similar definition,

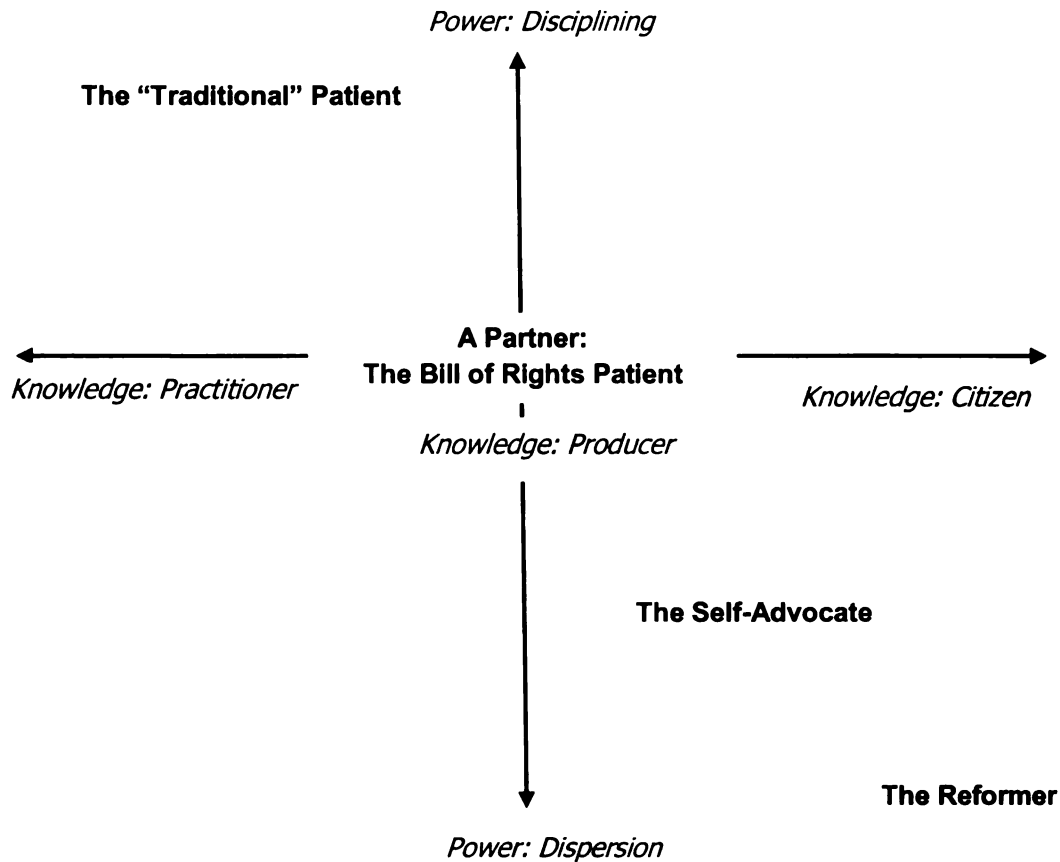


Figure 3
Four Possible Patients

conceiving health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Vernon et al 1). Both fit here. Literate in the sense of being able to read, this patient can understand basic health information and follow basic health instructions and does not act against medical advice or otherwise obstruct their own care. I have plotted this case higher up on the power continuum, close to disciplining: this is because this kind of patient is generally fully "disciplined," or indoctrinated in traditional expectations regarding doctor-patient relationships and content that doctor knows best. This

is Medicine's ideal patient: not precisely submissive, but cooperative, and knowledgeable enough.

It is important, at this point, to remember that variety is possible and infinite. Different types of informed patients exist all over this continuum of health literacy development. For example, I can envision two very different types of "traditional patient" occupying the same rough area of this concept map, patients who might appear the same, but whose practices are motivated by, and rooted in, very different contexts. Further, the same patient might occupy more than one position. This theoretical construct could be a patient with the luxuries of not having to worry certain aspects of health literacy work. Michael and Denise, for example, commented several times that patients with more money, and therefore more access to support services (like lawyers, accountants, and even professional medical advocates) have very different cancer experiences. These are the people, Denise and Michael say, who have the luxury of "coming back" from a cancer diagnosis. Not only are their lives less impacted financially, but also in terms of their time, and their interests. They are not overburdened with compulsory paperwork or research that continues to overtake the time once spent on things they enjoyed, and enjoyed researching. Alternatively, our traditional patient could be the quiet patient in the focus group, who does not research and "just goes by what the doctor says." The latter should concern us, particularly given the results of the National Assessment of Adult Literacy (NAAL) as presented in "Low Health Literacy: Implications for National Health Policy."

Remember, Flora revealed that our quiet patient is a Medicare recipient and believes, through her experience with this individual, that her practices are linked to her level of coverage. The NAAL offers support for this, explaining that “not having dependable health insurance is a significant deterrent to literacy in its own right, because uninsured persons are significantly less likely to use healthcare and, thus, may be that much more inexperienced in navigating the system” (Vernon et al 2). This report reveals decreasing levels of basic health literacy skills as one moves from those with employer provided insurance (with only 7% operating below basic levels of health literacy, the highest literate group), down through the military (12% below basic), those with privately purchased insurance (13% below basic skills levels), and finally Medicare and Medicaid recipients. Medicare and Medicaid recipients were found to be operating 27% and 30%, respectively, below basic health literacy skill thresholds. Further, the percentage of people operating at intermediate levels (40% and 38%) and proficient levels (3% each) were far lower than those in other covered groups, which ranged from 54 to 62% with intermediate skills and 9 to 14% with proficient skills (Vernon et al 2). Even the uninsured had slightly higher rates of health literacy development than do Medicare and Medicaid patients (Vernon et al).

Another useful position to consider is that at the center of the continuum where the line indicating disciplining and dispersion crosses the knowledge line, a

position I consider denotative of the "Patient Bill of Rights," which would be foundational to this patient's expectations of health and medicine.

The Patient's Bill of Rights was "adopted by the U.S. Advisory Commission on Consumer Protection and Quality in the Health Care Industry in 1998" ("The Patient's Bill of Rights"). The Bill seeks to clarify the rights and responsibilities of both patients and medical professionals, for the purposes of "helping] patients feel more confident in the U.S. health care system" and assuring "that the health care system is fair and it works to meet patients' needs" ("The Patient's Bill of Rights"). As part of this, the Bill also "encourages patients to take an active role in staying or getting healthy" and provides procedures for the redress of grievances, "giv[ing] patients a way to address any problems that they may have" ("The Patient's Bill of Rights"). The Bill states that all patients have the right to the disclosure of information in an "accurate and easily-understood" format; a choice in providers and plans; access to emergency services, the right to participate in decisions about their treatment, and that patients should expect respect, non-discrimination, and confidentiality ("The Patient's Bill of Rights").

This type of patient has some awareness of the practices and procedures of Medicine (and likely Insurance, a vital component in accessing medical care). This patient demonstrates more than mere knowledge; s/he can access information and produce knowledge about techniques, technologies and systems. This patient operates at the level of a partner, with veto rights. The "partner" patient, then, is health literate in the sense of being able to be an active

participant in one's own care, but is still largely accepting of traditional physician-patient roles, pushing back only when and as necessary to receive appropriate levels of care and respect. As an example: in Denise and Michael's leaving Big Waters without a referral or their records, insurance be damned, to consult a very carefully chosen clinic for a second opinion, they were reacting to clear violations in their basic rights as the recipients of medical care. At this moment, Denise and Michael began moving from "The Bill of Rights Patient" to a level of practice resembling that of the Self-Advocate. They possessed, by this point, not only a knowledge of existing practices and procedures, but also the ability to make new knowledge (as demonstrated in the criteria they used to choosing a treatment center and later, a treatment plan, one of a number of clinical trials and more traditional treatments available to Michael).

To consider the Self-Advocate and the Reformer, we must return to a concept mentioned earlier in this study: Paulo Freire's concept of critical consciousness, or *conscientizacao*. This is a critical to considering this stage of development, because it represents a very specific mode of political consciousness and carries with it a sense of personal empowerment and agency allowing one to address contradictions and oppressions. As patients and caregivers continue working on increasingly ill-defined medical problems they build more complex understandings not only of medical information but also of medical institutions, including insurance, developing a health literacy that

...encompass[es] the skills and abilities in these definitions: (1) functional health literacy--basic reading and writing skills to understand and follow

simple health messages; (2) interactive health literacy--more advanced literacy, cognitive, and interpersonal skills to manage health in partnership with professionals; and (3) critical health literacy--ability to analyze information critically, increase awareness, and participate in action to address barriers (Nutbeam qtd. in Korta 2.)

Critical health literacy, and true partnership with our physicians, requires breaking through many obstacles including disciplinary knowledges, but also ideologies. This critical health literacy, then, is something like *conscientizacao* in that it involves breaking through existing ideas about the doctor-patient relationship and being willing to take on the work of engaging with medical research as well as analyzing medical procedures and institutions in light of the very real power relations that exist. This is in some ways akin to Freire's pedagogy of the oppressed, in which "the oppressed unveil the world of oppression and through the praxis commit themselves to its transformation" (Freire 54). Critical health literacy is a crucial component in the most advanced levels of health literacy knowledge development, that represented by the citizenship code at the right-most edge of the continuum.

This level of critical development would be present in both the Self-Advocate and the Reformer, the differences would be in degree, and perhaps also in purpose. To illustrate: The patient I envision where I have plotted The Self-Advocate possesses all the abilities of The Traditional Patient and The Bill of Rights Patient, but also a critical awareness of the systems surrounding them, an awareness that is, at present, confined to advocating for the self. As an example, consider Denise and Michael, whose practices demonstrate that they are critically

aware of the pitfalls in current systems of medical coverage and health care. They frequently make remarks that reveal their deeply critical understanding of current systems of medicine and health coverage. For example, Denise speaks often of how medicine is shifting to a consumer-oriented model, and how patients must begin to make this shift as well:

...no matter what anybody says, medicine is a business even in a not-for-profit hospital. So it has to operate as a business, otherwise you end up doing layoffs and closing floors. Um, and...unfortunately, you can look at a procedure and we don't do this--we do it with our cars, we'll shop for a car, we decide on the model, and then we'll go to five or six different dealerships and we'll get a price. People don't realize you can go to five or six different hospitals and it's a different price. They don't realize that different insurances get a different price for a service, depending on how big a pool that insurance is and negotiates. They don't realize that if you don't have insurance you can go in and you can negotiate payment plans--not with every hospital or every medical facility, but there are a lot of them, if you can put a certain amount of cash up, they'll do a certain amount, and then take payments. We're just not used to that idea, because we're used to the idea that somehow if you're lucky enough to have insurance, insurance is supposed to take care of everything.

Insurance does not, however, take care of everything for this couple, and what it does take care of still requires much effort on their part: they, like our self-advocate, are too occupied with the day-to-day work of surviving to spend much time actively working to change things. Because, however, this individual is aware of the nature of the system their self-advocacy may sometimes serve the dual purpose of educating others. Denise and Michael are evidence of this. In their daily interactions with other patients, caregivers, physicians, and medical professionals, they are remaking the system by providing a different model of a

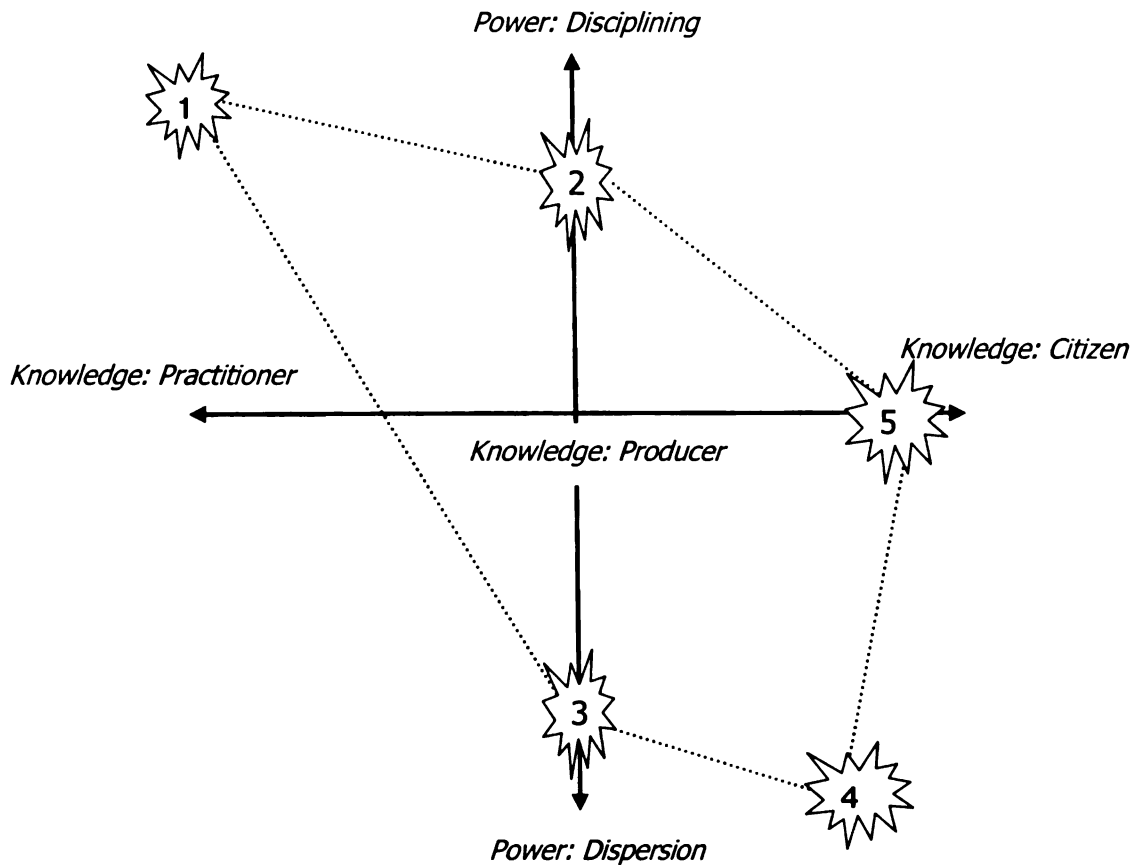
patient, a more informed, critically engaged patient. Consider, for example, their seeming innocuous act of teasing the nurse who doesn't as a matter of course share vital signs and other basic health information. That nurse may well rethink that aspect of her practice, and begin to share health information with patients more openly, which may, in turn, change their practices, all because of Denise and Michael's gentle acts of dispersion.

As Denise and Michael continue to push back against what they see as oppressive and limiting practices, and share that knowledge with others, they are in a sense moving from our self-advocate, to activism. So too has Celia, but because her relationship to medicine is more one of grudging acceptance than partnership her position would be slightly different, closer to dispersion than disciplining. The patients operating where I have denoted both the self-advocate and the reformer may, at times, engage in activism, sharing their knowledge, and making new knowledge, with others in attempts to reshape systems of medicine, health, and delivery; the difference, again, is one of degree but also intentionality.

The Reformer has a deeply critical orientation: this person is an activist working intentionally to change the system. This patient may be working from outside the system, and therefore be located closer, conceptually, to dispersion than disciplining. There are also likely patients mirroring this position on the other side of things, closer to "disciplining" than dispersion, as in, for example, patients who now work to change the system from within. A prime example of

this type of patient is Judy Jones, a CTCL patient who, frustrated at a lack of information about our condition, began moderating the CTCL listserv. Judy, along with Judith Shea (caregiver and surviving spouse of a CTCL patient, Lee Cohen), is also the driving force behind the Cutaneous Lymphoma Foundation, a non-profit organization operating in partnership with both physicians and patients to provide information, advocacy, and support, as well as to promote research (Cutaneous Lymphoma Foundation).

The weakness to the visual representation of this continuum is in the implied linearity: these are not necessarily successive or even static positions, nor are they all the positions possible. The degree to which a given individual progresses along the horizontal knowledge continuum is, I believe, deeply tied to the vertical plot: our development of health literacy skills and knowledges are dependent upon access and support. These often hinge upon whether our literacy work is sponsored. In other words, access is embedded in power; so then is the continuum of the informed patient, or health literate, patient's development. Patients who meet with extreme negative disciplinization may react by complying, or conversely, by dispersing, sometimes both at once, for any patient may occupy one or more positions at different points in time or even at the same time. Consider, for example, Celia's story (Figure 4, following page).



Legend:

1. Celia trusted her doctors' medical knowledge and followed orders.
2. Celia increasingly asked questions of medical professionals in order to learn more about the medicines and treatments prescribed.
3. Celia researched and implemented alternative and complementary therapies.
4. Celia BALKED when she felt it necessary.
5. Celia composed a text intended to help other patients view the medical system and the role one can play in one's own care differently.

Figure 4
Celia's Health Literacy

Celia revealed to us that she "trusted medicine to do what it must"--a stance we could consider like that of the traditional patient. At the same time, however, she asked questions and made new knowledge, and supplemented her

medical treatments with complementary treatments and therapies located, and often undertaken, entirely on her own. Celia's health literacy practices, then, concurrently occupy more than one position on the continuum, a complexity mere definitions of health literacy cannot account for. Understanding health literacy as a continuum helps to keep in sharp focus the contexts of skills development and use and the relationships between them, allowing for a much richer understanding of health literacy as an applied and enabling set of skills, of necessity flexible and contextual, and deeply affected by access (to information, conventions, and more.)

Health Literacy: Complex, Composite, Contextual

I have spent the last two years asking patients and caregivers what health literacy means to them, and listening to their stories of the knowledge work being a patient requires. Our conversations and my analysis of both these conversations and written artifacts volunteered by participants demonstrates that health literacy is a skill set that builds on literacy, or the ability to read and write; however, being health literate--like being fully literate in any other situation--is more complex than this surface level definition may suggest. Being literate depends on what the situation requires of you: it is contextual and variable. Someone who is functionally literate in their everyday life would likely not feel literate if suddenly transported from one context to another--from being, let's say, a high school physics teacher, and then suddenly an experimental astrophysicist. While the subject matter may be similar, these are two very

different contexts. The habits of mind, the support systems available, the prevailing ideologies--they are all different. It takes know-how to navigate epistemological systems: competency in one is no guarantee of competency in another. Serious consideration to how someone makes this kind of adjustment is not just an academic conceit. Any individual could be forced to make the transition that is the focal point of this study at any time. As Denise explains it, this work is simply the result of having a serious illness:

It's not the same thing when you get up [from "everyday" illnesses] into what we're having to deal with. And it's not the same thing for people with chronic illness. You know, diabetics go through this and as they progress and the disease takes its toll on them they have more and more things going wrong for a long time....

As Denise points out, the literacy demands placed on a patient or caregiver dealing with a serious or prolonged illness are different than those placed on patients dealing with "everyday" illnesses and treatment, compounding both the information required and the practices involved. Anyone could suddenly "move" from one category to the next. One troubling thing about supporting health literacy development is, therefore, the sheer scale of it. One cannot segment off a given area of society (say, the elderly or the less educated, assumed to have less access to digital information) Further, Denise sagely notes that when things go wrong for a long time "the insurance company doesn't like that." This reminds us, again, of the backdrop of health literacy work--the insurance and billing work that take as much time and literacy, or more, as learning about the condition, gathering information, and making decisions. Not only must patients and

caregivers learn how to learn about medicine, they must learn how to learn about insurance. Both are required to be health literacy in the modern American context.

Being able to make to develop the necessary skills--those that let one feel prepared, agentive, and capable of navigating the challenges that constitute health literacy--is not necessarily a matter of intelligence, or previous educational or occupational experience, or at least not solely. Full, active literacy of any kind requires the ability to engage in the literate practices of the particular disciplines or epistemological systems involved. The practices required to feel and function as one who is literate therefore require not only the disciplinary knowledges relevant to the situation, but many others kinds of skills as well. The same is true with health literacy.

Health literacy's component parts are, at minimum, functional literacy, or the ability to read and write at a level that enables understanding and following written health information, and: numerical literacy, useful for following medical instructions but also for timing and tracking dosages of multiple medications, charting symptoms, and more, as extremely ill patients and their caretakers often must do; information literacy, or knowing when and how to ask questions, and where to locate answers; and critical thinking skills, or the abilities to evaluate information, and from information build knowledge and make decisions. But it is impossible to list definitively all the skills that might make any individual feel fully literate, or fully health literate as again, this is a deeply context-bound

statement, and both literacy and health literacy are skill sets that are both the sum of many parts, and more than the sum of these parts.

Because of the complexity of this skill set--and also, perhaps, because of the shifting landscape of doctor-patient communication and prevailing ideologies about the "ideal patient" --issues of power, and instances of disciplining and dispersion, have the potential to either support or discourage skills development. How much a given individual develops may, then, be directly tied to issues of access and power. For this reason, health literacy at some stages of development also involves critical literacy, or something akin to Freire's *conscientizacao*, a movement from naivete to critical awareness and engagement. This is the kind of knowledge that enables criticism, and reformation, of governing systems.

Implications and Recommendations

This study was intended to help address the gap in voices participating in conversations about health literacy (and related conversations, like decisions about health policy) by making actual patient literacy practices visible in the literature, providing future researchers with a more complete view of health literacy in action, and patients with a source of more accessible and applicable information. My findings suggest several implications for rhetoric and composition's role in future health literacy discussions, as well as for policy makers and future health literacy researchers based in other disciplines.

In general, whatever is done to support health literacy work would be more effective if the following were taken into consideration.

- 1) Health literacy practices are clearly multimodal, with patients working across all available media types dependent on their purposes, and avenues for accessing information. It is important, then, to provide information in different forms. This both allows for different learning styles and for the multiplicity of people, with different skills, backgrounds, and interests, who work with and for patients. Patients in this study express a preference for written information under certain circumstances, and at these times favor brochures and other easy to read, portable forms. Their use of books on tape and mp3 archives of medical presentations and conferences is less expected, and much less frequently supported.
- 2) It is vital that we understand that "the patient" is not singular. The health literacy work done for any given patient may be done by the patient alone, or may involve a network of friends, family members, and other support systems. Information intended for use by the patient should be accessible by multiple individuals, or at least in forms that are easily shared. Assessments of patient health literacy skills, particularly those done in the office for the purposes of determining how best to work with a patient, must also take this into consideration. Low literacy skills on the patient's part do not mean it would not be worthwhile to send information home, for other support systems to make use of.

- 3) The only place I have really seen the possibility that “the patient” doing health literacy work may well be plural is in guides to culturally appropriate health care, in which physicians are often reminded that (for example) in certain cultures male family members may make decisions for females, or adult children may do so for parent (Mayer and Villaire). While this is encouraging, it is important to pay attention to the fact that for my study participants--almost uniformly White, middle class (or at least prior to illness), educated Americans--a group generally assumed as one cultural group, and as a mainstream group, and not one addressed in these guides to culturally relevant care--nonetheless describe patient agency and “health literacy work” as collaborative constructs.
- 4) Finally, it is important to consider the role of invention in developing health literacy skills. As documented in this study, a large number of practices are oral, with high levels of knowledge produced in conversations between doctor and patient, but also in those between patients and caregivers. It is vital that medical professionals understand the importance of asking questions and double checking understandings, and support patient and caregivers as they work to build knowledge about their conditions and treatments.
- 5) The number one recommendation made by patients and caregivers in this study is the request that physicians and other medical personnel simply realize each patient is an individual, with individual strengths, weaknesses,

and interests. Some patients want to know everything, some do not. *Ask questions, and listen attentively to the answers.*

The continuum is, I believe, the bit of this study that can have the most impact not only on medical and social practices related to our understandings of health literacy, but also to those fields I call home: literacy studies, rhetoric, and composition. While I do not overtly address literacy studies in this dissertation, this is only because I felt it more important at this stage to focus on opening conversation between literacy studies and medicine, a step that will be most effective once Medicine accepts the advantages of a language-based, rhetorical approach on questions they are already asking in their own ways. The steps I took towards this goal were, however, obviously informed by my educational encounters with literacy studies; many played a strong part in the choices I made in methodologies and methods, as well as in the personal stance I took as a researcher, and my beliefs about reciprocity. My study is obviously part of the "social turn...a research orientation to look beyond the individual to the social, cultural and political contexts in which people lead their lives" one of the patterns noted in current literacy research by Cushman et al's *Critical Literacy Sourcebook* (3): as such it is also attentive to digital technology and access to information, to multimodality, and to issues of cognition. My focus on distributed invention, or the symbiosis of health literacy, as well as the ongoing inventional requirements of advanced health literacy skills, mark this study as one of use to cognitive studies of literacy. My focus on health literacy as a skill set deeply imbued with

and embedded in issues of power and access make this study useful to those researchers focused on issues of power, privilege and discourse, or in ideological criticism, all issues near and dear to my own identity as a researcher. In all of these, I believe my study qualifies as an example of the new literacy studies called for by Brian Street.

I believe there is something of value in this study for many kinds of literacy scholars: it has something to say about the importance of narrative, the roles cultures and communities play in learning, and more. The one thing I hope others will most like to help me pursue, however, is the role of invention in literacy use and development. As this study progressed, I obviously came to treat invention as a feature of literacy. I believe that being able to move from knowing something as content to using that content to make new knowledge is part of being extremely literate in any given area, a state which must necessarily change as do questions, contexts, and purposes. Too often, though, we lose sight of the continual processes of invention and development inherent in any literate practice, and focus on binaries of literate and illiterate, of teaching and remediation. We must continue to pay serious attention to the contexts in which health literacy is developed, for knowing how to read and write isn't all of this (or any literacy). Being able to use skills in the current context, purposefully, is the true measure of any literacy. This brings me back to the importance of Street's ideological model of literacy. My study reveals that the development and acquisition of health literacy skills, as well as the specific content knowledge

gained through literacy skills, are often *still*, even in a digital age, deeply embedded in a mix of print-based AND oral practices which are themselves further “encapsulated within cultural wholes and within structures of power” (Street in Cushman et al 435). Health literacy is not neutral, in its acquisition or use, and the continuum is a relevant concept.

There are many areas of modern life in which not only justice but also equality, and at times, even the means to survival, are accessible only through the advanced use of language--research, reading, and writing. This study demonstrates the usefulness of rhetorical studies to medicine, a move I hope will encourage more researchers in our field to add their voices to the critical conversations over health care and health literacy ongoing in our nation today. But more broadly, rhetorical studies have much to offer anywhere access is an issue, and we need to be purposefully interdisciplinary in the ways exhorted by Ellen Barton, researching in ways and publishing in forums accessible to multiple concerned fields.

Finally, my study informs my work as a teacher of composition in that it underscores, for me, the importance of a rhetorically centered approach to teaching reading and writing. Each of our students comes to us with literacy skills, experiences, and challenges of their own--past, present and future. One of the most useful things we can do for our students is, therefore, teaching them to be active, thoughtful rhetors. They need to be capable of understanding the epistemologies and literate practices of many audiences, for purposes neither

they nor we can fully imagine today. Further, the successful modern communicator needs to be capable of extracting information from, as well as speaking through, many forms. This study underscores the multimodal nature of many modern literacies, including health literacy, validating movements to incorporate research, reading and writing tasks that challenge students to use digital, visual, and aural materials with as much facility as they use written, alphabetic text.

For future researchers, particularly those in rhetoric and composition, I have two further suggestions. First, the notion intentional interdisciplinarity is increasingly important. To illustrate: in the course of this research, I found a number of grants and programs geared towards supporting research on health literacy. My study could not have qualified for any of them: a medical provenance was almost universally required. This is largely, I believe, because the sponsors involved have no idea of the value our fields could bring to health literacy studies. Despite this, language oriented fields have important contributions to make. It is important that we continue designing useful and intentionally interdisciplinary studies, studies that make an acknowledged contribution to more than one field (Barton). Secondly, it is important that intentionally interdisciplinary studies are open about their methods and their methodologies. By doing this we support researchers in all interested fields, generating ever more useful and applicable research tools and findings.

In closing, my research participants ask that I pass a specific message on to policy makers interested in their health literacy practices. They wanted me to make clear that the best thing we can do to support patient health literacy development is to modify our insurance systems, increasing coverage and access to care, making insurance processes and policies more transparent, and improving and simplifying communication between patient, insurance providers, and medical providers. The most difficult thing that patients in this study dealt with was not accessing or understanding medical information: it was dealing with the endless work, and learning, related to coverage and billing. As Denise says:

The whole health care system has to change, because once you become a patient you're like that cog in this giant machine that's not going to let you go, and that cog that you've become now...can't be a person anymore, because you're a cog, caught in this. And you've got to ride it all the way through.

Michael adds:

A good analogy is like the space movies where they come on the black hole and they're being sucked in...well you know you can't get out. The best you can hope for is just to keep enough velocity to keep from being pulled into the middle of it.

The group comments, again, at this point that technology and the long promised electronic medical record might relieve some of the pressures on patients, enabling them to focus on health literacy tasks more crucial to their decision making processes than coverage should be. One member states:

...you know with the technology today...if these people would cooperate better.... The doctor's office and the insurance company? The doctor's office could put that information instantly into that insurance company. And quit bothering him [gestures to another group member who is

fighting a notoriously long battle caused by a communication breakdown between his insurance provider and his physicians] with paperwork.

To that, Michael replies:

Well, the problem is that there's so many different systems and they really don't talk to each other. And then on top of that you have...they're hamstrung with the HIPAA laws. The problem is nobody's agreed on a single system.

In closing a group member remarked, "that's called democratic society, where they can be as greedy as they want and as diversified as they want." Policy makers wishing to support health literacy must first do the obvious and difficult work of improving our systems of coverage. The National Assessment of Adult Literacy reveals correspondences between coverage and health literacy development that cannot be coincidental.

Appendix A

INITIAL SURVEY

| Participant Identification & Background Information | |
|--|---------------------------|
| Name, pseudonym, <u>or</u> responder id... (This information, and your contact information, is confidential, and will not appear in any writing based on this survey.) | |
| Are you a: ___ patient ___ caregiver ___ both | |
| If caregiver, for whom? | |
| Date of Birth: | Date of Diagnosis: |
| Telephone | Email Address |
| Education: ___ did not graduate high school, or not yet graduated ___ GED or high school equivalency ___ high school graduate ___ attended vocational, trade, or business school ___ college: less than two years ___ college: associate's ___ college graduate ___ postgraduate/no degree ___ postgraduate/degree | |

Diagnosis

What support systems do you have? (For example: friends; family; support groups; email list-servs; other...?) In what ways are they of help to you?

Did you question the diagnosis? ☐ Yes ☐ No

Why, or why not?

How did your doctor provide you with information about your diagnosis/treatment? ☐ orally ☐ in print ☐ both

Diagnosis

Were you satisfied with the information and explanations provided by your doctor? ☐ Yes ☐ No

Did you seek out a second opinion? ☐ Yes ☐ No

If yes, why?

Where did you get the second opinion?

What were the results? ☐ agreed ☐ disagreed

Did the second doctor provide you with:

☐ less information ☐ More information
☐ better information ☐ the same information

Treatment

What treatment plans were you offered?

Treatment

What treatment plan did you accept? Why?

What problems did you encounter (with, for example: getting appointments? receiving coverage? getting information? Other problems regarding your diagnosis and/or treatment?)

Financing Health Care

Do/Did you have adequate insurance? Yes No

Financing Health Care

How does/did your insurance coverage impact your treatment decisions?

What out-of-pocket costs will/did you pay?

On Information Gathering

Do you obtain copies of diagnosis information? Check all that apply.

☐ Lab

☐ X-ray

☐ CT

☐ MRI

☐ Other:

On Information Gathering

Do you seek out other information about your illness? Yes No
Do you seek out information about your medications? Yes No
Do you seek out information about alternative medications? Yes No
Do you seek out information about alternative treatments? Yes No

| How much of your health information comes from each source below? | A lot | Some | A little | None |
|--|--------------|-------------|-----------------|-------------|
| Family, friends, co-workers | 1 | 2 | 3 | 4 |
| Books | 1 | 2 | 3 | 4 |
| Brochures | 1 | 2 | 3 | 4 |
| Newspapers | 1 | 2 | 3 | 4 |
| How much of your health information comes from each source below? | A lot | Some | A little | None |
| Magazines | 1 | 2 | 3 | 4 |
| Medical journals | 1 | 2 | 3 | 4 |
| Radio & television | 1 | 2 | 3 | 4 |
| Internet | 1 | 2 | 3 | 4 |

What other sources of information are helpful to you?

On Information Gathering

What persons, if any, help you with finding, reading, and/or using health information?

How confident are you regarding your interpretation/understanding of medical information?

If you use the Internet for health related research:

What web sites do you use to conduct your searches?

What search terms do you use most often?

On Information Gathering

Which web sites do you find most useful?

How do you decide whether information is credible?

How do you decide whether information is relevant to your condition?

**How confident are you in the (accuracy?) of the information you locate?
Why/why not?**

On Information Gathering

Are your information gathering practices the same above for all illnesses you've experienced, personally or in the assistance of loved ones? If not, why....?

Do you belong to any e-mail list-servs or online discussion forums?

☐ Yes ☐ No

Do you belong to any support groups? ☐ Yes ☐ No

If yes, do these meet: ☐ face to face ☐ online ☐ other

Do you take information you have obtained on your own to your doctor?

☐ Yes ☐ No

How receptive is your doctor to discussing your research?

☐ Very Receptive ☐ Indifferent ☐ Disinterested ☐ Unreceptive

What is the most COMMON reading, writing, or research task you've had to deal with?

On Information Gathering

What is the HARDEST reading, writing, or research task you've had to deal with?

What is the most VITAL reading, writing, or research task you've had to deal with?

Living with Illness

Response key:

1= no problem 2 = can do with some difficulty

3= can do with great difficulty 4= can NOT do

| | | | | |
|----------|---|---|---|---|
| Sitting | 1 | 2 | 3 | 4 |
| Standing | 1 | 2 | 3 | 4 |

| Living with Illness | | | | |
|--|---|---|---|---|
| Walking | 1 | 2 | 3 | 4 |
| Going up or down stairs | 1 | 2 | 3 | 4 |
| Transferring positions | 1 | 2 | 3 | 4 |
| Lifting/carrying | 1 | 2 | 3 | 4 |
| Driving a vehicle | 1 | 2 | 3 | 4 |
| Sports/recreation/crafts/hobbies | 1 | 2 | 3 | 4 |
| Housework/yardwork (laundry, meal preparation, etc.) | 1 | 2 | 3 | 4 |
| Response key: 1= no problem 2 = can do with some difficulty 3= can do with great difficulty 4= can NOT do | | | | |
| Self-care (bathing, dressing, toileting, etc.) | 1 | 2 | 3 | 4 |
| Coordination (writing, buttoning, tying, etc.) | 1 | 2 | 3 | 4 |
| Reaching | 1 | 2 | 3 | 4 |
| Gripping | 1 | 2 | 3 | 4 |
| Working | 1 | 2 | 3 | 4 |
| Social interactions with friends and family | 1 | 2 | 3 | 4 |
| Leaving home to go out for something <i>other</i> than a medical appointment | 1 | 2 | 3 | 4 |
| Ability to remember/focus/concentrate | 1 | 2 | 3 | 4 |
| Reading | 1 | 2 | 3 | 4 |

About this Study:

I am interested in collecting information on how cancer patients and/or their caregivers use research, reading, and writing in the course of dealing with illness and treatments. I believe that people who teach writing, write materials for patients, or work with patients should understand how we research and write so that they can better help others to develop these skills. Thus far, most such

studies have not achieved an insider's view--a patient's view--of how reading, writing, and research are important in our health and medical care. I am therefore asking you to participate in a focus-group interview.

You will not be compensated for your participation in this study, but it is my hope that your participation in this study may contribute to a better understanding of why patients research, read, and write; what materials we use (and how); and how we learn the skills to do so. Sharing our experiences as informed patients may also help redefine "health literacy" as something deeper and more analytical than some current definitions suggest, which may eventually contribute to better health literacy programs and materials, and may also help our doctors and other health care staff (including those who write health/medical information, like pamphlets, websites, prescription information, and more) better meet our needs. I hope too that we'll be able to demonstrate how learning takes place outside formal instruction.

To share what we learn together about those issues, the data gathered through this research project will be used in my doctoral dissertation, which I hope eventually to revise and publish as a book so that it will be more widely available to help other patients learn from our experiences. In these materials, I will need to talk about the "work" (reading, writing, research) you did as a patient, and what motivated and supported that work; however, your identity will be kept confidential to the maximum extent allowable by law. You may choose pseudonyms for yourself, or any other identifying persons, places, or entities mentioned in your writing or your responses. Your survey responses, interviews, and any texts you share with the secondary researcher, Dundee Lackey, will be kept in a locked file cabinet, or on a password protected computer accessible only by Ms. Lackey. Files related to this study will be maintained for a period of ten years, at which time the original records will be destroyed. There are no foreseeable physical risks associated with participation in this research study. It is possible that discussing past events related to diagnosis or treatment could be upsetting or uncomfortable for some. You may choose not to answer specific questions or to stop participating at any time.

Participation in this research project is voluntary; you may choose not to participate at all, or you may refuse to participate in certain procedures or answer certain questions or discontinue your participation at any time without penalty or loss of benefits. Your privacy will be protected to the maximum extent allowable by law. You may opt out of this study at any time.

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the responsible researcher Dr. Jeffery Grabill at Suite 7, Olds Hall, Michigan State University, East Lansing MI, 48824; email Grabill@msu.edu or by phone at 517-xxx-xxxx. You may also contact the secondary researcher Dundee Lackey if you have any questions about this study at 5 Olds Hall, MSU, East Lansing MI, 48824;

lackeydu@msu.edu; 517-xxx-xxxx).

If you have questions or concerns about your role and rights as a research participant, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, by e-mail irb@msu.edu or by regular mail at 202 Olds Hall, MSU, East Lansing, MI 48824.

Your signature below means that you voluntarily agree to participate in this research study.

Please print your name here: _____

Signature: _____

Date: _____

Thank you for your participation in this survey! Your responses should help us to understand more fully the work of being a patient, which in turn should help us help others.

Please return this survey via email.

If you have questions, please don't hesitate to contact:

Dundee Lackey

Email: lackeydu@msu.edu Telephone: xxx-xxx-xxxx

Appendix B

QUESTIONS, INTERVIEW 1

Initially, participants completed a survey (Appendix A) designed to get them thinking about how and when they've used research, reading, and writing. This was followed up by an (approximately) one-hour interview, in which we discussed participants' survey responses. Questions were emergent--based on participant responses--and focused on eliciting greater levels of detail than are possible in a survey. My first round of interviews, then, consisted of questions like:

- Tell me more about (refer to specific response on survey)
- How did you learn to (refer to specific response on survey)
- Would you have done that differently now? Why/why not?

Appendix C

LITERACY DIARY

| Date | Start Time | Reading, writing, researching? | Your purpose/goal | Title(s) of texts read and/or title/address of websites visited? | End Time |
|-------------|-------------------|--|------------------------------|---|---------------------|
| | | <input type="checkbox"/> reading <input type="checkbox"/> writing <input type="checkbox"/> researching | | | |
| | | <input type="checkbox"/> reading <input type="checkbox"/> writing <input type="checkbox"/> researching | | | |
| | | <input type="checkbox"/> reading <input type="checkbox"/> writing <input type="checkbox"/> researching | | | |

Appendix D

QUESTIONS, INTERVIEW 2

Following our first interview, participants were asked to maintain literacy diaries (Appendix C). In these diaries, patients charted for a period of one week, all reading, writing, and/or research activity. This document formed the basis for a second interview, in which I asked patients emergent questions based on their diary entries, questions geared towards a better understanding of the motivations for and requirements of the work noted in the diary. As we looked over the diary, patients were asked the following questions.

- Do you feel this diary captures all the things you do that count as "reading," "writing" or "research"?
- Which of these items are things you've done only since your diagnosis?
- Do you read for different reasons now? What's changed?
- What was "at stake" in your reading BEFORE the cancer? (What was gained because of your reading? OR: What might have been lost if you had not read x?)
- What is "at stake" in your reading AFTER the cancer?
- Who did you write for/to before diagnosis?
- Who do you write for, or to, now, after diagnosis?
- Do you write for different reasons now?
- What's "at stake" in your writing before the cancer? (What was gained because of your writing? OR: What might have been lost if you had not written x?) And now?
- Did you use email and/or the Internet before your diagnosis? How?
- Do you use email and/or the Internet different now? What's changed?
- What kinds of information do you seek out online? Where do you look for it?
- What words do you use to search for it? How do you use this information?
- This (example of reading/research/writing)-- what did that achieve? What surprised you? How was it different from the (another example mentioned)? Had you ever written like that before? When/How did you learn how to write that?

- When/How are reading, writing, and/or research most commonly called for as part of your health or medical care? What texts do you have to help show others that work?
- What kind of reading, writing, and/or research tasks have been hardest? Which have been easiest? Why? What texts do you have to show as examples of your work and learning?
- Tell me about a time when reading, writing, and/or research were critical because of a health/medical situation? What texts do you have to help show others that work?

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