SOCIOCULTURAL STUDIES OF BIOMEDICINE AND HEALTHCARE IN EVERYDAY LITERATE LIFEWORLDS

BY

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DISSEPTION

Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in English with a concentration in Writing Studies with a minor in Gender and Women's Studies in the Graduate College of the University of Illinois at Urbana-Champaign, 2011

Urbana, Illinois

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Abstract

This dissertation uses sociocultural studies approaches to investigate the multimodal practices of reception that patients and medical professionals use in their everyday lives as they engage health-related information. People demonstrate their active uptake of professional writing through engagements with a variety of health-related texts, including technical texts, to produce knowledge and design their choices relating to their bodies and health. Following themes that arose during extensive discourse-based interviews with research participants, the chapters trace out three major concepts: a feminist and sociocultural approach to the analysis of everyday technical writing practices, the literate activity of the body including gesture in relationship to text, and the local situated practices of popular culture that inform understandings of medicine. These concepts are not typically under the purview of professional writing studies of medicine; however, by considering their roles in the everyday uptake of health-related literacy, we can see that these concepts do factor greatly into the production of professional texts.

In order to understand and record everyday health-related practices with a variety of texts, a research study was conducted over a two-year period, which included interviews with 9 participants in 13 extensive discourse-based interviews, and collected countless paper and electronic texts. The participants ranged from laypeople to medical professionals (e.g., dentists, an occupational therapist, a nurse) and alternative medical providers (e.g., a yoga instructor, a massage therapist). The body chapters of the dissertation look at their experiences with health and medical systems, analyze texts they've engaged, both professional and non-professional, and analyze their gesture in relationship to the data they were discussing in their interviews.
Using a interdisciplinary framework for analysis that draws on sociocultural studies (Bahktin, Engestrom, Prior and Shipka), science studies (Latour, Haraway, Kapsalis), feminist research methodologies (Kirsch, Royster), and medical rhetoric (Scott, Segal), I conclude that my participants chain together texts, bodies, people, and practices of their everyday lives in order to understand their own healthcare or to provide effective treatment to their patients/clients. These acts of chaining, or chains of reception, demonstrate that people can be actively engaged with the technical not only during their face-to-face encounters with medical professionals, but also in their everyday lifeworlds. I argue that in professional writing studies, if we adopt an orientation to and approaches for considering these technical practices as legitimate in the field, we can disrupt the autonomous discursive authority that has come to be associated with professional communication, and we can envision a field more aligned with everyday perspectives and locations instead of privileged actors.
Acknowledgements

I would like to acknowledge my research participants who gave generously of their time to participate in this project. I want to recognize my primary participants Elizabeth Edwards, George Bellwoar, and especially Meagan who generously shared their stories with me. I also want to recognize my secondary participants Bryan Kieft, Deb Lister, Eugenia Roberts, Brad Roberts, and Emily who shared their workspaces and work experiences with me. Throughout the data collection and analysis, my participants’ sense of humor and creativity not only made the project possible, but also made it a pleasure.

I would like to thank numerous people at the University of Illinois for their generous support to my research and writing. I would like to thank Paul Prior who directed this dissertation and has spent countless hours reading my writing and providing valuable feedback over the past nine years. He has always asked provocative questions that put a new spin on the work, without which the project would not have been nearly this interesting. I would also like to thank the other committee members Melissa Littlefield, Peter Mortensen, and Debra Hawhee for their unique reading and suggestions to push the work even further. Finally, I would like to thank my fellow graduate students and colleagues who read numerous drafts of this dissertation in various forms, especially those at the Writers’ Workshop and the graduate students in my various writing groups.

Finally, I would like to thank my family and friends who encouraged me to believe that I could write. I would especially like to thank Darren Hron for his patience and support. I have become even more aware that writing for me is always a collaborative process, and I am grateful that all of you have been willing to take this journey with me.
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Chapter 1  Professional Writing and the Non-Professional

In studies of medical discourse, including studies within the field of professional writing, researchers have generally focused on one of two phenomena: the conversations between doctors and patients in institutional settings (Barton, 2001; Hamilton, 2004; Sarangi, 2004; Vegni, Visoli, and Moja, 2005) or the writing of professionals such as nurses (Dautermann, 1997) or physicians (Pettinari, 1988). These studies tend to situate medical discourse within the boundaries of the institution, neglecting the ways that it gets taken up and used outside of those boundaries. By focusing on institutional contexts from the perspective of privileged actors, research in medical discourse studies, while contributing important insights into the nature of medical talk, has neglected the production and circulation of written texts around such exchanges. Research in the field of professional writing, while addressing production and circulation of texts, has neglected the roles of actors such as patients and the reception of health-related texts (in both conversations and writing) in homes, community organizations, and popular culture. This is problematic for the field of professional writing because it limits the scope of research and its applicability to rhetorical situations by assuming that the work of professionals only happens during the times they are physically at the workplace, while in fact workplaces are situated within the broader discourses of culture. This dissertation broadens the work and the possibilities for work in professional writing by using sociocultural methodologies to examine the literate practices of individuals. Because these sociocultural case studies are focused on the

1 e.g. hospitals, doctors’ offices, clinics. I use the term “institutional” to describe settings
situated activities of the participants, I follow people as they engage with the professional systems of biomedicine and healthcare inside but also outside of institutional boundaries, in their everyday lifeworlds.

Through these sociocultural case studies of everyday uptakes of medical discourse, medical audiences can receive the broader view of the literate practice that professional writing has to offer. In these medical communities, a focus on literacy has become increasingly important. Therefore, my dissertation is concerned with medical discourse studies that focus on literacy; it responds particularly to a 2004 report conducted by the Institute of Medicine, which highlighted the concept of “health literacy,” defined 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” (p. 4). This report emphasizes the importance of literate practices in healthcare, but like the other studies of medical discourse, it focused on issues within hospital settings, overlooking how people engage with healthcare materials in other settings such as their homes or communities. My study takes up the timely topic of health literacy by examining literate practices as they are dispersed throughout individuals' lives. Better understanding how these literate practices relate to biomedicine and healthcare contributes to researchers’ growing knowledge of the nature of literate activity in everyday worlds and informs research on health literacy from the perspective of writing studies.

Researchers in both professional writing and medical discourse studies have not yet focused sustained qualitative study on the literate practices and activity of individuals in everyday lifeworlds, outside of the doctor-patient relationships or professional practice. In order to do so while engaging both areas of research, my dissertation employs an
interdisciplinary approach. My qualitative research study identifies literate practices using a theoretical framework from sociocultural research and feminist science studies that considers the practices individuals use to organize and structure their lifeworlds (Prior and Shipka, 2003), the tools they use to mediate these worlds (Norris and Jones, 2005; Scollon and Scollon, 2003), the stories they tell about these practices (Charon, 2006; Klawriter, 2004), and the associations that their practices have with cultural and societal constructions of health (Scott, 2003; Segal, 2005). This interdisciplinary perspective allows for a more complete picture of the literate practices of individuals that includes the ways they engage with biomedicine and healthcare materials, not exclusively within the boundaries of medical institutions or through conversations with medical professionals, but also through conversations and literate activities of their everyday lives.

**Disciplining Professional Writing Studies and the Pedagogical Imperative**

Before exploring the specifics of my study, I outline a historical perspective on the field of professional writing\(^2\) to draw attention to the important work that researchers have done in this field. It is not my intent to suggest that researchers have not made important contributions to the field though I critique the field’s inattention to research sites outside of institutional boundaries. As I trace the associations that led to professional writing’s establishment as a field, I present connections to the pedagogical imperative\(^3\) that demonstrate the field’s current constraints on research. Researchers have begun to address

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\(^2\) I also include business and technical writing/communication in the field of professional writing, and I use this term to project a more inclusive view of the field than perhaps all of its researchers would consider.

\(^3\) See Kopelson. She describes the pedagogical imperative as “the implicit (and some would and do say *explicit*) mandate that any research or theorizing they do have relevance, and even immediate, direct application, to the writing classroom” (p. 752-753).
these constraints and situate their research outside of the classroom, but on the whole, the field remains focused on pedagogical sites and workplace sites as the spaces where technical communication happens. In particular, through exploring how researchers have been disciplining the field and how they’ve considered enculturation into professional writing practices, I show spaces within the field where we could begin to look at technical writing’s circulation in people’s everyday lifeworlds.

Disciplinarity⁴ has been an ongoing question for professional writing and technical communication. According to Kynell and Tebeaux’s (2009) history of the Association for Teachers of Technical Writing (ATTW), the organization arose in part to address the need for teaching materials and textbooks that technical writers had as they found themselves teaching the boom of technical writing and engineering classes that began in the United States during the first half of the 20th century. In 1973 the organization was founded to address the needs of the classroom. During the 1970s, the population of teachers shifted from people trained in technical writing to people trained in literary studies, and the field continued to develop textual resources for the teaching of technical writing.

According to Kynell and Tebeaux, in the 1980s and early 1990s, members of ATTW typically identified first as teachers of courses in professional, business, and technical writing and communication, but a new problem of disciplinary identity began to emerge; as people trained in universities rather than in technical writing settings, they knew very little about writing in specific workplaces. Thus, a lot of the earliest research in the field was

⁴ Klein (1990, 1996) and Latour (2005) suggest that disciplines are thought of as homogenous and unified on their own, when in fact disciplines become stabilized by the actors within them, and disciplines need to become stabilized and seem unified in order to be considered disciplines. Latour states that in order to understand how disciplines have formed, researchers have to trace associations, and follow the actors involved, observing how the social has been assembled.
interested in improving instruction in these writing courses through research into writing in the workplace. Because of this focus on what research could bring to the classroom, professional writing continued to emerge as a discipline about pedagogy. One of the earliest examples of this orientation was Odell and Goswami’s (1985) key edited collection in professional writing studies; it was one of the first to explicitly argue that writing in workplaces is important and should be studied in the field, and it started the trend of contributions to how workplace writing can be useful to pedagogy.

In their preface, Odell and Goswami discuss how they initiated their studies of nonacademic settings after they realized that they did not know enough about the kinds of writing students would be expected to do outside of school. They state that, “One intent in this volume is to represent some of this scholarship and to suggest ways it might become the basis for teaching and for further research” (p. viii). This argument defined a body of research for the field that does not necessarily have to draw only on classroom experiences to understand writing. Although most of the contributors connected their research to pedagogy, there were also chapters in the collection that suggested directions for further research. For example, Anderson’s chapter on “Survey Methodology” and Doheny-Farina and Odell’s chapter on “Ethnographic Research on Writing” both outlined research methodologies that would be useful to researchers in non-academic settings. Nevertheless, the pedagogical imperative is present in almost every chapter in a formulaic way: the contributors discuss their methodology, lay out their research study of a specific workplace site, and discuss the implications of their writing research for teachers and education.

Drawing on research methodologies that are similar to Odell and Goswami’s, Kogen (1989) explicitly seeks to define the discipline of business communication. She indicates
that the field has grown because "faculty assigned to teach [business communication] courses, some for the first time, want to know more about research and methodology in the field" (p. ix) and she states that her book "attempts to describe a growing and changing discipline—it's research, theory, and pedagogy" (p. xvi). However, the pedagogical imperative continues to be a primary way Kogen and her contributors define the field; each essay in the collection is either entirely about teaching professional writing or concludes with implications for teaching related matters. Although the focus is primarily on pedagogy, the contributors continue to conduct research outside of the classroom, examining sites such as government agencies, mutual fund companies, law firms, and academic workplaces.

Citing Odell and Goswami, Matalene's (1989) goal for her edited collection was to begin "asking questions about writing outside the academy" (p. v). Matalene claims that Odell and Goswami's research has helped the field "get beyond exclusively text-based notions of writing" and paved the way for more research into workplace writing to demonstrate "that what finally appears on paper—as a memo, proposal, or report—is but the end result of a complex set of negotiations" (p. v). The contributors to this collection begin to push for a sociocultural approach to workplace writing, and as they are making connections to pedagogy, Matalene asserts that this research into workplace writing implies the field can no longer teach writing "as the action of one individual working privately to create a finished document," paving the way for writing to be researched as "a collective, social activity by which texts are produced and transformed, knowledge is constructed and disseminated, communities are created and maintained, audiences are identified and persuaded" (p. xi). Although the contributors only approach writing at work
to examine activity networks of technical writing, in establishing the field as a discipline concerned with those networks, they open up a space for an examination of everyday networks as well. As a discipline that seems to be constantly questioning its responsibilities, technical communication seems well poised to recognize the work being done in everyday spaces.

As some of the previous work in defining the disciplines shows, researchers have been interested in studies of workplaces in order to become better trained to address workplace writing in the classroom. One of the themes these researchers often focus on is enculturation, conducting studies that examine the connections between writing in schools and writing in the workplace. In Winsor’s (1996) study of school and workplace enculturation, she follows four undergraduate writers and conducts retrospective interviews about the transitional period between school and the workplace, their co-op experience. Considering the ways students are learning to write during this transitional experience, Winsor examines how knowledge is rhetorically constructed for the engineers in these institutional sites of learning.

Dias, Freedman, Medway, and Pare (1999) also look at the connections between school and work in their research, which examines multiple case studies in four sites of academic and workplace writing: government, business, architecture, and social work. They compare workplace and academic writing in these settings by first researching the advanced composition courses in these areas and then researching the writing in those respective professions. Their research study is also set up as Winsor’s to look at academic

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5 Engineering students often participate in a co-op experience before they graduate. In a lot of ways, it is like an internship, except co-op experiences usually extend longer than an internship, and students learn a lot of what they’ll eventually be doing when they get post-graduation jobs as engineers.
writing and workplace writing in sites within the boundaries of those institutions. However, this comparative goal leads to some of the problematic conclusions of this book, as they assert that school writing fails to prepare students for workplace writing because the rhetorical activity of school and workplace are too different. However, if Dias, et al. considered everyday writing practices in a variety of sites rather than comparing only sites from school and the workplace, perhaps the authors might see the connections between school and work in how practitioners use their knowledge of writing from all aspects of their life, not just the institutional ones, to write in these differing contexts.

Beaufort (1999) also looks at enculturation of writers at work for reasons similar to those of Odell and Goswami and Matalene, to understand “what constitutes expert writing” and place the emphasis of pedagogy on “contextualized writing knowledge” (p. 9). Her study follows four writers at new jobs at JRC as they transition from school to work and become enculturated into their workplace writing. She describes the transition as a complex socialization process, complete with balancing conflicting goals of school and workplace writing. Because her research is focused on these transitions, the scope of the study is necessarily limited to school and workplace sites. She presents a view of learning to write in workplaces as socialization as well as a cognitive process and implies that learning to write is a situated negotiation between the specific discourses’ institutional settings and the sociocultural activity that individuals and communities bring with them. Although she limits the knowledge people bring with them to that of their school knowledge and generalizes workplace and school writing for pedagogical purposes, she conceptualizes certain roles that writers take on as a part of that institutional writing. Thus, her work into enculturation can be taken up in a broader study like mine, where I have
been able to examine how people carry over parts of their roles into different settings they encounter. Beaufort works hard to fit her framework in with the institutional discourse communities for which she sees her research having implications; however, her work could be expanded to consider how learning to use texts as a part of enculturation into medical worlds is serious technical work and part of the important negotiations that Beaufort outlines.

My research also considers enculturation as learning to write in different situations, but I suggest that by moving beyond studies that narrow enculturation down to spaces of school and work and replacing that with a model that considers everyday life practices as also a part of enculturation in institutional spaces, we could further the discipline into everyday domains where technical writing already is being understood, but that the field is just not paying direct attention to. The scholars I discuss categorize writing by specific definitions of academic and workplace writing, definitions that have often been determined by powers outside of the field, in part to fulfill the pedagogical imperative. They conceptualize the social as something confined to particular domains, thus conceptualizing technical writing as belonging to those domains as well. If instead, we begin to see ways technical writing is distributed across a variety of spaces and taken up in a variety of ways, if we see people’s enculturation into institutionalized medical discourse alongside their everyday practices of medical and alternative medical discourse, we might begin to see the social as not belonging to anyone in particular; instead, it is a horizontal network of activity that spans across settings and gets taken up by people in a variety of ways to address a variety of purposes in their everyday lives.
In most cases, the research I’ve highlighted is necessarily narrow in scope, and provides important insight into the contributions that research into workplaces can make to writing instruction in schools. However, if the field broadened its boundaries and took different views of sociocultural activity and workplace writing, professional writing researchers could find a more thorough view of workplace writing and how it operates in the world, and most importantly to my research, could identify people’s practices of reception to medical discourse in their everyday lives. If researchers begin to pay attention to and trace out associations to see how writing is connected to broader public forms of literate activity outside of school and workplaces, we would better understand writing as the complex socialization process that researchers have begun to point to in the field of writing studies.

Through this discussion of the pedagogical imperative and disciplinarity in the field, I have shown that the field has developed its research methodologies in important ways, and demonstrated that research in specific workplaces does enhance the field’s knowledge of workplace writing. I argue that a logical next step for professional writing research would be a sustained examination of people as they engage with and take up professional writing, both inside and outside the boundaries of specific workplaces. Not only could this research address in new ways the traditional goals of improving professional writing instruction in schools and the writing of professionals in the workplace, but it could also be used to enhance knowledge of the dispersed literate activity around professional domains, i.e., examining what people do with the professional texts outside of those regularly studied spaces and considering what kinds of technical reading and writing happens in everyday spaces. Even from the traditional orientation, such knowledge is important information
because people regularly configure and import medical texts into their everyday lives, and in many cases, their lives and their livelihoods depend on their understandings and uses of these texts.

**Recent Trends in Professional Writing Research: Users, Community, and Recovery Work**

In more recent professional writing research, three trends have begun to make a place for studies that engage everyday practices of reception to technical and professional writing, in particular, technical medical discourse. These three trends are user-centered theory, examining civic and community roles for professional writers and scholars, and feminist recovery practices. These trends show that everyday practices are already becoming increasingly important in the field; my research contributes to these trends and addresses the calls of this recent scholarship. However, I will argue that a sociocultural approach also extends these trends by attending in new ways to the everyday practices of reception and production.

Usability-testing has become an increasingly important research topic in the professional writing journals alongside discussions of technology in the workplace. Charney (1998) observed that in the 1980s “studies of writing processes of scientists and professionals in the workplace, studies of document production processes, as well as studies of text design and comprehension processes, supported calls for strategies like

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6 In several articles in response to a 2004 report conducted by the Institute of Medicine, which highlighted the concept of “health literacy,” defined 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” (p. 4), journalists refer to literacy as an epidemic that threatens healthiness.
user-testing or including writers on product design teams” (p. 15). These early approaches, as Scott (2008) has argued, focus on methods of setting up usability studies in textbooks, rather than focusing on “how to perform and adapt these in particular projects with varying user needs, writer-user relationships, time and cost constraints, and other elements of context” (p. 382). Thus, these early studies of user-testing take the perspective of producers of products, focusing on developing user-testing methods to inform producers rather than taking the perspective of users and examining their relationships to technologies.

In the field of technical communication, there has been a lot of critique of usability testing and the rhetorical construction of users; thus, the field has been shifting towards user-centered theory. Dilger (2006) critiques “extreme usability,” which he characterizes as the “monolithic embrace of ease” (p. 52) and argues that usability studies would become more effective if they began to “acknowledge the situated character of the practical knowledge that is its focus” (p. 64) and pay attention to cultural contexts that cultural studies explores. Similarly, Grabill (2006) argues that practices, which he defines as tactical “situated maneuvers that are knowledge-rich” (p. 160), demonstrate active agency, not passive reception, and that these local, situated practices are not just productive in terms of how they shape study design, but also in terms of how they lead to “community understandings and personal relationships that are valuable in their own right” (p. 166). Johnson (1998) argues that users make culture through the “arts and artifacts of technology” (p. 11), and thus are better equipped than designers to judge technology, but because they are often made invisible in the decision-making process, they have become seen as passive observers. Scott (2008) invokes Johnson’s conceptions of user-centered
design to develop his notion of the “practice of usability,” a collaboration between user and designer in testing technologies. All of these approaches employ cultural studies to critique the perspective that designers are the sole knowledge-makers about technology in the world. They posit the agency of users, theorizing collaboration, cooperation, and co-construction of technologies between users and designers.

There has also been a recent surge of research into technical communication used as advocacy in community organizations and civic and public discourse, as well as research of technical communication’s use in everyday life spaces. Bowdon (2004) discusses bringing specialized knowledge of technical communication to a community organization by describing her editing work for an HIV-prevention study. Koerber (2006) examines how the rhetorical agency of mothers and breastfeeding advocates is demonstrated in the ways they resist medical regulatory rhetoric through both their literate practices and their bodily activities. Grabill (2007) examines how infrastructures (global) are created locally through the everyday technological practices of community members’ interactions with information technology in Harbor, an industrial city where environmental contaminants are putting citizens at risk. Simmons (2007) is also interested in public participation, and she demonstrates the tactical public adoption of technical communication in her case study of citizens challenging chemical weapons disposal in a chemical depot in their neighborhood. Kimball (2006), like Grabill, looks at technical knowledge as a part of everyday life, viewing technical communication “happening outside, between, and through corporations and their institutions” (p. 67) because of consumer culture and its associations with “do-it-yourself” culture. He examines people who commune through
technical texts about cars using “extra-institutional7 documentation” that “can help us understand not only our own field, but also the relationship between technology, discourse, and people’s lives” (p. 84). All of these researchers are establishing a groundwork for the field to consider local practices of technical communication outside of workplaces, as Grabill puts it, addressing the “incomplete maps of what people actually do with writing and technologies in their day-to-day lives” (p. 3).

Feminist researchers in professional writing have joined their colleagues in other fields as they seek to value the undervalued and examine the underexamined in the academy8. Many feminist scholars in the field have engaged in recovery work, for example, a historical study that includes the home in the realm of technical expertise (Durack, 1997), an ethnographic study that examines the communication of mine workers in risky situations in order to make visible the invisible, non-textual technical practices that get overlooked (Sauer, 2002), or a study of the differences between professional breastfeeding manuals and laywomen’s breastfeeding knowledge in order to intervene between doctors and patients and allow for disparate forms of knowledge to be considered technical (Koerber, 2005). At its core, this feminist research employs methodologies that recover the writing and/or technical expertise of women as they negotiate their complex engagements

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7 Kimball uses the term extra-institutional to describe ways that the community of men who make “Locost (pronounced low cost) car[s]” (p. 78) by writing their own documentation outside of the walls of car companies, shift from users to producers of technical manuals. He states that, “This community depends on the ability to work around the strategic power of institutions and to scavenge, live, and drive through repairing and remaking what society has discarded. As extra-institutional systems, these communities spontaneously create and mutate technical documentation, thus taking their technological destiny into their own hands” (p. 82).

8 Royster’s (2002) methodology is a good example of this: suggestion, recognition, accreditation, acknowledgement, reconsideration, re-formation, review, and ultimately “recovery” (p. 25).
with technical discourse. Most feminist work in professional writing relies upon a second
wave\(^9\) feminist approach to research, looking at how humans occupying biologically female
bodies have contributed or can contribute technical knowledge to professional
communities and researchers of professional communities.

Although the work of feminist scholars in professional writing has largely relied
upon second wave feminist approaches and has been relegated to the special issue, which
Thompson points out in both 1999 and 2002, there are glimpses, or perhaps “traces” as
Royster terms it, of a more complex, third wave view of feminism that emerges in the field.
One example of this is Herrick’s (1993) work, unique for its focus on performances of
gender at a plastic manufacturing corporation. Herrick argued that language is not
connected to women because of their biological bodies, and as she examined the
relationships of “gender, language, and power” at the office, she engaged in a different kind
of recovery work that interprets language use as people “rhetorically engage the situation
of the moment” (p. 276). This work recovers the local, valuing how individuals perform
gender in different situations, and works against notions of “man” and “woman” as
universal. The study attributes agency to users of language and non-verbal practices; these
women make rhetorical choices in their performances of gender, although they are not
always aware of the consequences of these choices.

These three trends in professional writing research—user-centered theory,
ethnographic research into civic and community technical writing practices, and feminist

\(^9\) A second wave feminist approach in academia can be summarized as “women also”, i.e. in
the circles or ways that biologically male humans have technical knowledge, biologically
female humans also have that knowledge. A third wave feminist approach introduces the
“performative” (Butler, 1997) and suggests a complex view of gender that looks beyond the
contributions of biological bodies. For more information see Nicholson’s (1997)
introduction to *The Second Wave: A Reader in Feminist Theory*. 

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recovery practices—all call for researchers and scholars in professional writing to pay attention to spaces that we’ve not yet traditionally considered. These spaces include technical communication practices and should be incorporated into the field. However, the research studies I’ve outlined have not yet incorporated the sociocultural framework that I propose, which puts the local, situated practices of users in conversation with the broader cultural implications of these practices.

Usability Studies, Technology, and Active Practices of Reception

In their 2003 edited collection *How Users Matter: the Co-Construction of Users and Technology*, editors Oudshoorn and Pinch argue that in studying technologies, scholars have typically focused on the designers’ relationships to the technologies, keeping in mind how these designers have represented and understood the role of users in their technologies. In this book, they seek to move beyond such simplistic representations of users and the focus on agency and creativity of designers; instead they study “how users consume, modify, domesticate, design, reconfigure, and resist technologies,” in short, “whatever users do with technologies” (p. 1).

Oudshoorn and Pinch, along with their book’s contributors, are situated in the field of science and technology studies. They use the term “technology” to refer to objects such as computers, automobiles, vaccines, genetic tests, contraceptives, electric shavers; objects which represent technical and electronic advances of tools used by people in society. The term “users” refers to those people using the technology in their everyday lives, contextualizing this term by setting it in opposition to “designers” who conceptualize and physically assemble these objects before they are distributed for use. However, Oudshoorn and Pinch argue that users are co-constructors and in some cases even co-designers of
technology, pointing to the ways that these technologies in everyday use shape general societal notions of them.

The overall argument of my dissertation applies Oudhoorn and Pinch’s critique to the field of professional writing, arguing that we don’t pay enough attention to users as legitimate co-constructors of technology\textsuperscript{10}. When I use the term “technology” in this dissertation, I am also using this term to mean objects as Oudshoorn and Pinch do, technologies such as x-rays, pregnancy tests, and medications. I also focus on how people engage with these technologies in their everyday lives primarily through the use of texts, documents or images. Thus, I do not focus solely on technology for its uses in the acts of composing or writing processes of professionals, and I argue that the field should broaden its focus of how people take up and use technical writing, not only when they are at work and inhabiting professional roles.

In particular, I argue through a study of the local, situated practices of people taking up medical discourse, that the field needs to pay more attention to the uses of technical discourse in its distribution and circulation to multiple audiences. The participants in my study can be considered “users,” but I think about users differently than the field of professional writing, particularly those conducting usability studies. The first important consideration is that when participants in my study use medical discourse, they are also understanding, reconfiguring, and repurposing medical discourse according to their own motives.

\textsuperscript{10} Even as professional writing scholars define the term, “technology” is often used to mean the technologies that are employed by professionals for writing or composition, for example: computers, software, interfaces and programs such as wikis, blogs, email, the internet, etc. The term “users” is often attributed to the people who are doing the writing or composing. Scholars in professional writing studies thus tend to focus on people who produce, compose, and write in institutional spaces when talking about technology.
While in usability studies, the focus is typically on testing one particular product with a user, my research points to a complex network of multimodal texts that participants engage in their everyday lives. I use the term "multimodal" to include documents that are written, but also images and other forms of documented discourse (i.e. TV shows, movies, websites, internet discussion boards, books, magazines, newspapers, etc.) Rather than just using one particular product, participants might use and discard, read and ignore, look at and compose a variety of textual, visual, and oral sources, demonstrating the breadth of literate activity that participants engage with to understand and manage their health.

I use the term "literate activity" in place of "literacy" because as Prior (1998) suggests, writing is “situated, mediated, and dispersed,” and “literate activity, in this sense, is not located in acts of reading and writing, but as cultural forms of life saturated with textuality, this is strongly motivated and mediated by texts” (p. 138). My participants encounter medical worlds that are saturated with textuality and include both variety in the kinds of textual sources, people, and sites they encounter as well as variety in the practices through which they engage with these textual sources, people, and sites. Not only are they inundated with information from various official channels such as the hospital and medical professionals, but they also use information from various non-official sources such as websites, other laypeople, and television. There are a variety of spaces in which my participants receive and use these texts, including official spaces such as the doctor’s office but also non-official spaces such as their and other people’s homes—in effect, all of the varied spaces they move in and out of in their everyday lives.

Most importantly, participants engage in an active process as they receive and interact with health-related texts. As patients and users of texts and technologies, my
primary participants’ activities are not typically considered in usability studies. Although Barnum’s (2001) definition of usability indicates a focus on the user and not the product, she also states that her book is about “the place that usability testing... holds within the process of developing products that work for users” (p. 2, my emphasis). Because the purpose of usability testing is product improvement, the tests are not designed to account for users’ complex processes of chaining together texts. However, in my participants’ interviews, rather than focusing on any singular text, they point out ways that they tactically and purposefully chain together multiple health-related texts. This active process of selection, repurposing, and re-inscription is central to my argument for the consideration of technical communication outside of the boundaries of the workplace.

The intervention in this project broadens the sites and people we study in technical communication research. Users regularly engage numerous technical texts in a variety of sites and in collaboration with a variety of people, and they engage these texts for their own purposes and motives that have little or nothing to do with making better products, i.e. for personal reasons, work reasons, or entertainment. Significantly, my participants’ purposes reside within them as the users as much as they reside in the particular texts they use. Thus, people’s literate activities point out moments where technical communication crosses over between official and non-official spaces as people move between spaces of their everyday lifeworlds.

By approaching literate activity from the perspective of users’ intentions and motives for technology use in their own worlds, we see participants engaging in literate activity that is not just about the way they inhabit the made world of medicine, but how they remake this world for their own purposes, and how their remaking of this world...
constitutes active participation that should be considered by researchers as legitimate\textsuperscript{11} production of technical communication. Because usability studies have been interested in testing the products designers have constructed in order to improve those products (Barnum 2001), research in usability studies has typically examined how people have come to inhabit the worlds designers have made. With the application of sociocultural studies to the user-centered, civic, community, and feminist approaches to the everyday that I’ve pointed to, it becomes clear that usability studies’ consideration of already-made worlds is not enough to understand how people are using their products because it assumes that people intend to inhabit usability testers already-made worlds. In fact, people intend to remake their own worlds using the technologies/products that usability studies test. They remake their worlds by putting these technologies alongside other official and non-official texts and professional and non-professional people, tying together technologies with other literate practices in their everyday lifeworlds.

My theoretical approach to health literacy and user-centered research accounts for intention, extending and complicating the view of users as co-constructors and co-designers of texts that Oudshoorn and Pinch advanced. Although my dissertation focuses on health literate activity, situated studies of intention and local technical communication practices should not be limited to healthcare contexts. These types of situated studies can

\textsuperscript{11} My participants’ activities using writing to mediate their complex navigation of powerful medical systems is a legitimate use, appropriation, and remaking of technical communication for their own purposes. I define “legitimate” similarly to Lave and Wenger (1991), who take learning to be inherently social and argue that \textit{whole} persons participate in communities as legitimate peripheral participants until they are fully socialized into the community, becoming full participants. I too would question the notion that people need to become full participants in communities in order to become producers of text. The idea that \textit{whole} people participate and that their participation on the periphery is legitimate provides a useful framework to rethink the legitimacy of the literate activity of users.
be undertaken to elaborate on the breadth of research that has already been done by the field in offices and other professional locations of varied professional domains. Using this view, we can begin to re-imagine the scope of technical communication to include an approach to literacies (whether healthcare literacies or other forms of literate activity), across a range of sites, genres and texts that undo the privileging of patriarchal institutional spaces.

A key to understanding this sociocultural approach to health-related literate activity lies in my approach to reception. Instead of seeing reception of medical discourse as passive, I use the notion of *chains of reception* to indicate that patients actively chain together receptive practices and people to understand their health through documents, stories, and networks of people they identify. This active chaining together of people and texts helps them make knowledge and decisions about health in their everyday lives. Along the way, they often write texts on, around, or alongside the official texts as well as remaking those texts through interpretive work and application. Chains of reception indicate agency, i.e. the complex interactive uptake and production of technical texts outside as well as inside of institutional boundaries. My participants create chains of reception in their everyday lives in response to their medical encounters and in collaboration with the people around them, namely their doctors, nurses, friends, family members, people on discussion boards, and alternative health providers.

Throughout the dissertation, I follow participants’ chains of reception, and demonstrate the importance of an approach to technical communication that considers the circulation and active reception of technical medical texts in people’s everyday lifeworlds. Oftentimes my participants did not produce technical texts in the typical ways they have
been researched in the field; however, they produce and transform technical knowledge in their everyday lives through their active tactical repurposing, inscription, and reproduction of official and non-official texts in official and non-official spaces. Following this literate activity of participants and using ethnographic methods to gather data about their activity, I analyze that data to put their local, situated activity into conversation with the broader medical discourses and practices that surround them.

Latour (2005), Engestrom (1999), and Prior and Shipka (2003) each present a different set of tools for tracing activity across settings and locating literate practices across networks, helping to rethink where boundaries are located for technical communication research. Latour’s actor-network theory focuses on how activities are networked together and how all the participants (human and nonhuman, present and absent, now and in the past) are actors in such networks. Tracing the trail of associations between heterogeneous elements in these networks can lead researchers to consider how users of medical discourse are also legitimately participating in the network, and how through their literate practices, they carry technical communication through both official and nonofficial medical spaces. Engestrom et al. (1999) describe knotworking as the ongoing process of tying together, untying, and retying activity systems, and knotworking, like Latour’s emphasis on following actors wherever they go, supports the argument that users’ activity, rather than particular artifacts they encounter or the official spaces of a social practice, should be taken as the unit of analysis. Engestrom’s horizontal approach to activity can contribute to technical communication researchers following users’ activity and rethinking how those activities cross activity systems. Finally, Prior and Shipka bring these theories to the realm of literate activity, exploring how everyday practices (e.g., doing
the laundry, walking a dog, being a couple) come to be networked/knotted together with literate activities (e.g., keeping a notebook, drafting ideas, writing a paper for a college course). According to Prior and Shipka, literate activity

is about nothing less than ways of being in the world, forms of life... [and] is especially about the ways we not only come to inhabit made-worlds, but constantly make our worlds—the ways we select from, (re)structure, fiddle with, and transform the material and social worlds we inhabit. (p. 182)

Taken along with their concept of lamination, which is the layering of histories of literate practices that each person carries around with them, chains of reception then point to the active networked/knotted practices that users’ employ to rethink, repurpose and reimagine technical communication as something of their everyday worlds and not just for the use of privileged actors.

Taken together, Latour, Engestrom, and Prior and Shipka’s sociocultural approaches lay a groundwork for locating and understanding health-related literate activity in people’s everyday lives. Although professional writing studies has not yet sustained long term research studies of these chains of reception, it is very important that in the field, we initiate these studies in order to develop an understanding of production and reception processes of writing that accounts for networks of activity. These networks are situated in concrete interactions and at the same time improvised locally, and they are mediated by tools and practices such as machines, made objects, semiotic means (language, genres), institutions, structured environments, domesticated animals and plants, and people themselves. Because of these complex networks and active processes of reception that
participants engage in, a sociocultural framework like the one formulated from the work of Latour, Engestrom, and Prior and Shipka can begin to account for these everyday practices.

**A Sociocultural Study of Medical Discourse in Everyday Lifeworlds**

The research I have outlined in both professional writing and sociocultural theory points towards the kind of work I am undertaking in my research and dissertation project. Drawing on sociocultural and feminist research methodologies, I take a sustained look at the practices of my participants, following the chains of reception that they outline for me in their interviews. I identify themes that emerged from my research, and these themes make up the bulk of the data analysis throughout the dissertation.

My dissertation is organized into five chapters that introduce the study, analyze the main themes of the data, and theorize the contribution of this research to the field of professional writing. In Chapter 2, “A Qualitative Study of Health and Medicine in Everyday Lives,” I introduce my qualitative case study in more detail, drawing on Latour (2005) and theories of feminist qualitative research as a foundation to the project. I introduce this theory through detailed narrative from my experiences, and then weave the theory with narratives reproduced from my participants to foreground the study as one that seriously interrogates my relationship as a researcher to my research participants. I organize this chapter around three main ideas: the incorporation of reflexivity from feminist research methodologies into the framework for the study, the tracing of associations in recruiting and interviews based on the theories of Latour, and the recording of gesture as a part of semi-structured discourse based interviews. Through this situating of the study, I aim to introduce my readers to ways I was able to follow my participants’ interests in collecting and analyzing the data.
In Chapter 3, “Imagining Bodies: Literate Activity in Material Worlds,” I take up the call of scholars interested in body studies in the fields of rhetorical and feminist theory and seek to further their moves “beyond the text.” Much of the scholarship produced in these fields has examined representations of bodies that are either traditional graphic texts, or externalizations of text on the outside of the body. In this chapter, I outline a theory of the body itself as a representational space being aligned with other textual forms of knowledge, but also being itself a way to make knowledge, both directly and indirectly. Turning to the sociocultural perspectives on literate activity of Prior (1998) and Street (1985), I theorize how the physical body and the internal, felt sense of the body are indeed ways people make knowledge in relationship to a set of texts. Sometimes these texts are co-present with bodies in the situations I examine, but oftentimes they are not, although they continue to be part of participant chains of literate reception.

Next, I move to 2 examples from my participants that highlight different aspects of this theory of bodies as text. First, I discuss Elizabeth who uses only one traditional graphic text as a part of her job as a gyne instructor. Elizabeth learns to read bodies as she learns how to do her job, and she uses her body to instruct medical students. Then, I discuss Bryan, a massage therapist who talks about “reading” his clients through a complex process of interpreting talk and also physically feeling and assessing muscle tension. I conclude that these participants have used bodies in these ways in order to understand things they cannot see. Elizabeth has felt the inside of women’s bodies to understand them in order to teach the medical students proficiently, and Bryan has used touch to feel muscles that he cannot see because they are on the inside of the body in order to provide an effective massage to his clients. This examination of bodies as literate practice serves literacy studies
broadly because it points out how literacy is tied to imagination with and without the co-presence of traditional graphic texts.

Chapter 4 “Medicine, Popular Culture, and Literate Practice,” engages themes of cultural studies and sociocultural activity in the data of one of my key primary participants, Meagan. Because Meagan participated in four 60-90 minute interviews over a 2-year period and either referenced or provided me copies of more than 200 texts that she encountered during that time, this chapter focuses on key events she brought up throughout the study: her first pregnancy, diagnosis of a birth defect, and subsequent termination of this pregnancy, and a second pregnancy which resulted in the birth of a healthy baby boy. These stories are told chronologically, but they focus on Meagan’s chains of reception that show her critical engagement with medical discourse using a wide variety of practices and texts. Through this engagement, Meagan not only comes to understand medical discourse in her everyday life, but she repurposes and reconstructs these discourses according to her own motives.

In my conclusion, Chapter 5 “(Re)Visioning the Professional: Interdisciplinarity and Professional Writing,” I define (re)visioning first by looking at my previous work where I theorized through both written and visual critique of medical rhetoric surrounding digital technologies. Through this definition, I position (re)visioning as accounting for the past and future of feminist theory. I then turn to my research in the dissertation, pointing out ways it takes up my past work of (re)visioning by providing a new landscape for professional writing, but also ways it reforms and rethinks my past ideas about (re)visioning. Using the concepts of scripting from science and technology studies and compliance from medical discourse studies, I theorize this new landscape, one where the field focuses on how
people, professionals and non-professionals, actively engage medical discourse and oftentimes rescript it for their own purposes.

Taken as a whole, this dissertation represents new directions for the field of professional writing. Sociocultural case studies of technical discourse like my study which engages medical discourse push the field into new territory for research, territory that has long been present and a part of technical discourse; however, it has not been given sustained attention by researchers. By examining the multiple people, spaces and texts that are legitimately a part of technical communication, the field can continue to make the kinds of contributions to pedagogy and workplace writing that have been important, but it can also make new contributions as well. While I can imagine a new landscape of discourse-based studies of the local practices of people engaging with technical discourse and health literate activity in their everyday lives, I also imagine that there are numerous configurations of these sociocultural case studies that could open up other important and relevant futures. I imagine these futures to include interventions on the part of professional writers, researchers, and scholars, interventions that empower people to reshape technical discourse on their own terms and in rhetorically savvy ways, thus undoing the privileging that happens in patriarchal institutional spaces of technical discourse and medicine.
Chapter 2  A Qualitative Study of Health and Medicine in Everyday Lives

I consider myself to be something of a methodology junkie. My favorite part of any academic book is the introduction, and sometimes the conclusion, because I like to know what people think they’re doing in their writing and their research. This chapter explores this and various other obsessions I have with methodology, and how those obsessions came to be a reality in my dissertation project.

As many people like a good mystery, I really like a good research methodology, especially a feminist qualitative research methodology. I appreciate the inclusive orientation\(^{12}\) of feminist researchers, as they’ve sought to recover women’s practices in particular spaces over particular time periods. I am enamored with work that addresses the relationship between researcher and researched, especially if something goes wrong and the researcher struggles to figure out how to fix it. Often though not always in our field, the researcher is teacher, and the researched are students, thus putting the researcher in the precarious situation of power that many feminist researchers are just plain uncomfortable with. These negotiations seem to me to be importantly worked on, though not resolved, in much of the writing on how the researched contribute to, how they talk to, and how they share space with the researcher.

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\(^{12}\) The word “orientation” is especially important here, as feminist approaches have been critiqued for being exclusive and maintaining “white middle class” as the norm for all women (Mohanty, 1984).
I can trace this obsession with the teacher/student researcher/researched relationship all the way back to my early undergrad years. In my freshman year, I found myself at a large university in the city of Philadelphia, an experience not unlike my high school experience at a large Philadelphia public school, and incidentally, 50% of my high school class attended Temple University, my alma mater. I was among the “privileged” in that my GPA and SAT scores qualified me to take honors classes. At first I thought I’d try some classes in different majors, but quickly ruled out philosophy, political science, and history as possibilities because I couldn’t get higher than Bs on my papers. I decided to major in my old standby, English, because I loved to read, and I easily wrote and achieved As on all of my literature papers.

So I was good at English, but I didn’t love literary analysis. I would describe my relationship to English literature as detached. I read a lot of it for my survey classes, but I found myself zoning out during class and writing character sketches for novels instead of listening and participating.

So with my heart only half in college, in my sophomore year I scheduled all of my classes on Tuesday/Thursday so that I could work on Monday/Wednesday/Friday. That could have been disastrous, but instead it turned out to be serendipitous, as I needed an 8AM Tues/Thurs, and ended up in Sonia Sanchez’s class on Black Women Writers. At the time I thought to myself, “I read Alice Walker in high school, this will be easy.” But the class was not at all like the other literature classes I had taken, and Sonia’s teaching changed more than my relationship to literature, it changed my life.

We read Linda Brent’s (1973) Incidents in the Life of a Slave Girl first. I don’t remember exactly what we talked about, but I vividly remember Sonia writing something on the board about the psychology of being a black woman slave, the uniqueness of being owned not only
by your white master but by your black husband, and that the struggle to become free was not only a physical freedom in crossing over to the north, but a psychological and emotional freedom in believing yourself to be a human being who deserves to be treated as human and equal and free. She described this as a paradox, and it felt like a paradox I could relate to, despite the fact that I was never black nor a slave.

As we read other black women writers, a book a week, Sonia made the story and struggle of these women a human story, a story for anyone to identify with if only that someone was willing to identify themselves in the story, a story about universal connection and inclusion, but also a story where human beings can learn most from the particularities of black women. Looking back on it now, I find it strange that I began to imagine my Jewish white womanhood to be a part of the stories and struggles of the black women writers I was reading, from the slave narratives to the civil rights stories.

Sonia had a way of valuing every voice in her class, no matter who they were, black or not black, woman or not woman, each of us had something we could contribute to the whole of the class. At the end of every class period, Sonia had us stand up and form a circle around the room, holding hands. She didn’t really ever say, “this is what we will do,” we just followed her and did it. We went around the circle and each said something, most people said “thank you” to the people in the circle, but occasionally someone would say something more, and what we said was our contribution to the circle.

That circle means a lot of things to me, looking back. The circle was the great equalizer; we were all just people holding hands, not teacher and student anymore, or grad student and undergrad student. The circle put us all on the same level. The circle gave everyone a voice, and it gave everyone a face—we looked at each other, the people we shared the room with,
the people we shared our valuable ideas with—and we said something, voiced something, thanked each other. Even as I sit here typing these words, I have such a sense of awe that I had the privilege to be a part of that class, to share ideas, and to still remember to this day some of the people I shared that classroom with that I probably would have never met had there not been the little bit of openness and willingness to do something new that I entered into that classroom with. A little bit was enough for me to participate in the class where we as students shared our ideas, we did something that was against having an English literature canon made up of white men. But more than that, it was against oppression, against humans enslaving and demeaning other humans, against violence. I developed a sense that through reading, writing, and sharing ideas, we were actually changing the world.

Extending the Circle, or How My Participants Have Come to be Participants and Not Subjects

One of the things the circle taught me is that I am just one of many; my ideas are valuable, but valuable because others’ ideas are equally valuable, and not valuable because I am more or less than anyone else. I have come to join many feminist researchers in my belief that as a researcher, I personally have an ethical responsibility to understand and represent what I research, to locate myself in whatever role I am taking on, and to interrogate whatever privilege that role carries with it.

Margery Wolf’s (1992) *A Thrice-Told Tale* represents a classic anthropological example of the feminist activities of interrogation and location, or “reflexivity.” Wolf’s manuscript collects three different versions of the same story and intersperses each telling with Wolf’s commentary about her location and material circumstances at the time.
Through these different tellings, Wolf argues that researchers should not stop researching or representing as postmodernists asserted that researchers should do because there is not one “truth” of the story. Instead, she urges feminist researchers to follow in the footsteps of their feminist predecessors who had long been concerned with “questioning objectivity, rejecting detachment, and accepting contradictory readings” (p. 135). Wolf’s manuscript indicates that researchers should work with knowledge of these constraints rather than abandoning research because these constraints exist. She advocates for a shift away from seeing people being researched as “object,” instead seeing people as “subject” of research.

Reflexivity such as Wolf exhibits in her work can extend the metaphorical circle I mentioned before, because as the researcher locates herself in the circle, she identifies her biases and privileges in her positioning as researcher. However, numerous scholars have pointed out the limits of the “subject,” as reflexivity in this case can only do so much to change the hierarchies between researcher and researched. Kirsch and Ritchie (1995) propose a slightly different form of reflexivity for composition researchers, calling for them to “theorize their locations by examining their experiences as reflections of ideology and culture, by reinterpreting their own experiences through the eyes of others, and by recognizing their own split selves, their multiple and often unknowable identities” (p. 8). Furthermore, they call for researchers to invite people to collaborate as “participant,” participating not only in answering questions, but also in developing research questions,

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13 See Cooper’s discussion of “Death of the Subject” in her 2011 CCC article, “Rhetorical Agency as Emergent and Enacted.”
interpreting data, and shaping and guiding new lines of inquiry within the research project.¹⁴

In formulating a research study that invites people to talk about their own very personal engagements with medical discourse, I endeavored to build this reflexivity, collaboration and ethical representation into the design of the study itself. I sought to extend the circle to give participants input into my research framework in several ways:

(1) I organized my study around participants’ experiences and interests rather than around a particular condition or diagnosis, which is typically how studies of medical discourse are organized.

(2) In developing research questions, I sought to make the interviews open-ended, allowing participants to share stories that were significant to them, or make the choice to not share a story if they felt for some personal reason that they did not want to share it. (For Interview Protocol, see Appendix A)

(3) Once a person agreed to participate in my study, they had control in determining the level of their participation and identifiability on their consent forms. (For Consent Forms, see Appendix B)

Before I go into detail about the affordances and limits that each of these categories has in extending the circle to include both researcher and participant, let me first tell you about the types of participants in the study and introduce each of the participants.

Participants were divided into three categories: primary participants, secondary participants, and community participants. I asked primary participants to talk about their

¹⁴ In Traces of a Stream, Royster (2000) extend further the term participants by calling them mentors/guides of research.
own healthcare, providing texts they had encountered or used. There were no specific criteria for recruiting primary participants; I recruited through personal connections. Secondary participants were friends and family of primary participants, and they could be recruited through personal connections or through the consent of primary participants. I attempted to recruit several secondary participants; however, no secondary participants consented to join the study. The final category was community participants, medical and alternative medical professionals who I asked to talk about how they used texts in their professional practice and to provide these texts whenever possible. They also could be recruited through personal connections and through the consent of primary participants. Although I would ask each category of participants a different set of questions, my goals for interviews and my relationships to participants were similar. I hoped that by seeing how laypeople and professionals were encountering medical discourse with a wide variety of engagements, my participants would demonstrate the variegated and textured terrain of understandings and constructions of medical discourse in their everyday lives.

**Primary participants: Meagan, Elizabeth, Jenica, and George**

Meagan has been a close friend of mine for many years and was recruited to participate in the study through this personal connection. She was the first participant to join the study, and she provided the most data for me to examine. When Meagan was first recruited to join the study, she purposefully saved the majority of the documents she received in her healthcare encounters to share with me during our interviews. Meagan participated in four 60-90 minute interviews over a 2-year period and either referenced or provided me copies of more than 200 texts that she encountered during that time. These

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15 For a summary of data collected from each participant, see Appendix C.
texts center around 3 significant events: a diagnosis of ulcerative colitis; a first pregnancy, diagnosis of a birth defect, and subsequent termination of this pregnancy; and a second pregnancy which resulted in the birth of a healthy baby boy. Meagan chose to be identified by a pseudonym.

Meagan’s data makes up the majority of the data analyzed in this dissertation for several reasons. First, I have the most data from her both in terms of interviews and text collection. Second, because I have such a significant body of data from her, I was able to draw out several themes and lines of inquiry and look at those literate practices very closely. Finally, because Meagan and I maintained regular contact outside of our research meetings, as events unfolded in her life over the two year period, we scheduled interviews for her to have the opportunity to talk about them. We also had several follow-up conversations via email.

Elizabeth has also been a close friend of mine for many years and was recruited to be in the study through a personal connection. I recruited her because of her unique experience as a gyne instructor, evaluating medical students conducting breast and pelvic exams on her body, and her openness to talk about that experience. Elizabeth participated in one 90-minute interview, referencing many texts but providing me with copies of only a few of these because she did not have access to many of them at the time of the interview. Elizabeth’s data was particularly relevant to theorize making sense of and learning directly on bodies because of her education and responsibilities as a gyne instructor. Elizabeth chose to be identified by her real name throughout the study.

16 Although I recruited Elizabeth because of a professional experience, I was interested in other experiences in her life as well. Elizabeth is considered a primary participant because I asked her the primary participant set of questions rather than the community participant set of questions (See Appendix A Interview Protocol for more details on these questions).
Jenica has been a colleague and friend of mine for a few years, and I recruited her through this personal connection. She participated in one 150-minute interview with her parents, Drs. Bradley and Eugenia Roberts. Because the interview focused on their dental practice, Jenica shared her personal dental history with me so that I could understand the kinds of texts that patients see as a part of her parents’ practice. Jenica’s data is unique for a primary participant because I didn’t ask her specific questions about her healthcare; however, we looked at Jenica’s medical records during the interview so the Roberts could provide an example of what patients will read when they come to their office. Jenica chose to be identified by her real name throughout the study.

George is my father and was recruited though this personal connection. He participated in one 90-minute interview where he talked primarily about his diagnosis and treatment of prostate cancer. He provided me copies of 15 alternative and traditional medical texts relating to this diagnosis. George’s data is included in this chapter to provide an example of the documented narratives I use to analyze data throughout the dissertation. He is also included here because he is my father, and our relationship brings up unique concerns about the relationship between research and researched that I wish to explore. George chose to be identified by his real name throughout the study.

Community participants: Bryan, Emily, Deb, Brad and Eugenia

Bryan has been a friend of mine for many years and was recruited through this personal connection. I recruited him to participate in the study because he had his own independent massage practice that he ran out of his house. Bryan participated in one 90-minute interview, which included a tour of his massage room, and he provided me with copies of 11 texts that he used in his education to learn massage and in his practice to
provide to his clients. Bryan’s data was particularly relevant to theorize communicating through a combination of talk, text, and touch because of his education and experience as a massage therapist. Bryan chose to be identified by his real name throughout the study.

Emily was a community acquaintance and was recruited through this personal connection. I recruited her to participate in the study because of her jobs as a nurse, nurse manager, and nurse educator. Emily participated in one 90-minute interview. Although she did not provide me with any copies of texts she used in her practice, she spoke in detail about specific kinds of texts that nurses distribute as well as providing general information about how nurses think about and use texts as a part of patient care. Emily’s data was particularly relevant to thinking about how the field of nursing has thought about patient education and texts. Emily chose to be identified by a pseudonym throughout the study.

Deb was a community acquaintance and my yoga instructor and was recruited through this personal connection. I recruited her to participate in the study because of her practice as a yoga instructor and her training as an occupational therapist. Deb participated in one 90-minute interview and referenced several texts that she designed to incorporate yoga in occupational therapy practice, but she did not provide me with copies of these texts. Deb chose to be identified by her real name throughout the study.

Drs. Brad and Eugenia Roberts are the parents of Jenica and were recruited through my personal connection with her. They were recruited because of their private practice as dentists. Throughout their 150-minute interview, we toured several rooms in their dental office, and they showed me texts on their computer system, printing copies of 8 texts for me. They also provided me with some pre-printed materials and sample hand-drawn texts
they might produce for patients during the course of treatment. Brad and Eugenia both chose to be identified by their real names throughout the study.

Throughout the data analysis in the dissertation, I chose to focus in on participants who spoke in detail about issues that I found particularly relevant to examining engagement with medical discourse in people's everyday lives. In chapter 2, I wanted to focus on my role as a researcher relating to my research participants, and I found my relationship with George to be most productive for exploring that, thus I focus on the data in his interview. Chapter 3 addresses issues relating to the body, but in particular I wanted to think about how participants learned on and communicated directly with bodies, focusing on participants’ use of touch and movement to imagine the inside of the body. The data from Elizabeth’s interview about her experience as a gyne instructor and Bryan’s interview about his experience as a massage therapist were particularly relevant for this issue. In chapter 4, I focus on examples of participants who through their active practices of reception, show how they remake medical discourse in their everyday lives. To a certain extent all of my participants provide examples of this, however I chose to focus only on Meagan because the extensive amount of data I gathered from her provided an opportunity to do a close reading of these practices. Finally in chapter 5, I focus on (re)visioning and suggest how Emily’s nursing model of patient education addresses through use of multimodal texts, patients’ everyday life concerns. The data I gathered from other participants who are not given close attention (Deb and the Roberts) provided background about people’s active practices from a community participant perspective. Deb’s discussion of incorporating yoga in occupational therapy as a way of being an advocate for patients provided background for the other issues of advocacy I address, particularly those of
Elizabeth. The Roberts discussion of preventative medicine and their tour of the dentist’s office provided background to thinking about the ways Elizabeth, Meagan, and George engage preventative medicine in their everyday lives. All of the data I’ve collected has informed my analysis, and the issues that I’ve not had an opportunity to address here I plan to address in future work.

**Participant interests and open-ended interview questions**

In organizing the study around participants’ interests rather than a particular diagnosis, I was afforded the opportunity to learn about participants’ roles in negotiating a variety of medical issues and diagnoses. For example, though I had an interest in women’s health going into the study, I didn’t shape my research questions around this issue. Instead, I asked primary participants open-ended questions about their memories of going to the doctor as a child, transitioning into adulthood and going to the doctor on their own, and follow-up questions about any of the stories they shared. As a result, in my interview with Elizabeth, instead of just asking about her job as gyne instructor which was my original reason for interviewing her, I learned first about her dad being a doctor, which led her to go to Planned Parenthood instead of her father’s clinic so she could get birth control. I learned that when she had a cervical cancer scare, she sent her pap smear results to her dad to get confirmation that it was abnormal but not indicative of much else. I learned that after she broke up with her boyfriend, she had to go to the emergency room because of extreme pelvic pain, but that they never were able to diagnose her with a physical problem. I learned that as a gyne instructor, she focused on teaching future doctors how to talk to their patients about breast exams because of her mother’s and grandmother’s experience with breast cancer. I also learned that Elizabeth’s understanding of health is wrapped up in
the fact that she takes a multi-vitamin every day, and that she has an interest in nutrition and local foods as ways of keeping healthy. If I had only asked Elizabeth about her experience as a gyne instructor, I would have missed learning about all the other important ways she engaged with medicine in her everyday life, and the ways that she saw those engagements shaping her current understandings of her body, medical language, and advocacy.

Organizing my study differently than most studies of medical discourse has provided certain limits for me as researcher and scholar. I’ve struggled on occasion to locate my study amongst other studies of medical discourse because unlike them I don’t focus on particular diagnoses or medical issues. When I tell people about my research, I’m often inclined to speak about it generally to find some common ground, saying that I research health literacy or how patients are using documents in their healthcare.

But on the whole, I see this struggle for location in a field as liberatory more than it is limiting; while medical communities are busy categorizing people based on conditions (cervical cancer) or sex (women’s health), I can research how people see themselves rather than how medical institutions see them. I can represent people differently than medical institutions have constructed them, approaching their engagements on their terms rather than how they’ve been shaped and labeled by their medical condition. I’ve found that people often don’t think of themselves primarily as a patient or a condition or a diagnosis as medical professionals might see them. Rather than bracketing off medical discourse, my participants engage, repurpose, and even re-inscribe medical discourse in their everyday lives to achieve their own understandings and intentions for health. For example, Elizabeth considers her time as a gyne instructor as belonging to a particular location in her life, and
that is part of but not all of her identity. I believe that the orientation towards research participants that this organization allows for provides a validation of participants’ agency and experiences. This move is a feminist one because it locates agency in the lifeworlds of the participants, considering their activities as a legitimate construction of medical discourse.

Open-ended interview questions provided space for my participants to voice their experiences with medical discourse, giving them the opportunity to speak from their perspective to the circle, but as the researcher I still controlled that voice to a certain extent because I formulated and asked the follow-up questions and then selected data to report in the analysis. As I was conducting the interviews, I asked questions to satisfy my own curiosities about the participants’ experiences, and in so doing, sometimes missed participant perspectives that would add dimensionality to the terrain of the research. Even though I developed open-ended questions and focused on participants’ narratives throughout the interviews, on several occasions I found after the interviews as I transcribed my participants’ words, I sometimes led the conversation to a line of inquiry that cut off something particularly interesting a participant had said. Thus, I had several follow-up email conversations to collect additional texts or pursue clarifications about additional lines of inquiry. In this way, email became another method of interaction that allowed for more collaboration in the analysis stages of project.

**Informed consent**

Kirsch and Royster (2010) outline several keys to excellence in feminist research methodology that include paying attention to lived experience, engaging in dialogue with participants to understand perspectives that differ from our own, and respectfully
representing the words of those we study. For them, excellence in feminist research “entails an open stance, strategic contemplation, and creating a space where we can see and hold contradictions without rushing to immediate closure, to neat resolutions, or to cozy hierarchies and binaries” (p. 664). In order to reach standards of excellence then, I had to be open to resolutions that were not always neat and cozy. I find reflexivity in acknowledging the position I hold as a researcher and in seeking to center my work on the voice of my participants as much as possible. To that end, I offered several levels of participation for informed consent so that people who were willing to share sensitive information about their medical experiences could retain some control over what they shared.

Here are the choices involved in participation (for the specific language of the consent forms, see Appendix B):

(1) Participants were asked to voluntarily provide documents, and I never sought access to private documents that participants referenced (such as medical records). In this way, if a participant felt a document was too personal or did not want to talk about a particular medical experience, they could choose to leave it out from the interview. In the cases where participants provided private medical documents, they signed a “Personal Medical Document Release” form.

(2) Participants had full choice over their level of identifiability. I wanted participants to be able to be referred to by a pseudonym if they preferred or by their real name if they preferred. Also, they had choice in audio and video representation. They could choose to have their face represented or not represented in video or still shots, they could choose video for my analysis only which would not be
represented in presentations or publications, and they could choose no video or no audio taping. They also could decide these things for each individual interview.

(3) Participants could choose to have their interviews kept indefinitely and used as part of an archive for future educational purposes if they wished. In this way, other students and researchers could have access to their data as well.

(4) Primary participants could choose to identify secondary participants and consent to me contacting them and talking about personal information with them. I would not make these contacts without prior participant consent.

Because of these choices, participants could feel free to share as much personal information in interviews and through documents as they felt comfortable sharing. They could choose how they wanted to be identified, recorded, and represented in presentations and publications about their data. They could consent to have me talk to others about their medical information if they wanted me to. By allowing space for participants to have a voice in the level of their participation, the circle was extended to include their voices in the recording, analysis, and publication of their experiences.

**Tracing Associations: Latour and Extended Networks**

*When I started my study, I didn’t plan to interview my father; in fact, I didn’t know he’d been diagnosed with cancer.*

*I don’t even remember really when I found out he’d been diagnosed. I think it was sometime before the summer, the year before the interview, that I found out. My dad mentioned in our regular Sunday phone call that he was thinking of taking the train from Philadelphia to Baltimore to go to Johns Hopkins. It’s hard to know what’s going on with my dad really, because he never comes out and says something like “I’ve been diagnosed with*
prostate cancer.” Instead he says, “I’ve got to go to Baltimore,” and then I say “what for?” and he says “Johns Hopkins,” and after a few back and forth exchanges, he’d say something like “a follow-up biopsy for prostate cancer.” And then it’s hard for me to know what to freak out about, like should I freak out because my dad is sick, or because he’s going to take a train by himself from Philly to Baltimore to go to a hospital. So I’m sure I suggested something about getting my brother to drive him to Baltimore, and I’m not sure what really happened with it, but I suspect my dad just went by himself. My dad doesn’t really like bothering my brother for one, and he also doesn’t like being driven around by my brother because he thinks he drives too fast and too recklessly. So he probably went by himself.

Every summer my dad comes to visit me. We used to take a trip and go see a baseball game in a nearby city, but on this particular year, we didn’t travel because my dad had to fix a few things around my house before our new tenants moved in. Sometimes after his visit, we would make the drive to Philly so I could spend a week or so with family. My friend Jenica and I had been talking, and she worked it out so I could come interview her parents. So we stopped by their place on our way towards Philly.

When we arrived at Jenica’s before the interview, they had a nice spread set up for us to eat with them. They had grilled some burgers for us, and we went out on their back patio to eat and talk. We actually ended up talking about a lot of things that I tried to get them to repeat during the interview: how dentistry has pioneered preventative care, how an increasing number of healthcare professions are starting to follow the model of preventative care, how insurance companies often offer incentives for preventative care.

Then my dad just started talking about his health insurance. Had we not been with other people, it’s unlikely it would have ever come up. I started to get curious, wanting to
know what kind of treatments my dad was pursuing for his cancer. So I mentioned he might let me interview him, and he agreed.

I actually learned a lot about his cancer during that interview that put my and my siblings minds at ease. He spoke of having a high PSA and getting a biopsy, and then having them find cancer cells in that first biopsy. The first doctor recommended surgery, but my dad wasn’t sure, so he asked around church and ended up seeing a relative of one of the church members, who recommended fairly regular biopsies but no treatment unless they found the cancer was growing. As it turns out, men might die from something else before the prostate cancer would kill them 15 years later. My dad has had numerous biopsies since then, but no cancer has shown up since that first biopsy. In my dad’s opinion, prayer and nutrition were responsible for healing him. He has become a very picky eater in the last few years.

And even better than me actually finding out what the deal was with the cancer was being able to tell my siblings that he was ok. My sister found a letter for my dad reminding him to set up another biopsy, and not knowing what was going on since my dad never talks about it, she thought that it was a bad sign. But I told her the deal, the biopsies actually just mean that things are going well. If he had to have surgery or chemo, that’d be another story.

It may seem contradictory to have a project interested in deeply engaging feminist research methodologies and the sociocultural theories of Latour. Theorists (Mackay et al., 2000; Oudhoorn and Pinch, 2003) have critiqued Latour’s actor-network theory because they see his attention to nonhuman actors as devaluing human activity. Latour has critiqued all academic fields, but in particular the social sciences and sociology, for treating the social as a fixed element. Although these theoretical stances sometimes disagree, there
have been significant crossovers as well. For example, Haraway (1994) agrees with Latour (1987) that we need fresh sources of power such as science and technology for analysis and political action. She has drawn on Latour’s (1992) theory of human and nonhuman actors in her writing of the *Cyborg Manifesto*.

For this chapter, there are several key terms from Latour that align with feminist theory and have been particularly useful in developing a research methodology. The first is “black box” (Spinuzzi, 2007; Jones & Sidler, 2009). Latour (1987) says “black box is used by cyberneticians whenever a piece of machinery or a set of commands is too complex. In its place they draw a little box about which they need to know nothing but its input and output” (p. 2-3). The metaphor of opening the black box makes a lot of sense in relationship to feminist recovery practices. Oftentimes technical fields like medicine might black box technical language about bodies, positioning women to not know what was going on, and asking them to trust the system because the system knows better. Opening the black box might involve recovering alternative medical practices or practices of women at home. Valuing the contributions of women as legitimate contributions to science and technology aligns with feminist recovery projects and Latour’s work.

My participants often described situations where the language or concept was too complex. Both George and Meagan talked about colonoscopies for example. Meagan talked about meeting the doctor who performed the colonoscopy for the first time that day, how he was sitting at his computer in the procedure room, and how he didn’t turn around when she was wheeled in. George talked about having polyps in his colon that were removed, but he didn’t know how they were removed, just that it wasn’t through surgery. In both cases, doctors focused on explaining input and output for these procedures, and input involved
drinking a liquid beforehand to prepare, while output involved the results of the colonoscopy, a diagnosis of ulcerative colitis for Meagan, and removal of precancerous polyps for George. The necessity of opening the black box differed also for these participants: Meagan did a significant amount of research on her own to understand what was happening to her body. George also did research, but mostly about input; he attended classes to learn about nutrition and sexual function for example, but the medical details of colon polyp removal were not important to him as long as he knew they were gone and he was healthy.

As I mentioned before, feminists like Haraway have imported Latour’s idea of human and nonhuman into feminist theory. For Haraway, it resolves some of the debates of feminism and creates a unified front, opens up the possibilities for a unified feminist agenda. The concept of the cyborg puts agency back in the hands of women; everything in the world is made up of human and nonhuman, and human and nonhuman act on each other, so both are a part of the collective. Thus the cyborg allows women to break away from the constraints of their gender.

The image of the cyborg works in some ways for my participants, as they often look up information on the internet and compose with computers, engaging nonhuman actors consistently, and sometimes those nonhuman actors must serve as medical professionals when participants have difficulty accessing information from human actors. For my participants, the texts often become nonhuman actors. When Meagan can’t get access to clarification about information on her ulcerative colitis diagnosis, she turns to texts of all sorts in all sorts of spaces (the internet, friends, health food store) to receive clarification. She learns how to treat ulcerative colitis with nutrition to prevent flair ups, and learns that
prevention is the best course because it’s far less painful and lasts longer than treating the flair up once it occurs. She learns from texts and images how to locate the pain on the inside of her body, and she translates that location back into medical discourse in order to convey the location precisely to her doctors. The internet is a nonhuman actor and serves different roles for Meagan as she negotiates for the care she needs.

According to Latour (2005), the landscape of the collective is made up of heterogenous components that are assembled and reassembled, sometimes hardened and standardized and sometimes dynamic and fleetingly improvised. Latour critiques social sciences when he says that “even though most social scientists would prefer to call ‘social’ a homogeneous thing, it’s perfectly acceptable to designate by the same word a trail of associations between heterogeneous elements,” and that “…all those heterogeneous elements might be assembled anew in some given state of affairs” (p. 5). Latour asserts that we should look at how the social has formed through networks made up of human and nonhuman actors. By following the trail of associations between actors, things that appeared homogenous and fixed can be seen as heterogeneous and shifting, assembled together in ways that have been reified by the actors involved to appear fixed despite the fact that they are rarely fixed. In fact, the actors have not always been assembled together

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17 Often during presentations I have given about Meagan’s data, someone will ask a question about how doctors respond to their patients bringing information from the internet into the interaction. I talk about how doctors lament the fact that their patients consult the internet and bring in demands about their treatment, and yet they perpetuate that very need by spending less and less time educating and communicating with their patients. I don’t mean to suggest that if doctors spent more time communicating, people wouldn’t use the internet. I think the fact that doctors see the internet this way demonstrates Latour’s point about nonhuman actors because the doctor-patient interaction has become doctor-internet-patient interaction in many cases.

18 In Latour’s Reassembling the Social, the collective is society, the social.
that way, and given a different state of affairs, could have been assembled together differently.

In other words, the boundaries that have been drawn around domains such as medicine have been drawn that way for a reason, but these boundaries have been drawn differently in the past, and they will be redrawn in different ways for different purposes in the future. If studies of medical discourse take the institutional definitions of domains such as medicine as the basis for analyzing these domains, they overlook the historic nature of the sociocultural relationships and the future reassemblage of the heterogeneous elements. The human actors who often are able to draw these boundaries are the people in power, and feminist theorists often show ways that the oppressed cross and redefine boundaries for their own purposes (e.g., Anzaldua 1987). In this way, I see the work of “tracing associations” (Hart-Davidson, Bernhardt, McLeod, Rife, & Grabill, 2008; Propen, 2007) as a key component to a feminist project.

The role of the researcher then becomes to follow the “trail of associations” that has come to connect these elements. Following the trail challenges the boundaries of everyday social categorizations; professional writing has tended to define itself around those boundaries, while technical medical discourse is often assembled together in spaces and with people who are not within those boundaries. My feminist project relocates the locus of the interactions that make up technical medical discourse; by following the actors, choosing to follow female actors and choosing to follow patients, we see what spaces these interactions are occurring in rather than presupposing where or how they’re located. Instead of focusing on privileging a particular text such as those that come from the doctor
(typically what the doctor says and not what s/he writes), we can look at an amalgam of texts that actually make up constructions/understanding of medical discourse.

Tracing associations allows for both seeing ways elements have come together (or people have brought them together through their receptive practices\(^{19}\)) in a local context, while acknowledging the connections of the global or cultural context as well. This horizontal approach to social collectives is what Latour calls “flat” (p. 165). In a person’s everyday lifeworld, things that might not be considered “medical” by medical professionals come to be as significant as the resources the experts have provided for people to draw on. While medical discourse and medical worlds structure people’s activity, these worlds also get reshaped and structured by people as they import medical knowledge into their everyday lives for their own purposes.

Certainly, for Meagan, medical discourse is heterogeneous and happens across multiple settings including both official and non-official health-related spaces. These spaces are also connected to a number of textual repurposings and inscriptions: official discharge directions from her doctor, internet chat boards, pop culture references, and blended chains of oral and email conversation with her family. Starting with the encounters that my participants highlight in their discourse-based interviews, I work to trace the trails of associations that show how they build upon the official discourse by using their history and former knowledge of health as well as the research they do and the resources they rely on to understand these official discourses of health within which their literate practices, and their literate lives, are situated.

\(^{19}\) See Prior and Shipka (2003) who found that writers routinely select and structure their environments (environment-selecting and -structuring practices, or ESSP’s). They define ESSP’s as “the intentional deployment of external aids and actors to shape, stabilize, and direct consciousness in service of the task at hand” (p. 219).
In the research study, following the trail of associations starts with recruitment. Instead of recruiting people based on a particular age, race or gender, I recruited through personal connections, allowing me to recruit anyone I could form a connection with who might be interested in talking with me about their healthcare experiences. Then, through the discourse-based interviews, I followed the extended networks that participants traced out. Extended networks include people but also texts and artifacts, examining practices, tools, stories, and associations. Thus, I blended Latour and feminist theory for a framework that considers the practices that individuals use to organize and structure their lifeworlds, the tools they use to mediate these worlds, the stories they tell about these practices, and the associations that their practices have with cultural and societal constructions of health.

An example of recruitment is in the story I told about my interview with George. This includes another dynamic to the interaction—family—my family relationship in my roles as researcher and daughter. I followed the trail of Jenica’s associations to her parents, and incidentally, my father happened to be along. Because of the Roberts’ hospitality, we happened to all sit down together for a meal, wherein they talked about things related to medicine, and George joined in the conversation. Following the Roberts’ interests, I learned about George’s interests, so I asked him and he agreed to participate. I hadn’t really crossed my interests as researcher with George’s interests in medicine—the domains of my research and family remained separate in this case—but the domains crossed in the Roberts’ backyard. And I followed up, thus following the trail of associations.

In order to represent that trail of associations and chains of activity that participants engage in, I collected examples that participants encountered, both human and nonhuman. In what follows, I provide an example of a discourse-based documented narrative that
shows what George’s extended networks look like. First, they include medical professionals, particularly doctors who specialize in prostate cancer. But also they include urology and counseling reports that come from those doctors (Figures 2.1 and 2.2).

Figure 2.1 George’s urology report

Figure 2.2 George’s counseling report
Then, George’s primary doctor suggested he buy a book, which he bought at Barnes and Noble, a generic book on what prostate cancer is (Figure 2.3).

**Figure 2.3 Guide to Surviving Prostate Cancer**

His doctor also suggested he go to some community sessions on issues relating to prostate cancer, and he had some interaction with specialists and other men who had prostate cancer. George got some information there, but saved only the documents on nutrition, including some recipes.

At church, George asked his friends who were doctors for their suggestions, and ended up finding his primary doctor this way. A close friend of his believed strongly you can fight cancer with food, and he told George all kinds of things, including that products with tofu are bad for you, and so now George won’t eat tofu. Also, George’s extended networks came to include the church he attends because the pastor prays for him during the service, and individual church members who prayed for Him, and of course God (human or nonhuman?), all of whom were part of what George believes was his healing. The protestant bible verses (Figure 2.4), especially verses on healing, also have come to be tied up in George’s extended network. George considers his network of religion and the
heterogeneous elements, both human and nonhuman that make up his network, to be as legitimate a part of his current health, if not a more legitimate part, than the doctors who diagnosed and treated him. George also excluded certain elements, in particular his children, from being a part of his network, though in my role as a researcher, I was able to participate even more so than in my role as his daughter.

Figure 2.4 James 5: 14-15, Bible verses on healing

For George and for my other participants, extended networks are a very important part of the ways they understand health and take care of themselves in order to be healthy. Latour’s concepts of the black box, human and nonhuman, and trails of associations all contribute to research that accounts for these extended networks and the important parts of making sense that people engage with as they participate in these networks. The spaces where people participate, i.e. the backyard, often are not included when researchers consider spaces where medical discourse occurs. However, negotiations relating to health happen in these everyday spaces for all of my participants. Using Latour’s framework, I have been able to follow my participants into those spaces, into those mundane and
informal conversations and exchanges of text to see what kind of legitimate knowledge making practices occur there.

**Working with Video, Recording Gesture**

Another obsession I have as a meth(odology)-head is when I read something, I read it with an orientation to not only what data is being analyzed (be it about medical rhetoric, literate activity, feminist theory, science studies, or bodies), but also with an orientation towards how the author has chosen to analyze and represent the data.

I can trace this orientation back to my undergraduate days.

After Sonia’s class, I realized that I could learn more about anything from my teacher’s style than I could by choosing classes based on the subject. So I researched my teachers. How do you research teachers you may ask? By talking to people. I talked to my friends about what classes they took and how the teachers were, and I ended up taking other classes that changed the ways I thought about academic work. In Roland Williams’ African American literature class, we were required to go around the city and visit six African American historical sites, and then somehow represent those sites. Most students just took pictures and put them in a photo album, but I came up with what I thought was a very clever idea, and I made a book of collages with black and white photographs of the sites mixed together with contemporary news stories. Next to each collage was a one-page explanation of how that historical moment was still significant in contemporary society. I also took Rebecca Alpert’s class wherein I wrote a paper about racial profiling, including a personal narrative of how I as a white woman see black men while walking down the street. Rebecca nominated my paper to be presented at an undergraduate research conference, and I felt so honored that she thought my work was good enough for that. When I presented, I sparked an important discussion.
between the black and white people in the audience about these stereotypes associated with images of black men and white fear. I began to feel like my work actually meant something.

In Eli Goldblatt’s senior seminar, I wrote a personal narrative about my life. The second half of the semester was devoted to reading each other’s personal narratives and discussing them; we each got half a class period devoted entirely to our work. As it turned out, my personal narrative was as much about the stories I told as it was about the method through which I chose to tell them. I wove bible verses together with my story of moving away from religion, I traveled back and forth through time to significant experiences in my life that brought me from a rules-bound religion to a personal spirituality that celebrated my human failings as things that made me grow as a person rather than absorbing me as a sinful, good for nothing, human. So as it turned out, the senior seminar moment for me where I was supposed to be able to see myself as a graduate of an English program, that defining moment turned out to be all about methodology. It was all about how I did the research on my own life, and all about how I researched how other people represented their own lives, all about what I included in the story, and all about how I told the story.

I didn’t realize it at the time, but I was working multimodally. The work I liked the most was the work where the writing wasn’t just writing, but represented my ideas through various perspectives. I was given the opportunity to weave together these themes of my research: the racism I saw in myself, the history I saw in my city around me, my own personal spiritual journey. Developing a personal connection with the city and with histories of racism made ending racism relevant to my everyday life; reflecting on my personal experiences allowed me to represent that relevance to other people. Part of that representation, part of that making things relevant was physically putting things together: my body, the city, the
news, my experiences. It was in the how I represented my research that I felt I was truly contributing academic thought.

I carried this interest in multimodality with me into graduate school. I worked with image and web design in Gail’s class, narrative along with academic language in Paul’s class, I worked with image and web design along with sound and narrative in Paula Treichler’s class, and worked with video through the media group and teaching writing with video. Working multimodally became a way for me to express some of the same interests I had in how to represent theory that I developed in my undergrad.

My participants engage medical discourse with their whole selves, not just their intellect; they engage medical discourse with their bodies, their emotions, and in collaboration with other people. I wanted to capture and theorize how people interacted with text in all of these ways, not just the intellectual means of engagement. I decided that the discourse-based part of the interview should allow for people to show me the physical text and talk about how they used it. My participants, inundated with textual information, look at images and texts together, they visualize the inside of their bodies, they seek out images and wish to see more. I sought to demonstrate the multidimensional engagements with medical texts by theorizing these engagements multimodally.

Given my own history with writing, I knew there was something different that happened when I worked in lots of different modes. I expected my participants to recall memories as they explained physical texts throughout the interview. I also expected that the spaces in which people used physical texts, i.e. the ways they engaged texts with their bodies, would also invoke memories. I set up the research study to allow for interviews in
particular spaces as long as my interviewees gave approval\textsuperscript{20}. Thus, it was important for me in analyzing the data that I had a recording of participants’ tours of the spaces and the gestures they used so I could further understand their relationship to the text as a physical object. Semi-structured discourse-based interviews with audio and video recording became the \textit{how} of capturing data that I’ve used in these analyses.

To give you a sense of how semi-structured discourse-based interviews look, I’ve included examples of three different aspects of the kind gesture that I look at throughout the dissertation. The first aspect is how participants use gesture throughout interviews to formulate words, and the example I use is when Elizabeth taught me about her job as a gynae instructor. I use several examples from Elizabeth’s interview that show her inhabiting this role as teacher. While telling me a story about a medical student that made her uncomfortable during her breast and pelvic exam, at moments she also taught me about how students were supposed to conduct those exams.

As Elizabeth explained to me how to locate and gauge the size of a uterus, she first moved her hands together and showed the two fingers that would be inside the body feeling for the uterus. She said, “so the uterus is about the size of a lime, and one of the things you do in the pelvic exam is try to locate the uterus” (Figure 2.5).

\footnotetext[20]{For hospital spaces where the physical place had their own IRB, I would have to get approval from their IRB and amend my IRB to reflect this new site. Thus, I limited my interviews in particular spaces to non-IRB sites.}
Figure 2.5 Elizabeth demonstrates how to “locate the uterus”

Then Elizabeth moved her hands apart, and the bottom hand represented the hand that would be on the inside the body while the top hand represented the hand that would be on the outside of the body. The motion she used shows that she would be using her hands on the body to feel for the uterus. While she made this motion, she said, “and you move from the inside against your hand on the outside” (Figure 2.6).
Finally, she moved her hands horizontally back and forth to represent figuring out the size, and said, “so you can gauge the size of it” (Figure 2.7).
Elizabeth started these gestures before articulating her thoughts in words, which shows integrated movement and touch helps her find the words, and gesture then becomes a critical part of understanding her explanation. The movement also is significant in the explanation, first she touches, then moves her hands away to show one inside and outside of the body, and finally she moves her hands back and forth to show that gauging the size is a felt action.

These gestures contribute to an understanding of Elizabeth’s role as a gynecology instructor and her orientations towards it. Elizabeth verbally expressed her interest in being a teacher during the interview, and she often shifted into that role. As she told me stories and explained how to conduct exams using movement and touch, she showed her level of comfort, understanding, and experience with teaching. She also showed sensitivity towards me as a student, pausing during parts of the interview where there were things she thought I needed to know to understand her stories. Elizabeth’s explanations are much harder to understand without seeing her gestures and the ways her body became a contribution to her explanations of the tasks of gynecology instructors.

The second aspect in the interviews that I wish to highlight is how participants used gesture as they engaged with texts during the interview. Bryan used gesture as he read a book on how he learned to massage certain muscles. First he read aloud from the book, which said “locate the xiphoid process,” and then he moved his hands to locate the bone on his body (Figure 2.8), pausing before he said “which is the bone that sort of sticks out at the bottom of where your ribs connect.” Finally, he turned the book around and put it in front of me so that I could see where the muscles were and how he learned to locate them on his body.
Like Elizabeth, Bryan used movement and touch to feel things before he was able to put them into words. He not only used his gestures to explain the massage to me, but he used them to figure out for himself what was going on before he could explain them to someone else. Finally, after he understood and gave his explanation, he gave the book to me so I could see his process for myself.

The third aspect I would like to highlight is the role of video in capturing gesture in participants’ work spaces. Bryan gave me a tour of the massage room, and as part of that tour he gave me a breakdown of the stages of a massage by showing me the different parts of the table. As he moved his hands down the length of the table, he moved them as if there was a body on the table, remembering the different components with his gestures before explaining them to me. In Figure 2.9, Bryan formed his hands into a gesture as if he was
touching a client’s shoulders, and animated the massage to show where they would be located on the table.

Figure 2.9 Bryan tours the massage table

The three aspects of gesture I have highlighted all become part of my analysis of the data in future chapters, and are irreplaceable in understanding the relationship of participants’ bodies to their words and the texts they encounter. These include gestures that teach me about participant interactions, gestures used to animate text so that participants can formulate words to describe their activities, and gestures that tour and simulate activities in certain spaces. Like these examples I’ve provided, on particular occasions throughout the data analysis in the dissertation, I use screen shots of gesture to show things my participants are communicating through their gestures.
Heading Back Into the Circle

I’m not sure where my proclivities towards methodology will take me next. Sometimes I feel that my desire to be inclusive, to take into account all these fields that I’ve learned from, and to figure out precisely what I mean so I can tell it to someone else, is more of a burden than it’s worth most of the time. But then I remember Sonia’s circle. What would my life have been like if I never had that openness, if I didn’t appreciate her or didn’t want to look at myself? Where would I be now? I really don’t know. So for now, I’m happy enough to shoulder the burden of interdisciplinarity, because it suits me, and because it makes my work closer to where I want it to be. I hope that I along with my research participants can join with other feminist researchers and contribute to the circles that I think, even if it’s cheesy, are trying to make the world a better place.
Chapter 3 Imagining Bodies: Literate Activity in Material Worlds

In their 1999 edited collection *Rhetorical Bodies*, Jack Selzer, Sharon Crowley and their contributors embark on the task of defining, discussing, and embodying a material rhetoric in their research. They seek to move away from rhetoric’s preoccupation with “the text” and consider rhetoric as more than just a verbal art. The contributors’ projects advance beyond separating the content of text and speech from their delivery and reception. Take for example Blair, who writes about public memorial sites, and focuses on embodied experiences and the materiality of rhetoric. Following Judith Butler (1993), Blair critiques “the goal orientation of rhetoric,” stating that rhetorical theory misses out if it focuses only on the author’s, rhetor’s, or speaker’s goals in the production and/or performance of the text and overlooks the experience of the audience with the text. She describes how a public memorial emphasizes collective intentionality rather than situating the agency for change with a single rhetor. In Crowley’s conclusion of the collection in which she investigates a historical rhetorical approach to bodies by feminist theorists, she credits 2\textsuperscript{nd} wave feminism with an important turn towards the material. Though the 2\textsuperscript{nd} wave is often remembered for its failure to recognize that women are not all the same, Crowley reminds us that many of these feminists paved the way through their protest to protect women’s rights to control their bodies.

Like Crowley I see current efforts in feminist theorizing about bodies as contiguous with rhetorical theory of bodies and materiality. Many contemporary feminist scholars had made a turn towards theorizing bodies and materiality when *Rhetorical Bodies* was published. Balsamo (1996) writes about how bodies are gendered through technologies
such as female weightlifting or cosmetic surgery, Grosz (1994) writes about how bodies are treated as a universal construct in philosophy, and Bordo (1995) writes about women’s use of their bodies as resistance to patriarchy. Like Selzer and Crowley, these feminist scholars critique the ways that patriarchal academia has excluded the body from theory and focused primarily on text and the goals of authors, speakers, or rhetors, i.e., those who have the power in society. These scholars examine texts about bodies and the cultural messages attached to these texts. While Balsamo, Grosz, and Bordo are focused on recovering bodies in theory, the rhetorical studies scholars are focused on presenting a range of methodologies that explore how theories of bodies and materiality are a part of rhetoric.

In Rhetorical Bodies, there are generally two kinds of contributions: historical analyses of texts about bodies (Wells, 1999; Scott, 1999) and analyses of spaces where texts regulate movement of bodies (Blair, 1999; Haas, 1999). Although I agree with both the rhetorical body studies and feminist perspectives that academic work needs to consider bodies and materiality more seriously, both fields still seem to focus primarily on texts about bodies, representations of bodies, or texts linked to bodies (e.g., through identity that is rooted in bodily difference). The objects of inquiry are in almost all cases textual: archives, websites, memoirs, injunctions, advertisements, magazine articles, novels. These textual objects of inquiry are often approached for the ways they represent bodies, particularly how they gender bodies or represent women’s bodies.

In my initial approach to my research study, I was most interested in the latter kind of analyses from Rhetorical Bodies, one that approached spaces and ways that texts regulate movement of bodies within those spaces. I was particularly interested in Haas’s chapter because she focused on the placement of a “Permanent Injunction,” a document
which among other things prohibits picketing within a certain distance of a reproductive services clinic. This document is taped up on the front door of the clinic, signifying the line between the private clinical work going on inside and the public protest that takes place outside of the building. Thus, this document is not significant solely for its content; as Haas pointed out, very few of the clinical workers or protesters had read it and “it was very difficult to read: it was taped to the door so as to make pages 2 through 5 inaccessible, and the front page was weathered and torn” (p. 224). This document was most significant in this space for its materiality; the way its physical placement on the door signified a separation between inside and outside of the clinic and the legal regulation of bodies entering the clinic.

Scollon and Scollon’s (2003) theory of geosemiotics focuses on the significance of the placement of discourses and texts in the material world. Their interest in mediational means, which are the available resources or discourses that one might draw on in a space in order to make sense of that space, i.e. atmosphere, passageways, other people, signs, designed spaces, shop logos, etc., is similar to Haas’s interest in the permanent injunction as a material object. Both Scollon and Scollon and Haas contribute to a theory about the materiality of texts as objects in the space rather than a reading of texts as significant only for their content about and representations of bodies. As Celeste Condit puts it, “a materialist rhetoric must emphasize the particular performance of a discourse” (p. 339) and “materiality must take into account language’s physical manifestations” (p. 352). These researchers focus on the performances around texts and the physical manifestations of texts as objects in particular spaces. By marking a path for considering texts as material objects, they also open up possibilities for considering physical bodies as text.
Practices of Reading the Body as Text

In this chapter, I use the metaphor of body as text as a way to think about practices of the body in relationship to health-related texts. I find this metaphor to be a useful one primarily because my participants use it, but also because it provides a framework for considering how practices of the body, which are often not considered to be textual, are indeed a part of the literate activity of these participants. Before I further explore this metaphor, I would also like to acknowledge that like every metaphor, it has limitations. A body, unlike a text, is not an artifact; the bodies in this chapter are not separate from the consciousness of the people occupying them. When one learns on a text, the text tends to stay still for the moment, whereas bodies move and change constantly. However, it is this slipperiness that makes the metaphor more useful in a way, reflecting the slipperiness in the relationship between body and text during medical encounters.

Scholars have considered bodies as text in numerous ways. They’ve looked at practices of creating textualizations on the body in permanent ways such as through tattoos, branding, and cutting, and in less permanent ways such as through messages people might wear on their t-shirts. These types of practices can have numerous rhetorical purposes in different situations. There are also practices where the intention is to alter the body but have it remain unmarked, such as through plastic surgery, botox, and tanning.

This scholarship places the body itself as a text, marked or unmarked, to be read in certain

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21 Elizabeth talks about everything she does as a gyne instructor being on the body itself rather than on texts. Bryan talks about reading a client’s body as a way to evaluate muscle tension and provide a massage that is individualized and most effective for the particular client.
ways. In what follows I analyze tattooing and plastic surgery in more detail for the ways this scholarship looks at bodies as the center of analysis.

**Tattooing**

Studies of practices of tattooing demonstrate ways that bodies have been studied as literal texts. McNaughton (2007) for example examines tattooing as visual argumentation in a prison context. She quotes a prisoner as saying “this is my body. It’s my novel, man, my poem, and I’m gonna just keep writing on it” (p. 139). She asserts that this form of expression is like graffiti in that the prisoner’s body is considered state property, and by tattooing in prison, prisoners can be charged with defacing owned property. Even the size of the tattoo and the materials used communicate a message. Larger tattoos take a longer time, thus indicating a riskier process. Prison tattoos can also easily be identified as such since professional machines are not available. “The method of application, seen often in the letters tattooed across the knuckles to spell a word, is unrefined and produces a ragged image that is easily identifiable as a prison tattoo” (p. 140). Thus these tattoos produce arguments for both inside and outside the prison; inside giving a sense of power and control over one’s body, and outside coding the bearer as a prisoner and keeping them from getting hired post-incarceration.

Tattooing can also been seen as a radical feminist activity as Harlow (2009) points out. In the case of Jaylin who participates in an alterative genre of feminist performance, tattoos represent a way of breaking silence and the “patriarchal script that tries to limit women’s voice and bodies to supporting roles and scenery” (p. 186). Jaylin literally writes on her body as a way of promoting monstrous beauty, an alterative to traditional conventions of beauty in society. She inscribes her name in Hebrew, but not her given
name, instead she names herself in her writing. According to Jewish law, tattoos are prohibited, thus getting a tattoo of her Hebrew name indicates her rejection of religious rules. Harlow argues that tattoos are an alternative genre through which feminism and rhetoric converge and produce alternative ways of speaking and writing. They reject traditional “Playboy” (p. 194) standards of beauty and rhetorically etch new standards of beauty for women onto the body.

In addition to the visual argumentation that Harlow and McNaughton lay out, tattoos also tell a story. For the cases these scholars outline, the history of incarceration or the history of radical feminist revolt is told through the tattoos. People often tattoo to commemorate the passing of a loved one. These tattoos will depict dates and sometimes include detailed portraits of the loved one or symbolic images that person would like. These tattoos tell a story of the passed person’s life as well as their meaning to the tattooee in death.

**Invisible markings and surgery**

Similarly, surgery tells a story on the body, but one very different from the stories of tattoos. Both are technologically mediated inscription on the body, however while tattoos are meant to be visible and read by others, surgery is meant to be invisible. Surgeries are typically meant to change the inside of the body while leaving the outside of the body unmarked, with the exception of plastic surgery which changes the outside of the body, even though the markings that any surgery was performed are meant to remain invisible.

Balsamo (1996) addresses plastic surgery and invisibility and theorizes that cosmetic surgeons use video imaging during consults with potential clients to focus on the return to natural beauty and focus away from their role in making their patients beautiful.
When the surgeon manipulates an image of the client’s face, he or she emphasizes the imperfections that are considered unnatural, and thus implies that surgery can replace the abnormalities with a more natural beauty. Although these technologies are meant to portray more realistic images of what a patient might look like after surgery, Balsamo argues that not all surgeons agree with this:

several cosmetic surgeons in the Atlanta metro area have stopped using video imaging as a consultation method because they found it encouraged patients to form unrealistic expectations about the kind of transformations that can be accomplished through surgical procedures. They report that patients seemed to believe that if a modification could be demonstrated on the video screen, then it could be accomplished in the operating room—the video transformation guaranteed the physical transformation. Apparently, the digital transformation of one’s own face produces a magical, liquid simulation that is difficult to reject. What some patients fail to understand is that one of the significant difficulties with any kind of cosmetic surgery is that soft tissue changes are impossible to predict accurately. (p. 77)

In these situations, patients have put their trust entirely in the markings of computer imaging, so much so that they neglect to attend to the ways that scalpels actually may mark their bodies during surgery. Thus, these imaging technologies create unrealistic expectations that surgery is painless, seamless, neat and natural when it is actually violent, unpredictable, and does not necessarily produce the desired results.

Moglen and Chen (2007) address the power of body modification, claiming that many feminist accounts of “tattooing, piercing, anorexia, self-cutting, plastic surgery,
scarification, body-building\textsuperscript{22}, prosthetics, organ transplants and life extension technologies” (p. ix) have concentrated on the agency and power that women have exercised over their bodies. Pitts-Taylor (2007) takes up agency and power over bodies in her study of surgery junkies by saying that these types of feminist accounts assume that identity and subjectivities, i.e. the inside psyche, can be so easily altered with changes to the outside of the body. She suggests that, “in cosmetic surgery, the body becomes a zone of social conflict, coded on the one hand as a sign of interior wellness and self-enhancement and on the other hand as a sign of moral, political, and mental weakness” (p. 7). Thus, surgery is less about the way the patient is reading their own body and more about how the body is being seen, altered, and controlled by social forces. Whereas the patient may like to erase the markings or use them to look more natural, society works to enhance the markings as much as possible.

While plastic surgery is meant to change the outside of the body and then render those markings invisible, other types of surgeries change the inside of the body, while still rendering those markings invisible on the outside. Take for example, Koschmann, LeBaron, Goodwin and Feltovich’s (2007) study of gestures during surgical procedures in a teaching hospital that a medical student observed. In their study of an operating room, the surgeon used gesture to mark changes to the body after performing a surgery in order to teach the medical student how to find the changes. Because the surgery involved using a camera inside the body, it was not easy to locate the cystic artery with the naked eye after the surgery was complete. Thus, the surgeon used a surgical tool of a camera to gesture inside

\textsuperscript{22} Ralph Cintron’s \textit{Angel Town} (1998), body-building is one of the semiotic means of rhetorically representing identity. Also the TV show “Jersey Shore” and “GTL—gym, tanning, laundry” rhetorically represents identity.
the body, pointing to the places in the cystic artery that had been operated on, and as the surgeon’s hand moved, the changes were marked and reflected on the computer screen. In this way, the patient’s body is being used as a teaching tool, and read as a text/textbook. However, when the surgery is over and the body is sewn up, the patient will want the surgical markings in the body to remain invisible to an outside observer.

The alterations involved in tattooing and surgery are examples of ways that bodies have been studied as texts. In the case of tattoos, the body becomes a literal text, and its alterations are meant to communicate with readers. In the case of surgery, the alterations also communicate with outside readers but this time by rendering the markings invisible rather than drawing attention to them.

**Reading Bodies as Text**

My analysis of the reading and writing of bodies serves a different purpose than those that focus on markings on the outside of bodies, drawing on the work of Koschmann et. al. who focus on markings on the inside of the body. Significantly, my participants talk extensively about practices that involve a reading and understanding of what cannot be seen on the inside of the body. In order then to visualize and sense the inside of the body, my research participants have pointed to the ways their practices of looking and touch, sensation and feeling are networked with their other literate practices of reading and writing. In other words, they use their own physical bodies to read and in some cases to compose the bodies of other people during medical and alternative medical encounters.

In all of these approaches to body studies that I’ve outlined so far, externalizations of bodies: texts about the body, texts on the body, or (un)marked bodies have been the focus of the scholarship. Whether it is a text that is read for its content or used as a
meditational means to make sense of a space, or a body being marked on or altered, externalizations and thus vision remains the central focus. My research study also began with this focus; building on the work of Haas (1999) and Scollon and Scollon (2003), I was most interested in seeing how my participants act in relationship to the medical texts that surround them. However, when I began my interviews, I found that sometimes the traditional graphic texts that I expected to find were not present. Because one part of my theoretical frames was to think about textual and non-textual practices as a part of literate activity, I continued to ask questions about the practices that did not involve many traditional graphic texts.

Thus I have found that although scholars have often studied texts about bodies, or studied the outside of bodies as texts, they have rarely considered the possibilities for theorizing *bodies reading other bodies as text*, using touch, movement, and imagination in addition to vision. What happens in medical situations like the ones my participants describe wherein traditional graphic texts are present, but they are often not read for content? Further, what happens in medical situations where texts that represent bodies are not used, but instead bodies themselves are being learned on and being read as texts? Can practices such as movement, touch, and imagination that are most definitely tied together with what has been considered visual textual practices be considered under the purview of a writing studies project? If so, what possibilities does this research have to speak not only

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23 When I talk about “reading” here, I meant to extend reading metaphorically to mean interpretation of anything (e.g., reading the world), so that reading the body means making sense of it. Reading the body implies a set of practices involving an intertextual connection (backward or forward) between bodies about text and the physical body, i.e. movement, touch, and the other senses in relationship to texts as material objects in the world.
to writing studies, but the fields of body studies and cultural studies, i.e. how can these fields speak to each other?

Perhaps one way they can speak to each other is through considering Merleau-Ponty's (1962) work about internalized sense and how we feel with our bodies unconsciously. He uses the metaphor of a house to describe how this works: “The house has its water pipes, its floor, perhaps its cracks which are insidiously spreading in the thickness of its ceilings. We never see them, but it has them along with its chimneys and windows which we can see” (p. 82-83). Even though we can’t see the pipes inside the floor, they are still functioning to make the house work, and if the pipes break, we become conscious of them and fix them right away. Internalized felt sense works similarly, we may not be conscious of the ways we are using our bodies to compose, to write, to make sense of the world from the inside out, but my participants, through their talk and through their gesture, convey ways they are using the internal, the felt sense, as a part of their literate activity surrounding health. They talk about ways their reception of texts is an embodied process.

As these fields to speak to each other using ideas about internalized sense, we can begin to move beyond traditional ideas of learning and text and consider literate practices as ways of thinking and approaching the world, not only as textualizations. I consider my participants’ literate practices that center around physical bodies instead of traditional graphic texts to be commensurate with literate practices that go beyond text as the only way of making meaning. I am not suggesting that we as writing researchers stop studying traditional texts as traditional texts are present and used by all of my research participants, but I am suggesting that we move away from using traditional graphic texts as a way of
choosing interesting research sites. My participants describe research sites saturated with literate engagements\(^{24}\) that involve very few traditional graphic texts read for their content. I propose that we consider ways that the bodily practices in these sites are functioning as part of literate practice. In professional writing studies, most research is still centered around the production of text in workplaces and school. However, I argue here that it is important to consider the reception of these texts, especially outside of professional boundaries, and consider that the ideologies of professional texts, in this case particularly of medical texts, circulate and effect the everyday lives of people.

As Haas (1995) has pointed out, writing studies fields have frequently overlooked the materiality of writing. However, when looking at the reception practices of my research participants, it is difficult to overlook writing’s material nature as the material of the document often shapes its use. Even Haas overlooked the body as a technology for producing writing, but she pointed out that

> Writing is made material through the use of technologies, and writing is technological in the sense and to the extent that it is material. Human beings have used and continue to use technologies (e.g. sticks on sand, pen and ink on parchment, #2 pencil on legal pad, cursor on monitor) to bring language to material life. (p. 3)

The sticks, pen, pencil, and cursor are all attached to human body parts when they produce writing: hands, arms, shoulders, necks, heads, eyes. The desks and chairs she talks about further on are occupied by body parts, i.e. legs, butts, backs. Legs are used to roll chairs

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\(^{24}\) I use the phrase “literate engagements” to invoke the idea of literate practice understood in terms of sociocultural theory. In this sense, bodily practices are networked with traditional notions of reading and writing, such as Prior and Shipka (2003) discuss (e.g. walking the dog, being a couple).
around and pick up materials in the room, arms reach for books, hands page through those books, fingers type on keyboards, eyes read and check spelling and determine the next word to be written. And in fact the role of bodies is often invisible to people without disability; those with a disability must make bodily accommodations in order to compose and learn in mainstream situations, as disability scholars (Wilson, 2000; Bruegemenn & Kleege, 2003; Palmeri, 2006) have pointed out.

Technologies do not write on their own. Writing studies fields have examined repeatedly how minds write, but writing is really a thing that bodies and minds do at the same time. The examples I use in this chapter in particular are examples of using the body to learn about and sometimes recompose the body. These examples happen over a short period of time and demonstrate the inseparability of bodies, technologies, and texts in composition.

In all of these examples, I demonstrate instances where bodies are used in place of texts or alongside texts or to imagine and recall texts as a part of literate practice. In these instances, computer screens or paper texts are not the focal technologies of writing; the body itself has become the focal technology. I find these to be unique and often overlooked aspects of writing in general; somehow by taking bodies out of the composing with technologies process, we've in fact erased that bodies can compose without tools outside of the body. We’ve defined writing to be outside the body, when it starts as internalized and felt sense, and acts of composing are a back and forth between internalizations and externalizations. To substantiate my claims that these practices are in fact “writing,” I turn to the research projects of Paul Prior and Brian Street, both of whom think about literacy as
more than simply a proficiency in reading and writing. Prior (1998) writes about literacy as cultural practice. He says:

This notion of writing as situated, mediated, and dispersed is the basis for what I am calling literate activity. Literate activity, in this sense, is not located in acts of reading and writing, but as cultural forms of life saturated with textuality, this is strongly motivated and mediated by texts.” (p. 138)

Prior suggests then that it is important “to examine the concrete nature of cultural spheres of literate activity.” He argues that his research points to the heterogeneity and particularity in these spheres, thus calling for local analyses of particular contexts.

He also says “the synecdochical extraction of the figure of writing from the messy ground of the lifeworld has suppressed ways that other texts, talk, perception, activities, and institutions might come into play in situated textual production and reception” (p. 154). In his further work with Jody Shipka, he defines the “chronotopic lamination (Bakhtin, 1981; Prior, 1998) of writers’ literate activity” as “the dispersed, fluid chains of places, times, people, and artifacts that come to be tied together in trajectories of literate action along with the ways multiple activity footings are held and managed.” Prior and Shipka use the term “chains” throughout their chapter to show literate activity links between “places, times, people, artifacts” (p. 181), “concrete historical events” (p. 186), “invention and inscription over time and across multiple scenes” (p. 187), “acts, artifacts, and actors,” and “discourse and action” (p. 231). This is significant because even the practices of the body that don’t appear literate in a traditional sense (acts of reading and writing) are chained together with traditional literate acts. And bodies are certainly a part of these chains, in fact, the chains would not exist (people as we know them would not
exist) without bodies, and bodies are one of the multiple aspects of writing that must be managed.

Street (1985) also sees literacy as more than reading and writing when he discusses literacy as ideology.

The developments of such skills and knowledge and the construction of such literate forms is neither an individual matter nor is it necessarily the product of specific formal training: it is a development at the level of ideology, a social construction of reality embedded in specific collective practices in specific social situations. The social group which shared perceptions and uses of literacy in the village may not have all exhibited comparable levels of kinds of skills but they did share a common ideology and a common understand of the “meanings” of that literacy. (p. 176)

Street outlines an “ideological model” of literacy, using theorists such as Cole and Scribner, Graff, and Heath. According to this model, individual literate acts of reading and writing cannot be studied as fixed individual acts; instead they must be studied as a part of a social system.

Even in the moments during these examples I provide, sometimes in very short periods of time, when my participants are not reading and writing in a traditional sense, they are steeped in, entrenched in, surrounded by, and saturated with literate activity. The medical worlds these people participate in are deeply literate and highly saturated with text. The participants highlighted in this chapter use bodies, read bodies, and seek to understand bodies, often by using their own bodies, as a part of their roles in medical worlds. These bodily practices are a part of their literate systems of activity.
One very unique component of this idea of reading bodies as text is that when my participants read bodies, they are studying things that cannot be seen, i.e. the inside of the body. Therefore, they use the body to feel and touch, sensations often not associated with composition. Literacy is typically considered a visual practice. However, any kind of literate activity involves acts of imagination. The literate practices of the body that I research highlight how all literate activity involves imagination. When one engages in literate activity, they may see images in their head that shape how they actually receive the words and respond to them. So far, when the field has looked at text, researchers have been focused on that text to examine its production. But with a turn to a broader picture that includes acknowledging all these practices happen with bodies, we can begin to see how multidimensional and extensive literate practices really are.

In order to outline what I mean by reading bodies as text, I look at the situated practices of two of my research participants. First, I analyze Elizabeth, a gyne instructor for medical students. In order to learn to do her job, Elizabeth uses no traditional graphic texts. Instead, she learns to perform gyne exams on her fellow instructors and literally reads their bodies in order to learn. Then, I analyze the case of Bryan, a massage therapist. He is very interested in his clients seeing massage as more than relaxing and optional, but as a meaningful and integral part of their healthcare. In order to do this he communicates with his clients through text and talk, but also through touch. He uses touch as a way to communicate with bodies in order for his clients to understand the health benefits of their massage. Finally, I conclude that these two cases show ways that touch, movement, and imagination cannot be overlooked as textual practice simply because they involve body parts other than eyes.
**Gyne Instruction: Reading Bodies as Text**

Hannah: So for this part of it, you pretty much learn everything in the room.

They don’t have any pictures or anything?

Elizabeth: No, everything is in the room, because everything we’re doing is on the body... what we’re learning to do is just the manual parts and communication parts [of the exam].

In Elizabeth’s job as a gyne instructor, she taught 2nd & 3rd year medical students how to perform breast and pelvic exams. For all other physical exams, medical students “practice” on each other, but for breast and pelvic exams, medical schools hire female instructors, and for rectal exams they hire male instructors. In order learn to be a gyne instructor, also known as “practical instructor,” or as Elizabeth calls it, “spreading my legs for science,” the instructors had to learn to do all of these exams themselves and learn all of the language that physicians must use when performing the exam. Practical instructors were hired to test the students and ensure they could complete the mechanics of the exam, but also to test that the students understood and felt comfortable talking to and educating their patients during the course of the exam.

The gyne instructors learned to teach the students through reading each other’s bodies. Instead of using medical textbooks and images of the female anatomy as the medical students do, Elizabeth learned directly on the bodies of her fellow instructors, and then taught the medical students by allowing them to read her body, while also testing their communication skills. Gyne instructors then filled out an evaluation form for each
student, but other than this minimal use of texts, there were no other traditional graphic texts present.

Elizabeth’s job as a gyne instructor provides a foundation for rethinking learning and texts when it comes to literate practices of health. In professional writing studies, Elizabeth’s case might be overlooked because she doesn’t produce or even use traditional graphic texts to learn to be a gyne instructor. However, if we look at her case with the underlying ideas that literacy is not just reading and writing but also cultural practice (Prior, 1998) and ideology (Street, 1985), we can look at her practices as part of a network of literate activity, linked, indexically and instrumentally, to medicine as professionalized and institutionally disciplinary, a family of social practices saturated with textuality. Elizabeth’s literate activity is linked in this way to talk and interaction with students and other instructors, to identity as she plays the roles of instructor, doctor, and patient, and to movement and touch in the space of the exam room—practices that point to the reading of bodies rather than the reading of traditional graphic texts. In this section, I explore these pieces of the network as separate categories, but I do not mean to suggest they are separate, instead these practices often happen within the 20-30 minutes of the medical student’s test breast and pelvic exam.

**Talk and interaction with other instructors and students**

Kapsalis (1997) writes about gynecology and her experience as a teaching assistant, a job with similar responsibilities to Elizabeth’s job. Kapsalis calls the breast and pelvic exam that all medical students are required to perform a “rehearsal” and argues that these rehearsals are connected to visual and textual representations of the body in “official” textbooks such as Danforth’s *Gynecology and Obstetrics* (1986). The images from the
textbook that Kapsalis analyzes are graphic pictures of bare bodies, with a focus on images of abnormal bodies. Kapsalis links these images to pornography, arguing that both industries make a spectacle out of women’s bodies. In particular, she critiques medical textbooks for subscribing to narrow standards for what counts as normal in women’s bodies.

Kapsalis contrasts Danforth’s textbook with a self-help medical book published by women’s health centers called *A New View of a Woman’s Body* (1991) and discusses how this book includes a lot of text in the captions of the images to illustrate in very specific detail how many variations of women’s bodies are normal. Though Kapsalis does not think that this book is a perfect alternative to the traditional textbook, she appreciates the depathologizing representations that this book offers.

Elizabeth’s use of language as a gyne instructor is networked with students’ learning from textbooks like Danforth’s. Elizabeth talks about how afraid the students are to perform the exams:

This is for most of them the first time they’ve encountered the female body in a way that’s not sexual, or the first time they’ve encountered the female body since it was their mother or their sister. And for many women it’s the first time they’ve encountered the female body on the table in front of them rather than them being on the table having their own exams... there’s a lot of fear or intimidation: they’re afraid of hurting you or they’re afraid of doing something inappropriate because their only interaction with naked women has been sexual.

Kapsalis argues that images in textbooks such as Danforth’s link women’s bodies to pornography which also represents them as unusual and abnormal for sexual arousal.
Because students’ have mostly encountered the female body in sexual ways in our society, images in these textbooks do very little to represent women's bodies any differently. However, books like *A New View of a Woman's Body* seek to represent a range of women’s bodies as normal.

The physician in charge of Elizabeth’s gyne instruction program has designed elements of the instruction to work against this ideology from the textbooks. Through testing the students’ use of language, instructors counter cultural notions of women’s bodies as purely sexual and abnormal. For example, Elizabeth was taught a technique known as “wet hand, dry hand” which in medical practice is referred to as “clean hand, dirty hand.” Elizabeth’s group found the medical practice terminology “very upsetting,” because the wet hand that touches the women's body is equivalent to the dirty hand and the dry hand that touches the items in the room is equivalent to the clean hand.

And the message that this sends is that our bodies are dirty, and that the things our bodies produce naturally are dirty, but the room, which, who knows what’s going on in there, is clean. So that was one thing that we really emphasized, not just contamination, but that what you’re calling it matters.

Another way the program sought to counter these popular ideologies was through teaching the instructors to perform breast and pelvic exams on the other instructors before having the exams performed on them. This was one of the aspects of instruction that Elizabeth got really excited about even though she was very nervous at first because she didn’t want to hurt the other instructor during the course of the exam. “But when I performed my first exam, it was so cool getting to understand so much more about the female body and how it worked and where things were and what it felt like, and over the
two and change years that I was involved getting to know lots of different bodies, and seeing how a body changes over time” (my emphasis). Elizabeth explained that as she worked as a gyne instructor, she saw that something normal for her body may not be normal for someone else’s body, but that didn’t mean either of their bodies were abnormal. Thus, like a *New View of a Woman’s Body*, the program was able to counter an emphasis on abnormality and focus instead on a range of normal for women’s bodies, at least for the instructors if not the students as well.

Finally, an important component to the interaction between instructor and students is play, in this case what I am calling “playing to teach.” Elizabeth and the other gyne instructors were encouraged to express their own concerns about women’s health through their instruction because part of their jobs is to model what real patients will be like. They expressed these concerns by riffing off of each other during the course of the exam, interacting with and testing students’ ability to communicate with patients in comfortable and appropriate ways.

Often, play is considered something that children do, something fun, and something that has no place at work, especially serious and sensitive work like the work Elizabeth does. According to Csikszentmihalyi (1981), play can be serious and have serious real world consequences: “any given activity can be utterly earnest and entirely playful” (p. 19). Play allows people to imagine other possibilities and look at the world from different angles, as he says, “playfulness is most interesting because of what it tells us about our ability to redefine reality” (p. 25). Play serves a really important role in Elizabeth’s position as she is playing to teach; Elizabeth’s playful interaction with her students teaches them how to interact with patients.
Elizabeth’s preferred method to play during the exam is to ask the students questions and “be difficult patients” to try to simulate what will happen in the hospital when the students will be examining patients who are not as comfortable with their bodies, who are likely in pain and afraid, and who may not be very cooperative during the exam. Because gyne instructors are not alone in the room with the students, they are able to use each other to simulate this experience. “The two instructors would sort of rif off of each other a lot, maybe the instructor on the table would stop them to say, ‘Ok you’re not in the right spot but you should do this or you should do that.’” While one instructor might stop them to instruct them, sometimes Elizabeth and her friend “would make the students work a little bit harder” by only following the explicit instructions the students would provide: “So one of the things that you have a patient do is lie down and put one arm behind her head so that you can do the breast exam, but if they didn’t tell us to do that, we wouldn’t and then they would get in trouble.” Also, Elizabeth and her friend would work together to ask difficult questions:

When [students] were going through the script about needing to do your breast exam monthly and picking a day usually about a week after your period and doing it on the same day every month, [I would] say, “Well what if I’m pregnant? Well what if I don’t get a period? But what about this? But what about that?” You could see the students sort of punting trying to come up with something to answer the question.

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25 Gyne instructors play two roles during student instruction: they either play the role of the patient and have the exam performed on them, or they play the role of the instructor and make sure the student performs the exam correctly. There are always at least two instructors in the room so each of the instructors can play one of these two roles. In this way, they take care of each other while providing more thorough instruction.
This serious play off of each other and interaction with the students provides them with a more realistic view of gyno exams and patient experience. Ultimately, play works against the messages of the students’ medical textbooks and their representations of women’s bodies. It humanizes the woman on the table, challenging the students to begin to see a variety of bodies as normal.

**Identity and performance**

In the last section, I began to talk about the gyne instructors’ serious play in relationship to student ideology and medical textbooks. In this section, I will continue to talk about that play in relationship to literate activity, but of a different type. Elizabeth as a gyne instructor inhabited many roles including that of patient, instructor, and doctor. To analyze how this is a networked part of literate activity, I will take up Jan Blommaert’s notion of “identity.” He proposes “that we see identity not as a property or stable category of individuals or groups, but as particular forms of semiotic potential, organized in a repertoire” (p. 207). Using his notion of identity as semiotic potential, I argue that gyne instructors draw on a repertoire of semiotic resources to be identified as such. This does not mean that Elizabeth simply redefines her identity by drawing on the repertoire differently; Blommaert clearly outlines that “identities are constructed in practices that produce, enact, or perform identity—identity is identification, an outcome of socially conditioned semiotic work” and that “in order for identity to be established, it has to be

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26 Space/place shifts what resources are available in this repertoire. However, Blommaert suggests that these resources might be organized in terms of semiosis, “organized by topic, situation, genre, style, occasion, purpose, and so on” (p. 210). He describes these resources as not “chaotic and unrestricted” but as entailing “creativity and determination” (p. 211).

27 Blommaert gives the example of Judith Butler’s notion of performativity and her argument that “gender identity is something continually performed and enacted” (p. 205).
recognized by others” (p. 205). However, it does mean that identities have not been fixed or determined by a power structure; instead “people practically identify themselves” and “they do so through the deployment of whatever means they have at their disposal” (p. 210).

Elizabeth talks very specifically about how she constructs identity, drawing on semiotic resources available to both doctors and patients. She describes this as performative:

I’ve talked a lot about what you’re doing when you’re the instructor which is for the student, you’re modeling for them. But when you’re the patient you are also doing some teaching, in part because you’re modeling what a patient is going to be like, and in part because you’re the one who can feel what they’re doing so you can say “No that’s not right” or “You need more pressure or less pressure” and so on. Or you should stop and feel this one thing because that is a cyst or that is my ovary, whatever. So it’s a different kind of teaching.

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28 Thus, a patient who identifies herself as a doctor would have to successfully perform her identity as a doctor for others, and have others recognize her as a doctor before she could become a doctor. This concept of identity negotiation has been reflected in episodes of the TV shows St. Elsewhere and Scrubs. In the “Hearts” episode of St. Elsewhere, Ralph, a patient of the mental health ward, steals a lab coat and impersonates a Dr. Bullfinch. Because of his demeanor around patients and his proficient use of language, both doctors and patients at the hospital easily believe he is a doctor. In Scrubs, Janitor, sometimes known as “Dr. Ján Ítor,” impersonates a doctor in several episodes of the show. In the episode “My Female Trouble,” one of the female doctors with a male name, Dr. Elliott Reid, pretends to be a nurse, and ropes Janitor in to play the doctor in order to appease a sexist patient. Janitor wears a lab coat, but his proficiency with language is lacking, as he keeps referring to problems with the patient’s foot, even though the situation is with his heart. During the exam, Janitor also breaks character by taking out a spray bottle and cleaning the window, thus, his impersonation is ultimately not successful. However, the patient never says anything about these inconsistencies, and Janitor is not found out until another doctor walks by and recognizes him.
Elizabeth must balance her performances as doctor and patient with her identifications outside of the exam room. For example, the first exam Elizabeth had performed on her was done by her friend who was a new instructor at the same time she was. This was awkward for her because Elizabeth and her friend hadn't really talked about what it would be like to see each other’s vaginas. During the course of the exam, Elizabeth’s friend was nervous and forgot to close the speculum all the way, so it hurt her when her friend removed it. Afterwards they went and got ice cream to ease the awkwardness between them and restore them to their usual ways of relating to each other. Elizabeth described how ice cream became a tradition: “we definitely went and after a day of teaching we would go get ice cream because even if it went well, it was going to be uncomfortable.”

Because being the doctor was the most unfamiliar role that Elizabeth inhabited, the experienced instructor and new instructor go through the exam together, and Elizabeth says “it takes forever.” The new instructor is given the opportunity to do everything the doctor would do, including opening and closing the speculum, trying out the speculums in different materials such as metal and plastic, and raising and lowering the table. Since it is usually the new instructor’s first time performing an exam, they take a long time to make sure to get everything right. “Sometimes it takes so long that the experienced instructors will switch out so a different one can be on the table.”

In this case, they are using play to become comfortable identifying with an unfamiliar position, and drawing on the semiotic resources they have available to them to identify as doctors and empathize with the medical students. They play with the tools such as the speculum and table, they position themselves in the room as if they were the doctor, and they look and touch experienced instructors’ bodies, using bodies themselves as if they
were texts to read and learn from. After Elizabeth becomes experienced, new instructors use her body to learn how to perform the exams, shifting roles and semiotic resources available to her to play the patient and model instruction. Thus, a core component of Elizabeth’s job is competency in performing and shifting roles.

**Learn to play, or playing to learn**

As I mentioned, gyne instructors learn to perform the breast and pelvic exams on each other first before they are examined by the students. After the initial orientation meeting where new instructors decide if they’d like to join the program, returning instructors and new instructors get together for a couple of weeks and practice the exams.

When it’s the new instructors’ turns to perform the exam, they do all the things the experienced instructors modeled themselves. New instructors practice knocking on the door, introducing themselves, and washing their hands while experienced instructors coach them through. They are given the space to play with the equipment in the room and become familiar with their surroundings, “to get everything right.” For example, Elizabeth’s first exam that she performed took 45 minutes to an hour, and after 2 years of experience, it only takes 10 minutes start to finish.

The new instructors are given the space to fumble with the equipment, to be uncomfortable, to change their gloves over and over because they’ve contaminated. However, they also get to touch and learn on their colleagues’ bodies. Often, the experienced instructor upon whom the exam is being performed will stop a new instructor and suggest they feel something interesting on their body. They also get stopped when they do something wrong and do it again in order to feel what it’s supposed to feel like. In this
way, they are playing to learn, reading bodies with their fingers and learning about them in this context for when they start instructing students.

Throughout gyne instructor training, the instructors do not look at any traditional graphic texts except for the evaluation form. “Everything we're doing is on the body.” The instructors learn to do the manual and communication parts of the exam directly on the body, and they don’t learn how to do any tests like the pap smear. As Elizabeth explained how she learned about gyne exams on the body, she used gesture to further demonstrate how that was playful. She played with her hands, opening and closing them as she described “playing with the speculum” (Figure 3.1).

![Figure 3.1 Elizabeth opens and closes her hand as she describes opening and closing the speculum](image)

As Elizabeth explained that the women play to know how to use different kinds of speculum, she paused from the story to teach me in an aside what kinds of speculum exist in case I didn’t know, she said, “because there's plastic and metal and different sizes (Figure 3.2).”
Figure 3.2 Elizabeth explains that there are “different sizes” of speculums

These types of phrasing and gesture indicate that she continually shifted roles throughout the interview, inhabiting the role of my friend and interviewee telling me the story of her experiences, but also shifting into the role of teacher as she explained things about her position as a gyne instructor that I might not know.

Finally, to emphasize that women are learning directly on the body, she showed her hands when explaining that “the actual tools that we’re using are just our hands” (Figure 3.3).
Figure 3.3 Elizabeth shows the tools they were using were “just our hands”

Through these gestures, Elizabeth demonstrated several things: her shifting roles as teacher and student, the importance of play in learning to teach medical students about gyne exams, and the importance of learning to perform these exams directly on the body. As she fumbles with her gestures, modeling moving the bed up and down and modeling opening and closing the speculum, she shows how integral playing with and “fumbling” with these tools was in order to learn how to perform the exams. Finally, as she shows me only her hands, she once again emphasizes what a bodily and vulnerable position playing the doctor could be in her job as a gyne instructor.

To add to the performance aspect of the job, Elizabeth mentioned a script in relationship to the practical instructor’s interaction with the medical students. She mentioned this in particular with how they teach the medical students to talk to their patients. Elizabeth said “there isn’t a written script, but we’ve been given the evaluation forms up front so you know what you’re going to be testing the students on so you can make sure you’re developing those things.” She performed the script over and over,
altering it to meet her own criteria, as a way of testing students. For Elizabeth, one of the key criteria is testing how the students talked to the patients about the exam, their bodies, and preventative care.

Elizabeth, like her students, could learn to perform breast and pelvic exams through images, but she spoke of some of the benefits she felt she received from learning on bodies rather than through texts. She asserted that she understood more about the female body: how it worked, what things felt like, how bodies were different from each other and still normal, how bodies change over time, and what was normal for her body and how that differed from what was normal for other women’s bodies. By looking at and touching other women’s bodies, she learned things about her own body that she would never have known otherwise.

**Looking forward: advocacy in future medical encounters**

Elizabeth found her work as a gyne instructor empowering; she said it was really neat to work with these women because they knew their bodies well enough to point out what was normal or abnormal or interesting to the new instructors. They could, for example, look at the cervix and tell whether or not the woman has had a baby. They were comfortable explaining about their bodies by using their bodies because it was “educational.” Ultimately, Elizabeth said “it was a way that I could use my body to make a difference for other people.” It also gave her confidence in other areas of her life: “if I can teach someone while I’m laying basically naked on a table and someone is inserting a speculum into my body, I can probably teach them fully clothed and in front of a classroom.” In Elizabeth’s view, it was learning directly from other women’s bodies that
gave her this view; the experience would not have taught her the same things if she learned only with images or through student exams.

Elizabeth carried her experiences into the way she taught students to talk to patients. In addition to using the script as a way to play around and test the students, Elizabeth also developed her own script that emphasized breast cancer prevention. She felt this was a way to carry her experiences with breast cancer, which both her mother and grandmother had, into awareness and prevention for other women, and she considered this an important form of advocacy for her to engage in.

Though some of what Elizabeth learned, she learned by looking at bodies, most of it involved learning about bodies through touch. She learned to see a cervix, but also how to touch the speculum and what it was supposed to feel like when the med students used a speculum. She learned to feel the inside of the body to locate a uterus during a pelvic exam so she could test the medical students to feel and talk appropriately as they were expected to do. Without touching other women’s bodies, this would have been a very different experience.

Elizabeth’s carried her work as a gyne instructor into her own personal medical care as well. She spoke of a different confidence she felt after being a gyne instructor, a confidence she developed because of the way she learned to approach and see women’s bodies. She knew more about her own body, and thus knew how to ask her doctors for the kind of care she felt she needed, which was mostly preventative care. In a sense, she continued to educate, but this time with her own doctors.
Massage Therapy: Recovering Touch as Literate Activity

“I don’t necessarily describe everything I’m doing while I’m doing it. If there were a part [of the massage] that I thought someone was more unsure about or they mentioned at some point previously, I would say ‘see that’s what that feels like, what did you think?’ and they can let me know. In the first massage, there’s a lot of reading the client, seeing what they like and don’t like.”

--Bryan, massage therapist

When Bryan describes “reading the client,” he describes a set of semiotic practices that involves touch, talk (or silence), text, and visuals. For Bryan, the practice of reading a client’s body is tied up in his other literate practices that are intended to establish a personal connection with his client. Establishing a personal connection is a key component of a successful massage; it relaxes his client and makes the client feel safe, thus making the massage more effective. In what follows I provide some examples of how Bryan uses touch, talk, text and visuals to establish a personal connection. Like Elizabeth’s case, I explore each category separately, but these categories blend together as all of these things are being done during the course of a one-hour massage session.

For Bryan, touch is a key part of making a personal connection with his client. In school, he was taught that once a therapist places their hands on their client, the connection is made, so before removing their hands, therapists should explain what they’re doing and not remove their hands “unless it’s absolutely necessary.” Bryan has many routines at the end of the massage to make the removal of hands more comfortable for the client. He lays his hands on the client’s back and rests there a few seconds, sometimes
rocking them to establish a connection at the end. He also always says "thank you," and sometimes pauses or squeezes in order to let them know the massage is over. He then pulls out the bolster and brings the client a glass of water. This combination of talk and silence plus touch helps to indicate to the client that he's reached the end of the massage.

Bryan says that for clients, talking during the massage may help them make a personal connection with him because it makes them feel like the massage is tailored to their particular needs. Often during a client’s first massage, and for repeat clients usually before and at particular points during the massage, Bryan asks questions to get his clients to talk about what things they like and dislike about their massage. It’s important to Bryan that he not just pay attention to areas he perceives to be tight while he gives the massage, but also to the clients’ preferences. For example, if a client doesn’t like having their hands massaged despite the fact that they strain their hands regularly typing at work, Bryan will follow that oral communication over his own inclinations.

Bryan also interprets what the client means when they answer his questions. He has a had a few occasions when his client would say “Oh I have a high pain tolerance,’ and what they mean is ‘Oh I can grit my teeth and not say anything.” Instead of getting a massage that is comfortable for them, they continue to tense up, depriving them from the benefits they would otherwise get from their massage.

There are occasions when talk can hinder the personal connection. Bryan understands that for clients, it can be difficult to both talk and relax during the massage at the same time. In these times during the massage, silence is important. For example, Bryan had a client who talked about work throughout her entire massage, and he could feel her muscles tensing up. In other cases, he has had clients that said they didn’t like massage
because their therapist gave too much pressure or not enough pressure, which he believes indicates that the therapist didn't talk enough and wasn't very good at communicating. Comfortable touch for the client is a delicate balance between talking and silence.

For these reasons, Bryan calls a personal connection “a subtle connection.” It is important to him to make his clients feel safe, relaxed, and comfortable for their own specific needs. So during the massage, the talk is not just important for the client, but for the therapist as well. When Bryan gets caught up in conversation about things other than the massage, he can get distracted. So instead of making small talk, Bryan will tell his client in layman’s terms what he plans to do, for example, what parts he plans to massage and what parts he might focus on during the massage.

Reading and composing texts are more traditional examples of the literate activity Bryan engages in. Before the first massage, Bryan gives his clients brochures or other documents that include information about his education and biography (Figure 3.4). Often these documents also include a picture to help clients remember their therapist and make a personal connection.
Figure 3.4 Bryan’s document “About your massage therapist”

Bryan writes down general information and “random things” after a client’s first session in order for him to ask personal questions and help him remember personal info about the client for future sessions. Bryan also takes notes on each individual session using the SOAP notes method. SOAP stands for Subjective, Objective, Assessment, and Plan, and these notes are frequently used by doctors in medical situations. These will help him remember what happened during the last massage and what areas of their body on which each client wants focused attention.

Visuals are another more traditional example of literate activity that Bryan used, however the way he used them diverges from a traditional conception. When Bryan was learning to do massages, he was assigned a book in class called Trail Guide to the Body that was “specifically designed for massage therapists to feel muscles.” The book shows detailed pictures of the inside of the body, highlighting in red the muscles to be massaged.
When he was a student, he worked with other students to locate and feel each others’ muscles. They followed the detailed instructions given in the book on how to locate the muscles. For example, the image that taught students how to locate the rectus abdominis muscle shows the inside of a man's body including his ribs and internal organs in black and white, but it shows the rectus abdominis muscle in red. The instructions next to the picture tell the partner how to position themselves so the muscle can easily be found. Then it gives direction for which bones to locate first and use as “landmarks.” Also, there is talk involved; students must ask their partners to flex and relax certain muscles in order to locate the rectus abdominis. Finally as Bryan says “you place your hands between them and you can sort of end up feeling the muscles.” In Figure 3.6, Bryan is locating the muscles on his own body, but not only to show them to me; instead, in the interview he goes through the motion of locating in order to describe what it’s like to use the book. This demonstrates how touch is primary to talk in massage; Bryan can’t put things into words until he uses touch first.
Despite the specificity of the directions and pictures, Bryan sort of fumbles around and uses the landmarks until he can feel (not see, because the muscles are inside the body) the proper muscle. The writer of this book draws on knowledge of a common set of semiotic practices, map reading, in order to teach massage therapists how to locate muscles. Bryan uses his gesture to demonstrate how that map reading works (Figure 3.5), and uses his hands to map out where things are on the body.

In this case, Bryan combined the traditional reading of text and images with the movements of his partner. He talks about being able to “see exactly where the muscles are” even though he cannot see the muscles themselves through the surface of the skin. One thing that Bryan really liked about learning from this book is that it included pictures of things he said he would never see or feel as a massage therapist, and this demonstrates how everything in the body is connected. He gave the example of a client coming in with a hurt foot which
could make you limp, which causes you to walk differently, which causes different muscles to be used when you walk, and then it can pull your leg muscles so that your gluteal muscles also get pulled differently, and then your back gets bent in a different way, and finally you shoulder begins to hurt.

In this case, if Bryan was able to visualize how everything in the body was connected so that he identified his client’s shoulder was hurting because of a foot injury, and he could provide a much more effective massage.

In the timespan of one hour, Bryan is participating in many literate activities. While we might not traditionally think of massage or touching and applying pressure to muscles as literate, this activity is streamed together with the writing of certain texts, talk between therapist and client, and visualization. Bryan must visualize the inside of his client’s body based on textbook images he’s seen in the past and his past experience touching muscles to provide appropriate and effective touch.

Perhaps one reason we would not typically think of touch as a literate practice has to do with an idea that Bryan brought up several times during his interview, especially when comparing massage to other traditional forms of medicine; because touch has a physical component and is about the felt body, there is a lack of empirical evidence about the effects of massage. He says that physical pain and emotional pain are often similar “as far as knowing whether or not somebody’s feeling it and what they’re experiencing.” It’s hard to test and measure how tight somebody’s muscles are, and the way a therapist “tests” muscles is to feel them. Massage is about “intent,” thus it’s about how deep into the tissue the therapist intends to go and how deep they actually go during the course of the massage. As Bryan describes intent, he pauses and uses his hand motion and gesture to figure out
what intent feels like before he can articulate it, because it is difficult for him to put into words (Figure 3.6). So like counseling psychology which is about emotional pain, massage therapy has a lot do with the client/therapist connection made in a short amount of time rather than empirical evidence of pain relief. Bryan finds these things “hard to describe and figure out empirical evidence for.”

Figure 3.6 Bryan shows finding depth in the muscles through intention

Elaine Scarry (1985) explored this problem of using language to articulate pain. She said that although pain can be articulated differently in culture and language, this is a “problem that originates much less in the inflexibility of any one language or in the shyness of any one culture than in the utter rigidity of pain itself: its resistance to language is not simply one of its incidental or accidental attributes but is essential to what it is” (p. 5). According to Scarry, in medicine, physicians often do not trust the human voice, and sometimes the only record of the felt experience of pain is the patient’s verbal account: “Medical contexts, like all other contexts of human experience, provide instances of the
alarming phenomenon noted earlier: to have great pain is to have certainty; to hear that another person has pain is to have doubt” (p. 7). So although she would likely disagree that medical practitioners’ assessment of pain is empirical, it does seem that trusting the client’s personal experience and connecting to it is more important for a massage therapist who relies on that connection during the course of the massage. Without the use of touch to make that connection, the use of only language would fail since pain is resistant to language.

In conclusion, pain’s resistance to language, both oral and written, highlights the importance of Bryan’s work visualizing something he cannot see as a part of his literate practice. Bryan cannot look at a muscle and assess how tight it is, nor can he perform an empirical test to assess his client’s pain. Instead, he uses a combination of literate practices: talk, text, touch, and visuals in order to connect to his client and make some assessment of pain, thus enabling him to provide a massage to relieve the pain. As he mentions, this is a “subtle” connection, one that resists description, yet highlights many of the subtleties present in literate activity. Any kind of literate activity including reading and writing involves visualization: we read a text and think about and visualize our histories and past experiences as a part of understanding it. Similarly, as Bryan touches or “reads” his client’s body, he employs the same practices: visualizing the inside of the body as he learned from his textbooks and applying his history and past experiences to the moment on the table in order to connect with his client. Through his gestures, he shows how important touch, movement, and pressure/depth are to learning about and giving a healthy massage.
Theorizing the Body Composing

In both of the examples of Bryan and Elizabeth, practices on the body are being used to learn and compose, sometimes alongside but oftentimes absent of physical texts. However, because the spaces in which these bodily practices are happening exist within systems that are highly saturated with texts, I argue that we can consider them literate practices.

My participants have used bodies in a range of kinds of practices in order to understand things they cannot see. Elizabeth has felt the inside of women's bodies to understand them in a felt sense in order to teach the medical students proficiently. Bryan has used touch to feel muscles on the inside of the body, and massaging out tension, providing the best services to his clients that he can. This examination of bodies as literate practice serves literacy studies broadly because it points out how literacy is tied to imagination with and without co-presence with traditional graphic texts.

I think my participants’ stories in this case are particularly interesting for how they can help writing studies rethink how we treat bodies. All composing is done with bodies, but we often don't talk about or think about how bodies are actually composing. When talking about health-related texts with my participants, the conversation consistently went to the body, showing how texts and talk are connected to learning on bodies and composing with bodies. More analysis of gesture can show how people think with and compose first with their bodies before as a part of the writing process.

Like Prior & Shipka's (2003) work which shows the activity involved in writing—walking the dog, cups of coffee, taking a shower, listening to music—all practices which we don’t necessarily think of as writing, practices of the everyday, are shown to be integrally
connected to literate activity through the case studies I present. It is in this moment of connection that I’d like to push further, thinking about how bodies are involved in all literate practices, how internal felt sense is often a starting point of composing, how humans are body and mind, not just one or the other. Body studies has come very far in showing how bodies are represented and how practices are embodied, but it has focused mostly on these external aspects. By seeing how the body is a part of internal thinking as well, we can rethink how bodies are always a part of writing.
Chapter 4 Medicine, Popular Culture, and Literate Practice

Researchers in cultural studies have long been concerned with many of the same themes my study investigates: including resistance, representation, repurposing of power/patriarchy (e.g., technical communication) in everyday lifeworlds, disciplinarity, interdisciplinarity, enculturation, and activist or interventionist research agendas. Although cultural studies scholars grapple with similar notions, the methods for analysis in the field have focused on, according to Pickering (2008) "textual analysis" and the application of "techniques of close reading" (p. 1).

Pickering and his contributors outline methodologies that cultural studies could adopt from a variety of fields such as anthropology and the social sciences. They map out methodologies that draw on experience and narrative, qualitative methods for researching producers and consumers of culture, observation-based research, visual analysis, discourse analysis, and studies of memory and history. In this interdisciplinary project, I engage similar methodologies, as was outlined in chapter 2. I blend these interdisciplinary methods with sociocultural perspectives (Bakhtin, 1986; Engestrom, 1999; Latour, 2005) because both approaches are interested in studying how things have come to be in the world.

Using cultural studies and sociocultural perspectives, in this chapter I put cultural studies themes of action (i.e., resistance, representation, and repurposing of technical discourse) into conversation with Meagan’s literate activity (i.e., the local, situated data from Meagan, a primary participant in my research). The sociocultural theory I draw from allows for research agendas that follow the participants’ local, situated activity, examining
participant uptakes of particular cultural representations. According to Nelson, Treichler and Grossberg (1992), cultural studies, although “occasioned by an examination of specific cultural practices,” should not be identified with these practices, but instead be about “how and why such work is done, not just its content” (their emphasis, p. 11). Cultural studies sees pop culture artifacts as a way people make sense of the world around them. As sociocultural theorists are also concerned with the activity of learning and making sense of the world, these two research orientations work very well together in my research, examining and following the situated uptakes of culture that my participants discuss.

Elaborated by Anne Freadman (2002), “uptake” implies that textual genres are not about standardization but about “what it gets people to do with one another, and what they do with it” (p. 40). According to Freadman, uptakes have “ramified, intertextual, and intergenetic memories” and depend on “the adaptation of remembered contents to changed contents” (p. 41). Uptake is a useful way to think about health-related literate activity because it implies more than a passive reading of an individual text; instead, it offers a range of practices of a user’s engagement following their own motives. For Meagan, it’s not just about what texts she engaged with but how she engaged the text, i.e. whether she read it, threw it away, filed it away, modified it, challenged it, etc. At different times in her life, Meagan also engaged the same texts, but in very different ways. Texts that she quickly skimmed or skipped over were read critically and carefully when their content became significant in Meagan’s life. Thus, uptake reflects a range of dynamic and engaged interactivity with text, an orientation to text, which Meagan’s activity demonstrated. Uptake is appropriate to the overall goal of studying this range by following user’s motives into the different spaces and artifacts they encounter.
Thus, this chapter will further elaborate on the notion of chains of reception outlined in chapter one, this time by looking at a particular case study, Meagan’s uptakes of a variety of texts and practices she put together to make sense of pregnancy and abortion in her everyday lifeworld. I show through several examples of individual uptakes, namely Meagan’s uptakes of birth control, ovulation predictor kits, and pregnancy tests, how Meagan created her own chains of reception to texts. Through this laminated and situated activity with texts and technologies, Meagan resisted, discarded, repurposed, and rewrote technical medical discourse for her own purposes in her everyday lifeworld.

**Rhetorical-Cultural and Sociocultural Perspectives**

In Scott’s (2003) study about the rhetorical and cultural practices of HIV-testing, he defines and outlines several advantages for a “rhetorical-cultural” approach to research, drawing on Latour and Foucault: (a) analysis of the activity of both scientific and non-scientific actors, (b) analysis of how texts and practices have come to be rhetorically-culturally significant within their networks, and (c) critique and intervention in effects in order to change the power conditions at hand. As Scott has written extensively about service-learning and technical communication (2003, 2006, 2008, 2009), one of his interventionist roles was in his capacity as an HIV educator and test counselor, and in this role he was able to bring his knowledge of discourse to help “educators and clients understand problems with popular depictions of home testing” (p. 31). Scott situates this role as critiquing/intervening in specific rhetorical situations and local practices related to HIV testing: “To understand how HIV testing functions as a disciplinary technology, we must analyze it not just as a diffuse network of relations but also as local sets of practices or, to use rhetorical terminology, specific rhetorical situations” (p. 123).
Drawing on Scott, the research approach that I use incorporates many of these same elements: consideration of both scientific and non-scientific actors, a tracing of how texts come to be significant within people’s networks, and a cultural studies approach to local literate practices. Although I draw on similar theoretical elements, my primary data comes from qualitative case study research, blending Scott’s rhetorical-cultural approach with sociocultural perspectives. This blended perspective I offer emphasizes the rhetorical-cultural situatedness of Meagan’s active engagements with text, in other words, I pay attention both to the global cultural perspectives and the local, situated activity that inform Meagan’s engagements.

There are a couple of sociocultural perspectives that I find particularly relevant in understanding Meagan’s literate activity. First, while we might typically think of reception as a passive taking of whatever medical professionals distribute, I argue that Meagan’s receptive practices are active rather than passive, and I emphasize the active character of these practices through the term chains of reception, which orients the research towards the chains that Meagan builds as she takes up texts from health-related sources. As a part of Meagan’s chains of reception, she puts together a range of texts: cultural texts such as TV shows and advertisements, experiential online texts such as those found in chat rooms and web discussion boards, technical instructions that come along with ovulation predictor kits and pregnancy tests, and personal emails, notes, and experiential online texts that she composes. The range of texts that she reads, studies, and inscribes demonstrate her multidimensional orientation towards medical discourse through which she engages, reshapes, and repurposes the technical according to her own motivations.
Bakhtin (1986) emphasizes that all reception is active reception through his notion of utterance. He says that, “when a listener perceives and understands the meaning (the language meaning) of speech, he simultaneously takes an active, responsive attitude towards it” (p. 68). This responsive attitude can have a variety of shapes; listeners can agree or disagree, supplement it, or apply it to something in their own lives. Additionally, the active, responsive attitude extends throughout the entire utterance; thus, the listener is always actively responding the entire time. Even if listeners appear silent or passive at the time of the utterance, that is only an appearance, and Bakhtin says that eventually they will take action as response to the utterance.

Rather than being a grammatical unit of measuring language like a word or a sentence, an utterance represents language as a whole, made up of infinite heterogenous elements, and Bakhtin argues the we learn to use language by learning utterances, not grammar. Thus, the listener during an utterance will predict the plan of the speaker’s speech, and there are generic ways we speak in different contexts. People import these generic forms between contexts, or as Bakhtin says “one can deliberately mix genres from various spheres” (p. 80). Meagan does this constantly and deliberately, importing concepts from other spheres into her understandings of medical discourse, and importing concepts from medical discourse into her everyday life.

Finally, unlike a word or a sentence, which can be understood as abstract linguistic units, utterances are always concretely situated in activity. Because “any utterance is a link in the chain of speech communion” (p. 84), all utterances are referential, and can only be understood as such. In order to account for Meagan’s responses to medical discourse in any particular situation, we must account for the utterances that came before the response, and
we must account for how that current utterance becomes a part of Meagan’s future responses. This accounting for the past and the future is important because “utterances are aware of and mutually reflect one another” (p. 91), and all utterances are responses to other utterances that came before, and will be responded to in the future. Utterances are “shaped and developed in continuous and constant interaction with others’ individual utterances” (p. 89). Significantly then, all utterances are response, including those of medical professionals and those of non-professionals like Meagan, and all response is active response. Though these utterances may be situated by different expertise and genres of discourse, they must all be characterized by their active nature.

The second sociocultural perspective I would like to point to is that of Engestrom’s notion of “knotworking,” which contributes the both tentative and permanent nature of the chains Meagan is forming, and emphasizes that the chains are formed, being made, thus situated in Meagan’s activity. Engestrom, Engestrom, and Vahaaho (1999) developed knotworking to describe the activity of organizations whose work “requires active construction of constantly changing combinations of people and artifacts over lengthy trajectories of time and widely distributed in space” (p. 345). The work is highly collaborative, but the center of the organization does not hold, which means that people engaged in the work do not collaborate in relatively stable configurations of teams. Instead, people engaged in this kind of work consistently collaborate with a changing set of actors in a changing configuration of activity. This configuration is best referred to as a knot rather than a network; a knot implies the changing configuration, the tentativeness of connection, while at the same time acknowledging that the connection exists, and that
connection does some work in the world. Also, a knot must be tied (it is not simply there) and it can be untied (and later re-tied).

Engestrom et. al. characterize a knot as “a rapidly pulsating, distributed and partially improvised orchestration of collaborative performance between otherwise loosely connected actors and activity systems” (p. 346). They offer the example of a general practitioner (GP) providing services to a mental health patient. Over a period of 16 days, the GP “visits the patient’s home together with a home-care nurse, the police, and an ambulance crew” (351). The patient’s building service technician also becomes a part of the knot when he forcibly opens the patient’s door so the GP can take her to the mental hospital. The knot also involves a variety of improvised actions as the GP rings the doorbell, attempts to talk to the patient, calls the service technician, tries to open the door with a master key, gives up, and comes back when the police are called. The knot is also characterized by its trajectory over space and time, involving multiple kinds of spaces like home and hospital, and occurring over a 16-day period.

The concept of knotworking fits particularly well into the kind of activity that Meagan engages in. As the following accounts of her activities will show, Meagan involves multiple actors and practices over trajectories that cross time and space as she engages with medical discourse. But unlike a network that has stable connections (as stable as plugging something in or wirelessly connecting to something can be), the chains that Meagan puts together have tentative connections; things can be definitely connected together, but they can also be untied, as the flow of the knot is constantly changing. It’s also important to note that knots are characterized by improvisation, which like Bahktin’s
utterance shows the ongoing active nature of Meagan’s reception to and uptake of medical discourse.

In the following documented narratives of Meagan’s healthcare experiences, I use these notions of utterance and knotworking as part of an analysis of Meagan's active chains of reception and orientation towards medical discourse. I include evidence of this engagement, i.e., figures of the wide variety of texts she encountered, stories about practices she used to engage these texts, and the people she collaborated with over trajectories of a wide variety of spaces and periods of time, because this evidence shows Meagan as participating in the themes of cultural studies, actively resistant to oppressive structures, and actively engaged in representing herself and repurposing those structures according to her own motivations.

**Testing the Tests**

The first example of Meagan’s uptake of medical discourse that I explore is evidenced in how she conducted her own research using two kinds of tests related to tracking and regulating pregnancy: ovulation predictor kits and pregnancy tests. She researched both her own body and the tests themselves for their accuracy in measuring and regulating her body. As a part of that research, Meagan tied together several kinds of texts including technical documentation on how to conduct the tests, as well as advertisements and TV shows that culturally situated her interactions with the tests. Meagan’s chains of reception also involved multiple people including her husband and her sister, and they took place over a period of months and in several different spaces, including in her bathroom and in her living room at her computer.
When Meagan discussed ovulation predictor kits, she described a curiosity about menstrual cycles that she had not experienced prior to deciding to get pregnant. She opted to do “some research about ovulation” because she wanted to find out “how to get pregnant, how to time things... just because I wanted to find out about all this stuff.” She learned to track her cycle, and discovered that instead of being 28 days, her cycle was actually 26 days.

So there’s actually a difference when I check my due date on babycenter.com [see Figure 4.1], you enter in the first day of your last menstrual period and how long your cycle is, and they calculate from that, and I get a different due date there than I get at the doctor’s office because they use a 28 day cycle. There’s like a 3 day difference which is interesting.

In this way, instead of passively accepting what the doctor said, Meagan researched and sought out sources on her own for further understanding, and she used that information to accurately track her cycle so that she could get pregnant.

Figure 4.1 Babycenter.com due date calculator
After three months of trying to get pregnant, Meagan bought an over-the-counter ovulation predictor kit in order to better track her ovulation cycle so she could time having sex when she was more likely to get pregnant. When she told her spouse that she bought the kit, he wanted to make sure that she did not “announce” before sex that she could get pregnant, so she did not mention it out loud, but she maintained her awareness that she was using the kit to regulate sex, thus regulating the activity of her body: “you want it to be somewhat spontaneous, but I also really wanted to get pregnant.” Meagan used the chart included with the kit (Figure 4.2) to track her ovulation, but she also read discussion board posts by women talking about how they track ovulation: “I remember reading where women would talk about such specific details of their periods... And it seemed like these women had such a sense of their cycles that I never even thought about.”
Figure 4.2 Ovulation predictor chart

Thus, Meagan discovered through her use of the ovulation predictor charts and the online discussion boards that there was a lot to understand about her body’s cycles and functions, and she wanted to learn more. Although the end goal was pregnancy, she did not learn about these things solely for the purpose of controlling her ovulation; she was also curious about the complexities of women’s bodies and the differences among women.
Ovulation predictor kits were used to control her body but also to gain more knowledge about how it works.

When Meagan talked about pregnancy tests, she indicated that they represented more than a positive or negative result, but they also represented the anticipation and impact of pregnancy on Meagan’s everyday life. When Meagan took the test and saw the faint second line, her husband Chris asked her to consult the directions to make sure the test was definitely positive. According to Meagan, the directions read “any kind of line indicates most likely a positive pregnancy.” So Meagan called her sister, who was very excited because in her experience “it’s very common to get a false negative but a false positive isn’t very common.” Then they proceeded to talk about the details, such as if Meagan was going to tell the rest of the family and what their response to the news would be. After Meagan got off the phone with her sister, she and Chris took a picture of themselves and a picture of the test so they could “have a picture to show our kid, ok this is what we looked like the day we found out.” Through both of these examples, Meagan imagined progressions of time, and she chained together her everyday family relationships (being a sister, being a expectant mother, being a wife) with her literate activity of reading and interpreting pregnancy tests.

When Meagan started to have doubts about the accuracy of her pregnancy test because she had taken the test 5 days before she was supposed to, she bought 3 more test kits to serve as back up sources of information.

I got 2 of the digital kind, and seriously they display the words on an LCD screen pregnant or not pregnant, and I got another regular one with just the lines. I took all of them and they were all positive, and I called Chris and said “Yeah, I think it’s for
sure.” I mean the digital ones, I peed on the stick and within 10 seconds they were flashing pregnant, so I was like ok, that's pretty definite.

Since she could not be certain of the results and was not convinced by her sister who had had a similar experience with a faint line, she attempted to control her certainty by taking several tests, and including varieties of tests, both non-digital and digital, among them. In this case, Meagan found the advanced technology of pregnancy tests more reliable than her sister’s experiential knowledge, thinking the technology provided more certainty of her pregnancy; however, she developed that certainty by taking multiple tests, testing the test results against themselves.

Through Meagan’s local situated uptake of pregnancy tests, she transformed these technologies into things that she could use to control her own body in a situation where she had little control over it. Meagan also chained her experiential knowledge of pregnancy tests together with pop culture representations she had seen where pregnancy tests were represented incorrectly. Meagan brought these pregnancy test practices into conversation with pop culture as she discussed “the whole pregnancy test industry,” which included TV commercials for specific tests claiming 1 in 5 women misread them. She told a story about the TV show King of Queens wherein the impatient couple waiting for the test results start waving the test stick around like a Polaroid in order to develop the image more quickly. These stories about women misreading results on TV and in ads indicated how Meagan tied together her uptakes of pop culture notions about pregnancy test accuracy to her own practices of reading pregnancy tests.

To compensate for how easily Meagan thought women misread pregnancy tests, she read each set of directions to tests she took very closely, and she was incredibly meticulous
and careful each time she took a test because “I didn't want to mess anything up.” She made sure to pee on the stick or dip the stick for the correct number of seconds, wait to read the test the amount of time specified to wait, leave it on a flat surface and not touch it, and not read the test after 10 minutes because the results could be invalid. She even went so far as to test the test to see under what conditions it would become invalid, going back to the garbage can about 2 hours later to check the test, and incorporating what she had read about evaporation lines. Finally she came to see for herself that the strip does react to moisture and air, affecting its validity.

Meagan uptake of pop culture notions served to be part of the impetus for her thoroughness with pregnancy tests. Her meticulous practices helped her feel like she had some agency in a situation that she had so little control over, getting pregnant. She was able to exercise that feeling of control in this situation through her practices of “testing” the test, checking if the results changed as she tried different tests, and making her own range of experience with tests that she could trust more than her sister's experience or the representations on TV.

Meagan's desire for a “true” positive pregnancy test provided motivation for her literate activity. Meagan conducted her own experiment with ovulation and pregnancy by using online texts, information from her sister, instructional texts in the tests themselves, and pop cultures examples. Through her testing of these tests and her measurements of how the devices changed over time and with different technology, she felt she could exercise some control over the accuracy of the test, thus finding a true positive or negative result. As her literate activity became chained together in her conversations with family and her encounters with pop culture representations, even though the pregnancy test only
had two possible results, negative or positive, Meagan’s uptake of the tests, e.g., the literate practices she used to engage the tests, and the everyday practices she chained together with the tests, point beyond a passive reading of just the technical results. Meagan’s reception of texts/tests/technologies demonstrated her active engagement and formation of knowledge that served an important purpose in her life.

**Meagan’s Chains of Reception to Images**

Like Meagan’s engagements with ovulation and pregnancy tests wherein she carefully read and oriented herself towards particular texts in order to get pregnant, Meagan carefully looked at and considered a variety of images after she got pregnant. Her fascination with the human growth process in the womb grew out of her previous experience with visualization and research, and led her to seek out and look at three types of images. The first type of image is photographic rather than drawings, and look similar to Figure 4.3. Meagan received images like this one from medical professionals, for example, in a magazine called “As Your Baby Grows,” and she also sought out images like this on the internet.

![Figure 4.3 Image of Fetus used with permission of istockphoto.com](Figure 4.3 Image of Fetus used with permission of istockphoto.com)
She preferred photographic images because she thought that
they're pleasing to look at, they're fascinating and they're detailed. Even though
they're not completely accurate, and I'm well aware of that cause there's no way the
womb is this bright, of course it's gonna be pretty dark. It's not like if your head was
up in there you'd really see this much detail, but I've always been interested in
seeing what's going on inside me which is why I've always turned to those pictures.

Meagan identified dark and light and acknowledged how photographs work to represent
something through a particular lens, attending to the fact that light allowed her to see
something that she couldn't otherwise see, even if she felt it was an inaccurate
representation. She preferred this type of image because of the amount of detail it allowed
her to imagine.

The second type of image Meagan looked at was instructional and provided points
of reference; this type of image provided comparison so that people can imagine the size of
the fetus as it grows in the womb. Meagan looked at these images with her sister who was
also pregnant. They sought out many of the same sources including websites and books,
and they often shared sources with each other when they found something interesting or
funny.
Figure 4.4 Comparative slide show from babycenter.com

Figure 4.4 shows an online source that Meagan found, a slide show that gives a rough estimation of the fetus’s size using different fruits and vegetables for comparison. These images also include a quarter as a point of reference, as seen in the slide in Figure 4.4 where the poppy seed is set next to the quarter to illustrate the fetus’s size at 4 weeks. By sharing these images and laughing with each other, Meagan and her sister linked their experiences, making new knowledge together about pregnancy.

A third type of image that Meagan used was from her ultrasound, an imaging technique using sound instead of light to capture the image. Meagan had several ultrasounds during her pregnancy; at the first ultrasound the sonographer didn’t see any problems. It was during the second ultrasound when the sonographer couldn’t get the baby to stay still for measurements, that Meagan and Chris first heard that their baby might have
Trisomy 18. Her doctor saw the initial problems with the heart, brain, and clenched fists and recommended Meagan see a specialist for a third ultrasound.

At the third ultrasound, initially the sonographer didn’t have as much difficulty taking measurements of head and foot length, but when she started the echocardiogram to measure heartbeat and was having trouble, she asked the specialist to come in. As he started moving the sensor across Meagan’s body, he also started explaining genetic mutations and how they happen. He asked Meagan what medications she was taking, but concluded these meds wouldn’t make a difference, and that a lot of the times these things were just hereditary or caused by a genetic mutation. As he provided the general information, Meagan kept thinking “what’s wrong with my baby?!?” but suspected he was both providing important information and buying himself time to figure out what was going on.

And finally he just said, yeah well they’re right. That’s of course when I started crying again. He said I really wish that I could have said no, it’s fine, they just got some bad images or something. But he said no they’re right and then he started going into detail about what he was finding.

The doctor told Meagan and Chris that he found one side of the heart not fully developed, and the choroid plexus cysts plus clenched fists could mean Trisomy 18. He recommended an amniocentesis to confirm Trisomy 18 and said best case scenario, with no chromosomal disorder, the baby would have to be born in a different city and have surgery immediately after birth to fix the heart defect, and there’s a high mortality rate for babies who have surgery right after birth: “And I’m like fuck, cause best case scenario it means that my baby is having surgery right after birth and might die.”
Meagan and Chris decided to go forward with the amnio, and Meagan got up to use the bathroom while she waited. As she was walking out, she started to cry like crazy as she saw the sonographer cutting up pictures from the ultrasound to give to them. (Figure 4.5)

![Figure 4.5 Meagan’s ultrasound images](image)

At first, Meagan and Chris could not bring themselves to look at these images. Meagan described that:

> The sonographer was sitting across the room with her back to us, and as the doctor was talking I looked over at her and I realized what she was doing, she had printed all the pictures from the ultrasound and was cutting them up to give to us... I didn’t look at them... I think Chris actually kept them in his pocket, he didn’t look at them either, I think at one point he just took them out of his pocket and stuck them on top of the fridge so he didn’t think about them.

In this example, Meagan chose not to look at this particular set of images as she had with the other types of images, likely because seeing and imagining in this case invoked emotional pain.
The ultrasound images from Meagan’s second pregnancy would have a very different effect. These images were seen as early photographs of a baby. They were shared with friends and family via websites like Facebook and displayed in ways one would typically display baby pictures. Meagan had very different reactions to these two sets of ultrasound images from her two pregnancies even though these images looked remarkably the same. Because of the way her experiences with these two ultrasounds had come to be tied together in her everyday lifeworld, each set of images prompted different practices: the first set was purposefully ignored and put on top of the fridge while the second set was purposefully displayed for friends and family to see. Because ultrasound images represented more than just the physical fetus but also the projected experiences of “baby,” Meagan experienced different reactions to the images, in spite of how visually intelligible Meagan found them to be.

**Making Sense of Abortion**

Although in the last section I spoke about Meagan’s looking at images in her second pregnancy, I would like to shift back to Meagan’s first pregnancy for a detailed look at Meagan’s practices as she made sense of the diagnosis of Trisomy 18 and came to understand abortion and its implications and meanings in her everyday life. Meagan began research “immediately” after her 2nd ultrasound where the doctor spotted the original problem, showing how she shifted her orientation towards information for her own purposes of understanding. Meagan plugged the key technical terms she remembered the doctor mentioning (underdeveloped heart, choroid plexus cysts, and clenched fists) into search engines to further understand application and implication of these terms. Although Meagan didn’t completely discard the doctor’s preliminary findings, she also was reluctant
to accept them without understanding them, so she engaged in these practices to chain together her own understandings of the findings.

Initially, although Meagan met mostly dead ends out of her research except for finding that heart abnormalities kept leading back to sites related to Trisomy 18, she collaborated with her sister who also conducted an internet search. Collaboration with other women who are not medical professionals represents another layer of Meagan’s uptake of the discourses of power that discourage collaboration among laypeople as a way to make legitimate knowledge. Through her sister, Meagan found some information about clenched fists not having significant implications. Meagan also found discussion boards with mixed opinions; some people posted that their doctor found cysts and they were worried, and other people responded with their own experience saying cysts ended up not being a big deal and cleared up on their own. As Meagan had two days to wait for the additional ultrasound, rather than accepting what the doctor had mentioned about Trisomy 18, she found her way to the Trisomy 18 website, where she remembers “finding out that it’s really bad and doesn’t ever result in a long healthy life; it’s almost 100% terminal.” Although Meagan remained hopeful that they weren’t dealing with Trisomy 18, she also integrated this information she learned to be a part of future decision making in this process. Because she found mixed reports from experiential knowledge as the result of her research, Meagan thought perhaps they just couldn’t get a good heartbeat because the baby was moving around too much, and at that point in her experience, she remained hopeful that the abnormal ultrasound wouldn’t amount to anything.

Meagan continued in her process of making sense of abortion through internet research after she got a phone call with the results of the amnio, confirming Trisomy 18.
Meagan said that “once they confirmed Trisomy 18, I was looking it up all over the internet,” and she changed the search terms to the confirmed diagnosis and tried to get information from as many sources as she could. She found the Trisomy 18 foundation website to be “pretty important” and the family profiles on the site became her “main source of information.” During the interview, without my prompting, Meagan opened her laptop to show me the website. She navigated this site fluently, finding her way there within 10 seconds, and she turned the laptop to face me so she could show me around. Meagan demonstrated through quick access to the URL and her familiarity with the navigation of the site, that she had visited many times, thoroughly reading and incorporating information from this website as she was making sense of the diagnosis of Trisomy 18.

Meagan talked about the language she learned from the site, saying “and here’s where I learned of the terms that they use: carrying to term (Figure 4.6), or saying goodbye early (Figure 4.7). Which saying good-bye early is a much better term than termination or abortion.”

![Figure 4.6 Gesture for “carrying to term”](image)
Figure 4.7 Gesture for “saying good-bye early”

Through these gestures of opening her arms and using scare quotes, Meagan rearticulates her experience of how she read this website when she visited. Through her tone of voice and gesture, she expressed the emotion of this terminology, how it provided relief that she was not the only one to go through this experience, and that there were others out there making sense of it in better ways than she could on her own. The terminology helped her understand the confusing and emotional experience happening to her, and it gave her an outlet and words to express that experience to others.

Meagan then showed me the index page on “carrying to term” and began to read aloud to me in a very matter-of-fact tone the examples on the page:

Olivia Grace’s family carried to term, lived 2 precious days. Rayland Ellis lived 2 hours. Laurence Michael born still. Faith Isabella carried to term born still at 8 ½ months. Katie diagnosed 22 weeks carried to term lived 17 weeks. Another one 18 days... and it goes on. I mean there is one child [pauses as she scrolls down] carried to term, now 8 years old. That’s the only one that lived past a year, I believe. So not promising.
The language of “carrying to term” or “saying good-bye early” was not just a way of categorizing the limited choices as Meagan first indicated; this language also categorized the stories as told in the parents’ own words, which included pictures as well as extensive detailed accounts of their experience. Meagan went on to say that she read the “whole story” of the one child who lived past a year, and stated that his life was not without mental and physical developmental problems. She also mentioned looking up Trisomy 18 on Wikipedia and medical websites, but “none of them had good outlooks for Trisomy 18.”

When Meagan and Chris met with the doctor the following Wednesday, he confirmed many of the same things they’d been reading. He said there was pretty much no chance the baby would survive and presented termination as an option, and his nurse gave a brochure for a nearby facility. He emphasized that this nearby facility doesn’t advertise because they want to protect themselves and their patients from being shot at by extremists, but that the facility had a lot of experience with termination and they were very good.

Since Meagan had already done research on the experience of carrying to term with Trisomy 18, she felt it would be a million times harder to draw it out, and she didn’t want the baby to be in pain, so they went the same day to the facility to schedule the termination. Meagan said that although she understood that some people would want to carry the pregnancy to term, and although it wasn’t an easy choice to make or what they planned for their first pregnancy, both Meagan and Chris knew termination was the right choice for them.

Reading these stories about people who carried to term, I understand on some level that some people need to suck every minute of their pregnancy that they can, they
want the photographs from the ultrasounds, they want to go through the birth process and see their baby if that’s possible. For us, it’s the complete opposite, all of that would have made it a million times harder, as hard as it was, we just couldn’t imagine going through every day knowing that there was just no future for our baby. We didn’t know if our baby was in pain, if he would be in pain if we actually carried to term and he happened to be born, would he be in pain while dying, I mean it just seemed so not for us to keep him alive.

Meagan used the information she gathered from her research on the Trisomy 18 website to make sense of the experience of carrying to term by situating what she knew about herself within the choices and outcomes from the experiences of others. Experiential knowledge in this case represented a process of coming to understand the technical medical diagnosis of Trisomy 18, and during that process, Meagan chained others’ experiential knowledge together with her understandings of her feelings. From her understanding of other’s experiential knowledge chained together with what she knew about herself, Meagan quickly made and acted on the decision that was right for her.

After Meagan and Chris made the decision to terminate, Meagan researched what would be happening to her body in the week between deciding to terminate the pregnancy and her doctor’s appointment. Meagan could find little purpose in this search because she encountered only two types of websites: anti-abortion websites and discussion boards or clinical studies. “I tried different terms like therapeutic abortion, medical abortion, pregnancy termination, and really there was nothing that was really straightforward… nothing I hadn’t already heard from the doctor.” Because of this, Meagan didn’t search
again and in fact stayed away from the computer, choosing to come to understand her experience without looking at these sites.

This internet search on termination is particularly interesting because it shows Meagan diverging significantly from her typically engaged practices of searching. Meagan was not curious about these aspects of termination; thus, she shut down her typical practices of reading a variety of information to understand technical medical knowledge. During the interview, I asked Meagan if she consulted websites like the Women’s Health Collective, but she said the thought hadn’t occurred to her.

Yeah, I should have just looked at Planned Parenthood or something. But I did that [internet search] for a few minutes one night and just felt really crappy for what I was seeing, and I was like great, I don’t really want to be feeling guilty for my decision so, I’m not.

Instead, she made the choice to stop searching in her typical ways, shutting out a perspective that hindered her ways of making sense and didn’t serve her purposes.

Meagan’s process of shutting down research and her resistance to and dismissal of pro-life discourse represents part of the process of Meagan’s chains of reception. As she came to think about how others make sense of abortion, she realized that many people would associate what she was doing with abortion and would consider her actions to be immoral. Although she says that all along she realized that medically speaking this experience was aborting a pregnancy, Meagan didn’t immediately connect terminating the pregnancy with representations of abortion as murder. She noted that soon afterwards she hit a moment where she began to make this connection, the first time she visited the office of the doctor who performed the termination. When reflecting on why they went to the
doctor’s office to schedule the termination, and why they had to wait a week for the procedure, Meagan said:

Chris was like “Of course they want to know that whoever’s there is actually for real and going through the procedure. They do have to protect themselves.” And it sort of dawned on us when our doctor pointed out that they don’t advertise and when he pointed out the story of the other doctor when he got shot in the arms and when we realized when we met the doctor, it actually dawned on us, this is actually, I mean this is abortion, it’s lumped in with this one term, it’s lumped in with all these other cases.

It was this moment when Meagan and Chris began to connect ideologies associated with abortion to their own actions in this situation.

As Meagan made these connections, she was attending to multiple histories, for example, histories of radical violence against abortion doctors, and the histories of abortion as a back alley activity. She began to make connections with the idea of “abortion,” which has been charged with its association to a time when women’s choices were controlled by patriarchy and people in power. She realized that a lot of people in the world, including some of her family members, would strongly oppose her actions. She recognized that some people she knew would consider her a sinner, wrong, and immoral, “and that we’re doing this thing that is lumped in with that, I mean it is that, maybe I shouldn’t say lumped in. It is an abortion.” Because these histories of pro-choice and pro-life beliefs conflict so much, it took a process of research, sorting things out, and integrating information before Meagan could finally connect what she knew about “abortion” to her own experience. In this
process, Meagan chained together multiple spaces and times, cultural discourses and texts, and her own experiential knowledge as a part of her understanding and decision-making.

**Representing “Abortion” on Her own Terms**

During the decision-making and termination process, Meagan engaged in several practices of writing wherein she represented her own experience and feelings to others around her. The first of these practices was email; Meagan wrote several emails to friends and family as a way of sharing her decision and representing her experience in her own way. After Meagan’s second ultrasound, she responded to her sister’s phone message with email (Figure 4.8) because as she says, she was too emotional to talk on the phone. In these emails, Meagan used writing as a way to express the technical results of the ultrasound (heart was underdeveloped, choroid plexus cysts, clenched fists) and her emotions about the ultrasound (upset, scared, crying).

```
From: Meagan
To: Meagan’s sister
Subject: hey
Date: Tue, 7 Oct 2008 20:14:16 -0500

sorry i didn’t answer your call. it’s a boy.

unfortunately, the ultrasound was abnormal and i’m being referred to a specialist for a high tech ultrasound. we’re really upset and scared and i can’t talk about it without crying so i won’t be calling you until i know more. i’ll find out in the morning when the appointment is. don’t tell anyone yet (except r of course) - it’s still too early to know anything for certain. i’ll call you as soon as we know more. –M
```
From: Meagan
To: Meagan’s sister
Subject: RE: hey
Date: Wed, 8 Oct 2008 11:39:53 -0500

we have an appt for Friday at 9:30 with a perinatologist. The doctor said that the heart was underdeveloped (no idea how underdeveloped), there were choroid plexus cysts in the brain, and the baby didn’t want to open his hands, which made her think he has clenched fists. All of this together could indicate Trisomy 18, which is worse than Down syndrome (Trisomy 21). She’s already talking about termination as an option. I’m really not sure about anything right now. The ultrasound itself took forever and the first sonographer had to go get someone else to finish for her. The baby just wouldn’t stay still or wouldn’t get into the right position for measurements (which was really funny at the time, and the sonographers assured us it’s no big deal and happens all the time), so now I’m wondering if it was just a bad ultrasound. But the doctor seemed sure it was pretty abnormal. I don’t know. We’ll see what they say on Friday. –M

Figure 4.8 Meagan’s emails to her sister

Meagan expressed that it was easier for her to talk about the technical results of the ultrasound and amniocentesis than the feelings she had surrounding her pregnancy and termination. She said that talking about the “medical aspects” of the diagnosis and termination, or what was actually physically happening to her body, was “less uncomfortable” than realizing what was actually happening to her baby, or finding out what was happening the her baby:

I don’t mind having medical procedures done, that doesn’t bother me. I don’t care about the pain or anything like that. But it’s just all this information that’s overwhelming, and then having to make decisions based on it, we just never thought that we’d have to I guess.

In this respect, Meagan felt that she could not control her feelings and the situation that she was in, but email allowed her to have more control over how she represented the her feelings and her situation to others in her life.
Date: Weds, 15 Oct 2008
From: Meagan
Subject: Re: hey
To: Meagan's friends

Hi all,

You may have already heard this from P or H, but I wanted to tell you all myself. Chris and I received some very sad news last week. Our ultrasound revealed that our baby has some serious abnormalities. Another ultrasound and an amniocentesis with a specialist confirmed that our baby has trisomy 18, a severe, life-threatening chromosomal disorder. In our case, with the additional heart defect that was found, our baby has little chance of surviving the pregnancy and, if he did, would not survive more than a few moments after birth. After consulting with the genetic counselor, Chris and I decided that the best option for us and for the baby is to terminate the pregnancy.

We are incredibly hurt by this, but are dealing as best we can, taking comfort in the fact that we have each other. It will take time, but we know we'll be okay. It's still difficult to talk about this and we probably won't be telling many people beyond those close to us. Don't feel the need to keep this from anyone, though. It might actually be easier for now if you let others know.

Best,
Meagan

Figure 4.9 Meagan’s email to her friends

A second way Meagan represented her experience was through another literate act, this one more public. Meagan also reflected on how she felt about talking about the termination. In a future interview, Meagan told me that on the first day of the termination (it's a two day process), she was checking facebook and received a notice that Planned Parenthood was asking people to sign postcards (Figure 4.10) supporting Obama’s stance on abortion to be handed out in swing states. She decided that instead of just signing with the stock message, she would put her own story in.

And I had never done this before. And I don’t know what it was but at the moment I was just like “absolutely,” and I wrote a paragraph about what had happened, that
we had a baby with Trisomy 18, and that we had to do this. And I thought very carefully about how to word it, and I basically just wanted to make the point that there are many many different reasons for women to have abortions... there are many valid reasons for people to do this and that it’s not an easy decision by any stretch of the imagination. But it’s something to be taken very seriously and something that each woman and their loved ones should have a say in.

Meagan mentioned that giving specific details about what had happened to her “felt really good” because although she had never really felt personally attached to a cause before, she felt personally attached to Planned Parenthood and pro-choice rights. Before she sent the personal story, she did wonder if there might be backlash, but she decided that she didn’t care and that backlash didn’t matter to her.

Figure 4.10 Planned parenthood facebook page
As Meagan reflected on the act of writing, she said that it represented to her how she feels about talking about this situation. She doesn’t hide it from friends or family who ask her about it or want to know about it.

I feel very strongly, this is not something to ever hide or be embarrassed about, or be ashamed about. And I think the instance of sending that statement to Planned Parenthood and have it be something they might share with people who have very different opinions, that sort of stands out as a representation of my whole attitude towards this.

In this way, Meagan chained together this somewhat public act of activism with her representations to friends and family members in her everyday life.
Finally, Meagan said her attitude towards activism about abortion changed because of her experience filling out the comment card. Although she would not call herself more active in that she wouldn’t seek out pickets, she felt more passionate about the subject, and believed she spoke more carefully about the subject because of her personal investment in it. She calls herself “rhetorically savvy” in “trying to make people understand why pro-choice is important, why it needs to stay, and why I support pro-choice.” For Meagan, the issue now went beyond the templated postcard or the generic reasons to believe women should have control over their bodies.

I think though even before, although I knew in the abstract sense that there were medical reasons that women should have abortions, I never really knew what they were. I never knew about the variety of things that could happen until this happened so, I think I’m just a bit more well informed now too.

Because Meagan was able to put together her own experience with her cultural understandings of abortion, she was able to engage with and represent that experience to others in ways that were satisfying to her.

As Meagan attended to multiple representations of abortion that she had encountered in her life, she made clear distinctions between her actions and those representations. By carefully considering and writing her own story and distributing her story in a public way, Meagan was able to make her own representation of her experience. This literate act was a way for her to resist simplistic representation and characterizations she encountered of women who have abortions. Because of her particulars of her situation, she resisted the generic view and stereotypes that women only use abortion for birth control.
Through Meagan’s literate activity and local improvisations with text, Meagan represented her termination to her friends, family and the public in ways that she found important to her, resisting the dominant discourses that stereotyped women who have abortions. Through this process of writing, she integrated her understandings of abortion and how that played out in her everyday experiences of the termination.

**Attending to Cultural Studies and Sociocultural Perspectives of Activity and Action**

Meagan’s literate practices of reading and engaging texts as well as writing and representing her own experiences in texts, show the kind of range and multidimensionality of Meagan’s orientation towards her current engagements with medical discourse as well as her orientation towards future engagements. Through Meagan’s range of practices in chaining together texts, she not only constructed understandings of medical discourse, but she improvised action as part of a knot in order to integrate understandings into her everyday lifeworld, as she oriented towards particular texts that helped her understand what was happening to her body and what she was experiencing mentally and emotionally.

A sociocultural perspective allows for more than a close reading of a particular cultural text; instead, similar texts such as TV shows or advertisements become *texts-in-activity*, as we come to understand how Meagan orients towards them, engages with them, takes them up, and chains them together with other texts and artifacts as a part of her everyday lifeworld. In the documented discourse narratives, I looked at Meagan’s use of texts-in-activity through some of the happiest and most difficult moments of her engagements with medical discourse. Starting with Meagan’s first pregnancy, I traced these chains of reception and texts-in-activity as Meagan got pregnant, found out her baby was diagnosed with Trisomy 18, and terminated the pregnancy. Throughout these experiences,
Meagan used texts-in-activity to make connections and negotiate contradictions about medical discourse, find her voice and speak to medical worlds. In other words, Meagan used texts-in-activity to engage the very important themes of cultural studies work: resistance, representation, and repurposing of medical discourse.
Chapter 5 (Re)Visioning the Professional: Interdisciplinarity and Professional Writing

(Re)Visioning Healing in Feminist Spaces

In Spring 2005, I began embarking on a feminist research project that I called (re)visioning healing. (Re)visioning embodied looking towards directions that future feminist work could go. I started this work by taking on digital mammography, arguing that advertisements which positioned the digital as equal to health reveals certain societal assumptions about sickness in the gendered body, and the power of technologies to heal the gendered body, particularly visual technologies like mammograms and x-rays that only doctors use to see inside of the body. Ultimately, this rhetoric reinforces notions of a woman’s body as diseased and doctor’s body as the only one who can heal it because of what he can see through digital technology.

I saw this rhetoric as a problem of vision. The doctor is the only one who can see so he holds the agency in this case, not the woman. The text and imagery on the advertisements gave the illusion of choice because women could choose between digital or analog mammograms, but at that time, both types of mammograms were similar in accuracy, so this wasn’t much of a choice at all. Finally, the advertisement put forth a rhetorical vision of the woman’s body as diseased and in need of the digital technology to

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See Foucault’s (1973) *Birth of a Clinic* for the concept of medical gaze. I purposefully used the binary of doctor/man vs. patient/woman to theorize about power roles and gender. However, I think my current work is better served by moving beyond such binaries and embracing a range of possibilities of activity and gender roles for both men and women.
be healed. I thought that if these images could communicate such negative things about women's bodies, perhaps feminists could create images that communicated positive things, and perhaps these images could project a future feminist way of seeing for the world.

I wanted this future feminism to align with past feminist work, which opened up potential spaces and possibilities for embodied experiences of womanhood rather than closing off possibilities as the advertisement was doing. I thought one set of potential spaces could be in the transitions between technologies, spaces such as between photography and video or analog and digital. Instead of seeing only progress between these spaces, or only the ways these transitions reproduced cultural ideas about women's bodies, I wanted to encourage feminism to consider productive reconstructions of image. It was in these spaces that I thought feminists could work towards methods of (re)vision.

I thought of (re)vision as opening up a visual space for feminist theory that could realize two goals, both critique of existing representations and creation of new representations. I aligned (re)visioning with the work of Treichler, Cartwright, and Penley (1998), who discuss the paradoxes that they see operating in relationship to imaging technologies such as the digital mammogram. They state that:

The imaging technologies developed and popularized over the past decade or two are marked by continuing struggles over cultural authority and cultural inscription—over who will have authority to define the role and meaning of these technologies and determine how they will be institutionalized. Such struggles call attention to what, precisely, is and is not seen. (p. 9)
By calling feminists’ attention to cultural ways of making women’s realities invisible, Treicher, Cartwright, and Penley assert that a technology binary\footnote{The technology binary is a technophilia/technophobia binary. This would include digital=health because the message fits into the technophilia half of the binary.} takes precedence over more productive interpretations of technology. They state that “there is nothing wrong with discussing the pros and cons of various technological advances, but these concerns may preempt and displace more fundamental discussion of the cultural work that imaging systems accomplish and how they accomplish it” (p. 9), and they encourage a different kind of analysis of these imaging technologies, one that “seeks to avoid both the technophilia that characterizes much of medical imaging and related scientific inscription and the technophobia sometimes embraced by science and medicine’s critics” (p. 11). Thus, by critiquing existing representations of rhetoric surrounding digital mammography I could take up Treichler, Cartwright, and Penley’s call for critical analysis of imaging techniques.

But critique was only part of my concept of (re)visioning. As the critic, I wanted to make new representations as a part of theorizing and create alternative images that show a feminist view of technology and women’s bodies. Even if the images were not very good, I thought that they would be significant in reflecting on what I learned and how I theorized differently through making images. This type of work is not typically considered to be the domain of rhetorical critics, though perhaps the work of critical artists, but I believed that feminist critics needed to approach imagery from multiple directions in order to literally “make visible” possibilities for feminist (re)visions of healing.

This project of “making visible” took the form of a seminar paper and a web installation, the latter of which was eventually published as a part of the collaborative \textit{Kairos} piece “Resituating and remediating the canons: A cultural-historic remapping of
rhetorical activity.” The first image I created came directly from my research about digital mammograms. In the *Kairos* piece, I said that I created Figure 5.1 to make the point that one can theorize about images not only through writing but also through producing images. To produce the image, I drew on the methodology of Adbusters, who according to their website “are a global network of culture jammers and creatives working to change the way information flows, the way corporations wield power, and the way meaning is produced in our society.” They fulfill this mission by creating spoof advertisements that often reflect absurdity in culture.

![Figure 5.1 Spoof of hospital advertisement](image)
Like Adbusters, I called this image “ridiculous,” pointing to what I perceived were the ridiculous messages of the advertisement in Figure 5.2: (a) that digital mammography was a “healthier” technology than its predecessors, when in fact, digital mammograms still used radiation technology and only accurately detect cancer in 4 out of 5 cases, (b) that digital mammograms provided more agency to women, when in fact, the advertisement was really taking agency away from women and giving it back to the doctors who were the only ones who had the power “to see” cancer, and (c) that digital mammograms produced some sort of zen feeling—as the digital image of the woman doing yoga represents—when in fact,
digital mammograms still hurt a lot and are only digital in the storing of images, not in the actual taking of them (at least that was the case at the time). By rewriting the text of the advertisement and overlaying my images on top of the imagery that the advertisement used, I sought to produce an image that demonstrated those three ridiculous messages.

The second image (Figure 5.3) I created was more personal, and had to do with the message I wanted to convey in the Kairos piece, rather than a critique of digital technology that went along with my seminar paper. I wanted the first image that people encountered on the site to be provocative, so I used an image of my body overlaid with text from my medical records. On the site, I emphasized that this text “covers the body, yet it leaves holes, it is inscribed on the body, yet the body doesn’t absorb it.” Through the physical placement of the medical records on top of my body, I felt image demonstrated a way of seeing the relationship between my body and this text about my body. Although body and text were physically connected in the image, it was a constructed connection that I made myself, as medical records aren’t actually attached physical bodies as a matter of practice. This construction represents the constructed nature of the ways medical discourse defines bodies. In the image, the medical definitions are only placed on top of the body, representing how women don’t have to internalize these messages, and opening up a space for women to represent their bodies in the ways they wanted them to be seen.
My dissertation research and the four chapters you’ve just read theoretically align with the project of (re)visioning that I engaged in while creating the images for my Kairos piece, in that the dissertation shows active uptake of medical (and other authoritative, official) discourses in the context of people’s everyday lifeworlds. However, the practices I use to (re)vision in the Kairos piece and the dissertation diverge, so I thought it best to return to (re)visioning now that we’ve reached the conclusion of the dissertation. I intend
to show a new set of practices for (re)visioning that my participants have revealed to me, practices of rescripting and improvising in active reception. These practices continue the work of turning towards the future of feminist vision, inserting new representations of what feminist work can achieve.

**Scripting and Compliance**

I initially encountered the idea of scripts from Oudhoorn and Pinch (2003), who write that the concept of script is a central notion in semiotic approaches to user-technology relations. Theorists like Akrich and Latour (1992) use the concept of script “to describe the obduracy of objects. The concept of script tries to capture how technological objects enable or constrain human relations as well as relationships between people and things” (p. 9). They like the script approach because it “makes users more visible as active participants in technological development” (p. 10) in that both designers and users inscribe the world onto objects; however, they critique it in practice because most of the studies focus on designers and technological objects rather than users. They prefer cultural and media studies approaches because they “inspire us to transcend the artificial divide between design and use” (p. 16).

The concept of script in STS is very similar to the concept of compliance in medical discourse. Latour and Akrich define scripts as being something like a film script, as the text of what the various actors in the settings are doing to each other. In this way, there are texts built into technologies that dictate how designers envision users interacting with their technology, so it is difficult for users to do anything different because of both the cultural expectations and the design of the technology itself. For medical technologies and medical discourse in particular, this concept seems very relevant; the official texts that my
participants encountered from medical professionals often were embedded with a script for the patient’s actions in relationship to the text. These scripts reinforced cultural norms for the actions of both doctor and patient. An example of this type of text is the post endoscopy instructions that Meagan was given after her colonoscopy (Figure 5.4).

![Figure 5.4 Meagan’s post endoscopy instructions](image)

In Figure 5.4, the results of Meagan’s colonoscopy are written out for her, including a diagnosis of ulcerative colitis and treatment instructions. For each checked off box, Meagan is expected to perform an action. For example, the biopsy box is checked off, so Meagan is expected to wait 2-3 weeks for a phone call with the results, and if she doesn’t
receive a phone call after that period, she is expected to call. Also, the medications box is checked off, with a prescription for Asacol written in. Thus, Meagan is expected to take Asacol as prescribed by the doctor. At the bottom of the form, it says, “If you have any questions or concerns, PLEASE do not hesitate to call.” Instead of checking off the box next to “GASTROENTEROLOGY CLINIC,” the box and location are circled, and the phone number is printed below (I blacked the phone number out due to privacy issues). This implies that if for some reason Meagan wished to do something different than the form prescribed, instead of making the decision to do that on her own, she should call the doctor first.

In this case, compliance could be defined as following the script of the document. If Meagan followed all of the post endoscopy instructions as written, she would be in “compliance” with her doctor’s instructions, and if she didn’t follow the instructions exactly, the doctor would consider that “non-compliant.” Thus, the cultural norms of the doctor-patient relationship are reproduced through the script of this document. The doctor diagnoses conditions and prescribes treatment, and the patient follows the instructions exactly unless she receives prior approval from the doctor to deviate from the instructions. Following the script of the text makes her a compliant patient.

There are countless studies in medicine measuring patient compliance, including the Institute of Medicine’s (IOM) study of health literacy that oftentimes equates non-compliance with being illiterate. Take for example this situation from the study:

An African American woman was told she would need an exploratory laparotomy. She subsequently became agitated and demanded her family take her home. When approached by staff, she yelled ‘You will not make me a guinea pig!’ She later died of appendicitis. (p. 31)
In this case, the woman is thought to have denied the surgery because she didn’t know what a laparotomy was. Had she known that this explorative surgery was to diagnose any internal issues like appendicitis, perhaps she would have complied with the doctor’s recommendations. However, her decision to go home may have been influenced by countless factors that were not measured in the study, such as medicine’s historical abuse of African Americans as test subjects without their consent.32

This example reflects how problematic the concept of compliance is; either the patient is following the script and is compliant, or she is not following the script and is non-compliant. There are no variations, no possibilities for activity that differ from these two options. IOM so easily confounds literacy with compliance that the researchers very neatly conclude that the prescribed action for ending confusion and ending non-compliance is health literacy. In fact, as the examples of my dissertation have shown, people’s engagements with medical discourse are complex and multidimensional. Higher levels of literacy won’t necessarily make patients compliant; instead, proficiency with medical discourse may just increase a person’s range of activities that can be considered non-compliant.

Segal (2005) argues this medical concept of non-compliance is not rhetorically complex enough in its understanding of why people consult their doctors with their physical needs and why they choose to trust and rely on their doctors’ expertise. Physicians often rely on their authority to get patients to comply, but in a complex interaction where patients bring with them outside investments and factors, that authority is not enough to persuade patients to what their doctor tells them to do.

32 E.g., Tuskegee, for one.
Segal believes that measurement studies of non-compliance cast patients at one of two extremes: they are either delinquent or they are independent-minded, either too immoral to comply, or they think they are equal to the doctor and can do whatever they want. She says that neither extreme are very productive ways to think about doctor-patient relationships, and she argues for studying human behavior using a theory of rhetoric. She wants doctors to learn to think in rhetorical terms such as “identification,” “ethos,” “warrants of belief,” “structure of argumentation,” and “rhetorical situation” (p. 152) rather than in black and white concepts like compliance or non-compliance. Attending to these concepts rather than compliance would factor in variability in patient activity and allow doctors to account for means of persuasion other than their authority as doctors, thus finding more effective ways to communicate with their patients.

My interview with Emily, a nurse manager who has been in the nursing profession for over 30 years, supported some of Segal’s conclusions about patient compliance, indicating that nursing more often accounts for variety in patient behavior than the whole of medicine does. When Emily addressed the subject of compliance in terms of the documents nurses hand out to patients as a part of treatment, she spoke about how hard it is for nurses to “get the whole family on board” with a patient’s treatment plan, especially if they only hand out texts. Thus, nurses have developed a multimodal approach to patient education, using talk, hard copy handouts and brochures, videos, and computer texts, and paying careful to attention to the learning style of each individual patient.

Emily described how a nursing unit initiated a class for patients to attend with their family members and learn about ongoing treatment. The unit had many open heart surgery
patients whose lifestyles had to change significantly after discharge because “they can’t drive, they’ve got to exercise, they’ve got to check their pulse.” Emily said that:

[The nurses] read a best practice that was really showing good return and good satisfaction when you actually take [the patients] into a classroom setting, with their family ideally, but at a certain time in their stay, ideally day two or day three. And they have a dietician there, they have kind of a multi-disciplinary team there, and then the nurses educate and they go through this notebook and their family members are there... that’s actually increased our scores that [the patients] feel ready for discharge.

In this case, to deal with what might regularly be measured as an issue of non-compliance, Emily’s nursing staff instead thinks about it as a different kind of issue. Instead of blaming the patient for being delinquent or too independent-minded, they consider the constraints of the patient, and they consider other options for education that may be more persuasive. These methods include making the education more personal to the client as well as putting into a place a support system to help the client cope with their new lifestyle.

I think medicine as a whole can learn a lot from the kinds of practices like those of Emily’s nursing team who consider patients as active recipients of information, and think about ways to help patients understand and integrate the information they’re given. Perhaps medicine can take up Segal’s call to start thinking in more complex ways about patient activity. Perhaps medicine can learn to (re)vision their image of patients, supporting them as people who want to take care of themselves but need access to the doctor’s information in ways that laypeople can understand in order to take that care.
Rescripting as (Re)visioning

I’ve just spoken briefly about possibilities of (re)visioning for medicine, but the main intervention of my dissertation lies in (re)visioning the field of professional writing. Figure 5.4 is a document from Meagan’s medical records; it looks like a document that typically gets studied in the field. It was composed by professionals, follows a templated form, fits into genre conventions for writing in the field, and as I mentioned, reflects the cultural and ideological hierarchies of patient as passive receiver of medical discourse, putting all the power of decision-making and production of medical discourse into the hands of medical professionals. Even though this document is embedded with these scripts for patient activity, the people I’ve interviewed have demonstrated that they don’t necessarily follow those scripts; in fact, patients often rewrite the scripts for their own purposes through their improvisation.

Meagan received Figure 5.4 at the time of her diagnosis of ulcerative colitis. She had several instances where she was in so much pain that she had to go to the emergency room, so her doctor scheduled her for a colonoscopy, providing her with Figure 5.4 so she understood her discharge instructions. At home, Meagan followed the doctor’s prescribed course of action, but she continued to experience pain, cramping, and bloody diarrhea. Meagan was concerned by this and called the doctor’s office as instructed for other treatment such as a different prescription. However, she had a really hard time getting through to her doctor, and the nurse who responded to her phone calls seemed annoyed to be hearing from Meagan on multiple occasions. She told Meagan that she would not be able to get in to see her doctor for several weeks, leaving Meagan to deal with the pain on her own.
Because Meagan had a difficult time getting the medical professionals to respond to her questions, she acted through local improvisations (Engestrom et. al., 1999), making the decision to incorporate alternative medicine into her chain of reception, and she began to seek health-related discourses outside of traditional medicine to manage her pain. Meagan primarily sought out nutritional cures and alterations to her diet in response to the medical professionals’ aloofness:

That’s when we started trying to do our own research cause I didn’t really understand... Chris talked to Jen and Sharon, they work in the vitamins department at his work, and Sharon has studied holistic medicine, and there was a book there with some info, and they printed [these research articles] out on ulcerative colitis and nutrients, and that sort of thing. And then Chris looked up a soft diet (Figure 5.5)... and I started looking stuff up online, actually the Crohns and Colitis Foundation online, and I found that there’s no rule of thumb as far as what you can eat and what will upset you, that’s very much dependent on the person, but I was basically eating pasta and bread and tofu for weeks.

Through these collaborations with numerous people, Meagan chained together texts that look very different from Figure 5.4 yet provided the information she needed to care for her ulcerative colitis.

One of these texts that Meagan’s husband downloaded for her was the soft diet from Wikipedia. This document was unique in that it came from an open access reference tool that anyone can edit, thus this document was less regulated than documents like Figure 5.4.
Figure 5.5 Soft diet from Wikipedia

Perhaps partially due to its source, Meagan interacted with this text very differently than she interacted with her post-endoscopy instructions.

Meagan chained the Wikipedia soft diet text together with her everyday life practices by testing it out using her own body. She underlined certain food items and key terms on the document, she put a star next to certain food items on the list, she crossed out certain food items on the list, and she wrote notes about what kinds of foods she could eat in each category. For example, she crossed broccoli off from the bullet point “Carrots,
Broccoli, and other vegetables cooked soft or processed in the blender,” and underneath it she wrote “nothing from cabbage family (broccoli, cauliflower).” Her annotations suggest that she managed her pain through testing her body’s reactions to different foods; crossing out “broccoli” and writing the note indicated that she had a negative experience with these foods.

Meagan’s annotations demonstrate her local improvisations with the text; as she annotated the document, she also modified it, transforming the text from a definition, reference sheet, and descriptive text printed out from Wikipedia to a key document representing her body’s responses to her condition. Meagan could then use this document to manage her care in the absence of being able to manage it through traditional medical means. Through Meagan’s collaborative practices with others and her movements back and forth between the text and her body, she improvised in her decision making and shaped a care plan that addressed her needs and fit her purposes at that time.

Because Meagan’s rescripting of documents like the Wikipedia soft diet often happens in home or community spaces that are typically not considered professional, and because patients rather than medical professionals rewrite the script, the field of professional writing hasn’t paid much attention to these practices. The field is moving in this direction in recent scholarship (Scott, 2006; Grabill, 2006; Simmons, 2007; Koerber, 2006; Kimball, 2006), the landscape of the field is beginning to expand and be changed, making the interventions of this dissertation timely and necessary.

The Wikipedia soft diet is a representative example of what kinds of interventions can (re)vision the field of professional writing. Researchers considering potential research sites and participants may have only considered workplaces or classrooms as the spaces
where technical communications happens, but Figure 5.5 shows that there are potentially more spaces, participants, and types of technical documents that have always been a part of understanding and using technical communication. By including these documents, not only can we see a (re)visioned landscape of technical activity, including the practices of women and people whose active engagements are often elided, but significantly, professional and technical writing researchers can contribute to broader conceptions of how people make meaning in the world and not just in professional institutional spaces of medicine.

This dissertation project takes up the original call of (re)visioning through a critique of some of the historical and current research practices of the field that present a narrow and uncritical view of professional writing. The project also creates new representations of professional writing, considering the critically engaged active chains of reception that people create in their everyday lifeworlds in order to make sense of health for their own purposes. It presents a vision for what those practices look like, showing documents that people transform and rescript through their everyday practices.

But more than that, I think this project introduces new ideas for the potentials of (re)visioning. The original work involved impersonal interactions and images I created out of my own personal feelings about the messages of medical discourse. This new outline for (re)visioning shows that the cultural engagements I hoped could happen in response to the hospital advertisement (Figure 5.2) are actually happening. My participants are transforming those messages in their own lives, they are actively engaging sources of medical discourse, they are configuring and understanding their bodies on their own terms, they are rescripting medical technologies for their own purposes. (Re)visioning professional writing is already happening, we just have to pay attention.
References


Appendix A Interview Protocol


The following question sets represent the types of questions that will be asked of the primary, secondary, and community participants in the study during their interviews. These questions represent an attempt to explore the participants’ understandings of and approaches to health in their everyday lives.

1. Question Set One: Enculturation into Health Practices
What are your impressions of your experiences medical fields/professionals?
   • What kind of encounters have you had?
   • How do you see yourself engaging with medical fields/professionals?
   • How do you manage your healthcare?
   • What resources do you use to manage it?
   • What are your expectations for your interactions with different kinds of health professionals?
   • How were these expectations formed?

2. Question Set Two: Experiences with Particular Texts
Describe your healthcare experiences wherein you first used ______ text.
   • How did you receive the text? In what context did you acquire it? Where did you keep it?
   • What does it say? How does it communicate to you?
   • Once you acquired the text, how did you use it?
   • Did you seek out additional texts or literate practices in response to it?
   • How did you feel about this text or this healthcare experience in relationship to this text?
   • Why did you engage in these particular practices?

3. Question Set Three: Tracing out Literate Practices
Now that you've identified ________ literate practice you employed related to this text, describe how you engaged in that practice.
   • What texts did you read associated with this text? Where did you read them?
   • What texts did you write associated with text? Where did you write them?
   • What was the purpose of these various kinds of reading and writing?
   • Why did you engage in these practices?
   • Are there any kinds of literate practices you’ve been considering engaging in but have not yet done? Why or why not?
   • Do you see any relationship between these literate practices and other practices you’ve engaged in?
   • How did you learn these practices?
4. Question Set Four: Tracing out People and Spaces
Now that you've identified _______ person or space in relationship to your negotiation of health in your everyday life, describe your relationship to that person or space.
  • Why do you consult that person/space?
  • How do you use that consultation?
  • How do you feel about that consultation?

5. Question Set Five: Followup Questions for Group Interviews

Occasionally, the investigator (Bellwoar) may conduct group interviews with primary and secondary participants and ask any of the above questions. The following represent followup questions that might be asked of the secondary participants.

Now that (primary participant) has identified these particular texts, practices, people or spaces that have been used in developing understandings of health, describe your relationship with those texts, practices, people or spaces.
  • Did you also use these texts, practices, people or spaces in your understandings of health, in particular the primary participant's health? Why or why not?
  • How did you gain access to these texts, practices, people or spaces?
  • Did you use different texts, practices, people or spaces? How did you gain access to those?
  • Did you investigate any of these things on your own or work mostly with the primary participant?
  • Do you understand what the primary participant just said in the same way, or do you understand it differently?

6. Question Set Six: Questions for Community Participants

Because primary participants will not be identified for interviews with community participants, the following represent some different questions that will be asked only of the community participants.

How do you understand health in your own everyday practices, and in what capacity do you convey those ideas to others?
  • What kind of education have you had in healthcare fields?
  • Do you ever write documents pertaining to health? In what capacity do you write them? Who do you distribute them to?
  • Do you ever read documents that you or others have written about health? What do you think of those documents? How do you understand them?
  • Do you ever distribute written materials to people to help them understand health? In what capacity do you distibute them? What do you think of them?
  • What are your overall impressions of how people come to understand health? How do you see texts and literate practices' roles in understanding health?
Appendix B Informed Consent Forms

Informed Consent for Case Study of How Literate Activity in Individuals’ Everyday Lifeworlds Shape Understandings of Health and Medicine

Primary Participants’ Informed Consent Form

Purpose of the study
You are invited to participate in a research project that I (Hannah Bellwoar of the Department of English) am conducting under the direction of Professor Paul Prior, also of the Department of English. I am particularly interested in understanding the relationships between your literate practices and your healthcare and how you understand your health and your role in participating in your healthcare. I will focus this study on the everyday texts, practices, and spaces in which you construct your ideas about health, as well as the stories you tell about your healthcare experiences. I hope that this research will provide valuable information on the roles literate practices play in the interactions between people and medical knowledge in their everyday lives.

What the study involves
If you agree to participate, I will ask you to consider four kinds of voluntary participation. First, I will ask you to provide copies of texts that you may use or find significant in your everyday health practices. These could include popular articles, prescription drug inserts and labels, websites, educational materials, notes you’ve taken, emails you’ve sent, etc. Second, I will ask you to participate in interviews with me about your experiences using these texts in your everyday lives. These interviews may be audio- and video-taped with your consent in order to record gestures that may be important to your understanding of the texts. Third, during these interviews, I will ask you to identify people and spaces that have been significant to your understanding of health. People could be family, friends, medical professionals, alternative medical practitioners, etc. Spaces could range from home to school, workplaces, health food stores, yoga studios and other exercise formats, etc. I will ask for your permission to contact and interview family and friends that you identify about specific healthcare practices and sources that you’ve used. I will also ask for your permission to contact and interview other people that you have identified that are not friends and family, but I will not identify you or connect you to the specific healthcare practices and sources in these interviews. Fourth, I will ask you to participate in follow-up interviews in some of the spaces you identify, in order to further understand how you use these literate practices and texts in these spaces. A typical interview may last 45-90 minutes. Your participation could consist of a single interview or a series of interviews over an extended period of time. Because a key goal of this study is to follow your practices over time, I hope that you will participate periodically over a year or more. (Of course, as is stated below, you have the right to discontinue your participation at any time.)
Publication and identifiability

The results of this research may be published in journal articles, electronic publications, or books and may be presented in professional conferences or lectures with your consent. I may quote from or describe recorded activities or interactions, any texts you have made available for the research, and any interview comments you have made with your consent. I may also use still images from videotapes in written publications and might play excerpts of audio- or video-tapes in oral presentations of the research. It is likely that you could be recognized by people who know you if they hear or read such reports of the research.

To limit somewhat your identifiability, I can use a pseudonym for your name in all of my drafts and final reports of this research. I can also use various techniques in video-taping to prevent the recognition of your face, i.e. blackout, blurring, or editing.

Regardless of whether you are referred to by a pseudonym or not, to safeguard your privacy, I will keep any identifying data (audio- and video-tapes, copies of texts you provide, interview transcripts) in a private office where others will not have access to them and I will not release such raw data to anyone else. Additionally, I will use pseudonyms electronically in tracking and coding the data, and will keep all private identifying information securely locked in a file cabinet.

Maintenance of Data

To maximize the benefits of this research, I would like to maintain the data collected for future analysis and for educational purposes. Because of the qualitative nature of this study and for my own data analysis of this research, I am planning to keep the data indefinitely. This data can be very important in improving understandings of health literacy in society. It can help students, healthcare professionals, and community members better understand health, and it can also improve communication and health literacy throughout society. Therefore, I will request special permission to use this data for educational purposes in public sites. You will be provided with a lot of control over your identifiability in this data. You can provide me only with the information and texts that you feel comfortable sharing during your interviews, and you can choose to skip any question throughout the course of the interviews. You can identify and give permission for me to contact and interview other participants in the study. You will provide me with consent to be audio- and video-taped before each interview. You can choose that a pseudonym be used in all texts and publications of the data or that you be identified by your real name, and you can request that audio- and video-tapes be altered in order to reduce identifiability.

Your Rights, Benefits, and Concerns

You may benefit from the opportunities this research offers to reflect on healthcare and on the relationship between literate practices and healthcare. However, the primary benefit of this research is to increase knowledge of how health and medicine is understood in people’s everyday lives. Such understanding may eventually improve ways of communicating in doctor-patient interactions.

Your participation in this research is voluntary. Whether you choose to participate or not has no bearing on your access to or use of any services that I or others might offer in any
context, and it will not affect any relationship or standing you might have with UIUC. You may withdraw at any time after signing this form should you choose to discontinue participation in this research.

If you have any questions about this research project, please contact Hannah Bellwoar or Paul Prior. If you have any questions about the rights of research participants, you can call the UIUC Institutional Review Board. If you are out of town and identify yourself as a research participant, you may call collect.

You will be given a copy of this form to keep.

Please review and check off the options below to ensure that I know how your data may be used. If you have any questions, please feel free to ask me.

- I agree that any texts that I provide for this research may be quoted or paraphrased in publications or oral presentations (Yes____ No____).

- I agree to participate in interviews about my literate practices and their relationship to my healthcare (Yes____ No____) understanding that my interview comments might appear in reports of this research. (Specific permission for recording and using interview material will be requested at the time of any interview.)

- I agree that the interviews may be audio-taped (Yes____ No____) and video-taped (Yes____ No____). I agree to have my face represented in the video-taped interviews (Yes____ No____). I agree that any audio- or video-taped recording of me in interviews about my healthcare experiences may be excerpted as audio files, text quotes, or still photographs in publications or oral presentations (Yes____ No____) and may be selectively replayed in electronic publications or oral presentations (Yes____ No____). I agree that the recordings may be kept for an indefinite amount of time and maintained by Hannah Bellwoar (Yes____ No____). (Specific permission for use of each recording will also be obtained.)

- I agree that the data may be maintained and used for educational purposes in the future (Yes____ No____).

- I agree that I may be identified by my real name in relation to any of the data collected in this research and reported in any papers, books, talks, or other publications (Yes____ No____).

I have read this informed consent form and checked answers to the questions above, am 18 years of age or older, and I voluntarily agree to participate in this research.

______________________________    ______
(signature)                        (date)
Informed Consent for Case Study of How Literate Activity in Individuals’ Everyday Lifeworlds Shape Understandings of Health and Medicine

Community Participants’ Informed Consent

Purpose of the study
You are invited to participate in a research project I (Hannah Bellwoar of the Department of English) am conducting under the direction of Professor Paul Prior, also of the Department of English. I am particularly interested in understanding the relationships between individuals’ literate practices and healthcare and how they understand their health and their role in participating in their healthcare. I will focus this study on the everyday texts, practices, and spaces in which they construct their ideas about health, as well as the stories they tell about their healthcare experiences. I am asking you to participate in this study because of your general understandings of health and your knowledge and use of texts, practices, and spaces that some of my primary participants might engage with. I hope that this research will provide valuable information on the roles literate practices play in the interactions between people and medical knowledge in their everyday lives.

What the study involves
If you agree to participate, I will ask you to consider three kinds of voluntary participation. First, I will ask you to provide copies of texts that you may use or find significant to your general knowledge of health. These could include texts that you might distribute to clients or use in your interactions with clients. Second, I will ask you to participate in an interview with me about your experiences in your role as a practitioner in a health related field, using texts that you’ve provided. These interviews may be audio- and video-taped with your consent in order to record gestures that may be important to your understanding of the texts. Third, I may ask you to participate in follow-up interviews in the future. A typical interview may last 45-90 minutes. Your participation could consist of a single interview or a series of interviews over an extended period of time. Of course, as is stated below, you have the right to discontinue your participation at any time.

Publication and identifiability
The results of this research may be published in journal articles, electronic publications, or books and may be presented in professional conferences or lectures with your consent. I may quote from or describe recorded activities or interactions, any texts you have made available for the research, and any interview comments you have made with your consent. I may also use still images from videotapes in written publications and might play excerpts of audio- or video-tapes in oral presentations of the research. It is likely that you could be recognized by people who know you if they hear or read such reports of the research.
To limit somewhat your identifiability, I can use a pseudonym for your name in all of my drafts and final reports of this research. I can also use various techniques in video-taping to prevent the recognition of your face, i.e. blackout, blurring, or editing.

Regardless of whether you are referred to by a pseudonym or not, to safeguard your privacy, I will keep any identifying data (audio- and video-tapes, copies of texts you provide, interview transcripts) in a private office where others will not have access to them and I will not release such raw data to anyone else. Additionally, I will use pseudonyms electronically in tracking and coding the data, and will keep all private identifying information securely locked in a file cabinet.

Maintenance of Data
To maximize the benefits of this research, I would like to maintain the data collected for future analysis and for educational purposes. Because of the qualitative nature of this study and for my own data analysis of this research, I am planning to keep the data indefinitely. This data can be very important in improving understandings of health literacy in society. It can help students, healthcare professionals, and community members better understand health, and it can also improve communication and health literacy throughout society. Therefore, I will request special permission to use this data for educational purposes in public sites. You will be provided with a lot of control over your identifiability in this data. You can provide me only with the information and texts that you feel comfortable sharing during your interviews, and you can choose to skip any question throughout the course of the interviews. You can identify and give permission for me to contact and interview other participants in the study. You will provide me with consent to be audio- and video-taped before each interview. You can choose that a pseudonym be used in all texts and publications of the data or that you be identified by your real name, and you can request that audio- and video-tapes be altered in order to reduce identifiability.

Your Rights, Benefits, and Concerns
You may benefit from the opportunities this research offers to reflect on healthcare and on the relationship between literate practices and healthcare. However, the primary benefit of this research is to increase knowledge of how health and medicine is understood in people’s everyday lives. Such understanding may eventually improve ways of communicating in doctor-patient interactions.

Your participation in this research is voluntary. Whether you choose to participate or not has no bearing on your access to or use of any services that I or others might offer in any context, and it will not affect any relationship or standing you might have with UIUC. You may withdraw at any time after signing this form should you choose to discontinue participation in this research.

If you have any questions about this research project, please contact Hannah Bellwoar or Paul Prior. If you have any questions about the rights of research participants, you can call the. If you are out of town and identify yourself as a research participant, you may call collect.
You will be given a copy of this form to keep.

Please review and check off the options below to ensure that I know how your data may be used. If you have any questions, please feel free to ask me.

- I agree that any texts that I provide for this research may be quoted or paraphrased in publications or oral presentations (Yes____ No____).

- I agree to participate in interviews about my literate practices and their relationship to health as my practice of it (Yes____ No____) understanding that my interview comments might appear in reports of this research. (Specific permission for recording and using interview material will be requested at the time of any interview.)

- I agree that the interviews may be audio-taped (Yes____ No____) and video-taped (Yes____ No____). I agree to have my face represented in the video-taped interviews (Yes____ No____). I agree that any audio- or video-taped recording of me in interviews about my practice of health may be excerpted as audio files, text quotes, or still photographs in publications or oral presentations (Yes____ No____) and may be selectively replayed in electronic publications or oral presentations (Yes____ No____). I agree that the recordings may be kept for an indefinite amount of time and maintained by Hannah Bellwoar (Yes____ No____). (Specific permission for use of each recording will also be obtained.)

- I agree that the data may be maintained and used for educational purposes in the future (Yes____ No____).

- I agree that I may be identified by my real name in relation to any of the data collected in this research and reported in any papers, books, talks, or other publications (Yes____ No____).

- If you have provided documents that identify your workplace or organization: I agree that you may quote from these documents (Yes____ No____) in ways that identify the workplace or organization. If applicable, you should also request permission from ________________________________ before quoting from these documents.

I have read this informed consent form and checked answers to the questions above, am 18 years of age or older, and I voluntarily agree to participate in this research.

________________________________________ __________________
Appendix C Summary of Study Participants’ Data

Primary Participants

Meagan
Interview dates: July 14, 2008; November 19, 2008; January 29, 2009; June 10, 2009

Follow up contacts: Regular email and in person contacts between July 14, 2008 and April 16, 2011. Email contacts include Meagan forwarding me emails that she had sent to her friends and family. Because Meagan and I met monthly for purposes outside of research, in person contacts often consisted of Meagan sharing something informally about her health. Also on several occasions while transcribing her interviews, I had follow up questions about something she said that we didn’t talk about in detail during the interview, for example, her MRI. Often, issues that came up in conversation or while I was transcribing would be addressed in our next interview, thus the in person contacts regularly informed the direction of interviews.

Text inventory:
- “Patient registration and admitting information”—3 books, from 1st emergency room visit, 2nd emergency room visit, and clinic visit
- emergency department discharge form with medications and instructions
- next appt card from student health center
- personal medical data card
- hospital bracelet
- sticky note of medications
- next appt card for hospital
- student health center medication inserts for IBS
- handwritten medication schedule on back of medication inserts
- patient instructions following removal of teeth
- student health center medication inserts for wisdom teeth meds
- hospital notice of privacy practices
- hospital medications insurance receipt
- sticky note inventory of pain, bowel movements, food intake
- consumer medical information on hospital medications
- student health center medication inserts
- discharge report for ulcerative colitis diagnosis
- discharge medication report for patient
- discharge medication report for health provider (phone & room #s handwritten on the back)
- handwritten medication prescription
- social worker form letter on payment subsidy options
- application for community care assistance to help with hospital bill
• hospital list of charges for surgery
• chart for % discount based on income
• hospital patient education program info for smoking cessation & ending nicotine dependency
• Clinic @ hospital
• Patient history
• Surgical report
• Diagnosis report
• Consultation report
• 2nd surgical report
• 2nd diagnosis report
• KODI (personalize and print) Management of ulcerative colitis: Lifestyle
• KODI (personalize and print) Management of ulcerative colitis: Medications
• KODI (personalize and print) Discharge instructions for ulcerative colitis
• Copy of faxed lab report
• Color brochure about hospital website
• Paper rose insert from hospital auxiliary
• Handwritten note to reduce meds wrapping up cards with medication and lab orders
• Folder for home care instructions
• Ulcerative colitis brochure
• Special procedures post endoscopy instructions
• Patient health summary print out—medications description
• Print out on medication mesalamine
• Student health center medication inserts
• Patient education info special procedures post endoscopy
• Special procedures location card
• appt reminder
• “We want you to feel ‘special’” document with crossword puzzle on the back (wordlist: scope, balloon, small bowel, laxative, etc.)
• hospital name of procedure team members (with pictures)
• more patient education discharge instructions
• Cover letter from foundation
• Info on foundation membership
• Q & A brochure on ulcerative colitis
• Q & A brochure on women’s issues
• Q & A brochure on diet and nutrition
• Q & A brochure on questions about pregnancy
• Q & A brochure on surgery
• Print out from health food store on ulcerative colitis and nutrition
• Print out from health food store on soft diet
• Nutritionist article on aloe vera juice
• Photocopied brochure on Jarrow formulas Saccharomyces Boulardii + MOS
• Mayo clinic website print out on Pancreatitis
• NewHope.com website printout on the Probiotic solution for colitis
• WebMD printout on “Probiotic Bacteria induce remission of active ulcerative colitis”
• From Clinical and Experimental Immunology, 143: 389-397. Journal article “Gut motor function: immunological control in enteric infection and inflammation”
• From proteomics-journal.com “Glutamine regulates the expression of proteins with a potential health-promoting effect in human intestinal Caco-2 cells”
• From Lippincott Williams & Wilkins “Glutamine: role in gut protection in critical illness,” “Glutamine: mode of action in critical illness,” and “The glutamine story: where are we now?”
• From Procedure of the nutrition society “Glutamine in critical care: current evidence from systematic reviews”
• From PubMed “Is glutamine a conditionally essential amino acid?”
• From LookSmart “Glutamine-supplemented nutrition”
• From MayoClinic. Com “Chrohn’s disease”
• Packet of printouts about supplements
• Handwritten note to husband offering to go over info
• Student health center pregnancy info
• Choosing a pediatric care provider handout
• Student health insurance flier
• Handwritten note with Dr. names
• Brochures on mercury in fish and cystic fibrosis
• Prenatal community resources
• Hospital letter with OB estimates
• Card with student insurance contact info
• Newborn Joy binder (materials in pockets)
• Medication envelopes
• Card on stopping the early birth of your baby
• Magazine “As your baby grows”
• Patient instructions for ultrasound with Meagan’s handwritten notes listing baby products to register for
• Hospital instructions to dentist/oral surgeon
• Healthcare services estimate sheet
• Maternity leave form to fill out
• Quest diagnostic brochure on 1st trimester
• Quest diagnostic brochure on 2nd trimester
• Brochure on cystic fibrosis
• Brochure on genetic disorders
• OB class calendar
• Hospital info on caring for yourself after amniocentesis
• Bill for hospital services
• Student health center medication reconciliation
• Consent for HIV test and disclosure
• Emails to/from family and friends
• Ultrasound images
• General info on abortion services brochure
• 2nd trimester termination instructions
• HIPAA notice
• Aftercare for two-day surgical patients
• Ovulation testing kits

Text referenced:
• vaccination documentation
• prescriptions
• over the counter medication labels
• drug store shelves
• diagrams of the human body
• dictionary
• magazine
• drawings of the human body in art class
• in person birth control class materials
• online birth control class
• breast exam instructions for the shower
• vitamin labels
• health food store shelves
• scheduling books
• pre-procedure instructions
• online testimonials
• appointment reminder
• Patient registration and admitting information booklet (23 pages long)
• special procedure crossword puzzle
• intake forms
• forms with patient information in medical chart
• Dr.’s framed pictures of vacation
• Dr. typing on his computer
• Special procedure’s waiver
• Post-procedure instructions (personalized and handwritten)
• Post-procedure instructions (standardized handout)
• Ulcerative colitis illustrated color brochure
• Health summary
• Medication summary
• Medication information included with prescriptions
• Holistic medicine book
• Holistic medicine printout on nutrients for ulcerative colitis
• Print out of soft diet
• Crohns and colitis foundation website
• Online information about condition
• Internal surgical report, doctor’s notes
• Crohns and colitis foundation brochures (7)
• Management of ulcerative colitis printout from hospital
• Discharge instructions
• Lab results
• Lab orders
• Hospital online support network and message board
• Binder of information on pregnancy
• Online bio and pictures of doctors
• Hospital check-in papers
• OB class calendar
• Introduction to pediatricians
• Fact sheet on nutrition
• Book: *What to expect when you’re expecting*
• Medication information sheet
• Pregnancy websites
• Trisomy 18 foundation website
• Instruction sheet for ultrasound
• Babies R’Us website and registry
• Emails from family members
• Emails to family members
• Email to sister
• Internet research on “choroid plexus cysts”
• Email from sister, sister’s internet research
• Internet discussion boards
• Phone conversation about procedure codes
• TRISOMY 18 foundation website
• Info on the likelihood of TRISOMY 18
• Computer screen for Dr. and ultrasound screen for patient
• Computer for Dr. with complex keypad
• Stenographer measurements
• Oral explanation from MD
• Printed pictures from ultrasound
• Parking validation
• Phone calls to parents
• Testimonials on TRISOMY 18 foundation website
• Filled out forms at abortion clinic
• Privacy statement at abortion clinic (made effort to read everything)
• Termination billing statements from insurance company (not mailed)
• Documents from termination counselor
• Sign privacy statement on the computer
• anti-abortion websites, anti-abortion discussion boards, discussion boards about women who had gone through abortions with mixed responses, clinical studies, technical brief descriptions given in clinic.
• Receipts
• Planned Parenthood comment card
Elizabeth Edwards

Interview date: November 7, 2008
Follow up contact: Email contact December 3, 2008
Texts referenced:
  • Hospital lab reports
  • Evaluation form for medical students
  • Books on nutrition

Jenica Roberts

Interview date: August 2, 2009
Follow up contact: None
For Jenica’s texts, see Eugenia & Brad Roberts Interview

George Bellwoar

Interview date: August 9, 2009
Follow up contact: Phone contact on April 20, 2011
Texts inventory:
  • Dr. Patrick Walsh’s guide to surviving prostate cancer, book
  • American cancer association DVD
  • Recipe from ACA magazine
  • Needle biopsy pamphlet
  • Pre-op patient instructions pamphlet
  • Original diagnosis, patient counseling report
  • Notice from urology re: referrals
  • JHU patient website information
  • JHU guide, photocopied
  • Prostate cancer request for consult, history
  • Urology biopsy results 2 July 2008
  • Urology biopsy letter 24 June 2008
  • Health history form
  • Orally administered medications that increase bleeding time, list
  • Folders from ACA to organize information

Community Participants

Bryan Kieft
Interview date: November 2, 2008
Follow up contact: Email exchange on November 5, 2008
Text inventory:
• Trail guide to the body
• About your massage therapist
• Mapping your body
• Elemental touch Client treatment form
• Graduation letter
• AMTA standards of practice
• Elemental touch policy statement
• Elemental touch price list
• Elemental touch business card
• Business plan
• Billing letter

Emily
Interview date: February 6, 2009
Follow up contact: None
Texts referenced:
• Medication documents print out
• Computer education program
• Booklet for congestive heart failure
• Pamphlets and handouts for diabetes

Deb Lister
Interview date: May 19, 2009
Follow up contact: None
Texts referenced:
• Book with yoga positions
• Powerpoint for occupational therapists to incorporate yoga
• Class paper on research project about teaching yoga for high school students

Eugenia & Brad Roberts
Interview date: August 2, 2009
Follow up contact: None
Text inventory:
• CEREC pamphlet
• Crown/root canal drawing
• Treatment proposal
• About fillings
• Prescription print out and instructions
• Health history
• Check out document
• Focus on health article and advertisement featuring Eugenia
• Let’s compare whitening products
• Informed consent for Zoom
• Informed consent for take home whitening
• Instructions for after Zoom session
• Bleaching dos and don’ts